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Exceptions to the Rule:

Curing the Law's Failure to Protect Intersex Infants

Anne Tamar-Mattis[†]

We're not actually all that different. We are women, men, and occasional alternative genders such as transgender—just like non-intersex people. We are straight, gay, married, single—just like non-intersex people. We like to decide what happens to our bodies and like to be asked about our lives, rather than told. —Thea Hillman¹

INTRODUCTION

In 1967, a psychologist named John Money undertook a radical surgical and psychological experiment on a toddler, Bruce Reimer, whose penis had been accidentally mutilated due to complications of circumcision.² For Dr. Money,

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1. Thea Hillman, *Middlesex and the Limitations of Myth*, ISNA NEWS (Intersex Society of North America, Rohnert Park, Cal.), Spring 2003, at 2-3, available at <http://www.isna.org/files/hwa/spring2003.pdf>.
2. John Colapinto, *The True Story of John/Joan*, ROLLING STONE, Dec. 11, 1997, at 54 [hereinafter Colapinto, *True Story*]; Patricia L. Martin, *Moving Toward an International Standard in Informed Consent: The Impact of Intersexuality and the Internet on the Standard of Care*, 9 DUKE J. GENDER L. & POL'Y 135, 137-38 (2002) (noting that the widely publicized names John and Joan were pseudonyms for the child born Bruce Reimer and renamed Brenda, who took the name David for himself in adulthood). Because David Reimer chose to make his true identity public, *id.* at 135, I will refer to him throughout this article by the name he was using at the referenced time.

this tragedy represented an opportunity to test his theory that gender was socially constructed.³ He convinced the child's parents to consent to his surgically altering the child's genitals to give them a female appearance.⁴ He then instructed the parents to raise the child (renamed Brenda) as a girl, to begin a course of female hormones at adolescence, and never to tell her what had happened.⁵

As Brenda grew, Dr. Money reported that his experiment was a complete success. In the widely reported "John/Joan" case study, he contrasted her development as a "feminine" girl interested in "dolls, a doll house and a doll carriage" with her twin brother's more typically masculine interests in "cars and gas pumps and tools."⁶ This single case study, published in 1972, became the justification for surgical treatment of intersex infants—babies who are born with reproductive or sexual anatomy that does not seem to fit the typical definitions of female or male.⁷ Although Brenda Reimer was not intersex, the reported successful transformation of a typical male child into a girl was taken as conclusive evidence that a child with atypical sex characteristics could be raised as either a boy or a girl, and that genital-normalizing surgery would aid in the development of a normative gender identity.⁸ Doctors began to recommend immediate genital-normalizing surgery for many intersex infants, along with hormonal reinforcement of the assigned gender, strictly gendered upbringing, and—above all—secrecy.⁹ If Dr. Money's theory were correct, these procedures would enable intersex children to live happy, "normal" lives.¹⁰

It was twenty-five years before word got out that Dr. Money had lied.

A researcher named Milton Diamond followed up with "Brenda" Reimer in 1994 and found out that things had not gone as smoothly as Dr. Money had reported.¹¹ In fact, the child continuously had resisted the gender assignment and

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3. See Colapinto, *True Story*, *supra* note 2 (suggesting that as half of a set of identical twins, Bruce Reimer represented an ideal opportunity to test Money's controversial theories about gender identity development); Martin, *supra* note 2, at 141 (summarizing Money's career ambitions).
 4. 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, 7 (2000).
 5. *Id.* at 7-8.
 6. Colapinto, *True Story*, *supra* note 2, at 56.
 7. Beh & Diamond, *supra* note 4, at 17. Genital-normalizing surgeries on intersex babies actually began prior to 1950, Martin, *supra* note 2, at 140, but the John/Joan study led to large-scale adoption of the procedure. See Beh & Diamond, *supra* note 4, at 17 n.69.
 8. Beh & Diamond, *supra* note 4, at 9; Chanika Phomphutkul, Anne Fausto-Sterling & Philip A. Gruppuso, *Gender Self-Reassignment in an XY Adolescent Female Born With Ambiguous Genitalia*, 106 PEDIATRICS 135, 136 (2000).
 9. Beh & Diamond, *supra* note 4. Gender reassignment surgery also became the standard for a male infant whose penis was lost through trauma or accidental amputation. *Id.* at 16-17.
 10. See 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, 471 (2001).
 11. Colapinto, *True Story*, *supra* note 2; Beh & Diamond, *supra* note 4, at 9-10, 10 n.33.

the follow-up treatment: ripping off her dresses,¹² insisting to one psychiatrist that she was “just a boy in long hair and girl’s clothes,” and eventually becoming depressed and suicidal.¹³ At the age of fourteen he found out the truth about his treatment, and immediately began living as a boy, taking the name David.¹⁴ Dr. Money knew of the child’s strong resistance to the gender assignment, but failed to report it.¹⁵ David Reimer grew to adulthood as a man and formed a family.¹⁶ Still, he remained bitter and angry about his treatment, referring to his childhood as “a pit of darkness.”¹⁷ In 2004, at the age of thirty-eight, he committed suicide.¹⁸

Just as David Reimer suffered greatly from the attempt to force on him a female gender, so have many intersex people whose treatment was based on his case study. In the 1990s, intersex people who had been treated under Money’s concealment model began to find each other in spite of the secrecy that had been imposed on them.¹⁹ They learned that many of them had shared similar experiences: repeated surgeries throughout childhood, limited or absent sexual response, painful and scarred genitals, a sense of shame stemming from repeated and unexplained medical examinations of their genitals, infertility, difficulty forming relationships, and depression.²⁰ For many, the depression and shame turned to anger when they realized what had been done to them: an intimate part of their bodies had been taken without consulting them, when they were too young to be aware, or under the cover of lies and half-truths when they were children.²¹ The organized intersex community began to demand an end to unnecessary cosmetic genital surgery on intersex infants.²²

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12. John Colapinto, *Gender Gap: What were the real reasons behind David Reimer's Suicide?*, SLATE, June 3, 2004, <http://slate.msn.com/id/2101678/> [hereinafter Colapinto, *Gender Gap*].
 13. Colapinto, *True Story*, *supra* note 2; Beh & Diamond, *supra* note 4, at 10 (noting family members’ recollections of “extreme male-like behavior and rejection of femaleness”).
 14. Colapinto, *True Story*, *supra* note 2; Beh & Diamond, *supra* note 4, at 7 n.15, 11.
 15. Beh & Diamond, *supra* note 4, at 9.
 16. Colapinto, *True Story*, *supra* note 2.
 17. *Id.*
 18. Colapinto, *Gender Gap*, *supra* note 12.
 19. See, e.g., David Vandertie, *Appreciating Founder Cheryl Chase*, ISNA NEWS (Intersex Society of North America, Rohnert Park, Cal.), Spring 2003, at 2-3, available at <http://www.isna.org/files/hwa/spring2003.pdf>; Barron H. Lerner, *If Biology Is Destiny, When Shouldn't It Be?*, N.Y. TIMES, May 27, 2003.
 20. See generally MARCUS DE MARÍA ARANA, SAN FRANCISCO HUMAN RIGHTS COMM’N, A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION” OF INTERSEX PEOPLE (2005), available at http://sfhrc.org/site/uploadedfiles/sfhumanrights/Committee_Meetings/Lesbian_Gay_Bisexual_Transgender/HRC%20Intersex%20Report.pdf [hereinafter HRC REPORT]; Videotape: Hermaphrodites Speak! (Cheryl Chase, Intersex Society of North America 1997) (available for purchase at www.isna.org).
 21. Hermaphrodites Speak!, *supra* note 20 (intersex adults recounting false stories adults told them about their medical treatments as children). See also Beh & Diamond, *supra* note 4, at 2.
 22. Laura Hermer, *Paradigms Revised: Intersex Children, Bioethics, & the Law*, 11 ANNALS HEALTH L. 195, 197 (2002); Cheryl Chase, *What is the Agenda of the Intersex Patient Advocacy Movement?* 13 ENDOCRINOLOGIST 240, 240-242 (2003) [hereinafter Chase, *Intersex Agenda*].

As a result of the discrediting of the foundational study of genital-normalizing surgery on infants, mounting evidence of the resultant harm, and the unanimous²³ voice of the adult intersex community denouncing infant surgeries as harmful, the standard of care is slowly beginning to move away from the concealment model.²⁴ The legal community is also gradually awakening to the important questions raised when parents and doctors confront the reality of an intersex baby.²⁵ For legal scholars, there are interesting academic issues about the meaning of autonomy and liberty, family privacy and children's rights, judicial deference and the role of gender in the law.²⁶ For the intersex community, there are some more fundamental questions: How did the law allow this to happen? And how can the law work to prevent harm to intersex infants in the future?

Despite more than a decade of concerted action, intersex activists' call for an end to genital-normalizing surgeries on infants has had only limited effect on the practice of medicine.²⁷ It may take years more to assemble the consensus necessary for a complete moratorium. Meanwhile, there are intermediate steps available to increase legal protection of intersex children's interests. This paper proposes that court involvement could improve the decision-making process about genital-normalizing surgery on intersex infants, using a model that has successfully been applied to other ethically challenging medical decisions on behalf of children or wards: the categorical exception. Section I offers some

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23. When the legality of intersex surgeries was challenged in a Colombian court, the court accepted amicus briefs from sources worldwide. Julie A. Greenberg & Cheryl Chase, *Background of Colombia Decisions*, <http://www.isna.org/node/21> (last visited Mar. 14, 2006) [hereinafter Greenberg & Chase, *Colombia*]. Although the court provided a copy of ISNA's amicus brief to surgery advocates and requested a response, their request was either ignored or authorities admitted that they lacked any evidence that could refute ISNA's claims. *Id.* National intersex leaders claim to be unaware of any intersex person who is satisfied with surgical intervention, and no intersex person has stepped forward publicly to advocate for surgery. *See, e.g., id.*; HRC REPORT, *supra* note 20; Lerner, *supra* note 19. Some advocates of surgery do claim to know of satisfied patients, but none of these has spoken or been identified in a public forum. *See* HRC REPORT, *supra* note 20 (reporting Commission's inability to find intersex person to testify in support of surgery); Lerner, *supra* note 19.
 24. Beh & Diamond, *supra* note 4, at 3-4; Sarah M. Creighton et al., *Objective Cosmetic and Anatomical Outcomes at Adolescence of Feminising Surgery for Ambiguous Genitalia Done in Childhood*, 358 LANCET 124, 125 (2001); Phornphutkul, *supra* note 8; *see also* Martin, *supra* note 2, at 151-62.
 25. *See, e.g.,* Julie A. Greenberg, *Defining Male and Female: Intersexuality and the Collision Between Law and Biology*, 41 ARIZ. L. REV. 265 (1999) (addressing challenges of establishing criteria for legal sex); Alyssa Connell Lareau, *Who Decides? Genital-Normalizing Surgery on Intersexed Infants*, 92 GEO. L.J. 129 (2003) (exploring sufficiency of parental informed consent).
 26. *See, e.g.,* Sara A. Aliabadi, *Gender Assignment Surgery for Intersexed Infants: How the Substantive Due Process Right to Privacy Both Supports and Opposes a Moratorium*, 12 VA. J. SOC. POL'Y & L. 170, 179, 196 (2004) [hereinafter Aliabadi, *Due Process*]; Martin, *supra* note 2; Beh & Diamond, *supra* note 4; Ford, *supra* note 10; Hermer, *supra* note 22; Greenberg, *supra* note 25; Lareau, *supra* note 25.
 27. Intersex Society of North America, *What's the history behind the intersex rights movement?*, <http://www.isna.org/faq/history> (last visited Jan. 24, 2006) [hereinafter *Intersex History*].

background information on intersex treatment, including the theory behind genital-normalizing surgery, critiques of the surgical model, and options for non-surgical treatment of intersex children. Section II outlines the parent-doctor decision-making presumption – the standard process used in the United States for making medical decisions on behalf of children. The Section goes on to look at how this presumption works with cultural factors to perpetuate genital-normalizing surgery, raising doubt about the validity of the current decision-making process used in the context of treating intersex children. Section III presents an alternative process, highlighting two examples of categorical exceptions to the parent-doctor presumption in which the legal system is routinely involved: organ donation by children and sterilization of mentally handicapped wards. Section IV argues that genital-normalizing surgeries on children present an appropriate situation for a categorical exception because the treatment is medically unnecessary, the parents have a conflict of interest, and the decision implicates the fundamental rights of the intersex child. This Section concludes with a proposal for use of the categorical exception model to protect the rights of intersex children by providing a rigorous structure for decision-making in a medically uncertain and emotionally charged situation.

I. INTERSEXUALITY AND THE MEDICAL RESPONSE

A. Background on Intersexuality

No one knows exactly how many intersex babies are born every year. Estimates range from one out of every 100 to one out of every 2,000 live births.²⁸ Intersexuality occurs in a wide variety of forms. For example, a child may be born with a large clitoris and a shallow or absent vagina, with a micropenis and an opening in the scrotum that may resemble a vagina, with typical male or female external genitalia and atypical internal sex organs (such as retained testes in a person with typical female genitalia), with XY chromosomes and a typical female body, or with other characteristics that differ from the anatomical and hormonal features that doctors, nurses, and parents have been trained to expect.²⁹ Additionally, several chromosome patterns beyond the typical XX and XY patterns are possible, and these may result in a range of internal, external, and secondary sex characteristics.³⁰ Some intersex conditions

28. Intersex Society of North America, *How Common is Intersex?*, <http://www.isna.org/faq/frequency> (last visited Mar. 16, 2005) [hereinafter *How Common is Intersex?*]; Phomphutkul, *supra* note 8 (somewhere from one in 1000 to one in 2000 newborns have intersex conditions such that they are candidates for surgery).

29. Intersex Society of North America, *What is Intersex?*, http://www.isna.org/faq/what_is_intersex (last visited Mar. 16, 2005) [hereinafter *What is Intersex?*].

30. *How Common is Intersex?*, *supra* note 28. For more extensive background on the causes and forms of intersexuality, see ALICE DOMURAT DREGER, *HERMAPHRODITES AND THE MEDICAL INVENTION OF SEX* (1998) [hereinafter *MEDICAL INVENTION*]; SUZANNE J. KESSLER, *LESSONS FROM THE INTERSEXED* (1998); ANNE FAUSTO-STERLING, *SEXING THE*

are not apparent until puberty, and some are never discovered.³¹ While there is no universally agreed-on definition of “intersex,” this paper will use the definition put forth by the Intersex Society of North America: a condition in which a person is born with “a reproductive or sexual anatomy that doesn’t seem to fit the typical definitions of female or male” or “anyone born with what someone believes to be non-standard sexual anatomy.”³² In particular, the focus of this paper is on intersex people who are at risk of unnecessary, unwanted, or nonconsensual genital surgery.

B. Surgical Treatment of Intersex Infants and Children

Many of my colleagues do not believe we have been deceptive, and they would resent my saying we have been deceptive But we have been deceptive.
—Dr. Jorge Daaboul³³

The concealment model, which still forms the basis of the dominant standard of care for intersex infants, has its theoretical underpinnings in Dr. Money’s John/Joan experiment. Core elements of this model include early and conclusive assignment of gender, early genital-normalizing surgery (before two years of age), and secrecy and denial about the child’s condition.³⁴ The theory supporting early surgical intervention is that a child who has normative-looking genitals from a very early age, and is raised “unambiguously” in the gender that matches those genitals, will develop the desired gender identity³⁵ regardless of chromosome pattern, body structure at birth, or hormone exposure in the womb.³⁶ Many practitioners also believe that parents will be unable to accept or bond with their intersex children without genital-normalizing surgery, and that children with atypical genitals will suffer teasing from peers and rejection from potential partners as they grow.³⁷

BODY: GENDER POLITICS AND THE CONSTRUCTION OF SEXUALITY (2000).

31. *What is Intersex?*, *supra* note 29; Committee on Genetics, *Evaluation of the Newborn with Developmental Anomalies of the External Genitalia*, 106 AM. ACAD. PEDIATRICS 138, 139 (2000), available at <http://aappolicy.aappublications.org/cgi/reprint/pediatrics;106/1/138.pdf> [hereinafter *AAP Evaluation*].
32. *What is Intersex?*, *supra* note 29.
33. Interview in Louise Kiernan, *In Intersex Cases, Gender is a Complex Question*, CHI. TRIB., June 20, 1999, at 1.
34. Phomphutkul, *supra* note 8, at 135; Fausto-Sterling, *supra* note 30, at 64-66; Beh & Diamond, *supra* note 4, at 50-55.
35. Katherine Rossiter & Shonna Diehl, *Gender Reassignment of Children: Ethical Conflicts in Surrogate Decision Making*, 24 PEDIATRIC NURSING 59 (1998); Phomphutkul, *supra* note 8, at 135, 136. The treatment plan also aims at creating a heterosexual orientation, and parents are often reassured that the surgery will result in a child that grows up to be heterosexual. Martin, *supra* note 2, at 153.
36. Alice Domurat Dreger, “Ambiguous Sex” – Or Ambivalent Medicine? *Ethical Issues in the Treatment of Intersexuality*, 28 HASTINGS CENTER REPORT 24 (1998) [hereinafter *Ambivalent Medicine*].
37. Rossiter & Diehl, *supra* note 35.

The perceived need for a lack of ambiguity in the minds of parents, strangers, and the child about the child's gender motivates both the urgency and the secrecy of the treatment.³⁸ By "erasing" ambiguity, the surgeries are supposed to make parents more likely to accept their child's assigned gender, and ensure that the child will find nothing exceptional when s/he starts noticing physical differences between bodies.³⁹ Keeping the matter secret from neighbors, relatives, and caregivers is supposed to prevent anyone from teasing the child or questioning his/her gender.⁴⁰ Under this theory, it is essential that the entire affair be kept secret from the intersex person, even in adulthood.⁴¹

The concealment process begins with assigning a gender to the intersex baby. When a baby is determined at birth to be intersex, it is often because the external genitalia and/or the internal sex organs of the baby seem atypical to the medical attendants.⁴² Since the 1950s, the birth of an intersex baby has generally been treated as a medical emergency.⁴³ Although the vast majority of these babies have no medical condition that will result in physical harm,⁴⁴ doctors act quickly to assign a gender, and often pressure parents to consent to immediate surgery to conform the genitals to this assigned gender.⁴⁵ Parents are frequently misled both about the nature of their child's condition, and the nature and risks of treatment.⁴⁶ They are rarely offered psychological counseling to help adjust to this news, and mental health professionals are not routinely included in the

38. *Id.*; *Ambivalent Medicine*, *supra* note 36; Martin, *supra* note 2, at 153-54.

