

AN EMERGING ETHICAL AND MEDICAL
DILEMMA: SHOULD PHYSICIANS PERFORM SEX
ASSIGNMENT SURGERY ON INFANTS WITH
AMBIGUOUS GENITALIA?

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INTRODUCTION

In 1999 two men in their early twenties, one from the east coast and one from the midwest, independently contacted Professor Milton Diamond and revealed their extraordinary stories. When they were infants, their testicles were surgically removed and their genitals reconstructed. They were then raised as girls. As puberty approached, they were given female hormones to make their breasts grow and to force other female characteristics to emerge. They described their childhood bewilderment to Professor Diamond. They had never been comfortable as girls; they recalled always harboring inner thoughts that they were male. However, fear had prevented them from giving a voice to their doubts. One young man recalled asking his mother, "Does God make mistakes?" They described the shock they felt when in their teen years they pieced together information about their medical conditions and learned about secret surgical procedures performed on them when they were too young to remember or consent. They mourned for the person who might have been. Like their childhood years, their young adult years have been marked by a need for more surgery as they try to reclaim their male gender. One young man had gone to the "best malpractice firm" in his state, but was told he had no case, since doctors had done the best they could, given what they knew about his condition at the time. The other young man, unable to afford the mastectomies, the penile implant surgery, the male hormones he would need for the rest of his life to prevent osteoporosis and to provide some semblance of normalcy, asked Dr. Diamond if he could sue the doctors.¹ That there are others out there like these young people prompts this article.

This article discusses the development of a surgical approach to treating intersex infants and others with genital anomalies² that began

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1. The tapes of these interviews are on file with the authors. One young man had androgen insensitivity syndrome. Within weeks of his birth his small penis and testicles were removed and a vulva created and he was raised a girl. The other young man had micropenis and severe hypospadias of unknown etiology. At the age of two months, his testicles were removed and he too was raised as a girl. Both independently rejected their female form in their teens and now live as men.
 2. Intersexed individuals are those that are born with biological features simultaneously typically male and female. For instance they might have one ovary and one testis or gonads that contain features of both ovarian and testicular tissue. They can have chromosomes of XXY, XO or other configurations. There are more than 1 dozen categories of intersex. See Melvin M. Grumbach & Felix A. Conte, *Disorder of Sex Differentiation*, in WILLIAMS TEXTBOOK OF ENDOCRINOLOGY 1303, 1331 (J.D. Wilson et al. eds., 9th ed. 1998).

in the late 1950s and 1960s and became standard in the 1970s. Although professional literature has recently questioned the surgical approach to the treatment of infants, controversy surrounding treatment persists and the medical community now is divided. How sex reassignment surgery for intersex infants became a routine recommendation of practitioners and how parents were persuaded to consent to such radical surgeries provide a cautionary tale that is relevant to both medicine and law.

Over the past four decades, early surgical intervention for infants who are born with ambiguous genitalia or who suffer traumatic genital injury often has been recommended as standard procedure.³ Surgical advances in this century have made it possible for physicians to choose a gender⁴ for the child and to sculpt gender-appropriate genitalia of approximately normal-looking appearance. For the most part, when choosing surgical treatment, physicians have opted for a female form because it is easier to fashion female genitalia than male.⁵ Relying on a nurture-based theory of gender identity, physicians have advised parents to surgically alter their intersexed infant and to raise the child in a manner consistent with the child's surgically-altered genitalia, without regard to the gender identity that might have naturally developed.⁶ The same advice has been given when a male infant's penis has been severely mutilated by trauma or is considered significantly small. Clinicians have assured parents that the surgical potential for normal-looking genitalia should dictate the child's gender and that any innate gender propensity of the child can be changed by careful upbringing.

Despite a paucity of confirming evidence, medical literature since the 1970s, has promoted this treatment. This medical literature relied on a body of published reports which themselves were initially predicated on studies of intersexed individuals and most significantly, one infant's incredible case which was widely reported in medical, psychiatric and popular literature.⁷ In 1997, the medical community

Ambiguous genitalia are physical anomalies in which the genitalia are not clearly identifiable as male or female. They are often detected at birth and are a sign of intersex. Grumbach & Conte, *supra*, at 1401.

3. See *infra* notes 12, 109, 113.

4. Gender as used in this paper is a social term representing the social conditions of boy or girl and man or woman. This is in contrast to the biological terms of male and female. It is thus obvious that a male can live as a girl or woman and that a female can live as a boy or man.

5. See *infra* notes 111–115.

6. See *infra* note 12.

7. See John Money et al., *An Examination of Some Basic Sexual Concepts: the Evidence of Human Hermaphroditism*, 97 BULL. JOHNS HOPKINS HOSP. 301, 308 (1955) ("In place of a theory of instinctive masculinity or femininity which is innate, the

was reacquainted with that infant who had been long lost to follow-up.⁸ Only then did the medical community discover that the outcome of this single case was not as first reported. The foundation on which this treatment rests finally began to crumble.

Part II of this article discusses the remarkable case of John/Joan (J/J), the male infant whose penis was destroyed by a surgical accident and who was then intentionally castrated and surgically transformed into a female-looking infant.⁹ Accepted as a success, this case report had a significant impact on the standard of care that developed for treatment of certain intersex conditions, micropenis, and accidental penile trauma in infancy. Unfortunately, the outcome of the case was never fully reported until 1997.¹⁰ Had the true facts been revealed earlier, or its premises been subjected to more rigorous scientific inquiry, the medical standard that developed probably would have been different.

Part III of this article discusses generally how medical standards of care develop and how a poorly-grounded standard of care became entrenched through anecdotal reporting and without scientific validation. Part III concludes with a discussion and critique of tort law's self-imposed impotence in cases where a negligent standard of care develops because treatment has not been subjected to scientific scrutiny. While under ordinary negligence principles juries may find liability based on a profession's collective negligence in establishing customary practices, many jurisdictions accord more deference to medical standards. In jurisdictions that require physicians to conform to standards in the medical community, rather than to reasonable prudence, a claim that medical practice collectively has deviated from common sense and the rigors of science will not succeed. Ultimately, Part III argues that asking physicians to abide by community standards promotes professional inertia. When treatment practices are not validated by scientific studies, a deferential tort standard is not appropriate.

evidence of hermaphroditism lends support to a conception that psychologically, sexuality is undifferentiated at birth and that it becomes differentiated as masculine or feminine in the course of the various experiences of growing up"); John Money, *Cytogenetic and Psychosexual Incongruities With A Note on Space-Form Blindness*, 119 *AM. J. PSYCH.* 820, 820 (1963) ("It is more reasonable to suppose simply that, like hermaphrodites, all the human race follow the same pattern, namely, of psychosexual undifferentiation at birth."). In the early days intersexed individuals were known as hermaphrodites and pseudohermaphrodites.

8. Milton Diamond was one of the two researchers who reintroduced the patient to the medical literature in 1997. See Milton Diamond & H. Keith Sigmundson, *Sex Reassignment at Birth: Long Term Review and Clinical Implications*, 151 *ARCHIVES PEDIATRIC ADOLESCENT MED.* 298 (1997) [hereinafter Diamond & Sigmundson, *Sex Reassignment*].

9. See discussion *infra* Part II.

10. See *infra* notes 35–48 and accompanying text.

Part IV explores the role of the informed consent doctrine, particularly with regard to parental decision-making responsibilities for cases of ambiguous or traumatized genitalia. Part IV suggests that the medical community's confidence in recommending treatment, the practice of providing limited and simplistic information in order to shield and protect parents and the sense of urgency communicated to parents all compromised the ability of parents to give proper informed consent. Even more fundamentally, decision makers failed to consider childrens' potential for future self-determination. Compounding these already formidable informed consent obstacles, clinicians also held the belief that children would only accept the gender of assignment if they were raised in the selected gender without equivocation, and thus enlisted parents as accomplices to medical secrecy.

Part V offers the recommendations for change endorsed by critics of early surgery, including both medical ethicists and the Intersex Society of North America (ISNA). These recommendations give guidance to physicians and parents who, on behalf of children, must make very difficult medical decisions that have lifelong implications on sexual and gender identity and erotic and reproductive potentials.

I. THE REMARKABLE CASE OF JOHN/JOAN

The contemporary medical model for dealing with cases of ambiguous or traumatized genitalia started some four decades ago, but became firmly established when the case of John/Joan¹¹ was reported in the pediatric literature.¹²

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11. For accounts of the John/Joan case, see Diamond & Sigmundson, *Sex Reassignment*, *supra* note 8; Milton Diamond & H. Keith Sigmundson, *Management of Intersexuality: Guidelines for Dealing with Persons with Ambiguous Genitalia*, 151 ARCHIVES PEDIATRIC ADOLESCENT MED. 1046 (1997) [hereinafter Diamond & Sigmundson, *Management of Intersexuality*]; Kenneth Kipnis & Milton Diamond, *Pediatric Ethics and the Surgical Assignment of Sex*, 9 J. CLINICAL ETHICS 398 (1998) [hereinafter Kipnis & Diamond, *Pediatric Ethics*]. Colapinto provides the most thorough examination of J/J's life. See John Colapinto, *The True Story of John/Joan*, ROLLING STONE, Dec. 11, 1997, at 54 [hereinafter Colapinto, *The True Story*]; see also JOHN COLAPINTO, AS NATURE MADE HIM: THE BOY WHO WAS RAISED AS A GIRL (2000) [hereinafter COLAPINTO, AS NATURE MADE HIM]; ANNE FAUSTO-STERLING, SEXING THE BODY: GENDER POLITICS AND THE CONSTRUCTION OF SEXUALITY 66-71 (2000); SIMON LEVAY, QUEER SCIENCE: THE USE AND ABUSE OF RESEARCH INTO SEXUALITY 103-05 (1996).

Professor Greenberg discusses the case in a critique of law and medicine's rigid, binary approach to sex and gender. See Julie A. Greenberg, *Defining Male and Female: Intersexuality and the Collision Between Law and Biology*, 41 ARIZ. L. REV. 265 (1999).

12. See SUZANNE J. KESSLER, LESSONS FROM THE INTERSEXED 6 (1998) ("Virtually all academic writing on sex and gender refers to a case first described by sexologist John

In the early 1970s, John Money, a psychologist at The Johns Hopkins' Hospital, reported the case of an identical twin who lost his penis at the age of 8 months through a surgical mishap during phimosis repair.¹³ Along with psychologist Anka Ehrhardt, Money reported that, following counseling, the parents consented to sex-reassignment surgery (castration, removal of the scrotum and initial fashioning of a vulva) and to raising their once-son, John, as their new-daughter, Joan.¹⁴ This

Money in 1972."); Alice Domurat Dreger, "Ambiguous Sex"—or Ambivalent Medicine? Ethical Issues in the Treatment of Intersexuality, HASTINGS CENTER REP., May-June 1998, at 24, 26 (describing establishment of surgical standard).

For references to the surgical standard, see JOHN MONEY & ANKA A. EHRHARDT, MAN & WOMAN/BOY & GIRL: THE DIFFERENTIATION AND DIMORPHISM OF GENDER IDENTITY FROM CONCEPTION TO MATURITY (1972) [hereinafter MONEY & EHRHARDT, MAN & WOMAN]; Alan D. Perlmutter, *Intersex, in UROLOGIC SURGERY IN INFANTS AND CHILDREN* 2, 15 (Lowell R. King ed., 1997); Howard McC. Snyder III, MANAGEMENT OF AMBIGUOUS GENITALIA IN THE NEONATES, *in UROLOGIC SURGERY IN NEONATES & YOUNG INFANTS* 346, 369-70 (Lowell R. King ed., 1988); C. R. J. Woodhouse, *Ambiguous Genitalia and Intersexuality—Micropenis, in PEDIATRIC UROLOGY* 689, 690 (Barry O'Donnell & Stephen A. Koff eds., 3d ed. 1997); American Academy of Pediatrics, *Timing of Elective Surgery on the Genitalia of Male Children with Particular Reference to the Risks, Benefits, and Psychological Effects of Surgery and Anesthesia*, 97 PEDIATRICS 590 (1996) [hereinafter *Timing of Elective Surgery*]; Patricia K. Donahoe et al., *Clinical Management of Intersex Abnormalities*, 28 CURRENT PROBS. SURGERY 517, 527 (1991); Kurt Newman et al., *The Surgical Management of Infants and Children With Ambiguous Genitalia: Lessons Learned from 25 Years*, 215 ANNALS OF SURGERY 644 (1992); Katherine Rossiter & Shonna Diehl, *Gender Reassignment in Children: Ethical Conflicts in Surrogate Decision Making*, 24 PEDIATRIC NURSING 59 (1998); Emily Nussbaum, *A Question of Gender*, DISCOVER, Jan. 2000, at 92, 93-94.

13. The child's penis was "ablated flush with the abdominal wall" during an electrocautery procedure which burned the entire penis, causing it to eventually necrose and slough. See MONEY & EHRHARDT, MAN & WOMAN, *supra* note 12, at 118. Penile amputation or trauma may occur through surgical or childhood mishap. They are not common occurrences but are not rare. See, e.g., Bernardo Ochoa, *Trauma of the External Genitalia in Children: Amputation of the Penis and Emasculation*, 160 J. UROLOGY 1116 (1996) (reporting seven case studies); Joan McQueeney Mitric, *Merits of Circumcision A Subject of Dispute Disfigurement Lead to Two Lawsuits in Atlanta*, WASH. POST, Oct. 23, 1986, at Health 9 (reporting that two babies, on the same day, were burned during circumcision and one underwent sex-change surgery because of the severity of tissue destruction); Tracy Thompson, *Two Atlanta Physicians Get Reprimand Over Babies' Burns Suffered During Circumcisions*, ATLANTIC J. & CONST., Nov. 8, 1986, at B1.
14. The plan was developed as follows, "The parents agonized their way to a decision, implementing it with a change of name, clothing and hair style when the baby was seventeen months old. Four months later, the surgical first step of genital reconstruction as a female was undertaken, the second step, vaginoplasty, being delayed until the body is full grown. Pubertal growth and feminization will be regulated by means of hormonal replacement therapy with estrogen." MONEY & EHRHARDT, MAN AND WOMAN, *supra* note 12, at 118-19. The child underwent an orchiectomy (surgical removal of testicles) and preliminary vulva surgery before age two. See Diamond & Sigmundson, *Sex Reassignment, supra* note 12, at 298-99.

case is now known in the psychological and medical literature as the John/Joan case.¹⁵

The parents were counseled to raise the child as a girl and to provide the child only limited information:

They were broadly informed about the future medical program for their child and how to integrate it with her sex education as she grows older. They were guided in how to give the child information about herself to the extent that the need arises in the future; and they were helped with what to explain to friends and relatives, including their other child. Eventually, they would inform their daughter that she would become a mother by adoption, one day, when she married and wanted to have a family.¹⁶

The parents were further instructed to keep J/J's original sex a guarded secret. In fact, the parents later reported that, in order to foster secrecy, they were advised at the time to settle in a distant city.¹⁷

Since the children's family did not live close to The Johns Hopkins Hospital where Money had his office, the day-to-day care of the twins was left in the hands of a local psychiatric team under Money's direction. Once a year the twins were brought to The Johns Hopkins Hospital for evaluation and to insure adherence to the treatment plan.¹⁸ As subsequently reported by Money, Joan was satisfactorily developing

15. The names are pseudonyms. See COLAPINTO, *AS NATURE MADE HIM*, *supra* note 11, at xv; Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 299; Colapinto, *The True Story*, *supra* note 11, at 56. Now stepping forward, John, whose real name is David Reimer, has agreed to appear in public with the release of Colapinto's book.

Kitzinger writes on the case's widespread impact on the social sciences as well: "The John/Joan case is still amongst the most widely cited studies in social science textbooks on gender issues. Its popularity with textbook authors is due, in part to the . . . nature of a case [which seems better suited to science fiction than science]." Celia C. Kitzinger, *Gender, Sex and Knowledge: The construction of the John/Joan Case in Social Science Textbooks* (forthcoming) (manuscript at 1, on file with authors).

16. MONEY & EHRHARDT, *MAN & WOMAN*, *supra* note 12, at 119.

17. See Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 302. Peculiarly, in a text published in 1968, Money discouraged counseling parents to move ". . . it used to be commented in passing that when a new announcement of sex was necessary, the parents should move to a new town, find a new job, sever all connections with the past, and start life anew. I have found that this formula is completely untenable." JOHN MONEY, *SEX ERRORS OF THE BODY: DILEMMAS, EDUCATION, COUNSELING* 61 (1st ed. 1968) [hereinafter MONEY, *SEX ERRORS* 1968]. References to the second edition, published in 1994 will be cited as MONEY, *SEX ERRORS* 1994.

18. See Colapinto, *The True Story*, *supra* note 11, at 68.

as a girl in marked distinction to the other twin who was now developing as a normal boy.¹⁹

During the child's preadolescent years, Money reported that the parents were successfully raising the now-female child as a girl who appeared typical enough although with some "tomboyish traits."²⁰ Money did not report on J/J's refusal to cooperate in his counseling.²¹ Money was apparently untroubled by some childhood conduct that, in hindsight, would prove prescient, such as her persistence in standing to urinate despite her mother "teaching her how little girls go the bathroom."²²

Besides tomboyishness and standing to urinate, other warning signs developed as the child matured, and these did not appear contemporaneously in the medical literature. Starting from the age of twelve, Joan was given estrogens to stimulate breast growth, widening of hips and other features of typical female pubertal development. These changes were not welcome and Joan was openly showing signs of rejecting her female assignment.²³ The local psychiatrists attending to the child indicated their belief that Joan was a definite tomboy and expressed doubt she would develop into an acceptable and content female.²⁴ Although Money followed Joan until this point and after, these findings about the

19. See John Money, *Ablatio Penis: Normal Male Infant Sex Reassignment as a Girl*, 4 ARCHIVES OF SEXUAL BEHAVIOR 65 (1975) [hereinafter Money, *Ablatio Penis*]; see also Colapinto, *The True Story*, *supra* note 11, at 56.

20. For example, in 1972, Money reported:

Regarding domestic activities, such as work in the kitchen and house traditionally seen as part of the female's role, the mother reported that her daughter copies her in trying to help her tidying and cleaning up the kitchen, while the boy could not care less about it. She encourages her daughter when she helps her in the housework. See, MONEY & EHRHARDT, *MAN & WOMAN*, *supra* note 12, at 121. However, he continued, "[t]he girl had many tomboyish traits, such as abundant physical energy, a high level of activity, stubbornness, and being often the dominant one in a girls' group." MONEY & EHRHARDT, *MAN & WOMAN*, *supra* note 12, at 122.

21. See Colapinto, *The True Story*, *supra* note 11, at 68.

22. See MONEY & EHRHARDT, *MAN & WOMAN*, *supra* note 12, at 122. The mother noted times when the girl had "penis envy" on seeing her twin brother's penis in the bath. See MONEY & EHRHARDT, *MAN & WOMAN*, *supra* note 12, at 121.

23. A BBC documentary in 1980 suggested that treatment in the twins case was not developing as successfully as earlier reports indicated. See Milton Diamond, *Sexual Identity, Monozygotic Twins Reared in Discordant Sex Roles and a BBC Follow-up*, 11 ARCH. SEXUAL BEHAV. 181, 183 (1982) [hereinafter Diamond, *BBC Follow-up*] (describing and citing P. Williams & M. Smith, *Open Secret: The First Question* (Science Series, BBC Television Production 1980)).

24. See Diamond, *BBC Follow-up*, *supra* note 23, at 183.

child were not reported and Joan was seemingly “lost to follow-up.”²⁵ In actuality, due to the discord Joan felt about the counseling she was receiving in Baltimore, at the age of nine she began to object to returning. Parental “bribes” were used to induce her to return for periodic check-ups. In a dramatic gesture of displeasure and defiance, she ran away from the hospital at age thirteen and was found hiding on the roof of a nearby building.²⁶ Joan thereafter refused to return to The Johns Hopkins Hospital.²⁷

Although the case had been widely reported and cited in the medical literature,²⁸ the rejection of the assigned gender that the child exhibited did not appear in the literature²⁹ when it might have had an impact on the developing standard of care.³⁰ Instead the significance of the early reports of J/J’s supposedly successful sex change confirmed the apparent efficacy of this treatment as a “standard of care” for certain infants and contributed to its wide acceptance.³¹ Skepticism regarding its theoretical scientific base³² prompted one critic’s prolonged search to

25. Colapinto writes that Money did have further contact with the twins but this was not reported upon. See COLAPINTO, *AS NATURE MADE HIM*, *supra* note 11, at 154–55.

26. See Diamond & Sigmundson, *Sex Reassignment*, *supra* note 8 at 300; COLAPINTO, *AS NATURE MADE HIM*, *supra* note 8, at 71.

27. See Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 300.

28. See *infra* note 81.

29. See COLAPINTO, *AS NATURE MADE HIM*, *supra* note 11, at 199–204. More remarkably, it now appears that prior to the J/J reports in the 1970s, available data suggested that intersex individuals left to develop without surgery generally made satisfactory adjustments. Significantly, these data gathered in the 1950s by John Money went unreported in the professional literature. Had they been reported it most likely would have mitigated against the adopted surgical method of treatment. See COLAPINTO, *AS NATURE MADE HIM*, *supra* note 11, at 233–35.

