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# Sex, Lies, and Surgery: The Role of Informed Consent in Sex Assignment and Normalization Surgeries Performed on Intersex Minors

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SEX, LIES, AND SURGERY: THE ROLE OF INFORMED CONSENT IN SEX ASSIGNMENT AND  
NORMALIZATION SURGERIES PERFORMED ON INTERSEX MINORS

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Submitted in partial fulfillment of the requirements of the  
King Scholar Program  
Michigan State University College of Law  
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Professor Melanie B. Jacobs  
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## INTRODUCTION

Children born with ambiguous genitalia or with an intersex chromosomal condition are born into a society that is ill-equipped and ill-prepared to protect and care for them. Medical literature discussing how to approach intersex children has reinforced the social trepidation surrounding them, creating a medical phobia and leaving intersex children with underutilized legal protections.

The text of an oft cited medical treatise from 1969 reveals the early social and medical view of children born with intersex conditions.<sup>1</sup> “To visualize individuals who properly belong neither to one sex nor to the other is to imagine freaks, misfits, curiosities, rejected by society and condemned to solitary existence of neglect and frustration. Few of these unfortunate people meet with tolerance and understanding . . . and fewer still find even limited acceptance.”<sup>2</sup> The treatise goes on to suggest treatment be started as soon as possible after birth so the children can

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<sup>1</sup> See CHRISTOPHER J. DEWHURST & RONALD R. GORDON, *THE INTERSEXUAL DISORDERS* vii (1996); Laura Hermer, *Paradigms Revised: Intersex Children, Bioethics & the Law*, 11 *ANNALS HEALTH L.* 195, 209 (2002).

<sup>2</sup> Dewhurst, *supra* note 1, at vii.

lead “well adjusted” and in some instances “normal” lives.<sup>3</sup> “Treatment” consisted of sex assignment or sex normalization surgeries before the child reached the age of two, combined with raising the child in strict adherence with the designated sex.<sup>4</sup> Furthermore, it was considered best to keep the child’s condition secret so as not to interfere with or confuse the gender assignment.<sup>5</sup>

Only the rhetoric has changed. In 2000, the American Academy of Pediatrics (AAP) Committee on Genetics released a report which called the birth of an intersex child a “social emergency.”<sup>6</sup> Though the AAP set forth guidelines for determining the sex of rearing depending on the child’s circumstance, sex assignment or normalization surgeries are still recommended before the child is two, usually between six and eighteen months.<sup>7</sup>

Sex assignment and normalization surgeries performed on infants have significant consequences for the children once they reach adulthood. The surgeries produce considerable scarring and frequently result in diminished sexual sensitivity.<sup>8</sup> A significant number of children who receive the surgeries as infants later reject their assigned gender, sex or both.<sup>9</sup> Since tissue which could be used for sex assignment surgeries later in life is removed during the procedures sex reassignment surgeries are rendered onerous at best.<sup>10</sup>

Existing informed consent rules are underutilized and improperly applied because of social trepidation toward intersex individuals and unwarranted medical urgency to “correct” the problem. Nevertheless, the current rules of informed consent are adequate to protect the rights of

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<sup>3</sup> *Id.*

<sup>4</sup> See Hermer, *supra* note 1, at 196, 208.

<sup>5</sup> See *id.* at 197, 229.

<sup>6</sup> American Academy 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/reprint/pediatrics;106/1/138.pdf>. [hereinafter AAP].

<sup>7</sup> *Id.*, at 138.

<sup>8</sup> See Hermer, *supra* note 1, at 214.

<sup>9</sup> *Id.* See also *infra* Part II.

<sup>10</sup> *Id.*

individuals born with intersex conditions, if they are consistently and strictly applied. The rules of informed consent, particularly the requirement of a best interest analysis for minors, can alleviate many of the complex circumstances created by the current medical treatment of intersex minors. The best interest analysis, if enforced, would ensure that parents receive unabridged information, would provide a check on the parents' authority if their interests conflict with those of their child, and would take into account the child's preference, manifest through behavior and counseling as the child ages, assuring that sex assignment and normalization surgeries are not performed until or unless it is in the child's best interest.

Part I of this Article will discuss how the practice of performing sex assignment surgery soon after birth developed. Part II will explore the outcomes and consequences of sex assignment surgeries performed on intersex infants and minors. Part III will describe existing informed consent rules and how they are currently applied to intersex minors. Finally, Part IV will explain how application of informed consent is preferable to other theories offered to solve the dilemma of infant and minor sex assignment and normalization surgeries, and how the rules of informed consent ought to be applied to intersex minors.

#### I. DECEPTIVE RESEARCH CREATES A MEDICAL STANDARD OF INTERSEX INFANT SEX ASSIGNMENT AND NORMALIZATION SURGERY

Physicians are obligated to maintain the applicable medical standards of care when treating patients.<sup>11</sup> The medical standard of care is determined in each jurisdiction based on similar medical practitioners in the field in either a local, "like community," state, national, or other standard.<sup>12</sup> For children born with ambiguous genitalia or children who suffer traumatic

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<sup>11</sup> See Jay M. Zitter, Annotation, Standard of Care Owed to Patient by Medical Specialist as Determined by Local, "Like Community," State, National, or Other Standards, 18 A.L.R. 4th 603 (1982 supp. west 2007); Quijano v. United States, 325 F. 3d 504, 567-68 (Tex 2003).

<sup>12</sup> See Perry v. Magic Valley Reg'l Med. Ctr., 995 P. 2d 816 (Idaho 2000) (local standard); Hylick v. Halweil, 492 N.Y.S.2d 57 (1985) (same); Rann v. Twitchell, 71 A. 1045 (Vt. 1906) (same); Ives v. Redford, 252 S.E. 2d 315 (Va.

injuries to their genitalia as infants a national standard for medical treatment exists: surgery. This standard was theorized and disseminated by one individual, Dr. John Money.<sup>13</sup> He has dominated this field of medical science following a single experiment on a set of twins.<sup>14</sup> Shortly after birth, the identical twin boys underwent circumcision procedures; a botched procedure resulted in the dismemberment of one of the eight month old boys (David Reimer), while the other came through the procedure normally.<sup>15</sup> Dr. Money consulted and convinced the parents it would be in David's best interest to be surgically reassigned as a female.<sup>16</sup> The parents recalled being rushed by Dr. Money to make the decision to surgically assign their son as a female because, as Dr. Money put it, there was a short window of opportunity; they recalled Dr. Money even accused them of procrastinating.<sup>17</sup> He also advised the parents that David's medical history ought to be

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1979) (like community standard); *Thompson v. Lockert*, 237 S.E. 2d 259 (NC. App. 1977) (same); *Quijano* 325 F. 3d at 568 (same); *Vasquez v. Hunter*, 588 P.2d 326 (Ariz. App. 1978) (state standard); *Powers v. U.S.* 589 F. Supp. 1084 (D. Conn. 1984) (same); *Ketchum v. Ward*, 422 F. Supp. 934 W.D.N.Y. 1976) (national standard); *Naccarato v. Grob*, 180 N.W.2d 788 (Mich. 1910) (same); *see also* Zitter, *supra* note 11.

<sup>13</sup> Dr. John Money is a psychologist at Johns Hopkins' Hospital. *See* 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, 6 (2000-2001) [HEREINAFTER Beh & Diamond, *Emerging Dilemma*]. Social concern to limit the sexes to two easily definable classes, male and female, existed long before the frenzy to perform surgery at infancy. *See* ALICE DOMURAT DREGER, *A History of Intersex: From the Age of Gonads to the Age of Consent*, in INTERSEX IN THE AGE OF ETHICS 6-12 (Alice Domurat Dreger ed. 1999) [hereinafter Dreger, *A History of Intersex*]. Early sex determinations of sex were made on a strict basis depending on the gonads of the individual, irregardless of any external characteristics or behaviors. *Id.* at 6-9. This was based in the belief of a scientific definition of sex and social need for each individual body to contain only one sex; doctors were the ones to determine that sex. *Id.* Then, Blair Bell introduced a revolutionary idea, that while there was one "true sex" for each individual, it was not based on anatomical nature alone and surgery could be utilized to "help it along, by eliminating any sexually 'anomalous' characteristics." *Id.* at 10-11. It is noteworthy that doctors, not the individuals, decided which sex was the obvious "true sex." Blair paved the way for Money's theories to be easily digested by the medical community.

<sup>14</sup> Almost every piece of literature regarding the treatment of intersex individuals was either authored or coauthored by Dr. Money for nearly thirty years following the 1972 publication of this case. SUZANNE J. KESSLER, LESSONS FROM THE INTERSEXED 15, 136 n.10 (1998) [hereinafter Kessler, *Lessons*] (discussing Money's unchallenged dominance); *see also* ALICE DOMURAT DREGER, HERMAPHRODITES AND THE MEDICAL INVENTION OF SEX 181-82 (1998) [hereinafter Dreger, *Medical Invention of Sex*] (discussing Money's dominance); Beh & Diamond, *supra* note 15, at 19, n.81 (same).

