"First, Do No Harm"—The Fiction of Legal Parental Consent to Genital-Normalizing Surgery on Intersexed Infants

Kishka-Kamari Ford†

Medical professionals recognize the Latin mantra *Primum, non nocere*, "First, do no harm," as the first principle of medicine.¹ Yet, between one hundred and two hundred times a year in America,² pediatric surgeons do harm when they surgically "correct" the ambiguous genitalia of intersexed infants. These surgeries, which I call "genital-normalizing surgeries," are unjustifiably performed on an emergency basis and supported only by questionable science.

For at least two intersex conditions—clitoromegaly (large clitoris) and micropenis (small penis)—both the diagnosis of the condition and the ultimate result of the surgery are based on subjective notions of what doctors, parents, and society believe to be "normal-looking" genitals. The benefits of genital-normalizing surgery have yet to be documented. The physically and psychologically harmful effects have been all but ignored despite the outraged cries of the procedures' victims.

This Note exposes these surgeries as lacking legally necessary informed consent. Part I provides background information about the current medical diagnosis and treatment of intersexed infants in America. The scientific roots of the current model of treatment of intersexed infants are identified, and its principle assertions are critiqued. Part II reviews the doctrine of informed consent to medical treatment and considers whether the emergency exception to this doctrine can reasonably be applied to the birth of an intersexed infant. After consideration of the emergency exception to the general requirement of informed consent, this section discusses the legal fiction of parental consent to medical treatment for minor children. Part III analyzes the current model of treatment of intersexed infants to determine whether or not it can fairly be characterized as "experimental" treatment and thus outside of the bounds of that to which the parents of an intersexed infant can legally consent.

† Yale Law School, J.D. 2001.
1. Michael Kowalski, *Applying the "Two Schools of Thought" Doctrine to the Repressed Memory Controversy*, 19 J. LEG. MED. 503, 505 (1998) ("Primum non nocere (first do no harm) is a phrase recognized as one of the most significant admonitions from the Hippocratic Oath.").
I. THE DIAGNOSIS AND TREATMENT OF INTERSEXED INFANTS

Those born with genitalia displaying characteristics of both the male and female genders (so-called “ambiguous” genitalia) are commonly referred to as “intersexed.” Despite the secrecy surrounding the diagnosis and treatment of intersexuality, the birth of an intersexed infant is actually a frequent occurrence. Although an accurate quantification of the frequency of intersexuality is very much dependent upon the physician’s subjective determination of what counts as “ambiguous” in the appearance of an infant’s genitalia, most experts conservatively estimate that 1 in 2,000 babies born alive in America have ambiguous genitalia. The American Association of Pediatrics concurs that ambiguous genitalia rank among the “common childhood problems.”

A medical diagnosis of most intersex conditions is characterized by a newborn’s visibly ambiguous genitalia and focuses on the size, shape, and cosmetic appearance of the organ that usually develops into a clitoris for girls or a penis for boys. Examples of such conditions are “clitoromegaly,” “micropenis,” and “hypospadias.” Some conditions can be clearly diagnosed. For example, hypospadias is plainly characterized by a urethral meatus (opening of the urethra) which is located somewhere along the shaft of the penis instead of at its usual location on the tip. Other conditions are less distinct. For example, clitoromegaly is defined as the occurrence of an “abnormally large” clitoris on an infant girl, while micropenis is defined as the occurrence of an “abnormally small” penis on an infant boy.

The Current Model of Treatment of Intersexed Infants

Clitoromegaly and micropenis are almost always diagnosed at birth and...
immediately addressed with surgery. The model of treatment of intersexed infants was established a half-century ago by Johns Hopkins Sexologist John Money and his colleagues. This treatment model, which is currently upheld as the official policy of the American Academy of Pediatrics, is grounded in two principle assertions. First, that because infants are born psychosexually neutral at birth, they can be transformed into either gender as long as their sexual anatomy can be surgically altered before the age of two to believably conform to that gender. Secondly, that “normal-looking” genitals are critical for an infant’s healthy psychosexual development. These two assertions are mutually dependent to the extent that performance of genital-normalizing surgery to establish the second assertion depends upon the truth of the first assertion. In line with these two assertions, the birth of an intersexed infant is treated as an emergency requiring immediate gender assignment and genital-normalizing surgery.

Doctors employ a disturbingly unscientific methodology to assign a gender to an infant with micropenis or clitoromegaly. In following John Money’s theory that “the presence or absence of the penis [is] the critical anatomical factor,” this methodology focuses on the size of the infant’s phallus. The assignment of gender for infants with micropenis or clitoromegaly is made with two more principle assertions in mind. First, genetic males (those with XY genes) must have adequately-sized penises and no vagina if they are to be assigned the male gender. Secondly, genetic females (those with XX genes) should always be assigned to the female gender and surgically altered to look as much like normal girls as possible (that is, without abnormally large clitorises). A genetic male newborn’s penis is currently deemed “adequate” if it is no less than 2.5 centimeters long when stretched. A genetic female’s clitoris is deemed “too large” if it exceeds 1.0 centimeter at birth. According to Alice Domurat Dreger, author of “Ambiguous Sex”—or Ambivalent Medicine? Ethical Issues in the Treatment of Intersexuality, “surgeons seem to demand far more for a penis to count as ‘successful’ than for a vagina to count as such.” The default gender is therefore always female because it is the easiest gender
to create surgically. Domurat Dreger finds that "[f]or a constructed vagina to be considered acceptable by surgeons specializing in intersexuality, it basically just has to be a hole big enough to fit a typical-sized penis. It is not required to be self-lubricating or even to be at all sensitive." \(^{21}\)

The principle assertions that dictate genital-normalizing surgery lack a proper scientific foundation. Even the case on which John Money and his colleagues rely to justify current gender-normalizing practices is of ambiguous result. The test subject of that case, often referred to as the "John/Joan" case, \(^{22}\) has recently come forward to challenge the apparent success of the experiment.