39. Beh & Diamond, *supra* note 4, at 43-46, 50-55.

40. *Id.*

41. *Id.* at 50-55; see also A. Natarajan, *Medical Ethics and Truth Telling in the Case of Androgen Insensitivity Syndrome*, 154 CANADIAN MED. ASS'N J. 568 (1996) (winner of a medical ethics writing contest, proposing intersex condition as an example of a situation where lying to a patient would be ethically appropriate). For an interesting treatment of how the structure and practice of the medical system allowed this standard of care to evolve, and to persist even after the reported failure of the John/Joan experiment that provided its theoretical basis, see Beh & Diamond, *supra* note 4, at 12-34.

42. See *AAP Evaluation*, *supra* note 31, at 139.

43. See, e.g., *id.* at 138 ("The birth of a child with ambiguous genitalia constitutes a social emergency.").

44. There are a few intersex conditions, such as Congenital Adrenal Hyperplasia, which are correlated with medical conditions that do require immediate medical intervention to preserve life. In these cases, there is still no need for genital surgery. Ford, *supra* note 10, at 476 n.56; *Ambivalent Medicine?* *supra* note 36. Even rarer are cases in which a child will have physical problems if genital surgery is not performed, as when there is no opening for urine to void. Consortium on the Management of Disorders of Sex Differentiation, CLINICAL GUIDELINES FOR THE MANAGEMENT OF DISORDERS OF SEX DIFFERENTIATION IN CHILDHOOD 20 (2005), available at <http://www.dsdguidelines.org/clinical> [hereinafter *DSD Guidelines*]; Hermer, *supra* note 22, at 207.

45. Beh & Diamond, *supra* note 4, at 43-46. See also Rossiter & Diehl, *supra* note 35 (describing pressure put on parents unwilling to consent to genital-normalizing surgery, including sending letters by registered mail urging surgery and sending a counselor to the parents' home).

46. Beh & Diamond, *supra* note 4, at 47-50; Kiernan, *supra* note 33 (interview with Dr. Jorge Daaboul, recounting how he used to mislead parents in explaining their intersex child's condition and counseling treatment). See also *infra* notes 196-199 (citing misleading language from current medical protocols).

treatment of intersex babies.⁴⁷

Before assigning a gender, doctors usually determine the baby's chromosome pattern and internal reproductive organs (including the gonads, which will be the source of hormones that influence later development of secondary sex characteristics), and examine the external genitalia.⁴⁸ However, none of these factors is determinative in assigning a gender. Instead, the gender assigned is usually the one that the surgeons feel will have the best surgical outcome.⁴⁹ A "positive surgical outcome" for a male-assigned baby is a penis that is capable of penetration at maturity, and that can be used to urinate from a standing position;⁵⁰ a "positive surgical outcome" for a female-assigned baby is a vagina that can be penetrated by a penis.⁵¹ Most intersex babies are assigned female because, in the words of one famous pediatric urologist, "it [is] far easier to make a functional female than a male."⁵²

In the decision to surgically assign gender, the concealment model does not weigh such factors as preserving adult orgasmic potential or fertility⁵³ (at least for babies with testes⁵⁴). It also does not permit any consideration of the possibility that the child will later reject the assigned gender.⁵⁵ Genital surgeries on intersex infants remove potentially orgasmic tissue, interfere with nerves that

47. Beh & Diamond, *supra* note 4, at 45-46; Rossiter & Diehl, *supra* note 35 (team presenting parents with findings of intersexuality and recommendation for gender reassignment includes genetic counselor, pediatric endocrinologist, pediatric endocrine nurse and pediatric geneticist, but no mental health worker).

48. AAP Evaluation, *supra* note 31, at 139-40.

49. Beh & Diamond, *supra* note 4, at 3; Phornphutkul, *supra* note 8, at 135.

50. See Beh & Diamond, *supra* note 4, at 17-18; Phornphutkul, *supra* note 8, at 135; AAP Evaluation, *supra* note 31, at 141 (asserting that "the size of the phallus and its potential to develop at puberty are of paramount importance when one is considering male sex of rearing").

51. See AAP Evaluation, *supra* note 31, at 141 (stating that "the presence of a capacious, low-lying vagina is advantageous if assignment as a female is being considered, but this alone is not of critical importance"); Beh & Diamond, *supra* note 4, at 17-18, n.75 (pointing out the relative ease of surgically constructing "an insensitive hole"); Rossiter & Diehl, *supra* note 35 (stating that construction of a "vaginal pouch . . . would enable the child to grow to be a sexually functional adult female").

52. JOCELYN ELDERS AND DAVID CHANOFF, JOCELYN ELDERS, M.D.: FROM SHARECROPPER'S DAUGHTER TO SURGEON GENERAL OF THE UNITED STATES OF AMERICA 153 (1996).

53. See generally AAP Evaluation, *supra* note 31; Beh & Diamond, *supra* note 4, at 16-27. Arguably, these are the factors that may be more important to the child in the long term, and of less immediate importance to the adults making the decision whether to operate in infancy.

54. Nancy Ehrenreich, *Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of "Cultural Practices,"* 40 HARV. C.R. – C.L. L. REV. 71, 121-22 (2005) (noting that an intersex baby with the potential for male fertility will be assigned as female if the phallus is too small, while female fertility will be preserved in most cases).

55. Peter Lee & Philip A. Gruppiso, *Point/Counterpoint: Should Cosmetic Surgery Be Performed on the Genitals of Children Born with Ambiguous Genitals?*, 16 PHYSICIAN'S WEEKLY 31 (1999), available at http://www.physiciansweekly.com/archive/99/08_16_99/pc.html (mentioning case of child who was surgically assigned as a female and later adopted a male gender); Melissa Hendricks, *Into the Hands of Babes*, JOHNS HOPKINS MAGAZINE, Sept. 2000, available at <http://www.jhu.edu/~jhumag/0900web/babes.html> (reporting intersex child adopting new gender identity at age nine).

are delicate and poorly-understood, and leave scar tissue that can later interfere with genital sensation or sexual function.⁵⁶ Many adult intersex people who were subjected to surgeries in childhood report limited or absent sexual response.⁵⁷ Additionally, surgeons routinely remove gonads, regardless of potential function, if they will detract from normative genital appearance or if they will produce hormones that will cause development of the “wrong” secondary sexual characteristics.⁵⁸

C. Critiques of Genital-Normalizing Surgery

[W]hen I first realized exactly what had been done to me, my reaction was that I must have been truly repulsive to my parents and doctors if the result of the surgery performed on me could be considered an improvement.
— Joan W.⁵⁹

In making the decision to adopt the drastic measure of surgery, it seems likely that doctors and parents alike are motivated largely by concern for the child’s well being. Most parents want their child to have a happy, normal, uncomplicated childhood leading to a happy adult life.⁶⁰ It may seem self-evident to both doctors and parents that a “normal” body and a “normal” gender identity are necessary elements of a happy childhood.⁶¹ The birth of an intersex baby disrupts the parents’ dream of their child. Surgery seems to offer the possibility of banishing that disruption. I call this the “magic wand” theory of surgery: the simplified vision that surgery is a one-time, painless, cost-free event in which the child goes to sleep as intersex and awakens transformed into a

56. Alice Dreger, *Urologists: Agonize Over Whether to Cut, Then Cut the Way I’m Telling You*, at http://www.isna.org/articles/aap_urology_2004 (last visited May 12, 2005) (unofficial report on American Academy of Pediatrics Section on Urology meeting on Oct. 11, 2005) [hereinafter *Urologists Meeting*]; HRC REPORT, *supra* note 20, at 19, 21, 44; Hermaphrodites Speak!, *supra* note 20; Creighton, *supra* note 24, at 124-25 (noting undesirable cosmetic results of surgery and unknown impact on sexual function).

57. Hermaphrodites Speak!, *supra* note 20; Lerner, *supra* note 19. Some surgeons argue that current surgical practices are less damaging to sexual function than those performed 30-35 years ago. Martin, *supra* note 2, at 159-60. However, there are no studies to verify the effect of these surgeries on sexual function. Beh & Diamond, *supra* note 4, at 22-23.

58. Hermer, *supra* note 22, at 210-211. Undescended testes may be at increased risk of becoming cancerous, and doctors may favor removing them for this reason. However, some intersex advocates maintain that this risk is unlikely to manifest before puberty, and that it would be more appropriate to wait until the child is old enough to participate in the decision for prophylactic removal of gonads. *Id.* at 232. The AAP agrees that it is not necessary in all cases to remove undescended testes. *AAP Evaluation*, *supra* note 31, at 141.

59. Letter from Joan W. to her treating physician, *reprinted in* ISNA NEWS, (Intersex Society of North America, Rohnert Park, Cal.), May 2001, at 4, available at <http://www.isna.org/files/hwa/may2001.pdf>.

60. Elders, *supra* note 52, at 154 (“More than anything [parents] want clarity for themselves and normal, happy lives for their children . . . [P]arents are looking to do everything they can for the child’s benefit.”).

61. *Id.* at 153 (“The worst thing of all would have been not to have had clarity.”).

“real” boy or girl.

The problem, however, is that neither surgery nor gender is quite so simple.⁶² This section will summarize the major arguments against genital-normalizing surgery. Doctors, researchers, legal scholars, mental health experts, social commentators, and intersex activists have all presented the case against genital-normalizing surgery in a depth that is beyond the scope of this paper.⁶³ Because this paper is primarily concerned with improving the decision-making process that has led to negative outcomes for so many intersex people, I will briefly discuss the arguments that are most relevant to my proposal for changing the way these decisions are made. First, intersex adults who have undergone surgeries in childhood overwhelmingly oppose the practice as harmful. Second, the treatment remains essentially experimental in nature with no evidence of any real benefit to patients. Third, surgery fails to accomplish its stated goals. Fourth, postponing surgery will preserve the child’s options for the future.

1. Universal Negative Response From Intersex People

I don’t know one intersexed individual who is happy with the treatment they have received from the physicians that they have consulted with over the years – not one! Not one! I have spoken with people internationally, more than a thousand of them. I’m eager for the medical society to present these successful cases, because I can’t find one. —Howard Devore, Ph.D.⁶⁴

The strongest argument against genital-normalizing surgery on infants is that *every* intersex person who has spoken publicly on the subject has spoken against surgery.⁶⁵ At first, this may seem an extraordinary claim; it is rare for any community of people to speak with a single voice. It could be that the majority of intersex patients are satisfied with their surgeries. Because they are able to “blend in” as a result of surgery, they may not be eager to step forward publicly and assume a stigma they have so far avoided.⁶⁶ If the concealment was perfect,

62. HRC REPORT, *supra* note 20, at 21; Hendricks, *supra* note 55. See also Phomphutkul, *supra* note 8, at 135-36 (recounting story of “Baby G,” an intersex adolescent who rejected his assigned gender).

63. See, e.g., Beh & Diamond, *supra* note 4 (doctor and legal/medical scholar); Colapinto, *True Story*, *supra* note 2 (news reporter); Vandertie, *supra* note 19 (intersex activist); HRC REPORT, *supra* note 20 (testimony from varied sources at government hearing, including intersex activists, medical doctors and mental health specialists); Hermaphrodites Speak!, *supra* note 20 (intersex activists); Greenberg, *supra* note 25 (legal scholar); *Urologists Meeting*, *supra* note 56 (medical scholar).

64. Interview in Videotape: XXXY (hereafter XXXY) (Laleh Soomekh & Porter Gale 2000) (available at <http://www.planetout.com/popcornq/db/getfilm.html?63816>) (quoted in HRC REPORT, *supra* note 20, at 46).

65. See *supra* note 23.

66. HRC REPORT, *supra* note 20, at 51-52; Lerner, *supra* note 19 (surgeon states that most intersex patients are satisfied); Aliabadi, *Due Process*, *supra* note 26, at 179, 196 (referring to “numerous anecdotes” from intersex adults of positive outcomes of surgery, although citing only one physician who states, “My experience suggests that many, if not most, of the

perhaps they don't even know they are intersex.

However, the fact that not a single one of these satisfied patients has ever come forward greatly undermines the strength of this counter-argument. While the controversy over surgery has received broad coverage in the popular press, no reporter seems able to find an intersex person who is satisfied with the results of surgery.⁶⁷ The advisability of surgery is hotly debated in medical journals⁶⁸ and has been the subject of at least three public hearings by governmental bodies.⁶⁹ Yet in all of these discussions, those who identify themselves as intersex all seem to fall on one side of the debate.

Any intersex person could presumably command a national audience if she was willing to take up the argument in favor of surgery. Dozens of intersex people have come forward to argue against surgery, risking stigma and dredging up painful memories, for the sake of current and future intersex children they will probably never know.⁷⁰ Why would intersex people who believe that surgery will improve these children's lives refuse to do the same? To accept the claim that intersex opponents of genital-normalizing surgery are aberrational, we must also accept that the silent majority is, to a person, both more averse to publicity and less altruistic than those who think surgery is harmful. Such a scenario seems highly unlikely.

Intersex people who have spoken against surgery offer many reasons for their position. Many intersex people who have undergone surgery report inability to orgasm, chronic pain, and insensitivity caused by scar tissue⁷¹—problems

people who had surgery as infants are pleased.”).

67. See Lerner, *supra* note 19 (“I have yet to read about, hear or meet an intersex person who is grateful for surgery done on them as an infant.” (quoting sociologist and former Executive Director of the Intersex Society of North America Dr. Monica J. Casper)); Mireya Navarro, *When Gender Isn't a Given*, N.Y. TIMES, Sept. 19, 2004, § 9, at 1.; Natalie Angier, *New Debate Over Surgery on Genitals*, N.Y. TIMES, May 13, 1997, at C1; Colapinto, *True Story*, *supra* note 2; Martha Coventry, *Making the Cut*, MS. MAGAZINE, Oct.–Nov. 2000, at 59 available at <http://www.msmagazine.com/oct00/makingthecut.asp> (comments of Marut Schober).
68. See, e.g., Rossiter & Diehl, *supra* note 35; Lee, *supra* note 55; Milton Diamond & Keith Sigmundson, Commentary, *Management of Intersexuality: Guidelines for Dealing with Individuals with Ambiguous Genitalia*, ARCHIVES OF PEDIATRIC AND ADOLESCENT MEDICINE 151 (1997), available at http://www.hawaii.edu/PCSS/online_artcls/intersex/apam.html.
69. HRC REPORT, *supra* note 20, at 51-52 (quoting urologist Dr. Laurence Baskin's statement that doctors hear very little from patients who are satisfied with surgery, and pointing out his inability to produce statements from any of these satisfied patients after repeated requests); Order Changing Guardianship (Identification of Minor Suppressed), Sentencia SU-337/99 (Corte Constitucional, May 12, 1999) (Colom.), available at <http://www.isna.org/node/516>; *In re Guardianship XX*, Sentencia T-551/99 (Corte Constitucional, Aug. 2, 1999) (Colom.), available at <http://www.isna.org/node/516>; Sentencia No. T-477/95 (Corte Constitucional, 1995) (Colom.), available at <http://www.isna.org/node/516> [collectively hereinafter Colombia cases]. English summary of all three Colombia cases at Greenberg & Chase, *Colombia*, *supra* note 23.
70. See generally, HRC REPORT, *supra* note 20; Hermaphrodites Speak!, *supra* note 20; XXXY, *supra* note 64.
71. *DSD Guidelines*, *supra* note 44, at 20; Ford, *supra* note 10, at 474-85 (noting that surgery frequently results in loss of sensation or pain in the genital area).

which can cause a lifetime of sexual impairment. Most intersex people treated under the surgical model undergo three to five surgeries, although some have many more, often throughout childhood.⁷² Multiple surgeries are required because, frequently, one surgery is not enough to “normalize” the appearance of the genitals⁷³ or because common complications of surgery require additional surgery.⁷⁴ Some intersex adults report that much of their childhood vacation time was spent in hospitals, aware that something unspeakable was wrong with their genitals but not knowing what it was.⁷⁵ One intersex adult recalls a childhood of “horrible, tense visits to the pediatric endocrinologists to have [his] genitals gawked, fondled and stared at by hordes of what [he] perceived to be nasty, despicable men.”⁷⁶ The combination of physical trauma, secrecy, shame, and compulsory display of the genitals for medical examinations, all at the hands of authority figures, can have devastating results for intersex people.⁷⁷ In fact, many intersex people and some professionals compare the traumatic effects of the concealment model to the effects of childhood sexual abuse.⁷⁸

Thus, the magic wand theory of surgery begins to disintegrate when one looks more closely at the real costs of surgery and the real, lived experiences of intersex people. Although intersex people who have undergone genital-normalizing surgery do not share a uniform set of experiences, all of those intersex people who have spoken out about the topic have made it resoundingly clear that they believe the decision to undergo genital surgery should be made by the individual, not by doctors or parents.⁷⁹ This fact alone weighs strongly

72. FAUSTO-STERLING, *supra* note 30, at 86. *See also* Creighton, *supra* note 24 (noting that nearly all patients who undergo childhood genital surgery require further treatment).

73. Creighton, *supra* note 24 (“It is important that clinicians and parents understand that genital ambiguity cannot be corrected in infancy by a single procedure.”).

74. These complications may include infection, vaginal necrosis, fistulas, and development of painful scar tissue, and can make future surgeries unavoidable once the course of surgical treatment begins. Claude J. Migeon et al., *Ambiguous Genitalia With Perineoscrotal Hypospadias in 46,XY Individuals: Long-Term Medical, Surgical, and Psychosexual Outcome*, 110 PEDIATRICS e31 (2002), <http://pediatrics.aappublications.org/cgi/reprint/110/3/e31>. *See also* Kate Haas, *Who Will Make Room for the Intersexed?*, 30 AM. J.L. AND MED. 41, 62 (2004).

75. HRC REPORT, *supra* note 20, at 31; XXXY, *supra* note 64. *See also* Collins v. Sullivan, 679 N.E.2d 423 (Ill. App. Ct. 1997) (ordinary medical negligence action for surgical treatment of hypospadias, noting eleven surgeries from ages four to eighteen including such complications as multiple fistula repair).

76. Ehrenreich, *supra* note 54, at 108.

77. *Id.* at 107-08 (citing stories of doctors masturbating young intersex boys to check post-surgical penile function and forced dilations of young intersex girls’ surgically constructed vaginas).

78. *Id.*; T. Alexander, *The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse* (1997), available at <http://www.isna.org/articles/analog.html> (last visited Sept. 29, 2005) (“Children treated for intersex conditions within the medical establishment experience many of the same types of trauma as children who are sexually abused.”).

