

## Protecting the Rights of the Intersex Newborn

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### Abstract

*When a newborn's genitals are neither fully male nor fully female, parents have the option of authorizing genital-normalizing surgery on their intersex child. The surgery removes and rearranges genital tissue in order to construct genitalia that better match the child's assigned gender. Advocates of the traditional protocol for the treatment of intersex children hold that the surgery ensures normal psychosexual development. However, in the last decade intersex advocates have begun to question the legality of genital-normalizing surgery in infancy, suggesting that surgery interferes with the child's right to autonomy. Because genital-normalizing surgery may affect fertility and the capacity for sexual sensation, ethicists hold that there should be a moratorium on surgery. Because surgery often conflicts with the child's long-term interests, parents should not have a legal right to authorize surgery on their intersex child.*

### Introduction

After the birth of a newborn, parents hardly expect to be told by doctors that they need to wait before giving their child a name. When the gender of a newborn is not certain, parents cannot immediately be sure whether their child is a Sarah or a Sam, a John or a Julie, an Oliver or an Olivia. With most newborns, doctors can usually tell the gender of the child by a simple and cursory glance, and parents can name their child without hesitation or doubt. In about one out of two thousand births, however, the genitalia of the newborn are ambiguous – doctors are unable to definitively classify the child as male or female (Lareau 129). The child falls temporarily into a third, often stigmatized category: intersex.

Typically, doctors perform a series of tests before assigning the child a gender. But such tests are often inconclusive, and test results often contradict one another. For example, a steroid evaluation may classify the child as male yet a chromosome analysis may render the child female. The Intersex Society of North America holds that all intersex newborns should be assigned a gender even if test results are inconclusive (Chase 4). It is not the gender assignment of an intersex child that modern ethicists and intersex advocates find unsound. Rather, ethicists call into question whether parents have the right to authorize genital-normalizing surgery on the infant. Gender-normalizing surgery “corrects” the appearance of the ambiguous genitalia by re-sculpting the genitals to match the child's assigned gender. In most cases, the surgery is not medically necessary for the intersex newborn and serves a highly cosmetic purpose (Ehrenreich 72). Some form of surgery has been the dominant protocol when treating intersex newborns for the past century. Only within the last decade have bioethicists truly considered the

moral implications of the surgery and whether the surgery interferes with the rights of the intersex child. Alyssa Connell Lareau's piece "Who decides? Genital-normalizing surgery on intersexed infants" forms a framework to the discussion of whether parents have the right to authorize non-medically necessary genital-normalizing surgery on their intersex infant. Lareau, a lawyer who has written several articles regarding the rights of intersex newborns, contends that parents are incompetent of making informed decisions that that the medical community should push for a moratorium.

The question of who has the right to authorize genital-normalizing surgery forms an intricate net of social, legal, and ethical issues. Because so many biological factors affect whether intersex individuals will come to perceive themselves as male or female, it is often difficult to determine the eventual gender of the intersex person in infancy. Due to the fact the surgery is irreversible, serves a cosmetic purpose, and removes tissue that the child may one day want, parents should not have the right to authorize genital-normalizing surgery on their intersex newborn.

### **Defining the Intersex Condition**

An intersex person is traditionally defined as any individual with some type of sexual dimorphism at the chromosomal, gonadal, or hormonal levels (Blackless 161). However, some counter this traditional definition, describing it as too broad. Leonard Sax, an American psychologist focused on gender differences, presents a more narrow definition of intersex and includes only those who present outward signs and symptoms at birth (Sax 174). He does not include Klinefelter syndrome or Turner syndrome in his definition of intersex. Individuals with Klinefelter syndrome are genetically 47, XXY and live as male; individuals with Turner syndrome are genetically 45, XO and live as female (NOVA). They do not, however, typically display ambiguous genitalia at birth. Individuals with Klinefelter syndrome may develop small breasts, but their genitalia at birth are clearly defined as male. Although individuals with these syndromes would be considered intersex by Blackless' definition (they deviate from the traditional male or female dichotomy), they are not considered intersex by Sax's definition (they do not display ambiguous genitalia at birth). Neither definition is necessarily more correct. But because this essay focuses on the implications of genital-normalizing surgery in infancy, this essay will adopt Sax's definition of intersexuality when referring to individuals with an intersex condition.