The John/Joan case was the story of David Reimer ("John"), one of a set of infant male twins whose penis was severely burned beyond repair during circumcision. Faced with the tragic destruction of their infant boy's penis, John's parents sought the advice of John Money. Money recommended that John be surgically reassigned and reconstructed as a baby girl. This decision was motivated by the fear that, as a man without a penis, "[John] will be unable to consummate marriage or have normal heterosexual relations; he will have to recognize that he is incomplete, physically defective, and that he must live apart." \(^{23}\) Doctors "completed" John by removing his traumatized penis, fashioning a vulva out of his scrotum, and sending him home as "Joan."

John Money followed Joan's progress over a period of years and eventually concluded that "[Joan's] record to date offers convincing evidence that the gender identity gate is open at birth for a normal child no less than for one born with unfinished sex organs... and that it stays open at least for something over a year after birth." \(^{24}\) The "successful" John to Joan sex re-assignment was hailed for decades as proof that nurture, rather than nature, defines a person's sexual identity such that any infant can be surgically altered to fit either gender as long as surgery is performed early. \(^{25}\) But recently, the real outcome of John Money's experiment was revealed by John himself.

In 1994, Milton Diamond, Professor of Anatomy and Reproductive Biology, re-opened the John/Joan case and interviewed John about his experiences as "Joan." \(^{26}\) Milton Diamond reports that John is now in his thirties, living as a man, and married to a woman whose children he adopted (having himself been rendered infertile by the surgical removal of his testicles). \(^{27}\) He agreed to

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21. Id.
22. This summary of the John/Joan case draws upon JOHN MONEY & A.A. EHRHARDT, MAN AND WOMAN, BOY AND GIRL (1972); Kipnis & Diamond, supra note 2, at 398-402; and Domurat Dreger, supra note 4, at 24-25.
25. Domurat Dreger, supra note 4, at 25.
27. Id.
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speak to Milton Diamond because he "strongly desires his case history be made available to the medical community to reduce the likelihood of others having his psychic trauma."28

John and his mother report that Joan rejected the assigned female gender almost immediately.29 John's mother even remembers Joan trying to tear off her dress on the way home from surgery—"I think he knew it was a dress and that it was for girls and he wasn't a girl."30 His parents report that they are "guilt ridden" about having subjected their son to this experiment.31

Milton Diamond reports that "Joan's realization that she was not a girl jelled between ages 9 and 11 years."32 Joan remembers saving her allowance to secretly buy toys typically associated with boys and often trying to stand to urinate despite the absence of a penis.33 By the age of twelve Joan often refused to take the female hormones prescribed to help develop a female body.34 She was appalled by her development of breasts and adamantly refused to wear a bra.35 She was repeatedly terrorized by female schoolmates both for her masculine-appearance and tomboyish mannerisms.36

By age 14, Joan demanded answers of her father and was finally made aware of the gender reassignment. John remembers that after that conversation "[a]ll of a sudden everything clicked. For the first time things made sense and I understood who and what I was."37 Joan immediately reclaimed the male gender and became John again. From age 14 until the present, John has experienced a long, hard course of male hormonal treatments, mastectomies, and penile reconstruction surgeries. His mutilated genitals still appear far from normal and are barely functional, yet John feels every bit a man. His final recollections on his experience are profound:

"Doctor . . . said, it's gonna be tough, you're going to be picked on, you're going to be very alone, you're not gonna find anybody unless you have vaginal surgery and live as a female. And I thought to myself, you know I wasn't very old at the time but it dawned on me that these people gotta be pretty shallow if that's the only thing they think I've got going for me; that the only reason why people get married and have children and have a productive life is because of what they have between their legs . . . If that's all they think of me, that they justify my worth by what I have between my legs, then I gotta be a complete loser."38

John Money's "proof" of his theories about the flexibility of gender was

28. Id. at 299.
29. Id.
30. Id. at 299.
31. Id. at 303.
32. Id. at 299.
33. Id. at 299-300.
34. Id. at 300.
35. Id.
36. Id.
37. Id. at 300.
38. Id. at 301.
based only on the feigned success of the John/Joan case. Furthermore, John Money was virtually the only scientist to put forth any guidelines for the management of the intersexed. Milton Diamond has concluded after his reopening of the John/Joan case that “there is no support for the postulates that individuals are psychosexually neutral at birth or that healthy psychosexual development is dependent upon the appearance of the genitals.”

David Reimer’s broken silence proves that “Money’s hypothesis remains a mere hypothesis to this day.”

Because those who follow John Money’s model of treatment still regard the birth of an intersexed child as a medical emergency, American courts have never considered the requirement of legal consent in genital-normalizing surgery. The classification of genital-normalizing surgery as an emergency is a mistake and has resulted in disastrous outcomes. No data has supported the contention that such surgery is beneficial. On the contrary, available evidence reveals that genital-normalizing surgery causes substantial and unreasonable harm to infant subjects. Furthermore, an analysis of the questionable theoretical bases for the current model of treatment and the coercive behavior of surgeons who recommend genital-normalizing surgery reveals that the parents of intersexed infants are impeded from giving legal informed consent on their behalf.

