Intersex in 2018: Evaluating the Limitations of Informed Consent in Medical Malpractice Claims as a Vehicle for Gender Justice

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Each year, hundreds of individuals are born intersex, meaning they have genitalia that do not meet the criteria for being exclusively male or female. For decades, doctors have performed corrective genital surgeries on intersex infants in an attempt to make it easier for them to grow up as “normal” boys and girls. In recent years, however, there is a growing consensus that cosmetic genital correctional surgeries are both unnecessary and often harmful to the long-term wellbeing of intersex individuals. Given increasing recognition of negative outcomes over the past decade, critics and activists have called for a moratorium on corrective genital surgeries performed on infants. In 2017, an intersex youth named M. Crawford obtained the first legal settlement ever in the United States challenging infant correctional surgeries under the doctrine of informed consent.

This Note explores the implications of this landmark legal settlement on efforts to combat nonconsensual genital correction surgery performed on intersex children. In particular, this Note explores the strengths and weaknesses of pursuing litigation based on the informed consent claims raised in M.C.’s lawsuit. This Note also offers alternative methods to combat the practice of performing intersex correctional surgeries.

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I. INTRODUCTION

Soon after birth, M. Crawford (M.C.) presented doctors with an ethical conundrum. M.C. was born with one testicle and one ambiguous gonad with both ovarian and testicular tissue. He also had a phallus of considerable size as well as a small vaginal opening below the phallus. M.C. was born an apparent anomaly — doctors could not easily determine whether he was male or female.

Although doctors concluded that M.C. could be raised as a boy or a girl and that there was no medical necessity to remove any his genital tissue, they still operated under traditional societal and medical constraints. They did not challenge the assumption that every infant must go home with a designation of sex on their birth certificate: boy or girl. As such, they viewed M.C.’s genital ambiguity as a problem to be solved immediately.

When M.C. was born, doctors initially designated him as a boy due to external genitalia. For a brief moment, the trouble had been remedied: M.C. could be raised as a typical child. Soon after M.C. left the hospital, however, the state of South Carolina took M.C. into custody following allegations of parental neglect. Doctors continued to question M.C.’s sexual identity based on his “ambiguous genitals” over the next few years. When M.C. was six months old, a doctor from Greenville Hospital Systems performed exploratory surgery on M.C. to further investigate his gender status. The doctor described M.C.’s case as “confusing,” because M.C. had a vagina and uterus but also a well-developed phallus, a “scrotalized labia,” and high testosterone levels. After consultation, doctors eventually diagnosed M.C. with a case of “true hermaphroditism.” In more appropriate terms, M.C was intersex.

2. Id. at para. 3.
3. Id. at para. 3.
4. See generally Judith Butler, Gender Trouble (Routledge, 2d ed. 2006).
6. Id. at para 3.
7. Id. at para. 20–22.
8. Id. at para. 23.
“Intersex” is a term used for a variety of sexual and anatomical differences that do not meet the typical definitions of male or female. It can present in a variety of ways: some individuals appear to be one sex externally and another internally, and others have genitals that seem to display some male and some female characteristics. M.C., for instance, was born with what doctors describe as an “ovotesticular disorder of sexual development,” which is “characterized by the presence of both ovarian and testicular tissue in the same individual.”

Doctors noted that M.C. “continue[d] to do well with no specific concerns or problems,” but the doctors still felt obligated to correct M.C.’s non-conforming body parts shortly after birth. Frantic to fix the apparent problem, doctors initially determined that M.C. could be raised as either a girl or a boy “with appropriate surgery.” By the next month, doctors recommended that M.C. should receive surgery to make his genitals traditionally female. The State, which still had custody of M.C. at the time, consented to the surgery. Several months later, when M.C. was six months old, surgeons removed the majority of M.C’s phallus. Doctors also castrated M.C. by removing both his one functional testicular and the testicular tissue in his other gonad. As a consequence of the surgical knife, M.C. would now be raised as a girl.

M.C. was raised as a girl by his adoptive parents. However, early on, he showed signs of rejecting his surgically imposed identity and refused to be identified as a girl. When he was seven,
M.C.’s parents let him pick out a male name.21 Today, M.C. is a fourteen-year-old boy.22 His early experiences with gender correction surgery may contribute to a challenging adolescence and adulthood. Although he will be able to use hormone replacement therapy to induce typical male development as he approaches puberty, M.C. will eventually face a long list of potential side effects, including scarring, reduced sexual sensitivity, and loss of sexual function.23

When M. Crawford’s adoptive parents brought suit against the hospital and the doctors that performed the surgery in 2013,24 their efforts seemed futile, as there was no existing legal precedent supporting recovery for non-consensual gender normalizing surgeries. However, in 2017 M.C. Crawford received a total settlement of $440,000 from the hospitals involved in performing and recommending the surgery.25 This settlement was the very first of its kind — never before had an intersex individual been able to recover damages for a cosmetic genital surgery performed on them as an infant.26

This Note explores the implications of this the landmark legal settlement on efforts to combat nonconsensual genital correction surgery performed on intersex children. In particular, this Note explores the practical and ideological implications of pursuing litigation based on the informed consent claims raised in M.C.’s lawsuit. This Note also offers suggestions for potential litigators on how best to combat the continued pathologization of intersex bodies, while also fighting to eliminate the practice of performing intersex correctional surgeries on minors going forward.

Part II of this Note examines the historical and ethical underpinnings of the surgical treatment of intersex differences and critiques the modern medical tendency to try to “correct” deviations from the sex binary. Part III discusses and critiques the use of informed consent for the purposes of obtaining remedy for correctional surgery performed on minors. In particular, this Part

22 Complaint, supra note 1, at para. 16.
23 Id. at para. 29, 49.
25 Azeen Ghorayshi, supra note 12.
26 Id.
argues that claims based on violations of informed consent do not do enough to challenge both the medicalization of intersex bodies and the tendency to pathologize intersex differences, rather than to treat them as natural and acceptable sex variations. Part IV offers two suggestions for activists and lawyers considering challenging intersex surgeries using the informed consent model in the future in the hope that future lawsuits will do more to challenge harmful assumptions about intersex differences.

II. MEDICAL INTERVENTION IN INTERSEX BODIES

A. INTRODUCTION TO INTERSEX

“Intersex” is a term used to describe a variety of conditions in which a person is born with reproductive or sexual characteristics that do not fit the traditional definitions of male or female. Intersex conditions have varying genetic presentations and physical manifestations. Estimates of the frequency of intersex individuals in the population vary due to disagreements about what counts as an intersex condition. However, in the medical community, the most commonly accepted estimate of intersex

27. InterACT FAQ, INTERACT ADVOCATES FOR INTERSEX YOUTH, https://interactadvocates.org/faq/ (last visited Oct. 18, 2018) [perma.cc/VM9E-SWRY].

28. The American Academy of Pediatrics currently recognizes over thirty different intersex conditions. Usually, these variations occur during prenatal development and can be caused by genetic mutations, changes in the number of sex chromosomes, and unusual levels of exposure of sex hormones. See Intersex Definitions, INTERACT ADVOCATES FOR INTERSEX YOUTH, https://interactadvocates.org/intersex-definitions/ (last visited Oct. 17, 2018) [perma.cc/WY67-PY6C].

29. See generally Melanie Blackless et al., How Sexually Dimorphic Are We? Review and Synthesis, 12 AM. J. HUM. BIOLOGY 151, 152 (2000). Blackless et al. have argued that the prevalence of intersex individuals might be as high as 2%, though the frequency of individuals receiving corrective surgery might be closer to the generally accepted 0.1 to 0.2%. This figure is accepted by a significant portion of the intersex community and has been relied on in a variety of literature. See, e.g., KATRINA KARKAZIS, FIXING SEX: INTERSEX, MEDICAL AUTHORITY, AND LIVED EXPERIENCE 136 (2008).

30. Id. There has been significant controversy over the use of the term “intersex” versus “disorder of sexual development.” See Georgiann Davis, The power in a name: diagnostic terminology and unique experiences, 5 PSYCH. & SEXUALITY 15, 15–27 (2014). Intersex differences are often referred to as disorders of sexual development by medical practitioners in part due to the 2006 Consensus Statement on the Management of Intersex Disorders. The Consensus proposed that “disorders of sex development” (DSD) replace other controversial commonly used terms to refer to individuals with atypical sex characteristics, such as the pejorative term, “hermaphrodites.” However, this change in nomenclature was met with dismay by many intersex activists, who argued that the term “disorder” suggested that intersex differences should be subject to medical attention and treatment. See interACT Statement on Intersex Terminology, INTERACT ADVOCATES FOR
individuals in the population is between one and two per 1000 live births worldwide.\textsuperscript{31}

Medical intervention in intersex bodies has been common in Western culture for over half a century. This has left intersex individuals without agency and created physical and psychological harms. Feminist critiques and modern developments, however, have recognized some of these harms and set in motion a movement towards accepting intersex differences.

