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Paradigms Revised: Intersex Children, Bioethics & the Law

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INTRODUCTION

In November 2000, a four day-old infant lay supine on the operating table at a children's hospital in the United States, draped and prepped for surgery. The child's problem lay exposed to the view of the urology residents who crowded the operating room: rather than male or female genitalia, the child had a tiny phallus with a urethral opening at its base, two bifurcated scrota which appeared to form a labia minora, and a vagina which ended blindly, rather than leading to a uterus. The child's gonads were nowhere to be found. The surgical task was to find the gonads and take a sample of them to determine, among other matters, whether they were comprised of testicular or ovarian material. Upon analysis of the specimen, the laboratory found both types of tissue. This infant was neither male nor female, but "intersex."

Intersex individuals are classically defined as having both male and female sexual characteristics.[1] Researchers estimate that intersex conditions may affect up to one out of every 2,000 children born.[2] The notion of an intersex individual may bring to mind an image of Hermaphroditus, the fabled child of Aphrodite and Hermes who had the complete external genitalia of both a man and a woman. However, such cases are purely

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1. Julia S. Barthold & Ricardo Gonzalez, *Intersex States*, *in* PEDIATRIC UROLOGY PRACTICE 547 (E. Gonzales ed. 1999).

2. Melanie Blackless et al., *How Sexually Dimorphic Are We?*, 12 AM. J. HUM. BIO. 151-66 (2000); Intersex Society of North America *at* http://www.isna.org/faq/frequency.html (last visited May 14, 2002) (providing estimates of the frequency of specific intersex conditions among births, viewed on November 20, 2001). A review of the medical literature performed by Anne Fausto-Sterling suggests that children with intersex conditions comprise 1.7 percent of all births. ANNE FAUSTO-STERLING, SEXING THE BODY 51-53 (2000).

mythological. Intersex individuals instead have "ambiguous" genitalia. While the external genitalia may appear male, for example, the person also possesses ovaries rather than testes, and a functional uterus. Or a person may have a bifurcated scrotal sac/vulva and a urethral opening at the base of what appears to be a small, curved phallus, but, upon surgical exploration, has undescended testes and no female reproductive organs. While identification of a child as intersex can often be made by physical examination alone, in some cases normal-appearing external genitalia can hide an internal ambiguity or an anomalous chromosomal sex. As a result, families and physicians face a dilemma concerning how to treat such infants. Prior to the advent of modern surgery, such individuals were left as they were born. Some did not survive, depending on their respective medical conditions and urogenital structures. Enough lived to present perplexities in law and society; for example, the *Talmud* and *Tosefta* contain regulations for people of mixed sex,[3] and in 16th century England, Lord Coke declared with respect to the law of inheritance that "a hermaphrodite may be either male or female, and it shall succeed according to the kind of sex that doth prevail."[4]

Starting in the 1950's, once surgical practice became sufficiently sophisticated, physicians commonly believed the best practice with respect to such individuals was to assign them surgically to an "appropriate" sex prior to the age of two, if not earlier.[5] In many cases, physicians believed it was so important for parents to be able to identify a child as male or female at birth, based on the appearance of the child's sex organs, that they would suggest immediate surgical reassignment.[6] In conjunction with the surgery, parents were counseled to raise their child in strict adherence to convention in accordance with the

3. *See* FAUSTO-STERLING, *supra* note 2, at 33.

4. *See* JOHN MONEY, SEX ERRORS OF THE BODY AND RELATED SYNDROMES 3 (2d ed. 1994).

5. *See, e.g.*, Hazel Glenn Beh & Milton Diamond, *An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment Surgery on Infants with Ambiguous Genitalia?*, 7 MICH. J. GENDER & L. 1, 2-3 (2000).

6. *Cf.* Evan Kass et al., *Timing of Elective Surgery on the Genitalia of Male Children with Particular Reference to the Risks, Benefits, and Psychological Effects of Surgery and Anesthesia*, 97 PEDIATRICS 590 (1996) available at LEXIS, Medical & Healthcare Journals Library, Pediatrics File (noting that "opportunities for establishing a strong and stable mother-father-infant relationship must be fostered" during the first year of life, and that surgery is indicated at as early as six weeks of age).

chosen sex assignment, in order to ensure that the child's gender identity matched its assigned sex.[7]

For decades, very few researchers studied the psychosocial and psychosexual outcomes of these children as they matured to adulthood.[8] On the basis of several limited follow-up studies performed in the 1960's, it was assumed that gender was primarily a function of societal conditioning, rather than biological determination.[9] As such, most physicians believed that an individual assigned to a given sex, if raised appropriately and sufficiently surgically modified, would be assured a reasonable outcome; i.e., the individual would identify with the assigned sex and would become a heterosexual within that assignment.[10]

In the late 1990's, however, this assumption was knocked askew by the revelation that the most prominent research subject from the sex reassignment studies had definitively rejected his female assignment and was now married to a woman and living as a male in Canada, despite the fact that his penis had been ablated in a surgical accident in infancy, and his testes had been surgically removed in the subsequent effort to make him a female.[11] Contemporaneously, a small but vocal group of other individuals who had undergone cosmetic genital or sex assignment surgery in infancy and childhood came forward to demand a moratorium on such surgeries. Some of these individuals had rejected their assigned sex; others protested their loss of sexual sensation and function. These individuals found the surgeries to be unreasonable invasions of their bodily integrity and psychosexual and psychosocial identities.

The management of intersex infants and children is presently enmeshed in controversy. While the American Academy of Pediatrics still recommends sex assignment surgery and certain

7. *See, e.g.*, Kass et al., *supra* note 6. For example, Beh and Diamond note that the family of one boy who had been surgically reassigned as a girl were instructed not only to strictly raise the child as a girl, but also to move to another city in order to help keep the child's birth sex a secret. Beh & Diamond, *supra* note 5, at 7.

8. John Money, whose research is discussed in Part I, *infra*, performed one of the only such studies prior to the 1960's. *See* John Money et al., *Imprinting and the Establishment of Gender Role*, 77 ARCH. NEUROL. PSYCHIATRY 333-36 (1957).

9. Dr. Money published his results in the early 1970's. *See* JOHN MONEY & A. EHRHARDT, MAN AND WOMAN, BOY AND GIRL (1972).

10. This belief was held as recently as 1996. *See* Kass et al., *supra* note 6.

11. *See* Milton Diamond & H. Keith Sigmundson, *Sex Reassignment at Birth: Long-Term Review and Clinical Implications,* 151 ARCH. PEDIATR. ADOLESC. MED. 298, 298 (1997).

cosmetic genital surgeries in infancy,[12] a growing number of physicians and other health professionals are suggesting that, in many cases, surgical revision should wait until the child comes of age and can decide for itself whether to undergo surgery directed towards achieving male or female appearance and "function" or remain as it is.[13]

The controversy branches into several legal arenas. This paper will focus on two in particular, both of which may impact future medical practice concerning cosmetic genital and/or sex assignment surgeries as performed on intersex infant and children.[14] The first area is that of medical malpractice. What right, if any, do intersex individuals have to recover for surgeries performed upon them? If no such right exists, should they have any such right? The second area is that of informed consent. Some commentators argue that surgeries on intersex children were (and may still be) regularly performed with serious defects in informed consent. Given this history, should the practice of early cosmetic genital and sex assignment surgeries be allowed to continue? If so, then under what circumstances? Also, given that the surgery has such potentially major ramifications on the child's social and sexual identity, should parents be permitted to consent for non-emergent surgery on behalf of an intersex child?

In one of the few legal articles addressing the issue of intersex surgeries, Hazel Beh and Milton Diamond (the latter being the Honolulu professor of anatomy and reproductive biology who first uncovered and publicized the rejection of one research subject's sex reassignment) evaluate medical malpractice law and the law of informed consent as a means of controlling and/or ceasing the practice of cosmetic genital and sex assignment surgeries.[15] They ultimately conclude that deficiencies in informed consent warrant a moratorium on such surgeries.[16]

12. *See* American Academy of Pediatrics, *Evaluation of the Newborn with Developmental Anomalies of the External Genitalia*, 106 PEDIATRICS 138, 138 (2000) *available at* LEXIS, Medical & Healthcare Journals Library, Pediatrics File.

13. See, e.g., Kenneth Kipnis & Milton Diamond, *Pediatric Ethics and the Surgical Assignment of Sex*, 9 J. CLINICAL ETHICS 398 (1998); Bruce E. Wilson & William G. Reiner, *Management of Intersex: A Shifting Paradigm*, 9 J. CLINICAL ETHICS 360 (1998).

14. For a discussion of other legal issues, such as the right to marry and alter identifying legal documents, *see* Julie A. Greenberg, *Defining Male and Female: Intersexuality and the Collision Between Law and Biology*, 41 ARIZ. L. Rev. 265 (1999).

15. Beh & Diamond, *supra* note 5, at 2-3.

16. *Id.* at 56–59.

This extreme prescription, however, is likely as shortsighted as the prior practice of reflexively performing cosmetic surgeries on most intersex children in infancy. On the one hand, use of the legal system to interdict these surgeries may be necessary if one desires a rapid end to them. The other two alternatives, waiting for change in medical practice and using political agitation, will not likely achieve such a result in a short period of time. And political agitation, while useful in quickly bringing an issue to the attention of the public, will likely have only limited success in bringing the practice to an end without some assistance from the legal arena. On the other hand, however, the legal system is ill-equipped to deal with the cultural and social issues underlying intersex surgeries. Failing to come to terms with these issues threatens to leave in place the norms which brought about the surgical practices in the first place.

While certain changes in the management and treatment of intersex individuals are undoubtedly warranted, an absolute moratorium on childhood cosmetic genital and sex assignment surgeries cannot be justified. This paper advocates a middle approach to the treatment of intersex individuals, one which takes account not only of the concerns of intersex activists, but also of issues concerning medical research, family dynamics, and social and cultural considerations. Part I of this paper provides an overview of sex and gender. It briefly sketches part of the outline of the debate over what constitutes sex versus gender, and places intersex individuals within its context. Part II discusses intersex conditions, their present treatment and outcomes. Part III evaluates proposed methods of enlisting the legal system in modifying the present treatment regimen of intersex individuals. It concludes that the proposed legal solutions are inadequate to resolve the matter, as they do not address the social and cultural issues which underlie the present management and treatment of intersexuals. Without squarely facing and treating such issues, any alteration to the current treatment paradigm will be cosmetic at best. Thus, as developed in Part IV, the alterations proposed in this paper take into account not merely deficiencies in present data concerning treatment outcomes and legal deficiencies with prevailing treatment protocols, but also the mores which influenced the adoption of current treatment regimens and the social and psychological needs of intersex children and their families.

I. Overview of Sex and Gender

At least in recent centuries in the western world, sex traditionally has been considered to be biologically determined.[17] Conventionally, one's sex is determined by being born with a certain set of reproductive organs. This test has the ease of simplicity: what one finds between the legs determines one's sex. Physicians, midwives and farmers have used it for millennia. Chromosomal analysis has only recently entered into the picture, but now also has a standardized place; rather than using the visual test, one can instead do a chromosomal analysis and see whether one's chromosomal makeup, or "karyotype," is 46,XX, which usually yields a person with the reproductive organs and secondary sex characteristics of a female, or 46,XY, which usually yields a person with the reproductive organs and secondary sex characteristics of a male.[18] As for gender, under the traditional analysis, gender is simply the sociocultural manifestation of one's sex. The traditional definitions result in a binary system, in which a person is destined to be a man or a woman – socially, biologically and experientially – based on the sexual organs which he or she possesses.

