(De)constructing (Inter)sex: Paternalistic Medicine, Apathetic Law, and Praxis for Self-Determination

Elis L. Herman, Salem College

Abstract

In recent decades, issues affecting persons with intersex conditions (or “disorders of sex development” [DSD]) have become more widely politicized with increased inclusion under the lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTQIA) activism umbrella. Issues affecting intersex individuals, however, are unique and separate from those experienced by people of other marginalized sexual and gender identities, particularly because of the ways many intersexuals are forced into non-consensual and stigmatized interaction with medical institutions. This paper analyzes the unique experiences of intersex individuals in regards to their interactions with medical institutions and synthesizes praxis for social change through a disability theory framework.

In recent decades, issues affecting persons with intersex conditions (or “disorders of sex development” [DSD]) have become more widely politicized with increased inclusion under the lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTQIA) activism umbrella. Issues affecting intersex individuals, however, are unique and separate from those experienced by people of other marginalized sexual and gender identities, particularly because of the ways many intersexuals are forced into non-consensual and stigmatized interaction with medical institutions (Koyama & Weasel, 2002). This paper will analyze the unique experiences of intersex individuals in regards to their interactions with medical institutions. What are standards and ethics of medical treatment for intersex patients?
What factors determine whether or not medical treatment is successful? Throughout their lives, do intersex patients report satisfaction with the results of medical efforts to treat intersexuality? Finally, what are alternatives to medical “correction” of intersex characteristics?

Review of the Literature

Fundamental to feminist and queer theories is the idea that the body is a canvas upon which social and cultural meanings are written (Hester, 2004). Our bodies are politicized sites at which the intersections of sociocultural influence and personal choice lie. Critical to social legibility is a body’s ability to fit recognizably into one of two sex/gender categories (Preves, 2002). When a baby is born (or, with now commonplace sonogram technology, even within the womb), spectators immediately grapple for evidence of sex based on the ostensible appearance of its genitalia. By declaring, “It’s a boy!” in the delivery room, onlookers assign a gender to the infant according to a presumably self-evident signifier of sex. This gender, determined by a split-second observation of genitalia, arguably becomes one of the single most influential factors that affects every moment of the child’s life.

But what of babies who cannot be immediately categorized in the delivery room? Researchers estimate that between 1.7 and 4% of the world’s population can be categorized as “intersex,” or presenting any of a varied group of conditions that “result in atypical internal or external reproductive anatomies or chromosomal anomalies” (Haas, 2004; Koyama & Weasel, 2002, p. 169). When a newborn’s sex cannot be determined upon cursory examination, doctors sweep the child away for more thorough inspection and testing to discover its “true sex,” which is perceived to be merely obscured by ambiguous physical characteristics (Preves, 2003). The “answer” to the puzzle of ambiguous sexual characteristics is found through determination of binary sex. Assigning sex is time-sensitive; if not done with urgency and confidence, a (psycho)social emergency where the child is not reared definitely as one gender or the other may occur (Hester, 2004; Kessler, 1990; Murray, 2009). In approximately one in two
thousand births, medical professionals and parents choose to assign sex by altering the child’s body through surgical means (Koyama & Weasel, 2002). This is undertaken with the assumption that having atypical genitalia will cause a child psychological distress as they mature (Haas, 2004). It is also, however, a social act of physically inscribing recognizable sex (and, thus, gender) on an “unruly” body: “In order for gender to succeed, it must first carve out a sex when none 'obviously' exists” (Hester, 2004, p. 221).

Almost all historic literature regarding intersex focuses on medical discussions of diagnoses and treatment. Since the 1970s, medical ethics has become central to intersex-related writing. Feminist and queer theorists have also joined the dialogue, using intersex lives as exemplary of the unstable sex/gender dichotomy (Koyama & Weasel, 2002). Most scarce in existing literature are the voices of intersexed people themselves; academic conversation takes place mostly in a theoretical context amongst “outsiders.” This said, for the purpose of answering the research questions above, I group contemporary literature into four non-exclusive categories, which offer historical and scientific context for intersexuality, assess standards of intervention in intersex cases through a medical-legal ethical lens, examine intersexuality as a phenomenon with unique sociocultural meanings and consequences, and center the experiences and voices of intersex people through a social justice framework.

Before beginning to examine historic and contemporary discourses regarding intersexuality, it is important to consider the very language I will use in my own analyses. Attempting to categorize a wide range of similar and dissimilar experiences under a single umbrella term will naturally evoke controversy and debate, and intersexuality is no exception. Through the twentieth century, the word “hermaphrodite” was commonly used as a “neutral” term to describe an individual whose body differed from expectations of binary sex. Contemporarily, this term is widely considered offensive and/or inaccurate. In the 1990s, the term “intersex” arose as a replacement and was adopted by individuals and organizations involved in activism and advocacy. Still, the language was fraught. Some parents and
doctors expressed fear that the “sensationalized” and still-inaccurate label would negatively impact children’s social and medical well-being. In 2005, a conference of international experts (but only two intersex people) voted to normalize the term “disorder of sexual development (DSD)” in place of intersex (Alm, 2010; Reis, 2007). In the next year, the Intersex Society of North America (ISNA), the world’s largest intersex advocacy organization at the time, began advocating for the use of DSD over intersex in order to bridge gaps between individuals and doctors that negatively impact medical treatment (Morris, 2006). Contemporarily, both intersex and DSD are used in the various contexts of discourse.

