

MOVING TOWARD AN INTERNATIONAL STANDARD IN INFORMED CONSENT: THE IMPACT OF INTERSEXUALITY AND THE INTERNET ON THE STANDARD OF CARE

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“He was young; he was boyish; he did but as nature bade him.”¹

I. INTRODUCTION

What determines sexual identity? David Reimer’s revelation that he was raised as a girl beside his twin brother, and his rejection of the sex assignment made for him at the age of twenty-two months provides additional data for the age-old debate. No longer would Reimer be the “puppet” of Dr. John Money, psychologist and sexologist, who proclaimed nurture over nature in the determination of sexual identity. The painful story of David is related in the book, *As Nature Made Him*,² where author John Colapinto relates how David, through an accident of electricity and bad medicine, suffered through years of gender mis-identity, psychological abuse, child molestation, counseling, teasing and confusion.³ The publication of Reimer’s story (using his real name) and the scientific papers that preceded this revelation⁴ brought the issue of intersexuality into the public eye. Basic assumptions about human gender, sexual identity and sexual re-assignment, and what makes a person male or female, or man or woman, are being re-evaluated in light of David Reimer’s experience and subsequent revelations from intersexed individuals, concomitant with new medical procedures, theories and standards.

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1. VIRGINIA WOOLF, *ORLANDO: A BIOGRAPHY* 28 (Harvest Books 1993) (1928).
2. JOHN COLAPINTO, *AS NATURE MADE HIM: THE BOY WHO WAS RAISED AS A GIRL* (2000).
3. *Id.* at xi-xvii.
4. See Susan J. Bradley et al., *Experiment of Nurture: Ablatio Penis at 2 Months, Sex Reassignment at 7 Months, and a Psychosexual Follow-up in Young Adulthood*, 102 *PEDIATRICS* 9 (1998) (reporting on a case similar to David Reimer, a 46-chromosome XY male who sustained a burn of the skin of the penis during a circumcision and was assigned the female sex), available at <http://www.pediatrics.org/cgi/content/full/102/1/e9>.

Although David Reimer is not an intersexual, the exploration of intersex issues was fueled by David Reimer's revelations.⁵ Some of these intersex issues include the creation of "new genders," definitions of sexuality, the legal issues of rights of the intersexed, medical informed consent and standard of care issues, all of which are being questioned and challenged in part as a result of Reimer's experience and Dr. John Money's experiment. Now that the intersexed are in the open, the issue will not disappear. It is the purpose of this article to discuss the changing gender landscape, largely through the experience of David Reimer. His story is similar to that of the fairy tale puppet Pinocchio, a puppet who metamorphosed into a "real boy." David Reimer was also a puppet—an individual created, raised and advised by the paternalistic medical and psychological community as a female who struggled to find his own identity as a man, son, father, and husband.⁶ Just as Pinocchio encountered adventurers, con artists and misinformation and temptation throughout his journey to become his real self, so did David Reimer encounter difficulties, untruths and manipulators. Just as the story of Pinocchio has encouraged millions to value truth, David Reimer's deeply personal revelations have encouraged many intersexed individuals to reveal their own stories in both public and private forums, resulting in an increased awareness of intersex issues worldwide.⁷

The intersex movement is an international movement that has had an impact on both medicine and law. The Intersex Society of North America is active and gaining grass-roots support and public attention. As these intersexed individuals reveal their stories, abuses, misuses, and medical and psychological treatment histories, incidences of litigation will naturally rise. Current medical practices are being challenged.⁸ The practice of surgery on intersexed individuals at birth has been challenged at the highest court level in Colombia, and may have implications on international human and child rights in international courts.⁹

Although this article will include a brief look at the history of intersexuality, and some discussion of the current work on gender identity, the primary focus is to illustrate how the intersexed, through the internet, international connections and the example of David Reimer are impacting three medical-legal questions in the United States: 1) What is the appropriate and evolving standard of care for the intersexed individual? 2) What constitutes informed consent when physicians treat the intersexed individual and his/her family? 3) What

5. See *infra* Part III.

6. COLAPINTO, *supra* note 2; see, e.g., Intersex Soc'y of North America, Hermaphrodites with Attitude (Fall/Winter 1995-1996) [hereinafter Hermaphrodites], at <http://www.isna.org/newsletter/winter95-96/winter95-96.html>.

7. See Anthony Hubbard, *Mistaken Identity*, THE SUNDAY STAR TIMES, New Zealand, Nov. 5, 2000.

8. See generally 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 (2000).

9. See Amicus Brief from the Intersex Society of North America to the Constitutional Court of Colombia (Feb. 7, 1998) [hereinafter Amicus Brief], available at <http://www.isna.org/colombia/brief.htm>.

other torts might concern the medical professional when treating an intersexed individual?

The story of David Reimer is told in Part II. Part III gives a brief background of intersexuality and hermaphrodites, and includes some of the newer theories on sexuality and gender identity. This part sets the limits on this paper, and directs the reader to other issues created by questions of gender identity.

Part IV discusses informed consent and the standard of care in the context of intersexuality and surgical treatment of ambiguous genitalia. It also identifies corollary causes of action arising from the doctrine of informed consent. The specific current treatment for the intersexed and the current standard of care is covered in Part V. Part VI is a discussion of the factors forcing change in the standard of care, including the growth of intersex support groups, especially through the internet, new medical procedures and psychological theories, and recent revelations of long-term complications with standard intersexed treatment. Recent legal decisions in other countries that are affecting informed consent, and ethical considerations that may provoke change are discussed in this part as well.

Part VII explores several models of informed consent proposed in various disciplines and suggests a legally appropriate model for physicians to adopt and incorporate into their practice. Part VIII concludes with concerns for the physicians and the intersexed.

II. DAVID'S STORY: THE TRUTH ABOUT BRUCE AND BRENDA, JOAN AND JOHN

The lynchpin of the story of the intersexed, especially those with ambiguous genitalia or those who by accident have been assigned a sexual identity, is David Reimer. Born Bruce Reimer in 1965, in Canada, a second of two twins, David lost his penis in a circumcision accident (negligent/malpractice) incident in 1967. Given the doctors' dismal predictions regarding David's future as a boy and a man, his desperate parents turned to the charismatic and forceful psychologist Dr. John Money of the Johns Hopkins Gender Identity Clinic after seeing him present his successful sex change therapy on a television program.¹⁰ The parents traveled to Maryland and visited with Money, who convinced them that changing David's sex and raising him as a girl was David's only chance for a normal life.¹¹ As agonizing and difficult as the decision was for the parents, they wanted to do what was best for David.¹² They agreed with Money's plan of therapy, and brought David to Johns Hopkins for surgery that would castrate him and alter David into a female.¹³ His name was changed from Bruce to Brenda. What made this particular sexual reassignment case so attractive to Money and other researchers was the fact that David had a twin, Brian, who

10. A major theme of Colapinto's book deals with Money's personality, forceful and autocratic behavior and his unwillingness to be challenged or questioned. See COLAPINTO, *supra* note 2, at 38-40.

11. *See id.* at 49-51.

12. *See id.* at 52.

13. *Id.* at 53. The actual procedure was a bilateral orchidectomy, or removal of the testicles, and a surgically fashioned "rudimentary vagina."

could serve as a scientific control.¹⁴ At last Money's theories of nurture prevailing over nature, could be scientifically tested.

For the next seven years or so, John/Joan, as David was called in psychological literature, was a hallmark of Money's theories, and further solidified his reputation.¹⁵ Money capitalized on his success with the Reimer experiment until Milton Diamond's research and a BBC documentary in 1980 questioned the "success" of the experiment.¹⁶ While Money's reputation soared, Bruce/Brenda struggled through late childhood and early adolescence. Bruce/Brenda's personal difficulties negatively affected classroom performance and relationships with classmates.¹⁷ Dr. Money required once a year visits to Johns Hopkins for follow-up consultations, visits which Bruce/Brenda feared and reacted to violently.¹⁸ During these visits, Dr. Money approached the issue of vaginal surgery, which Bruce/Brenda also adamantly refused to discuss, much less consent to.¹⁹

Late in 1976, after a number of family upheavals, David's case was referred to Dr. Keith Sigmundson, a psychiatrist in Winnipeg.²⁰ Sigmundson's first impression was that Bruce/Brenda "had nothing feminine about her."²¹ However, Sigmundson felt his primary task was to "promote Brenda's female identification"²² and he referred Brenda to a series of female psychiatrists, one of whom believed that no further progress could be made until the child was told the truth.²³ At this stage Bruce/Brenda was also resisting female hormone therapy, although he finally began to take the pills under strict parental supervision.²⁴ The hormone regimen resulted, to David's horror, in a pair of breasts and fat around the waist, and his response was to overeat to conceal his new body shape.²⁵ Complicating David's identity confusion was a male voice change, even though his testes had been removed in the initial castration surgery.²⁶

Money remained unconcerned about "Brenda's" lack of progress, even though the psychiatrists updated him regularly and asked for his advice.²⁷ At age 14, David completely rebelled, and gave up trying to be a girl.²⁸ About the same time, A BBC cameraman caught David urinating standing up outside a classroom in an alley, and the story began to unravel.²⁹ When confronted, Dr.

14. COLAPINTO, *supra* note 2, at 67. Money first unveiled his "twins study" on December 28, 1972 at the annual meeting of the American Association for the Advancement of Science in Washington, D.C. *Id.* at 65.

15. *See id.* at 71.

16. *See id.* at 175.

17. *Id.* at 62-63.

18. COLAPINTO, *supra* note 2, at 79.

19. *Id.* at 80-96 for details of the other activities and evaluations that took place during these annual visits.

20. *Id.* at 112.

21. *Id.* at 113.

22. *Id.*

23. *See* COLAPINTO, *supra* note 2, at 123.

24. *See id.* at 130-31.

25. *Id.* at 131.

26. *See id.*

27. *Id.* at 136.

28. COLAPINTO, *supra* note 2, at 164.

29. *See id.* at 166-67.

Sigmundson agreed to speak with reporters on the condition of anonymity.³⁰ David was finally told the truth soon after that incident,³¹ and with a great sense of relief, immediately decided to revert to his biological sex.³² The process came at a cost—it included injections of testosterone, a double mastectomy, depression, surgery to create a penis, and numerous hospitalizations for infections.³³ He changed his name to David, and he eventually married a woman and adopted his new wife’s children.³⁴

III. A BRIEF BACKGROUND IN INTERSEXUALITY

Intersexuality and gender identity are fields of study in and of themselves, and fall into the even larger categories of biology, sociology and anthropology.³⁵ The following part is intended only to give a brief description of intersexuality, the underlying conditions, and how intersexed individuals have been treated historically.

A. Hermaphrodites in History

Although “intersexed” is a new term making its way into sociological and academic jargon, intersexuality is not new or unique to the twenty-first century. The popular press does not yet use “Intersexed.” It has been defined as “a range of anatomical conditions in which an individual’s anatomy mixes key masculine anatomy with key feminine anatomy.”³⁶ The term “transgendered” is gaining in use, and refers to those who have crossed over from male to female or female to male, often with surgery and hormonal therapy.³⁷ A more “Victorian,” yet familiar word, “hermaphrodite,” is used by many to describe individuals who seem to be neither male nor female, or have genitalia representative of both sexes.³⁸

30. *Id.* at 169-70.

31. *Id.* at 179-80.

32. *Id.* at 181.

33. COLAPINTO, *supra* note 2, at 183-84.

34. *Id.* at 195.

35. It is beyond the scope of this article to delve into all of the sociological-medical-gender studies that have been written in recent years on the topic of intersexuality. The intent here is to give a basic background so that the legal arguments can be put into their proper context and the issues identified appropriately. For excellent background and detailed descriptions of the life of the intersexed and the issue of gender identification, see SUZANNE J. KESSLER, *LESSONS FROM THE INTERSEXED* (1998); see also ANNE FAUSTO-STERLING, *SEXING THE BODY: GENDER POLITICS AND THE CONSTRUCTION OF SEXUALITY* (2000).

36. Intersex Soc’y of North America, Frequency: How Common Are Intersex People? [hereinafter Frequency], at <http://www.isna.org/faq/frequency.html> (last visited May 22, 2002).