In recent decades, however, certain theorists have questioned the traditional concepts of both sex and gender. Some posit that our definition of sex, rather than being scientifically objective, has a culturally-constructed component.[19] From this perspective, one might think of the body as "the point of intersection, as the interface between the biological and the social."[20] Sex is not merely a biological given; rather, it is conditioned by our perception of it within our historical and cultural context. This point becomes clearer when one considers how to apply the traditional definition of sex to an individual whose gonads do

17. For a detailed discussion of changes over time in the medical definition of sex in England and France, *see* Alice Domurat Dreger, Hermaphrodites and the Medical Invention of Sex (1998).

18. *See, e.g.*, Keith L. Moore, The Developing Human: Clinically Oriented Embryology 272 (3rd Ed. 1982).

19. *See, e.g.*, Michel Foucault, The History of Sexuality: An Introduction 154-55 (R. Hurley, trans.) (1978); Fausto-Sterling, *supra* note 2, at 23 ("To talk about human sexuality requires a notion of the material. Yet the idea of the material comes to us already tainted, containing within it preexisting ideas about sexual difference").

20. Rosi Braidotti, *The Politics of Ontological Difference*, *cited in* Lois McNay, Foucault & Feminism 24 (1992). *See also, e.g.*, Susan Bordo, The Male Body (1999) (noting, in her discussion of clothing, nakedness and masculinity, "we need to think about the body not only as a physical entity – which it assuredly is – but also as a cultural form that carries meaning with it").

not match his or her external genitalia, or who has a non-standard set of chromosomes. Can sex be determined solely by one's gonads, or by the external appearance of one's sex organs, or by one's chromosomes? How does one choose which criteria to use? Is it perhaps defined by some combination of the above? Who determines what sex is, and the contexts in which it is appropriate to define it?

Correspondingly, some philosophers and cultural theorists posit that gender is created by sociocultural and other factors, rather than being an outgrowth of sex.[21] Gender does not merely denote the manner in which one manifests whether one is male or female. Such a definition would limit gender to a description of the range of appearances, behaviors and interactions which a given society deems to be "male" or "female." Rather, gender encompasses the entire means by which these appearances, behaviors and interactions come into being in a given sociocultural setting.[22] Additionally, some theorists argue that, because gender is socioculturally produced, there is no necessary relation between sex and gender. In this context, "[g]ender becomes a free-floating entity with the consequence that 'man and masculine might as easily signify a female body as a male, and women and feminine a male body as easily as a female one.'"[23]

Against these theoretical backdrops, what does one make of intersex individuals? If gender is based on one's sex, and – a

21. *See, e.g.*, JUDITH BUTLER, GENDER TROUBLE: FEMINISM AND THE SUBVERSION OF IDENTITY 7 (1990).

22. *See, e.g., id.* Whether or not one agrees with the foregoing proposition, the following brief survey of bygone gender norms helps demonstrate the fluid, even arbitrary nature of gender:

> Female inverts were described in the literature as possessing "masculine straightforwardness and sense of honor" (Ellis, 1942, p. 250), having "a dislike and sometimes incapacity for needlework" as well as "an inclination and taste for the sciences" (Krafft-Ebing, 1893, p. 280), being demanding of voting rights, and skillful at whistling (Browne, 1923; Claiborne, 1914; Ellis, 1942). Accounts of male inverts include such descriptors as, "sentimental," "something of a chatterbox" (Carpenter, 1911, p. 132), "never smoked "entirely averse to outdoor games," and having a "fondness for cats" (Rivers, 1920, p. 22). Krafft-Ebing (1893) noted that this "abnormality of feeling and of development of the character [was] often apparent in childhood" (p. 279). On one such case, he wrote that "the boy likes to spend his time with girls, play with dolls, and help his mother around the house" (Krafft-Ebing, 1893, p. 279).

Nancy H. Bartlett et al., *Is Gender Identity Disorder in Children a Mental Disorder?*, 43 SEX ROLES: A JOURNAL OF RESEARCH (2000).

23. MCNAY, *supra* note 20, at 23.

crucial assumption – if one's sex is determined by the appearance of one's external genitalia, then under the traditional theory, sex assignment surgery should yield healthy individuals who identify appropriately with their assigned sex and gender of rearing. If, at the opposite extreme, gender is solely a sociocultural construct and has no necessary relation to sex, it would seem that an individual who was reared in an ideal social setting (another crucial postulate) to become a particular gender would, notwithstanding his or her physical or chromosomal sex, identify more with his or her gender of rearing rather than with the gender traditionally corresponding to the person's physiological or chromosomal sex. In such an idealized case, sex assignment surgery, which is supposed to make a person's genital appearance correspond with their assigned sex and gender, would be icing on the cake, a non-essential trapping to help reinforce the gender of rearing.[24]

Yet the problem is by no means this simple. Children who were surgically assigned to one sex in infancy and raised according to the reassignment have rejected it in adulthood. Most notoriously, this occurred to the subject of the most famous sex reassignment case in the medical literature. Until the individual's actual outcome had been reported, this case had formerly been the cornerstone on which the theory that a child could be successfully reared as either a boy or girl following sex assignment surgery was based. In this case, a surgeon accidentally burned "John's" penis so badly during a circumcision at the age of seven months that the majority of it was completely destroyed.[25] Before this time, John had been an otherwise normal boy. On the advice of John Money, then a psychologist at Johns Hopkins University, his parents agreed to have John surgically reassigned as a girl ("Joan").[26] Following the accident and reassignment, Dr. Money counseled the child's parents as to Joan's upbringing as a girl, and advised them never to disclose to Joan that s/he had been a boy.[27]

24. Due to the myriad different pressures society puts on individuals to conform with various gender norms based on the person's perceived sex, however, and given multiple other factors at play (such as the child's own preferences and the family's role in reinforcing or problematizing the child's assigned gender), it is unlikely that any social constructivist theorist would postulate that the outcome of rearing a child according to one gender norm or another could be guaranteed.

25. John Colapinto, *The True Story of John/Joan*, ROLLING STONE 54-97 (Dec. 11, 1998).

26. *Id.*

27. Beh & Diamond, *supra* note 5, at 7; *see also* Colapinto, *supra* note 25.

According to Money, other than displaying some tomboyishness, Joan had accepted his/her reassignment.[28] Money cited the case as a success, and, largely on its basis, recommended sex assignment surgery or surgery to "normalize" the genitals for intersex individuals in infancy.[29] If an otherwise normal boy could be successfully reared as a girl following the appropriate surgery, then – the theory went – such a strategy should surely make sense with respect to intersex children, whose sexual appearance is frequently ambiguous. Physicians and families could feel secure, based on this case, that their decision to assign an intersex child to a given sex in infancy would ultimately be in the child's best interest, and that the child would most likely grow up to be a sexually and psychosocially well-adjusted individual.

However, Money failed to publish signs of trouble in his reports on Joan. Joan eventually refused to participate in his/her counseling sessions.[30] S/he insisted in standing to urinate.[31] When s/he was given estrogen at the age of twelve in order to stimulate development of breasts, widened hips and other female secondary sex traits, Joan refused to take the hormone.[32] S/he thought s/he was a "freak," and began contemplating suicide.[33] At the age of fourteen, Joan finally learned the truth about his/her sex at birth from his/her father.[34] Immediately after hearing this news, Joan began living as a boy.[35] When Dr. Diamond, a critic of Dr. Money, found him again in 1994, John was living as a man, had married a woman, and had adopted the woman's three children.[36] John's true outcome did not become published until 1997.[37]

Notwithstanding the frank failure of John's sex reassignment, John's case had, up until that date, profoundly influenced the standard of care for treating intersex children since the 1960's in favor of surgical assignment in infancy.[38] Based on the case, which Dr. Money reported in 1972, a standard of care developed in which infants with ambiguous genitalia were surgically as-

28. Diamond & Sigmundson, *supra* note 11.
29. *See, e.g.*, Beh & Diamond, *supra* note 5, at 9.
30. *See* Diamond & Sigmundson, *supra* note 11.
31. *Id.*
32. *Id.*
33. *Id.*
34. *Id.*
35. *Id.*
36. Diamond & Sigmundson, *supra* note 11, at 300.
37. Beh & Diamond, *supra* note 5, at 9-10.
38. *See id.* at 12.

signed as a boy or girl as soon as possible after birth.[39] As late as 1996, the American Academy of Pediatrics Action Committee on Surgery stated that "children whose genetic sexes are not clearly reflected in external genitalia (i.e., hermaphroditism) can be raised successfully as members of either sex if the process begins before the age of two and one-half years. Therefore, a person's sexual body image is largely a function of socialization."[40] All the works to which the committee cited in support of the proposition were co-authored by Dr. Money. Thus, so as "[t]o prevent the development of cross-gender identification in children born with a physical intersex condition . . . early sex assignment and early correction of their genitalia" was typically considered necessary.[41]

II. Intersex Conditions: Current Treatments and Outcomes

Intersex conditions are myriad in number and type; virtually all develop in utero.[42] Around the age of six weeks, an embryo develops undifferentiated gonadal tissue, which may become male or female, depending on the presence or absence of certain genetic and hormonal factors. In the absence of these factors, an embryo will develop into a female, but in their presence, it will develop into a male. Intersex conditions can develop when an abnormality develops with respect to the fetus' sex chromosomes and/or hormones.[43]

Intersex conditions may be classified in a number of different ways. Most frequently, the medical literature – as a residual of the former primacy of gonads in defining sex – groups intersex individuals into "true hermaphrodites" and "pseudohermaphrodites."[44] True hermaphrodites are characterized as having both ovarian and testicular tissue. Pseudohermaphrodites, on the other hand, have gonadal tissue of only one type. The literature may also group those with mixed gonadal dysgenesis separately from other pseudohermaphrodites. Individuals with mixed gon-

39. *Id.* at 16.
40. Kass et al., *supra* note 6.
41. Froukje M E Slijper et al., *Long-Term Psychological Evaluation of Intersex Children*, 27 Arch. Sex. Behavior 125, 127 (1998).
42. The only exceptions are those created by surgical mistake, such as the circumcision disaster which befell John.
43. *See* American Academy of Pediatrics, *supra* note 12.
44. *See* Dreger, supra note 17, at 145-50; Fausto-Sterling, *supra* note 2, at 37-39.

adal dysgenesis have at least one immature or undifferentiated ("streak") gonad. The following provides examples of a number of the more common causes of intersex conditions potentially leading to ambiguous genitalia.

A. True Hermaphroditism

True hermaphrodites may be of a number of different karyotypes: 46,XX, 46,XX(or XO)/46XY mosaic, or 46XY karyotype, among others.[45] Such children usually have ambiguous genitalia. A constant or near-constant (eighty percent to one hundred percent of all cases) feature is the possession of a (frequently abnormal) uterus and vagina.[46] The gonads of a true hermaphrodite are either ovotestes or a combination of ovary, testis and/or ovotestis.[47] Almost all are infertile as males, and most – although not all – are infertile as females.[48] Presently, true hermaphroditic children are raised either as male or female (with more than seventy-five percent presently raised as male).[49] Recently, some researchers have advocated rearing them as females, given the slightly increased possibility for childbearing.[50] Depending on choice of gender, the incompatible portions of the child's gonads are usually removed, in order to avoid potential malignancies, as well as complications at puberty such as gynecomastia (development of female post-pubertal breasts) in males.[51]

B. Pseudohermaphroditism

Children with pseudohermaphroditism may have ambiguous genitalia, although, unlike true hermaphrodites, they possess only testicular or ovarian gonadal tissue, rather than a mixture. Pseudohermaphroditic conditions are usually linked to either chromosomal or endocrinological issues.