79. *See generally* HRC REPORT, *supra* note 20; Hermaphrodites Speak!, *supra* note 20; Erin Lloyd, *Symposium Report: Intersex Education, Advocacy & the Law: The Struggle For Recognition and Protection*, 11 CARDOZO WOMEN’S L.J. 283 (2005).

against continuing genital surgeries on infants who can voice no opinion.⁸⁰

2. Lack of Evidence to Support Surgery

While the idea of genital-normalizing surgery followed by secrecy may have intuitive appeal to both the distraught parent and to the well-intentioned medical provider, it remains arguably an experimental procedure.⁸¹ Dr. Money never conducted extensive or long-term follow-up with his patients after the failed experiment on David Reimer and, over fifty years later, no one else has conducted a comprehensive study of the effects of these surgeries on intersex patients.⁸² Because the arguments against surgery are based largely on anecdotal evidence, some advocates of early surgery insist that these intersex voices represent an unlucky few who experienced bad outcomes.⁸³ Certainly, such claims would have some support, and the debate over genital-normalizing surgery would be very different, if there were scientific or anecdotal evidence demonstrating that surgery benefits most intersex children. But such evidence does not exist.

To be specific, there are no studies demonstrating that surgery contributes positively to the child's gender-identity development or self esteem.⁸⁴ Since Money's John/Joan case study was discredited, not a single case has been found or cited to support the long-term physical and psychological successes of this surgery.⁸⁵ Furthermore, there is a lack of studies supporting the speculation that parents will be unable to bond with their children or that children will suffer greatly from schoolyard teasing if surgery is not completed early in the child's life.⁸⁶ While some surgeons claim that current surgical techniques are superior to those practiced in the past, they admit that they still cannot predict the effect of

80. The fact that so many intersex adults have complained about the results of surgery also distinguishes genital-normalizing surgery from other common surgeries used on children born with atypical anatomical features, such as cleft palate repair. Diamond & Sigmundson, *supra* note 68 ("[U]nlike individuals who have been given neonatal surgery for cleft palate . . . many of those who have had genital surgery or been sex reassigned neonatally have complained bitterly of the treatment.").

81. See Beh & Diamond, *supra* note 4, at 13-14, 22-23 (arguing that surgical intervention on intersex babies was never adequately tested, and does not carry the reasonable expectation of success to be considered standard care).

82. *Id.* at 22-23. The studies that do exist are small-scale and are primarily concerned with the "correctness" of the gender assignment or the cosmetic appearance of the genitals, rather than with the psychological impact of infant surgeries or the satisfaction of the patients with the surgical outcome. See Hermer, *supra* note 22, at 212-13.

83. Sara A. Aliabadi, *You Make Me Feel Like a Natural Woman: Allowing Parents to Consent to Early Gender Assignment Surgeries For Their Intersexed Infants*, 11 WM. & MARY J. WOMEN & L. 427, 436 (2005) [hereinafter, *Parents Consent*]; Lerner, *supra* note 19.

84. HRC REPORT, *supra* note 20, at 54 (citing report from Dr. Kate O'Hanlan).

85. Coventry, *supra* note 67, at 59.

86. These psycho-social justifications for surgery seem particularly weak when they are advanced by urologists or surgeons rather than mental health specialists. See, e.g., Lerner, *supra* note 19 (quoting pediatric urologist Dr. Kenneth I. Glassberg as stating that intersex children will "be considered freaks by their classmates" without surgery).

these techniques on the patient's future orgasmic potential, and that in general, medical understanding of the effects of genital surgery on sexual response is incomplete.⁸⁷

There is one area of agreement between advocates for and against surgery: both sides admit the urgent need for comprehensive study of the long-term effects of surgery.⁸⁸ However, it takes time to produce such meaningful analysis and until then, caregivers must continue to make decisions on behalf of intersex children.⁸⁹ The real question, then, is whether surgeries on infants and children should continue in the absence of conclusive evidence of its physical and psychological effects.

3. Surgery Does Not Accomplish Its Goals

I have never enjoyed sexual or romantic intimacy in my life, with men or with women. I believe that this is a direct result of my treatment. The clitoral surgery that was performed on me damaged my ability to experience sexual pleasure and it failed in its putative purpose of creating "normal" appearing genitalia.—Joan W.⁹⁰

One thing that is clear about genital-normalizing surgery is that it does not consistently accomplish its apparent goals; in fact, it sometimes causes the problems it purports to solve. For example, advocates of surgery point to the potential for shame resulting from schoolyard teasing faced by an intersex child with intact genitals,⁹¹ but critics of surgery note that both the surgeries and repeated medical displays of the child's genitals can themselves be sources of a deep and lasting sense of shame.⁹² Intersex adults have also pointed out that it can be much more difficult and embarrassing for children to conceal multiple surgeries and their after-effects from peers than to conceal their atypical genitals.⁹³ Complications from surgery and the need for multiple procedures

87. American Urological Association, Pediatric Conditions—Abnormalities—Ambiguous Genitalia, <http://www.urologyhealth.org/pediatric/index.cfm?cat=01&topic=31> (last visited Nov. 12, 2005); Creighton, *supra* note 24; Migeon, *supra* note 74. See also Coventry, *supra* note 67, at 59 ("At a recent meeting of intersex specialists, [pediatric surgical urologist] Marut Schober described new research that shows the clitoris is more densely laced with erotic nerves than formerly believed, nerves one cannot avoid cutting in a clitoroplasty [a common surgery for intersex babies]"); FAUSTO-STERLING, *supra* note 30, at 85-86 (critiquing claims of improved surgical techniques).

88. Aliabadi, *Parents Consent*, *supra* note 83, at 436; Phornphutkul, *supra* note 8. For a useful listing of most published research through 2005, see *DSD Guidelines*, *supra* note 44, at 28-37.

89. Aliabadi, *Parents Consent*, *supra* note 83, at 436.

90. Joan W., *supra* note 59.

91. Aliabadi, *Parents Consent*, *supra* note 83, at 436-37; Rossiter & Diehl, *supra* note 35.

92. See *DSD Guidelines*, *supra* note 44, at 2, 28-29; Ehrenreich, *supra* note 54, at 107-08.

93. See XXXY, *supra* note 64 (psychologist and intersex activist Howard Devore stating, "I would go back to school sometimes maintaining this plastic tube coming out of my genitals for up to six weeks, draining into a sack that I had strapped to my leg underneath my jeans.")

therefore subvert one key premise of early surgical intervention: that it will enable the child to have a normal childhood. “[Intersex people’s] statements strongly suggest that the very effects against which surgical and other treatments were designed to protect—shame, stigma, and a humiliating sense of being different—are instead the all-too-frequent *products* of those treatments.”⁹⁴

While the surgeries are intended to spare the child emotional trauma in the future, it is certain that surgery is no magic wand—it carries its own cost in trauma.⁹⁵ Surgery is both painful and frightening for children.⁹⁶ Even advocates of surgery acknowledge that genital surgery on children can cause separation trauma, fear of physical harm, guilt, pain, anxiety and emotional disturbance.⁹⁷

A primary goal of surgery is normalization of the genitals, yet the reconstructed genitals often do not have a “normal” appearance or function.⁹⁸ Some commentators have even described the post-surgical results as “deformed.”⁹⁹ Furthermore, if it takes years to “reconstruct” the genitals, even those that ultimately have an acceptable cosmetic outcome will presumably not look normative during the supposedly critical childhood years.¹⁰⁰

Advocates of surgery further speculate that intersex people will be unable to find romantic partners or have “normal” relationships in adulthood without surgery.¹⁰¹ Normalization of the genitals, then, has a goal of promoting the formation of romantic relationships in adulthood. However, many intersex adults who have undergone surgery report difficulty in forming romantic relationships, a problem some attribute to the effects of childhood trauma related to their medical treatment.¹⁰² The scarring, pain, loss of sensation, and shame that result from genital-normalizing surgery can all inhibit the formation of healthy romantic bonds.¹⁰³

(quoted in HRC REPORT, *supra* note 20, at 46).

94. Ehrenreich, *supra* note 54, at 108 (emphasis in original); See also 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, 591, 593 (1996) [hereinafter *Elective Surgery*].
95. Ehrenreich, *supra* note 54, at 114 (noting patients’ experiences of childhood surgery as “coercive violation of their bodily integrity”).
96. See HRC REPORT, *supra* note 20, at 44; *Elective Surgery*, *supra* note 94 (noting pain and psychological stress of surgery for children).
97. *Elective Surgery*, *supra* note 94.
98. Creighton, *supra* note 24 (“The outcomes of childhood genital surgery are substantially poorer than reported previously with nearly all children requiring further treatment.”); Hermer, *supra* note 22, at 212-14 (reviewing scientific literature and concluding that surgical outcomes are frequently poor).
99. Ford, *supra* note 10, at 474-485 (noting that surgery frequently results in noticeable “deformation” of genitals). See also Creighton, *supra* note 24 (finding poor cosmetic outcomes in 41% of patients studied).
100. See FAUSTO-STERLING, *supra* note 30, at 62 (noting common occurrence of multiple surgeries throughout childhood).
101. Hermer, *supra* note 22, at 227; Rossiter & Diehl, *supra* note 35 (stating that an intersex child raised as a boy without surgery would be “nonfunctional” and “inadequate” as a male).
102. Ehrenreich, *supra* note 54, at 109; *DSD Guidelines*, *supra* note 44, at 24.
103. Ehrenreich, *supra* note 54, at 109; *DSD Guidelines*, *supra* note 44, at 20; Ford, *supra* note

Finally, as demonstrated in the John/Joan case, the original goal of ensuring development of a normative gender identity via genital-normalizing surgery is often not achieved.¹⁰⁴ However, since David Reimer stepped forward to discredit the case study, even proponents of surgery have backed away from this claim.¹⁰⁵ Instead, they emphasize different goals: protecting the child from shame and other emotional trauma,¹⁰⁶ creating “normal-looking” genitals,¹⁰⁷ and increasing the intersex person’s chances of forming healthy adult relationships.¹⁰⁸ These are laudable goals, but once again, when we listen to the stories of intersex people who have lived through this experiment, we hear that non-consensual childhood surgery is not the way to achieve them.

4. Postponing Surgery Keeps Options Open with No Demonstrated Harm

The alternative to immediate genital-normalizing surgery is to postpone surgery until the child is old enough to participate in the decision.¹⁰⁹ Critics of this strategy correctly point out that it, too, is unsupported by long-term comprehensive study.¹¹⁰ However, the growing body of studies of intersex people who avoided surgery that does exist does not suggest any resulting physical or psychological harm.¹¹¹ Anecdotally, we know that some of these intersex people are thankful to have grown up without surgery.¹¹²

Postponing surgery preserves the intersex child’s options for the future. As noted above, there is no guarantee that the intersex child will in fact adopt the

10, at 484.

104. Ehrenreich, *supra* note 54, at 102-03.

105. *AAP Evaluation*, *supra* note 31, at 141 (recommending surgery but acknowledging that some intersex individuals will reject their assigned gender). *See also* Lloyd, *supra* note 79, at 292 (noting shifting justifications for continuing surgical intervention); Migeon, *supra* note 74 (noting continuing uncertainty about how gender identity develops, and inability to accurately predict an intersex infant’s eventual gender identity).

106. Aliabadi, *Parents Consent*, *supra* note 83, at 436-37; Rossiter & Diehl, *supra* note 35.

107. Rossiter & Diehl, *supra* note 35.

108. Hermer, *supra* note 22, at 227; Rossiter & Diehl, *supra* note 35.

109. *See also* American Academy of Pediatrics, Committee on Bioethics, *Informed Consent, Parental Permission and Assent in Pediatric Practice*, 95 PEDIATRICS 314, 315 (1995) [hereinafter *Assent*] (recommending that children be involved in medical decisions to the maximal extent possible, and urging practitioners to prioritize gaining assent where consent is not legally possible, even if this means delaying non-urgent treatment). This leads naturally to the question of when exactly the child is old enough to provide meaningful consent or assent to these procedures. This is an important question to answer once it is established that the child’s participation is necessary, but it is beyond the scope of this paper.

110. Lerner, *supra* note 19; Phornphutkul, *supra* note 8.

111. *DSD Guidelines*, *supra* note 44, at 28. One such study was the topic of John Money’s doctoral dissertation, which was never published. Coventry, *supra* note 67, at 60. *See also* Ehrenreich, *supra* note 54, at 109-10, 112, 123.

112. Hermaphrodites Speak!, *supra* note 20; Eli Nevada, *Lucky to Have Escaped Genital Surgery*, HERMAPHRODITES WITH ATTITUDE, (Intersex Society of North America, Rohnert Park, Cal.), Fall/Winter 1995-96, at 6, available at <http://www.isna.org/files/hwa/winter1996.pdf>.

assigned gender.¹¹³ Some do not.¹¹⁴ The child and his/her parents must then confront the fact that the parents chose to surgically impose a gender on the child's body that feels wrong.¹¹⁵ If the intersex person ultimately rejects the assigned gender, the surgery is impossible to "reverse."¹¹⁶ This leaves the adult with fewer surgical options than would have been available absent childhood surgery.¹¹⁷ Even those intersex people who do adopt their assigned gender may feel that normative genital appearance is not the most important part of their gender identity, and may wish that they had been given the opportunity to choose for themselves whether their genitals would be altered.¹¹⁸ Some intersex people who underwent surgery feel poignantly the loss of the unique bodies with which they were born.¹¹⁹ In contrast, the few intersex people who avoided surgery in childhood and who have addressed the issue publicly have stated that they are happy with their unaltered bodies.¹²⁰

It is clear that postponing surgery will allow for consideration of the child's expressed gender identity and will leave the widest range of surgical options open if the intersex person should later elect surgery.¹²¹ Postponing surgery will enable an intersex person who later elects surgery to benefit from any technical advances that have emerged in the intervening period. It will also leave the intersex person free to avoid surgery entirely, a choice that some intersex adults, given the option, have already made.

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113. Gender identity is a person's internal sense of being a man or a woman (or some other gender/s). Gender identity development is a complex process that is believed to result from an interaction between genes and environment. *DSD Guidelines*, *supra* note 44, at 25-26. Even children born with bodies considered to be in the "normal" range sometimes develop a gender identity that differs from the one assigned at birth, as in the case of transsexual people. *See id.* In the concealment model, there is a great deal of emphasis on getting the gender identity correct and then enforcing that identity through surgery. Beh & Diamond, *supra* note 4, at 43-45. However, since the mechanism of gender identity development is not understood, surgeons are not always able to predict correctly what the intersex child's gender identity will ultimately be. *See AAP Evaluation*, *supra* note 31.
114. Hendricks, *supra* note 55; Phornphutkul, *supra* note 8, at 135-36; Migeon, *supra* note 74.
115. HRC REPORT, *supra* note 20, at 46-47 (quoting parents of intersex children who describe the regret they and their children feel about surgery); XXXY, *supra* note 64 (parent and adult intersex child discussing regret and distress after realizing decision for infant surgery was wrong); Ford, *supra* note 10, at 484. It's important to note that the major critique in such a situation is not that the gender *assignment* is incorrect. The problem is the non-consensual surgical alteration of genitals. However, the struggles of children who are assigned the wrong gender may be exacerbated when they realize what they lost in genital-normalizing surgery. Beh & Diamond, *supra* note 4, at 2 (describing the "shock" and "mourning" of two young men upon discovering that they had been born intersex and surgically assigned as girls).
116. HRC REPORT, *supra* note 20, at 53 (report of Dr. Kate O'Hanlan, gynecologic cancer surgeon); Creighton, *supra* note 24, at 124.
117. Ehrenreich, *supra* note 54, at 113.
118. Ford, *supra* note 10, at 485-86; Hermer, *supra* note 22, at 213-14.
119. Hermaphrodites Speak!, *supra* note 20.
120. *See, e.g., id.*; Nevada, *supra* note 112.
121. *See DSD Guidelines*, *supra* note 44, at 20 (recommending postponing surgery until patients can "decide for themselves what anatomical features accord with their self identities"); Coventry, *supra* note 67 (quoting Dr. William Reiner speculating that an adolescent might appropriately request surgery to bring her body in line with her self-image).

D. Alternatives to Early Surgery

As an intersexual who has been fortunate enough to escape surgery . . . I cannot see how my life would have been improved in the least by genital surgery.—Eli Nevada¹²²

Alternatives to both immediate cosmetic genital surgery and secrecy for intersex infants do exist. Some providers now recommend assigning a gender of rearing soon after birth, but postponing surgery until the child is old enough to participate in the decision.¹²³ Rather than focusing on potential cosmetic surgical outcome, the choice of an initial gender of rearing may instead take account of such factors as preservation of fertility, androgen exposure *in utero*, and probable internal sense of gender.¹²⁴ Some providers also maintain that the gender assignment should be considered contingent and that parents should be advised to allow children to assert their own sense of gender as they grow.¹²⁵ Immediate and long-term counseling for parents and children is recommended as a less drastic strategy than surgery for managing the effects of parental discomfort or potential schoolyard teasing.¹²⁶

Advocates of delaying or avoiding genital-normalizing surgery point out that non-surgical alternatives are actually the oldest method of “treatment.” Indeed, since intersexuality is a natural variation, intersex people have lived without surgical intervention in all cultures throughout history.¹²⁷ The legal status of intersex people is addressed in historic sources such as early English treatises¹²⁸ and important rabbinic sources from antiquity through the 19th Century,¹²⁹ raising the logical inference that intersex people in those cultures were fulfilling social roles: marrying,¹³⁰ purchasing land,¹³¹ offering testimony in court,¹³² performing religious obligations¹³³ and inheriting property.¹³⁴ There are

122. Nevada, *supra* note 112.

123. Diamond & Sigmundson, *supra* note 68; *DSD Guidelines*, *supra* note 44, at 17-18, 20-21.

124. Diamond & Sigmundson, *supra* note 68. Some intersex conditions seem more likely to lead to a male gender identity and some to a female one, regardless of the gender assigned. *Id.*

125. Diamond & Sigmundson, *supra* note 68; Hendricks, *supra* note 55; *DSD Guidelines*, *supra* note 44, at 18.

126. Diamond & Sigmundson, *supra* note 68; *See DSD Guidelines*, *supra* note 44, at 28, 32, 34.

127. *See* Martin, *supra* note 2, at 139-40; Greenberg, *supra* note 25, at 267, 275-78 (noting recognition of a third or alternate sex in various cultures).