A common intersex condition in which the external genitalia are ambiguous is congenital adrenal hyperplasia (CAH). Individuals with CAH are genetically 46, XX (the

karyotype of a normal female) but because of neonatal androgen exposure are born with virilized genitalia (Sloane 152). The term “virilized” in this context refers to the development of male characteristics in the genitals. Instead of an internal vaginal opening, individuals with CAH may have an elongated clitoris with an external vaginal opening or may have fused labia. A similar condition that instead affects genetic males is Androgen Insensitivity syndrome (AIS), also referred to Testicular-Feminization syndrome. AIS is a condition in which males with a 46, XY karyotype have testes in the abdomen and external female genitalia. The external genitalia during development are insensitive to androgens, the principal male hormones, and thus the penis does not form or is severely underdeveloped.

Even more complicated intersex conditions arise when the intersex person has a mosaic karyotype. Katrina Karkazis, a researcher at the Stanford Center for Biomedical Ethics, describes a case in her book “Fixing Sex” in which a child was born with a karyotype of 45,XO/46,XY (90). The child was diagnosed with mixed gonadal dysgenesis. Newborns with this condition have both male and female physical traits; the child may have an enlarged clitoris with an external urethral opening, a vagina, fallopian tubes, and internal testes (Sohval 155). Related to this diagnosis is perhaps the most complicated of intersex conditions. Known as “true hermaphroditism,” this condition describes individuals who have both ovarian and testicular tissue (Kim 1013). Cases of mixed gonadal dysgenesis and true hermaphroditism are often so complex that a team of doctors and specialists fail to reach a consensus as to whether the child should be assigned male or female.

### **Three Modern Models of Treatment**

Currently, three protocols exist for the treatment of intersex infants. The first protocol calls for immediate surgery and hormonal intervention, citing a need for the child’s body to conform to the traditional male-female dichotomy (Money 51). The approach was widely accepted for the second half of the twentieth century – experts argued that the child would suffer severe psychological trauma if surgery was not performed to “correct” the intersex condition. The protocol further emphasized a need to minimize the information given to parents about the condition. The *Canadian Medical Association Journal* in 1996 awarded second prize in a medical student essay contest to a student who wrote that doctors had an ethical duty to lie to parents of patients with androgen insensitivity syndrome about the true nature of the patient’s condition (Anne Fausto-Sterling 299). Lying to parents – or at least not revealing all information about the

child's condition – is not only condoned but encouraged through this model. Within the last ten years ethicists began to truly reconsider this approach.

Completing diverging from this traditional model, the Intersex Society of North America argues that there should be a complete moratorium on surgery that is not medically necessary for the intersex newborn (Chase 2). Lareau similarly favors a moratorium, and she questions the reasoning behind the traditional approach and holds that the secrecy that surrounds genital-normalizing surgery will inevitably cause feelings of guilt and shame in parents of intersex children (136). The need to correct the intersex condition only perpetuates the stigma against any condition and deviates from the socially-established norms of gender. As aforementioned, the majority of advocates for a moratorium on genital-normalizing surgery *do not* recommend that the child should not be assigned a gender. Rather, they argue that surgery that is not necessary on medical grounds interferes with the rights of intersex newborn.

The last approach and the most widely accepted protocol today is known as the “middle ground” approach. As its name suggests, this protocol serves as an intermediate between the traditional model espoused in the mid- to late-twentieth century and the recent approach that calls for a complete moratorium of genital-normalizing surgery in infancy. This protocol advocates fully informing parents about the child's condition and holds that the parents have the right to ultimately decide whether they want to pursue a surgical option. Supporters of this approach believe that the traditional model leaves defers too much authority to doctors treating the intersex child yet a complete moratorium interferes with the rights of the parents to decide treatment for their child (Greenberg 90). They believe that parents who are fully educated about the advantages and potential risks of surgery are in the best position to decide appropriate treatment for the intersex child.

Though this last model may appease lawmakers and ethicists, a closer examination of the middle ground approach shows that it has major flaws on both ethical and legal levels. Opponents of the middle ground approach question whether parents are truly in the best position to decide what is best for their child. Holding to the principals of autonomy and self-determination, supporters of a moratorium believe that only the intersex individual can decide surgery for him or herself. Although the middle ground approach appears to be a fitting compromise, it fails to hold water under further critical analysis. Neither the traditional model nor the middle ground approach is an ethically sound model for the treatment of intersex newborns.

## Refuting the Traditional Model

During the mid-twentieth century, it was widely believed that a child's gender identity was predominantly the result of rearing (Karkazis 50). This view was perpetuated by John Money, a leading psychologist who claimed that a child is born as a blank slate and gender neutral. If the intersex child is reared as a girl, he argued, the child will come to perceive herself as a girl; if the intersex child is reared as a boy, the child will come to perceive himself as a boy. Crucial to psychosexual development and gender identity were genitalia that matched the child's assigned gender. In an article published in *Pediatrics* Money argued, "psychosexual identity may contradict chromosomal, gonadal, or hormonal sex. It more generally agrees with the external genital morphology and the assigned sex." (Money 51). The surgery, according to the traditional model, simply allows children to develop smoothly into a defined gender.