30. After the widely publicized report on the J/J case by Diamond and Sigmundson in 1997, Money, in 1998, acknowledged the failure of treatment but theorized that other variables including surgical delay may have caused the child to reject the assigned gender. See JOHN MONEY, *SIN, SCIENCE, AND THE SEX POLICE: ESSAYS ON SEXOLOGY AND SEXOSOPHY* 314–19 (1998) [hereinafter MONEY, *SEX POLICE*]. Colapinto reported that in 1975 Money knew that Joan had sexual fantasies about girls, her father reported that Money asked him “how they felt about raising a lesbian,” yet this “clinical finding was not in his next report on the twins which appeared in 1975.” Colapinto, *The True Story*, *supra* note 11, at 70. While continuing to acknowledge tomboyish play, Money stated “[h]er behavior is . . . that of an active little girl, and so clearly different by contrast from the boyish ways of her twin brother.” Money, *Ablatio Penis*, *supra* note 19, at 71.

31. See *infra* note 81.

32. Diamond had challenged Money’s theories since the 1960s, but Money was not dissuaded by critics. See MONEY & EHRHARDT, *MAN & WOMAN*, *supra* note 12, at 154 (citing and criticizing works of Diamond and others who challenged the correctness of early surgical intervention). Money continues to defend his work. See MONEY,

find the adult J/J to see how she had actually developed and matured.³³ In 1994 both J/J and Dr. H. Keith Sigmundson, the psychiatrist in charge of J/J's "local" care, were located and the child's life was reintroduced to the professional literature in 1997.³⁴

Suffice to say, the outcome was not as reported or predicted. At the time the twin was located again, he was a married man, the father of three adopted children. Moreover, his true childhood experiences were not as positive as had been first reported.³⁵

Family members recollected that J/J, while yet quite young, showed extreme male-like behavior and rejection of femaleness. Joan refused "girl" toys, had little interest in girl activities and refused to wear dresses. She preferred to "play army" and often stole her brother's trucks and other toys to play with. In her prepubescent years, Joan "thought [she] was a freak or something" and eventually "figured [she] was a guy" but "didn't want to wind up opening a can of worms."³⁶ She was constantly teased at school because of her "boy looks and her girl clothes" and "contemplated suicide."³⁷ "At age 14 years, she was caught standing to urinate in the girls' bathroom so often that the other girls refused to allow her entrance. . . . Joan would also sometimes go to the boy's lavatory to urinate."³⁸ Throughout all of these years, despite all of the medical and psychiatric contact Joan endured, and despite expressing "strong fears that something [had] been done to her genital organs," no

SEX POLICE, *supra* note 30, at 314–23 (responding to critics, including Milton Diamond); *see also* FAUSTO-STERLING, *supra* note 11, at 69–71.

33. In 1994, co-author of this article, Milton Diamond, located the twin with the assistance of H. Keith Sigmundson, a psychiatrist with the Ministry of Health in Victoria, British Columbia, who had treated J/J under Money's supervision. It took Diamond some dozen years to locate and contact Sigmundson.
34. Although initially reluctant to cooperate with Diamond in following up this case, Sigmundson was finally convinced that to do so was in the greatest interest of medicine. Sigmundson confesses that he knew of Diamond's persistent attempts at contacting him, "but I couldn't bring myself to answer." Colapinto, *The True Story*, *supra* note 11, at 92. He admitted to being "shit-scared of John Money. . . . He was the big guy. The guru. I didn't know what it would do to my career." Colapinto, *The True Story*, *supra* note 11, at 92. J/J now a married man, agreed at Sigmundson's and Diamond's urging to cooperate after he learned of his textbook fame "as a success," in his own effort to stop this form of treatment on others. *See* Colapinto, *The True Story*, *supra* note 11, at 94.
35. *See* Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 300; Colapinto, *The True Story*, *supra* note 11, at 92.
36. Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 299–300.
37. Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 300.
38. Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 300.

one told her the nature of her condition.³⁹ Indeed, they were advised not to do so.⁴⁰

After years of “fruitlessly trying to implement Dr. Money’s plan,” the local psychiatric team had a change of heart.⁴¹ They had noticed Joan’s preference for boy’s activities and refusal to accept female status, including her contemplation of suicide, so they had already discussed among themselves the possibility of accepting Joan’s change back to male. They knew doing so would be against the accepted standard of care within the medical community.⁴²

Joan’s turning point occurred at the age of 14, when she, on her own initiative, began living as a boy, John. John recalls how soon thereafter he finally learned the truth: “In a tearful episode following John’s prodding, his father told him of the history of what had transpired when he was an infant and why. John recalls: ‘All of a sudden everything clicked. For the first time things made sense and I understood who and what I was.’”⁴³

Ultimately, John underwent mastectomies to remove the estrogen-induced breast growth and requested phalloplasty to construct a penis. The orchiectomy (removal of the testicles) in infancy necessitated life-long male hormone replacement.⁴⁴ Following the transition, John’s life dramatically changed although social problems continued:

After the surgical procedures [female to male sex reassignment surgery], John adjusted well. As a boy he was relatively well accepted and popular with boys and girls. At 16 years, to attract girls, John obtained a windowless van with a bed and bar. . . . When occasions for sexual encounters arose, however, he was reluctant to move erotically. When he told 1 girlfriend why he was hesitant, that he was insecure about his penis, she gossiped at school and this hurt John very much. Nevertheless, his peers quickly rallied around him and he was accepted and the girl rejected.⁴⁵

39. Colapinto, *The True Story*, *supra* note 11, at 70.

40. See COLAPINTO, *AS NATURE MADE HIM*, *supra* note 11, at 56.

41. Colapinto, *The True Story*, *supra* note 11, at 72.

42. See COLAPINTO, *AS NATURE MADE HIM*, *supra* note 11, at 178–79.

43. Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 300.

44. See Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 302. The testicles are the prime source of androgens (male hormones). These substances are needed for normal male development and every-day processes.

45. Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 300.

John later married a woman and adopted her three children. He has bonded with them as a father.⁴⁶ "Coitus is occasional with his wife. They mostly pleasure each other with a great deal of physical affection and mutual masturbation. John can have coital orgasm with ejaculation."⁴⁷

Notwithstanding John's present level of social acceptance and success as a male, he is bitter and angry over his treatment and his lost childhood. These dramatic and significant events in John's adolescent and adult life, were not entered into the professional literature and thus did not counter the positive reports of the case nor impact the standard of care as it had developed since the 1960s, until the Diamond and Sigmundson publication in 1997.⁴⁸

II. THE DEVELOPMENT OF A SURGICAL STANDARD OF CARE

Using the situations attendant to the treatment of genital trauma or ambiguities as a model, the following sections explore how standard medical practice sometimes develops from case reports, word-of-mouth and the gradual clinical acceptance of innovative therapy without true scientific scrutiny of its effectiveness. The article then describes how the surgical standard for treatment of these cases moved from innovation to standard practice. Although the long-term results of J/J's surgery would not be known for many years, surgery became accepted treatment as the case was recounted in the literature. The article next explores how medical standards of practice are judged by the law and questions the premises surrounding traditional judicial deference to medical standards of care.

A. Standards Of Care Within The Medical Community

Medical standards of care are always evolving; they are often neither static nor clearly delineated.⁴⁹ Because medical science is

46. See Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 302.

47. Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 301, explaining that while J/J's testicles were removed, he still retains his accessory reproductive glands—Cowper's gland, prostate and seminal vesicles—and these, more than sperm, contribute the bulk of semen).

48. See generally Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11.

49. See generally Mark A. Hall, *The Defensive Effect of Medical Practice Policies in Malpractice Litigation*, 54 LAW & CONTEMP. PROBS. 119, 126–29 (1991).

evolutionary, patients do not receive uniform care. For example, some medical treatment involves experimentation. Medical *experimentation* typically means that physicians treat patients according to a protocol designed to test an hypothesis and to contribute to the body of medical knowledge.⁵⁰ Medical *practice*, on the other hand, involves treatment by accepted therapies, typically considered “interventions that are designed solely to enhance the well-being of an individual patient or client and that have a reasonable expectation of success.”⁵¹

Innovative therapy is neither experimental nor standard practice; it involves treatment that is “‘designed solely to enhance the well-being of an individual patient or client’ but ha[s] not been tested sufficiently to meet the standard of having ‘a reasonable expectation of success.’”⁵² Because innovative therapies are not sufficiently tested, “the potential benefits and risks of innovative therapies are less well known or predictable.”⁵³ Thus, innovative therapies, while formulated with the best interests of the patient in mind, nevertheless expose patients to “a greater likelihood that the balance of benefits and risks may be unfavorable due either to the therapies being ineffective or entailing greater, possibly unknown risks.”⁵⁴ In order to minimize the number of patients exposed to the attendant unknown risks of innovative therapy, “[r]adically new procedures . . . should . . . be made the object of formal research at an early stage in order to determine whether they are safe and effective.”⁵⁵

50. See NATIONAL COMMISSION FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAVIORAL RESEARCH, THE BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH 3 (1979) [hereinafter BELMONT REPORT]. The Belmont Report remains a cornerstone of the National Institutes of Health’s guidelines of human subject research; cf. PROTECTING HUMAN RESEARCH SUBJECTS INSTITUTIONAL REVIEW BOARD GUIDEBOOK xxi–xxiii & Appendix 6 (DHHS 1993) [hereinafter HUMAN RESEARCH SUBJECTS].

51. BELMONT REPORT, *supra* note 50, at 3.

52. Dale H. Cowan, *Innovative Therapy Versus Experimentation*, 21 TORT & INS. L.J. 619, 621 (1986) (quoting NATIONAL COMMISSION, REPORT & RECOMMENDATIONS: RESEARCH INVOLVING CHILDREN (DHEW Pub. No. (OS) 77-0004, 1977)). See also BARRY FURROW ET AL., HEALTH LAW § 6-5, at 386 (1995) (discussing medical innovation); Dieter Giesen, *Civil Liability of Physicians for New Methods of Treatment and Experimentation: A Comparative Examination*, 3 MED. L. REV. 22 (1995).

53. Cowan, *supra* note 52, at 621; see also Giesen, *supra* note 52, at 33.

54. Cowan, *supra* note 52, at 621–22.

55. BELMONT REPORT, *supra* note 50, at 3; see also Giesen, *supra* note 52, at 33. When experimentation follows innovation, institutional review boards provide an early airing and review of ethical issues. No such review occurs when innovative therapy becomes standard in an ad hoc fashion.

Unfortunately, scientific assessment of innovative surgical procedures is not the norm within the practice of medicine.⁵⁶ “[M]ost innovations have become accepted as ‘standard procedures’ without ever having been subjected to the rigorous testing for efficacy of a [randomized controlled trial].”⁵⁷ “[I]f rigorous assessment [of medical

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56. Others have noted this phenomenon with regard to medical practices that become standard before validation. For instance, David H. Spodick, *The Surgical Mystique and the Double Standard*, 85 *AMERICAN HEART JOURNAL* 579–83 (1973), found, after reviewing 70 reports in specialty journals appearing in 1971, only 9 of 16 medical treatment studies were controlled; none of 49 studies of surgical intervention involved a controlled study. Consider the following comment:

There follows a period during which the innovation (having received professional and public support and legitimation through state endorsement and third-party coverage) achieves the privileged status of a “standard procedure.” For a period of time it becomes generally accepted by interested parties as the most appropriate way of proceeding with a particular problem or situation. It is probably incorrect to refer here to the activity as an “innovation” . . . since at this stage it has graduated from being just another promising performance (something new with great potential) to the position of being an established and respected activity. Although there is a bias against reporting unsuccessful or untoward performances, they certainly occur but are usually dismissed as infrequent, the result of having poor material to work with, public misunderstanding, and so forth. So entrenched has the activity become that it takes rare courage for any individual or group even to question its effectiveness or desirability. To do so, as we shall see, is to invite retaliation from professional organization interests, public indignation, and even in rare cases sanctions from the state.

John B. McKinlay, *From “Promising Report” to “Standard Procedure”: Seven Stages in the Career of a Medical Innovation*, 59 *MILBANK MEMORIAL FUND Q.* 374, 387–88 (1981); see also Margaret Lent, Note, *The Medical and Legal Risks of the Electronic Fetal Monitor*, 51 *STAN. L. REV.* 807 (1999). Lent explains that fetal monitoring to avoid hypoxia during delivery became standard care in the 1970s before scientific validation of its efficacy. Over the years, use has expanded beyond high risk deliveries so that this technique is now used for 83% of all American births. See Lent, *supra*, at 812. Now, in twelve randomized control studies, with one exception, none suggest that electronic fetal monitoring decreases fetal mortality. See Lent, *supra*, at 813. Moreover, in one study, the fetal monitored group actually suffered an increase in neurological disorders. See Lent, *supra*, at 814. In sum, overwhelming scientific evidence disputes its efficacy. See Lent, *supra*, at 814–15. Nevertheless, routine fetal monitoring with its attendant increased cost in time and effort remains an entrenched practice in delivery, perhaps out of fear of legal liability for abandoning an established standard, see Lent, *supra*, at 822–23, or “professional inertia.” See Lent, *supra*, at 808.

57. Nancy M.P. King & Gail Henderson, *Treatments of Last Resort: Informed Consent and the Diffusion of New Technology*, 42 *MERCER L. REV.* 1007, 1021 (1991); see also David A. Grimes, *Technology Follies: The Uncritical Acceptance of Medical Innovation*, 269 *JAMA* 3030, 3030 (1993) (“The need for ongoing assessment of both new and

innovations] occurs, it takes place quite late in the 'career' of an innovation, after it has been reported anecdotally, adopted by professionals, medical organizations, public advocates, and third party payers, and accepted as 'standard practice.'"⁵⁸ Commentators note that physicians often display a premature eagerness to adopt innovative therapy before adequate studies are conducted.⁵⁹ In fact, few medical practices have been subjected to randomized clinical trials.⁶⁰ Instead, medical standards often develop in an *ad hoc* fashion, as physicians try new techniques and share early reports of their experiences among their colleagues.⁶¹ Thus, innovative therapy often crosses over to standard therapy through informal acceptance rather than validation and acceptance. Thereafter, clinicians become entrenched in following particular therapies, and become resistant to adopting superior therapies.⁶² Significantly, critics note that there also tends to be reluctance toward publishing reports of unsuccessful procedures or treatments.⁶³

old medical technologies is undisputed. Nevertheless, much, if not most, of contemporary medical practice still lacks a scientific foundation."); Robert L. Kane & Judith Garrard, *Changing Physician Prescribing Practices*, 271 JAMA 393 (1994).

58. King & Henderson, *supra* note 57, at 1013; *see also* McKinlay, *supra* note 56, at 376.
59. *See* McKinlay, *supra* note 56, at 381; *see also* Donald E. Kacmar, *The Impact of Computerized Medical Literature Databases on Medical Malpractice Litigation: Time for Another Helling v. Carey Wake-Up Call?*, 58 OHIO ST. L.J. 617 (1997)
60. *See* King & Henderson, *supra* note 57, at 1021 (citing OFFICE OF TECHNOLOGY ASSESSMENT, THE IMPACT OF RANDOMIZED CLINICAL TRIALS ON HEALTH POLICY AND MEDICAL PRACTICE: BACKGROUND PAPER, 98th Cong., 1st Sess. (1983) (estimating fewer than ten to twenty percent); Grimes, *supra* note 57, at 3030-32 (arguing many contemporary medical practices still lack a scientific foundation); *see also* Lent, *supra* note 56, at 811-13.
61. *See* Grimes, *supra* note 57, at 3031-32; Kacmar, *supra* note 59, at 642 (commenting "doctors tend to look to informal information sources, such as other colleagues, for answers in lieu of looking outside their own medical circles for new studies, data, or procedures"); King & Henderson, *supra* note 56, at 1023 (identifying this phenomenon as part of the conceptual conflict "Is medicine essentially science or essentially treatment?"); McKinlay, *supra* note 56, at 376. *See generally* DAVID L. SACKETT ET AL., EVIDENCE-BASED MEDICINE: HOW TO PRACTICE & TEACH EBM 5-9 (1997) (describing deficiencies in clinical practice).
62. *See* Kacmar, *supra* note 59, at 631-32; Bruce E. Wilson & William G. Reiner, *Management of Intersex: A Shifting Paradigm*, 9 J. CLIN. ETHICS 360, 367 (1998) (commenting, "As with many clinical paradigm shifts, in the absence of data, adherents of each protocol become increasingly dogmatic that their preferred approach is better for the patient, and that it would be unethical to subject the patient to the other 'less acceptable' treatment. Individual clinicians' attachment to specific treatment regimes result in the ongoing polarization of paradigms.").
63. *See* Grimes, *supra* note 57, at 3031 (commenting on resistance to change, "let sleeping dogmas lie"); McKinley, *supra* note 56, at 379.

B. The Surgical Standard in Treatment of Ambiguous Genitalia

Since innovative therapy often becomes standard therapy through informal acceptance and common use,⁶⁴ it should come as no surprise that the practice of recommending early surgical intervention in cases of genital ambiguity became standard prior to rigorous study of treatment outcomes.⁶⁵ The treatment, first promulgated by Money, was based on a nurture theory of development supposedly derived from his analysis of clinical cases of intersexed individuals rather than from experimental investigation. It essentially began when his reports, based on studies of hermaphrodites, implied that it made no difference if such intersexed children were raised as either boys or girls; they would equally adapt to either gender assignment.⁶⁶ The only caveats Money expressed regarding sex reassignment were that it be done as early as possible (preferably before the 18th to 24th months of life), that no ambiguity be allowed in the gender of the child's upbringing and that the infants' genitalia be reconstructed to match the gender of assignment.⁶⁷ Money's theory essentially held that children raised as boys will develop as such and those raised as girls will so develop. Since it would be easier to surgically repair the genitals with female-like anatomy, that should be the preferred method of management.⁶⁸

64. See SACKETT, *supra* note 61, at 5–9.

65. The kinds of surgeries performed on infants with genital anomalies are numerous. Sex reassignment is the most radical, but other surgeries also have erotic and reproductive ramifications. See KESSLER, *supra* note 12, at 40–64 (discussing surgical interventions); MONEY, SEX ERRORS 1994, *supra* note 17, at 52–55 (discussing surgical interventions); Diamond & Sigmundson, *Management of Intersexuality*, *supra* note 11, at 1047–48 (discussing nonsurgical options).

66. See *supra* note 7.

67. See MONEY, MAN & WOMAN, *supra* note 12, at 152–53, 176, 179; see also KESSLER, *supra* note 12, at 14–15; ANNE FAUSTO-STERLING, *supra* note 11, at 45–46, 63. In a 1998 book, Money contends that other researchers early on misstated his contention that sex could be changed up until the age of two; that he had always asserted that “the crucial age is somewhere around eighteen months.” MONEY, SEX POLICE, *supra* note 30, at 313. However, he was less clear in his original writings, “the critical period is reached by about the age of eighteen months. By the age of two and one-half years, gender role is already well established.” MONEY, SEX POLICE, *supra* note 30, at 312 (quoting his work from 1955). He now contends that J/J’s disastrous outcome could be the result of parental delay in surgery until 22 months (among other possibilities). MONEY, SEX POLICE, *supra* note 30, at 319. Money also notes that J/J’s “social reassignment” had occurred at seventeen months. MONEY, SEX POLICE, *supra* note 30, at 315.

68. See Dreger, *supra* note 12, at 29 (noting that it is easier to surgically construct a “functional” vagina than a penis).

The initial reports of the J/J case,⁶⁹ particularly as reported in the 1972 book *Man & Woman, Boy & Girl*,⁷⁰ and the treatment's purported success spread rapidly and were frequently recounted in the professional literature.⁷¹ The theory that an infant's sex could be successfully reasigned thus profoundly influenced the standard of care for infants born with ambiguous genitalia or a micropenis and those whose penis was lost through trauma or accidental amputation.⁷²

Cases of infants born with ambiguous genitalia are not common but neither are they rare.⁷³ Of the 3 to 4 million children born annually in the United States, approximately 1 in 2000 are born with ambiguous external genitalia (thus approximately 1,500 to 2,000 such children yearly).⁷⁴ An estimated 100-200 pediatric surgical sex reassignments are performed in the United States annually.

As the J/J case originally disseminated into literature, the prevailing treatment view became that when amputation or birth defects result in ambiguous genitalia, or genitalia are seemingly incompatible with male

69. Although some sex reassignment surgery had occurred previously, the J/J case might be considered the "ground zero" case for justifying this standard of care.

70. MONEY & EHRHARDT, *MAN & WOMAN*, *supra* note 12.

71. See, e.g., KESSLER, *supra* note 12, at 6-7, 13-14:

According to all of the specialists interviewed, management of intersexed cases is based upon the theory of gender proposed first by John Money, J.G. Hampson, and J.L. Hampson in 1955 and developed in 1972 by Money and Anke A. Ehrhardt that "gender identity is changeable until approximately eighteen months of age.

72. See generally ALICE DOMURAT DREGER, *HERMAPHRODITES AND THE MEDICAL INVENTION OF SEX* 181-82 (1998); KESSLER, *supra* note 12, at 6; Dreger, *supra* note 12, at 27.

