



Sexing the Intersexed: An Analysis of Sociocultural Responses to Intersexuality

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Sexing the Intersexed: An Analysis of Sociocultural Responses to Intersexuality

Explore here the social construction of gender in North America through an analysis of contemporary and historical responses to infants who are born genitally ambiguous, or intersexed (hermaphroditic).¹ Bodies that are sexually ambiguous challenge prevailing binary understandings of sex and gender. Individuals who are intersexed have bodies that are quite literally queer or “culturally unintelligible” (Butler 1993, 2). That is, their bodies do not conform to an overarching and largely unexamined social expectation that all humans belong to one of two clearly delineated sex categories, female or male (Wilson 1998).

While being born with ambiguous sexual organs indeed problematizes binary understandings of sex and gender, the majority of intersexed children do not require medical intervention for their physiological health (Diamond and Sigmundson 1997b; Dreger 1998b; Kessler 1998).²

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¹ I view the terms *intersex* and *hermaphrodite* synonymously, despite their divergent historical context. When speaking in contemporary terms, I use the more contemporary term *intersex*. However, when using historical references, I use the more popular pre-twentieth-century term *hermaphrodite*. Interestingly, the term *intersex* emerged in the late nineteenth century and was used not only when referring to hermaphrodites but to homosexuals as well (Epstein 1990). For example, a woman who sexually desired other women was often labeled *intersexed*. Preceding the emergence of the term *intersex*, the label *hermaphrodite* was also used in relation to homosexuals in the seventeenth and eighteenth centuries (Pagliassotti 1993; Hekma 1994; Trumbach 1994).

² While the majority of intersex conditions are found to be physiologically benign, some conditions do require surgical or hormonal intervention for reasons of physiological health. Most notably, this occurs in cases where elimination of urine and feces is rendered difficult

Nevertheless, the majority of these infants are medically assigned a definitive sex, undergoing surgery and hormone treatments to “correct” their variation from the anatomies expected by the designations of female and male. The impetus to control intersexual “deviance” stems from cultural tendencies toward gender binarism, homophobia, and fear of difference (Butler 1990, 1993).

According to Erving Goffman (1963), the great rewards associated with “normalcy” will motivate individuals to attempt to pass as normal, whether they are or not. The case of intersexuality provides a poignant example of normative expectations remaining unfulfilled. When presented with someone or something that disrupts our basic understanding of the human body, such as intersexuality, we are presented with a case of what Goffman would label as *stigma*. Prevailing sex assignment theory suggests the psychological necessity of correcting intersexual “deviance” to preclude such stigma (Money 1968, 1991a, 1995; Money and Ehrhardt 1972).

Current medical interventions on intersexed bodies rest on the fundamental assumption that without the medical alteration of genitals to aid in unambiguous sex/gender assignment, intersexuals will live a life of alienation and despair. There is limited empirical evidence to demonstrate this and some recent research and activism that contradict this mode of thinking.³ As is the case with most medical conditions, there are no mandatory or legislative standards of care for intersex conditions, only the work of individual scholars and researchers to guide physicians on medical protocol.

In some medical models, intersexuals and their bodies are treated as passive objects in need of medical action to correct “pathologies.” This approach devalues intersexuals’ own experiences with the very phenomenon or condition under consideration. Rather than listen to intersexuals’ own critical perspectives, clinicians focus on the development of new technologies and techniques for performing genital surgeries and administering exogenous hormones. The medical approach is founded on the belief that intersex is pathological. Similar to the medicalization of other phenomena—and menopause is a good example—intersex is perceived to need treatment despite inconclusive evidence demonstrating the effectiveness of current treatment protocol. In addition to being framed as pathological, intersex is also seen as potentially disease causing, as evidenced by the

due to physiological complications or, in rare cases of salt-wasting congenital adrenal hyperplasia, where hormone therapy is required to regulate the endocrine system (Diamond and Sigmundson 1997b; Kessler 1998; Wilson and Reiner 1998).

³ Several sources reveal this recent challenge. See, e.g., Kessler 1998; Dreger 1999; and Preves 2000.

emergency gonadectomies performed to prevent cancer (Kupfer, Quigley, and French 1992; Warne 1997; Grumbach and Conte 1998).⁴

Pejorative constructions of difference privilege normalcy in that they tend to assume that the person of difference is damaged and that the marker or observer is not. In addition, the persistent focus on the abnormality of intersexed bodies further privileges bodies that are not intersexed (Davis 1995). In other words, stressing intersexuals' deviance confirms a normal/abnormal opposition (Namaste 1996). As Lennard Davis says of the deaf/hearing dichotomy, "the 'problem' is not the person with disability; the problem is the way that normalcy is constructed to create the 'problem' of the disabled person" (1995, 24). Thus, when studying "deviance" one must also study "normalcy" in an effort to comprehend the very production of normalcy itself. Paying attention to an aberration merely serves to enforce its difference from that which is considered normal, thus perpetuating the categories of normal and abnormal or "insider" and "outsider." While Davis is writing of disability, his idea is easily applied to other types of difference that have been stigmatized, including intersexuality.

In his research on the production of deaf culture, Davis (1995) turns to Gustave Flaubert's *Madame Bovary* (1887) to further illustrate his point that "normals" experience and produce disease. In Flaubert's classic novel, one of the characters, Hippolyte, is discriminated against because of his clubfoot. Individuals in Hippolyte's social circle persist in telling him that his foot is abnormal and in need of aesthetic repair. This social condemnation is contrary to his own experience of his clubfoot as the far stronger and more reliable of his two feet. Succumbing to social pressure, he undergoes "corrective" surgery, which in the end renders him disabled. He sacrificed the strength of his foot in order to make it aesthetically pleasing to others. There are direct parallels between Flaubert's Hippolyte and intersexuals who claim irreversible nerve damage to their genitals caused by "corrective" operations.⁵

Gender binarism and the biological construction of gender

Historically in debates about the genesis of gender, biological factors have been given more weight than social or environmental factors. Biological factors are often granted temporal primacy as well, meaning that gender identity and presentation are assumed to evolve naturally from physiological sex (Hawkesworth 1977). According to Suzanne Kessler and Wendy McKenna,

⁴ Note that the same is true in other medicalized conditions. For example, menopause is seen by some as a causal agent of both heart disease and osteoporosis.

⁵ I explore intersexuals' experiences with medical sex assignment further in my forthcoming book *Intersex Medicalization, Mobilization, and Social Change: Stories of Negotiating the Contested Self* (Rutgers University Press).

the word “‘biological’ has become synonymous for ‘unchangeable’ and ‘natural,’” further reifying the notion of biology as causal (1978, 42).

We have come to differentiate the physical and the social by defining *sex* as physiological (i.e., genitals, gonads, chromosomes, and hormones) and *gender* as the (subsequently developing) sense and presentation of self as a sexed individual.⁶ More explicitly, we tend to infer children’s gender from their genital sex in infancy, reading their behaviors as “feminine” or “masculine.” As children age, the reverse process occurs: as we are typically unfamiliar with a child’s genital composition, we infer its sex from gender presentation. As we operate within a culture that is heteronormative (Butler 1990, 1993), there is often the presumption that “feminine” children without penises and “masculine” children with penises will grow up to desire one another.⁷ It is this complex set of linear and causal assumptions of sexual identity development that Judith Butler calls the heterosexual matrix (1990, 1993). Given the tendency to conflate these categories, Kessler and McKenna (1978; Kessler 1998), Butler (1990), and others see no meaningful distinction between the two terms *sex* and *gender* and, therefore, primarily use the concept of “gender” throughout their work. The conflation of these terms is most evident in the medical practices aimed at quieting physiological sexual ambiguity.

