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Engendering Differences Ethical Issues about Intersex

by Kate Scannell, MD, Editor

In 1993 biologist Dr. Anne Fausto-Sterling published "The Five Sexes," a provocative and somewhat tongue-in-cheek essay that challenged the traditional dichotomous model of human sex and sexuality. In addition to the existence of females and males, she proposed that there existed "herms" (named after true hermaphrodites, born with both a testis and an ovary), "ferms," (female pseudohermaphrodites — people born with ovaries and some expression of male genitalia), and "merms," (male pseudohermaphrodites, people with testes and some expression of female genitalia). In addition, she calculated that about 1.7 percent of all births were, in some form, intersexual (i.e., characterized by various interminglings of male and female sex characteristics), and that genital surgery was performed on approximately 2,000 children in the U.S. each year.

Dr. Fausto-Sterling's challenge of the traditional binary sex and gender system stimulated extensive controversy and disturbed entrenched medical values and social norms. Besides forcing the issue of intersex into medical and public discussions, she also recommended a radical reconceptualization of the way the medical establishment should and could treat intersexed children. The customary approach had been surgical since the 1970s: operative removal of gonads and genitalia attributed to one of the two traditional sexes, and surgical and hormonal enhancements of those attributed to the opposite sex. Usually, the choice of sexual phenotype promotion was made according to the appearance of the child's extant genitalia. At a minimum, it was thought that a boy should have a penis at least one inch long in stretched length at birth, and a girl should not have a clitoris longer than 3/8 inch. Body "normalizing" also generally included as-needed surgical provision of a vagina suitable for future intercourse for girls, and, for boys, a urethral opening at the tip of the penis.

During recent years, segments of the medical and intersex communities have questioned the practice of surgical genitoplasties and sexual assignments of intersex infants.

Modern-day medical opinion is now divided. The American Academy of Pediatrics' 2000 guidelines for evaluation and management of intersex infants with "ambiguous genitalia" call for early surgeries in selected cases; they also include the following statement: "Although newborns with ambiguous genitalia are encountered rarely in a primary care pediatrician's practice, their diagnosis and prompt treatment require urgent medical attention."

But challenges to conventional surgical approaches and views of intersexed conditions as "medical emergencies" have arisen largely because of the increasing visibility of intersex persons who have reached adulthood now and who offer us their experiences. These experiences are critical in that they are spoken by the subjects of surgical procedures that are performed as standard practices despite the absence of scientific data supporting their benefits. To this date, there exist no comprehensive, retrospective studies that establish a therapeutic benefit from surgery.

What we are learning anew from the intersex community is that sexual and gender identifications are more complex than any surgical decision that purports to divide human experience of it into two neat classifications. That many intersex children later suffer their surgical assignments because of strong identifications with the "excised" sex or lessened sexual sensitivity of their modified organs. That there is cause to consider a moratorium on surgical interventions performed on intersex infants until some evidence supports its benefit.

Seven years after the appearance of her essay, Dr. Fausto-Sterling published "The Five Sexes — Revisited" in the same journal, *The Sciences*. In this revisitation, she noted that since 1993 "modern society has moved beyond five sexes to a recognition that gender variation is normal." She also acceded to a view of gender attribution that gave less signifying power to genital makeup and more weight to both gender performance and self-determination of sexual and gender identity. She proposed: "It might seem natural to regard intersexuals and transgendered people as living midway between the poles of male and female. But male and female, masculine and feminine cannot be parsed as some kind of continuum. Rather, sex and gender are best conceptualized as points in a multidimensional space."

In this issue of *Ethics Rounds*, Dr. Fausto-Sterling responds to a case involving an intersexed infant. Her response is paired with commentary from attorney Sherri Groveman, JD, who is herself intersexed. Ms. Groveman is also the founder of the US branch of the Androgen Insensitivity Syndrome Support Group (AISSG), and she serves on the Board of Directors of both AISSG and the Intersex Society of North America (ISNA). Her critical analyses and views of the medical treatment of intersex have been published in the *Journal of Clinical Ethics*, the *Journal of the American Medical Association*, *The Canadian Medical Association Journal*, *American Family Physician*, and *Discover*.