II. THE DOCTRINE OF INFORMED CONSENT

The doctrine of informed consent is based on the legal principle of battery, which holds that an offense to personal dignity occurs when one violates another’s bodily integrity without full and valid consent. Generally, if a doctor obtains a patient’s consent to medical treatment without informing that patient of the nature of the treatment or the extent of the harm that is necessarily involved, the patient’s consent is held not to be an “informed consent.” Legal informed consent requires the satisfaction of three criteria before a medi-
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egal informed consent requires the satisfaction of three criteria before a medical decision will be seen as legally informed. First, the decision must be informed. This requires the doctor to provide the patient with adequate information about the proposed treatment, including its alternatives. Second, the decision must be voluntary. This requires the doctor to abstain from coercing or otherwise improperly influencing the patient’s decision. Third, the decision must be competent. This requires that the patient “have an 'appreciation' of the nature, extent, and probable consequence of the conduct consented to.” By ensuring that the patient knowingly consents to being treated by the clinician, the doctrine of informed consent serves both to protect the patient’s body from uninvited invasion and to protect the clinician from unwanted tort liability.

The Emergency Exception to the Requirement of Informed Consent

When a doctor provides treatment necessary in a medical emergency, that treatment is excepted from the general requirement of informed consent. In the celebrated case Schloendorff v. Society of New York Hospital, Justice Cardozo, writing for the majority, reasoned that the requirement of informed consent is necessary “except in cases of emergency where the patient is unconscious, and where it is necessary to operate before consent can be obtained.” Since Schloendorff, courts in all jurisdictions have repeatedly returned to Justice Cardozo’s famous words and refused to find a person who responds to a medical emergency in violation of the law.

Defining what exactly constitutes an “emergency” has been difficult. In Dunham v. Wright, the Third Circuit struggled with what it described as the “delicate balance between the right of the patient to choose the treatment he wishes to undergo and the freedom of the physician to practice responsible and progressive medicine without fear of frequent litigation.” However, two criteria must be satisfied before a person who acts upon another person will be said to have been responding to an emergency. First, that the person acted upon is, or is reasonably believed to be, in immediate danger. Second, that the

way he sees fit, then the patient’s consent was induced by a substantial mistake and . . . is not effective”).

46. Id. at 35-38.
47. Id. at 35 (citing RESTATEMENT (SECOND) OF TORTS § 892A (1979)).
48. Id. § 892D (1979).
50. Id. at 93.
51. E.g., Barnett v. Bachrach, 34 A.2d 626 (D.C. 1943) (holding that consent is unnecessary when a patient requires an immediate operation); Luka v. Lowrie, 136 N.W. 1106 (Mich. 1912) (finding that a doctor who amputated an unconscious accident-victim's foot to save his life not liable for battery).
53. Id. at 941 (defining an emergency as a situation "which places the patient in immediate danger"); see also RESTATEMENT (SECOND) OF TORTS § 892D (1979) ("[A]n emergency makes it neces-
actor has no reason to believe that the person acted on would have declined the action if they had been able.\textsuperscript{54} In the specific case of minors, the second prong of the emergency response test is dropped and courts simply define emergency action as action “appropriate to protect the ‘life or health of the child.’”\textsuperscript{55}

The practice of genital-normalizing surgery on infants does not pass either prong of the emergency response test. First, there is nothing life-threatening about a large clitoris or a small penis. In fact, it is conceded as medical fact that the genitals of an intersexed infant “are not diseased and do not have to be treated as pathological.”\textsuperscript{56} The intersexed infant is in no immediate danger because of the size and shape of his/her penis or clitoris. In fact, the intersexed infant is not even in future danger because of the size and shape of his/her penis or clitoris. Secondly, recent advocacy by post-operative intersexuals who resent the imposition of genital-normalizing surgery on them as infants reveals that many post-operative intersexuals would have declined the action if they were able.\textsuperscript{57}

Despite the fact that intersexuality is not a life-threatening disorder, medical professionals have continued to treat it as an emergency by focusing not on the physical dangers of ambiguous genitalia but on the psychosocial problem of intersexuality. Unfortunately, this focus is misguided.

Science rebuts the contention of John Money and his followers that “normal-looking” genitals are critical for an infant’s healthy psychosexual development. Research shows that most children under the age of two display no concern about differences in the size and shape of their own genitals. Pediatrician Janet Goodall’s studies of children under the age of two reveals that “the[ir] approach to life is totally egocentric.”\textsuperscript{58} She concludes that “[c]hildren are more involved in their own internal world than in making more than superficially disparaging comparisons, such as something’s being bigger or smaller than is desirable.” Given that genital-normalizing surgery can be performed at any time in a person’s life, and in fact may have better physical results if per-

\textsuperscript{54} Restatement (Second) of Torts § 892D (1979).
\textsuperscript{55} Tania E. Wright, A Minor’s Right to Consent to Medical Care, 25 How. L.J. 525, 528 (1982).
\textsuperscript{56} Dreger, supra note 3, at 352. There is only one intersex condition that fairly constitutes a medical emergency and that is congenital adrenal hyperplasia which may indicate an underlying life-threatening metabolic problem. Bruce E. Wilson & William G. Reiner, Management of Intersex: A Shifting Paradigm, 9 J. CLINICAL ETHICS 360, 365 (1998) (“[T]he only true medical emergency in the vast majority of newborns with intersex conditions is the evaluation for congenital adrenal hyperplasia.”).
\textsuperscript{58} Dr. Janet Goodall, 337 THE LANCET 33, 34 (Jan. 5, 1991).
formed only after the genitals are fully grown, it is difficult to justify immediate surgery to the infant on the basis of medical necessity.