<sup>15</sup> Beh & Diamond, *Emerging Dilemma*, *supra* note 13, at 6.

<sup>16</sup> *Id.*

<sup>17</sup> Hazel Glen Beh & Milton Diamond, *David Reimer's Legacy: Limiting Parental Discretion*, 12 CARDOZO J. L. & GENDER 3, 9 (2005-2006) [hereinafter Beh & Diamond, *Limiting Parental Discretion*].

kept secret from him, and directed the parents to move far away and establish a new life in order to preserve the secret.<sup>18</sup>

In 1972, Dr. Money composed the results of his study of the twins, and declared to the world that David was successfully being raised as a girl and demonstrated only some “tomboyish traits.”<sup>19</sup> He used this one experiment to confirm his theory that infants are sexually neutral and adapt to the sex they are reared as; therefore, it makes no appreciable difference if a child is raised as a boy or a girl.<sup>20</sup> Dr. Money never performed a control group study to support his theories or his reported results from the original experiment.<sup>21</sup>

Facilitated by his research in the case discussed above, Dr. Money established a series of standards for determining when a child’s sex ought to be assigned and which sex should be assigned. His first approach was based entirely on the premise that infants are sexually neutral at birth; he encouraged surgery and suggested the surgeons assign whichever sexual characteristics

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<sup>18</sup> Beh & Diamond, *Emerging Dilemma*, *supra* note 13, at 7.

<sup>19</sup> *Id.* at 8. Money’s theory is based off of the Victorian philosophy that each individual has one true sex. *See supra* note 13 and accompanying text. However, the Victorian philosophy is based on the belief that sex and sexual identity is a product of nature; Money’s theory placed the creation of sex and sexual identity as a production of nurture. Dreger, *A History of Intersex*, *supra* note 13, at 11. Money put forth the theory that any child can be made “either gender as long as you make the sexual anatomy *reasonably believable*.” *Id.* (emphasis added). Money did however hold to the Victorian belief that there is only one true sex, a hermaphroditic identity cannot exist, and that the doctors should be the ones to determine the individual’s sexual identity. *Id.* at 12.

<sup>20</sup> Beh & Diamond, *Emerging Dilemma*, *supra* note 13, at 18. There are three types of medical treatments, experimental treatment, innovative treatment, and standard care treatment. *Id.* at 12-16. Experiments are used to test new theories and hypotheses on patients. *Id.* at 12-13. Innovative treatment is not a standard of care, but is treatment that has not been tested to create a “reasonable expectation of success” and has “unknown risks,” but its intended use is solely to “enhance the well being of the patient.” *Id.* at 13. Once a procedure is accepted by the medical community it becomes a “standard procedure” and the standard of care for that particular medical treatment. *Id.* at 14-16.

<sup>21</sup> *Id.* at 19. However, it is important to note that many, possibly a majority of, innovative treatments are accepted by the medical community as standard procedures without testing in control groups for efficacy. *Id.* at 14; *see also* David H. Spodick, *The Surgical Mystique and the Double Standard*, 85 *AMERICAN HEART J.* (1973) (Spodick found that around 50% of most treatments in his study were studied with control groups and that none of the surgical treatment in his study were studied with control groups before becoming standard procedures); Nancy M.P. King & Gail Henderson, *Treatment of Last Resort: Informed Consent and the Diffusion of New Technology*, 42 *MERCER L. REV.* 1007 (1991); David A. Grimes, *Technology Follies: The Uncritical Acceptance of Medical Innovation*, 269 *JAMA* 3030 (1993).

were easiest to surgically implement.<sup>22</sup> Dr. Money's theory has altered only marginally through the passage of time; he continues to advocate surgery to assign sex before the age of two.<sup>23</sup> He set forth eight criteria, in order of importance, to consider when deciding which sex to assign an infant: 1) genetic or chromosomal sex; 2) gonadal sex (testes or ovaries); 3) internal morphologic sex (vesicles/prostate or vagina/uterus/fallopian tubes); 4) external morphologic sex (penis/scrotum or clitoris/labia); 5) hormonal sex (androgen or estrogen) 6) phenotypic sex (facial hair or breasts); 7) gender of rearing; and 8) sexual identity.<sup>24</sup> As a result of Dr. Money's command over the literature regarding treatment of intersex infants surgery was quickly accepted by the medical community as the standard of care.<sup>25</sup>

In 1994, Drs. Milton Diamond and Hazel Glen Beh, longtime critics of Dr. Money, located the "boy who was made a girl;" he had been lost to follow up for three decades.<sup>26</sup> David had rejected the assigned sex and was living as an adult male married to a woman and raising her two children.<sup>27</sup> Furthermore, he explained that "his childhood experiences were not as positive as first reported."<sup>28</sup> Drs. Diamond and Beh published these findings in 1997; Dr. Money continues

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<sup>22</sup> Beh & Diamond, *Emerging Dilemma*, *supra* note 13, at 18. The construction of functioning female genitalia was far easier than male so that was the preferred or suggested treatment in most cases. *Id.* at 16, n.68. If an infant was born with a micropenis, it was transformed into a clitoris and a vagina was constructed; likewise if an infant was born with a clitoris that was too large it was reconstructed regardless of the effect it had on sensitivity. *Id.* at 18-21. See also Alice Domurat Dreger, "Ambiguous Sex" – or Ambivalent Medicine? *Ethical Issues in the Treatment of Intersexuality* HASTINGS GENTER REP. May-June 1999 at 29 (discussing the decision to surgically assign infants as girls because an insensitive hole can easily be constructed in anyone).

<sup>23</sup> See JOHN MONEY, *SEX ERRORS OF THE BODY AND RELATED SYNDROMES: A GUIDE TO COUNSELING CHILDREN, ADOLESCENTS AND THEIR FAMILIES* (2d ed. 1994); Julie A. Greenberg, *Defining Male and Female: Intersexuality and the Collision Between Law and Biology* 41 ARIZ. L. REV. 265, 278 (1999) [HEREINAFTER Greenberg, *Defining Male and Female*].

<sup>24</sup> See MONEY *supra* note 23, at 4; Greenberg, *Defining Male and Female*, *supra* note 23, at 278.

<sup>25</sup> Beh & Diamond, *Emerging Dilemma*, *supra* note 13, at 17-18; see also note 14 and accompanying text.

<sup>26</sup> Beh & Diamond, *Emerging Dilemma*, *supra* note 13, at 9-10.

<sup>27</sup> *Id.* at 10.

<sup>28</sup> *Id.* He refused to play with girl toys as a child, stood to urinate, the girls at school would refuse to allow him into the bathroom and he would use the boys' room instead, he refused to take his hormone supplements to facilitate female characteristics, at age thirteen he ran away from therapy and refused to go thereafter, and he often contemplated suicide. *Id.* at 9-12. At the age of fourteen, he began to believe he was a boy and on his own initiative began living as a boy. *Id.* Finally, his father told him the truth about his medical history, he underwent a sex-reassignment surgery. *Id.*

to defend his research.<sup>29</sup> Further follow up revealed David committed suicide in 2004, at the age of 38.<sup>30</sup>

As long as surgery remains the standard of care intersex individuals who have scarring, loss of sexual sensation, or who reject their assigned sex have the utmost difficulty proving negligence for a medical malpractice suit against physicians. This is because the physicians did not violate the medical standard of care by choosing to perform the surgery.<sup>31</sup> Prior to Dr. Money's facilitation of surgery as a standard of care, a study was done on 250 intersex individuals unaltered by surgical procedures.<sup>32</sup> The study found the individuals were not living as "freaks, misfits or curiosities," but rather they had adjusted, integrated into society, and were leading relatively normal lives with sexual fulfillment.<sup>33</sup>

Not a great deal has changed since 1994 when the accurate results of the legendary "boy who was made a girl" were first published. Scholars continued to rely on Dr. Money's eight factors for determining which sex to assign.<sup>34</sup> In more recent years, the AAP has developed new criteria for determining which sex to assign.<sup>35</sup> Though the rhetoric has changed, the new criteria are remarkably similar to Dr. Money's old standards and surgery is still recommended before age two.<sup>36</sup>

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<sup>29</sup>*Id.* at 9 n. 32.

<sup>30</sup> Beh & Diamond, *Limiting Parental Discretion*, *supra* note 17, at 12

<sup>31</sup> See Hermer, *supra* note 1, at 215; *see also* 18 A.L.R. 4th 603 ("standard of care owed to patient by medical specialist as determined by local, state, national, or other standards").

<sup>32</sup> This study was performed sometime prior to 1952 but, for some unknown reason, was left unpublished in professional literature. *See* Beh & Diamond, *Emerging Dilemma*, *supra* note 13, at 24 n.103; JOHN COLAPINTO, *AS NATURE MADE HIM: THE BOY WHO WAS RAISED AS A GIRL* 233, 235 (2000).