37. See John Cloud, *His Name is Aurora*, TIME, Sept. 25, 2000, at 90 (using the word “transgender” when referring to a support group that is assisting a boy raised as a girl); see also Encarnation Pyle & Misti Crane, *Couple Fights for Son, 6, They Say is Girl at Heart*, THE COLUMBUS DISPATCH, Aug. 26, 2000, at 1G.

38. See, e.g., Hermaphrodites, *supra* note 6; see also Fausto-Sterling, *The Five Sexes, Revisited*, THE SCI., Jul./Aug. 2000, at 22; FAUSTO-STERLING, *supra* note 35, at 31 (“Hermaphrodite” comes from the names of the Greek god Hermes, and the Goddess Aphrodite, who produce a child. One myth describes the child as “so thoroughly endowed with the attributes of both” that the parents were unable to determine its sex.).

Historical references to hermaphrodites pre-date Plato, and references to the intersexed condition are common in biological and physician studies from medieval and renaissance periods.³⁹ Students of biology and medieval physicians recognized that this “third sex”⁴⁰ existed fairly commonly, and that even the “three” sexes appeared in a spectrum or continuum of sizes and shapes.⁴¹ When the sex of an individual had to be determined, lawyers or judges, the “primary arbiters of intersexual status” made the distinction.⁴² The advances in medicine, and especially surgical techniques, made way for new arbiters of sex in the early twentieth century however: “physicians were recognized as the chief regulators of sexual intermediacy.”⁴³ Hormonal and surgical treatments made it possible to eliminate the outward manifestations of hermaphroditism and “make” an individual male or female.⁴⁴ By 1950, as surgical techniques improved and doctors developed a more sophisticated understanding of the hormonal and biochemical functions of the body, physicians were able to “catch” intersexuals at the time of birth and perform surgery to eliminate ambiguous or “abnormal” physical genital traits.⁴⁵

B. The Spectrum of Sexuality

Recent studies on sexuality and gender argue that humans are not limited to two genders. One important discussion on this topic is found in *Sexing the Body*, by Anne Fausto-Sterling. Fausto-Sterling, a professor of Biology and Women’s Studies at Brown University, argues, partly tongue-in-cheek, for five sexes, not just male and female. She suggests a spectrum of sexuality, including “Herms” (true hermaphrodites), “Merms” (male pseudo-hermaphrodites) and “Ferms” (female pseudo-hermaphrodites), in addition to male and female.⁴⁶ Fausto-Sterling’s idea provoked support, moral outrage and creativity when she proposed it in 1993,⁴⁷ but today, following David Reimer’s revelations, it seems less preposterous than when first proposed.⁴⁸ While Fausto-Sterling’s work focuses on intersexuality from the biological, medical and historical context, Professor Julie Greenberg approaches intersexuality from a legal perspective. She too challenges the binary sexual classifications, arguing its impact on legal issues and the legal system and therapeutic jurisprudence.⁴⁹

39. FAUSTO-STERLING, *supra* note 35, at 32-36.

40. *Id.* at 33.

41. *Id.*

42. *See id.* at 40.

43. *Id.*

44. FAUSTO-STERLING, *supra* note 35, at 44.

45. *Id.*

46. *Id.* at 78.

47. *Id.* at 78-79.

48. The “spectrum idea” is particularly relevant to the intersexual issue. Because we are talking about a wide range of variations in genitalia, sexual identity, size and appearance, the fact that there is no one “normal” appearance is important. It is helpful to think in terms of range, spectrum or continuum in dealing with this subject.

49. *See* Julie A. Greenberg, *Defining Male and Female: Intersexuality and the Collision Between Law and Biology*, 41 ARIZ. L. REV. 265, 267, 276-78 (1999) (noting that, from an anthropological perspective,

If one uses an objective standard to classify gender, eight identifiable factors should be considered: 1) chromosomal sex (XX, XY); 2) gonadal sex (ovaries and testes); 3) external morphologic sex (penis, scrotum; clitoris, labia); 4) internal morphological sex (seminal vesicles, prostate; vagina, uterus and fallopian tubes); 5) hormonal patterns (androgen and estrogen); 6) phenotype (secondary sexual characteristics such as facial hair, chest hair, breasts); 7) assigned sex (such as that assigned by Dr. Money to David Reimer); and 8) personal sexual identity (such as that shown by “Aurora”). Even within these classifications, there is a continuum of manifestations, and varieties: for example, the chromosomal combinations can include XXX, XXY, XXXY, XYY, XYYY, XYYYY and XO.⁵⁰ When all of these factors converge and are consistent with one sex, classification is simple, either male or female. It is when ambiguity in one or even more of these characteristics occurs that an intersexed condition can exist.⁵¹ In general, “intersexuality constitutes a range of anatomical conditions in which an individual’s anatomy mixes key masculine anatomy with key female anatomy.”⁵²

The underlying presumption in the treatment of the sex reassignment cases from the 1950s through the late 1980s was that nurture and environment were the predominant forces producing “social phenomena” such as sexual roles.⁵³ The theory was most widely propagated and propounded by Harvard Ph.D. John Money of Johns Hopkins, a New Zealander by birth, and a researcher and clinician. By the mid-1960s, he was known as “the world’s undisputed authority on the psychological ramifications of ambiguous genitalia”⁵⁴ and he was a pioneer in establishing the Gender Identity Clinic at Johns Hopkins, the first in the United States to perform transsexual surgeries.⁵⁵ Money’s work, and that of his colleagues, Joan G. Hampson and John L. Hampson,⁵⁶ was influential worldwide, but so were his personality, prestige and pre-eminence in this field. Through his clinic and research, Money intended to dominate the theories, research and publishing of results relating to human sexuality.⁵⁷

many cultures recognize, and even deify a third or alternate sex—the Dominican Republic, Papua New Guinea, Native Americans, India, and ancient cultures such as Greece).

50. Greenberg distinguishes between gender and sex: Gender is “cultural or attitudinal qualities that are characteristic of a particular sex. Sex is one’s status as a man or woman based upon biological factors “such as external genitalia or chromosomal test.” *Id.* at 271, 274, 278, 281-82.

51. *Id.* at 281.

52. Alice Domurat Dreger, “*Ambiguous Sex*” or *Ambivalent Medicine?*, 28 THE HASTINGS CENTER REP. 24 (1998), available at <http://www.isna.org/library/dreger-ambivalent.htm>.

53. Anna J. Catlin, *Ethical Commentary on Gender, Reassignment: A Complex and Proactive Modern Issue; Response to Article in this Issue*, 24 PEDIATRIC NURSING 63 (1998); see also Cheryl Chase, *Rethinking Treatment for Ambiguous Genitalia*, 25 PEDIATRIC NURSING 451 (1999).

54. COLAPINTO, *supra* note 2, at 25.

55. *Id.* at 37 (Although he was not a medical doctor, Money was skilled at influencing those around him. He convinced key surgeons, endocrinologists and Johns Hopkins administrators that the United States needed a clinic to perform these surgeries. Money influenced the public relations policies about the procedures and the publicity that surrounded them.).

56. FAUSTO-STERLING, *supra* note 35, at 20.

57. COLAPINTO, *supra* note 2, at 37 (Colapinto makes the point that many of these theories seem ludicrous today in light of recent medical and social research. In his book he sets the stage for Money’s dominance in this field, including the atmosphere at universities towards research, the politics of receiving grant money, and the broader social picture of the fledgling women’s movement and the rising influence of the behaviorist school of psychology.).

Specifically, Money's view was that infants started as gender neutrals, and he and his colleagues had seven determining criteria for sex or gender determination: 1) sex of assignment; 2) chromosomal sex; 3) gonadal sex, 4) hormonal sex; 5) sex of internal organs, 6) sex of external genitalia, 7) psychological or gender role.⁵⁸ The fewer the overt or obvious signs or indications of a particular sex, for example having only two of the seven characteristics, the stronger was the presumption that gender reassignment was a correct diagnosis and treatment.⁵⁹

While Money was propagating the sex clinic at Hopkins, Milton Diamond was a young researcher at the University of Kansas, who, although keenly aware of Money's work, began to publish the results of his own research, which ran contrary to Money's theories.⁶⁰ As prenatal hormonal research became more refined and determinative, Money's influence began to wane in some schools, and the nurture argument began to be questioned.⁶¹ Current research suggests that the explanation is not as simplistic as Money proclaimed. The explanations for the differences in the appearances of human genitalia are several, but it now appears that "gender identity may be a function of the degree and timing of brain exposure to male hormones during development."⁶²

C. Frequency of Intersexuality

Sexuality itself is difficult to define, so classifying the range of intersexed conditions and then applying statistical analysis may seem futile--however, it is significant that intersexuality is not a rarity. The most common forms of gender variance and the occurrences, although not necessarily resulting in an intersexual condition, are as follows: late onset adrenal hyperplasia occurs in 1 in 66 individuals;⁶³ hypospadias (urethral opening between con and tip of glans penis) occurs in one in 770 births; Klinefelter's Syndrome (XXY) one in 1,000,⁶⁴ and "Not XX and not XY", one in 1,666 births.⁶⁵ The total number of births whose bodies "differ" from "standard" is one in 100, and one to two of every 1,000 births results in a surgery to "normalize" external appearance of the genitalia.⁶⁶ "Five children a day are born in the United States with some form of intersexu-

58. Catlin, *supra* note 53.

59. *Id.* Looking at this same set of characteristics, Money's audacity in reassigning David Reimer's sex becomes even more absurd: Reimer exhibited all of the male characteristics in each of the categories, and only became "ambiguous" after a bad circumcision. Reimer became, in a sense, the ultimate travesty of the nurture versus nature argument: born unambiguously male, yet raised as a girl.

60. COLAPINTO, *supra* note 2, at 40-42.

61. *See id.* at 212-13.

62. Cheryl Guttman, *Task Force to Draft Guidelines on Intersex Disorders*, UROLOGY TIMES, Sept. 2000, (quoting Dr. Aaronson).

63. Frequency, *supra* note 36.

64. *See infra* note 74.

65. *Id.*; *see also* FAUSTO-STERLING, *supra* note 35, at 20 (estimating 1.7% of people are intersexual in some form).

66. Frequency, *supra* note 36, at 1-2.

ality.”⁶⁷ New Zealand reports about 30 “intersex” children born each year.⁶⁸ 14 percent of the world’s population may have ambiguous genitals, and 7-10 million intersexuals may be in the U.S. alone.⁶⁹ It is the last number that is significant for the issues being discussed in this paper. Many of these individuals are surgically corrected at birth: one in every 2000 live births.⁷⁰ The obstetrician who delivers babies in a typical practice may see several cases in the course of her career.⁷¹ Some theorize that the incidences of intersexed conditions are increasing.⁷² A recent BBC documentary about Joella Holliday, a girl who was classified as male at birth, suggests that the Pill or other chemicals in the environment could be factors that have an estrogen effect on humans and other animals.⁷³ Clearly intersexuality is an issue that affects thousands of people: those with the physical manifestations, and the families who raise and nurture them.

D. Limits in this Article

The wide range of intersexual conditions precludes adequate discussion of each in depth.⁷⁴ This paper will focus on the condition of ambiguous genitalia

67. Louise D. Palmer, *Hermaphrodite Activists Urge Medical Reforms; Doctors Rethink Practice of Choosing Sex for Baby*, THE TIMES-PICAYUNE, Dec. 12, 1999, at A28.

68. *Doctors Told of Intersex Ordeal*, THE DOMINION (Wellington), Oct. 23, 2000, at 3.

69. Greenberg, *supra* note 49, at 281.

70. See Palmer, *supra* note 67.

71. E-mail from Philip Gruppuso, M.D., Department of Pediatrics, Brown University, to author (Nov. 17, 2000) (on file with author). Those conditions that have received attention in the medical literature, such as classical congenital adrenal hyperplasia (CAH) and Androgen Insensitivity Syndrome (AIS), occur much less frequently, one in 13,000 births.

72. See Anjana Ahuja, *Chemical fear over 'Joella' babies*, THE TIMES (London), Dec. 5, 1998. The argument about estrogen creating environmental problems was a factor in Japan when the birth control pill was in the approval process. Publicity over studies of feminized fish created fears of the effects of estrogen on the water supply in Japan, and may have slowed the approval of the Pill. Patricia L. Martin, *Potency and Pregnancy in Japan: Did Viagra Push the Pill?*, 35 TULSA L.J. 651, 656 (2000).