The most common pseudohermaphroditic (and intersex) condition is congenital adrenal hyperplasia (CAH), when it appears in chromosomal females. One study suggests that individuals

45. Barthold & Gonzalez, *supra* note 1, at 556.
46. *Id.*
47. *Id.*
48. *Id.* (noting that 21 pregnancies have been reported in true hermaphrodites, almost all of whom have had at least one normal ovary and a normal uterus).
49. *Id.*
50. Barthold & Gonzalez, *supra* note 1, at 556.
51. *See id.*

with CAH comprise over 1.5 percent of all births.[52] Females with this condition generally have a normal female karyotype, and a normal uterus and ovaries. However, due to a congenital defect in the adrenal gland which causes it to produce high amounts of androgens, they develop partially or completely masculinized external genitalia (i.e., they possess a phallus which is longer than the average clitoris and may even be "penis-sized," and may have no externally-apparent vagina). Most karyotypically female children are presently raised as females in America, although those with fully masculinized external genitalia are occasionally raised as males.[53]

Another relatively common condition is androgen insensitivity syndrome. Children with this condition are karyotypically 46,XY, and thus chromosomally male, but are either partially or totally insensitive to androgens.[54] Because of the insensitivity, these children appear to the observer to be partially or completely feminized. Those with complete androgen insensitivity syndrome (CAIS) have the external genitalia and, after puberty, secondary sex characteristics of a woman.[55] However, they usually also have inter-abdominal testes, a blind-ending vagina, and lack a uterus and ovaries.[56] Virtually all such individuals are raised as girls, and in fact are usually not identified as having CAIS until puberty, when they fail to menstruate.[57] Children with partial androgen insensitivity syndrome (PAIS) vary in their genital development in a spectrum from complete external feminization to virilization producing hypospadias (a condition in which the penis is very short, squat and/or curved and the urethra exits from the shaft or base rather than from the glans,

52. FAUSTO-STERLING, *supra* note 2, at 53.

53. Barthold & Gonzalez, *supra* note 1, at 559-60; *see also* Jaime Frias et al., *Technical Report: Congenital Adrenal Hyperplasia*, 106 PEDIATRICS 1511 (2000) *available at* LEXIS, Medical & Healthcare Journals Library, Pediatrics File. One form of CAH can cause a life-threatening metabolic crisis within day or weeks of birth. Thus, a diagnosis of CAH can be a true *medical* – not surgical – emergency. The crisis is forestalled by cortisol injections. Cosmetic genital surgery plays no role in this treatment. *Id.*

54. *See* Amy B. Wisniewski et al., *Complete Androgen Insensitivity Syndrome: Long-Term Medical, Surgical, and Psychosexual Outcome*, 85 J. CLINICAL ENDOCRIN. & METAB. 2664 (2000).

55. *Id.*

56. Barthold. & Gonzalez, *supra* note 1, at 564.

57. *See, e.g.*, Wisniewski et al., *supra* note 54 (noting additionally that 100 percent of their adult CAIS study participants expressed satisfaction with their female sex of rearing).

among other abnormalities) and partial scrotal development.[58] PAIS children may experience further virilization at puberty, or may develop breasts, depending on the degree of their androgen insensitivity.[59] They may be raised as either boys or girls.[60]

Another endocrine disorder is 5-alpha reductase deficiency. This hereditary deficiency, seen in chromosomal males, causes moderate to severe genital ambiguity *in utero*, often including a significantly small penis with severe hypospadias, variable degrees of scrotal development, and undescended testes.[61] They are frequently raised as females, prior to puberty. If untreated, these children become masculinized at puberty, with moderate penile growth, testicular descent and, generally, a change in gender identity from female to male (although a minority retain their female gender).[62] They are usually infertile.[63]

Exstrophy, a major but rare congenital anomaly, may affect both chromosomal males and females.[64] In children with exstrophy, the abdominal wall over the bladder as well as the bladder itself, the urethra, and the penis or clitoris are split in two.[65] In males, the interior of the bladder and of the penis and urethra are open and visible. In females, the clitoris is duplicated and there may be other minor genital anomalies. Early surgery is necessary in order for the child's urinary tract to function.[66] Because of the particularly small penile size occurring in certain forms of the anomaly, males with exstrophy may be surgically reassigned as females.[67]

Rarely, males who are otherwise karyotypically and endocrinologically normal are born with a micropenis or without any penis at all. The condition can be caused by the torsion and death of the children's testes during their descent *in utero*, prior

58. Barthold. & Gonzalez, *supra* note 1, at 564.

59. *Id.*

60. *Id.* at 564-65.

61. *See, e.g.*, Berenice B. Mendonca et al., *Male Pseudohermaphroditism Due to Steroid 5-Alpha-Reductase 2 Deficiency: Diagnosis, Psychological Evaluation, and Management*, 75 MEDICINE 64 (1996).

62. *Id.*

63. *Id.*

64. *See* William G. Reiner et al., *Psychosexual Dysfunction in Males with Genital Anomalies: Late Adolescence, Tanner Stages IV to VI*, 38 J. AM. ACAD. CHILD & ADOLES. PSYCHIATRY 865 (1999), *available at* 1999 WL 11376171.

65. *Id.*

66. *Id.*

67. *Id.*

to full penile development.[68] While some boys with a micropenis are presently raised as a male, others, as well as boys born without any penis at all, are often surgically reassigned to the female sex in infancy.[69]

C. *Gonadal Dysgenesis*

Children with gonadal dysgenesis generally have some combination of streak or absent gonad and dysgenetic testis or ovary.[70] The condition may manifest in a number of different ways. In Swyer's Syndrome, the child is chromosomally 46,XY, however, due to problems with the Y chromosome, the child fails to develop testes.[71] Such a child, although karyotypically male, appears phenotypically female, and usually is raised as such.[72] As with CAIS, the child's condition may not be discovered until adolescence, when the child fails to start menstruating.[73]

In children with partial gonadal dysgenesis, one most often finds hypospadias with cryptorchidism (missing testes), or another form of ambiguous genitalia.[74] Occasionally, one finds fully masculinized external genitalia, however, such children also have a uterus and at least one fallopian tube.[75] These individuals are, under present management, often raised as females.[76]

D. *Treatment*

The treatment of intersex conditions is currently undergoing revision. Previously, the birth of a child with an intersex condition was considered an emergency requiring the immediate determination of a sex of rearing and the first surgery to establish the child in that sex. A quote from a 1969 treatise on the subject is instructive as to the attitude taken towards such children:

68. Interview with Dr. Lars J. Cisek, Assistant Professor of Pediatric Urology, Baylor University, Houston, Tex. (Nov. 27, 2001) [hereinafter Cisek Interview].

69. Barthold & Gonzalez, *supra* note 1, at 566-67. Incidentally, there apparently is significant variation in the results of measurement of stretched penile length from one clinician to another. *See, e.g.*, Michael L. Ritchey & David Bloom, *Summary of the Urology Section*, 96 PEDIATRICS 138 (1995), *available at* LEXIS, Medical & Healthcare Journals Library, Pediatrics File.

70. Barthold & Gonzalez, *supra* note 1, at 550.

71. *Id.*

72. *Id.* at 550-52.

73. *Id.*

74. *Id.* at 555

75. *Id.*

76. *Id.*

> [The] normal functioning [of sex] is vital to the survival of our race, essential for our full assimilation as individuals into society, and pervades every aspect of our lives. To visualize individuals who properly belong neither to one sex nor to the other is to imagine freaks, misfits, curiosities, rejected by society and condemned to a solitary existence of neglect and frustration. Few of these unfortunate people meet with tolerance and understanding from their fellows and fewer still find even limited acceptance in a small section of society: all are constantly confronted with reminders of their unhappy situation. The tragedy of their lives is the greater since it may be remediable; with suitable management and treatment, especially if this is begun soon after birth, many of these people can be helped to live happy well-adjusted lives, and some may even be fertile and be enabled to enjoy a normal family life.[77]

As recently as 1996, the American Academy of Pediatrics (AAP) espoused a treatment regimen arguably deriving from this perspective, in which sex assignment or genital normalizing surgery was recommended to be undertaken as early as possible, ideally between six weeks and fifteen months of age.[78]

The AAP recently issued new guidelines for the evaluation and treatment of intersex conditions.[79] According to these guidelines, the birth of a child with an intersex condition constitutes a "social emergency" – but notably not a surgical one.[80] Contrary to their prior recommendations, the new AAP guidelines suggest that physicians refrain from suggesting a diagnosis or gender assignment at birth, and that parents refrain from registering the birth until a sex of rearing is established.[81] The guidelines suggest that the following factors should be used in determining the sex of rearing: (1) fertility potential; (2) capacity for normal sexual function; (3) endocrine function; (4) potential for malignant gonadal change; and (5) testosterone imprinting.[82] Fertility is usually only an issue with respect to girls with CAH (although assisted reproduction techniques may be able to broaden this).[83] Despite the presence of externally-male genitalia, chromosomally-female children with CAH usu-

77. CHRISTOPHER J. DEWHURST & RONALD R. GORDON, THE INTERSEXUAL DISORDERS vii (1969).
78. Kass et al., *supra* note 6.
79. *See* American Academy of Pediatrics, *supra* note 12.
80. *Id.*
81. *Id.*
82. *Id.*
83. *Id.*; Cisek Interview, *supra* note 68.

ally have fully-formed and fully-functional uteruses and ovaries, and can be fertile. Thus, the AAP recommends raising these individuals as girls, notwithstanding the condition of their external genitalia and any androgenizing effects on the brain.[84] With respect to most other intersex conditions, fertility is significantly diminished or absent, and thus plays a less significant role or no role at all.[85]

In the early decades of sex reassignment surgery, individuals undergoing "feminizing" surgery – usually females with CAH – frequently had their phallus completely resected, if it was deemed to be too large to be considered feminine.[86] Although this does not represent the present dogma, capacity for normal (i.e., conventional heterosexual) sexual function, valuing male capacity for penetration and female capacity for receptivity, remains a strong determinant of the sex of rearing. In this connection, the AAP recommends evaluating the size of the infant's penis and its likelihood for increasing in size at puberty.[87] Those with a phallus too small for conventional heterosexual intercourse as a male (or who are chromosomally female yet whose phallus is so large as to shock the sensibilities of family and/or physicians) may be surgically assigned as females.[88] Such individuals will undergo surgery to reduce their phallus in size, if deemed excessively large in appearance for a clitoris, will have their testes removed, if any, and will eventually undergo vaginoplasty, or the construction of a blind-ending hole into which an average-sized penis can fit.[89]

Proper endocrine function is important, not only for the development and support of secondary sex characteristics at puberty, but also for development and maintenance of bone density.[90] The sex hormones produced by gonads are essential for proper endocrine function. Gonads need to be removed, however, if they conflict with the sex of assignment, as they may lead to development of inconsistent secondary sex characteristics at puberty. An individual whose gonads are removed must

84. American Academy of Pediatrics, *supra* note 12, at 141.

85. *Id.*

86. *See, e.g.*, DEWHURST & GORDON, *supra* note 77, at 41 (noting that, although "in theory preservation of the glans has something to recommend it, the results of amputation appear satisfactory," and is the "simplest" method for clitoral reduction).

