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Health Care Issues Affecting People with an Intersex Condition or DSD: Sex or Disability Discrimination?

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HEALTH CARE ISSUES AFFECTING PEOPLE WITH AN INTERSEX CONDITION OR DSD: SEX OR DISABILITY DISCRIMINATION?

*Julie A. Greenberg**

People with an intersex condition or a Difference of Sex Development (DSD) depend on health care professionals for critical medical treatment. Many intersex activists assert that some current medical practices are not in the best interests of patients with an intersex condition. They contend that greater safeguards should be adopted to ensure that the rights to liberty and autonomy of people with a DSD are respected.

Thus far, intersex advocacy has focused on extralegal strategies. The movement is at a point, however, where legal challenges to current medical protocols could provide an additional tool to improve life-altering health care practices. This Article examines whether the intersex movement could effectively use legal frameworks developed by feminists, the LGBT movement, and disability activists to advance its goal of modifying current medical procedures that are based on sex, gender, sexual orientation, and disability stereotypes.

* Professor of Law, Thomas Jefferson School of Law. I want to thank Anne Tamar-Mattis and Robert Irving for their extremely helpful comments on earlier drafts of this Article. My sincere gratitude goes to the *Loyola of Los Angeles Law Review* for organizing an extraordinary Symposium on LGBT Identity and the Law and inviting me to participate. This Article builds on ideas presented in JULIE A. GREENBERG, INTERSEXUALITY AND THE LAW: WHY SEX MATTERS (2012), published by NYU Press.

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Other Symposium participants examined the problems confronting lesbians, gays, and bisexuals (LGBs) seeking access to effective health care. People with an intersex condition or a DSD (Difference of Sex Development) and transgender people are affected by similar issues of stigma and discrimination in the provision of medical services. Intersex and transgender people, however, face an additional problem not encountered by LGBs; they are often dependent on health care professionals for critical medical treatment related to their intersex and transgender conditions. The number of health care professionals experienced in the treatment of intersexuality and transgenderism is limited, and often medical professionals' treatment recommendations are at odds with the desires of their intersex or transgender patients. Therefore, when intersex and transgender people advocate for changes in the health care provided to people in their communities, they must carefully consider how the approaches they adopt will be received by the medical professionals who, to a large extent, control their medical treatment options.

This Article examines the unique health care issues confronting the intersex community.[1] It explores whether the intersex movement could effectively use legal frameworks developed by the disability rights movement, feminists, and LGBT activists and scholars to advance the intersex movement's major goal of modifying current medical practices. Thus far, intersex advocacy has focused on extralegal strategies.[2] The movement is at the point, however, where legal challenges to current medical protocols could provide an additional useful tool to challenge life-altering health care practices.

1. A number of publications have addressed the special health care issues facing people who are transgender. *See, e.g.*, Kari E. Hong, *Categorical Exclusions: Exploring Legal Responses to Health Care Discrimination Against Transsexuals*, 11 COLUM. J. GENDER & L. 88 (2002); Dean Spade et al., *Medicaid Policy and Gender-Confirming Healthcare for Trans People: An Interview with Advocates*, 8 SEATTLE J. FOR SOC. JUST. 497 (2010); NAT'L COAL. FOR LGBT HEALTH, AN OVERVIEW OF U.S. TRANS HEALTH PRIORITIES: A REPORT BY THE ELIMINATING DISPARITIES WORKING GROUP (2004), *available at* http://transequality.org/PDFs/Health Priorities.pdf; *Transgender Health and the Law: Identifying and Fighting Health Care Discrimination*, TRANSGENDER LAW CTR. (July 2004), http://transgenderlawcenter.org/pdf/Health%20Law%20fact%20sheet.pdf.

2. JULIE A. GREENBERG, INTERSEXUALITY AND THE LAW: WHY SEX MATTERS 85–95 (2012).

Understanding the special health care concerns of people with an intersex condition requires an understanding of the historical and current medical treatment of intersexuality. The major intersex conditions and the medical and societal treatment of people with an intersex condition are described in Part I. Part II provides greater detail regarding the intersex community's concerns about current medical protocols. Part III examines the informed consent doctrine and explains why medical procedures performed on children with an intersex condition should be scrutinized more carefully than they are under current informed consent protocols. Part IV explores the potential legal theories the intersex movement could adopt to accomplish its primary goal of modifying current medical practices. The Article concludes by examining whether the intersex movement could effectively advance its agenda by adopting legal strategies developed by feminists, LGBT scholars and activists, and disability rights advocates.

I. TERMINOLOGY AND HISTORY

A. What Is Intersexuality?

The meaning of the term "intersex" has varied and is still a topic of sometimes intense discussion.[3] Although doctors and activists in the intersex community continue to debate exactly what conditions qualify as "intersex," the term is often used to include anyone with a congenital condition whose sex chromosomes, gonads, or internal or external sexual anatomy do not fit clearly into the binary male/female norm.[4] Some intersex conditions involve an inconsistency between a person's internal and external sexual features. For example, some people with an intersex condition may have female-appearing external genitalia, no internal female organs, and testicles.[5] Other people with an intersex condition may be born

3. *Id.* at 131–32; M. Morgan Holmes, *Straddling Past, Present and Future*, *in* CRITICAL INTERSEX 1, 1 (Morgan Holmes et al. eds., 2009).

4. *Intersex FAQ*, INTERSEX INITIATIVE, http://www.ipdx.org/articles/intersex-faq.html (last updated June 29, 2008); *What Is Intersex?*, INTERSEX SOC'Y OF N. AM., http://www.isna.org/faq/what_is_intersex (last visited Jan. 25, 2012).

5. For example, women with complete androgen insensitivity syndrome (CAIS) have XY chromosomes and normal functioning testes. Because of a receptor defect, their bodies are unable to process the testosterone produced by the testes and their bodies follow the female developmental path. External female genitalia will form but no internal female reproductive

with genitalia that do not appear to be clearly male or female. For example, a girl may be born with a larger than average clitoris and no vagina.[6] Similarly, a boy may be born with a small penis or no penis.[7] Some people with an intersex condition may also be born with a chromosomal pattern that does not fall into the binary XX/XY norm.[8]

Not all intersex conditions are apparent at the time of birth; some conditions are not evident until a child reaches puberty.[9] In some conditions, a child whose genitalia appeared to be female at birth will masculinize in puberty.[10] Other intersex conditions may be discovered at puberty when the child fails to develop typical male or female traits. For example, the condition may be discovered when a girl reaches puberty and fails to menstruate.[11]

Because experts do not agree on exactly which conditions fit within the definition of intersexuality and some conditions are not evident until years after a child is born, it is impossible to state with precision exactly how many people have an intersex condition. Most experts agree, however, that approximately 1–2 percent of people are

organs (uterus and fallopian tubes) will develop. *See* Melissa Hines et al., *Psychological Outcomes and Gender-Related Development in Complete Androgen Insensitivity Syndrome*, 32 ARCHIVES SEXUAL BEHAV. 93, 93 (2003). For a more detailed description of this and other intersex conditions, see ANNE FAUSTO-STERLING, SEXING THE BODY: GENDER POLITICS AND THE CONSTRUCTION OF SEXUALITY 52–53 (2000); Julie A. Greenberg, *Defining Male and Female: Intersexuality and the Collision Between Law and Biology*, 41 ARIZ. L. REV. 265, 281–92 (1999).

6. For example, infants with partial androgen insensitivity syndrome (PAIS) have XY chromosomes and their bodies are able to partially process the androgens produced by their testes. Their genitalia will partially masculinize. S. Faisal Ahmed et al., *Phenotypic Features, Androgen Receptor Binding, and Mutational Analysis in 278 Clinical Cases Reported as Androgen Insensitivity Syndrome*, 85 J. CLINICAL ENDOCRINOLOGY & METABOLISM 658, 658 (2000).

7. *See e.g.*, William G. Reiner & Bradley P. Kropp, *A 7-Year Experience of Genetic Males with Severe Phallic Inadequacy Assigned Female*, 172 J. UROLOGY 2395 (2004).

8. For example, a number of people have chromosomal patterns that vary from the typical XX and XY patterns. People have been found with XXX, XXY, XXXY, XYY, XYYY, XYYYY, and XO (signifying only one sex chromosome). ROBERT POOL, EVE'S RIB: SEARCHING FOR THE BIOLOGICAL ROOTS OF SEX DIFFERENCES 70, 71 (1994).

9. *See e.g.*, Julianne Imperato-McGinley et al., *Steroid 5 Alpha-Reductase Deficiency in Man: An Inherited Form of Male Pseudohermaphroditism*, 186 SCIENCE 1213 (1974).

10. For example, people with 5-alpha-reductase deficiency have XY chromosomes and testes but appear phenotypically female at birth. Despite a female appearance during childhood, by the onset of puberty the body will masculinize. The testes descend, the voice deepens, muscle mass substantially increases, and a penis that is capable of ejaculating develops from what was thought to be the clitoris. *Id.*

11. For example, sometimes physicians are unaware that an infant with typical female genitalia at birth has CAIS if the testes are nestled in the abdominal cavity. The condition may not be discovered until puberty, when the girl fails to menstruate. *See* Hines et al., *supra* note 5, at 93.

born with sexual features that vary from the medically defined norm for male and female.[12] Approximately one in 1,500 to one in 2,000 births involve a child who is born so noticeably atypical in terms of genitalia that a specialist in sex differentiation is consulted and surgical alteration is considered.[13]

The term "intersex" itself is controversial. Many doctors and community activists favor abandoning the term "intersex" in favor of the term "Disorders of Sex Development" (DSD). Some who support the use of DSD terminology have argued that the term "disorder" should be dropped and the initial "D" should stand for differences rather than disorders.[14] Throughout this Article, the terms intersex and DSD (denoting Differences of Sex Development) will be used interchangeably.

B. Intersexuality Compared to Transsexuality and Transgenderism

Some people are confused about how intersexuality compares to transsexuality and transgenderism. Generally, intersexuality refers to a condition in which a person's biological sex markers are not all clearly male or female, while transgenderism and transsexuality are used to describe behaviors or identities of people whose gender expression, gender identity, or both, do not necessarily conform with the binary sex norm or may be different from the sex assigned to them at birth.[15] Not all communities use the terms "transgender" and "transsexual" consistently and different groups and individuals have strong feelings about which term they prefer.[16]

12. Melanie Blackless et al., *How Sexually Dimorphic Are We? Review and Synthesis*, 12 AM. J. HUM. BIOLOGY 151, 161 (2000).

13. *Id.* Some experts place the number of genital anomalies at birth as 1 in 4,500. Peter A. Lee et al., *Consensus Statement on Management of Intersex Disorders*, 118 PEDIATRICS e488 (2006).

14. For a more detailed discussion of the debates regarding terminology, see GREENBERG, *supra* note 2, at 118–19; Holmes, *supra* note 3, at 6–7; and Alyson K. Spurgas, *(Un)Queering Identity: The Biosocial Production of Intersex/DSD*, *in* CRITICAL INTERSEX, *supra* note 3, at 97, 97–111.

15. *See GLAAD Media Reference Guide – Transgender Glossary of Terms*, GLAAD, http://www.glaad.org/reference/transgender (last updated May 2010).

16. One major LGBT organization, GLAAD, suggests the following definitions:

> Transgender: An umbrella term (adj.) for people whose gender identity and/or gender expression differs from the sex they were assigned at birth. The term may include but is not limited to: transsexuals, cross-dressers and other gender-variant people. Transgender people may identify as female-to-male (FTM) or male-to-female

C. The Medical Treatment of People with an Intersex Condition

Before the 1950s, infants who were born with an intersex condition were not subjected to any medical treatment. If a child was born with atypical genitalia, doctors would assign a sex to the infant that they believed was most appropriate and would not otherwise surgically or hormonally alter the child.[17]

During the middle of the twentieth century, however, two developments occurred that changed the manner in which medical experts treated the birth of a child with an intersex condition. First, surgical techniques were developed that made it possible to modify genitalia to what was considered to be a "cosmetically acceptable" appearance.[18] Second, the idea that gender identity was based upon nurture and not nature became the conventional wisdom. In other words, most doctors, sociologists, and psychologists believed that children were born without an innate sense of being male or female.[19] They believed that gender identity would develop

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> (MTF). . . . Transgender people may or may not decide to alter their bodies hormonally and/or surgically.
>
> Transsexual (also Transexual): An older term which originated in the medical and psychological communities. While some transsexual people still prefer to use the term to describe themselves, many transgender people prefer the term *transgender* to *transsexual*. Unlike *transgender*, *transsexual* is not an umbrella term, as many transgender people do not identify as transsexual. *Id.*

The University of San Francisco Medical Center defines the terms as follows:

> Transgender: literally "across gender"; sometimes interpreted as "beyond gender"; a community-based term that describes a wide variety of cross-gender behaviors and identities. This is not a diagnostic term, and does not imply a medical or psychological condition.
>
> . . . .
>
> Transsexual: a medical term applied to individuals who seek hormonal (and often, but not always) surgical treatment to modify their bodies so they may live full time as members of the sex category opposite to their birth-assigned sex (including legal status). Some individuals who have completed their medical transition prefer not to use this term as a self-referent. Ctr. of Excellence for Transgender Health, *Transgender Terminology*, UNIV. OF CAL., S.F., http://www.transhealth.ucsf.edu/trans?page=protocol-terminology (last visited Feb. 25, 2011).

17. Alice Domurat Dreger, *A History of Intersexuality: From the Age of Gonads to the Age of Consent*, 9 J. CLINICAL ETHICS 345, 345–49 (1998) [hereinafter *A History*].

18. Alice Domurat Dreger, *"Ambiguous Sex"—or Ambivalent Medicine? Ethical Issues in the Treatment of Intersexuality*, HASTINGS CENTER REP., May–June 1998, at 24, 28 [hereinafter *Ambivalent Medicine*].

19. *Id.* at 27–28.

consistently with the appearance of the child's genitalia and the gender role in which the child was raised.[20]

Beginning in the 1950s, the standard protocol for treating newborns with ambiguous genitalia involved surgical alteration of "unacceptable" genitalia into "normal" genitalia.[21] "Normal" genitalia for boys required an "adequate" penis.[22] If doctors believed that an XY infant had an "adequate" penis, the child would be raised as a boy.[23] A child without an "adequate" penis would be surgically altered and raised as a girl.[24] The penis became the essential determinant of sex because medical experts believed that a male could only be a true man if he possessed a penis that was capable of penetrating a vagina and allowed him to urinate in a standing position.[25]

Medical technology at this time was capable of creating an adequate vagina (defined as one that was capable of being penetrated by an adequate penis), but the technology was not advanced enough to create a fully functional penis (one that was capable of penetrating a vagina). Therefore, surgeons would typically recommend to parents that their XY infants with smaller penises or infants with other genital ambiguities be raised as girls after the doctors surgically and hormonally feminized them.[26]

Under this protocol, some XY infants were surgically and hormonally altered and raised as girls because of the dominant belief that growing up as a boy with an "inadequate" penis was too psychologically traumatic to risk.[27] Some of these XY infants had fully functional testicles, and were therefore capable of reproducing. Doctors would destroy their reproductive capacity rather than

20. *Id.*; John G. Hampson et al., *Hermaphroditism: Recommendations Concerning Case Management*, 16 J. CLINICAL ENDOCRINOLOGY & METABOLISM 547 (1956); John Money et al., *An Examination of Some Basic Sexual Concepts: The Evidence of Human Hermaphroditism*, 97 BULL. JOHN HOPKINS HOSP. 301 (1955).

