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ARTICLES

BEYOND THE LOCKER ROOM:

CHANGING NARRATIVES ON EARLY SURGERY FOR INTERSEX CHILDREN

*Alison Davidian**

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* LLM, Harvard University; LLB, University of Sydney; BA, University of Sydney.

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My child has tried to commit suicide twice in her 10 little years because she says she hates her body. She constantly asks me why they . . . cut up her genitals.

- Debbie Hartman¹

The most horrible experience I remember is laying in bed with IV's in both arms, having my doctor and at least fifteen student doctors stare at my genitals, and leaving without pulling down my hospital gown. I laid there exposed for over an hour until the nurse finally came in to change the IV bag.

- Lynell Stephani Long²

My father said it most clearly. He didn't think that he was being offered a choice. And, I think that most parents have this experience.

- Howard Devore³

I was beginning to understand something about normality. Normality wasn't normal. It couldn't be. If normality were normal, everybody could leave it alone. They could sit back and let normality manifest itself. But people - and especially doctors - had doubts about normality. They weren't sure normality was up to the job. And so they felt inclined to give it a boost.

- Jeffrey Eugenides, *Middlesex*⁴

INTRODUCTION

Is it a boy or a girl? This is usually the first question that greets parents who have welcomed a child into our world. Sex and gender are such inherent parts of our identity and culture that we often do not even stop to think about it. But for some individuals, this question is not so binary or straightforward.

1. MARCUS DE MARIA ARANA, HUMAN RIGHTS COMM'N OF THE CITY AND COUNTY OF S. F., A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL "NORMALIZATION" OF INTERSEX PEOPLE 47-48 (2005), available at http://www.isna.org/files/SFHRC_Intersex_Report.pdf [hereinafter HUMAN RIGHTS REPORT] (quoting Debbie Hartman).

2. *Id.* at 43 (quoting Lynell Stephani Long).

3. *Id.* at 46 (quoting Howard Devore).

4. JEFFREY EUGENIDES, *MIDDLESEX* 446 (2002).

The term “intersex”⁵ does not have a universally accepted definition. It is a blanket term used to denote a variety of congenital conditions where a person is born with reproductive or sexual anatomy that does not fit the typical definition of male or female.⁶ Some intersex children may be born with “normal” male or female external genitals that do not correspond to their hormones, some are born with male or female characteristics that correspond to their chromosomes but do not correspond to their internal gonads, some are born with a noticeable combination of male and female external features, and some may be born with genitals that seem to be in-between the male and female standard, for example, a girl may be born with a noticeably large clitoris, or lacking a vaginal opening, or a boy may be born with a notably small penis, or with a scrotum that is divided so that it has formed more like labia.⁷

The definition of intersex is also context specific, dependent on the state of scientific knowledge at the time and the general culture of the society. For example, what are considered intersex genitals depends on local standards for penises and clitorises. A person with a small penis does not necessarily create sex ambiguity; however, a medical diagnosis of a “micropenis” has been treated by physicians as an intersex condition.⁸ Similarly, “a person with no obvious sex ambiguity but with ‘sex chromosomes’ other than simply XX (female-typical) or XY (male-typical) is today considered an intersex person by some intersex advocates, medical researchers, and clinicians, but not all.”⁹ Yet such a person would not have been considered intersex before the ability to diagnose sex chromosomes. However, having said this, “there are some forms of intersex that make a person’s body obviously different from what is usual – for example, when a child is born otherwise male but without a penis, or . . .

5. It must be noted that many intersex people have rejected the term “intersex.” Objections “include that the term sexualizes them (or their children if the objector is a parent) by making the issue one of eroticism instead of biology; that it implies they have no clear sex or gender identity; and that it forces on them an identity, especially a queer identity, to which they do not relate,” Alice D. Dreger & April M. Herndon, *Progress and Politics in the Intersex Rights Movement: Feminist Theory in Action*, 15 GLQ: J. LESBIAN & GAY STUD. 199, 208 (2009). Some have advocated using the term “disorders of sex development” (DSDs), although this is also a term of contention, *see id.* at 211-14. For the purposes of this paper, the term “intersex” will be used. Labeling something a “disorder” places it firmly in the medical world. This paper will argue that the medical narrative that has dominated the way we see intersexuality needs to be pierced and challenged.

6. This is the current definition accepted by the Intersex Society of North America, *see* Intersex Soc’y of N. Am., “*What Is Intersex?*,” http://www.isna.org/faq/what_is_intersex (last visited Feb. 22, 2011).

7. ANNE FAUSTO-STERLING, *SEXING THE BODY* 36-39, 48-54 (2000).

8. Micropenis is a medical term that describes an unusually small penis. The term applies to a penis with a stretched length more than 2.5 standard deviations (SD) less than the mean for penis size age, Peter A. Lee, et al., *Micropenis. I. Criteria, Etiologies and Classification*, 146 THE JOHNS HOPKINS MED. J. 156, 156-57 (1980).

9. Dreger & Herndon, *supra* note 5, at 200.

otherwise female but with a very small vagina and a large clitoris.”¹⁰ So while intersex is context specific, these biological variations are real.¹¹

The number of variations and thus people included in the category intersex depends on time, culture and the societies into which children are born.¹² For this reason, it is difficult to quantify the number of intersex births per year. Figures are published and withdrawn and estimates range. Some experts report that up to 4% of the world’s population is born with an intersex condition¹³ while others claim the incidence is 0.018% of all births.¹⁴

Surgery to normalize the appearance of genitals is part of the general standard of care afforded to intersex children in the United States.¹⁵ The risks and implications of this surgery have led many to question not only whether early surgery is appropriate, but whether parents of intersex children should have the authority to consent to such procedures on behalf of their child.¹⁶ This paper will consider the issue of authority to consent to such procedures where a child is not in imminent medical danger (i.e. where the surgery is largely for cosmetic rather than medical reasons). Part I will evaluate the dominant treatment model developed by Dr John Money, the risks associated with surgery and the current approach to treatment of children born intersex in the United States. Part II will examine the attempt of intersex activists to bring international human rights law into the debate through comparing genital normalizing surgery with female genital mutilation. Part III will discuss parental consent. It will consider jurisprudence from Columbia and the limitations of parental consent in this area. Part IV will propose a role for law in this discussion. Despite the risks involved, intersex surgeries have been presented as purely a medical issue and constructed as outside the law.¹⁷ This paper argues that law offers the potential to improve the decision-making process for whether such surgeries should occur and challenges the medical discourse of intersex as a dysfunction, mapping onto the intersex body a discourse of rights.

