DAVID REIMER'S LEGACY: LIMITING PARENTAL DISCRETION

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I. INTRODUCTION

In this essay, the authors examine parental decision-making and challenge parental authority to consent to infant surgery to "normalize" ambiguous genitalia of intersexed infants. The authors contend that consent to sex assignment and genital normalizing surgery in particular exceeds parental authority because it unnecessarily forecloses the child's right to an open future. Moreover, conflicted by their own anxieties, guilt, shame, or repugnance, parents may not be able to act solely in their child's best interest. Making matters worse, the lack of adequate long-term follow-up studies as well as clinical experience suggests that parents often decide with incomplete information about surgical outcomes and the psychosocial adjustment of intersex individuals who have not had surgery. This article is not intended as criticism of parents for past decisions, but rather to encourage parents now making medical decisions not to yield to unwarranted fears about their child's future. The increasing activism of the intersex community, the extraordinary resources available on the internet, and a growing body of evidence suggests that genitalia are of little consequence to gender identity, and this knowledge should empower parents to resist what has been characterized as a "monster approach" to treating ambiguous genitalia. The law has a role to play in diffusing the terror, and in supporting parents who are faced with the prospect of raising children with genitalia that fall outside of the "normal" standards, the narrow limits of which are imposed and perpetuated by intolerance.

Accounts from parents of children with ambiguous genitalia reported in recent news articles about intersex surgery illustrate the nature of their concerns regarding their children's future:

My problem is the adolescent period . . . . Growing up a teenage girl is hard enough. I never want her to feel different. I never want her to have extra
issues to deal with . . . . When she’s a teenager, and she’s in a girl’s locker room, it’s not going to be a cute situation . . . . Society is a big issue here. I tell my husband, if we lived on a deserted island she’d never need this.1

It’s hard for a parent not to think of the psychological damage.2

You’re the parent, you make the decisions . . . . We felt this needed to be done right now.3

The doctor said that the surgery preserves the blood supply and the nerves, so she will be able to have an orgasm. Anita [the mother] wondered whether, even if [her daughter] Emma’s responsiveness is reduced, she would be able to tell the difference. Wouldn’t it be more difficult to have a sensitive but “weird” set of genitals, which might make it too embarrassing to wear a bathing suit, let alone be naked with another person?4

In an ideal world, I would do what is medically necessary and leave her alone. And she would be absolutely accepted for who she is, the special person she will be . . . . But that’s not the way our world works.5

These quotes illustrate how parental fear that their child will endure a blighted childhood and adolescence overwhelms parents and leads them to consent to surgery on their intersex infants despite increasing evidence that cosmetic surgery on intersex infants may be unwarranted and improvident. Pressured and isolated in a medical quandary, these parents are discouraged by the prospect that their children might be reviled and rejected during their formative childhood and teen years, and want to spare them such pain. They are convinced that a cosmetic “fix” is preferable to a later locker room revelation that their child has ambiguous genitals, even if a satisfactory psychological and physical outcome cannot be assured.

The following quote, taken from a respected medical text published in 1969, reveals how physicians viewed the fate of intersex infants:

One of the few fundamental aspects of life is that of sex. Its normal functioning is vital to the survival of our race, essential for our full assimilation as individuals into society, and pervades every aspect of our lives. 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 of neglect and frustration. Few of these unfortunate people meet with tolerance and understanding from their

1 Mirreya Navarro, When Gender Isn’t a Given, N.Y. TIMES, Sept. 19, 2004, § 9, at 1, 6 (interviewing anonymous parents who opted for clitoroplasty on a four year old with CAH).
2 Id. (interviewing Lisa Greene, mother of infant with CAH who opted for surgery to create a vaginal opening and rebuild urethra, but not clitoroplasty).
3 Id. (interviewing Jeff Spear, who consented to clitoroplasty and other surgeries on a six month old infant).
5 Id.
fellows and fewer still find even limited acceptance in a small section of
society: all are constantly confronted with reminders of their unhappy
situation. The tragedy of their lives is the greater since it may be
remediable; with suitable management and treatment, especially if this is
begun soon after birth, many of these people can be helped to live happy
well adjusted lives, and some may even be fertile and be enabled to enjoy a
normal family life.6

Thus, physicians since the latter half of the twentieth century have persuaded
parents to embrace a surgical solution to intersexuality by fueling parental fears that
their infant would otherwise be doomed to a freakish future.

The story of David Reimer, now with its very sad postscript,7 has been
extensively discussed in medical literature and elsewhere8 since his story was
published as Sex Reassignment at Birth: Long Term Review and Clinical
Implications in the Archives of Pediatric and Adolescent Medicine in 1997.9 There,
and subsequently, Diamond and others have challenged the premise that surgical
sex assignment and other cosmetic genital surgery on intersexed infants and
children is clinically appropriate.10

David’s death should serve as a reminder and a warning to those involved in
the issue of surgical treatment of infants that the problem here is not merely an
intellectual debate over the use of an experimental procedure; many people have
been and continue to be affected by these decisions.11 After David’s suicide, John

(emphasis added).
7 David Reimer committed suicide in 2004. David was born a boy. During phimosis repair at the
age of eight months, his penis was destroyed. His parents eventually located a psychologist at Johns
Hopkins Hospital who proposed that the parents change David into a girl through surgery and raise him
as a girl. David was renamed Brenda, and the reported success of his case became the basis of surgical
standard of care for intersex infants for the next three decades. See generally Hazel Glenn Beh &
Milton Diamond, An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex
Assignment Surgery on Infants with Ambiguous Genitalia?, 7 MICH. J. GENDER & L. 1 (2000); Milton
Diamond, Pediatric Management of Ambiguous and Traumatized Genitalia, 162 J. UROLOGY 1021
(1999).
8 See, e.g., JOHN COLAPINTO, AS NATURE MADE HIM: THE BOY WHO WAS RAISED AS A GIRL
9 Milton Diamond & Keith Sigmundson, Sex Reassignment at Birth: Long Term Review and
Clinical Implications, 151 ARCHIVES PEDIATRIC & ADOLESCENT MED. 298-304 (1997). See also
Kenneth Kipnis & Milton Diamond, Pediatric Ethics and the Surgical Assignment of Sex, 9 J. CLINICAL
10 The authors have argued elsewhere that doctors should stop performing sex assignment surgery
on intersex infants until much more is known about the long-term consequences of surgery. They also
argued that parents exceeded their authority by consenting to this needless, unproven, and life-altering
surgery. Further, it constituted malpractice for physicians to persist in performing surgery without
evidence that the treatment would yield satisfactory results. Physicians were obligated, when obtaining
informed consent, to inform parents that the surgery proposed had not yet been validated. Moreover, the
authors noted that there was a paucity of scientific studies to support a surgical standard of care. To
date, the anecdotal reports and limited reported hindsight studies from intersex adults who have had
surgery as children suggested that in many cases, surgery did not bring about the positive results
predicted. See Beh & Diamond, supra note 7.
11 Ironically, David was not intersexed, yet his case became the standard for treating intersex
conditions. It was reasoned that if a typical male could be successfully reared as a girl, then surely an
intersexed male could also be. Likewise, when the failure of his treatment became known, it affected
Colapinto, the author who collaborated with David to write As Nature Made Him reflected on his death. While acknowledging David had “multiple motives” for suicide, Colapinto wrote: “[I]n the end, of course, it was what David was inclined to brood about that killed him. David’s blighted childhood was never far from his mind.”

This article pays tribute to David Reimer by questioning parental authority to consent to surgical interventions. Both children and parents will be best served if treatment decisions preserve the child’s bodily integrity, autonomy, and open future. The authors acknowledge that raising a child with nonconforming genitalia may challenge parents, but these children are not freaks or monsters, and need not be perceived as such. To be sure, society’s narrow construction of gender tormented David throughout his life. When he was an infant, without a penis, it led his loving but distressed parents to consent to radical surgery to turn him into a girl. When he was a girl, his classmates relentlessly ridiculed him because he acted like the boy he was, and school officials failed to protect him. As a young adult, when David reclaimed his male identity and briefly became a cause célèbre, he still could not move beyond what had been done to him and how he then saw himself. However, what truly tortured David throughout his life was not the loss of his penis but the imposition of surgical and social interventions that made him someone he was not and did not want to be. David reflected,

If I had grown up as a boy without a penis? Oh, I would still have had my problems, but they wouldn’t have been compounded . . . . I would have been way better off if they had just left me alone, because when I switched back over, then I had two problems on my hands, not just one, because of them trying to brainwash me into accepting myself as a girl.