73. See Ahuja, *supra* note 72. Professor Hughes describes the effects of estrogen as follows:

[E]strogen compounds get deposited in fat and stick there. . . It then leeches out over a long time. During pregnancy the mother acquires large fat deposits to see the baby through. At 8-12 weeks, exposure to hormones determines which tissues are formed for internal and external genitals. This is a critical time for male babies. If oestrogens in the environment interfere with exposure to androgens (male hormones) it's possible that androgens can't do their job as efficiently.

Id.; see also FAUSTO-STERLING, *supra* note 35, at 54.

74. See Greenberg, *supra* note 49, at 283-288 (As discussed in the previous section on common occurrence of intersexuality, intersexuality can be caused by disorders such as Klinefelter's Syndrome—a syndrome in which a male has two more X chromosomes and a testes and penis that are smaller than average. Turner Syndrome affects females, and they have an XO chromosome and may not have complete ovaries or testes. Swyer Syndrome manifests itself in streak gonads with XY chromosomes, but the sex-delineating chromosome segment may be missing, testes do not develop and masculinizing hormones are absent. The child with Swyer Syndrome is often raised as a girl. A hermaphrodite comes in three forms: male pseudo-hermaphrodite, female pseudo-hermaphrodite, and true hermaphrodite. The true hermaphrodite has ambiguous external genitalia, often some ovarian and some testicular tissue. True hermaphrodites are very rare. Male pseudo exhibits testes, no ovaries, and some female genitalia. Female pseudo exhibit ovaries, not testes and some male genitalia. Intersexual conditions can be caused by Partial Androgen Insensitivity Syndrome (PAIS), Congenital Hyperplasia (CAH). Hormonal disorders such as Androgen Insensitivity Syndrome

that results in a surgical alteration and choice of sex for the individual by the treating physicians or parents. This also includes those cases of individuals born with “normal” genitalia that undergo surgery to change their gender due to accident or medical mistake, such as David Reimer.⁷⁵

Sexual identity affects a number of legal issues, including the primary documentation required by our society: birth certificates,⁷⁶ drivers’ licenses, social security cards, draft registration, school registration, passports—each of these documents requires a sexual identification of male or female.⁷⁷ For those who do not fit into a “binary” system of sexual identity, fundamental rights such as access to education, marriage rights, freedom from sexual harassment in the workplace,⁷⁸ inheritance and succession,⁷⁹ or even participation in the Olympics can be affected.⁸⁰ The law has not adopted Fausto-Sterling’s five classifications of sexes, but social forces and the growth of the voice of the intersexed and transgendered may force new classifications.

(AIS) manifests itself in individuals with an XY chromosome test, who cannot process male hormones (androgens). The result is that the body goes to the default path of development and develops as a female. The male with AIS cannot be externally distinguished from XX females at birth—usually this diagnosis occurs at puberty when male development does not take place. CAH females have an XX chromosome and ovaries but also an abundance of androgen during the fetal stage. Their genitalia may be ambiguous and resemble male genitalia. Some CAH babies are identified as male at birth while others are surgically treated and given hormone therapy and classified as female.)

Social factors can also contribute to genital identity disorders, and individuals affected by these social factors are often called transsexuals. A transsexual is someone whose physical anatomy does not correspond to the individual’s sense of being or sense of gender. For a discussion of genital identity disorders in a legal context see *Littleton v. Prange*, 9 S.W.3d 223, 224 (Tex. App. 1999).

75. Note that we have definitional problems even when narrowing the scope: as Dr. Alice Dreger points out, “How small should a baby’s penis have to be before it counts as ‘ambiguous?’” Dreger, *supra* note 52.

76. *Littleton*, 9 S.W.3d at 233 (holding that a surgically altered transsexual (man to woman) married to a man had an invalid marriage and could not institute a wrongful death cause of action as a spouse. The dissent in this case noted that the birth certificate had been legally amended to indicate that Littleton was female and the court should have considered the original birth certificate a nullity.). Texas law allows birth certificate inaccuracies to be corrected with an amended birth certificate. *Id.* at 223.

77. Greenberg, *supra* note 49, at 317.

78. See *id.* at 292; see also Pyle & Crane, *supra* note 37, (describing the legal issues confronting a couple who tried to enroll their “male” child, diagnosed with gender identity disorder, in school as a girl. Legal ramifications include the child being put in a Children’s Services foster home following an anonymous phone call and the parent’s consideration of a lawsuit based on federal sex-discrimination against the school district.)

79. See Neil Mackay, *Tale of the Transsexual Baron Finally Laid to Rest*, SUN. HERALD, Oct. 22, 2000, at 4 (Sir John Forbes of Craigievar battled his hermaphrodite cousin for the title of baron—which could only go to a “male” heir. The transsexual hermaphrodite cousin, Sir Elizabeth/Ewan, inherited. Sir John inherited in 1991 when Sir Ewan died. Sir John died in October 2000.)

80. Colin Adamson, *The Girls from Brazil who Share a Sydney Secret*, EVENING STANDARD (London), Sept. 27, 2000, at 22 (Two Brazilian athletes, hermaphrodites—were allowed to compete, but not without controversy and cruel attacks. Past Olympic Committees have disallowed athletes based on various types of sex tests.)

IV. INFORMED CONSENT

A belief in the fundamental adult human right to determine what will be done to his own body is the foundational principle leading to the doctrine of informed consent in the doctor-patient relationship.⁸¹ As a relatively new and unnatural addition to the practice of medicine, torts for the breach of informed consent assume a patchwork pattern throughout jurisdictions in the United States.⁸² The suits alleging an informed consent violation can be brought in battery or in negligence.⁸³ Most states have abrogated the battery basis for informed consent suits when implementing malpractice reform.⁸⁴ In these jurisdictions, the common cause of action is negligent non-disclosure, which is more favorable for the physicians, as it allows more defenses.⁸⁵ Inadequate informed consent is analyzed under traditional negligence concepts, including conforming to a standard of care.⁸⁶

Informed consent is an issue of concern for the intersexed, and affects parents, the intersex child, and the doctor-parent, parent-child and doctor-patient relationships.⁸⁷ Consent remains an issue even if the recommended standard is followed and a psychologist is involved, because the course of treatment decided upon often includes deliberately withholding medical information from the child.⁸⁸ The intersexed and professionals who treat them are questioning whether or not the surgeries and course of treatment recommended for these individuals constitutes informed consent.⁸⁹ Possibly the patients and their parents are not completely informed as to the “anatomically strict psychosocial model” followed by the intersex team.⁹⁰ They often are not informed that current practice is a theory, which is unconfirmed by long-term studies and is being challenged by the John/Joan case, and other contrary studies.⁹¹

81. See BARRY R. FURROW ET AL., HEALTH LAW 310-11 (2d ed. 2000).

82. See *id.* at 311.

83. Pennsylvania remains the only state that considers failure to obtain informed consent a battery. See *Gouse v. Cassel*, 561 A.2d 797, 798-99 (Pa. Super. Ct. 1989), *aff'd in part, rev'd in part* 615 A.2d 381 (Pa. 1992).

84. FURROW ET AL., *supra* note 81, at 312; see also *Wilson v. Landry*, 748 So. 2d 655, 659 (La. Ct. App. 1999) (holding that recovery for lack of informed consent for a circumcision improperly brought under battery, but should have been brought under Louisiana’s Medical Malpractice Act as a breach of duty of care by physician).

85. FURROW ET AL., *supra* note 81, at 312.

86. *Id.* at 313.

87. Dreger recounts the story of Sherri Grovenam, a patient with AIS, who was told that she had “twisted ovaries” instead of the fact that her testes were removed. She discovered the truth on her own in a medical library. Consequently the relationship with her parents and her physicians soured due to the lack of truthfulness. See Dreger, *supra* note 52, at 9; see also *Hermaphrodites*, *supra* note 6, at 5.

88. See Dreger, *supra* note 52, at 14; see also COLAPINTO, *supra* note 2, at 50 (questioning whether Reimer’s parents understood that the procedure was experimental, that early sex assignment had been done only on hermaphrodites, and that this had never been attempted on a child born with normal genital and nervous system. Money emphasized the possibilities of success.).

89. See Dreger, *supra* note 52, at 10.

90. *Id.*

91. See *id.*

Furthermore, the successes of the physical aspects of sex assignment surgery may have been exaggerated.⁹² Long-term scarring, lack of sexual function, or gratification, risk of infection, and multiple surgeries are only some of the complications and difficulties experienced by the intersexual.⁹³ Dreger asserts that this creates an ethical problem as well because “risky surgeries are being performed as standard care and are not being followed-up.”⁹⁴

A. Standards of Disclosure

The standard of disclosure for informed consent varies from state to state but assumes one of three forms: 1) a physician based standard; 2) a reasonable patient standard; and 3) the subjective patient standard.⁹⁵

The physician-based standard requires expert testimony, and measures the duty of disclosure by the standard of a reasonable medical practitioner in a similar situation.⁹⁶ More than 25 states have adopted this standard.⁹⁷ The reasonable patient standard, held in the landmark case, *Canterbury v. Spence*,⁹⁸ calls for a judgment as to what a reasonable patient would find material in making an informed decision. This approach does not require expert testimony and has been adopted in almost all of the remaining states.⁹⁹ The third standard, the subjective patient standard, has not gained support, because it gives the patient the option to testify as to what information she would have found important, and that she would have declined treatment, had the information been disclosed.¹⁰⁰

A list of the factors that must be disclosed to satisfy the elements of informed consent may help to illustrate the intersexed position and concern on informed consent.¹⁰¹ Physicians must disclose:

- (a) Diagnosis
- (b) Nature and Purpose of Treatment
- (c) Material Risks and Outcomes¹⁰²
- (d) Skills or Status Risks
- (e) Alternatives¹⁰³

92. See KESSLER, *supra* note 35, at 64-68.

93. See Dreger, *supra* note 52, at 15.

94. *Id.*

95. See, e.g., *Bourgeois v. McDonald*, 622 So. 2d 684 (La. Ct. App. 1993); *Robinson v. Bleicher*, 559 N.W.2d 473, 478 (Neb. 1997); *Wheeldon v. Madison*, 374 N.W.2d 367, 374 (S.D. 1985); see also 61 AM. JUR. 2D, *Physicians, Surgeons and Other Healers* §§ 187-196 (2002); John H. Derrick, *Annotation, Medical Malpractice: Liability For Failure of Physician to Inform Patient of Alternative Modes of Diagnosis or Treatment*, 38 A.L.R. 4th 900 (2001); W.M. Moldoff, *Annotation, Malpractice: Physician's Duty to Inform patient of Nature and Hazards of Disease or Treatment*, 79 A.L.R.2d 1028 (2001).

96. *Smith v. Weaver*, 407 N.W.2d 174 (Neb. 1987).

97. FURROW ET AL., *supra* note 81, at 314.

98. 464 F.2d 772 (D.C. Cir. 1972).

99. *Savold v. Johnson*, 443 N.W.2d 656 (S.D. 1989) (holding that when a factual dispute exists as to whether material risks were explained or given at all, expert testimony is not required).

100. *Bourgeois*, 622 So. 2d at 689.

101. FURROW ET AL., *supra* note 81, at 315.

102. See, e.g., *Hezeau v. Pendleton Methodist Mem'l Hosp.*, 715 So. 2d 756, 762 (La. Ct. App. 1998) (holding physician was liable when patient was not informed infection was risk of surgery).

- (f) Prognosis if Treatment Declined
- (g) Prognosis with Treatment
- (h) Conflicts of Interest¹⁰⁴

Failure or negligence in any one of these eight elements can contribute to a cause of action for negligence in informed consent. The following section highlights the aspects of informed consent that are most applicable in the treatment of intersexuals.

B. Variations on a Tort

In addition to the differences in the standard of disclosure,¹⁰⁵ the negligence in informed consent can take a variety of forms and duty, which may be applicable to the intersex issue. Particularly, these issues come to the fore when parents and doctors are faced with the decision of whether or not to perform cosmetic or corrective surgery on intersex infants soon after birth. The possible duties a health professional might incur include a duty to inform of subsequently discovered danger,¹⁰⁶ the duty to obtain parental consent,¹⁰⁷ a duty to advise the patient to consult a specialist, and liability for failure to inform patient of alternative methods of treatment or diagnosis.¹⁰⁸ Current changes and theories in intersex treatment, and the rapidly spreading increase in information on the condition for patients creates the potential for one or more of the following torts to be used as a cause of action for an intersex patient injured by treatment or surgery.

