The Intersex Movement and Medical Double Standards

U.S. doctors label children whose sexual anatomies differ significantly from the cultural ideal “intersexes” or “hermaphrodites” (a misleading term because these children are born with intermediate genitals, not two sets). Medical practice today holds that possession of a large clitoris, or a small penis, or a penis that has the urethra placed other than at its tip is a “psychosocial emergency.” The child would not be accepted by the mother, would be teased by peers, and would not be able to develop into an emotionally healthy adult. The medical solution to this psychosocial problem is surgery—before the child reaches three months of age or even before the newborn is discharged from hospital. Although parental emotional distress and rejection of the child and peer harassment are cited as the primary justifications for cosmetic genital surgery, there has never been an investigation of nonsurgical means—such as professional counseling or peer support—to address these issues.

The federal Law to Ban Female Genital Mutilation notwithstanding, girls born with large clitorises are today routinely “normalized” by excising parts of the clitoris and burying the remainder deep within the genital region. And boys with small penises? Current medical practice holds that intersex children “can be raised successfully as members of either sex if the process begins before 2½ years.” Because surgeons cannot create a large penis from a small one, the policy is to remove testes and raise these children as girls.

This is accomplished by “carving a large phallus down into a clitoris, creating a vagina using a piece of [the child’s] colon,” marveled a science writer who spoke only to physicians and parents, not to any of the intersex people subjected to this miracle technology. Efforts to create or extend a penile urethra in boys whose urethra exits other than at the tip of the penis—a condition called hypospadias—frequently lead to multiple surgeries, each compounding the harm. Heart-rending stories of physical and emotional carnage are related by victims of these surgeries in “Growing up in the Surgical Maelstrom” and, with black humor, in “Take Charge: A Guide to Home Catheterization.”

“Reconstructive” surgeries for intersex infant genitals first came into widespread practice in the 1950s. Because intersexuality was treated as shameful and physicians actively discouraged open discussion by their patients—indeed, recommended lying to parents and to adult intersex patients—until recently most victims of these interventions suffered alone in shame and silence.

By 1993 the accomplishments of a progression of social justice movements—civil rights, feminism, gay and lesbian, bisexual and transgender—helped make it possible for intersex people to speak out. Initially, physicians scoffed at their assertions that intersexuality was not shameful and that medically unneces-
sary genital surgeries were mutilating and should be halted. One surgeon from Johns Hopkins, the institution primarily responsible for developing the current medical model, dismissed intersex patient-advocates as “zealots.” Others cited the technological imperative. Doctors “don’t really have a choice” about whether or not to perform surgery insists George Szasz.12

By 1997 the intersex movement had gathered enough strength to visit Congress and ask that the Law to Ban Female Genital Mutilation be enforced to protect children not only against practices imported from other cultures but also against this uniquely American medicalized form of mutilation. Their work won coverage in the New York Times and on Dateline NBC, and by the following year the Urology Times was reporting a small but growing “new tidal wave of opinion” from physicians and sex researchers supporting the activists.13 Sad to report, the struggle of intersex activists against American medicalized genital mutilation has yet to attract significant support or even notice from feminists and journalists who express outrage over African genital cutting.

Hermaphrodites: Medical Authority and Cultural Invisibility

Many people familiar with the ideas that gender is a phenomenon not adequately described by male/female dimorphism and that the interpretation of physical sex differences is culturally constructed remain surprised to learn how variable sexual anatomy is.14 Although the male/female binary is constructed as natural and therefore presumably immutable, the phenomenon of intersexuality offers clear evidence that physical sex is not binary. Intersexuality therefore furnishes an opportunity to deploy “the natural” strategically as a means for disrupting heteronormative systems of sex/gender/sexuality. The concept of bodily sex, in popular usage, refers to multiple characteristics, including karyotype (organization of sex chromosomes); gonadal differentiation (e.g., ovarian or testicular); genital morphology; configuration of internal reproductive organs; and pubertal sex characteristics such as breasts and facial hair. These characteristics are assumed and expected to be concordant in each individual—either all-male or all-female.

Because medicine intervenes quickly in intersex births to change the infant’s body, the phenomenon of intersexuality has been, until recently, largely unknown outside specialized medical practices. General public awareness of intersex bodies slowly vanished in modern Western European societies as medicine gradually appropriated to itself the authority to interpret—and eventually manage—the much older category of “hermaphroditism.” Victorian medical taxonomy began to efface hermaphroditism as a legitimated status by settling on gonadal histology as the arbiter of “true sex.”15 The Victorian taxonomy (still in use by medical specialists) required both ovarian and testicular tissue types, microscopically confirmed, to be present in a “true hermaphrodite.” Conveniently, given the limitations of Victorian surgery and anesthesia, such confirmation was impossible in a living patient. All other anomalies were reclassified as “pseudo-hermaphroditisms” masking a “true sex” determined by the gonads.16