How is it that the repugnance associated with ambiguous genitalia is so great that caring physicians advise, and good, loving parents consent to radical surgery on infants? Alice Dreger characterized the current response to such intersex conditions as the “monster” ethics approach: “Unfortunately, the present treatment of intersexuality in the U.S. seems to be deeply informed by the monster intersex treatment. See Milton Diamond, Sex, Gender, and Identity over the Years: A Changing Perspective, in 13 CHILD & ADOLESCENT PSYCHIATRIC CLINICS: SEX & GENDER 591-607 (Milton Diamond & Alayne Yates, eds. 2004) [hereinafter SEX & GENDER].

See generally COLAPINTO, supra note 8.


14 We are in no way criticizing David’s parents. They, as many other well-intentioned parents, did what they were led to believe as best for their son. David himself had forgiven his parents for being misinformed. In fact, their own anguish and guilt is testament to the harm of leaving such a monumental decision to parents. See COLAPINTO, supra note 8, at 256.

15 COLAPINTO, supra note 8, at 262.

approach; ethical guidelines that would be applied in nearly any other medical
intervention are, in cases of intersexuality, ignored. Monster ethics allow
parents and doctors to ignore sound medical practice in treating intersex infants.

Secrecy, shame, and stigma are common among intersex children and may
well produce lasting impressions. However, adults recall that the shame, stigma,
and secrecy came from being treated as medical oddities. Parents who de-
medicalize the intersex child rather than adopting the “monster” approach can
ameliorate such social scars. Interviewing intersex adults, Celia Kitzinger observed
that “[t]he hushed conversations, the embarrassment of doctors, the explanations
which don’t add up, lead women and girls with [Androgen Insensitivity Syndrome]
to the belief that they have a defect so monstrous that nobody is willing to discuss
it.”

In the 1990s, and particularly after David Reimer’s case was reintroduced
into the medical literature in 1997, activists called for a moratorium on genital
surgery which was intended to “normalize” the appearance of a child’s genitals. Although some in the medical community accepted this premise until more could
be known about the proper treatment of intersex infants, others argued that fuller
disclosure of the medical uncertainty of the procedures would suffice and the
traditional method of “normalization” should continue. While fuller informed
consent is laudable, informed consent by parents alone cannot legitimize surgery to
normalize infant genitalia when it is not medically necessary. Parents do not have
the authority to consent to genital normalizing and sex assignment surgery on
behalf of their infants. In the spirit of optimism, this article also addresses how the
law can best support parents and give them the strength of parental character to
love, cherish, and nurture the child that is. Ultimately, law informed by the truth
will best serve the children.

II. INTERSEXUALITY

Atypical sexual differentiation occurs in more than one percent of live
births. The incongruities may be of a genetic, gonadal, hormonal and/or genital
nature and can occur at the time of gamete formation, fertilization or during fetal

17 Dreger, supra note 16, at 33.
19 Celia Kitzinger, Women with Androgen Insensitivity Syndrome, in WOMEN’S HEALTH CONTEMPORARY INTERNATIONAL PERSPECTIVES 387 (Jane M. Ussher ed., 2000).
20 Diamond & Sigmundson, supra note 9; see also Kipnis & Diamond, supra note 9, at 398-410. This is also the position of different intersex groups, such as the Intersex Society of North America (ISNA), http://www.isna.org; Bodies Like Ours, http://www.BodiesLikeOurs.org; and A Kindred Spirit, http://www.kindredspiritlakeside.homestead.com.
22 PEGGY T. COHEN-KETTENIS & FRIEDMAN PFÄFFLIN, TRANSGENDERISM AND INTERSEXUALITY IN CHILDHOOD AND ADOLESCENTS 25 (2003):
Medical science, like western society, has long assumed that "there is a single universally correct development pathway" and that variations in sexual dimorphism are based on error. Increasingly, biologists questioned "a priori belief in complete genital dimorphism" and expressed the view that intersex conditions may instead represent normal and to-be-expected biological variation in humans.

Infants with intersex conditions may be born with visible genital ambiguities or their circumstance may not become apparent until adolescence or later. There are well over a dozen intersex conditions, each having unique and different characteristics. In some conditions, such as Complete Androgen Insensitivity Syndrome (CAIS) or Klinefelter's syndrome (KS), an infant's genitals typically do not reveal a problem. For instance, because of a genetic mutation to the androgen receptor gene, an XY (male) infant with CAIS will be born with female-appearing genitalia and will likely be reared as a girl unless some medical condition prompts early medical testing. At puberty, the condition may be diagnosed when the child fails to menstruate or has some other developmental anomaly. In contrast, infants with Partial AIS (PAIS) often are noticed soon after birth when parents and physicians observe incomplete masculinization of the genitals. Congenital adrenal hyperplasia (CAH), a disorder that results in the prenatal overproduction of androgens, shows up at birth in affected female infants. An XX (female) infant

Sexual differentiation disorders can be classified in various ways. Traditionally, genetic sex or gonadal histology is used as an organizing principle. Female and male pseudohermaphroditism, true hermaphroditism, and gonadal differentiation disorders are then the resulting categories. In true hermaphroditism both testicular and ovarian tissue are present. Female or male pseudohermaphroditism indicates that respectively only ovarian or testicular tissue is present. In incomplete or complete gonadal dysgenesis one or both gonads are streak gonads. Some of these conditions co-occur with sex chromosome anomalies, while others do not, but the two phenomena are frequently associated.

Id.

23 Id. at 49.
25 Blackless et al., supra note 21, at 151 (summarizing literature). In fact, while medicine has adhered to a view of absolute sexual dimorphism in "sex chromosome composition, gonadal structure, hormone levels, and the structure of genital duct systems and external genitalia," people culturally recognize that other traits of male and female are not so absolute. "Our culture acknowledges the wide variety of body shapes and sizes characteristic of males and females. Most sexual dimorphisms involve quantitative traits, such as height, build, and voice timbre, for which considerable overlap exists between males and females." Id. at 151, 161. See also Milton Diamond et al., From Fertilization to Adult Sexual Behavior: Nonhormonal Influences on Sexual Behavior, 30 Hormones & Behav. 333-53 (1996).
26 Blackless et al., supra note 21, at 161.
27 Beh & Diamond, supra note 7, at 2 n.2. See generally Melvin M. Grumbach et al., Disorders of Sex Differentiation 842-1002 (2003).
28 Although there may be some physical clues, Klinefelter's syndrome, a sex chromosome disorder, is often not diagnosed until breast development at puberty. Both CAIS and KS may only be diagnosed with a work-up for infertility after marriage. Diamond & Watson, supra note 18, at 631-32.
29 Id. at 624.
30 Id. at 624-25.
with CAH will have virilized genitalia, ranging from "minor clitoral enlargement or labial fusion to virilization so severe that the infant is mistaken for a male at birth."\(^{31}\)

Most intersex babies probably do not have surgery in infancy. Some intersex conditions do not manifest in infancy and there is no genital ambiguity in others. Gauging the number of infants that undergo genital surgery is difficult. However, estimates of the number of candidates for genital surgery vary from 1.62% to "between one and two in a thousand" infants.\(^{32}\)

III. THE MONSTER IN THE LOCKER ROOM

A. David Reimer and the Failure of Surgical Sex Assignment

In 1997, the case of John/Joan told the story of the person we now know as David Reimer.\(^{33}\) The account described the failed sex reassignment of a child who had been originally presented to the medical world as a case success.\(^{34}\) David Reimer and his twin brother were born as normal boys. However, David’s “penis was accidentally burned to ablation during phimosis repair by cautery” at eight months of age.\(^{35}\) His distraught parents eventually consulted with John Money, a leading psychologist at The Johns Hopkins Hospital at the time. David’s parents were advised that while their son’s penis could not be repaired, he could be raised as a girl with surgically reassigned genitalia. The parents deliberated and ultimately decided to accept the offer to change David into a girl.\(^{36}\) David’s testicles were removed and a rudimentary vaginal exterior was fashioned from his scrotal tissue.\(^{37}\) In effect, David, a 46 XY male who was not born intersexed, was treated as if he were. His testicles were removed, female-appearing genitalia were constructed, and he was raised as a girl.

