

**Gender Players and Gender Prisoners:  
When Intersex Activism, Medical Authority, and Terminology Collide**

BY

GEORGIANN DAVIS

B.A., Northeastern Illinois University, 2004

M.A., University of Wisconsin-Milwaukee, 2006

THESIS

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Defense Committee:

Barbara Risman, Chair and Advisor

Lorena Garcia

Laurie Schaffner

Sharon Preves, Hamline University

Verta Taylor, University of California at Santa Barbara

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## SUMMARY

A study of the social construction of intersexuality was conducted using qualitative methodologies. A total of sixty-five in depths interviews were conducted with intersexed individuals and activists, the parents of such individuals, and medical experts on intersexuality. Interviews were supplemented with ethnographic observations in the public spaces of intersex social movement organizational meetings.

Intersexuality does not usually require medical attention because it isn't typically life threatening. Yet, these conditions are almost always surgically and/or hormonally treated in order for the children born with them to more neatly fit into the socially constructed sex binary. Given the absence of urgent medical need, there are strong debates on how intersexuality should be treated between medical professionals, parents, adult patients, and social movement activists. This raging debate is evident by the need for the *American Academy of Pediatrics* to issue two consensus statements in six years on the medical management of intersexuality. This project is an attempt to understand this debate about the diagnosis and treatment of intersexuality.

Findings suggest intersex activists, most of whom are intersexed themselves, initially came together in the early 1990s to claim intersex as an identity in order to more effectively mobilize against medical professionals whom they were critical of for unnecessarily surgically modifying their bodies. They did so by protesting at pediatric medical association meetings holding banners and wearing t-shirts that read "Hermaphrodites with *Attitude*." Medical professionals were initially resistant to such confrontational mobilization strategies, but in a relatively short amount of time were receptive to intersex activism and even began inviting intersex activists to speak at their professional association meetings and many indeed did. By the

## SUMMARY (CONT.)

year 2000, the *American Academy of Pediatrics* created a consensus statement on the management of intersex conditions advising doctors and clinicians to avoid using “it” to refer to a baby born with ambiguous genitalia, and to refrain from using sex-specific pronouns such as “he” or “she” when referring to such children. Doing so, the consensus statement warned, could psychological harm parents of children with atypical genitals and adult patients as they eventually face their intersex condition. In 2006, the *American Academy of Pediatrics* revised their diagnosis of, and treatments for, intersex conditions to include, among other less controversial items, a shift away from “intersex” language altogether in favor of new terminology that conceptualized bodies that fall between sexes as having “disorders of sex development” or “DSDs” for short. This shift was not welcomed by all intersex activists, which as a result, fueled a great divide in the movement with implications for those personally impacted by intersexuality.

## INTRODUCTION

Summer in Chicago is a time for residents and visitors to explore the city, visit Lake Michigan, enjoy great food, and participate in debates about why the Cubs can't seem to win. However, in the summer of 2008, a group of over one hundred individuals, mostly white middle class women both young and old, from around the country gathered just outside of the windy city at your run of the mill conference hotel for an annual support group meeting. Most would choose to stay inside the hotel rather than discover what Chicago has to offer.

Unlike other meetings, there were no posted signs throughout the hotel naming the conference. Attendees followed signs to their registration site, but the signs, which depicted a colorful orchid and the bold letters read only "Women's Support Group" followed by "Please do not disturb." To curious hotel employees and guests not affiliated with the conference, the meetings were mysterious. One hotel employee asked me during the conference, "Why are all of you needing support?" I shrugged my shoulders not sure how to respond.

Those in attendance were born with a sex deemed by the medical profession to be as biologically ambiguous as the signs that directed participants to their reserved meeting spaces. Almost everyone in attendance was born with an intersex condition, or with someone who was. In many instances, these conditions result in physical bodies incongruent with sex chromosomes. In the past, these individuals might have been considered hermaphrodites, a term now considered derogatory by some but definitely not all in the intersex community. Terms that are less contentious include intersex, intersexed, intersexuality, and intersexual. I use these terms throughout this work despite concerns that my linguistic choices will anger some. I revisit controversy in detail later, but in short, medical professionals have constructed new diagnostic

terminology, disorders of sex development, or DSDs for short, to name intersexuality. Some individuals impacted by intersexuality are embracing this new nomenclature, while others resist it citing the pathologization behind the “disorder” terminology.

Intersexuality is a condition where one’s physical body doesn’t neatly match his or her sex chromosomes. For instance, people with androgen insensitivity syndrome (AIS) are “chromosomally and gonadally male (that is, XY with testicles), but lack a key androgen receptor that facilitates the ability, fetally and onward, to respond to androgens (male hormones) produced in normal amounts by the testes” (Preves 2003, 27-28). 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 internal undescended testes.

Swyer syndrome, sometimes referred to XY gonadal dysgenesis, is another example of an intersex condition. Similar to AIS individuals, those with Swyer syndrome have sex chromosomes that are inconsistent with their phenotype. For example, Swyer syndrome is characterized by the presence of testes (usually internal), yet unlike AIS, those with Swyer syndrome usually have a uterus (albeit smaller than the “average” uterus). People who are born with conditions such as AIS or Swyer syndrome are referred as, “intersexed,” meaning they do not fall into the binary of “male” or “female.” According to the Intersex Society of North America, approximately fifteen different intersex conditions have been identified by the medical profession.<sup>1</sup>

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<sup>1</sup> Avail: <http://www.isna.org/faq/frequency>, Retrieved June 23, 2008.

The medical profession doesn't fully understand the biological cause(s) of intersexuality, which might, at least in part, explain why any estimates of its occurrence in the population are problematic. There is no national consensus on what defines intersexuality nor are there any formal records of those born with such "abnormalities" (Karkazis 2008). This hasn't stopped attempts at estimating the intersexed population. Blackless et al. (2000), for example, have estimated that intersexuality appears in 1 in 100 births. However, Fausto-Sterling (2000a) offers a different estimate that ranges from 1 in 1000 to 1 in 2000.

Regardless of the estimate one relies on, the conference attendees share a unique medical history and report a strong connection with each other. Those in attendance are there to support one another as they heal from what for many has been a life full of medical lies, deception, and unnecessary surgical intervention where doctors have been known to reshape "abnormal" external genitals and remove internal sex organs in order to fit intersexual bodies into a socially constructed sex binary (e.g., Karkazis 2008; Preves 2003; Fausto-Sterling 2000, 1993).

None of this, however, would be obvious to you if you just happened to stumble into that Chicago hotel that summer weekend. Without the signs indicating that a group of women were meeting for support, you might imagine yourself in the middle of a meeting of sorority sisters or a local Mary Kay convention where everyone looked as though they were subscribers to Glamour magazine. I was told by an elected support group official that one reason for the desired secrecy was to prevent any attendees from feeling uncomfortable or "freakish" should the true reason for the meeting be made public. This was why the conference location wasn't noted on the support group's public website.

Like others before me, I found this particular support group on the internet as I searched for information about intersex "abnormalities" (Preves 2003). As a twenty-eight year old

intersexual with complete androgen insensitivity syndrome (CAIS), I had only met one other person with an intersex condition, a friend from work who was as private about her diagnosis as I had been. Although I was diagnosed with CAIS when I was thirteen, I didn't find out about my diagnosis until I obtained my own medical records as a young adult. At that time, I was very uncomfortable learning that I had "testicular feminization syndrome"—what my condition was labeled when I was initially diagnosed. What was more unsettling was what the gynecologist scribbled in my chart after our first meeting:

After extensive discussion I feel pt 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.

After reading the few medical records I was able to obtain, I disposed of them not wanting to be reminded of the diagnosis nor the surgery that couldn't be undone. I didn't try to find my medical records from when I was first diagnosed.

Almost a decade later, I found myself in a sociology doctoral program exploring feminist theories and gender scholarship. This positioned me to revisit my personal experience with sex, gender, and sexuality binaries. The assigned readings and thoughtful classroom discussions encouraged me to share my medical history initially with close graduate school friends and faculty. Eventually I would share with anyone who cared to listen. I felt liberated and sought out others like myself.

I realized quite quickly during my first day at the 2008 Chicago support group conference meeting that not everyone who discovered their intersexuality shared my liberation. Many were deeply scarred and wounded by how they, or rather we, were treated by medical professionals.

By the third day of the conference, it was clear where my intellectual journey was headed. Studying intersexuality and the intersex rights movement has allowed me to combine my personal and professional interests in an attempt to understand the social stigma associated with living on the periphery of a sex, gender, and sexuality binary. My hope is that such understanding will help to ameliorate how sex, gender, and sexuality binaries constrain all of us, regardless of genitalia.

### **Applying Gender Structure Theory**

Feminist scholars argue that gender ought to be understood as a stratification system not only residing in individuals but also at the interactional and institutional levels of society (e.g., Butler 2004; Martin 2004; Risman 2004, 1998; Ferree, Hess, and Lorber 1998; Lorber 1994; Connell 1987). Butler (2004), for example, has argued a body embodies the self, the individual, and the society which is in constant dialogue with its limitations. While one could rely on many of the conceptualizations of gender as a stratification system to study social phenomena (e.g., Butler 2004; Martin 2004; Risman 2004, 1998; Ferree, Hess, and Lorber 1998; Lorber 1994; Connell 1987), I rely on Risman's (2004, 1998) gender structure theory. I find it to be a useful theoretical tool that frames 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). At the individual level, Risman argues, is where the development of gendered selves emerges through the internalization of either a male or female identity and the personality attributes of such identities (e.g., Chodorow 1978). The interactional dimension of gender structure involves the sex categorization that triggers stereotypes and gender expectations about women and men that ultimately influences how each is treated by others (e.g., Garfinkel

1967; Goffman 1959). And, last, Risman maintains the institutional dimension of gender structure perpetuates inequality through a variety of structural processes including organizational practices (e.g., Giddens 1987).

In this project, I analyze intersexuality at each of the dimensions in gender structure theory—individual, interactional, and institutional. At the individual level, I examine how intersexuals understand and make sense of their “abnormalities.” Do they try to fit into the gender binary? What are the benefits of adopting a hegemonic male or female gender personality? What are the challenges of rejecting a normative gender personality? At the interactional level, do parents engage in excessive attempts at gender socialization? Do they depart from typical gender socialization when their child’s body defies normative ideologies about sex and ultimately the belief that one’s sex is neatly correlated with gender and sexuality? Parents are of importance because the intersex diagnosis usually surfaces at birth or early in life. They play a key role in imposing—or not—gender expectations on their intersex children. At the institutional level, I examine the medical profession by investigating how medical professionals make sense of and approach the presence of intersexed bodies in a biological binary system where only two sexes are recognized. What current treatment protocols are in place and what do such protocols suggest about the medical institution’s power and control over bodies? I simultaneously study the organizational activism behind shifts in intersex medical management by studying how the dominant organizations within the intersex rights movement have shifted their mobilization strategy away from confrontation in favor of collaboration. Such organizational activism constantly changes the institutional level of analysis.

## Methods

Relying on extensive qualitative data including over three-hundred hours of informal observations in the public meeting spaces of intersex organizational meetings and sixty five in-depth interviews with intersexuals, intersex activists, parents of intersex children, and medical professionals that are experts on such conditions, I address how intersexuality is understood, experienced, and contested by those in the community. Most of the data was collected over a twenty-two month period from October of 2008 to August of 2010. A few additional interviews took place in April 2011. As a feminist sociologist with an intersex condition, I began this project from a unique standpoint having lived my life impacted by intersexuality.

Informants were initially recruited from four organizations: the Intersex Society of North America (ISNA), Accord Alliance, the Androgen Insensitivity Syndrome Support Group-USA (AISSG-USA), and Organisation Intersex International (OII). ISNA was the largest intersex activist organization in world with a mailing list of 3,500 and over 1,000 donors<sup>2</sup> before it closed its doors in the summer of 2008. A new organization, Accord Alliance, run by several former ISNA executive officers including Cheryl Chase, took its place as the largest activist organization within the intersex rights movement. Participants were targeted from these four organizations because, based on my initial assessment of their websites, each organization appeared to be involved in the intersex rights movement in different ways. For instance, ISNA and OII are activist organizations, while AISSG-USA is a support group and Accord Alliance is an organization that seeks to distribute educational resources to medical professionals. Snowball sampling was also employed by asking initial informants to name others who may share different views from their own (Biernacki and Waldorf 1981). To protect confidentiality, all non-medical

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<sup>2</sup> Mailing list and donor information from Preves (2004).

professional informants were asked at the start of the interview to choose a pseudonym that would be used in any presentations or writings produced from the project. In some instances, informants elected to use their given first name, and accordingly, such requests were honored. Medical professionals were assigned a random letter from the alphabet beginning with “A.” Since there are so few medical professionals in the United States that are experts on intersex conditions, only very limited demographic information about each medical informant is presented. The demographic information that is presented was done so at my discretion to protect confidentiality. Informed consent was obtained at the start of every interview before the recording device was turned on. All interviews were transcribed and coded using ATLAS.ti, and after such, all audio files were deleted and destroyed.

Over one-hundred hours of interview data were collected. Each interview ranged from twenty-five minutes to well over three hours. I traveled all around the U.S. from the west coast to the east coast and from the north to the south to conduct the interviews face-to-face in order to gain informant’s trust and establish a level of comfort only possible in person. The actual interviews took place at a location chosen by the informant, which ranged from a semi-private area in a hotel during a support group meeting to a person’s office, home, or place of work. Several interviews were conducted in public spaces such as coffee houses and bagel shops, and one interview was conducted in a rental car. A total of sixty-five individuals including thirty-six adults with intersex conditions, seventeen parents of children with such conditions, nine medical professionals that proclaim to be experts on intersex conditions including surgeons, urologists, endocrinologists and mental health professionals<sup>3</sup>, two social movement organizational board

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<sup>3</sup> Two of the medical professionals I spoke with did not have an MD, PsyD, or PhD degree, yet I refer to such individuals as “Dr.” throughout in order to protect all of my informants.

members that were not medical professionals nor had an intersex condition, and one medical professional that also identified as intersexed were interviewed.

## **Overview**

This dissertation is divided into four parts.

In Part I, I begin with what was immediately clear at the onset of this project: medical professionals conceptualize gender in drastically different ways than do social scientists, an argument supported throughout this dissertation. In chapter one, I trace the development of this distrust in social science to psychologist John Money's (1972) infamous John/Joan case that was later not only discredited but found to be unethical (Colapinto 1997). Fundamental to Money's optimal gender rearing theory was the idea that babies could be socialized to be either boys or girls, regardless of anatomical sex. However, his theory was based on falsified longitudinal data, which I argue left many medical professionals distrustful of social scientists and their research. In chapter two, I explain my methodology, including a discussion of my own standpoint where I focus on my unique position as an intersexual with insider/outsider status. Intersexuality has always been a part of my life, but it was only in the summer of 2008 that I connected with the intersex community. Thus, as a woman living with intersexuality, I was able to personally relate to those living with an "abnormal" body which provided a tremendous amount of legitimacy. At the same time, I was new enough in the community that I had yet to form any opinions about activist organizations or relationships with specific individuals that would potentially interfere with data collection efforts. Almost three years have passed since my first introduction with the intersex community, and it would be misleading to say that I am still an insider/outsider. Throughout this project, I have formed many relationships on all sides of the community.

In Part II, I show how the development and progression of the intersex rights movement is an example of how scientific knowledge has influenced objects of study in ways that support what sociologist Anthony Giddens labels “reflexivity”. It is here that I address why the intersex rights movement has shifted from what I label “collective confrontation” to “contested collaboration” (chapter three).

In Part III, I frame the intersex community as multiple stakeholders who share some similar goals, centered on the amelioration of stigmatization, yet are divided around strategies to reach them. I argue that such tension results from individuals holding very different explanations for the source of intersex stigmatization.

In chapter four, I define the contemporary medical management of intersexuality as a “turf war” over medical jurisdiction over intersexuality. I show how the socially constructed diagnostic process is connected with other social constructions specifically sex, gender, and sexuality. I offer evidence that medical professionals rely on essentialist understandings of gender to justify the continued medicalization of intersexuality, which they currently are doing through a nomenclature shift away from intersex terminology in favor of the new language of disorders of sex development, or “DSDs” for short, first implemented in 2006. I conclude by arguing that medical professionals advocate for this nomenclature shift in order to reassert their authority and reclaim jurisdiction over intersexuality in light of intersex activism that was beginning to successfully frame intersexuality as a social rather than biological problem.

In chapter five, I show the various ways in which intersexuals are impacted by this ongoing “turf war.” In doing so, I highlight the voices of intersexed individuals by using gender conceptualized as a stratification system to show that gender is a prison with very real consequences for both those who live within it (“gender prisoners”) and those who attempt to

play outside it (“gender players”). I argue that gender prisoners who try hard to follow gender rules receive some of the best medical care and much familial support, yet such care and support comes at a cost of being plagued by debilitating fears of failing to fit into the sex binary. Gender prisoners live in fear of failing to exist as “normal” women, and in some cases, “normal” men. On the other hand, gender players reject normative gender rules by playing on the periphery of the gender structure but are confronted with great personal costs, including fractured medical care and often minimal familial support.

This dissertation ends in Part IV with an optimistic conclusion through directions for social change. However, before I introduce such strategies, I offer two overlapping explanations for why the intersex rights movement divided when it did, each connected to John Money. After John Money’s research lost its credibility, I argue medical professionals refused to engage in any social science scholarship having been misled for decades by Money’s falsified data. As a result, medical professionals returned exclusively to biological explanations of gender, as evident in the reframing of intersexuality as a DSD. The second explanation is grounded in Taylor’s (1989) study of the women’s movement where she argues movements “contract and hibernate, sustaining the totally dedicated and devising strategies appropriate to the external environment” (Taylor 1989, p. 772). Although intersex activists experienced success in the 1990s through their newly formed intersex rights movement which was fueled by gender scholarship (e.g., Chase 1998b), some intersex activists have now decided to abandon gender scholarship altogether in order to collaborate with medical professionals. While such collaboration is contested by other intersex activists, it remains the dominant mobilization strategy. Taylor’s (1989) argument would suggest the dominant intersex activists wanted to solidify their gains after John Money was exposed, and they did so by going into temporary abeyance.

Although a deconstruction of the gender prison would most certainly lend itself to a permanent end to the stigma, shame, and secrecy faced by intersexuals, such a task is a long-term and cumbersome process that does not offer much immediate assistance to those born with “abnormal” bodies. While I most certainly advocate for those invested in wrestling with the gender prison to continue with their efforts to overthrow gender stratification and the inequalities that rests within it<sup>4</sup>, I end with a more practical strategy for the immediate reduction in intersex stigma, shame, and secrecy centered on a set of tools I see as necessary for a liberatory transformation. These tools include: 1. the elimination of medically unnecessary genital surgeries that by default define individuals as “abnormal”, 2. true collaboration with medical professionals as opposed to one characterized by superficial collaboration, 3. connecting with others similarly situated through support groups that ought to move toward being more inclusive, 4. overcoming the fear of public exposure, and most importantly, and 5. recognition that sex, gender, and sexuality are independent, and not always connected, social constructs where gender inequality is maintained, reproduced, and perpetuated.

### **An Insider/Outsider Within**

My personal experience with intersexuality has substantially shaped my career trajectory in unimaginable ways of which this project is evidence. There is no question that my lived familiarity with intersexuality has shaped this project from conceptualization to data collection to analysis. However, throughout each stage, I have stayed true to feminist methodologies. I supplemented information my participants offered during often emotionally intense interviews with ethnographic observations. I recognized patterns when I found them, and, most importantly, I questioned data that seemed to deviate. This process involved returning to the data on

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<sup>4</sup> Of course, as a gender scholar I do believe all of us regardless of our training should be invested in such a project given the inequality embedded within the gender stratification system.

numerous occasions to revise typologies I constructed. There were many times throughout data collection that I thought I found a pattern only to have it disrupted after an incredibly informative interview. Following sociological tradition, I continued this process until I was confident the patterns I observed were as stable and predictable as possible. In the end, I imagine some will read this analysis with trepidation and/or skepticism given my position in the community, and I welcome such readings. However, I ended data collection convinced I captured an accurate account of the United States intersex community at this point in history. This project has been incredibly invigorating for me personally and professionally, and I hope it is for others regardless of their connection to intersexuality or the intersex community.

## 1. GENDER ACROSS DISCIPLINES

What is gender? This question has been studied in virtually all disciplines including biology, psychology, and sociology. It has been conceptualized as a naturally occurring biological outcome of reproductive anatomy and consequently strongly correlated with sexuality, an identity, or as a stratification system tied to inequality. There is no question that the definition of gender relied on is tied to the discipline from which one is situated. Yet, there has been surprisingly little discussion about the similarities and differences in competing conceptualizations of gender. Intersexuality, a biological condition where one's sex chromosomes do not usually match one's phenotype at birth, forces an investigation of the integration of the various meanings of gender. While intersexuality has been referred to by various names throughout time by different people from hermaphroditism to disorders of sex development, it is studied across disciplines. Born with "abnormal" bodies, intersexuals do not, quite simply, fit neatly into narrow definitions of sex, gender, nor sexuality. The result I argue is that intersexuality provides a trope for theoretical discussions among academics at a time when gender complexities are at the core of intersexual stigmatization.

Conceptualizations of gender have developed differently across disciplines, albeit with a brief period of overlap in the 1970s when psychologist John Money (1972) introduced his "gender dimorphic behavior" theory. Fundamental to Money's gender dimorphic behavior theory was the idea that babies could be socialized to be either boys or girls, regardless of anatomical sex. However, since the 1970s, conceptualizations of gender have developed in different directions. This divide emerged when one of Money's most infamous case studies, and then much of the rest of his work, was discredited because of falsified data and unethical research

practices. In the pages that follow, I outline these various conceptualizations of gender. The medical profession, for example, stopped taking gender scholarship seriously after Money's problematic research was exposed, and now treat gender scholarship with great suspicion and scrutiny.

I begin this chapter with a history of sex and gender in twentieth century science (e.g., Bell 1916) before turning to a discussion of John Money's (1972) gender socialization thesis and then the reasons it was discredited (e.g., Colapinto 2000, 1997). I end with contemporary conceptualizations of sex and gender drawing attention to how such conceptualizations vary by discipline (Holterhus et al. 2009; Brizendine 2006; Lippa 2005; Martin 2004; Risman 2004; Cahill 2003; Cooke et al. 1998; Ferree, Hess, and Lorber 1998; Collaer and Hines 1995; Lorber 1994; Oudshoorn 1994; Acker 1992, 1990; Williams 1992; Zimmer 1988; Connell 1987; West and Zimmerman 1987; Arnold and Gorski 1984; Kanter 1977). My ultimate goal is to invite the medical profession, as well as intersex activists, to re-engage with gender scholarship by taking seriously new conceptualizations of gender not only tied to behavior or identity but also to power and privilege.

### **The History of Sex & Gender in 20<sup>th</sup> Century Science**

The idea that gendered behaviors are prescribed by our DNA and reinforced during gestational development has real implications for all of us, especially those with biological bodies that defy normality. Endocrinologists, medical doctors with expertise on the production, maintenance, and regulation of hormones, have long been interested in the relationship between sex hormones and sex differences. From early on, endocrinologists believed masculinity and femininity were the result of sex hormones (Lillie 1939). For instance, it was believed that:

In the higher vertebrates, the mechanism of sex differentiation is taken over by extracellular agents, the male and female sex hormones (Lillie 1939, p. 7-8)

Sex hormones were, in short, viewed by endocrinologists as the “chemical messengers of messengers of masculinity and femininity” (Oudshoorn 1994, p. 22). These claims that males and females are hormonally different have been at the heart of debates on sex based inequalities. For example, early sex hormonal arguments that maintained women and men are biologically destined for different futures (e.g., Thompson 1914; Heape 1913) kept women from obtaining higher education while also legitimizing women’s confinement to the home (see Long Hall 1976).

In essence, then, gendered behaviors were seen as the direct result of sex hormones. In other words, sex hormones were believed to predispose an individual to act in masculine or feminine ways. William Blair Bell, a British gynecologist, made this explicitly clear in his 1916 publication where he argued that “the normal psychology of every woman is dependent on the state of her internal secretions, and...unless driven by force of circumstances—economic and social—she will have no inherent wish to leave her normal sphere of action” (Bell 1916, p. 129). The theory that sex hormones explains gendered behaviors rested on three assumptions: first, males have testosterone while females have estrogen with no overlap, second, sex hormones exclusively serve to influence reproduction and sex, and third, sex hormones were believed to be distinct from one another with each serving a unique purpose that could only be offset through exposure to the directly oppositional sex hormone.

However, a theoretical roadblock emerged when estrogen was detected in the urine of horses (e.g., Zondek 1934a,b) leading sex endocrinologists to speculate that human bodies contain both testosterone and estrogen (e.g., Evans 1939; Parkes 1938; Zondek 1934a,b; Siebke

1931; Frank 1929; Laqueur 1927). Sex hormones were found to serve a purpose not only in the realms of reproduction and sex, but also in “multiple body systems that are not sex specific, such as liver growth and nitrogen metabolism” (Jordan-Young 2010, p. 23). Research on rats, guinea pigs, and the like challenged the assumption that sex-specific hormones would bring about gender specific behavior (Fausto-Sterling 2000). Male laboratory animals exposed to female sex hormones didn’t engage in feminine behaviors. The same was true with female laboratory animals that were exposed to male sex hormones. Scientists, quite simply, couldn’t accurately change an animal’s “gendered” behaviors. Research on homosexual men who exhibited feminine behaviors also challenged the alleged connection between sex hormones and behaviors (for details see Jordan-Young 2010; Fausto-Sterling 2000; Sengoopta 1998; Oudshoorn 1994). Homosexual males who had their testes replaced by transplant with the testes of heterosexual males did not experience any changes in their feminine behaviors (e.g., Jordan-Young 2010; Fausto-Sterling 2000; Sengoopta 1998; Oudshoorn 1994).

This theoretical roadblock in explaining gendered behaviors as the result of biological predisposition wouldn’t last for long. In 1965, William Young, Robert Goy, and Charles Phoenix, would pick up where the sex hormones critique left off by exploring the role of the human brain on prescribing gendered behaviors. Young, Goy, and Phoenix (1965) would come to maintain “the realization that the nature of the latent behavior brought to expression by gonadal hormones depends largely on the character of the soma or substrate on which the hormones act. The substrate was assumed to be neural” (Young, Goy, and Phoenix 1965, p. 179). In other words, researchers believed sex differentiated brains might explain why males and females responded differently to sex hormones (Young et al. 1965; see also Phoenix et al. 1959).

This was quite a provocative claim when it was made, as it classified the brain as just as much a reproductive organ as are our genitals. The argument was that male and female brains are as biologically different as are sperm producing testes and egg producing ovaries. The brain was believed to account for sexual differentiation as well as one's sexual orientation and gendered behaviors (Phoenix et al. 1959). The findings, derived from laboratory research on the mating behaviors of guinea pigs, correlated sex with sexuality (Phoenix et al. 1959). William Young and his colleagues maintained:

Attention is directed to the parallel nature of the relationship, on the one hand, between androgens and the organization of the neural tissues destined to mediate mating behavior in the adult (Phoenix et al. 1959, p. 369).

These claims, although when first published were considered preliminary by the researchers, made waves throughout the medical profession. The impact was so substantial that the notion of a "brain sex" remains prevalent today.

In some ways, then, claims that gendered behaviors are the product of "brain sex" is a complex continuation of earlier sex hormone arguments. While historical arguments maintained sex hormones, and sex hormones alone, explained gendered behaviors, brain sex theories suggest sex hormones during gestation result in sex differentiated brains. In other words, brains are now seen as the intervening link between sex hormones and gendered behaviors.

This is not to say that the idea of a brain sex has been without its critics. However, while brain sex theories have been challenged and critiqued (e.g., Jordan-Young 2010; Kaiser et al. 2009; Sommer et al. 2008; Vogel, Bowers, and Vogel 2003; Fausto-Sterling 2000; Epstein 1996), they have not lost legitimacy and credibility (e.g. Brizendine 2006; Lippa 2005; Cahill 2003; Udry 2000). Instead, I argue brain sex theory is experiencing a resurgence in the medical

profession. It currently is being used to explain everything from gender differences in reasoning to sexual variation, which I return to later (Holterhus et al. 2009; Brizendine 2006; Lipka 2005; Cahill 2003; Cooke et al. 1998; Collaer and Hines 1995; Oudshoorn 1994; Arnold and Gorski 1984). In the sections that follow, I attribute this resurgence in brain sex to a general distrust in social science that emerged when psychologist John Money's gender socialization theory was discredited due to unethical research practices and falsified data.

### **Gender as the Result of Socialization**

The psychologist John Money was very influential to scholars of all disciplines during the 1970s, 80s, and 90s. In 1972, John Money and one of his students, Anke A. Ehrhardt, published *Man & Woman, Boy & Girl: Differentiation and Dimorphism of Gender Identity from Conception to Maturity*. Although Money and Ehrhardt argued that the human brain was at least somewhat influenced by hormonal exposure during gestation (see, for example, their chapters "Fetal Hormones and the Brain: Human Clinical Syndromes" and "Gender Dimorphism in Assignment"), they maintained that childhood gender socialization was most significant in explaining an adult's gender identity. To support their argument, they cited their clinical data which consisted mostly of intersexuals. Money and Ehrhardt concluded:

The noteworthy lack of masculinization in fetal androgenization pertains to those pathways of the brain that subsequently will mediate love and eroticism in response to a mating partner. Evidently, the deciding factor as to the characteristics of the sexual mate as male or female operates postnatally and not prenatally (Money and Ehrhardt 1972, 103).

Money and Ehrhardt's (1972) empirical support for the gender socialization thesis would serve as a respectable go to example for gender scholars in the social sciences to refute claims that gendered behaviors were biologically determined. Although gender scholars were working

with different terminology notably “sex role socialization,” the ideas behind their theoretical claims were in line with Money’s gender dimorphic behavior theory. Kimmel (2008) concisely summarizes sex role socialization theory:

Sex role theory overemphasizes the developmental decisiveness of early childhood as the moment that gender socialization happens. Developmental psychologists have provided compelling evidence concerning the acquisition of gender identity in early childhood. Through socialization, especially in families and schools, the basic elements of gender identity are established, the foundation laid for future elaboration and expression (Kimmel 2008, 106-107).

Money’s research was extremely significant to gender scholars in the social sciences because it was “hard” evidence of their sex role socialization thesis. Money, in short, had empirical evidence from a clinical setting. This is not to say that his work was without criticism. In Fausto-Sterling’s (1985) *Myths of Gender: Biological Theories about Women and Men*, she primarily refuted brain sex evidence by critiquing the objectivity scientists responsible for such purport throughout their research. Yet, at the same time, Fausto-Sterling (1985) also critiqued scholars like Money and Ehrhardt (1972) for routinely basing their analysis on hegemonic gender and sexuality stereotypes.

Money’s research also had implications beyond feminist scholarship, most notably around the treatment of intersexuality. In the 1950s and 1960s, technological advancements in the medical profession led to the discovery that “normally” bodied males were distinguishable from females by their sex chromosomes, XY for males and XX for females (Moore and Barr 1955; Moore, Graham, and Barr 1953; Barr and Bertram 1949). Although it is true that intersexuality can result in outwardly obvious ambiguous genitalia, it is also true that many intersex conditions are not noticeable through external examination. In either case, but especially

in cases where one's external genitalia is ambiguous enough that doctors are unsure what sex the infant is by physical examination alone, doctors could find solace in Money's theory.

