

PROGRESS AND POLITICS IN THE INTERSEX RIGHTS MOVEMENT

Feminist Theory in Action

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Since 1990, when Suzanne Kessler published her groundbreaking feminist analysis of the understanding of gender among clinicians treating children with intersex, many academic feminists have produced important scholarly work on intersex and intersex rights.¹ A notable few have also lent their energies to actively working for intersex rights in medical and mainstream social arenas. Although the intersex rights movement and feminist scholarship on intersex have both progressed considerably since 1990, there remains theoretical and political irresolution on certain key issues, most notably those involving intersex identity and the constitution of gender.

This essay considers the progress made in intersex rights since 1990 and delineates important points of contention within feminist intersex scholarship and intersex politics. We argue that in the last fifteen years much progress has been made in improving medical and social attitudes toward people with intersex, but that significant work remains to be done to ensure that children born with sex anomalies will be treated in a way that privileges their long-term well-being over societal norms. We also argue that, while feminist scholars have been critically important in developing the theoretical underpinnings of the intersex rights movement and sometimes in carrying out the day-to-day political work of that movement, there have been intellectual and political problems with some feminists' approaches to intersex.

The authors have a foot in both camps considered here—academic feminism and intersex rights work. We are academic feminists who also worked

as paid directors at the Intersex Society of North America (ISNA), the longest-running, best-funded, and historically most influential intersex advocacy group. Alice Dreger began working with ISNA in 1996 and volunteered as chair of its board of directors from 1998 to 2003 and 2004 to 2005, and as chair of the fundraising committee in the 2003–4 interim. In 2005 she left the board to take on the paid, part-time position of director of medical education, which she completed in late 2005. April Herndon was employed full-time as director of programming for ISNA from June 2005 to May 2006, producing and updating educational and Web site materials, organizing speakers and volunteers, writing grants, and so forth. Dreger's graduate training is in the history and philosophy of science; in academic practice she is an historian of medicine and a bioethicist. Herndon's graduate training is in American studies; in academic practice she is a women's studies and cultural studies scholar.

A word on terminology is in order here. In this essay we use the term *intersex* to refer to variations in congenital sex anatomy that are considered atypical for females or males. The definition of *intersex* is thus context specific. What counts as an intersex phallus, for example, depends on local standards for penises and clitorises. Similarly, as we elaborate below, a person with no obvious sex ambiguity but with "sex chromosomes" other than simply XX (female-typical) or XY (male-typical) is today considered an intersex person by some intersex advocates, medical researchers, and clinicians, but not by all.² Yet such a person could not have been considered intersex before the ability to diagnose "sex chromosomes." So the definition of intersex depends on the state of scientific knowledge as well as general cultural beliefs about sex.

For this reason, in practice we define a person as intersex if she or he was born with a body that someone decided isn't typical for males or females. (This is also ISNA's current definition—not a coincidence, since Dreger helped develop this definition at an ISNA board retreat around 2000.)³ Delineating intersex ultimately depends on delineating males and females, and when you get into the nitty-gritty of biology, this is not a simple task; nature is messy and often surprising, as Vernon Rosario argues in this volume.⁴ That said, there are some forms of intersex that make a person's body obviously different from what is usual—for example, when a child is born otherwise male but without a penis, or when a child is born otherwise female but with a very small vagina and a large clitoris. So when we say that intersex is context specific, we do not mean to imply that these biological variations are not real but that how many variations (and thus people) are included in the category intersex depends on time and place.

Several dozen known biological variations and conditions may be con-

sidered intersex. Some have their basis in genetic variations. Some result from nongenetically caused prenatal developmental anomalies. A few involve “ambiguous” genitalia, but not all do; some involve more subtle blends of female and male types—for example, when a person has the external appearance of one sex but internally most of the organs of the other sex. Making things rather confusing to the novice, the medical names for various intersex conditions may refer specifically to the genotype (genetic basis), or to the phenotype (body type), or to the etiology (causal pathway of the condition), or to some combination of these. So saying someone is “intersex” does not tell you anything specific about a person’s genes, anatomy, physiology, developmental history, or psychology. *Intersex* functions as a blanket term for many different biological possibilities—and as we show, many different political possibilities too.

Background History of Intersex

Historical records in the West suggest that until well into the twentieth century intersex people tended simply to blend in with the general population, living their lives as unremarkable boys, girls, men, and women. Given that notable genital ambiguity shows up once in about every two thousand births, if genital ambiguity had been considered terribly disturbing throughout Western history, there would likely exist significantly more records of legal, religious, and medical reactions.⁵ Indeed, although largely ignored by medical practitioners who treat intersex today, there is in fact a body of medical literature from the nineteenth and twentieth centuries that shows that people with “ambiguous” sex anatomies lived relatively uneventful lives psychologically and socially.⁶ The only reason many of these people even show up in that medical literature is that they wandered into the medical systems for some other concern, and then the physician noted their sex anomalies. Doctors often seem to have been more concerned with sex anomalies than many of their patients.

Historically the tendency in the West—in legal, medical, and religious affairs—has been to try to keep people sorted into clear male and female roles, and people with intersex seem to have generally participated in that binary sorting.⁷ Lorraine Daston and Katherine Park found that in early modern France people labeled hermaphrodites were strictly required to adhere to one gender (male or female) and to partner only with someone of the other gender, to avoid the appearance of homosexual or other “deviant” sexuality.⁸ Dreger, Christine Matta, and Elizabeth Reis have shown that a similar system took hold in European and American medicine by the late nineteenth century.⁹ The growing specter of homosexuality—*behavioral*

sexual ambiguity—drove many late-nineteenth-century physicians to insist that *physical* ambiguity—hermaphroditism—must be illusory and solvable through careful diagnosis of “true” sex. Matta, for example, shows “the connection between physicians’ increased interest in preventing ‘abnormal’ sexual behavior and their insistence that interventionist surgeries were the most appropriate means of treating cases of hermaphroditism.”¹⁰ Reis meanwhile notes that “nineteenth century doctors insisted on certainty rather than ambiguity in gender designation. . . . Choosing an infrangible sex (despite indefinite and contradictory markers) was mandatory.”¹¹