According to Colapinto’s account, the information the Reimers—neither of whom had finished high school—received about the surgery was woefully

\(^{31}\) Melissa Hines, *Psychosexual Development in Individuals Who Have Female Pseudohermaphroditism, in SEX & GENDER, supra* note 11. A male (XY) may also have CAH, but that child will not have genital ambiguities and may be diagnosed later.

\(^{32}\) Blackless et al., *supra* note 21, at 161.

\(^{33}\) John/Joan was the pseudonym Diamond and Sigmundson assigned to David Reimer. David was given the name Bruce Reimer by his parents in infancy. Following surgery at twenty-two months of age, his parents named him Brenda. When he re-established his male identity, he took the name David. See COLAPINTO, supra note 8, at 9, 53, 182.


\(^{35}\) COLAPINTO, supra note 8, at 11.

\(^{36}\) *Id.* at 51-54.

\(^{37}\) *Id.* at 53-54.
Indeed, they could not have been assured of any particular outcome since this treatment was entirely experimental. David’s parents did not appreciate that the treatment had never been attempted on a child born with an established typical sex. Anxious for a good outcome, however, they were impressed with Money’s confidence and optimism that the operation would be successful. In fact, Janet Reimer said, “I looked up to [John Money] like a god. . . . I accepted whatever he said.” They also recalled being rushed to decide because Money believed that there was a short window of opportunity; they were even accused of “procrastinating.”

It is now well known that David’s family struggled mightily to carry out the doomed treatment plan for over a decade. Yet it all collapsed in adolescence when David could not deny his own innate gender. At the age of fourteen he threatened suicide unless he could live as a male. David was then finally told the truth about his birth, the loss of his penis, the surgery, and the highly secret treatment plan to raise him as a girl. David thereafter reclaimed his male identity and lived as a man. He underwent four surgeries to construct a penis. He eventually married and adopted his wife’s children. David later collaborated with John Colapinto on a book about his life, As Nature Made Him: The Boy Who Was Raised as a Girl. On May 4, 2004, David ended his life at the age of 38.

David’s twin brother, Brian, had died of a drug overdose two years earlier.

B. The Traditional Approach: Fear and the Allure of the Quick Fix

When an intersex condition or genital ambiguity is apparent in infancy, parents and physicians must consider how to proceed. Sometimes, medical intervention is essential to preserve the child’s life, such as in the case of cloacal extrophy and more commonly in cases known as salt-losing CAH. Such
medically necessary management must be distinguished from sex reassignment or genital "normalization" surgery.\textsuperscript{50} Cosmetic surgery to "normalize" the appearance of genitalia stands on a different footing than medically necessary treatment.

After birth, parents are anxious to know the sex of their child and to announce it to others. The inability to identify the sex of the child has been characterized as a social emergency.\textsuperscript{51} This so-called emergency, including the theoretically associated parental crisis, has for many years justified early surgery on children with visibly ambiguous genitalia. It is these decisions to "normalize" the genitals rather than life-saving surgery or tentative gender assignment without surgery that has become most controversial.

Misinterpretation of earlier studies involving intersexed persons drove the idea that that surgical sex reassignment of David Reimer and of infants born with ambiguous genitalia could be successful. In a summary of findings of their work with hermaphrodites, the term for those intersexed in the 1950s, John Money and others advanced the theory that the gender in which the child was reared could determine the child's own sexual identification.\textsuperscript{52} Therefore, they suggested that surgical assignment to achieve a good aesthetic appearance was a primary consideration in the case of intersex infants:

In briefest summary, our findings point to the extreme desirability of deciding, with as little diagnostic delay as possible, on the sex of assignment and rearing when a hermaphroditic baby is born. Thereafter, uncompromising adherence to the decision is desirable. The chromosomal sex should not be the ultimate criterion, nor should the gonadal sex. By contrast, a great deal of emphasis should be placed on the morphology of the external genitals and the ease with which these organs can be surgically reconstructed to be consistent with the assigned sex.\textsuperscript{53}

One caveat was that reassignment must be done in the "early months of life," in the "critical period" or else it would be "psychologically injurious."\textsuperscript{54} Money

\textsuperscript{49} Melissa Hines,\emph{ Congenital Adrenal Hyperplasia, in SEX & GENDER, supra note 11, at 643.}
\textsuperscript{50} See Reiner,\emph{ supra} note 48, at 659.
\textsuperscript{51} \textsc{American Academy of Pediatrics, Evaluation of the Newborn with Developmental Anomalies of the External Genitalia, 106 PEDIATRICS 138, 138 (2000) ("The birth of a child with ambiguous genitalia constitutes a social emergency."); Kessler,\emph{ supra} note 21, at 15.}
\textsuperscript{52} John Money et al.,\emph{ Imprinting and the Establishment of Gender Role, 77 Archives Neurology \& Psychiatry 333 (1957).}
\textsuperscript{53} \emph{Id.} at 334.
\textsuperscript{54} \emph{Id.} at 336. Timing became ever more determinative to Money's evolving sex assignment theory but what remained a constant in his writing was that the time to indisputably make a boy or a girl was not fixed until sometime after birth.
and his colleagues were strong proponents of surgical assignment and not just social assignment, stating that “[t]hough the sex of rearing could transcend external genital morphology in psychologic importance, absence or correction of ambiguous genital appearance was psychologically beneficial.”

Furthermore, Money wrote confidently about surgery on female genitalia: “Clitoral amputation in patients living as girls does not, so far as our evidence goes, destroy erotic sensitivity and responsiveness, provided the vagina is well developed. If clitoridectomy is performed in early infancy, the chances of undesirable psychologic sequelae are negligible.”

A psychologist by training, Money believed that parents, and ultimately the intersexed child, could not come to terms with the social and psychological ramifications of ambiguity. “Before contemporary medical interventions, many children with a defect of the sex organs were condemned to grow up as they were born, stigmatized and traumatized.” Money perceived parents as unable to cope, insistent on a definite sex assignment, and willing to surrender to medical authority.

Money often wrote about how to counsel parents to re-announce the sex of their child with the least social trauma; if properly done, re-announcement presented a short-lived and minor crisis that would resolve with “consistency of rearing” in the assigned gender.
Money attempted to fight against cruel stereotypes by calling intersex conditions "errors." Apparently, he thought that simply by referring to intersex conditions as "sex errors," he was triumphing over stigmatizing stereotypes:

Words can wound. Medicine can be very cruel in diagnostic terms as gruesome as bird-faced dwarfism and prune-belly syndrome. That is why serious thought went into the decision to continue using Sex Errors in the title of this second revised and enlarged edition. Medical terms such as hermaphroditism or intersex are too stigmatizing for people born with a syndrome that affects the sex organs. They find it stigmatizing to have to talk about themselves as having an abnormality, anomaly, defect, deviance, deficiency, or handicap. They would rather use the term sex error. It implicates their anatomy, not themselves.61

Thus it was, with well-meant intent, that Money viewed intersex conditions as errors of the anatomy which could be corrected with surgery. The authors observe that it is less stigmatizing to characterize intersex conditions as to be expected and not uncommon developmental variations.