### **Gender Dimorphic Behavior/Sex Role Socialization Theory and the Medical Profession**

Gender scholarship, notably Money's gender dimorphic behavior theory, provided surgeons the assurance, and ultimately confidence, to surgically treat intersexuality. While other gender scholars were proposing their own take on understandings of gender under the theoretical umbrella of sex role socialization theory (Bem 1974), the medical profession was fixated on Money's claims given they were derived from empirical tests in a clinical medical setting unlike the theoretical claims posited by other gender scholars. Money's research was the closest to a positivist paradigm, which medical professionals have been trained to work within. Although the medical profession never really engaged with gender scholarship from outside of the safety of the medical arena and the positivist claims from which it operates, the fact that medical professionals were even engaging with theoretical claims outside of a purely biological space was incredible progress. In a way, the presence of intersexuality necessitated such. Regardless of the surgical decision to construct a vagina or attempt to construct a penis, an intersex infant was believed to be able to live a normal life providing that he or she was socialized in accordance with his or her surgically constructed sex. This assumption necessitated a belief in a gender socialization theory, whether Money's gender dimorphic behavior theory or Bem's sex role socialization theory.

One example of successful collaboration between medical professionals and gender scholars would be the now defunct Gender Identity Clinic at Johns Hopkins Hospital. The clinic, which Money co-founded in 1966, was for decades the state of the art center to medically treat

intersexuality and transsexuality (Distinguished 1986). Money and his team received referrals from medical doctors across the country. In 1985, Money was even awarded the prestigious Distinguished Scientific Award for the Applications of Psychology by the American Psychological Association. The committee's decision to grant Money the prestigious award can be summarized in an excerpt from the April 1986 issue of *American Psychologist* where he was described as having made:

unparalleled contributions to theoretical analysis and clinical treatment in human sexuality. He originated the seminal concepts of gender identity and gender role which form a cornerstone in all modern theories of sexuality. His extensive contributions to theory and research are characterized by a biosocial perspective which combines animal experiments with ethnological reports, and by a longitudinal approach extending from prenatal sex determination to gender role changes during old age. His clinical contributions include effective hormonal treatments of male sex offenders, hypogonadal impotence, and of virilism in congenital adrenal hyperplasia. He has excelled in psychological management of families having children with symptoms of intersexuality (Distinguished 1986, p. 354).

With such reputation, the medical profession, quite simply, could not ignore Money's gender dimorphic behavior theory. Even his harshest professional critic, Dr. Milton Diamond, a prominent and powerful Professor of Anatomy, Biochemistry, and Physiology at the University of Hawaii, had to at the very least engage with Money's claims (Diamond 1979, 1978, 1976, 1968, 1965; see also Gadpaille 1980; Imperato-McGinley et al. 1979; Zuger, 1975, 1970). For example, in response to Money's research, Diamond argued in 1982:

My own research and clinical experience in dealing with homosexuals, transsexuals, and other individuals with various sexual and gender identities while on the Board of Directors of the Hawai'i Sexual Identity Center and as a medical school faculty member have led me to suspect otherwise, and I have several times challenged the correctness of the theory and the validity of the recommended practice as well as the predicted success of the outcome of this case (Diamond, 1965, 1968, 1976, 1978, 1979). Others, too, have questioned the theory and practice (Zuger, 1970, 1975; Gadpaille, 1980).

Although some of Money's medical peers remained critical of his theories, he would routinely be cited as evidence of the gender socialization thesis having published "approximately 300 scientific papers, 75 scholarly reviews and textbook chapters, and 11 books [either] authored [or] coauthored, edited, [or] coedited" (Distinguished 1986, p. 355).

### **John Money's John/Joan Scandal and the Beginning of His Professional Deterioration**

In the late 1990s, Money and his team would be faced with their harshest critic, a former patient by the name of David Reimer. In *Man & Woman, Boy & Girl*, Money and Ehrhardt (1972) relied on their unprecedented case study of identical twins to support their gender socialization argument. The twin boys highlighted in the case study were, unlike the majority of patients Money and his team treated, genetically "normal" males born on August 22, 1965. Circumcision was not considered until months later when their mother noticed that they were having difficulty urinating because of unnecessary foreskin complications, a treatable condition known as phimosis. On April 27, 1966 the twin boys were scheduled for the routine circumcision procedure. However, one of their sons, who would eventually be known as David Reimer, was subjected to a "surgical mishap [during the circumcision procedure] at the age of seven months in which the penis was ablated flush with the abdominal wall" (Money and Ehrhardt 1972, p. 118). Worried that David would never live a normal life with a severely "abnormal" penis, his parents contacted Money and his team for medical advice. Money assured them that he had a solution. Money and his team would surgically remove what was left of David's penis and in its place construct a vagina. As long as the parents socialized their sex reassigned child as a girl, their problem would be solved. In Money and Ehrhardt's own words:

In particular, [the parents] were given confidence that their child can be expected to differentiate a female gender identity, in agreement with her sex of rearing. They were broadly informed about the future medical program for their child and how to integrate it with her sex education as she grows older. They were guided in how to give the child information about herself to the extent that the need arises in the future; and they were helped with what to explain to friends and relatives, including their other child. Eventually, they would inform their daughter that she would become a mother by adoption, one day, when she married and wanted to have a family (Money and Ehrhardt 1972, 119).

The baby was “successfully” surgically modified, and through Money’s encouragement, the baby’s parents engaged in extreme gender socialization in an effort to reinforce their baby’s sex reassignment. John Money would come to publish extensively on what would be known in academic literature as the John/Joan case (e.g., Money and Tucker 1975; Money 1973; Money and Ehrhardt 1972). Although Money long had his critics (e.g., Diamond 1979, 1978, 1976, 1968, 1965; Gadpaille 1980; Zuger 1975, 1970), the John/Joan case was used for decades as sound empirical evidence that supported the gender socialization hypothesis.

However, in 1997, Diamond and Sigmundson offered sound evidence that Money’s theoretical claims derived from the John/Joan case were based on falsified data. It was later that same year, on December 11, 1997 to be exact, that the credibility of the John/Joan case, and ultimately Money himself, would for once and for all be challenged in *Rolling Stone* of all places by John Colapinto—a journalist. In the feature piece of the 775<sup>th</sup> issue of *Rolling Stone*, Colapinto reports:

For 25 years, the case of John/Joan was called a medical triumph — proof that a child’s gender identity could be changed — and thousands of “sex reassignments” were performed based on this example. But the case was a failure, the truth never reported. Now the man who grew up as a girl tells the story of his life, and a medical controversy erupts (Colapinto 1997, 54).

In Colapinto's account, David Reimer shared that he was incredibly unhappy with his sex reassignment and imposed gender identity. He also validated essentialist claims by sharing that while growing up he never felt comfortable as a girl and always knew something wasn't right.

Colapinto reports:

For when Joan daydreamed of an ideal future, she saw herself as a 21-year-old male with a mustache and a sports car, surrounded by admiring friends. "He was somebody I wanted to *be*," [David Reimer] says today, reflecting on this childhood fantasy. By now Joan was ever more certain that submitting to vaginal surgery would lock her into a gender in which she felt increasingly trapped.

Colapinto's news story would eventually earn him the prestigious *American Society of Magazine Editors* (ASME) award. And, several years later, Colapinto would publish a book length account of David Reimer's story in *As Nature Made Him: The Boy Who Was Raised as a Girl*. Sadly, at the age of thirty-eight, David Reimer committed suicide.

### **Medical Professionals Betwixt and Between Social Theory**

There was a period of change around the medical management of intersexuality in the 1990s due to pressures from intersex activists and their newly formed intersex rights movement. I discuss the formation and current direction of the intersex rights movement in depth in chapter three, but in short, I show medical professionals were forced to listen to intersex activists who demanded that they stop surgically modifying their bodies. Fueled by feminist scholarship (e.g., Fausto-Sterling 1993; Kessler 1990), intersex activists organized together to collectively claim medical professionals were performing unnecessary sex assignment surgeries under the guise that such was necessary for intersexuals to avoid malignancy (Preves 2003, 2002, 2000). In the process, intersex activists challenged binary understandings of sex by claiming a "third sex" identity

(Turner 1999). However, when John Money was discredited (Colapinto 2000; 1997), this progress would come to an end.

The medical profession found itself perplexed. Medical professionals could no longer treat intersexuality under the security of Money's gender dimorphic behavior theory which suggested gender was the result of childhood socialization. The result was a resurgence of the medicalization of intersexuality especially around claims that the body has a true biological sex, and a binary one at that.

In 2000, the *American Academy of Pediatrics* instituted guidelines for the treatment of infants born with intersexuality (Committee 2000). The guidelines recommended that the parents of intersex infants should be informed that "abnormal appearance can be corrected and the child raised as a boy or a girl as appropriate." This does not presume gender is the product of childhood socialization, as the guidelines also stated that the gender assignment should be determined after discovery of "true" sex. The guidelines indicated that a true sex can be reached by a number of factors including "fertility potential" and "capacity for normal sexual function." Here, we can see a return to the assumption that sex, gender, and sexuality are not only all neatly correlated but also grounded in our biological bodies.

In a 2010 *Urology* article, pediatric physicians Jennifer Yang, Laurence Baskin, and Michael DiSandro acknowledge that Money was discredited by the medical profession. They specifically state, "[d]espite the eventual discovery of the inaccuracy of the reported success of this particular case, the concept of nature vs nurture has remained influential in the management of infants and children with ambiguous genitalia" (Yang et al. 2010, 154). Yet, at the same time, they go on to say that:

[T]here has been increasing evidence of the role of genetic and prenatal factors in influencing an individual's ultimate gender identity. The potential affect of male hormone levels during fetal development and its influence on the development of the central nervous system remains an important factor (Yang et al. 2010, 154).

Yang and her colleagues are an example of how biological explanations for gender are now privileged by medical professionals over arguments with more complex biological and social interaction.

### **A Resurgence of Brain Sex Theories**

Although arguments about brain sex first originated in the late 1950s and early 1960s (Young et al. 1965; Phoenix et al. 1959), in the last twenty or so years that there has been a resurgence of such research (Holterhus et al. 2009; Brizendine 2006; Lippa 2005; Cahill 2003; Cooke et al. 1998; Collaer and Hines 1995; Arnold and Gorski 1984). Cooke et al.'s 1998 review article concluded that "there is ample evidence of sexual dimorphism in the human brain, as sex differences in behavior would require, but there has not yet been any definitive proof that steroids acting early in development directly masculinize the human brain" (quoted in Diamond 2009, p. 625). Hrabovszky and Hutson (2002) and Collaer and Hines (1995) claim prenatal androgen exposure is strongly correlated with postnatal sex-typical behavior. Juntti, Coats, and Shah (2008) have more recently argued that, at least for mice, sex hormones are capable of controlling gender-specific behavior. In other words, contemporary brain sex theories have not replaced explanations for gendered behaviors centered on sex hormones. Rather, brain sex theories of the 21<sup>st</sup> century maintain that brains are the intervening link between sex hormones and gendered behavior.

Intersex individuals are an exemplary group of research subjects to study the relationship between gender behaviors and hormonal exposure. In fact, in the summer of 2009, I was invited to participate in a study on brain sex which was being conducted at Emory University in Atlanta, Georgia. Research subjects included self-identified women with complete androgen insensitivity syndrome—a condition where prenatal androgen exposure was completely blocked because of a chromosomal “abnormality”—and a control group which consisted of “normal” XX women. Research participants were flown to Atlanta, Georgia to have an MRI of their brain while simultaneously being exposed to a variety of pornographic images. Although not directly related to the study I was invited to participate in, similar studies on intersexuals with congenital adrenal hyperplasia (Berenbaum and Resnick 1997; Ehrhardt and Meyer-Bahlburg 1981) have found that individuals “exposed to androgen during gestation” tend to “engage in more rough play compared with other girls” (Yang et al. 2010, p. 154). Similarly, Berenbaum and Bailey (2003) have shown that “[f]emales with [congenital adrenal hyperplasia] have been shown to have higher aggression scores compared with female controls, suggesting that prenatal androgens contribute to human aggression” (Yang et al. 2010, p. 154). In line with assumptions that sex, gender, and sexuality are neatly correlated, research has shown that intersexuals with congenital adrenal hyperplasia are more likely to identify as bisexual than their non-intersexual counterparts (Ehrhardt and Meyer-Bahlburg 1981). Prenatal hormonal exposure has also been shown to overpower any postnatal hormonal interventions. Yang et al. (2010) notes that “[s]ex-atypical behavior has been found to be associated with the degree of inferred prenatal, but not postnatal, androgen excess” (Yang et al. 2010, p. 155; see also Berenbaum, Duck, and Bryk 2000).

Medical research such as that cited here is evidence that medical research on brain sex ignores contemporary gender scholarship. There has been a sharp return to biological explanations for sex, gender, and sexuality, and in the process, the tacit assumption is that all are neatly correlated. The medical profession's search for an intersexual's "true sex" through scientific discovery is not new, but what is new in this research is that gender is exclusively grounded in biology, and therefore, also subjected to scientific discovery. This turn of events were at least accelerated if not created by the rejection of John Money and his unethical research practices and falsified data. In result, along with Money, the complexity of social life was also rejected.

### **Did Gender Scholars Avoid the John Money Crisis?**

Colapinto's (2000, 1997) exposure of David Reimer's story and ultimately the falsified evidence behind Money's John/Joan case shocked anyone who read the story, including gender scholars. However, in the 1990s, gender scholars had moved beyond conceptualizing gender as exclusively an individual personality characteristic developed during childhood socialization. Sex role socialization theory, their terminology for John Money's gender dimorphic behavior theory, was problematized much earlier when Sandra Bem's Sex Role Inventory ran into methodological complications (Locksley and Colten 1979; Pedhazur and Tetenbaum 1979; Edwards and Ashworth 1977).

In the 1970s and 1980s, masculinity and femininity were believed to be independent measures distinct from biological bodies (Bem 1974). However, this wasn't empirically supported (e.g., Locksley and Colten 1979; Pedhazur and Tetenbaum 1979; Edwards and Ashworth 1977). Sex role socialization theory was heavily critiqued by gender sociologists for

four overlapping reasons (see Kimmel 2008). First, sex role terminology was said to minimize the importance of gender by associating it with role terminology as if one chooses to occupy a gender role as they do others roles in society like mother, teacher, and the like (e.g., Lopata and Thorne 1978). Second, sex role theory implied that masculinity and femininity were singular and static measures, which is problematized when one considers how each varies across time and space. Third, sex role socialization theory maintained that femininity and masculinity were non-relational measures, yet “[s]urveys indicate[d]...that men construct their ideas of what it means to be men *in constant reference* to definitions of femininity. What it means to be a man is to be unlike a woman” (Kimmel 2008, p. 103; e.g., Connell 1995). Last, sex role theory was critiqued for overlooking ways in which gender is situational, or more specifically, relies considerably on the context with which it is measured (Rhode 1997).

Left to work through this theoretical roadblock, socialization became controversial to explain gendered behavior. Scholars began studying gender inequality in various settings. There were claims that organizational structures in the form of unequal opportunity, power, and reward were at the core of gender inequality. Kanter’s (1977) classic *Men and Women of the Occupation* is such an example. However, theories such as Kanter’s (1977) were eventually challenged (e.g., Acker 1992, 1990; Williams 1992; Zimmer 1988). Gender scholars offered empirical evidence that one’s gender matters in terms of opportunity and reward beyond tokenism (Williams 1992; Zimmer 1988). Organizations were also beginning to be defined as gendered spaces (Acker 1992, 1990, 1988). Arguments were being made about the presentational link between bodies and gender (West and Zimmerman 1987). West and Zimmerman (1987) wrote their classic argument that gender is something we are held morally accountable to perform, as our biological

sex isn't visible in non-intimate settings (West and Zimmerman 1987). In other words, we all "do gender" (West and Zimmerman 1987).

Most recently, there has been considerable effort to conceptualize gender as a stratification system that exists beyond individual characteristics (e.g., Martin 2004; Risman 2004, 1998; Ferree, Hess and Lorber 1998; Lorber 1994; Connell 1987). Most sociologists now define gender as a stratification system which controls, operates, restricts, and/or encourages certain actions in individuals and in all aspects of society including the economy, family, religion, and the like. In the paragraphs that follow, I focus on three of these leading multidimensional gender frameworks (e.g., Martin 2004; Risman 2004; and Lorber 1994).

In 1994, Lorber argued gender is a social institution that can and should be empirically studied and approached like other societal institutions. She contended that the social institution of gender is central to our day-to-day lives, and thus as it is today, is unavoidable. Gender is found inside and outside of our homes through a variety of social structures operating through micro and macro level politics that effect domestic work, family life, and the workplace. Lorber concluded that gender, as a historically established institution, has created and perpetuated differences between men and women and existed to create gender inequality. Although Lorber presents gender as a social institution, she does not suggest that it is impossible for it to be challenged and or deconstructed. As with any social construct, Lorber maintains that since gender was constructed by society it can equally be deconstructed (Lorber 2005, 1994). Lorber (2005, 1994) argues gender, or for that matter any other demographic variable, should not be the means by which individuals are classified, for privilege and inequality are embedded within categorization practices. She challenges us to eliminate gender inequality, but also acknowledges

that “society has to be structured for equality” for such to occur (Lorber 1994, p. 294; see also Lorber 2005). Gender equality can only occur, Lorber maintains, when all individuals are guaranteed equal access to valued resources. Only then will we truly see gender equality.

Building on Lorber’s (1994) conceptualization of gender as a social institution, Martin (2004) presents twelve different criteria that characterize institutions to document the pervasiveness, salience, and existence of gender as a social institution. Martin maintains that institutions include, involve, and/or are capable of: (1) collectivities of people; (2) existence across time and space; (3) reoccurring social practices; (4) constrain and facilitating behavior; (5) expectations, rules/norms, and procedures; (6) exist because of active embodied agents; (7) meaningful and embedded throughout participants’ identities; (8) include a legitimating ideology; (9) are infiltrated with conflict; (10) repeatedly change; (11) are controlled by power; and (12) are inseparable from individuals. Martin concludes that gender meets each of these criteria, and thus suggests that gender should be studied like other social institutions such as the family and religion.

Risman (2004, 1998) offers an alternative gender framework by conceptualizing gender as a social structure that has consequences at the individual, interactional, and institutional levels. Each dimension helps frame the processes by which gender inequality is produced, maintained, and recreated. The individual level accounts for the development of gendered selves that emerge through the internalization of either a male or female identity. She does not deny there may be some influence of bodies, by shape or size, on how selves develop. For intersexuals, this is heavily scripted, as they must choose an identity consistent with binary sex, gender, and sexuality ideologies that defy their bodies. The interactional dimension of gender structure,

Risman claims, involves using sex categorization to trigger stereotypes about women and men. It is within this dimension that intersexuals are held accountable to live within binary sex, gender, and sexuality ideologies. And last, the institutional dimension of gender structure perpetuates gender inequality through a variety of social processes including sexist organizational practices. For intersexuals, we can see how sex, gender, and sexuality ideologies remain regulated by almost all institutions found throughout society from medicine to government. By incorporating three dimensions, Risman (2004, 1998) critiques the idea that there is a correct way to explain or study gender inequalities while opening up a discussion of causality “between gendered phenomena on each dimension” (Risman 2004, p. 434).

Throughout this dissertation, I analyze intersexuality at each of the dimensions in gender structure theory—individual, interactional, and institutional. At the individual level I ask, how do intersexuals understand their diagnoses? At the interactional level I ask, are intersex identities policed by parents, and if so, in what ways? At the institutional level I ask, how does the medical profession, through its protocols on the medical management of intersexuality, attempt to control sex, gender, and sexuality? Within this level, I also study the mobilization strategies enacted by dominant intersex social movement organizations focusing specifically on how such strategies have shifted over time.

## **Conclusion**

I have explained here why medical professionals have rather recently come to ignore gender scholarship. For a brief period in history medical professionals depended on gender scholarship; however, this changed after John Money’s research was discredited due to unethical research practices and falsified data. The medical profession has since chosen to turn its cheek on gender

scholars. Although gender scholarship historically paved the way for the formation of the intersex rights movement (e.g., Chase 1998b), some intersex activists have now decided to reject it in order to gain legitimacy with medical professionals, while others continue to organize around it (see chapter three). John Money, of course, does not define gender scholarship. As I've shown in this chapter, when Money's John/Joan case was exposed for what it was, gender scholars were beyond it theoretically and therefore able to avoid any crisis. Gender scholars were no longer conceptualizing gender as purely an identity or something based on parental socialization captured through behaviors. They were already conceptualizing gender as a system of stratification far beyond individual characteristics (e.g., Martin 2004; Risman 2004, 1998; Ferree, Hess and Lorber 1998; Lorber 1994; Connell 1987).

It does not matter if gender has a biological component from exposure to prenatal sex hormones and/or in our neural development. What does matter is that gender is real in its consequences, as it plays out in the gender structure. In order to move to a society where gender isn't constraining, Lorber (2005, 1994) has argued persuasively that we must make it visible. We must begin by acknowledging gender structure's existence. Everyone from medical professionals to intersex activists to our neighbors are potential agents of change to end the inequalities found throughout the gender structure. The core of intersexual stigmatization does not rest in being born with an "abnormal" body. Rather, what is at its core is being born into a gender social structure that is invisible and unchallenged by those with the power to promote change.

## 2. METHODOLOGY

Like many of my informants, my experience with intersexuality has left me with some pretty horrific physical and emotional scars. However, it simultaneously has been at the core of my intellectual passion and academic commitment. On January 7, 2010, I met the founder of the intersex rights movement, Cheryl Chase, who after an emotionally intense interview wrote on a piece of scratch paper, “Georgiann, Finish your PhD and change the world!” That note along with a framed picture of us greets me each and every time I sit down at my desk. It is much more to me than memorabilia from the field. It is symbolic of my commitment to the entire community, no matter how divided it is today.

This project was conceptualized shortly after I attended my first Androgen Insensitivity Syndrome Support Group-USA (AISSG-USA) meeting in the summer of 2008. I was initially worried that I would have difficulty gaining access to a community that hasn’t had the most pleasant of experiences with researchers, notably psychologist John Money. However, I was wrong. AISSG-USA was incredibly supportive of my research, as were each of the other organizations I studied. Part of what was clear during data collection was that my personal experience with intersexuality provided an inroad into the field. Many people noted that if I didn’t have an intersex condition or wasn’t the parent of someone who did, they would be reluctant to participate in such a research study. I revisit this in much more detail in the sections that follow.

The type of access, support, and assistance I received in connecting with intersex community members resulted in a tremendous amount of data that I was able to collect in,

relatively speaking, a short amount of time. During data collection, I formed friendships throughout the intersex community. I am not, and will never be, only temporarily connected to the intersex community. My personal experience with intersexuality would, quite simply, never allow for such. I am not only studying “the monkey cage”, I am in it as one of my informants so clearly articulated (Peggy, personal interview).

I couldn't have been in the field at a better time. When I began data collection in 2008, intersex terminology was being highly contested among intersex community members. There had been a controversial 2006 medical consensus statement which advocated for new diagnostic terminology, disorders of sex development (or DSDs, for short) instead of intersex and intersexuality. Initially a handful of medical professionals were the ones advocating for the new DSD terminology. However, soon thereafter, several activists also started advocating for DSD language. Other activists hotly contested this and were adamantly opposed to the new diagnostic terminology. Being in the field during the time when this nomenclature shift was being debated by activists has offered insight into how diagnoses are reinvented and experienced, a central theme in chapters four and five.

The access I was granted in the field—especially given my personal experience with intersexuality—comes with an incredible amount of responsibility. I fully anticipate some community members will take issue with my analyses and the suggestions for change I offer in the conclusion of this dissertation. I demonstrate in chapter three that the intersex rights movement is divided. I'm not outside the debate. I want nothing more than to end the stigma, shame, and secrecy for those born into bodies that defy binary understandings of sex, and ideologies that require sex, gender, and sexuality to be neatly connected. I am committed to this journey, which I believe can be advanced through critical analyses.

In this methodology chapter, I begin with a discussion of access to a rather invisible intersex community. I focus specifically on how and why I developed trust with the community before collecting interview data. I also acknowledge that my personal experiences and observations at organizational meetings helped me ask the right questions during interviews with my informants. After discussing access, I turn to a detailed discussion of how participants were recruited to participate in my study before turning to a description of my informants. I provide as much information as possible about each participant I spoke with within my discretion to protect confidentiality of community members and medical professionals. I then turn to my insider/outsider status to argue that the data I present is unique given how my lived experience with intersexuality offered unique access. I end this chapter by turning the methodological lens onto myself. Using the concept of the looking glass self, I argue that without meaning to, I altered my identity throughout data collection to satisfy how I *believed* I would be perceived by those I was studying, regardless if such perception was warranted or not.

### **Trust Matters**

I began building relationships with key players in the intersex rights movement during my first AISSG-USA meeting in the summer of 2008. I attended the meeting as an individual with CAIS, not as a researcher. Still, at this meeting, I connected with organizational board members, intersex activists, parents of children with intersex/DSD conditions, and medical professionals who are experts on intersexuality. While I received IRB approval in October 2008 (see Appendix), my first interview wasn't conducted until the summer of 2009. I believed from early on that building a rapport with key informants is critical to the research process—especially in this instance where intersexuals have had horrific experiences with the research process. I also

wanted any individuals I spoke with to feel that they could trust not only me but also the research process. Interview data is only as good as the trust present during the actual interview (e.g., Whyte 1984 & Oakley 1981). Whyte (1984), for instance, identifies rapport as the first concern of the interviewer. I would also argue that it is the most important part of an interview. Without rapport, why would any informant feel compelled to share their information and knowledge with a researcher?

### **Recruitment**

I entered the field with an intent to interview up to one-hundred individuals affiliated with the intersex rights movement, or until the point when no new information was being collected, which is commonly referred to as “saturation.” I selected informants based on their current or past involvement with the Intersex Society of North America, Accord Alliance, Androgen Insensitivity Syndrome Support Group-USA (AISSG-USA), and/or Organisation Intersex International (OII). I initially aimed to recruit participants from these four organizations because, based on my assessment of their websites, they appeared to be involved in the intersex rights movement in different ways. In chapter three, I discuss each organization’s formation and development including its goals, mobilization strategies, and membership. In this chapter, I’ve chosen to focus on the informants themselves, which includes individuals with intersex/DSD conditions, the parents of children with intersex/DSD conditions, as well as medical professionals that claim to be experts on intersex conditions. My target population was as follows:

- Individual was a member or past-member of ISNA, Accord Alliance, AISSG-USA, and/or OII and was at least 18 years of age at the time of the interview.

and/or

- Individual was the parent or guardian of an intersexed child whom is affiliated with ISNA, Accord Alliance, AISSG-USA, and/or Organisation Intersex International and was at least 18 years of age at the time of the interview.

and/or

- Medical professional who self-identifies as an expert of intersex conditions and was at least 18 years of age at the time of the interview.

I recruited current and former members affiliated with ISNA, Accord Alliance, the AISSG-USA, and/or OII to participate in my research in various ways:

- An invitation to participate was distributed electronically to members involved with ISNA, Accord Alliance, AISSG-USA, and/or OII that have publicly available contact information.
- The invitation to participate was also circulated at the 2009 and 2010 AISSG-USA's annual meeting.

The invitation that was circulated provided details about the study including its purpose. The invitation also emphasized that participation in the research was entirely voluntary and confidential. It also informed potential participants that all interviews would be audio taped unless one requested otherwise.

Many individuals responded to my invitation, especially at the annual AISSG-USA support group meetings. However, in order to access a diverse sample of informants and opinions, I asked participants to introduce me to others in the community, regardless of connection to ASSIG-USA, who may share different views from their own. I continued this process of snowball sampling until I uncovered no new data (see Becker 1998 & Biernacki and Waldorf 1981). As I implemented the snowball sampling technique, I was careful to ask participants to introduce me to others he or she believes would disagree with his or her position.

Otherwise, I would have obtained little, if any, variation in my sample. Hagedorn (1996) perhaps best outlines the problems with snowball sampling if one isn't careful when he or she samples.

Informed consent was obtained at the start of every interview and before the recording device was turned on and interviewing began. Before documenting a participant's consent with a consent form, I attempted to make sure that he or she understood the study by asking open-ended and non-directive questions, such as "Would you please explain to me what you think I am going to ask you to do?" Every informant was offered a signed copy of the consent form for their records.

Informants were reminded before, and repeatedly throughout the interview, that participation is voluntary. I instructed my informants that they could skip any questions they do not want to answer, request that the recording device be turned off, or terminate the interview at any time without any penalty. During the interviews, I used the interview schedule to address specific content areas. My goal was to have each participant respond to all topics covered in the interview guide. Of course, the questions were, at times, modified in accordance with the participant's responses during the interview, which was scheduled at his or her convenience. The interviews were carried out as follows:

- (N=38) In-Depth Interviews with Organizational Staff: Current and former ISNA, Accord Alliance, AISSG-USA and/or OII staff and members, eighteen years of age and older, who agreed to take part in this research were asked to participate in one or more in-depth interviews. These interviews lasted, on average, one hour, and unless a participant objected, he or she was audio-taped. Interviews were conducted at a location that the participant chose.
- (N=17) In-Depth Interviews with Parents/Guardians of Intersexed Children: Parents or guardians (at least eighteen years of age) of intersexed children who agreed to take part in this research were asked to participate in one or more in-depth interviews. These interviews lasted, on average, one hour, and unless a participant objected, he or she was audio-taped. Interviews were conducted at a location that the participant chose.

- (N=10) In-Depth Interviews with Medical Professionals: Medical professionals (at least eighteen years of age) who self-identify as intersex experts were asked to participate in one or more in-depth interviews. These interviews lasted, on average, one hour, and unless a participant objected, he or she was audio-taped. Interviews were conducted at a location that the participant chose.

As with any research study that involves data collection, there were possible risks and benefits to those who participated. These risks included the possibility of distress from answering interview questions which necessitated discussing information that was incredibly personal and sensitive. However, these risks were no greater than what individuals would encounter during everyday life conversations or interactions. During data collection, I was concerned that informants might initially be uneasy about being audio-recorded, but I expected participants would feel at ease soon after the interview starts. Such seemed to be the case. While there were a number of occasions during different interviews where individuals requested to go “off record”, such occasions were few and far between. Of course, participants had the option to continue with the interview without being audio-recorded, and all participants were reminded that they could elect to withdraw from the research study at any time. All of my informants agreed with being audio-recorded, and every individual that agreed to be interviewed continued with the interview until its completion. I suspected participants would be concerned about confidentiality and privacy, thus I repeatedly assured them that data that is identifiable or that had the potential to identify them will not be made publicly available at any time. All audio-recordings created during data collection have been destroyed. Throughout this dissertation, and any written work that has already been produced from it, I’ve only used pseudonyms for my informants.