I try to use language that reflects, as accurately as possible, the way that individuals with lived experiences prefer to describe themselves. I choose to use “intersex” over the myriad of other terms available in hopes of centering medical opinion regarding what terms are adequate, acceptable, and accurate. Instead, I hope to center shared, yet unique, cultural experience (which is, indeed, incontrovertibly informed by medicine). I seek to respect the self-definition of people who have historically been subject to the language of others defining their lives. The language I use here is not chosen with the intent to advocate for any particular set of terms over another; as a non-intersex person, I have neither stake nor credibility in making these claims. I acknowledge that any of the terms I have chosen not to use are claimed or reclaimed by any number of people who live these experiences. As with all controversial topics, the language of sex development is politicized. Rather than futilely attempting to de-politicize my own discourse, I choose language with full acknowledgement of its many implications and limitations.

History and Medicine

Many distinct conditions may fall under the intersex umbrella, and each may have different medical standards regarding treatment. Fetal sexual development is a complex, multi-layered process,
and any stage may give rise to an intersex condition. Biological sex is developed through a dual process of sex determination and sex differentiation. Sex determination is the phase in which internal gonads (testes/ovaries) develop. Sex differentiation describes the process by which a fetus develops secondary sex characteristics and external sex structures. During each of these two processes, events may occur that disrupt typical developments of sexual dimorphism and result in intersex conditions. In the sex determination stage, genetic mutations may occur that affect the development and replication of chromosomes and genes. These “errors” may be caused by gene omission, translocation, or spontaneous sequence disruption. Klinefelter’s syndrome, a relatively well-known condition resulting in “47XXY” chromosomal makeup, is an example of a variance in sex chromosome production. Other conditions, such as androgen insensitivity syndrome and congenital adrenal hyperplasia, arise from hormonal divergences (which occur during sex differentiation) and affect sex organs and the formation of secondary sex characteristics, rather than genetic makeup (Chau & Herring, 2002). Overall, researchers estimate that approximately one in 100 babies are born with bodies that do not fit the definition of “standard” male or female, and up to two in 1000 people are subject to surgical “normalization” (Hofman, 2012).

Though contemporary discussions of intersexuality are laden with medical jargon and intervention, intersex bodies have not been pathologized throughout history. Medical writings from twelfth century Europe indicate that “hermaphrodites” were considered to constitute a distinct sex in themselves. Though social acceptance varied, the twelfth century Church generally allowed hermaphrodites a great degree of self-determination in choosing their lived genders, so long as they selected one and abided by its prescribed sexual roles. Until the eighteenth century, most childbirths were presided over by communities of women and occurred without the aid of doctors. Because of this, cases of sexual ambiguity were handled privately by individuals and families, rather than through a medical establishment. Technological innovation in medicine changed the circumstances of childbirth. In
order to access pain-relieving and life-saving resources not available to the general public, women began including doctors in routine childbirth for the first time. Soon, babies were being born in hospitals, rather than homes, and formerly private matters became the jurisdiction of a class of medical professionals (Preves, 2002). Surgical intervention for intersex cases did not begin until the 1930s (Haas, 2004). Cultural fears of homosexuality led to a heightened focus on marriage, which concretized both the social and legal importance of legible and stable sex (Preves, 2002). By this time, the concept of hermaphrodites as a “third sex” had disappeared, replaced instead by the belief that every person has a “real sex” of either male or female (Haas, 2004). By the 1950s, surgical and hormonal intervention in intersex cases had become routine and codified (Haas, 2004; Preves, 2002).

Critical to informing the more recent history of medical intervention in intersex cases is the work of psychologist/sex researcher John Money. It is the rather disreputable outcome of Money's own research that brought the treatment of intersexuality into wider public awareness for the first time. Though Money's research study was not actually conducted on biologically intersex subjects, it was used for years to support the theory that gender identity is not biologically inherent, but learned through socialization. In this particularly infamous case study, Money suggested that a young male, whose penis had been badly burned during circumcision, be reared as a girl. According to his theory of psychosexual neutrality in infants, Money believed that the child could successfully adapt to either gender assignment, so long as the rearing environment established and enforced a clear-cut gender identity within a particular period of time (typically within 18-24 months). For years, it seemed that the child Money studied was living happily within the assigned girl gender, and the “success” of the case was used as evidence in favor of Money's theory. Decades later, however, another researcher reconnected with the subject, and it was revealed that the individual had not felt comfortable in his assigned gender, after all. After experiencing sex dysphoria, the individual pursued surgery and hormones to reconstruct his
male body. Ultimately, the individual committed suicide (Fausto-Sterling, 2000; Haas, 2004; Hofman, 2012; Lareau, 2003).

Though the strongest of Money's claims of “psychosexual neutrality” have been largely discounted as new evidence has come to light, his studies on the psychosocial construction of gender nonetheless led to the development of a set of standards used for surgical sex assignment in intersex children known as “optimal gender policy” (OGP). According to OGP, the most important factors in determining how to best treat intersex conditions are: “(a) reproductive potential (if attainable at all); (b) good sexual function; (c) minimal medical procedures; (d) an overall gender-appropriate appearance; (e) psychosocial well-being; and (f) a stable gender identity” (Zucker, 2002, p. 269). These standards, which prioritize heterosexuality, are still common practice in making medical decisions regarding surgically assigning sex to intersex infants.

