

"Ambiguous Sex"--or Ambivalent Medicine?

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Abstract

Ethical issues in the treatment of intersexuality are examined. It is not at all clear if all or even most of the intersex surgeries done today involve what would legally and ethically constitute informed consent.

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What makes us "female" or "male," "girls" or "boys," "women" or "men"—our chromosomes, our genitalia, how we (and others) are brought up to think about ourselves, or all of the above? One of the first responses to the birth of a child of ambiguous sex by clinicians, and parents, is to seek to "disambiguate" the situation: to assign the newborn's identity as either female or male, surgically modify the child's genitalia to conform believably to that sex identity, and provide other medical treatment (such as hormones) to reinforce the gender decided upon. The assumptions that underly efforts to "normalize" intersexual individuals and the ethics of "treatment" for intersexuality merit closer examination than they generally receive.

A number of events have lately aroused substantial public interest in intersexuality (congenital "ambiguous sex") and "reconstructive" genital surgery. Perhaps the most sensational of these is the recent publication of unexpected longterm outcomes in the classic and well-known "John/Joan" case.¹ "John" was born a typical XY male with a twin brother, but a doctor accidentally ablated John's penis during a circumcision at age eight months. Upon consultation with a team of physicians and sexologists at the Johns Hopkins Hospital (circa 1963) it was decided that given the unfortunate loss of a normal penis John should be medically reconstructed and raised as a girl—"Joan." Surgeons therefore removed John/Joan's testes and subsequently subjected Joan to further surgical and hormonal treatments in an attempt to make her body look more like a girl's. The team of medical professionals involved also employed substantial psychological counseling to help Joan and the family feel comfortable with Joan's female gender. They believed that Joan and the family would need help adjusting to her new gender, but that full (or near-full) adjustment could be achieved.

For decades, the alleged success of this particular sex reassignment had been widely reported by Hopkins sexologist John Money and others as proof that physicians could essentially create any gender out of any child, so long as the cosmetic alteration was performed early. Money and others repeatedly asserted that "Johns" could be made into "Joans" and "Joans" into "Johns" so long as the genitals looked "right" and everyone agreed to agree on the child's assigned gender. The postulates of this approach are summarized succinctly by Milton Diamond and Keith Sigmundson: "(1) individuals are psychosexually neutral at birth and (2) healthy psychosexual development is dependent on the appearance of the genitals" (p. 298). While not a case of congenital intersexuality, the John/Joan case was nevertheless used by many clinicians who treat intersexuality as proof that in intersex cases the same postulates should hold. The keys seemed to be surgical creation of a believable sexual anatomy and assurances all around that the child was "really" the assigned

gender.

But reports of the success of John/Joan were premature—indeed, they were wrong. Diamond and Sigmundson recently interviewed the person in question, now an adult, and report that Joan had in fact chosen to resume life as John at age fourteen. John, now an adult, is married to a woman and, via adoption, is the father of her children. John and his mother report that in the Joan-years, John was never fully comfortable with a female gender identity. Indeed, Joan actively attempted to resist some of the treatment designed to ensure her female identity; for instance, when prescribed estrogens at age twelve, Joan secretly discarded the feminizing hormones. Depressed and unhappy at fourteen, Joan finally asked her father for the truth, and upon hearing it, "All of a sudden everything clicked. For the first time things made sense, and I understood who and what I was" (p. 300). At his request, John received a mastectomy at age fourteen, and for the next two years underwent several plastic surgery operations aimed at making his genitals look more masculine.²

Diamond and Sigmundson are chiefly interested in using this new data to conclude that "the evidence seems overwhelming that normal humans are not psychosocially neutral at birth but are, in keeping with their mammalian heritage, predisposed and biased to interact with environmental, familial, and social forces in either a male or female mode."³ In other words, sexual nature is not infinitely pliable; biology matters.

In their report, Diamond and Sigmundson also take the opportunity of publication to comment on the problem of the lack of long-term follow-up of cases like these. But what is also troubling is the lack of ethical analysis around cases like this—particularly around cases of the medical treatment of intersexuality, a phenomenon many orders of magnitude more common than traumatic loss of the penis. While there have been some brief discussions of the ethics of deceiving intersex patients (that discussion is reviewed below), the medical treatment of people born intersexed has remained largely ignored by ethicists. Indeed, I can find little discussion in the literature of any of the ethical issues involved in "normalizing" children with allegedly "cosmetically offensive" anatomies. The underlying assumption grounding this silence appears to be that "normalizing" procedures are necessarily thoroughly beneficent and that they present no quandaries. This article seeks to challenge that assumption and to encourage interested parties to reconsider, from an ethical standpoint, the dominant treatment protocols for children and adults with unusual genital anatomy.

Frequency of Intersexuality

Aside from the apparent presumption that "normalizing" surgeries are necessarily good, I suspect that ethicists have ignored the question of intersex treatment because like most people they assume the phenomenon of intersexuality to be exceedingly rare. It is not. But how common is it? The answer depends, of course, on how one defines it. Broadly speaking, intersexuality constitutes a range of anatomical conditions in which an individual's anatomy mixes key masculine anatomy with key feminine anatomy. One quickly runs into a problem, however, when trying to define "key" or "essential" feminine and masculine anatomy. In fact, any close study of sexual anatomy results in a loss of faith that there is a simple, "natural" sex distinction that will not break down in the face of certain anatomical, behavioral, or philosophical challenges.⁴

Sometimes the phrase "ambiguous genitalia" is substituted for "intersexuality," but this does not solve the problem of frequency, because we still are left struggling with the question of what should count as "ambiguous." (How small must a baby's penis be before it counts as "ambiguous"?) For our purposes, it is simplest to put the question of frequency pragmatically: How often do physicians find themselves unsure which gender to assign at birth? One 1993 gynecology text estimates that "in approximately 1 in 500 births, the sex is doubtful because of the external genitalia."⁵ I am persuaded by more recent, well-documented literature that estimates the number to be roughly 1 in 1,500 live births.⁶

The frequency estimate goes up dramatically, however, if we include all children born with what some physicians consider cosmetically "unacceptable" genitalia. Many technically nonintersexed girls are born with "big" clitorises, and many technically nonintersexed boys are born with hypospadiac penises in which the urethral opening is found somewhere other than the very tip of the penis.

