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FROM THE HOSPITAL TO THE COURTROOM: A STATUTORY PROPOSAL FOR RECOGNIZING AND PROTECTING THE LEGAL RIGHTS OF INTERSEX CHILDREN

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I. INTRODUCTION

The last ten years has seen a dramatic increase in discussion concerning the treatment of children born with intersex conditions. Adults with intersex conditions have become an outspoken group, due in large part to the Intersex Society of North America (ISNA) and other similar organizations advocating on their behalf.[1] Academic articles from the legal and medical communities have explored the ethics of surgical treatments, the legal obligations owed to incompetent minors, the constitutional rights that may be implicated by such surgeries and the failures of the current treatment protocol.[2]

However, in the summer of 2004, the suicide of David Reimer brought new awareness to the dangers of the still-unproven methods of current medical treatments. Although Reimer was not born with an intersex condition, he became famous as "John/Joan" in John Money's sex reassignment experiment in the 1960s, and then as himself in the biography entitled *As Nature Made Him: The Boy Who Was Raised a Girl* published in 2000 by John Colapinto.[3] Those familiar with the intersex surgery debate know about Reimer, who was surgically reassigned as a female after an accident during his circumcision left his penis ablated. His case embodied the failures of the medical and the legal communities in addressing

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[1] *See* Intersex Society of North America (ISNA), *at* http://www.isna.org (last visited Jan. 15, 2006); *see also* Intersex Initiative, *at* http://www.intersexinitiative.org (last visited Jan. 15, 2006); Bodies Like Ours, *at* http://www.bodieslikeours.org (last visited Jan. 15, 2006).

[2] *See, e.g.*, Kishka-Kamari Ford, *"First, Do No Harm"—The Fiction of Legal Parental Consent to Genital-Normalizing Surgery on Intersexed Infants*, 19 YALE L. & POL'Y REV. 469 (2001); Kate Haas, *Who Will Make Room for the Intersexed?*, 30 AM. J.L. & MED. 41 (2004); Laura Hermer, *Paradigms Revised: Intersex Children, Bioethics & the Law*, 11 ANNALS HEALTH L. 195 (2002).

[3] JOHN COLAPINTO, AS NATURE MADE HIM: THE BOY WHO WAS RAISED AS A GIRL (2000). *See also* John Colapinto, *The True Story of John/Joan*, ROLLING STONE, Dec.11, 1997, at 54.

intersex concerns.[4] Although his sex reassignment surgery was reported as a resounding success, Reimer rejected his reassigned sex as a female in his early teens and began living as a male, eventually marrying and adopting his wife's children.[5] While Reimer's suicide cannot be blamed entirely on what some would call negligent medical care, it highlights the long-term psychological and emotional issues that the current surgical treatment can cause for intersex patients.

This note is an appeal to the legal community to shift the current intersex discussion away from education and toward stern legal action. Existing academic work has documented, and this note will also discuss, the fact that constitutional challenges and the current standards in medical malpractice lawsuits create serious roadblocks to those seeking compensation, or a change in the medical protocols as related to informed consent in the context of intersex surgeries. In many ways, the medical community is insulated from legal action that challenges intersex surgeries. Despite educational efforts and critiques from within and without the medical community,[6] physicians have not, on a wide scale, changed their practices to take into account the needs and desires of intersex patients. The most daunting problem adult intersex patients face when seeking legal action is simply to have their claims heard. Medical standards of care, statutes of limitations, and parental authority to give consent on behalf of children pose considerable obstacles to merely accessing the legal system, let alone winning a lawsuit. To overcome these obstacles, activists and practitioners must engage in the debate over infant genital surgery with a cautious eye toward the protection of patient autonomy, the right to bodily integrity, and the right to develop one's own identity for intersex children—a silent and vulnerable community.

This note argues that the decision to subject a child to medically unnecessary genital surgery or hormone treatment requires judicial intervention to ensure that the decision is based on truly informed consent, and to help balance the interests of the child with those of the parents. Part II briefly discusses the intersex conditions

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[4] Although Reimer was not born with an intersex condition, the fact that his case provided the premise and the basis of the current protocol for treatment of intersex children lends itself to the notion that he became "intersexed after birth." Also, Reimer's experience is similar to those of intersexuals because he attributed his suffering to primarily the medical treatments; likewise, many adult intersexuals argue that the negative consequences of sex reassignment surgery outweigh the possible benefits.

[5] *See* COLAPINTO, *supra* note 3.

[6] For some examples of criticism offered by individuals outside the medical community, see KESSLER, LESSONS FROM THE INTERSEXED (1998); Alice Domurat Dreger, *"Ambiguous Sex"—or Ambivalent Medicine? Ethical Issues in the Treatment of Intersexuality*, 28 HASTINGS CENTER REP. 24-35 (1998), *available at* http://www.isna.org/articles/ambivalent_medicine; Cheryl Chase, *Surgical Progress is Not the Answer to Intersexuality*, 9 J. CLINICAL ETHICS 385 (1998). For examples of criticism offered by those within the medical community, see Sarah Creighton & Catherine Minto, Editorial, *Managing Intersex: Most Vaginal Surgery in Childhood Should Be Deferred*, 323 BRIT. MED. J. 1264 (2001); Hazel Glenn Beh & Milton Diamond, *An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment Surgery on Infants with Ambiguous Genitalia?*, 7 MICH. J. GENDER & L. 1, 17-18 (2000); Milton Diamond & H. Keith Sigmundson, *Management of Intersexuality: Guidelines for Dealing with Persons with Ambiguous Genitalia*, 151 ARCHIVES PEDIATRIC ADOLESCENT MED. 1046 (1997); Bruce E. Wilson & William G. Reiner, *Management of Intersex: A Shifting Paradigm*, 9 J. CLIN. ETHICS 360 (1998).

for which genital surgery is generally recommended, and Part III is an introduction to different types of medical treatments and the treatment protocols for those intersex conditions subject to surgery. Part IV addresses the legal or medical standard of care in medical malpractice cases and why this legal doctrine precludes recovery by intersexuals. Part V explores the topic of informed consent and the right of parents to make decisions on behalf of their minor children, and Part VI consists of an analysis of the reasons those legal doctrines fail to protect children with intersex conditions subjected to genital surgery. Part VII focuses on potential parental conflicts of interest, many of which are already identified by statute, common law, and other legal or medical scholars. Part VIII introduces a model statute that requires a judicial order based on medical necessity and other factors in cases in which genital surgery or hormone treatment is recommended to address the intersex condition of a minor.

II. WHAT IS INTERSEX?[7]

While the term "intersex" does not have one universally accepted definition, it is a blanket term "used to denote a variety of congenital conditions in which a person has neither the standard male nor the standard female anatomy."[8] Some experts estimate that between 1.7 to 4 % of the world's population is born with an intersex condition,[9] while others claim the incidence is between one in 500 and one in 1500 live births.[10] In the United States, it is thought that approximately 1500 to 2000 children are born with ambiguous external genitalia annually, 100 to 200 of whom are subject to pediatric surgical sex assignment.[11]

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[7] A complete discussion of the various types of intersex conditions is beyond the scope of this note. Common intersex diagnoses include clitoromegaly, androgen insensitivity syndrome—either complete (CAIS) or partial (PAIS), hypospadias, micropenis, 5-alpha reductase, and congenital adrenal hyperplasia (CAH). For more information about particular diagnoses, see ISNA, *supra* note 1.

[8] Alice Domurat Dreger, *A History of Intersexuality: From the Age of Gonads to the Age of Consent*, 9 J. CLINICAL ETHICS 345, 345 (1998). *See also What is Intersex?*, ISNA, *at* http://www.isna.org/faq/what_is_intersex (last visited Jan. 15, 2006) (describing intersex as "a variety of conditions in which a person is born with a reproductive or sexual anatomy that does not seem to fit the typical definitions of female or male"); *Ambiguous Genitalia*, UrologyHealth.org, *at* http://www.urologyhealth.org (last visited Jan. 15, 2006) (defining intersex as "a number of well understood conditions which affect the formation of the genitalia early in embryonic development, often resulting in an appearance which is typical of neither a boy nor a girl").

[9] Haas, *supra* note 2, at 41 (citing ANNE FAUSTO-STERLING, SEXING THE BODY: GENDER POLITICS AND THE CONSTRUCTION OF SEXUALITY 51 (2000)).

[10] Dreger, *supra* note 6. Dreger referred to a study by Denise Grady of more than 6500 female athletes, of whom one in 500 showed evidence of an intersex condition, but "unfortunately Grady does not provide a reference to the published data from that study." *Id.* at n.5 (citing Denise Grady, *Sex Test of Champions*, DISCOVER, Special Issue: The Science of Sex, June 1992, at 78). Dreger also cited the work of Anne Fausto-Sterling for the estimate of one incident of intersex condition in every 1500 live births. *Id.* at n.6 (citing ANNE FAUSTO-STERLING, SEXING THE BODY: HOW BIOLOGISTS CONSTRUCT SEXUALITY (1999)).

[11] Beh & Diamond, *supra* note 6. The use of the terms "sex assignment" and "sex reassignment" is distinguished as follows: "sex assignment" refers generally to circumstances in which doctors *choose* a sex for who will otherwise be considered an ambiguous intersex patient; "sex reassignment," in contrast, refers to patients whose born sex was clear but changed for other reasons, as in the case of David Reimer.

Intersex conditions vary widely in symptoms, cause, and treatment. For example, while a small penis does not necessarily create sex ambiguity, a medical diagnosis of "micropenis" is considered an intersex condition because of the way it has been treated by physicians. It is generally accepted in the medical community that a penis measuring less than two centimeters at birth when stretched is "inadequate."[12] The adequacy of the penis is judged by whether it has "the potential to be big enough to be readily recognizable as a 'real' penis"[13] and whether it has the capacity to penetrate a vagina. Another condition is known as Androgen Insensitivity Syndrome (AIS),[14] in which patients are unable to process and respond to androgen, or "male hormones."[15] Patients with AIS are genetically 46 XY males and typically born with undescended testes and a short or almost absent vagina.[16]

The most common intersex condition is congenital adrenal hyperplasia (CAH),[17] in which exposure to testosterone in-utero causes varying degrees of virility, or development of male physical characteristics.[18] Genital ambiguity resulting from CAH can range from an enlarged clitoris resembling a penis with a shallow vagina to an almost fully formed penis and no vaginal opening.[19] Nearly all CAH females, however, have the reproductive system of a female and retain the ability to carry a child and/or conceive a child.[20]

Not all intersex conditions are discovered at birth, which explains in part the disparity between the instances of intersex birth and that of genital surgeries performed. Often, the virilization in girls is not significant enough to warrant attention, but some conditions do not become apparent until later in life. One example is 5-alpha reductase, in which the child appears to be a typical female, but during puberty the body responds to hormonal changes and begins to virilize, exposing the fact that the child is, in fact, a boy.[21]

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[12] David B. Joseph, M.D., *Intersex Part II*, *in* AMERICAN UROLOGICAL ASSOCIATION UPDATE SERIES, Volume XXII, Lesson 6, at 42 (2003). *See also* AMERICAN ACADEMY OF PEDIATRICS, *Evaluation of the Newborn with Developmental Anomalies of the External Genitalia*, 106 PEDIATRICS 138, 139 (2000), *available at* http://www.pediatrics.org/cgi/content/full/106/1/138 (last visited Jan. 15, 2006).

[13] Dreger, *supra* note 6, at 19.

[14] AIS can be either complete (CAIS) or partial (PAIS). For a fuller discussion of AIS, see *Androgen Insensitivity Syndrome*, ISNA, *at* http://www.isna.org/faq/conditions/ais (last visited Jan. 15, 2006). *See also* Androgen Insensitivity Syndrome Support Group, *at* http://www.medhelp.org/www/ais/ (last updated Jan. 15, 2006).

[15] *Androgen Insensitivity Syndrome*, *supra* note 14.

[16] *Id.*

[17] ISNA estimates the prevalence of CAH-related intersex conditions at between one in 20,000 to one in 36,000 births each year but it does not cause an apparent intersex condition for those with XY chromosomes, or "male" births. *Congenital Adrenal Hyperplasia (CAH)*, ISNA, *at* http://www.isna.org/faq/conditions/cah (last visited Jan. 15, 2006).

[18] *Id.* Although CAH can be found in both male and female children, only an XY female child with CAH is considered intersexed because her body displays attributes of a boy as a result of virilization. *Id.*

[19] AMERICAN ACADEMY OF PEDIATRICS, *supra* note 12, at 141.

[20] *Id.*

[21] *Is It a Boy or a Girl?* (Discovery Channel 2000). This documentary chronicles the life of a Dominican Republic man with 5-alpha reductase who was raised as a girl, but began to show physical

III. MEDICAL PROTOCOL FOR INTERSEX CHILDREN: EXPERIMENTATION, INNOVATION OR STANDARD MEDICAL PRACTICE?

All medical care falls generally into three broad categories: standard medical practice, experimental therapies, and innovative therapies.[22] Treatments involving experimentation, such as those performed on David Reimer, are "designed to test an hypothesis and to contribute to the body of medical knowledge." [23] In contrast, standard medical practices are intended "solely to enhance the well-being of an individual patient or client," and "have a reasonable expectation of success."[24] Similarly, innovative therapies are used only to address the needs of a particular patient.[25] Unlike medical practice, however, these treatments have not been proven to have a "reasonable expectation of success."[26]

Ideally, new procedures are subjected to rigorous studies to determine effectiveness and to assess the associated risks.[27] In the case of those born with ambiguous genitalia, what began as innovative treatment in the 1960s became accepted practice in the absence of any scientific studies, and with only one anecdotal case upon which to rely.[28] The treatment originated from John Money, a sex researcher at Johns Hopkins University Hospital, who sought to prove that humans are all born psychosexually neutral[29] and that gender is essentially a learned characteristic. Money insisted that children can be assigned a gender and will conform to that assignment as long as the secondary sex characteristics are those of the assigned gender, and such assigned gender is accepted and reinforced by family members.[30] According to Money, success was dependant upon the timing of the surgery. He recommended the performance of the surgery between

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and behavioral signs of a boy at puberty. With the knowledge of the community, he openly transitioned into a man and subsequently married a woman from his village. Interviews with his mother and other villagers reveal that the community accepted his condition and transition, and that he is now fully accepted as a man.

[22] *See generally* Dale Cowan, *Innovative Therapy versus Experimentation*, 21 TORT & INS. L. J. 619, 621 (1986); Dieter Giesen, *Civil Liability of Physicians for New Methods of Treatment and Experimentation: A Comparative Examination*, 3 MED. L. REV. 22 (1995).

[23] *See* Cowan, *supra* note 22, at 620 (discussing medical experimentation).

[24] *See id.* at 621 (discussing standard medical treatment).

[25] *See id.* at 623 (discussing medical innovative therapies).