By the mid-nineteenth century, some surgeons began offering “corrective” operations for large clitorises, short vaginas, and hypospadias (wherein the urinary meatus—the “pee hole”—appears somewhere other than the tip of the penis). Occasionally such operations were requested by patients or by parents of intersex children.¹² But surgical “normalization” did not become the standard of care for intersex children until the 1950s, when the psychologists John Money, Joan Hampson, John Hampson, and their colleagues at Johns Hopkins University developed what came to be known as the “optimum gender of rearing” model, which held that *all* sexually ambiguous children should—indeed *must*—be made into unambiguous-looking boys or girls to ensure unambiguous gender identities.¹³

The optimum gender of rearing (OGR) model was based on the assumption that children are born psychosexually neutral at birth—that gender is primarily a product of nurture (upbringing), not nature (genes and prenatal hormones)—and that having a sex anatomy that appeared to match one’s gender identity is necessary to a stable gender identity. Money and the Hampsons believed that children could be steered one way or the other so long as the steering began before the age of two, give or take a few months.¹⁴ After the 1950s, surgeons at Hopkins and then at other major U.S. medical centers operated early to make children’s genitals more closely approximate the typical genitals of the gender assigned. They also removed gonads that did not match the assigned gender, even if those gonads were healthy and potentially fertile. When the child reached the age of puberty, endocrinologists administered hormones to push secondary-sex development in the direction of assigned gender if the hormones produced by the child’s own endocrine glands were inadequate to the task. Most children were assigned female because of the belief that it was easier to make a convincing-looking girl than a convincing-looking boy. (At least one surgeon has summed it up, “You can make a hole but you can’t build a pole.”)¹⁵ Boys were expected to have reasonably sized and reasonably functional penises; girls were primarily expected to be able to be on the receiving end of penile penetration.¹⁶

The team at Hopkins also provided intensive psychological gender coach-

ing, though this last aspect of treatment was less common at other medical centers, even while everyone agreed intersex represented a psychosocial concern.¹⁷ Although defenders of the Hopkins OGR team point out that their publications include suggestions that intersex children be told their medical histories in age-appropriate ways, in practice and in print many clinicians favored deception and withholding of medical records, lest patients become confused and depressed by their intersex states.¹⁸ By the early 1990s it was common practice for medical students and residents to be taught that their ethical duty meant deceiving women born with XY chromosomes and testes, telling them, if anything, that they had “twisted ovaries” that had to be removed.¹⁹ The pediatric endocrinologist Jorge Daaboul remembers telling women with XY chromosomes that they had one regular X chromosome and one X chromosome with a short arm, something he knew a Y chromosome is not.²⁰

History of the Intersex Rights Movement

Kessler’s 1990 *Signs* article, the first publication to provide a sustained feminist critique of the OGR model, explored the sexist and heterosexist assumptions made by clinicians working with intersex patients regarding what counts as normal for girls and boys.²¹ Using published medical literature as well as original interviews with intersex clinicians, Kessler demonstrated that the medical treatment of intersex was directed primarily at obscuring, and when possible eliminating, apparent sex and gender ambiguity.

Anne Fausto-Sterling brought a feminist understanding of intersex to a wider audience in 1993 by simultaneously publishing “The Five Sexes” in *The Sciences* and an op-ed called “How Many Sexes Are There?” in the *New York Times*.²² In these companion pieces Fausto-Sterling reiterated and thus publicized the existing medical taxonomy of five sex types, a division that had coalesced in the late nineteenth century.²³ These included males, females, true hermaphrodites (which Fausto-Sterling called “herms”), male pseudohermaphrodites (“merms”), and female pseudohermaphrodites (“ferms”). “Herms” were people with both ovarian and testicular tissues; “merms” were people with ambiguous or mixed-sex anatomy and testes; “ferms” were people with ambiguous or mixed sex anatomy and ovaries. Fausto-Sterling’s purpose was to challenge the pervasive belief that sex (and thus, in many people’s minds, gender) came in a simple dichotomy.

In response to Fausto-Sterling’s article Cheryl Chase (now known as Bo Laurent) published a letter in *Sciences* announcing the formation of ISNA.²⁴ Cognizant of how people with intersex were treated as if they were shameful and in

need of strict social discipline, Chase originally planned to call the organization “Intersex Is Not Criminal.”²⁵ Around the time of Fausto-Sterling’s articles, Chase and other intersex people, including Max Beck, Morgan Holmes, and Kiira Triea, had come to the realization that they had been wronged by the medical establishment and that they needed to agitate for the rights of children born like them.²⁶ Because intersex activists felt the harm that had come to them had occurred largely because of the medicalization and medical mismanagement of intersex, they focused their attentions on critiquing the OGR model. In doing so, these activists were informed by principles of feminism (particularly the right to speak for oneself and critiques of sexism), gay and lesbian rights (particularly critiques of heterosexism and homophobia), and patients’ rights (especially regarding autonomy, informed consent, and truth telling).²⁷

Slowly at first (from about 1993 to 1999) and more rapidly later, intersex activists found allies in academic feminism, medicine, law, and the media. Like the activists born intersex, the great majority of nonintersex allies focused their attentions on the contemporary medical standard of care for intersex. Among the problems noted with the OGR model were these: it treated children in a sexist, asymmetrical way, valuing aggressiveness and sexual potency for boys and passiveness and reproductive/sexual-receptive potential for girls; it presumed that homosexuality (apparent same-sex relations) and transgenderism (changing or blurring gender identities) constituted bad outcomes; it violated principles of informed consent by failing to tell decision-making parents about the poor evidentiary support for the approach; it violated the axioms of truth telling and “first, do no harm”; it forced children to have their bodies adapted to oppressive social norms, using surgeries and hormone treatments that sometimes resulted in irrevocable harm; it generally involved treating psychosocial issues without the active participation of psychosocial professionals such as psychologists, psychiatrists, and social workers.²⁸ A more recent critique questions whether there is any reason to believe nonstandard genitals constitute a psychological risk factor; in fact, the medical literature fails to support the medical establishment’s foundational assumption that having intersex genitals significantly increases psychosocial risk.²⁹