10. *Id.*

11. *Id.*

12. *Id.*

13. SHARON E. PREVES, INTERSEX AND IDENTITY: THE CONTESTED SELF 2 (2008).

14. Leonard Sax, *How Common is Intersex? A Response to Anne Fausto-Sterling* 39 J. SEX RES. 174, 177 (2002).

15. See Peter A. Lee et al., *Consensus Statement on Management of Intersex Disorders*, 118 PEDIATRICS e488, e490, e496 (2006), available at <http://pediatrics.aappublications.org/cgi/content/full/118/2/753> (last visited Feb. 28, 2011) [hereinafter *Consensus Statement*].

16. Samantha S. Uslan, Note, *What Parents Don’t Know: Informed Consent, Marriage, and Genital-Normalizing Surgery on Intersex Children* 85 IND. L.J. 301, 303 (2010).

17. Jo Bird, *Outside the Law: Intersex, Medicine and the Discourse of Rights*, 12 CARDOZO J.L. & GENDER 65, 66-67 (2005).

I. "TREATING" INTERSEX

A. *The Dominant Treatment Model*

During the 1950s, the dominant treatment model¹⁸ was developed where surgery to "normalize" genitals became the standard of care for children born intersex.¹⁹ One of the pioneers of this approach was the American psychologist John Money who was based at Johns Hopkins University in Baltimore.²⁰ He believed that in terms of gender identity, children are born as blank slates and develop a gender identity that conforms to the gender role in which they are raised, as long as their gender role matches the appearance of their genitals.²¹ In other words, if you made a child look like a girl, then raised her as a girl and made others believe she was a girl, she would also *think* she was a girl and would thereby become one. He saw gender as nurture, not nature. He therefore encouraged physicians to surgically alter children born with genitalia that did not conform to male or female norms and thereafter tell parents to raise the child according to the surgically assigned gender.²² As a result, "[m]ost children were assigned female because of the belief that it was easier to make a convincing-looking girl than a convincing-looking boy."²³ As one surgeon commented, "You can make a hole but you can't build a pole."²⁴

The dominant treatment model emphasizes the need for early surgical and hormonal intervention conforming the child's body to societal norms.²⁵ The birth of an intersex child is seen as a social emergency that must be operated on immediately with physicians posited as being the most qualified to determine the best interests of the parents and the child.²⁶

Central to this treatment model is the requirement that intersex children are raised without any ambiguity about their gender.²⁷ As a result, physicians encouraged parents not to tell their child about their condition and often told parents less than the whole truth.²⁸ The rationale was that this would reduce

18. This model is also referred to in the literature as the optimum gender of rearing model, see Alice Domurat Dreger, *Intersex and Human Rights*, in *ETHICS AND INTERSEX* 74 (Sharon E. Sytsma ed., 2006).

19. Julie Greenberg, *Legal Aspects of Gender Assignment*, 13 *Endocrinologist* 277, 277 (2003).

20. Kate Haas, *Who Will Make Room for the Intersexed?* 30 *AM. J.L. & MED.* 41, 45 (2004).

21. *Id.*; Greenberg, *supra* note 19, at 277.

22. See Greenberg, *supra* note 19, at 277.

23. Dreger & Herndon, *supra* note 5, at 202.

24. Dreger & Herndon, *supra* note 5, at 202.

25. Dreger, *supra* note 18, at 73, 74; Julie A. Greenberg, *International Legal Developments Protecting the Autonomy Rights of Sexual Minorities*, in *ETHICS AND INTERSEX* 87, 88-89 (Sharon E. Sytsma ed., 2006).

26. See Dreger, *supra* note 18, at 74; Greenberg, *supra* note 25, at 88-89.

27. Greenberg, *supra* note 19, at 279.

28. *Id.*; Greenberg, *supra* note 25, at 88.

psychological distress for both the patient and the parents.²⁹ The ultimate goal was to make intersex disappear.

B. The John/Joan Case

In 1972, Money was given the opportunity to test his theories when the parents of David Reimer approached him.³⁰ David had been accidentally castrated during a routine circumcision.³¹ Following the accident, his parents were told by doctors that David would be unable to have a normal sex life and would “grow up feeling incomplete and physically defective.”³² Money’s solution was to perform sex-reassignment surgery and for David’s parents to raise him as a girl called “Brenda.”³³ As Brenda approached puberty, she was given female hormones to trigger breast development and other female secondary characteristics.³⁴ The early accounts of Money’s surgery reported the operation as a success; Brenda was a healthy and happy young girl.³⁵ Money’s research was published throughout the world in what became known in medical and psychological literature as the John/Joan case, convincing doctors that gender was entirely socially constructed and providing a theoretical foundation for intersex surgery.³⁶ This story, however, has far from a happy ending.

Researchers seeking to challenge Money’s theory of gender identity started searching for Brenda in the late 1980s. They discovered that Brenda had changed her name to David and was now living as a man.³⁷ Despite corrective surgery and hormonal therapy throughout his childhood and teenage years, David suffered serious emotional distress at all stages of his development and was never comfortable in the female body constructed for him.³⁸ As a child, he would often stand to urinate despite not having a penis.³⁹ Other girls at school barred “Brenda” from their bathroom, threatening to kill her if she came in, eventually causing her to use the boys’ toilets or a back alley every time she needed to use the bathroom.⁴⁰ She was constantly teased because of her “boy

29. See Greenberg, *supra* note 19, at 279.

30. HUMAN RIGHTS REPORT, *supra* note 1, at 12; Haas, *supra* note 20, at 45. Note that David Reimer was baptized with the name “Bruce,” later changing his name to David. See *David Reimer: The Boy Who Lived as a Girl*, CBCNEWS (May 10, 2004), <http://www.cbc.ca/news/background/reimer/>.

31. HUMAN RIGHTS REPORT, *supra* note 1, at 12.

32. Haas, *supra* note 20, at 45.

33. *Id.*

34. 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, 8 (2000).

35. Haas, *supra* note 20, at 46.

36. Beh & Diamond, *supra* note 34, at 9.

37. Haas, *supra* note 20, at 46.

38. *Id.*

39. Beh & Diamond, *supra* note 34, at 8.

40. Kenneth Kipnis & Milton Diamond, *Pediatric Ethics and the Surgical Assignment of Sex*, in INTERSEX IN THE AGE OF ETHICS 173, 179 (Alice Domurat Dreger ed., 1999).

looks and her girl clothes,” felt isolated, deeply confused and contemplated suicide.⁴¹

David dreaded trips to see Money at John Hopkins University.⁴² He threatened to kill himself if he had to go again, and without knowing his history, he made the decision to stop living as a girl.⁴³ Following the transition, on the advice of psychiatrists, David’s parents told him the truth.⁴⁴ He then underwent multiple surgeries to restore his male genitalia.⁴⁵ Ultimately though, on May 5 2004, at the age of 38, David Reimer took his own life.⁴⁶