A changing field: Intersex medical management

Although we lack conclusive frequency data on the prevalence of intersex, current estimates based on a review of recent medical literature suggest that approximately 1 or 2 per 2,000 children are born with bodies considered appropriate for sex assignment surgery (Fausto-Sterling 2000) and that nearly 2 percent are born with chromosomes or other nongenital features that could be considered intersexed (Blackless et al. 2000).⁸ Prior

⁶ See Money 1991b for a related history of his coining the terms *gender identity* and *gender role* and Rosario’s 1997 historical critique.

⁷ I discuss the “penis = boy; no penis = girl” sexing logic in detail in subsequent nn.

⁸ Additional estimates note the frequency of intersex as comprising approximately 1–4 percent of all births (Edgerton 1964; Fiedler 1978; Money 1989). These estimates vary widely, depending on one’s definition of intersex (Dreger 1998c; Kessler 1998). For example, some low estimates reflect acceptance of the traditional definition of *true hermaphroditism*, which accounts only for the rare occurrence of mixed gonadal tissue (i.e., the presence of ovarian and testicular tissue in the same body). Other researchers include children born with *pseudo hermaphroditism*, which typically presents in a child with internal gonads that are consistent with the karyotype (typically XX or XY) and external genitals that are incongruent with internal gonads and chromosomes. Finally, other researchers may also include chromosomal variations such as those found in Turner’s syndrome (45, XO) and Klinefelter’s syndrome

research in this area has been predominantly biomedical, with an emphasis on the etiology of intersexed conditions and the protocol for and success of medical intervention. In recent years the scope and focus of this field have been changing rapidly and significantly, especially since the emergence and activism of several intersex advocacy groups in the 1990s and the emergence of research results that contradict prior findings regarding the success of sex assignment.⁹ Prior to this activism and research, the medical “sexing” of intersexuals remained largely unchallenged.

In the 1950s, U.S. clinicians developed recommendations for surgical and hormonal sex assignment (Money, Hampson, and Hampson 1955). John Money and other researchers in this area emphasize the psychological need to clarify the genital sex of intersexed infants at birth to alleviate social stigma (Money 1968, 1991a, 1994). In a summary of the first twenty years of case study research on intersex, Money and Anke Ehrhardt (1972) conclude that biological factors alone are not responsible for gender development. Rather, they contend that gender socialization is pivotal and argue that if an intersex infant receives a clear physical sex assignment from doctors before eighteen months of age, and is raised unambiguously according to that assignment, gender identity development will be normal and the potential for stigma will be reduced.¹⁰

The most (in)famous case documenting the influence of socialization on gender development concerns identical twins born in Canada in 1965 with typical male sexual development. The twins were not circumcised at birth, but at the age of eight months they both developed phimosis, a painful tightening of the foreskin. One of the twins, David Reimer (referred to as “John” in the literature), lost his penis due to accidental burning during routine electrocautery circumcision. After learning of David’s horrible outcome, the twins’ parents decided to cancel his brother’s operation.¹¹

Although David had no chromosomal or endocrinological ambiguity and had been raised as a male for nearly a year, Money and his colleagues

(e.g., 47, XXY). Blackless et al. 2000 suggest that the total frequency of nongenital intersex (intersex chromosomes or nongenital body parts) is much higher than 1 in 2000 and that working with a more inclusive definition of intersex would yield frequency estimates closer to 1 or 2 per 100.

⁹ See, e.g., Van Seters and Slob 1988; Reilly and Woodhouse 1989; Schober 1998a; Bin Abbas et al. 1999.

¹⁰ Note that although this theory of gender development and destigmatization aims to deemphasize physical difference, medical practitioners pay significant attention to intersexuals’ ambiguous anatomy during physical exams (Chase and Coventry 1997–98; Dreger 1999).

¹¹ As is quite common, David’s twin brother’s phimosis resolved itself shortly thereafter without any medical intervention (Colapinto 2000).

recommended that he be reassigned as female because he lacked a penis and could not, therefore, develop a normal male gender identity.¹² David was twenty-two months old before he was surgically and socially reassigned as “Brenda” (“Joan” in the literature) (Diamond and Sigmundson 1997b; Colapinto 2000). Money reported Brenda’s gender reassignment a success (1975; Money and Ehrhardt 1972).

This case has been widely cited in the sociological, psychological, and other literature as proof that gender is socially malleable, at least in early childhood.¹³ An unfortunate surgical accident turned what was a tragedy to the twins’ family into an “experiment of nature” (Colapinto 1997, 62) for researchers and others interested in gender identity acquisition. Money and colleagues used this opportunity to test the effect of gender socialization by rearing a male child as female and using his genetic twin as an empirical control.

In 1997, biologist Milton Diamond and psychiatrist Keith Sigmundson (1997b) revealed that David Reimer was never satisfied with a female gender identity and that s/he began the process of male reassignment at age fourteen when David’s father finally revealed to him the history of the surgical accident and gender reassignment. Currently David is in his mid-thirties and married. He has adopted his wife’s children from a previous relationship. He has undergone a double mastectomy to remove the breasts that were created by exogenous hormones and a phalloplasty, among other procedures, to assist his gender transition (Colapinto 1997, 2000; Diamond and Sigmundson 1997b; Kipnis and Diamond 1998).¹⁴ Diamond and Sigmundson regard the persistence of David’s male identity as evidence of biological determinism (Diamond 1996b, 1997; Diamond and Sigmundson 1997b) and used the attention garnered by their publication of David’s male identity to make recommendations for intersex clinical management (Diamond and Sigmundson 1997a; Kipnis and Diamond 1998; Diamond 1999).

The major media were abuzz with reports of biological determinism within days of Diamond and Sigmundson’s publication. The media also

¹² For further critical discussion on the medicalization of masculinity, see Fausto-Sterling 1996.

¹³ I have seen reports of Joan’s successful gender socialization in sexology texts published as recently as 1997.

¹⁴ The Reimer twins were named Bruce and Brian at birth. Upon sex reassignment, Bruce’s parents changed his name to Brenda. When Brenda reassumed a male gender identity and presentation at age fourteen, s/he took the name David. David Reimer and his family remained anonymous until February 2000, when Canadian journalist John Colapinto published *As Nature Made Him: The Boy Who Was Raised as a Girl*. Upon publication of the book, the Reimer family, at David’s lead, made several talk show and news program appearances.

became interested in other cases of infant sex reassignment and turned to newly emergent intersex activists and parents for their stories. Print media reports included front-page and additional coverage in the *New York Times* (Angier 1996, 1997a, 1997b) and cover stories in *Newsweek* (Cowley 1997), *Rolling Stone* (Colapinto 1997), *Time* (Triea 1997), *On the Issues* (Coventry 1998; Hassibi 1998), *Out* (d'Adesky 1996), and *Mademoiselle* (Moreno and Goodwin 1998). In addition, television media featured this story on *NBC Dateline* (1997), *Inside Edition* (1997), and *Prime Time Live* (1997), with interviews of David Reimer himself, leaders of intersex support groups, and biologists Anne Fausto-Sterling and Milton Diamond.¹⁵ Similar coverage followed Colapinto's publication of *As Nature Made Him: The Boy Who Was Raised as a Girl* (2000).