With advances in anesthesia, surgery, embryology, and endocrinology, however, twentieth-century medicine moved from merely labeling intersexed bodies to the far more invasive practice of “fixing” them—altering their physical appearance to conform with a diagnosed true sex. The techniques and protocols for physically transforming intersexed bodies were developed primarily at Johns Hopkins University in Baltimore during the 1920s and 1930s under the guidance of urologist Hugh Hampton Young. “Only during the last few years,” Young enthused in the preface to his pioneering textbook Genital Abnormalities, have we begun “to get somewhere near the explanation of the marvels of anatomic abnormality that may be portrayed by these amazing individuals. But the surgery of the hermaphrodite has remained a terra incognita.” The “sad state of these unfortunate” prompted Young to devise “a great variety of surgical procedures” by which he attempted to normalize their bodily appearances to the greatest extent possible.17

Quite a few of Young’s patients resisted his efforts. Emma T., a “snappy young negro woman with a good figure” and a large clitoris, had married a man but found her passion only with women. Emma refused surgery to “be made into a man” because removal of her vagina would mean the loss of her “meal ticket” (i.e., her husband).18 By the 1950s, the principle of rapid postnatal detection and intervention for intersex infants had been developed at Johns Hopkins, with the stated goal of completing surgery early enough so the child would have no memory of it.19 One wonders whether the insistence on early intervention was not at least partly motivated by the resistance offered by adult intersex people to “normalization” through surgery. Frightened parents of ambiguously sexed infants were much more open to suggestions of normalizing surgery than were intersex adults, and the infants themselves could, of course, offer no resistance whatsoever.

Most of the theoretical foundations justifying these interventions are attributable to psychologist John Money, a sex researcher invited to Johns Hopkins by Lawson Wilkins, founder of pediatric endocrinology.20 Wilkins’s numerous students subsequently carried these protocols from Hopkins to hospitals throughout the United States and abroad.21 In 1998 Suzanne Kessler noted that
Money's ideas enjoyed a "consensus of approval rarely encountered in science." But the revelation in 2000 that Money had grossly misrepresented and mishandled the famous "John/Joan" case (in which an infant was castrated and raised as a girl after his penis was destroyed in a circumcision accident) sent Money's stock into a steep decline. In keeping with the Hopkins model, the birth of an intersex infant is today deemed a "psychosocial emergency" that propels a multi-disciplinary team of intersex specialists into action. Significantly, they are surgeons and endocrinologists rather than psychologists, bioethicists, intersex peer support organizations, or parents of intersex children. The team examines the infant and chooses either male or female as a "sex of assignment," then informs the parents that this is the child's true sex. Medical technology, including surgery and hormones, is then used to make the child's body conform as closely as possible to the assigned sex. Current protocols for choosing a sex are based on phallus size: to qualify for male assignment the child must possess a penis at least one inch long; clitorises may not exceed three-eighths inch. Infants with genital appendages in the forbidden zone of three-eighths to one inch are assigned female and the phallus trimmed to an acceptable size. The only exception to this sorting rule is that even a hypothetical possibility of female fertility must be preserved by assigning the infant as female, disregarding masculine genitals and a phallus longer than one inch.

The sort of deviation from sex norms exhibited by intersex people is so highly stigmatized that emotional harm due to likely parental rejection and community stigmatization of the intersex child provides physicians with their most compelling argument to justify medically unnecessary surgical interventions. Intersex status is considered to be so incompatible with emotional health that misrepresentation, concealment of facts, and outright lying (both to parents and later to the intersex person) are unabashedly advocated in professional medical literature.

The Impact of "Reconstructive" Surgeries

The insistence on two clearly distinguished sexes has calamitous personal consequences for the many individuals who arrive in the world with sexual anatomy that fails to be easily distinguished as male or female, who are labeled "intersexuals" or "hermaphrodites" by modern medical discourse. About one in one hundred births exhibits some anomaly in sex differentiation, and about one in two thousand is different enough to render problem-
Children assigned female are subjected to surgery that removes the troubling hypertrophic (i.e., large) clitoris. This is the same tissue that would have been a troubling micropenis (i.e., small penis) had the child been assigned male. Through the 1960s, feminizing pediatric genital surgery was openly labeled "clitoridectomy" and was compared favorably to the African practices that have now become the focus of such intense scrutiny. As three Harvard surgeons noted, "Evidence that the clitoris is not essential for normal coitus may be gained from certain sociological data. For instance, it is the custom of a number of African tribes to excise the clitoris and other parts of the external genitals. Yet normal sexual function is observed in these females." Authors Robert E. Gross, Judson Randolph, and John F. Crigler apparently understand normal female sexual function only as passive penetration and fertility. A modified operation that removes most of the clitoris and relocates a bit of its tip is variously (and euphemistically) called clitoroplasty, clitoral reduction, or clitoral recession and described as a simple cosmetic procedure in order to differentiate it from the now-infamous clitoridectomy. The operation, however, is far from benign.

Johns Hopkins surgeons Joseph E. Oesterling, John P. Gearhart, and Robert D. Jeffs have described their technique. They make an incision around the clitoris, at the corona, then dissect the skin away from its underside. Next they dissect the skin away from the upper side and remove as much of the clitoral shaft as necessary to create an "appropriate size clitoris." Then they place stitches from the pubic area along both sides of the entire length of what remains of the clitoris; when they tighten these stitches, the tissue folds, like pleats in a skirt, and recedes into a concealed position behind the pubic mound. If they think the result still "too large," they further reduce the tip of the clitoris by cutting away a pie-shaped wedge.