Historical Background

I came to this topic as an historian and philosopher of science. My initial interest was actually in learning how British and French medical and scientific men of the late nineteenth century dealt with human hermaphroditism. The late nineteenth century was a time when the alleged naturalness of European social sex borders was under serious challenge by feminists and homosexuals and by anthropological reports of sex roles in other cultures. I wanted to know what biomedical professionals did, at such a politically charged time, with those who inadvertently challenged anatomical sex borders.

The answer is that biomedical men tried their best to shore up the borders between masculinity and femininity.⁷ Specifically, the experts honed in on the ovarian and testicular tissues and decided that these were the key to any body's sexual identity. The "true sex" of most individuals thus by definition settled nicely into one of the two great and preferred camps, no matter how confusing the rest of their sexual anatomies. People with testicular tissue but with some otherwise "ambiguous" anatomy were now labeled "male pseudo-hermaphrodites" that is, "true" males. People with ovarian tissue but with some otherwise ambiguous anatomy were labeled "female pseudo-hermaphrodites" "true" females.

By equating sex identity simply with gonadal tissue, almost every body could be shown really to be a "true male" or a "true female" in spite of mounting numbers of doubtful cases. Additionally, given that biopsies of gonads were not done until the 1910s and that Victorian medical men insisted upon histological proof of ovarian and testicular tissue for claims of "true hermaphroditism," the only "true hermaphrodites" tended to be dead and autopsied hermaphrodites.

Nevertheless, new technologies—specifically laparotomies and biopsies—in the 1910s made this approach untenable. It now became possible (and, by the standing rules, necessary) to label some living people as "true" hermaphrodites via biopsies, and disturbed physicians noted that no one knew what to do with such people. There was no place, socially or legally, for true hermaphrodites. Moreover, physicians found case after case of extremely feminine-looking and feminine-acting women who were shown upon careful analysis to have testes and no ovaries. The latter were cases of what today is called androgen-insensitivity syndrome (AIS), also known as testicular feminization syndrome. We now know that individuals with AIS (roughly 1/60,000⁸) have an XY ("male") chromosomal complement and testes, but their androgen receptors cannot "read" the masculinizing hormones their testes produce. Consequently, in utero and throughout their lives, their anatomy develops along apparently "feminine" pathways. AIS is often not discovered until puberty, when these girls do not menstruate and a gynecological examination reveals AIS. Women with AIS look and feel very much like "typical" women, and in a practical, social, legal, and everyday sense they are women, even though congenitally they have testes and XY chromosomes.

In the 1910s, physicians working with intersexuality realized that assigning these women to the male sex (because of their testes) or admitting living true hermaphrodites" (because of their ovotestes) would only wreak social havoc. Consequently, in practice the medical profession moved away from a strict notion of gonadal "true sex" toward a pragmatic concept of "gender" and physicians began to focus their attentions on gender "reconstruction." Elaborate surgical and hormonal treatments have now been developed to make the sexual anatomy more believable, that is, more "typical" of the gender assigned by the physician.

Dominant Treatment Protocols

Thus the late twentieth century medical approach to intersexuality is based essentially on an anatomically strict psychosocial theory of gender identity. Contemporary theory, established and disseminated largely via the work of John Money⁹ and endorsed by the American Academy of Pediatrics¹⁰, holds that gender identity arises primarily from psychosocial rearing (nurture), and not directly from biology (nature); that all children must have their gender identity fixed very early in life for a consistent, "successful" gender identity to form; that from very early in life the child's anatomy must match the "standard" anatomy for her or his gender; and that for gender identity to form psychosocially boys primarily require "adequate" penises with no vagina, and girls primarily require a vagina with no easily noticeable phallus.¹¹

Note that this theory presumes that these rules must be followed if intersexual children are to achieve successful psychosocial adjustment appropriate to their assigned gender—that is, if they are to act like girls, boys, men, and women are "supposed" to act. The theory also by implication presumes that there are definite acceptable and unacceptable roles for boys, girls, men, and women, and that this approach will achieve successful psychosocial adjustment, at least far more often than any other approach.

Many parents, especially those unfamiliar with sex development, are bothered by their children's intersexed genitals and receptive to offers of "normalizing" medical treatments. Many also actively seek guidance about gender assignment and parenting practices. In the United States today, therefore, typically upon the identification of an "ambiguous" or intersexed baby teams of specialists (geneticists, pediatric endocrinologists, pediatric urologists, and so on) are immediately assembled, and these teams of doctors decide to which sex/gender a given child will be assigned. A plethora of technologies are then used to create and maintain that sex in as believable a form as possible, including, typically, surgery on the genitals, and sometimes later also on other "anomalous" parts like breasts in an assigned male; hormone monitoring and treatments to get a "cocktail" that will help and not contradict the decided sex (and that will avoid metabolic dangers); and fostering the conviction among the child's family and community that the child is indeed the sex decided "psychosocial" rearing of the child according to the norms of the chosen sex. Doctors typically take charge of the first two kinds of activities and hope that the child's family and community will successfully manage the all-critical third.