128. *See, e.g.*, II Bracton on the Laws and Customs of England 31 (S.E. Thorne trans., William S. Hein & Co., Inc., 1997) (1968) (classification of “hermaphrodites”), *cited in* Katrina C. Rose, *A History of Gender Variance In Pre-20th Century Anglo-American Law*, 14 TEX. J. WOMEN & L. 77, 87 (2004).

129. *See, e.g.*, MAIMONIDES, MISHNEH TORAH, *Hilchot Ishut* 2:24 (classifying various intersex conditions).

130. *See* JOSEPH CARO, SHULHAN ‘ARUKH, *Even Haezer* 44:5.

131. Sir Thomas Littleton, Coke Upon Littleton 3 (Thomas Coventry ed., 1830) at 88 [hereinafter Coke], *cited in* Rose, *supra* note 128.

132. JOSEPH CARO, BEIT YOSEPH, *Hoshen Mishpat* 35:15.

133. *See* MAIMONIDES, MISHNEH TORAH, *Hilchot Avodah Zarah* 12:4 (assigning gender-related

several examples from history of intersex people living productive lives without surgery.¹³⁵

In modern times, Dr. Money himself authored a doctoral dissertation reporting on a study of adult intersex people who had not undergone surgical intervention, concluding that they were healthy and well-adjusted.¹³⁶ There are a few intersex adults today who escaped surgery in childhood; those who have come forward have been outspoken about their satisfaction with their bodies and their lives.¹³⁷ These success stories, combined with the stories of intersex people who have had genital-normalizing surgery, offer convincing evidence that it is time to reconsider the surgical standard of care.

E. The Movement Away from Genital-Normalizing Surgery

Over the last ten years or so, momentum has been building for the adoption of new, less invasive standards of care for intersex infants, with some influential doctors speaking out about the issue.¹³⁸ In 2000, the American Academy of Pediatrics released recommendations for treatment of intersex newborns that represented some retreat from the concealment model, including involving the parents in all discussions and acknowledging some uncertainty about how gender identity develops.¹³⁹ More recently, the Consortium on the Management of Disorders of Sex Differentiation, a group of doctors, psychologists, parents of intersex children and intersex adults, released new recommended clinical guidelines calling for delay of elective surgeries until the children are old enough to participate in the decision.¹⁴⁰ In addition, many providers are now calling for comprehensive, long-term follow-up studies.¹⁴¹

These developments are largely the result of educational efforts by the intersex community. Intersex activists have reached a large audience with their stories through mass media.¹⁴² They have also gained access to the medical community through work with researchers, presentations at medical conferences, and outreach to medical students.¹⁴³ It seems likely that these efforts, which have

obligations); JOSEPH CARO, SHULHAN 'ARUKH, *Yoreh Deah* 262:3 (circumcision); *Minchat Hinuch* 419 (studying Torah).

134. Coke, *supra* note 131, at 8a. See BABYLONIAN TALMUD, *Baba Bathra* 140b.

135. See generally MEDICAL INVENTION, *supra* note 30.

136. Unfortunately, he never published his dissertation, which predated the John/Joan experiment. Coventry, *supra* note 67, at 60.

137. Hermaphrodites Speak! *supra* note 20; Nevada, *supra* note 112; HRC REPORT, *supra* note 20, at 32; Chase, *Intersex Agenda*, *supra* note 22, at 241.

138. Diamond & Sigmundson, *supra* note 68; Phornphutkul, *supra* note 8; Martin, *supra* note 2, at 156-57; Hendricks, *supra* note 55; *Urologists Meeting*, *supra* note 56.

139. *AAP Evaluation*, *supra* note 31, at 139.

140. *DSD Guidelines*, *supra* note 44, at 20. This protocol represented the first time the experiences of patients and parents were included in such a document. *Id.* at 2.

141. Aliabadi, *Parents Consent*, *supra* note 83, at 436; Phornphutkul, *supra* note 8.

142. *Intersex History*, *supra* note 27.

143. *Id.*

already begun to affect written standards of care, will eventually affect the actual provision of care by reducing or eliminating non-consensual genital-normalizing surgeries.¹⁴⁴ However, the creation of new standards of care is not binding on medical providers, and it can take many years for medical practices to change in accordance with new information.¹⁴⁵ Meanwhile, genital-normalizing surgeries remain standard procedure in most hospitals.¹⁴⁶

The pace of change is too slow for many in the intersex community who are calling for an immediate moratorium on genital-normalizing surgery.¹⁴⁷ Many legal scholars are troubled as well by the medical community's slow response to this serious issue.¹⁴⁸ Some are beginning to propose a role for the legal system in ensuring that the interests of intersex infants are adequately protected.¹⁴⁹

II. MAKING DECISIONS FOR INTERSEX CHILDREN

What is done to these children, what was done to me, is legally and scientifically sanctioned traumatic sexual abuse. We are sexually traumatized in dramatically painful and terrifying ways and kept silent about it by the shame and fear of our families and society. This trauma is carried out by trusted authorities with our parents' approval and against our own will, as we are incapable of understanding "choice" as a helpless infant.—David¹⁵⁰

Currently, the decision of whether or not to perform genital-normalizing surgery on a child is made by the same process as most other medical decisions made on behalf of children: doctors make recommendations based on a standard of care and parents make decisions based on these recommendations. Because doctors' recommendations form the base for the validity of the parents' decision, I have called this the parent-doctor decision-making presumption. This Section will explore the legal basis for the presumption, including parents' authority to make medical decisions for their children and doctors' authority to set a medical standard of care. Next, I will look at how specific cultural factors influence this

144. Hendricks, *supra* note 55; Martin, *supra* note 2, at 156-57; Phomphutkul, *supra* note 8; Lerner, *supra* note 19.

145. Beh & Diamond, *supra* note 4, at 12-15, 31-32.

146. *Urologists Meeting*, *supra* note 56; Hendricks, *supra* note 55. *See also infra* notes 196-199 (citing current hospital protocols recommending genital-normalizing surgery).

147. *See Chase, Intersex Agenda*, *supra* note 22.

148. *See Beh & Diamond, supra* note 4, at 22-34; Ford, *supra* note 10, at 485-88; Hermer, *supra* note 22, at XX.

149. Lareau, *supra* note 25, at 145-51 (suggesting raised standard of informed consent). *See also* Martin, *supra* note 2, at 166-68; Hermer, *supra* note 22, at 223; Beh & Diamond, *supra* note 4, at 42-58 (suggesting failure of informed consent); Ford, *supra* note 10, at 488; Haas, *supra* note 74, at 61-64.

150. David, *I am not alone!*, HERMAPHRODITES WITH ATTITUDES, (Intersex Society of North America, Rohnert Park, Cal), Winter 1995, at 5, available at <http://www.isna.org/files/hwa/winter1995.pdf>.

medical decision-making process in the case of intersex children. Lastly, an examination of the flaws in the current decision-making process around genital-normalizing surgery will be discussed in two parts. First, I propose that informed consent fails in these cases because parents are making their decisions with inadequate information, while doctors may be acting outside the scope of their legitimate authority. Second, I suggest that parental consent to genital-normalizing surgery is inherently inadequate, both because the parents have a conflict of interest and because these surgeries may compromise the intersex child's fundamental rights to liberty, privacy and procreation.

A. The Parent-Doctor Decision-Making Presumption

For obvious reasons, children, especially infants, are not legally competent to give consent for their own medical treatment.¹⁵¹ The law presumes that parents have the authority to make these decisions on behalf of their children; parental consent substitutes for the child's consent.¹⁵² As long as these decisions are in line with an accepted medical standard of care, courts will rarely intervene in them.¹⁵³ In other words, doctors decide which treatments to recommend, and parents decide whether or not to proceed with the recommended treatment by giving or withholding their consent. When doctors and parents are in agreement about a medical decision for a child, there is rarely any additional oversight.¹⁵⁴ Below, I will discuss the legal basis for this structure: parental privacy rights, the presumption that parents are best situated to determine the child's best interest, and courts' traditional deference to doctors' authority to determine the medical standard of care.

1. Parental Authority to Make Decisions Regarding the Medical Care of Their Children

The basis for parental control over the medical decisions for treatment of children is two-fold. It arises out of both the concept of a constitutional right to family privacy and the legal presumption that parents are best situated to make good decisions because "natural bonds of affection lead parents to act in the best interests of their children."¹⁵⁵ Although parental rights are not absolute,¹⁵⁶

151. 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, 5-8 (2000).

152. *Id.*

153. See, e.g., *Rosebush v. Oakland County Prosecutor*, 491 N.W.2d 633, 637 (Mich. Ct. App. 1992) (reviewing jurisdictions and concluding that "the decision-making process should generally occur in the clinical setting without resort to the courts" unless "an impasse is reached.").

154. *Id.*

155. *Parham v. J.R.*, 442 U.S. 584, 602 (1979). See also *Pierce v. Soc'y of Sisters*, 268 U.S. 510, 535 (1925) (holding that parents have the "right, coupled with the high duty" to make decisions on behalf of their children); *Wisconsin v. Yoder*, 406 U.S. 205, 213 (1972); *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944); *Meyer v. Nebraska*, 262 U.S. 390, 400 (1923).

parents do have broad latitude in making these decisions.¹⁵⁷ In general, courts are willing to override parental medical judgments only where the life or well being of the child is endangered and the court has determined that the parents are failing to provide standard medical care.¹⁵⁸

For example, in *Guardianship of Phillip B.*, a court overrode the parents' decision not to consent to heart surgery that would both prolong and improve the quality of their disabled child's life, holding that continued parental custody would result in harm to the child.¹⁵⁹ A central factor in the ruling was the parents' "emotional abandonment" of the child, which "effectively depriv[ed] him of any of the substantial benefits of a true parental relationship."¹⁶⁰ The court acknowledged the parents' good intentions,¹⁶¹ but found that the child's disability had led to the parents' emotional detachment.¹⁶² This detachment, combined with a showing that the parents' decision would result in harm to the child, empowered the court to displace the parents as decision-makers.¹⁶³

Such cases seem most likely to arise when the parents are *refusing* treatment in opposition to medical advice. When parents are choosing from among accepted medical treatments, courts will rarely intervene to reverse the parents' decision.¹⁶⁴ This is true even where the treatment is unorthodox and accepted by only a minority of practitioners.¹⁶⁵

Decisions regarding infant genital-normalizing surgeries do not fall into the category of parental medical decision-making cases that typically end up in court

156. See Part IV below; Prince, 321 U.S. at 166; *In re Doe*, 418 S.E.2d 3, 7 n.6 (Ga. 1992) (parents do not have an "absolute right to make medical decisions for their children.").

157. See generally *Assent*, *supra* note 109.

158. See, e.g., *A.D.H. v. State Dep't of Human Res.*, 640 So. 2d 969 (Ala. Civ. App. 1994) (ordering AZT treatment for child's HIV over mother's objection); *Petra B. v. Eric B.*, 265 Cal. Rptr. 342 (Ct. App. 1989) (ordering medical treatment for child's serious burns despite parents' desire to treat with herbal remedies); *Custody of a Minor*, 379 N.E.2d 1053 (Mass. 1978) (ordering chemotherapy despite parents' pessimism). Where the life of the child is not in danger and the benefit of the proposed treatment is uncertain, courts have been less willing to intervene. See, e.g., *In re Hudson*, 126 P.2d 765 (Wash. 1942) (upholding parent's decision to refuse amputation of child's abnormally enlarged arm where there was substantial risk of death from the procedure). However, as discussed in Part III below, courts have also been willing to intervene in certain cases where a proposed procedure threatens the child's exercise of fundamental rights.

159. 188 Cal. Rptr. 781, 791-92 (Ct. App. 1983).

160. *Id.* at 792 (emphasis in original).

161. *Id.*

162. *Id.* at 787.

163. *Id.* at 792. Where a child's life or well being is at stake and the benefits of treatment are fairly certain, the state can even override a compelling parental interest in refusing a child's medical treatment. *Jehovah's Witnesses in State of Wash. v. King County Hosp.*, 278 F. Supp. 488, 504-05 (W.D. Wash. 1967) (holding that a state may override parents' religious objections to blood transfusion when the child's life or health is at risk), *aff'd*, 390 U.S. 598 (1968), *reh'g denied* 391 U.S. 961 (1968).

164. *In re Hofbauer*, 393 N.E.2d 1009, 1014 (N.Y. 1979) ("The court's inquiry should be whether the parents . . . have provided . . . a treatment which is recommended by their physician and which has not been totally rejected by all responsible medical authority.").

165. *Id.*

for three reasons. First, the surgeries are not perceived to be life-threatening. Second, the parents typically are acting out of demonstrable concern for the child's well-being. Third, the surgeries are an accepted medical practice. Indeed, no one in the United States has questioned in court the parental authority to make this decision.¹⁶⁶ As long as doctors continue to recommend the surgical model, the parent-doctor presumption will allow parents to choose surgical treatment for their intersex children that is medically unnecessary and that these children, once old enough to understand, may wish had not been chosen for them. Thus the parental presumption fails to protect the interests of intersex children.

2. The Medical Profession's Authority to Determine the Standard of Care

I have found that one of the reasons physicians resist calls for reform is the pain of having to face the possibility that they have inadvertently harmed their patients. I know if someone told me that, after years of dedicating my life to helping people, I had accidentally been harming people, I would be pretty resistant to that criticism.—Alice Dreger, Ph.D.¹⁶⁷

Doctors receive even more deference than parents in making medical decisions. The medical profession has the relatively unique authority to conclusively determine its own legal standard of care.¹⁶⁸ As long as doctors act in accordance with this standard, they are not performing negligently, and consequently there is no mechanism for court oversight of medical judgment.¹⁶⁹ The main reason for this rule is judicial deference to the specialized knowledge of doctors.¹⁷⁰ Courts have determined that it is better for the judiciary to avoid second-guessing the medical profession as a whole.¹⁷¹ In general, this practice is reasonable. Litigation can be a poor vehicle for developing medical standards of care, possibly leading to practices that are faulty or costly, or causing doctors to override their good judgment due to the fear of liability. Furthermore, medical

166. Greenberg & Chase, *Colombia*, *supra* note 23; Ford, *supra* note 10, at 474.

167. Alice Dreger, *Why Do We Need ISNA?*, ISNA NEWS (Intersex Society of North America, Rohnert Park, Cal.), May 2001, at 2-3, available at <http://www.isna.org/files/hwa/may2001.pdf>.

168. *Toth v. Cmty. Hosp. at Glen Cove*, 239 N.E.2d 368, 372 (N.Y. 1968); Theodore Silver, *One Hundred Years of Harmful Error: The Historical Jurisprudence of Medical Malpractice*, 1992 WIS. L. REV. 1193, 1213 (1992) ("It is thus recognized that the medical profession has the curious advantage of establishing, on its own, the standard of care to which it is legally obliged."). This rule has changed in a few jurisdictions, but is still the majority rule. See, e.g., Silver, *supra* note 168, at 1213-14.

169. Silver, *supra* note 168, at 1214 ("[O]ne who is injured by a physician's unreasonable professional conduct may not recover unless that conduct happens to contravene prevailing medical custom."); *Gorab v. Zook*, 943 P.2d 423, 427 (Colo. 1997) (en banc); *Harris v. Groth*, 663 P.2d 113, 115 (Wash. 1983) (en banc).

170. Silver, *supra* note 168, at 1214-15; *Osborn v. Irwin Mem'l Blood Bank*, 7 Cal. Rptr. 2d 101, 126 (Ct. App. 1992).

171. *Osborn*, 7 Cal. Rptr. 2d at 126.

doctors are probably better positioned than judges or juries to evaluate medical information.¹⁷²

But what if the profession itself has been negligent in *developing* the standard of care? Dr. Milton Diamond (who uncovered the truth about David Reimer) and Professor Hazel Glenn Beh argue persuasively that the process of establishing the surgical model as the standard of care, based on a single case study and with no long-term follow-up, was negligent.¹⁷³ Even after the discrediting of the foundational study and widespread reporting of intersex adults' statements that they were harmed by the surgeries, the field remains slow to respond.¹⁷⁴ The deference that the law affords medical judgment results in an absence of legal tools to look behind the medical standard of care and examine whether due care was used in creating and perpetuating that standard.¹⁷⁵

Like the rule of parental decision-making, the rule for determining a medical standard of care fails to protect the interests of intersex infants.¹⁷⁶ As long as genital-normalizing surgeries are considered the standard of care, or even one of many acceptable standards of care, doctors who perform them are immune from suit for malpractice.¹⁷⁷ Under the current model, the power ultimately lies in the judgment of doctors—if a treatment is considered to be an acceptable medical standard of care, then it is generally shielded from judicial review either for negligence or for parental ability to provide consent.

B. Specific Cultural Factors Influencing Decisions About Genital-Normalizing Surgery

I believe that it is time for us to counter physicians' assertion that life as a hermaphrodite would be worthless, by embracing the word and asserting our identity as hermaphrodites. This is the way to break the vicious cycle in which shame produces silence, silence condones surgery, and surgery produces more shame. —Cheryl Chase, founder, Intersex Society of North America¹⁷⁸

In order to understand why the usual process for medical decision-making is producing dissatisfactory results for so many intersex people, it is important to acknowledge the unique cultural factors influencing the decision-makers. These cultural factors can severely inhibit parents' and doctors' ability to weigh the

172. *Id.*

173. Beh & Diamond, *supra* note 4, at 34 (“[T]he profession has not even abided by its own recommendations for the evaluation of a standard.”).

174. Hendricks, *supra* note 55; Lareau, *supra* note 25, at 146 n.10.

175. Hermer, *supra* note 22, at 217-20.

176. *See* Beh & Diamond, *supra* note 4, at 32.

177. Of course, they must still meet the standard of care in performing the surgeries. *See* Hood v. Philips, 537 S.W.2d 291, 294 (Tex. App. 1976).