I had no trouble recruiting individuals to participate. Since ISNA, Accord Alliance, AISSG-USA, and OII are organizations affiliated with activism, I anticipated participants would be eager to discuss their activism and affiliation with such organizations that have been a

substantial part of their lives or the lives of their children. This was very true. Once word got around that I, a researcher who was personally impacted by intersexuality, was conducting this study, I was contacted by many who expressed not only a willingness to be interviewed but also a sincere desire to participate. Not surprisingly, I had little difficulty in recruiting medical professionals who self-identify as intersex experts to participate in my study. Given they identify as an intersex expert either in publications or in the intersex community, their interest in participating in my research made sense. It is my understanding that medical professionals who volunteered to participate in the study experienced minimal, if any, distress from their participation, as in order to have been included in the study, the medical professionals needed to self-identify as intersex experts. I speculate that participation in this research was rather enjoyable for medical professionals who identify as intersex experts, for they were discussing a topic that they have spent a great deal of their career mastering. Also, it is probable many of the medical professionals I invited to participate did so out of reciprocity. Medical professionals routinely ask individuals with intersex conditions to participate in their research studies, and as one doctor politely put it when 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.”

### **Data Description**

I obtained extensive qualitative data that includes over three-hundred hours of informal observations in the public meeting spaces of intersex organizational meetings and sixty-five in-depth interviews with intersex activists, parents of intersex children, and medical professionals that are experts on such conditions. The majority of data collection occurred between October of 2008 and August of 2010. However, several additional interviews took place in April of 2011.

Over one-hundred hours of interview data were collected with each interview ranging from twenty-five minutes to well over three hours. Interviews were conducted face-to-face in order to gain informants trust and establish a level of comfort only possible in person. All informants were able to choose the interview location which ranged from public spaces such as coffee houses and bagel shops to a person's office, home, or place of work. A total of sixty-five individuals including thirty-six adults with intersex conditions, seventeen parents of children with such conditions, nine medical professionals that proclaim to be experts on intersex conditions including surgeons, urologists, endocrinologists and mental health professionals, two social movement organizational board members that weren't medical professionals nor had an intersex condition, and one medical professional that also identified as intersexed were interviewed.

Table 2.1 offers select demographic information about each of my informants including their connection to the community (individual with intersex/DSD condition, parent, medical professional, or organizational board member), gender presentation, age, self-reported sexuality, and educational status. Although I've collected far more demographic information about each of my participants than presented here, I've selectively chosen which characteristics about each informant to share with the goal of protecting confidentiality. I strongly believe in disseminating the research presented here beyond the walls of the academy, and the intersex community is incredibly interested in reading it. I've already, for example, received numerous requests from activists, parents, and medical professionals inquiring about my analyses. Since many intersex community members know one another, it is of key importance to be highly selective in which demographic characteristics are presented in order to protect confidentiality. Limiting the quantity of demographic variables is my attempt to do such.

**Table 2.1: Select Demographic Characteristics of Informants (N=65)**

<b>Informant</b>	<b>Background<sup>1,2</sup></b>	<b>Gender Presentation<sup>3</sup></b>	<b>Age</b>	<b>Self-Reported Sexuality</b>	<b>Education Status<sup>4,5</sup></b>
Aimee	Individual	Woman	30-39	Heterosexual	College educated
Alexis	Parent	Woman	40-49	Heterosexual	Some college
Alice	OBM	Woman	40-59	Heterosexual	College educated
Ana	Individual	Woman	30-39	Homosexual	Some college
Ann	Individual	Woman	50-59	Gay	College educated
Bruce	Individual	Man	40-49	Refused	College educated
Caitlin	Individual	Woman	20-29	Queer	Didn't finish HS
Cheryl	Individual	Woman	50-59	Lesbian	College educated
Chris	Individual	Man	50-59	Asexual	College educated
David	Individual	Man	60-69	Asexual	College educated
Donna	Individual	Woman	50-59	Lesbian	College educated
Drew	Parents	Man	30-39	Heterosexual	College educated
Dr. A	Doctor	Man	50-69	Heterosexual	College educated
Dr. B	Doctor	Woman	50-69	Heterosexual	College educated
Dr. C	Doctor	Man	40-59	Heterosexual	College educated
Dr. D	Doctor	Woman	50-69	Unknown	College educated
Dr. E	Doctor	Woman	50-69	Lesbian	College educated
Dr. F	Doctor	Woman	50-69	Heterosexual	College education
Dr. G	Doctor	Woman	40-59	Heterosexual	College educated
Dr. H	Doctor	Man	40-59	Gay	College educated
Dr. I	Doctor	Woman	30-49	Heterosexual	College educated
Dr. J	Doctor	Man	50-69	Homosexual	College educated
Emily	Individual	Woman	50-59	Bi-sexual	College educated
Esther	Individual	Woman	50-59	Lesbian	College educated
Eve	Individual	Woman	20-29	Complicated	College educated
George	Parent	Man	50-59	Heterosexual	College educated
Hannah	Individual	Woman	40-49	Lesbian	College educated
Hope	Parent	Woman	40-49	Heterosexual	Some college
Irene	Individual	Woman	70-79	Bisexual	College educated

Jane	Individual	Woman	Unknown	Heterosexual	Some college
Jeanne	Individual	Woman	40-49	Bi-sexual	College educated
Jen	Parent	Woman	30-39	Heterosexual	Unknown
Jenna	Individual	Woman	30-39	Straight	College educated
Jeff	Parent	Man	50-59	Unknown	College educated
John	Parent	Man	30-39	Heterosexual	College educated
Karen	Individual	Woman	50-59	Straight	College educated
Kelly	Individual	Woman	30-39	Heterosexual	College educated
Kimberly	Individual	Woman	30-39	Lesbian	College educated
Laura	Parent	Woman	20-29	Heterosexual	College educated
Leigh	Individual	Woman	20-29	Queer	College educated
Liz	Individual	Woman	30-39	Heterosexual	College educated
Maria	Individual	Woman	30-39	Bi-sexual	College educated
Mariela	Individual	Woman	20-29	Straight	Some college
Marilyn	Individual	Woman	50-59	Straight	College educated
Marty	Parent	Woman	40-49	Heterosexual	Some college
Mercurio	Individual	Woman	40-49	Lesbian	College educated
Michael	Parent	Man	60-69	Heterosexual	College educated
Michelle	Parent	Woman	40-49	Heterosexual	Some college
Millarca	Individual	Woman	40-49	Lesbian/Dyke	College educated
Paul	Individual	Man	50-59	Asexual	College educated
Peggy	Individual	Woman	50-59	Heterosexual	College educated
Pidge	Individual	Woman	20-29	Queer	College educated
Rachel	OBM	Woman	40-59	Straight	College educated
Rebecca	Individual	Woman	30-39	Lesbian	College educated
Rosland	Individual	Woman	60-69	Heterosexual	College educated
Sarah	Parent	Woman	50-59	Heterosexual	HS graduate
Shelby	Parent	Woman	30-39	Heterosexual	College educated
Sheryl	Parent	Woman	40-49	Heterosexual	Some college
Skywalker	Individual	Woman	30-39	Heterosexual/Bisexual	College educated
Steve	Parent	Man	50-59	Heterosexual	Didn't finish HS
Stevie	Individual	Woman	40-49	Queer	College educated

Sue	Parent	Woman	50-59	Heterosexual	College educated
Susan	Parent	Woman	50-59	Straight	College educated
Tara	Individual	Woman	20-29	Heterosexual	College educated
Vanessa	Individual	Woman	40-49	Heterosexual	College educated

1. “OBM” refers to an organizational board member who doesn’t have an intersex/DSD condition nor is the parent of someone who does.
2. Two of the medical professionals I spoke with didn’t have a MD or PhD degree, yet I refer to such person as a “Dr.” throughout in order to protect confidentiality.
3. Gender presentation is based off of my perception given hegemonic United States cultural cues. Every informant was categorized into a binary gender presentation of “woman” or “man” without difficulty.
4. “Some college” refers to having completed some college that did not result in a four year degree.
5. “College educated” refers to having completed at least a four year degree.

One demographic characteristic that is of key importance here is social class. The sample from which my analyses are based is, relatively speaking, homogenous in terms of social class. There are two possible explanations for this finding. First, intersexuality only impacts those from more privilege backgrounds. This explanation is clearly not justifiable. The second explanation is two-fold and centered on access to healthcare and embodied cultural capital that provides educated individuals with the tools to seek out intersex social movement organizations. Since my participant recruitment was limited to the four organizations identified above, I had an incredibly difficult time locating folks who did not have a formal higher education. Steve, a fifty something year old high school dropout, is an example. As a parent of a college educated intersexual adult, his daughter was connected with several intersex social movement organizations, he however was not. It was through his daughter that I was able to invite him to participate in my project. When I interviewed Steve over breakfast at an urban diner, I asked him if he felt connected to the intersex community, or more specifically, other parents whose children have intersexuality. He shared:

I dunno about intersex communities. My daughter had this problem, and I want her healthy. I dunno about intersex communities. [Georgiann asks: have you ever searched the internet for more information about intersexuality?] [Steve laughs] 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 get some help right away.

Sarah, a high school graduate without any college education, expressed something similar:

I'm not stupid, but there ain't any reason to go on the internet. [Georgiann asks: do you use email?] [Sarah rolls her eyes and laughs]. No, I don't have time to waste on that shit.

Both Steve and Sarah didn't have the tools that would lead them to intersex social movement organizations. They didn't use the internet, and they didn't see the internet as a source of

resourceful information. This poses a real problem for data collection and any generalizations that are made from the data I've collected.

Most intersexuals, in fact, find out in-depth details about their condition directly from the web pages of these supports groups (Preves 2003). Intersexuals that visit support groups on the Internet usually end up joining their email list serves and telephone trees as a way to stay connected with other intersexuals (Preves 2003). Most of what we know about intersexual identity is rooted in research with individuals affiliated with intersex support groups (Preves 2003). While I experienced firsthand the obstacles of locating intersexuals through other means, it is important to, at the very least, consider how much of our understanding of intersexuality and intersex identity is rooted in a middle class framework. For instance, how has framing intersexuality as a middle-class condition biased our knowledge about the diagnosis? What can we learn about intersexuality from personal narratives outside of the middle class? While I do not have the type of sample to address these questions in this dissertation, they are important to at the very least acknowledge here.

My sample was, relatively speaking, racially and ethnically diverse. Approximately 30% of my sample of individuals with intersex/DSD conditions was of a racial/ethnic minority status. However, racial and ethnic minorities in my sample did not differ from the white individuals in terms of how they experienced intersexuality. In other words, there were no racial or ethnic differences. It is my assumption that the absence of racial/ethnic differences has more to do with the lack of educational variation in my sample than any potential claim that racial and ethnic minorities, at large, experience intersexuality in similar ways as do white individuals. The racial and ethnic minorities in my sample had at least some college and most were college educated.

What I'm suggesting is that the cultural capital gained from educational attainment is what is mediating the lack of any observed relationship between race/ethnicity and experience with intersexuality. This is, of course, an empirical question that is worthy of verification.

None of my informants presented themselves androgynously. I was able to classify every individual I interviewed as either presenting as a man or a woman, and my classification was consistent with their self-reported gender. This does not mean that all individuals presented themselves in stereotypical feminine or masculine ways. Rather, it points to the importance that intersexuality does not innately result in ambiguous gender presentations. We all, regardless of our genitalia, are morally obligated to do gender (e.g., West and Zimmerman 1987), and intersexuals are no exception. The same, however, was not true for sexuality. The sexuality I predicted one would claim given the absence or presence of certain cues tied to gender didn't always match with a respondent's self-reported sexuality. Given such, the demographic table presented above lists my perception of an informant's gender presentation at the time of the interview (which always matched with their self-identification) and their self-reported sexuality (which was not always consistent with what would have been my guess).

### **Insider/Outsider**

Throughout data collection, I knew I would not exclusively study intersexuality for academic purposes. As an intersexed individual, I am personally implicated in the movement. I am also committed to using my unique standpoint to present a scholarly study of intersexuality from the perspective of an intersexed feminist academic. As Koyama and Weasel (2002) document, most of what we know about intersexuality has been presented by non-intersexed academics and clinicians, and while unquestionably valuable as pieces of the conversation, they do not make up

the entire puzzle. My status as an insider/outsider proved to provide unprecedented access to intersex community members who would otherwise not have participated in such a project. I return to this shortly, but first, I clarify my definition of insider/outsider.

Individuals can hold an insider or outsider standpoint in every community; it is the collection of these standpoints in the process of gaining knowledge that is beneficial to the production of scientific knowledge (e.g., Sprague 2005; Naples 2003; Harding 1998; Hartsock 1983). For example, as a sociologist, I am an insider within the discipline. I've studied under sociologists in universities that have resulted in several sociology degrees, I teach sociology courses, and I publish in sociological journals and volumes. Thus, I define "insider" in the research context as a researcher who has a personal *and* historical connection to the population or phenomenon being studied. In as much as every individual is an insider within certain communities, we are also outsiders to different communities. Therefore, my definition of "outsider" in the research context is where a research doesn't have *either* a historical nor personal connection to the population of phenomenon being studied.

I argue here that I occupied a unique insider/outsider status throughout this project. I was an insider in the sense that I was born with an intersex condition. I grew up with intersexuality and share similarities with those I've studied. Born with sex chromosomes that do not match our phenotypes, my informants and I have shared experiences. However, I'm not truly an insider, because when I began this project, I didn't have a historical connection to any intersex community nor any other individuals with intersexuality. In fact, it wasn't until 2008 that I was aware that an intersex community even existed, and it was only shortly thereafter that I met someone who identified as having an intersex/DSD condition. The result is the "insider/outsider"

status that I claim here. I define “insider/outsider” status in the research context as a researcher who has a personal connection with the phenomenon being studied but without the historical connection to others who are similarly situated.

My insider/outsider status proved to be incredibly useful in not only gaining access to the intersex community but also in the type of data I was able to receive. As an insider, participants expressed increased comfort in speaking with me. For example, Ann, a woman with an intersex condition, shared that “It made it more comfortable...it’s easier for me to talk to you.” Since I have an intersex condition and experienced living with it since birth, interviews went smoothly in the technical sense given I was personally familiar with many of the themes that came up including everything from terminology to difficulty in engaging in penetrative sex because of a shortened vaginal canal and/or vaginal dryness. Jenna, who herself has an intersex condition, shared:

I guess as far as ease of explanation it’s a little easier because you know the terminology...you know when I say TFS...you know I meant testicular feminization...and I say AIS or I say gonadectomy or I say whatever....you know what I’m talking about...you know it, you have it.

I also found that my personal experience with intersexuality resulted in increase willingness to participate in my study. For example, Marty, a parent of a teenager with an intersex/DSD condition shared:

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 sister hood.

While many informants shared Marty’s view, there were others who stated that they would have participated regardless of my personal experience with intersexuality. Still, given my

insider/outsider status, these individuals expressed a type of comfort that most researchers can only strive for. Mariela summarized such quite nicely:

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 similarly shared:

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 with intersexuality as having directly resulted in my ability to ask questions "in a way that hasn't been asked before," I do believe that my insider/outsider status uniquely positioned me to ask questions that other researchers may not have thought about given their outsider status.

Being an insider/outsider rather than just an insider was also incredibly useful given how divided I found the intersex rights movement, the central theme of chapter three which follows. If I was an "insider" rather than an "insider/outsider", I'm quite convinced I would not have had access to individuals on all sides of the divided intersex rights movement. For example, I interviewed individuals affiliated from four different organizations that are, in some ways, in opposition with one another, especially Organisation Intersex International. While I cannot be certain, it is my assumption that I would have had much more difficulty gaining access to individuals on various sides of the debate if I was known to be firmly planted on one side. Since

I did not have a historical connection to the intersex community, I was not foreshadowed to hold any particular beliefs. My personal views on intersexuality were, in other words, left mysterious, intentionally or not, throughout data collection. This allowed for the collection of more complete information.

### **Turning the Methodological Lens**

In 1902, Charles Horton Cooley introduced the concept of the “looking-glass self.” In short, the looking-glass self suggests individuals see themselves, and consequently construct themselves, in relation to how they believe they are perceived. Cooley (1902) argued, “Each to each a looking-glass, Reflects the other that doth pass.” We can apply the looking-glass self to methodology, specifically the collection of data. Cooley (1902) maintained:

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.

Turning the methodological lens on to myself, I realized that in all of my field notes, I always made a mention to what I was wearing and how my hair was styled despite the fact I never consciously acknowledged outside of my ethnographic field notes 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 alas 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 that are really homophobic. While short hair isn't necessarily a sign of being gay, I feel my height (5'10") complied with the fact that I am very

overweight will result in 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 having the type of white people 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...

Reading through this excerpt from my field notes, it is very apparent that I was making decisions about my presentation throughout data collection. However, I never really considered this to be a theme until re-reading my field notes during data analysis. Looking back, I went an entire year without cutting my hair to a shorter, and admittedly more stereotypically butch, hairstyle. After having longer hair for over a year, I simply couldn't continue with it. So, I cut it all off last summer. Since I wasn't quite done with data collection, I consciously tried to style my hair in a way that was more feminine each and every time I was in the field collecting data.

I've had a number of different hairstyles throughout my life, and each was likely influenced by how I thought I was going to be perceived wearing such hairstyle. Choosing a hairstyle based on how we want to be perceived is not new. My point here is not so much about my hair length or hairstyle, rather it is that as a *researcher* I made decisions about the length and style of my hair given how I *believed* I would otherwise be perceived by my informants. When I interviewed folks who I knew in advance identified as gay, lesbian, or queer, my self-policing of sexuality was absent. I wore what I wanted regardless of how I would be perceived and similarly styled my hair. In this regard, I subconsciously aimed to construct an identity that would align with how I thought my informants would view me as a researcher with an intersex/DSD condition. My identity shifted based on perception alone. The existence of the looking-glass self in the methodological arena is then what interests me.

While interview effects have long been of concern of survey methodologists and qualitative researchers alike (Groves, Fowler, Couper, Lepkowski, Singer, and Tourangeau 2004), the focus seems to overlook how we, as researchers, shift our identity to appease our own methodological concerns. In some cases, this might mean constructing a self that is in direct opposition to the way in which we believe we will otherwise be perceived. This is not an incredibly new idea. Research has shown us that by constructing an identity tied to a university, we can increase our response rate due to the legitimacy we gain from attaching ourselves to the academy (Groves, Fowler, Couper, Lepkowski, Singer, and Tourangeau 2004). What is new is when studying issues around 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.

## **Conclusion**

Methodology is at the heart of any empirical project. Without data, one can only offer unverifiable speculations. What I've aimed to do in this chapter is offer a detailed look into my data, including how it was gathered and from whom it came. As I've demonstrated above, the trust I established with the intersex community was of extreme importance in gaining access, which came with greater ease given my insider/outsider status. Most of what we know in the academy about intersexuality has been presented by those outside of the community (e.g., Dreger and Herndon 2009; Feder 2009; Reis 2009; Karkazis 2008; Preves 2003; Fausto-Sterling 2000a,b, 1996, 1993; Dreger 1998a,b; Kessler 1997). Koyama and Weasel first made this critique in 2002. While the research and perspectives presented by non-intersexed academics have been incredibly valuable, we also need empirical studies about intersexuality from those who have a personal connection with it. By no means would I suggest that only insiders or

insiders/outsideers should study a given phenomenon. This would serve none of us well. Instead, we need studies from multiple angles and perspectives. Only then will we be able to gain a more complete understanding of the phenomenon in question.

### 3. FROM “COLLECTIVE CONFRONTATION” TO “CONTESTED COLLABORATION”

I first entered the intersex community as a participant, not a researcher. Like others with intersex conditions, my body was surgically modified under questionable consent. I was young when my internal un-descended testes were removed. As I was rolled into the operating room on a plastic medical cart, I was not aware that such surgery was purely elective. I also wasn't aware that I had testes, never mind that they were going to remove them. Instead, I was told that they were going to be removing underdeveloped ovaries that were at a great risk of turning malignant.

While I didn't initially enter the intersex community with plans to study it academically, I did engage the intersex scholarship. I read a handful of the classic intersex publications during my undergraduate training in sociology including Fausto-Sterling's (1993) “Five Sexes” and excerpts from Kessler (1998, 1990). Years later when I was in the sociology graduate program at the University of Illinois at Chicago, I read Turner's (1999) *Gender & Society* article where she concluded:

Embodying what they feel is a failure of medicine to make them what they cannot be in the first place, [intersexuals] envision a wholly new intersection of sex and gender, a kind of ‘third sex’ that evades gender determination yet also somehow solidifies into a category of identity (Turner 1999, 459).

Given my exposure to intersex scholarship, admittedly limited at the time, I entered into the intersex community expecting a strong collective intersex identity and a movement from which such emerged. What I found was a hotly divided movement where activists were essentially against one another for reasons unknown to me. There was not a collective intersex identity, nor was the notion of a “third sex” widely embraced. As I stated earlier in my introduction, it was

this divide that initially peaked my professional interest and ultimately shaped my career trajectory.

When I went to the literature, I found a rich discussion around collective identity and successful social movement organizing (e.g., Rupp and Taylor 1999; Hunt and Benford 1994; Taylor and Whittier 1992; Valocchi 1999). For instance, it has been argued that “[c]ollective identities are articulated, manipulated, packaged, and deployed by movement actors to maximize resources and support from constituents” (Dugan 2008, 21). Furthermore, a “[c]ollective identity describes imagined as well as concrete communities” (Polletta and Jasper 2001, 298). As Bernstein (1997) has argued, activists either promote an identity of similarity with those outside of the movement to gain public support, or activists construct an identity of difference whereby they exemplify their difference from the general public. The collective identity constructed by activists can shift, especially in response to political changes (Bernstein 1997). Previous social movement research has also shown that emotions play a crucial role in the formation and perpetuation of a collective identity, and that emotions are also strategically deployed to form specific identities in ways that construct medical illnesses as a source to bring about social change (Taylor 1996; Brown 2007; Taylor and Leitz 2010).

Although scholars more or less agree that mobilizing around a sense of sameness is necessary for collective action, Gamson (1995) has warned that such strategy creates divisions and dissidents by marginalizing other identities (e.g., Ghaziani 2008). In breaking down traditional notions of identities by deconstructing sexual identities as natural and fixed categories, queer mobilization is an alternative strategy. Queer theorists see identities as oppressive in the way they confine individuals into rigid categories; however, according to social

movement theory, a collective identity is fundamental to any successful social movement. This, Gamson (1995) claims, is the queer dilemma.

Reger, Myers, and Einwohner (2008) add to this discussion by arguing against the necessity of a singular shared identity in successful social movement organizing. They maintain that activists manage multiple identities in order to reach movement goals, an intricate process that occurs inside *and* outside their organizations (Reger, Myers, and Einwohner 2008). Polletta and Jasper (2001) also argue that a “[c]ollective identity is not the same as common ideological commitment” (298). They suggest people can join a movement for its goals without sharing an identity with its fellow members.

In the case of the intersex activism, I have seen that a collective intersex identity was necessary to dismantle the secrecy, shame, and stigma tied to the intersex diagnosis. It was in the 1990s that intersex activists, who shared a collective identity centered on their “abnormality” (Turner 1999), made the most progress by pushing both the 2000 and 2006 medical consensus statements on the management of intersex conditions described later in detail. The intersex rights movement is now more divided than it ever was, especially around its mobilization strategies. The competing mobilization strategies presently at play throughout the intersex rights movement make it impossible for a collective intersex identity to form. It is within these divided mobilization strategies that I start my research.

We know that behind every social movement are social movement organizations (e.g., McCarthy and Zald 1977), yet there has been limited collaboration between social movement and organizational scholars. For example, despite considerable interest in gender as a social stratification system rather than a characteristic of individuals (Martin 2004; Risman 2004; Ferree, Hess and Lorber 1998; Lorber 1994; Connell 1987) and a growing body of organizational

literature that argues organizations are gendered (Britton 2000; Acker 1998, 1992, 1990; Collinson and Hearn 1994; Calas and Smircich 1992), there has been little attention paid to how an organization's awareness of gender structure may affect mobilization strategies. Acker calls for organizational scholars to wrestle with her conceptualization of gendered institutions, and the idea that "gender is present in the processes, practices, images, and ideologies, and distributions of power in the various sectors of social life" (1990, 567). Many have taken on this challenge (e.g., Calas and Smircich 1992; Collinson and Hearn 1994) but there is still much to learn about the relationship between gender, social movement organizations, and their mobilization strategies. Clemens and Minkoff (2004) maintain that "social movements are embedded in organizational fields, and that their relationships to and with other organizations in the field can take various forms that have implications for their operation and functioning" (163).

It is clear that mobilization strategies are fundamental to social movement organizations (e.g., McCarthy and Zald 1977), regardless of the mobilizations tactics at play (e.g., Taylor and Van Dyke 2004; McCarthy, McPhail, and Smith 1996; Jenkins and Eckert 1986; McAdam 1982; Tilly 1978). Katzenstein (1990), for example, argued women activists within the Catholic Church and U.S. military in the 1980s and 1990s engaged in "unobtrusive mobilization" to promote change and raise "gender consciousness" by working within institutions as opposed to engaging in a more public and confrontational mobilization strategy. Martin's (2005) study of rape crisis centers offers further evidence to support the success of "unobtrusive mobilization." Rape crisis centers are successful in gaining support, resources, and attention from those outside of their organization by not "stand[ing] outside and allocate[ing] blame," but rather employing "unobtrusive mobilization" by "persuad[ing] outsiders to adopt their versions of laws, police

officer training, rape exams, and school health education messages” (Schmitt and Martin 1999, p. 379; also see Martin 2005).

This chapter is focused on the intersex rights social movement, including its birth, formation, and current trajectory. I hope to both advance our understanding of social movement theory and also to analyze the possibility for intersex activists to organize even more effectively to end the shame, secrecy, and stigma all of us confront on a regular basis. I address two major questions. First, how do intersex social movement organizations define intersexuality and gender? Does the presence of competing views of gender affect successful social movement organizing? Second, what mobilizing strategies and tactics do intersex social movement organizations employ and how, if at all, do they reflect particular missions, goals, and understandings of the gender structure?

To analyze the questions raised above, I have studied four non-profit intersex social movement organizations, which I call here intersex social movement organizations (ISMOs). I see each of the four organizations I’ve studied to be social movement organizations because they have a common goal of changing society’s understanding of intersexuality. I initially chose to study the Intersex Society of North America (ISNA), the Androgen Insensitivity Syndrome Support Group (AISSG-USA), Organisation Intersex International (OII), and Accord Alliance (AA).

Based on my initial assessment of their websites, it seemed that each of these organizations was involved in the intersex rights movement in different ways. For instance, ISNA and OII are activist organizations. AISSG-USA is a support group, and Accord Alliance is an organization that distributes educational resources to medical professionals. In addition to recruiting participants for the interview portion of my study from these four organizations, I also

analyzed each organization's publicly available material including their web pages, brochures, and handbooks focusing specifically on their history, goals, membership, mobilization strategy, and labeling of intersexuality.

I argue the movement began with a focus on the medicalization of intersexuality and its feminist critiques. Such feminist critiques were instrumental in the development of the intersex rights movement and its earliest organizations. I then explore how ISMOs mobilize and how their differing mobilization strategies can be traced to their framing of gender as a stratification system or as an essentialist individual characteristic. I rely on Taylor's (1999) study of the postpartum depression self-help movement by using her framework as a model to explain how ISMOs within the same social movement come to adopt competing mobilization strategies.

I found what was once a monolithic intersex rights movement is now fractured. The first moment characterized by what I label "collective confrontation" (1993-2006), intersex social movement organizations worked together to form a collective intersex identity in order to challenge the medical profession's treatment of intersexuality. Since then they have become divided by mobilization strategies. This divide has resulted in the current pattern (2006-present) of "contested collaboration." The dominant ISMOs are now working with medical professionals *on* their terms and *with* their terms despite criticism from other activists.

Each strategy reflects, in part, a particular framing of the gender structure (Risman 2004). ISMOs that work within the medical system do not see gender as a stratification system that needs to be challenged. Instead, they adopt an "unobtrusive mobilization" strategy that is "less confrontational...in contrast to the more public protests of the 1960s and 1970s" (Schmitt and Martin 1999, 368; Katzenstein 1990). On the other hand, ISMOs that approach gender as a stratification system adopt a public and confrontational mobilization strategy to promote its

deconstruction. Table 3.1 on the following page presents a detailed overview of each of the four organizations I studied. The table also includes a concise overview of my findings which I discuss in detail throughout the remainder of this chapter.

**Table 3.1: The Historical and Political Background of Prominent Intersex Social Movement Organizations**

	<b>Intersex Society of North America (ISNA)</b>	<b>Androgen Insensitivity Syndrome Support Group-USA (AISSG-USA)</b>	<b>Organisation Intersex International (OII)</b>	<b>Accord Alliance (AA)</b>
<b>Founding Date</b>	1993	1995	2003	2008
<b>Founder</b>	Cheryl Chase	Sherri Groveman Morris	Curtis Hinkle	Dr. Arlene Baratz
<b>Founding Purpose and Goals</b>	to reduce the stigma of intersexuality and to end “unwanted genital surgeries”	to reduce the stigma of intersexuality; to offer emotional support; to disseminate medical knowledge about intersex conditions; to improve medical treatment	to reduce the stigma of intersexuality; to end forced gender assignment for intersexuals; stop the surgical treatment of intersexuality	end the language of “intersex,” “intersexuality,” and “intersexual” by campaigning for a “disorder of sexual development (DSD)” label; reduce the stigma around DSDs (i.e., intersexuality); collaborate with the medical profession to promote change
<b>Membership and Organization Composition</b>	3,500 members with 1,000 donors <sup>5</sup> : most are highly educated white women that are intersexed or the family member of an intersexed individual; a number of medical professionals and academics are also members	approximately 150 members: the majority are white women; many are college graduates and several have advanced degrees; roughly 5 percent of the members are children under the age of 18; several physicians that self-identify as “intersex experts” are also members	the largest intersex organization in the world with the most members (membership not confirmable through publicly available information): racially, ethnically, and gender diverse membership; educational levels unknown	membership numbers publicly unknown: gender diverse membership, but few are intersexed themselves; overwhelmingly white medical professionals with advanced degrees
<b>Mobilization Strategies and Tactics</b>	From 1993-early 2000 public and confrontational: protests at medical association meetings; narratives that are critical of the medical profession shared with the public through major media outlets  From late 2000-2008 collaborative with medical professionals: intersex activists worked with medical professionals to produce consensus statements and treatment plans/protocols	collaborative: medical professionals refer most members to the group; new membership granted only after existing members vote to include a new member in the group; members gather yearly to share stories, hear current medical developments, and connect with others similarly bodied	public and confrontational: dissemination of critical writings, images, and narratives that negatively depict medical professionals and intersex activists that work collaboratively with medical professionals	collaborative: medical professionals viewed as important actors for social change; production and distribution of handbooks on dealing with DSDs (i.e., intersexuality) are widely disseminated to medical professionals and parents; separate handbooks are produced for medical professionals and parents
<b>Labeling of Intersexuality</b>	From 1993-early 2000 “Intersex” with awareness of sex and gender.  From late 2000-2008 “DSD” emphasis on remedicalization	“Orchids,” “Orchid Sisters,” “Intersex,” and “DSD”	“Intersex” substantial opposition to “DSD” terminology	“DSD”

<sup>5</sup> Membership and donor data from Preves, Sharon E. 2004. “Out of the O.R. and Into the Streets: Exploring the Impact of Intersex Media Activism.” *Research in Political Sociology* 13:179-223.