B. HISTORY OF THE TREATMENT OF INTERSEX BODIES

Dr. John Money was one of the first doctors to seriously consider the intersex conditions through a pathological lens. In the 1950s and 1960s, he published a series of papers arguing that the most important determinant of gender outcome is gender socialization, or the “sex of assignment and rearing.”\textsuperscript{32} He argued that his research proved that the most predictive determinant of an intersex individual’s gender role and sexual orientation was the sex they were assigned at birth.\textsuperscript{33} Money concluded that intersex individuals could be successfully assigned either gender at birth, so long as they become “acquainted with and decipher[ ]” social signs that point in the direction of their assigned gender.\textsuperscript{34} Over the next twenty years, Money’s findings were used to justify surgical intervention on infants born with atypical genitalia at birth, based on the belief that proper socialization would ensure compliance with assigned sex.\textsuperscript{35} Mainstream medical practitioners

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INTERSEX YOUTH, https://interactadvocates.org/interact-statement-on-intersex-terminology/ [https://perma.cc/P7QH-6A3W] (last visited Nov. 12, 2018). The general population of intersex individuals is also divided on the desirability of DSD as nomenclature. A December 2017 study regarding attitudes about various names for intersex conditions found that the most preferred diagnostic term was “intersex,” followed closely by “variation in sex development” and “difference of sex development.” As such this Note uses the terms “intersex” and “intersex differences.”


32. John Money et al., Imprinting and the Establishment of Gender Role, 13 OBSTETRICAL & GYNECOLOGICAL SURVEY 293 (1957), reprinted in 77 A.M.A. ARCHIVES OF NEUROLOGY & PSYCHIATRY 333, 336 (1957). While the concept of gender socialization may bring to mind modern notions of gender as a social construct, Money’s ideas to deny agency to the individual in forming a gender identity.

33. Id. at 336.

34. Id. at 335.

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accepted Money’s theory of sex socialization, and Johns Hopkins Hospital established a Gender Identity Clinic, which performed genital correction surgery on infants for decades.\textsuperscript{36}

Money’s theory of gender socialization remained persuasive until the 1990s, when David Reimer, one of Money’s former subjects, publicly expressed extreme dissatisfaction with his genital correction surgery, as he felt he had been erroneously surgically assigned a female identity.\textsuperscript{37} In 2004, Reimer committed suicide following a battle to establish his male identity.\textsuperscript{38} Reimer’s public outcry about the suffering inflicted on him caused the medical community to reevaluate Money’s claim that sexual identity could be surgically molded.\textsuperscript{39} Over time, Money’s ideas have been increasingly criticized because they promote unnecessary surgical interventions that have failed to produce satisfactory outcomes for intersex patients.\textsuperscript{40}

Modern scientists have come to a more complete understanding of the many factors, including the variety of hormones and genes, that create intersex differences.\textsuperscript{41} However, many doctors still maintain an instinct to correct intersex differences, as they implicitly subscribe to a theory of gender essentialism, or the idea that “there are certain essential, biologically based or psychologically universal features of gender.”\textsuperscript{42} Most doctors in Western society\textsuperscript{43} subscribe to gender essentialism and believe

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that biological sex only has two possible expressions: male and female.\textsuperscript{44} When doctors who subscribe to the sex binary encounter intersex individuals, they may recommend surgery to ensure the individual fits into the established, rigid category of male or female.\textsuperscript{45} The medical profession’s tendency to reject and attempt to correct intersex bodies rather than accept them as natural expressions of sexual difference contributes to the continued practice of performing cosmetic gender correctional surgery on intersex infants.\textsuperscript{46}

In the days since John Money performed his first surgery on an intersex child in an attempt to correct his non-binary genitalia, numerous sex assignment surgeries have been performed on intersex infants, often without any urgent medical necessity.\textsuperscript{47} In rare instances, surgical intervention may be required to repair damage to urinary tract or exposed bladders, to prevent infertility, or in some rare cases, to remove gonads to prevent cancer (although such surgery can be undertaken after puberty).\textsuperscript{48} This Note does not dispute the necessity of such medically necessary surgeries. However, many of the surgeries undertaken on intersex minors are purely cosmetic and are performed to fix a perceived abnormality.\textsuperscript{49} Examples of operations designed to normalize intersex differences include clitoral reduction surgeries, which permanently remove sensitive and erotic parts of the clitoris, and gonadectomies (removal of gonads), which cause sterilization and end the natural production of sex related hormones.\textsuperscript{50} Unfortunately, there is no comprehensive database documenting the number of purely cosmetic surgeries performed on intersex minors, and practitioners, but medical literature demonstrates

\textsuperscript{44} Davis, supra note 36, at 72.
\textsuperscript{45} Id. at 78.
\textsuperscript{46} Id. at 72.
\textsuperscript{48} Id. at 23–24.
\textsuperscript{49} Id. at 24–25.
\textsuperscript{50} Id. at 25. For a complete list of the types of surgeries performed on intersex children at birth, see Peter A. Lee et al., Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care, 85 HORMONE RES. IN PAEDIATRICS 158 (2016).
that doctors across the United States continue to perform these surgeries.\footnote{Hum. Rts. Watch, supra note 47, at 48–49.}

**C. MODERN DEVELOPMENTS IN TREATMENT**

The most widely used contemporary criteria for identification and classification of intersex children was developed by a working group of fifty international experts working on intersex issues alongside several intersex activist groups in 2006.\footnote{Lee et al., supra note 41, at 488.} The resulting consensus (the “2006 Consensus”) called for more cautious and sensitive treatment of intersex differences. For example, the 2006 Consensus recommends weighing a multitude of factors when assigning a gender to an intersex child, including the “diagnosis, genital appearance, surgical options, need for lifelong replacement therapy, potential for fertility, views of the family, and, sometimes, the circumstances relating to cultural practices.”\footnote{Id. at 491.} The 2006 Consensus also acknowledges ongoing uncertainty about gender identity in intersex individuals and recognizes that “gender identity may change into adulthood.”\footnote{Id. at 496.}

However, the 2006 Consensus still operates within a gender essentialist framework that places premier importance on identifying a gender identity that falls within the binary soon after birth.\footnote{Id. at 490.} According to the 2006 Consensus, intersex individuals should be assigned a gender in an “expedit[ed]” manner so as to minimize “uncertainty” that is “unsettling and stressful for families.”\footnote{Id. at 491.} Furthermore, the 2006 Consensus using the controversial “disorders of sexual development” nomenclature, codifying the assumption that deviation from the sex binary is an abnormality to be treated and corrected.\footnote{Id. at 488.}

In 2016, physicians published an update to the 2006 Consensus (the “Consensus Update”).\footnote{Lee et al., supra note 50.} The Consensus Update keeps the controversial “disorder of sexual development” nomenclature despite acknowledging the “stigma of ‘disorder’” experienced by
many intersex individuals. Furthermore, despite admitting that “the concept of ‘gender identity’ is a psychological one” and that there is no “biomarker of gender identity,” the Consensus Update continues to stress the importance of giving intersex individuals a sex assignment of male or female at birth.

D. FEMINIST CRITIQUES

There are several distinct lines of criticism of infant correctional surgery in the intersex community. The first line of critique is pragmatic and is accepted even by those who adhere to strict gender essentialism and view intersex as a disorder. It is based on the premise that, while the benefits of correctional surgery at a young age are largely unproven, the potential negative outcomes are well-documented and widespread.

In 2014, Milton Diamond, a leading proponent of a moratorium on intersex correctional surgeries on children, published an article in the leading pediatric urology journal reviewing evidence of the efficacy of such surgeries from various studies from 1974 to 2012. Diamond found that the studies purporting to demonstrate positive outcomes for correctional surgery on children suffered from “methodological weakness[es]” and that they “lack the necessary detail [on which] to base further recommendations.”