178. *Welcome, Readers!, HERMAPHRODITES WITH ATTITUDES* (Intersex Society of North America, Rohnert Park, Cal.), Winter 1995, at 1, 6, available at <http://www.isna.org/files/hwa/winter1995.pdf>.

risks and benefits of surgery. For example, the “erasing” of intersex people that is central to the concealment model means that few people have access to an articulated intersex voice.¹⁷⁹ This absence makes it easier to understand and address the needs of the parents or doctors than the needs of the child. It is easy to imagine the pressure and distress parents must feel, and doctors’ desire to help both parents and child. Medical providers may find it easier to focus on the perceived need of the parents to have a “normal” infant than on the projected needs of the child as s/he grows to adulthood.¹⁸⁰ Parents, meanwhile, may find it easier to comply with doctors’ efforts to “fix” the problem than to question whether these efforts are truly in the child’s best interest. In order to even formulate such a question, parents would first have to recognize that forgoing surgery is an option. Yet it may be almost impossible for many people to conceive of life in an intersex body. This failure of imagination—the inability to envision a happy, productive life for a visibly intersex person – is both cause and consequence of the surgical “erasing” of intersex bodies.¹⁸¹

In fact, a strong culture of gender binaries can make the decision in favor of surgery seem self-evident.¹⁸² Only in a society in which sex is understood in binary terms (everyone is either male or female) does the hermaphroditic body become abnormal. Rather than conceptualizing such individuals as . . . occupying various points along a sex continuum, our society chooses to see them as suffering abnormalities that require repair.¹⁸³

Or, as one surgeon put it, “if the parents have a child with a very large phallus that looks like a penis, can that parent feel comfortable training that child as a female?”¹⁸⁴ This binary may overwhelm other factors even when parents are well-informed about the risks of surgery and its uncertain outcome.¹⁸⁵

Traditional mores around children and sexuality may also be an obstacle to objective consideration of the risks and benefits of surgical intervention. Parents may be hampered in making decisions that affect their child’s adult sexual life because they may be uncomfortable thinking about the child as a sexual or

179. Coventry, *supra* note 67.

180. See *DSD Guidelines*, *supra* note 44, at 20; *AAP Evaluation*, *supra* note 31, at 1 (stating that intersex infants require “individual consideration based on physical examination, laboratory studies, and parental feelings”); Lloyd, *supra* note 79, at 285 (citing physician concern with parent comfort around child’s genitals, as well as what to tell the babysitter and family members).

181. To quote a 1969 medical treatise recommending surgery, “To visualize individuals who properly belong neither to one sex nor to the other is to imagine freaks, misfits, curiosities, rejected by society and condemned to a solitary existence.” Hermer, *supra* note 22, at 209, quoting CHRISTOPHER J. DEWHURST & RONALD R. GORDON, *THE INTERSEXUAL DISORDERS* vii (1969).

182. Ehrenreich, *supra* note 54, at 117-21.

183. *Id.* at 117-18.

184. Lloyd, *supra* note 79, at 285.

185. One doctor tells a story of parents who considered putting off surgery, but then decided postponement “was beyond what we felt we could do,” in spite of worries that the child might later resent having the decision taken away from her. Hendricks, *supra* note 55.

potentially sexual being.¹⁸⁶ Homophobia and transphobia are also factors.¹⁸⁷ Indeed, doctors routinely reassure parents that the surgical treatment will result in a child who is not gay or lesbian, and who has a normative gender identity.¹⁸⁸

Even caregivers who are open to discussions of children and sexuality or to critiques of the gender binary may have trouble accessing alternative paradigms for treating intersex infants. The self-reinforcing nature of the concealment model tends to stifle dissenting voices, making it difficult to gain recognition of alternatives to these norms. There are relatively few intersex people, and the concealment model has kept many of them separated from each other, unaware of the nature of their conditions, and ashamed to speak out.¹⁸⁹ Those intersex adults who do speak out are isolated as “gender radicals” or as a disgruntled minority.¹⁹⁰ These factors stand in the way of a neutral analysis of the effects of surgery and make the standard of care particularly resistant to question or change.

The invisibility of intersex people, a strong culture of a gender binary, resistance to discussions of children’s sexuality, and the marginalization of intersex voices all work together to influence doctors’ and parents’ consideration of early genital-normalizing surgery. These cultural influences inhibit the normal function of the parent-doctor decision-making process. Ultimately, doctors’ decisions to recommend genital-normalizing surgery and parents’ decisions to approve it may be based on cultural norms rather than on medical need.¹⁹¹

186. *DSD Guidelines*, *supra* note 44, at 24. One researcher cites a study in which adult men and women were asked if they would want genital-normalizing surgery had they been born intersex. Lareau, *supra* note 25, at 143. A majority said they would not want their bodies altered in such a situation. *Id.* Interestingly, they answered differently when asked what they would do had their children been born intersex. *Id.* Cf. Teemu Ruskola, *Minor Disregard: The Legal Construction of the Fantasy that Gay and Lesbian Youth Do Not Exist*, 8 YALE J.L. & FEMINISM 269, 274-76 (1996) (suggesting that adult discomfort with children’s sexuality is central to the societal denial of the existence of gay and lesbian youth).

187. Homophobia is the irrational fear of homosexuality. Transphobia is the irrational fear of gender variance. See also Ehrenreich, *supra* note 54, at 127-28 (discussing genital-normalizing surgery as enforcing heteronormativity); *DSD Guidelines*, *supra* note 44, at 27 (noting that desire to avoid the appearance of homosexuality has been a motive for clinicians recommending surgery).

188. Martin, *supra* note 2, at 153; HRC REPORT, *supra* note 20, at 13, 19, 23, 31; Beh & Diamond, *supra* note 4, at 56-57.

189. Coventry, *supra* note 67, at 59 (describing Cheryl Case’s struggle to get her medical records and found the Intersex Society of North America and her isolation during the process).

190. Hermer, *supra* note 22, at 228 (suggesting that critics of surgery are trying to use intersex children as “guinea pigs” in an effort to “alter our present sex and gender systems”); Aliabadi, *Parents Consent*, *supra* note 83, at 436 (quoting doctor’s statement that intersex adults who object to surgery “represent a small group of patients”); Rossiter & Diehl, *supra* note 35 (dismissing views of intersex activists because “these individuals admit to persistent feelings of inadequacy.”).

191. Ehrenreich, *supra* note 54, at 114-120. It is interesting to compare the cultural forces at work in genital-normalizing surgeries with those involved in female genital mutilation, which is prohibited in the United States by federal statute. Both practices are not necessary for physical health, and are justified by the need to make genitals conform to the standards of the relevant culture. See generally *id.*

C. The Decision-Making Process Fails to Protect the Interests of Intersex Children

The two presumptions that underlie the current process of medical decision-making on behalf of children are: 1) that parents, in consultation with doctors, are best situated to determine the best interests of the child; and 2) that parents have a constitutional right to make decisions on behalf of their children. These are only presumptions, however. They are not conclusive. In the case of genital-normalizing surgery, serious questions arise as to whether this process is adequate to protect the rights and interests of intersex children. The first part of this Section will explore whether the process as applied in the situation of intersex children leaves parents adequately informed to provide meaningful consent to surgery. The second part of this Section questions whether parental consent could ever be adequate to authorize this medically unnecessary surgery—even with full information—given the conflicts of interest between caregivers and intersex children and the potential for lifelong impact on the child’s exercise of fundamental rights.

1. Failure of Informed Consent

When doctors assured my father that I would grow up to have “normal sexual function,” they didn’t mean that my amputated clitoris would be sensitive or that I would be able to experience orgasm (or any pleasure at all). —Morgan Holmes¹⁹²

They said they could correct the problem and that we could raise her as a girl. They [the doctors] thought that was the best way to handle it. —father of an intersex child¹⁹³

There is a serious question as to whether parents make the decision for surgery after doctors explain the options, or whether doctors are the true decision-makers. In the past, parents were frequently under-informed and often did not even fully understand the nature of the intersex diagnosis.¹⁹⁴ Some parents of intersex children have felt as if they were not offered a choice about whether or not their child should undergo surgery.¹⁹⁵ Medical protocols and information given to parents continue to present surgery as a foregone

192. Morgan Holmes, *I’m Still Intersexual*, HERMAPHRODITES WITH ATTITUDES, (Intersex Society of North America, Rohnert Park, Cal.), Winter 1995, at 5, 6, *available at* <http://www.isna.org/files/hwa/winter1995.pdf>.

193. *Interview in XXXY*, *supra* note 64 (*quoted in* HRC REPORT, *supra* note 20, at 46).

194. FAUSTO-STERLING, *supra* note 30, at 64; Lerner, *supra* note 19.

195. HRC REPORT, *supra* note 20, at 47-49 (quoting parents of intersex children stating they did not feel doctors offered adequate information prior to surgery). *See also* Rossiter & Diehl, *supra* note 35, at 3 (describing medical providers’ efforts to change parents’ decision to reject surgery).

conclusion in many cases.¹⁹⁶ Few parents of intersex children know anything about intersex conditions before they are presented with the recommendation for surgery, and they may be pressured into making a decision before they have had adequate time to think about what it might be like to raise a child who has an atypical body.¹⁹⁷

Doctors, perhaps acting out of concern for the child's well-being or the parents' comfort, frequently filter information in such a way that parents make the decision to authorize genital-normalizing surgery on the basis of incomplete information and without having considered other options. For example, doctors may downplay the existence of mixed markers of the infant's sex¹⁹⁸ or display unwarranted optimism about the outcomes of surgery.¹⁹⁹ In addition, since many physicians who treat intersex infants do not consider postponing surgery to be a viable option,²⁰⁰ they presumably do not present it to parents as such. Even the

196. *AAP Evaluation*, *supra* note 31, at 141 ("Infants raised as girls will usually require clitoral reduction." No discussion of a non-surgical treatment plan); Greater Baltimore Medical Center, *Greater Information: Ambiguous Genitalia*, at <http://www.gbmc.org/greaterinformation/index?pageid=P03079> (last visited Nov. 12, 2005) ("Treatment . . . will usually include corrective surgery." No discussion of a non-surgical treatment plan).

197. HRC REPORT, *supra* note 20, at 47-49 (quoting parents' statements that they had to make decisions based on inadequate information); Ford, *supra* note 10, at 487-88 (discussing pressure parents face); See also Perinatal Advisory Council/Leadership, Advocacy and Consultation, *Prenatal and Intrapartum Guidelines of Care: Ambiguous Genitalia*, http://www.paclac.org/Manuals_Guidelines/Ambiguous_Genitalia_Final_5.19.98.pdf, at 7 (last visited Mar. 20, 2006) [hereinafter PAC/LAC] ("A plan for surgical intervention, hormone treatment and other therapies should be in place before the neonate is discharged." There was no discussion of a non-surgical treatment plan).

198. See Ehrenreich, *supra* note 54, at 118-119. Doctors commonly describe the intersex child's body to the parents as an instance of "unfinished" development which the surgeon can complete without changing the "true" sex. *Id.*, This is misleading because:

[t]he very definition of intersexuality—that it is a condition characterized by a mixture of "key masculine anatomy with key feminine anatomy"—recognizes that a variety of criteria are used to classify people within the binary sexual classifications of male and female. . . . An intersex condition arises when genetic and/or hormonal patterns cause an embryo to exhibit a pattern of sexual differentiation that combines elements of *both male and female developmental pathways*.

Id. at 98-99 (emphasis added) (quoting *How Common is Intersex?*, *supra* note 28); See also PAC/LAC, *supra* note 197, at 2-3 (advising medical caregivers: "Parental notification should be made in careful terms. Suggested language might include the following: 'the genitalia are unfinished in their development and we will need a few days to perform some studies to determine which sex your baby was intended to be.'"); Mayo Clinic, *Ask a Children's Healthcare Specialist: Ambiguous Genitalia*, at <http://www.mayoclinic.com/health/ambiguous-genitalia/AN00750> (last visited Nov. 12, 2005) (stating that the "genetic sex of a child is established at conception," and further implying that all infants have either XX or XY chromosomes and that ambiguous genitals are attributable to hormone imbalances).

199. Joel Hutcheson & Howard M. Snyder, III, *Ambiguous Genitalia and Intersexuality*, e-Medicine, <http://www.emedicine.com/PED/topic1492.htm> (last visited Nov. 12, 2005) (stating "the techniques of surgical genital reconstruction have been mastered" and failing to mention non-surgical options, potential for complications or lack of understanding of impact of surgeries on orgasmic potential); *AAP Evaluation*, *supra* note 31, at 141 (asserting that "current techniques will result not only in a normal-looking vulva but preservation of a functional clitoris" but later acknowledging that "few studies have been done that address the . . . sexual outcomes for affected adolescents and adults.").

200. See Lerner, *supra* note 19 (stating that some doctors oppose a blanket policy of not operating

physician's attitude that the intersex child presents an emergency requiring immediate intervention may have a powerful effect on the parents' outlook, encouraging the sense that there is no time for reflection.²⁰¹

This problem is compounded when doctors' influence over parental decision-making draws on false authority. The issue here is a social one—"a social emergency," to quote one influential protocol—²⁰² but doctors' authority is medical. For example, a pediatric urologist may be acting outside her area of expertise if she recommends surgery based on her predictions of how a child is likely to function socially, how a child's internal sense of gender may develop, or how parent-child bonding will likely proceed.²⁰³ For a parent struggling to understand this unexpected situation, however, a doctor's culturally-biased recommendations masked as medical expertise can carry unduly influential weight.²⁰⁴ In such a case, the notion that the parent gives "informed consent" is really illusory.²⁰⁵

Most legal scholars who have addressed the issue of genital-normalizing surgeries on infants have called for higher standards of informed consent, suggesting that parents would decline to authorize surgery if they knew of the long-term problems faced by intersex adults who have undergone surgery, the questionable theoretical background for such surgeries, and the lack of evidence of benefit to the child.²⁰⁶ A Colombian court has ruled on this question, reaching the conclusion that genital-normalizing surgery on infants should be treated differently from other medical decisions for children, with special attention to properly informing the parents.²⁰⁷ The Colombian court fashioned a sort of super-informed consent standard just for this situation, which set out explicit procedures for decision-making in stages that stretch over a long period of time.²⁰⁸ Whether modeled on the Colombian example or not, improved standards for informed consent could address some of the weaknesses in the current

on intersex infants); Rossiter & Diehl, *supra* note 35.

201. Ford, *supra* note 10, at 486-87.

202. *AAP Evaluation*, *supra* note 31, at 138.

203. Ehrenreich, *supra* note 54, at 114-15.

204. *Id.* at n.246 (speculating that these psychosocial factors may actual bear *more* weight when articulated by "hard" scientists, despite their lack of qualification in the subject matter).

205. Ford, *supra* note 10, at 486-88 (reviewing requirements for informed consent and concluding that "[t]he current model of treatment for intersexed infants fails the test for legal informed consent at every step.").

206. Lareau, *supra* note 25, at 145-51 (reviewing arguments for a raised standard of informed consent, and discussing proposed American Bar Association resolution recommending greater informed parental consent); Martin, *supra* note 2, at 166-69 (reviewing proposed standards for informed consent); Beh & Diamond, *supra* note 4, at 42-58 (criticizing on five grounds the current method practitioners use to gain informed consent for genital-normalizing surgery); Hermer, *supra* note 22, at 223; Aliabadi, *Parents Consent*, *supra* note 83, at 440-42. Several commentators have also suggested that intersex adults who were subjected to surgery in the past might have claims based on a failure of informed consent due to these defects. Martin, *supra* note 2, at 145-51; Beh & Diamond, *supra* note 4, at 42-58; Ford, *supra* note 10, at 488; Haas, *supra* note 74, at 61-64; Hermer, *supra* note 22, at 231-35.

207. Greenberg & Chase, *Colombia*, *supra* note 23; Colombia cases, *supra* note 69.

208. Greenberg & Chase, *Colombia*, *supra* note 23; Colombia cases, *supra* note 69.

decision-making process, encouraging more deliberate consideration of the risks and benefits of surgery by both parents and doctors.

However, the problem with simply raising the standard for informed consent is that, while it may improve the quality of the decision in some cases, it does not remove the parental conflict of interest that makes it particularly difficult to evaluate the long-term interests of the intersex child.²⁰⁹ Nor does it address the cultural biases influencing the decision.²¹⁰ Essentially, efforts to address this problem through the informed consent process carry the implication that it would be acceptable for parents to authorize the surgery *for any reason*—parental discomfort, embarrassment over raising a son with a small penis or a daughter with a noticeable clitoris, desire for a child of one gender or the other—as long as they were fully informed of the risks.²¹¹ Furthermore, at least one scholar has questioned the value of informed consent in an arena where we know so little about the long-term outcomes of surgery—how can consent be truly informed when the body of information is so inadequate?²¹²

2. Failure of Parental Consent Generally

[T]he right to procreate is more than a byproduct of a right of choice. Its roots go deeper; they are *constitutional* in the physical sense, implicating the individual's rights to physical integrity and to retention of the biological capabilities with which he or she was born into this world.²¹³ — Chief Justice Rose Bird (arguing against the sterilization of a mentally impaired woman)

As the Colombian court recognized when it outlined a special, super-informed consent process, the decision to proceed with genital-normalizing surgery on an infant is different from other medical decisions on behalf of children.²¹⁴ However, that court did not go far enough. The particular conflicts of interest that exist in such a case, combined with the potential for intrusion on the intersex child's fundamental rights to privacy, liberty, bodily integrity, and procreation, cast doubt on the sufficiency of parental consent to authorize the

209. Ford, *supra* note 10, at 486-88 (reviewing factors that may make meaningful informed consent impossible). The Colombia court found that parents are likely to base decisions on their own fears and concerns, rather than what is best for the child. Greenberg & Chase, *Colombia*, *supra* note 23. As the clerk of the court noted, some “parents who consent to surgery may actually be discriminating against their own children.” *Id.*

210. See Ehrenreich, *supra* note 54, at 117-29 (discussing cultural views of sexuality as binary requiring conformity to one sex or the other).

211. Lareau, *supra* note 25, at 148-51.

212. Ford, *supra* note 10, at 488 (“The fact is that there is just not enough accurate information available on the benefits or consequences of genital-normalizing surgery for even the most well-meaning and contemplative parents to make truly informed decisions for their infants.”).

213. Conservatorship of Valerie N., 40 Cal. 3d 143, 181 (1985) (Bird, C.J., dissenting).

214. Greenberg & Chase, *Colombia*, *supra* note 23.

surgery even with fully-informed consent.²¹⁵

a. The Usual Decision-Makers Have Conflicts of Interest

Without undermining the assertion that care for the child is normally the primary motivating factor, I would also suggest that parents and doctors have interests of their own that are met by the decision to perform surgery.²¹⁶ The parents may be in shock and grieving at this challenge to their vision of what their baby would be like.²¹⁷ The doctors, who entered their field to help people and to provide cures, want to be able to do both in this difficult situation.²¹⁸ Doctors and parents alike may be profoundly uneasy with the baby's body.²¹⁹ The idea that a simple surgery can fix everything is comforting to all the adults involved.²²⁰ Thus, the decision to perform surgery may be centered more around the needs of the caregivers than the needs of the child.