## **The Medicalization of Intersexuality**

In the 20<sup>th</sup> century, technological advancements provided the medical profession at large with the tools to surgically modify individuals who deviated from the sex binary system to fit into a male or female body (Preves 2003, 2000; Fausto-Sterling 2000a, 1993; Dreger 1998a,b; Kessler 1998, 1990). The first sex reassignment surgery on a trans individual was performed in Denmark in the 1920s (Preves 2003; Fausto-Sterling 2000a, Dreger 1998a,b; Kessler 1998, 1990). While sex reassignment surgeries for trans individuals were popularized and regarded as successful treatment of gender identity disorder in Denmark, it wasn't until 1952 that sex reassignment came to America when Christine Jorgensen became the first American to undergo sex reassignment surgery (Preves 2003; Dreger 1998a; Kessler 1998; Feinberg 1996). She became the feature story of news reports across America. This began to direct attention toward sex reassignment across the U.S. medical profession, reinforcing doctor's authority over bodies, sexualities, and gender (Preves 2003; Dreger 1998a; Kessler 1998).

During this moment of scientific advances which allowed for the shaping of bodies, the U.S. medical profession began to develop guidelines for the treatment of intersexuality that included the surgical and hormonal medical treatment of abnormalities (Preves 2003; Fausto-Sterling 2000a; Dreger 1998a,b; Kessler 1998, 1990). The medical profession assumed if artificial hormones and surgery ameliorated social stigma and isolation for trans individuals, such would also work for individuals affected by intersexuality. Thus, the medical profession primarily treated intersexuality in the same manner as transsexuality by relying on technological advancements to physically alter the bodies of intersexuals to fit a sex binary (Hird 2000; Fausto-Sterling 1996). Intersexuals were defined as having “abnormal bodies” that needed medical and surgical attention in order to fit into the sex system and arguably ameliorate the stigma and

shame associated with not comfortably fitting into the sex categorization system (Preves 2003, 2002; Fausto Sterling 2000a, 1996; Dreger 1998a; Kessler 1998, 1990).

### **Feminist Response to Medicalization**

Feminists were critical of the medical management of intersexuality due to their conceptualization of sex and gender as socially constructed binaries. In 1993, Fausto-Sterling argued that if we must organize our bodies into sexual categories, we ought to move beyond male and female and include true hermaphrodites (the “herms”), male pseudohermaphrodites (the “merms”), and female pseudohermaphrodites (the “ferms”). Although written “tongue firmly in cheek,” Fausto-Sterling (1993) defined “herms” as having one ovary and one testis—a “true” hermaphrodite. Male pseudohermaphrodites or “merms” have testes but do not have ovaries despite having some other “normal” component of female genitalia. Female pseudohermaphrodites or “ferms” have ovaries but do not have testes despite having some other normal component of male genitalia. By arguing for the recognition of five sexes, Fausto-Sterling attempted to debunk the sex binary system rooted within dichotomous notions about sex. Kessler (1998) later critiqued Fausto-Sterling’s “Five Sexes” by maintaining affected individuals should be thought of as evidence of sexual “variability” rather than sexual “ambiguity.” According to Kessler (1998), it is neither possible nor logical to maintain the sex system when recognizing the existence of multidimensional sexual variability. To categorize intersexuals by sex, Kessler maintains, is to perpetuate the validity of the categorization system. In 2000, Fausto-Sterling accepted Kessler’s critique. Specifically she stated, “It would be better for intersexuals and their supporters to turn everyone’s focus away from genitals” (Fausto-Sterling 2000b, 22).

## The Birth of Intersex Advocacy

By providing an analytic ground for activists to challenge the medical profession (Fausto-Sterling 1993; Kessler 1990), feminist writers helped to spark an intersex rights movement that eventually changed how physicians treat intersexuality. Fausto-Sterling, for instance, is credited with facilitating the formation of the Intersex Society of North America (Preves 2003; Fausto-Sterling 2000a,b; Chase 1998b, 1997). The publication of her 1993 essay, “The Five Sexes,” inspired Cheryl Chase to organize ISNA, at one time the world’s largest intersex advocacy and support group, despite her open criticism of the piece. (Chase 1998b,c, 1997). Chase described the process as follows:

So I picked up *Myths of Gender* by Fausto-Sterling...and it says, ‘So what is the difference between male and female?’ It says well, men are people who impregnate and ejaculate, and women are people who ovulate and menstruate and gestate, and I forget what else. I thought man...that is really fucked up. So I called her, at Brown, and I said – ‘In fact, the way that sex differentiation happens, you’re not going to be able to draw a clear line between male and female, no matter what you do. Wherever you draw the line, I can produce examples of real-life people who your line produces surprising results. She said ‘yes, I agree with you, I’ve changed my mind since I wrote that and in fact I have this article in press right now, and the article is ‘The Five Sexes’. And I said, let me see it. She sends it to me, and I said well, part of what you missed here is how horrible it is what they do to people like me now, and partly, this thing ‘The Five Sexes’...I hate it, it’s stupid. It’s not any less stupid than two sexes. It ratifies gonadal histology, which nobody can even see. What kind of thing is that?’ She said ‘I’ll tell the editors [of the journal] they should publish a letter from [you]’. When I came to the US and I started to realize there’s a lot of people, I sort of thought it’s time for me to figure out how to get them together to talk about it. So I wrote a letter to *The Sciences*.

In this letter, Chase identified herself as the president of ISNA—an organization she fabricated when she constructed her reply— in order to gain credibility despite the fact that it didn’t exist (Preves 2003). However, not long after Chase’s response was published, many intersexuals contacted Chase inquiring about membership. She explained:

Pretty soon...I'm getting all these letters from intersex people. They're coming in the P.O. box and I'm calling them and when I call them, they want to tell me their story and they want to be on the phone for hours and hours and hours because they never imagined in their whole life that they'd ever meet anybody else. So I bought a headset and also that was right at the beginning of when the Internet was beginning to be available and I remember teaching people how to use e-mail and stuff.

Soon thereafter, ISNA was formally born. Its membership grew exponentially to include a mailing list of approximately 3,500 with over 1,000 donors for the identity based intersex rights organization (Preves 2004). With such numbers, ISNA became the catalyst for the intersex rights movement, including the Androgen Insensitivity Syndrome Support Group-USA (Preves 2003).

Androgen Insensitivity Syndrome Support Group-USA (AISSG-USA) was founded in 1995 by Sherri Groveman Morris. When AISSG-USA was formed, some of its goals were in line with ISNA's mission. The founding purpose of AISSG-USA was to reduce the stigma of intersexuality by connecting intersexed individuals with others similarly situated. From early on, AISSG-USA was also concerned with improving the medical management of intersexuality. However, unlike ISNA, AISSG-USA's primary goal was to offer emotional support to intersexed individuals and their families. While only a handful of its members viewed AISSG-USA as an activist organization, I approach it as such given it serves as an educational organization that reaches out to intersexed individuals and their families by offering emotional support while simultaneously disseminating medical knowledge.

### **Demanding Change: "Collective Confrontation"**

Through the collective effort of ISNA activists and its supporters, many of whom had overlapping membership with AISSG-USA, the intersex rights movement pressured the medical profession to reconsider its surgical treatment of intersexual bodies. While feminist scholarship

fueled the formation and progression of the intersex rights movement (Preves 2003; Fausto-Sterling 2000a,b, 1993; Chase 1998b,c, 1997; Kessler 1998, 1990), the success of the intersex rights movement was due in part to confrontational mobilization strategies that necessitated medical professionals acknowledge the voices of intersexuals in their guidelines (e.g., Chase 2002).

ISNA activists employed confrontational mobilization strategies by routinely protesting outside of pediatric medical association meetings in order to raise awareness about the surgical, and in most cases unnecessary, modification of intersex genitalia (Karkazis 2008; Preves 2003; Chase 1998a,b,c). ISNA activists also reclaimed the language of “hermaphrodite” by promoting its usage within their community. Early Intersex Society of North America newsletters were even titled “*Hermaphrodites with Attitude*”<sup>6</sup> and many wore t-shirts and banners with similar slogans while protesting outside of medical association meetings in ways that gained much media attention. David, one the earliest members of the movement, shared with me just how grassroots the movement was and the ways in which intersex activists targeted medical professionals:

I remember [Cheryl Chase] saying to me once in the car, will you help me create the Intersex Society of North America, will you help me you know, be this movement? And she was like, she would get people together to go to like pediatric conferences and protest outside them... and she had this huge banner that said “*Hermaphrodites with Attitude.*”

The founder of the intersex rights movement, Cheryl Chase, shared: “Any movement that can’t get attention needs to do some attention-getting things, which we did.

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<sup>6</sup> The first newsletter was titled “*Hermaphrodites with Attitudes.*” It was distributed in the winter of 1994.

These attention-getting things at times involved heated discussions and informal debates with medical professionals. Kimberly, an early activist, recounted one such confrontation:

- K: So I did a talk a couple of years ago, and it was a group of nurses who worked with infants in ICU, the intensive care unit. Neonatal Nursing Conference...I spoke to them twice. The second time, they had a guy come in. He was doing a study on how not telling – it was a bunch of CAH women that were in the study – and he had all this proof about how not disclosing, doing the surgery, and this stuff was beneficial. We had this fight, like a literal...
- G: Who was it...a doctor?
- K: It was a doctor, and I don't remember who he was. I'm kind of surprised it didn't come to blows, because I was ready to hit him. We just yelled at each other for like twenty minutes, it was terrible. I was completely unprofessional as was he.

Intersex activists were angry because they felt violated and manipulated by medical professionals who often kept the diagnosis secret from intersexed children. Hannah accounts finding out about her condition in a college biology classroom:

- H: I have complete androgen insensitivity syndrome.
- G: How did you find out about your condition?
- H: Um, I was doing a buccal smear in college...when you swab the inside of the cheek...And it came up 46 XY. And I'm like *what?* So I had to do some investigation and went to the teacher and asked about it, and she was kind of like 'I'm not sure' and I don't know if she knew and was like 'I'm not saying anything' or what, but I basically had to go research what I had. She was just like 'well, write down your results whatever they are' kind of indifferent about it...I knew I couldn't have children but I thought that I had some kind of hysterectomy when I was 13 because I was told that my ovaries were precancerous and they had to be removed. So I was always worried that the cancer was going to come back or something. Now I know I was worrying for nothing. But I went to the library in school and I found some books and that's where I found the term 'testicular feminization'...and I was like, oh my god, that's what I have.

The efforts of early intersex activists eventually brought about change, as the medical profession would later denounce keeping the diagnosis from intersexed individuals.

In 1997, the American Academy of Pediatrics refused to engage “zealous” intersex activists (Fausto-Sterling 2000a,b; Diamond 1997). However, three years later, Chase was delivering a plenary address to the Lawson Wilkins Pediatric Endocrine Society, a group she had earlier protested against (Karkazis 2008). In her presentation, she questioned their morality, their ignorance, and their approach to intersexuality (Preves 2003; Fausto-Sterling 2000a,b). This successful activist encroachment into medical turf was highly unusual for two overlapping reasons. It marked the first time an activist’s perspective was solicited by organizers of a major U. S. medical conference (Karkazis 2008). And, it was “the first time that the society’s annual symposium was devoted to intersexuality” (Karkazis 2008, p. 257). The American Academy of Pediatrics eventually acknowledged that their historical treatment of intersexuality created a professional “social emergency” (Blizzard 2002). Dr S recounts the medical profession’s eventual understanding of early intersex activism quite concisely:

So the original folks who self-aggregated *hated* the medical community, or were very angry with them, not inappropriately, for the way that they had been treated.

Shortly thereafter the medical profession instituted guidelines for the treatment of intersexuality including, but not limited to, avoiding sex assignment at birth (Preves 2003).

The Intersex Society of North America was incredibly successful as an activist organization. The efforts of ISNA activists resulted in the American Academy of Pediatrics publishing their 2000 medical consensus statement on the management of intersex conditions (Committee 2000). While this 2000 consensus statement did contain several problematic recommendations, it remains evidence that ISNA activists pressured the medical profession in ways that necessitated a formal response.

The 2000 medical guidelines for the treatment of intersexed infants recommended that intersex infants “should be referred to as ‘your baby’ or ‘your child’—not ‘it,’ ‘he,’ or ‘she,’ (Committee 2000). Surgery was, unfortunately, still on the table. The guidelines noted parents should be informed that “abnormal appearance can be corrected and the child raised as a boy or a girl as appropriate.” The guidelines stated that a number of factors should be considered when determining which sex category, or in their language “gender assignment,” should be recommended for a given intersex child. Most notably, these factors included “fertility potential” and “capacity for normal sexual function”, which are deeply rooted within heteronormative notions about sexuality (see Butler, 2004, 1990; Foucault, 1980).

In 2003, one of ISNA’s activists started a new group, The Organisation Intersex International (OII). Initially, OII was formed in order to connect intersex activists from around the world, as ISNA’s membership was primarily U.S. based activists. As documented on their website, Organisation Intersex International’s agenda is to create:

a decentralised network established to give voice to intersex people both outside and inside the USA, those speaking languages other than just English, and people who do not fit the medicalised categories of disorder promoted by some other intersex groups. It is for people born with bodies which have atypical sex characteristics. OII resists all efforts to make intersex invisible, including genital mutilation, medicalisation and normalisation without consent and offers another face to intersex lives and experience by highlighting the richness and diversity of intersex identities and cultures.<sup>7</sup>

With a number of prominent U.S. based intersex social movement organizations in existence, the intersex rights movement was incredibly strong. While the Intersex Society of North America, the Androgen Insensitivity Syndrome Support Group-USA, and Organisation Intersex International each had a unique purpose when they were formed, their fundamental goals were

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<sup>7</sup> Avail: [http://www.intersexualite.org/Organisation\\_Intersex\\_International.html](http://www.intersexualite.org/Organisation_Intersex_International.html)

similar: end intersex stigma and eliminate unnecessary genital surgeries. Each organization, in fact, shared many members.

### **From “Collective Confrontation” to “Contested Collaboration”**

In 2006, the American Academy of Pediatrics would revise their policy regarding the treatment of intersexed individuals in such a way that would serve as the beginning of what would become a divided intersex rights movement. The medical profession maintained that their protocol needed to be revised due to “progress in diagnosis, surgical techniques, understanding psychosocial issues, and recognizing and accepting the place of patient advocacy” (Lee et al., 2006). In the revised guidelines they offered a number of new recommendations in this policy revision including revisiting the language of “intersex,” “pseudohermaphroditism,” “hermaphroditism,” and “sex reversal.” The guidelines maintain “intersex” should now be referred to as “disorders of sex development (DSD).” This shift in diagnostic language had major implications for the conceptualization of the condition, for the newly constructed “identity” was transformed into a condition that requires medical attention. This nomenclature shift became the fault line at which intersex social movement organizations shifted from what I label “collective confrontation” to “contested collaboration.”

ISNA’s mission was always very clear. As stated on their webpage, ISNA was “devoted to systemic change to end shame, secrecy, and unwanted genital surgeries for people born with an anatomy that someone decided is not standard for male or female.”<sup>8</sup> And, yet, in the summer of 2008, the world’s largest intersex social movement organization closed its doors. Despite its success at increasing awareness of intersexuality, challenging the medical profession’s treatment

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<sup>8</sup> Avail: <http://www.isna.org/>, Retrieved June 23, 2008.

of intersexuality, and providing a place for intersexuals to connect with one another, ISNA's founder, Cheryl Chase, and other leaders dissolved the organization. Announcing its closure, ISNA released a statement explaining the decision:

This is ISNA's dilemma: we finally have consensus on improvements to care for which we have advocated for so long, but we lack a consistent way to implement, monitor, and evaluate them. At present, the new standard of care exists as little more than ideals on paper, thus falling short of its aim to improve the lives of people with [Disorders of Sex Development] and their families.<sup>9</sup>

What was most controversial for those involved in the intersex rights movement is that a handful of ISNA members—including the founder of ISNA and several others—eventually advocated with medical professionals to label the intersex condition as a “disorder of sex development (DSD)” as opposed to “intersex” or “intersexuality. Many former ISNA activists are going along with this nomenclature shift in order to be able to work with medical professionals. They felt, in short, that their organization's early history of engaging in radical and confrontational mobilization strategies that directly confronted and challenged the medical profession (i.e., public protests at professional pediatric association meetings) prevented them from working with the medical profession (i.e., collaboration) to promote social change around the treatment of intersexuality—which their new guidelines and recommendations necessitated. Chase shared:

As we begin to have an audience with parents and doctors, we need to be able to talk with them not from a radical stand. It was a case both that the people who are our target audience to change their mindset, who have control over that experience of families in the healthcare system, wouldn't allow us to become more moderate...they just wouldn't believe it. There were people outside the healthcare system who just wanted to keep picketing doctors. There were some people who picketed healthcare conferences after we were already inside speaking at them, and that doesn't help. We came to realize that the reputation that we had had been an asset in early days but it had become a negative asset. It prevented us from talking to other people that we cared to talk to, and that's why we decided to change.

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<sup>9</sup> *ibid*

Jane echoed something similar:

Although to demonize members of the medical profession might be part of the history of the intersex rights movement, it certainly did something to raise awareness and start people talking about it, but it does absolutely nothing, quite the contrary as far as changing the standard of care and it certainly doesn't open up a dialog when you're calling people names and threatening them with personal harm and um, screaming and shouting.

The decision to close ISNA wasn't made public for quite some time, and this angered many intersex activists. Roughly half of the intersex activists I interviewed were against ISNA's closure. Millarca, a long time ISNA activist, only found out about ISNA's closure through a secondary source after the closure decision was already made. Millarca shared:

I called Cheryl Chase and said, 'What's going on?' She said, 'We're closing ISNA.' I said, 'Are you fucking kidding me?' She said, 'Yeah, we're closing ISNA, we're opening a more conservative organization that's going to have the medical profession accept intersex and DSD more. And we're changing the name from 'intersex' to 'DSD'.' I was like, 'Really?'

Other intersex activists refrained from contacting Chase directly to voice their disappointment.

Mercurio shared:

And I actually started a letter to Chase, and I never sent it, basically personally asking her to drop the term [DSD], to just change it. I mean, it's an online document. I don't know, she probably needs the approval of all the doctors on the consensus committee so actually that would probably be pretty difficult unfortunately at this point, or at least to change it to 'differences'.

A few powerful ISNA members, including Arlene Baratz and Cheryl Chase<sup>10</sup>, who decided to close its doors agreed to form a new organization in order to gain access and eventually collaborate with the medical profession—a position not supported by all intersex activists. Although ISNA no longer exists, it remains alive through the new organization, Accord Alliance.

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<sup>10</sup> Avail: <http://www.accordalliance.org/our-people.html>, Retrieved on December 15, 2008.

Founded in 2008, Accord Alliance was established to replace ISNA, which as noted above, in the eyes of a select group of powerful and influential ISNA's former members<sup>11</sup>, was ineffective in promoting social change within the medical profession.

Kimberly shared:

I needed to be able to get them involved and on my side and that just being confrontational with them and having an 'us and them' attitude wasn't doing me any good. So it was a real turning point for me of recognizing a bit more on how this has to be done, and how to have the medical community...they need to be allies. I guess I came from a place originally where they were the enemy. The first year or two, I remember the most I could kind of come up with was well, maybe they're not enemy *enemy*, but because of their incompetence, how many people have suffered kind of thing. They might have gone in with the best of intentions, but their incompetence was screwing up people's lives, and that's what it was. To recognizing, these are people who are trying to do the best thing, they need more information, but we need to speak their language to get that information across. So that was an evolution for me personally and I think it was an evolution in the community as well.

Whereas ISNA had a history of engaging in public protests outside medical association meetings to challenge the historic surgical treatment of intersexuality, Accord Alliance seeks to work with the medical profession to manage intersexuality by maintaining that DSDs are medical abnormalities that necessitate education and awareness. Accord Alliance defines its mission as one that "promote[s] comprehensive and integrated approaches to care that enhance the health and well-being of people and families affected by disorders of sex development," and according to Accord Alliance, they do so "by fostering collaboration among all stakeholders."<sup>12</sup> While ISNA and AA share similar goals that aim to destigmatize intersexuality, Accord Alliance's strategy is to work with medical professionals rather than adopt ISNA's public confrontational

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<sup>11</sup> *ibid*

<sup>12</sup> Avail: <http://www.accordalliance.org/>

strategy where the medical profession's practices and treatment of intersexuality were challenged through public protests. Jane shared:

So the door is open and the discussion starts. So as a pragmatist, do you understand how powerful that is? I can be on the outside of the room arguing about terminology and if I embrace this and the door opens and let's have a real good substantive conversation about this because we're talking about the same thing, you can call me frog. I don't give a crap what you call me as long as we're moving forward and advocating for families and advocating for small children who don't have a voice... My local children's hospital has been warm towards me in ways that I would never, ever anticipate.

Many medical professionals shared Jane's sentiment and openly embraced the shift in mobilization strategies. Dr. S summarized such quite nicely:

Over time, there were individuals who didn't hate the medical community so much and wanted to make things better for their children, or their peers, or their siblings, and those who followed after them had said, 'We cannot just be angry, we have to do something'.

Both Accord Alliance and the Androgen Insensitivity Syndrome Support Group-USA presently employ unobtrusive mobilization strategies by implementing "discursive politics" and an "occupy and indoctrinate" strategy. Defined by Schmitt and Martin (1999), discursive politics "includes talking as well as the production of tangible or symbolic materials that are aimed at political change.... the telling of stories about, for example, rape victims, crimes, and justice" (369). Working within the gender stratification system, Accord Alliance and AISSG-USA do not seek to challenge binary understandings of sex and gender to promote change and awareness about intersexuality. Instead, they discursively disseminate the trauma filled stories and experiences. Accord Alliance focuses on the medical community, while AISSG-USA focuses on the rest of society. Defined by Schmitt and Martin (1999), the "occupy and indoctrinate" strategy involves working "from the inside to the inside, in order to imbue the mainstream with its political understandings" of the social issue at hand (Schmitt and Martin 1999, p. 369). Accord

Alliance embraces the “occupy and indoctrinate” strategy by establishing teams of medical professionals situated within various hospitals across the country that are influenced by and/or even actively recruited by the Accord Alliance to promote its agenda. AISSG-USA routinely invites medical professionals to speak at their conferences.

This collaborative mobilization strategy is currently contested by other intersex activists. Roughly 50 percent of the intersex activists I spoke with were critical of collaborative mobilization strategies, especially those employed by Accord Alliance. Consequently, many chose not to be affiliated with Accord Alliance. Millarca shared with passion:

I don't have a relationship with Accord Alliance. I know the people that are affiliated with Accord Alliance. I see them at conferences and I'm polite and I say, “hi.” I don't believe in an organization that is trying to help kids by having medical professionals on the board whose purpose is against what our focus was in the beginning.

Mercurio also expressed similar distaste for the shift in mobilization strategies. Mercurio explained:

Working *with* the medical community has become working *for* the medical community because there's been no specific gains. And now, the pathologizing terminology, which originated in the medical community because some practitioners were using ‘disorder’ already, has been stamped upon us so it's like what have we got out of this?

Chris, one of very few intersexuals that identifies as a man, echoed something similar although with a much more critical view of medical professionals:

I basically see the medical community as it applies to intersex like a cult, a religious cult. It's like a high priest in white coats, and they're performing rituals to initiate the unclean and the unwashed into this mythical male/female. And they know this is bullshit, some of them. But some of them are still blinded. Doctors are not assigning a sex. This is all deceptive. It's a hoax. They're assigning a gender identity to children because if they were assigning a sex, in many cases they wouldn't be able to decide our sex by the current standards. What they're actually putting on birth certificates is not a sex, it's a gender identification and

then they're going to start transforming our bodies by what gender identity they think we should develop.

Chris went on to explain his understanding of the mobilization shift as follows:

ISNA, I felt it started out as somewhat of a support group and it gradually morphed into an organization that seemed basically just interested in talking to doctors, not providing support, and they seemed to be wanting to talk to doctors because they wanted to change the current treatment. And I felt like what happened is that they became too devoted to the donors, many of which who were probably doctors, and they were in such a dialogue that they had lost any close relationship with the people they were supposedly advocating in favor of, which was the intersex people....And see, the problem is, once a marginalized groups starts letting people be in an organization on a board with people that have elevated social status, it's going to be very hard to not have a lot of the members feel subservient, and they can slowly take over without your being aware of it...If you start accepting large amounts of money from medical people, well, that could be a real conflict of interest....I felt like that ISNA became too doctor-focused and too medically focused to where they lost contact with the grassroots. I feel like that's what happened. They were talking to doctors, but they weren't talking to any of the rest of us. And I think the doctors are part of the problem.

### **A Divided Movement**

After ISNA was replaced by Accord Alliance and its unobtrusive mobilization strategies, confronting medical professionals would be a thing of the past for the intersex rights movement. AISSG-USA never engaged in unobtrusive mobilization strategies, but now had even more reason not to. There is one exception, Organisation Intersex International (OII). As described earlier, an ISNA activist started OII in 2003 in order for intersex activists from around the world to connect with one another. However, while the other U.S. based intersex social movement organizations started working with medical professionals through unobtrusive mobilization strategies, OII continues to refuse to do so. Organisation Intersex International's official position states that they seek social change by "campaigning in favour of changing the current medical paradigm," or as Connell (1987) would say, disrupting the medical profession's "gender regime"

which can be defined as the perpetuation and control of hegemonic gender ideologies that maintain women and men are innately different and men are defined as socially superior to women.<sup>13</sup>

Of the intersex social movement organizations I have studied, OII is the only active one to openly, directly, and confrontationally challenge the gender stratification system and its binary ideologies around sex gender, and sexuality. Consequently, OII is prevented from engaging in unobtrusive mobilization strategies. Instead, OII engages in a more confrontation mobilization strategy by publicly criticizing medical professionals for their treatment of intersexuality rather than working with them unobtrusively to promote change—much like the Intersex Society of North America (ISNA) did in its early existence. OII activists continue to publicly protest against medical professionals and their treatment of intersexuality. They also have created “DSD warning labels” that are produced and disseminated to the public on OII’s website. One “warning label” equates DSD terminology with physical abuse while another connects it to the holocaust. The “warning labels” also attach DSD language to the policing of gender by medical professionals and activists in favor of DSD terminology. They refer to “gender police” and even describe the language of DSDs as equivocal to “eugenics,” “heterosexism,” “transphobia,” and “homophobia.”

## **Conclusion**

The development and progression of the intersex rights movement is an example of how modernity has shaped scientific knowledge and ultimately human behavior in what Giddens (1990) labels “reflexivity,” the process by which scholarship can influence the object of study

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<sup>13</sup> Avail: <http://www.intersexualite.org/English-Offical-Position.html>

(e.g., Melucci 1989). Academics not only study society but also shape it in such way that influences all of our lives. The intersex rights movement is one such example. In the 1950s, technological developments and medical advancements allowed for the surgical treatment of intersexuality. Such surgical procedures left individuals affected by intersexuality feeling violated and mutilated (Preves 2003). During this time and throughout the next couple of decades, the second wave of the feminist movement was taking off which uniquely positioned feminist scholars, such as Fausto-Sterling (1993) and Kessler (1990), to critique the medical treatment of intersexuality—and eventually even each other (Fausto-Sterling 2000; Kessler 1998). Such scholarship paved the way for Cheryl Chase to form the Intersex Society of North America in 1993, which would eventually lead the intersex rights movement. Not long after ISNA was formed, many other intersex social movement organizations were born with each sharing the same goal to end the shame, secrecy, and stigma associated with intersexuality.

However, intersex activists, and the organizations they run, are presently engaging in two different mobilization strategies which I argue is paradoxical. With ISNA no longer active, Organisation Intersex International is the only organization I studied that continues to employ confrontational mobilization strategies. Accord Alliance and Androgen Insensitivity Syndrome Support Group-USA, the other organizations I studied, continue to accept the constraints of gender stratification in order to continue to enact unobtrusive mobilization strategies.

The competing mobilization strategies reflect, in part, each organization's understanding of the gender structure. ISMOs that work within the gender structure approach gender as an essentialist characteristic of individuals. They do not challenge gender stratification but rather adopt an unobtrusive mobilization strategy that is “less confrontational...in contrast to the more public protests of the 1960s and 1970s” (Schmitt and Martin 1999, 368; Katzenstein 1990). On

the other hand, ISMOs that conceptualize gender as a stratification system challenge it by adopting a public and confrontational mobilization strategy, much like William Gamson (1975) documented in his study of movements that target the state. For the intersex rights movement, there has been a historical shift in dominant mobilization strategies. Unlike earlier where intersex activists were protesting outside of a pediatric medical association meeting with a banner that read “Hermaphrodites with *Attitude*”, the more commonly enacted mobilization strategy is now one of collaboration with medical professionals. Yet, the collaboration with medical professionals is highly contested by Organisation Intersex International and its members including intersex activists like Chris, Millarca, and Mercurio whose views were presented above.

While Martin (2005) argued confrontational strategies were problematic for rape crisis centers (e.g., Epstein 2007, 1996), I suggest that unobtrusive mobilization strategies used by intersex activists may actually result in the further stigmatization of intersexuals. ISMOs that engage in “unobtrusive mobilization” collaborate with the medical profession because they believe framing intersexuality as a medical disorder will bring about better treatment for intersexuals. But, in the process, they overlook the possibility that the stigmatization faced by those with intersex conditions is due to a belief in the societal endorsement of a binary sex, gender, and sexuality logic that is at the core of gender stratification. Acknowledging gender stratification and understanding it through a deconstruction of this binary leads to the possibility of change.

The most effective organizational mobilization came during the “collective confrontation” stage where activists and their supporters challenged the medical profession’s treatment of their bodies. They did so by forming a collective intersex identity. Activists made

connections between their experiences and came together on a common ground. The medical profession had to acknowledge wrong-doing and change their protocol (Karkazis 2008; Preves 2003; Blizzard 2002). In the chapter that follows, I argue that the medical profession reclaimed jurisdiction over intersexuality by co-opting the intersex rights movement, leaving the reframing of intersexuality as a social not biological problem short lived. The medical profession was able to reclaim authority over intersexuality by successfully proposing a shift in diagnostic nomenclature. The new diagnostic terminology, disorders of sex development, disrupted the collective intersex identity that so many intersex activists before had mobilized around. Once DSD language was introduced, the movement's solidarity was shattered as was their "common ideological commitment" to an intersex identity that initially brought them together (Polletta and Jasper 2001, p. 298).

Intersex activists never consciously deconstructed binary sex, gender, and sexuality logic by exploding categories and attempting to do away with them (e.g., Gamson 1995). Instead, intersex activists raised awareness of gender stratification by challenging the binary sex, gender, and sexuality ideologies at its core. Many did so by claiming a "third sex" identity (Turner 1999). A binary logic can be disrupted by claiming a category outside of the norm (e.g., Taylor and Rupp 2006; Rupp and Taylor 2003). Binary sex, gender, and sexuality logic all presumably correlated is at the root of intersexual stigmatization and at the core of gender stratification, failing to address it when mobilizing is counterintuitive. My analysis of the contemporary intersex rights movement suggests the absence of a singular shared collective identity minimizes earlier social movement accomplishments and instead results in "contested collaboration."