It is my contention that it is the parents and doctors of intersexed infants who are experiencing a medical emergency, not the intersexed infant. Intersexed genitalia make almost everyone—doctors, parents, and society as a whole—uncomfortable. The terms “disfiguring and embarrassing,” “ungainly,” “unsightly,” and “offensive” are commonly found in medical journals when describing ambiguous genitalia. In fact, medical professionals admit that it is the psychosocial problem of intersex that makes it an emergency. Doctors act quickly not because the infant is in any medical danger, but “to spare parents the trauma of seeing their child as intersexed each time they change the infant’s diaper.”

The psychosocial emergency surrounding the birth of an intersexed infant is “[c]ultural imperative, masquerading as medical necessity.” As such, the practice of genital-normalizing surgery on infants does not pass the test for medical emergency. A medical emergency requires that the action is appropriate to protect the life and health of the child, not the psychological welfare of the child’s parents or physicians. Because the birth of an intersexed infant does not qualify as a medical emergency, doctors can perform genital-normalizing surgery only with the informed consent of an infant’s parents.

Parental Consent to the Medical Treatment of Their Minor Children

The underlying principles of informed consent break down when the medical treatment of infants is at issue. Infants’ underdeveloped communication and comprehension abilities preclude appreciation of the nature, extent, and probable consequences of a proposed treatment. Nor can they weigh its alternatives. Therefore, infants are literally unable to give legal informed consent for their own medical treatment. So who speaks for the infant?

The infant’s impediment to the traditional rule of informed consent has

60. Kessler, supra note 40, at 35, 36.
61. E.g., Justine Marut Schober, A Surgeon’s Response to the Intersex Controversy, 9 J. CLINICAL ETHICS 393, 394 (1998) (“Early surgery addresses parental comfort and a societal view of what constitutes either a male or female genital appearance.”); Gerardo Izquierdo, M.D. & Kenneth I. Glassberg, M.D., Gender Assignment and Gender Identity in Patients with Ambiguous Genitalia, 42 UROLOGY 232, 232 (1993) (“Gender assignment ... must be considered a psychosocial emergency.”); Cynthia H. Meyers-Seifer & Nancy J. Charest, Diagnosis and Management of Patients with Ambiguous Genitalia, 16 SEMINARS IN PERINATOLOGY 332, 332 (1992) (“The birth of an infant with ambiguous genitalia is a social and potentially medical emergency.”).
64. RESTATEMENT (SECOND) OF TORTS § 59 (1965); RESTATEMENT (SECOND) OF TORTS § 892A (1979); Bonner v. Moran, 126 F.2d 121, 122 (U.S. App. D.C. 1941) (“[M]any persons by reason of their youth are incapable of intelligent decision.”).
been overcome by the creation of the legal fiction that a parent’s informed consent may be taken in place of the infant’s. This legal fiction is the doctrine of substituted judgement. With its history in the nineteenth century English law of lunacy, the doctrine of substituted judgement purports to allow a third party to advocate a course of action for one incompetent to speak for him or herself. Although the doctrine of substituted judgement has been revised over time, it still assumes that the third party is legally able to advocate what is in the incompetent’s best interests.

The doctrine of parental consent goes even one step further than the doctrine of its roots. It does not just assume, but actually takes as fact that the parent knows what is in the best interests of the infant. Time and again, courts have upheld parental consent on the basis that parents, as the natural guardians of their children, are best situated and best able to make important decisions on their behalf. Herein lies the danger of parental consent.

Louise Harmon discusses the various concerns about substitute judgement in her article *Falling Off the Vine: Legal Fictions and the Doctrine of Substituted Judgement.* She finds that legal fictions become dangerous when understanding of the inherent falsity of the statement is lost and those who are substituting their judgement are seen as truly speaking for that person. Richard W. Garnett, in his article *Why Informed Consent? Human Experimentation and the Ethics of Autonomy,* echoes these concerns by arguing that “‘proxy consent’ is an oxymoron if consent truly aims at protecting self-autonomy and self-determination.” Even the American Academy of Pediatrics recognizes this danger, finding that “‘proxy consent’ poses serious problems for pediatric health care providers” because “a person who consents responds based on unique personal beliefs, values, and goals.”

Despite the dangers inherent in the falsity of the legal fiction, in a variety of contexts courts have continued to rely on the presumption that parents know what is best for their infant and should be trusted to act on that knowledge. It
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is currently generally accepted at common law that the informed consent of the parent is necessary for the medical treatment of the infant.\(^7\) A fair characterization of the breadth of the parental consent doctrine is that “most courts . . . defer to parental discretion within a broad spectrum of situations ranging from those which are medically necessary, to those which do not threaten the health of the child.”\(^7\)

But, a parent’s prerogative to consent on behalf of his or her infant is not absolute. Rather, when the child’s health and safety are at risk, the Court has placed limitations on the use of parental discretion. For example, in *Prince v. Massachusetts*,\(^7\) the Supreme Court did not hesitate to convict a child’s guardian for breaking child labor laws and endangering the child’s health and welfare, even though the decision abridged the guardian’s religious freedom. It was in *Prince* that the now famous words were first declared: “[P]arents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children.”\(^7\) The courts have continually returned to this argument in *Prince* when a parent’s discretionary decision has threatened the child’s health and welfare.\(^7\) Even in cases where the parent’s discretionary decision has been upheld, courts have been careful to consider whether the parent’s decision is really in the best interests of the child.\(^7\)

**III. ANALYSIS OF THE CURRENT MODEL OF TREATMENT OF INTERSEXED INFANTS**

The question of what is in the best interests of the child is most often implicated when the proposed medical treatment may be fairly characterized as “experimental.” The definition of “experimental” treatment is revealed by reviewing cases brought by parents seeking court approval for their minor or

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\(^7\) Meyer v. Nebraska, 262 U.S. 390, 399 (1923) (upholding the rights of parents to direct the upbringing and education of their children).