59. Id. at 159.
60. Id. at 168.
64. Id. at 2.
Even studies documenting positive outcomes for early surgery were limited in their claims about the usefulness of early surgical intervention, often advocating for medical restraint. Recent studies have also documented a wide range of negative effects from early surgery. In 2001, one study found that “adult patients are unhappy and feel mutilated and damaged by surgery performed on them as young children.” After studying a variety of intersex differences over the next several years, she argued that “most vaginal surgery in childhood should be deferred.” Christopher Houk and Peter Lee reviewed cases of children born with congenital adrenal hyperplasia, the most prevalent cause of intersex difference among people with XX chromosomes, and found that many patients raised as males without surgical intervention were satisfied with their outcomes.

Diamond also argues that doctors lack evidence to support their recommendations that infants undergo early correctional surgery. For example, in 2010, the Endocrine Society (the “Society”) admitted there was a complete deficit of studies of “either the best age or the best methods for feminizing surgery” for infants with congenital adrenal hyperplasia and that there was “no evidence at this time that either early surgery or late surgery better preserves sexual function.” Despite this lack of evidence, the Society has continued to recommend early surgery, even in infancy, for severe cases.

65. Id. at 4.
70. Phyllis W. Speiser et al., Congenital Adrenal Hyperplasia Due to Steroid 21-Hydroxylase Deficiency: An Endocrine Society Clinical Practice Guideline, 95 J. OF CLINICAL ENDOCRINOLOGY & METABOLISM 4133, 4143 (2010). Early surgeries typically occur when an individual is an infant and cannot consent to the surgery. Later surgeries occur when the individual is an adolescent and may begin consenting to surgical procedures without a legal guardian.
71. Id. at 4133. Severe cases of CAH involve deviations from typical female genital presentation including the presence of an enlarged phallus, fusion of the labia, and a partially formed scrotum.
The benefits of early surgical intervention are unproven at best. At worst, early surgical intervention in the absence of imminent danger to health can interfere permanently with an individual’s erotic sensitivity and bodily autonomy, and often leaves patients traumatized for life. Given the insufficient evidence that the surgeries are working as intended, activists and some members of the medical profession have begun to call for a moratorium on corrective genital correctional surgery on infants.

The second line of criticism of correctional surgery performed on intersex surgery focuses less on the practical outcomes of the surgery and more on the belief that intersex differences are accepted expressions of human sexual diversity and attempts to force bodies to conform to the sex binary are wrong. This line of criticism is based in large part on recent developments in feminist and scientific understanding of human sexual diversity. There has been a general movement amongst feminists towards rejecting the belief that sex classification is solely determined by biology. Instead, feminist theories argue that the sexual binary is a construct and does not reflect the true range of human sexual diversity.

73. HUM. RTS. WATCH, supra note 47, at 9.
74. HUM. RTS. WATCH, supra note 47, at 154.
75. Some feminists view gender and sex as distinct categories. Gayle Rubin, for instance, suggests that while sex reflects real biological differences, gender is the “socially imposed division of the sexes” that dictate how women and men should behave. See Gayle Rubin, The Traffic in Women: Notes on the ‘Political Economy’ of Sex, in TOWARD AN ANTHROPOLOGY OF WOMEN 157, 179 (1975). Other feminists, like Judith Butler, argue that there are no relevant distinctions between sex and gender, as both exist only as social constructions. See Butler, supra note 4; see also Allison Stone, Essentialism and Anti-Essentialism in Feminist Philosophy, 1 J. OF MORAL PHILOS. 135, 137 (2004). By the 1980s and 1990s, biological essentialism was no longer a commonly held viewpoint by feminists. However, some feminists have since endorsed non-biological forms of essentialism — namely, the idea that women essentially share certain socially constructed experiences and identities. Although anti-biological essentialism rejects the idea that biology is the sole determinant of sex and that sex is determined entirely by biological features, there is still room for debate over whether some differences between the sexes have biological causes. Some feminists are willing to embrace the idea that biology plays an important role in sex development. For example, some feminists are striking out to develop a new field of “feminist neuroscience,” which aims to further investigate the neuroscientific bases for sex and gender while addressing the sexist biases that have long pervaded neuroscientific research on the subject. See Schmitz & Hoppner, Neurofeminism and Feminist Neurosciences: A Critical Review of Contemporary Brain Research, FRONTIERS IN HUM. NEUROSCIENCE (July 25, 2014).
76. The work of queer theorists and feminists has been especially influential in the realm of social work. In particular, members of the social work community have called on their peers to avoid adhering to the traditional gender dichotomy when dealing with
Beyond feminist theory, there is significant empirical evidence that the biological division between male and female is not as straightforward as previously believed. Scientists have isolated more than twenty-five genes that affect sex development in a variety of ways, some obvious and some subtle. Furthermore, individual cells inside the same typical human body can have different sets of sex chromosomes. As such, it is becoming increasingly clear that “anatomy, hormones, cells, and chromosomes... are actually not usually aligned with one binary classification.”

The existence of intersex differences also supports claims that biology is not the sole determinant of sex and that sex can extend beyond binary categories. Suzanne Kessler was one of the first feminists to identify intersex differences as evidence that the sex binary cannot encompass the full diversity of human sex. In 1990, she published a landmark study of intersex bodies, coming to striking conclusions about the current medical protocols for dealing with intersex children. She criticized the tendency of the medical profession to think of intersex differences as abnormalities rather than natural and otherwise immutable iterations of sex, despite the physician’s understanding that “concordance and dimorphism do not always exist” in the biological world. She suggested that physicians instead accept genital ambiguity as a “natural option” rather than attempt to perpetuate the myth of binary gender.
Anne Fausto-Sterling similarly argues that genital correction surgeries performed on infants are wrong because they are “performed to achieve a social result — reshaping a sexually ambiguous body” to ensure it conforms with the binary system. In her book *Sexing the Body*, Fausto-Sterling explores a future where new technology would allow doctors to ensure all children are perfectly within the binary of male or female. She rejects this future and instead calls for a society that avoids medical enforcement of the gender binary and “permits ambiguity to thrive.” Similarly, Kessler suggests that cosmetic genital correctional surgery should never be used to impose the gender binary on infants. Instead, in a society more tolerant of gender variation, such procedures would exist only for adults consenting to mold their genitals, much like getting a haircut.

Feminist critiques of correctional surgery performed on intersex infants are increasingly making their way into mainstream publications. In 2017, Human Rights Watch published a 160-page report entitled “I Want to Be Like Nature Made Me: Medically Unnecessary Surgeries on Intersex Children in the US.” This report adopts feminist arguments that biological explanations of sex are “oversimplif[ied]” and that sex exists on a “spectrum” rather than within a binary. Human Rights Watch advocates for a moratorium on cosmetic correctional surgeries in children, arguing that such early interventions are effectively a “surgical solution for a social problem.” Additionally, the United Nations Special Rapporteur on Torture has recently condemned intersex correctional surgeries, not only because the “procedures are rarely medically necessary” and may cause health problems later in life, but also because the surgeries “contribut[e] to stigma” against members of the intersex community and

84. Id. at 101.
85. Id.
87. Id.
88. HUM. RTS. WATCH, supra note 47, at 5.
89. HUM. RTS. WATCH, supra note 47, at 105.
91. Id.
constitute “discrimination on the grounds of sexual orientation or gender identity.”92 The shift in viewing intersex correctional surgeries not only as a medical problem but as a social issue based on heteronormative conceptions of gender is paramount to the advancement of intersex rights going forward.

In the next Part, when discussing the use of informed consent as a tool for vindicating the rights of intersex individuals, this Note relies heavily on the feminist belief that intersex differences are not medical problems to be corrected but rather natural expressions of human sexual diversity.