21. Use of the terms "normal," "adequate," and "acceptable" genitalia in this Article reflect the language used in the medical literature. The Author believes that the atypical genitalia referred to in the literature are differences or variations and should not be labeled with the normative terms "normal," "adequate," and "acceptable."

22. *Ambivalent Medicine*, *supra* note 18, at 27–28.

23. *Id.*

24. *Id.*

25. *Id.* at 29.

26. SUZANNE J. KESSLER, LESSONS FROM THE INTERSEXED 19 (1998).

27. *See Ambivalent Medicine*, *supra* note 18, at 27.

recommending that they be raised with a penis that was considered smaller than the norm.[28]

XX infants with a phallus that appeared to be more similar in length to a penis than a clitoris were treated differently. Instead of recommending that these children be raised as boys, doctors would surgically remove the clitoris or reduce it to a size that they considered acceptable,[29] even if the surgery might diminish or destroy the person's ability to engage in satisfactory sex.[30]

The dominant protocol practiced during most of the last sixty years was based on three interrelated sex and gender stereotypes. First, heteronormativity dominated the equation. When determining whether a child would be happier as a boy or a girl, doctors considered the child's capacity for engaging in traditional heterosexual intercourse in adulthood.[31] Doctors presumed that all boys required a penis capable of being inserted in a vagina and all girls required a vagina capable of accommodating a penis. They operated on the assumption that everyone would want to engage in heterosexual sexual relationships.[32]

Second, gender stereotypes about the importance to females of physical appearance compared to sexual satisfaction also affected the treatment decision.[33] Doctors would remove a girl's clitoris if they decided the clitoris was too large.[34] Doctors performed these surgeries even though they often impaired the girl's ability to engage in satisfactory sex.

Finally, medical treatment decisions were dominated by stereotypical presumptions about what doctors believed would be important to males and females. Health care providers presumed that males would prioritize the size of their penis over reproductive

28. *See id.* at 28.

29. L.H. Braga & J.L. Pippi Salle, *Congenital Adrenal Hyperplasia: A Critical Appraisal of the Evolution of Feminizing Genitoplasty and the Controversies Surrounding Gender Reassignment*, 19 EUR. J. PEDIATRIC SURGERY 203, 204 (2009). Until the 1970s, doctors would amputate the entire clitoris based on the belief that the clitoris was not necessary for normal sexual function. *Id.*

30. FAUSTO-STERLING, *supra* note 5, at 59–61.

31. *Id.*; *A History*, *supra* note 17, at 349.

32. FAUSTO-STERLING, *supra* note 5, at 58–59.

33. *Id.*

34. A clitoris is considered acceptable if it is less than one centimeter in length. Phalluses between 1 and 2.5–3 centimeters are considered unacceptable and are surgically altered under current medical practices. *Id.* at 59.

capabilities. Therefore, doctors would surgically and hormonally feminize XY infants who may have been able to reproduce[35] rather than allow the children to grow up as boys with what doctors believed was an inadequate phallus. The focus for females was different. Doctors assumed that females would prioritize the ability to procreate even if they could not fully enjoy the act that leads to procreation.[36] Therefore, doctors would retain reproductive capacity for XX infants who were capable of conceiving and giving birth but surgically remove or reduce the size of the clitoris, which often diminished or destroyed a female's ability to enjoy sexual acts.[37]

Because infants with an intersex condition were considered "abnormal," their births were typically shrouded in shame and secrecy.[38] Doctors often told parents half-truths about their children's condition.[39] Parents were also encouraged to lie to their children about the nature of their condition.[40] The children were viewed as "freaks"; their conditions were to be studied by physicians and hidden from society.[41]

During the 1990s, a number of people began to question the premises underlying the dominant treatment protocol for infants born with "ambiguous" genitalia.[42] Many authorities, including experts in a variety of disciplines and intersex activist organizations, started to challenge the standard medical practices for three reasons.

- They asserted that the dominant protocol, which was based upon half-truths and secrecy, led to psychological trauma because it exacerbated a person's sense of shame by reinforcing cultural norms of sexual abnormality. People with an intersex condition who were subjected to the standard treatment protocol perceived the practices as

35. Some of these males would have required Assisted Reproductive Technologies (ART) to reproduce.

36. FAUSTO-STERLING, *supra* note 5, at 59; Bruce E. Wilson & William G. Reiner, *Management of Intersex: A Shifting Paradigm*, 9 J. CLINICAL ETHICS 360, 363–64 (1998).

37. FAUSTO-STERLING, *supra* note 5, at 59.

38. *See, e.g.*, KESSLER, *supra* note 26, at 97; *Ambivalent Medicine*, *supra* note 18, at 27.

39. *See, e.g.*, KESSLER, *supra* note 26, at 97; *Ambivalent Medicine*, *supra* note 18, at 27–28.

40. *See, e.g.*, KESSLER, *supra* note 26, at 95–96; *Ambivalent Medicine*, *supra* note 18, at 27.

41. *See, e.g.*, KESSLER, *supra* note 26, at 95; *Ambivalent Medicine*, *supra* note 18, at 31.

42. For an excellent overview of the harm caused by the traditional treatment protocol, see Anne Tamar-Mattis, *Exceptions to the Rule: Curing the Law's Failure to Protect Intersex Infants*, 21 BERKELEY J. GENDER L. & JUST. 59, 64–74 (2006).

a sexual violation leading to a profound loss of their autonomy and extreme humiliation.

- They argued that gender identity could not be manipulated by surgical and hormonal alteration. Therefore, they contended that these interventions could lead to irreversible harm if the child's gender identity did not develop in conformity with the surgically altered genitalia.
- They asserted that in cases where the gender assignment was not controversial, cosmetic genital surgeries caused more physical and psychological trauma than allowing the children to grow up with atypical genitalia. Many adults with an intersex condition who had been subjected to cosmetic genital surgery maintained that it often caused a loss or diminishment of erotic response, genital pain or discomfort, infections, scarring, urinary incontinence, and cosmetically unacceptable genitalia.[43]

Based upon these concerns, many experts began to call for either a moratorium or a severe limitation on the practice of surgically altering infants with an intersex condition. They asserted that the standard medical protocol should be modified in three ways. First, they encouraged more honesty and openness about the treatment of intersexuality to diminish the stigma and psychological trauma experienced by people with an intersex condition and their family members. Second, they called for an end to surgeries that feminized XY infants on the flawed assumption that gender identity is malleable. Third, they asserted that cosmetic genital surgeries that often cause pain, scarring, incontinence, sexual dysfunction, and other physical and psychological trauma could only be performed

43. Hazel Glenn Beh & Milton Diamond, *An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment Surgery on Infants with Ambiguous Genitalia*, 7 MICH. J. GENDER & L. 1, 55 (2000); Justine M. Schober, *Feminizing Genitoplasty for Intersex*, *in* PEDIATRIC SURGERY AND UROLOGY: LONG TERM OUTCOMES 549, 556–57 (Mark D. Stringer et al., eds., 1998); *A History*, *supra* note 17, at 352; Milton Diamond & H. Keith Sigmundson, *Sex Reassignment at Birth: A Long Term Review and Clinical Implications*, 151 ARCHIVES PEDIATRICS & ADOLESCENT MED. 298 (1997); William Reiner, *To Be Male or Female—That Is the Question*, 151 ARCHIVES PEDIATRICS & ADOLESCENT MED. 224 (1997); KESSLER, *supra* note 26; Milton Diamond, *Pediatric Management of Ambiguous and Traumatized Genitalia*, 162 J. UROLOGY 1021 (1999); Kenneth I. Glassberg, *Gender Assignment and the Pediatric Urologist*, 161 J. UROLOGY 1309 (1999); Cheryl Chase, *Surgical Progress Is Not the Answer to Intersexuality*, 9 J. CLINICAL ETHICS 385, 389–91 (1998).

with the informed consent of the person undergoing the treatment. In other words, they argued that parents should not have the power to consent to these potentially traumatic surgeries.[44]

Advocates calling for these changes have been extremely successful in accomplishing the first goal. The intersex movement has been very effective in educating the medical community about the harm of telling parents half-truths and lying to children. In 2006, leading experts from a variety of disciplines published a "Consensus Statement on the Management of Intersex Disorders" ("the 2006 Consensus Statement").[45] The 2006 Consensus Statement emphasizes the importance of open communication and participatory decision making. It encourages the use of a multidisciplinary treatment team—including psychologists, psychiatrists, social workers, and ethicists—who can adequately address the emotional aspects of the parents' decision-making process. It also urges treating physicians to emphasize that intersexuality is not shameful and that children have the potential to become well-adjusted adults.[46]

Intersex advocates have experienced some success in accomplishing their second goal. XY infants with an "inadequate" penis are no longer automatically surgically altered and raised as girls. Some doctors have been persuaded to limit the number of feminization surgeries on XY infants. The 2006 Consensus Statement recommends that physicians carefully consider a number of factors before assigning a gender to a newborn with an intersex condition. These factors include: the etiology of the intersex condition, genital appearance, surgical options, the need for life-long hormone replacement therapy, the potential for fertility, the views of the family, and sometimes, the circumstances relating to cultural practices.[47] The 2006 Consensus Statement recognizes that children are born with an innate sense of gender that cannot be manipulated by surgery and hormones.[48] The 2006 Consensus Statement also acknowledges that any type of surgical alteration of the genitalia may

44. *Supra* note 43.
45. *See* Lee et al., *supra* note 13.
46. *Id.* at e490.
47. *Id.* at e491.
48. *Id.* at e492–93.

be problematic because between 5 and 25 percent of people with a DSD will ultimately reject the assigned gender.[49]

The intersex movement has not been as successful at accomplishing its third goal: curtailing cosmetic genital surgeries designed to conform a child's genitalia to a binary sex norm.[50] If a child with an intersex condition is going to be raised as a girl, many physicians will reduce the size of her clitoris if they believe it is too large.[51] If a child with an intersex condition is going to be raised as a boy and the urethral opening appears someplace on the shaft rather than on the tip of the penis, doctors typically perform surgeries to modify the penis.[52]

II. THE INTERSEX MOVEMENT'S MAJOR GOAL: RETURNING CONTROL OF THEIR BODIES TO PEOPLE WITH AN INTERSEX CONDITION

Many medical experts and people with an intersex condition believe that a moratorium should be imposed on all cosmetic genital surgeries that are being performed without the express informed consent of the person undergoing the treatment.[53] In other words, they believe that parents should not have the authority to consent to these surgeries on behalf of their children. Instead, they assert that these surgeries should be delayed until the children reach the age when they have the capacity to determine for themselves whether to undergo any type of medical treatment.[54]

49. *Id.* at e491–92. The rejection of the assigned gender varies with the type of DSD. For example, more than 90 percent of people with 46,XX congenital adrenal hyperplasia (CAH) and all people with 46,XY complete androgen insensitivity syndrome (CAIS) assigned female in infancy develop a female gender identity. *Id.* Approximately 60 percent of people with 5-alpha-reductase deficiency who were assigned female in infancy and who virilize at puberty end up living as males. *Id.* Twenty-five percent of the individuals with partial androgen insensitivity syndrome (PAIS), androgen biosynthetic defects, and incomplete gonadal dysgenesis, are dissatisfied with their sex of rearing, whether they were raised as males or females. *Id.*

50. *See* discussion *infra* notes 165–199 and accompanying text.

51. *See* discussion *infra* notes 165–169 and accompanying text.

52. *See* discussion *infra* notes 194–199 and accompanying text.

53. S*upra* note 43.

54. *Supra* note 43. Surgical interventions are not the only technique doctors have relied on to produce "acceptable" genitalia. Some doctors have also experimented with other methods of altering the appearance of the genitalia of infants with an intersex condition. *See, e.g.*, Saroj Nimkarn & Maria New, *Prenatal Diagnosis and Treatment of Congenital Adrenal Hyperplasia*, 67 HORMONE RES. 53 (2007). Instead of performing surgery after the child is born, some doctors administer drugs to pregnant mothers who may be carrying a child with one type of intersex condition, 21-hydroxylase deficiency congenital adrenal hyperplasia (CAH), an adrenal disorder

Those supporting a moratorium on cosmetic genital surgeries on infants with a DSD believe that parents should not be given the authority to consent to these surgeries performed on their infants because:

- they are not medically necessary;
- they can interfere with sexual satisfaction;
- they frequently result in severe scarring and pain;
- multiple invasive surgeries are often required;
- children who undergo these surgeries often suffer from stigma and trauma from being treated as abnormal and in need of fixing;
- medically unnecessary surgery should not be used to relieve the anxiety of the parents for their intersex child; and
- the children's sense of autonomy may be harmed when they are old enough to understand the procedures and their consequences.[55]

Recent studies support these assertions. In 2001, a group of experts published a study in the respected British medical journal *The Lancet* of forty-four adolescent patients, all of whom had undergone surgery in infancy between 1979 and 1995.[56] These experts concluded that medically unnecessary cosmetic surgeries should be delayed until a child is old enough to make the decision.[57] Another publication from the United Kingdom concluded from a study of fourteen patients with CAH that the results of early surgery were disappointing and recommended that surgery generally be delayed until after puberty.[58] In 2011, a group of German physicians also agreed with this assessment and recommended that genital surgery generally be performed in adolescence and only with the

that can lead to the formation of atypical genitalia. *Id.* See *infra* notes 170–83 and accompanying text for a more detailed discussion of this treatment protocol.

55. *See* Julie A. Greenberg, *Legal Aspects of Gender Assignment*, 13 ENDOCRINOLOGIST 277, 279–84 (2003); Tamar-Mattis, *supra* note 42.

56. Sarah M. Creighton et al., *Objective Cosmetic and Anatomical Outcomes at Adolescence of Feminising Surgery for Ambiguous Genitalia Done in Childhood*, 358 LANCET 124, 124 (2001).

57. *Id.* at 124–25.

58. N.K. Alizai et al., *Feminizing Genitoplasty for Congenital Adrenal Hyperplasia: What Happens at Puberty?*, 161 J. UROLOGY 1588, 1589 (1999).

informed consent of the person undergoing the procedure.[59] They based their recommendation on the high dissatisfaction rates expressed by people with a DSD in the surgical result, clitoral arousal, and overall sex life.[60]

In 2004, the Hastings Center, a well-respected nonpartisan organization that studies ethical standards in health and medicine, convened a multidisciplinary group to consider the medical, psychosocial, and ethical issues associated with the care of children born with atypical genitalia. This group of experts concluded that it is unethical to perform surgery to normalize the appearance of people's genitalia without the informed consent of the patients (the children).[61] They determined that parental consent was not adequate to protect the child's interests.[62] They acknowledged that some surgeons maintain that technical considerations warrant some early surgeries, but they concluded that the irrevocable nature of the surgery warranted extreme caution and questioned whether surgical expediency could ever outweigh the psychosocial and ethical considerations for waiting until children reach the age when they can meaningfully participate in the decision.[63]

The 2006 Consensus Statement provides the most thorough analysis of the current treatment protocols for children with an intersex condition. It encourages physicians to adopt a more cautious approach before undertaking surgical intervention. It suggests that clitoral reduction be limited to cases of severe genital virilization (the development of male sex characteristics in a female) and should not be performed on all clitorises that are larger than the norm.[64] It emphasizes that the focus of such surgeries should be on functional outcome (orgasmic function and erectile sensation) rather than on cosmetic appearance.[65] It also acknowledges that absolutely no evidence exists to support the long-standing assumption that genital

59. Birgit Kohler et al., *Satisfaction with Genital Surgery and Sexual Life of Adults with XY Disorders of Sex Development: Results from the German Clinical Evaluation Study*, 97 J. CLINICAL ENDOCRINOLOGY & METABOLISM 1441 (2011).