While this case had been widely reported and cited in the 1970s and 1980s, David’s rejection of the assigned gender did not appear in medical literature until 1997.⁴⁷ At this late stage, the damage had largely been done. It has been the early reports of David’s supposedly successful sex change that have had the greatest impact on developing the accepted standard of care for intersex children.⁴⁸ Despite the revelation of the true outcome of the John/Joan case and the flawed theoretical underpinnings for surgery on intersex children, this treatment model was widely accepted as standard medical practice.⁴⁹

Supporters of this model believe that living with ambiguous genitalia leads to ostracism from peers (examples of such ostracism are often related back to encounters in the locker room), severe psychological trauma for the child, and the potential weakening of the bond between parents and their child.⁵⁰ One practitioner commented that “it is important to begin surgery early in order to spare parents the trauma of seeing their child as intersexed each time they change [their] diaper.”⁵¹

The full story of the John/Joan case, and the significant risks associated with genital normalizing surgery have seen this model come under fierce attack, the loudest objections coming from intersex people themselves.⁵²

41. Beh & Diamond, *supra* note 34, at 10.

42. Kipnis & Diamond, *supra* note 40.

43. *Id.* at 179-80.

44. *Id.* at 180.

45. David Salt, *Intersex: The space between the genders*, 15 COSMOS MAG. 57, 60, June 2007, available at <http://www.cosmosmagazine.com/node/1461>.

46. For accounts of the John/Joan case, see generally JOHN COLAPINTO, AS NATURE MADE HIM (2000); Kipnis & Diamond, *supra* note 40, at 179-80; Milton Diamond & H. Keith Sigmundson, *Sex Reassignment at Birth: Long-Term Review and Clinical Implications*, 151 ARCHIVES PEDIATRICS & ADOLESCENT MED. 298, 299 (1997).

47. See Diamond & Sigmundson, *supra* note 46, at 299. Beh & Diamond, *supra* note 34, at 9, 9 n. 30.

48. Beh & Diamond, *supra* note 34, at 9; Diamond & Sigmundson, *supra* note 46, at 299.

49. Beh & Diamond, *supra* note 34, at 9; Diamond & Sigmundson, *supra* note 46, at 299.

50. Greenberg, *supra* note 19, at 279.

51. Erin Lloyd, *From the Hospital to the Courtroom: A Statutory Proposal for Recognizing and Protecting the Legal Rights of Intersex Children*, 12 CARDOZO J.L. & GENDER 155, 173 (2005) (internal quotations omitted).

52. See e.g., HUMAN RIGHTS REPORT, *supra* note 1, at 48.

C. *Risks of Genital Normalizing Surgery*

Given the variation in intersex conditions, not all surgeries carry the same risks. Some surgeries, such as vaginoplasty, carry severe risks, including the risk of sterilization, a loss of sexual functioning, a loss or diminishment of the ability to experience sexual pleasure, and long-term physical pain.⁵³ These procedures are performed in the absence of any long-term studies on their effectiveness.⁵⁴

Surgery for treatment of intersex is still quite novel. There are no long-term studies demonstrating that surgery contributes positively to the child's gender-identity development, self esteem, general physiological health, and the benefits of early as opposed to later surgery.⁵⁵ Furthermore, "[s]ince Money's John/Joan case study was discredited, not a single case has been found or cited to support the long-term physical and psychological successes of this surgery."⁵⁶ Notions of success and effectiveness are also complex in this kind of surgery: is a surgery successful when the patient's genitals look more "normal" but they have lost their ability to have children or experience sexual pleasure?

Critics of early surgical intervention argue that the dominant treatment model approach is misleading and potentially damaging. It implies to parents that the intersex condition is one of genital malformation and not one of gender ambiguity, thus blurring the complex relationship between the two. Hazel Glenn Beh and Milton Diamond argue that "merely changing the genitals does not alter the chromosomal, genetic or hormonal determinants of sex and so does not change an intersex child . . . into an infant of the assigned sex."⁵⁷ Indeed, there are reports documenting children born intersex who have rejected the sex assigned to them,⁵⁸ raising the argument that it is more important that the sex assignment be correct rather than fast.

In addition to physical complications, normalizing surgery often has damaging psychological effects. The San Francisco Human Rights Commission's investigation into the medical normalization of intersex people

53. HUMAN RIGHTS REPORT, *supra* note 1, at 21.

54. Haas, *supra* note 20, at 51 n. 117 (citing Julie A. Greenberg & Cheryl Chase, *Background of Columbia Decisions*, Intersex Society of North America, <http://www.isna.org/node/21> (last visited April 6, 2011) for the proposition that "the only point upon which proponents and critics of the surgery seemed to agree, found the Judges, is that there are no long-term studies which would substantiate either position"). Alice Domurat Dreger, "Ambiguous Sex" – or Ambivalent Medicine?, 28 HASTINGS CENTER REP. 24, 25 (1998), available at http://www.isna.org/articles/ambivalent_medicine; Hazel Glenn Beh & Milton Diamond, *David Reimer's Legacy: Limiting Parental Discretion*, 12 CARDOZO J.L. & GENDER 5, 5 (2005).

55. See *Consensus Statement*, *supra* note 15, at e496.

56. Anne Tamar-Mattis, *Exceptions to the Rule: Curing the Law's Failure to Protect Intersex Infants*, 21 BERKELEY J. GENDER L. & JUST. 59, 71 (2006); See Dreger, *supra* note 54, at 25.

57. Beh & Diamond, *supra* note 34, at 49.

58. Bruce E. Wilson & William G. Reiner, *Management of Intersex: A Shifting Paradigm*, in INTERSEX IN THE AGE OF ETHICS 119, 126 (Alice Domurat Dreger ed., 1999).

documents the pain and loss of many who were forced to undergo normalizing surgery.⁵⁹ The shame and stigma that surgery is designed to address are often the products of the treatment. This is no doubt generated by the silence and secrecy that accompanies intersex surgeries.⁶⁰ These feelings are also compounded by the fact that genital surgery is often not a simple one time procedure but usually requires extensive follow up.⁶¹ The constant trips to doctors and subjection to repeated medical examinations has been said to create feelings of loss of control and autonomy over one's own body.⁶² Morgan Holmes writes that the push for intersex surgery reinforces rather than undermines the social perception of intersex people as anomalies.⁶³ The surgery is motivated by the perception of intersexuality as something that must be fixed. The act of surgery therefore perpetuates the understanding of intersexuality as a condition to be corrected, even while the goal of surgery is to produce a child who feels completely "normal."⁶⁴

Perhaps the strongest argument against surgery is the voices of the intersex people themselves. During the last decade, a number of intersex adults who were treated under the dominant model have come forward to speak about their experiences of physical and psychological trauma.⁶⁵ Woven through the testimonies is an incredible sense of loss, loss of potential, loss of autonomy.⁶⁶ Perhaps there are satisfied people out there. Perhaps the surgery has helped them blend into society such that the thought of stepping forward to assume a stigma they have so far avoided is unthinkable.⁶⁷ But the fact that not one has come forward to voice even token support is telling.