As intersexed people clearly demonstrate, strict sexual dimorphism does not exist in Nature. And as human nature does not abide by cultural rules, rigid and anatomically based conceptualizations of gender identity do not suffice to account for the authentic experiences of human beings being human.

It is a simple truth that intersex children are born, and this fact can serve as an elegant reminder about the diversity of sex and the human body at a cellular level. At a cultural level, we have been learning much about the wide spectrum of sexual and gender identities that defy binary classification systems. And we have witnessed the changing and fluid "boundaries" imperfectly separating both male and female societal roles, and feminine and masculine traits and behaviors. Recognizing the myriad ways that human lives are born into the world in all their various shapes and sexes and sizes and degrees of health may reflect and foster a respectful acceptance of humanity at the level of "what is."

References:

- Fausto-Sterling A. "The Five Sexes." *The Sciences*. 1993; March/April.
 Fausto-Sterling A. "The Five Sexes, Revisited." *The Sciences*. 2000; July/August.
 American Academy of Pediatrics, "Evaluation of the Newborn with Developmental Anomalies of the External Genitalia" (RE9958). *Pediatrics*. 2000; 106: 138-42. Available online: <http://www.aap.org/policy/RE9958.html>

Case

When an Intersex Child is Born

Ira and Karen were shocked when doctors informed them that their newborn child, Jamie, was a hermaphrodite. The doctors offered to perform "sexual assignment surgery" for Jamie's "correctable deformity" in order to protect the child

and parents from any sense of ambiguity. They summarized Jamie's "ambiguous genitalia": one undescended testicle; a phallus longer than a clitoris but lacking the definitive features of a penis; an absent vaginal opening; and a rudimentary intraabdominal ovary and uterus. They explained that they surgically assigned most intersexed babies as female because the surgical techniques were more successful and they could not create a functioning penis. Female hormones and surgical construction of a vagina could be delayed until Jamie was sexually active.

Ira and Karen brought Jamie home and argued about the decision. Ira insisted that the surgery be performed so Jamie could experience a "basic human need for a sexual identity." Karen disagreed, echoing advice she received from both a psychologist and a counselor at an intersex support agency. She said that Jamie could be raised with a regular gender identity without genital reconstruction, but with a sex-stereotypical name and clothing. She insisted that Jamie should decide whether to have sexual assignment surgery when she reached adulthood.

At medical follow-up, the pediatrician and urologist informed Ira and Karen that Jamie's intersexuality was caused by chromosomal mosaicism — an XY/XO pattern. They recommended removing Jamie's intra-abdominal gonad and undescended testicle to reduce cancer risks, minimize and move the enlarged urethral opening to make space for future vaginal construction, create labia from foreskin and scrotal skin, and perform a clitoroplasty by reducing Jamie's phallus to the size of a clitoris. They were concerned that, without imminent surgery, hormonal exposure would further masculinize the brain, gender-imprinting Jamie, and thus resulting in a male identity.

When doctors inquired whether a decision had been reached on sexual assignment surgery, Ira broke down and voiced his fears that, without surgery, Jamie would face constant derision and alienation, embarrassment in the locker room, and hesitation initiating a sexual life in adulthood. But Karen was as fearful that a clitoroplasty would diminish Jamie's future sexual sensitivity, and, if Jamie were already gender-imprinted to identify as male, that the proposed surgery would leave Jamie sexually damaged.

What should Jamie's parents do?

What ethical principles are raised in this case?

Are sexual assignment surgeries cosmetic or medical?

What are the doctors' obligations to Jamie?

Whose opinion prevails when the parents disagree about medical procedures for their children?

Case Commentary

Ethics Primer for Clinical Management of Intersex by Sherri Groveman, JD

Ira and Karen are confronting a number of difficult decisions at a time when they most likely have not worked through their own disappointments and anxieties about having a child born with mixed gonadal dysgenesis. Of primary importance in this case is that **Jamie does not face any immediate health risk** attendant to being intersexed. It is, therefore, critical that Jamie's doctors not suggest a false sense of urgency that will cause Ira and Karen to make a hasty decision about genital surgery. Instead, as Ira and Karen acclimate to their child's diagnosis, they will reach a better position from which to make a decision based on their reasoned assessment of what serves Jamie's best interest.