60. *Id.*

61. Joel Frader et al., *Health Care Professionals and Intersex Conditions*, 158 ARCHIVES PEDIATRICS & ADOLESCENT MED. 426, 427–28 (2004).

62. *Id.*

63. *Id.*

64. Lee et al., *supra* note 13, at e491.

65. *Id.*

surgery carried out for cosmetic purposes during the first year of life relieves parental distress or improves the parent-child bond.[66]

The 2006 Consensus Statement and its recommended guidelines have been applauded by many and endorsed by the American Academy of Pediatrics.[67] The 2006 Consensus Statement, however, fails to resolve the remaining vital issue: should medically unnecessary cosmetic infant genital surgery ever be performed? Some have criticized the 2006 Consensus Statement for supporting surgery in cases of severe virilization even though current studies do not support the conclusion that current surgical techniques preserve sensation.[68] Others have supported the 2006 Consensus Statement's affirmation of the parents' right to consent to genital surgery.[69] No studies, however, have examined the effect that the 2006 Consensus Statement has had on current practices.

III. POTENTIAL APPROACHES TO ENHANCING THE AUTONOMY OF PEOPLE WITH AN INTERSEX CONDITION

People calling for a moratorium on cosmetic genital surgeries being performed on infants with an intersex condition believe that parents should not have the legal authority to consent to these surgeries. No one questions whether the parents making these decisions are motivated by love and a genuine desire to help their children. Those who support a moratorium are concerned, however, that parents may not be able to completely comprehend what might be in their children's long-term best interests. They emphasize that parents should be provided complete information about their children's conditions and offered appropriate professional counseling and peer support. They assert that medical treatment should be limited to conditions that pose an actual physical health risk. They believe that only the affected children, when they are old enough to

66. *Id.*

67. *Id.* at e492; *Section on Endocrinology Policy*, AM. ACAD. PEDIATRICS, http://www2.aap.org/sections/endocrinology/endopolicy.htm (last visited Mar. 17, 2012).

68. Katrina A. Karkazis, *Early Genital Surgery to Remain Controversial*, 118 PEDIATRICS 814, 814 (2006).

69. *Id.*

appropriately assess the risks and benefits, should have the power to decide whether they want to undergo cosmetic surgery.[70]

Most doctors, however, oppose a moratorium on infant genital cosmetic surgeries and believe that surgical alteration is in the best interests of a child born with an intersex condition. They are concerned that an untreated child may suffer psychological trauma from growing up with atypical-appearing genitalia. They believe this potential risk of psychological harm is more detrimental than are the potential risks of surgery. They assert that parents should continue to be allowed to consent to these surgeries because they are in the best position to determine what treatment would be in their child's best interests.[71] This group believes that parents who are fully educated about all the risks and benefits of the different protocols should have the authority to determine what is in the best interests of their child.[72]

A significant minority of parents now decline or postpone surgery on their children with atypical genitalia. According to one comprehensive study published in 2007, however, most parents still choose to consent to genitoplasty on behalf of their infants.[73]

Adults with an intersex condition also disagree about whether parents should have the ability to consent to these surgeries during their child's infancy. One study, published in 2004, surveyed seventy-two patients with an intersex condition and XY

70. *See e.g.*, Beh & Diamond, *supra* note 43; Chase, *supra* note 43, at 385; Diamond & Sigmundson, *supra* note 43; Kenneth Kipnis & Milton Diamond, *Pediatric Ethics in the Surgical Assignment of Sex*, 9 J. CLINICAL ETHICS 398, 406 (1998); Alyssa Connell Lareau, *Who Decides? Gender Normalizing Surgery on Intersexed Infants*, 92 GEO. L.J. 129 (2000); Tamar-Mattis, *supra* note 42; Bruce E. Wilson & William G. Reiner, *Management of Intersex: A Shifting Paradigm*, 9 J. CLINICAL ETHICS 360 (1998).

71. KATRINA KARKAZIS, FIXING SEX: INTERSEX, MEDICAL AUTHORITY, AND LIVED EXPERIENCE 134–35 (2008); *see also* Claudia Wiesemann et al., *Ethical Principles and Recommendations for the Medical Management of Differences of Sex Development (DSD)/Intersex in Children and Adolescents*, 169 EUR. J. PEDIATRICS 671, 674–76 (2009) (discussing ethical principles and guidelines for the medical treatment of infants with a DSD).

72. *See*, *e.g.*, S. F. Ahmed et al., *Intersex and Gender Assignment: The Third Way*?, 89 ARCHIVES DISEASE CHILDHOOD 847 (2004); Robert M. Blizzard, *Intersex Issues: A Series of Continuing Conundrums*, 110 PEDIATRICS 616 (2002); J. Daaboul & J. Frader, *Ethics and the Management of the Patient with Intersex: A Middle Way*, 14 J. PEDIATRIC ENDOCRINOLOGY & METABOLISM 1575 (2001); Wiesemann et al., *supra* note 71.

73. Melissa Parisi et al., *A Gender Assessment Team: Experience with 250 Patients over a Period of 25 Years*, 9 GENETICS MED. 348 (2007); *see also*, KARKAZIS, *supra* note 71, at 134–35 (concluding, after conducting interviews with parents and visiting Web site support groups, that a fair number of parents continue to choose genital surgery for their children).

chromosomes.[74] Some of the surveyed patients had been raised as males and others had been raised as females. Not all had been subjected to surgery as infants, and those who had been surgically altered had undergone a variety of surgical interventions. Opinions about the appropriate timing for genital surgery varied. Forty-six percent believed that surgery should not be performed before adolescence, and an additional 4 percent believed surgery should not be performed before a child reached elementary school age.[75] Forty-nine percent supported surgery during infancy or toddlerhood.[76] In other words, almost one-half of the people interviewed supported delaying surgery until adolescence or adulthood when the person undergoing the procedure can meaningfully participate in the decision-making process. The authors of the study recognized that their sample size was small and may not have been representative. They called for those who are in a position to control the guidelines for treatment of infants with an intersex condition to obtain additional data to determine the optimal treatment protocol.[77]

Until comprehensive retrospective studies are conducted that clearly establish whether surgical alteration of an infant with an intersex condition is beneficial, these interventions will continue to be controversial. Given the critical interests at stake and the polarized nature of the debate, legal institutions will likely be brought into the dispute. Legislatures may be asked to enact statutes and, in the absence of legislative action, courts may be asked to intervene. Thus far, no country or state has enacted controlling legislation[78] and Colombia is the only jurisdiction in which the highest court has rendered an opinion on this issue. Therefore, if courts are asked to resolve the legal, medical, and ethical issues

74. H.F.L. Meyer-Bahlburg et al., *Attitudes of Adult 46, XY Intersex Persons to Clinical Management Policies*, 171 J. UROLOGY 1615, 1615 (2004).

75. *Id.* at 1617.

76. *Id.*

77. *Id.* at 1618.

78. South Africa considered adopting legislation. *See Legislation Mooted to Regulate Intersex Surgery*, ANC DAILY NEWS BRIEFING (Nov. 30, 2004), http://www.e-tools.co.za/newsbrief/2004/news1201.txt. The city of San Francisco also held hearings on this issue and issued a report condemning current practices. *See* S.F. HUMAN RIGHTS COMM'N OF THE CITY & CNTY. OF S.F., A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL "NORMALIZATION" OF INTERSEX PEOPLE 4 (2005), *available at* http://www.sf-hrc.org/ftp/uploadedfiles/sfhumanrights/Committee_Meetings/Lesbian_Gay_Bisexual_Transgender/SFHRC%20Intersex%20Report(1).pdf.

surrounding consent to the treatment of children born with an intersex condition, the outcome is far from clear.

Courts or legislatures could modify current practices to ensure that people with an intersex condition have their right to autonomy and decision-making power over health care decisions affecting them respected. Legal institutions could ban these procedures unless they are performed with the informed consent of the person undergoing the procedure. Alternatively, they could allow the procedures to continue but mandate oversight by a court and/or a hospital ethics board. Finally, they could impose enhanced informed consent procedures.[79]

A. The Informed Consent Doctrine

The most likely legal doctrine that will be used to challenge the current medical treatment protocol for infants with an intersex condition is the doctrine of informed consent. The informed consent doctrine protects an individual's right to bodily integrity and self-determination and respects patients' rights to autonomous decision making. The informed consent doctrine requires that doctors (1) fully inform their patients about all material risks associated with any proposed medical treatment; and (2) receive the patient's consent to the procedure. The principle of autonomy requires deference to a patient's treatment choices unless the government has a compelling interest that justifies overriding a competent person's right to autonomy. Courts rarely find such an overriding state interest.

The informed consent doctrine is premised on the patient's ability to understand and weigh the risks and benefits of the suggested procedure. Sometimes patients are unable to reach an informed decision because they are too young or they suffer from a disabling condition that precludes them from understanding the advantages and disadvantages of a procedure. In these cases, informed permission is required from a surrogate, typically the minor's (or incompetent's) parent(s) or guardian(s).[80]

Parents' decisions on behalf of their children are generally accorded great deference for two reasons. First, legal institutions

79. For the advantages and disadvantages of these approaches, see GREENBERG, *supra* note 2, at 35–43.

80. Am. Acad. of Pediatrics, Comm. on Bioethics, *Informed Consent, Parental Permission, and Assent in Pediatric Practice*, 95 PEDIATRICS 314, 314 (1995).

presume that parents will make decisions that are in the best interests of their children.[81] Second, the Constitution protects family privacy and parental authority.[82] Therefore, courts rarely become involved in parental medical decisions,[83] as long as the parents and the physicians agree on the treatment.[84]

Typically, parents are allowed to consent to medical treatment for their minor children, even if the treatment involves a significant risk of harm. Parents can consent to inoculations, complex surgeries, experimental treatments, radiation, chemotherapy, and other potentially harmful procedures. The law presumes that parents will weigh the potential benefits and risks of each procedure and make decisions that are in the best interest of their children.[85]

In some circumstances, however, courts and legislatures have determined that complete deference to parental decisions may not be in a child's best interests. If the potential gravity of the consequences of the medical treatment is particularly severe and the situation involves potentially conflicting interests, courts may carefully review parents' consent to the treatment of their child. The classic cases requiring close scrutiny involve (1) terminating the life of a child in a persistent vegetative state; (2) authorizing an organ donation to benefit another family member (typically a sibling of the

81. *See, e.g.*, Parham v. J.R., 442 U.S. 584, 602 (1979) (involving decisions by parents to institutionalize their children with a psychiatric condition).

82. *See, e.g.*, Troxel v. Granville, 530 U.S. 57 660, 667 (2000) (involving the right of a parent to determine visitation by grandparents); *Parham*, 442 U.S. at 604.

83. Courts have intervened when they believe the parents are not capable of reaching a well-reasoned decision that would be in the child's best interests. *See, e.g.*, A.D.H. v. State Dep't of Human Res., 640 So. 2d 969 (Ala. Civ. App. 1994) (ordering appropriate HIV treatment over the mother's objection when the mother adamantly denied that her child was infected with HIV).

84. Beh & Diamond, *supra* note 43, at 39. Litigation regarding parental consent may occur when parents refuse to agree to a medically recommended procedure. These cases typically arise when a doctor suggests a potentially life-saving treatment for a child and the parents refuse to consent because the procedure violates the parents' religious beliefs. *See, e.g.*, In re Petra B., 265 Cal. Rptr. 342 (Ct. App. 1989) (ordering treatment of a minor's serious burns over the objections of the parents, who wanted to treat the burns with herbal remedies for religious reasons). These cases involve unique issues involving the First Amendment. Cases involving infants with an intersex condition are not analogous to the religious-refusal cases for two reasons. First, in the cases involving an infant with an intersex condition, doctors and parents agree about the desired treatment, but in the religious-refusal cases, the doctor is recommending a procedure that the parent is refusing. Second, the parental decision in the intersex cases is not based on religious practices and therefore does not involve First Amendment issues.

85. *See* Beh & Diamond, *supra* note 43, at 39.

incompetent child); and (3) approving the involuntary sterilization of a minor or incompetent adult.[86]

In these cases, courts do not simply defer to the parents. Instead, they require judicial oversight of these procedures for three reasons. First, these choices potentially infringe on the children's constitutionally protected rights, including the right to life and the right to reproductive choice. Second, they involve a significant risk of harm to the children. Finally, parents may be in a position in which it is difficult for them to separate their child's interests from their own interests. For example, in the organ-donation cases, parents are making a decision that may save the life of one child who requires a kidney transplant and at the same time expose their other child, the kidney donor, to a serious risk of harm. Similarly, in involuntary-sterilization cases, parents may want to spare their child from the difficulties of bearing and rearing a child, but they may also be motivated by their concern about having to care for a grandchild, should their incompetent child become pregnant or father a child. Therefore, courts will carefully scrutinize these decisions to ensure that the child's constitutional rights are protected and that the decision is in the best interests of the child.[87]

In addition to termination of life, organ donation, and sterilization procedures, some jurisdictions have ruled that other invasive procedures—including involuntary psychosurgery, electroconvulsive therapy, and administration of antipsychotic medications—are life-altering treatments that require additional measures to protect the child's rights.[88] Recently, the Washington Protection and Advocacy System (WPAS), a federally funded watchdog agency charged with investigating discriminatory treatment of people with a disability, investigated a case involving the administration of growth-attenuating hormones and the removal of the uterus and breast-bud tissue from a developmentally disabled

86. *See* Jennifer Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?*, 73 TEMP. L. REV. 1, 45–46 (2000).

87. *See, e.g.*, *In re* Romero, 790 P.2d 819, 821 (Colo. 1990); Estate of C.W., 640 A.2d 427 (Pa. Super. Ct. 1994).

88. *See* DAVID R. CARLSON & DEBORAH A. DORFMAN, INVESTIGATIVE REPORT REGARDING THE "ASHLEY TREATMENT" 17–18 (2007), *available at* http://www.disabilityrightswa.org/home/Full_Report_InvestigativeReportRegardingtheAshleyTreatment.pdf.

child. The WPAS determined that these types of procedures, because they were invasive and irreversible, also required court supervision.[89]

B. The Informed Consent Doctrine Applied to Surgeries Performed on Infants with an Intersex Condition

Allowing parents to consent to cosmetic genital surgery on an infant with an intersex condition involves similarly complex issues. Currently, parents can consent to these surgeries, and these procedures are not subjected to any external oversight or approval. Based on the important interests at stake, courts or legislatures could be convinced to place stricter limitations on the circumstances under which these procedures can be performed. The extent of the regulation would depend on many factors. The most important consideration would be whether the procedure affects a constitutionally protected right.