As intersex advocacy grew so did the number and prominence of activist and support organizations for people born with intersex. Partly to make up for the gap left by ISNA’s move away from day-to-day support toward systematic medical reform, the Internet-based, U.S.-located Coalition for Intersex Support, Activism, and Education (CISAE), founded by Triea and Heike Boedeker, and Bodies Like Ours, founded by Janet Green and Betsy Driver, sought to provide active peer support for parents and affected adults. Emi Koyama conceived Intersex Initiative

as a relatively local group, originally focused on Portland, Oregon, but she has since brought it to national prominence. Diagnosis-specific groups such as the international Androgen Insensitivity Syndrome Support Group (AISSG) thrived throughout the late 1990s and continue today. However, not all relevant patient advocacy groups agreed with ISNA, Bodies Like Ours, and Intersex Initiative that the OGR model had to go: for example, the CARES Foundation (for congenital adrenal hyperplasia) and the MAGIC Foundation (for conditions that affect children's growth, including some types of intersex), run mostly by parents and clinicians, tended to remain in agreement with the medical establishment.

Independent of advocacy organizations, some sex researchers and clinicians took a stand against the OGR, most notably Milton Diamond and his associates. Diamond and H. Keith Sigmundson reported what happened to David Reimer, the nonintersex boy whose transformation into a girl (following a circumcision accident) Money had directed.³⁰ Money had claimed Reimer's gender transformation worked—and that therefore the OGR system was likely to work for intersex children. But Money was lying; Money knew Reimer had not been happy as a girl, and indeed transitioned socially to a boy almost as soon as he learned of his past.³¹ Knowing this and hearing the painful stories of many adults with intersex, Diamond called in 1998 for a moratorium on intersex genital surgeries while data was collected on outcomes.³²

Initially the medical establishment mostly ignored critiques and calls for change, issuing only occasionally a restatement of the belief that the OGR model was necessary and effective.³³ These statements rarely answered the specific critiques noted above. When Dreger edited a 1998 special issue on intersex for the *Journal of Clinical Ethics* (which became the basis for the 1999 anthology *Intersex in the Age of Ethics*), she tried to find a clinician who would defend the OGR model, but could not. Notably, several were by that point willing to criticize it.³⁴ The one critique to which traditionalist clinicians did begin to respond was the lack of outcomes data in favor of the approach. The outcomes data that has recently emerged is mixed and tends to vary wildly in terms of implicit assumptions on the goal of intersex treatment.³⁵

Since about 2004, there has been a marked increase in interest among clinicians to reform practice. For example, thanks to the initiative of the feminist academic sociologist Monica Casper, who served as ISNA's executive director in 2003, ISNA developed a medical advisory board of approximately twenty-five people, most of them clinicians, something that seemed a distant dream as late as 1998. In 2004, at the American Academy of Pediatrics Section on Urology meeting, many clinicians were clearly agonizing over the choice of treatment in inter-

sex cases. Even surgeons who had historically been ardent defenders of the OGR model were publicly expressing serious reservations.³⁶ In October 2005 the highly influential Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology held a consensus meeting in Chicago that resulted in a hopeful degree of movement toward providing more psychosocial care, peer support, truth telling, informed consent, and outcomes data.³⁷

Also in 2005, a collective comprised mostly of the three stakeholder groups—intersex people, parents of intersex people, and clinicians—formed and issued new clinical guidelines and a handbook for parents based on a “patient-centered model of care,” an explicit alternative to the OGR.³⁸ That group, known as the Consortium on the Management of Disorders of Sex Development (or DSD Consortium for short), was formed as a result of grants given to ISNA to complete, produce, and distribute drafts written several years earlier by the social workers Sallie Foley and Christine Feick. The DSD Consortium includes founders and leaders of many of the major diagnosis-specific intersex support groups as well as clinicians from all the specialties involved in intersex care. (We were members of the DSD Consortium, and Dreger led the project as coordinator and editor in chief.)

The DSD Consortium’s *Clinical Guidelines* state:

Patient-centered care means remaining clearly focused on the well-being of individual patients. In the case of DSDs this specifically involves the following principles.

1. Provide *medical and surgical care when dealing with a complication that represents a real and present threat*. . . .
2. Recognize that what is normal for one individual may not be what is normal for others. . . .
3. Minimize the potential for the patient and family to feel ashamed, stigmatized, or overly obsessed with genital appearance; avoid the use of stigmatizing terminology (like “pseudo-hermaphroditism”) and medical photography; *promote openness*. . . .
4. Delay elective surgical and hormonal treatments *until the patient can actively participate in decision-making*. . . .
5. *Respect parents by addressing their concerns and distress empathetically, honestly, and directly*. . . .
6. *Directly address the child’s psychosocial distress* (if any) with the efforts of psychosocial professionals and peer support.
7. Always *tell the truth* to the family and the child.³⁹

These principles may seem like common sense, but they are considered somewhat radical by clinicians who have long believed that the presence in a child of a trait that challenges social norms means the most basic tenets of medical ethics can (and indeed must) be set aside.⁴⁰

The DSD Consortium's handbooks are drawing much interest and praise in medical centers around the United States and are being distributed by advocacy groups (such as the MAGIC Foundation) historically supportive of the medical establishment. Our own experience suggests that clinicians who until recently practiced the OGR model are quite receptive to the patient-centered alternative. We see this as clear evidence that the changes for which intersex activists first hoped in the early 1990s are finally happening. This is not to overlook continued delays in the implementation of a reformed model. In our experience many medical centers currently lack institutional resources—including adequately trained psychosocial professionals, leadership, cross-disciplinary relationships, and funding—needed to implement psychosocially attentive integrated team care. Some also suffer from disputes among clinicians over the best approach. But more and more are expressing interest in providing something like the patient-centered, multidisciplinary team approach recommended by the DSD Consortium.⁴¹