The sentiment that intersex conditions were monstrous defects is reflected in a medical text published in 1969 by Dewhurst and Gordon.62 They wrote:

That a newborn child should have deformity of any magnitude is a distressing thing, but that so fundamental an issue as the very sex of the child should be in doubt is a tragic event which immediately conjures up visions of a hopeless psychologic misfit doomed to live always as a sexual freak in loneliness and frustration.63

Fear of the monster still continues to dominate the decisional process. In Lessons From the Intersexed, Suzanne Kessler explored the distress of parents in the first few months after the birth of their intersex child and how the allure of a medical cure can indeed overwhelm parents.64 The crisis begins at birth when everyone asks whether the child is a boy or a girl, and apparently, the choice is between only one of two answers: "it is a boy" or "it is a girl." The urgency related to providing an answer for that question can only derive from parental and societal

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61 SEX ERRORS OF THE BODY AND RELATED SYNDROMES, supra note 24, at xiv.
62 DEWHURST & GORDON, supra note 6, at 1.
63 Id. at 1. In their preface, Dewhurst and Gordon wrote:

One of the few fundamental aspects of life is that of sex. Its normal functioning is vital to the survival of our race, essential for our full assimilation as individuals into society, and pervades every aspect of our lives. 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 of neglect and frustration. Few of these unfortunate people meet with tolerance and understanding from their fellows and fewer still find even limited acceptance in a small section of society: all are constantly confronted with reminders of their unhappy situation. The tragedy of their lives is the greater since it may be remediable; with suitable management and treatment, especially if this is begun soon after birth, many of these people can be helped to live happy well adjusted lives, and some may even be fertile and be enabled to enjoy a normal family life.

Id. at vii.
64 KESSLER, supra note 21.
need as a newborn infant hardly finds it necessary to provide an answer to such a seemingly weighty question. Quoting an interview with an endocrinologist, Kessler wrote:

Very frequently a decision is made before all this information is available, simply because it takes so long to make the correct diagnosis. And you cannot let a child go indefinitely, not in this society you can't . . . . There's pressure on parents [for a decision], and the parents transmit that pressure onto physicians.65

During the waiting period, parents are typically advised not to make a premature announcement about the sex of the infant and to altogether refrain from discussing the condition in order to avoid insistent questioning.66 Kessler commented, "[Physicians] talk as though they have no choice but to respond to the parents’ pressure for a resolution of psychological discomfort and as though they have no choice but to use medical technology in the service of a two gender-culture."67 The advice to keep the condition secret68 isolated parents within the medical arena, since physicians were the only ones with whom parents believed they were free to discuss the condition. It reinforced a sense of shame. "In short, parents are asked to sidestep the infant’s gender rather than admit that the gender is unknown [or in doubt], thereby collaborating in a web of white lies, ellipses, and mystifications."69

Reiner described the traditional medical approach that became entrenched for more than four decades as follows:

[I]nfluenced initially by Money’s work, varying clinical algorithms gradually evolved into a treatment paradigm:

- Assign neonates who have anomalous genitalia to female sex-of-rearing if they are genetically female or if they are genetically male but do not have an adequate phallus
- Perform Feminizing genitoplasty
- Instruct parents to inform no one of this birth history70

So it was that the physician’s construction of gender became the parents’ construction as well. The parents were educated that there were two sexes—male and female.71 They were informed that their child, by an error of nature, was not apparently male or female. They were told to delay any announcement of a sex, to confide in only a few discreet friends and family. They were told to act quickly because the condition required urgent treatment and surgical assignment could treat the condition. They were led to believe that if the genitals were normalized and if

65 Id. at 20.
66 Id. at 21-22.
67 Id. at 32.
68 SEX ERRORS OF THE BODY AND RELATED SYNDROMES, supra note 24, at 22 (advising parents to tell few people outside the family).
69 KESSLER, supra note 21, at 22; see also id. at 99.
70 Reiner, supra note 48, at 658.
71 See generally Beh & Diamond, supra note 7, at 42-59 (critiquing the informed consent process).
they raised their child with a consistent gender identity, a crisis could be averted, even if the infant underwent surgical sex re-assignment. Thus, parents were induced to simplistically believe that although their child was born intersexed, he or she need not remain so.\footnote{\textit{Id.}}

The confidence in surgical intervention as a solution, and the absolute imperative to project such surety, is remarkable. Perhaps signaling their acknowledgment that such treatment may in fact be a house of cards, Dewhurst and Gordon admonished:

> At the risk of repetition, we emphasize again that whatever is decided this decision must be underlined by appropriate surgical measures to make the genitalia conform to the chosen sex. Above all, unwanted gonadal tissue must be removed to prevent the appearance of heterosexual manifestations about the time of puberty, for these might destroy the confidence of the parents so carefully built up and would certainly have a distressing effect upon the child.\footnote{DEWHURST & GORDON, \textit{supra} note 6. Notice that Dewhurst and Gordon were concerned that if all of the gonadal tissue was not removed, heterosexual manifestations resulting from remaining gonadal tissue might emerge that for the reassigned adolescent would appear as a same-sex attraction. Christina Matta, \textit{Ambiguous Bodies and Deviant Sexualities: Hermaphrodites, Homosexuality, and Surgery in the U.S. 1850-1904}, 48 PERSPECTIVES BIOLOGY \& MED. 74-83 (2005) (claiming it was concern with homosexuality among hermaphrodites that led to the upswing in infant surgeries). Note also that there was the underlying assumption that the tendency to be heterosexual would be conflicted by a reassignment of sex and the reassigned individual "should" now exhibit behaviors that would be called homosexual.}

Secrecy, shame, overwhelming isolation, and medical dependency were certainly part of the Reimer family experience. When Janet and Ron Reimer, David's parents, first discovered John Money, they had some doubts about surgery. Eventually, however, their concern that David could not be a normal boy prevailed. With Dr. Money's advice in mind, Janet Reimer stated: "But I thought, with his injury, it would be easier for Bruce to be raised as a girl—to be raised gently. He wouldn't have to prove anything like a man had to do."\footnote{\textit{Id.}} Ron Reimer recalled thinking: "You know how little boys are . . . ‘Who can pee the furthest?’ Whip out the wiener and whiz against the fence. Bruce wouldn't be able to do that, and the other kids would wonder why."\footnote{\textit{Id.}} Colapinto wrote of his interviews with Ron: "Ron could not even imagine the humiliations and frustrations that would entail. As a girl or a woman, though, Bruce wouldn't face all that . . . If what Dr. Money told them was true, she could live a normal life, she could get married, she could be happy."\footnote{\textit{Id.}}
The Reimers were incredibly diligent in implementing the plan, as they were told to do. They went to extraordinary lengths to follow the treatment plan. Although twin brothers Brian and David began to dread returning to Johns Hopkins for annual visits, the Reimers insisted. Eventually, "they sweetened the pill... with a family vacation." David and Brian recollected emotionally painful, humiliating, and invasive psychiatric sessions at Johns Hopkins. Significantly, invasive and personally embarrassing situations are a common recollection of intersex children.

C. The Current Debate: Moratorium or Improved Informed Consent

Despite the general acceptance of early surgery as a treatment of intersex for more than four decades, many in the medical community began to question the premises of sex assignment following revelations about David Reimer in 1997. For example, William Reiner, a pediatric urologist who formerly performed surgeries on intersex infants, observed that sex assignment surgeries were not altogether satisfactory. In recent years, Reiner not only stopped performing surgeries and trained as a child psychiatrist, but also became a vocal opponent of

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77 Id. at 98-99, 114-15.
78 Brian and David resisted because the sessions were humiliating and degrading. Money discussed sexual matters well beyond what the children’s sexual maturity warranted. In some sessions, they were coerced to engage in “coital mimicry” and “sexual rehearsal play” in which they acted out sex play with one another. The treatment theory was based on the assumption that by doing so David would learn to assume a female role. To their mortification, photos were also taken. COLAPINTO, supra note 8, at 86-90.
79 COLAPINTO, supra note 8, at 91; Diamond & Sigmundson, supra note 9.
80 Id. at 86-88, 91-94, 129-30, 136-41.
81 Sherry A. Groveman, The Hanukkah Bush: Ethical Implications in the Clinical Management of Intersex, 9 J. CLINICAL ETHICS 356 (1998). Perhaps most disturbing are the descriptions in published interviews with children. JOHN MONEY, BIOGRAPHIES OF GENDER AND HERMAPHRODITISM IN PAIRED COMPARISONS (1991). The interviews with children are surprisingly graphic and one might question whether they were age-appropriate. For example, Case #2: Sex Reassigned as Boy, there is a lengthy description of numerous medical interventions and psychiatric interviews. At one point, the child remains in the hospital for eleven months, during the course of several failed surgeries. Id. at 276-78. The child was pressed at length about whether to become a boy through surgery or to remain a girl. Id. at 289-92. Ultimately, he returned “reluctantly” at twenty-four years of age, but as Money described, “he had long ago had his fill of doctors and their hospital, and wanted to be left alone.” Id. at 293. Frequently, Money employed so-called “parables,” a technique he believed could advance therapeutic goals. He would obliquely impart information and guide children to imagine the future as it could be with intervention. Id. at 441-43.
82 Diamond, supra note 11, at 591-607.