#### 4. MEDICAL JURISDICTION AND THE INTERSEX BODY

It was the middle of October 2010. I was in the Pacific Northwest practically running down the stairwell of a major U.S. pediatric medical center. I was following behind Dr. I., a world-renowned intersex expert, who graciously invited me to the hospital's weekly DSD medical meeting. Dr. I. agreed to an interview with me months before, but during the morning of the interview, she had an unexpected family emergency that left her running late. Understanding that I had traveled across the country to meet with her, Dr. I. was determined to help me with my project any way that she could, albeit given her family emergency now with much less time do so. While her interview was one of the shortest I conducted throughout this entire project, it was also one of the most useful. After answering as many questions as she could under strict time constraints, she invited me to attend her department's weekly DSD medical meeting which was already in session. The interview continued as we move across the hospital and down a flight of stairs. Eventually we entered a room occupied by a dozen or so medical professionals in white lab coats and hospital scrubs. The meeting, I learned, was a structured space for this particular hospital's "DSD Team" to discuss the medical management of its DSD patients. As soon as we entered, she made it explicitly clear that she personally invited me because I was "doing really great work."

My experience with Dr. I. was not unusual. I found most medical professionals supportive and helpful to me throughout data collection. I know from medical professionals, themselves, that they are trying to be the best doctors possible when they treat intersexuality. However, in this chapter, I argue medical diagnoses function to maintain medical authority. In order to explain the contemporary consequences of the re-medicalization of intersexuality, I must begin with its origins. I use a sociology of diagnosis frame in this chapter to analyze the

trajectory of medical management beginning with its origins and ending with the nomenclature shift from intersex to DSD.

I have three purposes for using a sociology of diagnosis frame (e.g., Jutel 2009). First, it allows for an understanding of how the diagnostic process is connected to other social constructions, specifically the belief that sex and gender are clear and correlated binaries. Second, I show how medical professionals define illness sometimes in ways that carries unintended negative consequences. The third purpose is to illustrate how medical professionals retain authority in the face of patient activism. I argue, that the nomenclature shift from intersex to DSD re-asserts the frame of intersexuality as a medical condition that can only be dealt with scientifically, including surgery.

The meaning and definitions of intersexuality have changed throughout history (see chapter one). Thus, the contemporary shift in the medical management of intersexuality is not unusual. Intersex medical treatment went from an “age of gonads” to the “age of conversion” (e.g., Fausto-Sterling 2000a p.40; Dreger 1998a). During the “age of gonads” from the 1870s to the 1930s, lawyers and judges, in consultation with “doctors or priests,” were the “primary arbiters of intersex status” given the “their own understanding of sexual difference.” The “age of conversion,” on the other hand, marks the period beginning around the 1930s where medical professionals “found it imperative to catch mixed-sex people at birth and convert them, by any means necessary to either male or female” (Fausto-Sterling, 2000a p. 40; Dreger 1998a). The “age of conversion” was followed by feminist critiques which brought attention to the social construction of sex and gender. As described earlier in chapter three, feminist writings led to the birth of the intersex rights movement (Dreger 1998a; Kessler 1998; Fausto-Sterling 1993). With

legitimacy gained from feminist scholarship, intersex activists were able to challenge medical authority.

In this chapter, I argue that in the context of this activist challenge to medical authority, the medical management of intersexuality has once again shifted. This time the shift has occurred with use of new nomenclature, shifting from framing the problem as intersexual identity to disorders of sex development. The new DSD terminology reinforces medical jurisdiction over intersexuality which had been contested by intersex activists. As the activists began to successfully frame intersexuality as a social rather than biological problem, they challenged medical authority. This chapter is about the medical establishment's response to intersex activism.

### **Naming Disease**

A medical condition is only as real as its definition. Until the medical profession acknowledges and classifies a particular symptom or condition of the body as abnormal, it does not officially exist (Conrad 2007; Lorber and Moore 2002; Scott 1990; Blaxter 1978). The process by which this acknowledgement and classification occurs is a complicated one. The incorporation of diagnostic terminology into Western medicine is relatively new. According to Veith (1981), ancient Greek medicine existed without specific diagnoses. In lieu of nosology<sup>14</sup>, descriptions of disease were the basis of medical treatment. Beginning in the 18<sup>th</sup> century, medical professionals turned to a botanical model of classification that linguistically identified, labeled, classified, and named a wide range of medical conditions (Fisher-Homberger 1970; Foucault 1975). As Jutel (2009) demonstrates in her review of the sociology of diagnosis literature, not all medical

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<sup>14</sup> Nosology refers to “a branch of medical science that deals with classification of diseases.” Avail: <http://www.merriam-webster.com/dictionary/nosology>, retrieved on July 27, 2011.

professionals were in agreement on this move toward naming (Broussais 1828), yet this “classificatory project” prevailed which resulted in “medicine shift[ing] its focus from individual symptoms to groups and patterns of symptoms that doctors could reliably recognise” (Jutel 2009, p. 280-281). Of course, the process by which medical professionals are able to name conditions is dependent upon a particular time and space and conditional upon technology. In the middle of the 20<sup>th</sup> century, technological advancements in the medical profession led to the discovery that “normally” bodied males were distinguishable from females by their sex chromosomes, XY for males and XX for females (Moore and Barr 1955; Moore, Graham, and Barr 1953).

The consequence of naming medical conditions can have implications for those labeled. Consider, for example, Goffman’s (1961) classical work on asylums. Those labeled mentally ill were forced to adopt an identity consistent with their diagnosis. When diagnosis and identity merge, there is little room for a reconsideration of a diagnosis, making it difficult for those diagnosed with a mental disorder to escape their label even when the symptoms that initially brought about the diagnosis disappear (Rosenhan 1973). Those diagnosed with post-traumatic stress disorder (PTSD) and those medically labeled alcoholic face a similar scenario (Blaxter 1978; Scott 1990). In both instances, the application of the label imposes an identity that is believed to coincide with the diagnosis, whether or not the diagnosis is specified (Blaxter 1978; Scott 1990). Diagnoses sometimes even lead to retrospective reinterpretations of identity (Cooksey & Brown 1998, p. 527).

### **Inventing Sex**

Brown (1990) maintains diagnoses involve two components: “diagnostic technique” and “diagnostic work.” Diagnostic technique “involves formalization of classification, including the

specific tasks, techniques, interviews, and chart recording necessary to make the formalized classification”, whereas diagnostic work “consists of the process by which clinicians concretely proceed with their evaluation and therapeutic tasks” (Brown 1990, p. 395). We can better understand the medical invention of intersexuality, when we dissect it into “technique” and “work.” As noted earlier, before the medical discovery of sex chromosomes, the recognition of intersexuality was not widespread. The discovery of chromosomes led to a medical justification for the formal sex classification, and ultimately naming, of intersexuality (“technique”). Once intersexuality was named and widely accepted by medical professionals, diagnostic “work” was considered medically justified, even as it became problematic to those outside the medical profession. While intersexuality was being named by medical professionals (the “technique”), the technological advancements were proliferating, as evident by the possibility of gender conformation surgeries (i.e., sex reassignment surgeries) on trans individuals. This advancement positioned the medical profession to respond to the intersex diagnosis through surgical intervention, which we can think of as the “work.”

The trajectory of intersex medicalization supports Conrad and Schneider’s (1980) five-stage model of medicalized deviance. Intersexuality was viewed as an unfavorable deviation from the sex binary (stage one). Then, with medical advancements, doctors had the tools to identify and describe intersexuality chromosomally (stage two). Soon after, medical professionals started claiming intersex expertise (stage three). What marks the fourth stage in Conrad and Schneider’s (1980) model is a battle over diagnoses (see also Brown 1995). As discussed in chapter three, the medical profession faced a substantial amount of resistance in this stage from feminist scholars and intersex activists determined to stop the fifth and final stage

where the condition in question becomes a legally recognized “abnormality.” It is this fifth stage I discuss here.

### **Turf Wars and Jurisdiction**

Debates around naming, defining, and treating diagnoses are not unusual (e.g., Brown 1995; Conrad 2007; Cooksey & Brown 1998). For example, consider attention deficit hyperactivity disorder (ADHD). Conrad (2007) argues that while the ADHD diagnosis expanded in the 1990s to include adults, it did so with criticism. The Church of Scientology, for instance, publicly critiqued the ADHD diagnosis (Conrad 2007). Some therapists were also concerned that the ADHD diagnosis was “becoming too prevalent” (Conrad 2007, p. 60). Disputes on the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) are another example. While the DSM is embraced by psychiatrists, “criticism of the DSM comes from social workers, psychologists, and others for whom it does not foster professional dominance” (Cooksey and Brown 1998, p. 549). Therefore, feminist critiques of medicine’s treatment of intersex conditions are in good company (e.g., Dreger 1998b; Fausto-Steling 1993; Kessler 1998, 1990).

What is unique about feminist critiques is that they helped spawn a social movement of intersexuals. Intersex activism initially sought to challenge the practices of intersex health care. We can historically trace this influence of feminist theory on activism (see chapter three). Consider, for example, Fausto-Sterling’s 1993 publication “The Five Sexes” which appeared in *The Sciences*. Although Cheryl Chase was openly critical of the piece, it inspired her to respond with a letter to the editor. In the letter, she identified herself as the president of the Intersex Society of North America, an organization she fabricated in order to gain credibility (Chase 1998b,c, 1997). Soon after Chase’s letter was published, she was contacted by many other

intersexed individuals who shared similar medical experiences. Almost immediately they got together and started protesting at pediatric medical association meetings in order to raise awareness about the surgical, and in most cases unnecessary, modification of intersex genitalia (Karkazis 2008; Preves 2003; Chase 1998a,b,c;). By the year 2000, Chase was delivering a plenary address to the Lawson Wilkins Pediatric Endocrine Society, a group she was once protesting against. This successful activist encroachment into medical turf was highly unusual for two overlapping reasons. As Karkazis (2008) notes, it marked the first time an activist's perspective was solicited by organizers of a major U.S. medical conference. And, it was "the first time that the society's annual symposium was devoted to intersexuality" (Karkazis 2008, p. 257). One of the unintended consequences of this challenge happened years later, the nosological change from "intersex" to "DSD." I argue the activists' challenge to medical authority actually led to the renaming of intersex as DSD. The nomenclature shift was a reaction to activist challenges to medical jurisdiction over intersexuality. Doctors' insistence on the new DSD terminology was a reassertion of their medical authority.

### **White Coat Gender Essentialists**

Seven out of ten intersex experts I spoke with held essentialist beliefs about gender, neatly described by stereotypical western, white, and middle class expectations of femininity and masculinity. I asked Dr. D., a well-respected endocrinologist, if there were instances when gender was incorrectly assigned. She passionately shared:

Yes. When an individual who's been raised as a female gender assignment, comes to the office having totally cut off all her hair, wearing army combat boots and fatigues...it sounds very stereotypical, but it really happens...wearing combat boots and fatigues, saying, 'Oh God, I hate having periods, it doesn't make any sense for my life, I don't like this'. Or they threaten to commit suicide or they're

institutionalized with substance abuse, and part of what comes out of their therapy through that substance abuse is that they don't know who they are or they think they weren't assigned to the way they feel now. And those are not always permanent, by the way...one of my fatigue-wearing persons came in a couple weeks later, wearing a miniskirt, makeup, and having dyed her hair.

Although Dr. D. seems to acknowledge that gender is, or at least can be, fluid by acknowledging an individual can present herself stereotypically male one day and female the next, she still holds on to essentialist understandings of gender. Dr. D. went on to explain:

My experience with girls with [congenital adrenal hyperplasia] suggests to me that it's pretty hard-wired. A lot of the CAH girls are significant tomboys...hey I was a tomboy, it's not a slap, it's a description. They're more of a risk taker, like at age 5 or 6, they'll leap off the porch because they think they can fly kind of things. They wanna take their skateboard and turn it into a hang-glider and take off from a cliff...Whether it's only with DSDs, or whether it's in folks where you couldn't find a DSD with a microscope, I think some of those behaviors are absolutely hard-wired.

As with many of the medical professionals I spoke with, what distinguishes feminine from masculine behaviors for Dr. D. are narrowly defined risk-taking activities tied to potentially dangerous actions.

Many doctors' explanations for gendered behaviors were grounded in hormonal exposure during gestation. Without hesitation, endocrinologist Dr. A. shared:

I think there's no question, again, based upon the [congenital adrenal hyperplasia] experience, or the experience of kids who are exposed to androgens externally during pregnancy, that there's very good reason to believe, and there's probably experimental data about this, to suggest that androgen levels during fetal development produce male-typical behavior later on, there's just no question about that.

Consistent with a binary logic that suggests sex, gender, and sexuality are all neatly correlated, most doctors used each interchangeably in justifying their essentialist views. When I asked Dr.

A. if he could clarify what he meant by “male-typical behavior” he elaborated with a discussion of sexuality:

Like in primates, where they’ve used high levels of androgens during fetal development in chromosomally female fetuses, those female monkeys are engaged in humping behaviors and things like that, which are much more typical of what male primates do as immature, and later sexually mature individuals...how they engage in intercourse.

Here “humping behaviors” are associated with ideologies about males, specifically that they are more sexually aggressive.

When I asked medical professionals to offer possible explanations for gender variation given their strong beliefs that gender was biologically determined, they commonly cited poor parenting. Dr. B.’s response to “gender deviants” was fairly typical of the medical professionals I spoke with. She shared:

I have worked with kids who’ve decided to kind of move forward in an opposite gender than the one that they were originally assigned to. But the cases that I’ve work with where that happened, were predominantly very poorly-controlled kids with congenital adrenal hyperplasia, who were very masculinized by the time. I worked with one young boy, adolescent male, who was really a genetic female had been born in another country, very poorly controlled, very masculine.

By suggesting gender variation among intersex kids is the result of being “poorly-controlled,” medical professionals unintentionally place a tremendous burden of responsibility on parents to police their child’s gender in stereotypical ways.

The surgical modification of intersex genitalia is a lucrative practice for urologists because the surgeries are imperfect and often require revisions and modifications in the form of reoccurring visits to a costly operating room. Urologists, however, had very different justifications for modifying intersex genitalia. Dr. G. shared:

Some of the babies are born where the base of the penis is really where they're urinating from. If the baby is going to be raised as a girl, that's an okay place. But if they're gonna be raised as a boy, then it may be that they're really needing to create the urethra tube and have the urine come out of the penis' tip. Some of the surgeries that are done on older children, you really get terrible outcomes.

Regardless of medical need, genital surgery on baby boys is justified by a social norm that maintains men urinate while standing.

### **When Gender Essentialists Create Diagnostic Terminology**

Medical professionals rely on gender essentialist views to justify the medicalization of intersexuality, and more specifically, the validity of the *disorder* of sex development diagnosis itself. Fundamental to a gender essentialist view is that gender is and should be neatly correlated with a binary sex and heterosexual sexuality. If one deviates from the pattern, modification is needed in order for normalcy and consistency to be achieved. Most of the medical professionals I spoke with believe intersexuality is usually a visible abnormality of the body that warrants and justifies treatment. When I asked Dr. D. if a person with a DSD was recognizable in a crowd of people, her response surprised me:

Some of them, yes. Because some have some very specific phenotypic features...it's as if you're trained to look for them. [Georgiann asks: And what are some of these big, obvious characteristics?] Okay, well Turner Syndrome. So there are phenotypic features of women with Turner Syndrome. And if you know what you're looking for...Short stature, droopy eyes, very prominent ears, a webbed neck, there are characteristic features of the fingers, and Klinefelter's Syndrome, not always, but some of the forms of where folks are just gonadal, they have long, thin body proportions with big, long arms, and a high-pitched voice, and not much facial hair or facial musculature or shoulder musculature, you can sort of go, 'That person looks like they might have a DSD'.

It's no wonder that many of the individuals with intersex conditions I interviewed expressed genuine concern that their diagnosis was outwardly obvious in public settings. During my

ethnographic observations at intersex social movement organizations, I found it impossible to identify those with an intersex condition from others in attendance.

With strong gender essentialist views, medical professionals have the justification they need to rely on medical testing to reach a definitive gender assignment. As the following quote illustrates, medical professionals do so entirely within a bio-medical paradigm, as evident by only a peripheral involvement of psychiatrists in the gender assignment process. Dr. C. shared:

We do all the biochemical information...we do all the morphometrics, radiologic assessment, and then we sit down – the endocrinologist, myself, sometimes a general surgeon – really, surprisingly, within our setting, very rarely, a psychiatrist. And we'll discuss primarily – in all discussions that I've had input into – who the child thinks they're going to be later. Which seems to be a fairly simple thing, which is did the child have significant testosterone exposure, [inaudible] testosterone receptors in utero? And then once that's been established, discuss the issues such as fertility and functional success of surgery.

Framed through a bio-medical paradigm (e.g., Foucault 1980), the validity of the recommended gender assignment is left unchallenged which then rationalizes surgical intervention.

Medical professionals' essentialist assumptions that there is a rigid correlation between sex, gender, and sexuality helped implement the nomenclature shift from intersex to the *disorder* of sex development. Dr. G. was one of many that held this view which explains her position on the diagnostic terminology:

I think it's so helpful to have such a broad category. So 'disorders of sex development', that's a pretty broad category, and it doesn't imply judgment, it doesn't imply that one's more severe than another, because underneath that umbrella are many many different diagnoses. So I think parents, if they're being seen by the 'disorders of sex development' clinic, they start appreciating that all of this has to do with how our sex develops, and how and that there is genetic and hormonal factors. We often use the analogy of...there are many different types of heart defects. Well our bodies are complex how we're put together and there are many differences in body shapes and sizes, and there are differences in how genitals have grown and developed.

Medical professionals view gender as something that should function, and to function properly it must be in line with sex and sexuality. And, when gender doesn't neatly match sex, it's a sign they haven't correctly sexed the individual in question. The alternative feminist explanation based on the social construction of sex, gender, and sexuality isn't seriously entertained by most medical professionals who are in a position of authority to define and treat bodies as they see fit. Their authority was challenged by a successful social movement in a relatively short amount of time (see chapter three). The result has been a forceful push away from social movement intersex terminology in favor of the new "DSD" language. Dr. C. explained:

First [are] the terms of the word 'intersex'. Again, the word 'sex' is highly emotionally charged, whether it's your gender, whether it's having sex, or anything else. And so moving away from a highly charged word like that which can mean a thousand different things to a thousand different people is what we should absolutely get away from right away...and I think no one would disagree...it's amazing it took so long to get rid of the word 'intersex'.

This nomenclature shift allows medical professionals to reassert their authority and reclaim jurisdiction on a condition that they once had exclusive control over.

### **(Re)Asserting Medical Authority**

Intersex activism problematized the medical treatment of intersexuality, which challenged the authority of intersex experts, and ultimately their integrity. Dr. C. shared:

[A]nyone who ever heard the story, physicians, especially parents, and patients to be extremely suspicious of everything we do, and rightfully so. I mean, it was all coming out. Your integrity is the one thing that you work the longest to get and with just one slight fraction, results in total dismissal of integrity. And I'm trying to teach [my kids this] all day long, that authority is the one thing you have to guard like your jewels...Now, it came under great suspicion, and I think that the only way to make it right is to make it now more clear.

Authority was made “more clear” by renaming intersexuality a “disorder of sex development” a term not politicized by activists. This linguistic shift reclaimed jurisdiction over intersexuality, a condition that intersex activists began to successfully reframe as a social rather than biological problem.

The new DSD nomenclature stopped such reframing dead in its tracks. By advocating for DSD language, doctors were able to draw comparisons to other diseases, including cancer. Dr. C. viewed DSD terminology as “an analogy. It’s like talking about skin cancer and brain cancer.” Similarly, Dr. A. shared that “DSD is a somewhat more complete and accurate term...DSD is a perfectly fine term, I now use it in my own work. I don’t worry about it. Several of us wrote a paper about supporting that change [*laughs*].” While most doctors are in support of DSD terminology, many activists contest it, the subject of chapter five.

Doctors’ authority over intersex conditions was also reasserted by creating medical management “teams” that would consist of various “experts” on intersex conditions. Such teams have been and continue to be viewed within the medical community as the best possible approach for treating intersexuality. Dr. A. shared:

I think it’s pretty clear that the best care is care that includes people with expertise from endocrinology, from urology, from psychology & psychiatry<sup>15</sup>, from ethics, etc. etc. There are only half a dozen places in the country that have them, if that.

In the face of challenged medical authority, medical professionals are able to reclaim and reassert their positions as experts by operating in teams. At the same time, they are able to minimize any potential liability for hormonally and/or surgically treating intersexuality. Dr. C.’s view summarizes such quite nicely:

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<sup>15</sup> As quoted on page 95, Dr C. noted that “surprisingly, within our setting, very rarely, a psychiatrist” is included in the gender assignment process.

We take solace in the fact that we're operating as a team, it's not generally blame, but the better way to look at that would be to say we're showing the families as clearly as possible just how much we're wrestling with the situation ourselves, and I think that's very important. ... We generally speak among all five pediatric urologists here as a group, telling the family we've had four second opinions without even needing anybody else here. But I think we take solace in that. I think it's a very important thing for the family to see, just how much we're wrestling with the choice ourselves.

The medical "team" then serves as a way for intersex experts to negotiate their authority given the tremendous amount of uncertainty around treating intersexuality. While the team frames themselves as knowledge providers rather than decision makers, parents I've spoken with see the team as the authority on intersexuality, especially since it is made up of not one but several medical professionals.

Intersex medical management teams work together to decide on the best possible medical intervention, which actively rests on reaching a diagnosis and an attempt to discover a patient's true sex, albeit within a binary sex framework. Dr. I. detailed how this process works on her team. She shared:

Number one, the child is referred to as 'baby' until we have a 'boy' or 'girl' status. Unfortunately, in the computer, they get assigned 'boy' or 'girl', because there's no just 'baby'. So the child is referred to as 'baby'. The family is aware that we are getting additional data. We have to wait for labs to come back, karyotypes to come back. We let the family know that there is not an emergency...once you say there's no medical emergency here, then we say, let's get some more data. And then we get more data. Once we have the data, we meet as a team – a pediatric urologist, a psychologist, a geneticist, an endocrinologist, and a genetic counselor, for example, that's the makeup of the team, with the possibility that we have utilized the ethics team for ethics consultation. We meet as a team and think about what are the options, which option we feel is medically in their best interest, and then we present the options to the family. And then we help the family reach a decision as soon as possible.

Dr. I.'s description of how the team operates was fairly similar across all medical institutions that had teams in place. In line with their mostly essentialist beliefs about gender, the team orders

diagnostic tests including assessments of hormonal levels, karyotype, and other biological “signs” of sex. This process not only frames gender as strictly tied to sex, but it also frames gender as something that can be biologically discovered.

Although intersex experts maintained the diagnostic process has little to do with gender identification, it remains embedded within any recommendation through a belief that sex, gender, and sexuality should be correlated. Dr. C. shared that the team:

need[s] to figure out hormonally if the child makes testosterone. We need to figure out genetically what the chromosomes are and then discuss what little knowledge we have in 2010, how we think this child’s going to think. Not in terms of gender preference or who they’re attracted to of course, but for gender identification, who they think they are.

Once again, we see the congruence theory at play which presumes that one’s sex is neatly tied to gender and sexuality.

Intersex experts, especially surgeons, need to operate in medical management teams in order to reclaim their challenged authority. Gender essentialist views justify surgical intervention. Dr. C. shared with me how he discusses his suggestions with the parents of newly diagnosed children with intersex conditions:

I always talk about it as nature...just about got it right but just this is the last few steps or last step, and we can complete that for you and then we take lots and lots of questions.

All of the medical professionals I spoke with maintained that parents approach the intersex diagnosis with lots of questions, and my interviews with parents support this. Medical professionals made it clear during interviews that parents welcomed their professional opinion with little resistance or hesitation. However, such wasn’t true for all families. Dr. C. recounted a recent consultation with a family that was very critical of his recommendations:

The father said, '[Doctor], can I ask you a question?' I said, 'Absolutely, this is your forum. I'm at your disposal. You're hiring me.' He said, 'Why should we do anything?' And I acted physically surprised, I'm sure I did. And I said, 'Well, I'm concerned that if you raise this child in a male gender role without a straight penis, he's not going to see himself as most other males and he's not going to certainly be able to function as most other males.' And the father said, 'Well, in our family we like to celebrate our differences and not try to all be the same and feel the social pressure to do everything like everyone else does.' ....I said, I do have to say one thing, and I think it's of key importance that you both see a psychiatrist.

While the 2000 and 2006 medical consensus statements encourage intersex experts to refrain from performing medically unnecessary surgeries to treat intersexuality, Dr. C., like other medical professionals I spoke with, continue to perform *cosmetic* surgical modifications. The consequence of which is the potential loss of sexual pleasure (e.g., Preves 2003). Given differences of power and expertise, in the end, parents usually grant consent (Conrad & Schneider 1980; Dreger 1998b; Zola 1986, 1972).

### **Outliers in the Medical Profession**

Only three of the ten medical professionals I interviewed—Dr. E., Dr. F. and Dr. H.<sup>16</sup>—were critical of the binary sex, gender, and sexuality logic. It was, in fact, only after intensive purposive recruitment strategies that I was able to find medical professionals that deviated from the norm. Influenced by feminist scholarship, Dr. E., Dr. F., and Dr. H. held very different views than the majority of intersex experts. For example, when I asked Dr. E. if she thought gender was biologically pre-determined, her response was grounded in feminist scholarship:

Well here I'm gonna probably diverge from any biological explanations for this, cause I don't know if you've read any of Anne Fausto-Sterling's stuff...she's very convincing to me...gender, sexual orientation, hormones, phenotype...I think has to do with the way nature works, and nature loves variety...maybe there's some

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<sup>16</sup> Dr. H. is particularly rare because he has been on both sides of medical management. He treats individuals with intersexuality, and he has an intersex condition himself which resulted in numerous genital surgeries.

way testosterone tends to make people act more boyish. But I think it's the way we then interpret that boyishness.

Although Dr. F. didn't rely on feminist scholarship as did Dr. E. to critique sex, gender, and sexuality binaries, she was still critical of binary logic. Dr. F. shared:

So we still have this dichotomous society that thinks in black and white, male and female, and there's nothing...you can't be anything but one or the other. It's some of these social constructs that seem to exist in the United States that maybe don't exist in other countries...

As noted earlier, the majority of intersex experts I spoke with believed that a person with a DSD could be recognizable in a crowd of people. Quoted earlier Dr. D. shared, "Some of them, yes." The assumption that intersexuality is outwardly obvious is grounded in medical professionals' belief in gender essentialism; I disagree. I spent hundreds of hours at intersex organizational meetings where it was impossible to distinguish intersexed individuals from their "normally bodied" parents and significant others who were also in attendance. The three progressive medical professionals who reject gender essentialist claims—Dr. E., Dr. F., and Dr. H.—support my ethnographic observations. For example, when I asked Dr. E. whether or not an individual with an intersex diagnosis was easily recognizable in a room full of people, she did not go to physical descriptions of the body that are alleged markers of sex. Rather, Dr. E. went to gender. She quickly replied to my visibility question, "No! [laughing]...In my experience, intersex people are so raised to conform to a gender role that they do."

Although parents are responsible for raising their children how they see fit, the progressive medical professionals I spoke with acknowledged that parents of intersex children were especially pressured by their medical peers to police gender. Dr. E. shared:

I think parents are really pressured...from doctors. Yeah, because part of the outcome was that [intersex kids are] supposed to adopt that gender role. I was

talking today about a client whose mother wouldn't let her wear tomboy clothes, wouldn't let her join the girls' softball team 'cause these were activities of men...

Dr. E. expressed real concern for intersex children. And, as a parent herself, she also understood parents' desire to raise "normal" children. She did her best to help parents understand one's gendered behaviors are not correlated with sexuality. Dr. E. explained:

When I talk with parents, for whom this is an issue...it's a somewhat easier issue now, because 20 or 30 years ago, the beliefs about what gender roles/stereotypes were, were a lot stricter than they are now, most parents now don't have trouble with their girls or daughters being athletes...but I really try to normalize that for them. There are lots of feminine, heterosexual adult women who were tomboys when they were little girls; this is not an ominous sign.

Dr. E. still frames a queer lifestyle as less desirable than a heterosexual lifestyle, but as a political strategy rather than a value judgment. As a lesbian medical professional herself, Dr. E. understood the heterosexism involved in the treatment of intersex children. She shared:

I think homophobia is always under this. Absolutely, in the medical community...and for a lot of parents there's a big anxiety...they don't know who they're supposed to marry or have sex with...That feels rough on some parts of me.

She was critical of such, but yet bit her tongue in order to push an agenda that allowed children to express their gender in ways they see fit. Since children aren't socially viewed as sexual beings, this approach made the most sense to her.

Fertility was almost always discussed as the single most important determinant of gender assignment. Dr. F. articulated this quite nicely. When I asked her to describe the processes involved with assigning a gender for those born with externally ambiguous genitalia, she explained:

Basically the outward appearance. To some extent, what structures the child has internally as well, can affect that...[Georgiann asks, What do you mean by structures?] Well, like a uterus for example. If a child does have part of a uterus,

that can be a guide...Physicians tend to go toward the female sex of rearing, because that has the potential for carrying a child. This is kind of the *holy grail* of being able to bear a child and carry a pregnancy. So that does tend to drive sex rearing towards female, if there's a uterus present.

Critical of the medical profession's early approach to surgery, Dr. F. went on to share:

But what I would hope in this circumstance, is that they actually *don't* do surgery, is that they just leave this child as is at least until sometime later in the child's life when it's clear what this child's gender identity appears to be.

Although she remains critical of such an approach, Dr. F. is unable to entirely escape hegemonic ideologies about gender. I asked her if a child's gender identity can ever be "clear" given her own view that gender is a "social construct." She explained:

I think there's...yes, but I think there's plasticity in that, I think it's malleable. I think we're endowed with this certain level of masculinity or femininity at birth, due to whatever prenatal influences we're exposed to, but I think there can be post-natal influences that may modify that, whether they're hormonal influences, or whether they're external, environmental influences. I'm not entirely sure how environmental influences would change that, I think it's probably more biological than sociological, from my perspective. But I do think there are probably cases where its malleable. And transgender individuals are kind of those examples, which are not part of this discussion.

As we can see with Dr. F., even the most progressive feminist intersex experts do not move entirely beyond essentialist understandings of gender.

While we can think of Dr. E., Dr. F., and Dr. H. as progressive medical professionals, they were still pessimistic when asked about the possibility for change. For example, Dr. F. shared that moving beyond binaries would be "almost a dream of utopia, to think about our society even getting to that point" because "urologists would have less work, so there would probably be some...you know..." As I've earlier shown, intersex experts in the field of urology are known to surgically modify a child's genitalia regardless of medical necessity if it means a child will be able to more comfortably fit into gendered expectations. Men's ability to urinate

while standing is such an example. Dr. F. was critical of such unnecessary surgical intervention.

She shared with me:

Why do they have to be able to urinate standing up? What's wrong with sitting down? Women sit down to urinate, so why can't a boy sit down to urinate? There's nothing physically wrong with sitting down to urinate. The stigmatization of social differences like sitting down to urinate as opposed to standing up, and boys and girls seeing their physical parts in locker rooms...