For many intersex people, this sort of arcane, dehumanized medical literature, illustrated with close-ups of genital surgery and naked children with blacked-out eyes, is the only available version of Our Bodies, Ourselves. Thus, even as fierce arguments over gender identity, gender role development, and social construction of gender rage in psychology, feminism, and queer theory, we have literally delegitimized the authority to police the boundaries of male and female, leaving intersex people to recover as best they can, alone and silent, from violent normalization.

My own case, as it turns out, was not unusual. I was born with ambiguous genitals. A doctor specializing in intersexuality deliberated for three days—and sedated my mother each time she asked what was wrong with her baby—before concluding that I was male, with micropenis, complete hypospadias, undescended testes, and a strange extra opening behind the urethra. A male birth certificate was completed for me, and my parents began raising me as a boy. When I was a year and a half old, my parents consulted a different set of intersex experts, who admitted me to a hospital for "sex determination." "Determine" is a remarkably apt word in this context, meaning both to ascertain by investigation and to cause to come to a resolution. It perfectly describes the two-level process whereby science produces through a series of masked operations what it claims merely to observe. Doctors told my parents that a thorough medical investigation, including exploratory surgery, would be necessary to determine (that is, ascertain) what my "true sex" was. They judged my genital appendage to be inadequate as a penis: too short to effectively mark masculine status or to penetrate females. As a female, however, I would be penetrable and potentially fertile. My anatomy having now been re-labeled as vagina, urethra, labia, and outsized clitoris, my sex was next determined (in the second sense) by amputating my genital appendage—clitoridectomy. Following doctors' orders, my parents then changed my name; combed their house to eliminate all traces of my existence as a boy (photographs, birthday cards, etc.); engaged a lawyer to change my birth certificate; moved to a different town; instructed extended family members to no longer refer to me as a boy; and never told anyone else—including me—just what had happened. My intersexuality and change of sex were the family's dirty little secrets.

At age eight, I was returned to the hospital for abdominal surgery that trimmed away the testicular portion of my gonads, each of which was partly ovarian and partly testicular in character. No explanation was given to me then for the long hospital stay or the abdominal surgery, nor for the regular hospital visits afterward in which doctors photographed my genitals and inserted fingers and instruments into my vagina and anus. These visits ceased as soon as I began to menstruate. At the time of the sex change, doctors had assured my parents that their once-son/now-daughter would grow into a woman who could have a normal sex life and babies. With the confirmation of menstruation, my parents apparently concluded that that prediction had borne out and their ordeal was behind them. For me, the worst part of the nightmare was just beginning.

As an adolescent, I became aware that I had no clitoris or inner labia and was unable to experience orgasm. By the end of my teens, I began to research in medical libraries, trying to discover what might have happened to me. When I finally determined to obtain my personal medical records, it took three years to overcome the obstruction of the doctors whom I asked for help.
When I did obtain a scant three pages from my medical files, I learned for the first time that I was a "true hermaphrodite" who had been my parents' son for a year and a half, with a name that was unfamiliar to me. The records also documented my clitoridectomy. This was the middle 1970s, when I was in my early twenties. I had come to identify myself as lesbian at a time when lesbianism and a biologically based gender essentialism were virtually synonymous. Men were rapists who caused war and environmental destruction; women were loving beings who would heal the earth; lesbians were a superior form of being uncontaminated by "men's energy." In such a world, how could I tell anyone that I had actually possessed the dreaded "phallos"? I was an impostor, not really a woman but rather a monstrous and mythical creature. And because my hermaphroditism and long-buried boyhood were the history that underlay the clitoridectomy, I could never speak openly about that either, or about my consequent inability to orgasm. I was so traumatized by discovering the circumstances that produced my embodiment that I could not speak of these matters with anyone.

Nearly fifteen years later, in my middle thirties, I suffered an emotional meltdown. In the eyes of the world I was a highly successful businesswoman, a principal in an international high-tech company. To myself, I was a freak, incapable of loving or being loved, filled with shame about my status as a hermaphrodite, about the imagined appearance of my genitals before surgery (I thought "true hermaphrodite" meant that I had been born with a penis), and about my sexual dysfunction. Unable to make peace with these facts about myself, I finally sought help from a professional therapist, only to find my experience denied. She reacted to each revelation about my history and predicament with some version of "no it's not" or "so what?" I'd say, "I'm not really a woman." She would say, "Of course you are. You look female." I'd say, "My complete withdrawal from sexuality has destroyed every relationship I've ever entered." She would say, "Everybody has their ups and downs." I tried another therapist and met with a similar response. Increasingly desperate, I confided my story to several friends who shrank away in embarrassed silence. I was in emotional agony and found myself utterly alone, with no possible way out. I decided to kill myself.