D. Current Approach in the United States

Until 2006, the dominant treatment model formed the basis for the standard of care for intersex infants in America with the birth of an intersex child considered a "social emergency" requiring early surgical intervention.⁶⁸ The American Academy of Pediatrics (AAP) has reconsidered its position on intersex treatment protocols. In 2006, a Consensus Statement on Management

59. HUMAN RIGHTS REPORT, *supra* note 1, at 48.

60. Sara R. Benson, *Hacking the Gender Binary Myth: Recognizing Fundamental Rights for the Intersexed*, 12 CARDOZO J.L. & GENDER 31, 44-45 (2005).

61. For example, vaginoplasty often requires repeated surgical follow-up. HUMAN RIGHTS REPORT, *supra* note 1, at 21, 54.

62. PREVES, *supra* note 13, at 66-67; FAUSTO-STERLING, *supra* note 7, at 86.

63. Morgan Holmes, *Rethinking the Meaning and Management of Intersexuality*, 5 SEXUALITIES 159, 173-74 (2002).

64. *Id.*

65. See HUMAN RIGHTS REPORT, *supra* note 1, at 48.

66. Morgan Holmes, *Distracted Attention: Intersexuality and Human Rights Protections*, 12 CARDOZO J.L. & GENDER 127, 133 (2005).

67. See Tamar-Mattis, *supra* note 56, at 68-69.

68. See Am. Acad. of Pediatrics, *Evaluation of the Newborn with Developmental Anomalies of the External Genitalia*, 106 PEDIATRICS 138, 138 (2000), available at <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;106/1/138>.

of Intersex Disorders (“the Consensus Statement”) was developed.⁶⁹ The Consensus Statement is a significant moment in the history of management of intersexuality as it represents the first time since the development of Money’s treatment model in the 1950s that clinicians and researchers revisited the medical standard of care for diagnosing intersex conditions.⁷⁰ The recommendations put forward in the Consensus Statement represent a significant change in thinking about how to treat intersexuality.⁷¹

The Consensus Statement no longer uses the language of “social emergency” to describe the birth of an intersex child but instead states that such a birth prompts “a long-term management strategy that involves myriad professionals working with the family.”⁷² It notes that physicians should consider a variety of factors before determining the child’s gender assignment, including the child’s medical “diagnosis, genital appearance, surgical options, need for lifelong replacement therapy, potential for fertility, views of the family, and, sometimes, circumstances relating to cultural practices.”⁷³ The Consensus Statement goes some way toward improving the secrecy that typically surrounds the birth of an intersex child, explaining that an intersex condition is not shameful.⁷⁴ However, it goes on to note that the “health care team should discuss with the parents ‘what information’ to share in the early stages with family members and friends.”⁷⁵ Thus, an element of secrecy is still implicit in the management strategy.

With regards to surgery, the Consensus Statement acknowledges that there is minimal data evaluating the long-term effects and consequences of genital normalizing surgery, that there is little documentation to support the widely held belief that early surgery relieves parental distress about atypical genitals, and that such surgery can risk affecting a patient’s sexual sensation and fertility.⁷⁶ For these reasons, it states that surgery should only be considered for young girls with “severe” genital virilization and that emphasis should be placed on “functional outcome” rather than on strictly cosmetic appearance.⁷⁷

There is no doubt that the Consensus Statement significantly improves on previous practice. However, there are still issues that remain. While it explains that surgery should only be considered in severe cases of virilization, it does not advocate that doctors cease performing early genital normalizing surgeries altogether.⁷⁸ It moves the emphasis on reasons for surgery from improving cosmetic appearance to preserving function, noting that surgical management

69. *Consensus Statement*, *supra* note 15.

70. Katrina Karkazis, Letter to the Editor, *Disorders of Sex Development: Improving Care for Affected Persons and Their Families*, 165 AM. J. PSYCHIATRY 265, 265 (2008).

71. *Id.*

72. *Consensus Statement*, *supra* note 15, at e488.

73. *Id.* at e491.

74. *Id.* at e490.

75. *Id.*

76. *Id.* at e491.

77. *Id.*

78. *Id.*

should consider options that will *facilitate* chances of fertility and maintain sexual functioning and sensation. However, these risks are not grounds for ruling out or delaying surgery. In any event, parents ultimately have the final decision.⁷⁹ The Consensus Statement comments that parents “now seem to be less inclined to choose surgery” for less severe cases, but if parents wish to proceed with surgery, they are able.⁸⁰ In addition, the new policy is only that – a policy. Thus, the “new standards of care [are] not binding on medical providers, and it can take many years for medical practices to change in accordance with new information.”⁸¹ As a result, the dominant treatment model remains the primary approach in many hospitals.⁸²

II. HUMAN RIGHTS AND CULTURE

A. *Intersex Surgeries and FGM*

Intersex activists have tried to bring human rights law into the debate regarding surgery for intersex children by comparing genital normalizing surgery with female genital mutilation (FGM).⁸³ In 1997, members of the Intersex Society of North America (ISNA) lobbied Congress to include intersex surgeries as a protected category under a new federal statutory ban of FGM claiming that the legislation should not only ban practices imported from other cultures but also “mutilation” of intersex infants.⁸⁴ Intersex activists have emphasized how FGM and surgeries on intersex infants result in almost identical psychological and physical harms, including impaired sexual functioning, infertility, genital infection, chronic genital pain, scarring and urinary problems.⁸⁵ In addition, they argue that both are medically unnecessary, performed without the informed consent of the intersex patient and violate a host of internationally recognized human rights, including the right to bodily integrity, health, privacy and autonomy, as well as the right to be free of cruel, inhuman and degrading treatment.⁸⁶ Just as FGM is used to reinforce gender norms, intersex activists argue that one of the goals of genital normalizing

79. *Id.* at e492.

80. *Id.* at e491-92.

81. Tamar-Mattis, *supra* note 56, at 78.

82. *Id.*; Uslan, *supra* note 16, at 308.

83. See Nancy Ehrenreich & Mark Barr, *Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of “Cultural Practices,”* 40 HARV. C.R.-C.L. L. REV. 71, 71 (2005).

84. Natalie Angier, *New Debate over Surgery on Genitals*, N.Y. TIMES, May 13, 1997, at C1; Anne Scheck, *Intersexuality Takes a Conservative Turn*, UROLOGY TIMES, Feb. 1, 1998, at 32-33.