The success of the intersex rights movement is almost certainly due in part to concomitant success in the LGBT rights movement. As noted above, the treatment of intersex has historically been motivated by homophobia and transphobia—that is, fear of apparent same-sex relations and fear of people changing or blurring gender categories. Positive changes in social attitudes toward queer-identified people have thus led to positive changes in social attitudes toward people with what some have called “queer bodies.”⁴² Success can also be credited to the fact that intersex advocates have been extremely effective at using the power of the media to change minds.⁴³ Substantial Western media attention to intersex people and intersex medicine, as well as the publication in 2002 of Jeffrey Eugenides's Pulitzer Prize-winning *Middlesex: A Novel*, has helped make the existence of intersex known, believed, and understood by tens of millions more people. We should note that, although a few intersex people objected to Eugenides's portrayal of an intersex person because it was a fictional story by a nonintersex man, our experience has been that the learning engendered by his novel for doctors and laypeople alike has been generally progressive. (Both of us have been surprised at how many conservative older men and women have told us excitedly what they learned about intersex from reading *Middlesex* in book clubs, including Oprah Winfrey's.) The intersex rights movement has also benefited from several talented writers—including Martha Coventry, Esther Marguerite Morris Leidolf, and

Trixa—who have conveyed their personal histories with eloquence and power.⁴⁴ We see therefore many reasons to believe that the intersex rights movement will continue to make marked progress in the coming years, even while we are concerned that the skyrocketing marketing of genital cosmetic procedures—including penile enlargement and labia reduction surgeries—has the potential to produce a negative effect on intersex clinical reform, as norms for genital appearance become increasingly visible and rigid.⁴⁵

Intersex Identity Politics

Although people sometimes refer to “the intersex community” as they do “the lesbian community,” this is somewhat misleading. There are online virtual communities of people with intersex, but large numbers of intersex people do not live together in brick-and-mortar communities, and only occasionally do they come together for meetings that are primarily about political consciousness-raising rather than about sharing information about particular medical diagnoses (like hypospadias or congenital adrenal hyperplasia). ISNA has hosted a few small invitation-only retreats, and a number of intersex people have come together at the annual Creating Change conference of America’s National Gay and Lesbian Task Force, and for one-time events such as the 2002 “Rated XXXY” San Francisco fund-raiser produced by the intersex advocate, performer, and poet Thea Hillman, but such gatherings remain either irregular or infrequent.

There are sizable annual meetings of diagnosis-specific groups like the AISSG, the CARES Foundation, and the Hypospadias and Epispadias Association, but often the participants of these meetings do not consider themselves “intersex” and are in fact offended by the term being used in reference to them. Objections we have heard include that the term sexualizes them (or their children if the objector is a parent) by making the issue one of eroticism instead of biology; that it implies they have no clear sex or gender identity; and that it forces on them an identity, especially a queer identity, to which they do not relate.⁴⁶

Historically the word *intersex* as we know it dates to the early twentieth century when it was coined by the biologist Richard Goldschmidt as a term for biological sex types that fell between male and female.⁴⁷ Throughout the twentieth century, members of the medical profession occasionally used the term to refer to what they would more typically call hermaphroditisms or pseudohermaphroditisms. Early intersex advocates chose the term because it was less confusing and stigmatizing than terms based on the root *hermaphrodite*, although occasionally they used those alternate terms for in-your-face self-empowerment. For example,

ISNA's first newsletter was called *Hermaphrodites with Attitude*, and Chase's 1996 video of ten intersex people telling their own stories was called *Hermaphrodites Speak!* But today few intersex advocates call themselves "hermaphrodites" both because the irony is lost on most people and because the term makes intersex people sound like mythical figures who are simultaneously fully male and fully female—something physiologically impossible but a frequent fantasy of certain fetishists who e-mail support groups seeking "hermaphrodite" sex partners. (Such people are known contemptuously in intersex activist circles as "wannafucks.") Early in the intersex rights movement, activists, scholars, and journalists sometimes referred to *intersexuals*, but this term has largely fallen out of favor because it can be essentializing and dehumanizing to equate people with one aspect of their physicality. Instead, many advocates and activists now prefer to use terms such as *person with intersex*, *intersex person*, or *person with an intersex condition*, taking a cue from the disability rights movement.⁴⁸

As suggested above, the question of who counts as intersex remains contentious. The people who made up the early intersex rights movement tended to share a common experience: they were born with noted sexual ambiguity, surgically "corrected" as young children, subjected to continued medicalization and stigma inside and outside the clinic, and they eventually developed a queer political consciousness that allowed them to understand their plight as unjust. But as the intersex rights movement grew, the diversity of actual experiences became more obvious, and this led to internal questions of identity politics. Were people intersex who "just" had hypospadias? Were women intersex who had well-controlled congenital adrenal hyperplasia and very little genital "masculinization" (so little it was never medically "fixed")?

The movement tended to welcome all these people out of the generosity that typically marks early social movements looking for people who will help and be helped.⁴⁹ But the anxiety about who should belong is obvious in venues like *Hermaphrodites Speak!* where Tom, born with hypospadias, jokes, "I'm the real hermaphrodite here—these people are just imposters." The intersex activist David Iris Cameron took to carrying around a card that asked, "Is XXY intersex?"⁵⁰ Cameron has Klinefelter syndrome (XXY chromosomes), which the layperson prone to a simplistic algebraic understanding of "sex chromosomes" might think of as obviously intersex. But many physicians do not count Klinefelter syndrome as intersex, just as they do not count Turner's syndrome (one X with no second "sex chromosome"), because in many physicians' minds, neither results in enough external sex-atypical development to count.