73. Traumatic injury, especially to male infants, although less common than intersex births, occurs with sufficient frequency to appear in the literature as well. See *supra* note 13.

74. No definitive statistics exist. Kipnis & Diamond, *Pediatric Ethics*, *supra* note 11, at 401 (citing estimates of one in 2000; Dreger, *supra* note 12, at 26, reports of estimates of 1 in 500, 1 in 1,500, and an even larger group of children with "cosmetically 'unacceptable' genitalia" possibly subjected to repair in infancy. Kessler notes and discusses the difficulty in determining the number of infants with intersex conditions and genitalia anomalies. See KESSLER, *supra* note 12, at 135 n. 4. Fausto-Sterling has recently estimated 1.7 in 100 births are intersex, by reviewing literature reporting incidence by category. See FAUSTO-STERLING, *supra* note 11, at 51-52.

J/J's unusual case of genital trauma is also not alone in medical literature. In another case study not lost to follow-up, a child lost his penis through trauma. The child underwent sex reassignment but "in adolescence the patient refused to continue hormonal medication and requested sex reassignment as a boy." Ochoa, *supra* note 13, at 1116. See also Geoffrey Cowley, *Gender Limbo*, *NEWSWEEK*, May 19, 1997, at 64 (reporting biographies and discussing changing standard of care).

sexual functioning (standing to urinate as a child and adolescent and inserting a penis into a vagina as an adult), such males were better off undergoing sex reassignment to assure satisfactory adult sexual function as a female.⁷⁵ Incorporating the theory that individuals are psychosexually neutral and would accept their gender of rearing, this proposal offered a relatively simple solution to what was seen as a difficult situation.⁷⁶ This view came to dominate pediatric and social science literature.⁷⁷ Since then medical wisdom in these cases has remained largely based on hypothetical “surgical potentials” rather than on data from studies or even the long-term outcome of these surgeries.⁷⁸ Importantly, those recommending a surgical standard have not been entirely clear whether childhood acceptance or adult comfort with gender is a paramount goal.⁷⁹

Surgical intervention became standard practice to the extent that, as recently as 1996, the American Academy of Pediatrics published these guidelines:

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75. Dreger explains why males were surgically turned into females whereas females were left as females:

[C]linicians treating intersex children often talk about vaginas in these children as the absence of a thing, as a space, a “hole,” a place to put something. That is precisely why opinion holds that “a functional vagina can be constructed in virtually everyone”—because it is relatively easy to construct an insensitive hole surgically.

- Dreger, *supra* note 12, at 29; see also Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 298 (citing medical literature). While there was no evidence that the constructed female genitalia would be a better substitute, the simplistic thinking at that time, was that to be a satisfactory sexually functioning woman meant only to have a female appearing pudenda and a vagina suitable to accept a penis.
76. See Wilson & Reiner, *supra* note 62, at 362–63 (describing the treatment protocol of early surgery).
77. See KESSLER, *supra* note 12, at 136 n. 10; KING, *supra* note 12, at 369–70 (reporting prevailing view, “Up to approximately 18 months of age, sexual identity is not established and gender reassignment may be well tolerated by the child”); Diamond & Sigmundson, *Sex Reassignment*, *supra* note 12, at 298 (citing medical texts); Kitzinger, *supra* note 15. See e.g., Donahoe, *supra* note 12, at 527; *Timing of Elective Surgery*, *supra* note 12; Woodhouse, *supra* note 12, at 689–90 (reporting on prevailing view to reassign gender in cases of micropenis of less than 2 cm).
78. KESSLER, *supra* note 12, 12–15 n.10, 14; Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 298; Dreger, *supra* note 12, at 27; Wilson & Reiner, *supra* note 62, at 367. See also Diamond & Sigmundson, *Management of Intersexuality*, *supra* note 11, at 1025 (calling for review of sex reassignments done over the past decades).
79. See Milton Diamond, *Intersexuality: Recommendations for Management*, 27 ARCHIVES SEXUAL BEHAVIOR 634, 638 (1998).

Research on children with ambiguous genitalia has shown that sexual identity is a function of social learning through differential responses of multiple individuals in the environment. For example, children whose genetic sexes are not clearly reflected in external genitalia (i.e., hermaphroditism) can be raised successfully as members of either sex if the process begins before the age of 2 1/2 years. Therefore, a person's sexual body image is largely a function of socialization.⁸⁰

Remarkably, the only references to support this proposition were to the decade-old or older works of John Money; no other corroborating work was cited.⁸¹

Not all neonatal surgical interventions for infants born with ambiguous genitalia involve sex reassignment.⁸² The surgical alteration of

80. Timing of Elective Surgery, *supra* note 12, at 590 (supporting this proposition with works authored or co-authored by Money and dating between 1957 and 1987: John Money et al., *Imprinting and the Establishment of Gender Role*, 77 ARCH. NEUROL. PSYCH. 333–336 (1957)); MONEY & EHRHARDT, *MAN AND WOMAN*, *supra* note 12; John Money & B.F. Norman, *Gender Identity and Gender Transposition: Longitudinal Outcome Study of 24 Male Hermaphrodites Assigned As Boys*, 13 J. SEX MARITAL THERAPY 75–92 (1987)).

81. Suzanne Kessler has written of Money's dominance in the field:

Almost all of the published literature on intersexed infant case management has been written or cowritten by one researcher, John Money Even the publications that are produced independently of Money reference him and reiterate his management philosophy. . . . Even though psychologists fiercely argue issues of gender identity and gender role development, doctors who treat intersexed infants seem untouched by these debates Why Money has been so single-handedly influential in promoting his ideas about gender is a question worthy of a separate substantial analysis.

KESSLER, *supra* note 12, at 136 n. 10; *see also* DREGER, *supra* note 72, at 181–82 (describing dominance of Money in developing the standards of care for intersex infants); FAUSTO-STERLING, *supra* note 11, at 67–68; Diamond & Sigmundson, *Sex Reassignment*, *supra* note 8, at 298 (describing Money's dominance); Kitzinger, *supra* note 15, at 1 (discussing Money's dominance).

Money's views have changed somewhat, although he generally still approves sex reassignment even in cases of traumatic amputation of the penis. *See* MONEY, *SEX ERRORS* 1994, *supra* note 17, at 84 (writing of total loss of penis: "All in all, it is a difficult situation, regardless of the sex of rearing[.]" and on reassignment generally: "the most expeditious rule to follow is that no child, after the toddler age, should have a sex reassignment imposed on the basis of a [physician imposed] dogmatically held principle.").

82. *See* William Reiner, *Sex Assignment in the Neonate With Intersex or Inadequate Genitalia*, AM. J. OF DISEASES OF CHILDREN 1044, Oct. 1999, at *2 available in WL Database AMA-JNLS [hereinafter Reiner, *Sex Assignment*] (discussing problem that children will reject the sex of rearing and commenting "surgical reduction of anen-

any female born with a clitoris larger than one centimeter is also recommended.⁸³ In keeping with the psychosexual neutrality-at-birth theory which says acceptance of the gender of rearing is contingent on having gender congruent genitalia, an enlarged clitoris was seen as needing reduction or removal to prevent psychosexual ambiguity and to promote parental bonding and affection.⁸⁴ Importantly, the efficacy of even these more modest surgical interventions to normalize genitalia has not been assessed by long-term study, and for similar reasons these interventions deserve the same scrutiny as sex reassignment.⁸⁵

larged [sic] clitoris can at times damage sensation and thus reduce orgasmic potential and genital pleasure and, like ablation of the testes, is irreversible.”); Dreger, *supra* note 12, at 28.

83. See e.g., Ian A. Aaronson, *Sexual Differentiation and Intersexuality*, in *CLINICAL PEDIATRIC UROLOGY* 977, 1005, 1007 (P. Kelalis et al. eds., 1992); KESSLER, *supra* note 12, at 43; Alice Domurat Dreger, *A History of Intersexuality: From the Age of Gonads to the Age of Consent*, 9 *J. CLINICAL ETHICS* 345, 349 (1998) [hereinafter Dreger, *History*](commenting on standard care for clitoral surgery, “If her clitoris is longer than 1 centimeter stretched at birth, surgeons will seek to surgically reduce it because they think it will bother the child’s parents and interfere with bonding and gender identity formation.”).
84. See KESSLER, *supra* note 12, at 52–64; Sherri A. Groveman, *The Hanukkah Bush: Ethical Implications in the Clinical Management of Intersex*, 9 *J. CLINICAL ETHICS* 356, 357–59 (1998); Wilson & Reiner, *supra* note 62, at 363; Nussbaum, *supra* note 12, at 93; see also MONEY & EHRHARDT, *MAN & WOMAN*, *supra* note 12, at 152; MONEY, *SEX ERRORS* 1994, *supra* note 17, at 82–83. There is no evidence that parents of children born with physical handicaps are any less bonded or otherwise protective or loving to their children. See KESSLER, *supra* note 12, at 91–94. Kessler, on the other hand, presents cases where the parents accept the intersex condition if it is presented well or have severe misgivings for giving in to the physicians’ urging for surgery. See KESSLER, *supra* note 12, at 91–94. There also are studies that show that children might be aware of the appearance of their own or peers’ genitals but don’t consider them crucial for classification of gender until about the age of 9. See RONALD GOLDMAN & JULIETTE GOLDMAN, *CHILDREN’S SEXUAL THINKING: A COMPARATIVE STUDY OF CHILDREN AGED 5 TO 15 YEARS IN AUSTRALIA, NORTH AMERICA, BRITAIN, AND SWEDEN* 192–215, 385 (1982).
85. See Diamond & Sigmundson, *Management of Intersexuality*, *supra* note 11, at 1046–1049; Dreger, *supra* note 12, at 32 (noting a lack of long-term follow-up on females undergoing clitoral surgery); Reiner, *Sex Assignment*, *supra* note 82; Cowley, *supra* note 74, at 66 (reporting on study of female pseudohermaphrodites (genetic females born with masculinized external sex organs) wherein five of twelve surgically reduced clitorises “had withered and died” as a result of surgical intervention). Annie Green, writes: “Thirty-two years have passed since my clitoris was taken from me. Though I was too young to be able now to recall the event, I feel that I will be grieving the loss for the rest of my life.” Annie Green, *My Beautiful Clitoris*, *CHRYSALIS*, Fall 1997/Winter 1998, at 12. Cheryl Chase, an advocate for the intersexed, warns that better clitoral surgery is not the proper response to an enlarged phallus. See Cheryl Chase, *Surgical Progress Is Not the Answer to Intersexuality*, 9 *J. CLINICAL ETHICS* 385, 386–87 (1998) [hereinafter Chase, *Surgical Progress*]. Physicians practicing today ac-

Unfortunately, like the practice of female genital alteration ("mutilation") for cultural reasons,⁸⁶ these surgical interventions can reduce or destroy the girl's potential for sexual satisfaction in adulthood and limit later surgical alternatives should the male gender preference manifest itself at adolescence.⁸⁷ Interestingly, the effect of the 1996 Criminalization of Female Genital Mutilation Act,⁸⁸ on medical treatment of infant females with enlarged clitoridies is unknown. While Congress intended the act to curb the cultural practices of "members of certain cultural and religious groups within the United States,"⁸⁹ it broadly bars circumcision, excision and infibulation of "the

knowledge that the techniques of clitoral surgery from just a decade ago yielded poor results. The comments of Associate Professor of Urology and Pediatrics Laurence Baskin in response to a visit by ISNA members to the University of California, San Francisco medical school are revealing: "Baskin admits that surgical technique in the past was not optimal. 'The surgery was done . . . by very well intended physicians, but we didn't understand the nerve supply well. We started to understand the nerve supply [to the clitoris] 10 years ago.'" Althaea Yronwode, *Intersex Individuals Dispute Wisdom of Surgery on Infants*, SYNAPSE, Mar. 11, 1999, available at <<http://itsa.ucsf.edu/~synapse/archives/mar11.99/yronwode.html>>.

Although more cautious in light of the J/J case, Kenneth Glassberg continues to perform surgery, including female gender reassignment and clitoral surgery. See Kenneth Glassberg, *Editorial: Gender Assignment and the Pediatric Urologist*, 161 J. UROLOGY 1308, 1308-09 (1999); see also Kenneth Glassberg, *The Intersex Infant: Early Gender Assignment and Surgical Reconstruction*, 11 J. PEDIATRIC & ADOLESCENT GYNECOLOGY 151, 153 (1998).

86. See generally Joleen C. Lenihan, *A Physician's Dilemma, Legal Ramifications of an Unorthodox Surgery*, 35 SANTA CLARA L. REV. 953 (1995); Joanne A. Liu, *When Law and Culture Clash: Female Genital Mutilation, A Traditional Practice Gaining Recognition as a Global Concern*, 11 N.Y. INT'L. L. REV. 71 (1998). Both Kessler and Dreger liken the surgical treatment of ambiguous genitalia for cosmetic and cultural reasons to female genital mutilation. See KESSLER, *supra* note 12, at 80-83; Dreger, *supra* note 12, at 33-34.
87. See Chase, *Surgical Progress*, *supra* note 85, at 386; Milton Diamond, *Pediatric Management of Ambiguous Genitalia and Traumatized Genitalia*, 162 J. UROLOGY 1021, 1024 (1999) [hereinafter Diamond, *Pediatric Management*]; Kipnis & Diamond, *Pediatric Ethics*, *supra* note 11, at 402-03. Meyer-Bahlburg has written:

Some female-assigned patients with a history of clitoromegaly will end up changing their gender to male, and in those cases, a history of clitorectomy or clitoral resection with the reduction loss of a penile organ altogether causes great regret. In my clinical experience, also some patients who live as lesbian women would prefer if their enlarged clitoris had been left intact.

Heino F.L. Meyer-Bahlburg, *Gender Assignment in Intersexuality*, 10(2) J. PSYCH. & HUMAN SEXUALITY 12 (1998) (internal citation omitted).

88. See Criminalization of Female Genital Mutilation Act, 18 U.S.C. § 116 (Supp. III 1998).
89. Congressional Findings, Criminalization of Female Genital Mutilation Act, Pub. L. No. 104-208, § 645(a)(1), 110 Stat. 3009-708 (1997).

whole or any part of the labia majora or labia minora or clitoris of another person who has not attained the age of 18 years"⁹⁰ unless it is "necessary to the health of the person on whom it is performed."⁹¹ It remains to be seen whether a court might view surgical treatment to achieve normally-appearing female genitalia as necessary to the health of infants.⁹²

Although surgical intervention became "standard care" for intersex infants, rather than considering it a proven treatment protocol, it would have been more appropriate to characterize it as "innovative" therapy all along, because the treatments have not been adequately grounded in long-term studies.⁹³ To this day, the recommended surgical management practices for ambiguous genitalia that have been promoted by the American Academy of Pediatrics,⁹⁴ remain unsupported by long-term study.⁹⁵ The appropriateness of early surgical intervention was never

90. 18 U.S.C. § 116 (a) (Supp. III 1998).

91. 18 U.S.C. § 116 (b)(1) (Supp. III 1998). See KESSLER, *supra* note 12, at 81–82 (commenting on ISNA position that the language is sufficiently broad to cover some intersex surgeries); Dreger, *supra* note 12, at 34. Some suggest that the act violates equal protection law because it protects females but not males from the customary practice of circumcision. See Ross Povenmire, *Do Parents Have the Legal Authority to Consent to the Surgical Amputation of Normal, Healthy Tissue from Their Infant Children?: The Practice of Circumcision in the United States*, 7 AM. U. J. GENDER SOC. POL'Y 87, 119–22 (1999).

92. Several rulings against genital cosmetic infant surgery have been issued in Bogota, Colombia. In 1999, the Constitutional Court of Colombia, its high court, issued two precedential decisions barring intersex surgery. These cases involved reducing the size of the clitoris and vaginoplasty. Prior to deciding the cases, the court sought comments from the Intersex Society of North America and others, including John Money and Milton Diamond. The court ruled the surgery cosmetic and unnecessary and held that surgical intervention should be postponed until the child is able to consent. Moreover, it ruled that intersex individuals are a protected minority. (SU-337/99, May 12 1999 and T-551/99, Aug 2, 1999). In 1995, the Colombia high court barred sex reassignment of a young male who had lost his penis in a traumatic accident (T-477/95). The cases are summarized at <<http://www.isna.org/colombia/>>.

93. For elaboration on the distinctions between innovation, practice and experimentation, see THE BELMONT REPORT, *supra* note 50, at 3; Cowen, *supra* note 52; King & Henderson, *supra* note 57; Karine Morin, *The Standard of Disclosure in Human Subject Experimentation*, 19 J. LEGAL MED. 157, 165–68 (1998).

94. See *Timing of Elective Surgery*, *supra* note 12.

95. See Cowley, *supra* note 74, at 66 (noting scarcity of both medical and psychological studies); Diamond, *Pediatric Management*, *supra* note 87, at 1026; Diamond & Sigmondson, *Sex Reassignment*, *supra* note 8, at 303 (noting lack of validating studies and need for long-term follow-up); Kipnis & Diamond, *Pediatric Ethics*, *supra* note 11, at 406; Nussbaum, *supra* note 12, at 99; Ochoa, *supra* note 13, at 1119 (calling for more study); William Reiner, *To Be Male or Female—That is the Question*, 151 ARCHIVES OF PEDIATRIC MEDICINE 224, 224 (1997) [hereinafter Reiner, *To Be Male*

well supported by scientific investigation, and, in fact, some of the recent research refutes its efficacy.⁹⁶ While J/J's case may have initially suggested a positive outcome was possible, the true test of the treatment's success could not be known until the patient reached adulthood.⁹⁷

Since the latest reports on J/J's case were revealed in 1997, the medical community has itself divided on this issue.⁹⁸ Critics of the traditional standard of care challenge the premises that purportedly supported surgical intervention. First, they argue that there is no established body of evidence that normal infants are born sexually neutral. The original beliefs were predicated on reports of hermaphrodites, not average males and females.⁹⁹ These reports were issued by a single investigator.¹⁰⁰ In particular, critics note that the last decade has produced genetic, neurological and biological studies that support a premise that

or Female] (calling for more research and cautioning, "It may well be that conclusions about sex reassignment as described in much of the literature are erroneous secondary to the conspicuous lack of such longitudinal data and appropriate longitudinal analysis."); Justine Marut Schober, *A Surgeon's Response to the Intersex Controversy*, 9 J. CLIN. ETHICS 393, 394 (1998) (noting lack of long-term studies regarding psychological adjustment); Wilson & Reiner, *supra* note 62, at 367; Woodhouse, *supra* note 12, at 692 (questioning wisdom of sex reassignment surgery in children with micro-penis and lack of long-term study).

96. See Ochoa, *supra* note 13, at 1119; William G. Reiner, *Androgen Exposure in Utero and the Development of Male Gender Identity in Genetic Males Reassigned at Birth*, presented at International Behavioral Development Symposium 2000, May 25–27, 2000 (reporting that 17 of 23 genetic males reassigned as females spontaneously declared male gender identity between ages 5 and 17). William George Reiner, *Case Study: Sex Reassignment in a Teenage Girl*, 35 J. AM. ACAD. CHILD & ADOLESCENT PSYCH. 799, 801–03 (1996) [hereinafter Reiner, *Teenage Girl*]; Reiner, *Sex Assignment*, *supra* note 82, at *1 (noting his own studies with "18 children who are 46, XY males with totally inadequate [sic] phalluses but normal testes, sex reassigned to female, demonstrates that parents tend to be uncomfortable with sex reassignment and that the children do not behave as typical little girls."); Reiner, *To Be Male or Female*, *supra* note 95, at 225; Woodhouse, *supra* note 12, at 692.
97. See Diamond & Sigmundson, *Sex Reassignment* *supra* note 8, at 302 (noting "[c]ases of infant sex reassignment require inspection and review after puberty; 5- and 10-year postsex reassignment follow-ups are still insufficient.>").
98. The medical community has become polarized on treatment issues. The Journal of Clinical Ethics's symposium issue on intersexuality reported, "The parties in this discussion have become increasingly estranged. Alice Domurat Dreger, guest editor of this special issue . . . informs us that she invited some of those who have acted as proponents of infant surgery to present their arguments, but none accepted." Edmund G. Howe, *Intersexuality: What Should Careproviders Do Now*, 9 J. CLIN. ETHICS 337, 338 (1998). See also Wilson & Reiner, *supra* note 62, at 367.
99. See *supra* note 7.
100. See Kitzinger, *supra* note 15, at 6–7, 13–14.

humans are, in keeping with their mammalian heritage, predisposed and biased to interact with environmental, familial and social forces in either a male or female mode.¹⁰¹

Second, critics point to evidence that persons born with genitalia that fall outside our normal expectations can achieve a satisfying psychosexual adjustment without surgical intervention¹⁰² and argue that the imperative to create typical genitalia is of overrated significance.¹⁰³ Notably, recent case studies of young males suffering accidental, traumatic loss of the penis (such as J/J's) suggest reattachment or surgical recon-

101. Wilson and Reiner note that there is "considerable support for the theory that there may be a neurobiologic component to many gender identities" and that gender may be influenced by hormone levels in the brain "prenatally or immediately postnatally" and conclude, "[c]ertainly gender development involves more than the behaviors of the parents in rearing the child." Wilson & Reiner, *supra* note 62, at 364. See generally Milton Diamond, *Biological Aspects of Sexual Orientation and Identity*, in *THE PSYCHOLOGY OF SEXUAL ORIENTATION, BEHAVIOR AND IDENTITY: A HANDBOOK* (L. Diamant & R. McAnulty eds., 1995); DEAN HAMER & PETER COPELAND, *LIVING WITH OUR GENES: WHY THEY MATTER MORE THAN YOU THINK* (1998); Simon LeVay & Dean H. Hamer, *Evidence for a Biological Influence in Male Homosexuality*, *SCIENTIFIC AMERICAN*, May 1994, at 44.