85. Ehrenreich & Barr, *supra* note 83, at 106.

86. For a discussion of FGM and human rights, see ANIKA RAHMAN & NAHID TOUBIA, FEMALE GENITAL MUTILATION 23-28 (2000).

surgery is to reinforce heterosexism and cultural norms of appropriate gender roles.⁸⁷

Western feminists have resisted the request of intersex activists to include genital normalizing surgery as part of the agenda to end FGM, drawing a distinction between the *social* or *cultural* problem of FGM and the *medical* problem of intersex surgeries.⁸⁸ However, Nancy Ehrenreich and Mark Barr have argued that intersex surgeries, like FGM, are a *cultural* practice. They argue that the medical profession's preoccupation "with the stigma that can attach to someone who is not readily identifiable as male or female is not that different . . . from [FGM] practitioners' conviction that women who fail to undergo genital surgery will be seen as dirty, promiscuous and unmarriageable."⁸⁹ Intersex treatment relies on sex and gender binaries, which prevail in the culture that we are a part. Rather than conceptualizing intersex individuals as a "normal" third sex or as occupying various points along a sex continuum, our society chooses to see them as having abnormalities that require repair. In relation to girls and women who have experienced FGM and individuals who are born intersex, practitioners are responding to very real social attitudes that can reasonably be expected to negatively affect the individuals in question.⁹⁰

Comparing intersex surgeries with FGM fails to acknowledge a crucial difference: while the debate about FGM has framed it as a cultural practice, raising issues of cultural relativism and human rights, the debate surrounding genital normalizing surgeries has been wholly shaped by the medical profession.⁹¹ Its history is rooted in socio-medical discourse, sanctioned and performed by practitioners of western medicine.⁹² By comparing the two practices, intersex activists risk shifting the focus from questioning the socio-medical discourse legitimizing intersex surgeries, to raising issues of culture that lie at the heart of the FGM debate.⁹³ Analogizing the two practices also

87. Opponents of early surgery argue that the dominant treatment model reinforces cultural stereotypes of appropriate gender roles. Doctors have turned XY (male-typical) infants into girls if they believe the child's penis is too small. This surgery was performed even if the child is chromosomally male and it would result in turning a child who is otherwise fertile (with functional testes that can produce sperm) into a female who is infertile. In contrast, an XX (female-typical) infant with a larger than typical clitoris, who is capable of bearing children, has had her female fertility maintained. At the same time, however, her clitoris has been surgically reduced even if such reduction could cause a loss or impairment of sexual pleasure. Thus, for males, the ability to penetrate a vagina is prioritized above fertility, and for women, their ability to bear children and be penetrated by a man is prioritized over their ability to enjoy sex, see Julie A. Greenberg, *Intersex and Intra-sex Debates: Building Alliances to Challenge Sex Discrimination*, 12 CARDOZO J. L. & GENDER 99, 107 (2005); Ehrenreich & Barr, *supra* note 83, at 119, 127.

88. Noa Ben-Asher, *The Necessity of Sex Change: A Struggle for Intersex and Transsex Liberties*, 29 HARV. J.L. & GENDER 51, 73 (2006).

89. Ehrenreich & Barr, *supra* note 83, at 115.

90. *Id.* at 129.

91. *Id.* at 76.

92. Ben-Asher, *supra* note 88, at 75-76.

93. *Id.*

fails to appreciate that because genital normalizing surgery is accepted as standard medical practice, there is not the political and social will behind having it criminalized. Thus, unsurprisingly, ISNA's legislative attempts to analogize intersex surgery to FGM failed. It is arguable that intersex surgeries are still permitted under the anti-FGM statute as cases of "medical necessity"⁹⁴

B. Intersex Surgeries and Male Circumcision

Rather than comparing intersex surgeries to FGM, it is perhaps more useful to draw analogies with male circumcision, a practice that is grounded in cultural as well as religious justifications.⁹⁵ Both male circumcision and intersex surgeries originated from accepted medical practices that have been endorsed by western practitioners, are based in medical-health narratives, and critics of both have used those same narratives to argue against the surgeries.⁹⁶ While circumcision rates are falling, it remains one of the most common operations performed on males in the United States.⁹⁷ It has continued even after its original rationales of deterring masturbation and treating other miscellaneous disorders were discredited.⁹⁸ Other purposes have been posited, including that circumcision protects against penile cancer, urinary tract infections, and reduces the risk of HIV infection.⁹⁹

While many believe circumcision has few negative consequences, opponents of the practice point to numerous studies that support serious adverse effects, including that the procedure is traumatic and painful for newborn children, results in heightened pain response, and that the excessive bleeding can sometimes result in death.¹⁰⁰ Like intersex activists, they offer medical data to support the proposition that male circumcision is cultural and not medically necessary and that it should not be forced upon the infant because it is in fact harmful.¹⁰¹

94. *Id.* at 73.

95. In western and non-western societies, male circumcision can be performed for purely cultural reasons. See MAYA SABATELLO, CHILDREN'S BIOETHICS 130-31 (2009).

96. Marie Fox & Michael Thomson, *Cutting It: Surgical Interventions and the Sexing of Children*, 12 CARDOZO J.L. & GENDER 81, 85, 95-96 (2005); Ben-Asher, *supra* note 88, at 75-78.

97. Ben-Asher, *supra* note 88, at 75. The Circumcision Reference Library reports that in 2006, the mean male circumcision rate for all states was 56.1%. Circumcision Reference Library, *United States Circumcision Incidence*, <http://www.cirp.org/library/statistics/USA/> (last updated Jan. 1, 2011).

98. Ben-Asher, *supra* note 88, at 75.

99. *Id.*

100. For a discussion of the implications of male circumcision, see DOCTORS OPPOSING CIRCUMCISION, GENITAL INTEGRITY POLICY STATEMENT 19-20, 27 (2008), available at <http://www.doctorsopposingcircumcision.org/pdf/GenitalIntegrityStatement.pdf>.

101. Ben-Asher, *supra* note 88, at 76.

C. *The Limits of Culture*

Intersex surgeries, like male circumcisions, are performed with a notion of empowerment and with the aim of including these children within communities. In this respect, it is important to note that individuals cannot be separated from the cultures into which they are born. We all live in communities and conforming to the culture of those communities is an essential part of sharing a common humanity and living as an active citizen. Our society is structured by gender. It is an organizing principle around which we live and shape our lives. From the moment we are born, from the colors chosen for us to wear as babies, girls and boys are socialized to inhabit and experience different social worlds.¹⁰² The need and desire to be socially accepted and understood cannot be overstated.

All cultures constrain in some way. Prohibiting cultural practices such as genital normalizing surgery and male circumcision may be liberating in one sense, but there are also liberating cultural aspects in the practice itself.¹⁰³ Yet this does not mean that all cultural practices must be allowed. It is clear that the far reaching effects and risks of early genital normalizing surgery are sufficient to raise the issue of whether the rights of intersex children are being violated and whether consenting to surgery should remain a private decision appropriately made by parents.