III. INFORMED CONSENT

A. A CASE STUDY ON THE USE OF INFORMED CONSENT TO CHALLENGE INFANT INTERSEX SURGERIES

For the first time, questions about the proper role of the medical profession in “treating” intersex differences have taken on a legal dimension. As discussed in Part I, in 2013, Pam and Mark Crawford brought a lawsuit on behalf of their adopted son, M.C., against the Medical University of South Carolina and the Greenville Hospital System, where M.C. received “medically unnecessary sex assignment surgery”93 at the age of sixteen months to treat his ovotesticular disorder of sexual development.94 They also sued the South Carolina Department of Social Services, which had held him in custody at the time of the procedure and consented to the surgical intervention.95 Although the Crawfords filed claims in both state and federal court, only the state court claims made it past a motion to dismiss.96

92. Id. at 19.
93. Complaint, supra note 1, at para. 1.
94. Complaint, supra note 1, at para. 6.
95. Complaint, supra note 1, at para. 4–5.
96. M.C. Crawford’s first lawsuit in federal court ended when the Fourth Circuit reversed and remanded so that the district court could grant the defendants’ motion to dismiss. In federal court, the Crawfords claimed that M.C.’s surgery violated his Fourteenth Amendment substantive and procedural due process rights. The Fourth Circuit found the plaintiffs did not allege sufficient facts to avoid dismissal of the defendant’s qualified immunity defense because they failed to “make out a violation of a constitutional right” that was “clearly established at the time” of the alleged violation. The court found that M.C.’s alleged constitutional rights, namely, “an infant’s constitutional right to delay sex assignment surgery,” the right to bodily integrity, the right to privacy, and the right to a “pre-deprivation hearing” prior to the surgery, were not “clearly established rights” that
The state court claims against the university and hospital system were brought under the doctrine of informed consent. The common law duty of informed consent obligates doctors to disclose information pertaining to diagnosis, procedures, and the likely outcomes of procedures. Furthermore, the duty “obligates doctors to take reasonable steps to ensure that the party providing consent is competent to do so.”

As a minor, M.C. was too young to provide consent, and was under the care of the South Carolina Department of Social Services at the time of the surgery. The complaint alleges that the Greenville Hospital System did not obtain informed consent from the South Carolina Department of Social Services because they “failed to adequately disclose the material risks of gender misassignment, loss of sexual function, and sterilization to the person who provided authorization for the surgery” and because they “did not disclose that surgery was not medically necessary for Plaintiff’s health, that it was irreversible, that it could be postponed until the gender identity was more certain, and that it could cause significant and permanent injury to Plaintiff.”

In July 2017, the Crawfords’ claims against both the Medical University of South Carolina and the South Carolina Department of Social Services settled for a total of $440,000. This settlement was the very first of its kind — never before had a plaintiff been

97. Complaint, supra note 1, at para. 42. The complaint further alleged gross negligence on the part of the South Carolina Department of Social Services under the South Carolina Tort Claims Act. However, this cause of action is generally outside the scope of this Note, as it pertains to the special relationship between M.C. and the state at the time of his surgery and is not applicable to the vast majority of cases involving intersex correctional surgery performed on infants, which usually involve a parental decision maker.

98. Complaint, supra note 1, at para. 42. As stated in the Complaint, the doctrine requires the doctor to disclose: “(1) the diagnosis; (2) the general nature of the contemplated procedure; (3) the material risks involved in the procedure; (4) the probability of success associated with the procedure; (5) the prognosis if the procedure is not carried out; and (6) the existence of any alternatives to the procedure.”

99. Complaint, supra note 1, at para. 42.

100. Complaint, supra note 1, at para. 44.


able to recover damages for “medical bills, pain and suffering, psychological damages, and permanent impairment” suffered as a result of intersex correctional surgery at birth.\textsuperscript{103} Although neither defendant admitted to liability in the settlement, the suit is instructive for potential intersex plaintiffs going forward.

B. DESCRIPTION OF INFORMED CONSENT

The doctrine of informed consent refers to the requirement that doctors must inform the patient about certain information about the nature of the treatment before they are able to legally consent to it.\textsuperscript{104} Informed consent is based on the idea that “[p]atients have the right to receive information and ask questions about recommended treatments so that they can make well-considered decisions about care.”\textsuperscript{105} The common law doctrine developed based on the tort of battery, but today is part of the doctrine of tortious negligence.\textsuperscript{106}

Informed consent standards vary from state to state. In about half of states, the physician-based standard measures the duty of disclosure according to what a “reasonable medical practitioner” would disclose in a similar situation.\textsuperscript{107} In the remaining states, a “reasonable patient” standard requires the provider to disclose “what a reasonable patient would find material in making an informed decision.”\textsuperscript{108} Although the standards may produce slightly different outcomes, informed consent generally requires disclosure of the following information: “(a) diagnosis; (b) nature

\textsuperscript{103} buzzfeednews.com/article/azeenghorayshi/intersex-surgery-lawsuit-settles [perma.cc/4Q6E-2LJW].
\textsuperscript{104} Id. at 2.
\textsuperscript{105} Peter H. Schuck, \textit{Rethinking Informed Consent}, 103 YALE L.J. 899, 907 (1994). In the health care context, the principle underlying informed consent is the idea that doctors owe patients a fiduciary duty to act in the patient’s best interests and to disclose all information material to those interests. In South Carolina, the physician is required to “inform patient of material risks inherent in proposed treatment or procedure.” Hook v. Rothstein, 281 S.C. 541, 553 (S.C.App.,1984). The scope of the duty “is measured by those communications a reasonable medical practitioner in the same branch of medicine would make under the same or similar circumstances.” Id.
\textsuperscript{108} Id. at 146.
and purpose of treatment; (c) material risks and outcomes; (d) skills or status risks; (e) alternatives; (f) prognosis if treatment declined; (g) prognosis with treatment; (h) conflicts of interest.”

Legal minors are considered incapable of giving informed consent. As such, courts have substituted the traditional informed consent requirement with a parental consent requirement in cases involving minors, based on the theory that parents both have a duty to provide care to their children and are presumed to act in the best interests of their children. Furthermore, courts assume that parents “possess what a child lacks in maturity, experience, and capacity for judgment required for making life’s difficult decisions.”

Accordingly, before a physician performs genital correctional surgery on an infant child, they must obtain informed consent from the child’s legal guardian or parent. M.C.’s complaint argued that the health care providers that performed M.C.’s surgery failed to obtain informed consent for the surgery from the State, which was serving as M.C.’s legal guardian at the time of the surgery. Specifically, the complaint alleged “defendants ... failed to adequately disclose the material risks of gender misassignment, loss of sexual function, and sterilization to the person who provided authorization for the surgery or to others involved in authorizing the decision.” In addition, the defendants allegedly “did not disclose that surgery was not medically necessary for Plaintiff’s health, that it was irreversible, that it could be postponed until the gender identity was certain, and that it could cause significant and permanent injury to Plaintiff.”

C. ASSESSING THE USEFULNESS OF INFORMED CONSENT IN THE INTERSEX CONTEST

Informed consent is a powerful tool for challenging intersex correctional surgeries performed on minors. M.C.’s settlement would not have been possible without it. However, this Note
recommends future litigants pursue lawsuits based on informed consent with a cautious. In particular, the use of informed consent is complicated for three reasons: (1) The standard of care for treating intersex individuals is controversial and ever-changing, and professionals do not agree about what constitutes a good outcome for intersex patients, what level of disclosure is required, and what constitutes a material risk; (2) Even if they are fully informed, parents may still consent to harmful surgeries due to their own biases and fears; and (3) The informed consent model fails to challenge the idea that intersex differences require cosmetic medical treatment. Although this Note does not suggest informed consent should never be used to challenge intersex surgeries, litigators and activists should keep such problems in mind when planning the best course of action for advancing the interests of intersex clients.

1. Disputes Over Standard of Care

As the Consensus Update puts it, “[n]o area of pediatric endocrinology engenders more controversy than the management of DSD conditions affecting reproductive development.” Medical professionals disagree about the standard of care for intersex individuals, including the proper “timing, procedure, and evaluation of outcome.” This is largely because a lack of outcome data “make[s] it difficult to determine whether and when to pursue gonadal or genital surgery.” Information about outcomes in the treatment for intersex individuals is sparse and incomplete for a variety of reasons. First, intersex individuals are uncommon, creating difficulties in obtaining a large enough sample size for a study. Second, follow-up studies are very rare, making generally accepted conclusions about outcomes for even the most standard treatments difficult. Furthermore, data about outcomes for intersex individuals who did not undergo any corrective surgeries

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116. Lee et al., supra note 50, at 176.
117. Lee et al., supra note 50, at 176. See also Aimee M. Rolston et al., Disorders of Sex Development (DSD): Clinical Service Delivery in the United States, 175 AM. J. MED. GENETICS 268, 276 (2017) (“Our survey also showed marked variability across institutions in practices surrounding continuing education, informed consent, and clinical management.”).
118. Lee et al., supra note 50, at 170.
120. HUM. RTS. WATCH, supra note 47, at 83.
is almost entirely nonexistent. This combination has contributed to widespread disagreement about when and how to perform correctional surgery on intersex minors.