Confronting suicide as a real possibility proved to be my personal epiphany. In contemplating my own death, I fantasized killing myself quite messily and dramatically in the office of the surgeon who had sliced out my clitoris, forcibly confronting him with the horror he had imposed on my life. But in acknowledging that desire to put my pain to some use, not to waste my life completely, I turned a crucial corner, finding a way to direct my rage productively out into the world rather than aim it destructively at myself. My breakdown became my breakthrough, and I vowed that, whatever it took, I would heal myself. Still, I had no conceptual framework for developing a more positive self-consciousness. I knew only that I felt mutilated, not fully woman, less than fully human even, but I was determined to heal. I struggled for weeks in emotional chaos, unable to eat or sleep or work. I could not accept my image of a hermaphroditic body any more than I could accept the butchered one left me by the surgeons. Thoughts of myself as a Frankenstein patchwork alternated with longings for escape by death, only to be followed by outrage, anger, and determination to survive. I could not accept that it was just or right or good to treat any person as I had been treated—my sex changed, my genitals cut up, my experience silenced and rendered invisible. I bore a private hell within me, wretchedly alone in my condition without even my tormentors for company. Finally, I began to envision myself standing in a driving rain storm but with clear skies and a rainbow visible in the distance. I was still in agony, still alone, but I was beginning to see the painful process in which I was caught up in terms of revitalization and rebirth, a means of investing my life with a new sense of authenticity possessing vast potentials for further transformation. Since then I have seen this experience described by other intersex and transsexual activists.44

I slowly developed a newly politicized and critically aware form of self-understanding. I had been the kind of lesbian who at times had a girlfriend but who had never really participated in the life of a lesbian community. I felt almost completely isolated from gay politics, feminism, and queer and gender theory. I did possess the rudimentary knowledge that the gay civil rights movement had gathered momentum only when it could effectively deny that homosexuality was sick or inferior and assert to the contrary that "gay is good." As impossible as it then seemed, I pledged similarly to affirm that "intersex is good" and that the body I was born with was not sick or shameful, only different. I vowed to embrace the sense of being "not a woman" that I had initially been so terrified to discover.

I began a search for community that brought me to San Francisco in the fall of 1992 on the theory that people living in the "queer Mecca" would have the most conceptually sophisticated, socially tolerant, and politically astute analysis of sexed and gendered embodiment. I found what I was looking for, in part because my arrival in the Bay Area corresponded with the rather sudden emergence of an energetic transgender political movement. At the same time, a vigorous new wave of gender scholarship had emerged in the academy. In this context, Morgan Holmes could analyze her own clitoridectomy for her master's thesis and have her study taken seriously as academic work.45 Openly transsexual scholars, including Susan
The Intersex Movement and Medical Double Standards

Stryker and Sandy Stone, were visible in responsible academic positions at major universities. 36

Into this healy atmosphere, I brought my own experience. I started telling my story to everyone I met. Before long I learned of six other intersex people—including two who had been fortunate enough to escape medical attention. Realizing that intersexuality, rather than being extremely rare, must be relatively common, I decided to create a support network. Soon I was receiving several letters per week from intersex people throughout the United States and Canada and a few from further afield. Although details varied, the letters gave a remarkably coherent picture of the emotional consequences of medical intervention:

All the things my body might have grown to do, all the possibilities, went down the hall with my amputated clitoris to the pathology department. The rest of me went to the recovery room—I’m still recovering.

—Morgan Holmes

I am horrified by what has been done to me and by the conspiracy of silence and lies. I am filled with grief and rage, but also relief finally to believe that maybe I am not the only one.

—Angela Moreno

As soon as I saw the title Hermaphrodites with Attitude I cried aloud for sheer joy. . . . Finally I can say, ‘I’m hermaphrodite, I’m intersex, I’m transgender, I’m queer and damn proud,’ as tears of joy and belonging stream down my face.

—Lee

Doctors never consulted me. . . . [T]he idea of asking for my opinion about having my penis surgically altered apparently never occurred to them. . . . Far too many people allow social stigma to cloud their judgment. It’s OK to be different.

—Randy

I pray that I will have the means to repay, in some measure, the American Urological Association for all that it has done for my benefit. I am having some trouble, though, in connecting the timing mechanism to the fuse.

—Thomas

Toward Social Justice

The peer support network that I formed grew into the Intersex Society of North America (ISNA). ISNA’s long-term and fundamental goal is to change the way intersex infants are treated. We advocate that surgery not be performed on children born with ambiguous genitals unless there is a medical reason (to prevent physical pain or illness) and that parents be given the conceptual tools and emotional support to accept their children’s physical differences. We also advocate that children be raised either as boys or girls, according to which designation seems likely to offer the child the greatest future sense of comfort. Advocating gender assignment without resorting to normalizing surgery is a radical position given that it requires the willful disruption of the assumed concordance between body shape and gender category. However, this is the only position that prevents irreversible physical damage to the intersex person’s body, that preserves the intersex person’s agency regarding their own flesh, and that recognizes genital sensation and erotic functioning to be at least as important as reproductive capacity. If an intersex child or adult decides to change gender or to undergo surgical or hormonal alteration of his/her body, that decision should also be fully respected and facilitated. The key point is that intersex subjects should not be violated for the comfort and convenience of others.