"True sex" and other curious notions: Tenets of medical sex assignment

The primary concern of intersex medicalization is the swift assignment of a genitally appropriate gender for an infant.¹⁶ Families typically remain marginal in the decision-making process regarding evaluation and treatment, while the medical team retains nearly exclusive control over the

¹⁵ Diamond first reported Joan's transition back to John in the 1980s in the *Archives of Sexual Behavior* (1982) as well as on a segment filmed by the British Broadcasting Company (*Open Secret* 1980). In addition, he reported these findings at a sexology conference in 1995. Interestingly, there was little or no response to these earlier reports. I believe that Diamond's early reports were given little weight because there was very little mainstream social awareness or acceptance of gender nonconformity and sexual ambiguity before mid-to-late 1990s transgender visibility. In addition, his recent publications have been in clinical journals, whereas a largely theoretical audience (nonpractioners) read his 1982 article. Clinicians would surely find more practical application for these findings. Despite the significant reaction to Diamond's recent publications, I maintain that there is little to be learned from this case about either social or biological influences on gender identity development and that the main benefit of Diamond's follow-up is its effect on intersex medicalization. John/Joan received both unambiguous male social and genetic influences until he was eight months of age. Despite Money's theory of gender flexibility until the age of eighteen months, I find it impossible to believe that no male gender salience had been created for this child in the first eight months of his life. Likewise, his internal physiology was entirely male. In addition, I suspect that John and his family had difficulty adjusting to the gender reassignment, which did not take place until he was twenty-two months of age. The biannual psychological and physical exams and other such scrutiny on the twins' development, as well as hormone therapy for "Joan," also called into question the feasibility of his gender reassignment. At the very least, generalizations regarding gender identity development, be they biological or sociological, should not be made on the basis of one case study, especially one where such conclusions are certain to be spurious.

¹⁶ See Voorhess 1982; Donohoe, Powell, and Lee 1991; Horowitz and Glassberg 1992; Meyers-Seifer and Charest 1992.

situation (Lee 1994; Kessler 1998). For example, a common method of handling an ambiguous birth involves telling the parent(s) at the time of delivery that the child's genitals are not yet "fully developed" and then whisking the infant away for myriad medical diagnostic procedures to ascertain the "most appropriate" gender assignment (Schwartz Cowan 1992; Kessler 1998). Most urban hospitals consult with members of their own gender ambiguity teams. Typically, these teams comprise urologists, pediatricians, pediatric endocrinologists, surgeons, and, at times, social workers or psychologists (Kessler 1998, 1990). Doctors often do not inform parents that the sex of their child is in question. Instead, they proceed to "uncover" an infant's "true sex," revealing it for all the world to behold. According to Ellen Hyun-Ju Lee, "Genital ambiguity is presented as 'hiding' and underlying sex, yet to be 'discovered' by the physicians" (1994, 17). Indeed, serious ethical implications are raised by physicians' failure to fully disclose the sexual ambiguity of the intersexed infant.¹⁷

Medical discussions about sex assignment revolve around infants' genitals, chromosomes, hormones, and gonads, with special emphasis given to the potential for appearance of genital, gender, and heterosexual normalcy in adulthood. The focus on genital appearance and size is so great, in fact, that normative ranges for infant clitoral and penile size have been codified. The range for medically acceptable clitoral size is between 0–0.9 centimeters, that is, three-eighths of an inch. Any phallus larger than 0.9 centimeters is considered too large and therefore unacceptable by Western clitoral standards. Thus, according to current medical standards, the overbearing clitoris must be "receded" or "trimmed back" despite potential loss of sexual function or other possible iatrogenic consequences. Conversely, to be considered a penis within this model, an organ must be at least 1 inch long, that is, at least 2.5 centimeters in length (Kessler 1997–98, 1998).¹⁸

The vast majority of intersex children are sexed as female. According to Patricia Donohoe, David Powell, and Mary Lee, "the decision to raise a child with male pseudohermaphroditism [XY sex chromosomes with ambiguous or female genitalia] as male or female is dictated entirely by the size of the phallus" (1991, 537). In other words, if an intersexed child has a Y chromosome, its "phallosclit" is examined for its social potential (read future size and sexual adequacy) as a penis.¹⁹ Conversely, if a child has no

¹⁷ See Kemp et al. 1996; Natarajan 1996; Kessler 1998; Wilson and Reiner 1998.

¹⁸ It is interesting to note that newborn penile size charts were first published in the 1960s. In striking contrast, newborn clitoral size charts were not published until the late 1980s (Lee 1994).

¹⁹ I use Holmes's (1994) term *phallosclit* to convey the ambiguity and bipotential of the genital tubercle to become clitoris or penis.

Y chromosome, or a small or “inadequate” penis, the child is sexed as female. There is also great concern that a child with a male sex assignment is able to urinate from the tip of his penis while standing.²⁰ Thus, a child’s genotypic makeup may be male, but unless the medical team deems the infant’s phallus to be of adequate size, capable of “proper” urination while standing, and likely to pass as (hetero)sexually “normal,” the child will likely be surgically and hormonally constructed as female (Donohoe, Powell, and Lee 1991; Kessler 1998; Slaughenhaupt and Van Savage 1999). According to a widely cited article from the *Johns Hopkins Magazine*, which includes interviews with leading intersex specialists Gary Berkovitz, John Gearheart, and Claude Migeon, “In truth, the choice of gender still often comes down to what the external genitals look like. Doctors who work with children with ambiguous genitalia sometimes put it this way, ‘You can make a hole [vagina] but you can’t build a pole [penis].’ Surgeons can decrease the size of a phallus and create a vagina, but constructing a penis that will grow as the child grows is another matter” (Hendricks 1993, 15). In philosopher Kenneth Kipnis’s experience, the “penis = boy, no penis = girl” logic is nearly palpable during his ethical consultations with physicians. He writes of one such experience with a pediatric surgeon:

The surgeon was immediately concerned about the child’s abnormally small penis: technically, a micropenis. Apprehensive about the possibility of the child being shamed in the boys’ locker room — psychosocial distress as he matured — the pediatric surgeon was counseling immediate surgical reassignment as a girl. According to the surgeon’s plan, the testes would be removed and the genitalia fashioned into a cosmetic vulva before the baby left the hospital. The parents would be instructed to raise the infant as an unambiguous girl. At about the age of twelve, estrogens would be administered to stimulate the development of female secondary sex characteristics. Eventually doctors would create an artificial vagina. Although the resulting woman would be unable to bear children, the surgeon anticipated that prompt surgical attention would allow the infant to enjoy a better and more normal life as a female than would be possible for a male with a very small penis. (Kipnis and Diamond 1998, 398)

The emphasis on infants’ phallic size as a correlate of adult phallic capacity is questionable as the normative ranges of infant phallic and clitoral size have been shown to be unrelated to adult genital size (Lee 1994). In