Clinicians treating intersexuality worry that any confusion about the sexual identity of the child on the part of relatives will be conveyed to the child and result in enormous psychological problems, including potential "dysphoric" states in adolescence and adulthood. In an effort to forestall or end any confusion about the child's sexual identity, clinicians try to see to it that an intersexual's sex/gender identity is permanently decided by specialist doctors within forty-eight hours of birth. With the same goals in mind, many clinicians insist that parents of intersexed newborns be told that their ambiguous child does really have a male or female sex, but that the sex of their child has just not yet "finished" developing, and that the doctors will quickly figure out the "correct" sex and then help "finish" the sexual development. As the sociologist Suzanne Kessler noted in her ground-breaking sociological analysis of the current treatment of intersexuality, "the message [conveyed to these parents] ... is that the trouble lies in the doctor's ability to determine the gender, not in the baby's gender *per se*."¹² In intersex cases, Ellen Hyun-Ju Lee concludes, "physicians present a picture of the 'natural sex,' either male or female, despite their role in actually constructing sex."¹³

Because of widespread acceptance of the anatomically strict psychosocial theory of treatment, the practical rules now adopted by most specialists in intersexuality are these: genetic males (children with Y chromosomes) must have "adequate" penises if they are to be assigned the male gender. When a genetic male is judged to have an "adequate" phallus size, surgeons may operate, sometimes repeatedly, to try to make the penis look more

"normal." If their penises are determined to be "inadequate" for successful adjustment as males, they are assigned the female gender and reconstructed to look female. (Hence John to Joan.) In cases of intersexed children assigned the female sex/gender, surgeons may "carve a large phallus down into a clitoris" (primarily attempting to make the phallus invisible when standing), "create a vagina using a piece of colon" or other body parts, "mold labia out of what was a penis," remove any testes, and so on.¹⁴

Meanwhile, genetic females (that is, babies lacking a Y chromosome) born with ambiguous genitalia are declared girls—no matter how masculine their genitalia look. This is done chiefly in the interest of preserving these children's potential feminine reproductive capabilities and in bringing their anatomical appearance and physiological capabilities into line with that reproductive role. Consequently, these children are reconstructed to look female using the same general techniques as those used on genetically male children assigned a female role. Surgeons reduce "enlarged" clitorises so that they will not look "masculine." Vaginas are built or lengthened if necessary, in order to make them big enough to accept average-sized penises. Joined labia are separated, and various other surgical and hormonal treatments are directed at producing a believable and, it is hoped, fertile girl.

What are the limits of acceptability in terms of phalluses? Clitorises—meaning simply phalluses in children labeled female—are frequently considered too big if they exceed one centimeter in length.¹⁵ Pediatric surgeons specializing in treating intersexuality consider "enlarged" clitorises to be "cosmetically offensive" in girls and therefore they subject these clitorises to surgical reduction meant to leave the organs looking more "feminine" and "delicate."¹⁶ Penises—meaning simply phalluses in children labeled male—are often considered too small if the stretched length is less than 2.5 centimeters (about an inch). Consequently, genetically male children born at term "with a stretched penile length less than 2.5 [centimeters] are usually given a female sex assignment."¹⁷

Roughly the same protocols are applied to cases of "true" hermaphroditism (in which babies are born with testicular and ovarian tissue). Whereas the anatomico-materialist metaphysics of sex in the late nineteenth century made true hermaphrodites an enormous problem for doctors and scientists of that time, clinicians today believe that "true hermaphrodites" (like "pseudo-hermaphrodites") can be fairly easily retrofitted with surgery and other treatment to either an acceptable male or acceptable female sex/gender.

One of the troubling aspects of these protocols are the asymmetric ways they treat femininity and masculinity. For example, physicians appear to do far more to preserve the reproductive potential of children born with ovaries than that of children born with testes. While genetically male intersexuals often have infertile testes, some men with micropenis may be able to father children if allowed to retain their testes.¹⁸

Similarly, surgeons seem to demand far more for a penis to count as "successful" than for a vagina to count as such. Indeed, the logic behind the tendency to assign the female gender in cases of intersexuality rests not only on the belief that boys need "adequate" penises, but also upon the opinion among surgeons that "a functional vagina can be constructed in virtually everyone [while] a functional penis is a much more difficult goal."¹⁹ This is true because much is expected of penises, especially by pediatric urologists, and very little of vaginas. For a penis to count as acceptable "functional"—it must be or have the potential to be big enough to be readily recognizable as a "real" penis. In addition, the "functional" penis is generally expected to have the capability to become erect and flaccid at appropriate times, and to act as the conduit through which urine and semen are expelled, also at appropriate times. The urethral opening is expected to appear at the very tip of the penis. Typically, surgeons also hope to see penises that are "believably" shaped and colored.

Meanwhile, very little is needed for a surgically constructed vagina to count among surgeons as "functional." For a constructed vagina to be considered acceptable by surgeons specializing in intersexuality, it basically just has to be a hole big enough to fit a typical-

sized penis. It is not required to be self-lubricating or even to be at all sensitive, and certainly does not need to change shape the way vaginas often do when women are sexually stimulated. So, for example, in a panel discussion of surgeons who treat intersexuality, when one was asked, "How do you define successful intercourse? How many of these girls actually have an orgasm, for example?" a member of the panel responded, "Adequate intercourse was defined as successful vaginal penetration."²⁰ All that is required is a receptive hole.

Indeed, clinicians treating intersex children often talk about vaginas in these children as the absence of a thing, as a space, a "hole," a place to put something. That is precisely why opinion holds that "a functional vagina can be constructed in virtually everyone" because it is relatively easy to construct an insensitive hole surgically. (It is not always easy to keep them open and uninfected.) The decision to "make" a female is therefore considered relatively fool-proof, while "the assignment of male sex of rearing is inevitably difficult and should only be undertaken by an experienced team" who can determine if a penis will be adequate for "successful" malehood.²¹

The strict conception of "normal" sexual anatomy and "normal" sex behavior that underlies prevailing treatment protocols is arguably sexist in its asymmetrical treatment of reproductive potential and definitions of anatomical "adequacy." Additionally, as Lee and other critics of intersex treatment have noted, "[d]ecisions of gender assignment and subsequent surgical reconstruction are inseparable from the heterosexual matrix, which does not allow for other sexual practices or sexualities. Even within heterosexuality, a rich array of sexual practices is reduced to vaginal penetration."²² Not surprisingly, feminists and intersexuals have invariably objected to these presumptions that there is a "right" way to be a male and a "right" way to be a female, and that children who challenge these categories should be reconstructed to fit into (and thereby reinforce) them.