However, case studies and scientific research suggest that the theory that a child's gender is independent of biological factors is incorrect. In a famous case study known as the John/Joan case, a normal 46, XY male had his penis severely burned in infancy. Due to the prevailing mindset that a child is gender neutral at birth, psychologists recommended that the boy be raised as a female. The boy's name was changed from John to Joan and the boy underwent genital-normalizing surgery. The surgery was initially thought of as a success; however, in 1997 a researcher found that "Joan" was now living as a male and was taking testosterone supplements (Lev 171). The failure of the John/Joan case lends credence to Lareau's argument against the traditional approach: because gender identity is not the result of rearing alone, genital-normalizing surgery in infancy does not necessarily ensure normal psychosexual development.

Other studies confirm the theory that gender identity is a result of both rearing and biological factors. A study published in 2004 suggests prenatal hormone exposure plays a significant role in gender identity. The study found that women with CAH (a condition in which genetic females develop virilized genitalia as a result of neonatal androgen disorder) reported weaker identification as females than did women without CAH (Hines 78). Though the women with CAH were raised as girls, they still did not come to fully perceive themselves as female. This study supports the idea that gender identity is not independent of biological factors.

The justification that surgery provides a means for healthy psychosexual development is irreducibly flawed because gender identity is a result of more than just rearing. Sculpting an intersex child's genitalia as female to match a female gender

assignment does not guarantee that the child will come to perceive herself as a girl. Because so many factors influence gender development, the gender of an intersex child often cannot be certain at birth. If doctors cannot be sure of the gender of the intersex child, performing an *irreversible* surgery on the child has the possibility of forever trapping the child in the wrong gender.

### **Lies and Deception**

Despite the fact that gender is not nearly as plastic as once believed, proponents of the traditional approach argue that revealing the truth about an intersex child's condition would undoubtedly cause the parents and intersex person deep psychological trauma. Withholding information from parents, according to this approach, is necessary in order to ensure that parents raise the child in a defined gender (Greenberg 88). However, such deception and lies do not prevent feelings of shame in the intersex child. Rather, deceiving the parents about the child's true condition tends to *augment* feelings of shame. It gives the parents and the intersex child the perception that the child's condition is "so grotesque, so pathetic, that any medical procedure aimed at normalizing [the genitalia] is morally justified" (Dreger 75). The view that ambiguous genitalia must be corrected perpetuates the stigma against intersex conditions. The secrecy that surrounds genital-normalizing surgery through the traditional approach makes the intersex child's condition seem so abnormal that even medical professionals cannot openly discuss it with parents. J. David Hester in "Intersex and the Rhetorics of healing" describes that when adults born with ambiguous genitalia describe the genital-normalizing process, they express "shame, powerlessness, isolation, and humiliation – much of it due to a lack of forthright discussion between doctors and physicians" (61). Secrecy does not protect the child from stigmatization, but furthers feelings of shame.

Hester presents a first-hand account of a man who underwent genital-normalizing surgery at a young age. The man describes, "I remember my parents privately telling my teacher about the surgery and encouraging the teacher to lie to the class and say I was having surgery on my arm ... obviously, the full truth would have been appropriate, but it sent a signal to me that it was something of which to be ashamed" (61). Intersex children who are forced to undergo surgery in secrecy often grow up with a sense that something is wrong yet have no one to talk to about the true nature of their condition. The deception encouraged by the traditional approach leads to confusion, frustration, and shame in both the intersex person and his or her parents. Lying to patients should not be condoned on any level, especially with an issue as sensitive as genital-normalizing surgery.

## The “Middle Ground” Approach: A Viable Option?

The middle ground approach fundamentally differs from the traditional approach in that it does *not* endorse secrecy and deception and calls for parents to be completely informed before deciding whether surgery is an appropriate option. Supporters of the middle ground approach argue that “parents who are fully educated about the risks and benefits of the different protocols are in the best position to assess what is in their child’s best interest” (Greenberg 90). Proponents of this protocol claim that as long as parents are completely informed about the full nature of their child’s condition, parents legally have the right to make medical decisions for their child. Laura Hermer, a professor of bioethics at the University of Texas, acknowledges that genital-normalizing surgery carries certain risks but holds that once parents are informed of the potential consequences of the surgery, the appropriate course of treatment for the intersex child is up to the parents’ discretion (Hermer 256). This approach, some argue, protects both the rights of the parents and the interests of the child.