102. Diamond and Sigmundson explain:

Most intersex conditions can remain without any surgery at all. A woman with a phallus can enjoy her hypertrophied clitoris and so can her partner. Women with AIS [androgen insensitivity syndrome] or virilizing CAH [congenital adrenal hyperplasia] who have smaller-than-usual vaginas can be advised to use pressure dilation to fashion one to facilitate coitus; a woman with partial AIS likewise can enjoy a large clitoris. A male with hypospadias might have to sit to urinate without mishap but can function sexually without surgery. A person with a micropenis can satisfy a partner and father children.

Diamond & Sigmundson, *Management of Intersexuality*, *supra* note 11, at 1049; see also Dreger, *supra* note 12, at 29–32.

103. See KESSLER, *supra* note 12, at 105–32; Dreger, *supra* note 12, at 33.

It was, unfortunately, only recently revealed that a study of more than 250 intersexed individuals who received no surgical intervention as babies was conducted prior to 1952 but left unpublished in the professional literature. The review by John Money found: "Far from manifesting psychological traumas and mental illnesses, the study showed, the majority of patients rose above their genital handicap and not only made an 'adequate adjustment' to life, but lived in a way virtually indistinguishable from people without genital difference." COLAPINTO, *AS NATURE MADE HIM*, *supra* note 11, at 233. One can only conjecture as to why this study was never mentioned nor considered by its author after its presentation as a senior dissertation at Harvard (available by written application to the Widener Library at Harvard University). See COLAPINTO, *AS NATURE MADE HIM*, *supra* note 11, at 235.

struction of the penis will yield better psychosexual results than sex reassignment.¹⁰⁴

Third, critics point to transsexuality, a condition in which individuals develop a sexual identity at odds with both their normal genitals and socially- and sexually-appropriate rearing.¹⁰⁵ The lives and comments of such individuals provide evidence that sexual identity is not solely linked to either the physical appearance of the genitalia or the socialization occurring in child rearing.¹⁰⁶ If the normal appearance of the genitals and unequivocal rearing are determinant, then there could be no explanation for incidences of transsexuality.

Finally, critics remind those who adhere to the surgical standard that, "after some three decades of these surgeries, there is still *not a single report of a nonintersexual boy having been successfully raised as a contented androphilic woman.*"¹⁰⁷

Another important new factor prompting reevaluation of the surgical standard is the emergence of criticism by former patients. Many of the individuals who have been subjected to sex reassignment or clitoral surgery are calling for an end to such practices.¹⁰⁸ The Intersex Society

104. Ochoa, *supra* note 13, at 1119; *see also* Judson J. Van Wyk, *Editorial, Should boys with micropenis be reared as girls?*, 134 J. PEDIATRICS 537, 538 (1999) (noting lack of study and stating that "micropenis by itself should not provide sufficient grounds to justify a female gender assignment"); Bassam Bin-Abbas et. al, *Congenital hypogonadotropic hypogonadism and micropenis: Effect of testosterone treatment on adult penile size—Why sex reversal is not indicated*, 134 J. PEDIATRICS 579, 582 (1999) (concluding that there is "no clinical, physiologic, or psychologic grounds to support the gender reversal of male infants with androgen-responsive micropenis").

105. *See* Diamond, *Pediatric Management, supra* note 87, at 1022.

106. *See generally* W.O BOCKTING & ELI COLEMAN, *GENDER DYSPHORIA: INTERDISCIPLINARY APPROACHES IN CLINICAL MANAGEMENT* (1992); *GENDER BLENDING* (Bonnie Bullough et al. eds, 1997); HOLLY DEVOR, *GENDER BLENDING: CONFRONTING THE LIMITS OF DUALITY* (1989).

107. *See* Diamond, *Pediatric Management, supra* note 87, at 1023. *See also* Reiner, *To Be Male or Female, supra* note 95, at 225 (reporting on his ongoing research and stating that he is following fifteen 46 XY children who were castrated at birth due to genital anomalies, stating that although reared as females the patients "do not appear to be classically male or female but display masculine characteristics that are in many cases quite striking"). A recent article reports of one individual who was sex reassigned and, at the age of 28, remains living as a woman. She, however, has a male-identified job and is ambisexually oriented. She is presently living with a female sexual partner. *See* Susan J. Bradley et al., *Experiment of Nurture: Ablatio Penis at 2 Months, Sex Reassignment at 7 Months Psychosexual Follow-up in Young Adulthood*, 102 PEDIATRICS 1 (1998) (full text also available at <<http://www.pediatrics.org/cgi/content/full/102/1/e9>>).

108. Reports of adverse outcomes have been met with ambivalence in the medical community. As psychiatrist and attorney Edmond Howe writes,

of North America, founded in 1993 and operated by intersexuals, has issued recommendations that call for avoiding unnecessary infant surgery and postponing irreparable surgical interventions.¹⁰⁹ They challenge the efficacy of surgery, pointing to their own cases as evidence.¹¹⁰

Nevertheless, some clinicians continue to evaluate male infants for sex reassignment based on the size or functionality of the penis and females for surgical alteration based upon clitoris size and they continue to perform surgical procedures to alter genitalia which forecloses later choices for patients.¹¹¹ So great is the fear of psychosexual maladjustment,¹¹² proponents of surgery continue to identify phallus size as a key

More recently, surgeons have been criticized because they have not accorded enough weight to patients' reports of adverse outcomes. There is a psychological reason that careproviders may ignore reports of adverse outcomes: if the claims are true, surgeons would have to acknowledge that performing surgery was a mistake. This would be exceedingly painful. The only way to avoid this pain would be to deny that these claims are true.

Howe, *supra* note 98, at 338; *see also* Nussbaum, *supra* note 12, at 94.

109. ISNA, Recommendations for Treatment Intersex Infants and Children, <<http://www.isna.org/recommendations.html>> [hereinafter "ISNA Recommendations"]. Money reserves particularly harsh criticism for ISNA, labeling the organization's policy as "militantly activist" in advocating raising the intersex child as an "it," which he regards as a step backward. MONEY, SEX POLICE, *supra* note 30, at 320-21. Money misstates ISNA's position. ISNA has never advocated raising children as "its." They advocate sexual assignment but without any surgery. *See* ISNA Recommendations, *supra*. Diamond also advocates raising the child in a clear gender but without cosmetic genital altering surgery. *See* Diamond, *Pediatric Management*, *supra* note 87, at 1025. Kenneth Glassberg, on the other hand, argues "[T]here are no data to support the benefits of delayed assignment or treatment of these infants and I cannot imagine any parent, without whose wholehearted cooperation any treatment program will fail, accepting such an approach." Glassberg, Editorial, *supra* note 85.
110. *See, e.g.*, Chase, *supra* note 85, at 385; Groveman, *supra* note 84, at 356.
111. *See* Diamond & Sigmundson, *supra* note 11, at 298 (discussing and citing medical literature recommending sex reassignment based on surgical potential); Nussbaum, *supra* note 12, at 93-94 (noting that treatment remains essentially unchanged with exception of a minority of physicians and recent critical publications); *see also* FAUSTO-STERLING, *supra* note 11, at 56-58; KESSLER, *supra* note 12, at 108-109 (discussing criteria for surgery in females and males); Donahoe, *supra* note 12, at 527 (commenting, "[g]enetic females should always be raised as females, preserving reproductive potential, regardless of how severely the patients are virilized. In the genetic male, however, the gender of assignment is based on the infant's anatomy, predominantly the size of the phallus."); Newman et al., *supra* note 12, at 645 (commenting, "In practical terms, regardless of the genotype, most children with ambiguous genitalia are best suited for the female role.>").
112. *See* KESSLER, *supra* note 12, at 34-35; MONEY & EHRHARDT, MAN & WOMAN, *supra* note 12, at 178-79; MONEY, SEX ERRORS 1994, *supra* note 17, at 82.

determinant of whether a genetic male should be surgically reassigned,¹¹³ even over male reproductive capacity.¹¹⁴ As Money explained for infants, “‘Too small now, too small later’ is a useful working rule with regard to construction or reconstruction of a penis.”¹¹⁵

C. Standard Care and Malpractice Claims

In medical malpractice cases, courts often hold physicians to a standard of care that differs from ordinary principles of negligence.¹¹⁶ In general negligence law, a jury’s view of “reasonable prudence” can prevail over a deficient standard of care in a particular profession or industry.¹¹⁷ As Judge Learned Hand explained,

in most cases reasonable prudence is in fact common prudence; but strictly it is never its measure; a whole calling may have unduly lagged in the adoption of new and available devices. It never may set its own tests, however persuasive be its usage’s. Courts must in the end say what is required; there are precautions so imperative that even their universal disregard will not excuse their omission.¹¹⁸

While “[w]hat usually is done may be evidence of what ought to be done,”¹¹⁹ Judge Hand reminds us that no profession is so collectively infallible that custom alone should establish reasonable prudence in every instance.¹²⁰

113. See, e.g., Donahoe, *supra* note 12, at 527 (“[I]t cannot be overly stressed that the 46, XY [genetic male] karyotype does not dictate rearing the child as a male if the phallus is inadequate in size. . . . If the phallus length is less than 2.0 cm and certainly less than 1.5 cm, we are quite concerned.”); King, *supra* note 12, at 369; Grumbach & Conte, *supra* note 2, at 1400–1404.

114. Some but not all intersex and ambiguous conditions impact reproductive capacity. Standard care encourages preservation of female reproductive capacity but decisions as to males is based on penis size, not reproductive capacity. See Donahoe, *supra* note 12, at 527.

115. MONEY, SEX ERRORS 1994, *supra* note 17, at 66.

116. See generally FURROW, *supra* note 52, at § 6-2, at 361; Sam A. McConkey, *Simplifying the Law in Medical Malpractice: The Use of Practice Guidelines as the Standard of Care in Medical Malpractice Litigation*, 97 W. VA. L. REV. 491, 496–97 (1995).

117. See *The T. J. Hooper*, 60 F.2d 737 (2d Cir. 1932).

118. See *T.J. Hooper*, 60 F.2d, at 739.

119. *Texas Pac. Ry. v. Behymer*, 189 U.S. 468, 470 (1903).

120. See *T.J. Hooper*, 60 F.2d at 739.

However, the prevailing view is that “[t]he law generally permits the medical profession to establish its own standard of care.”¹²¹ A physician must exercise “the degree of knowledge, skill, and care used by other physicians practicing the same specialty.”¹²² “[A] physician is negligent when the physician does an act which a reasonably careful physician would not do or fails to do an act which a reasonably careful physician would do.”¹²³ Physicians are not guarantors of positive outcomes, absent their own express promises;¹²⁴ there is “no presumption of malpractice from the mere fact of injury.”¹²⁵

Allowing the medical community to abide by its own established standard of care means that when the profession “unduly lags” or adopts a negligent standard of professional care, tort law’s deference to those standards will preclude liability.¹²⁶ Ordinarily, expert testimony is essential to establish the medical standard of care and a jury is seldom allowed to substitute its own evaluation of the reasonableness of that standard.¹²⁷

There are a few notable cases rejecting this extraordinary deference to an unassailable medical-community-based standard, most notably, *Helling v. Carey*.¹²⁸ In *Helling*, a 32 year old plaintiff suffered vision loss as a result of glaucoma.¹²⁹ The plaintiff asserted that the ophthalmologist was negligent for not conducting glaucoma screening. At the time

121. *Toth v. Community Hosp. at Glen Cove*, 239 N.E.2d 368, 372 (N.Y. 1968); see also FURROW, *supra* note 52, at 359–62.

122. *Gorab v. Zook*, 943 P.2d 423, 427 (Colo. 1997) (en banc).

123. *Gorab*, 943 P.2d at 427 (quoting Colorado Jury Instruction 15:2).

124. See *Turner v. Children’s Hosp., Inc.*, 602 N.E.2d 423, 427 (Ohio Ct. App. 1991).

125. *Turner*, 602 N.E.2d at 427.

126. See *Harris v. Groth*, 663 P.2d 113, 115 (Wash. 1983) (en banc) (discussing deference); see generally Hall, *supra* note 49, at 126–27 (noting distinction between “garden-variety tort cases” where jury is “ultimate arbiter” and medical malpractice where “jurors are instructed to judge physicians not by the jury’s sense of what is right, but by the custom that prevails in the profession”); Gary T. Schwartz, *Medical Malpractice, Tort, Contract, and Managed Care*, 1998 U. ILL. L. REV. 885, 890.

The existence of a uniform standard of care is probably more of a legal fiction than medical profession fact. See Hall, *supra* note 49, at 121 n.10, 128–30 n. 38 (commenting “the law has always presumed the existence of that which does not exist—established, concrete professional standards”).

127. See *Craft v. Peebles*, 893 P.2d 138, 149 (Haw. 1995) (“It is well settled that in medical malpractice actions, the question of negligence must be decided by reference to relevant standards of care for which plaintiff carries the burden of proving through expert testimony”). See also FURROW, *supra* note 52, at 361 (commenting that “[t]he standards for evaluating the delivery of professional medical services are not normally established by either judge or jury”).

128. 519 P.2d 981, 983 (Wash. 1974).

129. See *Helling*, 519 P.2d at 982.

the plaintiff suffered injury, the standard practice was to test persons over the age of 40 because incidence of glaucoma increased with age and was uncommon in younger persons.¹³⁰ However, glaucoma testing was also inexpensive, simple and posed no appreciable harm to patients.¹³¹ Relying on Judge Learned Hand's formulation of reasonable care, the Washington Supreme Court held that physicians could be held negligent as a matter of law even when they conformed their treatment to the standard practice of the medical community.¹³² The court explained that although early glaucoma testing did not represent "the standards of the ophthalmology profession, it is the duty of the courts to say what is required to protect patients under 40 from the damaging results of glaucoma."¹³³ Notably, following *Helling* the Washington legislature attempted to clarify the state's deferential standard and retreat from the ordinary negligence principles *Helling* established.¹³⁴

Helling is generally regarded as a minority view¹³⁵ and has been

130. See *Helling*, 519 P.2d at 982.

131. See *Helling*, 519 P.2d at 983.

132. See *Helling*, 519 P.2d at 983 (citing *The T.J. Hooper*, 60 F.2d 737 (2d Cir. 1932)) (holding that irrespective of medical standards, reasonable prudence would require providing inexpensive pressure tests to all ophthalmological patients where the test is inexpensive and simple).

133. See *Helling*, 519 P.2d at 983.

134. In *Harris v. Robert C. Groth, M.D., Inc.*, 663 P.2d 113 (Wash. 1983), the Washington Supreme Court recounted the professional and legislative reaction to its decision in *Helling v. Carey*, 519 P.2d 981 (Wash. 1974). *Harris*, 663 P.2d at 115-16. Notably, *Harris* held that even following the legislature's purported overruling of *Helling*, Washington continues to hold to a "reasonably prudent" physician and that "[t]he degree of care actually practiced by members of the profession is only some evidence of what is reasonably prudent—it is not dispositive." *Id.* at 120. See *Lent*, *supra* note 56, at 829-30.

135. See *FURROW*, *supra* note 52, at 361 ("Most jurisdictions . . . have been reluctant to follow *Helling* in replacing the established medical standard of care with a case-by-case judicial balancing."). Cases in apparent accord with *Helling* include: *United Blood Services, Div. of Blood Systems, Inc. v. Quintrana*, 827 P.2d 509, 520 (Colo. 1992) (en banc) (holding deficient):

If the standard adopted by a practicing profession were to be deemed conclusive proof of due care, the profession itself would be permitted to set the measure of its own legal liability, even though that measure might be far below a level of care readily attainable through the adoption of practices and procedures substantially more effective in protecting others against harm than the self-decreed standard of the profession, but holding that expert testimony is necessary to establish that one school of practice's standard of care is unreasonably deficient;

criticized by legal scholars.¹³⁶ As one commentator remarked, “[i]n all other areas of tort law, the jury retains the power to find that the entire industry has ‘unduly lagged;’ in malpractice cases—and these alone—the jury is typically deprived of this power.”¹³⁷

The risks of applying ordinary negligence to medical malpractice include usurping of the profession’s autonomy and substituting a jury- or judge-decreed standard of care. Standards of care developed through litigation may be faulty or costly. However, there is also a risk to according deference.¹³⁸ As one commentator noted, “[t]he legal malpractice framework may actually serve to entrench poor standards into mainstream practice, as adherence to custom is the benchmark by which a physician’s procedure is measured.”¹³⁹ Indeed a common ad-

Townsend v. Kiracoff, 545 F. Supp. 465, 468 (D. Colo. 1982) (citing The T.J. Hooper, 60 F.2d 737 (2d Cir. 1932) (“even if the defendant’s affidavits and evidentiary materials could establish that the hospital acted in accordance with the standard of care and custom of the community of Colorado hospitals, the plaintiff would still be entitled to prove at trial that the entire community’s custom is negligent”); Turner v. Children’s Hospital, 602 N.E.2d 423, 427 (Ohio App. 1991) (“although customary practice is evidence of what a reasonably prudent physician would do under like or similar circumstances, it is not conclusive in determining the applicable standard required.”); Nowatske v. Osterloh, 543 N.W.2d 265 (Wis. 1996) (denying that traditional malpractice standard differs from ordinary negligence).

136. See, e.g., Osborn v. Irwin Memorial Blood Bank, 7 Cal. Rptr.2d 101, 125–26 (Cal. App. 1992) (rejecting Helling v. Carey, and noting that most commentary and case law has been critical of the case); Clark Havighurst, *Private Reform of Tort-Law Dogma: Market Opportunities and Legal Obstacles*, 49 LAW & CONTEMP. PROBS 143, 159 n. 45 (1986); Schwartz, *supra* note 126, at 890; cf. Dan Dobbs et al., *Prosser and Keeton on the Law of Torts* § 33 at 30 n. 53 (noting “increasing number of courts rejecting customary practice standard in favor of reasonable care or reasonably prudent doctor standard” and citing cases) (5th ed. 1988 pocket part); Theodore Silver, *One Hundred Years of Harmful Error: The Historical Jurisprudence of Medical Malpractice*, 1992 WIS. L. REV. 1193, 1212–19 (arguing for a return to negligence principles).
137. Schwartz, *supra* note 126, at 890; see also Gary T. Schwartz, *The Beginning and the Possible End of the Rise of Modern American Tort Law*, 26 GA. L. REV. 601, 663 (1992) [hereinafter Schwartz, *Modern American Tort Law*] (noting that Helling v. Carey has not garnered support, “[malpractice] conservatism has largely survived the 1980s”); cf. Richard E. Leahy, *Rational Health Policy and the Legal Standard of Care: A Call for Judicial Deference to Medical Practice Guidelines*, 77 CAL. L. REV. 1483, 1502–06 (1989) (arguing that courts and juries have too much independence to establish and judge the medical standard of care and proposing judicial deference to professionally promulgated guidelines).
138. See Kacmar, *supra* note 59, at 631–32 (noting in malpractice actions there is substantial reliance on the medical profession to define its own standard of care and lack of incentive to keep abreast); Silver, *supra* note 136, at 1212–19; Leahy *supra* note 137, at 1495–97.
139. Kacmar, *supra* note 59, at 643.

monition to new doctors echoes this idea: "You will seldom be sued if you do what your teacher taught you."¹⁴⁰

Judging the standard of care is also difficult because standards evolve over time. While standard care requires that physicians "keep abreast" of "customary practice" as it develops and changes,¹⁴¹ few cases actually find liability based on the failure to keep pace with changing professional standards.¹⁴² More commonly, a physician who follows old practices will not be viewed as having failed to keep abreast of medical advances; rather his divergence more likely will be characterized as a difference of opinion in a divided medical community. In fact, disagreement among practitioners is a common occurrence: "[o]n many matters the medical community is divided as to the preferred method of therapy or treatment."¹⁴³ Generally, malpractice law protects those within a divided medical community; a physician following one of two schools of thought will enjoy freedom from liability even if the treatment chosen proves ineffective.¹⁴⁴ While there are exceptional cases,¹⁴⁵

140. Sackett reports on studies showing years from medical school negatively correlates with up-to-date knowledge. SACKETT, *supra* note 61, at 9.

141. *See* Rooney v. Medical Center Hosp. of Vermont, 649 A.2d 756, 759 (Vt. 1994):

To practice the profession of medicine, a physician is not required to be possessed of the extraordinary knowledge and ability that belongs to the few practitioners of rare endowments. But the physician is required to keep abreast of new techniques and knowledge and to practice in accordance with the approved methods and means of treatment in general use [in his field].

See also Kacmar, *supra* note 59, at 641.

142. *See* Angela Roddey Holder, *Failure to "Keep up" as Negligence*, 224 JAMA 1461, 1462 (1973).