\(^7\) See, e.g., Wisconsin v. Yoder, 406 U.S. at 234 (holding that parental discretion may be challenged “if it appears that parental decisions will jeopardize the health and safety of the child, or have a potential for significant social burdens”).

\(^7\) In re Phillip B., 92 Cal. App. 3d 796, 801 (Cal. Ct. App. 1979) (upholding a parent’s discretion to deny medical treatment for a child only after finding inconclusive evidence that the alternative would be in the best interests of the child).
mentally incompetent children to become live organ donors. A study of the case law in this context reveals the criteria by which courts judge a treatment to be experimental.

In the landmark case *Bonner v. Moran*, the D.C. Circuit plainly articulated the first criteria that must be satisfied before legal consent can be given for a minor to participate in experimental treatment. Although *Bonner* concerned the mature minor exception to the doctrine of parental consent, the court also discussed at length the performance of experimental treatment of minors. The issue in *Bonner* was whether a doctor had acted with legal consent when he removed skin from a fifteen-year-old boy for the purpose of treating the boy’s badly burned cousin. At issue was the nature of the procedures to which the doctor subjected the minor organ donor. Over the course of two months, during which the boy missed school, the doctor removed a tube of the boy’s skin from his arm to his waist and gave him several blood transfusions. The court noted the great degree of pain and sacrifice suffered by the boy and ultimately held that consent given by a minor or on the minor’s behalf is invalid when the treatment is not to the benefit of the child.

It is important to note that because the surgery was not for the benefit of the minor, the court demanded both the consent of the child and his parents. Similar to the reasoning in *Prince*, in the context of organ donation, an adult is free to make a martyr of herself but not of her child.

The requirement of a benefit to the child is supported by other cases in the organ donation context. For instance, in both *Hart v. Brown* and *Strunk v. Strunk*, courts allowed legally incompetent persons to be organ donors with parental consent only after an independent benefit to these donors could be established. In *Hart*, the Superior Court of Connecticut upheld parental consent to a seven year-old girl’s donation of a kidney to her twin sister. After hearing from the donee’s doctors, psychiatrists, clergyman, and court-appointed guardian *ad litem*, the court was convinced that the organ donor

80. The issue of experimental treatment also arises in the context of sterilization of minor children. See, e.g., *In re C.D.M.*, 627 P.2d 607, 612 (Alaska 1981) (requiring that the sterilization is in the best interests of the child before it may ordered); *In re Romero*, 790 P.2d 819, 822 (Colo. 1990) (allowing sterilization only after a showing that it is medically essential or in the patient's best interest); *In re Debra B.*, 495 A.2d 781, 783 (Me. 1985) (employing a best interests test to determine whether sterilization should be ordered).
82. *Id.* at 121.
83. *Id.*
84. *Id.* at 123 (“Here the operation was entirely for the benefit of another and involved sacrifice on the part of the infant of fully two months of schooling, in addition to serious physical pain and possible results affecting his future life.”).
85. *Id.* at 123.
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would be less harmed by the loss of her kidney than by the loss of her sister.\textsuperscript{89} The court was also careful to make "a close, independent and objective investigation of [the parents'] motivation and reasoning."\textsuperscript{90} After a careful balancing of all the interests and risks involved, the court made what it believed to be a beneficial decision for the organ donor. Similarly, in \textit{Strunk}, the Court of Appeals of Kentucky upheld parental consent for a twenty-seven-year-old mentally-disabled man to donate a kidney to his brother once it was reasoned that he would be more traumatized at the loss of his brother than at the loss of his kidney.\textsuperscript{91} Important to both decisions were the facts that kidney donation is a relatively safe procedure and that a person's life expectancy is not diminished with the removal of one kidney.\textsuperscript{92}

Conversely, the courts have refused to allow parental consent to organ donation by their legally incompetent children when no independent benefit to the organ donor can be established. For instance, in \textit{In re Richardson},\textsuperscript{93} the Louisiana Court of Appeals found the proposed psychological benefit to a mentally disabled organ donor "highly speculative."\textsuperscript{94} In \textit{In re Richardson}, the parents of Roy, a seventeen-year-old mentally disabled boy, sought to give parental consent for one of Roy's kidneys to be removed and placed into his thirty-two-year-old sister.\textsuperscript{95} The parents' attorney argued that donating his kidney would be in Roy's best interest because his sister might then live long enough to take care of Roy when they died.\textsuperscript{96} The court refused to see this speculative possibility as a clear benefit to Roy and declined to allow the organ transplant.\textsuperscript{97} The Wisconsin Supreme Court reached a similar conclusion in \textit{In re Guardianship of Pescinski}\textsuperscript{98} and refused to allow an organ donation by an incompetent donor to proceed "[i]n the absence of real consent on his part, and in a situation where no benefit to him has been established."\textsuperscript{99}