One part of reaching ISNA’s long-term goal has been to document the emotional and physical carnage resulting from medical interventions. As a rapidly growing literature (see the bibliography on our Web-site, <http://www.isna.org>) makes abundantly clear, the medical management of intersexuality has changed shockingly little in the more than forty years since my first surgery—doctors still cut up children’s genitals and still perpetuate invisibility and silence around intersex lives. Kessler expresses surprise that “in spite of the thousands of genital operations performed every year, there are no meta-analyses from within the medical community on levels of success.” 37 Surgeons admit to not knowing whether their former patients are “silent and happy or silent and unhappy.” 38 There is no research effort to improve erotic functioning for adult intersex people whose genitals have been cut, nor are there psychotherapists who specialize in working with adult intersex clients trying to heal from the trauma of medical intervention. To provide a counterpoint to the mountains of professional medical literature that neglect intersex experience and to begin compiling an ethnographic account of that experience, ISNA has worked to make public the lives of intersex people through our own publications (including our video, Hermaphrodites Speak!) and by working with scholars and the popular media. 39

ISNA’s presence has begun to be effective. It has helped politicize the growing number of intersex organizations as well as intersex identities themselves. When I first began organizing ISNA, I met leaders of the Turner’s Syndrome Society, the oldest known support group focusing on atypical sexual differentiation founded in 1987. (Turner’s Syndrome is defined by an XO genetic karyotype that results in a female body morphology with nonfunctioning
ovaries, extremely short stature, and, variably, a variety of other visible physical differences still described in the medical literature with such stigmatizing labels as “web-necked” and “fish-mouthed.” Each of these women told me what a profound, life-changing experience it had been simply to meet another person like herself. I was inspired by their accomplishments (they are a national organization serving thousands of members) but wanted ISNA to have a different focus—less willing to think of intersexuality as a pathology or disability, more interested in challenging the medicalization of sexual difference entirely, and more interested in politicizing a pan-intersex revolt across the divisions of particular etiologies in order to destabilize the heteronormative assumptions that underlie the violence directed at our bodies.

Public Discourse on Pediatric Genital Surgeries

Because the politicized intersex community is still quite young, and most intersex people remain too burdened by the crippling emotional consequences of what has been done to them to come out publicly, ISNA has deliberately cultivated a network of non-intersexed advocates who command a measure of social legitimacy and can speak in contexts where uninterpreted intersex voices will not be heard. Because there is a strong impulse to discount what intersex people have to say about themselves (as if we are too close to the issues to offer objective opinions), this sort of sympathetic representation has been welcome—especially in helping intersex people reframe intersexuality in nonmedical terms. Some gender theory scholars, feminist critics of science, medical historians, and anthropologists have been quick to understand and support intersex activism. Feminist biologist and science studies scholar Anne Fausto-Sterling—who wrote, years before ISNA came into existence, about intersexuality in relation to intellectually suspect scientific practices that perpetuate masculinist constructs of gender—became an early ISNA ally. Likewise, social psychologist Suzanne Kessler wrote a brilliant ethnography of surgeons who specialize in treating intersex. After speaking with a number of the normalized “products” of these medical programs, she, too, became a strong supporter of intersex activism. Historian of science Alice Dreger, whose work focuses not on hermaphroditism but also on other forms of atypical embodiment that become subject to destructively normalizing medical interventions (as in her discussion of conjoined twins in “Limits of Individuality”), has been especially supportive. Fausto-Sterling, Kessler, and Dreger have each written books that analyze the medical treatment of intersexuality as being culturally motivated and criticize it as often harmful to its ostensible patients.

Allies who help contest the medicalization of intersexuality have been especially important, because ISNA initially found direct, nonconfrontational interactions with medical specialists who determine policy on the treatment of intersex infants and actually carry out the surgeries to be both difficult and ineffective. Joycelyn Elders, the Clinton administration’s first surgeon general, is a pediatric endocrinologist with many years of experience in managing intersex infants. In spite of a generally feminist approach to health care and frequent overtures from ISNA, she rejected the concerns of intersex people themselves.53

Surgeon Richard Schlussel, at a pediatric plastic surgery symposium (which had rejected ISNA’s offer to provide a patients’ panel) at Mount Sinai Medical Center in New York City in 1996 proclaimed, “The parents of children with ambiguous genitals are more grateful to the surgeon than any—more grateful even than parents whose children’s lives have been saved through open heart surgery.”54

Another pediatrician remarked in an Internet discussion on intersexuality, “I think this whole issue is preposterous. . . . To suggest that [medical decisions about the treatment of intersex] are somehow cruel or arbitrary is insulting, ignorant and misguided. . . . To spread the claims that [ISNA] is making is just plain wrong, and I hope that this [on-line group of doctors] will not blindly accept them.” Yet another physician participating in that same chat, in a marvelous example of the degree to which practitioners of science can be blind to their complicity in constructing the objects they study, asked what was for him obviously a rhetorical question: “Who is the enemy? I really don’t think it’s the medical establishment. Since when did we establish the male/female hegemony?” Johns Hopkins surgeon Gearhart, quoted in a New York Times article on ISNA, summarily dismissed us as “zealots,” but professional meetings in the fields of pediatrics, urology, genital plastic surgery, and endocrinology are abuzz with anxious and defensive discussions of intersex activism.55 In response to a 1996 protest by Hermaphrodites with Attitude at the American Academy of Pediatrics annual meeting, that organization felt compelled to hold a press conference and issue a statement: “The Academy is deeply concerned about the emotional, cognitive, and body image development of intersexals, and believes that successful early genital surgery minimizes these issues.” The academy refused, however, to speak with intersex people picketing its meeting.