1. A Duty to Inform of Subsequently Discovered Danger

While a physician can avoid some liability by receiving informed consent, it is also possible that a physician might have a duty to inform of a subsequently

103. See, e.g., *Keogan v. Holy Family Hosp.*, 622 P.2d 1246, 1254-55 (Wash. 1980) (holding that physician breached his duty to disclose when he failed to inform patient suffering from intermittent chest pains that alternative diagnostic procedures were available).

104. *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479 (1990); see also FURROW ET AL., *supra* note 81, at §§ 6.11, 313-331.

105. Differences exist not only in the standard for informed consent, but also in the classification of the tort itself. In Colorado for example, the “claim for negligence based on lack of informed consent” is separate from medical malpractice and is based on the “information communicated by a physician to a patient before a particular procedure or treatment is commenced.” *Gorab v. Zook*, 943 P.2d 423, 427 (Colo. 1997). In contrast, Louisiana provides that lack of informed consent cases should be tried as medical malpractice cases under the Medical Malpractice Act for breach of a physician’s duty of care. *Wilson*, 748 So. 2d at 660, 666.

106. See *Schwartz v. United States*, 230 F.Supp. 536, 540 (E.D.Pa. 1964) (holding that government physicians, veterans administration clinics and the U.S. government were liable for failing to seek out and warn patient of carcinogenic danger of radioactive dye after grave warnings appeared in medical journals and other publications).

107. The general rule is that a physician may not treat a minor without parental consent. Danny E. Veilleux, J.D., *Annotation, Medical Practitioner Liability for Treatment Given Child Without Parental Consent*, 67 A.L.R. 4th 511 (2000).

108. See *Keogan*, 622 P.2d at 1254-55.

discovered danger.¹⁰⁹ This may be particularly applicable in intersexed cases.¹¹⁰ New information on treatment is appearing daily and because long-term studies and follow-up of intersexed individuals are lacking,¹¹¹ physicians and psychologists may be susceptible to these suits. A patient's long-term psychological damage,¹¹² inability to function in adult life and interaction, regret over infertility, and depression over not being "normal," may contribute to a physician's vulnerability to suit in this area. Furthermore, the late onset of some conditions and complications, which are only manifested at puberty or early adulthood, may form the basis for a claim against the medical practitioner who performs a neonatal assessment, sex assignment and surgery, and then fails to follow-up.

A physician's duty to inform of a subsequently discovered danger has been recognized in several jurisdictions, including Colorado. The case *Gorab v. Zook* illustrates the application of this duty.¹¹³ The court describes this as a "a new duty based on changed circumstances."¹¹⁴ *Gorab v. Zook* concerned the danger from continued use of a medication, and the court rejected the argument that the physician had a continuing duty to warn the patient in informed consent cases but left the door open for general negligence cases.¹¹⁵ A California case, *Tresemmer v. Barke*,¹¹⁶ also recognizes this duty, stating that the failure to warn arises from the "confidential relationship between doctor and patient. It is not a malpractice cause of action in the commonly understood sense but rather a malpractice action from the imposed continuing status of physician-patient when the danger arose from that relationship. It is also a cause of action for common negligence."¹¹⁷ As new complications in the surgery for intersexuals are discovered, or as long-term studies indicate negative results, doctors who were part of a team treating intersexuals may have a duty to locate and inform their patients of potential complications.

In the cases of the intersexed whose gender has been surgically assigned, new and substantial risks have arisen: scarring, gender misidentity and confusion, psychological trauma, sexual dysfunction, and an increased risk of suicide.¹¹⁸ Treating physicians may now have a duty to inform former intersex pa-

109. Kenneth Kipnis & Milton Diamond, *Pediatric Ethics and the Surgical Assignment of Sex*, J. CLINICAL ETHICS, Dec. 1998, at <http://www.afn.org/~sfccommed/pedethics.htm> (last visited Sept. 8, 2000).

110. *Id.*

111. *Id.*

112. One intersexual's reaction was "to me [the discovery that I was an intersexual] was extraordinarily threatening. Instead of being a human being with rights and privileges, I was supposed to be a medical problem." Hubbard, *supra* note 7, at 4.

113. 943 P.2d 423 (Colo. 1997) (giving an excellent history of the tort of lack of informed consent as a claim separate from general negligence); see also *Thornwell v. U.S.*, 471 F. Supp. 344, 350 (D.D.C. 1979); *Schwartz v. United States*, 230 F. Supp. 536, 540 (E.D.Pa. 1964); *Tresemmer v. Burke*, 86 Cal. App. 3d 656, 671-72 (1978).

114. *Gorab*, 943 P.2d at 430.

115. *Id.*

116. *Tresemmer*, 86 Cal. App. 3d at 672.

117. *Id.*

118. Katherine Rossiter & Shonna Diehl, *Gender Reassignment of Children: Ethical Conflicts in Surrogate Decision Making*, 24 PEDIATRIC NURSING 59 (1998).

tients of these potential dangers that have now come to light based on the new experiences of the intersexed.

2. Parental Consent

A second major issue in informed consent is the parental right to make decisions for their minor child.¹¹⁹ Generally, parental consent is required for treatment of a minor child, and a practitioner will be held liable for failing to obtain consent.¹²⁰ Exceptions are made in life-threatening cases, where immediate medical attention is required.¹²¹ One of the threshold issues is whether the treatment is for the minor's own benefit or for the benefit of a third party. One argument is that cosmetic genital surgery benefits the parents more than the child at the early stages.¹²² The ethical ramifications of informed consent and the parent's right to choose for the child are particularly ambiguous when the "illness" or "condition" is not life threatening.¹²³

One example is the case of Baby E,¹²⁴ a 46-chromosome XY child born with miniscule external genitalia. Although initial indicators and the standard of care would have called for a sex assignment of female, based on the newborn conditions, the parents, expecting a boy based on the amniocentesis diagnosis, refused to accept assignment as a female. Parents are empowered to make the decision for a child based on best interests.¹²⁵ The parents desired to spare their child additional pain (achieving a diagnosis had caused the child to endure much testing), and the parents did not accept the risks associated with what they perceived as an elective procedure.¹²⁶ These parents felt the decision for surgery was more appropriate for the child to make at puberty or at an age of understanding.¹²⁷ The 1998 article analyzing the case concludes that the case reached a less than satisfactory outcome. Today the ethical considerations, based on recent research and new information from intersexuals, might favor the parents' decision to do nothing and wait.¹²⁸

Another issue in parental consent is determining when a child is capable of understanding outcomes and consequences. Many organizations and medical

119. Veilleux, *supra* note 107.

120. See *Rogers v. Sells*, 61 P.2d 1018, 1019 (Okla. 1936); see also Veilleux, *supra* note 107.

121. *Tabor v. Scobee*, 254 S.W.2d 474 (Ky. 1951) (where a surgeon removed infected Fallopian tubes during an appendectomy, the removal of the tubes was not considered an emergency).

122. See Dreger, *supra* note 52, at 8.

123. Catlin, *supra* note 53.

124. Rossiter & Diehl, *supra* note 118.

125. *Id.*

126. *Id.*

127. Catlin reviews the ethical considerations of this case in the same journal, and evaluates case law in this context. The state can supervise parental authority only if:

(a) the medical profession is in agreement about the treatment, (b) whether the expected outcome of the treatment is what society agrees to be right for any child, one which would give a chance for a normal healthy life or a life worth living and (c) the expected outcome of denial of that treatment would mean death for the child.

Catlin, *supra* note 53 (citing J. Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy, in WHO SPEAKS FOR THE CHILD?: THE PROBLEMS OF PROXY CONSENT* 155 (W. Gaylin & R. Macklin eds. 1982)).

128. See Catlin, *supra* note 53; see also Rossiter & Diehl, *supra* note 118.

protocols are calling for a moratorium on early genital surgery, suggesting that the child give consent. A child's ability to give consent is generally thought to be when the child can appreciate the "nature, extent, and probable consequences of the conduct consented to."¹²⁹ This is a question of fact and depends on "age, ability, experience, education, training and maturity."¹³⁰ In the case of a conflict, a physician's "good-faith assessment" would minimize the liability in case of failure to obtain parental consent.

3. Fraudulent Affirmative Representations

A third informed consent variant concerns liability for a medical practitioner's negligent or fraudulent affirmative representations as to the nature of hazards of treatment. The premise for this cause of action is that a "medical practitioner's prediction as to the patient's future condition can be an actionable misrepresentation when the prediction implies the practitioner's knowledge of facts which the practitioner does not have knowledge of."¹³¹ A particular misrepresentation is that which will "...induce consent to surgery."¹³² Practitioners, who emphasize the benefits of cosmetic or correctional surgery for the intersex without revealing the now known risks may be liable under this cause of action. Arguably, John Money fraudulently misrepresented the surgery and sex assignment and its consequences to the Reimer family.

4. Duty to Advise to Consult a Specialist

Under malpractice and negligence tort law, a physician has a duty to advise his patient to consult a specialist or one qualified in a method of treatment, which the physician knows or should know she is not qualified to give.¹³³ Since the standard of care recommended by professionals in the transgender area states that surgeons should be qualified in the area of genital reconstruction, and that cases of ambiguous genitalia should be treated by a team,¹³⁴ all physicians who may encounter an individual with ambiguous genitalia in their practices should be aware of the treatment protocol in order to avoid *malpractice* claims. The national standard of care will be useful to plaintiffs in these cases, since it overcomes the problem of medical expert testimony.¹³⁵

129. Veilleux, *supra* note 107.

130. *Id.*

131. The most common medical misrepresentation seems to concern surgery. See, e.g., *Bloskas v. Murray*, 646 P.2d 907, 914 (Colo. 1982); *Hutton v. Craighead*, 530 So. 2d 101, 105 (La. Ct. App. 1988); *Schendt v. Dewey*, 520 N.W.2d 541, 548 (Neb. 1994).

132. See *Hutton*, 530 So. 2d at 105.

133. See *Roberts v. Fleury*, 987 F. Supp. 940, 941 (D. Md. 1997) (holding that physician fails to adhere to standard of care if she does not refer to specialist); see also *Wozniak v. Lipoff*, 750 P.2d 971 (Kan. 1988) (imposing liability for failure to refer patient to an endocrinologist when patient diagnosed with Graves disease).

134. Committee on Genetics, *Evaluation of the Newborn with Developmental Anomalies of the External Genitalia*, 106 AM ACAD. PEDIATRICS 138 (2000) [hereinafter *AAP Evaluation*].

135. See *Roberts*, 987 F. Supp. at 940.

5. Failure to Advise of Alternatives

As other alternatives to surgical treatment in infancy become more common and publicized, treating physicians will need to advise parents that counseling and minimal corrective surgery is an alternative to surgery. Physicians who fail to disclose feasible alternatives to proposed surgery may be held liable to patients for their later complications.¹³⁶

As shown above, several variations on the tort of informed consent are applicable to the current medical issues in intersex care. Obviously, informed consent is not the only cause of action available—negligence is also a viable cause of action in these situations. Statutes of limitations will need to be analyzed as well.

V. HOW THE STANDARD OF CARE RELATES TO INFORMED CONSENT

A. How a Standard of Care is Established

Establishing the applicable standard of care is the prerequisite or essential element of a medical malpractice or negligence tort case. For the informed consent torts, the standard of care that was breached must first be established. In some jurisdictions, “expert medical testimony describing the actual pattern of medical practice” is required.¹³⁷ Professional or expert testimony on the national standard of care basis is now the norm in most jurisdictions, rather than a standard of care for the “locality” rule.¹³⁸ Generally, the

Duty of care takes two forms: (a) a duty to render a quality of care consonant with the level of medical and practical knowledge the physician may reasonably be expected to possess and the medical judgment he may be expected to exercise, and (b) a duty based upon the adept use of such medical facilities, services, equipment and options as are reasonably available.¹³⁹

The judge or jury does not set those standards: the medical community sets them.¹⁴⁰ These standards are rapidly changing in the treatment of the intersexed. Physicians dealing with the intersexed need to be aware of these changes to avoid a breach of duty to their patients.