Medical professionals like Dr. E., Dr. F., and Dr. H. are rare in the medical world of intersexuality. They deviated from their peers because they were influenced by feminist scholarship. As quoted earlier, when I was interviewing Dr. E. she inquired, "I don't know if you've read any of Anne Fausto-Sterling's stuff...she's very convincing to me." Almost every intersex expert I interviewed was exposed to feminist scholarship, yet most weren't influenced by it. In fact, one medical professional even jokingly shared with me that she thinks "feminist scholarship is great for a rage filled feminist agenda...in medical practice, not so much."

Although the majority of medical professionals do not find feminist scholarship convincing, many intersexed individuals do for two fundamental reasons. First, feminist critiques of the medical management of intersexuality paved the way for the formation of the intersex rights movement (Chase 1998b). Without feminist scholarship (e.g., Kessler 1990; Preves 2003), intersex activists wouldn't have had the legitimacy to challenge medical professionals. Second, as I discuss in chapter six, many intersexuals find personal liberation in feminist scholarship because it openly critiques binary understandings of sex, gender, and sexuality which are at the core of their secrecy, shame, and stigma.

## **Conclusion**

The success of intersex activism centered on framing intersexuality as a social rather than biological condition was short lived. Medical professionals took back authority from intersex activists by linguistically reinventing the intersex diagnosis. DSD terminology constructs “sex” as a binary scientific phenomenon. Under such a frame, intersex experts bring intersexuality back to science, and thus are able to justify surgery. This places intersexuality neatly into medical turf and safely away from critics of surgery. The re-connection to scientific language increases medical credibility (Zola 1972), which was necessary to counter intersex activism. While DSD medical management teams are now operating with expertise from across medical specialties, psychiatry is less involved than others. Psychiatrists may be less valued because they are less likely than surgeons to hold essentialist beliefs about sex, gender, and sexuality. Psychiatrists are more likely to see intersexuality as a social phenomenon. The new DSD terminology takes intersexuality back to medicine where medical professionals, notably surgeons, can reclaim authority over the intersex body, a move that diminished much of the earlier efforts by intersex activists. The intersex rights movement has since divided around the new nomenclature. Although many intersex activists have decided to collaborate with medical professionals in an attempt to maintain their success, such collaboration is contested by other activists who refuse to work within the medical frame. As intersex activists debate with each other, medical professionals are able to gain authority and reclaim jurisdiction over intersexuality without substantial challenge.

## 5. GENDER PLAYERS AND GENDER PRISONERS

It was July of 2010, and I was staying at a University hotel not far from Music Row. Although I wouldn't publicly identify myself as a country music fan, I was secretly excited Nashville had been chosen for the 2010 AISSG-USA annual support group meeting. I had never been to Nashville, but always wanted to visit after it was featured in a Travel Channel program. Truth be told, I didn't get to see much of Nashville. Instead, like most other conferences I attended, I rarely left the hotel during the four day conference.

Each day was filled with back-to-back information and therapeutic sessions where conference attendees learned everything from new treatment options for osteoporosis<sup>17</sup> by medical experts to extremely intimate sessions where individuals shared personal experiences with intersexuality. I attended one particular session that I can still recall very clearly about "disclosure." Given that most intersexuals keep their diagnosis to themselves, I figured it would be a well-attended session. And, it was so. The session was so packed that a couple of folks found themselves sitting with their legs crossed on the floor, much like elementary school children at a band recital. I counted about forty people in attendance. Most in attendance were women with intersex conditions, although there were a few researchers in the room including two well-known scholars of intersex studies.

The session was facilitated by two outspoken activists, Jane and Janet. Each had a tremendous amount of experience publicly disclosing their experience with intersexuality. Jane, for example, had recently appeared on NPR. Janet had been quoted in numerous newspapers and has appeared in several new documentaries. The session started off with Jane and Janet each sharing their stories about going public with their intersex diagnosis. However, not too long after

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<sup>17</sup> Individuals with intersex conditions are at a much greater risk of developing osteoporosis earlier in life than individuals without intersex conditions.

the session started, a debate about the new disorder of sex development (DSD) nomenclature surfaced.

It was four years since the medical profession advocated for the nomenclature shift in their 2006 consensus statement—which was one means by which medical professionals reclaimed jurisdiction over intersexuality and the intersex body. It had already created a tremendous amount of tension between intersexuals. One of the session attendees, Kimberly, directly asked the room full of intersexuals why the terms “intersex”, “intersexuality”, and “intersexual” were less favored than DSD language. Kimberly was certainly not new to intersex activism, having been involved with the Intersex Society of North America since early in its formation. She even made appearances in some of the first documentaries distributed by the Intersex Society of North America. As she sought to hold on to intersex terminology, Kimberly was an outlier among this group of intersexuals. Those in support of DSD language explained to the room that intersex was an identity, something that one could choose to embrace or reject. DSD, on the other hand, was a useful medical term for the public to understand the origins and treatment of intersexuality.

Framed as a disorder of sex *development*, intersex bodies are understood as the result of an “abnormal” development of sex. According to those in favor of the new diagnostic terminology, DSD language makes it easier for the public to understand intersexuality with less stigmatizing outcomes. They also claim DSD language is useful in helping parents understand a child’s intersex condition. The debate around the new nomenclature extends far beyond this particular conference session. In fact, while people who rejected DSD terminology were rare in this setting, I found them far more common in the intersex community.

This debate over diagnostic language intrigued me early in my field work. I decided to find out how those personally impacted by intersex conditions view the nomenclature shift from “intersex” to “disorders of sex development.” Do understandings about gender influence one’s ideas about the nomenclature? And, has this shift reduced the stigma and shame historically tied to the intersex diagnosis? To foreshadow my answers to these questions, I argue in this chapter people who challenge the gender binary system, do so by rejecting the DSD diagnosis as pathologizing. I label these folks “gender players” because they “play” with understandings of gender by challenging its existence as an essentialist category. However, the process of doing so comes with very real consequences which sometimes limit their access to resources and support from doctors, and often parents as well. Those who embrace the DSD diagnosis have more access to medical resources and family support. I label these DSD embracers as “gender prisoners” because they are constrained by a binary understanding of gender that they feel they can never neatly fit into. They report insecurities around being differently bodied in ways that perpetuate shame and stigmatization.

### **Intersexuality or DSD: Two/Too *Different* Trajectories**

What was immediately clear at the conference and after is the controversy among intersexed individuals about the linguistic shift from “intersexuality” to “disorders of sex development.” My finding is in direct contradiction to previous research (e.g., Dreger and Herndon 2009; Feder 2009). For example, although Dreger and Herndon (2009) acknowledge “the new terminology has been mixed among people with intersex,” they conclude “we have found that [DSD] terminology accords with the experience of many intersex adults and patients, it gives them a term that feels right in that it seems simultaneously to name, scientize, and isolate what it is that

has happened” (Dreger and Herndon 2009, p. 212). Surprisingly their conclusion was reached without any systematic research, only anecdotal evidence. Feder (2009) even went so far as to label the new disorders of sex development language “progressive” (Feder 2009, p. 226).

I found no such consensus among intersexuals about what to label their condition. For example, Jeanne explained to me that “disorders of sex development is such a mouthful...and it is kind of a cold word....intersex...I identify with it.” When I asked Pigeon what she preferred to call her condition, she enthusiastically replied, “hermaphrodite or intersex...I feel like the language shift to DSD makes no sense to me...I don’t feel it was necessary.” Millarca expressed similar discontent with DSD language. With passion she explained that “DSD is not...is not something a lot of people want to identify with...nobody wants to be a disorder...who wants to be a fucking disorder?...I don’t.” Maria echoed something similar: “For technical reasons, I think DSD is appropriate...*but*...intersex really highlights that it really is different...it is not just some disorder.”

Others were not critical of DSD language. Jane explained her position as follows:

I can be on the outside of the room arguing about terminology and if I embrace [DSD] and the door opens and let’s have a real good substantive conversation because we are talking about the same thing...you can call me frog. I don’t give a crap what you call me as long as we’re moving forward advocating for families and advocating for small children that don’t have a voice...so, when people want to argue till the cows come home that ‘*disorder is such an ugly word*’ and ‘*were not disorders...were not disordered*’...oh get the fuck over it.

Liz seemed to have a different take on the nomenclature shift. She shared: “I really don’t care. I don’t get involved in that kind of garbage.” Yet, throughout the interview, Liz spoke of intersex and AIS as distinctly separate. She maintained: “I am not really familiar with the IS perspective, so I will speak to the AIS perspective.” AIS is a medical acronym for Androgen Insensitivity

Syndrome. AIS is an intersex condition; however, given its connection to medical terminology, it more neatly falls under the DSD umbrella than it does under intersex language. Tara also preferred the medical nomenclature of AIS, which is consistent with DSD language, over identity labels. She shared: “Hermaphroditism and all those kinds of ones...I am not a fan of obviously...I got my records and I wasn’t a big fan of seeing testicular feminization on there...I kinda want to see them change it to AIS or something.”

Support for DSD terminology was almost<sup>18</sup> evenly split between the thirty seven<sup>19</sup> intersexed individuals I interviewed. In order to make sense of this divide, I analyzed interview transcripts to distinguish the features between those who prefer “DSD” language and those that reject it. Two categories of intersex/DSD adults emerged from the data, who I call the “gender players” and the “gender prisoners.” These labels emerged only after I carefully analyzed the transcribed interviews to interrogate the features that set apart those critical of DSD language (“gender players”) from those who embrace it (“gender prisoners”). Aside from their different views on the new nomenclature, what primarily distinguishes gender players from gender prisoners are their conceptualizations of gender and sexuality. Gender players openly voice criticism of gender binary logic, often citing the fluidity of gender. They understand sexuality in similar ways. Gender prisoners, on the other hand, accept gender and sexuality as essentialist characteristics of the body that are strongly correlated with sex. There are consequences for gender players and gender prisoners based on terminology and conceptual understandings. In the sections that follow, I show that while gender players embrace intersexuality as an identity

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<sup>18</sup> Slightly more individuals were in favor of DSD terminology than not, but the number wasn’t substantial enough to confidently reject the possibility of a bimodal distribution.

<sup>19</sup> One intersexed individual out of the thirty seven noted here is a medical professional who himself has an intersex condition.

characteristic, they are often alienated from their parents who would rather see their children fit into the gender binary. They also receive limited resources and support from doctors given their open criticism of intersex medical management. In contrast, gender prisoners receive much more familial and medical support, yet they are constrained by feelings of abnormality centered on beliefs that they cannot fit into the gender binary system. Table 5.1 on the following page summarizes my findings.

I anticipate my “gender player” and “gender prisoner” terminology will be met with criticism. First, the word “prisoner” has a negative connotation. It symbolizes an individual who is found guilty of breaking the law. However, it also refers to one who is restrained or confined. It is the second definition that I rely on in my use of the word. Gender prisoners are emotionally inhibited by their understanding of gender. They are confined by the gender structure. If we see the gender structure and the inequalities that it perpetuates as oppressive, it makes sense to approach it as a prison. Second, while the words “player” and “playa” have been used in music to symbolize a man who is sexually involved with multiple women without their knowledge<sup>20</sup>, I use it in the theatrical sense. The gender structure is the stage that “gender players” “play” with and on. They do so by challenging the binary gender ideologies that rest at its core.

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<sup>20</sup> Consider, for example, Ice T’s “Don’t Hate the Playa” which was released in 1999 on his *The Seventh Deadly Sin* album.

**Table 5.1: Typology of Intersex/DSD**

<b>Gender Players</b>	<b>Gender Prisoners</b>
Critical of DSD Language	Embraces DSD Language
Diverse Gender Presentations (both normative and non-normative)	Normative Gender Presentations
Lesbian, Bisexual, or Queer Identified (even if in opposite sex relationship)	Straight or Heterosexual Identified
Few Concerns About their Body	<u>Concerns</u> “Normal” Appearance External Validation Inability to Reproduce Cancer Risks
Critical of Medical Professionals	View Medical Professionals as Supportive and Helpful
Estranged Parents	Supportive Parents

### **Views on Gender**

A substantial difference between gender players and gender prisoners is that the former believe gender to be a fluid social construction. Gender players speak of the fluidity of gender, regardless of their gender presentations. When Rebecca was asked how she believed boys and girls or men and women are different she replied quickly that “there is not a high degree of difference to be honest...outside of things like strength and height...the overlap between the two gender codes is so huge to almost make the differences between the two averages statistically insignificant...In terms of behaviors...really, honestly...no.” Donna similarly shared that, “look...neither sex nor gender are binary systems...neither are black or white...nature is not

perfect...gender is socially constructed...what clothes you put on, how you cut your hair, how you present, how you choose to identify is gender.”

While gender players believe in the social construction of gender, not all debunk traditional displays of femininity or masculinity. For example, Chris was “doing gender” in a stereotypically masculine fashion during his two-part interview by his full salt-and-pepper beard alone (e.g., West and Zimmerman 1987). Leigh, Donna, and several others also perform feminine gender in stereotypically ways. Throughout data collection, I commonly observed gender players “doing gender” in normative ways, yet they understand it to be a social construction that anyone could perform instead of an essentialist characteristic that they could not control. For example, when I asked Pigeon what advice she would give to an individual recently diagnosed with intersexuality, she passionately advised:

Play with your gender if you want...[*laughing*]...you can do whatever you want! It’s like, don’t just stick with what you’ve been assigned, check out all avenues of sexuality and gender and have fun with it. See it as a positive thing, because it is a positive thing. Being a hermaphrodite is so cool! And get a hermaphrodite tattoo if you want! [*laughing*].

Similar to many other gender players, Pigeon’s understanding of gender emerged from formal training in gender scholarship (a point I return to in the chapter that follows). Caitlin, however, came to understand gender as a social construction while working as a “stripper for a few years.” She shared:

[Stripping] was a performative femininity and that kind of started my femme identity in a lot of ways. Like it was a conscious, performed femininity so it started to be kind of fun to play with and it started to kind of seep out into the way I presented myself.

Regardless of how gender players come to their conceptualization of gender as a socially constructed phenomenon, they see it as something to perform.

Gender prisoners, on the other hand, understand gender as biologically defined in stereotypical ways. When Vanessa was asked how she believed boys and girls or men and women in general are different she shared that “when you think about kids, boys can be a little more physical, a little bit more aggressive, a little bit more active...even though girls can be.” Upon probing, Vanessa described the differences as being naturally occurring. Liz similarly understood gender differences. She shared, “girls are more touch feely. Girls are more sensitive. Girls do think more internally. Guys kind of gloss over things. They are much more third party type people. They like a lot of intensities. Their um....girls are much more judgmental...I think.”

Gender prisoners typically present themselves in stereotypical gendered ways. Unlike gender players who I observed doing gender in both normative and non-normative ways, I observed very little flexibility around gender performance for gender prisoners. Gender prisoners who identify as women almost always present themselves with makeup and feminine clothing accessorized with jewelry. Bruce was the only gender prisoner I interviewed who currently identifies as a man. He was raised as girl but decided to transition to a male gender identity later in life after feeling uncomfortable in his female gender identity. By presenting as a female, he felt he was being dishonest to himself and the public. He explained,

I’m a feminine on the inside, but there’s this part of me on the inside that [didn’t] feel comfortable with what I look like. This you know, and so I would say very definitely that I had the [male] looks, I had the male bone structure in my face, which you know made it, a little difficult to, to look completely female.

When I asked him if he believes strangers currently see him as more feminine or masculine, he answered:

I wear a mustache, they probably think this is an alpha male. This is a, this is a guy, this is a definitely masculine, over the top, macho type of guy.

Although he acknowledged his masculine gender presentation, like other gender prisoners, he was concerned with being deceptive.

### **Sexuality**

Another difference between gender players and prisoners is that players mostly claim a “lesbian,” “bisexual,” “asexual,” or “queer” sexuality while gender prisoners claim a “straight” or “heterosexual” sexuality. While most gender players are in same sex relationships, not all are. Several gender players, for instance, are living as one gender and partnered with a person of another gender. For example, Leigh, a woman who identifies as queer, is in a long term committed relationship with a man. Jeanne, a woman who identifies as bisexual, is also involved with a man. Similarly, Chris, a man who identifies as asexual, was also partnered with an individual of the opposite gender before her untimely death. An important theme to note is that gender players not in same sex relationships claim a bisexual, queer, or asexual sexuality.

In contrast, gender prisoners are exclusively involved in, or actively seek, a romantic relationship with an individual of the opposite sex. They always identify as “straight” or “heterosexual.” Longing to fit into the gender binary system, they find solace in heterosexual partnerships because they see them as evidence of achieving normalcy. The only thing superior to the heterosexual relationship itself is being able to sexually satisfy their partner. For example, Jenna shared:

Let’s say that your orgasm is a 100 on a scale of 0 to 100...for me having my partner reach climax which obviously with a dude it’s ridiculously easy...but having my partner climax is 95 out of 100...it doesn’t make me...but the satisfaction I get from that...is almost as much as me orgasm-ing...cause I’m like FUCK YEA! I DID THAT!!! THIS XY!! BA BAM! I’m not joking that’s how I am...I’m like THAT’S WHAT I’M TALKING ABOUT...

Gender prisoners commonly privilege their partner's sexual pleasure over their own. It is how they get their greatest satisfaction. Millarca, who fits into my gender player category, suggested that gender prisoners are in relationships to satisfy their insecurities about being differently bodied. She insisted:

These girls are in relationships because they're trying to be normal. They don't want to be different, but they are different and they can't accept that. We're different. You're different, and I'm different. Her normal 'I want to be normal' is different. That's where the turmoil lies in, in trying to be something you're not. If you can accept who you are, like I have, like other people have, what other people say don't mean shit. You're not trying to switch into some other box where you know damn well you can't fit into.

### **“Normal” Gender Appearance and External Validation**

Gender prisoners are also worried that their diagnosis interferes with their ability to pass as normal women or men. Like other gender prisoners, Tara expressed concern about claiming a female sex category. She shared:

After I found out that I technically am a genetic male...when I wear a baseball hat or something I kinda look in the mirror and, I'm like do I look like a dude...like can I look like a dude? Do I look like a girl? Or do I fall in this in-between and I could go either way if I really wanted to? Some women obviously look like women...

Jane echoed something similar although she is much more comfortable after being active in an androgen insensitivity syndrome support group:

Before I got into the support group that was a perpetual fear of mine. My friend...says she never went out of the house even in the summer without a coat on because people could tell from the shape of her body there was something weird about her...she looks like Doris Day...she's just so cute...[giggles] but...yes we conjure up this crap in our brain. Being tall and being big is a double whammy...because occasionally a waitress will not be paying too much attention to what she's doing and she'll say, 'what would you like sir?'. Well, for a regular woman, that's a piss off. For a woman with an intersex condition that's like...ya know...a shot of adrenalin up your rear end...its like, 'oh my god it's so

obvious!' Now I laugh it off because it's just ya know people not paying any attention. But, it probably happens to me because...especially when I have my hair pulled back in a pony tail...their only looking at me in the peripheral vision and they will say, 'sir' or whatever...all that used to burn.

The support group was indeed very helpful to Jane in understanding that many other intersexed individuals experience similar concerns about being perceived as a "regular woman." However, while the support group has been helpful, in general, most of its members embrace DSD terminology and ultimately the medicalization of their "abnormalities."

Many gender prisoners also express concern that their vaginas aren't "normal" in appearance. For example, they shared with me that they ask their boyfriends and husbands repeatedly about their vaginas despite the fact that only in very rare instances do they share with their spouses that they have XY sex chromosomes. For example, Liz shared:

Every time I was with a guy...I would tell him about it a little bit....and they were always really supportive...but, they didn't really care...it didn't really matter...I was very shocked by that though...it was really surprising...I was like, 'What do you think?' and they were like 'It doesn't matter. Why are you worried about it?'...but, I didn't tell them the XY thing either...even after I broke up with a guy I called him a few times and asked him, 'So, I want to know some details.' 'What were your thoughts?' And, 'How is it like?' 'How should I perceive this?'

Liz is one of several examples of how gender prisoners search for validation that their bodies, specifically their external genitalia, are normal in appearance and feel.

Gender players, on the other hand, don't express the same uneasiness or concern about their gender appearance nor are they worried that their external genitalia is abnormally shaped.

Stevie spoke of looking into the mirror very differently than Tara. In Stevie's own words:

Ultimately when we look in the mirror...and were like either shocked by oh my god I need some lipstick...or oh my god I want to toughen up...look more macho or butch...we basically are responding to the inner conversation in our mind's eye of what we want to see...how we want to appear...how we want to be perceived...

These are merely examples of how gender prisoners and gender players speak about their gender appearance. Gender prisoners regularly and repeatedly express frustration and anxiety about being able to effectively occupy a given sex category, while gender players recognize the performative aspect of gender can be altered, for example with lipstick as Stevie noted, should one desire.

### **Inability to Reproduce**

While both gender players and gender prisoners shared their frustration with not being able to reproduce—almost all intersex conditions impact the reproduction system—gender prisoners were much more concerned with their infertility than gender players. Gender prisoners usually spoke of how life shattering infertility was, while gender players accepted this as a piece of their intersex identity. For example, Tara, a gender prisoner, shared that “I always feel weird...well, I’m pretty okay telling guys I can’t have kids. My only issue is that if it is serious, I feel really bad about not letting them...have their own biological kids.” Similarly, Liz, the 33 year-old shared, “it has interfered with my life...um...I can’t have kids. It really sucks. I am really pissed off about it. I am very angry about it.”

While gender players somewhat struggled with the inability to reproduce, most accepted it. For example, Ana was only upset that she wasn’t able to reproduce during her female partner’s pregnancy—and even then the concern was minimal. Rebecca doesn’t want children and never lets the fact that she isn’t able to reproduce trouble her. However, she did note that she wishes she had the choice to make such decision. Chris found solace around not being able to reproduce in raising his grandchild, his wife’s biological daughter’s child. Not only did he help

financially support his grandchild, but he also continues to maintain a very committed and loving relationship with her despite his wife's death.

### **Cancer Risks**

Although there hasn't been any strong scientific evidence that intersexuality is correlated with either internal or external genital cancer, gender prisoners express concern that they would get cancer related to their disorder of sex development even after they had their internal testes removed. For example, historically, individuals with androgen insensitivity syndrome were told that the incidence of gonadal cancer was higher in their bodies than the "normal" bodied population. In part, highlighting a potential cancer risk provided medical professionals a legitimate, albeit definitely controversial, reason to surgically modify the intersex body (Karkazis 2008; Preves 2003). I've found that this pattern continues today. For example, Tara, who recently had a bilateral gonadectomy, explained that the "doctor shared that...we are going to remove the gonads...because the gonads could be cancerous...after that it was business as usual...unless your abdomen hurts or something...like they didn't get it all." Gender prisoners continue to believe in the presumed correlation between cancer and intersexuality. Jane shared:

To say a baby with complete AIS doesn't have medical issues is *absolutely* ignorant. To say a girl with Swyer's Syndrome doesn't have medical issues is *absolutely* ignorant...Some kinds of gonads have a *huge* rate of cancer.

There assumption that intersexuals are at a greater risk of developing cancer has not been proven. We have yet to see any evidence that links cancer and intersexuality, yet it continues to be a major fear for gender prisoners. A pediatric endocrinologist who has consulted on intersex cases around the United States supports this claim. When I asked Dr. F. to describe the fears intersex patients and their parents share with her, she answered:

The cancer fear is a significant fear. A lot of them come with the fear of cancer because that's what they've been told...because that's what their providers have read in the textbooks, or has been handed down to them, which is very indoctrinated dogma about these conditions...[Georgiann asks, Is it logical, in your medical opinion, to have these fears?] Oh, it's logical for the parents to have those fears, yes, because essentially, that's what they've been told. Is it logical for those fears to exist? There is some very old medical dogma that indicate...we can't go through all dogma...but there are reasons why that is kind of the default perspective.

While Dr. F. is reluctant to completely discredit the possibility of a correlation between intersexuality and cancer, she is also unwilling to substantiate it.

Gender players, in contrast, weren't convinced that intersexuality resulted in greater cancer risks. Instead, they framed the cancer risk as "lies" that lead to the surgical modification of their bodies. Caitlyn shared:

I was told I had like early onset cancer and underdeveloped [ovaries]– most of the lies that a lot of [us] are told. And then when I was about 17 to 18, around there, I did have the surgery and I thought I was having it preventative for cancer.

Rejecting the link between intersexuality and cancer, gender players are adamantly against genital surgeries. They see no reason to surgically modify their bodies. Pigeon warns intersexed individuals:

Never let [doctors] touch you in terms of surgery. That's number one. If they ask about surgery... don't do that. Don't do surgery, no matter what they say.

### **Relationships with Doctors**

Gender players are critical of medical professionals while gender prisoners viewed medical professionals as supportive and helpful. Medical professionals tried but failed to police gender players into traditional gender norms. The following consequences played out in the doctor's office: Millarca suggested this quite clearly, she shared, "I don't trust doctors...I have an

endocrinologist that gives me the medication I need...I shake his hand...and go home...I don't allow him to..um..examine me unless it is necessary.” Ann expressed similar concern that her sexuality would be a problem for her endocrinologist who was trying to assure that the correct gender assignment was made. She recalls, “I do remember, at 17, working with the endocrinologist...and I remember him asking me if I was...after the surgeries were done...if I was dating boys...I remember him asking me that...and that was sort of in my mind...the right thing would be to say ‘yes, I am’.. I remember thinking that I should just tell him that I am even though I was not.”

Many gender players refuse to defer to the prestige and authority society grants medical professionals. Chris perhaps best presents this. He shared:

Nothing can be more frustrating than trying to talk about this topic—and I've tried—with genetic experts...I just find them [long pause] it's like talking to people that are dogmatic... they have it all figured it out...and that doesn't sound like science to me when you think...once you close your mind. If ya know I have a disorder of sex development and you aren't even willing to consider it any otherway. This is why I say what's the point of dialogue with that person? I can accept the fact they think that. You see...at 57, you just don't care...you just don't give a damn any more. Just because they have a doctor in front of their name....when I was a younger...I was a lot more respectful of that...

This resistance to medical professionals is prevalent among most gender players. They challenge medical professionals' right to authoritatively define their bodies, and also challenge their positions as experts. While many intersex individuals shared that they often were the ones educating doctors about their “abnormalities”, gender players do so in ways that delegitimize doctor's authority over the intersex body.

Unlike Millarca and Ann, gender prisoners Liz and Tara viewed their experience with medical professionals in a much more positive light. Liz shared, “[A doctor] cleared everything

up... I saw a couple of other doctors [in my city] that also cleared everything up.” Tara similarly had positive experiences with medical professions. She elaborated:

[My diagnosis] was straight forward....this is what it is...this is what it means. The doctor was...she was actually like..ya know...really nice about it...supportive...kinda summed it up like...you basically are born like a woman that had a hysterectomy...you just have to take estrogen to help with your bones...we’re gonna remove your gonads....

Thus, gender prisoners currently have, in general, much more positive relationships with medical professionals than gender players. They embrace medical terminology, and they dare not challenge medical authority. In result, medical professionals are able to police the intersex body without challenge and without having their authority threatened (see chapter four).

Medical professionals are critical of other medical professions that resist DSD language. For example, Dr. D, a well-respected pediatric endocrinologist that is an expert of intersex conditions, explained:

What effects my interaction with the DSD community and my attempting to care for them best are my medical peers in other fields are not savvy and put their foot or foot in their mouth and hurt the families...wound them sometimes...that I can’t undo. So, a GYN who doesn’t know what he or she isn’t talking about who still uses words that weren’t even politically correct before the DSD movement...[Georgiann asks, “so, like hermaphrodite?”]...Yea...and testicular feminization hasn’t even been allowed for the last 15 years...and people are still told that...so, doctors have...in trying to be medically correct...have really continued to shoot me in the foot or their patients in the foot and really hampered are attempts to be followed and I can’t protect...there’s no way I know ahead of time who are going to be my patients and protect them from the rest of the world.

As explained in chapter four, most medical professionals hold very essentialist understandings of gender, and thus understand intersex conditions as an anomic condition of the human body that needs medical attention, both physical and mental.

## Relationships with Parents

Another key distinguishing feature between gender players and gender prisoners is their relationships with parents. Gender players often spoke of being estranged from their parents. Violating the gender binary by embracing intersex as an identity rather than a disorder creates social distance from their families. The parents of gender players were critical of their intersex adult children. For example, Stevie was estranged from her parents throughout her twenties and thirties due to the ways in which her parents policed her gender performance. Stevie shared:

My mother um wanted to get me involved in social philanthropic things that would sort of model ya know..what a woman in society does. [Can you give me an example of such?] Well, within [an organization my mother got me involved in] there was a modeling component to it...a 'modellette program'...and we basically had beauty and poise training....[My parents] knew they had a task to try to bring about a certain result...which was they had this child that was presumed to be a boy...then they were told this child would not be successful as a boy and you need to raise this child as a girl...and you need to try to bring about a certain result.

Since Stevie rejected her parents' gender policing, their relationship was fractured. Only recently has she become reacquainted with her father, and that reunion only happened after her mother's death.

Rebecca echoed something similar to Stevie. Rebecca was raised a boy, but decided to transition, against her parents' wishes, to a female sex category in her twenties after learning of her diagnosis. This really impacted Rebecca's relationship with her parents. Rebecca noted:

My parents were *incredibly* anti me being female. They didn't talk to me for seven years because of it. That made it an issue. I tried sitting down and explaining it to my mom...I doubt she's gonna really completely understand it. But, I've been surprised, so who knows. In the end, she decided I was her child in the end...um...that's why she decided to reconnect with me...and part of that was due to my dad dying...she realized she only has a chance...one chance to get back with me...so that's what she's done.

As described earlier, gender players see their sex category as a performance rather than an essentialist characteristic. However, they refuse to have their performance policed by others, including their parents. This results in constrained familial relationships.

When I asked Pigeon to describe if her parents encouraged her to be more feminine growing up, she shared:

I think a lot of times, our parents are so scared that the doctors made the wrong decision and we're going to veer off to this other gender world...so they kind of police it. My parents didn't technically tell me all the time that 'you're a girl and you're going to be a girl' but I'm sure it was always playing in the background of decision-making.

Millarca, a gender player who claims an intersex identity, has appeared in a number of documentaries and on numerous of talk shows. When I asked her how her parents responded to her intersex activism and comfort claiming an intersex identity in public settings, she replied:

Well my family was ashamed. They thought that I shouldn't talk about things in the family outside of the family. So they didn't want to hear or watch the documentary or the show or anything. They didn't want to participate in it because now their friends know that I'm intersex. My friends were supportive. My friends always knew that I was intersex and they're very supportive. [Georgiann asks, how is your relationship now with your family?] The same. It's still strange. We don't really associate very often...it's been like that most of my life. It's not like this just because I'm intersex, it's everything, like intersex, being gay, being into leather and S&M, and just not conforming to their politics...

Despite actively pursuing interviews with the parents of both gender players and gender prisoners through emailed invitations, asking their adult children to pass on my call for participants, and the like, it was far more difficult to convince parents of gender players to participate in my study, which is not surprising since gender players are usually estranged from their parents. I was only able to interview one parent of a gender player.

Alexis, the only parent of a gender player I was able to interview, agreed to meet with me after her daughter extended my invitation to participate. From the moment I contacted her to establish a time and place to conduct the interview, she was extremely accommodating. She informed me on numerous occasions that she wanted to help me with my project any way that she could because her daughter had asked her to. This isn't to say that they always had a positive relationship. Alexis explained:

We would argue all of the time...she said some pretty harsh things to me. She was going through so much pain inside...and she didn't say it right away. She was angry [Georgiann asks, with you?]....Mainly with me because she was with me all of the time. She was angry. She was so confused.