143. Schwartz, *Modern American Tort Law*, *supra* note 137, at 664.

144. *See* Hood v. Philips, 537 S.W.2d 291, 294 (Tex. App. 1976) (holding "a physician is not guilty of malpractice where the method of treatment used is supported by a respectable minority of physicians, as long as the physician has adhered to the acceptable procedures of administering the treatment as espoused by that minority"). *See also* Joan P. Dailey, *Comment, The Two Schools of Thought and Informed Consent Doctrines in Pennsylvania: A Model for Integration*, 98 DICK. L. REV. 713 (1994); Schwartz, *Modern American Tort Law*, *supra* note 137, at 664-65 (commenting that traditional tort law has held that "when intelligent doctors can disagree, the defendant cannot be found guilty of malpractice").

145. An alternative view is possible, one in which the two schools might be measured against one another. One court reasoned that where two schools differ, "plaintiff should be permitted to present expert opinion testimony that the standard of care adopted by the school of practice to which the defendant adheres is unreasonably deficient by not incorporating readily available practices and procedures substantially more protective against the harm caused to the plaintiff than the standard of care

the general rule is that so long as the medical community remains divided, malpractice law offers little protection to patients caught in the middle of an evolving standard of care.

Surgical treatment of ambiguous genitalia in infancy exemplifies an instance where prevailing medical wisdom, in an area of great significance to individuals and their families, developed without any conclusive evidence that surgical intervention was appropriate. Because surgical intervention developed without sufficient scientific inquiry and validation of its long-term success, the premises behind judicial deference toward the medical community, at least in the types of cases presented herein, are not particularly compelling.¹⁴⁶

The basic reason why professionals are usually held only to a standard of custom and practice is that their informed approach to matters outside common knowledge should not be "evaluated by the ad hoc judgments of a lay judge or lay jurors aided by hindsight." In the words of a leading authority, "When it can be said that the collective wisdom of the profession is that a particular course of action is the desirable course, then it would seem that the collective wisdom should be followed by the courts."¹⁴⁷

Thus, based on an assumption that the community standard is a product of collective wisdom and not of collective ignorance or a herd mentality, courts defer to the community standard. Courts presume that standards of care develop from scientific inquiry and validation, not from mere anecdotal evidence. But such is not always the case.¹⁴⁸ Despite a lack of confirming research it became "fairly common to recommend to . . . parents that they raise a male baby with micropenis as a girl"¹⁴⁹ and "fairly common to remove the enlarged, masculine-

adopted by the defendant's school of practice." *United Blood Services v. Quintana*, 827 P.2d 509, 521 (Colo. 1992) (en banc).

146. Furrow notes that "clinical innovation allows physicians to vary standard treatment to suit the needs of a particular patient, where the patient presents a particular problem or desperate situation." *FURROW ET AL.*, *supra* note 52, at § 6-5, at 385. However, he notes that courts rarely allow such a defense except in instances "when conventional treatments are largely ineffective or where the patient is terminally ill and has little to lose by experimentation with potentially useful treatments." *FURROW ET AL.*, *supra* note 52, at § 6-5, at 385.

147. *Osborn v. Irwin Memorial Blood Bank*, 7 Cal. Rptr.2d 101, 125-26 (Cal. App. 1992) (citations omitted).

148. See generally *McKinlay*, *supra* note 56.

149. See *MONEY, SEX ERRORS* 1968, *supra* note 17, at 48.

looking clitoris” of female-assigned hermaphrodites and pseudohermaphrodites.¹⁵⁰ By rejecting ordinary negligence principles in malpractice cases where treatment is not based upon collective wisdom but something much less, courts insulate the medical professional from liability for its collective shortcomings.

Moreover, the deferential standard reinforces professional inertia. Others have observed that slowness to change, even after new information comes to light, is not uncommon:

Perhaps more troubling [than adopting a standard without rigorous testing] is that even when trials are conducted, and the results published, physicians may not change their behavior, particularly when the trials report negative findings. Studies of the impact of [randomized controlled trials] on the practice of medicine, from the 1960s through the 1980s, have consistently found that [randomized controlled trials] have little direct impact on physician’s practice.¹⁵¹

When judicial deference allows the medical community to establish its own standards of care, courts surrender power to “in the end say what is required,”¹⁵² and allow the profession instead “to set the measure of its own legal liability, even though that measure might be far below a level of care readily attainable through the adoption of practices and procedures substantially more effective in protecting others against harm than the self-decreed standard of the profession.”¹⁵³ This is particularly so when the profession has not even abided by its own recommendations for the evaluation of a standard or guidelines for managing some specific clinical problem.¹⁵⁴ By allowing the medical community to set the standard by which negligence is determined and

150. See MONEY, SEX ERRORS 1968, *supra* note 17, at 93.

151. See King & Henderson, *supra* note 57, at 1021; see also Lent, *supra* note 56, at 808.

152. United Blood Services v. Quintana, 827 P.2d 509, 520 (Colo. 1992) (en banc) (quoting The T.J. Hooper, 60 F.2d 737, 740 (2d Cir. 1932).

153. See *United Blood Services*, 827 P.2d at 520.

154. Sackett discusses the problem of how clinicians can determine whether guidelines are valid. See SACKETT, *supra* note 61, at 114–16. Four guides were offered for the evaluation of a proposed medical guideline: 1) Were all important decision options and outcomes clearly specified?; 2) Was the evidence relevant to each decision option identified, validated and combined in a sensible and explicit way?; 3) Are the relative preferences that key stakeholders attach to the outcomes of decisions (including benefits, risks and costs) identified and explicitly considered?; 4) Is the guideline resistant to clinically sensible variations in practice? See SACKETT, *supra* note 61, at 115.

by protecting the divided medical community, tort law renders itself impotent to promote positive changes within the medical community.¹⁵⁵

III. PARENTAL CONSENT TO GENITAL SURGERY AND SEX REASSIGNMENT ON BEHALF OF CHILDREN

This section explores the informed consent doctrine and the challenges of actualizing informed consent in the context of infant medical care. This section also confronts the questions of how and why parents consent to radical, life-altering treatment of their intersex or mutilated infants and why the safeguards of informed consent seemingly fail. An atmosphere of urgency, partial and inaccurate disclosure of the condition and risks, a sense of secrecy and shame all impede true informed consent. Worse, both doctors and parents fail to include the child's right to self-determination in the decisional calculus.

A. The Doctrine of Informed Consent

The informed consent doctrine¹⁵⁶ preserves a patient's right to make medical decisions on his or her own behalf.¹⁵⁷ It protects "the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law."¹⁵⁸ Two key interests are at stake: bodily integrity and self-determination.¹⁵⁹ "The law of informed consent is predicated on notions of patient sovereignty and serves to safeguard the patient's right of choice."¹⁶⁰

155. See generally Kacmar, *supra* note 59, at 633–39.

156. See generally RUTH R. FADEN & TOM L. BEAUCHAMP, *A HISTORY AND THEORY OF INFORMED CONSENT* (1986) (tracing history and discussing moral underpinnings of informed consent doctrine in medical tradition).

157. See Susan D. Hawkins, *Protecting the Rights and Interests of Competent Minors in Litigated Medical Treatment Disputes*, 64 *FORDHAM L. REV.* 2075, 2093–94 (1996).

158. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 269 (1990) (quoting *Union Pac. Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891)).

159. See Hawkins, *supra* note 157, at 2094–2102 (other interests include privacy, to be free of unwanted physical invasions, and preservation of life); James Bopp, Jr. & Richard E. Coleson, *A Critique of Family Members as Proxy Decisionmakers Without Legal Limits*, 12 *ISSUES L. & MED.* 133, 134–35 (1996); see also *In re Fiori*, 673 A.2d 905, 909–10 (Pa. 1996) (commenting, "[t]he right to refuse medical treatment has deep roots in our common law. . . . From this right to be free from bodily invasion developed the doctrine of informed consent").

160. *Turner v. Children's Hosp., Inc.*, 602 N.E.2d 423, 431 (Ohio App. 1991).

Generally, informed consent includes an obligation to provide relevant information concerning alternatives to the proposed treatment,¹⁶¹ including "material risks incident to abstention from treatment."¹⁶² Although some courts continue to follow an older physician-oriented standard and measure the adequacy of disclosure with reference to the custom and standard within the medical community,¹⁶³ the decisional trend over the past two decades has been toward a patient-oriented standard, with reference to "what a reasonable person objectively needs to hear from his or her physician to allow the patient to make an informed and intelligent decision regarding proposed medical treatment."¹⁶⁴

The modern trend of judging informed consent by a patient-oriented standard stands in stark contrast to a physician-oriented standard for judging the standard of medical care.¹⁶⁵ Under the patient-oriented standard of informed consent, "what the *medical community* believes the patient needs to hear in order for the patient to make an informed decision is insufficient, without more, to resolve the question of what an *individual patient* reasonably needs to hear in order for that patient to make an informed and intelligent choice regarding the proposed medical treatment."¹⁶⁶ The modern, patient-oriented standard does not shield physicians just because their disclosure conforms to the

161. See Carr v. Strode, 904 P.2d 489, 493 (Haw. 1995).

162. Wheeldon v. Madison, 374 N.W.2d 367, 375 (S.D. 1985) (citing Canterbury v. Spence, 464 F.2d 772, 787 (D.C. Cir. 1972)).

163. See William J. McNichols, *Informed Consent Liability in a "Material Information" Jurisdiction: What Does the Future Portend?*, 48 OKLA. L. REV. 711, 716-17 (1995) (describing state trends); see generally Laurent B. Frantz, Annotation, *Modern Status of Views as to General Measure of Physician's Duty to Inform Patient of Risks of Proposed Treatment*, 88 A.L.R.3d 1008; Richard A. Heinemann, *Pushing the Limits of Informed Consent: Johnson v. Kokemoor and Physician-Specific Disclosure*, 1997 Wisc. L. REV. 1079, 1082-86 (discussing patient-oriented standard and describing trends).

164. Carr v. Strode, 904 P.2d 489, 500 (Haw. 1995). The seminal case rejecting the physician-oriented standard and adopting the patient-oriented standard is Canterbury v. Spence, 464 F.2d 772 (D.C. Cir. 1972). See also Congrove v. Holmes, 308 N.E.2d 765 (Ohio 1973); Arena v. Gingrich, 748 P.2d 547 (Or. 1988); Corrigan v. Methodist Hosp., 869 F. Supp. 1202 (E.D. Pa. 1994); Wilkinson v. Vesey, 295 A.2d 676 (R.I. 1972); Shadrick v. Coker, 963 S.W.2d 726 (Tenn. 1998); Stripling v. McKinley, 746 S.W.2d 502 (Tex. App. 1988), aff'd, 763 S.W.2d 407 (Tex. 1989).

165. See Gorab v. Zook, 943 P.2d 423, 428 n.5 (Colo. 1997) (en banc) (noting evidentiary differences between patient-oriented informed consent doctrine and medical community standard of care).

166. Carr, 904 P.2d at 499 (emphasis in original). Physicians must provide information concerning "material risks" and, at least in some jurisdictions, they must provide information about alternative treatments. See Doe v. Johnston, 476 N.W.2d 28, 30-31 (Iowa 1991).

established custom of their peers if that standard is inadequate to meet the needs of the particular patient.¹⁶⁷ Thus, in jurisdictions employing a patient-oriented standard of informed consent, patient autonomy rights prevail over medical-community standards.¹⁶⁸

The trend toward judging the adequacy of disclosure from the patient's vantage is justified because the patient-oriented standard "better respects the patient's right of self-determination and affixes the focus of the inquiry regarding the standard of disclosure on the motivating force and purpose of the doctrine of informed consent—aiding the individual patient in making an important decision regarding medical care."¹⁶⁹

Under either a patient-oriented or physician-oriented standard, physicians do not need to disclose information when the physician determines that the risk of disclosure poses a threat "of detriment to the patient as to [make disclosure] become unfeasible or contraindicated from a medical point of view."¹⁷⁰ Commonly known as the "therapeutic privilege," this exception to disclosure protects physicians from claims when the physician determines that disclosure would carry risks to the patient.

The classic therapeutic privilege case concerns a patient with peculiar apprehension or nervousness that suggests to physicians that full disclosure might pose additional health risks.¹⁷¹ Then, "[t]he medical

167. See *Cobbs v. Grant*, 502 P.2d 1, 10 (Cal. 1972) (en banc) ("A medical doctor, being the expert, appreciates the risks inherent in the procedure he is prescribing, the risks of a decision not to undergo the treatment, and the probability of a successful outcome of the treatment The weighing of these risks against the individual subjective fears and hopes of the patient is not an expert skill. Such evaluation and decision is a nonmedical judgment reserved to the patient alone."); *Cooper v. Roberts*, 286 A.2d 647, 650–51 (Pa. 1971) ("As the patient must bear the expense, pain and suffering of any injury from medical treatment, his right to know all material facts pertaining to the proposed treatment cannot be dependent upon the self-imposed standards of the medical profession."). Applying *Cobbs*, physicians are expected to explain the probability of success and to tell patients what they mean by success. See George J. Annas, *Informed Consent, Cancer, and Truth in Prognosis*, 330 NEW ENG. J. MED. 223, 225 (1994).

168. See Annas, *supra* note 167, at 225 ("Of course, the doctrine of informed consent is based on the recognition that people are not all the same and that physicians must let patients decide about treatment options so that they do not treat them 'always the same way for everybody alike.'") (quoting LEO TOLSTOY, *The Death of Ivan Ilych, in THE DEATH OF IVAN ILYCH AND OTHER STORIES* 95 (Aylmer Maude trans., The New American Library of World Literature, Inc. 1960).

169. *Carr*, 904 P.2d at 499.

170. *Canterbury v. Spence*, 464 F.2d 772, 789 (D.C. Cir. 1972).

171. See *Carr*, 904 P.2d at 494; *Nishi v. Hartwell*, 473 P.2d 116, 119–21 (Haw. 1970), *overruled on other grounds* (patient's fear and apprehension justified not telling him of

standard . . . [is] that a competent and responsible medical practitioner would not disclose information which might induce an adverse psychosomatic reaction in a patient highly apprehensive of his condition."¹⁷² In practice, few cases actually rely on the privilege as an excuse for nondisclosure.¹⁷³ Importantly, commentators and courts recognize that liberal invocation of the privilege nullifies the general obligations of disclosure and respect for patient autonomy and self-determination and should therefore be discouraged.¹⁷⁴

B. Informed Consent and Parental Decision Making on Behalf of Infants

While children and incompetents possess bodily integrity and self-determination rights in theory,¹⁷⁵ finding a practical framework that allows others to make decisions and yet assures the correctness of those decisions for that patient presents a legal and ethical challenge.¹⁷⁶ The

"collateral hazard" of paralysis associated with diagnostic procedure regarding aneurysm).

172. *Nishi*, 473 P.2d at 121.

173. See McNichols, *supra* note 163, at 728–79 & n.97 (noting scarcity of decisions based upon therapeutic privilege defense). Compare *Roberts v. Wood*, 206 F. Supp. 579, 583 (Ala. 1962) (finding disclosure adequate and noting, "Doctors frequently tailor the extent of their pre-operative warnings to the particular patient, and with this I can find no fault. Not only is much of the risk of a technical nature beyond the patient's understanding, but the anxiety, apprehension, and fear generated by a full disclosure may have a very detrimental effect on some patients.") with *Cornfeldt v. Tongen*, 262 N.W.2d 684, 700 (Minn. 1977) (rejecting therapeutic privilege defense where doctor testified that "he did not want to concern [the patient] with what he regarded as a foregone conclusion").

174. See *Canterbury*, 464 F.2d at 792; McNichols, *supra* note 163, at 728.

175. See *Rosebush v. Oakland County Prosecutor*, 491 N.W.2d 633, 636 (Mich. App. 1992) (commenting, "[t]he right to refuse lifesaving medical treatment is not lost because of the incompetence or the youth of the patient"); *Custody of a Minor*, 393 N.E.2d 836, 844 (Mass. 1979) (stating that incompetent persons enjoy "the same panoply of rights and choices" of competent persons) (citation omitted).

176. See generally American Academy of Pediatrics, Committee on Bioethics, *Informed Consent, Parental Permission, and Assent in Pediatric Practice*, in POLICY REFERENCE GUIDE 496 (1997) (also available at 95 PEDIATRICS 314 (Feb. 1995)); Joseph P. McMenamain & Karen Izzi Michael, *Children as Patients*, in LEGAL MEDICINE 396 (American College of Legal Medicine ed., 4th ed. 1998); Bopp & Coleson, *supra* note 159; Dena S. Davis, *Genetic Dilemmas and the Child's Right to an Open Future*, 28 RUTGERS L.J. 549 (1997); Leslie P. Francis, *The Roles of the Family in Making Health Care Decisions for Incompetent Patients*, 1992 UTAH L. REV. 861; Leonard H. Glantz, *Research with Children*, 24 AM. J.L. & MED. 213 (1998); Marcia Gottesman, *Civil Liability for Failing to Provide 'Medically Indicated Treatment' to a Disabled Infant*, 20 FAM. L.Q. 61 (1986); Louise Harmon, *Falling Off the Vine: Legal Fictions*

primary obligation for making medical decisions on behalf of children resides with the child's parents and the obligation to disclose information about treatment runs to them.¹⁷⁷

While the standard by which courts judge surrogate decision making on behalf of incompetents is a "substituted judgment standard,"¹⁷⁸ for infants the standard is better viewed as a "best interest standard" since an infant has no prior judgment from which decision-makers might draw.¹⁷⁹ Parental determinations of the child's best interest are accorded deference in order to protect family privacy and parental authority and autonomy; this authority, once based on a no-

and the Doctrine of Substituted Judgment, 100 YALE L.J. 1 (1990); Hawkins, *supra* note 157; Robert J. Katerberg, *Institutional Review Boards, Research on Children, and Informed Consent of Parents: Walking the Tightrope Between Encouraging Vital Experiments and Protecting Subjects' Rights*, 24 J.C. & U.L. 545 (1998); Ann MacLean Massie, *Withdrawal of Treatment for Minors in a Persistent Vegetative State: Parents Should Decide*, 35 ARIZ. L. REV. 173 (1993); Andrew Popper, *Averting Malpractice by Information: Informed Consent in the Pediatric Treatment Environment*, 47 DEPAUL L. REV. 819 (1998); Elyn R. Saks, *Competency to Refuse Treatment*, 69 N.C. L. REV. 945 (1991); Robyn S. Shapiro & Richard Barthel, *Infant Care Review Committees: An Effective Approach to the Baby Doe Dilemma?*, 37 HASTINGS L.J. 827 (1986); Walter Wadlington, *Medical Decision Making for and by Children: Tensions Between Parent, State, and Child*, 1994 U. ILL. L. REV. 311; Rachel M. Dufault, Comment, *Bone Marrow Donations By Children: Rethinking the Legal Framework in Light of Curran v. Bosze*, 24 CONN. L. REV. 211 (1991); Elizabeth J. Sher, Note, *Choosing for Children: Adjudicating Medical Care Disputes Between Parents and the State*, 58 N.Y.U. L. REV. 157 (1983).

177. Conceptually, the parent's duty to make decisions is sometimes characterized as a parental right. When the law views the parental obligation to make decisions as a parental right, then the child's rights might be subordinated to their parents. See INSTITUTE OF MEDICAL ETHICS, MEDICAL RESEARCH WITH CHILDREN: ETHICS, LAW, AND PRACTICE 132 (Richard H. Nicholson ed. 1986). Whether viewed as a right or duty, parental decisions are cloaked in deference arising out of the right to privacy and the right to parental autonomy under the Fourteenth Amendment. See, e.g., *Wisconsin v. Yoder*, 406 U.S. 205 (1972).
178. The judicial decision maker "must 'substitute itself as nearly as may be [possible] for the incompetent and . . . act upon the same motives and considerations as would have moved' the incompetent." DuFault, *supra* note 176, at 221 (quoting *City Bank Farmers Trust Co. v. McGowan*, 323 U.S. 594, 599 (1945)).
179. "The fundamental difference between the use of substituted judgment and the 'best interests of the child test' under such conditions, lies not in the decision reached, which may be the same, but in the vantage from which the decision is reached." DuFault, *supra* note 176, at 227. See *Rosebush*, 491 N.W.2d at 639 (discussing difference and commenting that preference in surrogate decisionmaking is to use a substituted judgment standard and best interest standard where a preference was never stated or is otherwise unknown); see also Catherine L. Annas, *Irreversible Error: The Power and Prejudice of Female Genital Mutilation*, 12 J. CONTEMP. HEALTH L. & POL'Y 325, 337 n. 123 (1996).

tion of "children as chattel,"¹⁸⁰ is now premised on the belief that "the natural bonds of affection" motivate parents to act in the child's best interest.¹⁸¹ The law presumes that "family members are generally most concerned with the welfare of a patient."¹⁸²

The authority of parents to make medical decisions, however, is not unbridled and the state may intervene where parental decision making seemingly fails to adequately protect the interests of the child.¹⁸³ Usually, conflicts between physicians and parents draw the state into medical treatment controversies.¹⁸⁴ It is unusual that anyone champions the interests of the child when the treating physician and parents agree on treatment, even though the child may have conflicting interests.¹⁸⁵

One notable exception to the general rule that no judicial review is necessary when parents and doctors are in accord is with regard to involuntary sterilization decisions.¹⁸⁶ Even when doctors and parents agree, significant statutory and common law oversight of the decision to involuntarily sterilize incompetents has developed in most states in order to prevent hasty involuntary sterilization of the mentally impaired,¹⁸⁷

180. Dufault, *supra* note 176, at 214–215.

181. *Parham v. J.R.*, 442 U.S. 584, 602 (1979); *see also* *In re L.H.R.* 321 S.E.2d 716, 722 (Ga. 1984); Dufault, *supra* note 176, at 218–19; Hawkins, *supra* note 157, at 2081; Sher, *supra* note 176, at 171–72.