The roots of resistance in the medical establishment to the truth—claims of intersex people run deep. Not only does ISNA’s existence imply a critique of the normativistic biases couched within most scientific practice but it also advocates a treatment protocol for intersex infants that disrupts convention-
al understandings of the relationship between bodies and genders. On a level more personally threatening to medical practitioners, ISNA’s position implies that they have—unwittingly at best and through willful denial at worst—spent their careers inflicting a profound harm from which their patients will never fully recover. ISNA’s position threatens to destroy the foundational assumptions motivating an entire medical subspecialty, thus jeopardizing their continued ability to perform what surgeons find to be technically fascinating work. Science writer Melissa Hendricks notes that Gearhart is known to colleagues as an “artist” who can “carve a large phallus down into a clitoris” with consummate skill. Given these deep and mutually reinforcing reasons for opposing ISNA’s position, it is hardly surprising that medical intersex specialists have, for the most part, turned at deaf ear toward us.

Thus, the most important aspect of our current activities is the struggle to change public perceptions. By using the mass media, the Internet, and our growing network of allies and sympathizers to make the general public aware of the frequency of intersexuality and of the intense suffering that medical treatment has caused, we seek to create an environment in which many parents will have already heard about the intersex movement when their intersex child is born. Such informed parents have proved better able to resist medical pressure for unnecessary genital surgery and secrecy and to find their way to a peer-support group and counseling rather than to a surgical theater.

The Double Standard: First-World Feminism, African Clitoridectomy and Intersex Genital Mutilation, and the Media

African practices that remove the clitoris and other parts of female genitals have lately been a target of intense media coverage and feminist activism in the United States and other industrialized Western societies, and the euphemism female circumcision has been largely supplanted by the politicoized term female genital mutilation (FGM). Analogous medical (rather than folk) operations performed on intersex people in the United States have not been the focus of similar attention—indeed, attempts to link the two forms of genital cutting have met with multiform resistance. Examining the way that first-world feminists and mainstream media treat African practices and comparing that treatment with their response to intersex genital mutilation (IGM) in North America exposes some of the complex interactions between ideologies of race, gender, colonialism, and science that effectively silence and render invisible intersex experience in first-world contexts. Cutting intersex genitals becomes yet another hidden mechanism for imposing normalcy upon unruly flesh, a means of containing the potential anarchy of desires and identifications within oppressive heteronormative structures.

In 1994 the New England Journal of Medicine paired an article on the physical harm resulting from African genital cutting with an editorial denouncing clitoridectomy as a violation of human rights but declined to run a reply drafted by University of California at Berkeley medical anthropologist Lawrence Cohen and two ISNA members detailing the harm caused by medicalized American clitoridectomies. In response to growing media attention, Congress passed the Federal Prohibition of Female Genital Mutilation Act in October 1996. That act specifically exempted from prohibition medicalized clitoridectomies of the sort performed to “correct” intersex bodies. The bill’s principal author, feminist Congresswoman Pat Schroeder, ignored multiple letters from ISNA members and Brown University professor of medical science Anne Fausto-Sterling asking her to recast the bill’s language.

“The New Law Bans Genital Cutting,” the New York Times proclaimed and refused to address documentation from ISNA and Michigan State University professor Alice Dreger pointing out that genital cutting continues to be standard medical practice in the United States. The Boston Globe’s syndicated columnist Ellen Goodman has been one of the few journalists covering African genital cutting to make any response to ISNA overtures. “I must admit I was not aware of this situation,” she wrote to me in 1994. “I admire your courage.” She continued, however, to discuss African genital cutting in her column without mentioning similar American practices. Ironically, Goodman is based in Boston, a Mecca of sorts after Johns Hopkins for the surgical management of intersex children, with prominent specialists operating at Harvard, Massachusetts General Hospital, and Boston Children’s Hospital. An October 1995 Goodman column on genital cutting was promisingly entitled “We Don’t Want to Believe It Happens Here” but discussed only practices imported to the United States by immigrants from third-world countries.

While anti-african immigrant women within the United States have been receptive to the claims made by intersex opponents to medicalized clitoridectomies, first-world feminists and organizations working on African genital cutting have totally ignored us. Only two of the many anti-genital-cutting activist groups contacted have bothered to respond to repeated overtures from intersex activists. Fran Hosken, who since 1982 has regularly published a catalog of statistics on female genital cutting worldwide, wrote me a terse note saying that “we are not concerned with biological exceptions.”
photojournalists in search of sensational clitoridectomy photos do not represent a veritable tourism boom for a country the size of West Virginia.