1. Procedures That Result in Sterilization Affect a Constitutionally Protected Right and Should Require Court Approval

Medical procedures that result in sterilization affect the constitutionally protected right to reproduce and require strict oversight. In 1942, in *Skinner v. Oklahoma*,[90] the Supreme Court began to impose strict restrictions on sterilization practices. The Court ruled that procreative choice is a fundamental human right protected by the U.S. Constitution.[91] Thus, the Court limited the circumstances under which states could sterilize people without their consent.[92]

After *Skinner*, some states adopted statutes regulating sterilization practices to ensure that a person's reproductive capacity would not be terminated inappropriately. These regulations typically

89. *Id.* at 22. WPAS is now called Disability Rights Washington. For a more detailed discussion see *infra* notes 100–01 and 210–20 and accompanying text.

90. 316 U.S. 535 (1942).

91. *Id.* at 541.

92. *Skinner* involved an Oklahoma statute that allowed the government to sterilize habitual criminals. *Id.* at 536. A constitutional claim based on the fundamental right to reproductive freedom must be based on a governmental act and not based on the actions of private individuals. *See* Jackson v. Metro. Edison Co., 419 U.S. 345, 349–50 (1974). Therefore, a doctor who is not employed by the state or a parent could not be held liable for violating a child's constitutionally protected right to reproduction. Because reproduction is considered a fundamental right, however, a number of states have limited the ability of private actors to engage in actions that affect reproductive freedom. *See infra* note 93 and accompanying text.

require judicial oversight and approval of sterilizations performed on people who are not capable of consenting to the procedure themselves. Full protection of reproductive rights requires that a court approve an involuntary sterilization before it is performed. During the judicial hearing, the child who will be subjected to sterilization must have a separate legal representative who advocates zealously on the child's behalf.[93]

Court approval is clearly required when the sole purpose of the procedure is sterilization. If the main reason for the medical treatment is something other than sterilization (e.g., removal of a cancerous growth) and sterilization is a byproduct, many doctors and attorneys believe that they can proceed without court approval.[94] The WPAS, however, has concluded that all sterilizations of developmentally disabled individuals, regardless of the primary motivation for the procedures, require court approval.[95]

Reproductive rights are compromised in a number of medical procedures performed on infants with an intersex condition. A number of current medical practices have the potential to destroy reproductive capacity. For example, doctors will remove the female reproductive organs of children with congenital adrenal hyperplasia who are going to be raised as males, thus destroying their ability to reproduce. In addition, doctors will remove the testicles of infants with complete androgen insensitivity syndrome, which could potentially affect the children's future reproductive capacity.[96] Finally, although the practice is no longer supported in the medical literature, anecdotal evidence indicates that some doctors may still recommend raising XY children with an "inadequate" penis as

93. States that have adopted legislation controlling the sterilization of people who are not competent to consent include Colorado, COLO. REV. STAT. §§ 27-10.5-128 to -131 (1997); Connecticut, CONN. GEN. STAT. §§ 45a-691 to -700 (1997); Maine, ME. REV. STAT. ANN. tit. 34, §§ 7001–7016 (1998)); Oregon, OR. REV. STAT. §§ 436.205–.335 (1995); and Vermont, VT. STAT. ANN. tit. 18, §§ 8705–8716 (1987). In states that do not have controlling legislation, courts have ruled that these procedures cannot be performed without a court order. *See*, *e.g.*, *In re* Romero, 790 P.2d 819 (Colo. 1990); Estate of C.W., 640 A.2d 427 (Pa. Super. 1994); *In re* Hayes, 608 P.2d 635 (Wa. 1980).

94. *See* CARLSON & DORFMAN, *supra* note 88.

95. *Id.*

96. Current technology does not exist that would allow women with CAIS to reproduce. Presently, the gonads cannot produce sperm that could be used for reproduction. It is possible, however, that future technology could allow for reproductive ability. When doctors make their recommendations, the potential for reproduction should be considered.

female. If the parents agree in these cases, the doctors will remove the testicles and eliminate reproductive capacity.

Although the sterilization statutes and cases have considered only children with developmental disabilities, the principles relied on and the rules adopted in these actions should apply with equal force to prohibit the sterilization of children with an intersex condition.[97] In fact, sterilizations of infants born with an intersex condition could be considered less justifiable than are sterilizations of profoundly disabled children. When infants with an intersex condition mature, they will be able to provide their informed consent to a procedure, whereas profoundly disabled children will never be in a position to provide informed consent. Thus, the justification for sterilizing infants with an intersex condition is even less defensible.

Sterilizations of infants with a DSD will eventually be reviewed by courts. First, doctors or hospitals who are concerned about potential liability may seek court approval before they proceed with interventions that involve sterilization.[98] In addition, people who have had their reproductive ability terminated without their consent may initiate lawsuits. Finally, governmental agencies could initiate investigations into these practices. When these lawsuits arise, courts should ban these types of procedures unless there is clear evidence that the sterilization would be in the child's best interests.

2. Because of Their Invasive and Irreversible Nature, Cosmetic Genital Surgeries Not Causing Sterilization Should Be Subjected to Heightened Scrutiny

Procedures that do not affect reproductive capacity do not involve the same fundamental rights as the sterilization cases. As a result, these procedures are not entitled to the same constitutional protection. Generally, parents' rights to make medical decisions on

97. In an unpublished opinion, a doctor was held liable for removing gonads and rendering a minor infertile when he proceeded without the consent of the minor or her parents. *See*, *e.g.*, Before the Minnesota Board of Medical Practice Stipulation and Order in the Matter of the Medical License of Michael H. Wipf, M.D., Date of Birth 1/31/1953, License Number 28,237 (on file with author).

98. *See*, *e.g.*, *Case I Part I (Sentencia SU-337/99)*, INTERSEX SOC'Y OF N. AM. (May 12, 1999), http://www.isna.org/node/166 [hereinafter *Sentencia SU-337/99, Pt. I*]; *infra* note 105. Doctors were responsible for initiating this case, which eventually resulted in the Constitutional Court of Colombia imposing safeguards to protect infants born with an intersex condition. The Colombian doctors were concerned that they might be held liable for performing cosmetic genital surgery, so they told the parents that they would not proceed without a court order.

behalf of their minor children are respected. Typically, if parents consent to a medically recommended procedure, their decision is not subject to any type of review.[99]

Not all parental decisions, however, are granted automatic deference. Although legal authority is sparse, some disability organizations have asserted that judicial approval is required for parental consent in cases involving invasive and irreversible procedures other than sterilization. For example, in a recent investigation involving the removal of the uterus and breast-bud tissue of a developmentally disabled child and the administration of hormones to her, the WPAS determined that these types of procedures should only be undertaken with court supervision.[100] In its extensive report, the WPAS stated,

> [T]he rights of parents to make treatment and other decisions for their minor children, however, are not unfettered. "[T]he state has a wide range of power for limiting parental freedom and authority in things affecting the child's welfare." [*Prince v. Massachusetts*, 321 U.S. 158, 167 (1944).] Parents generally have the right to make medical decisions for their minor children and provide informed consent for various procedures; however, courts have limited this authority when parents seek highly invasive and/or irreversible medical treatment of their minor children. [*Parham v. J.R.*, 442 U.S. 584, 585 (1979).] Courts and the Washington State Legislature, for example, have held that parents do not have the authority to consent to medical treatment in cases involving involuntary inpatient psychiatric care, [*Id.* at 584; State *ex rel.* T.B. v. CPC Fairfax Hosp., 918 P.2d 497, 503–04 (Wash. 1996);] the administration of electro convulsive therapy in non-emergency life-saving situations, [*In re A.M.P.*, 708 N.E.2d 1235, 1240–1241 (Ill. App. Ct. 1999); Wash. Rev. Code § 71.34.355(9) (2009);] psychosurgery, [Wash. Rev. Code § 71.34.355(10) (2009);] abortions for mature minors,

99. *See* Beh & Diamond, *supra* note 43, at 38–39. No oversight is typically imposed as long as the procedure is solely to benefit the patient. If the procedure is being performed to benefit another person—for example, removing a kidney for transplant into the patient's sibling—court approval is necessary. *See* Rosato, *supra* note 86, at 57.

100. CARLSON & DORFMAN, *supra* note 88, at 18–19.

> [*State v. Koome*, 530 P.2d 260, 265–66 (Wash. 1975);] sterilization, [*In re Hayes*, 608 P.2d 635 (Wash. 1980); *In re K.M.*, 816 P.2d 71 (Wash. Ct. App. 1991); *In re Mary Moe*, 432 N.E.2d 712, 716–717 (Mass. 1982); *In re Rebecca D. Nilsson*, 471 N.Y.S.2d 439 (N.Y. Sup. Ct. 1983);] and other similar invasive medical treatments, [*State v. Baxter*, 141 P.3d 92 (Wash. Ct. App. 2006) (denying a father the right to circumcise his eight year old son with a hunting knife),] particularly where the interest of the parent may not be the same as those of the child [*In re Hayes*, 608 P.2d at 640; *see also Koome*, 530 P.2d at 263].[101]

Many procedures performed on infants with a DSD have the potential to make orgasm difficult or impossible and may cause serious long-term medical complications.[102] These invasive and potentially irreversible surgeries can permanently and dramatically infringe on the rights of people with an intersex condition to bodily integrity and sexual self-determination.[103] In addition, safeguards are needed because parents may be making decisions at a time when they are suffering distress about giving birth to and raising an "abnormal" child. Under these circumstances, it is difficult for parents to determine objectively the treatment that would be in their child's long-term interests, especially because the issue may affect sexuality when the child becomes an adult. Thus, these procedures should only be allowed under conditions that ensure that the child's rights are protected.[104]

101. *Id.*

102. *See* Lee et al., *supra* note 13, at e491.

103. *See* Lawrence v. Texas, 539 U.S. 558 (2003) (recognizing that a liberty interest extends beyond reproductive rights). In *Lawrence*, the Court held that a statute that criminalized same-sex sodomy was unconstitutional. The Court indicated that its holding would apply to situations beyond the criminalization of same-sex sexual acts. *Id.* at 574 ("[T]hese matters, involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment. At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life." (quoting Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 851 (1992))). A court could accordingly find that children with a DSD should have the power to determine for themselves whether they want to undergo medical procedures that could have a profound effect on their sexual relationships and their sense of self.

104. Alicia Ouellette has argued that parental decisions authorizing medical and surgical interventions to sculpt children's bodies should be analyzed under a trust-based construct that would require neutral third-party approval, rather than giving complete deference to the parents' decisions. *See* Alicia Ouellette, *Shaping Parental Authority over Children's Bodies*, 85 IND. L.J. 955 (2010).

Only one high court, the Constitutional Court of Colombia, has considered whether parents can consent to cosmetic genital surgery being performed on their children with a DSD.[105] Because of a court decision in 1995, doctors in Colombia were concerned about potential liability for performing genital surgery on infants with an intersex condition. In two cases, doctors recommended that the children they were treating undergo cosmetic genital surgery, but the doctors who made the recommendation refused to proceed without a court order. The parents of the two children sought court authority for the procedures to occur.[106]

The Constitutional Court of Colombia considered evidence that supported the traditional model as well as evidence that criticized this model and supported a moratorium on cosmetic genital surgeries on infants with an intersex condition. The court concluded that the uncertain and conflicting evidence put the law at an impasse. The court reasoned that prohibiting surgery until the children reach the age of consent would be engaging in social experimentation, but allowing the surgery to continue under the standard protocol would not ensure that the best interests of the children were protected.[107]

The Colombian court decided that surgical modification of an infant with an intersex condition must be treated differently from other types of parental consent cases. The court decided that the traditional informed consent rules do not guarantee that parents are in the best position to make a decision on behalf of their child.[108] The court was concerned because (1) parents typically lack information about intersexuality; (2) intersexuality is viewed as a disease that must be cured; and (3) treating physicians frequently convey a false sense of urgency to provide a quick cure.[109] The Colombian court recognized that, under these circumstances, parents cannot easily distinguish their own fears and concerns from considerations of the

105. *See Case 2 (Sentencia T-551/99)*, INTERSEX SOC'Y OF N. AM. (Aug. 2, 1999), http://www.isna.org/node/126; *Sentencia SU-337/99, Pt. I*, *supra* note 98. These decisions are reported in Spanish and can be found at *Texts of Colombia Decisions*, INTERSEX SOC'Y OF N. AM., http://www.isna.org/node/516 (last visited Mar. 17, 2012). For a translation of a portion of decision SU-337/99 into English, see Nohemy Solórzano-Thompson, *The Rights of Intersexed Infants and Children: Decision of the Colombian Constitutional Court, Bogotá, Colombia, 12 May 1999 (SU-337/99)*, *in* TRANSGENDER RIGHTS 122 (Paisley Currah et al. eds., 2006).

106. Solórzano-Thompson, *supra* note 105, at 122.

107. *Id.*

108. *Id.* at 129–30.

109. *See id.* at 130, 132.

"best interests" of their child.[110] The court concluded that parents may approve these surgeries to "normalize" their children, whom they view as "strange beings."[111]

The Colombian court decided to follow a middle path to protect the human rights of infants. It struck a balance between allowing parents full autonomy to consent to surgical alteration on behalf of their infant and barring all such surgeries.[112] The court called on legal and medical institutions to establish "qualified and persistent" informed consent procedures to protect the rights of children with an intersex condition until comprehensive studies clearly establish the course of treatment that is in these children's best interests.[113]

The court held that "qualified and consistent informed consent" requires that the following conditions be met.

1. The consent must be in writing.
2. The information provided must be complete. The parents must be informed about the dangers of current treatments, the existence of other paradigms, and the possibility of delaying surgeries and giving adequate psychological support to the children.
3. The authorization must be given on several occasions over a reasonable time period to ensure the parents have enough time to truly understand the situation.[114]

Advocates seeking to limit the number of infant cosmetic genital surgeries could adopt a number of approaches. They could call for a complete moratorium on all such surgeries performed without the informed consent of the person undergoing the treatment. Alternatively, they could advocate in favor of an enhanced informed consent standard similar to the procedures adopted in Colombia. Finally, they could seek regulations that would require supervision or approval of these procedures by an independent entity, such as a court or a hospital ethics committee.

Convincing courts or legislatures to mandate any of these approaches will require that intersex advocates develop persuasive legal arguments supporting their assertion that cosmetic genital

110. *Id*. at 124.
111. *Id.* at 130.
112. *Id.* at 130–31.
113. *Id.* at 131.
114. *Id.*

surgeries should be subjected to enhanced scrutiny.[115] Two legal frameworks that could support their arguments, sex discrimination and disability discrimination, are discussed in the next section.

IV. INFANT COSMETIC GENITAL SURGERIES: SEX OR DISABILITY DISCRIMINATION?

Most states have adopted legislation prohibiting discrimination in the provision of health care.[116] In addition, the Patient Protection and Affordable Care Act (PPACA), which was signed into law in 2010, mandates that health care be provided on a nondiscriminatory basis.[117] The PPACA does not specifically address the medical treatment of people with an intersex condition, but it does prohibit both sex and disability discrimination.