Before addressing the specific ethical issues that this case raises, it should be emphasized that Jamie — not Ira and/or Karen — is the patient; as such, Jamie's needs are of primary importance. However, because Jamie is not able to give consent or otherwise participate in decisions concerning medical care, Ira and Karen will be acting as Jamie's proxy in making such decisions.

In addition to providing Ira and Karen with meaningful information before obtaining their permission for surgery, Jamie's doctors should also examine whether their own biases have influenced their recommendation that Jamie undergo genital surgery. Several critics of the current medical paradigm of treatment of intersex children object to its phallocentric premise. The current paradigm specifies that a male gender assignment will be made only if the newborn has a phallus that physicians believe will be capable of intromission in the future. This is generally interpreted to mean a stretched penile length in infancy of greater than 2.5 centimeters. (1) Any child unable to satisfy this standard is reflexively assigned female regardless of medicine's present inability to create a vagina that is free of surgical complications. (2) Thus, Ira and Karen should be told if the recommendation that Jamie be reared female is based primarily on consideration of penile length — rather than functioning of the clitoris or adequacy of a vagina that may need to be created surgically.

Moreover, Ira and Karen should be advised that while sexual functioning is the primary consideration for a male gender assignment, in making a female assignment such paradigm elevates the potential for fertility over how satisfactorily the surgically created vagina will function, or whether the child's capacity for orgasm will be impaired by surgery. (3) Furthermore, they should be informed that female gender assignments predominate, despite evidence that males with micropenis can enjoy a high quality of sexual functioning (4), and that female assignments for such individuals may prove unsatisfactory. (5)

While both parents and doctors in this case may be concerned primarily with Jamie's ability to achieve peer acceptance, the surgery is, by definition, cosmetic because it is not undertaken for Jamie's physical health. Interestingly, if Jamie had been born with a large nose, a medical recommendation for infant prophylactic rhinoplasty would be considered heretical, even if it could be shown that such surgery would prevent the child from being teased later in school. Yet Jamie's physicians' assurances (without benefit of supporting empirical data) that surgery offers psychological benefits to the patient and his or her parents reinforce a cultural mandate at the expense of allowing Jamie to decide independently whether such conformity is worth the risk of impaired sexual functioning and possible later gender dysphoria if the sex that is chosen does not match Jamie's gender identity.

A recommendation favoring genital surgery also ignores the possibility that any attendant psychological benefit may be more than offset by the clear communication to Jamie that there was something shameful about Jamie's genitals in their original state. Such shame is reinforced if, as is common medical practice, the truth about Jamie's being intersexed and having been born with ambiguous genitalia is withheld from Jamie in later childhood and adolescence.

Overall, it must be acknowledged that Ira and Karen are looking to Jamie's physicians for guidance at a time when they may be highly motivated to "normalize" their child's genital appearance in the short term without due regard for the long-term impact that their decision will have. Thus, it is incumbent upon Jamie's physicians to encourage Ira and Karen to seek counseling to sort out these various considerations, rather than using surgical intervention as a vehicle to quell Ira and Karen's anxieties about having an intersex child. (6)

Moreover, to the extent Ira and Karen cannot agree on whether to forego surgical intervention, counseling may also help them reach consensus on whether to authorize such procedures. However, if following counseling they still cannot agree on how to proceed, it is imperative that Jamie's physicians not "take sides" with either parent. In such an instance, because there is no immediate health risk to their patient, and because the requisite parental permission has not been obtained, Jamie's doctors should not perform surgery. Instead, the parent favoring surgical intervention can obtain, if appropriate, a court order mandating surgery. Such judicial intervention will protect the physician against potential liability to the parent who opposes such operation.

If Ira and Karen had not already been in touch with an appropriate intersex patient support or advocacy group, (7) Jamie's physicians should also put them in touch with one. (8) Ideally, because Ira and Karen have accessed this resource, the support group will connect them with adults who underwent similar surgical procedures as infants, as well as other parents who have been confronted with similar challenges.

This will allow them to become informed "consumers" in making decisions about Jamie's medical care and will also allow them to work through the natural process of grief and acceptance faced by parents of intersex children.