From the study of cases in the organ donation context, it becomes apparent that in addition to the basic requirements of legal informed consent, certain criteria must be satisfied before a parent may submit their minor to an experimental treatment. First, if the treatment is not medically necessary for the minor, it must not be unreasonably harmful. Second, the treatment must be to the benefit of the minor, and not just to the benefit of the minor's parents or other family members. The best interests of the minor are at the forefront of the deci-

\begin{itemize}
\item \textsuperscript{89} \textit{Id.} at 389.
\item \textsuperscript{90} \textit{Id.}
\item \textsuperscript{91} \textit{Strunk}, 445 S.W.2d at 146.
\item \textsuperscript{92} Hart \textit{v. Brown}, 289 A.2d 386, 388 (Conn. 1972) ("In this type of graft there is substantially a 100 percent change that the twins will live out a normal life span—emotionally and physically.").
\item \textsuperscript{93} \textit{In re Richardson}, 284 So. 2d 185, 187 (La. Ct. App. 1973).
\item \textsuperscript{94} \textit{Id.} at 187.
\item \textsuperscript{95} \textit{Id.} at 185.
\item \textsuperscript{96} \textit{Id.} at 187.
\item \textsuperscript{97} \textit{Id.}
\item \textsuperscript{98} \textit{In re Guardianship of Pescinski}, 226 N.W.2d 180, 182 (Wis. 1975).
\item \textsuperscript{99} \textit{Id.}
\end{itemize}
tion to permit or deny an experimental treatment. With these criteria in mind, the arguments against allowing parental consent to genital-normalizing surgery on their otherwise healthy intersexed infant are strong.

The Experimental Nature of the Current Model of Treatment of Intersexed Infants

The current model of treatment for healthy infants with micropenis or clitoromegaly is experimental at best. Part I of this Note revealed the questionable empirical support for imposing immediate genital-normalizing surgery on intersexed infants. This lack of reliable empirical support has led experts in infant surgery, psychology, and ethics, as well as intersexed individuals themselves, to loudly question why genital-normalizing surgery continues to be imposed on intersexed infants. This same sentiment was articulated by Robert A. Crouch in a volume of *The Journal of Clinical Ethics* entirely devoted to this issue: "Treatment decisions for intersexed children have not been made on a 'firm scientific basis,' yet they have been made nonetheless." Follow up studies are rarely conducted on infants subjected to genital-normalizing surgery. The few outcome studies that have been completed address only the physical appearance of the post-operative genitals, but not the psychological results for the patients. This is odd considering that the fundamental goal of genital-normalizing surgery is "to facilitate a patient’s positive psychosocial and psychosexual adjustment throughout life." There is, however, overwhelming evidence of the physical and psychological effects of genital-normalizing surgery from post-operative intersexed individuals themselves. The advent of the Internet has allowed post-operative intersexed individuals to voice the negative consequences of genital-normalizing surgery and form interest groups dedicated to preventing its harms to future intersexed infants.

100. Despite the fact that this Note concentrates only on the conditions of micropenis and clitoromegaly in this essay, it is the author’s position that the practice of non-medically-indicated genital normalizing surgery is abhorrent in all cases without the patient’s legal consent.

101. Crouch, supra note 9, at 374.

102. Marut Schober, supra note 61, at 393 ("[T]he long-term efficacy of the structural results of various surgeries and their impact on the individuals' psychological, social, and physical adjustment remains unknown.").

103. Domurat Dreger, supra note 3, at 351 ("What few outcome studies there have been of intersex management have basically focused on how good the specific surgical repair turned out.").

104. Marut Schober, supra note 61, at 393.

105. E.g., Intersex Society of North America, What is ISNA?, at http://www.isna.org (visited Mar. 27, 2000) ("The Intersex Society of North America (ISNA) is an education, advocacy, and peer support organization which works to create a world free of shame, secrecy, and unwanted surgery for intersex people (individuals born with anatomy or physiology which differs from cultural ideals of male and female."); Intersex Voices, What is Intersex Voices about?, at http://www.sonic.net/~cisae (visited March 31, 2000) ("The Intersex Voices page is written by intersexed people and is presented as an alternative voice to the writing which has heretofore appeared almost exclusively in the medical press, written by non-intersexed people. What you will find here are our voices, our experiences, our views and feeling about ourselves, our lives in the past and in the present.").
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These advocacy groups, with some support from those within the medical profession, criticize surgeons for not according weight to patients' reports of negative surgical and psychosocial outcomes.106

The collective stories of these intersexuals further corroborate evidence that genital-normalizing surgery performed without the patient's own consent is not beneficial. As noted by Bruce E. Wilson and William G. Reiner, experts in pediatric medicine and psychiatry who have studied the current management of intersex, "[t]he recurring voices of many individuals treated in accordance with [the current model] increasingly indicate that it just does not work the way it is supposed to work."107 Held to the legal standard applied to other forms of experimental treatment on infants, the practice of genital-normalizing surgery without the patient's consent fails both the general test for legal informed consent and the more specific requirement of an independent benefit to the infant.

The Unreasonably Harmful Results of Genital-Normalizing Surgery on Infants

An experimental treatment requires an independent benefit to the infant. Yet, recent scholarship reveals that, for many intersexuals, genital-normalizing surgery has resulted in deformed looking genitalia, pain, and loss of sexual sensitivity or function. Tragically, most of the long term physical injuries that result from genital-normalizing surgery cannot be evaluated until the infant reaches sexual maturity and discovers problems of pain or insensitivity at sexual arousal.108 But most patients are lost to follow up long before they even reach puberty.