Reiner had wholeheartedly subscribed to this model throughout the 1970s and ’80s, first as a urology resident at Hopkins and then as a [sic] urologist in private practice in central California. But over the course of his career, he had become troubled by a dearth of information on the psychological and sexual outcome of children with urogenital conditions.

Id.
surgical sex assignment in infants.\textsuperscript{84} In reviewing the development of the surgical standard, Reiner noted that the "clinical vacuum" that existed at the time Money began his studies allowed his views on gender fluidity during childhood to flourish.\textsuperscript{85} Reiner commented that although "[d]ata remained sparse... [t]he notion that gender-typical behaviors and gender identity could be products of surgical and social technique was appended to the clinical teaching repertoire as spoken truths of clinical practice."\textsuperscript{86} The "blank slate" concept of infant gender necessitated "a sense of urgency or emergency" for the assignment to succeed.\textsuperscript{87} "This intervention model—although it preceded research, so that the model was in search of data—became definitive treatment. It also transformed a broad psychologic conception into an inflexible clinical concept."\textsuperscript{88}

Importantly, by observing patients over time, Reiner concluded that sex and social gender assignment could not necessarily prevail over prenatal influences.\textsuperscript{89} When Diamond and Sigmundson reported on the failure of the David Reimer case, Reiner wrote an editorial supporting their findings and conclusions.\textsuperscript{90} Initially, the medical community engaged in substantial reflection in both the literature and at

\textsuperscript{84} Id. Reiner himself was confronted by a case of mistaken sex reassignment. See William Reiner, \textit{Case Study: Sex Reassignment in a Teenage Girl}, 35 J. AM. ACADEMY CHILD & ADOLESCENT PSYCHOL. 799-803 (1996).
\textsuperscript{85} See Reiner, \textit{ supra} note 48, at 661.
\textsuperscript{86} Id.
\textsuperscript{87} Id.
\textsuperscript{88} Id.
\textsuperscript{89} Id. at 659. Reiner's work with cloacal exstrophy patients is illuminating. Cloacal exstrophy is a rare condition; it occurs in approximately one in 400,000 births. Reiner estimates about ten such children are born a year in the United States. These children are either genetically and hormonally male or female, but they are born with severe and often life-threatening pelvic field defects, including among others, defects to the bowel, bladder and lower vertebrae. They also have "severe inadequacy or absence of genitalia."

In his follow-up study, twenty-four of the genetic males with cloacal exstrophy were assigned female, underwent feminizing genitoplasty and castration, and raised female. Reiner noted, "Of the 24 subjects who were sex-assigned female, 13 have declared themselves male:"
\textsuperscript{Id.} at 664. He further noted that they "all reported an aversion to strictly feminine attire... after the age of approximately 3 years." \textsuperscript{Id.} Of the subjects who continue to be reared as girls, parents have been conscious of their child's male-typical behaviors and attitudes. \textsuperscript{Id.} at 665. In sum, he concluded, "neonatal castration plus feminizing genitoplasty—coupled with social and legal assignment to female—does not seem to override the neurobiologic underpinnings of male sexual identity and male gender role preferences. Therefore, female sex assignment in genetically—and hormonally—male neonates risks personal internal confusion and social external conflict and contradiction." \textsuperscript{Id} at 671.

Other look-back studies on adults with other conditions show mixed satisfaction about their pediatric care. For instance, in one study, it was found that for a majority of seventy-two intersex adults with varying intersex conditions, "long term outcome appears to be more favorable than some current rhetoric suggests." However, the study also observed "a small minority of adult intersex patients are dissatisfied with their gender," and that a "more substantial [minority] are dissatisfied with genital status and sexual functioning, and they support policy changes." H.F.L. Meyer-Bahlburg et al., \textit{Attitudes of Adult 46 XY Intersex Persons to Clinical Management Policies}, 171 J. UROLOGY 1615, 1618 (2004). That same study is notable in another respect. Of forty-five individuals that had genital surgery, in hindsight, a total of 46% believed surgery should be postponed—22% supported postponing until adulthood and 24% until adolescence. On the other hand, 47% believe the surgery should be done in infancy. \textsuperscript{Id.} at 1617. Furthermore, fewer than half, only 45% of those surveyed reported being "mainly satisfied" with sexual functioning. \textsuperscript{Id.}

\textsuperscript{90} William Reiner, \textit{To Be Male or Female—That Is the Question}, 151 ARCHIVES PEDIATRIC & ADOLESCENT MED. 224-25 (1997).
professional meetings after the reports of failure in David’s case. As a result, there has been increasing acceptance of the view that surgeries performed on infants for the sake of appearance alone are unjustified. For example, in 2004, a fifteen-member multidisciplinary panel convened by the Hastings Center concluded: “None of the appearance-altering surgeries need be done urgently. Surgery to normalize appearance without the consent of the patient lacks ethical justification, in most cases.”

However, many in the medical community did not and still do not embrace the moratorium position. Those against a moratorium adhere to the view that not doing surgery also has its own inherent risks, principally related to social stigma and parental rejection of the infant. Pediatric urologist Kenneth Glassberg called for increased research but justified the continuation of surgery by pointing to intersex adults reportedly satisfied by infant surgery: “What about all of those patients who have done well after gender assignment? Should they have been condemned to growing up as what would inevitably be considered freaks by their classmates?” Proponents of at least some continuation of surgical treatment advocate more attention to informed consent until efficacy of surgical treatment is established or refuted. Physician Erica Eugster, criticizing the Hastings Center panel’s position, summarized the view of surgery proponents:

If parents maintain a strong prejudice in favor of surgery despite a complete education about its potential risks, the effects of unilaterally denying the option for a decade or more could surely be disastrous. Therefore, until rigorous comparisons of psychosexual functions in patients receiving early genital surgery using modern techniques versus no early genital surgery have been conducted, only TWO conclusions may safely be made. First, the ultimate decision regarding early surgery rests with the parents and should be made in the context of their own cultural beliefs only after a detailed and comprehensive review of all options, opinions, and available outcome data. Affording parents this authority does not present an ethical dilemma, since in our society all major decisions regarding minor children are traditionally made by parents. Second, when early genital surgery is performed, it should be undertaken by surgeons in centers of excellence with particular expertise in the care of patients with intersex conditions.

In keeping with such reasoning, proponents of early surgery have attempted to legitimize questionable surgery by heightening the informed consent process

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91 Joel Frader et al., Health Care Professionals and Intersex Conditions, 158 ARCHIVES PEDIATRIC & ADOLESCENT MED. 426, 427 (2004).
provided to parents. This approach, characterized as the “middle ground” between a moratorium and the traditional approach, has been advanced by others as well.\textsuperscript{95} Some legal commentators have also opposed a moratorium; Laura Hermer summed up the argument in favor of parental choice:

It must be recognized that, if we choose the latter course [a moratorium], we will have again used intersex individuals as guinea pigs of sorts, this time in a cultural experiment. However much any of us may wish to see Fausto-Sterling’s latter course prevail, the outcome is not certain. Thus, a physician cannot, in good conscience, assure the parents of an intersex infant that they ought not to choose cosmetic or sex assignment surgery for their child, on the ground that the unaltered child, along with his/her intersexual forebears and brethren, will (over time) alter our present sex and gender systems to make space for those who do not conform to the present norms. Given our present state of knowledge concerning the long-term outcomes of intersex individuals (both those who have and have not had surgery), and our current sex and gender systems and the fact that intersex individuals have no choice but to cope with them one way or another, there can presently be no reasonably certain “right” answer for physicians and parents of intersex children with respect to surgery.\textsuperscript{96}

\section*{IV. \textbf{Why Informed Consent Cannot Legitimize Medically Unnecessary Surgery}}

\subsection*{A. Surgery Merely to Normalize Genitalia Poses Substantial Risks of Harm Without Evidence of Benefits}

The fallacy of the argument in favor of heightened informed consent in lieu of a moratorium on surgery is that the argument presumes that parental informed consent can legitimize a surgical treatment that lacks a therapeutic rationale and poses a substantial risk of harm over the lifetime of the patient.\textsuperscript{97} The so-called “middle ground” position assumes that in the absence of knowledge about the outcome, the medical profession is entitled to proceed with surgery provided that there is fully informed parental consent. Implicitly, the position presupposes that


\textsuperscript{96}Laura Hermer, \textit{Paradigms Revised: Intersex Children, Bioethics \& the Law}, 11 ANN. HEALTH L. 195, 228 (2002). \textit{See also} Julie Greenberg, \textit{Legal Aspects of Gender Assignment}, 13 THE ENDOCRINOLOGIST 277, 279, 285 (2003) (calling for a “middle ground approach” of “qualified persistent informed consent” and commenting that “[u]ntil long-term studies prove that the dominant treatment protocol provides a better psychological outcome than the alternative treatment proposed, physicians need to ensure that any consent provided by parents is based on full information”).