In our experience some clinicians have played a sort of moving target game

whereby their definition of intersex changes from venue to venue, or moment to moment. We end up spending a remarkable amount of time just trying to agree on which diagnoses (and thus which people) count in the conversation we're trying to have. This does not usually seem to be a purposeful attempt to stall or derail conversation (although that does sometimes result); rather it seems to stem from a lack of systematic consideration of what the term might mean. For example, some want to call intersex only those born with visibly ambiguous genitalia, or only those who have had a particularly unusual mix of prenatal sex hormones.

Two illustrations: the physician William Reiner, a longtime ISNA ally, has tended to insist that males born with cloacal exstrophy are not intersex because their brains are not subjected prenatally to a sex-atypical mix of hormones.⁵¹ Yet in cases of cloacal exstrophy, because the gut wall does not form properly, males are born with no penis. Standard practice (challenged by Reiner's work) has been to assign these children as girls, castrate them, and give them feminizing hormones starting at the age of puberty. In other words, the children are *treated* as intersex. Indeed, in all other cases when a boy is born with very little or no penis, the child would fall under the category intersex. Yet Reiner—who has been a staunch advocate of both intersex rights and the well-being of children born with cloacal exstrophy—seems not to want to apply the intersex label to cloacal exstrophy males purely because they have male-typical prenatal brain development.

A second example: in a recent discussion with a clinician, the name of one particular intersex activist came up, and the clinician stopped conversation to say, “she isn't intersex, she was just progesterone-virilized.” In other words, given her genotype the activist in question would have developed as a standard female, but because her mother was given progesterone during pregnancy (presumably to prevent miscarriage), the activist's genitals had been virilized to some degree in the womb. So this activist was born with ambiguous genitalia, and as a result she was sent through the OGR system. Yet because she had medically induced (rather than “naturally” occurring) genital virilization, the clinician did not think she counted as intersex.

To make matters even more confusing, sex development is complicated enough that two people who share nominally the same condition may have quite different genotypes (genetic codes) or phenotypes (body types). For example, just knowing a person has ovotestes (misleadingly called “true hermaphroditism” in the medical literature) won't reveal much about the person's chromosomes or even his or her genitalia; a person with ovotestes may appear fairly feminine, fairly masculine, or in-between in terms of genitalia and overall physique. The majority of people with ovotestes have XX (female-typical) sex chromosomes, but others have

XY or some other combination. Moreover, genitals that start as “ambiguous” may become naturally less so, and vice versa. Sharon Preves notes the case of Sierra, a child born with a large clitoris. The doctors wanted to shorten the clitoris for psychosocial reasons. Her mother refused. Several weeks later Sierra’s clitoris shrunk to a normal size.⁵² She probably had genital engorgement—that is, blood had pooled in her genitals, causing them to temporarily swell, from her being squeezed through her mother’s birth canal. Had Sierra had surgery she might now count as intersex. Because of her mother’s good sense she now probably doesn’t count by anyone’s definition.

The definitional challenges encountered with physicians, combined with the rejection of the intersex label by many parents and affected adults, have led us to participate in a move toward using a new blanket term: *disorders of sex development* (DSDs). When we started working with the group that became the DSD Consortium, it became clear that we couldn’t reach agreement on practice unless we came to agreement on terminology. Otherwise we couldn’t say to whom our guidelines applied. Everyone recognized that it was critical to avoid all terms based on the misleading and stigmatizing “hermaphrodite.”⁵³ Alternative available medical terms included *disorders of sex(ual) differentiation* and *disorders of sexual development*. Terms with *sexual* in them were rejected because of the implication that we were talking primarily about an issue of sexuality (eroticism, orientation) instead of sex (anatomy and physiology). “Differentiation” was rejected in favor of “development” because of disciplinary disagreement about what “differentiation” means. (Endocrinologists mean one thing, geneticists another.) One participant, David Iris Cameron, suggested “variations of sex development,” but this was rejected for discounting the health concerns that come with some intersex conditions—concerns like dangerous endocrine imbalances and an increased risk of gonadal cancers. Besides, “variations” would describe every human, not just the people we meant to describe, namely, those liable to be treated as problematically sex-atypical. In the end handbook contributors settled on “disorders of sex development,” with many people in the group expressing enormous relief at this.

As noted above, the DSD Consortium’s handbooks represented significant progress. The consortium included past and present leaders from many other critically important advocacy and support groups, including the AISSG, the CARES Foundation, ISNA, the MRKH Organization (for girls and women born with conditions including incomplete vaginal development), and Bodies Like Ours. In other words, we achieved buy-in on a clearly articulated patient-centered model of care among people who previously appeared not to agree. We know that this would have been impossible without the shift of nomenclature to DSD.

At the same time that the DSD Consortium was working in earnest, in October 2005 the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology held their consensus conference on intersex. One agreement reached at that meeting was to abandon the terms *intersex* and *(pseudo)hermaphroditism* in favor of *disorders of sex development*, defined as “congenital conditions in which development of chromosomal, gonadal, or anatomical sex is atypical.”⁵⁴ This was not a coincidence; several clinicians from the DSD Consortium (notably the pediatric urologist and geneticist Eric Vilain, the pediatric psychiatrist and urologist Reiner, and the pediatric psychologist David Sandberg) called for the change in nomenclature. But it is worth noting that their call fell on receptive ears; clinicians were ready for this change.