Genital-normalizing surgery rarely results in "normal looking" genitalia. Cheryl Chase, Executive Director of the Intersex Society of North America, argues that "[s]urgery is good at removing structures, like infected appendices or localized tumors; it is much less useful for creating structures."109 For example, clitoromegaly is consistently addressed by removing all, or a significant part, of an infant's clitoris.110 To argue that a woman with no clitoris at all has "normal" genitalia is ludicrous. And yet, "[t]he definition of a 'successful' surgical result may well differ in the eyes of the surgeon and the eyes of the patient."111 Because surgeons consider the female anatomy to play a passive role in sexuality, a sexual reassignment that results in a functionally receptive

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109. Id. at 385.
110. Id. at 387.
vagina is considered successful, regardless of the state of the clitoris.\textsuperscript{112} The awful truth for many intersexuals is that the deformation of post-surgery genitals is “a fact immediately obvious to anyone who glances at the ‘after’ photos claimed as successes.”\textsuperscript{113}

But even an aesthetically pleasing result may leave an intersexual in pain or without sexual sensitivity. Edmund G. Howe, Professor of Psychiatry and Director of Programs in Medical Ethics, finds that many post-operative intersexuals “report that they have less sensation in their genital area and even feel pain.”\textsuperscript{114} Wilson and Reiner agree that “many surgeries to ‘reconstruct’ a ‘normal sized’ clitoris or penis result in decreased sensation and/or function.”\textsuperscript{115}

Even when genital-normalizing surgery results in aesthetically-pleasing and functional genitals, there is always the possibility that surgeons were altogether wrong about the future gender choice of the infant. For many intersexed infants, genital-normalizing surgery seems to have been a guessing game. Even when the physical results are “optimal,” they are sometimes proven to have been irreparably incorrect. David Reimer’s rejection of his assigned gender is not an isolated case. Many intersexuals end up developing sexual identities opposite to their sexually-assigned gender,\textsuperscript{116} reflecting the fact that, for many people, and especially for intersexuals, “stable gender identity is often assumed only as an adult.”\textsuperscript{117} Coping with this “gender dysphoria,” as it is termed in the medical community,\textsuperscript{118} is very difficult for an intersexual whose genitals of the sex with which they now identify were intentionally surgically removed with their parents’ consent.

It is hard to discuss the practice of genital-normalizing surgery without drawing an analogy to the practice of female genital mutilation. The American Academy of Pediatrics’ vehement condemnation of female genital mutilation seems grotesquely hypocritical considering its strong endorsement of genital-normalizing surgery. The following are official statements by the American Academy of Pediatrics concerning the practice of female genital mutilation:

“The World Health Organization and the International Federation of Gynecology and Obstetrics have opposed FGM as a medically unnecessary practice with serious, potentially life-threatening complications.”\textsuperscript{119}

\begin{thebibliography}{9}
\bibitem{113} Chase, supra note 108, at 389.
\bibitem{114} Howe, supra note 106, at 338.
\bibitem{115} Wilson & Reiner, supra note 56, at 364.
\bibitem{116} Howe, supra note 106, at 337 (“[M]any who have had this surgery report that they subsequently acquired a gender identity that is different from their anatomically assigned gender.”).
\bibitem{117} Wilson & Reiner, supra note 56, at 361.
\bibitem{118} See Schober, supra note 61, 394.
\bibitem{119} American Academy of Pediatrics Committee on Bioethics, \textit{Female Genital Mutilation}, 102 PEDIATRICS 153, 153 (1998).
\end{thebibliography}
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"The American Academy of Pediatrics . . . encourages its members to . . . decline performing all medically unnecessary procedures to alter female genitalia."\(^{120}\)

And yet, the removal of all or part of the sexual organs of young girls done in countries that practice female genital mutilation is functionally no different from the surgical maneuvers performed in America to "correct" clitoromegaly.\(^{121}\) Cheryl Chase reports interviewing both Western and third-world victims of clitorectomies and finding that "[i]n both groups, some women are deprived of clitoral sensation and orgasm; some retain sensation in the clitoral stump; and some of these retain orgasmic response."\(^{122}\) Beyond the geographic location of the surgery performed, there seems little functional difference between what is done by surgeons here and what they condemn elsewhere.

Cheryl Chase adds that "poor surgical outcomes are not the only—or even the primary—reason former patients feel harmed."\(^{123}\) The psychological effects of genital-normalizing surgery are perhaps the most painful of all. Alice Domurat Dreger reports that the current model of treatment, "while designed to be beneficent, appears in many cases to actually harm intersexed children and their families by treating them as pathological."\(^{124}\) Most intersexed feel that they would have been better left alone. "They contend that if they had not had surgery, they could form just as meaningful intimate sexual relationships and enjoy sexual sensations that would not have been diminished."\(^{125}\)

In her study of forty-one intersexed people, sociologist Sharon E. Preves noted that "many who had genital surgeries emphasized that the very operations that were intended to assuage feelings of difference only served to highlight their stigma."\(^{126}\) After conducting in-depth interviews with these intersexed adults about their life histories, Sharon E. Preves found that none of those interviewed would have preferred to have been born non-intersexed.\(^{127}\) Dr. Suzanne Kessler's survey of college students provides evidence that many intersexed adults would not choose gender-normalizing surgery for themselves and express regret and anger that surgery was imposed on them as children.\(^{128}\)

120. Id.
121. Id. The Academy discusses "Type 1 FGM" involving "excision of the skin surrounding the clitoris with or without excision of part or all of the clitoris." They refer to this practice as a "clitorectomy," the same term used by genital normalizing surgeons when they remove all or part of the clitoris of an intersexed individual with clitoromegaly.
123. Id. at 385.
124. Domurat Dreger, supra note 3, at 352.
125. Howe, supra note 106, at 338.
127. Id. at 417.
Many intersexuals who were subjected to genital-normalizing surgery in infancy have sought to reclaim their identity as intersexual rather than simply male or female.\(^{129}\)

In fact, studies have shown that those intersexuals who escaped genital-normalizing surgery are living normal, healthy lives. Americans can learn a lot from the treatment of intersexuals in other cultures. Robert A. Crouch has found that "many non-Western societies have socially available (institutionalized) third sex/third gender categories, where the differently sexed person has a special (or, at least, acceptable) social gender role to play."\(^{130}\) Anthropological and anecdotal evidence reveal that intersexed infants could be left as they are born and live normal, healthy lives. But in America, "the non-treatment of intersexed children clearly has not been a real option."\(^{131}\)