The PPACA provides:

> [A]n individual shall not, on the ground prohibited under . . . title IX of the Education Amendment Act of 1972 (20 U.S.C. 1681 et seq.) [prohibiting sex discrimination] . . . or section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794) [prohibiting disability discrimination], be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is

115. If the surgery results in sterilization, heightened scrutiny should be required and doctors should not be able to proceed without court review. The remainder of this Article focuses on surgeries not resulting in sterilization and explains why these surgeries should also be subjected to regulation and oversight.

116. States typically prohibit discrimination on the basis of sex and disability in the provision of health care under their public accommodations statutes. *See, e.g.*, CAL. CIV. CODE § 51 (West 2012); COLO. REV. STAT. § 24-34-601 (2006); CONN. GEN. STAT. § 46a-64 (2011); DEL. CODE ANN. tit. 6, §§ 4501–4504 (2009); D.C. CODE §§ 2-1401.02(24), -1402.31 (2010); HAW. REV. STAT. §§ 489-2 to -3 (2006); 775 ILL. COMP. STAT. 5/1-101 to -103 (2011); IOWA CODE §§ 216.2(13), .7 (2009); ME. REV. STAT. ANN. tit. 5, §§ 4553(8), 4592 (2010); MASS. GEN. LAWS ch. 272, §§ 98, 92A (2009); MINN. STAT. §§ 363A.11, .03 (2011); NEV. REV. STAT. § 233.010 (2011); N.H. REV. STAT. ANN. §§ 354-A:2, -A:17 (2009); N.J. STAT. ANN. §§ 10:5-4 to -5 (2010); N.M. STAT. §§ 28-1-7, -2 (2011); N.Y. EXEC. LAW §§ 292(9), 296(2)(a) (2011); R.I. GEN. LAWS §§ 11-24-2 to -2.1 (2005); VT. STAT. ANN. tit. 9, § 4502 (2011); WASH. REV. CODE §§ 49.60.215, .040 (2009); WIS. STAT. § 106.52 (2012).

117. *See* Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 1557, 124 Stat. 119, 260 (codified at 42 U.S.C.A. § 18116(a) (2010)).

> administered by an Executive Agency or any entity established under this title (or amendments).[118]

Therefore, to the extent that hospitals or physicians are subject to the PPACA or state laws prohibiting discrimination in the provision of health care, they would be violating the law if their medical treatment of infants born with an intersex condition is considered sex or disability discrimination.

A. Sex Discrimination

The PPACA and state laws prohibiting sex discrimination in the provision of health care are similar to other statues that prohibit discrimination because of "sex" in that they do not delineate acts that constitute impermissible sex discrimination. Although hundreds of federal, state, and local laws and regulations prohibit sex discrimination in a number of settings,[119] the meaning of the term "sex" in these legislative acts is far from clear. Therefore, during the last forty years, courts have been asked to determine exactly what types of acts violate statutory prohibitions against sex discrimination.

When laws prohibiting sex discrimination were first adopted, courts tended to rule that the purpose of the legislation was to provide equal opportunities for women and men. The typical early successful sex discrimination cases involved men or women who were treated differently because of their biological sex. For example, early decisions invalidated employer rules that provided only men could be airline pilots and only women could be flight attendants.[120]

During the first three decades after sex discrimination prohibitions were enacted in 1964, courts generally refused to expand the meaning of the term "sex" beyond this simple approach. Typically, the statutory ban against sex discrimination did not protect people from discriminatory treatment based on their status as a man or woman who failed to conform to gender role stereotypes,[121] a

118. *Id.*

119. *See*, *e.g.*, Education Amendment Act of 1972 tit. IX, 20 U.S.C. §§ 1681–1688 (2006) (prohibiting sex discrimination in education); Civil Rights Act of 1964 tit. VII, 42 U.S.C. §§ 2000e to e-17 (2006) (forbidding sex discrimination in employment).

120. *See, e.g.*, Diaz v. Pan Am. World Airways, 442 F.2d 385, 389 (5th Cir. 1971) (holding that Pan Am's policy of hiring only females for flight attendant positions violated Title VII).

121. *See* Joan C. Williams & Nancy Segal, *Beyond the Maternal Wall: Relief for Family Caregivers Who Are Discriminated Against on the Job*, 26 HARV. WOMEN'S L.J. 77, 103 (2003) (citing Chi v. Age Grp., Ltd., No. 94 CIV 5253 (AGS), 1996 WL 627580, at *1 (S.D.N.Y.

pregnant woman,[122] a gay or lesbian person,[123] or a transgender person.[124]

Whether these statutes would prohibit discrimination against a person with an intersex condition is also questionable. *Wood v. C.G. Studios, Inc.*[125] is the only reported case that has addressed discrimination directed against a person based on her intersex condition. In *Wood*, an employer terminated one of its employees after learning that the employee "had undergone surgery to correct her hermaphroditic condition."[126] The federal district court refused to treat the employer's actions as unlawful sex discrimination. The court analyzed the history of the act and found that the purpose of the legislation was to provide equal employment opportunities to women. Consequently, the court determined that the statute was not intended to remedy discrimination against individuals because they had undergone gender-corrective surgery.[127] The court limited the meaning of the word "sex" in the statute to what it considered to be the word's "plain meaning," and held that sex discrimination prohibitions do not encompass discrimination against "hermaphrodites" because of their intersex status.[128]

These limited visions of the scope of sex discrimination prohibitions began to dissolve in large part due to the feminist and

Oct. 29, 1996); Piantanida v. Wyman Ctr., Inc., 116 F.3d 340 (8th Cir. 1997); Martinez v. N.B.C. Inc., 49 F. Supp. 2d 305 (S.D.N.Y. 1999); Bass v. Chem. Banking Corp., No. 94 Civ. 8833 (SHS), 1996 WL 374151, at *1 (S.D.N.Y. July 2, 1996); Fuller v. GTE Corp./Contel Cellular, Inc., 926 F. Supp. 653 (M.D. Tenn. 1996)).

122. Gen. Elec. Co. v. Gilbert, 429 U.S. 125 (1976); Geduldig v. Aiello, 417 U.S. 484 (1974).

123. *See, e.g.*, Williamson v. A.G. Edwards & Sons, Inc., 876 F.2d 69, 70 (8th Cir. 1989); DeSantis v. Pac. Tel. & Tel. Co., 608 F.2d 327, 330–31 (9th Cir. 1979). A number of later cases have followed this approach, including *Simonton v. Runyon*, 232 F.3d 33, 36–37 (2d Cir. 2000), *Spearman v. Ford Motor Co.*, 231 F.3d 1080, 1085–86 (7th Cir. 2000), and *Higgins v. New Balance Athletic Shoe, Inc.*, 194 F.3d 252, 261 (1st Cir. 1999).

124. *See, e.g.*, Sommers v. Budget Mktg., Inc., 667 F.2d 748, 750 (8th Cir. 1982); Holloway v. Arthur Andersen & Co., 566 F.2d 659, 663–64 (9th Cir. 1977); Dobre v. Nat'l R.R. Passenger Corp., 850 F. Supp. 284, 285–86 (E.D. Pa. 1993); Doe v. U.S. Postal Serv., Civ. A. No. 84-3296, 1985 WL 9446, at *1–2 (D.D.C. June 12, 1985); Terry v. Equal Emp't Opportunity Comm'n, Civ. A. No. 80-C-408, 1980 WL 334, at *1–3 (E.D. Wis. Dec. 10, 1980); Powell v. Read's, Inc., 436 F. Supp. 369, 370–71 (D. Md. 1977); Voyles v. Ralph K. Davies Med. Ctr., 403 F. Supp. 456, 457 (N.D. Cal. 1975), *aff'd mem.*, 570 F.2d 354 (9th Cir. 1978); Grossman v. Bernards Twp. Bd. of Educ., No. 74-1904, 1975 WL 302, at *4 (D.N.J. Sept. 10, 1975), *aff'd mem.*, 538 F.2d 319 (3d Cir. 1976).

125. 660 F. Supp. 176 (E.D. Pa. 1987).

126. *Id.*

127. *Id.*

128. *Id.* at 176–78.

LGBT movements and feminist and queer theorists, who helped to educate society and the judiciary about the complex nature of sex discrimination. These scholars and activists helped courts develop a more nuanced understanding of the meaning and harm of sex discrimination.

The major expansion of the meaning of the word "sex" and the acts that encompass sex discrimination came from the Supreme Court's 1989 ruling in *Price Waterhouse v. Hopkins*.[129] In *Price Waterhouse*, an accounting firm denied a partnership to Ms. Hopkins, not because she was biologically a woman but because she failed to meet the partners' stereotyped expectations of how a woman should behave. The partners implied that her failure to conform to stereotypes of femininity blocked her path to partnership. Specifically, Hopkins was told that she overcompensated for being a woman and was too "macho."[130] She was advised to stop using profanity, to take a class at charm school, and to "walk more femininely, talk more femininely, dress more femininely, wear make-up, have her hair styled, and wear jewelry."[131] The Supreme Court ruled that discrimination against a woman because she failed to conform to societal stereotypes of femininity constituted discrimination based on "sex."[132]

The Court's acceptance of sex stereotyping as a form of impermissible sex discrimination reflects a more sophisticated understanding of the harms of sex-based discriminatory conduct. Based on the *Price Waterhouse* decision, individuals who are treated differently because they fail to conform to sex-related stereotypes have been able to prove that they were subjected to impermissible sex discrimination if they appropriately frame their claims as gender nonconformity or sex stereotyping discrimination.

A number of courts have embraced the concept that gender role performance, sexual orientation, and gender identity are part of a person's "sex." These courts have prohibited discrimination against people whose gender roles, gender behaviors, and gender identities fail to conform to societal norms. This more nuanced understanding of sex discrimination could form the basis for a claim that cosmetic

129. 490 U.S. 228 (1989).
130. *Id.* at 235.
131. *Id.*
132. *Id.* at 258.

genital surgery performed on an infant with an intersex condition constitutes discrimination because of "sex."

1. Gender Role Performance

Many men and women suffer from discrimination when they opt to fulfill roles that do not comport with societal stereotypes about appropriate functions for males and females. Courts originally ruled that sex discrimination statutes did not encompass discrimination based on gender role stereotyping.[133] Recently, however, some courts have allowed recovery based on this theory.

For example, new mothers have recovered when they sued for discrimination based on gender role performance stereotyping.[134] In these cases, employers discriminated against new mothers because the employers believed that the new mothers would fail to conform to the norm of the ideal worker. For example, in *Back v. Hastings on Hudson Union Free School District*,[135] a school psychologist, Elena Back, filed a sex stereotyping claim when she was denied tenure. Ms. Back took a maternity leave after she gave birth. She returned to work and was subsequently denied tenure. During the review process, her supervisors made comments questioning her ability as a new mother to devote herself to her job. The court held that these statements were evidence of impermissible sex stereotyping discrimination because they indicated a presumption that being a mother is incompatible with being an effective worker.[136]

Similarly, some courts have granted recovery to men who suffered discrimination because they failed to conform to the norm of a male breadwinner when they sought time off for family care responsibilities.[137] For example, in *Knussman v. Maryland*,[138] Maryland State Trooper Howard Kevin Knussman alleged that he suffered sex discrimination when his employer refused to grant him paid leave to care for his wife and newborn child. His wife suffered

133. *See* Williams & Segal, *supra* note 121, at 123–30.

134. *See, e.g.*, Back v. Hastings on Hudson Union Free Sch. Dist., 365 F.3d 107, 120 (2d Cir. 2004); Santiago-Ramos v. Centennial P.R. Wireless Corp., 217 F.3d 46, 57 (1st Cir. 2000); Sheehan v. Donlen Corp., 173 F.3d 1039, 1044–45 (7th Cir. 1999) (holding that discrimination against new mothers based on assumptions about the employees' ability to be both mothers and good workers constitutes impermissible sex stereotyping).

135. 365 F.3d 107 (2d Cir. 2004).

136. *Id.* at 120.

137. *E.g.*, Knussman v. Maryland, 272 F.3d 625 (4th Cir. 2001).

138. *Id.*

from medical problems during the pregnancy and after the birth. Knussman sought paid leave under a gender-neutral statute granting "nurturing leave" for the care of a newborn. The court ruled that the employer engaged in unlawful sex discrimination when it denied paid leave to Mr. Knussman. The court ruled that the employer's decision was based on stereotypes about the proper roles for men and women.[139]

2. Gender Behavior

Gays and lesbians, who before *Price Waterhouse* consistently lost their sex discrimination claims, are now sometimes successful in convincing courts that they were victims of sex discrimination when they were harassed or otherwise discriminated against because they failed to conform to sex and gender norms.[140]

For example, in *Rene v. MGM Grand Hotel, Inc.*,[141] Medina Rene, an openly gay male butler at the MGM Grand Hotel in Las Vegas, was able to prove that other butlers had engaged in impermissible sex discrimination. All the other butlers, including Rene's supervisor, were male. Rene testified that during a two-year period at the MGM Grand, he had been continuously subjected to harassment by his supervisor and fellow butlers. The harassers whistled and blew kisses at Rene; they called him "sweetheart" and "muñeca" (Spanish for "doll"); they gave him sexually oriented "joke" gifts; and they forced him to look at pictures of naked men having sex. He was also subjected to physical harassment of a sexual nature. Rene stated that the other employees would treat him as they would treat a woman because they knew he was gay. The court held that the fact that he was treated "like a woman" constitutes ample evidence of impermissible gender stereotyping.[142]

139. *Id.* at 636.

140. *See, e.g.*, Rene v. MGM Grand Hotel, Inc., 305 F.3d 1061, 1069 (9th Cir. 2002), *cert. denied*, 538 U.S. 922 (2003); Nichols v. Azteca Rest. Enters., Inc., 256 F. 3d 864 (9th Cir. 2001); Schmedding v. Tnemec Co. Inc., 187 F.3d 862 (8th Cir. 1999). A number of courts continue to deny recovery to gays and lesbians if the employees allege they were harassed because of their sexual orientation. *See, e.g.*, Hamner v. St. Vincent Hosp. & Health Care Ctr., Inc., 224 F.3d 701, 704 (7th Cir. 2000); Higgins v. New Balance Athletic Shoe, Inc., 194 F.3d 252, 259 (1st Cir. 1999); Dandan v. Radisson Hotel Lisle, No. 97 C 8342, 2000 WL 336528 (N.D. Ill. 2000); Mims v. Carrier Corp., 88 F. Supp. 2d 706, 714 (E.D. Tex. 2000).

141. 305 F.3d 1061 (9th Cir. 2002).

142. *Id.* at 1069.

Similarly, in *Nichols v. Azteca Restaurant Enterprises, Inc.*,[143] Antonio Sanchez, a male waiter, alleged that he had been subjected to an unrelenting barrage of verbal abuse because he was perceived as being insufficiently masculine. He was called sexually derogatory names, referred to in the female gender, and taunted for behaving like a woman. The court applied the *Price Waterhouse* gender stereotyping theory and concluded that harassment generated by a person's failure to conform to male stereotypical behavior constitutes impermissible sex discrimination.[144]

3. Gender Identity

Before the decision in *Price Waterhouse*, transgender plaintiffs consistently lost their cases when they tried to state a claim for sex discrimination. Early courts ruled that discrimination against people whose gender identity did not conform to the sex assigned to them at birth was not prohibited under sex discrimination statutes.[145] Since *Price Waterhouse*, however, a number of courts have held that discrimination against transgender people because their gender identity fails to conform to their natal sex constitutes impermissible sex discrimination.[146]

In *Smith v. City of Salem*,[147] firefighting lieutenant, Jimmie Smith, had worked for seven years in the Salem Fire Department without any negative incidents. After Lieutenant Smith began his transition to becoming a woman, his coworkers began questioning him about his appearance and commenting that his looks and mannerisms were not "masculine enough."[148] Smith decided to notify his supervisor that he was in the process of transitioning and

143. 256 F.3d 864 (9th Cir. 2001).