87. American Academy of Pediatrics, *supra* note 12, at 141.

88. *Id.*

89. *Id.*

90. *See, e.g., id.*

remain on hormone therapy for the duration of his or her life.[91] The AAP therefore recommends, whenever possible, retaining gonads appropriate to the sex to which an infant is assigned.[92] This is particularly important for an individual with ovaries or a partial ovary, as they may produce adequate levels of estrogen throughout the individual's life for these purposes.[93] Conversely, the testes of intersex individuals are less likely to produce sufficient amounts of testosterone throughout an individual's life for the maintenance of sufficient bone density and development of secondary sex characteristics, particularly if the individual is a true hermaphrodite or has mixed gonadal dysgenesis. For this reason, it is considered less problematic to remove testes if they are undescended.[94]

Potential for malignant gonadal change (i.e., cancer) is a less significant factor in determining the sex of assignment. Testes and immature gonads with a Y chromosome are at risk for developing cancer, particularly if they remain in the individual's abdomen rather than descend into a scrotum.[95] The AAP recommends attempting to retain such gonads where the individual is to be raised as a male, however, provided they contain normal testicular tissue, and can be brought down into a scrotum at a later date.[96]

The final factor considered by the AAP in their guidelines is testosterone imprinting. Over the past decade, the impact of testosterone imprinting on the brain has become an increasingly important factor to consider in choosing the sex of assignment. Studies have shown that exposure to significant amounts of testosterone *in utero* has a masculinizing effect on the individual's behavior.[97] Thus, for example, some studies have shown that CAH girls, who are exposed to high levels of androgens as a result of their condition, exhibit more "masculine" behavior than other girls, and may be more likely to have a lesbian sexual orientation.[98] The AAP therefore recommends "caution" in recommending a sex of rearing different than an individual's

91. *Id.*
92. *Id.*
93. American Academy of Pediatrics, *supra* note 12, at 141.
94. *Id.*
95. *Id.*
96. *Id.*
97. *Id.*
98. American Academy of Pediatrics, *supra* note 12, at 141; Barthold & Gonzalez, *supra* note 1, at 560.

chromosomal sex (particularly as the majority of intersex individuals are assigned to the female sex).[99]

E. Outcomes

There are alarmingly few studies reported in the literature evaluating the sexual and psychological success or failure of sex assignment surgeries, even though such surgeries have been performed long enough for a substantial cohort to have reached adulthood. One of the largest published studies evaluated fifty-nine intersex individuals, ninety-three percent of whom had been assigned to a sex within the first four weeks of life and underwent early genital surgery. Nearly forty percent of the cohort exhibited "general psychopathology."[100] Seven of the fifty-nine exhibited frank gender identity disorder.[101] These children exhibited "intense sadness and dissatisfaction with the assigned sex and a preference for behavior appropriate to the other sex."[102] Two had CAH, one had PAIS, one was a true hermaphrodite with an XY karyotype, one had cloacal exstrophy, one had a transversely constructed penis, and one had gonadal dysgenesis.[103] Twenty-five out of the forty-seven other individuals assigned as females exhibited "deviant" gender role behavior, or "boyish" behavior.[104] The authors of the study did not define what they meant by "deviant" gender role behavior or "boyish" behavior, but noted the latter included "wild, rough play."[105] CAH girls were most likely to exhibit "boyish" behavior, followed by formerly "male" pseudohermaphrodites and true hermaphrodites.[106] Individuals with CAIS were least likely to exhibit such behavior. "Deviant" gender role behavior was most often a source of concern for the parents of the formerly "male" pseudohermaphrodites, as it caused them to question the wisdom of the sex assignment.[107] None of the five individuals assigned as boys experienced gender identity disorder or "deviant" gender role behavior, although they were "not assertive" and were "fearful and bothered about the smallness of

99. American Academy of Pediatrics, *supra* note 12, at 141.
100. Slijper et al., *supra* note 41, at 134.
101. *Id.*
102. *Id.* at 136.
103. *Id.*
104. *Id.* at 137.
105. Slipjper et al., *supra* note 41, at 137.
106. *Id.*
107. *Id.*

their penis."[108] The study concluded that both hormonal and psychosocial influences led to the gender disturbances experienced by a significant number of the study participants.[109]

Another recent study evaluated cosmetic and anatomical outcomes in adolescence of feminizing surgery performed in infancy and childhood.[110] The cohort of 44 intersex individuals had a variety of diagnoses, including congenital adrenal hyperplasia, XXY and ambiguous genitalia, true hermaphroditism, XY females, mixed gonadal dysgenesis, and extrophy.[111] More than half (fifty-nine percent) had a good or acceptable cosmetic result (i.e., no surgery or only minor surgery or elective deferment of major surgery until after puberty was recommended).[112] However, forty-one percent of the cohort had a poor cosmetic result (i.e., further major surgery was recommended), and sixty-six percent had a poor overall outcome.[113] Moreover, ninety-eight percent needed further treatment to improve cosmetic appearance or to facilitate tampon use or sexual intercourse.[114] The authors note that the children's outcomes were poorer than previously reported.[115] They recommend delaying most surgeries until the child is old enough to be involved in the decision, and note that clinicians and parents must understand that "for most individuals further treatment will be necessary in adolescence and the long-term impact of such treatment on adult sexual function is still unknown."[116]

Anecdotally, one can find numerous histories told by intersex individuals who rejected both their sex and gender assignment, or who rejected their gender of rearing.[117] Many others resent having had operations performed upon them without adequate informed consent, and before they personally could choose what

108. *Id.*
109. *Id.* at 138.
110. Sarah M. Creighton et al., *Objective Cosmetic and Anatomical Outcomes at Adolescence of Feminising Surgery for Ambiguous Genitalia Done in Childhood*, 358 LANCET 124 (2001) *available at* 2001 WL 10159197.
111. *Id.*
112. *Id.*
113. *Id.*
114. *Id.*
115. Creighton et al., *supra* note 110.
116. *Id.*
117. *See, e.g.*, the Intersex Society of North America website *at* http://www.isna.org (last visited Apr. 22, 2002); the United Kingdom Intersex Association website *at* http://www.ukia.co.uk (last visited Apr. 22, 2002); and the Androgen Insensitivity Syndrome Support Group *at* http://www.medhelp.org/www/ais (last visited Apr. 22, 2002); *see also* DREGER, *supra* note 17, at 167–80.

they felt was best for them. The surgeries frequently result in the removal of tissue which otherwise could have been used for sex assignment surgery, if desired in the individual's adulthood. They also result in scarring and, often, decreased sensitivity.[118] As one intersex individual put it, a "very special form of sexuality, arousal, and all of that that was uniquely hermaphroditic was taken [by the sex assignment surgeries]. That is the crime."[119] The worst effect, however, appears to have been the secrecy with which many intersex individuals' conditions were treated. "[B]eing encouraged to keep silent about their differences and surgical alterations only served to enforce feelings of isolation, stigma and shame – the very feelings that such procedures are attempting to alleviate."[120]

III. The Court System As a Means of Modifying The Standard of Care

A. Medical Malpractice

Medical malpractice actions are arguably one means of policing the medical profession. Tort claims are thought to have deterrence value: the threat of liability allegedly helps prevent negligent conduct.[121] If this theory is correct, a large judgment or settlement against a physician for malpractice, along with the adverse publicity accompanying it, may prompt prudent health care providers to refrain from similar conduct. Some studies indicate that medical malpractice suits do have a significant role in spurring physicians to practice defensive medicine.[122] While some forms of defensive medicine appear to consist of inappropriate precautions which, at best, waste resources, others presumably comprise "intelligent precautions that tort law seeks to

118. *See, e.g.*, Cheryl Chase, Letter to the Editor, 28 Arch. Sex. Behavior (1999).

119. Videotape: Hermaphrodites Speak! (Intersex Society of North America 2000).

120. Sharon E. Preves, *For the Sake of the Children: Destigmatizing Intersexuality*, 9 J. Clinical Ethics 411, 414 (1998).

121. *See, e.g.*, Gary T. Schwartz, *Reality in the Economic Analysis of Tort Law: Does Tort Law Really Deter?*, 42 U.C.L.A. L. Rev. 377, 381 (1994).

122. *Id.* at 401-02 *citing* Paul C. Weiler et al., A Measure of Malpractice 127 (1993); Ann G. Lawthers et al., *Physicians' Perceptions of the Risk of Being Sued*, 17 J. Health Pol. Pol'y & L. 463, 470 (1992); Roger A. Reynolds et al., *The Cost of Medical Professional Liability*, 257 JAMA 2776, 2777-78 (1987); Stephen Zuckerman, *Medical Malpractice Claims, Legal Costs, and the Practice of Defensive Medicine*, 3 Health Affairs 128, 132 (1984)).

encourage."[123] Given the foregoing, might intersex individuals who underwent sex assignment surgery in infancy or childhood bring negligence claims against their surgeons as one means of altering the present standard of care in treating infants with ambiguous genitalia?

The answer is: not likely. Broadly speaking, all U.S. jurisdictions generally adhere to some form of the "professional custom" standard of care in medical malpractice actions. Unlike general tort claims, in which a defendant is held to the standard of care which a "reasonable person" would exercise under the circumstances, physicians alone determine the standard of care to which the members of their profession are legally held.[124] This poses a significant problem for intersex individuals who underwent sex assignment surgery in infancy and who wish to sue their surgeons for malpractice as a result of the surgery since, in short, it was the professional standard of care to treat such individuals with sex assignment surgery at the time that the surgery was performed. Thus, as there were no violations of the professional standard of care, the physician in question cannot be found negligent in most cases.

There have, however, been a handful of cases in which a court has refused to hold a physician merely to the standard set by his or her own profession, but instead has appeared to opt in part or whole for the traditional "reasonable care" standard used in most tort cases. The most famous is *Helling v. Carey*, a Washington case in which the court held the defendant ophthalmologist negligent for failing over a number of years to perform a glaucoma test on a young woman, who later lost much of her vision to the condition.[125] At the trial level, the physician's experts testified that it was not the standard of care for ophthalmologists to regularly perform glaucoma tests on individuals under the age of forty, as glaucoma is rare in younger individuals. The plaintiff's expert concurred in this testimony, and the defendant prevailed.[126]

123. *Id.* at 402; *but see, e.g.*, Michelle M. Mello, *Of Swords And Shields: The Role Of Clinical Practice Guidelines In Medical Malpractice Litigation*, 149 U. PA. L. REV. 645, 646 (2001) (noting some inefficiencies of defensive medicine engendered by medical malpractice litigation, and that the costs of such defensive medicine total nearly $7 billion annually).

124. *See, e.g.*, Theodore Silver, *One Hundred Years of Harmful Error: The Historical Jurisprudence of Medical Malpractice*, 1992 WIS. L. REV. 1193, 1194, 1201 [hereinafter Silver].

125. 519 P.2d 981, 983 (Wash. 1974).

126. *Id.* at 982.