Prior to Ira and Karen giving permission for any medical or surgical intervention, **Jamie's physicians have an ethical obligation to ensure that Ira and Karen are provided with all of the following ten safeguards.** (9) These safeguards are consistent with Policy Statement RE9510 "Informed Consent, Parental Permission, and Assent in Pediatric Practice" adopted by the American Academy of Pediatrics. (10) They are also consistent with two recent decisions of The Constitutional Court of Colombia in Bogota (SU-337/99, May 12, 1999 and T-551/99, Aug 2, 1999) which specifically addressed the issue of parental "proxy" consent to genital surgery on their children. Those decisions are noteworthy in that they represent the first time that a high court anywhere in the world has considered whether surgical editing of intersex persons poses a violation of human rights. The ten safeguards include:

1. Complete information about Jamie's medical condition.
2. The opportunity to consult further with mental health professionals who are experienced in counseling parents of children with intersex conditions as well as in the clinical management of intersex.
3. Presentation of the alternative of making a tentative gender assignment that is reinforced by dressing Jamie in clothing appropriate for such assignment, but delaying or foregoing genital surgery until Jamie's psychosexual orientation can be assessed, and Jamie can participate actively in any medical decision-making.
4. Information concerning the risks and complications attendant to any surgical intervention, including the possible diminution in sexual sensation resulting from damage to clitoral nerve tissue (11), the risk of dyspareunia stemming from surgically created scar tissue in the genital region, and the devastation to the child if the surgically reinforced sex assignment proves incorrect. (12)
5. Disclosure that no comprehensive retrospective studies establish any therapeutic benefit of surgery.
6. Disclosure that current recommendations for treatment focus on the length of the phallus rather than on psychological outcome studies. (13)
7. Information that several pediatric endocrinologists and urologists have called for a moratorium on infant genital surgery until retrospective studies demonstrate that the benefits of surgery outweigh its potential consequences. (14)

8. Disclosure that the risk of intratubular germ cell neoplasia and other gonadal tumors is generally small in a child whose gonads are left intact prior to the completion of puberty, and that the gonads can be monitored for gonadoblastoma rather than removed on an emergency basis now. (15)

9. An explanation that any hormonal imprinting resulting from the gonads has likely already occurred, and that, because the gonads will not be active again until later childhood or early puberty, their retention will potentially allow Jamie to access a natural source of hormones if Jamie identifies as male.

10. Assurances that Jamie's ability to receive medical care is not contingent upon Ira and Karen's consenting to surgery.

The Colombia Court held that all information concerning the risks of surgery should be communicated on at least two separate occasions over the course of several weeks to ensure that the parents have a complete understanding of the nature and consequences of such surgery. Moreover, the Court deemed it necessary that the risks of surgery be summarized in writing. In this case, such written summary will also allow Ira and Karen to weigh their decision at home with the benefit of such information.

Regardless of the decision Ira and Karen make, Jamie's physicians have a wonderful opportunity to educate them about intersex and help them to develop a sufficient level of comfort with the diagnosis to allow them, in turn, to help Jamie cope with the challenges of being intersexed. Far more than by surgical intervention, the outcome in this case will be directly impacted by how well Jamie's physicians can work in tandem with Ira and Karen to assist them in communicating their love for and acceptance of their child.

Author's Notes:

The author wishes to thank Professor Alice Dreger of the Lyman Briggs School of Michigan State University, Professor Julie Greenberg of the Thomas Jefferson School of Law, and Cheryl Chase, Executive Director of the Intersex Society of North America whose valuable insights have informed this article.

1. RE 9958 states "The size of the phallus and its potential to develop at puberty into a sexually functional penis are of paramount importance when one is considering male sex of rearing." See also: Kessler S. "The Medical Construction of Gender: Case Management of Intersexed Infants." *Signs: Journal of Women in Culture and Society*. 1990; 16(1): 3-26.

2. Bailez MM, Gearhart P, Migeon C, Rock J. "Vaginal Reconstruction after Initial Construction of the External Genitalia in Girls with Salt-Wasting Adrenal Hyperplasia." *J of Urology*. 1992; 148: 680-84.