144. *Id.* at 874–75.

145. *See supra* note 124.

146. *See, e.g.*, Glenn v. Brumby, 663 F.3d 1312 (11th Cir. 2011); Barnes v. City of Cincinnati, 401 F.3d 729 (6th Cir. 2005); Smith v. City of Salem, 378 F.3d 566, 575 (6th Cir. 2004); Rosa v. Park W. Bank & Trust Co., 214 F.3d 213 (1st Cir. 2000); Schwenk v. Hartford, 204 F.3d 1187 (9th Cir. 2000); Schroer v. Billington, 577 F. Supp. 2d 293 (D.D.C. 2008). The EEOC also adopted this approach in *Macy*. Macy v. Holder, EEOC Decision No. 0120120821 (2012), http://transgenderlawcenter.org/cms/blogs/552-24#ruling. The EEOC concluded that "discrimination against a transgender individual because that person is transgender is, by definition, discrimination 'based on . . . sex,' and such discrimination therefore violates Title VII." *Id.* at 14. The sex stereotyping theory has not been universally accepted in all cases involving transgender plaintiffs. *See, e.g.*, Etsitty v. Utah Transit Auth., 502 F.3d 1215 (10th Cir. 2007).

147. 378 F.3d 566 (6th Cir. 2004).

148. *Id.* at 568.

he would eventually undergo a complete physical transformation and become a woman. After he disclosed his transgender status, his employer instituted a plan to fire him.[149] The court held that the fire department discriminated against Smith based on the *Price Waterhouse* sex stereotyping theory because the treatment was based on Smith's failure to conform to gender norms of how men should look and behave. The Sixth Circuit ruled that the earlier cases that had denied the ability of transgender people to recover for sex discrimination were "eviscerated" by the 1989 holding in *Price Waterhouse*.[150] The Sixth Circuit reinforced this approach one year later in *Barnes v. Cincinnati*.[151]

In 2011, the Eleventh Circuit agreed with the Sixth Circuit's approach. In *Glenn v. Brumby*,[152] the appellate court affirmed the trial court's grant of summary judgment in favor of a transgender plaintiff who brought an equal protection sex discrimination claim. Vandiver Glenn sued for sex discrimination when the Georgia General Assembly's Office of Legislative Counsel fired her from her editorial position after she notified her supervisor that she identified as a woman and was beginning her transition to living and presenting as a female. Her employer, Sewell Brumby, stated that her appearance was inappropriate, and he found it "unsettling to think of someone dressed in women's clothing with male sexual organs inside that clothing," and "that a male in women's clothing is 'unnatural.'"[153] When he fired her, he stated that her "intended gender transition was inappropriate, that it would be disruptive, that some people would view it as a moral issue, and that it would make Glenn's coworkers uncomfortable."[154] The Eleventh Circuit ruled that discrimination against people because of their transgender status constitutes impermissible sex discrimination because the discrimination is based on their failure to conform to gender stereotypes.[155]

A number of other circuit courts have reached similar conclusions under other statutes prohibiting sex discrimination. For

149. *Id.*
150. *Id.* at 573.
151. 401 F.3d 729 (6th Cir. 2005).
152. 663 F.3d 1312 (11th Cir. 2011).
153. *Id.* at 1314.
154. *Id.*
155. *Id.* at 1320.

example, in *Schwenk v. Hartford*,[156] the Ninth Circuit ruled that discrimination against a transgender plaintiff because she failed to act like a man constituted impermissible sex discrimination under the Gender Motivated Violence Act. The First Circuit adopted a similar approach when it determined that refusing a loan to a transgender plaintiff because she failed to dress in accordance with prescribed gender roles violated the prohibition against sex discrimination in the Equal Credit Opportunity Act.[157] A number of district courts have also ruled that transgender plaintiffs who suffer differential treatment because of their failure to comply with stereotypical gender norms have been subjected to impermissible sex discrimination.[158]

The ability of transgender people to recover under a sex discrimination theory expanded dramatically after the 2008 federal district court ruling in *Schroer v. Billington*.[159] Diane Schroer, a male-to-female transsexual, applied for a position with the research division of the Library of Congress as a terrorism specialist providing expert policy analysis to Congress. When she applied for the job, she had not yet transitioned so she used her legal male name, David, on the application and she attended the interview in male clothing. She received the highest score of the eighteen candidates and she was offered the job. Diane accepted the position, but before she began work, she notified the person in charge of hiring that she would begin work as a female. The job offer was revoked and Diane sued.

The court found that the Library of Congress had engaged in unlawful sex discrimination for two reasons. First, the court found that Diane was denied the job based on the sex stereotyping theory developed in *Price Waterhouse*. The court concluded that different comments by the employer indicated that Diane was viewed as "an insufficiently masculine man, an insufficiently feminine woman, or an inherently gender-nonconforming transsexual."[160] The court

156. 204 F.3d 1187 (9th Cir. 2000).

157. Rosa v. Park W. Bank & Trust Co., 214 F.3d 213, 216 (1st Cir. 2000).

158. *See, e.g.*, Lopez v. River Oaks Imaging & Diagnostic Grp., Inc., 542 F. Supp. 2d 653, 659–61 (S.D. Tex. 2008); Mitchell v. Axcan Scandipharm, No. 05-243, 2006 WL 986971 (W.D. Pa. Feb. 21, 2006); Kastl v. Maricopa Cnty. Cmty. Coll. Dist., No. 02-1531PHX-SRB, 2004 WL 2008954 (D. Ariz. June 3, 2004), *aff'd*, 325 F. App'x. 492 (9th Cir. 2009); Tronetti v. TLC Healthnet Lakeshore Hosp., No. 03–CV-0375E(SC), 2003 WL 22757935 (W.D.N.Y. Sept. 26, 2003).

159. 577 F. Supp. 2d 293 (D.D.C. 2008).

160. *Id.* at 305.

stated: "[T]he Library was enthusiastic about hiring David Schroer—until she disclosed her transsexuality. The Library revoked the offer when it learned that a man named David intended to become, legally, culturally, and physically, a woman named Diane. This was discrimination 'because of . . . sex.'"[161]

More important, the court found that, in addition to stating a sex stereotyping discrimination claim, Schroer could recover under a straightforward sex discrimination theory and did not need to rely on the stereotyping approach. The court ruled that people who "change" their sex and suffer discrimination because of the transition have suffered sex discrimination. The court continued:

> Imagine that an employee is fired because she converts from Christianity to Judaism. Imagine too that her employer testifies that he harbors no bias toward either Christians or Jews but only "converts." That would be a clear case of discrimination "because of religion." No court would take seriously the notion that "converts" are not covered by the statute. Discrimination "because of religion" easily encompasses discrimination because of a *change* of religion. But in cases where the plaintiff has changed her sex, and faces discrimination because of the decision to stop presenting as a man and to start appearing as a woman, courts have traditionally carved such persons out of the statute by concluding that "transsexuality" is unprotected by Title VII. In other words, courts have allowed their focus on the label "transsexual" to blind them to the statutory language itself.[162]

The holding of the *Schroer* court calls into serious question the continuing validity of the single employment discrimination case involving an employee with an intersex condition.[163] In 1987, a district court held that Wilma Wood had not been subjected to sex discrimination when her employer fired her after learning about her intersex condition.[164] The court reasoned that sex discrimination prohibitions were designed to provide equal employment opportunities to women and were not meant to protect women who

161. *Id.* at 306.
162. *Id.* at 306–07.
163. Wood v. C.G. Studios, Inc., 660 F. Supp. 176, 178 (E.D. Pa. 1987).
164. *Id.* at 177–78.

had undergone gender corrective surgery. The holding in *Wood* is consistent with the understanding of the scope of sex discrimination prohibitions during the 1980s. All the cases at that time narrowly construed the reach of statutes prohibiting sex discrimination. Just as *Price Waterhouse* eviscerated the holdings in earlier sex discrimination cases brought by gay, lesbian, transgender, and other gender nonconforming people, it should be interpreted to eviscerate the holding in *Wood*. Discrimination against people with an intersex condition should be treated similarly to the treatment of transgender people in the *Schroer* decision. If discrimination against transgender people who have transitioned from one sex to the other constitutes impermissible sex discrimination, people who have been discriminated against based on their DSD status also have been subjected to unlawful sex discrimination.

4. Applying Sex Discrimination Principles to the Medical Treatment of Infants with a DSD

Now that courts recognize that statutory prohibitions against sex discrimination protect people from discrimination based on sex and gender stereotypes, a sex discrimination framework could be an effective tool for challenging cosmetic genital surgeries and other medical protocols performed on infants with an intersex condition. If infants with a DSD are subjected to differential treatment because they fail to conform to stereotypical sex norms, the differential treatment could be considered impermissible sex discrimination.

Therefore, the question that must be asked is why are children with a DSD being subjected to these procedures? Four current treatment protocols are based at least in part on sex and/or gender stereotypes:

a. Surgeries to reduce the size of a girl's clitoris;
b. Dexamethasone administration to pregnant women carrying children who are at risk of having congenital adrenal hyperplasia;
c. Surgeries to create a vagina in girls who are born with no vagina or a shortened vaginal canal; and
d. Surgeries to move the urethral opening to the tip of a boy's penis.

a. Surgeries to reduce the size of the clitoris

Many physicians treating infants with an intersex condition believe that children who will be raised as girls should not have a larger-than-average clitoris. If doctors believe a girl's clitoris is too large, they will recommend that the infant undergo clitoral reduction surgery. The basis for this recommendation is the unproven assumption that clitoral reduction surgery will enhance the girl's psychological well-being. Although no studies have proven the benefit of these procedures, these surgeries often lead to a number of serious problems. They may make it difficult or impossible for a woman to experience an orgasm. They may also cause infection, scarring, incontinence, and other severe physical complications. Many medical experts, scholars, and people who have been subjected to these surgeries assert that these medical procedures often cause stigma, psychological trauma, and lifelong physical complications, without proof of any benefit to the child.[165]

Why would parents consent to surgeries with these risks? One study indicates that parents prioritize genital appearance over erotic responsiveness. A study asked parents of children born with an intersex condition to rank the importance of sexual responsiveness and genital appearance. Ninety-five percent of the parents indicated that they would have authorized genital surgery, even if a reduction in sexual responsiveness was certain.[166] In other words, doctors recommend and parents consent to these surgeries based on the gender stereotype that females care more about their genital appearance than they do about their ability to engage in satisfactory sex.[167]

This assumption is not only a gender stereotype; based on a study of female college students, it also appears to be a false gender stereotype. A group of female college students was asked to imagine

165. *See* Tamar-Mattis, *supra* note 42; *see supra* note 43 and accompanying text.

166. Jennifer E. Dayner et al., *Medical Treatment of Intersex: Parental Perspectives*, 172 J. UROLOGY 1762, 1764–65 (2004).

167. Prioritizing conformity to cultural norms should not be used to justify a surgery that is not desired by the person undergoing the treatment. For an excellent comparison of the similarities between the cultural norms underlying female genital cutting as it is practiced in non-western societies and genital cutting of infants with an intersex condition that is performed in western nations, see Nancy Ehrenreich with Mark Barr, *Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of "Cultural Practices*,*"* 40 HARV. C.R.-C.L. L. REV. 71 (2005).

that they had been born with a clitoris larger than one centimeter at birth.[168] An overwhelming 93 percent of the students reported that they would not have wanted their parents to agree to surgery to alter the appearance of their genitalia if it resulted in the loss of orgasm or pleasurable sensitivity. More than 50 percent of the women would not have wanted surgery even if the condition was unattractive and made them feel uncomfortable. The students were more likely to want surgery to reduce a large nose, ears, or breasts than surgery to reduce an enlarged clitoris. This result is consistent with the women's ratings of the importance of genital sensation and capacity to orgasm, which they ranked as very important as compared to the size of the clitoris, which was ranked as only somewhat important.[169]

Therefore, surgeries being performed based on the false gender stereotype that women emphasize genital appearance over erotic response could be viewed as a form of impermissible sex stereotyping discrimination.

b. Dexamethasone administration to pregnant women carrying children who are at risk of having congenital adrenal hyperplasia

Surgical interventions are not the only technique doctors have relied on to produce "acceptable" female genitalia. Some doctors have also experimented with other methods to alter the genitalia of infants with an intersex condition. For example, instead of performing surgery after the child is born, some doctors administer drugs to pregnant mothers who may be carrying a child with one type of DSD, 21-hydroxylase deficiency CAH, which is an adrenal disorder that can lead to the formation of atypical genitalia.[170]

An XX fetus with CAH has adrenal glands that produce high levels of androgens, which are masculinizing hormones. Depending on the level of exposure, these children may be born with genitalia that have been partially masculinized. Some doctors are administering dexamethasone to pregnant women who are at risk of carrying an XX child with CAH because this drug may be effective in stopping the masculinization of the genitalia.[171]

168. KESSLER, *supra* note 26, at 101.
169. *Id.*
170. *See, e.g.*, Nimkarn & New, *supra* note 54, at 53.
171. *Id.* at 53, 56; Catherine Elton, *A Prenatal Treatment Raises Questions of Medical Ethics*, TIME, (June 18, 2010), http://www.time.com/time/health/article/0,8599,1996453,00.html.

This practice is problematic because it can cause significant harm to the fetus. Prenatal exposure to dexamethasone has been shown to cause brain changes.[172] Children who have been exposed have displayed problems with working memory, verbal processing, and anxiety.[173]

Administering this drug is also problematic because it exposes fetuses that will not be negatively affected by CAH to these dangers. To prevent masculinization of the genitalia, dexamethasone must be administered early in the pregnancy at approximately the sixth or seventh week of gestation.[174] At this point in the pregnancy, doctors are not able to determine whether the fetus is XX or XY or whether the fetus has CAH.[175] XY infants, with or without CAH, and XX infants who do not have CAH need not be exposed to this drug. The only purpose for administering the drug is to prevent virilization in XX infants who also have CAH.[176] A mother who has given birth to a child with CAH has a one-in-eight chance of carrying an XX fetus with CAH.[177] Therefore, the vast majority of fetuses exposed to dexamethasone have no reason to be exposed to the drug because it will provide absolutely no benefit. Dexamethasone could potentially provide a benefit to approximately 10 percent of the fetuses being exposed to it by preventing the development of masculinized genitalia in an XX fetus, but the goal of producing cosmetically acceptable genitalia is being sought at the expense of creating a significant risk of harm to the 90 percent of the fetuses that will receive absolutely no benefit.

172. Noel P. French et al., *Repeated Antenatal Corticosteroids: Effects on Cerebral Palsy and Childhood Behavior*, 190 AM. J. OBSTETRICS & GYNECOLOGY 588, 591–92 (2004).