[26] Beh & Diamond, *supra* note 6, at 13.

[27] *Id.* at 14. Innovative therapies, however, are often accepted without such scientific evaluation, and become standard practice in an ad hoc fashion. *Id.* at 15 (citing 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)). Additionally, once innovative therapies are accepted by the medical community and put into use, there is evidence that studies critical of the practice are rarely published. *Id.* at 15 (citing David A. Grimes, *Technology Follies: The Uncritical Acceptance of Medical Innovation*, 269 JAMA 3030, 3031 (1993); John B. McKinlay, *From "Promising Report" to "Standard Procedure": Seven Stages in the Career of Medical Innovation*, 59 MILBANK MEMORIAL FUND Q. 374, 379 (1981)).

[28] Beh & Diamond, *supra* note 6, at 16 (citing KESSLER, *supra* note 6, at 40-64; JOHN MONEY, SEX ERRORS OF THE BODY: DILEMMAS, EDUCATION, COUNSELING 52-55, 61 (1st ed. 1968); Diamond & Sigmundson, *supra* note 6).

[29] Beh & Diamond, *supra* note 6, at 15 n.62 (quoting Wilson & Reiner, *supra* note 6).

[30] JOHN MONEY & ANKE A. EHRHARDT, MAN & WOMAN, BOY & GIRL: THE DIFFERENTIATION AND DIMORPHISM OF GENDER IDENTITY FROM CONCEPTION TO MATURITY, 152-3, 176, 179 (1972).

eighteen and twenty-four months to ensure parental acceptance of the new gender and to preempt any self-awareness of sex on the part of the child.[31]

Money's theories were put to the test in the famous John/Joan case involving David Reimer,[32] which was widely reported in medical literature and quickly became the standard practice of physicians in the treatment of intersex patients, despite a lack of specific scientific studies on the subject.[33] Although recent studies have raised serious doubts about the effectiveness and ethical nature of Money's recommended treatment,[34] the standard treatment for those born with "ambiguous" genitalia remains sex reassignment or "normalizing" surgery.[35]

When a child is diagnosed with "micropenis," doctors may make the recommendation for reassignment to a female sex[36] by surgically recessing and reducing the phallus to become a "clitoris," building a vagina from the colon or other tissue, and using the testicular tissue to create the labia.[37] Reassignment is done regardless of the fact that micropenis conditions do not in themselves cause a genetic male to be sterile or sexually impotent.

In cases of AIS, despite the XY chromosomal pattern, doctors typically remove the testes to prevent any risk of cancer and often perform an operation called vaginoplasty for cosmetic purposes.[38] Like most genital surgeries, medical

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[31] *Id.* at 176. *See* Dreger, *supra* note 6 (describing Money's theories and belief that "from very early in life, the child's anatomy must match the 'standard' anatomy for her or his gender" in order for sex assignment to be successful).

[32] *See* COLAPINTO, *supra* note 3.

[33] Beh & Diamond, *supra* note 6, at 22; Diamond & Sigmundson, *supra* note 28, at 1047-48.

[34] *See* Beh & Diamond, *supra* note 6, at 23 n.96 (citing William G. Reiner, *Androgen Exposure in Utero and the Development of Male Gender Identity in Genetic Males Reassigned at Birth,* Presentation at the International Behavioral Development Symposium 2000, May 25-27, 2000 (reporting that seventeen of twenty-three genetic males reassigned as females spontaneously rejected their assigned gender identity between the ages five and seventeen)). John Money himself reviewed a recently unearthed study conducted prior to 1952 of more than 250 intersexuals who did not undergo genital surgery, and actually stated that "[t]he 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 differences." *Id.* at 24 n.103. *See also* Sharon E. Preves, *For the Sake of the Children: Destigmatizing Intersexuality,* 9 J. CLINICAL ETHICS 411, 415 (1998) (finding that out of forty-one intersexuals studied, not one would have preferred to be born non-intersex, and of those who had genital surgery, many stated that the medical attention served only to highlight their difference); COLAPINTO, *supra* note 3, at 233.

[35] AMERICAN ACADEMY OF PEDIATRICS, *supra* note 12, at 3 (noting that "[t]he size of the phallus and its potential to develop at puberty into a sexually functional penis are of paramount importance when one is considering a male sex of rearing," and that all infants born virilized as a result of CAH should be raised as girls to preserve fertility, therefore requiring genital reconstructive surgery). *See also* Dr. Robert M. Blizzard, Commentary, *Intersex Issues: A Series of Continuing Conundrums,* 110 PEDIATRICS 616 (2002), *available at* www.pediatrics.org/cgi/content/full/110/3/616 (discussing the recommendation of the American Academy of Pediatrics (AAP) to raise as girls all CAH children and noting that choosing fertility at the expense of a loss of sexual functioning and an inadequate vagina may be "too high a price to pay"); Beh & Diamond, *supra* note 6, at 26-27. *See generally* KESSLER, *supra* note 6; Dreger, *supra* note 6.

[36] AMERICAN ACADEMY OF PEDIATRICS, *supra* note 12, at 3. When an infant has a stretched penis measuring less than two centimeters, the AAP recommends that doctors administer a trial of testosterone injections and measure the response to determine whether sufficient growth will occur during puberty. *Id.* The child should *only* be raised as boys when there is a *very good* response. *Id.* (emphasis added).

[37] Dreger, *supra* note 6, at 29.

[38] *Id.*

practitioners recommend that vaginoplasty be performed in infancy or childhood, although some physicians recommend waiting until post-puberty or adulthood.[39] Since patients born with AIS do not menstruate and cannot bear children,[40] the purpose of the vaginoplasty is to create a vagina capable of "receiving" a penis.[41] After surgery, in order to maintain the surgically created vaginal opening, patients must manually dilate the vagina regularly and often for the rest of their lives; many need multiple surgeries.[42] Arguing for vaginoplasty procedures to be deferred until post-puberty or adulthood, critics note that "[t]he vagina is non-essential and not even visible in childhood."[43] In fact, in one medical study, the researchers noted that one patient who had not undergone vaginoplasty "was homosexual,"[44] a consideration that can only be taken into account well beyond infancy when an individual has determined her sexual orientation.

Not all surgeries involve gender assignment. Procedures such as clitorectomy or clitoral recession, which involves surgically reducing the size of an "enlarged" clitoris, and surgery to correct hypospadias, a condition where the urethral opening is somewhere other than the tip of the penis and where genital ambiguity may sometimes exist, are intended to make the genitals appear more typical.[45]

Intersex adults who oppose genital surgery on intersex children argue that these procedures are not only legally improper, but also create long-term health problems, inhibit sexual response and sexual functioning. Furthermore, sex assignment made by doctors and solidified by surgeons is not always accurate. Organizations such as the ISNA,[46] Bodies Like Ours[47] and Intersex Initiative[48]

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[39] Joseph, *supra* note 12, at 45 ("The timing of vaginal reconstruction remains controversial. Long-term results based on older techniques have identified vaginal fibrosis and stenosis as a frequent complaint in the post-pubertal female.").

[40] *Androgen Insensitivity Syndrome*, *supra* note 14.

[41] *Id.* ("Vaginoplasty surgery is frequently performed on AIS infants or girls to increase the size of the vagina, so that she can engage in penetrative intercourse with a partner with an average size penis."); *see* Joseph, *supra* note 12, at 46 (referring to a vaginoplasty procedure as creating "an acceptable vault for intercourse").

[42] *Vaginal Hypoplasia*, Androgen Insensitivity Syndrome Support Group (AISSG), *at* http://www.medhelp.org/www/ais/ (last updated Aug. 10, 2004). AISSG notes that the most common procedures utilized for vaginoplasty in infants and young children often end in poor results, and strongly recommends deferral until post-puberty so that manual dilation may be attempted first. *See also* Blizzard, *supra* note 35, at 3. Blizzard commented on the need for multiple surgeries and cited to new procedures that may be yield more "successful" results. He discussed two articles regarding a new vaginoplasty technique: "This procedure has yielded excellent results over the past 3-4 years." *Id.* (citing P.K. Donahoe & J.J. Schnitzer, *Ambiguous Genitalia in the Newborn*, *in* PEDIATRIC SURGERY, ch. 118 (J.A. O'Neill et al., eds., 5th ed. 1998); P.K. Donahoe & J.J. Schnitzer, *Evaluation of the Infant Who Has Ambiguous Genitalia and Principles of Operative Management*, *in* SEMINARS IN PEDIATRIC SURGERY 5, 30-40 (1996)).

[43] Creighton & Minto, *supra* note 6, at 1265.

[44] Amy B. Wisniewski et al., *Complete Androgen Insensitivity Syndrome: Long-Term Medical, Surgical and Psychosexual Outcome*, 85 J. CLINICAL ENDOCRINOLOGY & METABOLISM 2664, 2666 (2000).

[45] AMERICAN ACADEMY OF PEDIATRICS, *supra* note 12, at 5 ("Infants [with virilized genitalia] raised as girls will usually require clitoral reduction which, with current techniques, will result not only in normal-looking vulva but preservation of a functional clitoris.").

[46] ISNA, *supra* note 1.

have worked for years to educate medical practitioners about the experiences of intersex individuals, and to find legal remedies for the injuries they have suffered.

IV. TORT LAW LIMITS RECOVERY FOR INTERSEXUALS

The efforts of intersex adults to seek legal redress and to hold the medical community accountable for the harm caused by childhood genital surgeries have failed because the legal system precludes recovery. One may be able to sue a doctor for removing a kidney when a liver transplant was requested, or a merchant for being less than honest about the stereo she sold, or a restaurant owner for shirking his duty to keep the premises safe for customers, but intersex patients have discovered that the law does not protect them in the same way.

To determine whether an individual has been negligent under the law of torts, an individual's actions are compared to those of a reasonably prudent person under the same or similar circumstances.[49] However, the law recognizes a different standard of care for medical malpractice cases.[50] A physician is required to exercise the "degree of knowledge, skill, and care used by other physicians practicing the same specialty."[51] To determine negligence in medical malpractice cases, expert testimony is generally required to establish the particular medical standard against which the defendant in question is to be measured.[52] Where the medical community is essentially divided among several accepted practices, and the physician's actions are considered one of several available options, the physician will generally be considered to have acted non-negligently.[53]

Because the medical community itself defines the medical standard of care, it is nearly impossible to demonstrate that a particular accepted medical standard is negligent. As a result, where the medical community has lagged in its standards or its practices have not been proven effective, legal recovery for personal injuries has generally been precluded.[54] Courts have sometimes deviated from this deference

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[47] Bodies Like Ours, *supra* note 1.

[48] Intersex Initiative, *supra* note 1.

[49] DAN B. DOBBS. LAW OF TORTS § 117 (2000) ("The duty owed by all people generally—the standard of care they owe—is to exercise the care that would be exercised by a reasonable and prudent person under the same or similar circumstances to avoid or minimize risks of harm to others."); RESTATEMENT (THIRD) OF TORTS § 3 (Proposed Draft No. 1, 2005) (stating that a person acts with negligence if the person does not exercise reasonable care under all the circumstances).

[50] Beh & Diamond, *supra* note 6, at 28 (citing BARRY FURROW ET AL., HEALTH LAW § 6-2 , at 361 (1995)). *See* Sam 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 (1995).

[51] Gorab v. Zook, 943 P.2d 423, 427 (Colo. 1997).

[52] Craft v. Peebles, 893 P.2d 138, 149 (Haw. 1995).

[53] Hood v. Philips, 537 S.W.2d 291, 294 (Tex. App. 1976). *See* 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) (referring to Pennsylvania cases that call into question the "two schools of thought doctrine," under which a doctor can avoid malpractice liability if she chose one medically acceptable course of action instead of alternative treatments that are also medically accepted).

[54] *See* Harris v. Groth, 663 P.2d 113 (1983):

> The standard of care against which a healthcare provider's conduct is to be measured is that of a reasonably prudent practitioner possessing the degree of skill, care, and learning

to the medical community,[55] but those cases have sustained sharp criticism from legal commentators[56] and in some cases, deference has been reinstated by legislatures.[57]

The medical standard of care is deemed necessary to prevent judges and juries from imposing their own standard upon a particularly specialized field,[58] but such deference 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."[59] Additionally, the field of medicine is constantly changing as new procedures, medications, and technologies regularly become available to practitioners. Despite the fact that physicians are expected to follow the developments in their area of medicine,[60] physicians who continue to follow time-tested procedures will usually be protected even where more effective, more efficient or more innovative procedures are shown to be available.[61]

V. MINIMUM INFORMED CONSENT STANDARDS AND PARENTAL DECISION-MAKING RIGHTS

In addition to following the medical standard of care, doctors are required to gain informed consent from patients for all procedures, with only rare exception.[62] This requirement is intended to protect against paternalism and to involve patients in their own medical care.[63] As to children, however, parents are expected to make decisions about their children's medical care and to provide informed consent on behalf of their children.

> possessed by other members of the same profession in the state of Washington. The 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 generally* Gary Schwartz, *Medical Malpractice, Tort, Contract and Managed Care,* 1998 U. ILL. L. REV. 885 (1998).

[55] Beh & Diamond, *supra* note 6, at 28 (citing Helling v. Carey, 519 P.2d 981 (Wash. 1974)) (employing a cost/benefit analysis, the court held that physicians may be held negligent regardless of the medical community's standard of care, and specifically despite the fact that it was not the regular practice to institute glaucoma testing in patients under age forty).

[56] *Id.* at 29.

[57] *Id.* (noting that after *Helling*, the Washington State legislature responded by passing legislation that overruled the holding and reinstated the deferential standard).

[58] *Id.* at 30.

[59] *Id.* (quoting 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, 643 (1997)).

[60] *Id.* at 31 (quoting Rooney v. Med. Ctr. Hosp. of Vt., 649 A.2d 756, 759 (Vt. 1994)).

[61] *Id.*

[62] *See generally* William J. McNichols, *Informed Consent Liability in a "Material Information" Jurisdiction: What Does the Future Portend?*, 48 OKLA. L. REV. 711 (1995).

[63] *See* Bryan Warren, *Pennsylvania Medical Informed Consent Law: A Call to Protect Patient Autonomy Rights by Abandoning the Battery Approach*, 38 DUQ. L. REV. 917, 920-30 (2000).

A. Informed Consent Laws are Intended to Protect Patients

The doctrine of informed consent has developed from the legally recognized right to personal and physical autonomy.[64] This legal right, however, has not always been consistent with the practices of organized medicine.[65] Hippocrates himself encouraged doctors to conceal negative information from patients to avoid letting the patient dictate his own course of treatment.[66] The creation of a legal obligation of informed consent forced organized medicine to allow patients a more active role in their own healthcare decisions.[67]

The standard by which to measure whether a physician has adequately disclosed information to a patient before gaining consent is still under dispute.[68] The preeminent case addressing this determination is the 1972 decision in *Canterbury v. Spence*.[69] The court stated that "[t]he scope of the physician's communications to the patient . . . must be measured by the patient's need, and that need is the information material to the decision."[70] In response to *Canterbury*, most states have passed statutes pertaining to informed consent to clarify the jurisdiction's approach.[71] These statutes tend to implement a physician-oriented standard,[72] but can vary widely based on jurisdiction. Most states provide that

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[64] *Id.* at 920-21.