<sup>33</sup> *See* Beh & Diamond, *Emerging Dilemma*, *supra* note 13, at 24 n.103; COLAPINTO, *supra* note 32 at 235; Milton Diamond & H. Keith Sigmundson, *Management of Intersexuality: Guidelines for Dealing with Persons with Ambiguous Genitalia*, 151 ARCHIVES PEDIATRIC ADOLESCENT MED. 1014, 1049 (1997); *but cf.* note 2 and accompanying text.

<sup>34</sup> *See, e.g.* Greenberg, *Defining Male and Female*, *supra* note 23, at 278.

<sup>35</sup> *See* AAP, *supra* note 6, at 140-41 (1. Fertility potential; 2. Capacity for normal sexual function; 3. Endocrine function; 4. Potential for malignant gonadal change; and 5. Testosterone imprinting); Hermer, *supra* note 1, at 209.

<sup>36</sup> *See* AAP, *supra* note 6, at 141.

## II. OUTCOMES AND CONSEQUENCES OF INFANT INTERSEX SURGERIES

Few follow up studies exist evaluating the success or failure of sex assignment surgeries, even though an adequate cohort has attained adulthood for feasible completion of a considerable number of follow up studies.<sup>37</sup> Of the few studies that do exist, the results are not encouraging, though many of the studies are incomplete. One study found that fifty-eight percent of the cohort demonstrated psychopathology.<sup>38</sup> This study also found that fifty-three percent of the cohort “assigned as females exhibited ‘deviant’ gender role behavior.”<sup>39</sup>

Although the literature may be sparsely populated with studies evaluating the results of these surgeries, accounts of individuals who rejected their sex and gender assignments are abundant.<sup>40</sup> One compelling case, deemed “Jane’s Story” by the media, is a representative example. Jane was born with a complete working set of genitalia and internal organs for both sexes; this is a much rarer occurrence than a child born with merely ambiguous genitalia.<sup>41</sup> Jane’s parents chose to have Jane’s sex assigned as a boy.<sup>42</sup> S/he underwent several surgeries;

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<sup>37</sup> See Hermer, *supra* note 1, at 212.

<sup>38</sup> Froukje M E Slijper et al., *Long-Term Psychological Evaluation of Intersex Children*, 27 ARCH. SEX. BEHAVIOR 125, 134 (1998) (psychopathology included the diagnosis of one or more of the following disorders: depressive neurosis; anxiety disorder; selective mutism; sexual disorders; gender identity disorder; oppositional defiant disorder; and obsessive compulsive disorder. The mean age for the onset of the psychopathology was 9.8 years old, however, not all the children in the cohort had reached this age at the time of the study.); see also Hermer, *supra* note 1, at 212.

<sup>39</sup> Slijper, *supra* note 38, at 37 (the parameters of “deviant” behavior was not explained). In addition, the study noted that the children assigned as boys did not demonstrate deviant gender role behavior, but the study took care to mention they were all “fearful and bothered about the smallness of their penis.” *Id.*: see also Hermer, *supra* note 1, at 212.

<sup>40</sup> See, e.g., Androgen Insensitivity Syndrome Support Group, *Jane’s Story: Yes I’m a Girl Too*, (Mar. 2004), <http://www.medhelp.org/ais/stories/jane2.htm> [hereinafter Jane’s Story]; Elizabeth Weil, *What if It’s Sort of a Boy and Sort of a Girl*, N.Y. TIMES, Sept. 24, 2006, available at <http://www.nytimes.com/2006/09/24/magazine/24intersexkids.html?ex=1164171600&en=1ba49503324c8fe4&ei=5070>; The Cheers Health, *An Intersex Case Study: An Interview with Betsy Driver*, , [http://www.thecheers.org/article\\_428\\_Intersex-Issues---An-Interview-with-Betsy-Driver.html](http://www.thecheers.org/article_428_Intersex-Issues---An-Interview-with-Betsy-Driver.html) (last visited Nov. 20, 2006). See generally Androgen Insensitivity Syndrome Support Group, <http://www.medhelp.org/ais> (last visited Nov. 20, 2006); Intersex Society of North America, <http://www.isna.org> (last visited Nov. 20, 2006).

<sup>41</sup> Jane’s Story, *supra* note 40. Jane’s condition allowed the parents to make a choice of which sex they would prefer as both were equally feasible. *Id.* Jane’s condition was caused when a woman is carrying a set of twins, one male one female and the twins merge into one fetus; Jane even has some organs with two sets of DNA. *Id.*

<sup>42</sup> *Id.*

however, s/he never received an explanation of these surgeries and any questions only resulted in a change of subject.<sup>43</sup> This left Jane feeling confused yet aware that s/he was different. S/he identified as both a male and a female.<sup>44</sup> However, any feminine behavior resulted in “immediate verbal chastisement,” causing Jane to suppress these feelings during childhood as best s/he could.<sup>45</sup> Still, s/he remembers crying alone at night thinking: “I am a little boy but I’m a little girl too.”<sup>46</sup> Today, Jane lives as both, and wishes that s/he was “left alone” as a child.<sup>47</sup>

The physical consequences of surgically reconstructing intersex individuals’ genitals can be distressing. The goal of surgery is normality of appearance and some functionality;<sup>48</sup> sensation and future pleasure of the individual are not paramount concerns.<sup>49</sup> Of the few follow up studies that were performed through the late Nineties, success was measured by the appearance of the external genitalia.<sup>50</sup> These studies revealed that forty-one percent had a “poor cosmetic result” requiring further surgery, sixty-six percent had a “poor overall outcome,” and

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<sup>43</sup> *Id.* See Eros Corazza, ‘She’ and ‘He’ Politically Correct Pronouns, 111 PHILOSOPHICAL STUDIES 173 (2002) (discusses the use of the gender neutral s/he to refer to hermaphrodites and in other situations where gender neutral pronouns are appropriate).

<sup>44</sup> Jane’s Story, *supra* note 40.

<sup>45</sup> *Id.*

<sup>46</sup> *Id.*

<sup>47</sup> *Id.* See also Kessler, Age of Ethic, *supra* note 13 (contains articles written by several individuals detailing their personal stories and how they suffered due to unwanted surgical intervention they were too young to understand or voice an opinion in opposition of).

<sup>48</sup> See Beh & Diamond, Emerging Dilemma *supra* note 13, at 3, 17-21 (stating that medical practice was dictated by surgical potential to create normal looking genitalia, and that this desire normally leads to the decision to choose the female gender because it was surgically easier).

<sup>49</sup> *Id.* at 20-21, n.82 (citing William Reiner, *Sex Assignment in the Neonate With Intersex or Inadequate Genitalia*, AM. J. OF DISEASES OF CHILDREN 1004 (Oct. 1999)) (surgery damages the clitoris and greatly reduces the possibility of orgasms).

<sup>50</sup> Kessler, Lessons, *supra* note 14, at 54-55. Little criteria existed for evaluating the relative success of a procedure. *Id.* Kessler, upon review of twelve follow up studies conducted mostly by surgeons of their own patients, found a general, albeit vague, standard used. *Id.* Results are considered excellent if a near normal appearance is obtained; satisfactory if they are compatible with life as a female but the glands are enlarged; and unsatisfactory, offensive, and an embarrassment if the phallic enlargement is persistent and considered to be inconsistent with female life. *Id.*

ninety-eight percent needed additional surgeries or treatment to “improve cosmetic appearance, facilitate tampon use or sexual intercourse.”<sup>51</sup>

Loss of sensation appears to be a common and medically accepted side effect of these surgeries.<sup>52</sup> An early study found only five of twelve subjects, who were rated as having a satisfactory appearance, were capable of sexual gratification after testing.<sup>53</sup> One unsympathetic surgeon displayed this lack of concern for loss of sexual sensation by describing an intersexed woman’s genitalia to her as “a couple of centimeters in diameter with no feeling everything else is fine.”<sup>54</sup> Even more troubling than the reduction of or loss of sensation, the results of one of the rare follow up studies found that five of twelve “surgically reduced clitorises had withered and died.”<sup>55</sup>

Moreover, once surgery assigning a sex is performed on an infant, important tissue is removed; therefore any attempt at surgical reassignment at a later date is an onerous task. For example, a male child born with a phallus that is considered too small to function for conventional heterosexual sex will undergo a feminizing surgery; the phallus is reduced in size and the excess tissue is removed to create the appearance of a clitoris.<sup>56</sup> In addition, a blind-ending hole is constructed by removing additional tissue.<sup>57</sup> Finally, any existing gonad tissue that conflicts with the assigned sex is removed.<sup>58</sup> This often results in the child’s reliance on hormone

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<sup>51</sup> See Hermer, *supra* note 1, at 213 (citing Sarah M. Creighton et. al., *Objective Cosmetic and Anatomical Outcomes at Adolescence of Feminizing Surgery for Ambiguous Genitalia Done in Childhood*, 358 LANCET 124 (2001)).

<sup>52</sup> Beh and Diamond, *Emerging Dilemma*, *supra* note 15, at 19-21.