182. *Fiori v. Pennsylvania*, 673 A.2d 905, 912 (Pa. 1996) (citation omitted) (acknowledging right of mother to order removal of life support of adult son in persistent vegetative state).

183. *See In re Doe*, 418 S.E.2d 3, 7 n. 6 (Ga. 1992) (commenting that parents do not have an "absolute right to make medical decisions for their children"); INSTITUTE OF MEDICAL ETHICS, *supra* note 177, at 133–34 (discussing limits of parental authority); McMenamain & Michael, *supra* note 176, at 397; Dufault, *supra* note 176, at 213–16 (tracing historical perspective of parental right to make medical decisions); *see also* Povenmire, *supra* note 91, at 107–09.

184. *See Rosebush v. Oakland County Prosecutor*, 491 N.W.2d 633, 637 (Mich. App. 1992) ("We hold that the decision-making process should generally occur in the clinical setting without resort to the courts, but that courts should be available to assist in decision making when an impasse is reached.").

185. *See* Sher, *supra* note 176, at 168–69 (noting that the courts resolve conflicts between the state and the parent and "few courts recognize that children have an interest to articulate independent of their parents or the state").

186. *See generally* ROGER B. DWORKIN, *LIMITS: THE ROLE OF THE LAW IN BIOETHICAL DECISION MAKING* 54–60 (1996) (approving the increasingly adopted judicial case-by-case approach in involuntary sterilization cases); Povenmire, *supra* note 91, at 107–08.

187. *See generally* Roberta Cepko, *Involuntary Sterilization of Mentally Disabled Women*, 8 BERKELEY WOMEN'S L.J. 122 (1993) (describing statutory and case law approaches to sterilization of mentally disabled); Elizabeth Scott, *Sterilization of Mentally Retarded Persons: Reproductive Rights and Family Privacy*, 1986 DUKE L.J. 806, 818 (noting

especially in childhood.¹⁸⁸ “Any exercise of state power to order the non-consensual sterilization of an individual must be scrutinized carefully because of the individual’s rights and interests that are at stake.”¹⁸⁹ Appellate courts caution lower courts that, “because sterilization necessarily results in the permanent termination of the intensely personal right of procreation, the trial judge must take the greatest care to ensure that the incompetent’s rights are jealously guarded.”¹⁹⁰

Notwithstanding the general rule of careful judicial scrutiny in involuntary sterilization cases, the ethical issues surrounding genital surgery on the intersex child have not drawn much attention until very recently, although such surgery poses serious risks to the intensely personal rights related to identity and erotic and possibly reproductive potential.¹⁹¹ Critics of surgical interventions on intersex infants contend that ethical considerations warrant more attention from judges and ethicists than they currently receive.¹⁹² For example, requiring physicians and parents to establish the necessity of such surgery by “clear and convincing” evidence might be justified because of the life-long impact of the surgery on crucial aspects of life.¹⁹³

In surrogate decision making outside of compulsory sterilization, judicial involvement is not the norm unless parents and physicians disagree.¹⁹⁴ However, it remains useful to consider how courts generally

“[m]ost laws . . . embody strict procedural and substantive requirements that create a strong presumption against sterilization”).

188. See DWORKIN, *supra* note 186, at 58; Scott, *supra* note 187, at 848 n. 140; see, e.g., Haw. Rev. Stat. § 560:5-602 (1993) (“[p]ersons who are wards and who have attained the age of eighteen years have the legal right to be sterilized In no event, however, shall wards be sterilized without court approval unless sterilization occurs as part of emergency medical treatment”).
189. In the Matter of Romero, 790 P.2d 819, 821 (Colo. 1990) (en banc) (denying guardian’s request to sterilize brain-injured adult).
190. Estate of C.W., 640 A.2d 427, 428 (Pa. Super. Ct. 1994) (affirming mother’s request to sterilize adult mentally retarded daughter) (quoting *In re Mildred J. Terwilliger*, 450 A.2d 1376, 1382 (Pa. Super. Ct. 1982)).
191. See Dreger, *supra* note 12, at 28–29 (noting medical tendency to preserve female reproductive capacity but not male reproductive capacity).
192. See KESSLER, *supra* note 12, at 77–104, 132; Dreger, *History*, *supra* note 83, at 353; Kipnis & Diamond, *Pediatric Ethics*, *supra* note 11, at 406–07; Povenmire, *supra* note 91, at 122–23 (arguing for a heightened ethical evaluation in male circumcision cases as well).
193. Povenmire proposes this standard for evaluating male circumcision decisions, causing parents to weigh the medical justifications for the procedure against the procedure’s irreversibility and the child’s inability to consent. See Povenmire, *supra* note 91, at 102–03.
194. See, e.g., *Rosebush v. Oakland County Prosecutor*, 491 N.W.2d 633, 637 (Mich. Ct. App. 1992) (reviewing jurisdictions and holding that no judicial application is re-

evaluate infant medical treatment cases. Parental decisions to deny medical treatment for religious¹⁹⁵ or other reasons¹⁹⁶ may be challenged by the state and set aside by court if those decisions are deemed not in the child's best interest. While "parental autonomy is constitutionally protected," the state, as "guardian of society's basic values" sometimes has an overriding duty to protect children.¹⁹⁷ When opinions on the advisability of treatment conflict between parents and physicians, ethicists often advise weighing three factors in evaluating whether to interfere in parental decision making: 1) the decisional capacity of the minor; 2) the burden and risk of treatment; and 3) the effectiveness of the treatment.¹⁹⁸

While the first factor, decisional capacity, is seemingly inapplicable in considering medical treatment for infants, the infant's future

quired prior to removing life-support from minor in persistent vegetative state); *accord In re L.H.R.*, 321 S.E.2d 716, 722-23 (Ga. 1984) (holding that no prior judicial approval is necessary prior to termination of life-support of minor).

195. *See, e.g., In re Sampson*, 317 N.Y.S.2d 641 (Fam. Ct. 1970), *aff'd*, 323 N.Y.S.2d 253 (App. Div. 1971) (ordering surgery to correct facial deformity despite only psychosocial risk for nontreatment alternative and surgical risk to health); *State v. Perricone*, 181 A.2d 751 (N.J. 1962); *Jehovah's Witnesses v. King County Hosp.*, 278 F. Supp. 488 (W.D. Wash. 1967), *aff'd*, 390 U.S. 598 (1968). *See generally* Sher, *supra* note 176, at 161, nn. 19-23 (collecting cases).
196. *See, e.g., A.D.H. v. State Dep't of Human Resources*, 640 So.2d 969 (Ala. Civ. App. 1994) (ordering AZT treatment for AIDS); *Petra B. v. Eric B.*, 265 Cal. Rptr. 342 (Ct. App. 1989) (ordering medical treatment for burns where parents are treating child with herbal remedies); *Custody of a Minor*, 379 N.E.2d 1053 (Mass. 1978) (holding that child's best hope for recovery required chemotherapy despite and over parental concern for discomfort and parental pessimism); *In re Vasko*, 263 N.Y.S. 552 (App. Div. 1933) (ordering surgical removal of cancerous eye despite parental objection); *In re Rotkowitz*, 25 N.Y.S.2d 624 (Dom. Rel. Ct. 1941) (ordering operation on foot to correct progressive deformity). *But see In re Seiferth*, 127 N.E.2d 820 (N.Y. 1955) (upholding right of parent to decide not to treat cleft palate and harelip); *In re Tuttendario*, 21 Pa. D. 561 (1912) (holding parents could decide to withhold surgical intervention for deformity caused by rickets because they feared possible outcomes).
197. *Petra B.*, 265 Cal. Rptr. at 345-46 (quoting *In re Philip B.*, 156 Cal. Rptr. 48, 50-51 (Ct. App. 1979)).
198. *See generally* Kenneth Kipnis, *Parental Refusals of Medical Treatment on Religious Grounds: Pediatric Ethics and the Children of Christian Scientists*, in LIBERTY, EQUALITY AND PLURALITY 268, 272-74 (Larry May et al. eds., 1997); HUMAN RESEARCH SUBJECTS, *supra* note 50, at 6-18 to 6-25 (discussing considerations when children are subjects of research); Karine Morin, *The Standard of Disclosure in Human Subject Experimentation*, 19 J. LEGAL MED. 157, 189-90 (1998). *See also* *Petra B.*, 265 Cal. Rptr. at 346 (holding that the state may intervene upon consideration of the "seriousness of the harm," the "evaluation for the treatment by the medical profession," the "risks involved in medically treating the child," and the "expressed preferences of the child") (quoting *In re Philip B.*, 156 Cal. Rptr. at 51).

decisional capacity should be protected when decisions can be postponed. Protecting that potential decisional capacity remains a relevant consideration when weighing irremediable medical intervention such as the destruction of reproductive and erotic capacity or infringement on gender options.¹⁹⁹ Under a trust model of decision making that seeks to preserve a child's "right to an open future,"²⁰⁰ parents should attempt to safeguard a child's right of autonomy²⁰¹ and be "constrain[ed] . . . from consenting on the child's behalf to that which may impair the enjoyment of autonomy at maturity."²⁰²

The second factor, consideration of the risks and burdens, includes weighing both the possibility of a positive outcome as well as the "human costs of getting there."²⁰³ When the burden and risk are great, treatment may carry too high a price to be justified notwithstanding potential benefits.²⁰⁴

Finally, as to the third factor, decisionmakers must "consider whether the treatment is likely to be effective in securing some significant and subjectively valuable benefit for the child."²⁰⁵ "Demonstratively effective" treatments should be considered more valuable than "experimental or investigational" treatments.²⁰⁶ The burden should be on proving the enhancement of the quality of life rather than the absence of harm.

C. The Problems of Informed Consent and Infant Genital Surgery

In order to weigh the risks, benefits, burdens and effectiveness of treatment parents need information concerning the proposed treatment. However, perhaps acting in part out of an ill-conceived concept of

199. See Scott, *supra* note 187, at 849 n. 142 (noting the difficulty in assessing "how someone will function or act in the future").

200. See Joel Feinberg, *The Child's Right to an Open Future*, in *WHOSE CHILD? CHILDREN'S RIGHTS, PARENTAL AUTHORITY, AND STATE POWER* 124 (William Aiken & Hugh LaFollette eds., 1980).

201. See Feinberg, *supra* note 200, at 126, 151 ("if the child's future is left open as much as possible for his own finished self to determine, the fortunate adult that emerges will already have achieved, without paradox, a certain amount of self-fulfillment, a consequence in large part of his own already autonomous choices in promotion of his own natural preferences."); Dufault, *supra* note 176, at 218-19.

202. INSTITUTE OF MEDICAL ETHICS, *supra* note 177, at 131.

203. Kipnis, *supra* note 198, at 273.

204. See Kipnis, *supra* note 198, at 273.

205. Kipnis, *supra* note 198, at 273.

206. Kipnis, *supra* note 198, at 273.

therapeutic privilege, parents sometimes have been deprived of key information.

Importantly, the effectiveness of informed consent must be tested by both the content and manner of disclosure.²⁰⁷ This section questions how parental consent was secured for genital surgery. In particular, this section explores five grounds for criticizing the consent obtained by some practitioners in these cases: 1) the false aura of urgency; 2) the failure to impart complete and accurate information; 3) the oppressive secrecy in which parents were advised to not discuss the situation with others and to particularly withhold all information from the child; 4) the failure of physicians to reveal the uncertainty of the outcome; and 5) the failure to account for the child's "right to an open future" in the decisional calculation.

1. The Aura of Urgency

Clinicians have long imparted a sense of medical urgency to parents upon the birth of an intersex child.²⁰⁸ Although the intersex state is typically not life-threatening, parents are counseled to act quickly in

207. See Morin, *supra* note 198, at 191.

208. See Perlmutter, *supra* note 12, at 2 ("[t]he birth of an infant with genital ambiguity constitutes an urgent medical and social problem that requires a careful and thorough assessment to make an appropriate gender assignment as soon as feasible"); Wilson & Reiner, *supra* note 62, at 368 (commenting, "[i]t is interesting to note that ambiguous genitalia are essentially the only congenital anomalies viewed as a surgical emergency for cosmetic reasons."); Nussbaum, *supra* note 12, at 93 (describing the medical characterization of intersex as a "social and psychological emergency").

In the John/Joan case, the child's parents recalled how rushed they were to make the agonizing decision. In fact they received a letter from Money suggesting they were "procrastinating." They polled their family and their pediatrician, all of whom counseled against the surgery. But, they were persuaded by Dr. Money's "conviction that the procedure had every chance for success." Colapinto, *supra* note 11, at 64.

The informed consent process has not changed very much. Nussbaum describes a case in 1998. A psychologist on the treatment team "warned the family that without cosmetic surgery Emma might suffer from gender confusion and reassured Vicki that she knew well-adjusted girls who had received such operations." Nussbaum, *supra* note 12, at 95. Although the parent asked to meet "at least one adult intersexual who was happy with his or her childhood surgery" no name was ever provided. Nussbaum, *supra* note 12, at 95. The surgeon informed the parents "Emma would have an easier life as a female." Nussbaum, *supra* note 12, at 95. The mother reported that the physician did admit the possibility of the child's later regret. "He said, 'There's a group of people who believe we're doing the wrong thing. In 30 years we may find out they're right, but for now, this is the best we know how.'" Nussbaum, *supra* note 12, at 95.

order to establish a sex of rearing that is unequivocal.²⁰⁹ Many medical texts classify this decision-making process as a medical emergency.²¹⁰ Clinicians develop a treatment plan to facilitate conforming the child to a sex within days of birth.²¹¹ Money counseled parents to act quickly and to delay announcing the sex of a child born with ambiguity to avoid the trauma and embarrassment of a reannouncement of the child's sex and name.²¹²

Despite the impression of urgency that clinicians create, much surgical treatment of the genitals is essentially cosmetic and not medically urgent.²¹³ Instead, the message of urgency is based upon social and psychological considerations, including stigmatization and the nurture assumption.²¹⁴ Compassion for the parents and concern that

209. See KESSLER, *supra* note 12, at 17–21; Cowley, *supra* note 74, at 65.

210. See Dreger, *supra* note 12, at 30 (citing Patricia K. Donahoe et al., *Clinical Management of Intersex Abnormalities*, 28 CURRENT PROBLEMS IN SURGERY 515, 540 (1991)). Actually only the “salt-losing” category of CAH requires immediate attention. In rare conditions, gonads are prone to development of malignant tumors and may be removed prophylactically, but such surgery can be delayed. See Diamond & Sigmundson, *Management of Intersexuality*, *supra* note 11, at 1047.

211. See KESSLER, *supra* note 12, at 21–24; Dreger, *supra* note 12, at 27 (“In an effort to forestall or end any confusion about the child’s sexual identity, clinicians try to see to it that an intersexual’s sex/gender is permanently decided by specialist doctors within forty-eight hours of birth.”).

212. See KESSLER, *supra* note 12, at 17 (quoting a urologist, “One of the worst things is to allow them [the parents] to go ahead and give a name and tell everyone, and it turns out the child has to be raised in the opposite sex.”) (alteration in original); MONEY, *SEX ERRORS* 1994, *supra* note 17, at 65–66.

213. See Diamond & Sigmundson, *Management of Intersexuality*, *supra* note 11, at 1047 (cosmetic clitoral and sex reassignment surgery should be postponed until “the patient is able to give truly informed consent”); Dreger, *supra* note 12, at 30 (stating the clinicians view intersex states as a “social emergency”); Nussbaum, *supra* note 12, at 93; Wilson & Reiner, *supra* note 62, at 368.

One might argue, as has psychologist Meyer-Bahlburg that the adult actions and beliefs are predicated on what happens starting from infancy and therefore neonatal surgery is beneficial and not “merely” cosmetic since it will facilitate adjustment to the assigned gender. See Meyer-Bahlburg, *supra* note 87, at 14. However, no controlled study supports this thesis. The premise is quite dubious: parents must consent to emergency surgery on their infant’s genitalia to prevent psychosocial harm at a later date.

214. See *Timing of Elective Surgery*, *supra* note 12, at 590 (expressing concern that these congenital defects “may influence the mother’s attitude toward child” and noting disadvantage of “prolonging the child’s ‘defective’ status and crystallizing any disruption in family relationships that the child’s condition may have produced”); Cowley, *supra* note 74, at 65 (reporting view that physicians view “creating a normal appearance” as urgent). Instead of “normalizing” the sex organs, Diamond urges clinicians to counsel parents “that appearances during childhood, while not typical of other children, may

they would not bond²¹⁵ also prompts urgency; “the medical team will recommend that surgical therapy begin early in order to spare parents the trauma of seeing their child as intersexed each time they change the infant’s diaper.”²¹⁶

Critics argue that none of the core premises on which early surgery was based justify urgency. First, the theory that children raised unambiguously with normalized genitalia would accept the gender of rearing was untested by reliable studies.²¹⁷ In truth, physicians could not confidently assert, based on data, that surgery imposed at any age would be any more or less successful.

Second, the stigma clinicians feared would befall a child in the locker room could be mitigated through less drastic alternatives than immediate surgical alteration.²¹⁸ When Diamond and Sigmundson first recommended a moratorium on most cosmetic infant genital surgery, they nevertheless supported the early decision to socially assign the child to boy or girl classification.²¹⁹ They merely opposed taking the

be of less importance than functionality and postpubertal erotic sensitivity.” Diamond & Sigmundson, *Management of Intersexuality*, *supra* note 11, at 1047.

215. See MONEY, SEX ERRORS 1994, *supra* note 17, at 82–83 (cautioning that parents of children with birth defects of sex organs “may despise, criticize, and avoid the pathology in their child who, in turn, feels despised, criticized and avoided as a person.”); see also, *Timing of Elective Surgery*, *supra* note 12, at 590.
216. Wilson & Reiner, *supra* note 62, at 363 (citing Heino F.L. Meyer-Bahlburg, *Gender Assignment in Intersexuality*, 10 J. PSYCH. & HUMAN SEXUALITY 1–21 (1998)).
217. See Diamond & Sigmundson, *Management of Intersexuality*, *supra* note 11, at 1048.
218. See KESSLER, *supra* note 12, at 128–32; Dreger, *supra* note 12, at 32–33. Moreover, the haste and secrecy produces its own shame and stigma. See DREGER, *supra* note 72, at 192 (quoting Sherri A. Groveman, “the greatest source of anxiety . . . is [the] shame and fear resulting from an environment in which our condition is so unacceptable that caretakers lie”); Robert A. Couch, *Betwixt and Between: The Past and Future of Intersexuality*, 9 J. CLIN. ETHICS 372, 375 (1998) (noting that discomfort with intersexuality is culturally constructed); Sharon Preves, *For the Sake of the Children: Destigmatizing Intersexuality*, 9 J. CLIN. ETHICS 411, 415 (1998) (noting that surgery compounds shame rather than erasing it, and that parents might have been taught to deal with their different child rather than misguided attempts to “normalize” them through radical surgery); Wilson & Reiner, *supra* note 62, at 364 (commenting that silence produces “significant feelings of shame”). There is increasing recognition that gender exists along a continuum, much as medicine and society desire a binary gender construct. See KESSLER, *supra* note 12, at 132; Terry S. Kogan, *Transsexuals and Critical Gender Theory: The Possibility of a Restroom Labeled “Other,”* 48 HASTINGS L.J. 1233, 1238 (1997); see also Brynn Craffey, *Showering “Sans Penis,”* 2 CHRYSALIS: J. TRANSGRESSIVE GENDER IDENTITIES 55–56 (1997).
219. Diamond & Sigmundson, *Management of Intersexuality*, *supra* note 11, at 1047. See also KESSLER, *supra* note 12, at 119–32; Cowley, *supra* note 74, at 66 (reporting on recommendations of ISNA and biologist Anne Fausto-Sterling, “raise a child in the sex that seems most comfortable”).

irreversible surgical step of removing body parts, while still recommending children be raised with a clear gender status based on which gender will most likely develop.²²⁰ They wrote, “[i]n rearing, parents must be consistent in seeing their child as either a boy or a girl; not neuter. In our society intersex is a designation of medical fact but not yet a commonly accepted social designation.”²²¹

Finally, recommending prompt surgery based on the fear of parental rejection and failure to bond is premised more on medical opinion than fact.²²² Critics contend that while “Money has presented some data that having a child with ambiguous genitalia causes parental stress, . . . support for the second part of that hypothesis, that the stress on the parent (and presumably also child) is alleviated by surgical correction, is entirely absent.”²²³ As Alice Dormurat Dreger noted, even if physicians were motivated by a singular desire to alleviate psychosocial problems of both the family and the child, “it is not self evident that a psychosocial problem should be handled medically or surgically. We do not attempt to solve the problems many dark-skinned children will face in our nation by lightening their skins.”²²⁴ In addition, parental anxiety and distress can be enhanced by this medical attention rather than reduced. Parental tension and stress can be reduced by managing the intersex condition as a normal variation and imparting to the parents the knowledge that the genital variation, if of adolescent or adult concern, can be dealt with at a later age. Moreover, recommending surgery based on a concern for the sensibilities of parents and others is not appropriate, as only the best interest of the child is relevant.²²⁵

220. Diamond and Sigmundson’s views are supported by ISNA, an organization of and for adult intersexuals. ISNA, *supra* note 109; Chase, *supra* note 85, at 385.