²⁰ See Money 1985; Donohoe et al. 1991; Lee 1994; Kessler 1998.

addition, initial studies on boys raised with micropenises show that if their small penises are left intact, these boys fare quite well socially and sexually — far better than if they had feminizing genitoplasty.²¹

The social construction of disease and cure

In the 1970s, medical sociologists expanded their scope to include the study of natural human experiences labeled as “medically problematic.” Irving Zola first labeled this phenomenon *medicalization* (Bell 1990). The term *medicalization* refers to viewing a natural phenomenon in a medical framework where the medical view is seen as the authoritative, if not hegemonic, view (Conrad and Schneider 1992). Once a phenomenon is seen through this medical lens, medical treatments may seem logical. An example of the medicalization of intersex was evident in a recent episode of the popular television hospital drama *Chicago Hope*. In this episode, following the birth of a healthy intersexed infant, the delivering physician immediately consulted a pediatric endocrinologist and urologist to ascertain the baby’s sex. The medical team treated the infant’s sexual ambiguity as a medical emergency and, in the end, opted for a female sex assignment and genitoplasty due to the small size of the infant’s phallus. The necessity of surgical intervention was never discussed, it was simply presumed.

Medicalization both increases the range of social phenomena linked to medicine and those interpreted through the concepts of disease and treatment (Crawford 1980; Conrad and Schneider 1992). Zola (1990) notes the spread of medicalese into the language and thinking of the lay person. For example, when referring to newborns that are intersexed, clinicians typically describe an ambiguous phalloslit as an hypertrophied (enlarged) clitoris or a micropenis and use scientific instruments to measure and classify the ambiguous anatomy in question (Kessler 1997–98). This is especially notable when intersexuals talk about their own experiences using medical jargon, referring to their “conditions” or “endocrine disorders.” The use of medical jargon reflects the widespread acceptance of a medical paradigm, which makes it difficult for lay persons to question medical opinion or authority.

The disparity in status between patient and doctor is furthered by the elevation of doctors to privileged “knowers” of medical treatments and cures, making patients more dependent upon the specialized knowledge of their doctors. In this way, the physician is seen as healer while the patient

²¹ Van Seters and Slob 1988; Reilly and Woodhouse 1989; Schober 1998b; Bin Abbas et al. 1999.

and family are relegated to a dependent position and in need of a professional cure (Fisher and Groce 1985). This shift in power of sexing from the family and intersexed individual her/himself to medical committees on gender ambiguity is evident in the history of hermaphroditic treatment.²² In Alice Dreger's words, "By consulting with medical men, hermaphrodites supplied an acknowledgement of the medical men's authority, confirmation that the medical men were indeed the just and trustworthy arbiters of pathology and identity" (1995a, 57). In this way, as Goffman (1959, 1963, 1982) and others have demonstrated, the meaning of sexual ambiguity is created collectively by all the participants in social interaction and social discourse. It is certainly not just the "medical men" who desire the simplicity of gender binarism. Persons who are sexually ambiguous and their families (may) also desire some semblance of normalcy in terms of sociocultural expectations of sex and gender (Dreger 1995a). For example, prior to the medicalization of hermaphroditism in the West, intersexuals attempted to pass as "normal" through the use of observable signifiers of gender such as clothing and accessories, occupation, and sex/gender of partner. Most members of the population continue to use socially recognized gender signifiers as a means of identity expression in contemporary times.

Medicine and intersex: The case of hospital births

As a direct result of the continual expansion of the medical-industrial complex and the legitimation of medical authority in childbirth, medicine has gained control over birthing procedures and has, for the most part, successfully withstood challenges such as the 1970s natural/home birth movement (Romalis 1981; Eastman and Loustaunau 1987; Rothman 1990). Prior to the twentieth century, childbirth had a history of female lay control, overseen by the women giving birth and their female assistants (Martin 1987; Leavitt 1989). If an intersex birth occurred, unless circumstances required medical intervention, it was most often handled privately, within the family (Schwartz Cowan 1992). This is no longer the case as the vast majority of U.S. births now occur in hospitals (Romalis 1981; Eastman and Loustaunau 1987; Leavitt 1989) and there is significantly more medical intervention in situations where formerly there was none.

Although physicians first began attending births in the early to mid-1700s (Wertz and Wertz 1990), women retained control and authority in most situations and made use of the doctors' expertise when there was

²² Foucault 1978, 1980; Epstein 1990; Pagliassotti 1993; Dreger 1995b.

some doubt of a safe delivery (Leavitt 1989). The decision to request a physician's attendance during childbirth depended largely on financial resources. It was the women who could afford to pay doctor's fees who opened up the intimate atmosphere of traditional childbirth to include a physician (Leavitt 1989).

Wealthy women initially called upon the physicians of the eighteenth century to provide relief from the painful or dangerous aspects of labor such as excessive bleeding, excruciating pain, or prolonged labor. Physicians took on this more active role in childbirth because of the development of new technologies, including forceps and opium in the eighteenth century and anesthesia in the nineteenth century (Leavitt 1989). While the purpose of involving physicians in labor and delivery was to improve prospects for a safe delivery, doctors often aggravated nonproblematic situations by their lack of preparation. Throughout most of the nineteenth century, male physicians were instructed to deliver "without looking at women's genitals," and physicians commonly went straight from treating infectious patients to home birth sites without thoroughly washing their hands (Leavitt 1989, 304). Once physicians gained entrance into the private world of childbirth, they gained a degree of control they were reluctant to relinquish. As a result, access to technologies and information necessary to care for oneself became limited. In the eighteenth and nineteenth centuries, for example, the invention of forceps and the use of drugs such as opium aided in the speed and ease of delivery, but these were not made readily available to the lay public. More recent medical technologies used in birthing include fetal heart monitors and the use of intravenous fluids in standard hospital births (Romalis 1981; Young 1982).

In working with intersexed newborns, physicians are dealing with very vulnerable populations — parents who expect healthy (read normal) children and children who are unable to speak or choose for themselves. Indeed the imposition of medical authority is evident. As Kessler notes, "In the literature on intersexuality, issues such as announcing a baby's gender at the time of delivery, postdelivery discussions with the parents, and consultation with patients in adolescence are considered only peripherally to the central medical issues — etiology, diagnosis, and surgical procedures" (1990, 2).

A historical analysis of intersex medicalization

Michel Foucault's (1970, 1972) notion of conceptual genealogy is quite useful in understanding contemporary medical views of intersex as pathological. Here I provide a brief history of pre-twentieth-century conceptions

of intersex to historicize and contextualize contemporary debates surrounding intersex medicalization. During the early years of the Enlightenment, in the late eighteenth century, the medical establishment began to gain authority over the body. This was, in large part, related to the developing science of taxonomy (Foucault 1980; Moscucci 1991). This scientific focus on classification had a major impact on how clinicians viewed and treated human bodies, especially when bodies or body parts seemed to defy typical categorization.