\textsuperscript{97}Dissatisfaction with the assigned sex occurs with significant frequency, depending on the intersex condition. \textit{See} Diamond, supra note 11, at 602-03. \textit{See also} websites of ISNA, Bodies Like Ours and A Kindred Spirit, \textit{supra} note 20.
surgery can be justified based on the risk of social stigma in childhood, parental distress, and parental preferences.

Notably, in defending the surgery option, proponents of surgery mischaracterize the position of moratorium proponents, suggesting that the Intersex Society of North America (ISNA) and others are actually calling on parents to raise their intersex children as a "third" sex. For example, Diamond's position has been summarized as: "Diamond is of the opinion that sex assignment and genital surgery should be delayed until the child can decide for itself. This means that child should neither be raised as a boy nor a girl, but as an intersex person." Yet those opposed to surgery have never suggested that parents raise their child without assignment or subject them to a "cultural experiment" by raising them as genderless as Hermer, for example, characterized the non-surgical approach.99

We are not suggesting that intersexed children should be raised without gender... The aim must be to raise infants in a way that will most probably turn out to be comfortable for the maturing child. But gender assignment has to be provisional, subject to revision by the intersexed child as he or she matures.100

Thus, opponents of surgery simply seek to stop infant surgery to allow for the possibility that the gender of rearing might be wrong. The so-called cultural experiment is hardly as radical as proponents of surgery suggest.101 Although proponents postulate that gender of rearing and genital appearance must match for gender development, this proposition is doubtful and has not been established.102

98 Froukje M.E. Slijper et al., Long-Term Psychological Evaluation of Intersex Children, 27 Archives Sexual Behav. 125, 142 (1998). See also Ahmed et al., supra note 95, at 849.

99 Hermer, supra note 96, at 228.

100 Kipnis & Diamond, supra note 9, at 406. See also Milton Diamond, Pediatric Management of Ambiguous and Traumatized Genitalia, 162 J. Urology 1021, 1025 (1999). ISNA advises that children be raised with a gender assignment, just not a surgical assignment. See http://www.isna.org/articles/tips_for_parents. Dreger also has not advocated raising children without a gender. See Alice Domurat Dreger, A History of Intersexuality: From the Age of Gonads to the Age of Consent, 9 J. Clinical Ethics 345, 353 (1998) ("All children—no matter how intersexed—can and should be assigned a male or female gender."").

101 In light of the fact that genitals are covered by clothing and intersex children will be raised as boys or girls, it is hard to see why leaving a healthy body part alone is particularly radical. This is especially so, given the ability of children to be as modest and private as they deem fit. The locker room fear of exposure is also largely overrated. In recent years, group showers in public schools have become the exception, rather than the rule. See Randy Dotinga, Where Have All the Showers Gone?, Christian Sci. Monitor, Feb. 3, 2004, available at http://www.csmonitor.com/2004/0203/p12s01-legn.htm; see also Valerie Bonney, Squeaky Clean, AM. SCH. & U. Mag., July 1, 2004, available at http://asumag.com/mag/university_squeaky_clean/.

102 There is a paucity of evidence that surgery provides any benefit to gender development and in fact, there is accumulating evidence about its irrelevance to gender development:

There are scarce data on how children with complex genital anomalies perceive their genitals and how this relates to their gender development. Long term outcome studies of such boys indicate that male gender development does develop in the absence of gender specific genitalia. A systematic examination of the relation between genital appearance and gender identity in a group of girls with congenital adrenal hyperplasia, showed a link between atypical gender identity and prenatal androgen exposure, but not with the degree of virilisation. Taken together, this research suggests that genital appearance may not be
Proponents assert that the social stigma suffered by intersex individuals warrants medical intervention. Yet, experiences within the intersex adult community suggest another entirely possible reality—that as opposed to Dewhurst and Gordon’s prediction, being intersexed does not doom them as “freaks, misfits, curiosities, rejected by society and condemned to a solitary existence of neglect and frustration.”\(^\text{103}\)

In fact, such prediction of doom was not the case historically before surgery was possible,\(^\text{104}\) nor is it the case today.\(^\text{105}\) According to Colapinto, Money’s own doctoral dissertation studies in the 1950s supported the fact that intersex individuals can have satisfying and rewarding lives without surgical alteration.\(^\text{106}\) Alice Dreger’s historical account of the lives of intersexed individuals prior to the “medicalization” of intersex also supports the view that these individuals can lead satisfied lives without surgery.\(^\text{107}\) Reiner’s follow-up study of cloacal extrophy

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\(^{103}\) Dewhurst & Gordon, supra note 6, at vii. For life stories, see, e.g., websites of ISNA and Bodies Like Ours, supra note 20.

\(^{104}\) Daaboul, supra note 102. See also Matta, supra note 73, at 77 (tracing the history of surgery for intersex conditions and observing that “[p]hysicians who proposed surgery also found that their patients had different ideas about their bodies. Physicians could no more force patients to undergo surgery than they could force them to wear trousers instead of dresses, and as a result, patients often shrugged off their uncommon bodies as harmless and went about business as usual.”).

\(^{105}\) See Justine Murat Schoeber, A Surgeon’s Response to the Intersex Controversy, 9 J. CLINICAL ETHICS 393, 394 (1998) (noting that although surgery proponents postulated that genitals that conform to gender of rearing are necessary to the development of a solid gender identity, “[w]hether genital appearance significantly impacts a firm gender conviction remains undetermined”); see also A Conversation with Milton Diamond, in Dean Kotula, The Phallus Palace: Female to Male Transsexuals 35-56 (William E. Parker ed., 2002) (stating that it is also significant to consider that all transsexuals are brought up with typical genitalia and rearing yet conclude from internal cues that they must switch from their gender of rearing), available at http://www.kindredspiritlakeside.homestead.com/P_Dr_Diamond.html.


\(^{107}\) See Alice Domurat Dreger, Hermaphrodites and the Medical Invention of Sex (1998).
patients who were not sex reassigned as female suggests that individuals can enjoy a positive psychosexual outcome. He noted that “[t]he few male children who have cloacal extrophy and were raised as male do well psychosocially and psychosexually.” Significantly, Reiner also noted that those male children who were initially assigned to female and later rejected the assignment transitioned successfully. Studies of males with micropenis also indicate that such men can firmly establish a male role and successful sexual relationships. Additionally, personal testimonies of intersexed individuals about their reaction to surgery sheds light on whether surgery should be postponed until consent may be obtained from the individual:

My condition (PAIS) [partial androgen insensitivity syndrome] means that I would have been born a “normal” boy if my body responded normally to the testosterone my testes were producing (i.e. my body only partially responds to testosterone). Even though doctors knew this, they still decided to continue with their plan to raise me as a girl. I agree they had to make a decision, and that raising me as a girl was appropriate, but what I don’t agree with was their decision to perform irreversible, non-therapeutic treatment on me without my consent. Part of their ‘treatment’ plan was to also withhold the truth about my condition from my family, and from me as I got older. They also somehow believed that being a (non-identical) twin sister would help me grow comfortable as a girl. They were very wrong.