Indeed, beside the important (and too often disregarded) philosophical-political issue of gender roles, there is a more practical one: how does one decide where to put the boundaries on acceptable levels of anatomical variation? Not surprisingly, the definition of genital "normality" in practice appears to vary among physicians. For example, at least one physician has set the minimum length of an "acceptable" penis at 1.5 centimeters.²³

Indeed, at least two physicians are convinced (and have evidence) that any penis is a big enough penis for male adjustment, if the other cards are played right. Almost a decade ago Justine Schober (nee Reilly), a pediatric urologist now based at the Hamot Medical Center in Erie, Pennsylvania, and Christopher Woodhouse, a physician based at the Institute of Urology and St. George's Hospital in London, "interviewed and examined 20 patients with the primary diagnosis of micropenis in infancy" who were labeled and raised as boys. Of the post-pubertal (adult) subjects, "All patients were heterosexual and they had erections and orgasms. Eleven patients had ejaculations, 9 were sexually active and reported vaginal penetration, 7 were married or cohabitating and 1 had fathered a child."²⁴

Schober and Woodhouse concluded that "a small penis does not preclude normal male role" and should not dictate female gender reassignment. They found that when parents "were well counseled about diagnosis they reflected an attitude of concern but not anxiety about the problem, and they did not convey anxiety to their children. They were honest and explained problems to the child and encouraged normality in behavior. We believe that this is the attitude that allows these children to approach their peers with confidence" (p. 571).

Ultimately, Schober and Woodhouse agreed with the tenet of the psychosocial theory that assumes that "the strongest influence for all patients [is] the parental attitude." But rather than making these children into girls and trying to convince the parents and children about their "real" feminine identity, Schober and Woodhouse found that "the well informed and open parents ... produced more confident and better adjusted boys." We should note that these boys were not considered "typical" in their sex lives: "The group was characterized by an experimental attitude to [sexual] positions and methods.... The group appears to form

close and long-lasting relationships. They often attribute partner sexual satisfaction and the stability of their relationships [with women partners] to their need to make extra effort including nonpenetrating techniques" (p. 571).

"Ambiguous" genitalia do not constitute a disease. They simply constitute a failure to fit a particular (and, at present, a particularly demanding) definition of normality. It is true that whenever a baby is born with "ambiguous" genitalia, doctors need to consider the situation a potential medical emergency because intersexuality may signal a potentially serious metabolic problem, namely congenital adrenal hyperplasia (CAH), which primarily involves an electrolyte imbalance and can result in "masculinization" of genetically female fetuses. Treatment of CAH may save a child's life and fertility. At the birth of an intersex child, therefore, adrenogenital syndrome must be quickly diagnosed and treated, or ruled out. Nonetheless, as medical texts advise, "of all the conditions responsible for ambiguous genitalia, congenital adrenal hyperplasia is the only one that is life-threatening in the newborn period," and even in cases of CAH the "ambiguous" genitalia themselves are not deadly.²⁵

As with CAH's clear medical issue, doctors now also know that the testes of AIS patients have a relatively high rate of becoming cancerous, and therefore AIS needs to be diagnosed as early as possible so that the testes can be carefully watched or removed. However, the genitalia of an androgen-insensitive person are not diseased. Again, while unusual genitalia may signal a present or potential threat to health, in themselves they just look different. As we have seen, because of the perception of a "social emergency" around an intersex birth, clinicians take license to treat nonstandard genitalia as a medical problem requiring prompt correction. But as Suzanne Kessler sums up the situation, intersexuality does not threaten the patient's life; it threatens the patient's culture.

Psychological Health and the Problem of Deception

Clearly, in our often unforgiving culture intersexuality can also threaten the patient's psyche; that recognition is behind the whole treatment approach. Nevertheless, there are two major problems here. First, clinicians treating intersex individuals may be far more concerned with strict definitions of genital normality than intersexuals, their parents, and their acquaintances (including lovers). This is evidenced time and again, for example, in the John/Joan case:

John recalls thinking, from preschool through elementary school, that physicians were more concerned with the appearance of Joan's genitals than was Joan. Her genitals were inspected at each visit to The Johns Hopkins Hospital. She thought they were making a big issue out of nothing, and they gave her no reason to think otherwise. John recalls thinking: "Leave me be and then I'll be fine.... It's bizarre. My genitals are not bothering me; I don't know why it is bothering you guys so much."²⁶

Second, and more basically, it is not self-evident that a psychosocial problem should be handled medically or surgically. We do not attempt to solve the problems many dark-skinned children will face in our nation by lightening their skins. Similarly, Cheryl Chase has posed this interesting question: when a baby is born with a severely disfigured but largely functional arm, ought we quickly remove the arm and replace it with a possibly functional prosthetic, so that the parents and child experience less psychological trauma²⁷? While it is true that genitals are more psychically charged than arms, genitals are also more easily and more often kept private, whatever their state. Quoting the ideas of Suzanne Kessler, the pediatric urologist Schober argues in a forthcoming work that "Surgery makes parents and doctors more comfortable, but counseling makes people comfortable too, and [it] is not irreversible." She continues: "Simply understanding and performing good surgeries is not sufficient. We must also know when to appropriately perform or withhold surgery. Our ethical duty as surgeons is to do no harm and to serve the best interests of our patient. Sometimes, this means admitting that a 'perfect' solution may not be attainable."²⁸