These representations manifest a profound act of “othering” African clitoridectomy that contributes to the silence surrounding similar medicalized practices in the “modern,” industrialized West. “Their” genital cutting is barbaric ritual; “ours” is scientific. Theirs disfigures; ours normalizes the deviant. The colonialisum implications of these representations of genital cutting are even more glaringly obvious when contemporaneous images of intersex surgeries are juxtaposed with images of African practices. Medical books describing how to perform clitoral surgery on intersex children are almost always illustrated with extreme genital close-ups, disconnecting the genitals not only from the individual intersexed person but also from the body itself. Full body shots always have the subject’s eyes blacked out. Why is it considered necessary—or at least polite—to black out the eyes of American girls but not the eyes of the African girls used to illustrate Steinem’s “International Crime” or Life’s more recent “Ritual Agony”? I suspect one reason is that a Western reader is likely to identify with an American but not an African girl. Blacking out the American girl’s eyes allows the reader to remain safely on this side of the camera.

First-world feminist discourse locates clitoridectomy not only elsewhere in Africa but also “elsewhen.” An Atlantic Monthly article on African clitoridectomy, for example, asserted that the “American medical profession stopped performing clitoridectomies decades ago,” and the magazine declined to publish a letter from ISNA contradicting that claim. Academic publications are as prone to this attitude as the popular press. Feminist Martha Nussbaum, in a discussion of judging other cultures, acknowledges, “If two abuses are morally the same and we have better local information about one and are better placed politically to do something about it, that one seems to be a sensible choice to focus on in our actions here and now.” But then she counter-factually locates U.S. genital surgeries solely in the past: “As recently as the 1940s, [genital surgeries] were performed by U.S. and British doctors to treat female ‘problems’ such as masturbation and lesbianism.” By collaborating in the silence about intersex genital surgeries, Nussbaum excuses first-world feminists from any obligation to challenge their own cultural practices as rigorously as they do that of others.

In the influential Deviant Bodies anthology, visual artist Susan Jahoda’s “Theatres of Madness” juxtaposes nineteenth- and twentieth-century material depicting “the conceptual interdependence of sexuality, reproduction, family life, and ‘female disorders.’” To represent twentieth-century medical
clitoridectomy practices, Jahoda quotes a 1980 letter to the editor of Ms. magazine prompted by the Steinem and Morgan article. The writer, a nurse’s aid in a geriatric home, says she had been puzzled by the strange scars she saw on the genitals of five of the forty women in her care: “Then I read your article... My God! Why? Who decided to deny them orgasm? Who made them go through such a procedure? I want to know. Was it fashionable? Or was it to correct ‘a condition’? I’d like to know what this so-called civilized country used as its criteria for such a procedure. And how widespread is it here in the United States?”

While Jahoda’s selection of this letter does raise the issue of medicalized American clitoridectomies, it again safely locates the cutting in the past, as something experienced a long time ago by women now in their later stages of life. Significantly, Jahoda literally passes over an excellent opportunity to comment on the continuing practice of clitoridectomy in the contemporary United States. Two months earlier, in the April 1980 issue of Ms., noted feminist biologist Patricia Farnes (a medical doctor) and Ruth Hubbard also replied to Morgan and Steinem:

We want to draw the attention of your readers to the practice of clitoridectomy not only in the Third World... but right here in the United States, where it is used as part of a procedure to “repair” by “plastic surgery” so-called genital ambiguities. Few people realize that this procedure has routinely involved removal of the entire clitoris and its nerve supply—in other words, total clitoridectomy... In a lengthy article, [Johns Hopkins intersex expert John] Money and two colleagues write, “There has been no evidence of a deleterious effect of clitoridectomy. None of the women experienced in genital practices reported a loss of orgasm after clitoridectomy.” The article also advises that “a three-year-old girl about to be clitoridectomized... should be well informed that the doctors will make her look like all other girls and women” (our emphasis), which is not unlike what North African girls are often told about their clitoridectomies... But to date, neither Money nor his critics have investigated the effect of clitoridectomies on the girls’ development. Yet one would surely expect this to affect their psychosexual development and their feelings of identity as young women.

Although Farnes and Hubbard’s prescient feminist expose of medicalized clitoridectomies in the contemporary United States sank without a trace, there has been a veritable explosion of work like Nussbaum’s and Jahoda’s that keeps “domestic” clitoridectomy at a safe distance. Such conceptualizations of clitoridectomy’s cultural remoteness—both geographically and temporally—allow feminist outrage to be diverted into potentially colonialist meddling in the social affairs of others while hampering work for social justice at home.

Conclusion

Feminism represents itself as being interested in unmasking the silence that surrounds violence against women and in providing tools to understand the personal as political. Most medical intersex management is a form of violence based on a sexist devaluing of female pain and female sexuality: Doctors consider the prospect of growing up male with a small penis to be a worse alternative than living as a female without a clitoris, ovaries, or sexual gratification. Medical intervention literally transforms transgressive bodies into ones that can safely be labeled female and subjected to the many forms of social control with which women must contend. Why then have most feminists failed to engage the issue of medical abuse of intersex people?