Customary practice has been rejected by some courts if the practice is dangerous or out of date.¹⁴¹ How the standard of care develops is not straightforward: it often develops through interaction of medical academics, professional meetings, research reports, networking and case studies.¹⁴² The standard of care is not necessarily regulated nor promulgated by any national board or govern-

136. See *Harwell v. Pittman*, 428 So. 2d 1049 (La. App. 1983) (holding that physician was liable when he failed to disclose feasible alternatives to surgery for removal of a gall bladder).

137. FURROW ET AL., *supra* note 81, at 265.

138. *Id.* at 265.

139. *Id.* at 264-65 (citing *Hall v. Hilbun*, 466 So. 2d 856, 872-73 (Miss. 1985)).

140. *Id.* at 265; see also *Beh & Diamond*, *supra* note 8, at 27 (arguing that a “jury’s view of reasonable prudence” can prevail over a deficient standard of care).

141. See *id.* at 265 (citing Joseph Hiling Jr., *In Search of a Standard of Care for the Medical Profession—the “Accepted Practice” Formula*, 28 VAND. L. REV. 1213, 1236 (1975)).

142. *Id.* at 266.

mental institution.¹⁴³ Generally, through the meetings of academics, reports in literature, and clinical experience, a “clinical policy” develops. If it “becomes generally accepted, it becomes ‘standard practice.’”¹⁴⁴ One of the organizations that emphasizes developing clinical policies or protocols is the 55,000 member American Academy of Pediatrics (AAP):¹⁴⁵

The development of practice standards and guidelines by national medical organizations is accelerating the process of moving all medical practice toward national standards. Such guidelines provide a particularized source of standards against which to judge the conduct of the defendant physician, and their production. . . will be influential.¹⁴⁶

Because the American Academy of Pediatrics has developed a clinical protocol for evaluation of the newborn with ambiguous genitalia,¹⁴⁷ and these guidelines will be influential in determining the standard of care expected in a malpractice or negligence suit, this report is discussed in detail in Section VI.

B. The Standard of Care for the Child Born with Ambiguous Genitalia

For pediatricians and urologists from the 1950s to the early 1990s, the standard of care in cases of ambiguous genitalia¹⁴⁸ was straightforward and relatively uniform¹⁴⁹ and routinely included surgical modification of infant’s genitalia soon after birth.¹⁵⁰ For example, Joycelyn Elders, a pediatric endocrinologist and former Surgeon General of the United States, relates her experiences with the intersexed in this passage from her autobiography:

Whenever there were cases of ambiguous genitalia or any questions involving the child’s sex, I got called in immediately. The first thing I’d do was order chromosome and hormonal studies, to try to determine exactly what kind of defect we were dealing with. Once I knew that, I could attempt to correct the imbalance or replace the deficient hormones. Often the treatment was successful,

143. *Id.*

144. *Id.* at 266-67.

145. *Id.* at 267.

146. *Id.*

147. *See AAP Evaluation, supra* note 134.

148. Here, I am distinguishing between the standard of care for individuals born with ambiguous genitalia from those individuals with one of the other disorders such as severe gender dysphoria discussed *supra* Part III. For example, in California, the current standard of care legally recognized is that surgery is recognized as medical therapy only for gender dysphoria syndrome.” *J.D. v. Lackner*, Cal. App. 3d 90, 93 (1978) (cases holding that the surgical procedure to remove male genitalia and construct female genitalia was an expense to be covered by Medi-Cal); *G.B. v. Lackner*, 80 Cal. App. 3d 64 (1978) (same); *see also* Diamond & Sigmundson, *supra* note 8.

149. *See* FAUSTO-STERLING, *supra* note 35, at 46 (stating that “by 1969, when Christopher De-whurst and Ronald R. Gordon wrote their treatise on *The Intersexual Disorders*, medical and surgical approaches to intersexuality neared a state of hitherto unattained uniformity”).

150. *See* Julia Greenberg & Cheryl Chase, *Colombia High Court Limits Surgery on Intersexed Infants*, at <http://www.isna.org/Colombia/background.html> (last visited Sept. 8, 2000). This was most often a surgical “feminizing” of intersexed infants in part because “it’s easier to dig a hole, than to build a pole.” Androgen Insensitivity Syndrome Support Group, *Genital Plastic Surgery* [hereinafter *AIS Support Group*], *available at* www.medhelp.org/www/ais/33_SURGERY.htm (last updated Apr. 16, 2002).

at which point we'd have to look at fixing up the structures surgically. . . .Occasionally our work-ups would show a mosaic of male and female chromosomes, children who were both male and female. Then our problem was to decide which sex to make the child. We knew these things had to be done before the child got to be eighteen months or so. . . .It was far easier to make a functional female than a male.¹⁵¹

Usually, doctors tested the individual genetically, physically, and a team (geneticists, pediatric endocrinologists, urologists and psychologists), would then assign a sex at birth, performing surgery and follow-up hormonal therapy to reinforce the sexual assignment.¹⁵²

The basis of this treatment was the assumption that specialists (including the surgeon, pediatric endocrinologist, and psychologist)¹⁵³ could reassign the sex of an intersex child.¹⁵⁴ It was believed that this procedure had to be performed early, preferably before 30 months,¹⁵⁵ when children become aware of their own sexual identity.¹⁵⁶

Since the 1950s, treatment for intersexuals has been based on the underlying assumption that doctors could turn any intersexed child into either gender. Once the "optimum" sex is chosen at birth, doctors would reconstruct the genitals to best reflect that decision, telling the children—and often the parents—as little as possible to avoid raising the child with doubts about its gender.¹⁵⁷

Intersexuality was considered a problem that had to be dealt with at the neonatal stage or soon after birth—within three days of birth.¹⁵⁸ It was not only a physical, but also a psychological crisis for the parents.¹⁵⁹ "Early surgery and parental conviction that the sex chosen by doctors is the child's true sex is supposed to guarantee that the child develops into a happy girl or boy and, ultimately, a well-adjusted and heterosexual woman or man."¹⁶⁰ Those individuals who expressed doubts about their sexual identity were treated with extra estrogen.¹⁶¹ "Normalcy" was the model underlying assumption of the standard of care.¹⁶² The less debate or ambiguity on the part of the doctor, the easier it was thought to be for the parents to raise the child in the newly determined sex.¹⁶³ This standard of care left little room for consultation with parents. Since surgi-

151. Dr. Joycelyn Elders & David Chanoff, JOYCELYN ELDERS, M.D., FROM SHARECROPPER'S DAUGHTER TO SURGEON GENERAL OF THE UNITED STATES OF AMERICA 151-53 (1997).

152. See Chase, *supra* note 53.

153. See Dreger, *supra* note 52.

154. See Chase, *supra* note 53 (citing J. MONEY & A.A. ERHARDT, MAN AND WOMAN, BOY AND GIRL (1972)).

155. See COLAPINTO, *supra* note 2, at 51; Chase, *supra* note 53 (citing the 1996 American Academy of Pediatrics Section on Urology Report).

156. KESSLER, *supra* note 35, at 14-15.

157. Palmer, *supra* note 67, at A28.

158. See Chase, *supra* note 53; Dreger, *supra* note 52.

159. See Rossiter & Diehl, *supra* note 118.

160. Chase, *supra* note 53, at 451; see also KESSLER, *supra* note 35, at 46-51 for details of the surgical procedures.

161. Chase, *supra* note 53, at 452.

162. *Id.*

163. Palmer, *supra* note 67, at A28.

cally it was easier to “construct” females; a functional vagina being easier to create than a sexually functional penis,¹⁶⁴ many of the intersexed were surgically altered to be females. Two major factors in sex assignment were the “adequacy of the phallus in the male, potential fertility in the female and the cosmetic appearance of the reconstructed genitalia.”¹⁶⁵

Underlying the standard of care were some unwritten assumptions. One assumption was that surgeries are performed with confidence.¹⁶⁶ A second assumption was that the surgery itself was worthwhile—an unstated value judgment that a scarred and insensitive vagina, clitoris or penis is preferable to a “larger-than-typical” clitoris, or penis that does not urinate in a stream.¹⁶⁷ A third assumption was each sex has a “normal” range or appearance.¹⁶⁸ A fourth assumption was that being born with ambiguous genitalia was a “trauma” and called for an “emergency” action.¹⁶⁹ In any setting, a problem with a newborn is traumatic, and causes anguish for the parents.¹⁷⁰ Obviously an emergency response does not always take into account consideration of the long-term well being of the child.¹⁷¹

The assumption of trauma for the individual born with ambiguous genitalia is clear from the opinions of the professionals: boys must have a penis—“cannot be a boy without this insignificant organ. . . . They must be raised as females. . . . They are doomed to life as a male without a penis.”¹⁷² David Reimer was a victim of this particular assumption. The consultant from the Winnipeg Clinic, the head of the Department of Neurology and Psychiatry, Dr. G.L. Adanson evaluated David (then Bruce) Reimer’s future:

One can predict that he will be unable to live a normal sexual life from the time of adolescence: that he will be unable to consummate marriage or have normal sexual relations; in that he will have to recognize that he is incomplete, physically defective, and that he must live apart.¹⁷³

This damning diagnosis in 1967 pushed the parents of David Reimer to Dr. Money, who seemed to be the only voice offering them hope in a dark period.¹⁷⁴

Today the treatment is more varied and less uniform, and some physicians have expressed concern that the “successes” from the 1950s-1990s may rebound as failures.¹⁷⁵ Generally, physicians believe that the condition should be corrected immediately, but actual medical practice depends on the decisions made

164. *Id.*

165. W. G. Reiner, Abstract, *Assignment of Sex in Neonates with Ambiguous Genitalia*, in CURRENT OPINIONS ON PEDIATRICS 363-66 (1999).

166. KESSLER, *supra* note 35, at 74.

167. *Id.* at 75-76.

168. *See generally* FAUSTO-STERLING, *supra* note 35; KESSLER, *supra* note 35.

169. KESSLER, *supra* note 35, at 127.

170. *Id.* at 91.

171. *Id.* at 127.

172. *Id.* at 37.

173. COLAPINTO, *supra* note 2, at 15-16.

174. *Id.* at 23.

175. *See* KESSLER, *supra* note 35, at 75.

by individual surgeons, which is often based on their training or beliefs.¹⁷⁶ The next section discusses the movements toward change.

VI. SEX-CHANGERS, CHANGES IN THE MAKING AND THE CHANGE-MAKERS

The last decade of the twentieth century was a time of great change for the intersexed. Not only were conventional standards of care and treatment challenged, but those making the sex changes were challenged.¹⁷⁷ Those whose sex had been changed formed groups, coalitions and grass roots movements, and a change of procedures, perspectives and medical care and societal perceptions has become a priority of these groups. This section briefly discusses why and how these rapid changes have come about.

A. The Growth of the Intersexed as a Voice for Change

1. Connections and Coalitions: The ISNA, Intersexed Society of North America

The intersexed found a face when David Reimer revealed his life story to John Colapinto. They achieved a voice through the efforts of the Intersex Society of North America (ISNA) and its founder Cheryl Chase, and other support group and activist networks. In seven short years, Chase's group of activists and coalition of groups devoted to addressing and supporting the problems, concerns, and issues of the intersexed have "forced many prominent medical specialists to reconsider the prevailing model of treatment, to question whether the well-intentioned practice of surgically removing or altering the genitals of newborns so they appear 'normal' creates the very emotional, sexual and physical trauma it is designed to avoid."¹⁷⁸ Chase's motivations in forming the ISNA arose from personal traumatic experiences as an intersexual.¹⁷⁹ Labeled a boy at birth, but with both male and female sexual organs, Chase was raised a girl after surgery at eighteen months of age.¹⁸⁰ Driven to a point of contemplating suicide, with no idea as to why she had mutilated and numb genitals, Chase instead vowed to make a difference in the lives of other intersexuals.¹⁸¹

Chase has made a difference—more and more intersexed individuals are speaking out on the Internet, in videos, news programs and in medical, psychological and popular media.¹⁸² Activities of the ISNA have included applying for

176. See FAUSTO-STERLING, *supra* note 35, at 48. The training of physicians impacts the standard of care—should physicians be allowed to rely on the training received in medical school and continuing education, or can the standard of care be based on recent studies and newer research in this area? See discussion *supra* Parts IV and V.