Ironically, rather than alleviating feelings of freakishness, in practice the way intersexuality is typically handled may actually produce or contribute to many intersexuals' feelings of freakishness. Many intersexuals look at these two facts: (1) they are subject, out of "compassion," to "normalizing" surgeries on an emergency basis without their personal consent, and (2) they are often not told the whole truth about their anatomical conditions and anatomical histories. Understandably, they conclude that their doctors see them as profound freaks and that they must really be freaks. H. Martin Malin, a professor in clinical sexology and a therapist at the Child and Family Institute in Sacramento, California, has found this to be a persistent theme running through intersexuals' medical experience:

As I listened to [intersexuals'] stories, certain leit motifs began to emerge from the bits of their histories. They or their parents had little, if any, counseling. They thought they were the only ones who felt as they did. Many had asked to meet other patients whose medical histories were similar to their own, but they were stonewalled. They recognized themselves in published case histories, but when they sought medical records, were told they could not be located.... The patients I was encountering were not those whose surgeries resulted from life-threatening or seriously debilitating medical conditions. Rather, they had such diagnoses as "micropenis" or "clitoral hypertrophy." These were patients who were told-when they were told anything-that they had vaginoplasties or clitorectomies because of the serious psychological consequences they would have suffered if surgery had not been done. But the surgeries had been performed-and they were reporting longstanding psychological distress. They were certain that they would rather have had the "abnormal" genitals they [had] had than the "mutilated" genitals they were given. They were hostile and often vengeful towards the professionals who had been responsible for their care and sometimes, by transference, towards me. They were furious that they had been lied to.²⁹

Given the lack of long-term follow-up studies it is unclear whether a majority of intersexuals wind up feeling this way, but even if only a small number do we must ask whether the practice of deception and "stonewalling" is essentially unethical.

Why would a physician ever withhold medical and personal historical information from an intersexed patient? Because she or he believes that the truth is too horrible or too complicated for the patient to handle. In a 1988 commentary in the Hastings Center Report, Brendan Minogue and Robert Tarszewski argued, for example, that a physician could justifiably withhold information from a sixteen-year-old AIS patient and/or her parents if he believed that the patient and/or family was likely to be incapable of handling the fact that she has testes and an XY chromosomal complement.³⁰ Indeed, this reasoning appears typical among clinicians treating intersexuality; many continue to believe that talking truthfully with intersexuals and their families will undo all the "positive" effects of the technological efforts aimed at covering up doubts. Thus despite intersexuals' and ethicists' published, repeated objections to deception, in 1995 a medical student was given a cash prize in medical ethics by the Canadian Medical Association for an article specifically advocating deceiving AIS patients (including adults) about the biological facts of their conditions. The prize-winner argued that "physicians who withhold information from AIS patients are not actually lying; they are only deceiving" because they selectively withhold facts about patients' bodies.³¹

But what this reasoning fails to appreciate is that hiding the facts of the condition will not necessarily prevent a patient and family from thinking about it. Indeed, the failure on the part of the doctor and family to talk honestly about the condition is likely only to add to feelings of shame and confusion. One woman with AIS in Britain writes, "Mine was a dark

secret kept from all outside the medical profession (family included), but this [should] not [be] an option because it both increases the feelings of freakishness and reinforces the isolation."³² Similarly, Martha Coventry, a woman who had her "enlarged" clitoris removed by surgeons when she was six, insists that "to be lied to as a child about your own body, to have your life as a sexual being so ignored that you are not even given the decency of an answer to your questions, is to have your heart and soul relentlessly undermined."³³

Lying to a patient about his or her biological condition can also lead to a patient unintentionally taking unnecessary risks. As a young woman, Sherri Groveman, who has AIS, was told by her doctor that she had "twisted ovaries" and that they had to be removed; in fact, her testes were removed. At the age of twenty, "alone and scared in the stacks of a [medical] library," she discovered the truth of her condition. Then "the pieces finally fit together. But what fell apart was my relationship with both my family and physicians. It was not learning about chromosomes or testes that caused enduring trauma, it was discovering that I had been told lies. I avoided all medical care for the next 18 years. I have severe osteoporosis as a result of a lack of medical attention. This is what lies produce."³⁴

Similarly, as B. Diane Kemp—"a social worker with more than 35 years' experience and a woman who has borne androgen insensitivity syndrome for 63 years"notes, "secrecy as a method of handling troubling information is primitive, degrading, and often ineffective. Even when a secret is kept, its existence carries an aura of unease that most people can sense ... Secrets crippled my life."³⁵

Clearly, the notion that deception or selective truth-telling will protect the child, the family, or even the adult intersexual is extraordinarily paternalistic and naive, and, while perhaps well-intentioned, it goes against the dominant trend in medical ethics as those ethics guidelines are applied to other, similar situations. In what other realms are patients regularly not told the medical names for their conditions, even when they ask? As for the idea that physicians should not tell patients what they probably "can't handle," would a physician be justified in using this reasoning to avoid telling a patient she has cancer or AIDS?

In their commentary in the Hastings Center Report Sherman Elias and George Annas pointed out that a physician who starts playing with the facts of a patient's condition may well find himself forced to lie or admit prior deception. "Practically," Elias and Annas wrote, "it is unrealistic to believe that [the AIS patient] will not ultimately learn the details of her having testicular syndrome. From the onset it will be difficult to maintain the charade."³⁶ They also note that without being told the name and details of her condition any consent the AIS patient gives will not truly be "informed." As an attorney Groveman too argues "that informed consent laws mandate that the patient know the truth before physicians remove her testes or reconstruct her vagina."³⁷

Informed Consent and Risk Assumption

It is not at all clear if all or even most of the intersex surgeries done today involve what would legally and ethically constitute informed consent. It appears that few intersexuals or their parents are educated, before they give consent, about the anatomically strict psychosocial model employed. The model probably ought to be described to parents as essentially unproven insofar as the theory remains unconfirmed by broad-based, longterm follow-up studies, and is directly challenged by cases like the John/Joan case as well as by evermounting "anecdotal" reports from former patients who, disenfranchised and labeled "lost to follow-up" by clinicians, have turned to the popular press and to public protest in order to be heard. Of course, as long as intersex patients are not consistently told the truth of their conditions, there is some question about whether satisfaction can be assessed with integrity in long-term studies.