[65] *Id.*

[66] *Id.* at 920.

[67] *Id.* at 921. In a famous opinion by Justice Benjamin Cardozo, a surgeon was held liable for physical trespass, or battery, for extending the scope of the surgery beyond that agreed to by the patient. Schloendorff v. Soc'y of N.Y. Hosp., 211 N.Y. 125, 105 N.E. 92 (1914). Justice Cardozo emphasized the fundamental right to physical autonomy, the necessity for doctors to share information with their patients, and the patient's right to make decisions about her own treatment based on that information. "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages." *Id.* at 93.

[68] In *Salgo v. Leland Stanford, Jr. Univ. Bd. of Tr.*, 317 P.2d 170 (Ca. 1957), the California District Court of Appeals ruled that physicians have a duty to disclose all facts necessary for their patients to make intelligent decisions about their own treatment. This landmark case instituted a patient-centered informed consent standard that ran contrary to medical practice at the time. However, just three years later, the Kansas Supreme Court refused to follow the battery theory of informed consent in *Natanson v. Kline*, 354 P.2d 670 (1960), and instead adopted a negligence approach.

According to William J. McNichols, under a negligence theory, the plaintiff must prove that: there was a relationship between the doctor and the patient; there was a duty to disclose relevant information; the physician failed to disclose relevant information; the patient would not have consented to the procedure or treatment if she had known of the withheld information; and the doctor's failure to disclose was the proximate cause of the injury. Generally, the duty associated with disclosure includes "the procedures and risks connected with: the treatment proposed; feasible alternative treatments; and non-treatment alternatives." *See* McNichols, *supra* note 62, at 719. *See also* Cobbs v. Grant, 502 P.2d 1 (Cal. 1972). While the *Natanson* court did not provide an explicit rationale for rejecting *Salgo*, the California Supreme Court in *Cobbs* explained that it is inappropriate to use an intentional tort for recovery where the wrong was actually an omission rather than an intentional act and where there was no intent to injure the patient. *Id.* at 17-18.

[69] Canterbury v. Spence, 464 F.2d 772 (D.C. Cir.1972).

[70] *Id.* at 786.

[71] Warren, *supra* note 63, at 934 ("Rather than an attempt to promote patient autonomy, many of these [state] legislative efforts were aimed at reducing the impact of medical malpractice claims.").

[72] *Id.* Warren describes three categories of statutes: those with general requirements of disclosure which leave the details to the courts; those with specific requirements or that delegate the job of

physicians must disclose what a reasonable physician under similar circumstances would deem material to the patient's decision.[73]

B. *Limited Exceptions to the Informed Consent Doctrine*

There are rare exceptions to the informed consent requirement. Doctors have the liberty to withhold some information under the theory of therapeutic privilege, where the physician believes that disclosure would be detrimental to the patient from a medical point of view.[74] Therapeutic privilege is generally invoked where unusual nervousness or apprehension exists and poses a health risk;[75] information may be withheld "if it is countertherapeutic, dysfunctional, or distorting for the *particular* patient in question."[76] Courts have recognized that "in some situations it would be bad practice to make full disclosure to an unduly apprehensive patient."[77] However, the use of therapeutic privilege "nullifies the general obligations of disclosure and respect for patient autonomy and self-determination and should therefore be discouraged."[78]

Another exception to the informed consent doctrine involves medical emergency. This privilege has been described as one where "there is an emergency and the patient is in no condition to determine for himself whether treatment should be administered."[79] The essential characteristic of the doctrine is that the medical emergency makes it impossible or impracticable to discuss the risks or benefits associated with a procedure without causing further harm to the patient.[80] However, the privilege should not be confused with incapacity, in which the patient is legally competent to provide consent, except for the current emergency.[81]

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specifying requirements to a state medical board (only two states do the latter); and those which specifically recognize an action in negligence for failure to disclose certain information.

[73] *See, e.g.*, ARIZ. REV. STAT. ANN. § 12-563 (2004) (requiring physicians "to exercise that degree of care, skill and learning expected of a reasonable, prudent healthcare provider in the profession or class to which he belongs within the state acting in the same or similar circumstances"); FLA. STAT. ANN. § 766.103(3)(a)(1) (2005) (requiring a physician's actions in obtaining informed consent to be "in accordance with an accepted standard of medical practice among members of the medical profession with similar training and experience in the same or similar medical community"); KEN. REV. STAT. ANN. §304.40-320(1)-(2) (2004) (deeming that informed consent is sufficient where "[t]he action of the healthcare provider in obtaining the consent of the patient or another person authorized to give consent for the patient was in accordance with the accepted standard of medical or dental practice among members of the profession with similar training and experience" and a reasonable individual would have generally understood the procedure). *See also* Anthony Szczygiel, *Beyond Informed Consent*, 21 OHIO N.U.L. REV. 171 (1994).

[74] McNichols, *supra* note 62, at 721 (citing *Canterbury*, 464 F.2d at 789).

[75] Beh & Diamond, *supra* note 6, at 36-37 (citing Carr v. Strode, 904 P.2d 489, 494 (Haw. 1995); Nishi v. Hartwell, 473 P.2d 116, 119-21 (Haw. 1970) (overruled on other grounds)).

[76] Anne Cote, *Telling the Truth? Disclosure, Therapeutic Privilege and Intersexuality in Children*, 8 HEALTH L. J. 199, 203 (2000).

[77] *Nishi*, 473 P.2d at 121.

[78] Beh & Diamond, *supra* note 6, at 37. *See Canterbury*, 464 F.2d at 789; *McNichols*, *supra* note 62, at 728.

[79] Scott v. Bradford, 606 P.2d 554, 558 (Okla. 1979).

[80] McNichols, *supra* note 62, at 729-30.

[81] *Id.* at 730.

C. The Fundamental Right of Parental Decision-making on Behalf of Minor Children: Whose "Informed Consent" Matters?

To provide informed consent, the patient must be competent, meaning "the patient understands the risks and benefits of treatment and can make an informed decision to consent to or refuse treatment." [82] Legally, however, children are not competent to make their own medical decisions.[83] Courts have recognized that parents possess a fundamental right to make such decisions on their children's behalf.[84] In *Meyer v. Nebraska,* the United States Supreme Court held that due process rights include the right to "establish a home and bring up children."[85] The Court elaborated on this fundamental right in *Pierce v. Society of Sisters.*[86] After noting the right recognized in *Meyer*, the Court further stated: "The child is not the mere creature of the state; those who nurture him and direct his destiny have the right, coupled with the high duty, to recognize and prepare him for additional obligations."[87]

The Court set out the justification for affording parents this fundamental right in *Parham v. J.R.*:

> The law's concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life's difficult decisions. More important, historically it has recognized that natural bonds of affection lead parents to act in the best interests of their children.[88]

D. Constitutional Limits to Parental Decision-making Authority

While parental rights are constitutionally protected, they are not absolute. As early as 1944, the Court limited *Meyer* and *Pierce*, noting that "the state has a wide range of power for limiting parental freedom and authority in things affecting the

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[82] Jennifer L. Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?*, 73 TEMP. L. REV. 1, 32-33 (2000).

[83] *Id.* at 33. *See generally* Lee E. Teitelbaum, *Family History and Family Law*, 1985 WISC. L. REV. 1135 (1985); Barbara Bennett Woodhouse, *Who Owns the Child:* Meyer *and* Pierce *and the Child as Property*, 33 WM. & MARY L. REV. 995 (1992).

[84] Rosato, *supra* note 82, at 7.

[85] Meyer v. Nebraska, 262 U.S. 390, 399 (1923).

[86] Pierce v. Soc'y of Sisters, 268 U.S. 510 (1925) (holding as unconstitutional an Oregon statute requiring parents to submit to public school all children between the ages of eight and sixteen who have not completed the eighth grade).

[87] *Id.* at 535. *See also* Wisconsin v. Yoder, 406 U.S. 205, 232 (1972) ("The history and culture of Western civilization reflect a strong tradition of parental concern for the nurture and upbringing of their children. This primary role of the parents in the upbringing of their children is now established beyond debate as an enduring American tradition."); Lassiter v. Dep't of Soc. Servs. of Durham, N.C., 452 U.S. 18, 27 (1981) ("This Court's decisions have by now made plain beyond the need for multiple citation that a parent's desire for and right to 'the companionship, care, custody and management of his or her children' is an important interest that 'undeniably warrants deference and, absent a powerful countervailing interest, protection.'") (quoting Stanley v. Illinois, 405 U.S. 645, 651 (1971)).

[88] Parham v. J.R., 442 U.S. 584, 602 (1979). This assumption has not gone unchallenged. *See infra* notes 97-109 and accompanying text.

child's welfare[.]"[89] Under the doctrine of *parens patriae*,[90] courts have recognized an obligation to intervene where parental action or inaction may lead to death or serious harm,[91] and where it is in the best interests of the child in some cases.[92]

The legal deference to parental decision-making reflects the assumption that parents can generally be expected to act in the best interests of their child.[93] The medical community also prefers parents and family members to act as proxies where an incompetent patient requires medical treatment.[94] Families generally know the patient better, and therefore, likely know her values, needs and past experiences better.[95] Additionally, a family member's own relationship with the patient, it is believed, will motivate her to make decisions in the patient's best interests.[96] Not all legal and medical commentators agree that family members are the best proxies, however.[97] Even proponents of family surrogate decision-making recognize that parents are not always well suited for the task.[98] Moreover, there is very little evidence that family members are able to determine what a patient would want in a particular situation.[99]

Even assuming that parents are in a better position than most alternatives to make healthcare decisions on behalf of their adult or adolescent children, making

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[89] Prince v. Massachusetts, 321 U.S. 158, 167 (1994). *See also Developments in the Law*, 93 HARV. L. REV. 1156, 1353-55 (1980).

[90] "The state regarded as a sovereign; the state in its capacity as provider of protection to those unable to care for themselves." BLACK'S LAW DICTIONARY (7th ed. 2000).

[91] *Parham.*, 442 U.S. at 603 ("[A] state is not without constitutional control over parental discretion in dealing with children when their physical or mental health is jeopardized."). *See Yoder*, 406 U.S. at 205.

[92] *See* Troxel v. Granville, 530 U.S. 57 (2000).

> [S]o long as a parent adequately cares for his or her children (*i.e.*, is fit), there will normally be no reason for the State to inject itself into the private realm of the family to further question the ability of that parent to make the best decisions concerning the rearing of that parent's children.

Id. at 68-69.

[93] Beh & Diamond, *supra* note 6, at 39 (citing *Parham.*, 442 U.S. at 602, *In re* L.H.R, 321 S.E.2d 716, 722 (1984)). *See also* Fiori v. Penn, 673 A.2d 905, 912 (1995).

[94] Rosato, *supra* note 82, at 40.

[95] *Id.*

[96] *See* Ardath Hamann, *Family Surrogate Laws: A Necessary Supplement to Living Wills and Durable Powers of Attorney*, 38 VILL. L. REV. 103, 161 (1993) (arguing that medical decisions on behalf of incompetent persons should be made by family); *see also* Neal R. Splaine, *The Incompetent Individual's Right to Refuse Life-Sustaining Treatment: Legislating, Not Litigating, a Profoundly Private Decision*, 27 SUFFOLK U. L. REV. 905, 933 (1993) (asserting that an "incompetent patient's interests are best protected when family members act as surrogate decisionmakers" because "[m]embers of a family are likely to know and understand each other better than non-family members").

[97] *See generally* James Bopp, Jr. & Richard Coleson, *A Critique of Family Members as Proxy Decision makers Without Legal Limits*, 12 ISSUES L. & MED. 133 (1996) (criticizing the trend toward empowering family members to make medical decisions on behalf of incompetent patients as one that increases "the potential for violations of the incompetent patient's rights").

[98] *See* Kathleen Boozang, *An Intimate Passing: Restoring the Role of Family and Religion in Dying*, 58 U. PITT. L. REV. 549, 552 (1997).

[99] Bopp, Jr. & Coleson, *supra* note 97, at 149. *See also* Jacqueline Glover, *Should Families Make Health Care Decisions?*, 53 MD. L. REV. 1158, 1162 n.21 (1994) (citing several studies which challenge the assumption that families know the wishes of an incompetent patient).

decisions on behalf of a newborn is a very different matter altogether. In contrast to older children, parents have no better knowledge of a newborn's values and desires than the doctor who delivered her or even a stranger.[100] Parents who make serious medical decisions for very young children and newborns face specific difficulties that other parents do not necessarily face, particularly because "[p]arent-child bonding may not be complete, and the parental love assumed by society to exist in other contexts may not have yet developed."[101]

In the context of medical decision-making on behalf of persons with disabilities, James Bopp, Jr. and Richard Coleson identified several serious issues family members raised when called upon to make such decisions.[102] Many of these issues are applicable to parents making healthcare decisions for their intersex baby. First, "research suggests that problems arise in obtaining the required informed consent when the family is facing a medical crisis."[103] In particular, Bopp and Coleson pointed to the intimidation of the hospital environment, time pressures, and lack of communication skills in some parents.[104] Second, they argued that parents are asked to make difficult decisions under very emotional circumstances at this critical period when they are suffering from feelings "such as shock, denial, anger and guilt."[105] In addition to emotional reactions, there is the

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[100] Bopp, Jr. & Coleson, *supra* note 97, at 149-50 (discussing the difference between parental decision-making for a newborn whose concerns are subordinate to the parents, and an incompetent adult who has provided some insight of their desires).

[101] *Id.* at 152 (quoting T.S. Ellis III, *Letting Defective Babies Die: Who Decides?*, 7 AM.J.L. & MED. 393, 414 (1981)).

[102] Bopp, Jr. & Coleson, *supra* note 97, at 141-56.

[103] *Id.* at 141.

[104] *Id.* The authors discussed several studies on the subject:

One survey of 300 families at Chicago's Children's Memorial Hospital showed that "only 52% of the parents felt they had been given informed consent at the moment of initial treatment." *Id.* Approximately half the families said it took at least six months to feel they understood even half the information they felt was necessary for informed consent. *Id.* (citing D.G. McLone, Presentation, *The Handicapped Newborn: Diagnosis, Prognosis, and Outcome: The Neonatal View*, CONFERENCE ON THE HANDICAPPED NEWBORN IN AMERICAN SOCIETY, Fordham University 11, Mar. 28, 1985) (unpublished paper on file with the National Legal Center for the Medically Dependent and Disabled, Inc.)).