<sup>53</sup> See Kessler, *Lessons*, *supra* note 14, at 56. Cf. Hermer, *supra* note 1, at 213 (suggesting that the long-term impact of surgical treatment of adult sexual function is unknown). The assertion by Hermer that the long-term affects are unknown is either unpersuasive or demonstrates a further problem with follow up research because surgery has been the medical standard for over forty years, which would appear to be long enough to determine the long-term affects on adult sexual function.

<sup>54</sup> Kessler, *Lessons*, *supra* note 14, at 57.

<sup>55</sup> See Beh and Diamond, *Emerging Dilemma*, *supra* note 15, at 20 n.85 (citing William Reiner, *Sex Assignment in the Neonate with Intersex or Inadequate Genitalia* Oct. 1999 AM. J. OF DISEASES OF CHILDREN 1044 (1999)).

<sup>56</sup> AAP, *supra* note 6, at 138.

<sup>57</sup> *Id.*

<sup>58</sup> *Id.*

replacement treatment.<sup>59</sup> Similar surgeries are preformed if the child is born with an intersex condition possessing organs of both sexes.<sup>60</sup> Not all surgeries are intended to assign a sex; some are performed when the infant's genitals are ambiguous. For instance, if a female is born with a clitoris that is too large, a clitorectomy surgery is performed to reduce the size by cutting off the tip and refashioning the shape.<sup>61</sup>

The most damaging consequence of infant genital surgery appears to be the psychological trauma suffered when the truth is discovered, and the feelings of isolation, stigma, and shame surrounding the secrecy and silence with which their condition was treated.<sup>62</sup> One study found that of forty-one subjects, all had their true identity hidden from them and in some way discovered the truth for themselves.<sup>63</sup> Many of the subjects noted that because the information was kept from them it gained greater importance, causing them to question their "sense of self," knowing that something was being withheld but that it was deemed to be terrible for them to be

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<sup>59</sup> *Id.* See Heidi Walcutt, *Time for a Change*, in INTERSEX IN THE AGE OF ETHICS 195, 195 (Alice Domurat Dreger ed. 1999) (discussing the high risk of early onset osteoporosis due to the surgical removal of gonads).

<sup>60</sup> AAP, *supra* note 6, at 138.

<sup>61</sup> *Id.*; Erin Lloyd, *From the Hospital to the Courtroom: A statutory Proposal Recognizing and Protecting the Legal Rights of Intersex Children*, 12 CARDOZO J. L. & GENDER, 155, 172-75 (2005-2006). The legal consequences for those who reject their assigned sex are also unsympathetic in many states. State laws limiting marriage between a man and a woman and the federal Defense of Marriage Act (DOMA) limit their future potential to marry. *See, e.g., In re Estate of Gardiner*, 42 P.3d 120 (Kan. 2002); *Kantaras v. Kantaras*, 884 So. 2d 155 (Fla. Ct. App. 2004); *Littleton v. Prange*, 9 S.W.3d 223 (Tex. Ct. App. 1999). *See also* Julie A. Greenberg, *When is a Same-Sex Marriage Legal? Full Faith and Credit and Sex Determination* 38 CREIGHTON L. REV. 289, 297 (2004). *See also* Defense of Marriage Act Pub. L. No. 104-199 (1996) (codified at 28 U.S.C. § 1738C). As one scholar put it, "when a state limits marriage to a union between one man and one woman, they must also determine what makes a man a man and what makes a woman a woman." Greenberg, *supra* at 291. Some courts rely on chromosomal sex when determining the sex of an individual for marriage purposes. *Id.* This can cause problems for individuals who assigned sex does not match their chromosomal makeup. Other states rely on the sex assigned at birth. For example, Texas courts held that gender assigned at birth cannot be altered for the purpose of marriage. *Id.* at 298 However, other courts have taken up the issue and held on more scientific grounds that sex was based on the brain function of the individual. *Id.* at 299. Over 80% of states ban same sex marriage either by statute or by constitutional amendment; however, over half of the states have enacted legislation permitting amendments to birth certificates to reflect self-identified sex. *Id.* at 291, 281-98; *see also*, Kavan Peterson, *50 State Rundown on Same-Sex Marriage Laws*, available at <http://www.stateline.org/stateline/?pa=story&sa=showStoryInfo&print=1&id=353058>. The result of these conflicting state laws is that a marriage valid on one state could result in an illegal heterosexual union in another state, which limits mobility of married intersex couples. Greenberg, *supra* at 292.

<sup>62</sup> Sharon E. Preves, *For the Sake of the Children: Destigmatizing Intersexuality*, 9 J. CLINICAL ETHICS 411, 414 (1998). *See* Hermer, *supra* note 1, at 214.

<sup>63</sup> Preves, *supra* note 61, at 414; also available in INTERSEX IN THE AGE OF ETHICS 56 (Alice Domurat Dreger, ed 1999).

informed.<sup>64</sup> Dr. Money is adamant that the children's condition be kept secret from them, in case they become confused about the sexual identity that has been assigned them. Dr. Money went so far as to convince the Reimer parents not only to keep the boy's medical history secret from him, but to move far away and establish a new life in order to preserve the secret.<sup>65</sup>

Should these results and reactions seem too callous, one need only remember the intent of the surgery is not to assemble a sexually complete and satisfied member of society. There are two more pressing objectives behind the surgeries: 1) to alleviate the "social emergency" caused by a sex that is not clearly male or female,<sup>66</sup> and 2) to make the child appear physically acceptable to the parents.<sup>67</sup> Empirical evidence continues to support the belief that "prevailing social norms" may have a profound adverse effect on the bond between the infant and its parents.<sup>68</sup> Even so, more recent studies demonstrate that following the surgeries parents do not necessarily have an increased bond with their child.<sup>69</sup> One study of parents who received counseling found that fifty percent "were not able to work through the trials and tribulations their child's lack of gender clarity entailed."<sup>70</sup> In light of such uncertain results, the rush to neonatal surgery seems to warrant a close and informed decision. Though parental attachment and social norms may play a role in a decision, the best interest of the child is a consideration that comes

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<sup>64</sup> *Id.* at 56-57.

<sup>65</sup> Beh & Diamond, *Emerging Dilemma* *supra* note 13, at 7.

<sup>66</sup> See AAP, *supra* note 6, at 138; *supra* notes 13, 19 and accompanying text.

<sup>67</sup> Kessler, *Lessons*, *supra* note 14, at 55 (noting that the genital surgeries are intended to relieve the anxieties about the child with relatives and friends and that it is not uncommon for follow-up reports to "include observations 'that the parents were satisfied with the results of the genital surgery). Kessler also notes that in these early studies done by physicians of their own work, the physicians reports are vague and often conclusory without psychological support for their conclusions of parental or patient responses. *Id.* at 53-54.

<sup>68</sup> See Hermer, *supra* note 1, at 230; Bruce E. Wilson & William G. Reiner, *Management of Intersex: A Shifting Paradigm*, 9 J. CLINICAL ETHICS 360, 365 (1998) (discussing evidence that parents react poorly to children with malformed genitalia and mourn the loss of their expected perfect child).

<sup>69</sup> *Id.* at 230-31 (The studies showed that about fifty percent of parents rejected their abnormal child before surgery and the numbers did not appear to be any different after surgery).

<sup>70</sup> Slijper, *supra* note 3838, at 132. Of the twenty-seven couples in counseling for this particular study; two mothers and one father openly rejected their child; it was cited as playing an important role in five divorces; two couples had constant doubt that the wrong sex had been assigned to their child; and five other couples exhibited symptoms of trauma. *Id.*

into play far too infrequently when the decision to perform a sex assignment surgery on an infant can have such lasting and, under the wrong circumstances, disastrous consequences.

### III. INFORMED CONSENT AND ITS PREVAILING APPLICATION

The doctrine of informed consent has existed for only a short time, about fifty years, in the American Legal System.<sup>71</sup> Informed consent stands for the basic tenet of individual self-determination, which is so deeply imbedded in American ideology that the “right to be let alone” underlies much of American social jurisprudence.<sup>72</sup> Justice Cardozo drew on this principle long ago. “Every human being of adult years and sound mind has a right to determine what shall be done with his own body.”<sup>73</sup> His words have been quoted and used to shape the direction of informed consent as an issue of patient self-determination since the landmark case of *Canterbury v. Spence*.<sup>74</sup> The informed consent doctrine has evolved into an expansive protection of “the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.”<sup>75</sup> The right to be let alone includes the right to refuse any treatment – even necessary, life saving treatment.<sup>76</sup> This doctrine compels doctors to share decision making power with patients and furnish the information necessary to make meaningful decisions.<sup>77</sup>

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<sup>71</sup> See Hermer, *supra* note 1, at 221 (discussing the development of informed consent).