Not that I would necessarily have kept my phalloclit . . . . But I would have liked to have been able to choose for myself. I would have liked to have grown up in the body I was born with . . . But physically, someone else made the decision of what and who I would always “be” before I even knew who and what I “was”. . . . [The doctors] used surgical force to make my appearance coincide with the medical and social standards of a “normal” female body, thereby attempting to permanently jettison any trace of intersexuality.

As a woman, I am less than whole—I have a secret past, I lack important parts of my genitals and sexual response. When a lover puts her hand to my genitals for the first time, the lack is immediately obvious to her. Finally, I

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109 Id. at 664-65.
110 C.R.J. Woodhouse, supra note 106, at 690.
111 Personal letter from Tony Briffa in an online communication that was removed from the website, http://www.vicnet.net.au/~tonybriffa.htm, as part of a court case, in which Mr. Briffa was attempting to sue his physicians for their treatment (on file with the authors).
simply do not feel myself a woman (even less a man). But the hermaphrodite identity was too monstrous, too other, too freakish, for me to easily embrace. A medical anomaly, patched up as best the surgeons could manage.\textsuperscript{113}

B. Consent to Genital Surgery Exceeds the Limits of Parental Authority to Make Medical Decisions for their Children

A study involving twenty-one parents of intersex children—forty-six XX children with CAH and genital ambiguity—between the ages of eight months and thirteen years was recently reported.\textsuperscript{114} Eighty-nine percent of the parents had consented to genital surgery.\textsuperscript{115} The study reported one finding that 100 % of those parents who had consented to surgery "cited [among other reasons] the potential for a more natural genital appearance" when recalling "their reasoning and motivation for consenting" to genital surgery.\textsuperscript{116} Furthermore, when asked if they would consent to genital surgery if a reduction in sexual sensation/responsiveness were certain, 95 % of the parents indicated that the physical and psychological benefits of surgery in infancy permitted a more normal childhood by avoiding ostracism from others. Moreover, all the parents disagreed with postponing genital surgery until the children were old enough to consent.\textsuperscript{117}

One need only consider the contrast between the above findings with the personal testimonies of the now adult children to realize that parents should not be asked to give informed consent to surgery without external safeguards. How can parents presume to know whether sexual function or appearance in adulthood would serve the best interests of their child over the child's lifetime? The fact is, whether genital function and pleasure should be paramount to appearance is a question so essential to one's own bodily integrity, autonomy, and privacy that a parent cannot make the decision for a child absent a medical justification. When the decision can be postponed, it should be. The law, as it now exists, supports that position.

Traditionally, parental medical decisions on behalf of children are accorded deference in recognition "that natural bonds of affection lead parents to act in the best interests of their children."\textsuperscript{118} However, there are limits to such deference. The United States Supreme Court observed that "parents cannot always have absolute and unreviewable discretion to decide."\textsuperscript{119}

\textsuperscript{113} Cheryl Chase, \textit{Affronting Reason, in} \textit{LOOKING QUEER: BODY IMAGE AND GAY IDENTITY IN LESBIAN, BISEXUAL, GAY, AND TRANSGENDER COMMUNITIES} 205-219 (Dawn Atkins ed., 1998).
\textsuperscript{114} The forty-six XX "children had congenital adrenal hyperplasia (CAH), were virilized at birth and were being raised as girls." Jennifer E. Dayner et al., \textit{Medical Treatment of Intersex: Parental Perspectives}, 172 J. UROLOGY 1762, 1762-63 (2004).
\textsuperscript{115} \textit{Id.} at 1763.
\textsuperscript{116} \textit{Id.}
\textsuperscript{117} \textit{Id.}
\textsuperscript{119} \textit{Id.} at 604. \textit{See also} Planned Parenthood of Central Mo. v. Danforth, 428 U.S. 52, 74 (1976) ("Constitutional rights do not mature and come into being magically only when one attains the state-
Professor Jennifer Rosato has identified traditional instances where either categorical or situational conflicts call for placing limits on a parent's authority to consent to medical decisions for the child. Drawing lessons from bioethics, she has concluded: "1) Family members do not possess an inherent right to decide for the patient; 2) deference to family members usually furthers beneficence; and 3) conflicts of interest provide a reasoned basis for interfering with family decision-makers." According to Rosato, categorical conflicts of interests between parents and children:

include those in which the decision-maker makes treatment decisions that fall outside the range of reasonableness; where extraordinary medical treatment is involved; or where the treatment decision involves a countervailing constitutional right of the patient that, when exercised, is likely to interfere with the family member's decision. When a categorical conflict exists, a neutral third party, such as a judge, must determine whether the decision of the proxy accords with the beneficence principle.

The law has recognized such categorical conflicts when treatment implicates the child's sexuality, reproduction, or privacy interests, or that involve consent to non-therapeutic treatment.

Genital normalizing surgery raises issues common to the types of categorical conflicts Rosato has identified. It is an unreasonable, extraordinary medical

defined age of majority. Minors, as well as adults, are protected by the Constitution and possess constitutional rights.

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121 Id. at 35.
122 Id. at 43 (internal citations omitted).
123 Categorical conflicts include procedures such as: female genital mutilation, see Criminalization of Female Genital Mutilation Act, Pub. L. No. 104-208, § 645, 110 Stat. 3009, 3009-708 (1996) (codified as amended at 18 U.S.C. § 116); reproductive decisions of mature minors, see, e.g., Bellotti v. Baird, 443 U.S. 622, 633 (1979); sterilization, see, e.g., Matter of A.W., 637 P.2d 366 (Colo. 1981) (en banc); denial of lifesaving treatment based on religious beliefs, see, e.g., In re McCauley, 565 N.E.2d 411, 413 (Mass. 1991); Novak v. Cobb-County Kennestone Hosp. Auth., 849 F. Supp. 1559 (N.D. Ga. 1994); non-therapeutic research posing greater than minimal risk, see, e.g., Grimes v. Kennedy Krieger Institute, Inc., 782 A.2d 807, 853 (Md. App. 2001); organ donation from a minor to another, see, e.g., Hart v. Brown, 289 A.2d 386 (Conn. Super. 1972) ("natural 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"). Some courts have refused to allow donation by a person deemed incompetent. See, e.g., In re Richardson, 284 So.2d 185 (La. App. 1973) (holding that neither parents nor the courts could authorize kidney transplant of mentally retarded minor to his sister); In re Guardianship of Pescinski, 226 N.W.2d 180 (Wis. 1975).
124 Strictly speaking, the surgery might not meet Rosato's concept of unreasonableness because while the surgery is controversial, it remains for the time being an accepted medical practice among a minority of physicians. "A recent survey of pediatric urologists found two-thirds would call genetically male babies boys even if they have no penis—while five years ago almost all would have recommended raising them as girls." Surgery May Be Hasty for Unclear Gender Intersex, SCI. LETTER, Mar. 15, 2005, at 989, available at 2005 WLNR 3750081.
125 Australia, as a matter of national common law, has developed a categorical standard for extraordinary medical treatment for children: "Court authorisation to medical treatment is required where there is a significant risk of making the wrong decision, either as to a child's present or future capacity to consent or about what are the best interests of a child who cannot consent, and where the
intervention\textsuperscript{126} that impacts significant constitutional interests of the child.\textsuperscript{127} Rosato has also described "situational conflicts" between parent and child that limit parental authority to consent to treatment; these conflicts may be "financial, emotional, or value-based."\textsuperscript{128} These conflicts arise where parents do not necessarily share an identity of interests with the child and therefore may not act in accord with the child's best interests.\textsuperscript{129} To understand the full extent of the conflicts, one need only note that when an intersex child is born, a primary focus of physicians is the emotional needs of the parent.\textsuperscript{130} Indeed, one premise that has continued to justify infant surgery has been the concern that the appearance and uncertainty of the infant's sex was so distressing to parents that it jeopardized the parent-child relationship.\textsuperscript{131} The fact that physicians have seemingly regarded the parent instead of the child as the patient, and focused so much attention on parental discomfort and embarrassment exacerbates the situational emotional conflict of interest.\textsuperscript{132}

consequences of a wrong decision are particularly grave." Sec'y Dep't of Health and Cmty. Servs. v. JWB & SMB (1992) 175 C.L.R. 218. Notably, this standard has also been applied to intersex surgery. See Re A (1993) 16 Fam. L. R. 715 (giving permission to a minor—fourteen-year-old genetic female with Congenital Adrenal Hyperplasia identifying as a male—who was unable give informed consent for gender reassignment surgery). See also Margaret O'Rourke, Dilemmas When Gender Is Uncertain, AUSTRALIAN, Mar. 19, 2005, at C31, available at 2005 WLNR 4210025.