3. RE 9958 states "The presence of a capacious, low-lying vagina is advantageous if assignment as a female is being considered, but this alone is not of critical importance. A small, high-lying vagina presents more of a surgical challenge but this may be justified when such children are likely to be fertile."

4. An outcome study of twenty adult males with micropenis — who were actually reared male (without surgical intervention) but who would have been assigned female under the present standard of practice — reveals a satisfactory outcome. While six experienced teasing about their small penises, all of them reported feeling themselves to be male, and all had erections and orgasms. Nine had sexual intercourse satisfactory to themselves and their partners, seven were married or cohabiting, and still others were sexually active.

Reilly JM and Woodhouse CRJ. "Small Penis and the Male Sexual Role." *J of Urology*. 1989; 142: 569-572.

5. Colapinto J. "The True Story of John/Joan." *Rolling Stone*. December 1997.

6. Encouraging family counseling over surgical intervention in managing intersex has been recommended by Edmund G. Howe, Professor of Psychiatry and Director of Programs in Medical Ethics at the Uniformed Services University of the Health Sciences. Howe E. "Intersexuality: What Should Caregivers Do Now?" *J Clin Ethics*. 1998; 9(4).

7. In this case the parents can be referred to the Intersex Society of North America (ISNA) whose web address is: www.isna.org, as well as to the XY/XO Support Group whose website is located at <http://www.geocities.com/xyxous>, and to the Ambiguous Genitalia Support Network, <http://www.jps.net/agsn>, a support group founded by the mother of a child born with ambiguous genitalia.

8. American Academy of Pediatrics: Policy Statement: Evaluation of the Newborn With Developmental Anomalies of the External Genitalia (RE9958) *Pediatrics* (2000) (hereinafter "Policy Statement RE9958") acknowledges "[M]ost genetic and endocrine centers are able to refer families to appropriate support groups."

9. Such ethical obligation mirrors the legal obligations which Jamie's physicians have. One recent law review article suggests that surgeons may be civilly liable for performing genital surgery without carefully articulating to the parents all of the risks and unknowns of such surgery. See: Diamond D and Beh H. "An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment Surgery on Infants with Ambiguous Genitalia?" *Michigan Journal of Gender and Law*. Summer, 2000; 7.

10. American Academy of Pediatrics: Policy Statement: "Informed Consent, Parental Permission, and Assent in Pediatric Practice" (RE9510). *Pediatrics*. 1995. 95(2): 314-7. Available from: <http://www.aap.org/policy/00662.html>.

11. Schober JM. "Long-Term Outcome of Feminizing Genitoplasty for Intersex." In: PDE Mouriquand (Ed.), *Pediatric Surgery and Urology Long Term Outcomes*. Philadelphia, Penn: W.B. Saunders, 2000.

12. Phornphutkul C, Fausto-Sterling A, Gruppuso PA. "Gender Self-Reassignment in an XY Adolescent Female Born with Ambiguous Genitalia." *Pediatrics*. 2000; 106:135-137.

13. Dreger AD. "Ambiguous Sex — or Ambivalent Medicine? Ethical Issues in the Treatment of Intersexuality." *Hastings Center Report*. 1998; 28(3): 24-36.

14. See, e.g., Kipnis K and Diamond M. "Pediatric Ethics and the Surgical Assignment of Sex." *J Clin Ethics*. 1998; 9(4). Also: Wilson BE and Reiner WG. "Management of Intersex: A Shifting Paradigm." *J Clin Ethics*. 1998; 9 (4).

15. Manuel M, Katayama KP, Jones HW Jr. "The Age of Occurrence of Gonadal Tumors in Intersex Patients with a Y Chromosome." *Am J Obstet Gynecol*. 1976; 124:293-300.

Case Commentary

Anne Fausto-Sterling, PhD

Brown University Medical School

Author: *Sexing the Body: Gender Politics and the Construction of Sexuality*. Basic Books, 2000.

In making management decisions about a complex case of intersexuality, the first step should be a frank admission of uncertainty. Even the basic facts of the matter here are unclear. Is the gonad an ovary, as suggested at first, or a testicle? Is either of the gonads making hormones, which might be especially important for subsequent growth and bone development? How much of the body is mosaic? Will puberty be masculinizing or feminizing? And, most important of all, what will the child's gender identity be as he/she reaches conscious expression in the first decade of life? Neither the doctors nor the parents have reliable answers to any of these questions, no matter what they claim. Thus I think the most conservative approach should be taken — don't cut out anything that you may later decide you wish the patient still had.