221. Diamond & Sigmundson, *Management of Intersexuality*, *supra* note 11, at 1047.

222. See KESSLER, *supra* note 12, at 74–76. In regard to the effect on parents, even Money has written: “More than one-half of the parents (8/14) underwent only a short-lived, minor degree of crisis precipitated by having a micropenis baby [that they were told would need to be reassigned as a girl]. None had an extreme degree of crisis.” John Money et al., *Micropenis, Family Mental Health, And Neonatal Management: A Report On 14 Patients Reared as Girls*, 1 J. PREVENTIVE PSYCHIATRY 17–27, 17 (1981).

223. Wilson & Reiner, *supra* note 62, at 367.

224. Dreger, *supra* note 12, at 30.

225. See *Mack v. Mack*, 618 A.2d 744, 759 (Md. App. 1993); *Wentzel v. Montgomery Gen. Hosp., Inc.*, 447 A.2d 1244, 1245 (Md. 1982) (“in considering the best interests of an incompetent minor, the welfare of society or the convenience or peace of mind of the ward’s parents or guardian plays no part”); *Estate of C.W.*, 640 A.2d 427, 428 (Pa. Super. 1994) (quoting *In the Matter of Mildred J. Terwilliger*, 450 A.2d 1376, 1382 (Pa. 1982)) (“[I]n making the decision of whether to authorize sterilization [of an incompetent adult], a court should consider only the best interest

2. Imparting Incomplete Information

Clinicians treating children with congenital birth defects sometimes fail to impart accurate and complete information for a variety of reasons.²²⁶ The problem of inadequate disclosure during neonatal medical crises is not confined to the intersex infant:

The information available to the family in a medical crisis is quite often inadequate. Some have suggested that this problem is rooted in the complete dependence and lack of power of the patient and family. All information, of both the particular and general medical type, is held by the hospital staff. Physicians also have a propensity not to admit the limitations of their professional knowledge and ability. Additionally, the use of medical jargon during counseling clouds the ability of parents to be fully informed.²²⁷

Information about the diagnosis, the efficacy of treatment, and complications may be incomplete. Intersexed individual Howard Devore, a practicing psychologist who counsels other intersexed persons, has himself had 16 surgeries to repair his severe hypospadias. He complains physicians are too optimistic about the outcome:

[In regard to the surgery] there's going to be scarring and stricture formation and loss of sensation. No scar tissue is as flexible as skin. There's no way they can deny that. The 'informed consent' they give parents to sign is totally unrealistic. One of our main issues is that parents are told after a few surgeries, their children will have 'normal genitals.'²²⁸

As to explaining the nature of the condition, Money contended that in counseling, "parents [need to] have the necessary medical information (albeit somewhat simplified) [in order] to be able to explain

of the incompetent person, not the interests or convenience of the individual's parents, the guardian or of society.").

226. See Bopp & Coleson, *supra* note 159, at 142 (discussing studies demonstrating tendency of physicians to withhold information or not to admit the "limitations of their professional knowledge and ability").

227. Bopp & Coleson, *supra* note 159, at 141-42.

228. Yronwode, *supra* note 85. Complications, surgical failures and the necessity for multiple surgeries are high in genital surgery on children. See FAUSTO-STERLING, *supra* note 11, at 86-87.

their dilemma to themselves prior to explaining it to other people.”²²⁹ However, full and complete disclosure about the condition was generally not advised by professionals. Instead, counselors were advised that they should explain to parents that the child was “sexually unfinished.”²³⁰ The concept that these children are “unfinished” is particularly deceptive because it implies that with more gestational time unambiguous sex organs would have developed and that physicians are not “changing” something fundamental about the child but are merely “finishing” the child’s incomplete anatomy.²³¹ While simplistically appealing, the concept of being “unfinished” leaves parents ill-equipped to make thoughtful decisions.²³² As Suzanne Kessler points out, by em-

229. MONEY, *SEX ERRORS* 1968, *supra* note 17, at 62–63; MONEY, *SEX ERRORS* 1994, *supra* note 17, at 67.

230. MONEY, *SEX ERRORS* 1968, *supra* note 17, at 62. One of the patients discussed in the beginning of this paper reports that his parents were told he needed “corrective” surgery but never appreciated the nature of their child’s condition. A physician candidly recalled to a reporter how he and his colleagues counseled parents of intersex children:

[A] pediatric endocrinologist at Children’s Memorial Hospital in Chicago, would draw a pair of X’s [on a blackboard]. This, he would say, was what a normal female’s sex chromosomes looked like: XX.

Then, with the heel of his hand, he would erase the leg of one X. That, he would say was what happened to one of their daughter’s X chromosomes. It was incomplete, unfinished. This was why her sexual organs hadn’t developed the way they should, why her breasts would not grow, why she couldn’t ever have children.

What he did not say is that the “incomplete” X was not an X chromosome at all. It was a Y chromosome, the genetic marker for a male.

The child they were talking about was not a girl, at least not so far as her genes were concerned. She was a boy.

Louise Kiernan, *In Intersex Cases, Gender is a Complex Question*, CHICAGO TRIB., June 20, 1999, at 1-1 (interviewing Jorge Daaboul). Nussbaum provides a recent account of a 1998 case where the parents were better informed about the condition, Nussbaum, *supra* note 12, at 93–94, but still the parents were apparently not fully informed about the lack of long-term studies. In that case, the parent informed herself of contrary opinions through contacts with ISNA, yet ultimately chose surgery for the child. Nussbaum, *supra* note 12, at 95.

231. See FAUSTO-STERLING, *supra* note 11, at 50 (describing counseling techniques); KESSLER, *supra* note 12, at 21–24 (describing information provided to parents during diagnosis and noting deceptive and incomplete information imparted); COLAPINTO, *supra* note 11, at 95; Dreger, *supra* note 12, at 31 (recounting anecdotal reports of parents and adult patients being misinformed and deceived about the nature of the condition and the treatment); Cowley, *supra* note 74, at 64, 66.

232. The concept that intersex infants are incomplete may promote maternal guilt that more gestational time would have completed the infant’s sexual characteristics.

ploying the “unfinished” concept clinicians are suggesting to parents that it is the genitals that are ambiguous and not the gender:

The message . . . is that the trouble lies in the doctor’s ability to determine the gender, not in the baby’s gender per se. The real gender will presumably be determined/proven by testing, and the “bad” genitals (which are confusing the situation for everyone) will be “repaired.” The emphasis is not on the doctors’ creating gender but in their completing the genitals. Physicians say that they “reconstruct” the genitals rather than “construct” them. . . . The fact that the gender in an infant is “reannounced” rather than “reassigned” suggests that the first announcement was a mistake because the announcer was confused by the genitals. The gender always was what it is now seen to be.²³³

Physicians have provided parents information that simplistically concentrates attention on creating typical appearing genitals. For the parent with an intersex child or a male child without a penis, this is beguiling because it offers hope that physicians and parents can correct the condition by the surgical assignment of sex and careful rearing. Yet, physicians have long known that sex determination and sex differentiation are far more complex than what a child’s genitals look like.²³⁴ Merely changing the genitals does not alter the chromosomal, genetic or hormonal determinants of sex and so does not change an intersex child or a male without a penis (as J/J was) into an infant of the assigned sex. Surgery merely alters one aspect of sex differentiation: the appearance of the genitals. Moreover, infant cosmetic surgery on the genitals and careful rearing cannot erase the prenatal influences on sexual identity.²³⁵ Thus, at best, physicians adhering to Money’s theories could offer parents a child that “looked” like a child of the assigned sex and parents might rear a child to “act” like a child of the assigned sex. But parents

233. KESSLER, *supra* note 12, at 23.

234. Intersex is not merely a condition of the genitals, but of a sexually dimorphic brain. See Reiner, *Teenage Girl*, *supra* note 96 (noting the complexity of intersex conditions and uncertainty as to causes); see also Milton Diamond, *Human Sexual Development: Biological Foundation for Social Development*, in HUMAN SEXUALITY IN FOUR PERSPECTIVES 22, 38–39 (F.A. Beach ed., 1976); Grumbach & Conte, *supra* note 2, at 1304–31.

235. Grumbach & Conte, *supra* note 2, at 1330 (discussing role of prenatal hormones and other influences on sexual identity and acknowledging scientific uncertainty as to the determinants of sexual identity).

needed to understand that, given the complexities of sex determination, they would never have a typical child of that assigned sex, nor could they change fundamental aspects of sex differentiation that the child retained.

Parents require detailed information about the condition, the efficacy of treatment and the alternatives in order to weigh the burdens of surgically assigning a child to a gender, risking reproductive and erotic possibilities, necessitating future surgeries and lifelong medical and hormonal treatment.²³⁶

3. Perpetuating Secrecy and Deception

Deception and secrecy are probably the most unusual and harmful aspects of the medical treatment prescribed for intersex conditions.²³⁷ Money contended that the sex of rearing must be unequivocal and as a result, the treatment necessarily justified deception as the children matured. But, as the children grew older, this secrecy and deception had the added consequence of preventing their participation in later treatment choices.²³⁸ Parents were counseled to raise these children without

236. In the context of involuntary sterilization generally, one court commented, "An individual's right to procreate is fundamental. . . . Sterilization involves a surgical invasion of bodily integrity. It destroys 'an important part of a person's social and biological identity,' . . . can be traumatic for the individual, and can have 'long-lasting detrimental emotional effects.'" *In re Romero*, 790 P.2d 819, 821 (Colo. 1990) (en banc) (citations omitted) (upholding right of incapacitated mother of two to refuse sterilization where she expressed desire to have additional children).

237. A recent prize-winning student essay advocates deception in the case of androgen insensitivity syndrome (AIS) discovered at adolescence. AIS patients with the complete form of this condition are genetic males who, for lack of receptors necessary to masculinize, will grow up looking like females and developing a female sexual identity but possessing an underdeveloped vagina and lacking ovaries. The condition is sometimes overlooked until adolescence when it is discovered because the child fails to menstruate. The medical student argues that both the parents and the adolescent child should be shielded from knowledge of AIS. Since, "[t]he only services the physician can provide are surgical reconstruction of the vagina and counselling on adoption, . . . [the author suggests that if] the patient is completely comfortable with her female sexuality . . . [then] physicians who treat AIS patients are justified in not disclosing the information that the patient is genetically male." Anita Natarajan, *Medical Ethics and Truth Telling in the Case of Androgen Insensitivity Syndrome*, 154 CANADIAN MED. ASS'N J. 568-69 (1996).

238. See Colapinto, *The True Story*, *supra* note 11, at 95. JJ resisted hormone treatment and four years of unyielding pressure and deception by both Dr. Money and her local treatment team to undergo vaginal reconstruction. See Colapinto, *The True Story*, *supra* note 11, at 70-71; see also FAUSTO-STERLING, *supra* note 11, at 64-66 (discussing secrecy and deception); Groveman, *supra* note 84, at 357-59 (discussing life with

equivocation as to the child's assigned sex and to withhold information from the child so that the child would feel secure in his or her gender.²³⁹

AIS, recounting surgery and ongoing medical treatments, stating that doctors "implored my parents never to tell me the truth" and describing how she finally discovered her AIS diagnosis at age 20 by conducting her own medical detective work).

239. Wilson and Reiner describe the rationale for that secrecy:

At the time of initial gender assignment, to protect the child's psychosexual development from potentially hurtful comments, physicians have generally counseled families not to discuss any of this with other family members or friends. Further, based on the theory that any doubt may undermine development of a gender identity concordant with the assigned sex of rearing, they also advise the family not to discuss the child's condition with the child.

Wilson & Reiner, *supra* note 62, at 363. Wilson and Reiner explain that as medical records become more easily obtainable, secrecy is increasingly unrealistic and out of step with current views of patient rights and patient autonomy. See Wilson & Reiner, *supra* note 62, at 364; see also Diamond, *Pediatric Management*, *supra* note 87, at 1026 ("Parents and clinicians have often concealed aspects of surgery and treatment from the child and excluded maturing children from medical management decisions. . . . Adults who underwent these procedures in childhood are now presenting at clinics ignorant of their history."); Dreger, *supra* note 12, at 27, 30–32 ("Clinicians treating intersexuality worry that any confusion about the sexual identity of the child on the part of relatives will be conveyed to the child and result in enormous psychological problems, including potential 'dysphoric' states in adolescence and adulthood."); Groveman, *supra* note 84, at 357 (commenting that, when parents received AIS diagnosis and were told of the infant surgery, "the sole instruction my parents received . . . was one of 'damage control,' calculated to confirm a solid image that I was their daughter in the same breath that doctors enjoined them that they should not disclose my true diagnosis to anyone, least of all me.").

Money suggests that displayed ambivalence to the gender assigned is fatal to success. See MONEY, *SEX ERRORS* 1994, *supra* note 17, at 66 ("If a change must be made [in the announcement of sex], then it should be made only once and forever, with no delay or vacillation."); MONEY, *SEX POLICE*, *supra* note 30, at 319 (suggesting that "[t]he effect of hearing about one's infantile medical history from the children of adult members of the community grapevine" was a possible factor in the explanation for the failure of JJ's case). Fundamentally, Money's idea of a success was measured by whether the sex-reassigned person accepted without question the imposed gender switch. MONEY, *MAN & WOMAN*, *supra* note 12, at 153, 178–79. Arguably, a superior measure of success is whether the individual, given all the facts, would have made that gender decision or would have chosen to maintain the imposed gender.

Money acknowledged that secrecy was problematic in practice and so eventually advocated disclosure.

The withholding of information can be extremely traumatic, as the patient will soon realise that things are being withheld and will resort to inferential guesswork. . . . When they grew up, several of these [hermaphroditic] patients confronted me with the folly of this policy, for they had known all

The medical community's enthusiasm to raise intersexed or sex-reassigned babies without ambiguity is necessarily deceptive²⁴⁰ because, despite the dogma, the child's genitals and not the child's gender were rendered unequivocally male or female by surgery.²⁴¹ Secrecy persists even today, as one physician recently explained, "[i]f they have an excellent outcome and they look perfect, . . . I would want to downplay [the original ambiguity] as much as possible."²⁴²

In a revealing case study debated in the Hastings Center Report, ethicists considered whether *either* a sixteen-year-old female or her parents should be informed when the teen seeks treatment for failure to menstruate.²⁴³ Upon discovery "that the girl has an XY genotype, a genetic abnormality called testicular feminization"²⁴⁴ and "precancerous testes that require surgical removal" and will need vaginal surgery to have intercourse, the question arose whether the child or the parents should be told the genetic information or the fact that she is "really a guy."²⁴⁵ The treating physician wonders whether he can withhold the

along that they had been dealt with insincerely. In the majority of instances, they also knew exactly what information was being withheld. . . .

John Money, *Birth Defect of the Sex Organs: Telling the Parents and the Patient*, 10 BRIT. J. SEXUAL MED. 14, 14 (1983) [hereinafter Money, *Birth Defect*].

240. In her prize winning essay, Natarajan urges physicians to keep secret the genetic male status of women with androgen insensitivity. She reasons that the knowledge will be too psychologically damaging for them and so justifies the ethics of deception. See Natarajan, *supra* note 237, at 570.

AIS women themselves, on the other hand, express a desire to know the truth of their condition. See Anonymous, *Letter to Editor*, 154 CANADIAN MED. ASS'N J. 1832, 1832 (1996); Sherri A. Groveman, *Letter to the Editor*, 154 CANADIAN MED. ASS'N J. 1829, 1832 (1996); B. Diane Kemp, *Letter to the Editor*, 154 CANADIAN MED. ASS'N J. 1829, 1829 (1996). Co-author Milton Diamond's present research with 50 persons with AIS supports the contention that patients desire to know their complete history.

241. See Dreger, *supra* note 12, at 27-30. Moreover, when patients are not given complete information about their birth, they sometimes do not appreciate the sex-related risks they continue to bear. See Dreger, *supra* note 12, at 32-33.
242. Cowley, *supra* note 74, at 66 (quoting Dr. Antoine Khoury, chief of pediatric urology at Toronto's Hospital for Sick Children).
243. See Sherman Elias & George Annas, *Commentary, The Whole Truth and Nothing But the Truth*, HASTINGS CENTER REP. Oct./Nov. 1988 at 35, 35-36; Brendan P. Minogue & Robert Taraszewski, *Commentary, The Whole Truth and Nothing But the Truth?* HASTINGS CENTER REP. 34 Oct./Nov. 1988, at 34.
244. *Case Studies: The Whole Truth and Nothing But the Truth?*, HASTINGS CENTER REP., Oct./Nov. 1988, at 34, 34. Because of current sensitivity to the effect on the patient of labeling the condition "testicular-feminization" the condition has been relabeled "androgen insensitivity syndrome" (AIS). See MONEY, SEX ERRORS 1994, *supra* note 17, at 27.
245. Minogue & Taraszewski, *supra* note 243, at 34.

information until the child is twenty-one.²⁴⁶ Two authors suggest that the physician's concern is justified.²⁴⁷ They accept that the child's parents might become "emotionally distraught" and come to regard her as a "freak" or might at some point divulge the harmful information to her.²⁴⁸ The authors conclude that if "the functions of guardians to secure the wishes and welfare of minors . . . [cannot] be secured by disclosing [the patient's] genetic identity to her parents, then there seems no sound ethical reason to disclose this information in these circumstances."²⁴⁹

Addressing two fundamental questions, the authors reason:

"Would a typical physician act differently from [the hypothetical doctor withholding information]?" The answer is "No!" Some, of course might inform her, but disclosing the information is by no means customary within the profession. . . . "Would a hypothetical reasonable person want this information revealed to her at this time?" Probably not. What reasonable person would needlessly choose to make a bad situation worse?²⁵⁰

The essay authors suggest that a loosely-constructed therapeutic privilege applies to justify long-term deception of both the patient and the teen's parents based merely on the physician's belief that reasonable patients would not want to know such matters. Yet, contrary to this position, the judicial construction of the informed consent doctrine assumes patients want to know what is relevant and material to their condition.²⁵¹ As the *Canterbury* court cautioned when fashioning this therapeutic privilege to withhold information from the patient,

246. See Minogue & Taraszewski, *supra* note 243, at 34.

247. See Minogue & Taraszewski, *supra* note 243, at 34.

248. Cf. Minogue & Taraszewski, *supra* note 243, at 34-35 (recognizing the physician's concerns surrounding disclosure).

249. Minogue & Taraszewski, *supra* note 243, at 35. The authors suggest the information is not "relevant" since nothing can be done and all "immediate problems can be addressed without revealing the information about her genetic abnormality." Minogue & Taraszewski, *supra* note 243, at 34.

An alternate position has been advanced that suggests that full disclosure rather than deception to both parents and child may be preferable. See Elias & Annas, *supra* note 243, at 35-36.

250. Minogue & Taraszewski, *supra* note 243, at 35.

251. A physician bears the burden of producing evidence that the therapeutic privilege negates the duty to disclose, and only then, "the patient has the ultimate burden of proving the nonexistence of the exception." *Bernard v. Char*, 903 P.2d 676, 684 (Haw. App. 1995), *cert. granted and clarified on other issues*, 903 P.2d 667 (1995).

The physician's privilege to withhold information for therapeutic reasons must be carefully circumscribed, however, for otherwise it might devour the rule itself. The privilege does not accept the paternalistic notion that the physician may remain silent simply because divulgence might prompt the patient to forego therapy the physician feels the patient really needs. That attitude presumes instability or perversity for even the normal patient, and runs counter to the foundation principle that the patient should and ordinarily can make the choice himself. Nor does the privilege contemplate operation save where the patient's reaction to risk information, as reasonably foreseen by the physician, is menacing. And even in a situation of that kind, disclosure to a close relative with a view to securing consent to the proposed treatment may be the only alternative open to the physician.²⁵²

Physicians both marginalized the participation of parents and enlisted parents in maintaining secrecy into their children's adulthood²⁵³ without contemplating the actual risk of disclosure to the patient based on the unproven premise that unambiguous genitals, unequivocal child-rearing practices and a lack of information about the original condition would benefit children. The social and psychological costs and the

252. *Canterbury v. Spence*, 464 F.2d 772, 789 (1972) (footnotes omitted). See also *McNichols*, *supra* note 163, at 728 (commenting with approval on the narrow scope of therapeutic privilege crafted by *Canterbury*).