\textsuperscript{126} In Rosato's construction of categorical conflicts, genital normalizing and sex assignment surgeries are also extraordinary medical treatment, which is defined as a "'momentous' decision . . . that would . . . cause a permanent or unavoidable loss or impairment of important physical or psychological functions." Rosato, supra note 120, at 45 discussing and quoting ALLEN E. BUCHANAN & DAN W. BROCK, DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING 142-43 (1990).

\textsuperscript{127} Rosato, supra note 120, at 45. Genital normalizing and sex assignment surgery involves countervailing constitutional rights of privacy related to self-identity, sexuality, and in some instances, procreation. Although children may lack the ability to exercise these nascent rights, the right to make these choices should be preserved until they are able to do so. As the United States Supreme Court has stated, "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." Prince v. Mass., 321 U.S. 158, 170 (1944) (emphasis added).

\textsuperscript{128} Rosato, supra note 120, at 51.

\textsuperscript{129} See, e.g., Matter of A.W., 637 P.2d 367 (discussing parental distress as a motivation for treatment); see also DEWHURST & GORDON, supra note 6, at 4 ("At this early age the emotional reactions of the parents only and not of the child need be considered.").

\textsuperscript{130} See COHEN-KETTENIS & PFÄFFLIN, supra note 22, at 85 ("When the children themselves are too young to understand their situation, the first psychological care concerns the parents."); KESSLER, supra note 21, at 12-32.

\textsuperscript{131} See AMERICAN ACADEMY OF PEDIATRICS, supra note 51, at 138; KESSLER, supra note 21, at 12-32 (discussing parental distress as a motivation for treatment); see also DEWHURST & GORDON, supra note 6, at 4 ("At this early age the emotional reactions of the parents only and not of the child need be considered.").

\textsuperscript{132} KESSLER, supra note 21, at 16.
As evidenced from the selection of quotes cited in the Introduction of this article, parents largely focus on short period of time—childhood and adolescence—when they discuss their reasons for agreeing to infant surgery. Notably, this is the period of a child’s life when parents will be most involved and affected by the appearance of the child’s genitals. Yet childhood, and to a lesser extent adolescence, represents a period of life when the genitals are less sexually significant than during adulthood. Thus it may be that parents place greater emphasis on appearance than sexual function because problems related to appearance are more immediate and of more consequence to them than that of the sexual, erotic and/or gender issues in adulthood, if surgery proves improvident.

V. SUPPORTING PARENTS IN RAISING HEALTHY CHILDREN

Recently, Alice Dreger challenged physicians to recognize that they can perpetuate or work to eliminate harmful social norms:

[What I'm looking for in medicine today—at least around the treatment of children born with socially-challenging anatomies—is a radical change.... [What I hope I'm starting to work towards—is a radical medicine that recognizes and confronts the oppressive nature of social anatomical norms and questions the use of medicine to uphold, and even advance, particularly oppressive norms.]

Concerned about the vulnerability of infants with congenital or genetic conditions that fall outside societal views of the normal, Professor Wendy Anton Fitzgerald similarly challenged the law to “work toward a jurisprudence which will embrace all of human difference, genetic and congenital included.” She further challenged lawyers to “work toward broadening our jurisprudence to include children, indeed all human difference, in our legal understanding of personhood, hoping thus to transform our culture to become more inclusive as well.”

No doubt parenting has a substantial and lasting impact on children. However, there is no need to assume that parental reaction always dictates the proper, or the best, treatment of infants. In fact, it would be a disservice to parents and to the trust placed upon the irrationality of parental love, if one assumes

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135 *Id.*
136 Professor Barbara Woodhouse commented about a news article regarding a father saving his child from a burning building and she parenthetically quoted the local fire marshall who said, “That guy went through hell to get that baby out!”:

Perhaps my method seeks to remind the reader of something that is easy to forget in the quest for rigorous models: parents are not rational actors in the commonly accepted meaning of the term. Yet their seemingly irrational acts make perfect sense in the context of the human experience of parenthood.

parents cannot cope with babies who have nonconforming genitals. As their children’s guardians, parents are expected to rise to the challenges of countless uncertainties.

Consider these conclusions of a researcher comparing the experiences of children with micropenis raised by “different generations of parents”:

Half of the older group remembered unhappy experiences of teasing by their peers, while the younger group was more confident, only one being considered rather shy. In the younger group all eight were able to change and shower without comment from their peers, while half of the post-pubertal group were too embarrassed to do so. These differences are attributed to better counseling of parents. Supportive parents who encourage ‘normality’ produce confident and well-adjusted children.137

It is increasingly recognized that parental rights do not give parents blanket authority to make decisions on behalf of their children.138 Rather, parents have the responsibility to make decisions based on the child’s best interests. Similarly, parents of children within a sexual minority must act in their child’s best interest. Parental interests, biases and preferences are necessarily and correctly subservient to the child’s needs and rights.

But what of stigma, teasing and bullying? It is true that such possibilities face the intersex child and adolescent. Parental and societal responsibility must mean that neither parents nor the courts tolerate the victimization of sexual minorities. In this regard, the authors note with approval the recent judicial decisions that require schools to protect sexual minority students and allow them to be who they are with the full protection of the law. Parents must be assured that the courts will join them in their endeavor to protect their child. While there can

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137 Woodhouse, supra note 106, at 690.
139 In this regard, Matter of Shane T., 453 N.Y.S.2d 590 (Fam. Ct. 1982), is noteworthy. There, a father repeatedly called his son “fag,” “faggot” and “queer.” The father claimed this was “a form of legitimate parental discipline to cure the child of certain unspecified ‘girlie’ behavior.” The father stated “that it would be embarrassing for him if [his son] were queer.” Id. at 593. The court found the conduct constituted child abuse, as did the child’s mother’s failure to stop the conduct and to protect the child.
140 While a parent’s right to raise his or her child remains fundamental... it is equally fundamental that children have constitutional rights which must be respected by all, including their parents.... [T]he bill of rights is not for adults alone. Time and again, courts have reiterated the validity of state interference in the parental-child relationship when necessary to protect the child’s health and welfare. Id. at 593-94.
be no guarantee to parents that intersexed children will be free from stigma, will never be teased, and will never be bullied, it also cannot be denied that no child has ever come with such a guarantee.

VI. CONCLUSION

In this article, the authors have continued their criticism of traditional surgical interventions on children born with ambiguous genitalia. The developing "middle ground" approach is not appropriate because it attempts to legitimize surgical procedures that have not proven to be more beneficial than lesser interventions such as counseling, education, advocacy and protection against stigmatization. Furthermore, surgery has been shown to have catastrophic consequences for some. Surgery was premised on concerns about parental reaction, social stigma, and a theory that gender and genitalia must match to yield a solid gender identity. Before surgery was possible, it was known that intersexed individuals historically led private and satisfied lives. It is immoral to blame and punish the victim of bigotry rather than to use our efforts to resist the bigot. Moreover, it is questionable as to whether parents and infants share a community of interests sufficient to grant parental authority, and whether informed consent of parents can be valid.

We end with hope and expectation that parents will love and raise their children to be confident and satisfied, while preserving their child's right to make decisions so central to their identity and sexuality for themselves.

liability for refusing to allow male-to-female, fifteen year old to dress as a girl as recommended in her psychiatric treatment plan). There have been other positive developments for young victims of harassment. See, e.g., Nabozny v. Podlesny, 92 F.3d 446 (7th Cir. 1996). The United States Supreme Court recently held that school officials who act with "deliberate indifference" to known acts of student-on-student sexual harassment may be subject to liability. Harassment must extend beyond "mere teasing" and must be "so severe, pervasive, and objectively offensive that it effectively bars the victim's access to an educational opportunity or benefit." Davis v. Monroe County Bd. of Educ., 526 U.S. 629, 633 (1999).