In another study, there were "surprising instances of doctors withholding information from families," and of doctors hiding "the limits of their professional knowledge and ability." *Id.* (citing Lyn Quine & Jan Pahl, *First Diagnosis of Severe Handicap: A Study of Parental Reactions*, 29 DEVELOPMENTAL MED. & CHILD NEUROLOGY 232, 237 (1987)).

The authors also referred to a study which found that parents " 'routinely' signed operation permits without even seeing their child's defects or having treatment options explained." *Id.* (citing Raymond S. Duff & A.G.M. Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 NEW ENG. J. MED. 890, 893 (1973)).

Another study found that most of the parents of children born with spina bifida had never heard of the condition and believed that surgery would fully correct the disability. *Id.* (citing J.H. Walker et al., *Spina Bifida—and the Parents*, 13 DEVELOPMENTAL MED. & CHILD NEUROLOGY 462, 466 (1971)).

[105] Bopp, Jr. & Coleson, *supra* note 97, at 142-44. Referring to a study by Dennis Drotar, the authors noted that "parents' description of the emotional effects indicated a general period of crisis in which the usual problem-solving capabilities are grossly impaired. The shock can last for months, rendering parents incapable of making a rational decision."). *Id.* (citing Dennis Drotar et al., *The Adaptation of Parents to the Birth of an Infant with a Congenital Malformation: A Hypothetical Model*, 56 PEDIATRICS 710 (1975)).

Bopp, Jr. and Coleson also noted that when parents have a child with a disability, the birth can often feel like the death of their dream of a "perfect" baby. "Any death requires a certain grieving potential for conflicts of interest between the parents and the child.[106] "The same closeness that makes family members the most natural substitute decision makers also creates the greatest conflict of interest in the decision-making process."[107] Furthermore, family members often fail to recognize the risk that a child's interests may change over her lifetime.[108] For parents of intersex children, such interests may include sexual orientation, gender identity, and the desire to have children. Finally, Bopp and Coleson recognized that parental decision-making assumes a familial bond that does not always exist, particularly with children who have a disability.[109]

As a result of some of these concerns, the law recognizes exceptions to the right of parents to make healthcare decisions for their minor children. Many states prohibit parents from authorizing experimental medical procedures as treatment for an incompetent child patient without court approval.[110] Some state statutes restrict the right of parents to order bodily organs removed from a mentally incompetent child without "express court approval," except in the case of a life threatening condition.[111]

One of the most notable exceptions is that of forced sterilization of an incompetent minor. Because the right to procreate and make decisions about one's own reproduction is a constitutionally protected right,[112] most states have passed statutes that restrict the right of parents to sterilize their incompetent child.[113] For

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period. However, parents cannot fully grieve the 'loss' of the expected child because they are faced at the same time with the sudden and tremendous burden of the child with a disability who requires immediate attention." *Id.* (citing Walker et al., *supra* note 104).

[106] *Id.* at 146.

[107] *Id.* at 148. ("Family members may consider a decision favoring treatment as an act of love. Furthermore, they may consider a decision against treatment as an act of callous disregard for the loved one."). *Id.* at 147.

[108] *Id.* at 150.

[109] *Id.* at 151 ("The absence of familial ties is most notably demonstrated in the cases of newborns with disabilities. Parent-child bonding may not be complete, and the parental love assumed by society to exist in other contexts may not have yet developed.") (internal citation omitted).

[110] *See, e.g.*, ARK. CODE ANN. § 28-65-302(a)(1)(C) (2005).

[111] *See, e.g.*, ARK. CODE ANN. § 28-65-302(a)(1)(A) (2005) ("Consent on behalf of the incapacitated person to abortion, sterilization, psychosurgery, or removal of bodily organs [requires 'express court approval'] except when necessary in a situation threatening the life of the incapacitated."). *See also* Hart v. Brown, 289 A.2d 386, 391 (Conn.1972) (allowing an eight-year-old child to donate a kidney to an ailing identical twin based on parental consent, demonstration that the risk is negligible, and a showing that there is some benefit to the donor child); Curran v. Bosze, 566 N.E.2d 1319, 1326 (Ill. 1990) (finding that a court order for organ donation by either of a set of twins for the benefit of their half-brother was inappropriate where the relationship between the siblings was negligible and the twins were too young to determine their will at only three and a half years of age).

[112] *See* Roe v. Wade, 410 U.S. 113 (1973); *see also* Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833 (1992); *In re* Romero, 790 P.2d 819, 822 (Colo. 1990) (an individual's fundamental right to procreate extends to decisions preventing procreation); *In re* Grady, 426 A.2d 467, 475 (N.J. 1981) (a patient's incapacity "should not result in the forfeit of this constitutional interest" in procreation); *In re* Terwilliger, 450 A.2d 1376, 1382 (Penn. 1982) (finding clear and convincing evidence that forced sterilization is in the best interests of the incompetent patient is necessary to protect the fundamental right of procreation).

[113] *See, e.g.*, ARK. CODE ANN. § 20-49-101-303 (2004); GA. CODE ANN. § 31-20-3 (2004); UTAH CODE ANN. § 62A-6-101-103 (2004); N. D. CENT. CODE § 23-12-13 (2003).

example, Rhode Island makes it a felony punishable by up to five years in prison with a fine of $5000 to perform or aid in the sterilization of a minor, unless the act was performed to preserve the life or health of the minor.[114] Most other states provide a procedure by which parents and guardians can petition the court for permission to have their incompetent minor child sterilized. In Georgia, for example, the parent or guardian must file a petition with the court, after which the court appoints an examining team, including a psychologist or psychiatrist.[115] Georgia's statute specifies that the minor has the right to counsel at all stages of the proceedings.[116] During the required court hearing, the parent or guardian is required to prove by clear and convincing evidence that sterilization is in the best interests of the child.[117]

State neglect and abuse statutes, under the doctrine of *parens patriae*, also allow state intervention into parental care under certain circumstances.[118] In recent years, federal statutes have demonstrated that social consensus favors state intervention above maintenance of the family unit in cases of abuse or neglect.[119] Under the Adoption and Safe Families Act, for example, child welfare agencies are required to develop a permanency plan, which may or may not include reunification with the parents within twelve months after the child is removed from the home.[120] Additionally, the Proposed Parental Rights and Responsibilities Act of 1995 was rejected and failed to pass in the House.[121] The purpose of the proposed act was "[t]o protect the fundamental right of a parent to direct the upbringing of a child" and would have enshrined the right of "parental choices to prevail in a healthcare decision for a child unless, by neglect or refusal, the parental

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[114] *See, e.g.*, R.I. GEN. LAWS § 11-9-17 (2004).

[115] *See, e.g.*, GA. CODE ANN. § 31-20-2 (2004).

[116] *Id.*

[117] *Id.*

[118] For example, N.Y. FAM. CT. ACT § 1012(f)(i)(A) defines a "neglected child," in part, as a child under eighteen:

> whose physical, mental or emotional condition has been impaired or is in imminent danger of becoming impaired as a result of the failure of his parent or other person legally responsible for his care to exercise a minimum degree of care . . . in supplying the child with adequate . . . medical, dental, optometrical or surgical care[;]

and § 1012(e)(i) defines an "abused child," in part, as a child under eighteen:

> whose parent . . . inflicts or allows to be inflicted upon such child physical injury by other than accidental means which causes or creates a substantial risk of . . . serious or protracted disfigurement, or protracted impairment of physical or emotional health or protracted loss or impairment of the function of any bodily organ.

See, e.g., MISS. CODE. ANN.§ 43-21-105(L)(iv) (defining a "neglected child" as one "who, for any reason, lacks the care necessary for his health, morals or well-being").

[119] Rosato, *supra* note 82, at 9. *See* Adoption and Safe Families Act, 42 U.S.C. 675 § (5)(C) and § (5)(E).

[120] 42 U.S.C. 675 § (5)(C). The statute also notes that if the permanency plan includes a petition for termination of parental rights, the agency must have "documented to the State court a compelling reason for determining that it would not be in the *best interests of the child* to return home." *Id.* (emphasis added). While the statute uses the term "compelling reason," the standard is essentially the best interests of the child.

[121] H.R. 1946, 104th Cong. (1995).

decision will result in danger to the child's life or result in serious physical injury to the child."[122] The omission of such language in the law can be seen as evidence that Congress recognizes the need for the federal or state government to intervene even where the life of the child is not threatened and serious physical injury is not present.

VI. COLLUDING LEGAL DOCTRINE: PARENTS' [ILL-]INFORMED CONSENT HARMS INTERSEX CHILDREN

The peculiar nature of intersex surgeries poses unique problems in fulfilling the intent of the informed consent doctrine and in justifying parental authority over healthcare decisions for children. Together, these legal doctrines have the effect of limiting legal and remedial avenues for patients with intersex conditions where genital surgery is recommended and/or performed. While informed consent and parental authority are intended to be a shield for the vulnerable, both doctrines have become the sword, quite literally, used against intersex children.

The proper treatment of ambiguous genitalia is highly controversial, even within some medical circles.[123] A physician's own biases regarding the proper treatment may inform the way she discusses options with the parents of intersex children. For example, a doctor might tell parents that they may decide to postpone genital surgery until post-puberty or until the patient can make the decision him/herself, but that in the doctor's professional opinion, there is a high risk of psychological problems relating to gender identity or homosexuality.[124] However, unless the physician also discusses the lack of follow-up studies related to intersex patients who have undergone similar procedures and a myriad of other issues material to making such a decision, consent is *not* informed under these circumstances, as evidenced by the growing number of dissenting voices among intersex adults.[125]

Similarly, the logic of the medical community to treat genital abnormalities as a "psychosocial emergency,"[126] or a belief that ongoing uncertainty about a child's sex threatens to destabilize the emotional state of parents, may prevent doctors from disclosing as much information as would be necessary for a reasonable person to make such a decision for his or her child.[127] When parents are not fully informed about their child's condition, the consequences may be

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[122] *Id.*

[123] *See* Wisniewski et al., *supra* note 44, at 2664 ("Controversy concerning the most appropriate treatment guidelines for intersex children currently exist.").

[124] Betsy Driver, Co-Founder and Executive Director of Bodies Like Ours, Keynote Address at the Cardozo Women's Law Journal & Bodies Like Ours Symposium: Intersex Education, Advocacy and the Law (Feb. 22-23, 2005).

[125] *Id. See* Beh & Diamond, *supra* note 6, at 42-57.

[126] *See* AMERICAN ACADEMY OF PEDIATRICS, *supra* note 12, at 1 ("The birth of a child with ambiguous genitalia constitutes a social emergency.").

[127] *See infra* notes 145-48 and accompanying text. *See also* Beh & Diamond, *supra* note 6, at 43-49.

devastating both physically and psychologically. The child maybe deprived of important and necessary medical or psychological care because the parents unquestioningly follow directions of doctors. Further, if the child discovers she is intersex later in life, particularly in situations where the diagnosis has been kept a secret, parents may be unprepared and unable to help the child deal with the psychological trauma, the feelings of betrayal and distrust of those in authority, the sense of isolation, and subsequent medical problems.[128]

Law professor Hazel Glenn Beh and professor of anatomy and reproductive biology Milton Diamond severely criticize the ways in which the informed consent doctrine has failed to protect patient autonomy and self-determination of intersex children in their article, *An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment Surgery on Infants with Ambiguous Genitalia?*[129] Echoing concerns raised by other commentators and intersex adults, they argue that many practitioners confronted with a visibly intersex infant do not obtain effective informed consent from the parents of these children.[130] The authors offer five grounds for critiquing the methods used by these physicians: creation of a false sense of urgency; failure to disclose "complete and accurate information" about both the condition, and the risks and benefits associated with genital surgery; encouragement of parents to withhold information from the child; failure of physicians to acknowledge and discuss the uncertainty of the outcome of surgery; and the medical community's disregard of the child's "right to an open future" when making the decision to operate.[131]

A. The Aura of Urgency

In medical texts and literature, the birth of a visibly intersex child has been treated as "an urgent medical and social problem"[132] and a "psychosexual emergency."[133] Physicians assert that it is imperative to the success of genital surgeries, especially those that involve gender assignment or reassignment, that the child's sex and gender be quickly and clearly implemented for many reasons.[134]

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[128] To read about personal experience of an intersex patient reflecting these concerns, *see infra* text accompanying note 164.

[129] Beh & Diamond, *supra* note 6, at 42-59.

[130] *Id. Accord* Diamond & Sigmundson, *supra* note 6; Erin Lloyd, *Intersex Education, Advocacy & the Law: The Struggle for Recognition and Protection*, 11 CARDOZO WOMEN'S L.J. 283, 293-95 (2005).

[131] Beh & Diamond, *supra* note 6, at 43.

[132] *Id.* at n.10 (citing Alan D. Perlmutter, *Intersex*, *in* UROLOGIC SURGERY IN INFANTS & CHILDREN 2, 15, (Lowell R. Kind ed., 1988); Wilson & Reiner, *supra* note 6, at 368; Emily Nussbaum, *A Question of Gender*, DISCOVER, Jan. 1, 2000, at 92-93, 95, *available at* 2000 WLNR 6385604; Dreger, *supra* note 6, at 30.

[133] Blizzard, *supra* note 35, at 5 ("In most instances of an intersex problem, a *medical emergency* is not present but a *mental and/or social emergency* very likely is.").

[134] *See* KESSLER, *supra* note 6, at 17-21; Geoffrey Cowley, *Gender Limbo*, NEWSWEEK, May 19, 1997, at 64, 65; 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), *available at* http://aappolicy.aappublications.org/cgi/reprint/pediatrics;97/4/590.pdf.

As one practitioner phrased it, it is important to begin surgery early "in order to spare parents the trauma of seeing their child as intersexed each time they change the infant's diaper."[135] Often a team of physicians assigned to an intersex child will decide the sex and gender of the child within forty-eight hours of birth.[136]

Despite this sense of urgency, critics note that "ambiguous genitalia are essentially the only congenital anomalies viewed as a surgical emergency for cosmetic reasons."[137] In fact, the only intersex condition known to require immediate medical attention is the "salt-wasting" or "salt-losing" category of congenital adrenal hyperplasia (CAH). Indeed, genital surgery is not a response to the dangerous medical concerns—which are treated with hormones—but a cosmetic response to atypical genitalia.[138]

Physicians also use this false sense of urgency to stress the need for parents to bond with their child immediately, reflecting a belief that absent surgery, parents will be unable to bond with an intersex child.[139] The American Academy of Pediatrics (AAP) cites several studies that demonstrate the importance of parent-child bonding within the first year of life.[140] "The quality of this attachment will be affected by many variables; one of these, congenital birth defects, may influence the mother's attitude toward the child."[141] The recommendations urge the performance of genital surgery between six weeks and fifteen months to foster psychological development and parental bonding.[142] The AAP's recommendations also reflect the fear that children with visibly intersex conditions will develop poor self-image, and that parental response to the condition may have a large role to play in this development.[143] Additionally, the AAP cautions that waiting to perform the surgery can impact gender role development.[144]

While these concerns may have some merit, there is no evidence that surgery addresses them.[145] Critics argue that the parental response to children born with

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[135] Wilson & Reiner, *supra* note 6, at 363 (citing Heino F.L. Meyer-Bahlburg, *Gender Assignment in Intersexuality*, 10 J. PSYCHOL. & HUMAN SEXUALITY 1021 (1998)).