At a finer level, many of the latest particular cosmetic surgeries being used on intersexed babies and children today remain basically unproven as well, and need to be described as

such in consent agreements. For example, a team of surgeons from the Children's Medical Center and George Washington University Medical School has reported that in their preferred form of clitoral "recession" (done to make "big" clitorises look "right"), "the cosmetic effect is excellent" but "late studies with assessment of sexual gratification, orgasm, and general psychological adjustment are unavailable ... and remain in question."³⁸ In fact the procedure may result in problems like stenosis, increased risk of infections, loss of feeling, and psychological trauma. (These risks characterize all genital surgeries.)

This lack of long-term follow-up is the case not only for clitoral surgeries; David Thomas, a pediatric urologist who practices at St. James's University Hospital and Infirmary in Leeds, England, recently noted the same problem with regard to early vaginal reconstructions: "So many of these patients are lost to follow-up. If we do this surgery in infancy and childhood, we have an obligation to follow these children up, to assess what we're doing."³⁹ There is a serious ethical problem here: risky surgeries are being performed as standard care and are not being adequately followed-up.⁴⁰

The growing community of open adult intersexuals understandably question whether anyone should have either her ability to enjoy sex or her physical health risked without personal consent just because she has a clitoris, penis, or vagina that falls outside the standard deviation. Even if we did have statistics that showed that particular procedures "worked" a majority of the time we would have to face the fact that part of the time they would not work, and we need to ask whether that risk ought to be assumed on behalf of another person.

Beyond "Monster Ethics"

In a 1987 article on the ethics of killing one conjoined twin to save the other, George Annas suggested (but did not advocate) that one way to justify such a procedure would be to take "the monster approach." This approach would hold that conjoined twins are so grotesque, so pathetic, any medical procedure aimed at normalizing them would be morally justified.⁴¹ Unfortunately, the present treatment of intersexuality in the U.S. seems to be deeply informed by the monster approach; ethical guidelines that would be applied in nearly any other medical situation are, in cases of intersexuality, ignored. Patients are lied to; risky procedures are performed without follow-up; consent is not fully informed; autonomy and health are risked because of unproven (and even disproven) fears that atypical anatomy will lead to psychological disaster. Why? Perhaps because sexual anatomy is not treated like the rest of human anatomy, or perhaps because we simply assume that any procedure which "normalizes" an "abnormal" child is merciful. Whatever the reason, the medical treatment of intersexuality and other metabolically benign, cosmetically unusual anatomies needs deep and immediate attention.

We can readily use the tools of narrative ethics to gain insight into practices surrounding intersexuality. There are now available many autobiographies of adult intersexuals.⁴² Like that of John/Joan, whether or not they are characteristic of long-term outcomes these autobiographies raise serious questions about the dominant treatment protocols.

Narrative ethics also suggests that we use our imaginations to think through the story of the intersexual, to ask ourselves, if we were born intersexed, what treatment we would wish to have received. Curious about what adult nonintersexuals would have chosen for themselves, Suzanne Kessler polled a group of college students regarding their feelings on the matter. The women were asked, "Suppose you had been born with a larger than normal clitoris and it would remain larger than normal as you grew to adulthood. Assuming that the physicians recommended surgically reducing your clitoris, under what circumstances would you have wanted your parents to give them permission to do it?" In response,

.bq About a fourth of the women indicated they would not have wanted a clitoral reduction under any circumstance. About half would have wanted their clitoris reduced only if the

larger than normal clitoris caused health problems. Size, for them, was not a factor. The remaining forth of the sample could imagine wanting their clitoris reduced if it were larger than normal, but only if having the surgery would not have resulted in a reduction in pleasurable sensitivity.⁴³

Meanwhile, in this study, "the men were asked to imagine being born with a smaller than normal penis and told that physicians recommended phallic reduction and a female gender assignment." In response All but one man indicated they would not have wanted surgery under any circumstance. The remaining man indicated that if his penis were 1 cm. or less and he were going to be sterile, he would have wanted his parents to give the doctors permission to operate and make him a female. (p. 36)

Kessler is cautious to note that we need more information to assess this data fully, but it does begin to suggest that given the choice most people would reject genital cosmetic surgery for themselves.

As an historian, I also think we need to consider the historical and cultural bases for genital conformity practices, and realize that most people in the U.S. demonstrate little tolerance for practices in other cultures that might well be considered similar. I am, of course, talking about the recent passage of federal legislation prohibiting physicians from performing "circumcision" on the genitalia of girls under the age of eighteen, whether or not the girls consent or personally request the procedure. African female genital "cutting" typically involves, in part, excision of the clitoral tissue so that most or all clitoral sensation will be lost. While proponents of this traditional female genital "cutting" have insisted this practice is an important cultural tradition-analogous to male circumcision culturally advocates of the U.S. law insist it is barbaric and violates human rights. Specifically, in the federal legislation passed in October 1996 Congress declared that: "Except as provided in subsection (b), whoever knowingly circumcises, excises, or infibulates the whole or any part of the labia majora or labia minora or clitoris of another person who has not attained the age of 18 years shall be fined under this title or imprisoned not more than 5 years, or both."⁴⁴

Subsection "b" specifies that: "A surgical operation is not a violation of this section if the operation is (1) necessary to the health of the person on whom it is performed, and is performed by a person licensed in the place of its performance as a medical practitioner; or (2) performed on a person in labor or who has just given birth and is performed for medical purposes connected with that labor or birth."