On appeal, the plaintiff argued that the trial court improperly prevented her from arguing that the standard of care was inadequate to prevent her from harm.[127] The Supreme Court of Washington agreed with the plaintiff and reversed the trial court.[128] Quoting Judge Hand, it noted that:

> (I)n most cases reasonable prudence is in fact common prudence; but strictly it is never its measure; a whole calling may have unduly lagged in the adoption of new and available devices. It never may set its own tests, however persuasive be its usages. Courts must in the end say what is required; there are precautions so imperative that even their universal disregard will not excuse their omission.[129]

Using this rationale, it found that "reasonable prudence required" that the defendant give the glaucoma test to the plaintiff, even though it was not the standard of care for ophthalmologists to do so at the time.[130]

The standard set in *Helling* is a minority view. In fact, virtually no other court has adopted it since its inception.[131] Even Washington courts, while never expressly overruling it, do not generally follow it as written. Rather, the state's supreme court later backpedaled from the case's holding, noting that "[w]hile it is a reasonably prudent health care provider, rather than any reasonably prudent person, against which the defendant's conduct is to be measured, this qualification was also implicit in the standard established by *Helling* and *Gates*."[132]

As one California court of appeals noted in declining to follow *Helling*:

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127. *Id.*

128. *Id.* at 983.

129. *Id.* (citing *The T. J. Hooper*, 60 F.2d 737, 740 (2d Cir. 1932)).

130. *Helling*, 519 P.2d at 983.

131. *See, e.g.*, Osborn v. Irwin Mem'l Blood Bank, 7 Cal. Rptr. 2d 101, 126-27 (1992) (noting that most of the commentary on *Helling* has been "unfavorable," and that only one California case has followed it, notwithstanding established California law holding that "the professional standard of care is a function of custom and practice"). A case in apparent accord with *Helling* is Townsend v. Kiracoff, 545 F. Supp. 465, 468 (D. Colo. 1982) (citing *The T.J. Hooper*, 60 F.2d 737 (2d Cir. 1932) ("even if the defendant's affidavits and evidentiary materials could establish that the hospital acted in accordance with the standard of care and custom of the community of Colorado hospitals, the plaintiff would still be entitled to prove at trial that the entire community's custom is negligent"). This case, however, does not appear to be widely followed.

132. Harris v. Groth, 663 P.2d 113, 116 (Wash. 1983). The Washington Supreme Court held in *Gates v. Jensen*, 595 P.2d 919, 924 (Wash. 1979), a negligence suit against an ophthalmologist for failure to perform a glaucoma test, that the "reasonable prudence" standard articulated in *Helling* still applied.

> A contemporary observer wrote that the *Helling* court had 'unwisely . . . arrogated to itself medical decisions, superimposing its medical judgment upon the collective experience of the medical profession. Can it really be said that medical judgments of the courts will be 'right' more often than those guided by approved medical practices?'[133]

This is a significant problem. The "professional custom" standard in medical malpractice cases exists largely because of the technical and scientific complexity perceived to be involved in most areas of medical practice.[134] If one accepts this premise, should one expect a court to do a better job than a jury of evaluating medical judgments based solely on common sense?

Hazel Glenn Beh and Milton Diamond, in their discussion of potential remedies for intersex individuals who believe they were harmed by sex assignment surgeries in their infancies and childhood, argue that allowing physicians to set the standards of care by which they will be judged in medical malpractice actions promotes professional inertia.[135] They state that "[b]y allowing the medical community to set the standard by which negligence is determined and by protecting the divided medical community, tort law renders itself impotent to promote positive changes within the medical community."[136] This concern has been sounded elsewhere: "[w]ith professional custom as the standard, the nation's physicians may lawfully adopt and follow practices that are patently negligent and unreasonable under the standard of ordinary care to which all others are held. The medical community is answerable not for want of care but for want of conformity."[137] Beh and Diamond's discussion implies, without directly so stating, that the standard set in *Helling* may be a more appropriate one in select cases, such as those – like the intersex cases – in which the standard of care developed without reference to sound and thorough scientific research.[138]

133. Osborn, 7 Cal. Rptr. 2d at 126 (citing Joseph H. King, *In Search of a Standard of Care for the Medical Profession: The "Accepted Practice" Formula*, 28 VAND. L. REV. 1213, 1250 (1975)).

134. *See, e.g.*, Silver, *supra* note 124, at 1215 (citing the premise that "medical practice, being highly complex, is not susceptible to evaluation through ordinary common sense and must instead be assessed pursuant to the customs of those with experience" as one reason for the development of the professional custom standard).

135. *See* Beh & Diamond, *supra* note 5, at 33.

136. *Id.* at 33-34.

137. Silver, *supra* note 124, at 1213.

138. Beh & Diamond, *supra* note 5, at 33-34.

This is not a feasible suggestion, because it would expose practitioners to liability for failing to foresee, for example, that the studies on which they based their practice would later be exposed as fraudulent or faulty. Practitioners ought not to be held responsible for independently verifying the correctness of each and every piece of research on which they base their practice. Yet this is what would be required to find surgeons liable for the otherwise acceptably-executed sex assignment surgeries they performed on intersex children at infancy. Unless the surgeons themselves were responsible for the research in question, and knew of the fraudulent or faulty nature of their research yet nevertheless propounded it as correct, there should be no basis for finding them negligent for otherwise reasonably relying on research to inform and shape their practice.

It may be more prudent, instead, to impose a rule of negligence holding that physicians may be held not merely to the prevailing custom or practice of similar physicians, but also to that practice which is reasonable to expect, given the state of medical knowledge at the time of treatment.[139] As the Supreme Court of Wisconsin noted in *Nowatske v. Osterloh*, altering the usual standard of care to which physicians are held to include those practices which a reasonable physician would use, given current medical knowledge, would not frequently yield a difference between current practice and "reasonable" practice.[140] Nonetheless, it could make a significant difference in a small minority of cases in which prevailing practice lagged behind what the reasonable practice would have been, had prevailing practice reasonably kept up with notable and firm advances in medical knowledge.

In the case of intersex individuals, a revised standard such as this might yield some positive changes. First, given the doubt cast on current practice, such a revised standard would likely require health care professionals, at minimum, to reevaluate the current practice of sex assignment and cosmetic genital surgeries. It is now apparent that the management of intersex individuals developed on the basis of anecdotal case reports, including one which was later found to have omitted key information which would have significantly changed the conclusion to be drawn from it. Moreover, there are no large-scale studies of long-term outcomes of such surgeries for the children who

139. *See, e.g.,* Nowatske v. Osterloh, 543 N.W.2d 265, 272 (Wis. 1996).
140. *Id.*

underwent them.[141] Recent years have nevertheless yielded enough small studies, along with anecdotal evidence, to strongly suggest that many classes of cosmetic genital and sex assignment surgeries have been at least as detrimental as beneficial to those on whom they were performed.[142] The conclusions of the latter studies are by no means sufficiently certain to warrant a finding of malpractice for those physicians who now fail to heed them, even under the proposed revised standard. Nevertheless, they provide enough evidence, in conjunction with the flawed standard on which the prevailing practice is based, to problematize the prevailing practice and suggest that further study is necessary.

For the same reasons, the revised medical malpractice standard may also help contraindicate surgeries which would assign an individual to a sex which matched neither his/her chromosomal sex nor a sex congruent with significant androgen imprinting *in utero*.[143] While the requisite large-scale studies have not yet been performed, there is enough evidence on a smaller scale to suggest that certain sorts of sex assignments ought not to be frequently performed, as they may carry a significant risk that the individual will ultimately reject the assignment. Nonetheless, such a revised standard would not require a moratorium on all sex assignment surgeries, and would not impose any prohibitions at all on cosmetic genital surgeries. In both cases, there is presently an insufficient amount of research to determine with reasonable certainty which, if any, surgeries tend to be beneficial for the recipients (as opposed to, for example, the parents of the child),[144] and whether any of the surgeries tend to have more detrimental than beneficial effects for the recipients, to warrant

141. *See, e.g.*, Kenneth Kipnis & Milton Diamond, *Pediatric Ethics and the Surgical Assignment of Sex*, 9 J. CLINICAL ETHICS 398, 401 (1998).

142. Anne Fausto-Sterling, for example, reviewed with a colleague the (often scarce and anecdotal) literature on reduction clitoroplasties and vaginoplasties, among other surgeries. They found mentions of scarring, multiple surgeries (leading to increased scarring), and residual pain and/or hypersensitivity at the clitoris or clitoral stump in the review of reduction clitoroplasties. Frequently, the only criterion listed for the success of a reduction clitoroplasty was cosmetic appearance, not later sexual function. The literature on vaginoplasties revealed frequent multiple surgeries, scarring, and vaginal stenosis. Where specific criteria for evaluating the operation's success were given, it was frequently the ability to have vaginal intercourse. *See* FAUSTO-STERLING, *supra* note 2, at 80-87.

143. *See, e.g.*, American Academy of Pediatrics, *supra* note 12.

144. *See, e.g.*, Wilson & Reiner, *supra* note 13, at 363 (noting physicians often recommend early surgeries "to spare parents the trauma of seeing their child as intersexed each time they change the infant's diaper").

any changes in the practice based on a revised rule of negligence.[145]

The adoption of such a revised general standard of care for medical malpractice cases might thus add impetus towards a scientific evaluation of the long-term effects of sex assignment and genital normalizing surgeries and would prohibit some of the most controversial surgeries. It would not, however, have any appreciable effect on the majority of treatment protocols for intersex children. The proposed rule would therefore have little short-term impact. It would also leave the impetus for change largely in the hands of physicians and researchers, both of whom were responsible for the old treatment paradigms, and whose trustworthiness has been compromised in the eyes of some intersex activists as a result. Thus, altering the medical malpractice standard is inadequate to revise some of the more problematic aspects of current practices in treating intersex children.

B. Informed Consent

Informed consent is another area intersex activists have investigated as a potential source of legal action against physicians performing genital normalizing and sex assignment surgeries. Under the doctrine of informed consent, a competent patient (or his or her authorized representative) must decide whether to undergo medical treatment or surgery after his or her physician explains the risks and benefits of treatment, as well as treatment alternatives in some cases. Activists and others who have examined the issue note that cosmetic and sex assignment surgeries on intersex children are frequently performed without adequate disclosure, and under rushed circumstances which are not conducive to careful or thoughtful deliberation.[146]

145. Again, while there is anecdotal evidence that certain sex assignment and normalizing surgeries are more detrimental than beneficial for the recipients, few actual studies have been performed, and, apparently, none with a sufficiently large cohort and control group from which one could make reasonably certain conclusions.

146. *See, e.g.*, FAUSTO-STERLING; *supra* note 2, at 80-85; Beh & Diamond, *supra* note 5, *passim*. Recent research on gender identity and patient satisfaction by John Gearhart, M.D., et al. with respect to surgery performed for a variety of intersex conditions revealed that patients most often wished they had been given more information, even when they were otherwise satisfied with the outcome. *See* J.P. Gearhart et al., *CAIS: Long-Term Medical, Surgical and Psychosexual Outcome*; *PAIS and Partial Gonadal Dysgenesis: Long-Term Medical, Surgical and Psychosexual Outcome of Patients Reared Male or Female*; and *Micropenis, presented at* 2001 American Academy of Pediatrics National Conference and Exhibition, Section on Urology.