Technological developments now make surgical and/or hormonal measures for sex assignment common practice in cases of intersexuality. Various factors determine which surgical procedures for sex assignment are undertaken, but central to most medical decision making is the question of whether or not the child possesses a functional, “adequate” penis (Hofman, 2012). In assigning sex, phallic/clitoral tissue that measures between .9 and 2.5 cm is considered “ambiguous,” warranting investigation and intervention (Adkins, 1999). According to Money's theories, “maleness” is more dependent on penis size than genetic makeup or reproductive capability. If a child who otherwise possesses XY chromosomes and the ability to produce sperm is born with a penis that is shorter than the “acceptable” standard, Money recommended performing surgery to remove the penis and subsequently rearing the child as a girl. It is often uncertainty regarding a newborn's clitoris or penis that prompts further investigation into gonadal and chromosomal makeup, which, in turn, informs decisions regarding surgical or hormonal intervention. If a chromosome test on an infant with ambiguous genitalia reveals XX chromosomes, surgery to remove the “enlarged clitoris” is undertaken immediately. If, however, a genetic test finds a Y
chromosome, doctors proceed to test whether the child will respond to testosterone treatments that will cause the “phallus” to grow. If the infant’s genitals masculinize with testosterone, physicians will assign a male sex. If not, the tissue is considered an “oversized clitoris” and removed, and the child is raised as a girl (Kessler, 1990).

Since the outward appearance of genitalia is the primary concern in contemporary sex assignment, these decisions are based on the scientific capability of constructing “normal-looking,” functional genitalia. Modern scientific technology possesses the ability to construct visibly passable and functional vulvae and vaginas, yet surgeons are unable to create penises that are as credible. Because of this, intersexed infants are more often assigned “female” than “male” and given feminizing surgery (Hofman, 2012; Kessler, 1990). Ideas of “functionality” that are applied as standards to male or female sex assignment are defined according to expectations of heterosexual sexuality (Adkins, 1999). If female sex is assigned, an individual should possess a vagina capable of receiving (and providing pleasure for) a “normal” sized penis, without obstruction from an enlarged clitoris. The fact that more intersexed children are assigned female than male also demonstrates adherence to a heterosexual matrix: a male child allowed to mature with a small penis will be psychologically traumatized and emasculated in (hetero)sexual encounters, so it is in the child’s best interest to instead assign and construct functional female sex (Adkins, 1999; Kessler, 1990).

The Ethics of Medical Intervention

Who is responsible for making medical decisions for intersexed infants and children, and what are the legal foundations for this decision making? Much literature about intersexuality focuses on this question, considering issues of bodily autonomy in ethical-legal and human rights contexts. As many irreversible surgical procedures are performed upon intersex individuals beginning at a young age, the role of parents in making by-proxy choices for childrens’ bodies is frequently scrutinized.
Western culture affords parents a great degree of social and legal authority over dependent minors (Hofman, 2012). Legally, parents have the power to choose whether to educate minor children in public, private, or home schools. Because nuclear families are usually financially intertwined, parents' economic and cultural values affect the post-secondary education and careers children pursue, as well. Ultimately, an individual’s own relationships and family-making decisions are profoundly influenced, both explicitly and tacitly, by the values and desires conveyed by parents. Parental power extends to the realm of medicine when children are not old enough to give or withhold consent for themselves. In making health-related decisions that may dramatically affect their children's lives, parents are expected to act as objective judges of the best interest of their children (Lareau, 2003). This expectation of neutrality, however, is problematic, and the degree of control parents are given over children's bodies is ageist. Parents are not exempt from sociocultural influences that indisputably affect the decisions they make for themselves and their families. On the contrary, the cultural shame and confusion surrounding sex development divergences puts parents in unique positions in which they must navigate intense stigma and uncertainty (Hofman, 2012). Parents do not and cannot make these decisions based exclusively on what is in their child's best interest; they also take into consideration their own social selves and the repercussions they may face in deciding against “normalizing” their child (Hofman, 2012; Murray, 2009).

Hofman (2012) describes this duality as indicative of “categorical conflict,” defined as a situation in which there is substantial conflict of interest to warrant the intervention of a neutral third party. Three types of categorical conflict may occur when parents are placed in decision making capacity for intersex children. First, emotional conflict occurs when decision maker and patient have divergent, irreconcilable needs and interests. Secondly, cases of “extraordinary” medical treatment present a conflict because of their rarity and/or medically unnecessary nature. And, lastly, situations in which constitutional rights of dependents have the possibility of being violated create conflict between
parents' rights to make determinations for dependents, and children's rights to be protected from harm (Hofman, 2012).

Intersex cases demonstrate all three types of categorical conflict. Emotional conflict is evident as parents often react out of confusion, fear, and surprise when they learn that their child is intersexed. In addition, research shows a double standard between parents' opinions regarding early-life genital surgeries. When asked if they themselves would have preferred to be surgically assigned an alternate sex due to genital ambiguity at birth, the vast majority of adults say they would not. When asked to make a decision regarding their own hypothetical children, however, answers changed dramatically. This asymmetry may be attributed to the emotional nature of a situation in which parents must make decisions that have social ramifications for both themselves and their children (Hofman, 2012).