Cary Nederman and Jacqui True (1996) review twelfth-century theological and medical writings that characterize sex as continuous rather than binary. Unlike later, twentieth-century contentions that an intermediate intersexed state is not truly possible (Dreger 1995b; Nederman and True 1996), it appears that, during the twelfth century in Western Europe hermaphrodites were regarded as a discrete third sex.²³ This idea was based on Galen's second-century theory claiming that there were gendered differences in body temperature, especially in the reproductive and sexual organs ([170 C.E.] 1916).²⁴ According to this theory, sex distinctions were based on a continuum of heat, with males being internally hotter than females, thus creating the impetus for male external reproductive organs and female, "colder," internal organs.²⁵ In Thomas Laqueur's (1990) analysis, this differential temperature theory actually provided the basis for a one-sex conceptual model, with females being seen as the inverse of males. (That is, the vagina was viewed as an inverted penis, the uterus as a scrotum, the fallopian tubes as seminal vesicles, the ovaries as internal testicles, and so on.)

In the early seventeenth century, scientific thought about apparent females masculinizing at puberty was associated with Galen's temperature model. The esteemed seventeenth-century surgeon Ambroise Pare viewed an excessive amount of internal heat as the cause of this female pubescent masculinization. According to Pare (1634), this heat was typically brought on by the activities of children, such as jumping and playing roughly, which then led to the "pushing out" and transition of internal female

²³ Note that in the late nineteenth century, medical understanding regarded *hermaphrodite* as meaning male and female, whereas early use of the word *intersex* denoted in between male and female (Dreger 1998c).

²⁴ Galenists and Aristotelians disagreed on the point of women's contribution to the formation of the embryo. According to Aristotle, females did not contribute "seed" or "sperm" to their offspring; Galen thought females actively provided "seed" to their progeny (Cadden 1993).

²⁵ Aristotle valued "male" heat over "female" cold and viewed females' lack of heat as a sign of inferiority and even deformity (Cadden 1993).

organs into external male organs. Laqueur disagrees with both Pare and Galen. He claims that Pare's theory is based on "reading" male anatomy onto female bodies and that Galen viewed men not only as "hotter" than women but also as superior to them.

The widely read and highly acclaimed pseudo-Galenic *De Spermate* further defined sex differentiation in reproduction. According to *De Spermate*, both the male "seed" and the female uterus played active roles in determining the sex of the offspring. The uterus and testicles were seen as divided into hot (right) and cold (left) sections, with both having a mysterious indeterminate middle section. When male "seed" was planted in the warmer, right section of the uterus, the baby was a boy. A girl was produced by implantation in the colder, left side of the uterus. If the "seed" planted itself in the midsection, a hermaphroditic baby was produced (Cadden 1993; Nederman and True 1996). In this sense, with the uterus having a separate, "neutral" chamber for nurturing hermaphroditic fetuses, hermaphroditism was conceptualized as a natural, if not expected, state (Jones and Stallybrass 1991; Moscucci 1991; Nederman and True 1996). Further evidence of the definition of three distinct sexual categories comes from the late-twelfth-century Italian civil jurist Portius Azo, who wrote in his *Summa Institutionum* (1610): "There is another division between human beings, namely that some are male, others are female, others are hermaphrodites" (quoted in Nederman and True 1996, 512).²⁶ Although attitudes toward hermaphroditism varied widely in twelfth-century Europe, from viewing hermaphrodites as monsters to seeing hermaphroditism as natural, hermaphroditism was seen as a separate, third sex category (Nederman and True 1996).

Since this period precedes the separation of church and state, the writings of theologians had great influence. On the moral regulations applied to the hermaphrodites of the twelfth century, the Parisian, Peter the Chanter, wrote:

The church allows a hermaphrodite—that is, someone with the organs of both sexes, capable of either active or passive functions—to use the organ by which (s)he is most aroused or the one to which (s)he is most susceptible. If (s)he is more active, (s)he may wed as a man, but if (s)he is more passive, (s)he may marry as a woman. If, however, (s)he should fail with one organ, the use of the other can never be permitted, but (s)he must be perpetually celibate to avoid

²⁶ Although Azo wrote this text in the late 1100s, it was not published until early in the seventeenth century.

any similarity to the role inversion of sodomy, which is detested by God. (Quoted in Nederman and True 1996, 510–11)²⁷

This widely accepted tolerance of hermaphrodite choice in her/his sex/gender/sexuality stands in striking contrast to the rigidity of contemporary sex assignment.²⁸ It appears that although physiological ambiguity was allowed to persist in premedicalized times, the forms in which sexual identity could be displayed or expressed were culturally mandated.

In contemporary and historic times, legal concerns related to sex ambiguity are located within a system of gendered rights and obligations. In their normative breaching, “Hermaphrodites highlight the privilege differential between male and female precisely because they cannot participate neatly in it” (Epstein 1990, 124). Throughout history, family, church, and state have exercised control over overt expressions of gender such as choice of occupation, gender of marital/sexual partner, and type of clothing as a means to distinguish between women and men and to decrease the sex/gender/sexual ambiguity presented by hermaphrodites (Pagliassotti 1993). For example, in the mid-twelfth century, a person’s ability to serve as a legal witness depended on her/his predominant gender. As women were excluded from providing court testimony, voting privileges, and property rights, hermaphrodites who presented as more female than male were also precluded from exercising the legal rights accorded to males at the time (Nederman and True 1996).

Early surgical attempts to solder sex, such as lowering abdominal testicles, appeared in the beginning of the nineteenth century (Pagliassotti 1993). A primary motive for the social insistence upon outward displays of gender clarity was fear of homosexuality, or hermaphroditism of the soul (Hekma 1994), a threat that was present in the sexually ambiguous (or, quite literally, *bisexual*) body of the hermaphrodite. By appearing, outwardly, to be of the “other” sex, it was feared hermaphrodites would tempt heterosexual partners into homosexual relations (Dreger 1995a).

The legal motivation for making precise sex distinctions was, and is, grounded in a morally based attempt to preserve the heterosexual institution of marriage, which is predicated on sex difference.²⁹ By the end of the eighteenth century, “The sex of husband and wife was beset by rules and

²⁷ The translation of Peter the Chanter (Peter Cantor) used here by Nederman and True (1996) is Boswell’s (1980). Boswell’s translation is from Peter Cantor’s original Vulgate, with some Latin and Greek notation.

²⁸ For evidence of historic tolerance of hermaphrodites, see Pare (1634) 1968; Epstein 1990; Jones and Stallybrass 1991; Pagliassotti 1993; Nederman and True 1996.

²⁹ Ormrod 1972; Hawley 1977; Capron and D’Avino 1981; Greenberg 1999.

recommendations. The marriage relation was the most intense focus of constraints; it was spoken of more than anything else” (Foucault 1978, 37).

Regardless of the time period, demarcations for lawful marital unions are precise even when legal definitions of sex are lacking. According to Roger Ormrod, “To constitute a valid marriage the parties must be of different sexes, for the simple reason that is what the word [marriage] means” (1972, 85).³⁰ Although overt legal discourse surrounding the validity of marital unions concentrates on sex (as in genitals, gonads, and chromosomes), the underlying motive for the insistence upon “opposite” sex wedlock appears to be social insurance against sodomy. This is evidenced by legal clauses relating to the traditional penile-vaginal heterosexual consummation of marriage vows. Ormrod (1972) and Donna Hawley (1977) note that an inability to consummate a marriage in this manner provides legal grounds for annulment.