A lack of a uniform standard of care for intersex patients may make it difficult for lawyers, judges, and medical professionals to determine what conditions must be present for informed consent to be obtained in the first place. Although informed consent criteria vary in different courts, generally speaking, informed consent requires that the patient (or in this case, the patient’s parents) receive enough information from the physician to inform their consent to treatment. If health care practitioners are unable to agree on the proper standard of care because they do not know the consequences or outcomes of specific surgical treatments, it is difficult to see how judges in jurisdictions that follow the reasonable practitioner standard are supposed to discern what a “reasonable practitioner” would find relevant to disclose. This difficulty in discerning the proper standard of care makes it difficult for plaintiffs to argue that reasonable practitioners would disclose the disputed and relatively sparse empirical evidence that early intersex correctional surgeries may be harmful to individuals.

2. Disputed Disclosure Requirements

Additionally, the degree of honesty required of doctors telling parents about a child’s intersex condition is not settled within the medical community. Doctors treating intersex children have historically withheld essential information to parents when advocating for surgery “in part because of the belief that there would be difficulties accepting the implications of full disclosure.” The Consensus Update suggests that “open and complete communications are mandatory when there is uncertainty in decision making” about intersex conditions.

121. See HUM. RTS, WATCH, supra note 47, at 83. “There is also a lack of data regarding outcomes among individuals who did not undergo surgeries — a gap that practitioners frequently cited in interviews with Human Rights Watch as a reason they felt they could not advise parents to forego medically unnecessary surgery.” Ironically, health care providers do not appear to be as concerned about the lack of evidence supporting the idea that intersex individuals should be operated on as infants.


123. Lee et al., supra note 50, at 170.

124. Lee et al., supra note 50, at 170.
Human Rights Watch documented that, while intersex specialists are increasingly disclosing complete medical information, many doctors still “hesitate to be completely honest.”\textsuperscript{125} One provider stated that she has difficulty determining what level of information is appropriate to give parents and often strikes a balance between “answering [parents’] questions and not necessarily giving them too much information they don’t want to hear.”\textsuperscript{126} If it is still common practice for practitioners to withhold information pertaining to an intersex diagnosis, a judge may find no violation of informed consent requirements in cases where some information about correctional surgery is not disclosed, especially if operating under the “reasonable medical practitioner” standard of informed consent.

This problem may be slightly mitigated in jurisdictions that have a reasonable patient standard, because it is arguable that a reasonable patient would prefer doctors disclose all material information regarding correctional surgery. However, some parents of intersex patients do not want to be provided with all pertinent information about their child’s diagnosis. Some practitioners have encountered parents who requested they not disclose a child’s status to them at all.\textsuperscript{127} Judges faced with a variety of parental attitudes regarding disclosure might therefore find it practically difficult to determine how much disclosure a “reasonable” patient would require.

3. \textit{Disagreement about Material Risks}

Practitioners are also unable to agree about the likelihood that intersex correctional surgery will result in an adverse outcome, or even what constitutes an adverse outcome. This question bears directly on one of the most important components of informed consent in many jurisdictions — disclosure of material risks.\textsuperscript{128} Generally speaking, a physician has an obligation to “advise his or her patient of the material risks of undergoing a medical

\textsuperscript{125} Human Rights Watch, \textit{supra} note 47, at 39.
\textsuperscript{126} Human Rights Watch, \textit{supra} note 47, at 40.
\textsuperscript{127} Human Rights Watch, \textit{supra} note 47, at 39.
\textsuperscript{128} 88 A.L.R.3d 1008 (Originally published in 1978) (discussing the view that “a physician’s duty to disclose the risks of a proposed treatment exists as a matter of law if the risk of injury inherent in the treatment is material, if there are feasible alternative courses available, and if the patient can be advised without detriment to his well being”).
procedure.” Material risk has different meanings depending on the jurisdictional standard, but generally refers to risks that a “physician knows or ought to know would be significant to a reasonable person in the patient’s position in deciding whether or not to submit to a particular medical treatment or procedure.”

Faced with diverging information from practitioners about what constitutes a material risk and little statistical evidence to justify claims on either side, judges may determine informed consent for intersex correctional surgeries does not require disclosure of all risks inherent in the surgeries.

Widespread anecdotal documentation of the adverse effects of intersex correctional surgeries performed on children, includes evidence of scarring, loss of sexual function, loss of fertility, and lifelong pain. But Katrina Karakazis notes that “surgeons frequently dismissed the complaints of adults with intersex diagnoses as those of the disgruntled [and vocal] minority.” One surgeon suggested that “public debate over intersex surgeries was too often lopsided to favor the voices of those who were unhappy with their surgeries.” Another suggested “certain outcomes — such as being able to stand while urinating — could be important enough to justify the risks and loss of autonomy caused by surgery.”

One recent review of outcomes of intersex surgeries performed on infants was laden with such apparent contradictions between the doctor’s and the patient’s assessment of outcomes.

129. 61 AM. JUR. 2D PHYSICIANS, SURGEONS, ETC. § 173 (1981).
130. Id.
131. See id. at 6, 25, 55; see also Paul K H Tam et al., Long-term Implications and Global Impact of Paediatric Surgery, 390 THE LANCET 1012, 1012 (2017) (“For example, early reduction clitoroplasty for enlarged clitoris in female DSD can compromise later sexual function, and often leads to major concerns about gender identity, body habitus, and psychosexual functioning.”).
133. HUM. RTS. WATCH, supra note 47, at 98.
134. HUM. RTS. WATCH, supra note 47, at 100. Practitioners have expressed concerns that children will be bullied or face stigma if they are allowed to maintain their natural, gender nonconforming bodies. Practitioners regularly justify medical interventions on the ground that they will be preventing the child from being bullied later in life. Id. at 103. However, the proposed surgical remedies have never been shown to prevent bullying or social stigma. Id. On the other hand, a 2017 study on deferring surgical treatment of girls with congenital adrenal hyperplasia (which generally involves a statistically large clitoris) found that the participants and their parents did “not express . . . significant concerns regarding genital ambiguity.” Id.
135. One review of thirteen articles pertaining to outcomes of intersex care found that the studies were lacking in several respects. See Paula Machado et al., Follow-up of Psychological Outcomes of Interventions in Patients Diagnosed with Disorders of Sexual
This tendency of some doctors to determine the complaints of intersex individuals are either exaggerated, unproven, or relatively unimportant shows they are less likely to consider them material risks for the purposes of informed consent.

Other practitioners appear to overemphasize certain risks of refraining from surgery. In particular, one urologist “equated choosing not to do surgery on intersex children with setting them up for extremely negative psychological outcomes,” stating that “to abstain from surgery for sex assignment . . . would result in ‘97% of [his patients having] gender dysphoria.’”\(^{136}\) However, there is little evidence that leaving an intersex individual’s genitals intact causes psychological damage,\(^{137}\) suggesting that these doctors’ fears might be motivated in part by their own disquiet about intersex identities and cultural pressures to conform to societal norms.

When judges attempt to determine what constitutes material risk in the informed consent context for infant correctional surgeries, they will be guided by the relevant medical literature and standard of care. However, as discussed, many doctors either downplay or ignore altogether the complications and risks associated with infant correctional surgery. Additionally, a judge’s determination of the severity of the risks involved will be inevitably shaped by her own beliefs about whether intersex differences are abnormalities to be corrected. The lack of consensus regarding significant material risks exist in the infant development.

\(^{136}\) See \textit{Hum. RTS. Watch}, supra note 47, at 101. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), a gender dysphoria diagnosis involves “incongruence between one’s experienced or expressed gender and one’s assigned gender” and “is associated with clinically significant distress or impairment in social, school, or other important areas of functioning.” \textit{Am. Psych. Ass’n, Diagnostic and Statistical Manual of Mental Disorders} (5th ed. 2013).

\(^{137}\) See \textit{Lee et al.}, supra note 50, at 167 (“It has been hypothesized that body differences associated with DSDs may harm well-being although inconsistently. The high prevalence of the normalizing surgery makes it impossible to separate the psychological impact of body differences and surgical management.”).
correctional surgery context contributes to the considerable risk that judges will continue to allow doctors to escape liability for surgical procedures as long as they operate within the current and insufficiently protective boundaries of the standard of care for intersex children.