Early genital surgery is a case of extraordinary medical treatment. Hofman (2012) draws parallels between this surgery and organ donation between two siblings. For the donor sibling, the operation does not have ostensible medical benefit. In these situations, courts are almost always called upon to make a decision due to parental conflict of interest. In order for a judge to decide in favor of allowing the organ donation, parents and medical professionals must prove that benefit (usually the psychological benefit of avoiding the death of a sibling) outweighs risk for the donor child. For intersex children, surgical intervention is usually a cosmetic, rather than medically necessary, procedure. Due to the relative rarity of intersex conditions, medical intervention in these cases could be further called “extraordinary” (Hofman, 2012).

Finally, intersex cases present a conflict of interest because of the potential that surgical intervention will interfere with the individual's ability to procreate, considered by international law a fundamental human right. Hofman (2012) relates issues that arise in intersex cases to the legal precedent for parental consent regarding sterilization of disabled individuals. When a parent appeals to the authority of a court to approve non-medically necessary sterilization of disabled dependents, judges
must deliberate considering the deeply personal and emotional nature of sexuality and procreation. Often, courts rule against sterilization even in cases where the individual is deemed “incompetent” in the interest of protecting the right to procreation. The decision to operate on an intersex child can be examined through the same lens, as surgical genital “normalization” and subsequent sex-assignment treatments often leave individuals unable to procreate through both natural and artificial means (Hofman, 2012).

In cases of categorical conflict, a court or judge typically serves as a third-party arbiter. To date, however, few cases of court intervention exist internationally. The United States, home to the world’s largest intersex rights organizations, currently has no legal precedent or protocol for addressing categorical conflict in cases of intersexuality (Haas, 2004). The only rulings in the world that have been made regarding parental consent power for intersex children have come from the Constitutional Court of Colombia (Haas, 2004). In the first of such cases, Sentencia No. T-477/95 (“Gonzalez”), a male was surgically reassigned as female after accidental castration during circumcision. When Gonzalez became aware as an adult of what had happened, he sued the hospital. The Colombian Constitutional Court ruled in Gonzalez’ favor on the grounds that his constitutional right to dignity had been violated by performing sex-assignment surgery. In the decision, the court set precedent that doctors could not surgically reassign sex on any person without informed consent (Haas, 2004).

Sentencia No. SU-337/99 (“Ramos”), involved a child whose intersex condition was not evident until the age of three. The child, Ramos, raised as a girl, was found to have XY chromosomes and male gonads, but ambiguous external genitalia. When doctors realized the condition, they recommended surgery to remove gonads and construct a vagina. Due to the precedent set in Gonzalez, however, doctors would not perform surgery without informed consent. Ramos’ mother petitioned the court to accept her consent for the surgery. The court, noting that the child (now age eight) identified with a feminine gender identity, ruled against the petition (Davidian, 2011; Haas, 2004). The rationale for the
court’s decision reveals compromise, rather than unequivocal certainty in setting precedent for the future. In the decision, the court acknowledged that the dominant treatment model of surgical “normalization” was not necessarily based on evidence of necessity and effectiveness. At the same time, the court argued against an outright moratorium on surgeries, as intrusion in such decisions would violate family privacy rights. Ramos’ age was a primary factor in the court’s decision to deny her mother the ability to consent; because she was eight years old, the court viewed surgical intervention as a more dramatic invasion of bodily autonomy. Thus, the decision did little to set a precedent against medical intervention for infants and young children.

A third case, Sentencia No. T-551/99 (“Cruz”) arose in the wake of Ramos. Cruz, who was three years old at the time the case was heard, was born with XX chromosomes and an enlarged phallus. Cruz’s parents sought the court’s approval to surgically reduce the size of her phallo-clit. The lower court ruled that, due to the age of the child, parents could consent to genital surgery. After Cruz had received surgery, the Constitutional Court elected to rehear the case. In its investigation, the Court found that the parents who consented in place of the child had not been adequately informed of the implications of surgery, and thus Cruz’s constitutional rights had been violated (Haas 2004). In order to prevent such situations from happening again in the future, the Court established three criteria to govern by-proxy consent for children under the age of five: (i) the consent must be in writing; (ii) detailed information must be provided to parents so they are informed about the dangers of current treatments and the possibility of alternatives to surgery; (iii) the authorization must be given on several occasions over a reasonable time period to ensure the parents have time to truly understand the situation (Davidian, 2011, p. 16).

Though these criteria are a step forward for protecting against some rights violations, they still fall short of changing the status quo of intersex medical treatment. The standards do not determine what kind of or how much information is considered adequate for parents to consent, nor do they
question the fundamental assumption that intersexuality is a divergence that must be “treated” by medicine. They fail to address the pain, scarring, loss of sexual sensation, removal of reproductive capability, and possible incorrect gender assignment that can and do accompany genital surgeries performed on infants (Hofman, 2012). But Colombia's guidelines, however inadequate, still offer more protection than United States law.

Law in the United States does not explicitly protect intersex people in any way, nor does it possess any codified standards for informed consent. To date, no successful lawsuits have been filed against hospitals or doctors, as surgical genital “reconstruction” is currently considered best practice in response to intersexuality. The Fourteenth Amendment to the U.S. Constitution, which protects individuals' rights to life, liberty, and property, may provide grounds for individuals to successfully sue state hospitals. Even if a parent would offer informed consent to perform genital surgery on an intersexed child, the doctrine of parens patriae, which allows the state to intervene if a legal guardian makes or fails to make decisions that serve the best interest of a dependent, may serve to prevent surgical intervention (Haas, 2004). For parens patriae to serve intersexed children, however, surgical “correction” of intersex conditions must first be examined on an institutional level as potentially problematic.