The doctrine of informed consent has only recently appeared on the scene of medicine. Hippocrates, the ancient Greek philosopher of medicine, noted that "physicians should conceal 'most things from the patient while you are attending to him . . . revealing nothing of the patient's future or present condition.'"[147] Little changed in America from that time until the middle of the 20th century. "Three beliefs dominated pre-mid-20th century physician-patient relationships: patients must (1) honor physicians; (2) have faith in them; and (3) 'promise obedience.'"[148] These tenets were woven into physicians' codes of conduct. Until just a few decades ago, the American Medical Association (AMA) Code of Medical Ethics asserted in one form or another that a patient should obey the prescriptions of his or her physician, without heed to the patient's own opinion about the matter.[149]

The roots of the informed consent doctrine stem from the turn of the century, with cases such as *Schloendorff v. Society of the New York Hosp.* establishing the right of a patient to sue his or her physician for battery in the event of an unconsensual surgery.[150] The true birth of the doctrine, however, did not come until 1957, with the case of *Salgo v. Leland Stanford Jr. Univ. Board of Trustees*.[151] This case – decided less than fifty years ago – first recognized the doctrine of informed consent as an element of the physician-patient relationship, and permitted a negligence action on this basis.[152]

In the ensuing decades, the doctrine of informed consent has evolved to focus on protecting "the right of every individual to

147. Sheldon F. Kurtz, *The Law of Informed Consent: from 'Doctor is Right' to 'Patient Has Rights,'* 50 SYRACUSE L. REV. 1243, 1243 (2000) (quoting 2 HIPPOCRATES, DECORUM 297 (W. Jones trans., Cambridge: Harvard University Press 1967)).

148. *Id.* (citing JAY KATZ, THE SILENT WORLD OF DOCTOR AND PATIENT (1984)).

149. *Cf. id.* In contrast, the AMA Code of Medical Ethics states, in relevant part, that:

> The patient has the right to receive information from physicians and to discuss the benefits, risks, and costs of appropriate treatment alternatives. Patients should receive guidance from their physicians as to the optimal course of action . . . The patient has the right to make decisions regarding the health care that is recommended by his or her physician. Accordingly, patients may accept or refuse any recommended medical treatment.

AMERICAN MEDICAL ASSOCIATION, FUNDAMENTAL ELEMENTS OF THE PHYSICIAN-PATIENT RELATIONSHIP (last revised 1994).

150. 105 N.E. 92 (N.Y. 1914); *see also, e.g.,* State v. Housekeeper, 16 A. 382 (Md. 1889).

151. 317 P.2d 170 (Cal. Ct. App. 1957).

152. *See, e.g.*, Kurtz, *supra* note 147, at 1244-45.

the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law."[153] The doctrine generally requires that physicians share decision-making power with their patients.[154] It further requires that physicians give patients the information necessary for patients to meaningfully exercise such power.[155] For a consent to be valid, it generally must be informed, voluntary, and given by an individual who is both authorized and competent to give consent.[156] As minors are generally incapable of giving valid informed consent, their parents must do so for them.[157]

Beh and Diamond, among others, argue that sex assignment and cosmetic genital surgeries on intersex infants and children are deficient with respect to informed consent.[158] According to Beh and Diamond, parents frequently are not in a position to provide valid informed consent, as health care providers often fail to provide sufficient information concerning the proposed surgeries.[159] They note that health care providers often convey an aura of urgency regarding sex assignment and cosmetic genital surgeries that is not medically or surgically justified.[160] Information concerning the surgeries is frequently incomplete,

153. *See, e.g.*, Beh & Diamond, *supra* note 5, at 34 (*citing* Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 269 (1990)).

154. *Id.*

155. Jurisdictions differ over whether the information necessary for patients to meaningfully exercise such power should be judged on a professional or patient basis. Those jurisdictions employing a professional standard require a physician to disclose those risks which similarly-situated physicians disclose, as established by expert medical testimony. *See* Culbertson v. Mernitz, 602 N.E.2d 98, 102-03 (Ind. 1992). Conversely, the patient standard is based on the theory that "[r]espect for the patient's right of self-determination on a particular therapy demands a standard set by law for physicians rather than one which physicians may or may not impose upon themselves," and requires that physicians disclose all risks which a prudent patient would consider material to his or her decision whether to undergo treatment. *See* Canterbury v. Spence, 464 F.2d 772, 784 (D.C. Cir. 1972).

156. *See, e.g.*, FLA. STAT. ANN. § 766.103 (West 2001); 24 ME. REV. STAT. ANN. §2905 (West 2001); TX. HEALTH & SAFETY CODE §462.009 (West 2001).

157. Although there are variations, the law generally evaluates a parent's right to consent to medical treatment on behalf of her child in light of the child's "best interest." *See* Jennifer Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?*, 73 TEMPLE L. REV. 1, 7- 8 (2000).

158. *See, e.g.*, Beh & Diamond, *supra* note 5, at 34-60; Kishka-Kamari Ford, *"First, Do No Harm" – The Fiction of Legal Parental Consent to Genital-Normalizing Surgery on Intersexed Infants*, 19 YALE L. & POL'Y REV. 469, 474-88 (2001).

159. Beh & Diamond, *supra* note 5, at 34-60.

160. *Id.* at 43-46.

particularly issues concerning the cosmetic outcome and potential effects of scarring on future sexual sensation.[161] Secrecy concerning the surgeries has been fostered in the past, particularly with respect to what the intersex child does or does not learn about them.[162] Beh and Diamond also note that physicians have frequently failed to disclose the possibility that the child will ultimately reject the sex to which the surgery will assign him or her, and that surgical intervention in childhood forecloses that child's "right to an open future."[163]

Because of frequent deficiencies in information and misrepresentations, particularly concerning how the surgeries may affect the child once he or she reaches adulthood, Beh and Diamond conclude that a moratorium should be imposed on surgeries undertaken solely for cosmetic purposes on intersex children, and that such children and their families should instead be treated with counseling to manage the psychosocial issues.[164] They believe this strategy better protects the self-determination rights of intersex individuals by allowing them to decide for themselves, once they reach adulthood, whether they wish to undergo sex assignment or cosmetic genital surgery.[165]

There undoubtedly have been, and may still be, serious informed consent issues with many intersex surgeries on infants. This is not, however, a basis on which one can reasonably call for a moratorium on the surgeries, particularly when one can take the less drastic step of offering more complete information (e.g., indicating gaps in information, such as those concerning long-term outcomes). It also does nothing to expose *why* – es-

161. *Id.* at 47-50.

162. *Id.* at 50-55. Beh and Diamond's contentions are borne out by the literature. *See, e.g.*, FAUSTO-STERLING, *supra* note 2, at 63-66 (noting the explanations clinicians recommend giving to the parents of intersexuals, e.g.: "accurate patho-physiological explanations are not appropriate and medical honesty at any price is of no benefit ot the patient;" and "[E]very effort should be made to discourage the concept that the child is part male and part female. . . . This is often best handled by explaining that 'the gonads were incompletely developed . . . and therefore required removal'"). *See also* DEWHURST & GORDON, *supra* note 77, at 80 (in discussing how to counsel parents of an older intersex child who did not previously undergo genital surgery, noting that "[t]he idea which must be conveyed to them is that sex is being corrected not changed; that a mistake was made initially and this is now being put right; that the child was never male but always female or vice versa"); Susan Baker, *Psychological Management of Intersex Children*, 8 PEDIAT. ADOLESC. ENDOCR. 261 – 269 (1981) ("the first communication must include the information that the infant has a birth defect of *unfinished* genitalia") (emphasis added).

163. Beh & Diamond, *supra* note 5, at 56-59.

164. *Id.* at 59-60.

165. *Id.*; *see also* Ford, *supra* note 158, at 488.

pecially in light of informed consent law – physicians have frequently provided significantly incomplete or skewed information to parents with respect to their children's intersex conditions and surgeries. Or why the physicians employ euphemisms, gloss over poor information about long-term outcomes, and counsel secrecy. The historical problems with informed consent in this context suggest there are many hidden or obscured issues with intersex conditions and their treatment. Why was it once standard medical practice to openly advocate limiting and obfuscating information for parents and children concerning intersex conditions and surgeries in ways which likely violated informed consent norms?[166] Why did physicians regularly instruct the families of intersex individuals never to disclose the truth about their children's conditions, even though this secrecy may have had significant detrimental effects on the very individuals it was supposed to protect?[167] Without further investigation, merely criticizing defects in informed consent will not likely yield the desired effect of stopping the practice of cosmetic and sex assignment surgeries on intersex infants and children; rather, it may result simply in the proffer of more information to parents, while the surgeries themselves continue with little abatement.

Furthermore, while the desire to preserve the ability for patient self-determination in adulthood by refraining from surgery in childhood is laudable, there is no reason its citation alone should yield the necessary changes. Even if we decide that cosmetic genital and sex assignment surgeries should no longer be performed until the patient has reached the age of majority and can decide for him or herself whether to undergo them, we will not have done anything in the process to alter the social or cultural climate in which such decisions must be made. An exclusive dualism of "male" and "female" presently reigns in America, with significant exceptions only in small pockets of society. Although it has increased in the decades since the advent of the gay rights movement and the second advent of feminism, there is still little tolerance for gender ambiguity. A society which feels compelled to pass a Defense of Marriage Act,[168]

166. *See, e.g.*, FAUSTO-STERLING, *supra* note 2, at 63-66.

167. *See generally,* Preves, *supra* note 120, at *passim.*

168. 28 U.S.C.A. § 1738C (West 2002). The act also provided a federal definition of marriage: "In determining the meaning of any Act of Congress, or of any ruling, regulation, or interpretation of the various administrative bureaus and agencies of the United States, the word 'marriage' means only a legal union between one man and

which blamed a mother, who worked part-time, for the death of her infant at the hands of her au pair,[169] and which tacitly prevents men from taking advantage of their rights under the Family and Medical Leave Act[170] is not likely one which will, without some adjustment, openly embrace intersexuals who do not conform to current sex and gender norms. An empty right to self-determination carries little weight in the absence of an environment in which one can meaningfully exercise that right.

IV. Alternatives to Modifying the Standard of Care

It is therefore not enough to give intersexuals the right to decide for themselves, once they become adults, whether and how to alter the genitals with which they were born. Although there does not appear to be any evidence that the present methods of dealing surgically with intersex infants and children developed for sound scientific reasons, the present treatment protocols did not arise by accident or chance. Dewhurst and Gordon wrote in 1969 that society views intersexuals as "freak[s]" or "misfit[s] . . . condemned to a solitary existence of neglect and frustration."[171] More recently, another commentator noted that "the mystification of sex leaves no room for doubt, no place for ambiguity. The first thing asked of every new human being is whether it is a boy or a girl. It must be one or the other. There are no additional categories."[172] To such commentators, to think otherwise is to fall into the category of a "social constructionist . . . who maintain[s] that our concepts of man and woman are fictions dreamed up to keep everyone comfortably in their prescribed

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one woman as husband and wife, and the word 'spouse' refers only to a person of the opposite sex who is a husband or a wife." 1 U.S.C.A. § 7 (West 2002).

169. *See, e.g.*, Dave Howland, *Au Pair Trial: Public Scorns Parents*, Dayton Daily News, October 28, 1997, at 3A, *available at* 1997 WL 16061865 ("'It's almost chilling to gauge the reactions toward them,' said Court TV programming chief Erik Sorenson, who was struck by the number of callers who condemned Mrs. Eappen for choosing to work instead of caring for her children full time").

170. 29 U.S.C.A. § 2601 (West 2002); *see also, e.g.*, Martin Malin, *Fathers and Parental Leave*, 72 Tex. L. Rev. 1047, 1077-78 (1994) ("Large employers are least likely to experience negative financial effects from fathers taking parental leave. Yet . . . sixty-three percent of large employers considered it unreasonable for a man to take any parental leave, and another seventeen percent considered paternal leave reasonable only if limited to two weeks or less").