Today, Alexis has a much more positive relationship with her daughter, a well-known twenty-something year old intersex activist. When I asked Alexis to explain how they ended up repairing their relationship, she explained, "She did a lot of research later on...talked to so many people...got into this." Alexis was referring to her daughter's intersex activism:

I love it. I'm just so proud of her...so proud of her...because...ya know...for someone being so angry with this...ya know...she's just...to me...she's just so unique...ya know...I mean...for her to get...ya know...she wanted to know everything...she wanted to go out there and talk to people...she wanted to find out...she's such a go getter. I mean she's really determined.

Although Alexis is proud of her daughter's intersex activism, she still worries about how "people are going to treat her...ya know...but what's she doing I think is wonderful...I think it's wonderful."

Speaking about when her daughter started presenting herself in a more stereotypically butch fashion, she shared:

I never knew she was going to go through something like that. I feel so bad that I didn't know later on that in life things like this could happen or whatever...because oh my god I would have been like right away...talked about it

more as she got older...maybe I could take her somewhere...bring her somewhere to talk to...like therapy or whatever...even before she would have problems...and I never knew...I couldn't understand why she was angry for so long...

It was only after Alexis's daughter started college that her daughter learned of her diagnosis, in part due to feminist scholarship. Soon after Alexis's daughter started questioning her gender identity, she slowly began to present herself in a stereotypical butch manner. Alexis explained her daughter wasn't always butch:

If I would have thought about it, I would have brought out pictures...in high school, she would wear dresses, even when she was younger she would always pick out the girls clothes...and...uh things like that...and then change came when she went to college. And, it was a good thing. It was a good thing...she felt comfortable. [Georgiann asks, was her shift hard on you?] Uh...I didn't look at her in a different way...it's weird...it wasn't hard on me...it was just like oh wow...that...but I knew when I saw...as she was making that change...she was changing...and becoming more happy with herself...and that's all I wanted...that's all I wanted...and when I saw that...it wasn't hard for me at all. That's all I wanted for her.

There was one thing that Alexis continues to find troubling with her daughter's identity:

Just the one thing...the one thing I don't like...she doesn't shave any more. She doesn't shave her legs or her underarms...my mother used to say, 'Oh my god, tell her to shave.' Ya know...but...that's males...they don't shave...that's the only thing...when I see that I'm like oh my god, ya know? And, uh...because to me she's my daughter ya know what I mean? [Georgiann asks, does she identify as a man though?] [pause]...no....no...I just took it as the way she started changing and dressing and acting...

Since Alexis was the only parent of a gender player that I interviewed, it's impossible to know for certain if her views are similar or different to other parents of gender players. However, interviews with gender players themselves lead me to believe that they are. I asked every intersexed individual to describe their relationship with their parents, and they all described similarly fractured relationships.

Unlike the parents of gender players, when I invited the parents of gender prisoners to participate in my study, almost all of them agreed without hesitation. I attribute their willingness to participate in the study to the level of support they provide as their child or adult child negotiates his or her diagnosis. For example, George was very supportive of his daughter. During a break in a three day support group conference, he shared with his wife sitting by, “[we] have always held her in open palms to support her and let her go in the direction that she’s meant to go...and to be there for her for support. She’s made wonderful decisions.” Marty, a 43 year-old mother of a teenager daughter with a DSD, shared something similar. Holding back tears, Marty shared, “She is exactly the way she is supposed to be...”. She went onto say that she, “didn’t feel ashamed....and would always be there to support her.”

Gender prisoners, themselves, acknowledge the support they receive from their parents. For example, unlike gender players, Liz, a gender prisoner, reported a positive relationship with her parents. Liz’s mother even accompanied her to her first ever AIS support group meeting last year. Liz shared that her mother, “was supportive...she was just supportive...it was very good. She went through all the steps with me. She made sure I was moving along...took me to doctors and stuff. Very simple.” Tara shared something similar:

When I told [my mom about the community], she’s like, ‘Well how long have you been in the [group]?’ I was like I don’t know I’ve been discussing this for maybe like a year. She’s like, ‘Oh.’ I was just like they are going to help me fly out [to the annual conference] and blah blah bah. And she was like, ‘Oh, okay that’s good ask a lot of questions.’ Basically she told my dad and they drove me to the airport...when I came back they asked me one or two questions and I didn’t want to talk about it and that was that.

Gender prisoners almost always characterize their parents as exceptionally supportive—sometimes even too supportive as Tara described above.

Most of the parents of gender prisoners I interviewed deny encouraging their child to be either more feminine or masculine. They insist they allow their child to develop their own gender identity without any parental pressure. Although I do not have interview data to suggest otherwise, my ethnographic observations at organizational meetings lead me to wonder if such responses were influenced by social desirability bias. At every support group meeting I attended, I noticed that many parents chose to dress their intersex baby girls in pink bows and dresses. The adolescents in attendance always appeared in stereotypical feminine fashion, yet displays of femininity alone are not enough to convince me that parents control their children's gender identity. I would likely observe the same displays of femininity in a room full of any group of adolescent girls.

There were, however, two exceptions, Lucie and Penny<sup>21,22</sup>, who offer at least some evidence that parents of intersex children police their children's gender identity. Lucie is a white girl of high school age, most likely fourteen or fifteen. She wears her hair in a short masculine style, and dresses in clothing that is best described as stereotypically butch. Penny is a young white middle school aged girl who throughout the entire four day conference wore backward baseball caps, baggy knee length shorts, and matching sports jerseys. By not presenting themselves in a stereotypically feminine way, they stood out among the group of intersex children and teenagers at the conference. What I later learned from an intersex activist at the conference is that Lucie is interested in transitioning to a male sex category, which her mother did not agree with. Lucie did not want to attend the support group conference, but her mother insisted hoping her daughter would meet other intersex children and adolescents who were

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<sup>21</sup> Without IRB clearance to interview those under eighteen, I wasn't able to extend an invitation for each to participate in my study.

<sup>22</sup> Pseudonyms

comfortable in their assigned gender. Penny, on the other hand, was viewed by her parents as a sports loving “tomboy” who would in time outgrow her boyishness. Unfortunately, time constraints prevented me from extending their mothers an invitation to participate in my study.

A striking similarity among the parents of gender prisoners I interviewed is that they all spoke of their intersex daughters as completely feminine girls. During interviews, it was clear they were seeking my validation that their daughters were neatly fitting into the gender binary system. For example, Sue described her daughter as follows:

She looks [feminine]. She dresses that way. She’s grown up that way. Again, it’s not necessarily dresses all the time, she just looks like a girl...acts like a girl...nobody would ever assume she’s not.

George, Sue’s husband, went onto to describe their daughter as follows.

I think that really...she truly is what we say is...100% woman. I don’t think that she’s ever had any testosterone. She is a pure 100% woman, and that just comes through everything that she does.

Sharon similarly described her daughter. She expressed, “I mean, she’s all girl. Physically, she’s all girl and always has been.” John and Laura, parents of a young girl under the age of five with an intersex condition shared:

John: You know, I see her as the way she acts I don’t think we’ll have a problem with her acting like a girl. I think we’ll have more of a problem with her wanting to start wearing makeup at 10.

Laura: When she started growing up, we constantly were surprised at how girly she was. And we’d make comments all the time, ‘she’s a girly girl’.

John: A real prissy.

Seeking validation about their child’s gender identity, the parents of gender prisoners were strikingly similar to their children who, as described earlier in this chapter, similarly seek confirmation that they are able to fit into the gender binary.

However, there was some deviation from this pattern. Several parents noted their children are capable of displaying masculine features. In Susan's own words,

You know, she's not a girly-girl, but she's not really a tomboy either...like she's not athletic. I can see a little bit of masculine in her. Number one, she's tall. She's so strong-willed. I won't say domineering, but she's very strong in some respects. I see she applies her feminine side in terms of straightening your hair, and wearing makeup and jewelry, but she's never been [inaudible] really feminine in terms of her clothes or whatever. I'm not saying it well... [Georgiann asks: Have you always thought of your child in such a way?] [Susan pauses] I don't know. When she was born, she had very little hair. I used to put a dress on her sometimes, put a little pink thing on her head. People said they thought she was a boy, regardless of a little pink thing. Again, she's never been a girly-girl kind of girl, so I don't know. I don't really think of her in terms of masculine or feminine, it's just that I can see when the masculine comes through.

When I asked Drew and Shelby, parents of a girl under the age of two with an intersex condition, if they see their daughter as feminine, they shared:

Drew: I don't...I think it's too early to tell, personally. But yeah, I look at her and I say, every once in a while, I'm like if she didn't have the longer hair and she was wearing blue, what would she look like? All babies, I think, you know...look pretty similar.

Shelby: [to Drew] Like androgynous? [*laughing*]

Drew: Well, and I hate that idea. I don't think I should do that. But I do it. Just wondering, if you start to see male traits, I don't believe that we will in her case, but yeah, I mean...certainly too young at this point, but I think about it.

Parents believe their children's gender is an essentialist characteristic, something they can influence but can't entirely control.<sup>23</sup> When I asked Marty, a parent of a teenager with an intersex condition, how she defined masculinity, she shared:

Well, I know today they mentioned no, it's not about what you wear, it's more about how you look. I think there's a masculine look...They talked about in the conference that if you don't take your gonads out, some people masculinize.

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<sup>23</sup> This does not mean they don't still try to influence their children's gender.

Shelby similarly described gender as something that is biologically prescribed when I asked her where she thought gender originates from. In her own words:

I think it's hard-wired, definitely. I think people who are gay will tell you that they didn't raise their hand and say 'I want to be gay!' Like it's definitely something that happens...whether it happens in utero or what, that you know if it's a testosterone flush and they're a girl and they get a flush of testosterone in utero, chances are that they might be a lesbian 'cause their brain is then kind of hard-wired to prefer that sex.

## **Conclusion**

The medical profession reinvented the intersex diagnosis in 2006 by renaming it a disorder of sex development. In the previous chapter, I argued this was at least partly a way to reassert authority and reclaim jurisdiction over the intersex body. The consequence of such renaming poses a genuine dilemma for contemporary persons in the community. They can either reject the new terminology and hold onto intersexuality (“gender players”) or accept DSD language and the pathologization of their body (“gender prisoners”). Each position has very real consequences. For gender players, the consequences are a decrease in quality of medical care and familial relationships. For gender prisoners, the consequences rest in trying to fit into the binary gender system which results in discomfort about the size and shape of their physical body, or in intimate settings, the appearance and feel of their genitalia.

Recognizing that gender is not an innate biological characteristic allows gender players the ability to “play” on the periphery of gender structure (e.g. Risman 2004). Doing such, however, results in contested access to necessary resources and support. The alternative is also problematic. Gender prisoners try to neatly live by the rules of the gender structure, enforced and

policed by various actors, yet they struggle with their sense of self. They are worried that they aren't legitimately a "woman" or, in select cases, a "man."

Lorber (2005, 1994) argues that we must first debunk the gender binary system to move beyond the constraints of gender that impact all aspects of our lives. Early intersex activists were doing just that as "Hermaphrodites with *Attitude*" critical of the medical management of their bodies (chapter three). However, as explained in chapter four, they were challenging medical jurisdiction over intersexuality. The medical profession responded to this challenge by reinventing the intersex diagnosis. In this chapter, I have shown that intersexuals, themselves, are now in conflict with one another over the same condition that initially brought them together decades earlier. These debates distract intersex activists from collectively organizing. While intersex activists argue with one another, the medical profession is undoing the earlier efforts of intersex activists by reclaiming jurisdiction over intersexuality while solidifying the continued medical definition of intersexuality as a disorder.

## 6. “BRINGING INTERSEXY BACK”: TOOLS FOR LIBERATORY TRANSFORMATION

The intersex community, and its supporters, consists of people who want nothing more than to end the shame, secrecy, and stigma associated with intersexuality. Intersex activists are compassionate people concerned for the well-being of other intersexed individuals. Medical professionals want what is best for their patients. Parents wish for their children to live happy and healthy lives. Yet, despite common goals, my research shows our movement is divided.

It is not unusual for intersexuality to be at the center of heated debates. Intersexuality can be placed into two time periods<sup>24</sup>: the “age of gonads” and the “age of conversion” (e.g., Fausto-Sterling 2000a; Dreger 1998a). During the “age of gonads” between the 1870s and the 1930s, legal professionals such as lawyers and judges were the ones policing claims of intersex status. While legal professionals did consult with doctors before presenting a final decision, they were the ones that had final jurisdiction. However, beginning in and around the 1930s, we saw a transformation away from the “age of gonads” to an “age of conversion” where medical professionals “found it imperative to catch mixed-sex people at birth and convert them, by any means necessary to either male or female” (Fausto-Sterling, 2000a, 40; Dreger 1998a). The medical profession won exclusive jurisdiction over intersexuality during the “age of conversion” because of technological advancements that forever changed the field of medicine including, but not limited to, drastic improvement in surgical practices and later with the discovery of sex chromosomes (Moore and Barr 1955; Moore, Graham, and Barr 1953).

Until the 1970s, the medical sciences had exclusive jurisdiction over intersexuality. It was John Money, a young psychologist from Johns Hopkins, who introduced the field of medicine to social science (Money and Ehrhardt 1972). Money’s “gender dimorphic behavior”

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<sup>24</sup> I borrow the language from “age of gonads” to the “age of conversion” from Fausto-Sterling (2000a, 40).

theory was one reason why medical professionals kept intersex diagnoses from their patients. At the same time, Money's theory also justified their surgical intervention. According to Money, a child's gender identity was purely the product of early socialization, not anatomical sex. Gender scholars in the social sciences also found Money's theories compelling. They were proposing sex role socialization theory (Bem 1974), which was strengthened by Money's laboratory research. However, in the late 1990s, Money's research lost its credibility, as did he. Colapinto (2000, 1997), a *Rolling Stones* journalist, was successful in publicly<sup>25</sup> exposing the truth behind one of his most famous cases, the John/Joan twins. A botched circumcision was the perfect opportunity for Money to test his theory. The baby with the botched circumcision would be raised as "Joan," and his twin brother, "John" would be the control. Money published quite extensively that Joan was emotionally satisfied with her female gender identity (e.g., Money and Ehrhardt 1972). Colapinto (2000, 1997) exposed a very different story. It turns out Joan wasn't satisfied with her gender assignment. Money had falsified data. This result was medical professionals left behind social science and never looked back. Gender scholars, however, had long moved beyond conceptualizing gender as purely an identity, so they were able to altogether avoid the crisis Money created.

By the time Money's research lost its credibility, the intersex rights movement, in part fueled by feminist scholarship (e.g., Fausto-Sterling 1993; Kessler 1990), had already formed. Intersex activists were working together engaging in what I label "collective confrontation." In order to change medical protocol, they formed a shared intersex identity to collectively challenge the medical profession's treatment of intersexuality (Turner 1999). The movement made

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<sup>25</sup> Diamond and Sigmundson (1997) did so in an academic publication.

progress. Medical professionals listened to intersex activists and responded with the 2000 medical consensus statement on the medical management of intersexuality (Lee 2006; Blizzard 2002; Committee 2000). In 2006, the consensus statement was revised to do away with intersex, intersexuality, and intersexual language altogether in favor of disorders of sex development language, DSD for short. My research shows it was this new diagnostic terminology that divided the movement into what I label “contested collaboration.” While some intersex activists are currently collaborating with medical professionals, others actively resist working with them.

I argue medical professionals were in favor of the new DSD terminology in order to reclaim jurisdiction over intersexuality, which intersex activists were successfully framing as a social not biological problem. When intersex activists were engaging in “collective confrontation,” they were challenging medical authority. Medical professionals needed to respond to intersex activism in a way that reasserted their authority. The new nomenclature did just that. By doing away with intersex diagnostic language, the collective intersex identity that was formed in the 1990s was disrupted. Intersex activists, themselves, started contesting one another, leaving what was once a monolithic movement divided.

My research shows that there are far fewer individuals claiming intersex as an identity than was observed by Turner (1999) in the late 1990s when the intersex rights movement was at its pinnacle. This return to medicalizing the intersex body certainly has its advantages. Individuals who adopt the new frame receive medical and familial support as they negotiate their “abnormality.” However, under the medicalization frame, my research shows that individuals are left haunted by their diagnosis because they don’t feel normal. I label people who adopt the medical frame “gender prisoners.” Those who reject the new medical frame are institutionally

disadvantaged by receiving little, if any, medical and familial support, yet my research shows they are the ones socially liberated from the constraints tied to the assumption that sex, gender, and sexuality are each binary and necessarily connected. I label them “gender players.” They understand sex, gender, and sexuality are socially constructed phenomena, which allows them to “play” on the periphery of gender structure.

While I’ve shown that the transformation in intersex terminology is the result of medical professionals reclaiming authority over intersexuality, I’m left with a number of questions. Why did so many intersex activists go along with the re-medicalization of intersexuality? How and where can individuals born with intersexuality and their families best find liberation and relief from social stigma? Although answers to these questions are inherently complex, the research presented here leads me to conclude that liberation is a possibility through, in the words of one of my informant’s, “bringing intersexy back” a play on lyrics from a popular 2006 song.

### **John Money’s Long Lasting Impact**

Before people can choose their own terms, we must understand why the movement divided when it did. My data suggests two possible explanations, each connected to John Money.

When John Money’s research lost its credibility, medical professionals lost their faith in social science. After having been misled for decades by Money’s falsified data, medical professionals returned exclusively to biological explanations of gender. They specifically turned to the brain to understand gendered behaviors (Holterhus et al. 2009; Brizendine 2006; Lippa 2005; Cahill 2003; Cooke et al. 1998; Collaer and Hines 1995; Arnold and Gorski 1984). Medical professionals found brain sex research compelling in accounting for gender differences (e.g., Yang et al. 2010). Brain sex research is situated within the biological sciences far away

from social scientists. As new medical evidence emerged to explain gender as a biologically prescribed characteristic (Holterhus et al. 2009; Juntti, Coats, and Shah 2008; Brizendine 2006; Lippa 2005; Cahill 2003; Hrabovszky and Hutson 2002; Cooke et al. 1998; Collaer and Hines 1995; Arnold and Gorski 1984), medical professionals genuinely felt that they could once again help intersexed individuals. But, in order to do so, they needed to reclaim their legitimacy after having it challenged by intersex activists. For example, in 2000, Cheryl Chase, the founder of the Intersex Society of North America was delivering a plenary address to the Lawson Wilkins Pediatric Endocrine Society, a group she was once protesting against. As I've shown in chapter four, this marks the highest point where medical professionals were losing their jurisdiction over intersexuality and the intersex body. Medical professionals wanted to reclaim their authority in order to bring their new brain sex evidence to the table (Holterhus et al. 2009; Juntti, Coats, and Shah 2008; Brizendine 2006; Lippa 2005; Cahill 2003; Hrabovszky and Hutson 2002; Cooke et al. 1998; Collaer and Hines 1995; Arnold and Gorski 1984), and they did so through the nomenclature shift from "intersexuality" to "disorders of sex development." This transformation of diagnostic terminology allowed medical doctors to regain legitimacy.

What remains to be answered is how did medical professionals manage to get many of the "Hermaphrodites with *Attitude*" to work with them on their terms? Although some intersex activists are against medical collaboration, there are others who strongly advocate for such. Taylor's (1989) study of the women's movement where she argues movements "contract and hibernate, sustaining the totally dedicated and devising strategies appropriate to the external environment" offers insight (Taylor 1989, 772). Taylor's (1989) argument would suggest intersex activists wanted to solidify their gains after John Money was exposed, and they did so

by going into temporary abeyance. The intersex rights movement and its activists were at, one time, considered to be creating a “third sex” by demanding the medical profession not only acknowledge genital variation but also stop surgically modifying “ambiguous” genitals (Turner 1999). Intersex activists protested outside pediatric association meetings demanding to be acknowledged. They collectively were the “Hermaphrodites with *Attitude*.” This was all occurring in the early to mid 1990s before Colapinto (2000, 1997) publicly exposed John Money’s falsified data (see also Diamond and Sigmundson 1997). A shift toward working with medical professionals allowed intersex activists to hold onto their earlier achievements. Cheryl Chase is perhaps the best example. At one time, she protested outside of medical association meetings with other intersex activists holding the “Hermaphrodites with *Attitude*” banner, but when I sat down and spoke with her in January of 2010, she was convinced that working with the medical profession and their terminology was the best approach. Referring to the new disorder of sex development terminology Cheryl Chase shared:

I engineered the entire thing...not the consensus...but I engineered getting the language changed into that by working through allies. There were some progressive people in there and there were some powerful people who were on my side and I talked to them about what ISNA thought we would like to have happen...I said I want a language that is really appealing to doctors, that fits somehow into the way they think about things, so it’ll be easy to adopt...Other than that, I think whatever you come up that you think doctors will agree on and will use will be fine with me. The subgroup that was working on nomenclature...the head of that group consulted with me on what we should do, and it was my suggestion that we get the nomenclature in there...They wouldn’t listen to me...I was put in this committee where I couldn’t do any harm. I talked to people on the other committees and sort of back-channeled, and said, ‘This is what I want go get done, can you get it done in your committee?’ And then they went off and they decided there were some technical reasons why they preferred [disorders of sex] ‘development’ to [disorders of sex] ‘differentiation’, and they got it adopted.

Although Cheryl Chase, herself, acknowledges doctors only listened to her when she went through medical allies that were on her side, such wouldn't have been possible if she were opposed to medical collaboration.

While the move toward working with medical professionals has resulted in the intersex rights movement being able to hold onto their progress despite the John Money crisis, it has left many intersexed individuals, especially those newly diagnosed, emotionally frustrated, depressed, and concerned that they are “abnormal” women, or in a few cases, “abnormal” men. The shift in working with medical professionals has also angered other early intersex activists who feel the shift in mobilization strategies wasn't necessary. Millarca, a long-time intersex activist, was so angry with Cheryl Chase for shifting the entire intersex rights movement by working with medical professionals that she passionately shared with me in the summer of 2009: “She *sold out!* That's why everybody *hates* Cheryl Chase. She fucking *sold out!*” Millarca wasn't the only intersex activist frustrated with the mobilization shift. David, one of the movement's earliest members shared, “I wrote a really nasty letter to [the Intersex Society of North America] saying that had I known that this was coming down the pipe I never would have donated that money. I was really upset.”

### **Moving Beyond John Money**

Although no one would dare cite Money's scholarship in positive fashion, his work is still managing to influence the intersex community, notably medical professionals and intersex activists. Money's falsified data has turned medical professionals away from social science scholarship. It has also forced intersex activists into a temporary abeyance. If medical

professionals and intersex activists come together on this common ground, there is promise for a reduction in intersex social stigma.

This mistake made by medical professionals and intersex activists lies in the belief that Money's (1972) "gender dimorphic behavior" theory defines gender scholarship. In actuality, when Colapinto (2000, 1997) exposed Money, gender scholars were far beyond the gender socialization thesis. They were already conceptualizing gender as a stratification system that exists beyond individual characteristics (e.g., Martin 2004; Risman 2004, 1998; Ferree, Hess and Lorber 1998; Lorber 1994; Connell 1987), which is why gender scholars were able to weather—without difficulty—the storm John Money caused.

Gender, and the inequalities that emerge from it, are present in all organizations and institutions including law and medicine (e.g., Connell 1987; see also Calas and Smircich 1992; Collinson and Hearn 1994; Acker 1998, 1992, 1990). As Connell (1987) argues, each institution is its own "gender regime" which can be defined as the perpetuation and control of hegemonic gender ideologies that maintain women and men are biologically different and men are superior to women (Connell 1987, see also Jordan-Young 2010). Intersexuality is a prime example of how gender regimes work. Intersexuality has been regulated and controlled by both legal and medical arenas throughout history despite, as I have shown in chapter one, being conceptualized differently across disciplines.

While the consensus presented here is that the medical profession, like other institutions including law (see Schaffner 2006), is its own gender regime that perpetuates and rewards hegemonic ideologies about sex, gender, and sexuality, it is important to acknowledge that such reinforcement often occurs without conscious intent. Medical professionals are products of

society who internalize the same “lenses of gender” that all individuals, regardless of occupation, encounter (Bem 1993). However, the medical profession’s gender regime warrants considerable attention, especially as it pertains to intersexuality. The medical profession is, in other words, positioned to police the boundaries of what is legitimately “male” or “female” (see Karkazis 2008).

In order to reduce the shame and stigma associated with intersexuality, I encourage medical professionals and intersex activists to re-engage with social science gender scholarship. Contemporary feminist scholars frame gender as a stratification system (e.g., Martin 2004; Risman 2004, 1998; Ferree, Hess and Lorber 1998; Lorber 1994; Connell 1987). For example, Risman has framed gender as being “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). When gender is understood as a stratification system, it can serve as evidence that sex, gender, and sexuality are not necessarily correlated. This allows medical professionals to treat intersexuality in a way that is less stigmatizing to intersexed individuals and their parents. Intersex activists struggle daily to reduce the shame and stigma associated with intersexuality. My research shows that such can be accomplished by rejecting essentialist understandings of gender. One way to begin to do so is to re-engage with social science scholarship that is now far beyond framing gender exclusively in our identities or personalities. If medical professionals take social science seriously, they will be able to move in a direction currently avoided because of Money’s problematic research. At the same time, intersex activists will be able to collectively confront the source of their stigmatization.

### **Tools for Liberatory Transformation**

As an intersexed feminist sociologist, I'm personally and professionally invested in seeing an end to the shame, secrecy, and stigma attached to the intersex diagnosis. We can begin by confronting the gender structure. It is only after the gender structure is made visible that individuals born with intersexuality and their families will find liberation in the truest form. We deserve a genuine relief from being socially stigmatized for being unable to "naturally" fit into a socially constructed sex binary that claims our sex, gender, and sexuality all necessarily neatly fit like pieces of a puzzle. My research offers public policy suggestions and social movement strategies for intersexed individuals, their families, and medical professionals to begin to tackle the gender structure. I label these suggestions tools for liberatory transformation. I identify five tools in total. When used together, I argue these tools will deconstruct the shame, secrecy, and stigma that individuals with intersexuality and their families currently face by exposing the gender structure and making it visible for all of us, especially those of us whose lives are most constrained by it.

These five tools include: 1. the elimination of medically unnecessary genital surgeries that by default define individuals as "abnormal", 2. true collaboration with medical professionals as opposed to one characterized by superficial collaboration, 3. connecting with others similarly situated through support groups that ought to move toward being more inclusive, 4. overcoming the fear of public exposure, and most importantly, and 5. recognition that sex, gender, and sexuality are independent, and not always connected, social constructs where gender inequality is maintained, reproduced, and perpetuated. Below I explain each of these tools and offer suggestions for how they might be cultivated.

### **Tool #1: End Unnecessary Surgical Intervention**

The first tool in a liberatory transformation must involve holding medical professionals responsible for violating medical protocols on the medical management of intersexuality. Although both the 2000 and 2006 consensus statements on the medical management of intersexuality supports reducing surgical modification of intersex bodies, my research suggests elective cosmetic surgeries continue under the guise of constructing normalcy. There are no official estimates on the number of intersexed babies still undergoing sex assignment surgeries. However, my interviews with medical professionals indicate that roughly half of all individuals diagnosed with a disorder of sex development will undergo surgical modification within a year following diagnosis. Other scholars before me have written quite extensively on the physical and emotional scarring surgery causes (e.g., Karkazis 2008; Preves 2003). Intersex activists also continue to speak out against the surgical modification of intersex bodies.

During data collection, I observed one teenager share with other teenagers and young adults that she didn't want to go through with her scheduled bilateral gonadectomy. Such procedure involves surgical intervention to removed internal undescended testes, and although the procedure can usually be performed laparoscopically, the consequences are long lasting. She knew about the consequences from interacting with older intersexed individuals who were already surgically modified. When one young adult tried to reassure her by citing the possibility that the surgery would eliminate the risk of gonal cancer, the teenager asked for the percentage of individuals that develop cancer. After she was told the percentage was less than 1%, she asked, "I still don't know why I have to have surgery. Breast cancer has to be more common and we don't remove breasts." While this teenager's hesitance might be motivated by surgical fear, she undeniably raised a compelling argument. At a later date, I learned the teenager's efforts to

stop the surgical modification of her body were unsuccessful. Her doctors insisted that surgery was medically necessary to prevent the development of cancer, and her parents obliged.

### **Tool #2: Collective Collaboration with Medical Professionals**

The second tool necessary for a liberatory transformation requires that medical professionals engage in collaboration with intersex activists and their families. Medical professionals must also take seriously the developments of gender scholarship found throughout the social sciences. Medical professionals are trying to help their patients, yet they are working exclusively within their own arena with tools they acquired in medical school and training. However, for a true liberatory transformation to occur for intersexed individuals, medical professionals need to welcome the tools of others including intersex activists and gender and feminist scholars. A true collaboration is not one where intersex activists are superficially included on decision making committees. Activists should be taken seriously by all medical professionals, not only their allies. For example, although Cheryl Chase was invited to participate in the creating of the 2006 consensus statement, she felt she wasn't taken seriously by many of the medical professionals involved. She shared, "At that meeting, surgeons basically sat with their arms locked and bullied everybody." The only way she was able to be heard was "by working through allies." Without her allies working on her behalf, Cheryl Chase would not have been able to offer input. Nor is a true collaboration one that simply dismisses social scientists and their scholarship. The extreme hesitance by medical professionals is based on the John Money scandal, but that was decades ago. I trust their passion and commitment to helping others will eventually allow for collaboration with social scientists once again.

### **Tool #3: Networking**

The third tool I see as necessary for a liberatory transformation involves greater connection of intersexed individuals and their families. This tool is the easiest to use given how accessible intersex support groups are on the internet. A simple Google search would lead one to a dozen or so support groups, albeit AISSG-USA the largest intersex support group welcomes only women in their organization. As Preves (2003) reported, many intersexed individuals find other similarly bodied individuals through the internet. While I am aware that not everyone has access to the internet, I am convinced that given its presence throughout the country, individuals are much more likely to have access to support groups than they once were. Connecting with others is incredibly important in understanding a diagnosis. When I asked my informants for advice that they would give to a newly diagnosed individual, almost everyone was quick to share that they would strongly encourage such individual to meet other intersexed individuals. The intersexed individuals I spoke with found solace in knowing that they were not alone in their thoughts, feelings, and expressions. My interviews with parents further support the necessity of this tool. Every parent I spoke with reported that meeting other parents of intersexed children emotionally helped them make sense of the diagnosis. Most of the parents I spoke with shared with me that they felt directly responsible for their child's condition. They felt comfort from meeting other parents and hearing that their guilt was not unique. Given how helpful support groups are for intersexed individuals, I'd strongly recommend that they move toward being more inclusive of all individuals, regardless of gender. Otherwise, the power of this transformative tool will never fully be realized.