In reconsidering by-proxy parental consent for genital surgeries performed on infants, it may be useful to examine other situations in which the legal requirement for parental consent is suspended in favor of allowing minors to offer their own consent. In order to receive treatment or testing for sexually transmitted illnesses, pregnancy, and drug addiction, for example, minors typically do not need to seek parental consent. Like drug addiction or pregnancy, Haas (2004) argues, dealing with intersexuality puts young people in a difficult situation in which they must make deeply personal choices regarding their own health and well-being. These choices, which result in irreversible physical and psychological results, should rest in the hands of only the individual involved (Haas, 2004).
Social Theory and Intersex Bodies

Intersexuality has been analyzed by feminist and queer theorists as exemplary of the multiplicitous and constructed natures of both sex and gender (Koyama & Weasel, 2002). Scholars discussing intersexuality synthesize ideas presented by theorists such as Foucault, Butler, and Wittig to examine intersexuality as a type of disruption of the “normal” (Adkins, 1999). Feminist and poststructuralist literature proposes that intersexuality decenters the dichotomy of the altered vs. “natural” body. The sexed body is never natural; from the moment a body’s sex is noticed, the forces of cultural (re)production act upon that body to inscribe gendered meaning. Thus, the sexed body cannot exist in an unaltered state, so the medical-legal ethical debate is centered within a false dichotomy in which there is a non-existent absolute zero of alteration (Murray, 2009).

Sex itself has no absolute qualities or characteristics and cannot exist independently of a defining structure. According to Adkins (1999), “Gender and sex are not actually equivalent to the body, however, in that the body is (ontologically) a physical absolute of human existence, while gender and sexuality are only absolute in peoples’ imaginations” (p. 119). “Normal” constructions of sex, gender, and sexuality are products of naturalization and normalization. In naturalization, a fundamental matrix of expectations is continually constructed as essential and inherent; in normalization, these standards are reproduced on micro and macro levels through various structuring channels. The framework created and maintained through naturalization and normalization is unstable; it relies on our willingness to ignore and/or make “Other” exceptions which expose this instability in order to maintain hegemony (Adkins, 1999).

Adkins (1999) calls intersexed people “an emergency of the normal,” in that they disrupt the intentionally dimorphic construction of sex that we use to make generalizations regarding the structures of both contemporary and historic human experience. Intersexuality creates an emergency because it
troubles a dichotomy in which each categorization depends on the other. In order to discipline and control sex, medical procedures are undertaken to impose a readable sex (described as finding the “real” or “true” sex) on uncategorizable bodies. This forced assignment is an act of assigning value to bodies that would not “matter” in a sex-dimorphic matrix (Turner, 1999). Intersexuality unsettles the heterosexual matrix; if bodies exist that are not decisively male or female, then any act of sexuality is simultaneously both homosexual and homosexual, and neither heterosexual or homosexual. In addition, if bodies with unknown intersex conditions move through the world, all sexuality has the potential to be non-heterosexual. The success of the medical procedures undertaken to “normalize” intersex bodies is measured as the body's ability to function within the heterosexual matrix. When feminizing surgery is performed, the vagina must be constructed to be flexible enough to enable penetration by a penis; the “phallus,” if present, must be reduced in size so as not to threaten or interfere with the work of the penetrating penis. The penis is central in assigning sex. If it is “too small” for heterosexual sex, best practice maintains that it is better to surgically create a heterosexually functional female (Adkins, 2004; Kessler, 1990).

Medical-legal discussions of the ethics of performing genital-normalizing surgery on infants almost always examine issues of consent in terms of whether a parent has or should have the legal and ethical right to decide to permanently surgically alter the body of a dependent child (Haas, 2004; Uslan, 2010). By challenging binaristic juxtapositions of altered/unaltered bodies, feminist discourse can serve to recontextualize the role of parents as decision makers for intersex children. In both activist and medical-legal ethical discourse, parents are often presented as passive actors who are capable of making decisions only through the knowledge they receive through medical professionals (Haas, 2004; Murray, 2009). It is critical to examine the complex subjective position of the parent, as well as the intersex child. In holding legal and medical power over dependent children, parents are expected to make choices independent of their own biases in order to serve the child's best interest. But parents themselves are
culturally forced into ambiguous and conflicting subjectivity in relation to their children. Murray (2009) notes, “The birth of a new baby is defined by discourses about inarticulable bonds and closeness between parent and child, and yet the debates about intersex treatment decisions insist on the imposition of clear distinctions...between genders, between parents and children” (p. 269).

These contradictions expose the fallacy of binarism and distinction between self and other. Intersex theory can also call into question assumptions about the stability and immutability of sex. According to Hester (2004), the medical management of intersex bodies does not serve solely as a means of social control of sex/gender. On the contrary, intersexuality exposes the multiplicity and fluidity of sexed embodiment. Like Murray, Hester challenges the assumed passivity of the body, and in particular intersexual bodies, as their very nature proves to evoke violent repudiation. Hester locates the cultural importance in sex, rather than gender. Sex and gender “both necessitate and constitute one another” (Adkins, 1999, p. 122). That is, the social/cultural expectations of gender are assigned based on sex. It is still necessary, however, to maintain the perception of sex and gender as separate because it enables discipline of the division through both biological and cultural means (Adkins, 1999). This is evidenced in the medical management of intersex conditions: before a gender can be assigned and carried out properly, sex itself must be molded into legibility and normalcy (Hester, 2004). The existence of many sexes bolsters ideas of queer theory, for if sex is infinitely multiplicitous, how can gender and sexuality be qualified with terms like “normal” or “deviant”?