III. PARENTAL CONSENT AND CHILDHOOD AUTONOMY

A. *Columbian Jurisprudence*

The Constitutional Court of Columbia is the only court in the world to render an opinion on the issue of parental authority to consent to surgery on behalf of an intersex child.¹⁰⁴ In *Sentencia No. SU-337/99* (hereinafter Ramos), the Constitutional Court considered the case of an eight-year-old child raised as a girl but born with male chromosomes.¹⁰⁵ On account of the fact that she could not process male hormones, “her external genitalia did not fully develop. Ramos had a small penis, . . . folds of skin that did not contain testicles, male gonads, and a urinal opening at the base of her perineum.”¹⁰⁶ In fact, her “doctors were not aware that she was intersexed until she was three years old. Until that point, Ramos’ mother had raised her as a girl without questioning whether she might not have female chromosomes.”¹⁰⁷ Upon becoming aware of her intersex condition, Ramos’ doctor recommended that she receive genital reconstruction surgery to remove her penis and gonads and construct a vagina.¹⁰⁸ However, on account of a court decision in 1995, doctors in

102. PREVES, *supra* note 13, at 15.

103. SABATELLO, *supra* note 95, at 71, 130-31.

104. Haas, *supra* note 20, at 49

105. *Id.* at 50.

106. *Id.*

107. *Id.*

108. *Id.*

Columbia were concerned about the potential liability of performing genital surgery on intersex infants.¹⁰⁹ Her mother, afraid that delaying further would psychologically harm Ramos because she would grow up without clear gender identity, brought the action to force the hospital to accept her consent so the doctors could proceed with the surgery.¹¹⁰ However, “despite being raised female, the trial court found that Ramos’ gender was ambiguous because ‘in some aspects she behave[d] like a woman and in some aspects like a man.’”¹¹¹

The Court denied the mother’s petition holding that she could not consent to the surgery on behalf of her child.¹¹² In reaching this decision, the Court considered the evidence supporting the dominant treatment model approach as well as evidence that critiqued this model.¹¹³ The Court concluded that allowing surgeries to continue under the dominant treatment model would not ensure the best interests of the child are protected but prohibiting all surgeries until children reach the age of consent was also unsatisfactory.¹¹⁴ The Court acknowledged that the treatment proposed was invasive, proven to cause grave and irreversible harm to the patient and that its usefulness remains in doubt.¹¹⁵ However, the Court noted that it was not clear whether the treatments were entirely useless or harmful in the majority of cases.¹¹⁶ In addition, prohibiting treatment would invade family privacy and force families to engage in “a type of social experiment.”¹¹⁷ The Court reached a compromise, favoring the informed consent of the child with the mother’s guidance.¹¹⁸

In reaching its decision to deny the mother’s petition, the Court placed great emphasis on Ramos’ age and the fact that at eight years of age, she had already developed a gender identity.¹¹⁹ Surgery, therefore, represented a greater invasion of her autonomy.¹²⁰ As she was older, she had “gained a degree of autonomy that deserves a greater Constitutional protection.”¹²¹ “[H]ence, the legitimacy of . . . paternal consent is reduced.”¹²²

This decision has been heralded as a step forward for intersex rights. The Court focused on protecting the child’s future well-being and her autonomy. However, while the decision recognizes the importance of a child participating

109. *Id.*

110. *Id.* at 50-51.

111. *Id.* at 51.

112. *Id.*

113. *The Rights of Intersexed Infants and Children: Decision of the Colombian Constitutional Court, Bogota, Colombia, 12 May 1999 (SU-337/99)* (Nohemy Solórzano-Thompson trans.), in *TRANSGENDER RIGHTS* 122, 123-27 (Paisley Currah et al. eds., 2006) [hereinafter *Ramos Decision*].

114. *Id.* at 130-31.

115. *Id.* at 122, 123.

116. *Id.* at 125.

117. *Id.* at 127, 129.

118. *Id.* at 131.

119. *Id.*

120. *Id.*

121. *Id.* at 133.

122. *Id.*

in such an important decision for their lives, it affords little protection to infants and young children who are deemed not to have gained a degree of autonomy. The decision suggests it is the advanced age of Ramos and her *already* developed self-awareness and gender identity that prevents surgeons from imposing what would otherwise be a workable solution. For the intersex child who is *born*, the decision does nothing to question the authority of medical knowledge that preferences early surgery and thus implicitly endorses it.¹²³ It does nothing to protect their developing and potential autonomy. In these cases, it remains the right of parents to make this decision.¹²⁴ This was confirmed the next time the Court was required to rule on this issue.

Following Ramos, the Constitutional Court again considered the issue of consent to surgery for intersex children when it heard *Sentencia No. T-551/99* (hereinafter Cruz). This case involved a three-year-old born with female chromosomes and male external genitalia.¹²⁵ In order to make their child look more female, her parents sought to have the size of her clitoris/penis reduced, or removed completely.¹²⁶ However, instead of following Ramos, the Court decided that while children over the age of five years must give their informed consent before undergoing genital reconstruction surgery, for children under five, parents should be allowed to consent to surgery.¹²⁷ The Court explained that Cruz was too young to have formed a gender identity, and by prohibiting consent for surgery, the Court would be intruding into the realm of family privacy.¹²⁸ However, in order for this parental consent to be valid, the Court required that it be “qualified and persistent” and must satisfy three criteria: (i) the consent must be in writing; (ii) detailed information must be provided to parents so they are informed about the dangers of current treatments and the possibility of alternatives to surgery; (iii) the authorization must be given on several occasions over a reasonable time period to ensure the parents have time to truly understand the situation.¹²⁹

B. Parental Consent

When parents consent to genital normalizing surgery for their children, it cannot be doubted that they are acting with the best of intentions and out of a fierce desire to protect their children. The issue is not one of intentions; it is one of interests (i.e. whose interests are actually being protected and prioritized?). A factor complicating informed parental consent is that while it may improve the quality of decision making in some cases, it does not remove the parental

123. Morgan Holmes, *Deciding Fate or Protecting a Developing Autonomy? Intersex Children and the Colombian Constitutional Court*, in *TRANSGENDER RIGHTS* 102, 116 (Paisley Currah et al. eds., 2006).

124. *Id.*

125. Haas, *supra* note 20, at 52

126. *Id.*

127. *Id.* at 53.

128. *Id.*

129. *Id.* at 53-54.

conflict of interest that makes it difficult to evaluate the long-term interests of the intersex child.