173. *See, e.g.*, Tatja Hirvikoski et al., *Cognitive Functions in Children at Risk for Congenital Adrenal Hyperplasia Treated Prenatally with Dexamethasone*, 92 J. CLINICAL ENDOCRINOLOGY & METABOLISM 542, 544–47 (2007).

174. Svetlana Lajic et al., *Prenatal Treatment of Congenital Adrenal Hyperplasia*, 151 EUR. J. ENDOCRINOLOGY U63, U64 (2004).

175. *Id.*

176. *Id.*

177. *Id.* If a woman has given birth to a CAH child and she conceives another child with the same father, only one in eight pregnancies will be a female fetus with CAH who might be helped by the treatment. Four of the eight fetuses will be male and three of the eight fetuses will be unaffected females.

In 2010, a group of experts convened to review clinical practice guidelines for the treatment of CAH.[178] They decided that the administration of dexamethasone to pregnant women should be considered experimental.[179] They recommended that this treatment should be pursued only through "protocols approved by Institutional Review Boards at centers capable of collecting outcomes data on a sufficiently large number of patients so that risks and benefits of this treatment can be defined more precisely."[180]

Diminishing the size of the clitoris is not the only benefit that physicians claim this drug could accomplish. Researchers have also noted that this drug may enhance feminine thinking and behavior in an XX fetus with CAH.[181] Women with CAH have a higher likelihood of being bisexual or lesbian, and often display behavior that is considered "tomboyish."[182] Some researchers have implied that administration of dexamethasone to pregnant women may solve this "problem." One study reported:

> CAH women as a group have a lower interest than controls in getting married and performing the traditional child-care/housewife role. As children, they show an unusually low interest in engaging in maternal play with baby dolls, and their interest in caring for infants, the frequency of daydreams or fantasies of pregnancy and motherhood, or the expressed wish of experiencing pregnancy and having children of their own appear to be relatively low in all age groups.
>
> . . . .
>
> . . . Long term follow-up studies of the behavioral outcome will show whether dexamethasone treatment also prevents the effects of prenatal androgens on brain and behavior. . . .[183]

178. Phyllis W. Speiser et al., *Congenital Adrenal Hyperplasia Due to Steroid 21-Hydroxylase Deficiency: An Endocrine Society Clinical Practice Guideline*, 95 J. CLINICAL ENDOCRINOLOGY & METABOLISM 4133, 4137 (2010).

179. *Id.*

180. *Id.*

181. *See* Heino Meyer-Bahlburg, *What Causes Low Rates of Childbearing in Congenital Adrenal Hyperplasia?*, 84 J. CLINICAL ENDOCRINOLOGY & METABOLISM 1844, 1845–46 (1999).

182. *Id.*

183. *Id.* (citations omitted). For a thorough critique of the use of dexamethasone, see Alice Dreger et al., *Preventing Homosexuality (and Uppity Women) in the Womb?*, BIOETHICS FORUM

In other words, some doctors are suggesting that they could be improving girls' lives by enhancing the likelihood that they will want to fulfill the traditional female roles of housewife and mother. A treatment that carries significant risk to unaffected fetuses, as well as an XX fetus carrying CAH, that is designed to feminize the genitalia and potentially turn "tomboyish" girls into females who fantasize about becoming wives and mothers supports the argument that this health care protocol is based on gender stereotypes.

c. Surgeries to create a vagina

Some DSDs may result in a girl being born without a vagina or with a vaginal canal that is shortened.[184] Doctors will perform surgeries on these girls to create a vagina or to expand the shortened vagina. Females require a vagina for menstrual flow, giving birth, and engaging in traditional heterosexual intercourse. Some women with an intersex condition do not menstruate and cannot bear children, so the only reason for them to have a vagina created is to allow them to engage in heterosexual intercourse.[185] Although infants and young children do not have any use for a vagina, until recently, physicians typically performed these surgeries on infants based on the unsupported assumption that performing these surgeries while the child is too young to understand the significance is less psychologically traumatic.[186] These surgeries often require parents to dilate the vagina to maintain its size.[187]

The 2006 Consensus Statement recommends that these surgeries be postponed until adolescence.[188] Some physicians, however, still recommend that the vaginoplasty be performed in some circumstances when the child is still an infant.[189]

BLOG (June 29, 2010, 6:17 PM), http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4754&blogid=140.

184. Sarah Creighton, *Surgery for Intersex*, 94 J. FOR ROYAL SOC'Y MED. 218, 219 (2001). For example, girls with complete androgen insensitivity syndrome or congenital adrenal hyperplasia may have a normal vagina, a shortened vagina, or no vagina.

185. *Id.* For example, girls with complete androgen insensitivity syndrome do not have a uterus and ovaries. Therefore, they do not menstruate and they cannot bear children.

186. KESSLER, *supra* note 26, at 49; Speiser, *supra* note 178, at 4143.

187. KESSLER, *supra* note 26, at 49.

188. Lee et al., *supra* note 13, at e492.

189. Speiser, *supra* note 178, at 4143 (acknowledging that systematic long-term evaluation of the benefits and risks of early as opposed to later surgery do not exist).

The need to create a vagina in a girl who will not menstruate or bear children is based on the assumption that all females will desire a vagina so that they will be able to engage in sexual intercourse with a man. When parents consent to these surgeries, they may not be making the decision that their children would want. The same survey that asked female students whether they would have wanted their parents to consent to clitoral reduction surgery questioned women about whether they would have wanted their parents to consent to vaginoplasty.[190] Most of them would not have wanted vaginal surgery, even if the condition made them feel uncomfortable or limited their ability to engage in sexual intercourse.[191] The women surveyed believed that the impact of not having a vagina during childhood would not have affected their self-esteem.[192]

Therefore, creating a vagina in a female for the sole purpose of facilitating intercourse with a man is based on the false gender stereotype that all women will desire heterosexual intercourse. It also perpetuates the vision of women as passive recipients of men's sexual desires.[193] Not all women will want to engage in heterosexual intercourse, and those who have this desire can consent to the surgery when they decide to become sexually active. Creating a vagina in girls who will not menstruate or bear children and who may never desire a vagina for sexual intercourse with a man supports a finding that these medical procedures are based on gender stereotypes.

d. Surgeries to move the urethral opening to the tip of a boy's penis

A common congenital condition, hypospadias, occurs in approximately 1 in 200–300 live births.[194] In males with hypospadias, the urethral opening is located somewhere along the underside of the penis rather than at its tip. In the vast majority of cases, there is no medical reason to move the urethral opening. Typically, however, male infants are subjected to surgeries to move

190. KESSLER, *supra* note 26, at 102.
191. *Id.*
192. *Id.*
193. Ehrenreich, *supra* note 167, at 125.
194. Laurence S. Baskin & Michele B. Ebbers, *Hypospadias: Anatomy, Etiology, and Technique*, 41 J. PEDIATRIC SURGERY 463 (2006).

the urethral opening to the end of the penis. Doctors recommend that these surgeries be performed when the boys are six months old. Although these surgeries could be delayed until the males reach the age of consent and could decide for themselves whether to undergo this procedure, they are performed in infancy based on the unproven assumption that boys growing up with an atypical penis will suffer emotional trauma.[195]

Although some boys require only one surgery, many males with hypospadias have been subjected to multiple invasive surgeries. These procedures have resulted in physical scarring, poor cosmetic results, and difficulty in urinating,[196] without proof that they are beneficial.

When males were surveyed about whether they would have wanted their parents to consent to surgery if their urethral opening was off center, one-third of the men reported that they would not have wanted their parents to consent even if it meant that they would not have been able to urinate in a standing position.[197] Three-fourths of them would have rejected the surgery if it resulted in the loss of pleasurable sensitivity.[198]

Just as young girls with atypical genitalia are subjected to invasive cosmetic genital surgeries to conform their bodies to a feminine norm, infant boys with hypospadias are subjected to surgeries that have no medical justification solely to bring their bodies into conformity with stereotypical notions of masculinity. As one commentator wrote, "[B]oys who cannot urinate in what is referred to as the 'male' manner are said not to be able to 'demonstrat[e] their prowess at urinating at certain distances in competition with other boys . . . which could lead to competence anxieties related to their penis."[199]

Intersex advocates believe that these four medical procedures should no longer be performed on infants with a DSD. No studies prove that they are clearly beneficial and evidence exists that they may lead to serious physical and psychological trauma. Current

195. *Id.* at 467.
196. *Id.* at 466.
197. KESSLER, *supra* note 26, at 102.
198. *Id.*
199. *Id.* at 70 (quoting Mark Mureau et al., *Genital Perception of Children, Adolescents, and Adults Operated on for Hypospadias: A Comparative Study*, 32 J. SEX RES. 289, 290 (1995)).

treatment protocols for infants with an intersex condition (1) prioritize cosmetic appearance over the ability to orgasm for women; (2) are assumed to be beneficial because they may enhance the likelihood of "feminine" desires in girls; (3) are based on the presumption that all women will want to engage in heterosexual intercourse; or (4) are performed on the assumption that boys who cannot urinate in a standing position are not sufficiently masculine. To the extent that these procedures are performed for these reasons, the treatment decisions are based on sex and gender stereotypes about manhood and womanhood. If physicians and hospitals recommend these procedures because they decide that a child is not sufficiently masculine or feminine, they are arguably engaging in a form of sex discrimination.

B. Disability Discrimination

The current medical protocol for the treatment of infants with a DSD could also be considered a form of disability discrimination. Disability discrimination is prohibited under a number of federal and state laws.

1. The Americans with Disabilities Act (ADA)

The ADA provides the primary avenue in the United States for pursuing a disability claim.[200] This federal law prohibits discrimination against a person with a disability in a number of areas, including the provision of health services.[201]

Thus far, no one with an intersex condition has brought a claim under the ADA or other disability statutes. These statutes may provide a means to limit surgical alterations of infants with an intersex condition and eliminate the stigma associated with such conditions.

Section 12102(2) of the ADA provides the basic ADA rules. This section defines disability as:

> (A) a physical or mental impairment that substantially limits one or more major life activities of such individual;
>
> (B) a record of such an impairment; or

200. Americans with Disabilities Act, 42 U.S.C. §§ 12101–12213 (2006).
201. *Id.* §§ 12132, 12182.

(C) being regarded as having such an impairment.[202]

Some intersex conditions create medical risks that qualify as an actual impairment under § 12102(2)(A). For example, people with an intersex condition that impairs the endocrine and bladder functions or results in infertility meet the definition of having a physical impairment under this section.[203] Most people with an intersex condition, however, are not impaired. They are able to live full, productive lives without medical intervention.

Although most people with a DSD are not actually impaired, they could still be covered under § 12102(2)(C) of the ADA if they are subjected to medical procedures because they are "regarded as having such an impairment."[204] Therefore, the reasons underlying the current medical protocol for infants with a DSD must be analyzed to determine whether they are based on the perception that people with a DSD are impaired.

Doctors perform cosmetic genital surgery on infants with an intersex condition because they believe that people with a DSD will suffer psychological harm as children and as adults. They think that children who grow up with genitalia that look different from their peers' genitalia will suffer emotional trauma. They also believe that adults with atypical genitalia will face obstacles in forming romantic relationships or engaging in reproductive or other sexual acts. These surgeries are not performed because adults with a DSD are actually impaired in their ability to form romantic and other relationships. Many adults with atypical genitalia who have not been subjected to surgical intervention were well-adjusted children and have formed meaningful long-term romantic and sexual relationships.[205] Therefore, these life-altering surgeries are performed because people with DSDs are perceived as being impaired. This differential treatment appears to meet the requirements of § 12102(2)(C).

202. *Id*. § 12102(2).

203. *Id.* § 12102(2)(A). This Article focuses on whether people with a DSD could state a disability claim based on the perception that they are disabled. For a more thorough analysis of whether specific DSDs could qualify as an actual impairment under § 12102(2)(A), see Yamuna Menon, *The Intersex Community and the Americans with Disabilities Act*, 43 CONN. L. REV. 1221, 1238–40 (2011).

204. 42 U.S.C. § 12102(2)(C).

205. *See* Tamar-Mattis, *supra* note 42, at 77.

The ADA also requires that the impairment or perceived impairment limit a major life activity.[206] Under the ADA, major life activities include operations of major bodily functions, including but not limited to functions of the bladder, the endocrine system, and the reproductive system. Therefore, people with an intersex condition that affects these functions meet the requirement of a limitation of a major life activity.

People with a DSD that does not affect these functions are unlikely to be limited from participating in any major life activities. Therefore, they would not meet the requirements of § 12102(2)(A).[207] They could still meet the ADA's requirements under § 12102(3), which provides that for purposes of § 12102(2)(C):

> An individual meets the requirement of "being regarded as having such an impairment" if the individual establishes that he or she has been subjected to an action prohibited under this chapter because of an actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity.[208]

The Equal Employment Opportunity Commission (EEOC) has interpreted § 12102(3) to include individuals who are subjected to differential treatment because of the perceptions of others. The EEOC publication provides:

> (d) Persons Who Are Substantially Limited as a Result of Others' Attitudes—This subpart covers individuals who have stigmatic conditions that constitute physical or mental impairments but that do not by themselves substantially limit a major life activity. The impairments become substantially limiting only because of the negative reactions of others toward the impairments. For example, a person who has experienced severe burns may have an impairment that is substantially limiting solely because of the attitudes of others. Similarly, a person who has a cosmetic disfigurement may be continuously refused employment

206. 42 U.S.C. § 12102(2)(A).
207. *See id.*
208. *Id.* § 12102(3).

> because of employers' fears about the negative reactions of co-workers or clients. These persons would be covered under the third part of the definition of the term "disability."[209]

Infants with an intersex condition frequently are subjected to medically unnecessary cosmetic surgeries that may impair their ability to engage in satisfactory sex, affect continence, render them infertile, and inflict severe psychological trauma. These surgeries, which have not been proven to be beneficial, are being performed on healthy children with an intersex condition even though procedures that pose the same risks would not be performed on children who do not have an intersex condition. Therefore, one could argue that subjecting these children to potentially disabling invasive surgeries because they are "perceived as being impaired" constitutes disability discrimination.

2. State Disability Laws

In addition to federal disability laws, disability claims could also be based on violations of state laws. The recent report published by the WPAS involving the treatment of "Ashley X"[210] provides a potential basis to bring a claim on behalf of children with an intersex condition.[211] Ashley was born with profound developmental disabilities. Doctors predicted that her mental capacity would never develop beyond that of an infant. At the age of six, Ashley could not sit up, ambulate, or use speech. She was dependent on a gastronomy tube for her nutrition. Despite her disabilities, Ashley was an integral member of the family and her parents wanted to continue caring for her at home; they did not want her care to be put in the hands of strangers.[212]

When Ashley began to display signs of early puberty, her parents became concerned that they would not be able to care for her

209. *Section 902 Definition of the Term Disability*, U.S. EQUAL EMP'T OPPORTUNITY COMM'N (Nov. 21, 2009), http://www.eeoc.gov/policy/docs/902cm.html#902.8d (discussing § 902.8(d)).

210. *See* CARLSON & DORFMAN, *supra* note 88.

211. Ashley X did not have an intersex condition; she was born with profound developmental disabilities. The reasoning that the WPAS applied to a child with developmental disabilities, however, could apply with equal force to a child born with an intersex condition.