Surgeons treating intersexuality presumably would argue that the procedures they perform on the genitals of girls (which clearly include excision of parts of the clitoris) are indeed "necessary to the health of the person on whom it is performed." While it is easy to condemn the African practice of female genital mutilation as a barbaric custom that violates human rights, we should recognize that in the United States medicine's prevailing response to intersexuality is largely about genital conformity and the "proper" roles of the sexes. Just as we find it necessary to protect the rights and well-being of African girls, we must now consider the hard questions of the rights and well-being of children born intersexed in the United States.

As this paper was in process, the attention paid by the popular media and by physicians to the problems with the dominant clinical protocols increased dramatically, and many more physicians and ethicists have recently come forward to question those protocols. Diamond and Sigmundson have helpfully proposed tentative new "guidelines for dealing with persons with ambiguous genitalia."⁴⁵

As new guidelines are further developed, it will be critical to take seriously two tasks. First, as I have argued above, intersexuals must not be subjected to different ethical standards from other people simply because they are intersexed. Second, the experiences and advice of adult intersexuals must be solicited and taken into consideration. It is incorrect to claim,

as I have heard several clinicians do, that the complaints of adult intersexuals are irrelevant because they were subjected to "old, unperfected" surgeries. Clinicians have too often retreated to the mistaken belief that improved treatment technologies (for example, better surgical techniques) will eliminate ethical dilemmas surrounding intersex treatment. There is far more at issue than scar tissue and loss of sensation from unperfected surgeries.

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Alice Domurat Dreger, "'Ambiguous Sex'—or Ambivalent Medicine? Ethical Issues in the Treatment of Intersexuality," *Hastings Center Report* 28, no. 3 (1998): 24-36.

References

- ¹ Milton Diamond and H. Keith Sigmundson, [Sex Reassignment at Birth: Long-Term Review and Clinical Implications](#), *Archives of Pediatrics and Adolescent Medicine* 15 (1997): 298-304.
- ² For a more in-depth biography, see John Colapinto, [The True Story of John/Joan](#), *Rolling Stone*, 11 December 1997, pp. 55ff.
- ³ Diamond and Sigmundson, "Sex Reassignment," p. 303.
- ⁴ I discuss this at length in Dreger, [Hermaphrodites and the Medical Invention of Sex](#) (Cambridge, Mass.: Harvard University Press, 1998); see especially prologue and chap. 1.
- ⁵ See Ethel Sloane, *Biology of Women*, 3d ed. (Albany: Delmar Publishers, 1993), p. 168. According to Denis Grady, a study of over 6,500 women athletes competing in seven different international sports competitions showed an incidence of intersexuality of one in 500 women, but unfortunately Grady does not provide a reference to the published data from that study (Denise Grady, "Sex Test," *Discover*, June 1992, pp. 78-82). That sampled population should not simply be taken as representative of the whole population, but this number is certainly higher than most people would expect.
- ⁶ Anne Fausto-Sterling, [Sexing the Body: How Biologists Construct Sexuality](#) (New York: Basic Books, forthcoming 1999), chap. 2; Fausto-Sterling, "How Dimorphic Are We?" *American Journal of Human Genetics* (forthcoming); and personal communication. The highest modern-day estimate for frequency of sexually ambiguous births comes from John Money, who has posited that as many as 4 percent of live births today are of "intersexed" individuals (cited in Anne Fausto-Sterling, "The Five Sexes," *The Sciences* 33 [1993]: 20-25). Money's categories tend to be exceptionally broad and poorly defined, and not representative of what most medical professionals today would consider to be "intersexuality."
- ⁷ Dreger, *Hermaphrodites*, chaps. 1-5; for a summary of the scene in Britain in the late-nineteenth century, see Dreger, "Doubtful Sex: The Fate of the Hermaphrodite in Victorian Medicine," *Victorian Studies* 38 (1995): 335-69.

⁸ Stuart R. Kupfer, Charmain A. Quigley, and Frank S. French, "Male Pseudohermaphroditism," *Seminars in Perinatology* 16 (1992): 319-31, at 325.

⁹ For summaries and critiques of Money's work on intersexuality, see especially: Cheryl Chase, "Affronting Reason," in *Looking Queer: Image and Identity in Lesbian, Bisexual Gay and Transgendered Communities*, ed. D. Atkins (Binghamton, N.Y.: Haworth, 1998); "Hermaphroditism with Attitude: Mapping the Emergence of Intersex Political Activism," *GLQ* 4, no. 2 (1998): 189-211; Anne Fausto-Sterling, "How to Build a Man," in *Science and Homosexualities*, ed. Vernon A. Rosario (New York: Routledge, 1997), pp. 219-25; and Ellen Hyun-Ju Lee, "Producing Sex: An Interdisciplinary Perspective on Sex Assignment Decisions for Intersexuals" (Senior Thesis, Brown University, 1994).

¹⁰ American Academy of Pediatrics (Section on Urology), **Timing of Elective Surgery on the Genitalia of Male Children with Particular Reference to the Risks, Benefits, and Psychological Effects of Surgery and Anesthesia**, *Pediatrics* 97, no. 4 (1996): 590-94.

¹¹ For example, see Patricia K. Donahoe, "The Diagnosis and Treatment of Infants with Intersex Abnormalities," *Pediatric Clinics of North America* 34 (1987): 1333-48.

¹² Suzanne J. Kessler, "The Medical Construction of Gender: Case Management of Intersexed Infants," *Signs* 16 (1990): 3-26; compare the advice given by Cynthia H. Meyers-Seifer and Nancy J. Charest, "Diagnosis and Management of Patients with Ambiguous Genitalia," *Seminars in Perinatology* 16 (1992): 332-39.

¹³ Lee, "Producing Sex," p. 45.

¹⁴ Melissa Hendricks, "Is It a Boy or a Girl?" *John Hopkins Magazine* (November, 1993): 10-16, p. 10.