<sup>72</sup> See ARNOLD J. ROSOFF, INFORMED CONSENT: A GUIDE FOR HEALTH CARE PROVIDERS 1 (1981) (discussing the roots of informed consent); JAMES M MORRISSEY, ET. AL., CONSENT AND CONFIDENTIALITY IN THE HEALTH CARE OF CHILDREN AND ADOLESCENTS 13 (1986) (same). See also *Griswold v. Connecticut*, 381 U.S. 479, 482-85 (1965) (the Court discusses that underlying principal of several constitutional amendments creates a penumbra of privacy – a right to be let a lone); *Roe v. Wade*, 410 U.S. 113, 168 n.2 (1973) (Stewart J., concurring) (discussing the “right to be let alone by other people”).

<sup>73</sup> *Schloendorff v. Society of N.Y. Hosp.*, 211 N.Y. 125, 129 (1914).

<sup>74</sup> See 464 F.2d 772, 780 (D.C. Cir. 1972) (quoting *Schloendorff*, 211 N.Y. at 129).

<sup>75</sup> *Cruzan v. Mo. Dep’t of Health* 497 U.S. 261, 269 (1990)

<sup>76</sup> *Id.*

<sup>77</sup> *Id.* (an individual of sound mind has a right to determine what shall be done with his body); see also Hermer, *supra* note 1, at 222 (physicians must share decision making power).

## A. Informed Consent Modus Operandi

The doctrine of informed consent is relatively simple in theory, but complicated in practice because medicine is often performed under stressful and imperfect circumstances. In theory, the doctrine of informed consent requires only two things from physicians before performing a medical procedure: 1) the physician must obtain the patient's consent or the consent of a legal guardian, and 2) the consent obtained must be informed.<sup>78</sup> Each of the individual components of the informed consent doctrine are directed toward allowing the patient the broadest right to self-determination possible.

Informed consent laws are most stringent in the context of surgical procedures. To complete the famous words of Justice Cardozo cited above, "a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages."<sup>79</sup> However, consent is not required in emergency situations that "endanger the life or health of the patient," consent is presumed absent evidence to the contrary.<sup>80</sup> Ordinarily, consent must be expressly granted by the patient; however, under a few special circumstances, consent can be presumed when a patient submits to a procedure without objection.<sup>81</sup> Physically obtaining

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<sup>78</sup> See Rosoff, *supra* note 72, at 3- 59; J.B.G., *Consent as Condition of Right to Perform Surgical Operation*, 139 A.L.R. 1370 (1942 west. supp. 2007).

<sup>79</sup> *Schloendorff*, 211 N.Y. at 129. This principle has been well established in legal precedent. See, e.g., *Canterbury v. Spence*, 464 F.2d 772, 780 (D.C. Cir. 1972) (surgery performed without informed consent is a battery); *Wall v. Brim*, 138 F.2d 478, 481 (5th Cir. 1943) (same); *Dunham v. Wright*, 423 F.2d, 940 (3d Cir. 1970) (surgery without notice of alternative was surgery without informed consent and that is a battery). However, the law is less uniform when surgeries and other less invasive procedures are not involved; failure to obtain informed consent is a battery in some jurisdictions and in others it is simple negligence. See, e.g., *Robinson v. Cutchin*, 140 F. Supp. 2d 488 (D. Md. 2001) (failure to obtain informed consent is negligence); *Tinius v. Carrol County Sheriff Dept.*, 321 F. Supp. 2d 1064 (N.D. Iowa 2004) (failure to obtain informed consent is battery).

<sup>80</sup> See, e.g., *Chambers v. Nottebaum*, 96 So. 2d 716, 718 (Fla. App. 1957) (stating the rule regarding exceptions to informed consent in emergency situations); *Canterbury*, 138 F.2d at 788-89 (same); *Douget v. Touro*, 537 So. 2d 251, 260 (La. App. 1988) (same); see also Rosoff, *supra* note 72, at 14-19.

<sup>81</sup> See, e.g., *O'Brien v. Cunard S.S. Co.*, 28 N.E. 266 (Mass 1891) (Ship passenger stood in line for a vaccination, was aware that the vaccinations were taking place, and did not object when she was given a vaccination. The court determined this was implied consent to the medical services). Note that the facts for implied consent cases are very specific and uncommon.

consent is not an intricate obligation of informed consent except perhaps in the presences of an emergency; the veritable complexity is assuring that consent is truly informed.

The requirement that consent be actually informed places a duty on physicians to disclose necessary information to the patient. The legal field is divided over what standard to apply for determining the appropriate amount of information to disclose. The older standard, and currently the minority standard, permits the physician to disclose only what a reasonable physician would under the circumstances.<sup>82</sup> The second and more stringent standard is based on the disclosures a reasonable patient would expect to receive.<sup>83</sup> Under this standard, the physician must disclose all information and risks that would potentially affect the patient's decision in order to preserve the patient's self-determination and personal control over the decision.<sup>84</sup> Although there is no specific recitation of exactly what must be disclosed, over the years a partial and uninclusive list of important items has developed, including: diagnosis; nature and purpose of treatment; *risks and consequences*; probability of success; *feasible alternatives*; and prognosis if the treatment is not given.<sup>85</sup>

Like consent, there is an exception to the rule of disclosure; it is referred to as the therapeutic privilege to withhold information. The physician may withhold information that might have a physical or psychological impact on the patients' well being or when the patient is incompetent to give consent.<sup>86</sup> The courts have noted the need for this exception to be limited for fear it would swallow the rule. In order to prevent the exception from swallowing the rule, a

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<sup>82</sup> See, e.g., *Culbertson v. Mernitz*, 602 N.E.2d 98, 102-03 (Ind. 1992); see also *Hermer*, *supra* note 1, at 222; *Rossoff*, *supra* note 72, at 34-35.

<sup>83</sup> See, e.g., *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972); *Cooper v. Roberts*, 286 A.2d 647 (Pa. Super. 1 see also *Hermer supra* note 1, at 222; *Rossoff, supra* note 72, at 38-51.

<sup>84</sup> *Canterbury*, 464 F.2d at 786-87; *Matties v. Mastromonaco*, 709 A.2d 238, 248 (N.J. Super. 1998); see also, *Rosoff, supra* note 72, at 44-46.

<sup>85</sup> *Rosoff, supra* note 72, at 41, 41-51; *Morrissey, supra* note 72, at 14.

<sup>86</sup> *Goldberg v. Boone*, 912 A.2d 698, 703 (Md. 2006); *Ward v. Lutheran Hosp. & Homes Soc.*, 963 P.2d 1031 (Alaska 1998). See also *Rosoff, supra* note 72, at 54-56.

physician must use caution when withholding information based on the therapeutic privilege. Physicians may not withhold information based on a paternalistic notion that, if divulged, the patient would forgo treatment the physician deems necessary.<sup>87</sup> Therefore, this narrow exception applies only when the physician identifies “specific considerations in the individual patient’s case” that goes beyond the physician’s decision to withhold a specific medical fact out of the belief it will scare patients.<sup>88</sup>

## B. Application to Minors

Minors are considered incompetent to consent to medical treatment among other things due to their lack of maturity and ability to comprehend the consequences.<sup>89</sup> Thus, to perform medical procedures on a minor, physicians must obtain consent from the parents or someone standing *in loco parentis*.<sup>90</sup> Parents are entitled to all the information provided to the patient under the informed consent doctrine explained above.<sup>91</sup> In fact, some precedent suggests that parents, and others who provide proxy consent, are entitled to more extensive information.<sup>92</sup> In addition, the therapeutic privilege to withhold information would not apply as there is no fear that the information will physically or psychologically harm the *patient*.<sup>93</sup>

Thus, parents, and those acting *in loco parentis*, have the right to make informed consent decisions for minor children, as the children are not permitted to and sometimes unable to consent

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<sup>87</sup> *Canterbury*, 464 F.2d at 789; *Barcai v. Betwee*, 50 P.3d 946, 963 (Haw. 2002).

<sup>88</sup> *Barcia*, 50 P.3d at 963 (referring to *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972)).

<sup>89</sup> See Willard Gaylin, *Who Speaks for the Child?*, in WHO SPEAKS FOR THE CHILD: THE PROBLEMS OF PROXY CONSENT 3, 14-15 (Willard Gaylin & Ruth Macklin eds. 1982).

<sup>90</sup> Rosoff, *supra* note 72, at 188; *Bonner v. Moran*, 126 F.2d 121, 122 (D.C. Cir. 1941) (consent of parents is required for surgical procedures performed on minors). *Parham v. J.R.* 442 U.S. 584, 602 (1979) (“a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life’s difficult decisions”).

<sup>91</sup> Rosoff, *supra* note 72, at 187.