But what of the medical and emotional concerns? The cancer question is the easiest: in these cases, an increased risk of cancer emerges AFTER puberty, so there is no need to remove the gonads earlier. Furthermore, either a functional testis or ovary can aid bone development, reducing the risk of osteoporosis that results from gonadectomy. If the testis is functional and if Jamie adopts a male gender identity, it might even be possible to use spermatogonial nuclei for in vitro fertilization—thus permitting the possibility of fatherhood later in life. If the testis does not make its own hormones, but the child develops a male gender identity, then leaving the phallus intact will give the pediatric endocrinologist the possibility of using exogenous testosterone to induce growth.

What of Ira's fears about life in the locker room? With proper and practical counseling, the anticipated teasing can be

minimized or avoided. Parents can arrange for their children to have privacy while dressing and undressing in schools. There is nothing visibly odd about such children as long as they are wearing clothes. Proper counseling can also help family members talk with each other, developing an atmosphere in which sexual development can be explained to the child and in which all matters relating to Jamie's development can be openly discussed.

Finally, Ira is concerned that gender imprinting might have already occurred and that surgery could leave Jamie without the requisite parts needed to carry out that imprinting. Ira could be right, and that is the point. We don't really know how gender identity develops, but we do know that mistakes in gender assignment occur — i.e., the doctors' "best guess" about future gender identity sometimes turns out to be wrong. Again, this fact strongly suggests that the best course is to postpone surgery and provide maximum counseling to the family — including advice about how to protect Jamie from teasing by his/her peers. Close observation and discussions with Jamie should enable some clarity about gender identity within the first five years, and the child's voice should be listened to.

Articles and Books of Interest

Alice Domurat Dreger. *Hermaphrodites and the Medical Invention of Sex*. Harvard University Press, 1998. This book traces evolutionary thought through the late 19th and early 20th centuries about what makes a person male or female. At the time, one's "true sex" was assigned by the sole criterion of whether a testis or an ovary was present. Partly because of the simultaneous increase in access to gynecologic care, the reported number of intersexed people grew, leading to a perceived "need" to establish diagnostic criteria for "maleness" and "femaleness" in a period during which gender, sexuality and sex were indistinct notions.

Yronwode A. "Intersex Individuals Dispute Wisdom of Surgery on Infants." *Synapse*. March 11, 1999. This essay that appeared in the campus newspaper of the University of California at San Francisco Medical School includes dissenting opinions about the management of intersexed children. The writer interviewed local authorities who support early surgery, citing advancements in genital microsurgery that improve operative outcomes.

Alice Domurat Dreger (Editor). "Intersex in the Age of Ethics." *University Publishing Group*, 1999.

A wide range of ethical issues relevant to the treatment of intersex infants, children, and adults is represented by first-person narratives of intersexual persons and their families.

Diamond M, Sigmundson HK. "Management of Intersexuality: Guidelines for Dealing with Persons with Ambiguous Genitalia." *Arch Pediatr Adolesc Med*. 1997; 151:1046-1050.

The authors offer advice to facilitate an understanding of "biologically understandable" intersex conditions. They recommend: "We must allow the postpubertal individual time to consider, reflect, discuss and evaluate and then, have the last word in his or her genital modification and gender role and final sex assignment. The patients themselves must be involved in any decision as to something so crucial to their lives."

Blackless M, Charuvastra A, Derrryck A, Fausto-Sterling A, Lauzanne K, and Lee E. "How Sexually Dimorphic Are We?" Review and synthesis. *American Journal of Human Biology*. 2000; 12:151-166.

The article provides statistics about the prevalence of intersex conditions. "We conclude that the frequency may be as high as 2 percent of live births. The frequency of individuals receiving 'corrective' genital surgery, however, probably runs between 1 and 2 per 1,000 live births (0.1% - 0.2%)."

Nussbaum E. "A Question of Gender." *Discover Magazine*, January 2000; 92-9.