[136] Dreger, *supra* note 6, at 27.

[137] Beh & Diamond, *supra* note 6, at 43 n.208 (citing Wilson & Reiner, *supra* note 6, at 368; Dreger, *supra* note 6, at 30; Nussbaum, *supra* note 132, at 93).

[138] Dreger, *supra* note 6, at 30 (citing Patricia K. Donahoe et al., *Clinical Management of Intersex Abnormalities*, 28 CURRENT PROBLEMS IN SURGERY 515, 540 (1991)). All CAH patients suffer from an inability to produce cortisone naturally, but some patients also do not produce adequate hormones to regulate salt in the body, a condition that can be life-threatening. Once properly diagnosed, this latter form of CAH may be treated with cortisone and aldosterone, hormones that help to regulate electrolytes and blood pressure. *See* UrologyHealth.org, *supra* note 8.

[139] Beh & Diamond, *supra* note 6 (citing JOHN MONEY, SEX ERRORS OF THE BODY AND RELATED SYNDROMES: A GUIDE TO COUNSELING CHILDREN, ADOLESCENTS, AND THEIR FAMILIES 61, 82-83 (2d ed. 1994)).

[140] AMERICAN ACADEMY OF PEDIATRICS, *supra* note 134, at 590.

[141] *Id.*

[142] *Id.*

[143] *Id.* at 591.

[144] *Id.* (stating that boys who have surgery later are already aware they are unlike their peers—a realization that may increase "feminine" behavior).

[145] Beh & Diamond, *supra* note 6, at 45; *see also* Diamond & Sigmundson, *supra* note 6.

intersex conditions may be better addressed by treating the condition as a congenital abnormality, or atypical genitalia, rather than as a social and psychological emergency necessitating immediate surgical alteration.[146] Legally, it is questionable whether psychological trauma of the parents or the child can constitute a medical emergency in which time constraints make it impossible to discuss the risks or benefits of a particular treatment with a patient before performing it.[147] Deferring surgery and addressing the psychological needs of the parents and the child is a viable alternative that is recommended by many critics of the current treatment protocols.[148]

B. *Parents on a "Need-To-Know Basis"*

In their critique of the current medical approach to the treatment of intersex patients and their families, Beh and Diamond note that parents are often not given a realistic picture of what to expect from the results of genital surgery.[149] Parents are frequently told that their child is born "unfinished" and that surgery will complete a process that should have taken place in the womb.[150] For example, John Money urged that parents should "have the necessary medical information (albeit somewhat simplified) to be able to explain their dilemma to themselves, prior to explaining it to other people."[151]

Commentators critical of early surgical intervention argue that this approach is misleading and potentially damaging.[152] The medical approach implies to parents that the condition is one of genital malformation and not of gender ambiguity, blurring the complex relationship between the two:

> 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 into an infant of the assigned sex . . . . Moreover,

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[146] Beh & Diamond, *supra* note 6, at 45 (citing Diamond & Sigmundson, *supra* note 6, at 1048; Dreger, *supra* note 6, at 192; Preves, *supra* note 34 (noting that surgery compounds the shame associated with intersex conditions and that parents should have been urged to view their child as different rather than convinced to try to normalize them)).

[147] *See supra* notes 79-81 and accompanying text.

[148] *See* Diamond & Sigmundson, *supra* note 6 (calling for a moratorium on genital surgeries on intersex children); *What Does ISNA Recommend for Children with Intersex ?*, ISNA, *at* http://www.isna.org/faq/patient-centered ("Surgeries done to make the genitals look 'more normal' should not be performed until a child is mature enough to make an informed decision for herself or himself."); Bodies Like Ours Mission Statement, *at* http://www.bodieslikeours.org/content/view/16/73/ (last visited Jan. 15, 2006) (stating that an essential part of the organization's mission is "working towards ending non-consensual genital surgeries on infants and children without a voice in their self-determination").

[149] Beh & Diamond, *supra* note 6, at 48.

[150] *Id.* (citing MONEY, *supra* note 28, MONEY, *supra* note 139). *See also* Louise Kiernan, *In Intersex Cases, Gender is a Complex Question*, CHICAGO TRIB., June 20, 1999, at 1-1; Nussbaum, *supra* note 132, at 93-94.

[151] MONEY, *supra* note 28, at 62-63.

[152] *See* Beh & Diamond, *supra* note 6, at 49 n.231.

infant cosmetic surgery on the genitals and careful rearing cannot erase the prenatal influences on sexual identity.[153]

Critics also argue that the simplicity with which doctors explain the "finishing" process also implies that after the surgery the child's genitalia will be "normal."[154] In reality, children who undergo genital surgery may frequently face a lifetime of medical complications they would have otherwise avoided.[155] Moreover, when the inevitable time comes for the patient to be exposed to the genitals of like-gendered persons who have not undergone genital reconstructive surgery, it often becomes clear that the patient's genitals are not, in fact, "normal" even after "normalizing" surgery.[156]

C. *Secrecy: A Necessary Evil?*

In his theoretical work and approach to the John/Joan case, Money insisted that in order for sex assignment or reassignment surgery to be successful, the patient must not be told of his or her born sex or sex ambiguity.[157] Following Money's model, doctors argued in favor of secrecy and deception to avoid psychosexual ambiguity or confusion.[158] Beh and Diamond quoted Dr. Antoine Khoury, chief of pediatric urology at Toronto's Hospital for Sick Children: "[I]f they [the genitals] have an excellent outcome and they look perfect[159] . . . I would want to downplay [the original ambiguity] as much as possible."[160]

Furthermore, Beh and Diamond discussed commentary published in a 1988 Hastings Center Report, in which ethicists debated the best course of action for a sixteen-year-old female and her parents who sought treatment when the girl failed to menstruate.[161] The girl had AIS and would have to undergo surgery to have, among other things, penile intercourse. Doctors wanted to withhold the diagnosis from the patient and her parents until the patient was twenty-one but the doctors were uncertain whether that was an ethical course of action. Brendan Minogue and

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[153] *Id.* at 49.

[154] *Id.*

[155] *See* Haas, *supra* note 2, at 42 ("Older children may be subjected to multiple operations to construct 'functional' vaginas, to repair 'damaged' penises, and to remove internal sex organs."); *see also infra* notes 231-33 and accompanying text (comments from Dr. Howard Devore, an intersex adult with hypospadias).

[156] Ford, *supra* note 2, at 484 ("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.") (quoting Chase, *supra* note 6, at 386).

[157] Beh & Diamond, *supra* note 6, at 50; COLAPINTO, *supra* note 3, at 70. Money subsequently warned *against* secrecy, noting that several of his own patients had confronted him with the trauma it caused. John Money, *Birth Defect of the Sex Organs: Telling the Parents and the Patient*, 10 BRIT. J. SEXUAL MED. 14, 14 (1983).

[158] Beh & Diamond, *supra* note 6, at 52-53.

[159] *Id.* at 52. Dr. Khoury did not elaborate on the definition of "perfection"—whether the standard was based on a perfect likeness to the standard genitals or that of a satisfactory surgical result.

[160] *Id.*

[161] *Id.* (citing Sherman Elias, George Annas, Brendan P. Minogue & Robert Taraszewski, Commentaries, *The Whole Truth and Nothing But the Truth?*, HASTINGS CENTER REP. 34-35 (Oct./Nov. 1988)).

Robert Taraszewski argued, in the same report, that the emotional consequences to the parents, and in turn the patient, make disclosure of the diagnosis senseless.[162]

While that debate took place more than fifteen years ago, many have continued the approach of favoring secrecy. In a 1996 article for the Canadian Medical Association entitled *Medical Ethics and Truth Telling in the Case of Androgen Insensitivy Syndrome*, Anita Natarajan argued that a physician's role for patients with AIS is to construct an adequate vagina if none exists and counsel the patient on alternatives to childbearing.[163] Natarajan strenuously advocated *against* informing the patient of the diagnosis if the child grew up and accepted her feminine gender assignment, stating that "physicians who treat AIS patients are justified in not disclosing the information that the patient is genetically male."[164] The justifications for withholding the diagnosis from an intersex patient are, to an extent, consistent with the theory that the patient must never doubt her sex assignment. Parents are often encouraged to keep the truth from friends and family members as well,[165] ostensibly because the fewer people who know, the less chance the secret will be revealed and the patient's psyche damaged.

The court in *Canterbury v. Spence* sharply cautioned against the use of therapeutic or emergency privilege to deceive the patient when considering whether the doctor had a duty to disclose a risk of paralysis to the patient prior to spinal surgery:

> The physician's privilege to withhold information for therapeutic reasons must be carefully circumscribed, however, for otherwise it might devour the disclosure 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 . . . runs counter to the foundation principle that the patient should and ordinarily can make the choice for himself.[166]

For healthcare decisions, the presumption is that informed consent is necessary for all procedures, with limited exceptions. In an action for failure to obtain informed consent, the burden is on the physician to prove that a medical emergency or therapeutic privilege exists, which overrules the presumption of informed consent.[167] If the physician is unable to demonstrate medical emergency or therapeutic privilege existed, he or she will be held liable for violation of informed consent. In the case of genital reconstruction surgery on intersex minors, however, the medical community has instituted a presumption *against* informed consent based on an assumed medical emergency or therapeutic privilege without taking

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[162] Beh & Diamond, *supra* note 6, at 53 (citing Elias et al., *supra* note 161, at 35).

[163] Anita Natarajan, *Medical Ethics and Truth Telling in the Case of Androgen Insensitivy Syndrome*, 154 CAN. MED. ASS'N J. 568, 568 (1996).

[164] *Id.* at 569.

[165] Beh & Diamond, *supra* note 6, at 50.

[166] Canterbury v. Spence, 464 F.2d 772, 789 (1972).

[167] Bernard v. Char, 903 P.2d 676, 684 (Haw. App. 1995), *cert. granted and clarified on other issues*, 903 P.2d 667 (1995).

into account the individual circumstances, needs, or sophistication of the particular parents or patient.

In addition to the duty to obtain informed consent from the parents of intersex minors prior to performing surgery, there is some evidence that doctors have a fiduciary duty to tell the patient herself of any "abnormalities in his or her own body." In *Gates v. Jensen*, the court considered the fiduciary duty of a physician to inform a patient concerning the abnormalities of the patient's 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 . . . . These decisions must all be taken with the full knowledge and participation of the patient.[168]

The critical flaw in the physicians' promotion and practice of secrecy in these situations seems obvious—that is, the patient is likely to discover her diagnosis in one way or another at some point in her life.[169] Even John Money, the sexologist whose work on the John/Joan case created the standard of care at issue here, later recognized that secrecy cannot be maintained and began to advocate against it: "The withholding of information can be extremely traumatic, as the patient will soon realize that things are being withheld and will resort to inferential guesswork."[170]

The story of Cheryl Chase[171] is illustrative of the experiences of many intersex patients who discover their diagnoses in adulthood after suffering years of deception by healthcare workers and family members. Ms. Chase was never told that she was subjected to clitoral reduction surgery as a child, but she knew there was something different about her. At nineteen years old, she decided to seek out medical records on her own, which proved a daunting task. It took more than three years to obtain her *own* records and to discover that although she was originally

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[168] Gates v. Jensen, 595 P.2d 919, 922-23 (Wash. 1979) (en banc) (citation omitted).

[169] The personal stories that recount the long, hard road of adult intersex patients discovering their diagnoses may be found in many publications and websites. For an introduction to some intersex patients' experiences, see Angela Moreno, *In Amerika They Call Us Hermaphrodites*, CHRYSALIS: J. TRANSGRESSIVE GENDER IDENTITIES, Vol. 2, No. 5, Fall 1997/Winter 1998, at 12-13, *available at* http://www.isna.org/books/chrysalis/moreno; Martha Coventry, *Finding the Words*, CHRYSALIS: J. TRANSGRESSIVE GENDER IDENTITIES, Vol. 2, No. 5, Fall 1997/Winter 1998, at 27-29, *available at* http://www.isna.org/books/chrysalis/coventry; INTERSEX IN THE AGE OF ETHICS (Alice Domurat Dreger ed., 1999); *Personal Stories About Being Intersexed*, Bodies Like Ours, *at* http://www.bodieslikeours.org/content/blogsection/9/178/ (last visited Jan. 15, 2006); Sherri Groveman, *The Hanukkah Bush: Ethical Implications in the Clinical Management of Intersex*, 9 J. CLINICAL ETHICS 356, 357-359 (1998).

[170] Beh & Diamond, *supra* note 6, at n.239 (citing MONEY, *supra* note 151).

[171] Cheryl Chase is the founder of the Intersex Society of North America, one of the largest and most visible intersex activist organizations in the world.

deemed a male with micropenis and undescended testes, subsequent tests revealed she had an XX, or female, chromosomal pattern. When she was eighteen months old, her parents changed her name from Charles to Cheryl, had her large clitoris removed, and upon the advice of doctors, removed all vestiges of her existence as a boy.[172] For Chase, this revelation had tremendously damaging consequences. It took her years to talk to anyone about her condition and she went through intense depression, seriously considering suicide before she turned her anger into activism.[173]

While many adults eventually discover their condition, others do not and suffer the consequences warned of by the court in *Gates*,[174] namely being unable to fully participate in one's own medical care because of a lack of knowledge. For patients with conditions requiring the removal of hormone-producing gonads, or for those whose bodies cannot properly process certain hormones, such as androgen, not knowing their diagnosis may be fatal. Similar to post-menopausal women, these patients suffer from hormone deficiencies that may lead to severe and painful osteoporosis if left untreated. Some adults who learn about their secret diagnosis later in life may be dissuaded from getting medical attention for their condition as well as other needs because they no longer trust healthcare providers to act in their best interest.[175]

D. Physicians Project Dangerous Optimism

A fundamental premise of informed consent law is that physicians must provide the patient with information adequate to make an informed decision. Yet in cases of genital surgeries on intersex children, clinicians often not only fail to tell parents that a "successful" outcome is far from certain, but also project confidence about the outcome without factual data to justify such confidence.[176] As Kenneth Kipnis and Milton Diamond point out in their article, *Pediatric Ethics and the Surgical Assignment of Sex*, "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."[177]

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[172] *Is It a Boy or a Girl?*, *supra* note 21.

[173] *Id.*

[174] *Gates*, 595 P.2d at 919.