Though this protocol appears to be a suitable compromise, there are certain critical and insurmountable flaws in this approach. It makes the assumption that parents are best able to objectively determine what is in their child’s best interest. It is certainly reasonable to believe that parents who authorize surgery on their intersex infant are acting with the right intentions. But because parents are closest to the child and are most immediately affected by the child’s condition, they may in fact be in the *worst* position to consider what is best for the child in the long run. Lareau notes that parents are not given unchecked decision-making power. She states when parents are “making decisions regarding infant medical treatment in other contexts, courts have established criteria for overriding parental decisions...the state may challenge and set aside decisions that are deemed not in the child's best interest” (144). Though those opposed to a moratorium argue parents should have the right to decide treatment for their child, the courts have established legal procedures for determining whether a parental decision may violate the rights of the child.

In cases where the patient is in some way unable to consent to surgery, the decision-making power is deferred to another party, typically a close relative of the patient. In order for parents to legally consent to surgery for the patient, three criteria must be satisfied: the parents must be competent, the parents must be fully informed, and parents must make the decision on a voluntary basis (Ford 484). These criteria are meant to protect against imprudent and hasty decision-making by parents. Though proponents of

the middle ground approach argue that the criteria are satisfied as long as doctors educate parents about the consequences and implications of surgery, evidence suggests that *none* of the above three conditions are truly satisfied. The subsequent three sections reveal that when considered from a practical standpoint, the middle ground approach fails to satisfy the above three conditions necessary for legal informed consent.

### **Are Parents Truly Informed?**

Given the nature of genital-normalizing surgery and the lack of statistical evidence that addresses surgical outcomes, it is unlikely that parents fully understand the consequences of surgery. While doctors may be able to fully describe the medical details of the child's condition and the surgical process, parents often remain uninformed about non-surgical options. In one study of parents' experiences, "only one out of ten parents had sought information outside the medical setting" (Wickstrom and Zeiler 369). This suggests that the majority of patients do not truly consider other treatments and may not reach out to other parents of intersex children. No matter how much parents are informed about the potential risks of surgery, if they are not exposed to other options parents cannot be considered truly informed.

Because so few studies address the outcomes of genital-normalizing surgery in infancy, doctors are unable to provide parents with hard data pertaining to the potential consequences of surgery. Hermer, an advocate of the middle ground approach, contends that because the data do not conclusively show that surgery does more harm than good, parents should retain the right to authorize surgery on their child (Hermer 267). However, the fact that there is lack of data *refutes* the claim that parents have the right to authorize genital-normalizing surgery. Parents cannot make informed decisions if provided with such minimal information. Genital-normalizing surgery is experimental in nature: few reports demonstrate that surgery is better than non-surgical options.

The lack of data often causes parents to make decisions they later regret. In several interviews, parents voice that they wish they had known more about what genital-normalizing surgery entailed before authorizing the surgery on their intersex child. One parent relates, "At the time [surgery] seemed like the right thing to do, but I should have done more research then. By now I've talked to people who've had hypospadias repair, and they've gone through hell. The body has ways of undoing these surgeries. He's developed a leak . . . If I knew then what I know now . . ." (Wickstrom and Zeiler 369). Because so few parents seek information outside the medical setting, they are often left unaware of the potential consequences about surgery. If parents are truly informed, such

consequences should come as no surprise to parents. Unfortunately, because genital-normalizing surgery is experimental in nature, even doctors cannot be sure of the likelihood of post-surgical complications. With such a dearth of information, parents cannot be considered capable of making fully informed decisions.

### **Are Parents Truly Competent?**

A critical component to Lareau's argument against the middle ground approach is her contention that the parents are too emotionally charged to be considered competent of giving informed consent. Lareau argues that the middle ground approach does not fully protect the well being of the intersex child because "even if parents possess full knowledge of the arguments for and against genital surgery on infants, they can be in a fragile emotional state that may interfere with their ability to consider the infant's best interests" (133). Because parents are blinded by their own emotions, they may not be in an appropriate position to judge whether surgery is the best option.

From a psychological standpoint, initial feelings of shock and frustration may overcome rational decision-making. Social psychologists propose that when a child's genitals are ambiguous, parents find themselves unable to identify with the intersex child (Wickstom and Zeiler 361). Genitals are brought into the foreground and parents are often so shocked by the genitalia that they immediately look for a way to correct the seemingly foreign body part. Parents find their previously unquestioned view of gender suddenly threatened – with the birth of an intersex child, the belief that a person can only be male or female no longer seems valid. Because of the sudden threat to a deeply engrained view, parents are often quick to choose surgery to quickly normalize their child and to reaffirm their traditional view of the male/female gender dichotomy.