A common reason given for performing early surgery on intersex infants is the belief that without surgery, parents are unable to bond with their children. The Consensus Statement on Management of Intersex Disorders notes that while the systematic evidence is lacking, it is generally felt that early surgery “relieves parental distress and improves attachment between the child and the parents.”¹³⁰ In presenting arguments against a moratorium on surgeries, the Columbian Constitutional Court in *Ramos* states that “prohibition of these surgeries could deprive children of their parents’ love, because [the parents] believe a judicial decision left them with defective children.”¹³¹ If it is early surgery that will foster parental attachment to the child and overcome discomfort with the child’s intersex body, it is difficult to claim that parents are then able to prioritize the needs and interests of their child above their own in considering whether to provide consent for surgery.¹³²

The issue of interests also raises the fact that a child’s interests may change over time. When a child is born, normality is intimately connected to their appearance. Yet as a child grows and becomes an adult, normality can also include other factors, such as the ability to mother and father children and the ability to experience sexual pleasure. It may be difficult for parents under circumstances that are emotional and characterized by an atmosphere of urgency, and even emergency, to consider the child’s long-term interests and the fact that life extends beyond the proverbial locker room.

While parental rights are not absolute, parents have broad latitude in making decisions for the medical treatment of their children.¹³³ Indeed, “[T]he law presumes that parents have the authority to make . . . decisions on behalf of their children; substituting their consent for their child’s consent.”¹³⁴ Surgery for intersex children is not considered a category of parental decision-making that ordinarily requires a court order.¹³⁵ The reasons for this are largely cultural in that these surgeries are accepted as standard medical practice.¹³⁶ As long as a parent’s decision to consent to medical treatment for their child is in line with the accepted medical standard of care and doctors and parents agree about a particular medical decision for the child, there is rarely any additional oversight and courts will not intervene.¹³⁷

130. *Consensus Statement*, *supra* note 15, at e491.

131. *Ramos Decision*, *supra* note 113, at 126.

132. Tamar-Mattis, *supra* note 56, at 89-90.

133. *Id.* at 79-80.

134. *Id.* at 79.

135. *Id.* at 80-81.

136. *Id.* at 81.

137. *Id.* at 79-81.

IV. A ROLE FOR LAW

A. *Limitations on Parental Consent*

The authority of parents to make medical decisions on behalf of their children is not absolute.¹³⁸ In many circumstances, parents can have conflicts of interest that can influence their judgment when making a decision on behalf of their child. In some cases involving medical procedures, the potential for parental conflict of interest is so great that courts and legislatures have created exceptions to the usual process of parent-doctor decision making, recognizing that additional oversight is necessary to protect the interests and rights of children.¹³⁹ Such cases include decisions to sterilize children and allow them to serve as organ donors.¹⁴⁰

In most jurisdictions, parents and guardians are unable to authorize the sterilization of children and/or people with disabilities without a court order.¹⁴¹ The rationales for removing this decision from parents is that the right to procreation is fundamental and is irreversibly lost through sterilization.¹⁴² The concern that as much of the burden of an unwanted pregnancy would fall on parents, their desire to avoid such a situation may have an impact on their ability to fully consider the interests of the child.¹⁴³ In granting an order for the procedure, courts require compelling evidence that the benefits to the child outweigh the harm of sterilization.¹⁴⁴

Similarly, the consent of parents and guardians is generally insufficient for allowing children or incompetent adults to serve as organ donors.¹⁴⁵ Judicial approval is also required.¹⁴⁶ The rationales for removing the decision from parents is again similar: parents may have a conflict of interest if the person to receive the organ is a family member in dire need and extra caution is needed when a parent wants to consent to a medical procedure that offers no medical benefit to the child.¹⁴⁷ Evidence is required to show that there is some benefit to the donor child that outweighs the medical risk and harm.¹⁴⁸

As noted previously, the effects of intersex surgery are serious. In particular, in some cases genital normalizing surgery has the potential to result

138. *Id.* at 79-80.

139. *Id.* at 93; Lloyd, *supra* note 51, at 181-82.

140. Tamar-Mattis, *supra* note 56, at 94-97.

141. *Id.* at 96.

142. *Id.* (citing *In re Terwilliger*, 450 A.2d 1376, 1382 (Pa. Super. Ct. 1982)).

143. *Id.* (citing *In re Terwilliger*, 450 A.2d at 1385).

144. *Id.* at 97 (citing *In re Terwilliger*, 450 A.2d at 1382).

145. Jennifer L. Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for their Children: Is Deference Justified?*, 73 TEMP. L. REV. 1, 57-58 (2000); Tamar-Mattis, *supra* note 56, at 94.

146. Tamar-Mattis, *supra* note 56, at 94 (citing *Hart v. Brown*, 289 A.2d 386, 391 (Conn. Super. Ct. 1972)).

147. Rosato, *supra* note 145, at 57.

148. Tamar-Mattis, *supra* note 56, at 95 (citing, *e.g.*, *Little v. Little*, 576 S.W.2d 493, 499-500 (Tex. Civ. App. 1979)).

in sterilization and the loss of the ability to experience sexual pleasure.¹⁴⁹ Intersex scholars and activists have argued extensively how these surgeries compromise a child's right to bodily integrity, procreation, privacy and liberty.¹⁵⁰ In addition, these surgeries are largely medically unnecessary and carry real risks of parental conflict of interest.¹⁵¹ Under such circumstances, it is arguable that courts should have the same jurisdiction to intervene and protect the child's fundamental rights in the way they do for children who face elective sterilization or who are potential organ donors, and that before such surgeries are carried out, a court order must be obtained.¹⁵²

Such a proposal raises the question of why courts are any better placed to make such a decision than parents or even doctors. The judicial process can take an exceedingly long time exacerbating anguish and judges are also people who are influenced by prejudice, bias and culture. What makes them better decision makers? The benefit is not that moving the process to courts offers a better decision-maker but rather a better decision-making *process*.¹⁵³ These decisions have never left the medical world and the results have been less than satisfactory.¹⁵⁴ As long as surgeries remain accepted medical practice, parental consent to these operations will rarely be questioned or considered unreasonable, even though the theoretical justification for such surgeries has been found to be unsubstantiated and the long-term effects are unknown.

The judicial process provides an opportunity to critically evaluate the treatment and practices that have been accepted as standard, the short and long-term risks and benefits, the rights of the child at stake, and the views of the children themselves either directly or through the appointment of a child advocate. The time a judicial process takes and the subsequent delay in reaching a decision is also not necessarily a bad thing. It has the potential to remove the aura of urgency and emergency from the situation by forcing the medical world to confront the idea that surgery may be postponed while information is assessed and risks and benefits calculated.¹⁵⁵

Moving the debate into the courtroom also has the potential to make public what has been shrouded in secrecy, behind a medical veil. It could increase awareness of the issues surrounding genital normalizing surgery and provide a public space for debating the risks and benefits.

B. *Changing Narratives of Dysfunction*

Bringing the law into the intersex surgery debate has the ability to question and change the current medical narrative of intersex as a dysfunction.