<sup>92</sup> *Id.* See also, *Darrah v. Kite*, 301 N.Y.S.2d 286, 291-92 (N.Y. 1969) (information provided to parents may have been insufficient the case was remanded for this specific determination);

<sup>93</sup> Rosoff, *supra* note 72, at 187 (therapeutic privilege to withhold information does not apply because there is no fear that the information will cause the *patient* physical or psychological harm); *Canterbury*, 464 F.2d at 789 (therapeutic privilege to withhold information only applies when disclosure would cause the patient to become so ill or emotionally distraught as to foreclose rational decision making).

for themselves. As one scholar noted, “the obvious purpose is to protect the child from damaging the adult he is eventually to become.”<sup>94</sup> In order for the parent to reach informed consent conclusions, not only is the doctor required to provide the information, but the parent is obligated to obtain the necessary information so that decisions can be, and are, made in the child’s best interest.<sup>95</sup> Within the confines of the child’s best interest the parents’ right to consent or to withhold consent is not absolute. When the state determines that the child’s best interest is sufficiently in conflict with the parent’s decision it will intervene.<sup>96</sup> This is most common when the parent refuses necessary medical treatment for a minor for, *inter alia*, blood transfusions and cancer treatments.<sup>97</sup>

In most instances, minors, unlike adults, do not have the right to refuse necessary medical treatment.<sup>98</sup> Thus, anyone providing consent for the minor does not obtain this right by proxy because the child never possessed it. Beyond the state interference that may occur when a parent

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<sup>94</sup> Willard, *supra* note 89, at 15. *See, e.g.*, *Darrah v. Kite*, 301 N.Y.S.2d 286, 291-92 (N.Y. 1969) (remanding case to find if information parents received when they consented to child’s surgery was sufficient for informed consent).

<sup>95</sup> *See Parham*, 442 U.S. at 602 (“a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life’s difficult decisions. More important, historically, it has recognized that natural bonds of affection lead parents to act in the *best interests* of their children”) (emphasis added) *Novak v. Cobb County Kennestone Hosp. Auth.*, 849 F. Supp. 1559, 1577 (N.D. Ga. 1994) (“those acting *in loco parentis* have duty to consider best interest of the child”); 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, 7 (2000); Hermer, *supra* note 1, at 222. This standard is the evolution of the view of the parent’s role in their child’s life and continues to grow over time. *See Morrissey, supra* note 72, at 6. This has thus far been a three stage evolution. *Id.* First, children were seen as the property of their parents with no individual constitutional rights; the parents were entitled to the obedience and labor of their children and they were also entitled unquestioned control to make proxy decisions for their children. *Id.* at 2-3. In the second stage, parents were responsible for proper development of their children; control remained absolute but there was a shift in parenting and the emphasis was on producing grown children fit for the community. *Id.* at 3. The third stage is the child welfare stage, where society became concerned with the welfare of the child and decisions must be made in the child’s best interest. *Id.* at 4. In this stage the child still has no say, when the child’s best interest is not looked after the state will intervene. *Id.* However, in more recent developments the best interest of the child has begun to include the opinion of mature minors, and minors are granted more and more constitutional rights, yet still not on par with adults. *Id.* at 4-6.

<sup>96</sup> Gaylin, *supra* note 89, at 27, 31.

<sup>97</sup> *Novak v. Cobb County-Kennestone Hosp. Auth.*, 849 F. Supp. 1559 (N.D. Ga. 1994) (court ordered a mature minor to receive a necessary blood transfusion against the parents’ and minor’s wishes); *Hamilton v. McAuliffe*, 353 A.2d 634 (Md. 1976) (same); *In re Guardianship of L.S. & H.S.*, 87 P.3d 521 (Nev. 2004) (same).

<sup>98</sup> *See supra* note 97 and accompanying text; *c.f.* *Cruzan v. Mo. Dep’t of Health* 497 U.S. 261, 261 (1990) (adults may refuse life sustaining nutrients and hydration if that is their clear intent). This rule applies in most instances as the courts have begun to recognize expanded rights of “mature minors” allowing them a greater say in medical self-determination. Rosoff, *supra* note 72, at 188-90.

refuses to consent to medical treatment for a minor, there are instances when the interest of the minor and the parent may conflict.<sup>99</sup> “Although the full measure of constitutional rights has not been extended to minors, the assumption that minors have no protection under the Constitution has been decisively rebutted.”<sup>100</sup> Justice O’Connor took special note of the constitutional rights of children in the context of medical treatment in the landmark case *Cruzan v. Missouri Department of Health* stating: “[i]t is not disputed that a child, in common with adults, has a liberty interest in not being confined unnecessarily for medical treatment.”<sup>101</sup>

The state, in its *parens patriae* role, interferes in other instances when the medical interests of the child may conflict with the interests of the parent in order to preserve the constitutional rights of the child against the interests of the parent. In medical situations, the state most frequently intervenes during medical emergencies, such as blood transfusions.<sup>102</sup> However, the state can intervene in non-emergency situations. For instance, several states prohibit the sterilization of a child.<sup>103</sup> Other states prohibit parents from entering a child into an experimental medical program or from consenting to the removal of a child’s organs without a court order.<sup>104</sup> There is no need for a medical emergency threatening the child’s life before the state may intervene on behalf of the child. The state can, and often does, intervene when parents make decisions that either harm or expose the child to harm.<sup>105</sup>

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<sup>99</sup> Margaret O’Brien Steinfelds, *Children’s Rights, Parental Rights, Family Privacy, and Family Autonomy*, in WHO SPEAKS FOR THE CHILD: THE PROBLEMS OF PROXY CONSENT 223, 224 (Willard Gaylin & Ruth Macklin eds. 1982),

<sup>100</sup> *Id.* at 225 (referencing *In re Gault*, 875 S. Ct. 1428 (1967); *Tinker v. Des Moines Indp. Comty. Sch. Dist.*, 89 S. Ct. 733 (1969); *Carey v. Population Serv. Int’l*, 97 S. Ct. 2010 (1977); *Planned Parenthood v. Danforth*, 96 S. Ct. 2831 (1976)); *see also Parham*, 442 U.S. at 600.

<sup>101</sup> 497 U.S. 261, 288 (1990) (O’Connor, J., concurring) (citing *Parham*, 442 U.S. at 600).

<sup>102</sup> *See supra* note 97 and accompanying text.

<sup>103</sup> *See, e.g.*, ARK. CODE ANN. § 20-49-101-303 (2004); GA. CODE ANN. § 31-20-3 (2004); N.D. CENT. CODE. § 23-12-12 (2003). *See also* Lloyd, *supra* note 61, at 169.

<sup>104</sup> *See, e.g.*, ARK. CODE ANN. § 28-65-302(A)(1)(A),(C) (2005). *See also* Lloyd, *supra* note 61, at 169.

<sup>105</sup> *See, e.g.*, *Prince v. Massachusetts*, 321 U.S. 158 (1944) (holding that state could intervene and prevent child labor, even if religiously related work, if the state is acting to “guard the general interest in youth’s well being); *Parham*, 442 U.S. at 600-02 (required some due process for minors before they are committed to mental institution to assure that parents are motivated by child’s best interest).

Thus, it is becoming more and more important to take into account the constitutional rights of the child when making decisions that will greatly affect the child. This has led to the movement allowing “mature minors” more of a say in medical decisions, particularly when the interests of the minor conflict with those of the parent.<sup>106</sup> As one scholar noted; “in all areas [of life] it is incredible how often children are completely foreclosed from life-binding decisions – even when such decisions might easily be deferred until the age of their competence.”<sup>107</sup> As this statement exemplifies, the recognition of constitutional rights for minors, especially in regards to medical care, has created a push not just for consideration of the child’s best interest but for consideration of the child’s interests. Here, as in other areas of American Jurisprudence, the importance of individual self-determination takes command of the rights of third party decision makers.

### C. Current Application to Minors with Intersex Conditions

Informed consent is applied *loosely* when it comes to infant and minor genital surgeries. Essentially, physicians operate without the constraints of informed consent. This is accomplished by treating each intersex birth as a “medical emergency exception” under informed consent and by withholding information under the guise of the therapeutic privilege to withhold information exception to informed consent.<sup>108</sup> In addition, the physicians advise the parents to keep the child’s condition a secret from other family members. This advice “isolate(s) parents within the medical

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<sup>106</sup> Steinfelds, *supra* note 99, at 236-37; Rosoff, *supra* note 72, at 188-90; Morrissey, *supra* note 72, at 16. *See also*, e.g., Planned Parenthood 428 U.S. 52, 72-73 (1976) (stating that minor’s cannot be forced to seek parental consent in all but emergency situations when seeking abortions a bypass process must be provided); Gulf & S.I.R. Co. v. Sullivan, 119 So. 501, 502 (Miss. 1928) (seventeen year old is intelligent enough to understand and therefore consent to a vaccination)

<sup>107</sup> Gaylin, *supra* note 89, at 15. *See, e.g.*, Darrah v. Kite, 301 N.Y.S.2d 286, 291-92 (N.Y. 1969) (remanding case to determine if information parents received when they consented to child’s surgery was sufficient for informed consent).