The competency of parents is further complicated by the fact that parents naturally see themselves as the protectors of their children. Norm-challenging bodies carry a certain stigma, and parent may instinctually believe that correcting the stigmatized body part will best protect the child. However, parents' instinctual desire to protect their children may leave parents unable to truly weigh the benefits and risks of surgery. Lareau points to a study in which women were asked to imagine that they had been born with a large clitoris and men were asked to imagine that they were born with a micropenis. The majority answered that they would rather be left with their atypical genitalia than be surgically altered. However, Lareau notes, "the answers changed when subjects were asked what they would do for their children in the same situation" (143). This blatant double-standard suggests that parents may not be in the best position to objectively

determine what is best for their child. Because of the complicated emotions associated with the birth of an intersex child, parents may not be competent of making life-altering decisions for their child.

### **Do Parents Decide on a Truly Voluntary Basis?**

Physician rhetoric may further render parents unable to make an independent, informed decision. Doctors and surgeons are quick to pathologize the intersex condition: they perceive the ambiguous genitalia as a medical abnormality. However, in most cases the child's physical health is not affected by the intersex condition. David Hester in "Intersex and Informed Consent: How Physician Rhetoric Constrains Choice" suggests that doctors give parents the impression that their child's condition is a medical emergency that should be quickly corrected. Hester explains that "at no point has it been demonstrated that the gender indicators are a cause of either medical or psychosocial 'disease'... the underlying conditions are treated as incidental to the overwhelming "need" to surgically alter the child to conform to norms of genital appearance. It is the rhetoric employed by the physician that pathologizes the genitalia, not the condition behind the ambiguity" (38). By telling parents that their child will be "normal" after the condition is "cured" through surgery, physicians are suggesting to parents that the child's condition is *not* normal or socially acceptable. Physician rhetoric that pathologizes the intersex condition may sway parents in favor of surgery even before parents are informed about the nature of their child's condition. Because doctors often view the child's condition as a "disease," physician rhetoric tends to be more persuasive than informative.

Doctors may further influence parental decision-making by withholding crucial information from parents. Physicians may not inform parents of non-surgical options, or they may downplay non-surgical options by suggesting that only surgery can rectify the child's condition. Intersex advocate Alice Domurat Dreger in "Intersex and Human Rights" suggests that many do not inform parents about well-respected advocacy groups or tell parents that surgery is currently experimental in nature. Dreger states that "many physicians feel this sort of information is either not relevant or too political to reveal." Yet it seems to me – from conversation I've had with parents and with persons born with atypical anatomies – that this information is exquisitely relevant to making informed decisions" (77). By withholding crucial information, doctors severely constrain parental choice – even though other options exist, parents may not be encouraged to explore other options. Because doctors often do not encourage parents to fully explore other options, it

is questionable whether parents opt for genital-normalizing surgery on a truly independent basis.

## **Conclusion**

Parents undoubtedly want what is best for their child, but the nature of the intersex condition often renders parents unable to make informed, competent, and independent decisions. Though physicians do not operate with mal intent when recommending genital-normalizing surgery, surgical methods of treatment have the potential to severely rob the intersex child of certain fundamental rights. Because genital-normalizing surgery is irreversible, cosmetic in nature, and risks a child's fertility and capacity for sexual sensation, the only morally and legally permissible option is to postpone surgery until the intersex individuals themselves can decide whether surgery is an appropriate option. As Lareau suggests, the middle ground approach should not be accepted in the legal and medical communities as a viable compromise. Only a moratorium would ensure that the intersex child has a *role in the decision-making process*.

Because of the stigmatization surrounding the intersex condition, parents may feel anxious and uncertain at the thought of raising an intersex child. But through discussion with professionals and with other parents of intersex children, parents can address any concerns and discover a new way of looking at their child's condition. Though the child's condition may be distressing at first, "if given time parents can move past the initial fear and discomfort to see another reality: that they have given birth to a beautiful baby" (Karkazis 183). Surgery tends to treat the child's genitalia as a disease that must be cured. But if the intersex child's condition is not treated as a disease, it will not be perceived as a disease. With a moratorium on surgery and open, forthright discussion, the child's ambiguous genitalia will slowly fade into the background, and parents can shift their attention to the joy and warmth accompanied by the birth of any newborn child.

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