[175] *See* Beh & Diamond, *supra* note 6, at 55 (citing Kenneth Kipnis and Milton Diamond, *Pediatric Ethics and the Surgical Assignment of Sex*, 9 J. CLINICAL ETHICS 398, 407 (1998); Milton Diamond, *Pediatric Management of Ambiguous Genitalia and Traumatized Genitalia*, 162 J. UROLOGY 1021, 1026 (1999)).

[176] Beh & Diamond, *supra* note 6, at 56.

> 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.

Id., at 67.

[177] *Id.*, at n.261 (quoting Kipnis & Diamond, *supra* note 176, at 407).

The lack of follow-up studies with adult intersex patients creates severe problems with informed consent, as Kipnis and Diamond noted in their work.[178] This void in medical knowledge allows the medical community to make judgments of success on the basis of theory and immediate cosmetic results. As late as 1996, the American Academy of Pediatrics recommended that genital surgeries should be performed between eighteen and twenty-four months of age. The recommendation relied solely on Money's unproven theory that "a person's sexual body image is largely a function of socialization" and his research in the John/Joan case, which was entirely anecdotal.[179] Had David Reimer, the subject of Money's study, been part of a follow-up study, it would have revealed that he rejected his assigned female sex and began living as a male at the age of fourteen.[180]

Beh and Diamond noted that parents who consent to surgeries "might have responded differently had they understood the innovative nature" of the treatment.[181] While some parents would inevitably choose surgery even with the knowledge that follow-up is lacking and the results are uncertain, the confidence projected by physicians gives parents a false sense of security. If success appears certain or even probable, parents will be less likely to plan for the possibility that the sex assignment will be rejected, or that the child may struggle with her or his gender identity.

E. Short-Sighted Considerations Close Doors for Intersex Adolescents and Adults

While genital surgery has been promoted as a way of "normalizing" intersex children, Beh and Diamond argued that "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."[182] The possibility that the intersex individual "might desire to participate in their treatment decisions" is wholly disregarded.[183]

The theories upon which the current medical protocol rests reflect the larger failure of the medical community to take into account the rights of intersex children to make decisions and to develop in ways that are a given for non-intersex children. The medical protocol is rife with assumptions that all intersex children will not only grow to be heterosexual, but that it is the desired outcome.[184] The fact that

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[178] *Id.*

[179] MONEY, *supra* note 28. *See* AMERICAN ACADEMY OF PEDIATRICS, *supra* note 134. *See also* Beh & Diamond, *supra* note 6, at 57 n.265.

[180] *See* COLAPINTO, *supra* note 3.

[181] Beh & Diamond, *supra* note 6, at 56. *See* FURROW, *supra* note 50, at 386-87 (raising questions as to whether informed consent is even legal if uncertainty of outcome is not explained to parents). "[C]ourts seem willing to tolerate innovation so long as a patient is properly informed as to the innovative and untested nature of the procedure." *Id.*

[182] Beh & Diamond, *supra* note 6, at 57.

[183] *Id.*

[184] Katrina Karkazis, Address at the Cardozo Women's Law Journal & Bodies Like Ours Symposium, *supra* note 124 (discussing that heterosexual intercourse is seen as "proper sexual

vaginoplasty is performed on female infants born either without a vaginal opening or with one deemed inadequate for sexual intercourse reveals physicians' assumption that the child will one day grow to desire penile-vaginal intercourse. Clitoral reduction or recession is deemed necessary to feminize the genitals with seemingly no consideration that in a lesbian relationship, a large clitoris may be seen as desirable or at least non-threatening.[185] Sex reassignment is performed on some male babies with a diagnosis of micropenis under the explicit assumption that the child would be unable to adequately engage in heterosexual intercourse with a small penis, and that the better alternative is to at least ensure that the child can be receptive to heterosexual intercourse.

Many intersex adults complain that their surgery left them unable to engage in or enjoy sexual acts to their fullest. One intersex adult who had surgery in her early teens described her pre-operative vaginal area as a "smooth sheath of skin," responsive to sexual contact and even self-lubricating.[186] The surgery, she said, left her with scarred and desensitized genitalia that do not respond satisfactorily to sexual touching.[187] Dr. Howard Devore, a clinical psychologist and sex therapist born with hypospadias, said that he engages in sex but that years of surgery have made attaining an erection painful, as the scar tissue has become stiff and inflexible.[188]

In addition to the physical side effects of genital surgery, many intersex children experience confusion and conflict regarding gender, particularly where the assigned sex differs from the sex of birth, but also in cases where intersex adults express ambivalence about their gender. Dr. Devore, for example, feels that he is neither fully male nor female but somewhere in between, a sentiment that is echoed by several other intersex adults interviewed in the documentary *Is It a Boy or a Girl?*.[189] Surgery to assign or solidify a particular sex denies the intersex individual the opportunity to develop his or her own sense of who they are and the gender with which they most closely identify.

For these reasons, ISNA and other activist groups recommend that surgery should at least be postponed until such time as the child is able to take part in the decision-making process.[190] Such an intensely personal choice should be made by the individual her- or himself. Beh and Diamond noted that there may be a trend in

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function"); Jessica Knouse, *Intersexuality and the Social Construction of Anatomical Sex*, 12 CARDOZO J.L. & GENDER (forthcoming 2006). *See also* Lloyd, *supra* note 130, at 288, 292.

[185] Beh & Diamond, *supra* note 6, at n.87 (citing Heino F.L. Meyer-Bahlburg, *supra* note 135 ("In my clinical experience, [] some patients who live as lesbian women would prefer if their enlarged clitoris had been left intact.")).

[186] *Is It a Boy or a Girl?*, *supra* note 21.

[187] *Id.*

[188] *Id.*

[189] *Id.*

[190] *See* ISNA, *supra* note 1; KESSLER, *supra* note 6, at 17-21; Cowley, *supra* note 134; AMERICAN ACADEMY OF PEDIATRICS, *supra* note 134.

the work of medical ethicists toward recognizing the need for patient participation in such decisions.[191]

VII. INHERENT CONFLICTS OF INTEREST COUNTER THE PRESUMPTION OF PARENTAL DECISION-MAKING AUTHORITY

As noted earlier, parents and family members are not always trusted by the courts to protect the interests of children in medical decision-making.[192] In many circumstances, parents have at least a potential conflict of interest that may cloud their judgment when making a decision on behalf of their minor child.[193] In some cases, the potential for conflict is so great that judicial intervention is warranted.[194] Jennifer Rosato describes such circumstances as "categorical conflicts of interest,"[195] including decisions that most people find unreasonable, decisions that call for extraordinary medical treatment, and decisions in which the required treatment implicates a countervailing constitutional right of the patient that, if exercised, contradicts the parents' decision.[196]

Common law and statutory law have developed in response to such categorical conflicts of interest in areas such as organ donation by a minor child,[197] the removal of life support of infants,[198] exposure to experimental treatment,[199]

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[191] Beh & Diamond, *supra* note 6, at 58 (citing Dena S. Davis, *Genetic Dilemmas and the Child's Right to an Open Future*, 28 RUTGERS L.J. 549, 575-81 (1997)). As to genetic testing on intersex children, Beh & Diamond quoted a recommendation of Laurence McCullogh, Medical Ethicist, Baylor College of Medicine Center for Medical Ethics and Health Policy, *The Ethics of Gender Reassignment*, Presentation at the 1999 Pediatric Gender Reassignment: A Critical Reappraisal Conference (Dallas, Tex. Apr. 30, 1999):

> 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.

Beh & Diamond, *supra* note 6, at 58.

[192] Rosato, *supra* note 82, at 43.

[193] *Id.*

[194] *Id.* at 52:

> [A] conflict of interest approach would best protect the interests of children, while still allowing for a zone of privacy in which family decision-makers could make healthcare decisions without court intervention . . . . [T]hese cases should be decided using a conflict of interest approach similar to the one used when family members or guardians make decisions for incompetent patients.

[195] *Id.* at 43. This note uses the term to refer to circumstances where the risk of conflicts of interest is so high that judicial intervention should always be called for, or to circumstances where the law already imposes judicial intervention.

[196] *Id.* at 43. Rosato also identified "situational conflicts" that arise based on the particular facts. The note has specifically excluded consideration of situational conflicts because of the peculiarity of intersex genital surgery.

[197] *See, e.g.*, D.C. CODE § 21-2047(c)(1) (2005); ARK. CODE ANN. § 28-65-302(a)(2)(A) (2005).

[198] *See, e.g.*, ARK. CODE ANN. § 28-65-302(a)(1)(B) (2005); D.C. CODE § 21-2047(c)(3) (2005).

[199] *See, e.g.*, ARK. CODE ANN. § 28-65-302(a)(1)(C) (2005); N.D. CENT. CODE § 25-01.2-09(4) (2005).

and forced sterilization.[200] Where such a conflict exists, a neutral third-party, such as a judge, is generally called upon to determine whether the treatment is medically necessary or in the best interests of the child.[201]

A. Decisions "Outside the Range of Reasonableness"

A medical decision outside the range of reasonableness refers to instances in which a parent makes a medical decision that does not comport with that of a reasonable parent in the same or similar situation. Such a conflict reflects a belief that the parent may be considering factors designed to serve his or her own interests.[202] However, in situations where negative consequences of the decision are unlikely and minimal, a parental decision outside the range of reasonableness may be acceptable.[203]

Because of the subjective nature of this type of decision, the law generally relies upon the medical community to bring the conflict to the attention of courts.[204] Judicial intervention is therefore rare.[205] Commentators have argued that a complete refusal of medical care and the denial of a blood transfusion should both be considered decisions outside the range of reasonableness, especially if based on religious reasons.[206] While it is possible that an intersex child's parent may express wishes the physician believes to be unreasonable, it is unlikely that genital surgeries on intersex minors will be considered outside the range of reasonableness. For one, the physician and not the parent generally recommends surgery, making it unlikely that doctors themselves will call for judicial intervention. Additionally, where the parent does request such genital surgery, it is clearly within the current range of medical reasonableness as it is the standard treatment for intersex children. One situation in which the proposed treatment for an intersex child may be challenged as outside the range of reasonableness is where there are two parents involved in the decision-making process, and one parent strongly disapproves of the treatment. To prevent the other parent from going forward with the treatment, the disapproving parent may have the ability to challenge the decision.

These types of challenges—either by one parent against another or by the medical community—are rare, and relying on this argument to raise issues of

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[200] *See, e.g.*, N.D. CENT. CODE § 23-12-13(4) (2005); D.C. CODE § 21-2047(c)(1) (2005); R.I. GEN. LAWS § 11-9-17 (2005), CONN. GEN. STAT. § 45a-698 (2005); GA. CODE ANN. § 31-20-3 (2005).

[201] Rosato, *supra* note 82, at 43.

[202] *Id.* at 44. Rosato quoted several commentator regarding the "unreasonableness" standard as "not a decision that could reasonably be judged to be in the patient's best interest," COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, AMA CODE OF MEDICAL ETHICS § 2.20 (1999); and "no responsible physician would implement the choice or the decision is outside the boundaries of acceptable medical practice," Hamann, *supra* note 96, at 159-60.

[203] Rosato, *supra* note 82, at 43 (citing ALLEN E. BUCHANAN & DAN W. BROCK, DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION-MAKING (1989)).

[204] *See* Rosato, *supra* note 82, at 45-46 nn.261-75.

[205] *Id.* at 44.

[206] *Id.*

unreasonableness in the context of intersex conditions fails to adequately address the needs of intersex patients.

B. "Extraordinary Medical Treatment"

Many states have created common law or statutory exceptions to the fundamental right of parents to make healthcare decisions on behalf of their children where such decisions involve extraordinary medical treatment. In Massachusetts, for example, the exception has developed through the courts and includes forced sterilization,[207] among others.[208] A Colorado court also held that sterilization of an incompetent minor is extraordinary medical treatment that requires determination by the court that such treatment is in the best interest of the child.[209] Other states, such as Connecticut, Missouri, and New Hampshire, have passed statutes that require court approval prior to any extraordinary treatment of an incompetent minor.[210] Furthermore, extraordinary treatment generally must be medically necessary to protect the health or well-being of the child.[211]

Several states also consider organ donation an extraordinary treatment that requires parents to petition the court to determine that such donation is in the donating child's best interest.[212] These situations often arise when a minor child is called upon to donate an organ to a sibling. The child is legally incompetent and unable to provide consent; healthcare decisions are therefore left to the parents, unless restricted by such statutes. Certainly, it is easy to see the reasons state legislatures might require judicial intervention in such cases. Many times, parents are forced to choose between encouraging the donor child to undergo a potentially dangerous organ-removal procedure for the sake of another child, or accepting the possibility that the donee child will not get the organ she needs. As the surgery is not required for the health of the donor-child, it is considered extraordinary

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[207] *In re* Moe, 432 N.E.2d 712, 716, 724 (Mass. 1981) (holding that forced sterilization is extraordinary medical treatment).

[208] *In re* Roe, 421 N.E. 2d 40 (Mass. 1981); *In re* Spring, 405 N.E. 2d 115 (Mass. 1980).

[209] *In re* Romero, 790 P.2d 819 at 822 (Colo. 1990). *See also* Roberta Cepko, *Involuntary Sterilization in Mentally Disabled Women*, 8 BERKELEY WOMEN'S L.J. 122 (1993); Elizabeth Scott, *Sterilization of Mentally Retarded Persons: Reproductive Rights and Family Privacy*, 1986 DUKE L.J. 806, 818 (1986).

[210] *See, e.g.*, CONN. GEN. STAT. § 45a-698 (2005); MO. ANN. STAT. § 475.121 (2005); N.H. REV. STAT. ANN. § 137-J:2 (2005). *See also* D.C. CODE ANN. § 21-2047 (2005); MINN. STAT. ANN. § 525.56 (2005).

[211] *See, e.g.*, R.I. GEN. LAWS § 11-9-17 (2005):

> Every person who performs or aids and abets in the performance of a sterilization procedure on any person under the age of eighteen (18), unless the sterilization is incidental to, or is rendered necessary or unavoidable by, some other medical treatment or procedure required to preserve the life or health of that person, shall be guilty of a felony punishable by up to five (5) years imprisonment and a fine of up to five thousand dollars ($5000), or both.

Id.; *In re* A.W., 637 P.2d 366, 375-76 (Wash. 1980); Wentzel v. Montgomery General Hospital, Inc., 447 A.2d 1244, 1254 (Md. 1982). *See also* CONN. GEN. STAT. § 45(a)-698 (2005); GA. CODE ANN. § 31-20-3 (2005), KAN. STAT. ANN. § 59-3018 (2005), N.C. GEN. STAT. § 35A-1242 (2005).