Reception of the new terminology has been mixed among people with intersex. Several months after publication of the DSD Consortium’s handbooks, three participating intersex adults—Cameron, Esther Morris Leidolf, and Peter Trinkl—asked that a one-sentence disclaimer be added noting that, though they support the documents, they do not support the term. Several adults with intersex also objected to the term at an October 2006 conference held by ISNA and in written responses to the Chicago consensus document.⁵⁵ It is obvious from the way we write that, as scholars and activists, we still prefer the term *intersex* even while we recognize the usefulness of using *DSD* in many contexts.⁵⁶ Understandably, many people dislike having the label of disorder applied to them. Ironically, after years of trying to demedicalize intersex to some extent, the term we’re now using remedicalizes it. But we have found that the terminology accords with the experience of many intersex adults and parents; it gives them a term that feels right in that it seems simultaneously to name, scientize, and isolate what it is that has happened. It therefore makes the phenomenon seem more manageable by being less potentially all-encompassing of their identities. Moreover, the shift to this terminology clearly has allowed serious progress toward patient-centered care, in part because it has allowed alliance building across support and advocacy groups, and with clinicians. For that reason we have been pragmatists about the nomenclature change. We strongly suspect that as attitudes and behaviors among clinicians improve, it will become possible and indeed necessary to revisit the nomenclature issue. Reis’s recent suggestion of “Divergence of Sex Development” might turn out to be a viable compromise.⁵⁷

A number of transgender people who were not born with any apparent sex anomalies and were not subjected to intersex medical management believe they should count as intersex because something in their brains obviously makes them feel differently than average males and females. One transgender person wrote to

us that unless one believes in a mind-brain dichotomy (which we don't), obviously there is something sex-atypical in the brains of transgender people. But it is not clear that that sex-atypicality (always) represents a neurological intersex comprising a female brain in a male body, or vice versa. Some transgendered persons' brains may be different from the average in some way other than a neurological sex inversion.

For transgender adults, there are definite advantages to counting as intersex. For one, people in the United States tend to be more accepting of identities that have a definitive (or at least implied) biological basis. The current *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* provides another reason for transgender people to seek the intersex label. According to the *DSM-IV*, a person with atypical gender identity can be classed as having gender identity disorder only if the person is not intersex.⁵⁸ Thus being labeled with an intersex condition means avoiding the diagnosis of a "mental disorder" and possibly easier access to legal and medical sex reassignment.

Yet many intersex advocates have rejected the idea that transgender people are necessarily intersex. For one thing they (and we) have found that a few transgender adults claim specific intersex conditions (like 5-alpha-reductase deficiency or partial androgen insensitivity syndrome) they don't actually have. But even beyond that, some intersex activists argue that transgender persons have had radically different experiences from intersex persons who have been through the OGR mill. Of course many (though by no means all) transgender people have experienced significant stigma for being gender atypical since childhood. But Chase writes that some transgender advocates inappropriately imply that intersex often results in gender transition, an inaccurate implication that "facilitates the doctors' misguided perceptions that incorrect gender assignment is the only harm of OGR, and that studies documenting low transition rates are evidence of success."⁵⁹ While there is no singular intersex experience to which a singular transgender experience can be compared, we think it is important to acknowledge the concern that intersex experiences and advocacy may become muddled, co-opted, or misguided in the conflation of transgender and intersex.⁶⁰

Still, even though there may be differences between intersex and transgender, there are also reasons for intersex and trans activists to unite. As Leslie Feinberg notes, the divisive behavior of territory marking over identities often weakens the movement for human rights. Feinberg states emphatically that "we can never throw enough people overboard to win approval from our enemies."⁶¹ Feinberg goes on to say that "people who don't experience common oppression *can* make history when they unite."⁶² While there may be moments when intersex

activists are justified in their demands that people understand the particulars of intersex and transgender, there is also reason to carefully consider whether these particulars are always important and why such lines are drawn in the first place. If the particulars of transgender and intersex are highlighted only in order to make intersex people more intelligible or acceptable, then the result might be that transgender people are made less intelligible or even pathologized. Thus intersex activists doing the work of cleaving intersex and transgender must diligently examine their motives and the possible outcomes of such work.

Finally, on the issue of intersex identity politics we might note for other scholars thinking about stepping into identity-centered activism that we have each been criticized and had our motives questioned for being nonintersex people working on intersex scholarship and activism. For example, we have both had our intentions interrogated in online forums, and Herndon has been attacked for daring to point out the similarities between what intersex people and fat people face in terms of stigma and medicalization.⁶³ But this has by no means been a frequent occurrence. In general, activists born intersex have welcomed our collaboration and have often acted as enthusiastic advisers to and supporters of our efforts.

Intersex and the Nature of Gender

Much scholarship in science and the humanities on intersex (including our own) has been motivated by attempts to ascertain the nature of gender. Historically, feminist intersex scholarship has aligned with other feminist theoretical scholarship in that it has taken gender to be a social construct distinct from sex (anatomy and physiology). For example, Kessler's 1990 intersex work aligned with her earlier work on gender by showing how social assumptions about what it means to be a male or a female are taught, learned, and reinforced. Dreger, Fausto-Sterling, Myra Hird, Holmes, Iain Morland, and many other feminist scholars working on intersex have similarly shown how social beliefs about gender are actively imposed on people whose bodies don't fit the simplistic assumptions that gender equals sex and that sex-gender formations come in only two flavors.⁶⁴

Indeed, until relatively recently some feminists cited the alleged success of the OGR model as proof that gender is socially constructed.⁶⁵ But the concept of gender (as distinct from sex) as it developed in intersex clinical practice was hardly meant to be progressive. As Dreger has shown, the move in the early twentieth century to assigning a "workable" gender instead of a gender that aligned with a biological "true sex" was a conservative reaction to the unrelenting messiness of sex. Doctors dealing with intersex decided they had better resort to a sys-

tem of gender assignment that would allow them to socially sort everyone into two types no matter how apparently in-between they were physically.⁶⁶ As Kessler and others have shown, the work of the Hopkins team continued in this tradition.⁶⁷ So even while Money and his allies supported the idea that gender is to a large degree socially constructed, in intersex care they maintained traditionalist, sexist, and heterosexist concepts.