<sup>108</sup> *See* Lloyd, *supra* note 61, at 155, 172-75 (2005-2006). *See supra* notes 80, 86-87 and accompanying text.

arena since physicians [are] the only ones with whom parents believed they [are] free to discuss the condition.”<sup>109</sup>

The emergency exception to informed consent is ordinarily reserved for situations that “endanger the life or health of the patient.”<sup>110</sup> Physicians under the direction of Dr. Money, and now the AAP, rely on the fact that a child born with an intersex condition is considered to be a “social emergency” to circumvent this “technicality.”<sup>111</sup> Continuing with the emergency mentality, physicians often express an air of urgency concerning sex assignment and cosmetic genital surgeries.<sup>112</sup> To further this sense of urgency and demonstrate the “emergency” nature of the situation the infants are often isolated in the neonatal intensive care unit immediately after birth with an intersex condition, regardless of its life-threatening nature.<sup>113</sup> Several rationales have been advanced in an effort to explain the urgency; however, little empirical support evaluating the validity of these rationales has been produced. Dr. Money advances the theory that surgery “must be done in the ‘early months of life’ in the ‘critical period’ or else it would be ‘psychologically injurious.’”<sup>114</sup> In addition, physicians and psychologists assert the importance of parental bonding during the first years of the infant’s life and stress that bonding will be more difficult if a parent is not spared the trauma of seeing intersex genitalia every time they change their infant’s diaper.<sup>115</sup>

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<sup>109</sup> Beth & Diamond, Limiting Parental Discretion, *supra* note 17, at 16.

<sup>110</sup> See *supra* note 80 and accompanying text. See, e.g., *Chambers v. Nottebaum*, 96 So. 2d 716, 718 (Fla. App. 1957) (stating the rule regarding exceptions to informed consent in emergency situations); *Canterbury*, 138 F.2d at 788-89 (same); *Douget v. Touro*, 537 So. 2d 251, 260 (La. App. 1988) (same).

<sup>111</sup> See AAP, *supra* note 6, at 138; Beh & Diamond, Limiting Parental Discretion, *supra* note 17, at 3, 9 (maintains that the use of “monster ethics” allows parents and doctors to ignore sound medical practice in treating intersex infants).

<sup>112</sup> See Beh & Diamond, *supra* note 13, at 43-46; Hermer, *supra* note 1, at 222; Lloyd, *supra* note 61, at 172.

<sup>113</sup> See Helena Harmon-Smith, *A Mother’s 10 Commandments to Medical Professionals: Treating Intersex in the Newborn*, in INTERSEX IN THE AGE OF ETHICS 195, 195 (Alice Domurat Dreger ed. 1999) (contends that isolating the child in the NICU makes parents “feel something is very wrong with there child . . . isolates the family and prevents siblings, aunts uncles and even grandparents from visiting).

<sup>114</sup> Beh & Diamond, Limiting Parental Discretion, *supra* note 17, at 13.

<sup>115</sup> Lloyd, *supra* note 61, at 173.

The therapeutic privilege to withhold information is also misapplied when an infant is born with an intersex condition. The medical information provided to parents is often incomplete, overstates the potential for success, and understates harmful consequences such as scarring, loss of sensation, additional necessary surgeries, and poor aesthetic outcomes.<sup>116</sup> In essence, the parent is treated as the patient and information the physician believes may upset or embarrass the parent is withheld.<sup>117</sup> Physicians may also tell parents that the child is sexually unfinished – this is deceptive – it “implies that with more gestational time unambiguous sex organs would have developed” and that the doctors are not changing the child merely finishing it.<sup>118</sup> This also provides parents with the false sense that after surgery their infant’s genitals will be normal.<sup>119</sup>

This lack of information and rushed atmosphere combined with the emotional experiences of the parents does not leave much room for a reasoned consideration of what is in the child’s best interest. In addition, one of the foundations of parents’ proxy consent for their minor children is “that natural bonds of affection lead parents to act in the best interests of their children.”<sup>120</sup> Scholars have criticized this theory on the premise that during infancy the parental bonding may not be complete and the love assumed by society “may not have yet developed.”<sup>121</sup> Furthermore, scholars contend the parents are not in the ideal position to make a best interest determination as family members often fail to recognize that a child’s interest may evolve and grow with the child over time.<sup>122</sup> There is also the possibility that the parents are responding to the emotional strain and

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<sup>116</sup> See Beh & Diamond, *Emerging Dilemma*, *supra* note 13, at 47-55; Hermer, *supra* note 1, at 222-23; Lloyd, *supra*, note 61, at 174 (explains that parents are given information on a “need to know” basis).

<sup>117</sup> Beh & Diamond, *Limiting Parental Discretion*, *supra* note 17, at 27. See also Lloyd, *supra* note 61, at 173-75.

<sup>118</sup> Beh & Diamond, *Emerging Dilemma* *supra* note 13, at 48. Lloyd, *supra* note 61, at 174 (stating that telling the parents the child is unfinished confuses the malformed genitalia with ambiguous genitalia).

<sup>119</sup> Lloyd, *supra* note 61, at 175.

<sup>120</sup> *Parham v. J.R.*, 442 U.S. 584, 602 (1979).

<sup>121</sup> Lloyd, *supra* note 61, at 168.

<sup>122</sup> Lloyd, *supra* note 61, at 169 (notes possible changing interest include sexual orientation, gender identity, and the desire to have children).

shock of having a child that is not perfect, and parents mourn the loss of their perfect child.<sup>123</sup> During this period of emotional adjustment it would be difficult for parents to make a best interest determination for the child under urgent circumstances. Finally, the parents' interest may be in conflict with the overall best interest of the child.<sup>124</sup> Parents are often more concerned with the appearance of the child's genitalia to permit a more normal childhood and adolescence.<sup>125</sup> The parent takes less account of the period when the child becomes an adult and spends less time with the parent, in which functionality and sensation may be more important than mere physical appearance.<sup>126</sup>

Applied in this manner, informed consent laws provide little protection for children born with ambiguous genitalia or intersex conditions. Societal trepidation of a sex that is neither male nor female obstructs medical decisions and prevents the full realization of the legal protection of informed consent laws. The legal principles of informed consent are manipulated to bring about an outcome that is more palatable for society regardless of its future effect on the individual, and regardless of its destruction of the concept of individual self-determination.

#### IV. INFORMED CONSENT : A RETURN TO THE BEST INTEREST APPROACH

Existing informed consent rules are underutilized and improperly applied because of social trepidation toward intersex individuals and unwarranted medical urgency to "correct" the problem. Nevertheless, the current rules of informed consent are adequate to protect the rights of individuals born with intersex conditions, if they are consistently and strictly applied. The rules of informed consent, particularly the requirement of a best interest analysis for minors, can

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<sup>123</sup> Wilson & Reiner, *supra* note 68, at 365; *see also* Hermer, *supra* note 1, at 230.

<sup>124</sup> Beh & Diamond, Limiting Parental Discretion, *supra* note 17, at 27 (conflicts could be financial, emotional, or value-based).

<sup>125</sup> Beh & Diamond, Limiting Parental Discretion, *supra* note 17, at 28. A common concern is that the child will not be able to feel comfortable in the school locker room when it comes time for group showers. *See id.*, at 6.

<sup>126</sup> *Id.*

alleviate many of the complex circumstances created by the current medical treatment of intersex minors. The best interest analysis, if enforced, would ensure that parents receive unabridged information, would provide a check on the parents' authority if their interest conflict with those of their child, and would take into account the child's preference manifest through behavior and counseling as the child ages, assuring that sex assignment and normalization surgeries are not performed until or unless it is in the child's best interest.

The doctrine of informed consent is based on individual self-determination. For this principle of self-determination to be enforced the legal system will be required to pay close attention to physician who encounter intersex minors, and to the parents of these children.

#### A. Scholars Weigh in on Informed Consent's Potential for Intersex Surgeries

The combination of pressures placed on parents by physicians and their own emotional shock provides little room for reasoned consideration of the child's best interest under the principles of informed consent. However, this is not detrimental to the idea of informed consent. If the courts strictly enforce the principles of informed consent on physicians and parents, as it does when considering other medical procedures, these kinds of manipulations of the system would not be possible. Many scholars do not agree. They fall into two camps: 1) those who argue for a complete moratorium on genital surgeries until individuals reach the age of consent, and 2) those that argue for continued infant genital surgery with additional information for parents.

Drs. Milton Diamond and Hazel Glenn Beh, the psychologists who discredited Dr. Money's theories, recommend a moratorium on infant surgeries.<sup>127</sup> They suggest that counseling should be received and surgery should not be an option until the child reaches adulthood and the

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<sup>127</sup> See Beh & Diamond, Emerging Dilemma *supra* note 13, at 59-60; Beh & Diamond, Limiting Parental Discretion, *supra* note 110, at 21-23.

intersexed individual can make his or her own decision.<sup>128</sup> In addition, they contend that providing additional information to parents cannot “legitimize a surgical treatment that lacks a therapeutic rationale” and poses substantial risk to the patient while offering little benefit.<sup>129</sup> This proposition presumes that parents will never be able to make decisions in the best interest of their children and that a surgery before the child is eighteen will never be in the child’s best interest. It is effortless to look at the current application of informed consent principles and contemplate that the rules cannot protect this minority population. However, it is not the rules of informed consent that are the problem; it is continuing failure of society to enforce them for the protection of a minority population that is feared.