Additional reasons for requiring legal registration and classification of sex at birth include the prevention of fraud; restriction for the carrying out of sex-specific rights, duties, and obligations; and the preservation of morality and family life (otherwise known as the prevention of homosexual relations) (Capron and D’Avino 1981). In Alexander Capron and Richard D’Avino’s words, “To enforce the prohibition (and, incidentally, public sexual displays) between members of the same sex, society needs a legal means of classifying all individuals by sex” (1981, 220). In the same article, the authors reiterate the importance of maintaining a stable sex once it is proclaimed: “The state’s insistence on a dual classification [of sex] is usually accompanied by a requirement of *permanency* in the designation” (Capron and D’Avino 1981, 221). In fact, transgressions of sex/gender stability have been met historically by punishments as severe as death.

In early seventeenth-century France, hermaphrodites were allowed to marry a person “opposite” of their predominant sex. Once a hermaphrodite made this type of visible gender choice, they were morally and legally expected to adhere to that decision — to uphold the ascribed social status in gender.³¹ Echoing Peter the Chanter’s statement above, if a hermaphrodite turned against their sex/gender decision in a sexual relationship, they were charged with sodomy, publicly whipped, hanged, and/or burned (Jones

³⁰ This discussion is, of course, relevant to current legislative discourse regarding the legalization of homosexual marriage and the Defense of Marriage Act (Greenberg 1999). The recent Vermont Supreme Court ruling requiring the state of Vermont to provide the benefits of marriage to same-sex couples is a good example.

³¹ Gender is made ever more important because it is performed or realized through primary social institutions including economic, religious, and familial spheres.

and Stallybrass 1991; Trumbach 1994; Nederman and True 1996). In contrast with twelfth-century allowance of social gender choice, in eighteenth- and nineteenth-century western Europe, female pseudohermaphrodites who gained access to male privilege through outwardly male displays such as marriage to women and performing “male” occupations were often charged with fraud or usurping male privilege and subjected to public punishment such as whipping, hanging, and burning (Epstein 1990; Jones and Stallybrass 1991; Trumbach 1994).

Identity politics and the intersex social movement

In her 1993 article dealing with sexual categorization, Anne Fausto-Sterling stated that female and male sex categories exclude intersexuals. Using a taxonomic system established by British doctors George F. Blacker and T. W. P. Lawrence, she posed a five-sex system comprised of categories for female, female pseudohermaphrodite, true hermaphrodite, male pseudohermaphrodite, and male.³² Kessler (1990, 1997–98, 1998) suggests that instead of seeing intersexed genitals as aberrant, we should respond to them as one variety of genital possibilities. Foucault went as far as to question whether we really needed to bother with establishing one’s “true sex” (1980).

Recently, transgender activists have been quite visibly traversing, bridging, and blurring categories of sex, gender, and sexual attraction (Stone 1991; Bornstein 1994; Feinberg 1996). According to self-identified transactivist Leslie Feinberg, “*Transgender* people traverse, bridge, or blur the boundary of the *gender expression* they were assigned at birth” (1996, x; emphases in original).³³ Persons who identify as transgendered (i.e., persons who move across or beyond the standard binary categories of gender) have garnered significant attention in the 1990s as they have mobilized and created a social movement of identity politics. In this work transgendered individuals are participating in “social movements which seek to alter the self conceptions and societal conceptions of their participants” (Anspach 1979, 765). Rather than attempting to adapt and conform to normative expectations of gender and sexual expression, transactivists seek to normalize transgenderism.

³² Dreger’s historical research shows that British medical doctors George F. Blacker and T. W. P. Lawrence originated this five-sex system in 1896 (see Dreger 1998a).

³³ To my knowledge, *transactivist* is Feinberg’s term (1996). S/he uses it to refer to transgender activists.

While traditional transsexual hormonal and surgical interventions conformed to gender binarism, the recent transgender movement challenged the necessity of matching one's genitals to one's gender, effecting a paradigm shift in the way transgender identities are conceptualized (Bockting 1995, 1997a, 1997b). Today, a number of individuals born male and female are living differently gendered lives without the aid of hormonal or surgical treatments and with less emphasis on passing as standard women and men.³⁴ Many transsexuals are choosing to live with a blended gender identity that blurs the boundaries of male and female.

Identity politics movements, such as the case discussed here, acknowledge the importance of agency to individuals not only in constructing their own identities but also in responding to and negotiating social expectations of who they ought to be. In this way, identity movements expand Goffman's (1963) theory of stigma beyond its potentially deterministic stance on the "spoiled identities" of those who deviate from social norms. Rather than passively accepting a socially attributed stigmatized identity, individuals not only have the capacity to transform their self-conceptions but also the means to redefine how others see them (Bem 1995).

As I have noted, many individuals are now questioning the ethics and effectiveness of medical sex assignment procedures. From a biological perspective, Diamond and Sigmundson emphasize the importance of biological factors over postnatal socialization.³⁵ From a social constructionist perspective, Kessler (1998), Dreger (1998c), and Fausto-Sterling (2000) argue that intersex ought to be demedicalized as it is not in itself pathological. Rather, the pathology lies in the social system and its strict adherence to gender binarism. They contend that in a culture where childbirth is treated medically, intersex variation is seen within a medical framework—that is, as a disease requiring medical intervention. In addition, many individuals are questioning the ethics and effectiveness of current North American medical intervention on intersexed children,³⁶ and intersex individuals are openly expressing their dissatisfaction with this medical intervention.³⁷ Their dissatisfaction centers on the following issues: (1) certain medical interventions, from a strictly physical point of view, are not necessary for survival;³⁸ (2) as a result of medical intervention, both sexual and psycho-

³⁴ Bolin 1994; Rothblatt 1995; Bockting 1997b; Devor 1997.

³⁵ Diamond 1996b, 1997, 1999; and Diamond and Sigmundson 1997a.

³⁶ Chase and Coventry 1997–98; Dreger 1998a, 1998b, 1998c; Kipnis and Diamond 1998; Preves in press.

³⁷ Coventry 1998; Holmes 1998; Kaldera 1998; Chase 1999.

³⁸ Some rare cases of intersexuality do require medical intervention. This is especially true of salt-wasting forms of congenital adrenal hyperplasia (CAH) or when infants have difficulty

logical satisfaction and functioning are often impaired; and (3) for intersex individuals the lack of open discussion of their intersex status results in feelings of shame and isolation. Evidence of their discontent is abundant in the writings and personal stories of intersexuals (Horowitz 1995). For example, in Morgan Holmes's words, "Not that I would necessarily have kept my phalloclit. . . . But I would have liked to have been able to choose for myself. I would have liked to have grown up in the body I was born with. . . . But physically, someone else made the decision of what and who I would always 'be' before I even knew who and what I 'was.' . . . [The doctors] used surgical force to make my appearance coincide with the medical and social standards of a 'normal' female body, thereby attempting to permanently jettison any trace of intersexuality" (1994, 29–30). And in Cheryl Chase's experience,

Who am I? I now assert both my femininity and my intersexuality, my "not female"-ness. This is not a paradox; the fact that my gender has been problematized is the source of my intersexual identity. Most people have never struggled with their gender, are at a loss to answer the question, "how do you know if you are a woman (a man)?" I have been unable to experience myself as totally female. Although my body passes for female, women's clothing does not fit me. The shoulders are too narrow, the sleeves too short. Most women's gloves won't go on my hands, nor women's shoes on my feet. For most women, that wouldn't be more than an inconvenience. But when the clothing doesn't fit, I am reminded of my history. Of course, men's clothing doesn't fit either. The straight lines leave no room for my large breasts or broad hips. (1998a, 211–12)

And, "As a woman, I am less than whole—I have a secret past, I lack important parts of my genitals and sexual response. When a lover puts her hand to my genitals for the first time, the lack is immediately obvious to her. Finally, I simply do not feel myself a woman (even less a man). But the hermaphrodite identity was too monstrous, too Other, too freakish, for me to easily embrace. A medical anomaly, patched up as best the surgeons could manage" (1998a, 212).