A comprehensive lay review of the controversies surrounding management of the approximated 65,000 — 80,000 babies born each year who are not neatly categorized as either male or female.

Phornphutkul C, Fausto-Sterling A, Gruppiso PA. "Gender Self-Reassignment in an XY Adolescent Female Born with Ambiguous Genitalia." *Pediatrics*. 2000; 106:135-137.

This reports another case in which doctors "assigned" a boy as female because his penis was considered "too small", but, regardless, the girl grew up to become a boy. Examining available evidence, these authors call for open disclosure to intersexed patients and their parents and for a moratorium on early surgery.

Fausto-Sterling A. "Sexing the Body: Gender Politics and the Construction of Human Sexuality." New York: *Basic Books*, 2000.

Fausto-Sterling carefully chronicles and analyzes the ways by which scientists have politicized the human body. She demonstrates how social factors often influence a scientist's approach to research and interpretation of experimental results. She devotes three chapters of the book to the social management of intersexuality, concluding that intersexed people should not be forced to conform to flawed societal definitions of normality.

Diamond M and Beh H. "An Emerging Ethical and Medical Dilemma: Should physicians perform sex assignment surgery

on infants with ambiguous genitalia?" *Michigan Journal of Gender and Law*. Summer, 2000: 7.

This article **examines the legal liability of physicians** who treat intersexed infants with genital surgery and suggests that such practitioners may face exposure to claims based upon failure to obtain adequate informed consent. It closes with: "Providing parents with a fuller explanation of the risks, including the recently reported failures of treatment and information about the successful adaptation of individuals raised without surgery, may well curb parental consent. After all, few parents would consent to such extensive treatment if physicians reveal that there is no scientific evidence supporting the premise on which treatment is based and that the child may ultimately reject the treatment and be left worse off for having undergone it."

Dreger DA. "Ambiguous Sex" — or Ambivalent Medicine?" *The Hastings Center Report*. 1998. 28(3): 24-35.

The article provides extensive **ethical reflection about the treatment of intersexual persons**. The author writes, "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." She also reviews the famous case of "John/Joan" as reported by sexologist John Money that lay the foundation for establishing the modern-day practice of early surgery for intersexed children. Born a typical male and twin to a brother, "John" was medically reconstructed and raised as a female ("Joan") after his penis was accidentally ablated during a circumcision. For thirty years, the alleged success of this sex reassignment has been cited as proof that doctors could create any gender for a child if medical and surgical intervention occurred early. But other researchers exposed the fallacy of this case, revealing that Joan had chosen to resume life as John by age fourteen. He later married a woman with whom he adopted children.

Greenberg JA. "Defining Male and Female: Intersexuality and the Collision between Law and Biology." *Arizona Law Review*. 1998; 41(2): 265-328.

The author examines the law's treatment of people whose biology challenges the traditional binary assumptions about sexuality. She also reviews legal cases that have produced legal definitions of terms like "male," "female," and "sex." She writes, "The law, by clinging to a binary system that blindly ignores the existence of intersexuals and the importance of self-identity, reinforces the perception that intersexuality is unacceptable."

Web Resources

Intersex Society of North America (ISNA) offers frequently updated and extensive medical, legal, and ethical resources related to intersexuality. Its mission is "to create a world free of shame, secrecy, and genital mutilation for intersex people." <http://www.isna.org>

The North American Task Force on Intersex (NATFI) formed in response to controversies over standards of medical practice for treatment of intersex children. It aims to establish standards for informed consent and guidelines for management of children born with intersex conditions. <http://www.natfi.org/>

Short courses to "**Come to Terms**" with the vocabulary of sex and gender terminology. See:

<http://www.people.virginia.edu/~amb7p/terms.html>

Also, Transgender 101 available at:

http://lgbtrc.ucr.edu/trans_101.html

A somewhat tongue-in-cheek **Guide to Medical Intersexuality Vocabulary**:

<http://www.sexuality.org/l/transgen/intvoca.html>

Fausto-Sterling A. "**The Five Sexes, Revisited.**" *The Sciences*, July/August, 2000. 8-23. Available from: http://www.nyas.org/membersonly/sciences/sci0007/fausto_body.html.