149. Haas, *supra* note 20, at 60; Ehrenreich & Barr, *supra* note 83, at 106, 109-10.

150. These arguments have been made by a number of scholars. See Bird, *supra* note 17, at 74; Haas, *supra* note 20, at 66; Benson, *supra* note 60, at 59.

151. Tamar-Mattis, *supra* note 56, at 98.

152. *Id.*

153. *Id.* at 103.

154. See generally HUMAN RIGHTS REPORT, *supra* note 1, at 29-36 (describing experiences of intersex people who have undergone genital normalizing surgery).

155. Tamar-Mattis, *supra* note 56, at 98-106; Lloyd, *supra* note 51, at 187-90.

In this respect, an examination of how we construct disability is helpful. Many theorists studying disability issues reject the medical model of disability that focuses on the needs of those with disabilities in favor of a social model that centers the debate on the social environments in which we live.¹⁵⁶ Martha Minow has argued that difference is not something that is “inherent in the ‘different’ person but [rather] a feature of a comparison drawn between people.”¹⁵⁷ She uses the example of a student in a wheelchair to explain that the disability that causes her to be in a wheelchair, thereby distinguishing her from people who can walk (her “difference”), disappears when she is using a building that has ramps instead of steps and wide instead of narrow doorways.¹⁵⁸ The meanings of difference can change when people revise their relationships to the difference.¹⁵⁹ Disability and social model theorists have argued “that if society were structured so as to include the individual with an impairment in its idea of . . . ‘normal[,]’ . . . the disability would disappear.”¹⁶⁰ This analysis can be applied to the medical world’s construction of the intersex condition.

The medical world sees the intersex body as an abnormality.¹⁶¹ The current standard of care that supports and recommends early surgery to “normalize” genitals contributes to constructing intersex identity as one of disability and dysfunction.¹⁶² Genital normalizing surgery is a standard medical practice even though in the vast majority of cases, surgery is not *medically* necessary.¹⁶³ Despite the discrediting of Money’s original theory, the fact that so little is known about long-term outcomes of surgery, and the widespread testimony of intersex adults refuting the merits of surgery, the medical field has been slow to respond.¹⁶⁴ At the heart of this reluctance is a culture that promotes sex binaries. Only in a society where sex is understood in binary terms with everyone either male or female does the body of an intersex child become an abnormality that requires fixing.¹⁶⁵ This notion of a sex binary appears to overwhelm other factors in considering the merits and risks of surgery.

156. Ehrenreich & Barr, *supra* note 83, at 116.

157. MARTHA MINOW, MAKING ALL THE DIFFERENCE 12 (1990). *See also* Ehrenreich & Barr, *supra* note 83, at 116.

158. MINOW, *supra* note 157, at 12.

159. *Id.*

160. Ehrenreich & Barr, *supra* note 83, at 116; Shelley Tremain, *On the Government of Disability*, 27 SOC. THEORY & PRAC. 617, 630-31 (2001).

161. Ehrenreich & Barr, *supra* note 83, at 117-18, 120.

162. *Id.* at 120.

163. There are a number of commentators and intersex activists who describe genital normalizing surgery as unnecessary. *See, e.g.*, HUMAN RIGHTS REPORT, *supra* note 1, at 17, 30, 53; Ehrenreich & Barr, *supra* note 83, at 104.

164. As discussed above, until 2006 and the development of the Consensus Statement, the birth of an intersex child was considered a “social emergency” requiring early surgical intervention. *See supra* Part I (iv).

165. Ehrenreich & Barr, *supra* note 83, at 117-21.

Yet the fact remains that a number of children are born with bodies that are not typically male or female.¹⁶⁶ This is not to suggest that our society should necessarily move toward eliminating gender binaries, although this is what some argue,¹⁶⁷ but merely to propose that sex is not so binary and the intersex child is another version of normal.

Judith Butler describes one of the central tasks of gay and lesbian international rights as asserting in clear and public terms the reality of homosexuality, not as a truth or sexual practice, “but as one of the defining features of the social world in its very intelligibility.”¹⁶⁸ The discourse of international human rights and rights more generally offers the same potential for intersex people. It provides a way for calling into question what counts as reality and human life and remaking that reality. Asserting rights through legal means is a way of intervening in the socio-medical process by which the human is defined and articulated, subjecting it to renegotiation and imagining it differently.¹⁶⁹

Requiring a court order before intersex surgeries can take place allows for the possibility to question this medical narrative of dysfunction and disability and map onto the intersex body a different narrative emphasizing rights, including rights to bodily integrity and privacy. It also has the power to create a safer space for intersex children to realize their gender identity. Surgery may still be deemed necessary, but the context in which it is conducted may be changed from one of urgency, emergency and disaster. Perhaps more importantly, the realization will develop that early surgery is in fact only an option.

CONCLUSION

At this stage, the law has had little involvement or impact on this issue.¹⁷⁰ Early genital normalizing surgeries are wrapped in a medical narrative and produced as a purely medical issue.¹⁷¹ Thus, they have been constructed as outside the law. Purely existing in the world of the medical puts an incredible amount of power into the hands of doctors. The voices and now supposedly “normalized” bodies of intersex people cry that this power has been too much.¹⁷² We need to acknowledge these voices, to recognize the bodies that have been normalized as sites of lived experience, and take into account what that lived experience means. To bring law into this debate, to ensure that before genital normalizing surgery is performed a court order is obtained, questions the legitimacy of that power and creates room for negotiation.

166. FAUSTO-STERLING, *supra* note 7, at 36-39, 48-54.

167. *See, e.g., Preface to THIRD SEX, THIRD GENDER* 14-15 (Gilbert Herdt ed., 1996).

168. JUDITH BUTLER, *UNDOING GENDER* 29 (2004).

169. *Id.* at 29-30, 32-34, 36-38.

170. The Constitutional Court of Columbia is the only court in the world to have rendered an opinion on the legality of performing genital normalizing surgery on children. *See supra* Part III(i).

171. *See Bird, supra* note 16, at 66.

172. *See HUMAN RIGHTS REPORT, supra* note 1, at 29-36.

There are a number of issues that remain, including whether all genital normalizing surgery should require a court order as not all surgeries carry the same risks, whether there is an age or circumstances under which children should be deemed capable of consenting themselves without a court order, and how you actually get a case into the court room.¹⁷³ It is arguable that a statute requiring judicial approval may be necessary. While the exact terms and method by which law becomes involved are issues that require further thought, this paper has argued that law has the potential to offer a better decision making process for this issue, to make visible the bodies that have been invisible, and to challenge and pierce the medical narrative that has dominated this debate.

173. This inquiry can only begin when someone with standing raises the issue in court. However the fact that the Columbian Constitutional Court is the only court in the world to issue a decision on this issue reflects the fact that early surgery is accepted as dominant medical practice. When parents do consent to recommended practice and the child is too young to voice an opinion, courts rarely get involved. *See supra* Part III(i).