In fact, one of the common reasons cited by doctors for recommending the surgeries immediately (instead of waiting until the child is old enough to participate in the decision) is the psychological benefit to the *parents*. Doctors are concerned that the parents will be so disturbed by the appearance of intersex genitals that they will have difficulty accepting the child.²²¹ To the extent that this is the case, any benefit from surgery accrues only indirectly to the child.²²² Furthermore, the claim that the parent will be too alienated from the intersex child for normal parental attachment to occur undermines the premise on which parental authority to consent is founded: that the parent is best positioned to

215. See Lareau, *supra* note 25, at 142-45; Haas, *supra* note 74, at 55-60.

216. This paper will address parental conflict of interest extensively, and I want to be clear that most parents facing this difficult decision are primarily motivated by love for their child and concern for his or her well-being. I am using "conflict of interest" here to indicate that the parents may be responding to multiple conscious or unconscious needs – the child's, their own, other people's – that may make it confusing and difficult to weigh all aspects of this decision objectively. This very confusion and pressure may make it tempting to opt for, and believe in, the "magic wand" of surgery, so they can get on with loving and nurturing their baby.

217. *DSD Guidelines*, *supra* note 44, at 9-10.

218. *AAP Evaluation*, *supra* note 31, at 142. (acknowledging the "psychosocial distress" that parents feel at the birth of an intersex infant, and reassuring pediatricians of their "key role").

219. See Natalie Angier, *New Debate Over Surgery on Genitals*, N.Y. TIMES, May 13, 1997, at C1 (quoting pediatric urologist Dr. Anthony A. Caldamone as saying "I don't think parents can be told, this is a normal girl, and then have to be faced with what looks like an enlarged clitoris, or a penis, every time they change the diaper.").

220. See HRC REPORT, *supra* note 20, at 13.

221. *Elective Surgery*, *supra* note 94, at 590; Lareau, *supra* note 25, at 136-37; Hermer, *supra* note 22, at 230; Beh & Diamond, *supra* note 4, at 44-45. Of course, parents bond with children with a variety of physical conditions, and not all such differences are "corrected" by surgery.

222. *But cf.* Hermer, *supra* note 22, at 235 ("It must be recognized that the parental or familial needs driving this choice may be just as intense as any the intersex individual him/herself may experience. . . . [I]f surgery permits those parents to better relate to their child, then both the parents and the child will have benefited from it, *notwithstanding any ill effects the surgery may ultimately have on the child him/herself.*") (emphasis added).

understand the needs and interests of the child.²²³ As was demonstrated in *Phillip B.*, where parents are emotionally detached from their child, they may not be in a position to recognize the child's best interests.²²⁴

Parental discomfort with the child's intersex body, then, is at the heart of the parental conflict of interest. The parents' interest in a "normal"-appearing infant body may interfere with their ability to weigh the competing interests of the child in bodily integrity, avoidance of unnecessary surgery, and adult sexual capacity. Because the child's atypical body is at the center of the parents' potential conflict, it is particularly problematic to have the parents make the decision to alter the child's body. Where parental homophobia or transphobia are factors, the ability to consider the child's interest over a lifetime and to appreciate the real costs of surgery may be further limited.²²⁵ In any case, radical surgery on the child is not an appropriate way to treat parental discomfort or difficulty in attachment.²²⁶ A better strategy would involve treating the parents' psychological distress directly through counseling, while involving a more neutral decision-maker to determine whether surgery is in the child's best interests.

b. Genital-Normalizing Surgery Compromises Intersex Children's Fundamental Rights

When I was 12, my clitoris started to grow. . . . I knew that other girls probably weren't experiencing exactly the same changes in their bodies, but I experienced it as normal anyway. . . . I not only noticed its size growing more prominent, but I loved it. . . . I had this wonderful relationship with it. . . . I think of that time that I had . . . maybe six months before surgery—from the time that I noticed it and started to love it 'til the time that it was taken from

223. See *Parham v. J.R.*, 442 U.S. 584, 602 (1979) ("natural bonds of affection lead parents to act in the best interests of their children"); *Phillip B.*, 188 Cal. Rptr. 781, 792 (Ct. App. 1983) (citing parents' emotional detachment from child as factor in overriding their medical decision); Lareau, *supra* note 25, at 142-43 (suggesting that parents' emotional conflict following the birth of an intersex child hampers their ability to consider the child's best interests).

224. See *Phillip B.*, 188 Cal. Rptr. at 792; Ford, *supra* note 10, at 486-88 (questioning competence of parents to give consent to genital-normalizing surgery).

225. In the author's former work as a service provider for lesbian, gay, bisexual and transgender youth, she frequently encountered parents who had issued credible threats to kill their children if they turned out gay, or who actually threw their lesbian, gay, bisexual or transgender children out of the house to live in the street when they did come out. It is not difficult to imagine that such parents would consent to radical surgery if they thought it would ensure that their children were heterosexual and gender-normative, regardless of cost to the child.

226. Lareau, *supra* note 25, at 136-38; *But see* Hermer, *supra* note 22, at 230-35 (noting that data suggests that surgery often does not relieve parental discomfort or prevent parental abandonment, yet concluding that it may be in the best interest of some children to have surgery in order to secure the ongoing love and support of their parents).

me—. . . [as] this time in the pleasure garden before the fall. —Angela²²⁷

Parental authority to make medical decisions has limits when the decision impinges on the child's life or well-being, or otherwise compromises the child's fundamental rights.²²⁸ Genital-normalizing surgery potentially encroaches on the intersex child's fundamental rights in several ways.²²⁹ Any non-consensual surgery implicates the rights to liberty and bodily integrity.²³⁰ This in itself does not disqualify the parents from serving as decision-makers. However, the particular invasion of this medical intervention is extreme, potentially including major reshaping of genitals, removal of orgasmic tissue, clitorodectomy, and removal of gonads and other internal organs.²³¹ For some intersex infants this surgery also includes sterilization, a permanent denial of the fundamental right to procreation.²³² The extensive and permanent compromise of bodily integrity involved in genital-normalizing surgery should put it in a class with other cases where parental decision-making authority is not assured.²³³

Genital-normalizing surgery also impacts later sexual function. In many cases, it leads to inability to orgasm, difficulty in forming intimate relationships, and inability to function sexually as the person might have chosen without surgery.²³⁴ This harm arguably impairs exercise of the fundamental rights to privacy and liberty. The recent Supreme Court decision in *Lawrence v. Texas* indicates that sexual intimacy may be a constitutionally-protected right.²³⁵ The Court in *Lawrence* struck down a Texas criminal statute prohibiting same-sex sodomy because such a prohibition demeaned "conduct protected by the substantive guarantee of liberty."²³⁶ There is still much debate about what *Lawrence* ultimately means outside the realm of criminal law, but Professor Laurence Tribe argues convincingly that the opinion rested on an understanding that "the most private human conduct, sexual behavior" is deeply connected to

227. Interview in Hermaphrodites Speak!, *supra* note 20.

228. See discussion *supra* Section II.A.1. and *infra* Sec. III.

229. See Haas, *supra* note 74, at 55-61 (suggesting that genital-normalizing surgery on intersex infants implicates fundamental rights to bodily integrity, reproduction, and marriage).

230. *Parham v. J.R.*, 442 U.S. 584, 600 (1979) ("It is not disputed that a child, in common with adults, has a substantial liberty interest in not being confined unnecessarily for medical treatment."); *Winston v. Lee*, 470 U.S. 753, 761 (1985) (holding bodily integrity would be violated by compelling a criminal defendant to submit to surgery in order to retrieve evidence); *Union Pac. R.R. Co. v. Botsford*, 141 U.S. 250, 251-52 (1891) (holding that the court could not subject plaintiff to an inspection by a surgeon without her consent and before a trial).

231. Ehrenreich, *supra* note 54, at 105-14.

232. See, e.g., *Skinner v. Oklahoma*, 316 U.S. 535 (1942).

233. See discussion *infra* Section III.

234. *Ambivalent Medicine*, *supra* note 36; Ford, *supra* note 10, at 483-85; Hermer, *supra* note 22, at n.142.

235. 539 U.S. 558, 577-78 (2003); see also Laurence H. Tribe, *Lawrence v. Texas: The "Fundamental Right" That Dare Not Speak Its Name*, 117 HARV. L. REV. 1893 (2004). But see Lofton v. Dep't of Children and Family Servs., 358 F.3d 804, 815-17 (11th Cir. 2004) (disputing that *Lawrence* established private sexual intimacy as a fundamental right).

236. 539 U.S. at 575.

human dignity.²³⁷ The Court was not “attaching rights to . . . [particular acts or] configurations of body parts.”²³⁸ Rather, it was “protecting the right of adults to define for themselves the borders and contents of deeply personal human relationships.”²³⁹ Under such an interpretation of *Lawrence*, because genital-normalizing surgery in childhood impairs the later adult capacity for sexual intimacy, it implicates privacy and liberty interests. It is not clear that parents have the right or the legal capacity to make this kind of decision for their child.

Additionally, by literally inscribing the assigned gender on the child’s body, genital-normalizing surgery on infants may implicate other privacy concerns.²⁴⁰ While courts have so far been unwilling to recognize a right for non-intersex people to live in their gender of choice,²⁴¹ this does not foreclose the possibility that a child whose sex is indeterminate has the right to avoid surgical enforcement of the gender selected by doctors and parents.²⁴² As the *Lawrence* Court said, in tracing the historical development of the right of privacy:

[T]hese matters, involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment. At the heart of liberty is the right to define one’s own concept of existence, of meaning, of the universe, and of the mystery of human life.²⁴³

This expansive language was taken from *Planned Parenthood of Southeastern Pennsylvania v. Casey*, and extended the realm of privacy rights from abortion to include same-sex sexual intimacy.²⁴⁴ It arguably encompasses the situation of intersex people, who are declaring the right of intersex children to control their own destiny in this most intimate and personal of areas. As Professor Tribe points out in his analysis of both *Lawrence* and *Casey*, the fundamental right at issue is not in the act (sodomy or abortion), but in the allocation of decision-making power; human dignity resides in the ability to

237. Tribe, *supra* note 235, at 1949 (quoting 539 U.S. at 567).

238. *Id.*

239. *Id.*

240. It is important to distinguish gender *assignment*—the reversible selection of a gender in which to rear the child—from genital-normalizing surgery—the permanent surgical “confirmation” of that gender. Most of those who favor postponing surgery still advise assigning the child a gender of rearing, but letting him or her make the decision about surgery at an appropriate age. See, e.g., Chase, *Intersex Agenda*, *supra* note 22; *DSD Guidelines*, *supra* note 44, at 18; many also recommend preparing for the possibility that the child may later choose a different gender. Hendricks, *supra* note 55.

241. While transgender people are generally no longer forbidden from living in their self-identified gender, most courts refuse to recognize any positive right for them to be free from gender-based harassment or discrimination, and many courts will not recognize a right to marry in their identified gender. See generally Abby Lloyd, *Defining the Human: Are Transgender People Strangers to the Law?*, 20 BERKELEY J. GENDER, L. & JUST. 150 (2005).

242. Such recognition could also be a stepping-stone to recognizing the right of adult transgender people to live in their self-identified gender free of discrimination.

243. 539 U.S. at 574 (quoting *Planned Parenthood of Southeastern Pa. v. Casey*, 505 U.S. 833, 851 (1992)).

244. *Id.*

choose for oneself in these deeply personal areas.²⁴⁵ Such a concept of privacy could well extend to a right for a person to determine for herself whether to undergo radical genital surgery, with all of its implications.²⁴⁶

The serious and far-reaching effects of early genital-normalizing surgery on the intersex person's exercise of fundamental rights are sufficient to raise the issue of whether the child's interests in liberty, privacy, and bodily integrity might outweigh the parents' interest in being the decision-maker.²⁴⁷ The exceptional nature of this decision—an extreme and medically unnecessary procedure, with uncertain outcome and conflicts of interest for the caregivers—weighs against applying the usual parent-doctor decision-making presumption to this decision.

III. CATEGORICAL EXCEPTIONS TO THE RULE OF PARENT-DOCTOR DECISION-MAKING: A MODEL FOR THE SPECIAL SITUATION

Fortunately, a mechanism already exists in our legal system to address such difficult situations. The law recognizes that there are times when additional oversight is necessary to protect the interests of vulnerable children.²⁴⁸ Courts and legislatures have, in a few cases, carved out categorical exceptions to the usual process of parent-doctor decision-making.²⁴⁹ These categorical exceptions represent judicial and/or legislative recognition that certain *types* of medical decisions are not appropriate for the general parent-doctor decision-making model. They provide alternative models for judicial involvement to ensure that the child's rights are protected.²⁵⁰ The categorical exception model provides a useful framework for improving the way decisions are made on behalf of intersex children.

This Section will explore two such exceptions: children who are potential organ donors and (usually mentally ill or developmentally disabled) children whose parents want to have them sterilized. Lastly, an examination of the justifications used for removing these cases from the normal decision-making process will look at the key factors that make it necessary to remove an entire category of decision from the exclusive control of parents and doctors. It will also outline the processes used to ensure protection of the child's rights.

245. Tribe, *supra* note 235, at 1914-31.

246. In addressing this situation, the Colombian court held that "intersexed people [in Colombia] constitute a minority entitled to protection by the State against discrimination" and that genital-normalizing surgery "may . . . be a violation of autonomy and bodily integrity, motivated by parents' intolerance of their own children's sexual difference." Greenberg & Chase, *Colombia*, *supra* note 23.

247. See, e.g., *Prince v. Massachusetts*, 321 U.S. 158, 170 (1944) ("Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.").

248. Rosato, *supra* note 151, at 35-65.

249. *Id.*

250. *Id.*

A. Children as Organ Donors

Courts are routinely involved in decisions about whether a child or incompetent adult may serve as an organ donor.²⁵¹ Courts became involved when doctors, fearful of liability for performing such invasive procedures on healthy children, began to demand a court order before proceeding in these cases.²⁵² Once faced with the issue, most courts have held that parental consent is not enough to authorize such a procedure—judicial approval is also necessary.²⁵³ There are two rationales for displacing parents as decision-makers in such a case. The first is that the parent may have a conflict of interest: the donee is likely to be a family member in dire need of the organ, making it extremely difficult for the parents to consider independently the donor child's interest.²⁵⁴ Therefore, the parents' decision requires court approval of their "motivation and reasoning" and an independent assessment of the donor's interests.²⁵⁵

The second rationale for court oversight is that extra caution is needed when a parent wants to consent to a medical procedure that offers no medical benefit to the child.²⁵⁶ For example, in *Little v. Little*, a Texas appellate court found that the mother of a 14-year-old mentally incompetent girl could not authorize surgical removal of her daughter's kidney for transplant into the girl's brother absent court approval.²⁵⁷ This holding turned largely on the court's determination that a parent/guardian's power only extended to authorization of "medical treatment," defined as "the steps taken to effect the cure of an injury or disease."²⁵⁸ Kidney donation could not be considered "medical treatment," because it would not improve the physical health of the donor.²⁵⁹ While the court acknowledged evidence that the donor child would reap psychological benefits from donation, this evidence was not a factor when determining whether the surgery could be considered "medical treatment" for which parental consent was sufficient authorization.²⁶⁰

Once involved in the medical decision, courts generally undertake an assessment of the effects of the proposed surgery on the donor child. The precise

251. *Id.* at 57-58; Samuel J. Tilden, *Ethical and Legal Aspects of Using an Identical Twin as a Skin Transplant Donor for a Severely Burned Minor*, 31 AM. J.L. & MED. 87, 98 (2005).

252. Rachel M. Dufault, *Bone Marrow Donations by Children: Rethinking the Legal Framework in Light of Curran v. Bosze*, 24 CONN. L. REV. 211, 220 (1991).

253. *Id.* Hart v. Brown, 289 A.2d 386, 391 (Conn. Super. Ct. 1972) ("[N]atural parents of a minor should have the right to give their consent to an isograft kidney transplantation procedure when their motivation and reasoning are favorably reviewed by a community representation which includes a court of equity.").

254. Rosato, *supra* note 151, at 57.

255. *See, e.g.*, Hart, 289 A.2d at 391.

256. Rosato, *supra* note 151, at 57.

257. *Little v. Little*, 576 S.W.2d 493, 495 (Tex. Civ. App. 1979).

258. *Id.*, citing BLACK'S LAW DICTIONARY 1673 (rev. 4th ed. 1968).

259. *Id.*

260. *Id.* at 495, 498-99.

standard applied varies among jurisdictions,²⁶¹ but in general, “the key inquiry [is] the presence or absence of a benefit to the potential donor.”²⁶² In order for a child to serve as an organ donor, then, there must be an affirmative showing that there is some other benefit *to the donor child* that outweighs the medical risk and harm.²⁶³

This benefit can be shown through the presence of a close personal relationship to the proposed donee.²⁶⁴ For example, the *Little* court found that the prospective donor child had a strong sibling relationship with the donee, her younger brother.²⁶⁵ The evidence in this case conclusively established that the harm to the donor from losing a beloved sibling would outweigh the harm of losing a kidney.²⁶⁶ On this basis, the court approved the surgery.²⁶⁷

Courts have been less willing to allow parents to consent to organ donation in cases where the donor child’s relationship to the donee is less strong, and the benefits to the donor child are therefore not as compelling. In *Curran v. Bosze*, a court declined to order 3-1/2 year-old twins to undergo tests necessary for a bone marrow transplant to their half-brother, even though these tests carried little risk of long-term harm.²⁶⁸ A major factor in the court’s holding was that the twins had not established a “traditional sibling relationship” with their half-brother, whom they had never met, and that this fact significantly reduced the potential for the twins to benefit from the transplant.²⁶⁹

Again, the precise process courts have used to make these determinations varies, but the process approved by the *Little* court is representative.²⁷⁰ Important elements of this process include: parental consent to the procedure, expert medical and psychological testimony about the effects of surgery, evidence of the likelihood of success of the procedure, and evidence of the unavailability of other practical options.²⁷¹ The *Little* court also made a particular point of the importance of appointing an attorney *ad litem* who “assumed an adversarial role, asserting the child’s interest in not being a donor and vigorously questioning the power of the court to authorize the operation” in order to ensure that all sides of the issues would be heard.²⁷²

261. See Dufault, *supra* note 252, for a discussion of the various standards applied.

262. *Curran v. Bosze*, 566 N.E.2d 1319, 1331 (1990).

263. See, e.g., *Little*, 576 S.W. 2d at 499-500 (discussing the psychological benefits of donation to the donor child).

264. See, e.g., *Curran*, 566 N.E.2d at 1335-36 (discussing the lack of a close personal relationship with the donor children and the donee).