**Intersex Lives and Voices**

Academic literature about intersexuality is quick to point out the dearth of scientific research into the life courses and experiences of intersex people. That which does assesses intersexuality through either a psychomedical lens (Berenbaum, 2006) or studies intersex issues in conjunction with other lesbian, gay, bisexual, and, particularly, transgender, issues (Witten, 2003). These deficiencies are due, in
part, to the difficulty of undertaking retrospective studies on a group of people that has systematically been left mis- or under-informed by medical authority regarding the most personal aspects of their embodied histories. Because of this, researchers face issues in undertaking qualitative research of intersexed persons (Sytsma, 2004).

But arguments regarding the necessity of further research on intersex people exposes that scientific study itself harbors dangerous prejudice against intersex experience. In advocating for the necessity of overcoming the ethical dilemma of informed consent in order to conduct research, Sytsma (2004) declares that “We only have anecdotal, but not scientific, evidence that surgery is undesirable,” and that medical professionals need “good scientific study” to reconsider the current standards of treatment for intersexed persons (p. 397). Here, discourse again becomes entangled in the all-too-familiar power differential between those who possess “legitimate” knowledge (of science and medicine, for example) and those whose knowledge is purely experiential. Credence is given to “good science” alone while anecdotal experience is devalued. This is a shortcoming of classical scientific study in itself; large numbers of people may stake strong personal and experiential claims, but until the responses are scientifically codified, their voices are not considered legitimate.

Literature addressing the representation of intersex voices is often critical of the way intersexuality is used as evidence of sex and gender multiplicity in queer and feminist theorizing, yet does not center or prioritize intersex voices or experiences in praxis (Koyama & Weasel, 2002). As is often the case with marginalized groups of people, much academic literature is written by individuals who are outsiders to the lived experiences of intersexuals. Legal, medical, and academic discourse regarding intersexuality is almost entirely dominated by non-intersexed people. Doctors and parents who make decisions regarding surgical and hormonal treatment for intersexuality are almost universally not intersexed themselves. Medical institutions and courts that determine and litigate regarding “best practice” are largely comprised of non-intersexed people. Almost all researchers who gather and
synthesize information regarding the life courses of intersexual people are not out as intersexed. Very few academic theorists and professors who use intersexuality to bolster arguments made in queer and feminist theoretical frameworks are out as intersexed.

The above is not to imply that there are no intersexed people in court, medical, and legal systems. It is also not to say that intersexed people who are in these positions should “out” themselves as intersexed. In reading and writing about intersexed people, however, it is important to be aware that intersex voices are largely under- or unrepresented in the discussions that define intersex lives. Since subjective accounts are treated with less respect and credibility that “objective” science and law, intersex people who describe their experiences are relegated to the non-academic realm. Because most literature focuses on intersexuality as an abnormality that must be fixed, discourse advocating for improved methods of surgical sex assignment dominates, and intersex peoples' life experiences and identities are systematically devalued (Preves, 2003). Centering intersex voices in discourse can disrupt this medicalized paradigm.

What intersexed people have to say about their own experiences is essential and central in evaluating contemporary modes of addressing intersexuality and proposing alternatives for a better future. In some ways, it is difficult to make generalizations about the widely varied experiences of many intersexed individuals; in other ways, however, intersexual people find community with one another because of shared experiences of stigma, shame, and medical objectification. Sharon Preves' (2003) interviews with 37 intersexed adults revealed that the majority of them had strikingly similar experiences negotiating with medical institutions throughout their lives. Only two had not been subjected to non-consensual surgeries at a young age. All disclosed histories shadowed by secrecy that caused confusion and shame through childhood and adulthood. Of the 37 people Preves interviewed, the vast majority report that they would have preferred not to have been operated on without their expressed consent. This sentiment is common in other forums where intersexed people discuss
experiences, as well. Individuals confide feeling “horrified...by the conspiracy of silence and lies” and
“filled with grief and rage” (Chase, 2006, p. 306). But, in connecting with others, some intersex people
also feel “relief finally to believe that maybe I am not the only one” (Chase, 2006, p. 306).

Many respondents spoke to the importance of community in alleviating stigma and shame. In
these comings-together, intersexed people are able to be open, often for the first time, regarding
shared experiences of invisibility and isolation. The ability to create a collective source of information
and support (especially via the internet) allows intersexed people to develop senses of self that are
based on autonomy, rather than forced dependence on paternalistic institutions. Some intersexed
people discuss the importance of seeing the bodies of other intersexuals; they describe the experience
as liberating, empowering, and essential to developing a sense of identity and self. One respondent,
Martha, noted, “After having lived all my life in isolation with this, suddenly to hear another person
speak...It felt like I've been living on this alien planet...and now I've met my people from [my own]
planet” (Preves, 2003, p. 122). The sense of identity that develops through connectedness and
community inspires (and has the potential to further empower) social movements to change the culture
of shame and stigma surrounding divergences of sex development.