In light of the relative lack of physical or psychological benefits of genital-normalizing surgery, it is not surprising to find that there is heated controversy both within and without the medical community surrounding the continued use of this current model of treatment.\(^{132}\) Alice Domurat Dreger reports that "professional conferences, gender clinics, and the popular media are abuzz with the controversy over how medicine and society should handle intersex and intersexuals."\(^{133}\) Intersexual support groups have proliferated on the Internet,\(^{134}\) and the Discovery Channel recently carried a one-hour documentary on the controversy over surgical treatment of intersexuality.\(^{135}\)

**The Impediments to Legal Parental Consent**

In the midst of all of the controversy surrounding the practice of genital-normalizing surgery, parents of intersexed infants get lost. The questionable theoretical bases for early genital-normalizing surgery are rarely, if ever, disclosed to the parents of intersexed infants.\(^{136}\) The failure of this disclosure, amongst other deceptions by doctors who routinely advocate early genital-normalizing surgery, make legal informed consent to this surgery by parents impossible. The medical community’s failure to acknowledge the questionable

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130. Crouch, *supra* note 9, at 379.
131. *Id.* at 377.
132. Howe, *supra* note 106, at 338 (exploring the question: “Why Is This Controversy So Heated?”).
136. Domurat Dreger, *supra* note 3, at 352 (“Parents are at least in most cases not told that the treatment model is not proven to work, based on a peculiar theory of gender identity formation, and increasingly widely criticized.”).
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theoretical bases for genital-normalizing surgery preclude satisfaction of each of the three requirements for informed consent.

Legal consent must be informed. This requires doctors to provide the parents of intersexed infants with adequate information about the proposed genital-normalizing surgery, including its alternatives. This information “should include risks such as reduced sexual sensation, less than perfect cosmetic results, and possible interferences with sexual function.” Also included should be the risk that the infant ends up identifying with the other gender as in the case of David Reimer. But, surgeons who practice genital-normalizing surgery admit that “[l]ittle factual evidence or long-term outcome studies exist to guide choices.” Without the proper data, the potential risks of genital-normalizing surgery cannot be communicated to the parents of intersexed infants.

Unfortunately, even when doctors have relevant information, they “often do not tell intersexuals and their parents all that [they] know.” This leads to the tainting of the second requirement for informed consent: that the decision to give legal consent must be voluntary. Voluntariness of the decision requires the doctor to guard against coercing or otherwise improperly influencing the parents’ decision. Yet, Alice Domurat Dreger reports that “clinicians treating intersex individuals may be far more concerned with strict definitions of genital normality than intersexuals, their parents, and their acquaintances (including lovers).” This obsession with “normalizing” the infant may cause clinicians to inappropriately influence parents’ decision-making. Combined with negative social attitudes towards the intersexed, the doctor’s own opinions may be overwhelmingly coercive to parents. Since the current model of treatment does not require doctors to recommend that parents seek counseling by trained professionals, unable to work through their anxiety and guilt, parents are amenable to the quick fix to their problem that they believe genital-normalizing surgery offers. Parents who are still grieving over the loss of the “perfect” child they expected are especially vulnerable to what the doctor believes is in their best interests. Coercion and improper influence by doctors prevent the parents of intersexed infants from giving voluntary consent to genital-normalizing surgery.

The final requirement for valid legal consent is that it must be made by someone competent to make such a decision. This requires that the parents have an appreciation of the nature, extent, and probable consequences of genital-normalizing surgery. Yet, there is strong evidence that parents are not com-

138. Schober, supra note 61, at 394.
139. Domurat Dreger, supra note 3, at 349.
140. Id. note 4, at 25.
141. Groveman, supra note 63, at 357.
petent to give consent to genital-normalizing surgery on behalf of their intersexed infants. Edmund G. Howe, Professor of Psychiatry and Director of Programs in Medical Ethics, finds that “when surgeons recommend surgery in infancy, it may induce feelings of shame in the parents toward their child.”

The extreme stress of these circumstances combined with the fact that surgeons recommend immediate action may cause parents to make impulse decisions about whether to consent to genital-normalizing surgery. Even when parents are given all relevant information by doctors, some experts argue that “[m]any families are so devastated during the initial phases of their child’s evaluation and treatment that they may not fully comprehend and absorb the information presented to them.” Furthermore, “[s]ince parents cannot know whether their intersexed child will benefit more from having surgery or not,” there is no way to accurately weigh the possible consequences of genital-normalizing surgery. The fact is that there is just not enough accurate information available on the benefits or consequences of genital-normalizing surgery for even the most well-meaning and contemplative parents to make truly informed decisions for their infants.

The current model of treatment for intersexed infants fails the test for legal informed consent at every step. No matter how well-meaning their intentions, parents are incapable of giving legal informed consent to the performance of genital-normalizing surgery on their infants because the current model of treatment does not offer these parents the tools that they need to come to an informed, voluntary, competent decision.

CONCLUSION

Surgeons who perform genetic normalizing surgery, whether on an emergency basis or at the behest of the intersexed infant’s parents, should be aware that, because genital-normalizing surgery is not necessary nor proven beneficial for the infant with clitoromegaly or micropenis, the required elements of legal informed consent are likely to have not been met. In light of the questionable scientific basis behind its use, the lack of follow-up data on its benefits, and the overwhelming evidence of its negative physical and psychological results for many intersexuals, a moratorium should be declared on the use of defenseless infants as the experimental subjects of genital-normalizing surgery.

142. Howe, supra note 106, at 339.
144. Howe, supra note 106, at 340.