[212] *See, e.g.*, ARK. CODE ANN. § 28-65-302 (2005); KAN. STAT. ANN. § 59-3018 (2005); OKLA. STAT. tit. 30, § 2-119 (2005).

treatment and courts have required that parents demonstrate that there is *some* benefit to the donor-child.[213]

C. Treatments Which Threaten Children's Constitutional Rights

Where a healthcare decision threatens to infringe upon the constitutional rights of the child, the state is obliged to take steps to protect the child's future interests. Balancing the rights of the child with the rights of the parents is necessary to ensure the protection of the child's best interests. Constitutional and statutory law has already recognized this conflict of interests and provided protection for the minor in some circumstances. The Supreme Court recognized that the Constitution and its protections extend to minors in *Planned Parenthood of Central Missouri v. Danforth*:

> Constitutional rights do not mature and come into being magically only when one attains the state-defined age of majority. Minors, as well as adults are protected by the Constitution and possess constitutional rights.[214]

Three years later, the Supreme Court affirmed the Constitutional rights of minors, but noted that "the constitutional rights of children cannot be equated with those of adults" because of their vulnerability, their inability to make informed mature decisions, and "the importance of the parental role in childrearing."[215] The Court cautioned that flexibility and sensitivity to the needs of the parents and the children should be used in the application of constitutional principles to such cases.[216]

The Supreme Court exercised such careful balancing in deciding the constitutionality of state statutes requiring abortion providers to obtain consent from the parents of minors seeking abortion.[217] Applying the "undue burden" standard,[218] the Court in *Danforth* held that parents cannot have an absolute veto over their minor child's decision to obtain an abortion, and that states must create a procedure by which minors can bypass the parental consent requirement.[219] The procedure must allow the minor to demonstrate that the abortion would be in her best interests.[220]

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[213] *Hart*, 289 A.2d at 391; *Curran*, 566 N.E.2d at 1326. *See supra* note 111 and accompanying text.

[214] Planned Parenthood of Cent. Mo. v. Danforth, 428 U.S. 52, 74 (1976). *See also* Bellotti v. Baird, 443 U.S. 622, 633 (1979) ("A child, merely on account of his minority, is not beyond the protection of the Constitution.").

[215] *Bellotti*, 443 U.S. at 634.

[216] *Id.*

[217] *Danforth*, 428 U.S. at 74.

[218] The "undue burden" standard was announced in *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833 (1992), which prohibited states from placing restrictions that would cause undue burden on a woman's ability to obtain an abortion.

[219] *Danforth*, 428 U.S. at 74.

[220] *Bellotti*, 443 U.S. at 644.

Courts have also found that children have the right to bodily integrity.[221] Furthermore, the courts recognized that where a minor is unable to advocate for such rights, the parent or the guardian has the responsibility on the child's behalf to make decisions that would protect the rights in the best interest of the child.[222] Importantly, in 1996, Congress passed legislation criminalizing female genital mutilation of minors, regardless of parental consent.[223] The law was intended to protect the right to bodily integrity and privacy, specifically noting that "such mutilation infringes upon the guarantees of rights secured by Federal and State law, both statutory and constitutional."[224]

For intersex children, the rights to bodily integrity and to reproductive freedom are particularly important. While courts have already characterized the loss of bodily organs and functions as extraordinary treatment,[225] such treatment may also violate the child's constitutional rights.[226] The right to bodily integrity, the "right to be let alone," and the right to refuse treatment[227] are all threatened when an intersex child is subjected to genital surgery or sex reassignment surgery. The life-altering nature of the procedure itself threatens the right to bodily integrity in many cases. Certainly the removal of organs in the more dramatic cases, such as

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[221] *In re* Rosebush, 491 N.W.2d 622, 680 (Mich.1992):

> Courts variously have found the a right to forego life-sustaining medical treatment on the basis of three sources: (1) the common-law right to freedom from unwanted interference with bodily integrity, (2) the constitutional right to privacy or liberty, or (3) statute . . . . The right to refuse lifesaving medical treatment is no lost because of the incompetence or the youth of the patient.

See also Custody of a Minor, 393 N.E.2d 836, 845 (Mass. 1979) ("[T]he child's own rights of privacy and bodily integrity are fully recognized in principles set out in this opinion."); *In re* Fiori, 673 A.2d 905, 909-10 (Pa. 1996) (recognizing that "[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") (discussed in Beh & Diamond, *supra note* 6, at 34 n.159).

[222] *Rosebush*, 491 N.W.2d at 680.

[223] 18 U.S.C.S. § 116 (2005).

[224] Criminalization of Female Genital Mutilation Act, Pub. L. No. 104-208, § 645, 110 Stat. 3009, 3009-708(3) (1996) (codified as amended at 18 U.S.C. § 116). *See also* 110 Stat. 3009-708(6) (stating that Congress is invoking its right to pass legislation to protect guaranteed liberties under the Fourteenth Amendment: "Congress has the affirmative power under... section 5 of the fourteenth amendment... to the Constitution to enact such legislation.").

[225] *See, e.g., Hart*, 289 A.2d at 387; *Curran*, 566 N.E.2d at 1321; Little v. Little, 576 S.W.2d 493, 494 (Tex. 1979). *See also supra* note 111 and accompanying text.

[226] Many commentators have argued that intersex surgeries, if challenged, may be held as violations of the Constitutional rights of the children. While that argument has much merit, it is an impractical solution for the immediate future. The Constitution prevents encroachment of the government upon the rights and liberties of individuals and therefore generally cannot be imputed to private actors. In order to be successful in a constitutional claim, the plaintiff is required to demonstrate that the wrong-doer is a "state actor" and therefore subject to the limitations of the Constitution—a requirement that severely limits the remedial value in the case of intersex surgeries on minors, since many procedures are performed at private hospitals and by individuals not acting with authority of the state. Therefore, while this note invokes constitutional principles, it is used as support for the argument that the state, in its role as *parens patriae*, has the affirmative duty to protect the rights of incompetent minors from the imposition of parental interests. For more information on constitutional arguments in this context, see Haas, *supra* note 2, at 55-61, 64-66; Sara Benson, *Hacking the Gender Binary Myth: Recognizing Fundamental Rights for the Intersexed*, 12 CARDOZO J.L. & GENDER (forthcoming 2006); Lloyd, *supra* note 130, at 294-95.

[227] *Rosebush*, 491 N.W.2d at 680.

sex reassignment of a genetic male born with micropenis or a genetic female born with an enlarged clitoris, should at minimum be recognized as within the protections of the right to bodily integrity. The practice of exposing the genitals of intersex children to a parade of hospital staff for research or educational purposes without the consent of the patient or, often times, even the parents, alone could amount to an invasion of bodily integrity in some cases.[228]

Many adult intersexuals complain of sexual dysfunction as a result of their surgeries. Cheryl Chase and Betsy Driver have both acknowledged that the removal of their clitorises have left the area with little to no sensation or sexual response.[229] Angela Moreno was twelve years old when her clitoris was removed, and recalled that the organ responded to sexual stimuli before the surgery. She said the surgery "decreased [her] responsiveness by a factor of five or ten."[230] Male patients with hypospadias, a condition in which the urethral opening of the penis is located somewhere other than at the tip of the penis, also complain of the effects of surgical intervention. In the film *Is It a Boy or a Girl?*,[231] Dr. Howard Devore, a clinical psychologist and sex therapist, says that he underwent dozens of surgeries until his late twenties when he refused any further surgery to correct his hypospadias.[232] With each surgery came more scar tissue, which became less pliable with the passing time, causing discomfort and sometimes pain when an erection is achieved.[233]

The right to procreate and make choices about reproduction is firmly rooted in our nation's jurisprudence.[234] In addition to Constitutional protections, most states have passed legislation protecting minors and incompetent persons from forced sterilization, requiring judicial intervention to determine the best interests of the person before an order will be issued.[235] For intersex patients, however, the

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[228] While delivering the keynote address at a recent symposium, Betsy Driver, the director of Bodies Like Ours and an intersex adult, said that she remembers doctors and residents coming into her room late at night to look at her genitals and that sometimes people other than her doctor were allowed to touch her genitals. She referred to herself as "an object of spectacle" at the hospital prior to her surgery. Driver, *supra* note 124. Angela Moreno said that the trauma of hospitalization and surgery was compounded by "putting me on show for parades of earnest young residents with 'you're-a-freak-but-we're-compassionate' grins on their faces. This, all without nurses or my parents anywhere around." Moreno, *supra* note 169.

[229] Driver, *supra* note 124; *Is It a Boy or a Girl?*, *supra* note 22 (Chase describes the procedure she underwent and its effects on her body).

[230] Moreno, *supra* note 169, at 12. Moreno also wrote: "I do have some clitoral sensation. I sometimes masturbate and I do have an experience which I call orgasm—some faint muscular contractions. But the response is unreliable, and nothing like the tremendous sensitivity and wonderful juicy orgasms I had before the surgery." *Id.*

[231] *Is It a Boy or a Girl?*, *supra* note 21.

[232] To correct hypospadias, a man-made urethra is extended to the tip of the penis so that the boy can stand to urinate and ostensibly to prevent infections in the most extensive cases. However, because of the acidity level of urine, man-made materials break down over time, requiring further surgery.

[233] *Is It a Boy or a Girl?*, *supra* note 21. As shown on the documentary, Dr. Devore's comments are echoed by other men with hypospadias, who also complain of constant urinary tract infections. One man stated that he has to plan for an infection approximately every six weeks.

[234] *See supra* note 106 and accompanying text.

[235] *See, e.g.*, N.D. CENT. CODE § 23-12-13(4) (2005) ("No person . . . may provide consent for sterilization . . . without a mental health proceeding or other court order."); D.C. CODE § 21-2047(c)

ability to procreate is deemed less important than the ability to have adequate heterosexual intercourse. This is most notably true for male children born with a micropenis where doctors recommend sex reassignment to female. In such cases, all reproductive organs are removed, vaginoplasty is performed, and feminizing hormones are prescribed.

The right to marriage is also directly implicated in some circumstances of genital surgery on intersex children. In *Loving v. Virginia,* the Supreme Court stated that marriage is a fundamental right protected by the Fourteenth Amendment's equal protection clause.[236] However, the Federal Defense of Marriage Act (DOMA),[237] and similar legislation in most states,[238] limits marriage to unions between one man and one woman, and the way sex is determined for purposes of marriage can vary from state to state.[239] States generally rely on birth certificates to reflect the sex of the parties applying for marriage, [240] but some states allow changes to the birth certificates under certain circumstances. Therefore, the right to marriage is threatened in cases such as that of David Reimer, where the intersex child grows up to reject the surgical sex assignment, or develops a gender identity not in line with their given gender assignment. In these cases, the intersex adult's ability to marry a person of the opposite sex may very well depend on his or her state of residence.

VIII. CONFLICTS OF INTEREST DEMAND JUDICIAL INTERVENTION: A MODEL STATUTE REQUIRING COURT APPROVAL FOR "NORMALIZING" TREATMENT OF INTERSEX CHILDREN

The failure of the current legal system to either protect intersex children from unwanted genital surgeries, or to provide intersex adults with redress for damaging genital surgeries, is an urgent problem that must be addressed. The problematic clinical practices and the conflicts of interests of the current medical approach call for legislative action that severely restricts the ability of doctors and parents to make decisions in cases of intersex births that they are not allowed to make in other contexts. Federal and state legislation, such as the Model Statute recommended by the author of this Note, is an example of an effective way to propel immediate

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(2005) ("A guardian shall not have the power: (1) to consent to . . . sterilization . . . unless the power to consent is expressly set forth in the order of appointment or after subsequent hearing and order of the court."). *See also* R.I. GEN. LAWS § 11-9-17 (2005); CONN. GEN. STAT. § 45a-698 (2005); GA. CODE ANN. § 31-20-3 (2005).

[236] Loving v. Va., 388 U.S. 1, 12 (1967) ("Marriage is one of the 'basic civil rights of man,' fundamental to our very existence and survival.").

[237] 28 U.S.C. § 1738C; 1 U.S.C. § 7 (2005).

[238] *See, e.g.,* FLA. STAT § 741.212 (2005) (refusing to recognize marriages between persons of the same sex); IND. CODE § 31-11-1-1 (2005) (expressly limiting marriage to opposite-sex couples); 23 PA. CONS. STAT. § 1704 (2005) (limiting marriage to opposite-sex couples).

[239] *Compare* Littleton v. Prange, 9 S.W.3d 223 (Tex. 1999) (denying standing in a wrongful death suit to a surviving transsexual spouse on the basis of chromosomes) *with* M.T. v. J.T., 355 A.2d 204 (N.J. 1976) (stating that the validity of the marriage depends on the ability to engage in sexual activity consistent with reconciled anatomy).

[240] *See* Knouse, *supra* note 184.

change in the face of medical resistance and public ignorance on the subject of the treatment of intersex children.

The fundamental premise of the Model Statute is to change the way physicians treat children with intersex conditions through full and open exploration of the issues as they relate to a particular child. Even in a less adversarial setting like that of the family court, the adversarial system provides a context in which the parties must provide evidence and arguments to convince a neutral arbiter that one choice is better than its alternative. Furthermore, the credibility of the parties is not assumed and the evidence is viewed with skepticism. That courts are the best arenas for resolving the conflicts created by intersex births is not necessarily a foregone conclusion, however. Jenifer Rosato, a law professor, noted that many commentators, and even courts, have criticized the use of judges as substitute decision-makers in medical decisions:[241] "Some of the common concerns with judges as decision-makers are that the judicial process takes too long, judges do not know the patient or her situation well enough, and they possess their own set of biases."[242] While in some circumstances, delayed proceedings may cause harm to the parties, the delay may serve the needs of the parties well in the case of childhood genital surgery in particular. By removing the situation from the context of an emergency and allowing the parties to have a fuller dialogue, albeit in a less than ideal setting, parents will inevitably be exposed to more information, particularly as compared to that provided to them under the current system. Additionally, physicians may be forced to confront the idea that surgery may be postponed beyond the first eighteen months of age.

As Rosato asserted, it is true that judges will never know the situation of the particular child as completely or as intimately as the parents. On the other hand, neither the physicians nor the hospital spend time getting to know the family and the child on an intimate level in most circumstances. Although the "neutral arbiter" may be an idealistic image of the role a judge, a judge does have the ability to be as disinterested as anyone else in these cases. If the conflicts described in section V are as potentially harmful to the child as they appear, the goal should be to have a decision-maker *not* so intimately involved that she is affected by such conflicts. Because judges are human beings, with their own life experiences, bias is inherent in all judicial cases to some extent. While there is no way to ensure that judges will leave their biases at the door, strong advocacy and creative lawyering skills may serve to mitigate any harm one particularly biased judge may cause by preserving issues for appeal.

Rosato also expressed concern that judges must decide moral or ethical issues in cases involving intersex surgeries on children: "[J]udges cannot weigh the moral and ethical considerations that are integral to [medical decision-making] because

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[241] *See* Rosato, *supra* note 82, at 42; *see also* Splaine, *supra* note 96, at 934.