171. Dewhurst & Gordon, *supra* note 77, at vii.

172. Louis Gooren, *Forward to the Second Edition*, *in* Money, *supra* note 4, at ix.

place."[173] If one accepts such a schema, the need for surgical correction of intersex conditions is virtually a given. To fail to do so would presumably be to "ignore[ ] the very real pain and suffering experienced by individuals with sexual anomalies."[174]

Do statements such as those cited above truly represent general American societal views of intersexuals? According to Carl Elliott they likely may. Elliott argues that physicians who advocate early cosmetic genital surgeries for intersex children rather than suggesting restraint until the children are old enough to decide what to do for themselves are not making a "conscious effort to fend off threats to a cultural order."[175] Instead, "we treat these children the way we do because this is how we see the world."[176] We take for granted our concepts of male and female in our culture, and their exclusively binary nature. Yet there is nothing necessary in our conceptions of sex and gender, Elliott states. Rather, one can look at other cultures – for example, the Navajo in the 1930's, who had a third gender with a special social status – to see this. This is not because the Navajo (or any other society with different concepts of sex and gender) are more or less enlightened than ours. Rather, extending upon Ludwig Wittgenstein's philosophy,

> [t]he issue dividing us and the Navaho . . . is one of commonsense judgments, our untutored, no-nonsense, matter-of-fact attitudes towards the world. It isn't just that what the Navaho call *nadle* we call hermaphrodites or transvestites, or that what certain Dominican Republic villagers call *guevedoche* we call (some of us, anyway) 5-alpha-reductase deficiency syndrome. The difference lies in our basic apprehensions of the obvious, the way life is, once it is stripped of artifice and theory and intellectual pretensions: the things anyone knows (or at least anyone with a lick of sense).[177]

Given our conceptual framework, Elliott notes, the intersex child does not fit into our usual way of seeing the world, and therefore poses a problem. Presently, we usually deal with this problem by performing cosmetic genital surgery on intersex children in infancy or early childhood in order to make the individual conform to our dominant notion of gender. This of

173. *Id.* at x–xi.
174. *Id.* at xi.
175. *Id.* at 40.
176. *Id.*
177. CARL ELLIOTT, BIOETHICS, CULTURE AND IDENTITY: A PHILOSOPHICAL DISEASE 36 (1999).

course does not mean that practice of early cosmetic and sex assignment surgeries should therefore continue. Instead, it indicates that successfully changing the paradigm will require more than a mere alteration in medical practice.

As a number of commentators have noted, physicians' management of intersex infants and children is already undergoing some flux.[178] Diamond and Sigmundson's revelation of the actual outcome of the John/Joan case, in conjunction with vocal protests from intersex activists and increasing attention from academicians, is starting to lead to a more "rational and comprehensive" evaluation which recognizes that "it is more important that the [gender] assignment be right than that it be fast."[179] This shift has nothing to do with a change in beliefs about gender, however. On the one hand, physicians may increasingly refrain from making hasty pronouncements concerning a child's sex to the child's parents, and may wait longer to perform genital surgeries except where deemed to be medically necessary (e.g., due to cancer risk or significant urinary tract impairment). They may also increasingly involve the parents in the decision-making concerning the child's gender and management on a more equal basis. On the other hand, however, physicians will also likely continue to recommend infant and childhood cosmetic and sex assignment surgeries to parents on a number of grounds, including the specter of locker room humiliations for adolescent intersex children, as well as social shame and stigma with respect to dating and sexual relations during adolescence and early adulthood. Grounds such as these were also used to justify the older methods of surgical management. But because the social views of sex and gender remain virtually the same, there is no reason for them to have disappeared just because other aspects of intersex management are in the process of altering. As long as the current exclusive dualism prevails in the mainstream view of sex and gender in this society, justifications such as the above will likely remain compelling reasons to at least some parents for early surgery.[180]

178. *See, e.g.*, Alice Domurat Dreger, *A History of Intersexuality: From the Age of Gonads to the Age of Consent*, 9 J. CLINICAL ETHICS 345, 353 (1998); Wilson & Reiner, *supra* note 13, at 364-65.

179. Wilson & Reiner, *supra* note 13, at 365.

180. Note, for instance, that the most recent guidelines from the American Academy of Pediatrics still advocate early genital surgeries for intersex individuals, even though it also acknowledges that "some suggest[ ] that the current early surgical treatment should be abandoned in favor of allowing the affected person participate in

So how best to proceed? As Anne Fausto-Sterling notes, intersex individuals have been used as a "natural experiment" in the search for hormonal causes of behavioral differences between the (two) sexes, serving as nature's guinea pigs, so to speak.[181] Yet she also makes the following observation:

> [c]urrently, [intersexual] bodies are . . . 'unthinkable, abject, unlivable.' By their very existence, they call into question our system of gender. Surgeons, psychologists, and endocrinologists, through their surgical skills, try to make good facsimiles of culturally-intelligible bodies. If we choose to eliminate mixed-genital births through prenatal treatments . . . we are also choosing to go with our current system of cultural intelligibility. If we choose, over a period of time, to let mixed-gender bodies and altered patterns of gender-related behavior to become visible, we will have, willy-nilly, chosen to change the rules of cultural intelligibility.[182]

It must be recognized that, if we choose the latter course, we will again have used intersex individuals as guinea pigs of sorts, this time in a cultural experiment. However much any of us may wish to see Fausto-Sterling's latter course prevail, the outcome is not certain. Thus, a physician cannot, in good conscience, assure the parents of an intersex infant that they ought not to choose cosmetic or sex assignment surgery for their child, on the ground that the unaltered child, along with his/her intersexual forebears and brethren, will (over time) alter our present sex and gender systems to make space for those who do not conform to the present norms. Given our present state of knowledge concerning the long-term outcomes of intersex individuals (both those who have and have not had surgery), and given our current sex and gender systems and the fact that intersex individuals have no choice but to cope with them one way or another, there can presently be no reasonably certain "right" answer for physicians and parents of intersex children with respect to surgery.[183]

Nevertheless, there does appear to be a likely "wrong" answer with respect to the timing of surgery, if any is to occur at

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gender assignment at a later time." American Academy of Pediatrics, *supra* note 12, at 141.

181. *See* FAUSTO-STERLING, *supra* note 2, at 73.

182. *Id.* at 76.

183. Of course, allowing present norms to sway one's decisionmaking will only further cement those norms. *See, e.g.*, ELLIOTT, *supra* note 177, at 28 (discussing "'the ethics of complicity': the notion that by giving in to the[ ] pressures that you justifiably feel are oppressive, you are yourself reinforcing the very norms that produce them").

all. Contrary to the prevailing norm, there appears to be few good reasons to perform cosmetic genital and sex assignment surgeries early in an intersex child's life. Surgeries in infancy have been advocated on a number of grounds. The one proposed by Money – that gender identity is malleable in the first months and years of life – has largely fallen out of favor after the revelation of John/Joan's true outcome. A second major reason for early surgeries has been its ability to keep children from knowing about their original condition. This secrecy, however, has been branded as harmful or otherwise strongly problematic by most reports from adult intersexuals.[184] As numerous other recent commentators have noted, this secrecy must cease.[185] Thus, early surgery ought not to be justified on that ground.[186] Improved wound healing in infants is an additional reason set forth for early surgeries. Certainly, if there is inevitably going to be a surgery, it is better – all else being equal – to perform it when visible scars are less likely to form, as is the case in infancy.[187] However, with respect to surgeries which are not necessary to preserve the physical health of the child, all else

184. *See, e.g.*, Gearhart et al., *supra* note 146; Preves, *supra* note 120, at 414-15; FAUSTO-STERLING, *supra* note 2, at 80-85.

185. *See, e.g.*, Dreger, *supra* note 178, at 352 ("In no other realm in medicine do doctors regularly argue for active, nearly wholesale deception"); Sherri A. Groveman, *The Hanukkah Bush: Ethical Implications in the Clinical Management of Intersex*, 9 J. CLINICAL ETHICS 356, 358-59 (1998) ("of the more than 60 women with AIS whom I personally know, I have not heard of a single instance where someone has reported that it was worse to know the truth than to live with lies"); Edmund G. Howe, *Intersexuality: What Should Careproviders Do Now*, 9 J. CLINICAL ETHICS 337, 338 (1998) (reporting that the shame of genital surgeries "was further exacerbated by doctors withholding information, which implied that their condition was too shameful to discuss"); Kipnis & Diamond, *supra* note 141, at 407 ("Unless the entire profession is complicit . . . one must expect that the truth will emerge. And when it does, the patient will learn anyway what she or he was never supposed to have found out. If the patient is going to find out anyway, surely it is better for the physician to initiate disclosure"); Justine Marut Schober, *A Surgeon's Response to the Intersex Controversy*, 9 J. CLINICAL ETHICS 393, 395 (1998) ("We desire the easiest psychological adjustment for a patient. Though deception might allow an easier adjustment in some cases, the parent and patient have a right to know, as well as the right to make educated, prospective choices"); Wilson & Reiner, *supra* note 13, at 364 ("Ultimately, as with most attempts to keep diagnostic/prognostic information from a child . . . the truth is not as devastating as what the child imagines").

186. Note as well detrimental psychological effects of surgery cannot be avoided merely by operating at an early age. The 1996 American Academy of Pediatrics recommendations for genital surgeries on boys, for example, notes several studies evaluating the psychological risks of surgery on children, some of which conclude the risks are greatest for children between the age of one and three. *See* Kass et al., *supra* note 6.

187. *Cf.* Cisek Interview, *supra* note 68.

is not equal. It may be that the intersex individual, if given the opportunity to decide for him/herself once s/he is older, would choose not to undergo the surgery. If the intersex individual's preference is to be given any significant weight, the ability to achieve a better cosmetic result by timing the surgery earlier pales in comparison.

The remaining reason justifying earlier surgery cannot be so quickly dispelled. Prevailing social norms may significantly and adversely affect an intersex infant in two ways. First, parents may bond poorly with or even reject an intersex child, due to its malformed genitals. As Wilson and Reiner note in the context of difficulties in involving parents in decisionmaking concerning their intersex child, parents will likely grieve the loss of their "expected 'perfect' child."[188] Kass et al. recommend genital surgery between the ages of six weeks and fifteen months, as waiting longer "potentially prolong[s] the child's 'defective' status and crystallize[s] any disruption in family relationships that the child's condition may have produced."[189] Second, parents are not the only ones with whom relationships may be disrupted; given the large number of children in day care, a diapered intersex infant's genitals will likely be exposed regularly to other caretakers.

Data suggests, however, that cosmetic genital or sex assignment surgery may not alleviate these issues. Slijper et al. report that, out of a group of 27 couples with intersex children who underwent surgery for their conditions in infancy:

> [d]espite the intensive counseling . . . 50% [of the couples] were not able to work through the trials and tribulations their child's lack of gender clarity entailed. Two mothers and 1 father openly rejected their child as a result. The following factors played a role in the acceptance process: (i) the time when assistance was offered: for 5 couples who had problems dealing with their child's lack of gender clarity, help came too late, since it had already been several years since the trauma; (ii) the instability of the marriage for 5 couples, the child's anomaly played an important role in their divorce; (iii) the number of times the sex assignment was revised the 2 couples whose child's sex assignment was revised twice continued to doubt whether they had made the right decision regarding the sex

188. Wilson & Reiner, *supra* note 13, at 365; *see also* Dreger, *supra* note 178, at 353.

189. Kass et al., *supra* note 6, at 590. For data which may help support this contention, notwithstanding the small sample size, see Slijper, *supra* note 41.