The United Kingdom Intersex Association (UKIA) is an education and advocacy support organization for intersexed people. <http://www.ukia.co.uk/index.htm#list>

Quotations from Other Pages

In Ovid's *Metamorphoses*, Hermaphroditus is the child of Hermes and Aphrodite, whose two names are joined in his. Like Narcissus, he is said to have come to the side of a pool, where he encountered a nymph, Salmacis, who desired him. The naïve Hermaphroditus resisted her embraces, but she nonetheless pursued him, clung to him, and would not let go. Salmacis prayed to the gods to make them one flesh: 'so were these two bodies knit in close embrace: they were no longer two, nor such as to be called, one, woman, one, man. They seemed neither, and yet both.

— From: Marjorie Garber, *Vice Versa — Bisexuality and the Eroticism of Everyday Life*. Simon and Schuster, 1995.

Evaluation of newborn with external genitalia abnormalities

To explain to the family the cause of their newborn's genital abnormalities, the practitioner needs to understand the genetic and hormonal influences that are responsible for normal genital development. Before about 6 weeks' gestation, male and female embryos develop undifferentiated gonadal tissue and have primordial structures with the potential to produce either male or female genitalia. The genital appearance of the newborn is largely determined by the presence or absence of genetic and hormonal influences responsible for the active process of male differentiation. The fetus tends to develop as a female in the absence of these male influences. Intersex conditions arise because of an abnormality along the male pathway that interferes with complete masculinization or, in the case of a genetic female, some virilizing influence that acts on the developing embryo.

Male sexual differentiation is initiated by the SRY gene on the short arm of the Y chromosome. Under the influence of SRY, the undifferentiated gonad forms a testis, which produces the hormonal milieu that results in male sexual differentiation: testosterone stimulates the wolffian structures (epididymis, vas deferens, and seminal vesicles), and anti-Müllerian hormone suppresses the development of the Müllerian structures (fallopian tubes, uterus, and upper vagina). The conversion of testosterone to dihydrotestosterone occurs in the skin of the external genitalia and masculinizes the external genital structures. Most of this male differentiation takes place by about 12 weeks, after which the penis grows and the testes descend into the scrotum. In the absence of SRY, female sexual differentiation occurs. An error in genital morphogenesis may occur at any step in this developmental pathway.

—From: American Academy of Pediatrics, "Evaluation of the Newborn with Developmental Anomalies of the External Genitalia" (RE9958). *Pediatrics*. 2000; 106: 138-42.

Conferences

Kaiser Teleconference

Thursday, June 14, 2001, 12:30 - 1:30: Medical Mistakes.

2001 Kaiser New Member Ethics Orientations

9 AM — 4:30 PM.

— May 17, Santa Clara Facility, Bldg. K, Room 4B

— Sept. 28, San Francisco, Geary Bldg., 3rd Floor, Diamond Room

— November 29, Stockton Facility, MOB, Room C

To register, phone Jonathan Cabrieto at 510-987-3243 or tie line 8-427-3243, or e-mail at jonathan.cabrieto@kp.org

Genetics and Disability — Ethics of Pre-implantation

Genetic Diagnosis. Theresa Drought, PhD, RN, Co-Director, Regional Ethics Program, Kaiser Permanente Northern California. May 8, at the Stanford Medical Center, Room M104, Noon -1:15. Call 650-498-7869 for further information.

Identity after the Human Genome Project. Laurie Zoloth, PhD, Director, Jewish Studies Program, San Francisco State University. June 12, from 12-1 PM, in Room M-110 of the Stanford Medical Center. Call 650-498-7869 for more information.

End Quotes

"Doctors have come from distant cities just to see me — stand over my bed disbelieving what they're seeing. They say I must be one of the wonders of God's own creation."

— Natalie Merchant, from the song "Wonder"

"O my body! I dare not desert the likes of you in other men and women,

nor the likes of the parts of you.

I believe that the likes of you are to stand or fall with the likes of the soul

(and that they are the soul).

I believe that the likes of you shall stand or fall with my poems,

and that they are my poems,

Man's, woman's, child's, youth's, wife's, husband's, mother's, father's,

young man's, young woman's poems . . ."

— Walt Whitman, *Song of Myself*

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