Analysis

The preponderance of historical literature regarding intersexuality has been written in support
of surgically altering intersex peoples' bodies to conform to cultural standards of binary sex. More
contemporary perspectives are emerging, however, that prioritize intersexed individuals' experiences
and challenge the status quo of medicalization. This movement towards social justice-oriented discourse
provides theoretical and applied praxis for a future rooted in bodily autonomy and self-determination
for intersexed people.
Traditionally, intersexuality has been examined primarily through feminist and queer theoretical frameworks. Feminist theory highlights the sexism in medical responses to intersexuality. For example, feminists discuss how intersexed infants are more commonly assigned female due to heterosexist standards of genital appearance and sexual function. In queer theory, intersexuality is often used as evidence as to the malleability and inherent multiplicity of gendered embodiment. Radical disability theory is a useful framework for examining intersexuality for two reasons. First, it positions intersex people as experts in their own experiences. And, secondly, it encourages dialogue that centers practical solutions to injustice.

Disability theory is centered in the idea that physical or psychological conditions which impair “normal” movement and function within the world are not, in themselves, inherent disabilities. Rather, we live in an environment and culture in which individuals with certain conditions are stigmatized and viewed as fundamentally flawed. It is this stigmatization, which prevents people from fully participating in social life, that is disabling (Koyama, 2006). Disability scholar Mike Oliver (1990) discusses disability in terms of two different interpretive models. Our culture is constructed in terms of what Oliver calls the “individual model of disability” (sometimes called the “medical model of disability). This model asserts that adaptive issues are located within individuals, and that the condition of disability is caused by these physical and/or psychological limitations. In the individual model, disability is medicalized and treated as illness or disease. Radical disability theory, on the other hand, operates in a different framework, which Oliver calls the “social model of disability.” Rather than defining the problem of disability as individual failure to adapt, the social model contends that our society itself creates a disabling environment. Due to society's failure to provide appropriate and adequate support for all of its members, individuals who fall outside of definitions of “normalcy” are unable to participate equally (Oliver, 1990).
Oliver (1990) declares that disability is “a social state and not a medical condition” (p. 2). Thus, medicalization of disability is neither acceptable nor necessary, as disability is not equivalent to illness. Though some illnesses may cause disability, and most everyone (including disabled people) will invariably fall ill at times throughout their lives, the two are, in reality, separate experiences with dramatically different social effects. Illness is a temporary condition which is usually treated and/or cured by doctors and other medical professionals. Disability, however, cannot be cured, as it is a social state. The medical profession, then, has no business undertaking interventions with the purpose of treating or curing disability. But in the individual model, doctors do just that, resulting in medicalization and, ultimately, discrimination and oppression (Oliver, 1990).

In order to transition from the current cultural understanding of disability as an individual problem that requires treatment, Oliver (1990) demands we interrogate the power held by medical “experts.” Doctors receive training in treating illness; this training does not equip them to examine or make recommendations for addressing social problems. Still, doctors are afforded substantial credibility and power in determining the conditions of disabled peoples' lives. Medical interventions in cases of disability are undertaken with the purpose of normalization. When they are not able to normalize people through methods of common practice, doctors may still intervene at will (often experimentally) in hopes of achieving a modicum of normalization, with no regard for the suffering it may cause to the individual in question. This great disparity gives medical professionals irrefutable power and leaves disabled people with none. In order to transition to the radical social model, in which disabled people have power and autonomy over their own lives, we must work to develop a framework that redefines doctors' roles in addressing disability (Oliver, 1990).

These general critiques of medical interventions in disabled peoples' lives engender unmistakable parallels to critiques of the role of psychomedical institutions in surgically altering intersex infants. Intersexuality, too, can be examined in terms of the social model of disability. Doctors perform
surgery on intersex children in the interest of creating bodies that can be recognizable and functional according to heterosexual standards of normalcy. Doctors and parents fear that neglecting to perform surgery will cause the child in question to grow up physically and psychosocially dysfunctional or disabled. In applying the social model, it is evident that the heterosexist, homophobic, and ageist infrastructure of our society is what disables intersexed people through shame and stigma. Disability theory is a useful framework for examining intersex experiences because it decenters medical power positions it, instead, in the hands of intersexed people themselves.

**Solutions**

At the most fundamental level, the reason early genital “reconstruction” surgery is performed on intersexed infants is because of the cultural expectation of adherence to a sex/gender binary. In addition, ageism that prevents young people from making decisions regarding their own bodies and lives has been central in medical and legal discourses regarding the appropriateness of surgery. Using the ideas of disability theory, it can be said that our environment is constructed so that in order to be functional, individuals must conform to one or the other “binary” sex; non-conformity is equivalent to dysfunction, which is considered diseased. To change this paradigm requires long-term work on both individual and institutional levels. It is extremely unlikely, however, that a social system built with binary sex as a foundation will change significantly overnight. Though it is critical to work on changing the ways in which oppressive systems define our lives, we must also remember that each day approximately 6 infants are being subjected to non-consensual genital surgery in the name of “normalization.” We must also immediate action through medicine and the law to halt this injustice.

Destigmatization of divergences of sexual development and social acceptance of sex and gender diversity is the ultimate goal in intersex advocacy. This would necessarily entail a moratorium on performing genital surgeries on individuals who cannot consent. A moratorium is not simply a legal
issue; rather, for non-consensual medical intervention to be halted and replaced with a new paradigm of
self-determination and dignity, a halt in surgical intervention must be reached through both litigation
and changes in medical culture. Both are required in order to recontextualize intersexuality, and both
depend on one another to create wider social change.