Despite the medical aim to erase or hide sexual ambiguity, some intersexuals are finding each other through their own activism and are attempting to reclaim their difference as prideful. In fact, in the last twelve years intersexuals have been implementing their own networks of support

voiding urine or feces (Diamond and Sigmundson 1997b; Kessler 1998; Wilson and Reiner 1998).

and avenues for social change at a rapid pace. Here I provide a brief overview of a few of the significant developments on this front.³⁹

The Turner's Syndrome Society, founded in Minneapolis in 1987, was the first-known support group for persons with atypical sex differentiation. This organization was founded by women who have Turner's syndrome and currently serves thousands of members nationally as a medical information clearinghouse.⁴⁰ A year later, in 1988, the mother of a girl with androgen insensitivity syndrome (AIS) founded the U.K.-based AIS Support Group.⁴¹ At the time of this writing, the group has chapters in five countries and a widely distributed newsletter called *ALLAS*. In 1989 the mother of a child with Klinefelter's syndrome founded the U.S.-based K. S. & Associates.⁴² This organization now serves over one thousand families.

In 1993 intersex activist and scholar Cheryl Chase founded the Intersex Society of North America (ISNA). Chase initially announced ISNA's exist-

³⁹ I am indebted for much of this history to Chase 1998b.

⁴⁰ Turner's syndrome is the most common form of "female" chromosomal variation where the typical karyotype is 45, XO, meaning that one sex chromosome is missing. A fetus with a 45, YO karyotype is not sustainable and will die (Grumbach and Conte 1998). Individuals with Turner's syndrome typically develop unambiguous female genitalia yet have underdeveloped breasts, uteruses, and vaginas. Some have testicular tissue and primitive gonadal "streak" tissue. They commonly do not develop secondary sex characteristics, are very short (dwarfism), have a webbed neck, a "shield chest," short fingers and toes, renal disorders, heart and circulatory problems, and are prone to deafness and mental retardation (Money 1968; Money and Ehrhardt 1972; Glanze et al. 1996; Grumbach and Conte 1998).

⁴¹ In androgen insensitivity syndrome (AIS), individuals have a male-typical 46, XY karyotype but lack a key androgen (male hormone) receptor that incapacitates the ability, fetally onward, to respond to the androgens produced in normal amounts. This results in a feminization of the external genitalia and, typically, abdominal testicles. Some individuals with AIS are completely insensitive to androgen, and some only partially. Most individuals with AIS are sexed as female unless virilization is only slightly affected by insensitivity to androgen, in which case male sex assignment would prevail (Quigley et al. 1995; Diamond and Sigmundson 1997a). At puberty, individuals with AIS respond to the normal levels of estrogen produced by their bodies and develop breasts. Individuals with AIS typically develop very little, if any, body hair, and are tall and lean. (It is indeed paradoxical that appearance of AIS "boys" is consistent with contemporary Western ideals of female beauty.) Individuals with AIS are sterile, but many do adopt children (Josso 1981; Glanze et al. 1986; Kupfer et al. 1992; Grumbach and Conte 1998).

⁴² Klinefelter's syndrome is a type of chromosomal variation in which a "male" child has a karyotype with more than one X chromosome, such as a 47, XXY (or 48, XXYY, 48, XXXY, or 49, XXXXY). Genital ambiguity is not present, but testes may be small and firm, and breast development (gynecomastia) is common. Secondary sex characteristic development is limited, and these men are almost always sterile (Money 1968; Money and Ehrhardt 1972; Glanze, Anderson, and Anderson 1996; Grumbach and Conte 1998).

tence by publishing a letter to the editor in response to Fausto-Sterling's article, "The Five Sexes" in *Sciences* (Chase 1993). In this letter, Chase listed a post office box for ISNA, which soon began filling with mail from other intersexuals around the world. The Intersex Society of North America published the first issue of its newsletter, *Hermaphrodites with Attitude*, in the winter of 1994, started bimonthly support groups in January 1995, and went on-line with an Internet Web site in January 1996 (Chase 1997, 1998b). In addition to the support it offers to intersexuals and their families, ISNA's mission is to destigmatize intersexuality and to legitimate genital variability (Kessler 1997-98). In a political move, the ISNA linked its objective of preventing genital surgery to the emotional and political movement against female genital mutilation. Since the October 1996 U.S. federal legislation banning female genital mutilation, ISNA has been lobbying against "intersex genital mutilation" (Chase 1997, 1998b; Harvey 1999). The society has approximately 1,500 members.

In 1995 the mother of an intersexed child formed the Ambiguous Genitalia Support Network (AGSN), an organization that fosters pen pal relationships among parents of intersexed children. In 1996, another mother founded the Hermaphrodite Education and Listening Post (HELP). This group offers peer support and medical information to its members. Both AGSN and HELP were started by mothers who were dissatisfied with intersex medical protocol. Both had children who at birth had male chromosomes and gonads and genitals deemed inadequate to be male. Each mother countered medical advice for feminizing surgery and is raising her young son as a boy. More recently, in 1998, an intersexed woman formed the U.S.- and Christian-based Intersex Support Group International. In support of its opposition to intersex medicalization, this group cites biblical passages referring to the sanctity of all God's creations.

Although the objectives of the above groups differ, all provide information and support to their members. The Intersex Society of North America has been most visible and vocal in its mission and significantly influenced scholars' suggestions for clinical change (Diamond and Sigmundson 1997a; Kipnis and Diamond 1998). The ISNA's model for treatment is as follows: (1) avoid surgery unless there is imminent medical risk to the infant; (2) provide in-depth counseling for the entire family of the infant; (3) insist that this counseling be given by qualified mental health professionals well versed in issues relevant to sex therapy and sexology; (4) provide age-appropriate information about medical care, diagnoses, and support patient autonomy, allowing intersexuals full knowledge of their situation and access to medical records; (5) provide peer support to intersexuals by connecting them to one of the many available support

networks; and (6) provide access to surgical and/or hormonal medical technologies only after attaining the informed consent of the intersexual her/himself.⁴³

Social movements and identity formation

I would be remiss in not commenting on the particular sociocultural context within which this new intersex identity is emerging. First, the intersex social movement of the very late twentieth and early twenty-first centuries is largely the accomplishment of prior activists, and particularly gay, lesbian, bisexual, and transgender (GLBT) individuals. The great strides these activists have made in the last three decades have furthered GLBT human rights, identity politics movements, and the development of queer theory. The increasing visibility of GLBT persons has clearly provided an increased level of social tolerance for those with nonbinary genders and sexualities, ultimately paving the way for the intersex movement to move to center stage. In addition, both queer theory and GLBT activism parallel the politics of prior difference movements, such as the disability rights movement, in which paradigmatic understandings of disability shifted focus from moral, to medical, to minority concepts of difference (Mona 1998). The intersex movement is also quite reliant technologically upon electronic media and communications, including the Internet and electronic mail (Turner 1999).