265. *Little*, 576 S.W.2d at 498.

266. *Id.* at 498-99 (considering both short-term suffering and long-term risk from the operation, and weighing these against expert testimony on the psychological benefits of donation).

267. *Id.* at 500.

268. 566 N.E.2d at 1335-38.

269. *Id.* at 1336.

270. See, e.g., *In re Guardianship of Pescinski*, 226 N.W.2d 180, (1975); Hart, 289 A.2d at 391.

271. *Little*, 576 S.W. 2d at 499.

272. *Id.*

B. Sterilization of Children and Mentally Handicapped People

Three generations of imbeciles are enough.²⁷³ —Justice Oliver Wendell Holmes in *Buck v. Bell* (declaring the constitutionality of a law allowing sterilization of mentally handicapped people for eugenic purposes)

The judiciary will always bear with it the legacy of branding entire classes of human beings as Untermenschen, whose bodies are for the disposition at the whim of others.²⁷⁴ —Hon. Keith A. Pesto (lamenting the decision in *Buck v. Bell*)

For many decades, scientific and popular theories of eugenics justified the sterilization of tens of thousands of mentally ill and developmentally disabled people.²⁷⁵ Justice Holmes's infamous quote in *Buck v. Bell* established judicial approval of this practice.²⁷⁶ Eventually, the practice fell out of favor. While *Buck v. Bell* was never explicitly overruled, many state courts now recognize procreative choice as a fundamental right.²⁷⁷ In most jurisdictions, legislatures or courts have ruled that parents and guardians may no longer authorize the sterilization of children or wards in their care without judicial approval.²⁷⁸ This situation arises most commonly with wards, either adults or minors, who are mentally ill or developmentally disabled.

The rationale for removing this decision from the parents is two-fold. First, it is based on the notion that procreation is a fundamental right that is irreversibly lost through sterilization.²⁷⁹ Second, it grows out of a concern that parents of a candidate for involuntary sterilization may have a conflict of interest: much of the burden of an unwanted pregnancy would fall on them, and desire to avoid such a situation may interfere with their ability to consider the child's interests independently.²⁸⁰ In considering orders authorizing sterilization of a ward, courts are cognizant of the abusive history of the practice in the past.²⁸¹ For this reason, modern courts are especially cautious in considering

273. *Buck v. Bell*, 274 U.S. 200, 207 (1927) (Holmes, C.J.) (declaring the constitutionality of a law allowing sterilization of mentally handicapped people for eugenic purposes).

274. *Lake v. Arnold*, 1998 U.S. Dist. LEXIS 23053, *11 (W.D. Pa. 1998), *aff'd in part, vacated in part and remanded* 232 F.3d 360 (3d Cir. 2000).

275. Paul A. Lombardo, *Three Generations, No Imbeciles: New Light on Buck v. Bell*, 60 N.Y.U. L. REV. 30, 30-32 (1985).

276. *Id.* at 30-31.

277. Rosato, *supra* note 151, at 60; *see also* Skinner, 316 U.S. at 541.

278. *In re Moe*, 432 N.E.2d 712, 716-17 (Mass. 1982).

279. *In re Terwilliger*, 450 A.2d 1376, 1382 (Pa. Super. Ct. 1982). It is not clear why genital-normalizing surgery that results in sterilization of intersex infants has not already triggered the kind of judicial review that is routine for other non-necessary sterilizations of children or mentally incompetent people.

280. *Id.* at 1385.

281. *In re Moe*, 432 N.E.2d at 716-17; Lake, 1998 U.S. Dist. LEXIS at *11; Rosato, *supra* note 151, at 59.

orders to authorize sterilization.²⁸²

As with organ donation by children, courts adamantly require strong affirmative evidence of a benefit *to the child* that outweighs the harm or risk of sterilization. Without such evidence, they will not issue a court order for the procedure.²⁸³ As one leading case held, “[n]o sterilization is to be compelled on the basis of any State or parental interest.”²⁸⁴ Because of the potential for abuse in this area, the standards protecting the ward’s interest are particularly rigorous.²⁸⁵ Complex tests are required in most districts to ensure that sterilization is truly in the best interest of the ward.²⁸⁶

For example, in *In re Moe*, the parents of a mentally handicapped woman petitioned the court for an order permitting sterilization.²⁸⁷ The parents alleged that she had a mental age of about four, that she had been sexually active, and that she was unable to either practice any alternative form of birth control or care properly for a child.²⁸⁸ The appellate court ruled that this rudimentary justification was not enough; in order to ensure that the fundamental rights of the ward were adequately protected, a much more searching inquiry was necessary before granting such a petition.²⁸⁹ The court laid out an extensive procedure for making this determination.²⁹⁰ Salient requirements of the process included: *only* the interests of the ward should be considered; the court must assure an adversarial process by appointing an attorney for the ward to vigorously oppose the procedure; and the court must consider the workability of less intrusive measures, the medical necessity, risks and benefits of the procedure, and the possibility of future competence of the ward.²⁹¹

C. Summary of Key Factors for a Categorical Exception

While the legal doctrines surrounding organ donation by children and sterilization of mentally incompetent people seem to have developed independently of each other, the decision-making schemes employed in the two situations are remarkably similar. In both kinds of cases, common features of the process include: 1) a clear affirmative showing of a benefit to the child that outweighs the risks; 2) evidence that the proposed procedure is the least intrusive

282. Rosato, *supra* note 151, at 59-60.

283. See, e.g., *In re Terwilliger*, 450 A.2d at 1382.

284. *In re Moe*, 432 N.E.2d at 721.

285. Rosato, *supra* note 151, at 59-60.

286. See, e.g., *In re Terwilliger*, 450 A.2d 1376; *In re Grady*, 426 A.2d 467 (N.J. 1981); *In re A.W.*, 637 P.2d 366 (Colo. 1981).

287. 432 N.E.2d at 715.

288. *Id.* at 716 n.1.

289. *Id.* at 720-22.

290. *Id.* at 721-22.

291. *Id.* at 720-22. Some courts are particularly hesitant to allow a parent to consent to sterilization on the child’s behalf where there is a possibility that the child may become competent to make the decision for him/herself in the future. *In re Terwilliger*, 450 A.2d at 1383.

option to achieve that benefit; 3) refusal by the court to consider the interests of other parties in the procedure; and 4) appointment of an *ad litem* representative for the child who must vigorously oppose the procedure.²⁹² The similarities in these judicial processes reflect the similarities in the substantive factors that remove these decisions from the usual process in the first place: 1) an absence of demonstrable medical benefit; 2) significant potential for parental conflict of interest; and 3) impairment of the child's fundamental rights.²⁹³ These same substantive factors exist in the case of genital-normalizing surgery on children, suggesting that the existing categorical exceptions may be useful models to ensure the protection of intersex children's interests.

IV. THE CATEGORICAL EXCEPTION AS A POTENTIAL TOOL TO IMPROVE DECISION-MAKING ON BEHALF OF INTERSEX INFANTS

In my medical records the surgeon who performed the clitorrectomy on me finished his summary of the procedure by saying that after the surgery the patient had "a relatively normal genitalia." He did not bother to qualify his statement with "normal looking;" he said "normal." Of course my clitoris was less normal than before because it no longer existed. . . . The belief that early surgery fixes the problems of intersexed people is wrong. It only makes the problem disappear in the eyes of the parents and the doctors and shifts the entire burden onto the child. —Joan Whelan²⁹⁴

Because genital-normalizing surgery is medically unnecessary and carries real risks of parental conflict of interest, courts should have jurisdiction to intervene and protect the fundamental rights of the infant in the same way they do for children who are potential organ donors or who face elective sterilization. Where there are strong indications that parental instincts and medical judgment are not sufficient to protect the interest of the child, we can look to the existing categorical exceptions for a model of decision-making that ensures independent consideration of the child's interests. In this Section, I will explore the factors that make genital-normalizing surgeries an appropriate case for a categorical exception, address possible objections to the use of this model, consider possible benefits of the model, and outline a test to frame the considerations particular to the decision about genital-normalizing surgery. Finally, I will consider how such an exception might come about.

A. Genital-Normalizing Surgeries in Childhood fit the Criteria for a

292. See discussion *infra* Section IV. A. and B.

293. For an argument that the categorical exceptions should be extended to include many such medical decisions for children where parents face a conflict of interest, see Rosato, *supra* note 151, at 35-65.

294. Joan Whelan, Address at the Robert Wood Johnson Medical School Intersex Panel for Sex Week (Jan. 2002) (transcript available at <http://www.isna.org/articles/whelan2002>).

Categorical Exception

It's horribly unfair that one's sexual feelings, one's ability to be able to feel like you can couple in an intimate way with another human being is literally destroyed by some doctor's idea of how genitals are supposed to look. — Howard Devore, Ph.D.²⁹⁵

Genital-normalizing surgery on infants implicates three of the major factors underlying the requirement of judicial oversight for parental consent to organ donation by or sterilization of a child: 1) there is no demonstrated or expected medical benefit to the procedure;²⁹⁶ 2) there is the potential for parental conflict of interest;²⁹⁷ and 3) genital-normalizing surgeries can infringe on fundamental rights of the child, namely those of bodily integrity, privacy, and sometimes reproduction.²⁹⁸

1. Lack of Medical Benefit

There is no medical benefit to genital-normalizing surgeries because intersex conditions generally pose no danger to life or health.²⁹⁹ The surgeries are primarily intended to be cosmetic, not to improve function.³⁰⁰ In fact, genital-normalizing surgeries often have short- and long-term negative effects on function, leading to complications such as scarring, pain, difficulty in urination, impaired sexual function, and inability to orgasm.³⁰¹ Repeated follow-up surgeries to manage these complications frequently follow.³⁰² As noted above in Section I.C.2., there is no clear evidence of psychological benefit—indeed, there is quite a bit of anecdotal evidence of psychological *harm* resulting from the concealment model.³⁰³

295. XXXY, *supra* note 64 (quoted in HRC REPORT, *supra* note 20, at 46).

296. Ford, *supra* note 10, at 476; *Ambivalent Medicine?* *supra* note 36. *DSD Guidelines*, *supra* note 44, at 20.

297. See discussion *infra* Section III.C.2.a; see also Lareau, *supra* note 25, at 142-45; Haas, *supra* note 74, at 55-60.

298. See discussion *infra* Section III.C.2.b; see also Haas, *supra* note 74, at 55-61.

299. As noted *supra* note 44, there are rare cases when physical harm will result without surgery. In such cases, either the doctrine of emergency consent or a showing of benefit to the child in court should suffice to protect the child's interest in having genital surgery as necessary to preserve life or health. See Ford, *supra* note 10, at 476, n.56.

300. Beh & Diamond, *supra* note 4, at 19-21; Ford, *supra* note 10, at 477.

301. *Ambivalent Medicine*, *supra* note 36; Creighton, *supra* note 24; Ford, *supra* note 10, at 483-85; Hermer, *supra* note 22, at 219 n.142.

302. Creighton, *supra* note 24; Migeon, *supra* note 74, at 2.

303. See, e.g., *Ambivalent Medicine*, *supra* note 36; Hermer, *supra* note 22, at 212-14 (summarizing research suggesting a wide range of physical and psychological problems, as well as poor cosmetic outcomes, for a significant number of intersex patients); Martin, *supra* note 2, at 160-61 (summarizing anecdotal reports).

2. Parental Conflict of Interest

In the case of intersex children, the needs of the parent are so pressing that they may interfere with independent evaluation of the child's best interest, and skew the decision to proceed with surgery.³⁰⁴ Genital-normalizing surgery offers the promise of relieving the parents' discomfort at having a child whose body does not conform to cultural standards of binary gender.³⁰⁵ Parents are further conflicted by shock at the unexpected news,³⁰⁶ pressure from care providers to consent to surgery,³⁰⁷ embarrassment at the prospect of telling friends and family about the baby's intersexuality,³⁰⁸ and the desire to bring a quick end to the resulting tension.³⁰⁹ Taken together, these conflicts are sufficient to throw doubt on the authority of the parents as decision-makers.³¹⁰

3. Protecting Fundamental Rights of the Child

Like organ donation, genital-normalizing surgery is an unnecessary invasion of bodily integrity that may result in more harm than benefit for the child.³¹¹ As with sterilization, genital-normalizing surgery implicates fundamental rights, including the right to procreate, and might be better postponed until the child can make his/her own decision.³¹² In such a situation, requiring parents who desire medical intervention to make a strong showing in court that the benefits of the treatment outweigh the drawbacks is a reasonable

304. Lareau, *supra* note 25, at 142-43.

305. See Ehrenreich, *supra* note 54, at 117-20.

306. Lareau, *supra* note 25, at 142-43.

307. Ford, *supra* note 10, at 487.

308. See Hermer, *supra* note 22, at 234.

309. Lareau, *supra* note 25, at 142-43.

310. See Rosato, *supra* note 151, at 46-49 (discussing how such situational conflicts can disqualify family members as the appropriate decision-makers of health care decisions for their children). *But see* Hermer, *supra* note 22, at 234-35 (maintaining that parents are the best decision-makers in this case, and that the needs of parents and families should legitimately weigh in the decision); Aliabadi, *Parents Consent*, *supra* note 83, at 442 (suggesting that parents could more easily relieve such pressures by putting their intersex infant up for adoption, and that parents who do not do so have the best interests of their child at heart when choosing surgery).

311. See Haas, *supra* note 74, at 58-59 (arguing that genital reconstruction surgery may be the "ultimate infringement of an individual's bodily autonomy"); Ford, *supra* note 10, at 480-82 (analogizing intersex surgeries and organ donation by children).

312. See *Skinner v. Oklahoma ex rel. Williamson*, 316 U.S. 535, 541 (1942) *noting*:

Marriage and procreation are fundamental to the very existence and survival of the race. The power to sterilize, if exercised, may have subtle, far-reaching and devastating effects. In evil or reckless hands it can cause races or types which are inimical to the dominant group to wither and disappear. There is no redemption for the individual whom the law touches. Any experiment which the State conducts is to his irreparable injury. He is forever deprived of a basic liberty.

(emphasis added). This statement seems particularly applicable to the case of genital-normalizing surgery on intersex infants. See also Beh & Diamond, *supra* note 4, at 5 (chiding medical decision-makers for "fail[ing] to consider children's potential for future self-determination").

way to ensure protection of the fundamental rights of the child.³¹³

B. Addressing Objections to Creating a Categorical Exception

There are potential objections to creating a categorical exception to the rule of parental decision-making for genital-normalizing surgeries on children. Foremost of these objections is that it is unwise to override the parents' decision-making authority.³¹⁴ Putting medical decisions into the courtroom may arouse further resistance.³¹⁵ Furthermore, there is no assurance that a court's decision will be any better than the parents' or doctors' in such a difficult situation. While all of these objections merit serious deliberation, there are countervailing considerations that justify the categorical exception as a useful compromise.

1. Overriding Parents' Decision-Making Authority

For a court to usurp parental control requires careful balancing of the child's fundamental rights with those of the parents.³¹⁶ The United States has a long tradition of deference to parental authority, and parents' interest in the care and control of their children has been accorded constitutional status.³¹⁷ This interest extends to making medical decisions on behalf of the child.³¹⁸ However, as noted above, parental rights do not extend to the point of making decisions that are physically harmful to the child.³¹⁹

In fact, the parental role in medical decision-making is really a presumption that the parent is best situated to determine the best interest of the child—it is not a right to do as the parent wishes with the child's body.³²⁰ But this presumption is not conclusive, particularly where there is a conflict of interest.³²¹ The categorical exceptions exist to address such conflicts, allowing courts to step in and ensure independent consideration of the child's interest.³²²

In the case of intersex infants, one particular manifestation of a conflict of interest makes it especially appropriate to question parental deference—emotional alienation from the intersex infant. As the *Phillip B.* court noted, the absence of emotional connection to the child can undermine the presumption that

313. Beh & Diamond, *supra* note 4, at 40.

314. Aliabadi, *Parents Consent*, *supra* note 83, at 456 (arguing that parents are best positioned to make an individualized determination of best interest).

315. *Id.* at 454-56 (critiquing impersonal nature of judicial decision-making as compared to parental decisions).

316. *Troxel v. Granville*, 530 U.S. 57, 88 (2000) ("The parent's interests in a child must be balanced against the State's long-recognized interests as *parens patriae*.").

317. *Pierce v. Soc'y of Sisters*, 268 U.S. 510, 535 (1925). *See also* *Wisconsin v. Yoder*, 406 U.S. 205, 213 (1972); *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944); *Meyer v. Nebraska*, 262 U.S. 390, 400 (1923).

318. *Parham v. J.R.*, 442 U.S. 584, 602-604 (1979).

319. *See* *Guardianship of Phillip B.*, 188 Cal. Rptr. 781, 792 (Ct. App. 1983).

320. Rosato, *supra* note 151, at 5-9.

321. *Id.* at 57-60.

322. *Id.*

the parent is best situated to determine the child's best interest.³²³ But one of the main arguments advanced for early genital-normalizing surgery is that the parents will not be able to bond with the child without it.³²⁴ If the parents are completely alienated from the intersex child, as some doctors suggest they must be, then they lack the foundation for their presumed authority to determine the child's best interest. If the parents are not alienated, then one of the strongest arguments for doing surgery before the child can participate in the decision evaporates.

2. Putting Medical Decisions in the Courtroom

Many have argued that the courtroom is not the appropriate place to make difficult medical decisions.³²⁵ Intuitively, most people believe that families are the best decision-makers when individuals cannot decide for themselves, and that courts lack the intimate connection necessary to make such personal decisions.³²⁶ The broad social consensus is that families and doctors are generally better off making medical decisions for children without the involvement of courts.³²⁷ These factors underscore precisely why the exception model is an appropriate way to address the issue of surgery on intersex infants. It allows for special consideration of an extraordinary situation without undermining the role of parents and doctors in most medical decisions.³²⁸

The categorical exception, based on the existence of a serious conflict of interest in caregivers, has already been used successfully to allow courts to protect the interests of children in extraordinary situations.³²⁹ Using the categorical exception model for decisions about genital-normalizing surgeries on children would allow consideration of the individual child's situation, while still insulating the decision from considerations other than the child's best interest.

3. Litigation May Not Produce Better Decisions

Opponents of surgery will point out that there is no guarantee that judges will be better decision-makers than parents or doctors in every case. Judges carry biases and cultural conditioning just as doctors and parents do.³³⁰ The lack of definitive studies on the outcomes of surgery means that judges will face the same uncertainty that doctors and parents face in evaluating risks and benefits.

The primary advantage to the categorical exception model, though, is that

323. 188 Cal. Rptr. at 792.