There is a growing body of evidence that indicates that performing early genital-normalizing
surgeries on infants has negative effects on long-term psychological and physical well-being (Dittman,
1998; Dreger, 1998; Lareau, 2003). Rather, determinations of “success” are made regarding the
aesthetic function and “passability” of surgically altered genitalia, with no investigation into the personal
experiences of those who underwent the procedures themselves (Kessler, 1990). In addition, there
remains little empirical evidence in favor of the claim that these surgeries have psychological benefit.
These findings (and lack thereof) can be used as evidence in legal cases arguing for a ban on infant
genital surgery. Currently, it is difficult to initiate litigation against doctors and private hospitals because
performing surgery to treat intersexuality is considered best practice. The Fourteenth Amendment,
which protects individuals from state violation of bodily rights, may provide an opening for lawsuits
against state hospitals (Haas, 2004). A successful lawsuit may lead to stronger informed consent
standards, as in Colombia's Cruz. So long as surgical intervention remains best practice when intersex
children are born, providing families with more information and better support is central.

These improvements in medical care, though small, may serve as a modicum of protection for
intersexed people while activists work on creating broader social change. Doctors who interact with
patients and parents view performing “normalizing” surgery on infants as an ethical duty in order to
ensure that the child is accepted by parents and peers (Roen, 2005). Clinicians do not favor surgery out
of sadism; rather, they are responding in what they believe is in the “best interest” of a child who will
grow up in a world that does not tolerate ambiguity or abnormality. This view of “best interest” exposes
dynamics of power and paternalism in medical practice. The power physicians possess to define and
construct “acceptable” bodies is maintained by a contemporary framework of medical ethics in which physicians may, without question, carve heteronormative meanings into vulnerable bodies (Roen, 2005). Stricter rules and protocol for informed consent in addressing intersex cases may help moderate this power disparity.

In order to reach a moratorium, the current paradigm that prioritizes sex assignment must be replaced by a model that centers individual medical and psychological needs. Alice Dreger (2003) calls the current standards for addressing intersexuality the “Concealment Centered Model.” In this framework, intersexuality is considered a psychosocial emergency, which must be dealt with as soon as possible in order to avoid distress, ridicule, and shame. This model advocates for silence about intersex conditions, arguing that divulging too many details may lead to gender confusion. Ultimately, intersexuality is considered a disease that may one day be cured or prevented through scientific technology.

In opposing the current paradigm, Dreger (2003) proposes a “Patient Centered Model.” This model stresses that intersexed individuals should be afforded the same ethical rights that non-intersexed people enjoy, and that surgical sex assignment should not be performed on non-consenting children. Once an individual reaches an age in which they are able to give consent, they should be able to make their own decision regarding whether or not to pursue surgery. The Patient Centered Model proposes a culture of openness and support for intersexed individuals and their families. By equipping intersexed people with accurate information regarding their own health histories and the risks and benefits of medical intervention, this model centers self-determination and bodily autonomy. In this alternate paradigm, intersexuality is merely one of many manifestations of human diversity, and intersexuals should be treated with dignity and respect.

Organizations and groups have been working to connect intersexed people in shared community and create social change for decades. In 1993, Cheryl Chase created the Intersex Society of North
America (ISNA). Initially, Chase’s immediate goal in promoting the organization was to form a community of intersex people to provide stigma-management and support for one another. In the long run, the organization sought to ensure better lives for intersexed people and families through challenging the best practice of early-life surgeries, establishing support networks for parents and families, and creating political pressure for better legal protections for intersex people. During its tenure as the largest intersex rights organization in the world, the ISNA did all of those things. Because of ISNA’s visibility, dozens of other social and political organizations seeking intersex rights and recognition began to form, and alliances were built between the burgeoning movement and other queer, feminist, and transgender-oriented groups. One such group, Hermaphrodites with Attitude, organized the first ever public protest for intersex rights (Chase, 2006).

In 2008, ISNA closed and passed its work on to the Accord Alliance. Accord Alliance has continued to pursue ISNA's advocacy goals by convening multidisciplinary teams that include intersex people, medical professionals, and allies in order to create better standards of addressing intersexuality. By facilitating these discussions among groups traditionally separated by hierarchies of power, Accord Alliance works to implement the “Patient Centered Model” that Dreger (2003) proposes. After convening the Consortium on the Management of Disorders of Sex Development, which consisted of several dozen intersex individuals, allies, and medical and legal professionals, the Alliance published an extensive set of guidelines for addressing intersex conditions in children. These recommendations were developed through a framework of patient-centered care that prioritized seven principles: to intervene medically only in cases of immediate illness or physical threat; to avoid forcibly assigning sex simply to meet a social norm; to minimize shame and facilitate supportive connections; to allow patients to advocate for themselves through informed decision making; to address the concerns of parents; to psychosocially support children; and, finally, to always tell the truth to individuals and parents (Accord Alliance, 2008).
Destigmatization of sex difference is essential for creating a society in which diversity is celebrated, rather than shamed. Even if a moratorium on infant genital surgery is enacted, some intersexed people may desire to pursue surgeries on their own. It is important that individuals be able to access medical interventions that enable autonomy and self-determination. Intersex activist Cheryl Chase asserts, “Medicine should be at the service of intersexed people rather than a power that operates on our bodies to normalize us whether we want to be normalized or not” (Chase & Hegarty, 2000).

References