> assignment; and (iv) the personality structure of the parents, particularly as regards rigidity and the inability to cope with setbacks and tolerate embarrassment.[190]

The data suggest that, even where surgery had been performed, many parents of the children still did not perceive their infant as "normal," or otherwise had significant difficulties accepting them. Those with children whose gender and sex assignments differed from the child's chromosomal sex also experienced particular difficulties.[191] Given the sample size, the study is not conclusive, however, it suggests that, notwithstanding surgery, the very issues surgeons hope to avoid through early surgery may nevertheless arise for a sizable number of families. In the meantime, the intersex individual's ability to provide input into the decision as s/he matures will have been completely sidestepped.

The dearth of large, long-term studies makes it impossible to provide well-schooled suggestions for clinical and surgical practice. However, in light of the foregoing, several conclusions can nevertheless be drawn. First – and most importantly – physicians need to discuss the child's condition openly with the child's parents and, as the child matures, with the child him/herself. The old policy of withholding information both prevented intersex individuals from knowing significant medical facts about themselves which were pertinent to their health, and exacerbated feelings of stigma and shame rather than preventing them.[192] Candor and full disclosure should therefore replace the prior policy of secrecy. The child, who will face psychological and social problems regardless of his/her medical and/or surgical treatment, should also be referred for counseling and, once of sufficient maturity, to intersex support groups.[193]

Second, physicians need to present the options available to parents in a neutral and inclusive fashion. Early surgeries should be limited to those necessary to establish normal urinary tract function and correct conditions that could cause recurrent infections or other damaging physical problems.[194] With respect to surgeries performed for cosmetic or sex assignment purposes, physicians should emphasize to parents that hasty decisions are

190. Slijper et al., *supra* note 41, at132.
191. *Id.*
192. *See, generally, supra* note 132.
193. *See, e.g.,* Dreger, *supra* note 178, at 354; Wilson & Reiner, *supra* note 13, at 365-66.
194. *See* Wilson & Reiner, *supra* note 13, at 365.

neither warranted nor advisable. They should further make clear that, while early cosmetic or sex assignment surgeries used to be (and still are) the norm, there is no definitive scientific evidence to recommend them and that, moreover, there is evidence that they may ultimately cause more harm to their recipients' later sexual function than good. Where relevant, they should also note that, with respect to sex assignment surgeries, there is evidence that some people later reject their assigned sex and that, if surgery has already been performed, there may not be enough tissue remaining with which to fashion functional genitals, should the individual later desire such surgery.[195] Additionally, they should emphasize that, in many cases, surgery will not provide their child with "normal" genitals, but may instead merely bring the genitals' appearance more in line with the norm, potentially at the expense of their function and sensation and at the cost of further surgeries.[196] Also, inter-abdominal testes which pose minimal cancer risk in a child's first years should be left intact whenever feasible until shortly before puberty, even if they have a chance of becoming malignant thereafter, so that the child will have some time to determine his/her gender.[197] As Wilson and Reiner advocate, hormone therapy should also be avoided whenever possible until the child has a chance to come to some decision about his/her gender identity.[198]

Third, parents need early psychological counseling and support.[199] Parents of children whose anatomical appearance is outside the norm typically "grieve the loss of the anticipated 'normal' child."[200] Given this likely effect, in conjunction with

195. *Cf.* Kipnis & Diamond, *supra* note 141, at 405-06.

196. *See, e.g.*, Creighton et al., *supra* note 110.

197. *See* Wilson & Reiner, *supra* note 13, at 365-66.

198. *Id.* at 366. Wilson and Reiner note in this connection:

> a recent referral[,] involv[ing] a child diagnosed as a true hermaphrodite with a female sex assignment referred by her pediatric psychologist. Her endocrinologist wanted to use estrogen therapy early to quiet the child's feelings of perhaps being male. But such an attempt to deny the child's sense of identity and suppress the gender confusion would seem to risk greater gender confusion and conflict as an adult, similar to that experienced by adult transsexuals. In addition, there is no data that feminizing hormones affect the evolution of gender identity.

Id.

199. Dreger, *supra* note 178, at 353; *see also* Wilson & Reiner, *supra* note 13, at 365.

200. Dreger, *supra* note 178, at 353. *See also* Wilson & Reiner, *supra* note 13, at 365.

the medical and social issues which the parents will face, counseling is advisable. Alice Dreger notes that a professional counselor, rather than a surgeon, urologist, or other member of the intersex child's medical team at birth, should perform this role, likely due to the inculcation of most of the latter in the traditional surgical management of intersex conditions.[201] Parents should also be referred to peer support groups for parents of intersex children.

Fourth, the parents and physicians should determine a gender of rearing for the infant.[202] This is a gendered society. An intersex child should be raised as a boy or a girl, even though the child may later reject the chosen gender and forge his or her own way. Physicians can assist parents in determining which gender a child will most likely choose; as an easy example, most children with CAIS will likely identify with the female gender, rather than the male, notwithstanding their testes and 46,XY karyotype, and therefore should probably be raised as girls.

Fifth, as Dreger points out, physicians should provide parents (and later, their children) with non-pathologized images of intersex individuals. If provided only with pathologized images, parents, intersex individuals – and members of the medical community – "will inevitably see intersexuality as deeply pathological."[203] The intersex community, rather than the medical community, can provide a source for these images.[204]

Notably, these suggestions do not include a moratorium on all early surgeries other than those necessary for the physical health of the intersex child. As Wilson and Reiner observe, there is very little data suggesting that parents can (or, for that matter, cannot) raise children with ambiguous genitalia unambiguously in one gender.[205] There is similarly little data concerning how well intersex children interact with their peers during adolescence, when ambiguities are likely to come to light in gym class and elsewhere (if they have not already done so).[206] Children are particularly hard on those whom they perceive to be different. Despite the dearth of data, however, Wilson and Reiner, among others, recommend a moratorium on genital surgeries which are not necessary for the physical health of the intersex

201. Dreger, *supra* note 178, at 353.
202. *See, e.g., id.*; Wilson & Reiner, *supra* note 13, at 365.
203. Dreger, *supra* note 178, at 353.
204. *Id.*
205. Wilson & Reiner, *supra* note 13, at 366-67.
206. *Id.*

child.[207] They note that this recommendation (among others) is largely the product "of a relatively small number of very vocal former patients and of a pilot study of six adolescents sex-reassigned at birth."[208]

It is undisputed that there are intersex individuals who have been harmed physically and/or psychologically by childhood cosmetic and/or sex assignment surgeries. Intersexuals have also been harmed by their deception at the hands of physicians and family members concerning their condition, and by the stigma and shame they felt as a result. Some of these individuals argue forcefully and persuasively that the decision to operate during their childhood, rather than waiting until they could decide for themselves what to do, was wrong. This does not mean, however, that such decisions are wrong for all people with an intersex condition. As discussed above, parents generally have a legal right to consent for their child's surgical treatment. If contested, courts frequently use a best interest test to determine whether consent or lack of consent was appropriate. Until larger, long-term studies are performed which show that cosmetic genital and/or sex assignment surgeries are generally not in an intersex child's best interest, neither an outright ban on such procedures nor removing parents' general right to consent to such surgeries can be justified, either ethically or legally.

Moreover, it is not merely the intersex individual who is affected by his/her condition. Rather, the parents, who must rear the child, and the child's family are also affected, as well as other close members of the child's community. Given that the intersex child does not enter into the world as an autonomous and independent being, the ability of the parents and others in the child's life to rear and relate to the child must be taken into account in determining which treatment options to permit and which to foreclose. However close-minded or otherwise regrettable it may be, not all parents may be able to cope with their child's anatomy without surgical alteration. And without a reasonable amount of love and support from their parents, intersex children – like any other children – will be more likely to experience significant social and/or psychological problems, both as children and as adults.

207. *Id.* at 365; *see also, e.g.*, Cheryl Chase, *Surgical Progress is not the Answer to Intersexuality*, 9 J. CLINICAL ETHICS 385, 391 (1998); Dreger, *supra* note 178, at 353; Kipnis & Diamond, *supra* note 141, at 405-06.

208. Wilson & Reiner, *supra* note 13, at 366.

Again, physicians should strongly counsel parents against making hasty decisions. Also, parents should be counseled to respect and consider their child's future independence and decisionmaking power, and to recognize that their child's future desires may conflict with the parents' own present ones. Helena Harmon-Smith, founder of Hermaphrodite Education and Listening Post, a peer support group for parents of intersex children, counsels against scheduling the first surgery before the child leaves the hospital following birth, as it "foster[s] fear in the parents that this is life-threatening and they have an abnormal or damaged child."[209] She also counsels against taking any "drastic" steps in the first year, as they will need that time to adjust to their child, understand his/her condition, and learn his/her needs.[210] Nevertheless, it must be recognized that some parents – ideally only a very small minority, at most – may ultimately opt for cosmetic genital and/or sex assignment surgery after careful and lengthy consideration of all the choices at hand and their potential outcomes. It must be recognized that the parental or familial needs driving this choice may be just as intense as any the intersex individual him/herself may experience. One can criticize or even condemn those needs. However, if surgery permits those parents to better relate to their child, then both the parents and the child will have benefited from it, notwithstanding any ill effects the surgery may ultimately have on the child him/herself.

V. Conclusion

Intersex conditions pose a thorny set of problems for affected individuals, families, and medical practitioners. Parents who had hoped for a "normal" child must face coping with physiological differences which, in our present society, throw the child out of relation with others on the basis of sex and gender. Physicians, viewing the difference as pathological, seek to use their skills to "correct" the child's genitals. And the intersex individuals themselves must grapple not only with the fact that their physical bodies, and sometimes also gender identities, do not fit neatly into our concepts of either 'man' or 'woman,' 'male' or 'female,' but also with potential stigma in the way others have treated them and their condition throughout their lives.

209. Helena Harmon-Smith, *10 Commandments*, 9 J. Clinical Ethics 371, 371 (1998).
210. *Id.*

In recent years, activists and a small group of researchers have largely overthrown the theory that early cosmetic genital or sex assignment surgery, in conjunction with rearing that strictly reinforces the child's gender assignment, yields individuals who accept and are well-adjusted with respect to their assigned gender and sex. As many intersex individuals and commentators have noted, a new treatment paradigm is now necessary. Many steps can be taken to ameliorate present management and treatment of intersex conditions. Contrary to some recommendations, however, a moratorium on cosmetic genital and sex assignment surgeries for infants and children is not warranted. It would swing the pendulum to the other extreme: while such surgeries have previously been recommended and performed with scant, if any, data to support their beneficial effects, a moratorium would similarly cease all such surgeries on the basis of several small studies and some negative reports from a number of individuals who underwent the surgeries in infancy and childhood.

Instead, medical practitioners should focus on providing complete information to parents and, as they mature, to intersex children. Both parents and children should be timely referred to counselors and intersex peer support groups. When discussing surgical options, physicians should provide full disclosure to parents about prior practices and the dearth of data, decades after the practices began, to support them. They and/or the parents' counselors should also emphasize that there is no need to perform cosmetic genital and/or sex assignment surgery early, before the child can contribute to or direct the decision. While the parents must be able to accept their child, it is the child, him or herself, who must live most directly with the consequences of any decision the parents make on his or her behalf. Nevertheless, medical, social and familial considerations require that the option to operate in childhood should remain as one potential tool among many to be used in the management and treatment of intersex children. The gravity of such a decision counsels restraint, regardless of the path ultimately chosen.