[242] Rosato, *supra* note 82, at 42 (citing Hamann, *supra* note 96, at 134; Splaine, *supra* note 96, at 934).

they are circumscribed by existing law."[243] Yet if surgeries are an effort to "normalize" intersex children as typical male and female children, as many activists in the intersex movement have argued,[244] it is a reasonable inference that moral and ethical issues may lead physicians and parents to minimize or to ignore factual and scientific data that actually discourage such genital surgeries.[245] Given that, then asking judges to determine whether a procedure appears to be medically necessary may be the only way to give such data more weight and consideration than the moral and ethical considerations suggested by Rosato.[246]

There may also be additional benefits to bringing the debate into the courtroom. Clinicians may be forced to be more forthright with their information in the context of judicial proceedings that are conducted on the record and testimonies that are taken under oath. In contrast to the hospital setting, where parents may feel intimidated or overwhelmed, the adversarial nature of a courtroom allows for someone as authoritative as a doctor to confront and question the treatment and practices under the circumstances. In a court of law, doctors must account for their standard of care—something that is nonexistent today; no doctor has ever had to defend the practice of genital surgeries on intersex children in an American court. Indeed, it is uncertain how a doctor might be able to do so.

Of course, even with all the safeguards in place, there is always a chance that judges will be swayed by the arguments of physicians or even defer to their collective knowledge. A statute that specifically addresses the issue serves to guard against such deference, but there is no guarantee that a judge in any particular case will view the facts and weigh them as they are, rather than sympathize the parents' plight. In such a case, the judicial process will at minimum serve to reduce the aura of urgency of the situation, and provide for the opportunity of a more reasoned decision-making process on the part of the parents. Armed with more information and a more balanced account of the benefits and risks of the treatments, parents will be more aware and better equipped to deal with the potential struggles that their intersex child may encounter in the future. Such a process may convince some parents to be more open with their child as he or she matures, removing some of the shame and secrecy that many adult intersexuals say they experience.

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[243] *Id.* (citing Cindy H. Rushton & Elizabeth E. Hogue, *The Role of Families as Surrogate Decisionmakers after* Cruzan v. Director, Missouri Department of Health, 7 J. CONTEMP. HEALTH L. & POL'Y 219, 223 (1991)); Hamann, *supra* note 96, at 137-40; Michelle Yuen, Comment, *Letting Daddy Die: Adopting New Standards for Surrogate Decision-making,* 39 UCLA L. REV. 581, 605 (1992)).

[244] *See* Dreger, *supra* note 6, at 6 (noting that the underlying theory of genital surgeries assumes that there are "definite acceptable and unacceptable roles for boys, girls, men, and women"). *See generally* Knouse, *supra* note 184; FAUSTO-STERLING, *supra* note 9; KESSLER, *supra* note 6.

[245] J. David Hester, Address at the Cardozo Women's Law Journal & Bodies Like Ours Symposium, *supra* note 124. Hester discussed the use of rhetoric by the medical community in cases of intersex children, noting that "rhetorical invention necessitates medical intervention." He further stated that such rhetorical invention allows the medical community to reject empirical evidence which indicates that science uncovers a multiplicity of possible genders. *See also* Lloyd, *supra* note 130, at 291-92.

[246] Rosato, *supra* note 82, at 42.

Based on the framework provided by the existing statutes that regulate forced sterilization,[247] the removal of bodily organs,[248] and the guardianship of incompetent or incapacitated persons,[249] the Model Statute seeks to create a judicial process that will promote full understanding of the intersex child's condition, desires, needs, and rights. The Model Statute aims to reinforce the concept that the parents' psychological trauma at the birth of an intersex child is not an acceptable emergency that justifies genital surgery or hormone treatment, and that the children, as they mature, will be the better decision-makers as to the gender with which they best identify, and as to whether steps should be taken to change their physical appearance.

The Model Statute requires a standard of clear and convincing evidence of medical necessity, rather than the best interests of the child, so to avoid placing undue weight on the wishes of the parents, or the possible psychological effects to the child. The Model Statute therefore addresses the critics' arguments that intersex issues are best dealt with through psychological assistance and not surgical procedures or hormonal treatments. Additionally, the Model Statute defines informed consent and ensures that the decision does not solely depend upon the informed consent of the parents. Mature children are afforded greater deference than parents, reflecting the understanding that no statute should prohibit an individual capable of providing informed consent from obtaining medical care that she or he desires for her- or himself.

As discussed earlier, many intersex adults complain that the process of examination by clinicians was at least as traumatic as the surgical aftermath. The privacy of the child should therefore always be a primary concern. The precise language of the statute ensures that physical and psychological evaluations of the child should occur only when necessary for the resolution of the case and the well-being of the child. Provisions to ensure, and protect the privacy of the child from public scrutiny in court proceedings is also necessary and included in the Model Statute.

While it may be impossible to address the concerns of all intersex adults and critics of the current medical protocol, the proposed Model Statute below is a comprehensive attempt to remedy the harms perpetrated against intersex children by the medical and legal communities:

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[247] *See* GA. CODE ANN. § 31-20-3 (2004) (setting forth procedures for obtaining a court order for sterilization of a mentally incompetent person). The Model Statute in this note borrowed much of its language from the Georgia statute, which served as a most useful model for a full evidentiary hearing regarding matters of medical care for an incompetent patient. *See also* UTAH CODE ANN. § 62A-6-107-116 (2004) (setting forth procedures for obtaining a court order to sterilize a handicapped person).

[248] *See* OKLA. STAT. tit. 30, § 3-119 (2005) (prohibiting the removal of a bodily organ by order of a guardian without specific court authorization).

[249] *See* D.C. CODE ANN. § 21-2047 (2004) (describing the general powers and duties of guardians of incapacitated individuals).

MODEL STATUTE: THE PROTECTION OF INTERSEX CHILDREN ACT

§ 1. Definitions.

(a) "Intersex child" or "intersex adult" refers to any person born with an anatomical, chromosomal, or genital variance from what is considered medically standard male or female anatomy, chromosome pattern or genitalia; any person born with genitalia or other organs displaying characteristics of both male and female genitalia or organs; or any person with genitalia so atypical that corrective surgery is recommended, including persons not born with the conditions just described, but who, through some event after their birth, now have genitalia so atypical that corrective surgery is recommended.

(b) "Intersex child" means any person under the age of eighteen (18) who has an intersex condition described in § 1(a).

(c) "Minor child" under this chapter means any person under the age of sixteen (16) years of age.

(d) "Mature child" under this chapter means any person older than fifteen (15) but younger than eighteen (18) years of age who the court determines is able to provide informed consent as defined in § 1(f).

(e) "Surgery" or "surgical intervention" refers to the excision, modification or reduction of any organ or tissue for purposes of treating the conditions described in § 1(a) or symptoms thereof.

(f) "Informed consent" in the case of a mature child means consent that is voluntary and based on an understanding by the person who is to be the subject of the proposed surgery, surgical intervention, hormonal treatment or other medical intervention of the nature and consequences of that person's condition and of the proposed surgery, the reasonably foreseeable risks and benefits associated with the proposed surgery, and any and all viable treatment alternatives. In the case of a minor child, "informed consent" means consent that is voluntary and based on an understanding by the parent(s) or guardian(s) of the child who is to be the subject of the proposed surgery, surgical intervention, hormonal treatment or other medical intervention of the nature and consequences of that person's condition and of the proposed surgery, the reasonably foreseeable risks and benefits associated with the proposed surgery, and any and all viable treatment alternatives.

§ 2. Surgery for intersex conditions subject to judicial order.

(a) It is unlawful for any person to perform or to aid or abet in the performance of surgery to treat an intersex condition described in § 1(a) or symptoms thereof, where such surgery is not immediately necessary to protect the physical health or save the life of such child, without first obtaining an order of the court under this chapter.

(b) It is unlawful for any person to publish, exploit or profit from research obtained through treatment of an intersex child without an order of the court under this chapter or informed consent as it is defined in § 1(f) of an intersex adult.

(c) Nothing in this chapter shall be construed to prohibit surgical intervention or surgery for an intersex child to correct or treat existing medical or physical ailments not described in § 1(a) or to respond to a medical emergency; except that:

  (1) Under no circumstances is the mental or psychological condition of either the intersex child or the intersex child's parent(s) or guardian(s) to be considered a factor in determining whether or not a medical emergency exists; and

  (2) Under no circumstances shall surgery be performed on an intersex child to address, alleviate or prevent any emotional or psychological condition of the intersex child or the intersex child's parent(s) or guardian(s) without first obtaining an order of the court under this chapter; but

  (3) Nothing in this chapter shall be construed to prohibit or limit the rights of an intersex adult, over the age of eighteen (18) years, from seeking surgery otherwise prohibited or limited under this chapter.

§ 3. Application to the court; hearing.

(a) Whenever a parent or guardian seeks to obtain surgery for an intersex child, whether a minor child or a mature child, to treat an intersex condition described in § 1(a) or symptoms thereof, such parent or guardian must file an application for consent with Family Court.

(b) Upon receipt of such application, the Family Court judge shall appoint an uninterested party to provide legal counsel to and represent the interests of the intersex child throughout all stages of the Family Court proceedings and all appeals, at the expense of the state. An intersex mature child may, if the court deems the mature child to be aware of the risks and consequences of the decision, refuse such representation and opt for either self-representation or private counsel, provided that such private counsel has no pre-existing relationship with the intersex child's parent(s) or guardian(s) or any other potential conflict of interest.

(c) Prior to the hearing, the judge shall appoint an examining team of physicians well versed in the particular intersex condition described in the application and the proposed medical or surgical intervention at the expense of the state. Additionally, the judge shall appoint a psychologist to conduct interviews with both the intersex child and the parent(s) or guardian(s) party to the case at the expense of the state. Additional interviews may be ordered at the discretion of the judge, all at the expense of the state. The physician team shall investigate and examine the intersex child as necessary but in the least physically intrusive manner available, to confirm diagnosis, and shall submit a detailed report on their findings and whether, in their opinion, the proposed surgery is medically necessary or in any way advantageous to the intersex child, including any known viable alternatives. The psychologist shall submit a detailed report of the general content of his or her interviews and analysis of the intersex child and the parent(s) or guardian(s).

(d) Nothing in § 3(c) shall prevent the judge from ordering additional experts as needed in her discretion, provided that all examinations and interviews be conducted in the least intrusive manner possible. All additional experts shall be paid for by the state.

(e) Both the physician team report and the psychologist report, and any further reports ordered, shall be sealed by the court and remain under seal even after resolution of the case, unless and until the adult intersex patient provides the court with written permission to release such documents. Except for courtroom purposes, all medical professionals called upon to examine the patient or testify in the case shall consider their relationship with the intersex child to be that of physician and patient, protected by all privileges that would apply to such a relationship in the applicable jurisdiction. A copy of each report shall be filed with the court no less than ten (10) days prior to the application hearing. The court shall cause copies of each report ordered by the court to be served upon all parties, including the intersex child's representative or directly upon the mature child if self-representation has been approved, no less than five (5) days prior to the application hearing. Each author or contributor to any report ordered by the court shall be available for questioning by the court and cross-examination by any party.

(f) Prior to a hearing on the application, evidence shall be presented to the court that the surgical intervention described in the application has been approved for the intersex child by a committee of the medical staff of the accredited hospital in which the surgery is to be performed. The approval of such committee shall be based upon a finding that the proposed surgery is medically necessary. Such evidence shall be served upon all parties and the court no less than ten (10) days prior to the hearing.

(g) If the intersex child or the intersex child's representative requests that the hearing be closed to the public, the judge shall close the hearing to the public unless an overriding or compelling reason can be shown as to why such hearing should not be closed to the public.

(h) For an order of the court to be issued in favor of surgery, the Family Court judge must find by clear and convincing evidence that:
   (1) The surgery proposed is an accepted method within the particular field to address the intersex condition presented; and
   (2) That the proposed surgery is medically necessary to protect the health or life of the intersex child; and
   (3) That the potential benefits substantially outweigh the risks and potential adverse effects on the intersex child.

(i) In any case, if the judge deems it appropriate, she may order ongoing psychological treatment, including but not limited to court-monitored family or individual counseling and periodic reporting to the court on the well-being of the child and the family.

(j) When receiving evidence or testimony, the judge:
   (1) May, in her discretion, consider the wishes of the minor child, but shall not give such wishes overriding weight; and
   (2) May, in her discretion, consider the wishes of the mature child and give such wishes greater weight than those of a minor child and the mature child's parents if she finds such mature child is able to provide informed consent as defined in §1(f).

(k) If the Family Court judge finds the requirements of § 3(h) have been fulfilled, she shall enter an order and judgment authorizing the physician to perform such surgery, except that:
   (1) No such action shall be taken for at least thirty (30) days; and
   (2) If any party enters an appeal under § 3(l), no action shall be taken until full resolution of any and all such appeals.

(l) Any party may appeal the judgment of the Family Court judge to the superior court within thirty (30) days of such judgment. Such appeal shall be reviewed *de novo*. Any decision of the superior court may be appealed to the higher courts of this state as in other civil cases.

§ 5. Violations; penalties.

(a) Violation of any provision in § 2 of this chapter shall be a felony punishable by a fine of no less than ten thousand dollars ($ 10,000) or imprisonment of no less than twelve (12) months, or both.

(b) Violations of any provision in § 2 of this chapter shall subject the violator to civil penalties, including but not limited to punitive damages, for up to twenty (20) years after the date of the violation or after the intersex child reaches eighteen (18) years of age, whichever is later, notwithstanding any other statute of limitations under the code of this state.

(c) Nothing in this chapter shall be construed to preclude civil liabilities or criminal penalties under any other laws of this state.

IX. CONCLUSION

While the education efforts of adult intersex activists have not gone entirely unheeded by the medical community, every day intersex children continue to be subjected to unnecessary and often harmful genital surgeries aimed to "normalize" them. Although physicians and ethicists have admitted that the lack of follow-up studies on intersex patients is troubling, the admission has not spurred an end to the performance of surgeries on intersex infants until concrete evidence show that such treatments are beneficial. Instead, the response has been a *post hoc* attempt to justify surgeries with hindsight surveys of adult intersex patients. While surgeons continue to boast the development of new, improved techniques to address the concerns of intersex individuals, there is no way to know the long-term implications of such procedures for years into the future.

Every intersex child who undergoes cosmetic genital surgery is, in essence, part of an ongoing medical experiment. Until the legal system recognizes its failures in regard to these most vulnerable subjects of the state, physicians will continue to have the last word on the efficacy of intersex surgeries. It is time for the laws that already protect children from the questionable decisions of doctors and parents, such as those that currently govern organ donation, sterilization, and other extraordinary treatments, to be comprehensively extended to children born with an intersex condition.