#### **Tool #4: Replacing Fear with Power**

The fourth tool required for a liberatory transformation involves replacing the fear of not fitting into the sex binary with empowerment that comes from speaking out. From my interviews with intersexed individuals, I learned that the individuals most emotionally comfortable with their intersex diagnosis are the ones that do not feel constrained by their “abnormality.” Rather, such individuals embrace their “abnormality” as part of their identity, albeit not necessarily the part that defines them. These individuals are known for speaking publicly at various venues and to various audiences about their lived experiences ranging from the unwanted surgical intervention that they were subjected to as children to answering questions about being differently bodied. Such events are as wide ranging as appearing on daytime television talk shows like The Oprah Winfrey Show to sharing experiences on the popular show Medical Mysteries. They also include speaking to medical audiences at medical schools across the country and/or at organized medical panels. Many intersexed individuals also speak publicly at universities across the country. The outcome of such public exposure is a positive sense of self, and a destigmatization of intersexuality that benefits the entire intersex community. Given how important the media has been for the intersex community, Stevie, an intersexed woman, shared with me her view that there needed to be “More public exposure...just getting the word out...getting more airtime on television, and other forms of media.” Power is embedded throughout the gender structure (e.g., Risman 2011). It’s time for those less powerful to reclaim it.

#### **Tool #5: Formal and Informal Exposure to Feminist Scholarship**

The fifth and final tool for a liberatory transformation is the most important. It is the only tool that alone connects all of the others. Ideas can themselves be liberatory, and classrooms can be

spaces where ideas are shared (e.g., hooks 1994). My interviews with intersexed individuals who were exposed to gender scholarship were strikingly different from others. Although most were introduced to gender scholarship in a formal educational setting, others were introduced to it by friends. Those who were exposed to gender scholarship reported much more positive senses of self and were much more comfortable with their intersex diagnosis than those who weren't exposed to such scholarship. For example, Aimee shared:

I didn't know the difference between sex and gender until I was a senior in college...and honestly for me, that was really freeing for me...because honestly I felt wrong saying that I felt like...I felt like a liar....saying that I was a woman...and then I learned that sex and gender are two different things...And even if I do have XY sex chromosomes I identify as a woman...that was really powerful for me to learn that distinction. [Do you remember what you've read?] Yeah, we read a piece by Anne Fausto-Sterling..."

Chris, one of the few intersexed men I interviewed, echoed something similar:

I was fascinated with [Judith Butler] several years ago with her ability to see this performative theory, because I studied that in linguistics...[Do you think her writings helped you understand your own experiences as an intersex man?]... Mhmm, very much so. I've learned a lot from her... her theories surrounding gender is performative...that affected me a lot.

Eve, a young woman in her twenties, had a different experience with feminist scholarship than Aimee and Chris, yet it too ended with at least some liberation. During a humanities seminar that Eve was enrolled in, students were required to write a seminar paper on a topic that they could choose. One of Eve's classmate's chose to write about intersexuality. Having never shared her intersex diagnosis with any classmates or instructors, Eve initially felt uneasy being in a classroom where a fellow student would be studying her condition. She shared with me:

So anyway, it seemed like it was going to be really interesting, because she was going to write about the feminist movement and intersex, and everyone was really interested in it, but I was sitting there in the classroom kind of thinking to myself, God, am I really just going to sit here for like four months and let people talk

about me and not say something? So one day, I was just like okay, I worked up my courage and I ran after her after class and I was like, 'Hey, I just have to tell you, I'm intersex and I have AIS'. She's like, 'Oh, okay, that's cool. Yeah, I think I read about AIS. So we ended up talking for like 15 minutes. I just, I knew that I needed her to know so that she would like not be more sensitive, but just maybe be like aware of the fact that there was someone in the room that was really affected by everything that people were talking about. I don't know. It was just important to me to not be silent...it felt really good to share it with her after it was done.

Direct formal exposure to gender scholarship wasn't the only way for individuals to acquire this tool. In fact, far more individuals I spoke with cited the media as the source of their introduction to intersexuality from a feminist lens. Liz, for instance, shared with me that she first sought out others like herself after seeing an Oprah Winfrey Show that featured a panel of three individuals with different intersex conditions and historian Alice Dreger who has written quite extensively on the topic of intersexuality (see, for example, Dreger 2009, 1998a,b).

When I interviewed Vanessa in October of 2009, she was uncomfortable with her intersex diagnosis. I asked her to describe what was at the core of her frustration with the intersex diagnosis and she shared, "It's not the reproduction. It's more of like the reproduction as a symptom. It's more of the actual identity... It's more of being different. It's the issue of being different and not fitting into a category." Several months later I found myself on an airport bus with Vanessa. We were on our way to a four day long social gathering of intersexed individuals. Vanessa inquired about the progress of my project, and during such inquiry pulled from her bag Anne Fausto-Sterling's (2000) *Sexing the Body*. She told me one of our mutual friends recommended she read it, and while she was most interested in whether or not I was familiar with the book, it was almost immediately clear that Vanessa had a different sense of the

self than she had when I interviewed her only several months earlier. Connecting with others in combination with being introduced to gender scholarship was incredibly transformative for her.

Another memorable account that occurred during data collection exemplifies my claim that feminist scholarship has the potential to be liberating. In the summer of 2010, I found myself in a private session at an Androgen Insensitivity Syndrome Support Group meeting. The session was one where individuals with intersex conditions could share their experiences, frustrations, and concerns. There were at least thirty women present in this particular private session. Having attending this session two years in a row, I can honestly say that it is always the most emotionally charged couple of hours during the entire conference. The mood is somber, as everyone gets an opportunity to share anything on their mind. When it was my time to share something with the group this year, I was determined to infuse my gendered humor into the room. It wasn't planned, and I certainly didn't know how my story would be received. Either way, I felt inclined to try to change the mood of the room. I shared the following experience which occurred almost seven years earlier during my undergraduate days when I participated in market research studies for extra money:

As an undergraduate, I participated in market research studies for extra money. They paid quite well and covered an array of topics ranging from pet food to pizza to chocolate. One particular study left me sitting around a conference room table with six other women including the facilitator. The walls of the room were covered with one way mirrors, and multiple microphones strategically dangled from the ceiling to capture our every word. When we first entered the room, I chose to sit at the first seat adjacent to where the focus group facilitator was positioned. Throughout all of my classroom experiences, I've always chosen to sit closest to the instructor, so this wasn't new. When everyone was comfortably situated, the facilitator informed us that we would be discussing sanitary napkins. Being born with androgen insensitivity syndrome, I never had a menstrual period but figured I would do a good enough job pretending in order to get the \$150.00 compensation I was promised for my feedback. The facilitator decided to begin by asking me how many pads I use in a typical cycle. I must have looked like a

deer in headlights when I responded, “Four.” The look on everyone’s face can only be described as a strange combination of shock and confusion. I quickly modified my answer, “a day.” With their faces unchanged, I again modified my answer, “on a light day?” I asked.

As I shared this story with those in the private session, the room drastically transformed from a somber space to one full with laughter, some were even brought to tears with laughter. I told everyone that I found solace living as I am. I recognized my agency in replacing stigma with knowledge of the social construction of sex, gender, and sexuality. It was then that I realized this was easier for me to do than it might be for others given the theoretical frameworks I was exposed to throughout my sociological training.

There were many other instances during data collection where I subconsciously changed the object of study through the process of “reflexivity” (e.g., Giddens 1990). For instance, in January of 2010, I was interviewing an activist who was historically connected to ISNA but wasn’t familiar with Organization Intersex International outside of knowing it existed. When the activist asked me what I knew about OII, I shared its publicly available information, including its mission statement. I knew this activist would find support in OII given its conceptualization of sex, gender, and sexuality, and they later did. The activist wrote me in March of 2010:

FYI, I joined OII (Organization Intesex International) in February as a way to bond with other intersex folks who DON'T like DSD, & they asked me to be their [major organizational representative]. i accepted, & so far it's been going great. They are on the shit list amonsgt DSD activists b/c they called [pro-DSD activists] out big time on all the unethical stuff around DSD. however, internationally that has made them VERY well liked, as the int'l community overwhelmingly rejects DSD...the founder of OII, speaks more languages than anyone i've ever met, which has been fantastic for creating a global community.

My time during data collection is evidence that scientific knowledge, and the process of obtaining it, is capable of shaping human behavior (e.g., Giddens 1990). What is yet to be

determined is if my analysis of the intersex rights movement combined with my personal connection to the community will have any influence on its course of direction.

### **“Bringing Intersexy Back”**

Each of the five tools for a liberatory transformation presented above must work together if we are serious about seeing and experiencing a true liberatory transformation where intersex stigma and shame are deconstructed and eventually eliminated. Although each tool is useful in and of itself, any given tool is far less effective than the collective combination of them all. While each tool is equally important, it is safe to assume that the last tool introduced above which refers to formal and informal exposure to gender scholarship is arguably the most important, and consequently, the most difficult tool for one to cultivate. It is the most important tool because each of the other tools is easier to employ when one has been exposed to gender scholarship, for gender scholarship offers theoretical frameworks that directly confront the sex, gender, and sexuality binaries with which intersex stigma, shame, and secrecy rests.

When one seriously engages with gender scholarship, it becomes clear that the DSD terminology, regardless of intent, carries with it far more negative consequences for intersexed individuals and their families than does an intersex identity. For this reason, there are two major overlapping reasons why we ought to be “bringing intersexy back.” The first is centered on how earlier progress was achieved. The second rests on the negative emotional consequences attached to the medicalized DSD diagnosis. Each of these reasons is discussed below.

First and foremost, the majority of progress around ending intersex stigma was accomplished in the 1990s when intersex activists were beginning to successfully create a “third sex” category in order to come together to challenge the medical profession (e.g., Turner 1999).

The 2000 and 2006 consensus statements are evidence of progress, albeit themselves controversial. Prior to the formation of the U.S. intersex rights movement, doctors were withholding the intersex diagnosis from individuals in order to protect intersexuals from being confused about their gender identity (Karkazis 2008). However, such practices were actually found to be the most detrimental to well-being (Preves 2003). When hermaphrodite, intersexual, and the like were reclaimed by intersexed individuals in the 1990s, there was a sense of community solidarity. Intersexed individuals, at least temporarily when together, no longer felt “abnormal.” Instead, their energy was directed toward demanding change in the medical management of intersexuality.

The second major reason for “bringing intersex back” rests on the reasons why intersexuality is a problem in the first place. Intersexuality is only a stigmatized condition because of the sex, gender, and sexuality binaries that it directly challenges. Once one acknowledges sex, gender, and sexuality are socially constructed binaries that serve to harbor and perpetuate inequalities, we are liberated to move beyond their limitations. My research offers at least some evidence that this is possible. In chapter five, I introduced my “gender prisoners” and “gender players” typology to show how gender players were able to use understanding of sex, gender, and sexuality as social constructions to “play” on the periphery of gender structure. Although gender players suffer from fractured familial and medical relationships, such negative consequences exist only because most parents and medical professionals hold on to narrow understandings of sex, gender, and sexuality. If parents learned to play with gender, they could be their children’s supporters once again.

## **Conclusion**

This isn't just a study about the medical management of intersexuality. It is a glimpse into the power gender structure continues to have over all of us, regardless of genitalia. Until gender is acknowledged as a stratification system with implications at the individual, interactional, and institutional levels (Risman 2004), I fear most intersexed individuals and their families will continue to be stigmatized. I recognize the origins of gendered behaviors and gender identities are debated among medical professionals and social scientists, with medical professionals connecting gender to biological predisposition and social scientists much less so, if at all. However, different beliefs about gender should not divide us, not when the well-being of young children are at stake. The real issues fall within the ideology that maintains sex, gender, and sexuality are neatly constructed binaries. Intersexed individuals are real life proof this is not the empirical reality.

As a feminist scholar, I approach sex, gender, and sexuality as social constructions, but the origins of each are not at the core of intersex stigmatization. Instead, what drives the stigmatization is the idea that there are only two sexes, two genders, and two sexualities, all correlated. The existence of intersexuals alone challenges such binary ideologies, yet they continue to organize our lives. We cannot deny that intersexed individuals have existed throughout history (e.g., Reis 2009), nor should we want to. Until we acknowledge that intersex bodies are controlled at the individual, interactional, and institutional levels of gender structure (e.g., Risman 2004), intersexed individuals will be stigmatized. Based on hundreds of hours of interviews with community members and ethnographic field observations, I strongly recommend those committed to ending the stigma faced by intersexuals and their families seriously entertain

the possibility of “bringing intersex back” by doing away with the pathologizing disorder of sex development diagnostic terminology. The tools for liberatory transformation offered above are a starting point to be able to do so. “Gender players” are already attempting to do this, but now are faced with extreme resistance from medical professionals, their parents, and surprisingly other intersexed individuals who want nothing more than to hide within the pathologizing DSD label. It is, thus, not surprising that the “gender players” are the most contested individuals in the entire intersex community. To that I end with a plea for those truly invested in ending intersex stigma and shame: don’t hate the gender player, hate the gender game.

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## APPENDIX

### UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)  
Office of the Vice Chancellor for Research (MC 672)  
203 Administrative Office Building  
1737 West Polk Street  
Chicago, Illinois 60612-7227

#### Approval Notice Initial Review – Expedited Review

October 14, 2008

Georgiann Davis, MA  
Sociology  
1007 W Harrison Street  
M/C 312  
Chicago, IL 60612  
Phone: (312) 996-3006

**RE: Protocol # 2008-0881**  
**“A Gender Structure Analysis of the Intersex Rights Movement”**

Dear Ms. Davis:

Members of Institutional Review Board (IRB) #2 reviewed and approved your research protocol under expedited review procedures [45 CFR 46.110(b)(1) on October 6, 2008. You may now begin your research

Your research meets the requirement(s) for the following Expedited Review Approval Categories [45 CFR 46.110(b)(1)]:

- (5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis);
- (6) Collection of data from voice, video, digital, or image recordings made for research purposes; and
- (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the following information about your approved research protocol:

**Protocol Approval Period:** October 6, 2008 - October 5, 2009  
**Approved Subject Enrollment #:** 100  
**Additional Determinations for Research Involving Minors:** These determinations have not been made for this study since it has not been approved for enrollment of minors.  
**Performance Sites:** UIC  
**Sponsor:** None  
**Research Protocol(s):**  
a) A Gender Structured Analysis of the Intersex Rights Movement;10/01/2008  
**Recruitment Material(s):**  
a) E-mail Invitation; Version 1; 09/22/2008

**Informed Consent(s):**

- a) Consent; Version 1; 09/22/2008

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
10/03/2008	Initial Review	Expedited	10/06/2008	Approved

Please remember to:

→ Use only the IRB-approved and stamped consent document(s) enclosed with this letter when enrolling new subjects.

→ Use your **research protocol number** (2008-0881) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements of the, "**UIC Investigator Responsibilities, Protection of Human Research Subjects**"

**Please note that the UIC IRB has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.**

**Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.**

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS office at (312) 996-1711 or me at (312) 355-2908. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Charles W. Hoehne  
Assistant Director, IRB # 2  
Office for the Protection of Research Subjects

Enclosure(s):

1. **UIC Investigator Responsibilities, Protection of Human Research Subjects**
2. **Informed Consent Document(s):**
  - a) Consent; Version 1; 09/22/2008
3. **Recruiting Material(s):**
  - a) E-mail Invitation; Version 1; 09/22/2008

cc: Albert Thompson, Sociology, M/C 312  
Barbara Risman, Sociology, M/C 312

UNIVERSITY OF ILLINOIS  
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)  
Office of the Vice Chancellor for Research (MC 672)  
203 Administrative Office Building  
1737 West Polk Street  
Chicago, Illinois 60612-7227

**Approval Notice  
Continuing Review**

August 2, 2010

Georgiann Davis, MA  
Sociology  
1007 W Harrison Street  
M/C 312  
Chicago, IL 60612  
Phone: (312) 996-3006

**RE: Protocol # 2008-0881  
“A Gender Structure Analysis of the Intersex Rights Movement”**

Dear Ms. Davis:

Your Continuing Review was reviewed and approved by the Expedited review process on July 26, 2010. You may now continue your research.

Please note the following information about your approved research protocol:

**Protocol Approval Period:** August 20, 2010 - August 19, 2011  
**Approved Subject Enrollment #:** 100 (54 subjects enrolled)  
**Additional Determinations for Research Involving Minors:** These determinations have not been made for this study since it has not been approved for enrollment of minors.  
**Performance Sites:** UIC, Organisation Intersex International  
**Sponsor:** None  
**PAF#:** - Not Applicable  
**Research Protocol(s):**  
 b) Interview Protocol; Version 2; 08/01/2009  
 c) A Gender Structured Analysis of the Intersex Rights Movement; Version 2; 08/17/2009  
**Recruitment Material(s):**  
 b) E-mail Invitation; Version 2; 08/01/2009  
**Informed Consent(s):**  
 b) Consent; Version 2; 08/01/2009

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis).

(6) Collection of data from voice, video, digital, or image recordings made for research purposes. (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

**Please note the Review History of this submission:**

Receipt Date	Submission Type	Review Process	Review Date	Review Action
07/21/2010	Continuing Review	Expedited	07/26/2010	Approved

Please remember to:

→ Use your **research protocol number** (2008-0881) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,  
**"UIC Investigator Responsibilities, Protection of Human Research Subjects"**

**Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.**

**Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.**

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Marissa Benni-Weis, M.S.  
 IRB Coordinator, IRB # 2

Office for the Protection of Research Subjects

Enclosure(s):

4. **UIC Investigator Responsibilities, Protection of Human Research Subjects**
5. **Informed Consent Document(s):**
  - b) Consent; Version 2; 08/01/2009
6. **Recruiting Material(s):**
  - b) E-mail Invitation; Version 2; 08/01/2009

cc: Barbara Risman, Sociology, M/C 312

UNIVERSITY OF ILLINOIS  
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)  
Office of the Vice Chancellor for Research (MC 672)  
203 Administrative Office Building  
1737 West Polk Street  
Chicago, Illinois 60612-7227

**Approval Notice**  
**Amendment to Research Protocol and/or Consent Document – Expedited Review**  
**UIC Amendment # 1**

August 31, 2009

Georgiann Davis, MA  
Sociology  
1007 W Harrison Street  
M/C 312  
Chicago, IL 60612  
Phone: (312) 996-3006

**RE: Protocol # 2008-0881**

**“A Gender Structure Analysis of the Intersex Rights Movement”**

Dear Ms. Davis:

Members of Institutional Review Board (IRB) #2 have reviewed this amendment to your research and/or consent form under expedited procedures for minor changes to previously approved research allowed by Federal regulations [45 CFR 46.110(b)(2) and/or 21 CFR 56.110(b)(2)]. The amendment to your research was determined to be acceptable and may now be implemented.

Please note the following information about your approved amendment:

**Amendment Approval Date:** August 31, 2009

**Amendment:**

Summary: UIC Amendment #1, dated 17 August 2009 and submitted to OPRS 14 August 2009, is an investigator-initiated amendment regarding the following: (1) revisions in materials and recruitment/consent documents reflecting a change in nomenclature used in the field to refer to a "disorder of sex development" or "DSD" instead of the terms "intersex," "intersexuality," or "intersex condition" (revised protocol, version 2, 8/17/2009; Invitation to Participate in a Research Study about "The Intersex/DSD Rights Movement," version 2, 8/1/2009; Consent, version 2, 8/1/2009 submitted), (2) addition of the Organisation Intersex International as a research site (Letter of Support dated 27 August 2009 submitted), (3) addition of observations of public meetings as part of data collection methodologies, and (4) submission of a revised interview protocol (version 2, 8/1/2009 submitted).

**Approved Subject Enrollment #:** 100

**Performance Sites:** UIC, Organisation Intersex International

**Sponsor:** None

Research Protocol(s):

a) **Interview Protocol; Version 2; 08/01/2009**

b) **A Gender Structured Analysis of the Intersex Rights Movement; Version 2; 08/17/2009**

**Recruiting Material(s):**

a) **E-mail Invitation; Version 2; 08/01/2009**

Informed Consent(s):

a) **Consent; Version 2; 08/01/2009**

**Please note the Review History of this submission:**

Receipt Date	Submission Type	Review Process	Review Date	Review Action
08/14/2009	Amendment	Expedited	08/20/2009	Modifications Required
08/28/2009	Response To Modifications	Expedited	08/31/2009	Approved

Please be sure to:

→ Use your research protocol number (2008-0881) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,  
**"UIC Investigator Responsibilities, Protection of Human Research Subjects"**

**Please note that the UIC IRB #2 has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.**

**Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.**

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Marissa Benni-Weis, M.S.  
 IRB Coordinator, IRB # 2  
 Office for the Protection of Research Subjects

Enclosure(s):

1. **UIC Investigator Responsibilities, Protection of Human Research Subjects**
2. **Informed Consent Document(s):**
  - a) Consent; Version 2; 08/01/2009
3. **Recruiting Material(s):**
  - a) E-mail Invitation; Version 2; 08/01/2009

cc: Barbara Risman, Sociology, M/C 312

UNIVERSITY OF ILLINOIS  
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)  
Office of the Vice Chancellor for Research (MC 672)  
203 Administrative Office Building  
1737 West Polk Street  
Chicago, Illinois 60612-7227

**Approval Notice  
Continuing Review**

August 2, 2010

Georgiann Davis, MA  
Sociology  
1007 W Harrison Street  
M/C 312  
Chicago, IL 60612  
Phone: (312) 996-3006

**RE: Protocol # 2008-0881  
“A Gender Structure Analysis of the Intersex Rights Movement”**

Dear Ms. Davis:

Your Continuing Review was reviewed and approved by the Expedited review process on July 26, 2010. You may now continue your research.

Please note the following information about your approved research protocol:

**Protocol Approval Period:** August 20, 2010 - August 19, 2011  
**Approved Subject Enrollment #:** 100 (54 subjects enrolled)  
**Additional Determinations for Research Involving Minors:** These determinations have not been made for this study since it has not been approved for enrollment of minors.  
**Performance Sites:** UIC, Organisation Intersex International  
**Sponsor:** None  
**PAF#:** - Not Applicable  
**Research Protocol(s):**  
 d) Interview Protocol; Version 2; 08/01/2009  
 e) A Gender Structured Analysis of the Intersex Rights Movement; Version 2; 08/17/2009  
**Recruitment Material(s):**  
 c) E-mail Invitation; Version 2; 08/01/2009  
**Informed Consent(s):**  
 c) Consent; Version 2; 08/01/2009

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis).

(6) Collection of data from voice, video, digital, or image recordings made for research purposes. (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

**Please note the Review History of this submission:**

Receipt Date	Submission Type	Review Process	Review Date	Review Action
07/21/2010	Continuing Review	Expedited	07/26/2010	Approved

Please remember to:

→ Use your **research protocol number** (2008-0881) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,  
**"UIC Investigator Responsibilities, Protection of Human Research Subjects"**

**Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.**

**Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.**

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Marissa Benni-Weis, M.S.  
 IRB Coordinator, IRB # 2

Office for the Protection of Research Subjects

Enclosure(s):

- 7. UIC Investigator Responsibilities, Protection of Human Research Subjects**
- 8. Informed Consent Document(s):**
  - c) Consent; Version 2; 08/01/2009
- 9. Recruiting Material(s):**
  - c) E-mail Invitation; Version 2; 08/01/2009

cc: Barbara Risman, Sociology, M/C 312

UNIVERSITY OF ILLINOIS  
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)  
Office of the Vice Chancellor for Research (MC 672)  
203 Administrative Office Building  
1737 West Polk Street  
Chicago, Illinois 60612-7227

**Approval Notice  
Continuing Review**

July 11, 2011

Georgiann Davis, MA  
Sociology  
1007 W Harrison Street  
M/C 312  
Chicago, IL 60612  
Phone: (312) 996-3006

RE: **Protocol # 2008-0881**  
**“A Gender Structure Analysis of the Intersex Rights Movement”**

Dear Ms. Davis:

Your Continuing Review was reviewed and approved by the Expedited review process on July 7, 2011. You may now continue your research.

Please note the following information about your approved research protocol:

**Protocol Approval Period:** July 7, 2011 - July 5, 2012  
**Approved Subject Enrollment #:** 100(65 subjects enrolled to date)  
**Additional Determinations for Research Involving Minors:** These determinations have not been made for this study since it has not been approved for enrollment of minors.  
**Performance Sites:** UIC, Organisation Intersex International  
**Sponsor:** None  
**PAF#:** - Not Applicable  
**Research Protocols:**

- f) Interview Protocol; Version 2; 08/01/2009
- g) A Gender Structured Analysis of the Intersex Rights Movement; Version 2; 08/17/2009

**Recruitment Material:**

- d) E-mail Invitation; Version 2; 08/01/2009

**Informed Consent:**

- d) Consent; Version 2; 08/01/2009

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis),.

(6) Collection of data from voice, video, digital, or image recordings made for research purposes., (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

**Please note the Review History of this submission:**

Receipt Date	Submission Type	Review Process	Review Date	Review Action
06/28/2011	Continuing Review	Expedited	07/07/2011	Approved

Please remember to:

→ Use your **research protocol number** (2008-0881) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,  
**"UIC Investigator Responsibilities, Protection of Human Research Subjects"**

**Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.**

**Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.**

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 355-1609. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Rahab Gandy, B.S.  
 IRB Coordinator, IRB # 2

Office for the Protection of Research Subjects

Enclosures:

**10. UIC Investigator Responsibilities, Protection of Human Research Subjects**

**11. Informed Consent Document:**

d) Consent; Version 2; 08/01/2009

**12. Recruiting Material:**

d) E-mail Invitation; Version 2; 08/01/2009

cc: Barbara Risman, Sociology, M/C 312

## VITA

### GEORGIANN DAVIS

#### **Education**

Ph.D., (2011) Sociology, University of Illinois at Chicago  
M.A., (2006), Sociology, University of Wisconsin-Milwaukee  
Thesis: Increasing Diversity, Maintaining Hierarchy: An Assessment of Medical Specialization  
B.A., (2004), Summa Cum Laude, Sociology, Northeastern Illinois University, Chicago, IL  
A.A., (2002), General Studies, College of Lake County, Grayslake, IL

#### **Academic Positions**

8/2011-Present      Assistant Professor, Department of Sociology and Criminal Justice Studies  
Southern Illinois University-Edwardsville

8/2006-7/2011      Part-Time Instructor, Department of Sociology  
Northeastern Illinois University

#### **Scholarships, Fellowships, and Funding Awards**

2011 Midwest Sociological Society Graduate Student Paper Competition, 3rd Place for:  
"DSD is a Perfectly Fine Term": Reasserting Medical Authority through a Shift in Intersex Terminology

2010-11 UIC Chancellor's Supplemental Graduate Two Year Research Fellowship  
2010 UIC Graduate Student Teaching Award  
2010 Rue Bucher Memorial Award, UIC University Wide Dissertation Award  
2010 Alice J. Dan Dissertation Award, UIC's The Center for Research on Women & Gender  
2010 SAGE/Pine Forge Teaching Innovations & Professional Development Award  
2010 Brauner Fellowship at UIC (Renewable until Degree Completion)  
2009 Beth B. Hess Memorial Scholarship (jointly awarded by SWS, SSSP, and ASA)  
2009 UIC Kellogg Merit Scholarship from UIC's Gender & Sexuality Center  
2004 Chancellor's Graduate Student Award at the University of Wisconsin-Milwaukee

#### **Research and Teaching Interests**

Gender and Sexuality	Gender and Social Movements
Intersexuality and Intersex Identity	Qualitative Methodology
Race, Ethnicity, and Gender Inequalities	Statistics, Undergraduate and Graduate
Sociology of Work and Occupations	

**Publications**

- Davis, Georgiann. (2011). “‘DSD is a Perfectly Fine Term’: Reasserting Medical Authority through a Shift in Intersex Terminology,” for Volume 12 in the *Advances in Medical Sociology* series, “Sociology of Diagnosis” Editors PJ McGann and David J. Hutson.
- Collins, Sharon and Georgiann Davis. (2011). “Protecting White Power in a Corporate Hierarchy” in *Covert Racism: Theories, Institutions, and Experiences* edited by Rodney Coates. Brill Publishers.
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**Invited Presentations**

- Davis, Georgiann. 2010. “Dancing Around the Body: Sex, Gender, and Intersexuality.” Invited Presentation. UIC School of Public Health.
- Davis, Georgiann. 2010. “Gender Players, Gender Prisoners: Conflicting Views of the Linguistic Shift from ‘Intersexuality’ to ‘Disorders of Sex Development’” Invited Presentation. American Sociological Association, Atlanta, GA.
- Risman, Barbara and Georgiann Davis. 2010. “Sex & Gender: Conceptual Confusions.” UIC’s College of Medicine Interdisciplinary Research Seminar: Building Interdisciplinary Research Careers in Women’s Health.
- Davis, Georgiann. 2008. Discussant. “Contexts Magazine Townhall Meeting.” Midwest Sociological Society, St. Louis, MO.

**Presentations at Professional Meetings**

- Davis, Georgiann. 2011. “From Collective Confrontation to Contested Collaboration: A Divided Intersex Rights Movement.” Midwest Sociological Society, St. Louis, MO.
- Davis, Georgiann. 2010. “Voices from the Field: Conflicting Views of the Linguistic Shift from Intersexuality to Disorders of Sex Development.” Midwest Sociological Society, Chicago, IL.
- Davis, Georgiann. 2010. “Voices from the Field: Conflicting Views of the Linguistic Shift from Intersexuality to Disorders of Sex Development.” Sociologists for Women in Society, Santa Barbara, California.
- Davis, Georgiann and Barbara J. Risman. 2009. “Beyond Sex, Beyond Gender: A Gender Structure Analysis of the Intersex Rights Movement.” Midwest Sociological Society, Des Moines, IA.

- Davis, Georgiann. 2008. "Increasing Diversity, Maintaining Hierarchy: An Assessment of Medical Specialization." American Sociological Association, Boston, MA.
- Davis, Georgiann and Sharon Collins. 2008. "White Coats, Black Specialists? The Racial Hierarchy of the Medical Profession." Midwest Sociological Society, St. Louis, MO.
- Davis, Georgiann. 2007. "Diagnosing Doctors' Debt: An Assessment of Medical School Graduates." Midwest Sociological Society, Chicago, IL.
- Davis, Georgiann. 2006. "Increasing Diversity, Maintaining Hierarchy: An Assessment of Medical Specialization." Midwest Sociological Society, Omaha, NE.
- Davis, Georgiann. 2005. "The Undiagnosed Dilemma: Unequal Access to Medical Specialties." Midwest Sociological Society, Minneapolis, MN.
- Davis, Georgiann and Virginia Rossi. 2004. "The Intersection of Race and Gender in Medical Students' Choice of Specialty." Midwest Sociological Society, Kansas City, MO.
- Davis, Georgiann and Virginia Rossi. 2004. "The Effects of Affirmative Action." Midwest Sociological Society, Kansas City, MO.

### **Professional Service**

- 2010-2011 Graduate Student Representative, ASA Sexualities Section
- 2007-2009 Graduate Student Recruitment Day Committee, UIC
- 2008-Present Ad-Hoc Reviewer, *Sociology of Health and Illness*, 2008-Present.
- 2003-2004 Sociology Club President, Northeastern Illinois University

### **Professional Memberships**

- American Sociological Association (2004-Present)
- Sex and Gender Section (2009-Present)
- Sexualities Section (2009-Present)
- Body and Embodiment Section (2009-Present)
- Section on Teaching and Learning in Sociology (2010-Present)
- Midwest Sociological Society (2004-Present)
- Society for the Study of Social Problems (2009-Present)
- Sociologists for Women in Society (2008-Present)

### **References**

Available upon request

(updated 8/11/11)