4. Parental Conflicts of Interest

Even if medical practitioners could agree on a standard of care that would satisfactorily protect the interests of intersex minors, such that judges could create an informed consent standard that would adequately warn the parents of minors of all associated risks of early correctional surgery, there would still be no guarantee that the parents of intersex children would decline surgical intervention. Parents do not make medical decisions about their intersex children’s medical treatment in a vacuum — they import all of their own cultural assumptions about gender and sex into the decision-making process. Even if doctors provide parents with all relevant information about the risks and outcomes of early correctional surgery, some parents will still decide to approve the surgery. As such, the doctrine of informed consent may be inadequate to protect intersex minors from the conflicting interests of their own parents.

Many parents of intersex children experience extreme distress when faced with the diagnosis, even when doctors provide accurate and complete information about the diagnosis. Psychologist Vickie Pasterski and her colleagues found that “both mothers and fathers [of intersex children] reported overall levels of PTSS [post-traumatic stress syndrome] that were comparable to those reported by parents of children diagnosed with other disorders, in this case, cancer.” Some practitioners have documented “broad parental concerns about how the child would grow up — ranging from gender identity outcomes to fears of homosexuality.” Other parents are overwhelmed by the practical realities of having an intersex child and feel unequipped to raise a child with ambiguous genitalia and unique medical needs.

139. HUM. RTS. WATCH, supra note 47, at 114.
Even if parents are adequately informed about the risks of correctional surgery, fear may drive the decision. Many parents adhere to biological essentialist accounts of gender and base their decisions to perform surgery on a desire to conform to the norms of the gender binary. Families will often view intersex characteristics as a “medical problem” that can be easily fixed via a medical solution and find themselves unwilling to entertain more complex views of gender identity and development. In interviews, parents who elected correctional surgery sometimes stated they would perform the surgery again “no matter what risk types or rates the surgeons had cited to them — they wanted their children to look ‘normal.’” One doctor summarized: “[s]ome families, for cultural, religious, or psychological reasons, may feel very strongly about the importance of trying to have their child look more typically male or female.” Another stated that “most parents of infants still see surgery as a quick fix option no matter what we say.” Under such circumstances, doctors may feel obligated to perform these surgeries in order to comply with parental wishes.

Informed consent will offer no legal recourse to the intersex individual whose parents elected correctional surgery despite adequate knowledge of the condition, material risks, and possible outcomes of the surgery. Such outcomes are likely so long as parents feel the need to conform to societal, cultural, and religious conceptions of gender and sex.

140. Id. at 115.
141. Id. at 12.
142. DAVIS, supra note 36, at 123. In her interviews with the doctors of intersex children, Georgiann Davis found that many practitioners justified performing such surgeries in part on the grounds that parents wanted to “align a child’s sex and gender” as quickly as possible.
143. HUM. RTS. WATCH, supra note 47, at 115.
144. This is because informed consent claims require both that the physician or medical provider did not present the risks and benefits of the proposed treatment and that with full information, the patient (or their representative) would have declined the treatment. In cases where parents are fully aware of all the material risks and benefits of the treatment and still consent to the treatment for their infant child, there is no informed consent claim. See Edward L. Raab, The Parameters of Informed Consent, 102 TRANS. AM. OPHTHALMOLOGICAL SOC’Y 225, 226 (2004).
D. INFORMED CONSENT AND THE MEDICALIZATION OF INTERSEX BODIES

Challenging the performance of cosmetic surgeries on intersex individuals for violations of informed consent may also inadvertently reinforce the idea that intersex differences should be viewed as medical conditions from the outset. Informed consent challenges do nothing to dispute the idea that cosmetic medical intervention can be performed on minors so long as the parents are appropriately aware of the risks and outcomes. Informed consent suits do not challenge cosmetic surgical intervention as ipso facto violations of fundamental rights or discrimination against gender minorities. In fact, if actions for violations of informed consent become the standard method for challenging cosmetic surgical interventions on intersex bodies, all that doctors will have to do to avoid liability is ensure transparency with parents about risks and outcomes of the surgeries.

Davis argues that the continued medicalization of intersex bodies, namely, the current propensity towards letting questions of intersex identities continue to be resolved by medical professionals rather than by members of the intersex community or other interest holders “perpetuate[s] medical authority over the intersex body.”\(^\text{145}\) Operating within the medical malpractice model also codifies and reinforces the use of clinical terms, such as “disorders of sexual development,” that continue to make doctors the principal determinants of the validity of intersex identities.

If intersex advocates elect to operate within the informed consent framework, they are accepting the medical profession’s initial premise that intersex bodies should be subject to medical intervention. For example, M.C.’s complaint focuses on the damage inflicted by doctors and the state for “fail[ing] to adequately disclose the material risks of gender misassignment . . . “including the fact that the surgery “was not medically necessary for the Plaintiff’s health, that it was irreversible, that it could be postponed until the gender identity was certain, and that it could cause significant and permanent injury to Plaintiff.”\(^\text{146}\) What is missing from the complaint (and necessarily from any medical malpractice claim regarding intersex differences) is a discussion of

\begin{footnotes}
\item[145] Davis, supra note 36, at 7.
\item[146] Complaint, supra note 1, at para. 44.
\end{footnotes}
the variety of social and moral wrongs perpetuated by medical providers who impose the gender binary and ideologies of gender essentialism on their patients. The informed consent tort cannot address or call into question the underlying assumption inherent in the treatment of all intersex bodies: there is something about this body that needs to be fixed. There is no discussion of potential violations of fundamental human rights, such as the right to self-determination, bodily integrity or the right to reproduction. There is no inkling that such surgeries might inherently constitute discrimination against a sexual minority.

The problem of intersex is not a problem of medical science per se. Rather, it is a problem of social conditioning in which medical providers are able to impose their own ethical accounts of what constitutes “normal” and what constitutes “disordered.” Causes of action based on whether a particular provider adhered to a generally accepted standard of care as created by the medical community cannot address the broader social question of whether intersex bodies should be subject to ‘correction’ in the first place. As suggested by Hester, “improvements” to informed consent will not change “the argumentative representation of the intersexed condition as a non-normal/non-normative that constrains the choices made by both parents and physicians.”\(^{147}\) They offer little space to question and dismantle the inherently value-laden assumptions of the medical profession that the gender binary is a good thing and children should adhere to it, even if they must undergo permanent and painful surgery in order to do so.\(^{148}\)

IV. LOOKING FORWARD

Informed consent plays an important role in the movement to vindicate the rights of intersex individuals and to protect intersex children from unnecessary surgical intervention without their consent. Advocates and litigators may also find the informed

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148. See Tania M. Jenkins & Susan E. Short, Negotiating Intersex: A Case for Revising the Theory of Social Diagnosis, 175 SOC. SCI. & MED. 91, 95 (2017). Jenkins uses the theory of social diagnosis to argue that a variety of extra-medical structures frame diagnosis and the medicalization of intersex issues. Id. at 92. She suggests that social actors can use the framework of social diagnosis to examine the various factors contributing to medicalization and to “resist the pathologization of symptoms and conditions” in the future. Id. at 91 (emphasis omitted).
consent model alluring, given that no other claims have led to successful settlements thus far. Furthermore, informed consent claims may prove more viable than efforts to enact legislative bans on infant correctional surgery in politically conservative states. However, as discussed above, the informed consent model has both practical and structural limitations, especially as society and the medical profession largely continue to adhere to outdated conceptions about the relationship between sex, gender, and sexuality. Although the informed consent model is plagued with problems, it is unlikely that advocates will abandon it entirely in the future. As such, this Note offers two practical recommendations for advocates to consider in framing future complaints and arguments in the informed consent context.

A. CHARACTERIZE GENITAL CORRECTIONAL SURGERY AS “EXPERIMENTAL TREATMENT”

In several states, informed consent in the context of “experimental” treatment requires the health practitioner to disclose the experimental nature of the treatment. In *Ahern v. Veterans Administration*, the Tenth Circuit held that under the Federal Tort Claims Act, physicians who “engag[e] in drastic or experimental treatment which exceeds the bounds of established medical standards” must inform their patient of the “experimental nature of treatment and of foreseeable consequences of that treatment.” In this lawsuit, John Ahern received treatment from the Veteran’s Administration for a cancerous tumor that included radiation in quantities that were perceived by medical experts to be “drastic” given the short time frame in which they were administered. Ahern admitted he was aware that he would be given the radiation treatment but argued he had not been “fully informed of the experimental aspects of the treatment,” including “the possible consequences of administering large daily dosages.” The court agreed that the treating physician could not avoid liability for this experimental treatment unless the patient was fully informed of its experimental nature and risks.