324. Lareau, *supra* note 25, at 136-37; Hermer, *supra* note 22, at 230; Beh & Diamond, *supra* note 4, at 44-45.

325. Rosato, *supra* note 151, at 42.

326. *Id.* at 41-42.

327. *Id.* at 36-42.

328. *Id.* at 42.

329. *Id.* at 57-60.

330. *Id.* at 42.

it offers a rigorous structure for reasoning in an area where such logic is badly needed. As long as surgery remains an accepted standard of care, doctors may continue to recommend it, even as its theoretical basis is crumbling.³³¹ It will remain the standard of care as long as doctors recommend it.³³² This circular reasoning leaves little room for clear-headed analysis.³³³ Parents, meanwhile, are free to decide on surgery for any reason at all. The parental presumption does not require them to offer justification, and hence offers no safeguard against an emotionally-charged decision made under pressure.

In this situation, there is potential for disastrous outcomes for the parents as well as the child. Although the stakes are enormous, the quality of information is poor and the potential for conflict of interest is high.³³⁴ The judicial process offers a chance to evaluate the evidentiary quality of the advice parents receive and to independently consider the child's best interest. In this model, the court may only authorize surgery if proponents make an affirmative showing of benefit to the child, and then only after considering the arguments against surgery. The benefit of the categorical exception is not so much that it offers a better decision-maker as that it offers a better decision-making process.

C. Practical Benefits of Implementing the Categorical Exception Model

In addition to the benefits of a rational decision-making framework with independent representation of the child's interest, the categorical exception model offers practical benefits in implementation. It is an achievable improvement in a flawed decision-making process. While commentators have advanced compelling arguments for an outright end to surgery,³³⁵ and some have suggested a statutory ban,³³⁶ the societal consensus for such a ban has yet to emerge. It would take a great deal of political strength to end genital-normalizing surgery outright through the political process.³³⁷ The intersex community is gaining strength, but it is still relatively small and scattered,³³⁸ perhaps too much so to mount a successful legislative campaign at this time. A courtroom strategy, on the other hand, can be implemented without a large-scale organizing effort.

331. Beh & Diamond, *supra* note 4, at 28.

332. *Id.* at 31-32.

333. *Id.* at 30-31 (remarking that this framework actually works to reinforce poor standards of care).

334. *See id.* at 55 (noting that harms caused by surgery can do irreparable damage to the parent-child relationship); Ehrenreich, *supra* note 54, at 108-109 (describing depression and suicidal tendencies among intersex adults who have undergone surgery).

335. *See* Chase, *Intersex Agenda*, *supra* note 22; Ford, *supra* note 10, at 488 (concluding that there should be a moratorium on surgeries until there is clear evidence of benefit); Haas, *supra* note 74, at 67-68 (arguing that genital reconstruction surgery is still an experimental procedure and therefore a violation of the Nuremberg Code, which prohibits countries from conducting experimental medical treatment without the patient's express informed consent).

336. Ehrenreich, *supra* note 54, at 131-137 (detailing possible statutory schemes).

337. *See id.* at 132-33, 136.

338. *See, e.g.,* Vandertie, *supra* note 19.

Furthermore, a categorical exception may be more palatable to the general public because it is an individualized, best-interest determination rather than a sweeping restriction. Thus, there may be less resistance to such a strategy.

Moreover, the categorical exception may achieve the same outcome as a ban with a much smaller battle. The medical standard of care is beginning to change.³³⁹ A few court decisions against early surgery might give the trend the impetus it needs to overcome the medical field's inertia and become universal. Meanwhile, the strategy allows intersex children as a group to benefit from incrementally changing public opinion. As intersex activists continue to educate the public about the problems resulting from genital-normalizing surgery,³⁴⁰ increasing public sophistication about the issues can impact the courtroom process. Because each case will require a renewed inquiry into risks and benefits, intersex children will also benefit from increased knowledge about long-term effects of surgery as it accumulates.³⁴¹ While we wait for clear evidence and societal consensus to emerge, intersex children continue to be born. The categorical exception model offers the best chance to make good decisions for them in the absence of either proof that genital-normalizing surgery is beneficial or the political will to ban it outright.

D. Proposed Process for Judicial Oversight

Courts can model the process for making these decisions on the processes already developed for other categorical exceptions. Judicial consideration of a motion to authorize genital-normalizing surgery on an intersex infant or child should begin with appointment of an attorney or a guardian *ad litem* to represent the child's interests. As in the case of child sterilizations or organ donations, this representative should be charged with arguing vigorously against the proposed surgery in order to assure a meaningful adversarial process.³⁴² Similarly, the only consideration for the court should be the best interest of the child, and the

339. See Diamond & Sigmundson, *supra* note 68 (recommending guidelines for dealing with individuals with ambiguous genitalia); Phomphutkul, *supra* note 8 (discussing how accumulating long-term follow-up data has led them to modify their approach to gender assignment in patients with ambiguous genitalia); Hendricks, *supra* note 55 (discussing the modifications some doctors have made to their views of the proper treatment for intersex individuals).

340. See *Intersex History*, *supra* note 27.

341. See *DSD Guidelines*, *supra* note 44, at 28 (noting recent studies throwing doubt on surgical model). Of course, there is also the (increasingly remote) possibility that long-term studies will eventually clearly demonstrate a net benefit in most cases from early surgery. Such a showing would require a new analysis of parental competence to decide on surgery. *But see* Alice Dreger, *Intersex Treatment as Standard Medical Practice, or How Wrong I Was* (Oct. 1, 2004), <http://www.isna.org/articles/howwrongiwas> (suggesting that non-consensual genital surgery would still be unethical even if there was evidence showing statistical probability of benefit).

342. See *Little v. Little*, 576 S.W. 2d 493, 499 (Tex. Civ. App. 1979); *In re Moe*, 432 N.E.2d 712, 720-21 (Mass. 1982).

interests of parents or other parties should not weigh in the decision.³⁴³ Proponents of surgery should have to make an affirmative showing of benefit to the child that outweighs the risks and known harms in order for the court to authorize surgery.³⁴⁴ Factors for the court to consider could include:

- Short- and long-term physical risks and benefits.

The court should consider the pain and risk attendant to surgery, likelihood of complications, need for follow-up surgeries, potential for nerve damage, likelihood of future orgasmic capacity, effect on fertility, need for long-term hormone replacement in adulthood if gonads are removed, availability of any less-intrusive options (including counseling), and any physical benefits resulting from surgery such as improved urine flow.

- Short- and long-term psychological risks and benefits.

These would include the stress of surgery performed in infancy, as well as the stress of follow-up surgeries or of performing initial surgery later in childhood at the child's request. The court should also consider evidence of the psychological impact of increased need for medical examinations of the genitals with multiple surgeries, the social effects for the child of growing up with non-standard genitals, and the effects of surgical and non-surgical options on gender identity development. (It is important here to note that difficulty in parental bonding is a psychological problem of the *parent* that might not be appropriately treated through surgery on the child.³⁴⁵)

- Maximizing the child's future options.

The court should consider the effects of performing or delaying surgery if the child adopts the assigned gender and if the child later wishes to change gender. This inquiry should include how the decision will affect future surgical options if: 1) the child later wishes to live with an un-altered body; 2) the child later wishes surgical construction of standard male genitals; and/or 3) the child later wishes surgical construction of standard female genitals. Evidence might be available about the statistical likelihood of

343. See *In re Moe*, 432 N.E.2d at 721; *In re Terwilliger*, 450 A.2d 1376, 1382 (Pa. Super. Ct. 1982).

344. See *Little*, 576 S.W.2d at 499-500.

345. Lareau, *supra* note 25, at 136.

acceptance of the assigned gender given the child's particular medical condition.³⁴⁶ The court should also consider the effects on the child of puberty with and without the proposed surgeries, and the options that will exist at puberty for surgical and hormonal treatment. The court should also hear evidence of whether advances in fertility technologies might allow a patient now considered infertile to contribute to procreation in the future.³⁴⁷

- The quality of the evidence offered.

In an area so fraught with uncertainty, the court should pay particular attention to the quality of the evidence. Considerations here would include the size, relevance³⁴⁸ and length of follow-up of any offered studies; the qualifications of any expert witnesses; and the certainty or uncertainty of any predictions.

- The child's input.

If the child is old enough to voice an opinion, the court should consider the child's desires, the child's asserted gender, and the child's capacity to appreciate the implications of the current decision. If the child is not old enough to voice an opinion, the court should consider the possibility of future capacity to decide.

It will also be necessary to define just when these decisions will require court approval. Because there are several different medical conditions that might be categorized as intersex,³⁵³ and many possible combinations of genital-

346. See, e.g., Diamond & Sigmundson, *supra* note 68.

347. *DSD Guidelines*, *supra* note 44, at 29.

348. For example, a study that asks whether intersex adults are happy with their *gender assignment* does not necessarily have implications for whether they are happy with the results of *genital surgery*. See, e.g., Migeon, *supra* note 74 (finding over two-thirds of participating intersex patients to be satisfied with their gender assignment, without exploring whether these patients benefited from genital surgery).

353. See, e.g., Ehrenreich, *supra* note 54, at 98-101 (describing different intersex conditions, including androgen insensitivity syndrome, 5-Alpha-Reductase Deficiency, congenital adrenal hyperplasia, Klinefelter syndrome, and hypospadias).

normalizing surgical procedures,³⁵⁴ an attempt at listing procedures or conditions by name risks being under-inclusive. A narrow definition that would still protect the fundamental rights of children born with non-typical sex characteristics would require judicial approval of any surgery not necessary for physical health that will alter the appearance or function of a child's genitals or result in sterilization of a child or removal of a child's gonads or reproductive organs.

E. Getting In the Courtroom Door

In order to establish a categorical exception for genital-normalizing surgery, opponents of surgery will have to find a way through the courtroom door. An inquiry such as the one outlined above can only happen when someone with standing raises the issue in court. Generally, when parents approve a doctor's recommended course of treatment and the child is too young to voice an opinion, there is no call for judicial involvement in the first place. In cases of genital-normalizing surgery, however, there may be several ways for a court to find jurisdiction.

One way to ensure the issue is raised in court would be to enact a statute requiring judicial approval of genital-normalizing surgeries on children. This is how the exception for sterilization of mentally disabled wards was established in many states.³⁵⁵ While a statute would be effective, it could take a long time for the intersex community and other allies to this cause to accumulate the necessary political muscle.³⁵⁶ Two additional difficulties with enacting a statute could be the difficulty in getting legislative support for such a complicated issue that affects such a small population, and reluctance to legislate medical decisions. Hence, this approach would be a poor use of intersex activists' limited resources.

It seems more likely that doctors themselves will bring this question to court. Many states established the categorical exceptions for sterilization and for organ donation via such a path.³⁵⁷ Doctors, recognizing the legal risk of performing these operations with only parental authorization and fearing later

354. See, e.g., *id.* at 101-10 (noting various procedures, including clitoroplasty, removal of penis, hypospadias repair, vaginoplasty, castration, clitorodectomy, clitoral recession, clitoral reduction, and follow-up surgeries).

355. Rosato, *supra* note 151, at 45-46.

356. See Ehrenreich, *supra* note 54, at 132, 136 (noting practical difficulty of passing anti-surgery statute over objections of the medical profession). A few commentators have suggested that intersex children could be brought under the protection of 18 U.S.C. § 116 (2000), the federal statute banning female genital mutilation. See, e.g., Haas, *supra* note 74, at 64-66. There are several political and practical problems with this strategy. These include the fact that the statute's language seems to exclude some, and arguably all, genital-normalizing surgeries on intersex infants. Ehrenreich, *supra* note 54, at n.322. Another problem is that it is a criminal statute—it seems unlikely that the public would approve criminal sanctions on the doctors who perform these surgeries. *Id.* at 132-33 (Notwithstanding the American public's willingness to apply criminal sanctions to practitioners who cut non-intersex female babies' genitals in order to align their bodies with *their* families' cultural norms). A civil strategy seems more promising.

357. Dufault, *supra* note 252, at 220; Rosato, *supra* note 151, at 57.

lawsuits from dissatisfied patients, insisted on declaratory judgments before operating.³⁵⁸ Similarly, this process is how the question of genital-normalizing surgery got to court in Colombia.³⁵⁹ In a 1995 lawsuit, a young man, who had undergone sex reassignment in infancy after traumatic loss of his penis, prevailed in his claim that his parents' consent to the operation was invalid.³⁶⁰ Subsequently, surgeons in that country continued to recommend the surgeries but refused to perform them without a court order, leading to the two cases in 1999 that resulted in raising the standard for informed consent for genital-normalizing surgery.³⁶¹ If doctors in the United States become concerned that parental authorization will not be enough to protect them from later suits by their intersex patients, they may decide to start bringing such defensive actions before performing genital-normalizing surgeries.

This is a plausible scenario; the likelihood is increasing that a lawsuit by an intersex person dissatisfied with the long-term results of surgery could succeed. Thus far, doctors and intersex patients alike in the United States have believed that later malpractice suits were unlikely for several reasons: the surgeries have been in accordance with the existing standards of care,³⁶² the parents gave informed consent that seemed adequate,³⁶³ and the statute of limitations had generally run by the time the intersex patients reached adulthood and recognized their loss.³⁶⁴ The ground is shifting, however. Many providers now consider postponing surgery to be a preferred option, and the critiques of genital-normalizing surgery have been widely publicized.³⁶⁵ Doctors who do not inform parents adequately of the risks of and alternatives to surgery may be subject to suit.³⁶⁶ As the procedures are increasingly challenged in the public arena and the medical literature, and anecdotal accounts of negative outcomes reach the national stage,³⁶⁷ it becomes increasingly unclear what risks doctors must disclose to meet the standard for informed consent.³⁶⁸ Those who fail to disclose

358. See, e.g., *In re Moe*, 432 N.E.2d at 716.

359. Greenberg & Chase, *Colombia*, *supra* note 23.

360. *Id.*

361. *Id.* See also *supra* note 209 and accompanying text.

362. See Ehrenreich, *supra* note 54, at 135.

363. See *id.*

364. J. Barad, *Can You Sue Your Doctors?*, HERMAPHRODITES WITH ATTITUDE (Intersex Society of North America, Rohnert Park, Cal.), Spring 1995, at 4, available at <http://www.isna.org/files/hwa/spring1995.pdf> (legal opinion letter to ISNA member, reprinted for general information, advising against suit).

365. *DSD Guidelines*, *supra* note 44, at 28. See also *Intersex History*, *supra* note 27.

366. Martin, *supra* note 2, at 151-52 ("[The] standards are rapidly changing in the treatment of the intersexed. Physicians dealing with the intersexed need to be aware of these changes to avoid a breach of duty to their patients.").

367. See, e.g., *Intersex Babies: Controversy Over Operating to Change Ambiguous Genitalia* (ABC News Television Broadcast, Apr. 19, 2002); Navarro, *supra* note 67.

368. Martin, *supra* note 2, at 145-51 (suggesting that current practice does not meet standard for informed consent); see also Beh & Diamond, *supra* note 4, at 42-58; Ford, *supra* note 10, at 488; Haas, *supra* note 74, at 61-64; Hermer, *supra* note 22, at 231-35.

enough may find themselves losing lawsuits years from now.³⁶⁹ As hospitals and surgeons begin to recognize the increasing risk of successful suit by former patients,³⁷⁰ they may take the initiative to push for court orders before undertaking genital-normalizing surgery.

A final way the issue could arise in court is through action by a state agency. The question of genital-normalizing surgery can arise for children in state custody due to parental death, abandonment, or termination of parental rights. Because balancing parental rights would not be an issue in this type of scenario, it might be easier to focus objectively on the child's interests. As awareness of this issue grows, it is possible that a state agency having custody of an intersex child could look for a judicial ruling on the best interests of the child in regard to genital-normalizing surgery. Such a case could set precedent that would be relevant for other intersex children by establishing the categorical exception or by acknowledging the impact of surgery on the child's exercise of fundamental rights to bodily integrity, privacy, and procreation.

V. CONCLUSION

The story of genital-normalizing surgery is one of both hubris and of best intentions going awry, with tragic results for many intersex people. When we consider the flawed theoretical basis of the surgeries, the inadequate basis of knowledge about the impacts of surgery, the life-altering negative impact reported by many intersex adults, and the incredible pressure that parents may feel to agree to surgery, it is clear that intersex children need and deserve a more careful decision-making process. The categorical exception model provides a protective and proven structure for making difficult medical decisions affecting the fundamental rights of children when their parents face a conflict of interest. This model could help insure that intersex children's fundamental rights are protected until they have the ability to decide for themselves.

To encounter the stories of the individuals who make up the intersex rights movement is a touching and humbling experience. Many intersex people have experienced enormous personal tragedies at the hands of their doctors and with the consent of their parents. They would be justified in calling for revenge or restitution. Yet the rhetoric of the intersex movement rings with compassion—

369. See Martin, *supra* note 2, at 151-52.

370. At least one appellate-level case addressing sterilization further suggests that when a child's fundamental rights are violated, the fact that the violation was part of the standard of care at the time and that the parents authorized it are no bar to later recovery. *Lake v. Arnold*, 1998 U.S. Dist. LEXIS 23053 (W.D. Pa. 1998) (holding that a mentally handicapped woman stated a claim for conspiracy to violate her fundamental rights when she had been sterilized with her guardian's consent prior to any holding that such sterilization was unconstitutional). This case also found that parents who authorized such a violation could not be expected to press the child's cause of action afterwards, therefore effectively tolling the statute of limitations. *Id.* See also Martin, *supra* note 2, at 162-63 (suggesting that suit could be brought in the United States in the near future); Haas, *supra* note 74, at 57 (describing possibilities for potential lawsuits).

for each other, for their parents, and even for doctors. Those who have escaped surgical intervention might understandably choose not to step forward and call attention to themselves. Yet many intersex people have come forward, demonstrating a sense of their responsibility as members of the human community to protect helpless infants from future tragedies. Thus far, the law has failed intersex infants, but aided by such vision and leadership, surely it can rise to this challenge.

* * * * *

But we cannot be made to fit in! That's the whole point! We are who we are and no amount of surgery and hormones and even conditioning (to the point of brainwashing) can change that. Though I have tried for decades to fit a gender role (with the 'aid' of surgery and hormones), I still cannot feel comfortable with it. Finally I am forced to face the truth, my truth, which is this: I am who I am, no more and no less and I am not who I am not. I cannot be altered in such a fundamental way as gender. —David³⁷¹

371. David, *I am not alone!*, *supra* note 150, at 4-5.