Nevertheless, particularly in the early years of the intersex rights movement, many intersex people found feminist writings about the social construction of gender empowering and liberating. They could use this work to see how one particular construction had been forced on them and how their lives might have been better (and could yet be better) under different social constructions.⁶⁸ Social constructivism also gave solace to those who felt their gender identities did not fit into the simplistic male-female dichotomy promoted by Western popular culture. It was especially painful, therefore, for some intersex women (particularly women with AIS) to find their self-identities as women rejected by Germaine Greer in her book *The Whole Woman* because she insisted that “it is my considered position that femaleness is conferred by the final pair of XX chromosomes. Otherwise I don’t know what it is.”⁶⁹ As Morland has noted, when Greer was challenged by women with AIS and family members of girls with AIS, she was “dismissive; she then used the book’s second edition not to retract the claims, but to publicly mock the AIS correspondents by referring to them too as men.” Morland has persuasively argued that ironically “in trying to criticize the social construction of femaleness and intersex, Greer disenfranchised precisely those people who live at the intersection of the two categories.”⁷⁰ Greer’s simplistic and essentialist position seemed to represent something of a rearguard action against admitting anyone who might be a male-to-female transsexual into the ranks of real womanhood. Yet, we confess to never really understanding the intellectual balancing act performed by Greer and people like the leaders of the Michigan Womyn’s Music Festival (who have tried hard to keep a “womyn born womyn only” policy of admission): they seem simultaneously to condemn and employ essentialist notions of womanhood.

In fact, neither a hard-line social constructivist nor a hard-line biological essentialist theory of gender seems supportable by the real-life experiences of people with intersex. On the one hand, if gender identity were purely a matter of social construction, it would not make sense that people with certain intersex conditions tend to revert to one particular gender identity despite monumental efforts aimed at making them the other. Consider, for example, the high percentage of males born with cloacal exstrophy, castrated and raised as girls, who declare themselves to be boys.⁷¹ Similarly, many transgender people present gender identities in con-

tradition with the intensive gender training they've received—or indeed identities that confound any description in gendered terms.⁷²

On the other hand, a simplistic biological explanation for gender identity also fails in the face of intersex. Not all males born with cloacal exstrophy or a micropenis and raised girls decide they are really boys or men. Of course, some who retain their female gender identities may be unaware of their medical histories or have plenty of reasons to decide to stay with the gender they were assigned. Gender transition comes at significant financial, physical, and emotional costs.

Ultimately it seems illogical to have so firm a belief in either the biological determination or social construction of gender that all of us with stable gender identities amount to either biologically programmed robots or victims of false consciousness. As Diana Fuss pointed out in *Essentially Speaking*, even hard-core constructivism amounts to an essentialism itself—in this case, actually a biological essentialism that presumes everyone is born with a blank slate for a brain where gender is concerned.⁷³

Chase has argued that it is the very obsession with “the gender question” that has led to so much harm for people with intersex. According to Chase, while some people (like Money and some feminists) have used intersex to sit around debating nature versus nurture, real people with intersex have been hurt by these theories and their manifestations. Chase has therefore argued that “intersex [has been] primarily a problem of stigma and trauma, not gender.”⁷⁴ Clearly, most OGR clinicians—from Money through today—have disagreed, arguing instead that “problems of gender identity development are *the core concern* in the psychosocial management of medical conditions involving ambiguous genitalia.”⁷⁵ Yet a close reading of intersex autobiographical writing suggests that relatively few feel that getting the “wrong” gender assignment formed the central cause of their suffering. Indeed, this is a finding supported by outcome studies by OGR clinicians, . . . who then take this as proof that they've been on the right track all along!⁷⁶ This failure to see why they're on the wrong track results from believing that “successful” gender identity means success in intersex patient care. Most intersex autobiographies support Chase's argument, showing how shame (including, but not limited to, shame about gender variation), secrecy, and medical mismanagement led to significant suffering.⁷⁷

Nevertheless, contrary to Chase's simple formulation, clearly for a significant number of intersex people, gender—in the form of gender identity and gender role expectations—is a central concern in their lives. It is not uncommon for people with intersex to ponder how their gender identities and histories relate to their intersex. A few, like Mani Mitchell, feel that their intersex biology explains their

feelings of being bigendered or intergendered.⁷⁸ Indeed, some have claimed that ISNA's message (that intersex is mostly about shame and trauma, not gender) fails to acknowledge their socially atypical genders. In fact, ISNA has never suggested people should not have the right to express their genders however they wish. ISNA (like the DSD Consortium, Bodies Like Ours, and all the diagnosis-specific support groups) has advocated raising all children as boys or girls, providing a best-guess gender assignment based on what can be surmised (after extensive tests) about the child's biology and future psychology, including how the parents are thinking about the child's gender. The reasoning behind this is twofold: (1) raising a child in a third or no gender is not a socially feasible way to reduce shame and stigma; (2) intersex is not a discrete biological category, so someone would always be deciding who to raise as male, female, or intersex: three categories don't solve the problem any more than two or five or ten do.

ISNA argued that gender assignment should not be reinforced with surgeries—that healthy tissue should be left in place for the patient to decide herself or himself what, if anything, to do with it. Although certain members of the medical establishment erroneously believed (and some still do believe) that ISNA advocated “raising children in a third gender,” this was never the case. The cause of confusion seems to come from the fact that many clinicians can't understand what it would mean to raise a child with “ambiguous” genitalia as a boy or a girl, despite plenty of historical evidence that this has worked, no doubt because sex anomalies are largely hidden by clothing.⁷⁹

We've been asked innumerable times why ISNA did not want to get rid of gender altogether. This question typically comes not from intersex adults but from scholars and students in gender studies. As Herndon noted while she was director of programming, ISNA privileged what is known from adults with intersex, and most adults with intersex don't have any problem with having a gender as men or women, nor do most reject the gender assignments given to them as children.⁸⁰ Many enjoy publicly “doing their gender,” as Judith Butler would say.⁸¹ This is true even for those who see themselves privately as third-gendered or ungendered. As noted above, most intersex adults agree that the problem with the medical management of intersex is not gender assignment but surgical and hormonal reinforcement of the assignment and other risky—and indeed physically and emotionally *costly*—manifestations of shame and secrecy.