212. Daniel F. Gunther & Douglas S. Diekema, *Attenuating Growth in Children with Profound Developmental Disability: A New Approach to an Old Dilemma*, 160 ARCHIVES PEDIATRICS & ADOLESCENT MED. 1013 (2006).

as she continued to grow and mature. Ashley's parents and doctors developed a plan to stunt Ashley's growth and to repress her sexual development by having doctors perform a hysterectomy to prevent menstruation and a mastectomy to prevent development of breast tissue. They also planned to administer estrogen to prevent her from reaching her projected adult height and weight. The goals of these treatments were to allow Ashley's parents to continue her home care and to avoid potential complications of early puberty.[213]

Because of the extensive nature of the planned intervention, Ashley's physicians sought guidance from the hospital ethics committee. The committee approved the proposed treatment and advised the parents to obtain legal advice regarding the procedures that would lead to sterility. The parents hired an attorney to advise them about whether they required a court order before they could initiate the procedures. Their attorney advised them that they did not need a court order, so they proceeded without one.[214]

When news about Ashley's treatment became public, disability rights groups protested.[215] They argued that the motivation for the treatment may have been to benefit Ashley's parents, rather than Ashley. They also argued that the treatment was dehumanizing.[216]

Ashley's treatment was subsequently investigated by the WPAS, the federally mandated protection and advocacy agency for the state of Washington. The WPAS has legal authority under federal law to investigate allegations of mistreatment of persons with a disability within the state of Washington. The WPAS determined that Ashley's treatment violated her constitutional and common law rights and was a direct violation of Washington law. The agency ruled that parents and doctors cannot agree to sterilize children without a court order determining that the sterilization is in the child's best interest.[217] The court proceeding must be adversarial and the child's interests must be zealously represented by a disinterested third party.[218]

213. *See id.*

214. CARLSON & DORFMAN, *supra* note 88, at 14.

215. *See* Dave Reynolds, *Advocates Speak Out and Call For Investigations over "Ashley Treatment,"* INCLUSION DAILY EXPRESS (Jan. 12, 2007), http://www.inclusiondaily.com/archives/07/01/12/011207waashleyx.htm.

216. *See id.*; William Peace, *The Ashley Treatment and the Making of a Pillow Angel: Protest from a Bad Cripple*, COUNTERPUNCH (Jan. 18, 2007), http://www.counterpunch.org/peace01182007.html.

217. CARLSON & DORFMAN, *supra* note 88, at 1.

218. *Id.* at 19.

The WPAS did not limit its holding to the procedures that resulted in sterilization. It also held that Ashley's constitutional liberty and privacy rights were affected by any procedures that were invasive and irreversible.[219] Therefore, the WPAS determined that the removal of Ashley's breast buds and the administration of high doses of hormones also implicated her constitutional rights to liberty and privacy and should be subjected to court review.[220]

Parental consent to cosmetic genital surgery performed on infants with a DSD involves issues similar to those that were raised in Ashley X's case. Ashley's parents and parents of children with a DSD who are faced with the difficult decision about whether to have their children undergo surgical alteration are clearly motivated by love and their desire to act in the best interests of their children. The procedures performed on Ashley X and infants with a DSD, however, are different from other life-altering decisions that parents make for their children. In cases involving profoundly disabled children and infants with a DSD, parents have limited information about the benefits and risks of the proposed procedures and may have difficulty separating their interests from their child's best interest. In addition, some of these surgeries have the potential to infringe on constitutionally protected liberty and privacy rights. Therefore, before these procedures are performed, they should be subjected to additional review by a court and/or hospital ethics committee. Such a review can guarantee that all the relevant information is considered and that safeguards are followed to ensure that the best interests of the child undergoing the procedure are paramount.[221]

Arguably, surgeries performed on infants with an intersex condition should be subjected to even greater scrutiny than are the treatments performed on children with developmental disabilities because eventually children with a DSD will mature and will be able to make these decisions for themselves. A person with developmental disabilities as severe as Ashley's will never be able to

219. *Id.* at 22.

220. *Id.* at 24–25.

221. For an excellent discussion of the pros and cons of adopting various review approaches when the issue involves growth attenuation of profoundly disabled children, see Benjamin S. Wilfond et al., *Navigating Growth Attenuation in Children with Profound Disabilities: Children's Interests, Family Decision-Making, and Community Concerns*, HASTINGS CENTER REP., Nov.–Dec. 2010, at 27.

understand and consent to the treatment administered. She will always require her parents' care and she will never be in a position to make these decisions for herself. In contrast, children with an intersex condition will eventually reach an age when they are able to provide their own informed consent. Therefore, performing highly invasive and potentially life-altering surgeries on infants with an intersex condition on the basis of parental consent alone is less justifiable. Given the fact that children with an intersex condition will eventually be able to make this decision on their own, a stronger argument exists for nonintervention during infancy.

3. Reaction of the Intersex Community to Use of a Disability Framework

Although disability discrimination statutes might prove to be a productive avenue for intersex advocates who want to limit or end infant cosmetic genital surgeries, many people with an intersex condition object to the use of a disability framework. A recent transition in the terminology used in this area illustrates this unease. Most physicians and some intersex activists have rejected the term "intersex" in favor of the term "Disorders of Sex Development." [222] Although DSD is becoming the norm in many medical publications, this change in terminology has not been met with universal support.

Some activists reject the use of the term "disorder" because of the stigma that some in our society associate with people who are disabled or disordered.[223] Some prefer that the "D" in DSD represent "difference" rather than "disorder," while others have advocated for the use of VRD to represent "variations of reproductive development" because these terms avoid the stigmatization associated with the word "disorder."[224]

222. Holmes, *supra* note 3, at 2–5.

223. Organisation Intersex International (OII) is critical of the term "DSD" because it increases medical pathologization and stigma associated with the term "disorder." Curtis E. Hinkle, *Why Is OII Not Using the Term DSD or "Disorders of Sexual Development"?*, OII, http://www.intersexualite.org/Response_to_Intersex_Initiative.html (last visited Feb. 8, 2012). For a more detailed discussion of the debates regarding terminology, see GREENBERG, *supra* note 2, at 118–19; Holmes, *supra* note 3, at 6–7; and Spurgas, *supra* note 14, at 97–111.

224. *See*, *e.g.*, Margaret Simmonds, Comments on *Consensus Statement on Management of Intersex Disorders*, ARCHIVES OF DISEASE IN CHILDHOOD (Aug. 17, 2006), http://adc.bmj.com/content/91/7/554/reply; *see also* Wiesemann et al., *supra* note 71, at 671 & n.1, 672 (choosing to use the term "difference").

This aversion to the term "disorder" stems from the twentieth-century medical model under which people with disabilities tend to evoke pity. Opponents of the DSD terminology fear that the label "disorder" will result in people with a DSD being viewed as not fully functional.[225] They are concerned that the societal response will be to "cure" their disorder by medically modifying their bodies and rehabilitating them so that they can become as "normal" as possible.[226] Opponents of the term "DSD" fear that the label will perpetuate stigma and social prejudice because some people view those with disabilities as inferior to those who are "normal."[227]

Disability rights groups using critical disability theory have challenged such frameworks. Instead of focusing on the individual who is different, critical disability theorists focus on the barriers that society has created to block the full participation of people with disabilities.[228] Under this view, disabilities are only impairments if society is not structured so that those with disabilities are able to participate fully.[229] The classic example used to illustrate this alternative vision is a person in a wheelchair. Those who cannot walk are unable to participate fully in a society that provides only stairs and escalators and not ramps and elevators. In a world in which all buildings are accessible to those in wheelchairs, those who cannot walk are not disabled from full participation. By shifting the focus away from the bodies of disabled people and onto societal structures that inhibit full participation, critical disability theorists argue that body differences can become no more significant than hair or eye color.[230]

Most people with an intersex condition are able to participate fully in society and do not consider themselves disabled or

225. *See, e.g.*, Elizabeth Reis, *Divergence or Disorder?: The Politics of Intersex*, 50 PERSP. BIOLOGY & MED. 535, 535 (2007) (arguing that using the term "disorder" is problematic because it implies medical conditions in need of repair, when some intersex anatomies, though atypical, do not necessarily need surgical or hormonal correction).

226. *See, e.g.*, Emi Koyama, *Frequently Asked Questions About the "DSD" Controversy*, INTERSEX INITIATIVE (June 29, 2008), http://www.ipdx.org/articles/dsdfaq.html.

227. *See id.*

228. *See* Richard Devlin & Dianne Pothier, *Introduction: Toward a Critical Theory of Dis-Citizenship*, *in* CRITICAL DISABILITY THEORY: ESSAYS IN PHILOSOPHY, POLITICS, POLICY, AND LAW 1–2 (Dianne Pothier & Richard Devlin eds., 2006).

229. *See id.*

230. *See id.*; Jennifer L. Levi & Bennett H. Klein, *Pursuing Protection for Transgender People Through Disability Laws*, *in* TRANSGENDER RIGHTS 74 (Paisley Currah et al. eds., 2006); Ehrenreich et al., *supra* note 167, at 116–20.

disordered. Critical disability theorists assert that social institutions that use bright-line tests to distinguish male bodies from female bodies and that view all bodies that do not meet these binary tests as abnormal create the disability. The societal disposition to divide bodies into normal and abnormal and to privilege some types of bodies over others renders people with an intersex condition "disabled." As intersex activist Esther Morris has written, "Being born without a vagina was not my problem. Having to get one was the real problem."[231]

Although some intersex activists oppose the use of a disability model, disability laws can be effective tools in the fight against discrimination because of their extensive coverage and liberal interpretation. People with an intersex condition who suffer discrimination in the provision of health care could assert that they have been subjected to differential treatment because of their perceived disability. Intersex activists could use disability laws and join the battle with others in the critical disability movement who are working to end the shame and stigma associated with disabilities and disorders. If that goal is achieved, people with an intersex condition would no longer require disability laws to protect them because the perception that they are impaired and in need of fixing will have been successfully debunked.

V. CONCLUSION

Intersex advocates began challenging current medical practices in the mid-1990s. In a relatively short time, the intersex movement has increased public awareness about health care issues facing the intersex community and commenced a productive dialogue with medical practitioners. These educational efforts have led to critical changes to some formerly well-accepted practices. Doctors no longer feminize all XY infants with smaller penises and they have stopped recommending that people with a DSD be told lies or half truths about their conditions.

Most doctors, however, still recommend that parents of newborns with a DSD consent to medically unnecessary cosmetic genital surgery on behalf of their children. Most parents follow their

231. Esther Morris Leidolf, *An Additional Monologue*, MRKR ORG. (Oct. 2000), http://mrkhorg.homestead.com/files/ORG/AdditionalMonologue.htm.

physician's advice and approve of these procedures. Although the law typically grants great deference to parents regarding the medical decisions made on behalf of their children, traditional informed consent procedures are inadequate to protect the best interests of children with a DSD. Greater oversight of these procedures should be imposed for a number of reasons:

- *The surgeries affect important rights.* These surgeries have the potential to affect a person's ability to engage in satisfactory sexual relations. Although this is not a fundamental right on par with the right to reproduce, the U.S. Supreme Court has recognized that the constitutionally protected liberty interest encompasses the ability to engage in intimate conduct.[232] Surgeries that affect an important constitutionally protected right should only be performed with the informed consent of the person undergoing the procedure. If the person being subjected to the treatment is unable to consent, additional safeguards should be imposed to ensure that these important rights are not abridged.
- *Parents may not be able to completely understand their child's interests.* Parents who consent to cosmetic genital surgery have their children's best interests at heart. When parents make these decisions, however, they are visualizing their infants as children and not as adult sexual beings. Studies show that parents consent to these medical interventions because they are concerned about the emotional well-being of their offspring as children. Studies of adults, however, indicate that the majority of adults would not want their parents to consent to these surgeries, especially if there is a risk that the medical procedure will affect their ability to engage in satisfactory sexual relations.[233] Therefore, these procedures should not be performed under traditional parental consent practices.
- *These medical procedures are based on sex, gender, and sexual orientation stereotypes.* Although some infants

232. Lawrence v. Texas, 539 U.S. 558, 578 (2003).
233. *See supra* notes 166–69, 190–92, 197–98, and accompanying text.

with atypical genitalia must undergo interventions to repair conditions that threaten their health, most DSD conditions do not impose any health risks. Most of these surgeries are undertaken for purely cosmetic reasons. These surgeries are performed based on false sex, gender, and sexual orientation stereotypes, including the assumptions that women prioritize cosmetic appearance over sexual pleasure, men need a penis that will allow them to urinate in a standing position, and all men and women will want to engage in traditional heterosexual intercourse. Sex stereotypes should not be used to support life-altering health care practices.

- *These surgeries are undertaken not because these infants are actually disabled but based on the perception that they are impaired.* Most infants with a DSD are able to participate in all major life functions and are not actually disabled or impaired. They are subjected to invasive, irreversible, and potentially harmful medical interventions to bring their bodies into conformity with societal norms. People who are perceived as disabled should not be subjected to invasive procedures to conform their bodies to societal expectations. The cure is not the surgical alteration of the child; the cure is educating society to accept bodies that are different.

Thus far, only one legal institution, the Constitutional Court of Colombia, has been asked to address current medical procedures performed on infants with a DSD. After an extensive analysis, the Colombian court determined that standard informed consent practices are inadequate to protect infants with a DSD from potentially harmful medical procedures.[234] Legal institutions in the United States and other countries should follow the lead of Colombia and consider imposing additional legal safeguards to ensure that the rights of people with a DSD are adequately protected.

No study has proven that cosmetic genital surgeries benefit people with a DSD, and evidence exists that these procedures can lead to serious physical and emotional harm. Given the interests at stake, courts and legislatures should consider imposing legal

234. *Sentencia SU-337/99, Pt. I*, *supra* note 98.

safeguards to ensure that health care decisions made on behalf of infants with a DSD are actually in their best interests. Legal institutions should consider imposing a moratorium on these procedures until they have been proven to be beneficial, enhancing informed consent practices for these procedures, or requiring external oversight or approval by a court or hospital ethics committee.[235]

The law recognizes that people whose bodies, behaviors, and identities are different require protection from societal discrimination. Feminists and LGBT advocates have helped courts understand how discrimination based on sex, gender, and sexual orientation stereotypes constitutes unlawful sex discrimination. Similarly, disability advocates have educated society and legal institutions about the need to modify societal norms to fit the needs of all people.

The justifications for performing cosmetic genital surgeries on infants with a DSD are based on sex, gender, sexual orientation, and disability stereotypes. Current norms require that children raised as girls have female appearing genitalia, including a clitoris that is not "too large" and a vagina that is capable of accommodating a penis. These belief systems also require that children who are going to be raised as boys have a penis that is capable of penetrating a vagina and that allows the male to stand while urinating. Bodies that fail to comport to these standards are often perceived as nonconforming, disabled, and in need of repair. Typically, the "fix" is to subject these children to surgeries that have, in some cases, led to lifelong physical complications and psychological harm. Legal institutions need to carefully consider whether these "fixes" constitute impermissible sex and disability discrimination.

235. For a more extensive discussion of the potential advantages and disadvantages of these options, see GREENBERG, *supra* note 2, at 35–43.