The social context within which contemporary intersex identity is emerging is not the only important consideration. It is also important to examine the problem of group identity and the essentialism involved on a far broader scale. Identity-based political movements such as the intersex movement are potentially problematic when they present categorizations as unified and generalized phenomena (Scott 1993; Loury 1996). Critics of such generalizations claim that there is no such thing as *the* “gay” or “straight” or “intersexed” identity. Speaking to the drawbacks of such essentialism, Steven Seidman writes that “positing a gay identity, no matter how it strains to be inclusive of difference, produces exclusions [and] represses difference” (1995, 135). In a similar vein, Ki Namaste (1996, 198–99) asks several questions that are pertinent to the discussion of identity-based social movements: “How do categories such as ‘gay,’ ‘lesbian,’ and ‘queer’ emerge? From what do they differentiate themselves, and what kinds of identities do they exclude? How are these borders demarcated, and how can they be contested? What are the relations between the naming of sexuality and political organization it adopts, between identity and com-

⁴³ Chase 1998a, 1998c, 1999; see the ISNA Web site at <<http://www.isna.org>>.

munity? Why is a focus on the discursive production of social identities useful? How do we make sense of the dialectical movement between inside and outside, heterosexuality and homosexuality?” Moving away from traditional definitions of identity, Seidman offers a poststructural approach to identity, observing that poststructuralism “dissolves any notion of a substantial unity in identity constructions leaving only rhetorics of identities, performances, and the free play of difference and possibility. Whereas identity politics offers a strong politics on a weak, exclusionary basis, poststructuralism offers a thin politics as it problematizes the very notion of a collective in whose name a movement acts” (1995, 135).

According to Seidman (1995), Davis (1995), and others, identity politics movements create a new kind of nationalism, as identity-based social movements erect artificial boundaries and borders. The consequences of relying on a taxonomy-based self-concept include both assimilation and separatism. According to Davis, “the deaf have created their own ‘nationalism’ as a resistance to audist culture” (1995, 78–79). The issue of exclusivity is especially apparent as medicalization becomes a defining catalyst of intersex identity, since so much intersex support and advocacy are focused on recovery from medical trauma. This reinforces the equation between sexual identity and medical trauma and increases pressure to conform to a dichotomous understanding of sex and gender.

Implications for clinical reform

Physicians are faced with a difficult dilemma: they are taught to improve the lives of their patients. Certainly surgery is warranted in those rare intersex cases where intervention is mandatory (as when elimination of feces or urine is not possible without such intervention). However, the vast majority of intersex conditions are simply not life threatening (Diamond and Sigmundson 1997a; Kessler 1998; Wilson and Reiner 1998). Given the injunction “do no harm” and the lack of data conclusively demonstrating the efficacy of more cosmetically based medical interventions, clinicians should opt for the least invasive treatment procedures and not conduct any irreversible surgical or hormonal intervention without the patient’s direct consent.⁴⁴

Perpetuating treatments that seem to be ineffective and even harmful raises serious ethical questions. Viktor Gecas notes that autonomous control over one’s own existence is exceedingly important in the development

⁴⁴ By “patient,” I mean only the person on whom a procedure will be performed, not parent(s) or guardian(s).

of a positive self-concept: "It is the quality of the individual-environment interaction, primarily with regard to the opportunities it provides for engaging in efficacious action . . . that continues to be the major condition for self-efficacy throughout a person's life" (1989, 300). Why this reluctance to discontinue treatment when there is doubt as to its effectiveness? Resistance to clinical reform is evident in the continued use of ineffective treatments, especially use of various aversion or "reparative" therapies for GLBT individuals whose families hope for their "heterosexual conversions" or "shifts." According to Paulo Freire (1970), persons in positions of power, such as medical authorities, may disregard the misgivings and mobilization efforts of those they serve because supporting their dissent would only undermine their efforts to perpetuate and uphold the status quo. We can see this trend among intersex clinicians who regard intersex activists as "radical zealots" representing perhaps only 3 percent of the entire surgically altered intersex population (Yronwode 1999).

As Thomas Kuhn (1962) and Freire (1970) demonstrate, paradigmatic shifts are hard won, especially when attempted by disempowered or marginal populations. In order to affect change, open communication and collaboration must occur to ensure that those operating within the prevailing model have the capacity to be affected by the personal experiences and efforts of those seeking change. It is through such personal interaction, when both parties approach each other with compassion, humility, and hope, that change is possible. Both sides must be flexible enough to change their thinking and to compromise when necessary (Freire 1970; Bockting, Rosser, and Coleman 1999). As it is the patients who must live with the results of medical treatments, the doctors who serve them should take their experiences, perspectives, and desires into full consideration.

As a result of the highly vocal criticisms of intersexuals, clinicians are beginning to reform their practices and to become far less eager advocates of surgical intervention on intersexed infants and children (Schober 1998b; Wilson and Reiner 1998; Nussbaum 1999).⁴⁵ These changes have been made by physicians who have had personal interaction with adult intersexuals who are critical of medicalization because they have suffered sexual dysfunction due to iatrogenic nerve damage and incorrect gender role assignment (Kipnis and Diamond 1998; Schober 1998a; Wilson and Reiner 1998).

⁴⁵ This shift was notable in pediatric urologist Yuri Reinberg's (1999) grand rounds presentation at the University of Minnesota Medical School. During his presentation and the discussion following it, several noted proponents of intersex surgery spoke of their newfound reluctance to perform genital operations on infants and children due to adult intersexuals' critiques of sexual dysfunction and inappropriate sex assignment.

Conclusions

Contemporary intersex activism emerged as a reaction to the broad societal marginalization experienced by intersexed individuals, with a specific critique directed at disempowering medical interventions. Before the existence of intersex support and advocacy organizations, intersexuals were dependent on their physicians for access to related resources. Even though they may be disappointed with the information they receive from their physicians, intersexed individuals turn to medical authorities for assistance with their medicalized condition rather than to typical avenues of social support (Berkun 1986). Cleo Berkun uses menopause as an example of this phenomenon: "Because of the perceptions of the private, medical, and moral nature of their [menopausal] thoughts, they did not turn to their usual sources of support and information but, rather, sought 'factual' information from physicians with which they were not satisfied" (1986, 381). Autonomy is so critical to one's self-concept that Edward Jones et al. claim that "the self-esteem of stigmatized individuals will increase to the extent that the individuals come to view themselves as other than helpless, dependent, and worthless" (1984, 136).

Several individuals and groups have already proposed new clinical guidelines to protect the rights and autonomy of intersexed individuals.⁴⁶ Through the development of alternative and compassionate understandings of intersex with less social focus on genitals or gender, the pejorative meanings associated with it may, perhaps, begin to be cast off. In order to transform social discourse in this way, far more consideration must be given to the impact of small-scale social movements and social support networks as vital agents of social change.

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