A few critics have suggested that a better system than ISNA's would be more like what Feinberg, Kate Bornstein, and some other transgender activists promote. But our readings of Feinberg and Bornstein do not seem to be inconsistent with the message of ISNA—that people should ultimately be allowed to

express their genders as they wish. Recounting a tense moment with a lesbian friend, Feinberg notes that many people believe that gender expression can only be oppressive. She writes of her friend, “She believes that once true equality is achieved in society humankind will be genderless. . . . If we can build a more just society, people like me will cease to exist. She assumes that I am simply a product of oppression.”⁸² Meanwhile, Bornstein notes that her own work is received in many different ways by members of the trans community, with some people agreeing with her and others being upset by her views. Trying to explain these disparate reactions, Bornstein writes, “Every transsexual I know went through a gender transformation for different reasons, and there are as many truthful experiences of gender as there are people who think they have a gender.”⁸³ Thus several of the most visible leaders of the trans movement express views similar to those expressed by many intersex activists—that people’s gender expressions need not be read only as oppressive and that the vast majority of people will have at least some positive investment in their gender expression.

The Future

Serious progress has been made in intersex rights in the last fifteen years, progress that we believe would have been much slower or even impossible without the philosophical and practical efforts of many academics who have devoted their energies to trying to end the oppression of intersex people. There remains much theoretical and practical work to be done in and around the intersex rights movement, and we fully expect that academic feminists will continue to be an essential part of this work. We believe there are key insights feminists interested in helping can develop from the history we have presented here. For one, feminists should seek to listen carefully to intersex people in the same way they have listened to other marginalized groups, rather than assume they know what is true or right for intersex people.⁸⁴ Additionally, they should seek to write about intersex people on their own terms rather than just appropriate intersex for talking about other issues like the social construction of gender. They may also help by doing more than theorizing—by helping with the day-to-day fund-raising and advocacy work that support the intersex rights movement. Finally, such feminist commentators should acknowledge that many intersex (and also transgender) people have suffered even more than biologically typical women from sexist and heterosexist oppression.

Notes

During the publication process of this essay, ISNA closed. Its Web site content remains available, and its assets have been transferred to a new nonprofit organization, Accord Alliance (www.accordalliance.org). We are grateful to Myra Hird, Emi Koyama, Bo Laurent, Esther Morris Leidolf, Kiira Triea, and especially Iain Morland for comments on earlier drafts of this essay.

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- Elizabeth Reis, *Bodies in Doubt: An American History of Intersex* (Baltimore: Johns Hopkins University Press, 2009).
7. For an example of an exception, see the story of Thomas/Thomasine Hall in Reis, "Impossible Hermaphrodites."
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 9. Dreger, *Hermaphrodites*; Matta, "Ambiguous Bodies"; Reis, "Impossible Hermaphrodites."
 10. Matta, "Ambiguous Bodies," 74.
 11. Reis, "Impossible Hermaphrodites," 412–13.
 12. Dreger, *Hermaphrodites*; Matta, "Ambiguous Bodies"; Reis, "Impossible Hermaphrodites."
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 14. Money, Hampson, and Hampson, "Imprinting and the Establishment of Gender Role."
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 16. Alice Domurat Dreger, "'Ambiguous Sex'—or Ambivalent Medicine? Ethical Problems in the Treatment of Intersexuality," *Hastings Center Report* 28, no. 3 (1998): 24–35.
 17. For examples of Hopkins's gender coaching, see John Colapinto, *As Nature Made Him: The Boy Who Was Raised as a Girl* (New York: HarperCollins: 2000); and Kiira Triea, "Power, Orgasm, and the Psychohormonal Research Unit," in Dreger, *Intersex in the Age of Ethics*, 141–44.
 18. For a recommendation of disclosure, see John Money, Joan G. Hampson, and John L. Hampson, "Hermaphroditism: Recommendations Concerning Assignment of Sex, Change of Sex, and Psychological Management," *Bulletin of the Johns Hopkins Hospital* 97 (1955): 284–300. On withholding, see Dreger, "Ambiguous Sex"; and Anita Natarajan, "Medical Ethics and Truth-Telling in the Case of Androgen Insensitivity Syndrome," *Canadian Medical Association Journal* 154 (1996): 568–70.
 19. Sherri Groveman, "The Hanukkah Bush: Ethical Implications in the Clinical Management of Intersex," in Dreger, *Intersex in the Age of Ethics*, 23–28.
 20. Jorge Daaboul, "Does the Study of History Affect Clinical Practice? Intersex as a Case Study: The Physician's View" (paper presented at the annual meeting of the American Association for the History of Medicine, Bethesda, May 2000).
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32. Kenneth Kipnis and Milton Diamond, “Pediatric Ethics and the Surgical Assignment of Sex,” *Journal of Clinical Ethics* 9 (1998): 398–410.
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35. See, for example, Dreger, “Cultural History and Social Activism”; Heino F. L. Meyer-Bahlburg et al., “Attitudes of Adult 46,XY Intersex Persons to Clinical Management Policies,” *Journal of Urology* 171 (2004): 1615–19; Lee et al., “Consensus Statement”; Justine M. Schober, “Feminization (Surgical Aspects),” in *Pediatric Surgery and Urology: Long-Term Outcomes*, ed. Mark D. Stringer, Keith D. Oldham, and Peter D. E. Moriquand, 2nd ed. (Cambridge: Cambridge University Press, 2006), 595–610; and Schober, “Surgeon’s Response.”
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39. Consortium, *Clinical Guidelines*, 2–3; emphases in original.
40. Dreger, “Ambiguous Sex”; Alice Domurat Dreger, *One of Us: Conjoined Twins and the Future of Normal* (Cambridge, MA: Harvard University Press, 2004).
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 62. Feinberg, *Transgender Warriors*, 99; emphasis in original.
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 66. Dreger, *Hermaphrodites*.
 67. See, for example, Kessler, “Medical Construction of Gender.”
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