177. See COLAPINTO, *supra* note 2, at 71-72.

178. Palmer, *supra* note 67, at A28.

179. *Id.*

180. *Id.*

181. *Id.*

182. The evolution of the Internet has coincided with the rise of the ISNA and has greatly facilitated its reach and outreach. Individuals can contact the website to "chat," to exchange ideas and access information, all with anonymity if desired. See *Sixty Minutes: A Crime Against Nature: Sexual Reassignment* (CBS television broadcast June 25, 2000), available at http://sixtyminutes.ninensn.com.au/60/stories/2000_06_25/story_185.asp (last visited Sept. 18, 2000).

association with the National Organization for Rare Disorders; responding to medical journal articles on areas related to treatment of intersexuals; offering to provide a panel of intersex patients as part of a symposium on genital pediatric surgery; and, ultimately, some members demonstrating at the 1996 American Association of Pediatrics meeting in Boston.¹⁸³ A few dissident physicians supported the protest by the ISNA, and some clinicians are reappraising the standard model of care for intersexuals.¹⁸⁴ What Chase's efforts and those of other support groups illustrate is that the only experts on this issue may be the intersexed themselves.¹⁸⁵ The voice of the intersexed is being heard as intersexual activists have been willing to publicly expose their own pain and trauma.¹⁸⁶ Bolstering its "appearance" are the links on the Internet and beyond with other groups. The website for ISNA, for example, reveals anecdotal evidence of sex reassignment issues.¹⁸⁷ Significantly the ISNA wrote an amicus brief to the Constitutional Court of Colombia regarding intersex surgery on two infants, which was influential in the court ruling against intersex infant surgery.¹⁸⁸ Chase has contributed to the medical literature as well by arguing against early genital surgery.¹⁸⁹

2. International Intersexuality

As mentioned earlier, intersexuality is not only a North American issue. Chase's networking with other organizations reveal worldwide phenomena of growth of the voice of the intersexed. The courage and revelations of other intersexed have led to the growth of support groups and activist organizations circling the globe, including Australia, New Zealand, the United Kingdom, Canada, Japan, Germany, and Holland.¹⁹⁰ However, since the United States is the provider of some of the best medical care in the world, groups such as the ISNA and the American medical community may well take the lead in changing the standards of care on this issue.

B. Medical Studies

The standard of care for intersexed individuals is changing not only because of the David Reimer story and the influence of the ISNA and other support groups for intersexuals, but also because of the new research and surgical techniques in the medical field which are coming to light. Indeed, "the paradigm for sex assignment in newborns is in transition," says a study by psychiatrist W.G. Reiner of Johns Hopkins.¹⁹¹ Not only have intersexual groups lobbied

183. Chase, *supra* note 53, at 452.

184. *Id.*

185. Palmer, *supra* note 67, at A28; see also *Doctors told of "intersex" ordeal*, *The Dominion* (Wellington) Oct. 25, 2000.

186. Palmer, *supra* note 67, at A28; see also Hubbard, *supra* note 7. A support network for New Zealand intersex people is found at www.circumstitions.com.

187. Ricki Lewis, *Reevaluating Sex Assignment*, 14 *THE SCIENTIST* 6 (Jul. 10, 2000).

188. See discussion *infra* Part VI.D.1.

189. Chase, *supra* note 53, at 5.

190. See Amicus Brief, *supra* note 9, at 13.

191. William G. Reiner, Abstract, *Assignment of Sex in Neonates with Ambiguous Genitalia*, 11 *CURRENT OPINIONS ON PEDIATRICS* 363 (1999).

their doctors and clamored for change in the treatment of the intersexual, but the thinking and hypotheses of specialists in surgery, endocrinology, psychology, ethics, psychiatry, genetics, and public health have begun to reflect the clinical responses to genital ambiguity.¹⁹² The major specialties involved in treatment of the intersexed are re-evaluating their presumptions about sexual assignment, and long term studies are being initiated to add to this new body of research. This will impact not only surgical treatment, but also long-term psychological, hormonal, urological and sociological treatment of the intersexed.¹⁹³

Most significantly and recently, the American Academy of Pediatrics (AAP) reported in July 2000 a new standard of care for the treatment of individuals with ambiguous genitalia.¹⁹⁴ Much of this report was formulated *before* the recent publicity and “widely publicized cases” of David Reimer and others.¹⁹⁵ The AAP report stated the approach, care and follow-up for the intersexed patient, beginning with the explanation for the genetic and hormonal factors creating sexual orientation.¹⁹⁶ Written for pediatricians, the article emphasized the “team” approach in treatment of these individuals, a team which includes pediatricians, pediatric endocrinologists, urologists, plastic surgeons and a psychiatrists.¹⁹⁷

In addition to this study, a task force has been formed to study the long-term clinical responses to genital ambiguity.¹⁹⁸ The North American Task Force on Intersexuality (NATFI) first met in October 1999, and it will utilize its research outcomes to analyze and evaluate the AAP report with the purpose of “formulat[ing] optimum guidelines for care of children with intersex disorders.”¹⁹⁹ NATFI is endorsed by a number of organizations, and its mission is to suggest a new nomenclature for the intersexed and sex classifications.²⁰⁰ The AAP report was formulated around January of 1999 and at that time the AAP still favored early surgical intervention.²⁰¹ NATFI may recommend a modification of those guidelines.²⁰² The task force, chaired by Dr. Ian Aaronson, M.D., Professor of Urology and Pediatrics, and Director of Pediatric Urology at the Medical University of South Carolina, will publish its management guidelines in 2004, after identifying patients in its first year, interviewing and evaluating the intersexed above age sixteen in years two and three, and analyzing and interpreting this data for its report in year four.²⁰³

192. Revelation of cases of failed reassignments and the emergence of intersex activism have led an increasing number of pediatric endocrinologists, urologists and psychologists to reexamine the wisdom of early genital surgery. See FAUSTO-STERLING, *supra* note 35, at 21.

193. Reimer, *supra* note 191.

194. See *AAP Evaluation*, *supra* note 134.

195. Guttman, *supra* note 62; see also *Task Force is Studying Effects of Cross-Gender Surgery on Kids*, SEATTLE POST-INTELLIGENCER, Mar. 13, 2000, at D2.

196. *AAP Evaluation*, *supra* note 134, at 138.

197. *Id.*

198. See FAUSTO-STERLING, *supra* note 35, at 22.

199. Guttman, *supra* note 62.

200. See FAUSTO-STERLING, *supra* note 35, at 22.

201. Guttman, *supra* note 62.

202. FAUSTO-STERLING, *supra* note 35, at 22.

203. Guttman, *supra* note 62.

1. Diamond's Opposition and A Second Study

Clearly a major factor producing change was the revelation of John/Joan (David Reimer), following Milton Diamond's and Keith Sigmundson's article reporting on David's (John/Joan's) rejection of his female identity, and questioning the recommendation that those individuals presenting XY ablatio penis be raised as a girl.²⁰⁴ Diamond, who had been continuing his work on hormonal influences during gestation, followed the progress of John/Joan and contacted Sigmundson through a notice in an American Psychiatric Society newsletter.²⁰⁵ Sigmundson was Reimer's treating psychiatrist and had anonymously revealed the unsuccessful aspects of the experiment to the BBC. Diamond and Sigmundson collaborated on an article that revealed the failure of the experiment, after visiting extensively with David Reimer.²⁰⁶ The final paper, which "went against three decades of dogma. . .set off shock waves in medical circles around the world, generating furious debate about the ongoing practice of infant sex reassignment."²⁰⁷ The article documented the outcome of the John/Joan experiment and debunked Money's theories of successful sex reassignment based only on a theory of nurture and environment and early and unambiguous reassignment.²⁰⁸ Diamond and Sigmundson then proposed "alternative principles for the management of intersexual children and of boys suffering from penile trauma."²⁰⁹

2. Assignment at 7 Months, Reiner, and Baby G

Similarly, a second study on an ablated penis case in Canada compared this child's experience with that of David Reimer.²¹⁰ In this second case, after an electrocautery circumcision, the XY male was assigned to the female gender at age seven months. Although this patient more clearly identified with the female sex, at the age of twenty-six the patient was a bisexual and living with a woman. The patient experienced ambivalent partner preferences.²¹¹ This Canadian study questioned Money's theories, and advocated additional studies in order to create a different management model for these cases.²¹²

Dr. William Reiner, trained as a pediatric urologist, was supportive of Diamond and Sigmundson's paper. He had spent much of his medical career re-assigning sex, but after an encounter with "Baby G," a 46XY male raised as a

204. Bradley et al., *supra* note 4.

205. COLAPINTO, *supra* note 2, at 199. The ad said: "Will whoever is treating the twins please report." Sigmundson was afraid to publish the outcome of the case, because of the Money connection and potential detrimental impact on his career. *Id.*

206. *Id.* at 209-10. Diamond's paper was begun in 1994, but was not published until 1997 in the *Archives of Pediatrics and Adolescent Medicine*.

207. Lewis, *supra* note 187, at 6; COLAPINTO, *supra* note 2, at 220-222.

208. Chanika Phornphutkul et al., *Gender Self-Reassignment in an XY Adolescent Female Born With Ambiguous Genitalia*, 106 PEDIATRICS 135 (2000).

209. *Id.*; see also Beh & Diamond, *supra* note 8.

210. See Bradley, *supra* note 4, at 9; see also COLAPINTO, *supra* note 2, at 273-76 (reporting on some cases in progress).

211. See Bradley, *supra* note 4, at 9.

212. *Id.* at 9.

girl, Reiner began warning other physicians against the idea that nurture could overcome biological theory.²¹³

Baby G was born with ambiguous genitalia, the distinguishing feature of which was a “micropenis,” or enlarged clitoris.²¹⁴ Based on phallus size, doctors assigned Baby G a female gender on day four of life.²¹⁵ Chromosome history revealed a 46 XY karyotype.²¹⁶ The parents agreed to the sex assignment as a female and removal of the testes to avoid possible malignancy.²¹⁷ Later the mother stated that she was not informed of or did not remember the chromosome test results.²¹⁸ At about age sixteen, the patient questioned her diagnosis, and after discussions with physicians, declared herself male.²¹⁹ He was then started on testosterone replacement and had to undergo a mammoplasty.²²⁰ The mother was supportive during this period, but the father was not, and a divorce resulted.²²¹ This report, “taken together” with Diamond’s work and that of others suggest “that early sex assignment as female does not ensure female gender self-identification in XY infants with female external genitalia.”²²²

3. Changes in Surgical Techniques and Procedures

The intersexed face both functional and cosmetic surgery. Surgical techniques and procedures over the last several years produced unprecedented refinements and results. Transgender surgeries, which are distinguishable from intersex surgery in infancy, are considered an established procedure in most countries.²²³ Current techniques that were not possible 30–35 years ago now can

213. COLAPINTO, *supra* note 2, at 212.

214. Literature defines a penis that is less than 1.5 centimeters in size as a micropenis and it is considered inadequate for development of a “functional” penis—described as the ability to have intercourse and to urinate standing up. *See id.* This is an issue in the ethics of intersexual treatment: an “adequate” penis is necessary for male sex assignment, but “adequate” and “acceptable” are subjective terms and measurements. *See Dreger, supra* note 52, at 5. Gender discrepancies arise in the assignment of sex: vaginas are “easier” to construct and have lower standards than for a penis. *Id.* at 6. Traditionally, if a newborn’s stretched organ is about 1 inch, or longer, the baby is a he; if under 3/8 inch, the baby is a she. If between of 3/8 to 1 inch the organ is usually shortened, so the penis becomes a clitoris. Further surgery takes place during puberty, along with hormone treatments. *See Lewis, supra* note 187, at 2.

215. *See Phornphutkul et al., supra* note 208, at 2.

216. *Id.*

217. *Id.*

218. *Id.*

219. *Id.*

220. Phornphutkul et al., *supra* note 208, at 2. Mammoplasty is “plastic surgery on the breast to alter its shape, size, re-position, or all of these.” ILLUSTRATED STEDMAN’S MEDICAL DICTIONARY (24th ed., 1982).

221. Phornphutkul, *supra* note 208, at 2.

222. *Id.* at 3; *see also* M. Beshati et al., *Gender Assignment in Male Pseudo-Hermaphrodite Children*, 22 UROLOGY 604, 607 (1983) (reports a study of male pseudo hermaphrodites in Toronto that compares males who were assigned female gender and 12 who were not raised female).