I suggest that intersex people have had such difficulty generating mainstream feminist support not only because of the racist and colonialist frameworks that situate clitoridectomy as a practice foreign to proper subjects within the first world but also because intersexuality undermines the stability of the category “woman” that undergirds much first-world feminist discourse. We call into question the assumed relation between genders and bodies and demonstrate how some bodies do not fit easily into male/female dichotomies. We embody viscerally the truth of Judith Butler’s dictum that “sex,” the concept that accomplishes the materialization and naturalization of culturally constructed gender differences, has really been “gender all along.” By refusing to remain silenced, we queer the foundations upon which depend not only the medical management of bodies but also widely shared feminist assumptions of properly embodied female subjectivity.

In 1990 Suzanne Kessler noted, “[T]he possibilities for real societal transformations would be unlimited [i]f physicians and scientists specializing in the management of gender could recognize that] finally, and always, people construct gender as well as the social systems that are grounded in gender-based concepts... Accepting genital ambiguity as a natural option would require that physicians also acknowledge that genital ambiguity is ‘corrected’ not because it is threatening to the infant’s life but because it is threatening to the infant’s culture.”

To the extent that we are not normatively female or normatively women, we are not the proper subjects of feminist concern. Western feminism has represented African genital cutting as primitive, irrational, harmful, and
deserving of condemnation. The Western medical community has repre¬
semed its genital cutting as modern, scientific, healing, and above reproach. When will Western feminists realize that their failure to examine either of these claims “others” African women and allows the violent medical oppression of intersex people to continue unimpeded?

Notes


13. “Histology” refers to the structure of the tissue of the sex glands when a sample is surgically removed, stained, and observed under a microscope.


with Ambiguous Genitalia," *Seminars in Perinatology* 16, no. 6 (1992): 365–68; Meyers-Seifer, "Diagnosis and Management."


29. Hendricks, "Is It a Boy or a Girl?" Quotation on 15.

30. Steckler, "Hypospadias Cripples."

31. Devore, "Surgical Maelstrom."


33. Oesterling, "Unified Approach."


40. Similarly, some Western feminist opponents of African genital cutting have taken it upon themselves to speak for those affected, under the assumption that they are either too ignorant or too vested in the practices to make any valid contributions (Claire C. Robertson, "Getting beyond the Ew Factor: Rethinking U.S. Approaches to African Female Genital Cutting," chapter 2 in this volume).


42. Kessler, "Medical Construction of Gender."


46. Mt. Sinai School of Medicine, Conference on Pediatric Plastic and Reconstructive Surgery, New York City, May 16, 1996.

47. Angier, "Intersexual Healing."

48. Hendricks, "Is It a Boy or a Girl?" More than one ISNA member has discovered that the surgeons who operated on them did so at no charge. A 1994 wire service news article (Tom Majeski, "Surgery Changes Russian Child’s Sex," *San Jose Mercury News*, July 25, 1994, A11) relates how a Moscow family, driven to thoughts of murder-suicide by their one-year-old son Misha’s anatomy, searched high and low until they connected with an American pediatric urologist. The urologist operated for free, the hospital donated its services,
and an airline footed the expenses for a round trip to St. Paul for the entire family. Doctors removed Misha's penis, testis, and ovary and instructed the family to rename him and to move. The family plans never to reveal any part of the story to relatives or to their now-daughter Masha. The medical establishment's fascination with its power to change sex and its drive to rescue parents from intersex children are so strong that intervention can be delivered across national borders and without regard to the commercial model that ordinarily governs U.S. medical services.

49. The first exception was urologist Justine Schober, who, after watching a videotape made at the 1995 ISNA retreat and receiving other input from various intersex groups, suggested in a new textbook on pediatric surgery that technology has advanced to the point that "our needs [as surgeons] and the needs of parents to have a presentable child can be satisfied," it is time to acknowledge that there are problems that "we as surgeons, despite the most technically perfect surgeries, cannot address." She then called for a thorough reevaluation of the protocols surrounding medical intervention of intersexuality: "Surgery makes parents and doctors comfortable, but counseling makes people comfortable too, and is not irreversible." Justine M. Schober, "Feminizing Genitoplasty for Intersex," in Pediatric Surgery and Urology: Long Term Outcomes, ed. M. D. Stringer et al. (London: W. B. Saunders, 1998), 549–58. By early 2001, there was finally growing acknowledgment within the medical community that all is not well. Surgeon Ian Aaronson, in forming a "North American Task Force on Intersex" in 2000, acknowledged that "long-term outcome data on intersex genital surgeries is very sparse and selective, and this puts surgeons on tenuous ethical grounds." The July 2000 issue of the American Academy of Pediatrics' journal Pediatrics carried an article that called for a moratorium on pediatric genital surgeries: Chanika Phornphutkul, Anne Fausto-Sterling, and Philip A. Gruppuso, "Gender Self-Reassignment in an XY Adolescent Female Born with Ambiguous Genitalia," Pediatrics 106, no. 1 (2000): 135–37. Unfortunately, it also carried an announcement of a newly adopted policy of the academy calling for continued pediatric genital surgeries as standard practice (American Academy of Pediatrics Section on Endocrinology and Section on Urology Committee on Genetics, "Evaluation of the Newborn").


51. Isabelle R. Gunning, "Female Genital Surgeries: Eradication Measures at the Western Local Level—A Cautionary Tale" (chapter 4 in this volume).

52. Dugger, "New Law Bans Genital Cutting."