149. *Ahern v. Veterans Admin.*, 537 F.2d 1098, 1102 (10th Cir. 1976).
150. *Id.* at 1099.
151. *Id.* at 1101.
152. *See id.* at 1102.
Subsequent courts and legislatures have followed suit in a variety of contexts. In 1981, the FDA amended its rule regarding informed consent to require disclosure of the nature of all experimental procedures.\textsuperscript{153} Several state courts have also found causes of action in cases where the experimental nature of a procedure was not disclosed to a patient.\textsuperscript{154}

There is no generally applicable definition of an “experimental,” as opposed to “standard,” treatment — and there are good reasons to suggest most procedures exist somewhere on a sliding scale rather than as a dichotomy.\textsuperscript{155} Stanley Reiser argues that experimental treatment becomes standard when four criteria are met: (1) the treatment has “established indications of use” that specify “the issues of for whom, for what, and how much a given therapy should be used”;\textsuperscript{156} (2) the treatment has “specified outcomes of care” so that there is limited uncertainty about the “short- and long-term benefits and harms” of the procedure;\textsuperscript{157} (3) the treatment has “standardized requirements of application” that homogenize “the manner in which a given therapy is applied”;\textsuperscript{158} and finally (4) the treatment has “articulated criteria for learning and certification” defining the requirements and skills needed by a professional to administer the treatment.\textsuperscript{159}

Gender correctional surgery, especially when performed on minors, does not meet several of the requirements as postulated by Reiser for a standard procedure. First, as discussed previously, evidence about the short- and long-term outcomes of correctional surgeries is extremely limited by both the small population size of the intersex community and the lack of follow-up on outcomes into

\begin{itemize}
  \item \textsuperscript{154} See Estrada v. Jaques, 70 N.C. App. 627, 630, 321 S.E.2d 240, 254 (1984) (“Where the health care provider offers an experimental procedure or treatment to a patient, the health care provider has a duty, in exercising reasonable care under the circumstances, to inform the patient of the experimental nature of the proposed procedure.”); see also Shadrick v. Coker, 963 S.W.2d 726, 732 (Tenn. 1998) (“The patient must also be informed of alternative methods of treatment, the risks and benefits of such treatment and, if applicable, that the proposed treatment or procedure is experimental.”).
  \item \textsuperscript{155} See generally Lars Noah, Informed Consent and the Elusive Dichotomy Between Standard and Experimental Therapy, 28 AM. J.L. & MED. 361 (2002).
  \item \textsuperscript{156} Stanley Joel Reiser, Criteria for Standard Versus Experimental Therapy, 13 HEALTH AFF. 127, 130 (1994).
  \item \textsuperscript{157} \textit{Id.} at 130.
  \item \textsuperscript{158} \textit{Id.} at 130.
  \item \textsuperscript{159} \textit{Id.} at 130–31.
\end{itemize}
adulthood.\textsuperscript{160} Second, there is increasing evidence that the surgeries have “catastrophic”\textsuperscript{161} and often irreversible physical and emotional effects. Additionally, the treatment currently lacks both established indications of use\textsuperscript{162} and standardized requirements of application,\textsuperscript{163} as medical practitioners in the field increasingly disagree about when, how, and if the surgery should be performed at all. For example, Human Rights Watch found that “a growing number of doctors are opposed to doing unnecessary early surgery under such conditions.”\textsuperscript{164} As early as 2006, the medical professionals involved in drafting the 2006 Consensus admitted that “the pattern of surgical practice in DSD is changing with respect to the timing of surgery and techniques used,”\textsuperscript{165} demonstrating the lack of uniformity amongst practicing experts in the field. The lack of evidence regarding outcomes, combined with growing disagreement regarding the timing and usage of genital correctional surgeries, suggests such surgeries should be classified as experimental rather than standard treatments.\textsuperscript{166}

Discussing intersex correctional surgeries as experimental rather than standard and widely accepted medical practice would have tangible effects. Parents who understand a certain course of treatment to be experimental are less likely to defer blindly to their physician’s recommendations. Georgiann Davis argues that “expos[ure] to [the] medical uncertainty” involved in the diagnosis and treatment of intersex differences might cause parents to “slow down their own desire for immediate medical response to their

\textsuperscript{160} See HUM. RTS. WATCH, supra note 47, at 83–87.
\textsuperscript{161} See HUM. RTS. WATCH, supra note 47, at 5.
\textsuperscript{162} See Lee et al., supra note 50, at 170 (“The lack of outcome data and different preferences make it difficult to determine whether and when to pursue gonadal or genital surgery.”).
\textsuperscript{163} See Lee et al., supra note 50, at 173 (“Since the Consensus Meeting in Chicago, DSD surgery continues to raise unresolved questions and dilemmas regarding indications, timing and procedures in the various categories of DSDs.”).
\textsuperscript{164} See HUM. RTS. WATCH, supra note 47, at 8.
\textsuperscript{165} Lee et al., supra note 50, at 496.
\textsuperscript{166} Health insurers are typically the overseers of whether a treatment is experimental. Experimental treatments are typically not covered under insurance contracts. Insurers have wide latitude for determining whether a given treatment is experimental, so long as they are in compliance with the Affordable Care Act and other federal and state insurance regulations. See Claire Levitt & Julie O’Brien, The Impact of the Affordable Care Act on Clinical Trials, ALICARE MED. MGMT. (Fall 2014), http://www.alicaremed.com/news/issuebrief/amc_trial/The-Impact-of-the-Affordable-Care-Act-on-Clinical-Trials.html [https://perma.cc/Q43J-ZYBP]. Courts have also frequently played a role in determining whether the processes insurance companies use for determining whether a treatment is experimental are adequate. See, e.g., Villarreal v. Inland Empire Elec. Workers Health and Welfare Tr., No. 1:16-cv-03114-SAB, 2017 WL 4769426, at *1 (E.D. Wash. June 16, 2017).
child’s intersex trait.” One could posit that parents who are asked to consent to experimental, rather than standard, procedures for their child are more likely to pause and seek outside consultation or do their own research before letting their child undergo surgery. This would further the important goal of preventing correctional surgeries performed on minors in the future.

Furthermore, treating correctional surgery as experimental might ease the plaintiff burden in suits based on informed consent. If judges are convinced that correctional surgeries are experimental, they will require that practitioners disclose not only the nature of the intersex correctional surgery but also its experimental nature and the associated risks of the surgery. Because many practicing doctors performing such surgeries do not adequately discuss the material risks and uncertainties involved, a “heightened” standard for informed consent in experimental procedures could make legally proving medical malpractice more feasible in the future.

B. CREATE A CATEGORICAL EXCEPTION TO INFORMED CONSENT FOR INTERSEX CORRECTIONAL SURGERIES

Anne Tamar-Mattis has proposed carving out a categorical exception to the rule that parents can consent to the medical treatment of minors. Assuming a court or legislature imposed a categorical exception rule for intersex correctional surgeries, parents would have to obtain an order from a judge before

167. Davis, supra note 36, at 120.
168. See Anne Tamar-Mattis, Exceptions to the Rule: Curing the Law’s Failure to Protect Intersex Infants, 21 BERKELEY J. GENDER L. & JUST. 59, 93 (2013). The categorical exception doctrine is based on the recognition that “certain types of medical decisions are not appropriate for the general parent-doctor decision-making model” (emphasis omitted). Id. The categorical exception rule is designed to protect children in instances where parents are likely to have a conflict of interest or when the medical procedure has little medical benefit for a child. See id.
proceeding with the surgery.\textsuperscript{169} Although politically ambitious,\textsuperscript{170} success in obtaining a categorical exception would provide one extra layer of protection for minor children against intersex correctional surgery.