¹⁵ Barbara C. McGillivray, "The Newborn with Ambiguous Genitalia," *Seminars in Perinatology* 16 (1991): 365-68, p. 366. 16. Kurt Newman, Judson Randolph, and Kathryn Anderson, "The Surgical Management of Infants and Children with Ambiguous Genitalia," *Annals of Surgery* 215 (1992): 644-53, pp. 651 and 647.

¹⁷ Meyers-Seifer and Charest, "Diagnosis and Management," p. 337. See also Kupfer, Quigley, and French, "Male Pseudohermaphroditism," p. 328; Rajkumar Shah, Morton M. Woolley, and Gertrude Costin, "Testicular Feminization: The Androgen Insensitivity Syndrome," *Journal of Pediatric Surgery* 27 (1992): 757-60, p. 757.

¹⁸ Justine Schober, personal communication; for data on this, see Justine M. Reilly and C.R.J. Woodhouse, "Small Penis and the Male Sexual Role," *Journal of Urology* 142 (1989): 569-71.

¹⁹ Robin J.O. Catlin, *Appleton eF Lange Review for the USMLE Step 2* (East Norwalk, Connecticut: Appleton & Lange, 1993), p. 49.

²⁰ See the comments of John P. Gearhart in M. M. Bailez, John P. Gearhart, Claude Migeon, and John Rock, "Vaginal Reconstruction After Initial Construction of the External Genitalia in Girls with Salt-Wasting Adrenal Hyperplasia," *Journal of Urology* 148 (1992): 680-84, p. 684.

²¹ Kupfer, Quigley, and French, "Male Pseudohermaphroditism," p. 328.

²² Lee, "Producing Sex," p. 27.

²³ See Donahoe, "The Diagnosis and Treatment of Infants with Intersex Abnormalities."

- 24 Reilly and Woodhouse, "Small Penis," p. 569.
- 25 Patricia K. Donahoe, David M. Powell, and Mary M. Lee, "Clinical Management of Intersex Abnormalities," *Current Problems in Surgery* 28 (1991): 515-79, p. 540.
- 26 Diamond and Sigmundson, "Sex Reassignment," pp. 300-301.
- 27 Cheryl Chase, personal communication.
- 28 Quoted in Justine M. Schober, "Long-Term Outcomes," ed. Pierre D. E. Mouriquand (Philadelphia: William B. Saunders, for Intersex), *Pediatric Surgery and Urology: Long Term Outcomes*, ed. Pierre D. E. Mouriquand (Philadelphia: William B. Saunders, forthcoming).
- 29 H. M. Malin, personal communication of 1 January 1997 to Justine M. Schober, quoted in Schober, "Long-Term Outcome."
- 30 Brendan P. Minogue and Robert Taraszewski, "The Whole Truth and Nothing But the Truth?" (Case Study), *Hastings Center Report* 18, no. 5 (1988): 34-35.
- 31 Anita Natarajan, **Medical Ethics and Truth Telling in the Case of Androgen Insensitivity Syndrome**, *Canadian Medical Association Journal* 154 (1996): 568-70. (For responses to Natarajan's recommendations by AIS women and a partner of an AIS woman, see *Canadian Medical Association Journal* 154 [1996]: 1829-33.)
- 32 Anonymous, **Be Open and Honest with Sufferers**, *British Medical Journal* 308 (1994): 1041-42.
- 33 Martha Coventry, **Finding the Words**, *Chrysalis: The Journal of Transgressive Gender Identities* 2 (1997): 27-30.
- 34 Sherri A. Groveman, **Letter to the Editor**, *Canadian Medical Association Journal* 154 (1996): 1829, 1832.
- 35 B. Diane Kemp, **Letter to the Editor**, *Canadian Medical Association Journal* 154 (1996): 1829.
- 36 Sherman Elias and George J. Annas, "The Whole Truth and Nothing But the Truth?" (Case Study), *Hastings Center Report* 18, no. 5 (1988): 35-36, p. 35.
- 37 Groveman, "Letter to the Editor," p. 1829.
- 38 Newman, Randolph, and Anderson, "Surgical Management," p. 651.
- 39 "Is Early Vaginal Reconstruction Wrong for Some Intersex Girls?" *Urology Times* (February 1997): 10-12.
- 40 Intersexuals are understandably tired of hearing that "long-term follow-up data is needed" while the surgeries continued to occur. On this, see especially the guest commentary by David Sandberg, "A Call for Clinical Research," *Hermaphrodites with Attitude* (Fall/Winter 1995-1996): 8-9, and the many responses of intersexuals in the same issue.
- 41 George J. Annas, "Siamese Twins: Killing One to Save the Other" (At Law), *Hastings Center Report* 17, no. 2 (1987): 2729.
- 42 See, for example, M. Morgan Holmes, "Medical Politics and Cultural Imperatives: Intersex Identities beyond Pathology and Erasure" (M.A. Thesis, York University, 1994); Chase,

"Hermaphrodites with Attitude"; Geoffrey Cowley, "Gender Limbo," *Newsweek*, 19 May 1997, pp. 64-66; Natalie Angier, "New Debate Over Surgery on Genitals," *New York Times*, 13 May 1997; "Special Issue: Intersexuality," *Chrysalis: The Journal of Transgressive Gender Identities* 2 (1997). Intersexual autobiographies are also from peer support groups, including the Intersex Society of North America. For information about support groups see the **special issue of Chrysalis**, vol. 2, 1997.

⁴³ Suzanne J. Kessler, **Meanings of Genital Variability** *Chrysalis: The Journal of Transgressive Gender Identities* 2 (1997): 33-37.

⁴⁴ Omnibus Consolidated Appropriations Bill, H.R. 3610, PL. 104-208.

⁴⁵ Milton Diamond and Keith Sigmundson, **Management of Intersexuality: Guidelines for Dealing with Persons with Ambiguous Genitalia**, *Archives of Pediatric and Adolescent Medicine* 151 (1997): 1046-50.

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