223. *See* The Cleveland Clinic, *Sex Reassignment Surgery* (Nov. 2001) [hereinafter *Sex Reassignment Surgery*], at mywebmd.com/content/article/2953.533 (last visited June 20, 2002). Although “transgender” and “intersex” are two distinct populations, the point here is that genital surgery has become refined and more common in the recent past as compared with the surgical techniques available at infancy to those who are now adults; *see also* B. Leidl, *Sex Reassignment Surgery in Female to*

maintain nerves and sensitivity of the organs, and some experimental evidence shows that sensitivity may be preserved.²²⁴ However, these techniques are new and the patients on whom such techniques have been performed are not yet adults. Thus, the long-term effects of such surgical procedures are still unknown.

Technology to reconstruct a penis has also improved.²²⁵ Still “only 2-3 centers in the United States have experience creating penises ‘out of nothing’” and “[t]he surgical results are not perfect.”²²⁶ Generally, doctors do not perform a clitorectomy (complete removal of the clitoris), instead creating a clitoral recession, which reduces the length but maintains the nerve supply.²²⁷ Scarring is often inevitable, especially in male-to-female surgeries.²²⁸ Studies that address the psychological effects between cosmetic successes, late sexual gratification, and “general psychological adjustment” are not yet available.²²⁹ For this reason, the debate in the pediatric endocrinology community over the proper treatment of intersexed individuals continues to rage.²³⁰ The results of purely cosmetic surgeries however are also unproven and physicians must report that the results of cosmetic surgery have not been proven when asking parents to give consent for such surgery.²³¹ Even after distinguishing between cosmetic and corrective surgery, doctors have difference of opinion and thus a differing standard of care.²³² In a “watershed” moment this year, Claude Migeon, another Johns Hopkins surgeon, “stood before the pediatric endocrine society and announced that follow-up studies on his intersexed patients led him to conclude that genital surgeries never produce perfect results.”²³³

4. Long-term Problems are Surfacing

Anecdotal reports from the intersexed are revealing the following long-term difficulties, including:

- (1) A failure to convince parents that the gender of the child was changed as a result of surgery;²³⁴
- (2) A sense of betrayal felt by the intersex, that parents, doctors, and therapists “deceived” the individual regarding the original of gender;²³⁵
- (3) Damaged sexual function and feelings of “shame and freakishness;”²³⁶

Male and Male to Female Transsexuals, FORTSCHRITTE DER MEDIZIN (EMBASE 1999240401) (last visited Nov. 2, 2000).

224. Lewis, *supra* note 187, at 3.

225. *Id.*

226. *Task Force*, *supra* note 195 (quoting Dr. Aaronson of the NATFI).

227. AIS Support Group, *supra* note 150.

228. Leidl, *supra* note 223, at 3.

229. *See Dreger*, *supra* note 52, at 12.

230. *Point/counterpoint*, PHYSICIAN'S WEEKLY, Aug. 16, 1999, at <http://www.physiciansweekly.com> (last visited Nov. 25, 2000).

231. Dreger, *supra* note 52, at 12.

232. *Id.*

233. Palmer, *supra* note 67, at 6.

234. *See Chase*, *supra* note 53, at 2.

235. *Id.*; *see also Dreger*, *supra* note 52, at 9.

236. Chase, *supra* note 53, at 2.

- (4) Manifestation of a gender identity contrary to sex assigned by doctors;²³⁷
- (5) Low self-esteem and depression directly attributable to early surgery (infant surgery conveys a strong message that “baby was not acceptable” as he or she was born);²³⁸
- (6) Vaginal stenosis in females who had CAH and underwent vaginal reconstruction in infancy and childhood;²³⁹
- (7) A reportedly high incidence of homosexuality and bisexuality in genotypic males reassigned as females;²⁴⁰ and
- (8) Bitterness and silent despair.²⁴¹

Furthermore, repeated surgeries are the norm. A study in Australia showed that 90 percent would require further surgery because the early intervention was inadequate.²⁴² Many of the intersex surgeries permanently destroy fertility and negatively affect sexual sensation.²⁴³

5. Problems with Hormonal Therapy

The corollary treatment for the intersexed, after a sexual determination has been made, is hormonal therapy. Depending on the underlying condition, the treatment varies depending on sex, but ranges from steroids and birth control pills to testosterone injections. Often this treatment cannot be started until puberty. Pediatric endocrinologists try to create a “normal” puberty, sometimes with estrogen or progesterone or birth control pills. Testosterone injections or patches are also prescribed.²⁴⁴

6. Lack of Long-Term Studies

One of the major hurdles to insuring informed consent for parents and patients is the lack of long-term studies and follow-up of individuals with ambiguous genitalia.²⁴⁵ As mentioned earlier, changes are taking place with the formation of a task force,²⁴⁶ and as more intersexed individuals make themselves known and submit to questioning and information gathering, more information may become available. To contribute to research on the nature/nurture issue, Dr. William Reiner at Hopkins is studying children with cloacal exstrophy,²⁴⁷ which is a condition of major trunk abnormalities and severely deformed geni-

237. *See id.*

238. *Id.*; *see also* Hubbard, *supra* note 7, (stating that “one of the complications of medical intervention as a child is that you’re not acceptable unless you’re re-fashioned into some ideal. The message that you send a child is that they’re not OK”); Dreger, *supra* note 52, at 8.

239. *Id.* at 10. Vaginal stenosis is a narrowing of the vaginal opening. *See Sex Reassignment Surgery*, *supra* note 223.

240. Rossiter & Diehl, *supra* note 118, at 3.

241. Beh & Diamond, *supra* note 8, at 7.

242. *See* AIS Support Group, *supra* note 150.

243. *See* Lewis, *supra* note 187, at 6.

244. *See id.*

245. Chase, *supra* note 53, at 2; *see also* Dreger, *supra* note 52, at 9.

246. AIS Support Group, *supra* note 150.

247. A developmental anomaly in which an area of intestinal mucosa is interposed between two separate areas of the urinary bladder.

talia.²⁴⁸ One of Reiner's conclusions is that "changing the sex at birth in these children may not be in their best interests. . .and I think they will have a lot of trouble [when told the truth] with that psychologically."²⁴⁹ Reiner also reported that normal male gender identification can develop without a penis and even after testicles are removed.²⁵⁰

The AAP report is also concerned with the lack of long-term studies, stating, "caution should be exercised when a recommendation is made that the sex of rearing should differ from the chromosomal sex."²⁵¹ Few studies have addressed the non-physical/medical outcomes: the social, psychological and sexual outcomes.²⁵² Most of the data on the intersexed surgeries focus on short-term cosmetic results.²⁵³ Those studies that address the problem are showing a "psychopathology developing in about 40 percent of people treated" by the Money model of sex assignment and surgery before 24 months.²⁵⁴

Others outside of medicine, in the fields of medical history, bioethics, social psychology, sociology, and anthropology, also believe there has been a lack of adequate studies and follow-up on the issue of early surgery for individuals with ambiguous genitalia.²⁵⁵

D. Legal Changes

1. Colombia Constitutional Court Decision

The Colombia Constitutional Court was charged with deciding whether parents had the right to authorize genital surgery on their child, in two cases, one involving a two-year-old child and the other involving an eight-year-old child. In a 1995 decision, the court had ruled on a case similar to John/Joan, in which a boy was assigned as female following a traumatic accident that destroyed his penis.²⁵⁶ The boy "never developed a female gender identity."²⁵⁷ He brought suit for redress to the Constitutional Court and won when the court held that "parents cannot give consent on a child's behalf to determine sexual identity."²⁵⁸ This court's latest decision built on the 1995 standard and, in addition, designed new informed consent guidelines for legal and medical professionals to incorporate into their practices.²⁵⁹ The court in its findings relied

248. See Ed Susman, *Boys Play Baseball, Girls Play House: Study of rare sex disorder*, BIOTECHNOLOGY NEWSWATCH, Nov. 6, 1995; see also Lewis, *supra* note 187.

249. Susman, *supra* note 248, at 1.

250. Lewis, *supra* note 187, at 1.

251. AAP *Evaluation*, *supra* note 134, at 5. This report acknowledges the changes in the last decade from the "nurture" theory in medical studies, stating that "it has become apparent that testosterone imprinting and fetal brain may play a role in determining male sexual orientation."

252. *Id.* at 6.

253. See Chase, *supra* note 53, at 2. This reports long-term follow-up on vaginal replacement, suggesting the vagino plasty at or near puberty is more appropriate than at infancy. *Id.* at 5.

254. *Id.* at 2.

255. *Id.* at 6.

256. See Greenberg, *supra* note 49; see also Chase, *supra* note 53.

257. Chase, *supra* note 53.

258. *Id.*

259. See discussion *infra* Part VII.B.1.

heavily on the Amicus Brief of the ISNA, opinions by the European Court of Human Rights, and opinions on discrimination/protection for homosexuals and transsexuals, as well as Colombian medical experts, and videotapes of intersexuals speaking out on the issue of surgery on infants.²⁶⁰ The Colombian court could find “no case in which any other high court in the world had considered the issue” and thus was “unable to rely on legal precedent.”²⁶¹

Two implications for the North American legal and medical communities come to mind as a result of this decision. First, the Colombian Court decision is representative of how a well-organized and persuasive argument, presented effectively, can affect the judiciary and create new law. The ISNA, the American Academy of Pediatrics, Milton Diamond and many other scientists and experts now believe that this surgery on infants is wrong. Although no reported cases similar to those in Colombia have appeared yet in the United States, it is conceivable that an informed consent action or an injunction requesting a prevention of surgery could be brought in the near future. The ISNA is clearly geared up to present evidence supporting a moratorium on this type of surgery, as evidenced by the Colombia case. Secondly, the Colombian decision, although not binding authority, may be persuasive to a court hearing a similar case of first impression in the U.S.

2. Violations of World-Wide Conventions and Medical Ethics Standards

The amicus brief written to the Constitutional Court of Colombia by the ISNA identifies several world standards that might be violated by the practice of cosmetic or correctional genital surgery on infants or children unable to consent. First, the ISNA equates the surgery with medical experimentation, because of the lack of long-term studies on outcomes.²⁶² The Nuremberg Code specifically states the primary requirement of experimentation as: “The voluntary consent of the human subject is absolutely essential.”²⁶³ Following the reasoning of the ISNA, allowing genital surgery that is experimental on nonconsenting minors is a *prima facie* violation of the Nuremberg code of medical ethics, and that is a “moral[ly] and legally repugnant” practice.²⁶⁴ The ISNA argues that this particular infant surgery also violates the United Nations Convention on the Rights of the Child, which requires all parties to the Convention “to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation. . .while in the care of parent(s), legal guardian(s) or any other person who has the care of the child”²⁶⁵ and “no child shall be subjected to torture or other cruel, inhuman or degrading treatment.”²⁶⁶

260. Greenberg & Chase, *supra* note 150, at 1.

261. *Id.*

262. See Amicus Brief, *supra* note 9, at 4.

263. FURROW ET AL., *supra* note 81, at 378-79 (citing the Nuremberg Code, later incorporated in the Declaration of Helsinki).

264. Amicus Brief, *supra* note 9, at 4-5.

265. *Id.* at 6 (citing Article 19 of the United Nations Convention on the Rights of the Child, dated November 20, 1989 but not ratified by the United States).

266. *Id.* (citing Article 37 of the United Nations Convention on the Rights of the Child).

Female Genital Circumcision (FGC, also referred to as Female Genital Mutilation or FGM) is also analogized to infant genital surgery in the ISNA amicus brief, stating that a “wide variety of human rights authorities and organizations have determined that involuntary genital surgery performed on female children violates basic human rights to bodily integrity and personal dignity and autonomy.”²⁶⁷ FGC, which is the “removal of all or part of the clitoris, inner labia or outer labia”²⁶⁸ has been condemned by a long list of international organizations, including the United Nations Commission on Human Rights, UNICEF, the World Medical Association, the World Health Organization, the 1993 United Nations World Conference on Human Rights and has been labeled “barbaric” and a “violat[ion] of human rights” in the U.S.²⁶⁹

This inconsistency in how FGC is treated as compared to how intersex surgery is treated may be a basis for legal challenges to intersex surgery in the U.S.²⁷⁰ Milton Diamond points out that “medicine has been vocal in its condemnation of [FGM] even as it continues to recommend [normalizing genital surgery].”²⁷¹

4. Legal Ethical Conflicts

Briefly, the ethical considerations are many and have been discussed and developed by Alice Dreger,²⁷² and Milton Diamond, among others.²⁷³ Dreger states that the treatment of the intersex “hit all the buttons [in bio-ethics], paternalism, informed consent, the doctor-patient relationship, and the Hippocratic Oath to ‘do no harm.’”²⁷⁴ Dreger thinks that the treatment of the intersexed and especially John Money’s work will one day rank with Tuskegee as a long-term (40 plus years) unethical experiment.²⁷⁵ The practice also raises the bio-ethical-technology question: just because we know how to do it, should we do it?” Is this another area where medical technology has outpaced our moral, ethical and

267. *Id.* at 5 (citing AMNESTY INTERNATIONAL, WOMEN’S RIGHTS ARE HUMAN RIGHTS (1995)).