There are a few categorical exceptions to parental consent already in place.\textsuperscript{171} In these instances, either a legislature or judge has decided that “certain types of medical decisions are not appropriate for the general parent-doctor decision-making model.”\textsuperscript{172} In particular, several states require judicial approval for the surgical removal of a child’s organ for donation purposes and for the sterilization of children and persons with intellectual disabilities.\textsuperscript{173} According to Tamar-Mattis, categorical exceptions have been imposed when a potential type of procedure meets the following criteria: (1) “there is no demonstrated or expected medical benefit to the procedure”; (2) “there is the potential for parental conflict of interest”; and (3) the procedure may “infringe on fundamental rights of the child, namely those of bodily integrity, privacy, and sometimes reproduction.”\textsuperscript{174}

Tamar-Mattis argues that cosmetic genital correctional surgery performed on minors meets all three justifications for categorical exceptions to informed consent. (1) Medical providers are increasingly recognizing the uncertainties and harms in genital correctional surgery.\textsuperscript{175} (2) There is a great risk of a conflict of interest between the parent and the child.\textsuperscript{176} Parents may be greatly distressed by the discovery of intersex differences and

\textsuperscript{169} Id. at 94. When a categorical exemption rule is in place, parents must seek court approval before the medical treatment is performed on the child. The court then will undertake an assessment of the effects of the proposed surgery on the child, weighing whether or not there is a benefit to the child. In the case of children serving as organ donors, for example, there must be an affirmative showing that there is some benefit (including the presence of a close personal relationship) to the donor child that outweighs the medical risk and harm. \textit{See id.}

\textsuperscript{170} Generally speaking, categorical exemption rules must be put in place via legislation. The intersex community is very small, and it could take a long time for the community to convince politicians this is an issue worth pursuing. However, recent efforts to introduce legislative bans on correctional surgeries performed on infants, such as California’s S.C.R. 110, 2017–2018 Leg., (Cal. 2018), show that it is possible to mobilize the intersex community, alongside the general LGBT rights community, to obtain legislative change.

\textsuperscript{171} Tamar-Mattis, supra note 168, at 93.

\textsuperscript{172} \textit{Id}. (emphasis omitted).

\textsuperscript{173} Id. at 94, 96.

\textsuperscript{174} Id. at 99.

\textsuperscript{175} \textit{See} Lee et al., supra note 50, at 173.

\textsuperscript{176} Tamar-Mattis, supra note 168, at 90.
attempt to “fix” their child as soon as possible by surgical means, even when the surgery may not be in the best interests of the child in the long run.\footnote{177} A categorical exception for intersex correctional surgery may be necessary to protect the fundamental rights of the child.\footnote{178} Intersex children are occasionally subject to accidental or intentional sterilization by the surgical procedures, implicating the right to procreate. Additionally, intersex surgeries implicate a minor’s right to bodily autonomy\footnote{179} and self-determination.\footnote{180}

Tamar-Mattis also proposes a process for imposing judicial oversight in enforcing the categorical exception to parental consent for intersex children.\footnote{181} She suggests courts should appoint an attorney \textit{ad litem} to represent the child and inform the court of the drawbacks and concerns associated with correctional surgery.\footnote{182} Courts would exclusively consider the best interests of the child, ignoring the desires of the parents, to determine whether the benefits of the proposed surgery outweigh the costs.\footnote{183}

Tamar-Mattis proposes that such a categorical exception could be statutory, like the exception in several states for sterilization of children with intellectual disabilities.\footnote{184} She also considers the possibility that doctors themselves, “recognizing the legal risk of performing these operations with only parental authorization and fearing later lawsuits from dissatisfied patients” might ask courts for declaratory judgments before operating.\footnote{185} Finally, she suggests that a state agency might get involved in seeking a “judicial ruling on the best interests of the child.”\footnote{186}

Tamar-Mattis admits that the creation of a categorical exception for intersex individuals would be politically difficult to achieve.\footnote{187} And even so, judges may prove no more able to protect

\begin{flushleft}
\footnote{177}{\textit{Id.} at 83.}
\footnote{178}{See \textit{id.} at 100–01.}
\footnote{179}{Lee et al., \textit{supra} note 50, at 177.}
\footnote{180}{\textit{Id.} at 160.}
\footnote{181}{Tamar-Mattis, \textit{supra} note 168, at 104.}
\footnote{182}{\textit{Id.} at 104.}
\footnote{183}{\textit{Id.} at 104–05.}
\footnote{184}{See Tamar-Mattis, \textit{supra} note 168, at 107.}
\footnote{185}{\textit{Id.} at 107–08.}
\footnote{186}{\textit{Id.} at 109.}
\footnote{187}{\textit{Id.} at 107 (“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. 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.”).}
the interests of intersex children than doctors or parents. As Tamar-Mattis admits, “[j]udges carry biases and cultural conditioning just as doctors and parents do.” However, she argues that the categorical exception model offers an advantage to the traditional informed consent model in providing a “rigorous structure for reasoning in an area where such logic is badly needed.” Tamar-Mattis is correct in arguing that judicial review is an added layer of protection for intersex children and that 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.” However, Tamar-Mattis fails to account for the fact that judges tasked with determining the best interest of an intersex child, will necessarily defer to the standards of care articulated by doctors. As long as medical experts continue to offer testimony and evidence making the case that correctional surgery is the best course of action for an intersex child, there is little reason to suspect that ordinary judges will be anything but deferential to that advice. In fact, this categorical exception may merely stand to legitimate intersex correctional surgeries so long as the medical profession continues to insist they are necessary. As such, this categorical exception to informed consent suffers from the same innate flaw as the informed consent model in general — it is unable to substantially change the ideological bent of the medical profession towards the idea that intersex differences are abnormalities that should be subject to medical intervention.

Still, the creation of a categorical exception would at least provide an additional layer of judicial protection for intersex children, and would become more effective as societal and judicial attitudes about the inherent validity of intersex identities evolve.

C. IMAGINING AN IDEAL FUTURE

M.C.’s settlement is the beginning of a new era of activism in the intersex community. For the first time, obtaining legal recourse is more of a possibility than a fantasy. Although it is likely that informed consent will be most salient in the immediate future, it is worth considering what a better future would look like.

188. Id. at 102.
189. Id.
190. Id. at 103.
191. Id.
An ideal legal action would avoid contributing to the ongoing tendency to medicalize intersex bodies instead of treating them as acceptable expressions of human sexuality. Remedies based on informed consent and medical malpractice inherently codify norms that intersex differences are medical conditions to be remedied rather than examples of normal biological variance. The action would also protect intersex children from any and all correctional surgery, even when the surgery is supported by the parents of the child. The informed consent model fails to protect intersex children from parents who would consent to the surgeries, even understanding all of the potential risks involved. Instead, only intersex individuals who are old enough to consent for themselves to cosmetic surgeries should be allowed to do so.

An ideal future would also include a legislative ban on corrective surgeries performed on intersex minors. In August 2018, California passed a resolution calling for such a ban.192 This law does not outlaw nonconsensual surgeries performed on infants and has no binding legal effect, but it is being hailed by human rights advocates as “the first successful move by any state legislature in the United States to call on the medical community to establish standards of care for intersex children that take into account their human rights.”193 The passage of this resolution suggests that the momentum legally ban the performance genital correctional surgeries on minors altogether sometime is possible. Advocates should focus efforts on legislative reform as a viable long-term strategy for protecting intersex infants from correctional surgery.

192. See S.C.R. 110, 2017–2018 Leg., (Cal. 2018) (“Resolved, That the Legislature recognizes that intersex children should be free to choose whether to undergo life-altering surgeries that irreversibly — and sometimes irreparably — cause harm; “Resolved, That the Legislature calls upon stakeholders in the health professions to foster the well-being of children born with variations of sex characteristics, and the adults they will become, through the enactment of policies and procedures that ensure individualized, multidisciplinary care that respects the rights of the patient to participate in decisions, defers medical or surgical intervention, as warranted, until the child is able to participate in decisionmaking, and provides support to promote patient and family well-being.”).
V. CONCLUSION

M.C.’s landmark settlement demonstrates the potential utility of lawyers and litigation to challenge intersex correctional surgeries performed on minors. The informed consent model used in M.C.’s lawsuit is an important tool for obtaining remedies for intersex minors who were operated on in conditions of secrecy and misinformation. However, activists and lawyers must keep in mind that their purpose in challenging these surgeries is not just to ensure that medical providers are careful about disclosing the material risks and outcomes of surgery to avoid future medical malpractice lawsuits. Lawyers must also duly consider the broader goal of eliminating the tendency to pathologize gender and sexual differences.

These two practical solutions offered for improving the informed consent model for challenging correctional surgeries may produce some better outcomes for litigants seeking damages, but they fail to dismantle the medical establishment’s presumption that intersex differences require intervention. Society must come to respect and accept intersex differences as legitimate before the medical profession will stop trying to fix intersex bodies altogether.