253. The *J/J* case, communications from former patients, and ISNA discussions share a striking common theme that information, even in adulthood, was desperately wanted but difficult to obtain. See Kipnis & Diamond, *Pediatric Ethics*, *supra* note 11, at 406–07. These stories suggest a deviation from the so-called common view:

[A] physician has a fiduciary duty to inform a patient of abnormalities in his or her body. The basis of this duty is that the patient has a right to know the material facts concerning the condition of his or her body, and any risks presented by that condition, so that an informed choice may be made regarding the course which the patient's medical care will take. The patient's right to know is not confined to the choice of treatment once a disease is present and has been conclusively diagnosed. Important decisions must frequently be made in many non-treatment situations in which medical care is given, including procedures leading to diagnosis. . . . These decisions must all be taken with the full knowledge and participation of the patient. . . . The existence of an abnormal condition in one's body, the presence of a high risk of disease, . . . are all facts which a patient must know in order to make an informed decision on the course which future medical care will take.

Gates v. Jensen, 595 P.2d 919, 922–923 (Wash. 1979) (en banc) (citation omitted).

medical damage that secrecy can promote were left out of the equation.²⁵⁴

A last cost of secrecy should be mentioned. Typically, patients eventually discover their condition from an inadvertent family slip, community gossip or personal investigation into puzzling aspects of their lives. The patients thus learn what they were never supposed to have found out. Even more disturbing to them, the former patients discover that their deformities are unspeakably shameful in the minds of parents and physicians. This revelation, usually coming without support, can be devastating.²⁵⁵ They wonder why they were not accepted and loved as they were. This makes manifest the fear of romantic/erotic relations and reduces the pursuit of intimate contacts. Last, former patients learn that since childhood they have been systematically deceived by the very people who should have been the most trustworthy: parents and physicians. The harm caused by deception is needless²⁵⁶ and often drives a wedge between the children, their parents, and physicians that persists into adulthood. Critics of deception argue that honesty, full disclosure, and counseling is a therapeutically superior approach.²⁵⁷

254. See Preves, *supra* note 218, at 414.

255. The experience of Cheryl Chase, Director of the Intersex Society of North America, is instructive

At the age of 35 Chase had a nervous breakdown. Although she had been able [with difficulty] to access her medical records in her early 20s, . . . [t]he years of secrecy, unexplained surgeries, and sexual dysfunction caused by removal of her clitoris had taken a huge toll on her. "Until I was 35, I was ashamed and terrified that people would find out that I was different than a woman. Like many, supposedly happy and successful patients, I was silenced."

Yronwode, *supra* note 85, at 1. Money counseled against secrecy by 1983:

I learned my lesson, the hard way, particularly in those cases in which the parents forbade the transmission of any of the diagnostic history and clinical information to the child. When they grew up, several of these patients confronted me with the folly of this policy, for they had known all along that they had been dealt with insincerely.

Money, *Birth Defect*, *supra* note 239, at 14.

256. See Kipnis & Diamond, *Pediatric Ethics*, *supra* note 11, at 407; Diamond, *Pediatric Management*, *supra* note 87, at 1026.

257. See, e.g., Diamond & Sigmundson, *Management of Intersexuality*, *supra* note 11, at 1048; Dreger, *supra* note 12, at 31–32; Elias & Annas, *supra* note 243, at 35–36; Kipnis & Diamond, *Pediatric Ethics*, *supra* note 11, at 407; Preves, *supra* note 218, at 417–18.

4. Failing to Disclose The Uncertainty of the Long-Term Outcome

Parents consenting to surgeries might have responded differently had they understood the innovative nature of the treatment;²⁵⁸ certainly it was the obligation of clinicians to so inform them.²⁵⁹ However, because the J/J case as originally presented had become a classic for the academic and medical community,²⁶⁰ clinicians probably projected more confidence in the procedure than it deserved.²⁶¹ Clinicians asserted the potential for successful “normalization” because the literature suggested such, when, in fact, insufficient data existed to support their premises.²⁶² Indeed, clinicians were advised as recently as 1994, to project confidence in the treatment recommendations when counseling parents:

This [simplified medical] knowledge will help [parents] feel convinced that what is being done is correct and that it is their own decision as well as that of experts. *Otherwise, they might easily feel that they are acquiescing to an intervention based on trial and error, which might prove to be all error.*²⁶³

As to treatment of micropenis in particular, Money counseled:

It is [. . .] fairly common to recommend to the parents that they raise a male baby with micropenis as a girl. This is, of course, a very difficult decision for parents to make, and they must be given all the information possible to understand the rationale and consequences of the decision. First and

258. The premise that the surgery would be successful was so ingrained that one 1998 nursing journal characterized refusal to consent to sex assignment surgery as child neglect. See Rossiter & Diehl, *supra* note 12, at 61. However, a responsive comment by Anita Catlin noted that the success of intersex surgery is so uncertain that parental refusal should not be overridden. Anita J. Catlin, *Ethical Commentary on Gender Reassignment: A Complex and Provocative Modern Issue*, 24 J. GYNECOLOGICAL & NEONATAL NURSING 63 (1998).

259. See FURROW, *supra* note 52, at 386–87 (commenting, “courts seem willing to tolerate clinical innovation so long as a patient is properly informed as to the innovative and untested nature of the procedure”).

260. See Diamond & Sigmundson, *Management of Intersexuality*, *supra* note 11, at 1046.

261. See Kipnis & Diamond, *Pediatric Ethics*, *supra* note 11, at 406 (“it is not possible for a patient’s parents to give informed consent to these procedures, precisely because the medical profession has not systematically assessed what happens to the adults these infant patients become.”).

262. See Dreger, *supra* note 12, at 32; Diamond, *Pediatric Management*, *supra* note 87, at 1026.

263. MONEY, SEX ERRORS 1994, *supra* note 17, at 67 (emphasis added).

foremost, *they [parents] need to know that gender identity and role are not preordained by genetic and intrauterine events alone, but that their differentiation is also very much a postnatal process and highly responsive to social stimulation and experience. Thus, they need to be reassured that their baby can grow up socially as a girl and fall in love as a female.*²⁶⁴

The assurances that counselors were urged to convey concerning the effectiveness and foundation of the treatment were not accurate because the only experience which clinicians could report was actually drawn from anecdotal and incomplete case reports that were appearing in the medical literature.²⁶⁵ Thus, practitioners who followed the counseling advice misled parents by reassuring them that the treatment could work without a sound basis for that premise.

5. Ignoring the Child's Right to an Open Future

Surgical intervention has been promoted as a way to offer the intersexed child a more "normal" life. Remarkably, proponents of surgical treatment ignore the possibility that the child might one day have a different concept of "normal" and want to choose a different course of treatment, or none at all.²⁶⁶ Surgical proponents discount the possibility that the intersexed adult might desire to participate in their treatment decisions.²⁶⁷

264. MONEY, *SEX ERRORS* 1994, *supra* note 17, at 54 (emphasis added).

265. Indeed, the American Academy of Pediatrics, in its 1996 recommendations on timing male genital surgery, stated "a person's sexual body image is largely a function of socialization" referencing only the decade-old and older work of John Money. *Timing of Elective Surgery*, *supra* note 12, at 590.

266. There is no doubt that doctors are choosing treatments based on social or personal value judgments; consider the following quote concerning clitoral surgery that favors appearance:

The clitoris is not essential for *adequate* sexual function and sexual *gratification* . . . but its preservation would seem to be *desirable* if achieved while maintaining *satisfactory* appearance and function. . . . Yet the clitoris clearly has a relation to erotic stimulation and to sexual gratification and its presence is desirable, even in patients with intersexed anomalies if that presence does not interfere with *cosmetic, psychological, social and sexual* adjustment.

KESSLER, *supra* note 12, at 37 (quoting Judson Randolph & Wellington Hung, *Reduction Clitoroplasty in Females with Hypertrophied Clitoris*, 5 J. PEDIATRIC SURGERY 224, 230 (1970)).

267. Wilson and Reiner comment:

A relevant rule extrapolated from the ethics surrounding the genetic testing of children is emerging that would weigh more heavily on the child's autonomy and right to an open future when making elective medical decisions. Recently, Laurence McCullough, medical ethicist at Baylor College of Medicine Center for Medical Ethics and Health Policy recommended:

When genetic conditions for which a child is at risk do not have biopsychosocial consequences until adolescence or adulthood, genetic testing for such condition should be postponed until later when the child can engage in informed assent as an adolescent or informed consent as an adult. Intersex conditions that neither are life-threatening nor involve chronic morbidity should be managed under this rule. Intersex conditions that are chronic and that involve manageable psychosocial consequences until adolescence or adulthood should be managed under this rule.²⁶⁸

Thus, he recommends that in balancing the desirability of normal-appearing genitalia with the foreclosure of the child's ability to later consent, the scales tip in favor of delaying treatment.²⁶⁹

[T]he right of the individual to determine what happens to his or her body has been increasingly asserted. Patients and families are demanding a voice in the issue of sex assignments and therapies. After all, the child's sex-of-rearing and gender identity are profoundly important to that child's life-long development and adjustment. Although parents may give consent for surgery, there is increasing movement toward obtaining a child's assent to procedures, particularly those which, like most genital "reconstructive" procedures, are elective from a medical viewpoint. This means delaying surgery until we can take into account the affected individual's determination of his or her own gender.

Wilson & Reiner, *supra* note 62, at 364; *see also* Schober, *supra* note 95, at 394 ("For the best long-term outcomes, we need to consider that surgical treatment methods do not 'cure' intersexuality, and that a procedure such as vaginoplasty should address a consenting and requesting patient's needs and desires, not parental and societal comfort.").

268. Laurence McCullough, "The Ethics of Gender Reassignment," Presentation at conference *1999 Pediatric Gender Reassignment: A Critical Reappraisal*, Dallas, Texas (April 30, 1999). *See also* Dena S. Davis, *Genetic Dilemmas and the Child's Right to an Open Future*, 28 RUTGERS L.J. 549, 575-81 (1997) (noting and approving of trend against conducting genetic tests to predict late-onset diseases and suggesting that parents who opt for testing "preclude the child's right and opportunity to make that decision for himself in adulthood").
269. In a 1998 case described by Nussbaum, the parents ultimately consented to surgery, even knowing the possibility the child might reject the assigned gender. They re-

IV. LEARNING FROM THE PAST: WHAT SHOULD THE FUTURE HOLD?

Some people increasingly doubt the efficacy of early surgery and many more acknowledge that more study is needed.²⁷⁰ Given the current state of medical knowledge, ethical considerations suggest the course of treatment should change. Medical uncertainty, the infant's inability to consent to this life-altering treatment and the child's right to an open future suggest that a "moratorium" on infant surgery is the best course when surgery is solely intended to cosmetically change ambiguous genitals.²⁷¹

These critics argue that parents of children with ambiguous genitalia would be better counseled to manage the psychosocial consequences of genital differences in childhood rather than opting for a surgical response. Nonsurgical approaches, such as individual and family

garded the potential social rejection of ambiguous gender as more destructive than the possibility the assigned gender would ultimately be rejected or the child would have lessened sexual sensitivity:

"As parents, we're often forced to make decisions for our children that are hard. And this is one of 'em, as far as I'm concerned." If Emma has regrets, Vicki [the mother] said, she'll be able to blame her family instead of herself. But Vicki's worst nightmare was that Emma might grow up and identify as male. In that case, it would be too late.

Nussbaum, *supra* note 12, at 97.

270. See *supra* note 95.

271. See KESSLER, *supra* note 12, at 74; Diamond, *Pediatric Management*, *supra* note 87, at 1025–1026; Diamond & Sigmundson, *Management of Intersexuality*, *supra* note 11, at 1047; Kipnis & Diamond, *Pediatric Ethics*, *supra* note 11, at 405–406; Reiner, *Sex Assignment*, *supra* note 82, at 1044. Kipnis and Diamond also recommend the moratorium remain in effect until the positive value of the surgery is documented with adequate follow-up study. Kipnis & Diamond, *supra* note 11. Others remain convinced that cosmetic clitoral surgery is appropriate. See Meyer-Bahlburg, *supra* note 109, at 15; Glassberg, *supra* note 85, at 152–153 (both defending cosmetic surgery). While suggesting that surgery continue on ambiguous genitalia, Glassberg is also open to change:

... we must learn from patients who resent how they were treated and those who are satisfied. If data become available to prove that a given approach should be changed, we should do this promptly. Today with valid, unbiased follow up data, and genetic, pharmacological and surgical tools, we should be able to produce a satisfying outcome for nearly all children born with this potentially devastating problem.

Glassberg, *supra* note 85, at 1309.

counseling to mitigate the stigma and develop coping strategies, preserve a child's right to self-determination.²⁷²

Those who have already undergone surgical treatment present other ethical dilemmas in light of the revelation that some continue to struggle with gender confusion, have unanswered medical questions and cannot obtain information as to what surgical procedures were performed on them when they were infants. There is no rational reason why secrecy surrounding the early treatment should persist into adulthood. The incomplete or inaccurate medical information can result in mistaken assumptions about the actual health risks individuals bear.²⁷³

For example, gonadectomy exposes patients to a definite risk of osteoporosis and creates a need for life-long hormone replacement and medical management.²⁷⁴ Adult intersexed individuals report that their attempts to obtain a clear diagnosis and understanding of the treatment in infancy are often frustrated.²⁷⁵ Therefore, some critics suggest that patients treated as infants whose treatment was cloaked with secrecy should be recontacted so that they can be provided with complete medical information.²⁷⁶ To the extent that new knowledge of J/J's case suggests that ongoing medical and psychological risks can be alleviated or lessened by more medical information, practitioners may have continuing ethical and legal duties to their former patients.²⁷⁷

272. See Diamond & Sigmundson, *Sex Reassignment*, *supra* note 11, at 303; see also Dreger, *supra* note 12, at 30, 33–34; see generally, Preves, *supra* note 218.

273. See, e.g., Preves, *supra* note 218, at 415 (reporting on fear of cancer as a result of incomplete medical information); Groveman, *supra* note 84, at 357–58.

274. See Intersex Society of North America, *Frequently Asked Questions: Hormone Replacement Therapy and Osteoporosis*, (visited July 15, 1999) <<http://www.isna.org/faq/htm>> (warning that persons who have had their gonads removed in childhood are at exceptionally high risk of osteoporosis).

275. See Morgan Holmes, *Is growing up in silence better than growing up different?* 2 *CHRYSLIS: THE JOURNAL OF TRANSGRESSIVE GENDER IDENTITIES* 7–9 (1997/1998) (describing mental disturbance and suicidal ideation); see, e.g., Cowley, *supra* note 74, at 66 (discussing case of Cheryl Chase, “not only was [she] denied information as a child but was lied to by doctors when she later tried to obtain her medical records.”); Colapinto, *supra* note 11, at 95 (recounting incidents of secrecy and resulting psychological pain and suffering).

276. See generally, Diamond, *Pediatric Management*, *supra* note 87, at 1026 (recommending that physicians “find ways to own up to these adults, initiating disclosure of medical histories that have been concealed”); Kipnis & Diamond, *Pediatric Ethics*, *supra* note 11, at 406–07 (same).

277. See, e.g., *Blaz v. Galen Hosp. Illinois, Inc.*, 982 F. Supp. 556, 560 (N.D. Ill. 1997) (noting that where there is a continuing duty the cause of action does not accrue until the defendant “had sufficient facts to understand that its treatment had placed [the] plaintiff at risk”); *Mink v. Univ. of Chicago*, 460 F. Supp. 713, 720 (N.D. Ill. 1978) (citing *Canterbury v. Spence*, 464 F.2d 772 (D.C. App. 1972)) (recognizing

CONCLUSION

We introduced this article with stories of two young men. One had contemplated a law suit against the physicians but was dissuaded when he learned that the medical malpractice standard in his state protected physicians who followed community standards of practice. The other young man was just discovering what occurred when he was a child.²⁷⁸ Their stories are remarkably similar to J/J's. Only through persistent medical detective work provoked by their inherent feelings of not belonging to their assigned gender were they able to learn of the failed surgical treatment that they had undergone in childhood. Neither parents nor physicians provided information until confronted.²⁷⁹ Like J/J,

ongoing duties to notify women of cancer risks related to treatment with DES discovered after treatment); *Schwartz v. United States*, 230 F. Supp. 536, 541 (E.D. Pa. 1964) (holding that veteran's hospital has duty to inform patient of newly discovered risks associated with prior treatment); *Tresemmer v. Barke*, 150 Cal. Rptr. 384, 394 (Cal. App. 1978) (holding that doctor had continuing duty to warn of later discovered risks associated with Dalkon Shield and statute of limitations was inapplicable); *Reyes v. Anka Research Ltd.*, 443 N.Y.S.2d 595, 597 (Sup. Ct. 1981) (noting that cause of action for failing to notify patient of recall of IUD continued until the time of reasonable discovery). *But see Schendt v. Dewey*, 520 N.W.2d 541, 548 (Neb. 1994) (holding that there is no duty to warn of cancer risks from radiation following termination of the physician-patient relationship). *See generally* Lori B. Andrews, *Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks*, 29 Hous. L. Rev. 149, 169 (1992) (discussing on-going duties to warn where genetic testing later reveals other as-yet-unknown links to diseases and carrier states); Andrea G. Nadel, Annotation, *Duty of Medical Practitioner to Warn Patient of Subsequently Discovered Danger From Treatment Previously Given*, 12 A.L.R.4th 41 (1981 & 1997 Supp.).

278. He explained, "the conclusion was that the doctors at the time of my birth did the best they knew how to do." Interview with Name Withheld on March 16, 1999.

279. One of the young men discussed above, sex reassigned at two months of age due to a micropenis, learned of his surgical procedures during family therapy in his teen years. This marked a turning point in his relationship with his parents, who then supported his decision to live as a man. He remains close to them. He reports that for a long time he felt, "how could you do this to me? . . . If they had known I was born as a boy, they wouldn't have raised me as a girl." He also explained that he never felt he was a girl, "When I was ten, I asked my mother if God makes mistakes." "My mother was left in the dark as much as I was [about my condition]." The doctors told his parents his testes were cancerous (although they were not). His parents were not clear at the time that he was born a boy, although he later learned that genetic tests at the time revealed he had a normal 46 XY karyotype a micropenis and normal testes. Interview with Name Withheld, on May 30, 1999.

The other learned of his medical history by confronting his physicians. He is now estranged from his parents. Interview with Name Withheld 2, on October 25, 1999.

each young adult now faces a lifetime of medical and surgical treatment to restore himself to his preferred gender.

What would a jury's reaction be if it were to judge the standard of care that clinicians employed in these cases? In jurisdictions rejecting *Helling v. Carey* and the application of ordinary negligence principles to malpractice actions, tort law renders itself impotent to hold the medical community accountable for decisions based on failed medical standards or to be an agent for change. These jurisdictions presume that the medical profession's internal safeguards sufficiently protect the public and that the standards so developed deserve judicial deference. Jurisdictions rejecting *Helling* presume that the medical community's standard of care springs from collective wisdom and not from collective ignorance. It is in these circumstances especially that the wisdom of Judge Hand rings most true.

Fortunately, the informed consent doctrine has more potential to change collective practices. The practice of deception and secrecy was never ethically well-grounded. Especially in those jurisdictions that have adopted a patient-oriented standard to judge informed consent, the counseling approach clinicians employed in the past is not defensible. The informed consent doctrine requires physicians to reveal material data including risks, efficacy and alternatives to patients, or their parents, in order to allow them to make informed decisions. The patient-oriented standard leaves little room for the inaccuracy and secrecy formerly employed in advising parents and patients. Providing parents with a fuller explanation of the risks, including the recently-reported failures of treatment and information about the successful adaptation of individuals raised without surgery, may well curb parental consent. After all, few parents would probably consent to such extensive treatment if physicians reveal that there is no scientific evidence supporting the premise on which treatment is based and that the child may ultimately reject the treatment and be left worse off for having undergone it.²⁸⁰

Finally, a fuller airing of the ethical dimensions of treatment and the duties of informed consent may prompt a more cautious approach to surgical intervention.²⁸¹ Recognizing the child's right to an open fu-

280. *But see* Nussbaum, *supra* note 12, at 94–97 (describing parents' decision to consent to surgery recommended by surgeons even after meeting members of ISNA and learning of risk of rejection of the assigned gender, potential loss of sexual sensitivity, and meeting dissatisfied former patients and no satisfied ones).

281. *See* KESSLER, *supra* note 12, at 75–76; Catlin, *supra* note 258, at 65; Diamond & Sigmundson, *Management of Intersexuality*, *supra* note 11, at 1047; Dreger, *supra* note 12, at 34; Kipnis & Diamond, *Pediatric Ethics*, *supra* note 11, at 405–407.

ture as part of the decisional calculation may yield a more measured approach in these difficult cases. Waiting to see what the child desires is the most sensible approach because, as it has been often stated: the most important sex organ is between the ears rather than between the legs.²⁸² ❄

Unfortunately, Dreger notes that ethicists have historically not been included in this debate. See Dreger, *supra* note 12, at 26 (noting the scant attention to the ethical issues until now). Times are changing, as evidenced by the devotion of an entire issue on this topic in the *Journal of Clinical Ethics* in 1998.

282. Milton Diamond, *Self-Testing: A Check on Sexual Identity and Other Levels of Sexuality*, in *GENDER BLENDING*, *supra* note 106, at 122.