268. *Id.* at 6.

269. Amicus Brief, *supra* note 9, at 6. The ISNA also uses the arguments against Female Genital Circumcision in its brief.

270. Dreger, *supra* note 52, at 12. Legislation passed in 1996 by the U.S. Congress called for penalties to anyone who “knowingly circumcises, excises, or infibulates the whole or any part the labia majora or labia minor or clitoris of another person who has not attained the age of 18 years.” The legislation creates an exception:

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

Id.

271. Kenneth Kipnis and Milton Diamond, *Pediatric Ethics and the Surgical Assignment of Sex*, J. CLINICAL ETHICS, at <http://www.afn.org/~sfcommmed/pedethics.htm>. (last visited May 24, 2002).

272. See Dreger, *supra* note 52.

273. See Kipnis & Diamond, *supra* note 271.

274. Lewis, *supra* note 187.

275. Dreger is equating the treatment of the intersexed from the 1950s through the 1990s with the Public Health Service study of syphilis among African-American men in Tuskegee Alabama. See JAMES. H. JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT* (1993).

another area where medical technology has outpaced our moral, ethical and psychological reactions?²⁷⁶

VII. WHAT THE STANDARD OF CARE AND INFORMED CONSENT SHOULD BE TODAY

A. An Emerging Standard of Care

Although “the medical community is still debating the appropriate standard of care,”²⁷⁷ based on this most recent literature and studies, the standard of care for those with ambiguous genitalia in the United States may begin to look like the following:

- (1) Care should be taken in the delivery room and with conversations with parents not to suggest a diagnosis or offer a gender assignment.²⁷⁸ Doctors and nurses in the delivery area should call the child “your baby,” “your child,” not “it,” she, or he.²⁷⁹
- (2) Specialized care and counseling should be provided for parents and child, during diagnosis period and as follow-up care.²⁸⁰ This includes a “positive atmosphere” and emotional tone established by the health professionals.²⁸¹
- (3) Accurate recurrence risk counseling should be communicated.²⁸²
- (4) Sex should be based on the most likely outcome.²⁸³ Deciding the sex should be based on these criteria: fertility potential, capacity for normal sexual function, endocrine function, malignant change, testosterone imprinting and timing of surgery.
- (5) Terms such as “typical,” “usual,” “most frequent” should be used rather than “normal” when describing the sex characteristics of the newborn.²⁸⁴
- (6) “Reconstructive surgery should be delayed until the patient’s gender identity can be incorporated into the decision-making process.”²⁸⁵ (This

276. Other ethical considerations, but not necessarily with legal implications are these: Should parents be making the decisions—are they able to make the best decision for the child at the early states? See Catlin, *supra* note 53, at 2. Is sexual intercourse the most important thing a human does? Is the penis the most important sexual organ? (asks Dr. Reiner). See Lewis, *supra* note 187. Catlin queries “is a functional, full size penis of essence to human male existence?” Catlin, *supra* note 53, at 4.

277. Carl T. Hall, *Guidelines Created for Intersex Babies*, S.F. CHRON., July 4, 2000, at A2 (quoting Dr. Christopher Cuniff, co-author of the AAP Report).

278. *Id.*

279. *Id.*

280. *Id.*

281. *Id.*

282. *AAP Evaluation*, *supra* note 134.

283. Beh & Diamond, *supra* note 8, at 2.

284. *Id.* at 1.

285. Chanika, *supra* note 208; see also Beh & Diamond, *supra* note 8. The Journal recommends that the surgeon should be Board Certified and either a urologist, gynecologist, plastic surgeon or general surgeon. *Id.* at Part III Sec. XI. A surgeon should ideally have experience and knowledge with more than one technique in genital reconstruction in order to meet the specific needs of the patient. *Id.*

is the most controversial point and has not yet been adopted by the AAP).

- (7) Current reports indicate that diagnosis of micropenis (in infancy) should result in the assignment of the male gender.²⁸⁶
- (8) “Immediate and extensive medical workup” is required to determine the underlying diagnosis and any life-threatening hormonal blockages.²⁸⁷
- (9) Testosterone injections should be given only in equivocal cases, and the child should be “raised as a boy only when there is a very good response.”²⁸⁸
- (10) Medical professionals should recognize that while a child born with ambiguous genitalia may constitute a “social emergency,” this is not a “medical emergency” in the sense that intervention is not necessary immediately in order to save the child’s life (except in the cases of congenital adrenal hyperplasia (CAH)).²⁸⁹
- (11) A step-by-step approach leading to a speedy diagnosis is essential.²⁹⁰

Recognizing the potential changes in the standard of care and incorporating them into practice may prepare physicians who encounter a child with ambiguous genitalia to treat the child appropriately. The physician may then properly fulfill her duty to obtain full and informed consent from the parents and the child, if the child is old enough.

B. New Informed Consent

Those promoting informed consent laws based on the new information, medical studies and legal landscape should consider the following:

1. Colombia Court Model

The 1999 Colombia Constitutional Court decisions²⁹¹ on intersex surgery²⁹²—for a two year old and an eight year old child—both found that the “consent given by the parents for genital surgery was invalid.”²⁹³ In making this decision, the court required that the legal and medical communities establish a new category of consent. The court said there must be “qualified, persistent informed consent” with the following elements:

286. Phornphutkul et al, *supra* note 208; *see also* Dreger, *supra* note 52, at 7.

287. Rossiter & Diehl, *supra* note 118.

288. *AAP Evaluation*, *supra* note 134, at 5.

289. *Id.* at 1; *see also* FAUSTO-STERLING, *supra* note 35, at 21.

290. *See AAP Evaluation*, *supra* note 134, at 8 (History and exam should include obstetric history; the physical exam should look for malformation, external diagnosis, and palpitation of gonads. Laboratory and Imaging Studies should be employed to discover placement and size of internal genital; blood, hormonal and chromosomal analysis is required.).

291. Order Changing Guardianship (Identification of Minor Suppressed), Sentencia SU-337/99 (Corte Constitucional, May 12, 1999) (Colum.); In re. Guardianship XX, Sentencia T-551/99 (Corte Constitucional, Aug. 2, 1999) (Colum.).

292. *See* Julie A. Greenberg and Cheryl Chase, *Colombia High Court Restricts Intersex Genital Mutilation*, available at www.isna.org/pr/pr10-25-99.html (last visited Sept. 9, 2000).

293. *Id.*

- (1) Parental authority depends on the “exigency and urgency” of the procedure, the invasiveness, and the “age and autonomy” of the child.
- (2) Parents may consent only if they have been given accurate information about risks and alternate treatment protocols.
- (3) Consent must be written, and must be given over an extended period of time, not just at the initial surgery.
- (4) Parents cannot consent for children over age five. These children are autonomous, and have identified with a gender.²⁹⁴

The Colombian Court held in a similar John/Joan case, in 1995, that “[P]arents cannot give consent on a child’s behalf to surgeries intended to determine sexual identity.”²⁹⁵ In response to the 1995 ruling, surgeons began to recommend surgery, but refused to perform it, resulting in the 1999 cases, requesting surgery for two children.²⁹⁶

2. ISNA Model

The ISNA considers surgeries performed in infancy to be IGM—Intersex Genital Mutilation.²⁹⁷ The ISNA has also stated that doctors should not be “insulated from any liability for harm caused by performing non-consensual genital surgery on children precisely at the moment when scholarly opinion is changing.”²⁹⁸ The ISNA might agree that parents need to be informed that: 1) “there is no medical reason to reduce the size of a large clitoris, no illness or pain is a side effect, and the main reason for reduction is cosmetic and a belief that it will enhance the psychological state of the child;” 2) “the reduction surgery is irreversible,” because tissue cannot be reconstructed and scarring results, so psychological counseling should be substituted; 3) the surgery is actually less complicated in a larger child than in an infant; 4) the surgery itself can cause harm: scarring, chronic pain, irritation, reduced sexual sensation in addition to the inherent risks of any surgical procedure (infection, anesthetics, etc.); 5) no long-term data are available on the outcomes of this type of surgery; and 6) a safer alternative is now available that would allow management of the intersexed condition and meet the criteria of informed consent.²⁹⁹

3. Diamond’s Model

Informed consent should consist of full and honest disclosure about the condition to the parents and the patient (depending on age).³⁰⁰ The family should be informed that much of the influence genetically and through the endocrine system will manifest at puberty, and when pre-adult and secondary sex characteristics and genitalia appear.³⁰¹ When surgery is an issue, informed consent should include a distinction between cosmetic surgery and that required for

294. *Id.*

295. *Id.*

296. *Id.*

297. Amicus Brief, *supra* note 9.

298. *Id.*

299. *Id.* at 1.

300. Beh & Diamond, *supra* note 8, at 2; *see also* Kipnis & Diamond, *supra* note 109, at 8.

301. Beh & Diamond, *supra* note 8, at 3.

maintaining physical and mental health, emphasizing functionality over appearance. The parents and child (if this is done at puberty) should also be informed that such surgery could impair sexual/erotic function.³⁰²

Parents should be informed at birth that true informed consent cannot be achieved before puberty, but should be warned about the repercussions of waiting until that time.³⁰³ Patients should be informed of the effects and contraindications of “major prolonged steroid hormone administration,”³⁰⁴ as a number of intersexed individuals have not been pleased with the outcomes of this treatment.³⁰⁵ Furthermore, parents need to consider when the child should be told of the surgery.³⁰⁶ Because it is such a drastic step, before removing the gonads, surgeons should obtain full consent from parents.³⁰⁷ Parents should also know that untreated ambiguous genitalia may create problems for children when they attend school, resulting in serious psychological repercussions.³⁰⁸ Informed consent should emphasize the alternate treatment option of therapy, which includes psychological counseling.³⁰⁹

Of these models, Diamond’s is most likely to be acceptable to the medical community in the United States. However, treating physicians should be keenly aware of, and should move towards, the other standards that are advocated by the ISNA, and the standard adopted by the Colombian Court.

VII. CONCLUSIONS

“Take this as a metaphor for the intersex life: a rich mystery afloat on the sea, unsure of the rules but still determined to make a way forward.”³¹⁰

Information, intersexuality, the Internet, internationalization, and intersexual genital mutilation are all part of the new vocabulary of our 21st century world. Technology is moving more rapidly than we can adapt, and new studies and surgical techniques and inventions are changing both the way we look at the world and the way we look at and classify each other. The intersexed are part of that world, and face difficult issues in gender identification, choosing surgical procedures and lifestyles that may be difficult for many to understand. The medical community is an integral part of the intersexed life choices, whether it is providing surgery or continued counseling to manage the issues caused by the physical condition. Health professionals and providers face changes and challenges in treating the intersexed, as the issues are not only medical, but legal and ethical as well.

Informed consent is an essential element of medical treatment of the intersexed. Knowing the choices, knowing the chances, and knowing the children

302. *Id.*

303. *Id.*

304. *Id.*

305. *Id.*

306. Kipnis & Diamond, *supra* note 109, at 8.

307. *See id.* at 4.

308. *See* Guttman, *supra* note 62.

309. *See* FAUSTO-STERLING, *supra* note 35, at 21.

310. Hubbard, *supra* note 7, at 6.

involved will equip health professionals and others treating the intersexed to treat the patient first, by doing what is best for the patient, and by avoiding (and avoiding potential liability from) drastic, morally wrong and irreversible mistakes. Health professionals and patients alike need to be informed of the recent changes in the gender landscape. At this juncture, given divided opinion in the medical community, the lack of long-term studies, and the traumatic revelations made by David Reimer and the intersexual community, the new treatment protocol should include a “time out:” a time to slow down, a time to think, and a time to listen to the voices of the intersexed.