Some scholars argue against the moratorium principle, and in favor of merely providing some additional information to parents before they make the decision regarding infant genital surgery.<sup>130</sup> Their reasoning is that some parents, even after having all information provided to them regarding the risks of infant surgery, will “maintain a strong prejudice in favor of surgery.”<sup>131</sup> They argue that infant genital surgery does not create an “ethical dilemma” because the ultimate decision regarding early surgery, like all other major decisions regarding children, lies with the parents and “should be made in the context of their own cultural beliefs.”<sup>132</sup>

The fact that the parents may have a “strong prejudice” in favor of surgery indicates that they may have a conflict of interest with the child’s best interest. The informed consent principles require that the decision maker be able to consider the best interest of the child, if that

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<sup>128</sup> See Beh & Diamond, Emerging Dilemma, *supra* note 13, at 59-60.

<sup>129</sup> Beh & Diamond, Limiting Parental Discretion, *supra* note 17, at 21.

<sup>130</sup> See *id.* at 20 (citing Erica A. Eugster, *Invited Critique*, 158 ARCHIVES PEDIATRIC & ADOLESCENT MED. 426, 429 (2004)).

<sup>131</sup> *Id.*

<sup>132</sup> *Id.*

cannot be done by the decision maker the state, in its *parens patriae* role, steps in to advocate for the best interest of the child.<sup>133</sup>

Furthermore, the view that parents should be able to subject their child to genital surgery so that the child will conform to the parents' cultural beliefs contravenes the very idea of individual self-determination. This country has gone to great lengths to prevent the mutilation of the genitalia of minors based on cultural beliefs or any other unsound reason. In 1996, the Criminalization of Female Genital Mutilation Act was enacted.<sup>134</sup> It states in pertinent part: “[e]xcept as provided in subsection (b), whoever knowingly circumcises, excises, or infibulates the whole or any part of the labia majora or labia minora or clitoris of another person who has not attained the age of 18 years shall be fined under this title or imprisoned not more than 5 years, or both.”<sup>135</sup> It remains unclear how the Act applies to those born with intersex conditions; the continued legality of the surgeries may depend on the existence of actual medical necessity rather than a desire for cosmetic normalization.<sup>136</sup> One thing is sure: neither the Act nor informed consent principles anticipate legal surgeries for minors based on the parents' cultural satisfaction with their child's genital appearance.

One scholar suggests a middle ground is possible, and that increased information from physicians to parents would correct the flaws, or at least manage them sufficiently.<sup>137</sup> She contends that ending infant surgeries will not correct the societal discrimination they will face without a sex in an intolerant society.<sup>138</sup> She contends that not performing surgery forces parents to enter their children into a social experiment, that without the cosmetic appearance the children

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<sup>133</sup> See *supra* notes 96-97, 102-05 and accompanying text.

<sup>134</sup> 18 U.S.C. § 116(a) (2006).

<sup>135</sup> *Id.*

<sup>136</sup> *Id.* See also Beh and Diamond, *Emerging Dilemma*, *supra* note 13, at 21; Kessler, *supra* note 14, 81-82.

<sup>137</sup> See Hermer, *supra* note 1, at 224.

<sup>138</sup> *Id.*

could not be raised within the current sex and gender system.<sup>139</sup> Based on this, she reasons there can be no right answer for parents and infant surgery as an option should not be foreclosed.<sup>140</sup>

However, she ignores two realities. First, if the child does not undergo cosmetic surgery as an infant the child can still have a sex of rearing. There is no reason the child must be raised sexless, or treated as a “freak of nature” that fits nowhere into society simply because the child has ambiguous genitalia. The parents can select a gender of rearing, or attempt to raise the child in a gender neutral manner until a preferred sex is determined; whichever they ascertain is in their child’s best interest. This will depend on the individual condition of each child. Second, the parent in most cases will not and cannot know what gender the child will identify with when the child is an infant, and rejection of surgically assigned gender is a real possibility that can have lasting and damaging consequences.<sup>141</sup> Because the parent cannot know they must make the decision based on other factors and it is possible that they will use interests that conflict with those of the child to make this decision, such as their own “anxieties, guilt, shame, or repugnance.”<sup>142</sup>

While all of these reasons may support a moratorium on infant sex assignment surgeries, a moratorium is unnecessary to protect the interests of intersex children from the social forces at work against them. Strict adherence to all the principles of informed consent has all the safeguards necessary to protect these children. However, it will require the cooperation of the legal system to enforce the protections of informed consent that these children deserve. For too many years the legal system has allowed the medical profession to apply Victorian principles of

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<sup>139</sup> *Id.* at 228.

<sup>140</sup> *Id.*

<sup>141</sup> See *supra* notes 38-40 and accompanying text for discussion of adult rejection of assigned sex. The consequence on future marriage potential can also be significant if a state restricts the individual to the sex assigned at birth for the purpose of marriage and then applies DOMA to prevent marriage. See *supra* note 61.

<sup>142</sup> Beh & Diamond, *Limiting Parental Discretion*, *supra* note 17, at 5.

paternalism to intersexed children and their parents, thereby disregarding all thoughts of individual self-determination and informed consent. The doctrine of informed consent is based on individual self-determination.

## B. Manifestation of Proxy Informed Consent: Recognizing the Role of the Parents

Proxy informed consent is utilized when an individual is considered legally incompetent to offer consent on their own behalf.<sup>143</sup> Parents providing proxy informed consent for their minor children who are incompetent due to age is one of the most common uses of this device.<sup>144</sup> Parents are thus entitled to make medical decisions in the best interest of their children because their children are legally and, unless they are mature minors, physically incapable of making these decisions for themselves. However, before parents make such decisions they have an obligation to obtain and consider the necessary information from the physicians. In this way proxy informed consent provides a check on the paternalistic nature of the medical community and requires that information be divulged in full so that parents can make informed decisions.

### *1. Physician Disclosure Requirements and Parental Obligation to Know*

Parents need access to greater information than a typical patient would need in order to provide proxy informed consent for their children. Nonetheless, under current conditions surrounding intersex minors, physicians do not give parents the information necessary to make informed decisions. The physicians withhold information or provide it in simplified and misleading descriptions.<sup>145</sup> The physicians justify this under the therapeutic privilege to withhold information. However, this exception is narrow and applies only when the physician identifies “specific considerations in the individual patient's case” that goes beyond the physician’s

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<sup>143</sup> See *supra* notes 88-90 and accompanying text.

<sup>144</sup> See *supra* notes 88-90 and accompanying text.

<sup>145</sup> See *supra* notes 116-19 and accompanying text.

decision to withhold a specific medical fact out of the belief it will scare patients, such as patients with nervous conditions or other psychological conditions.<sup>146</sup> The parents are not the patients and the infants are not born with any psychological conditions attributed to their intersex condition. There is no evidence that directly links birth with an intersex condition to a psychological inability to handle medical information; at least none has been offered by the medical community to rationalize their use of this privilege. Even if such a condition existed, this would not justify withholding full information from the parents who are providing proxy medical consent and therefore are entitled to all available information so that a decision may be made in the best interest of the child.

In addition to divulging the information, physicians have a duty not to mislead the parents by displaying an unwarranted sense of urgency or treating the child's condition as a medical emergency if it poses no danger to the life or health of the child. Physicians limit parents' ability to make decisions by forcing them to operate under emergency like conditions. The information parents receive about their intersex infants is shrouded in urgency and cushioned in euphemisms. This is unnecessary; in most instances intersex conditions do not threaten the life or health of the child. The birth of the child is considered a "social emergency," and the medical emergency is based on the cosmetic appearance of the child's genitalia.<sup>147</sup> There is no other "medical emergency" allowing for the evasion of informed consent principals based on cosmetic appearance of the child, even when the child is visibly physically deformed.<sup>148</sup> Therefore, there is no appreciable reason offered for this particular condition to be treated as a

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<sup>146</sup>*Barcia v. Betwee*, 50 P.3d 946, 963 (Haw. 2002) (referring to *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972)).

<sup>147</sup> See *supra* note 6 and accompanying text.

<sup>148</sup> See *e.g.*, *In re Seiferth*, 127 N.E.2d 820 (N.Y. 1955) (child with a harelip and clef palate is not a medical emergency and court would not intervene when father refused consent for the cosmetic surgery to correct). See also *Lloyd*, *supra* note 61, at 173 (stating that no other medical emergencies are based on cosmetics); *Rosoff*, *supra* note 72, at 197-98 (in depth discussion of *Seiferth*).

medical emergency. Dr. Money argues that there is a critical time period during which surgery should be preformed and sex assignment determined based on the sexual neutrality at birth.<sup>149</sup> However, he offers no empirical evidence that the results and psychological trauma suffered by individuals who undergo infant surgery is any less severe than an individual who selects a sex or elects whether to have surgery or not later in life.

The physicians must remember that it is the child who is the patient and not the parent; the parent is providing proxy consent for the child. Though the parents may be upset to learn that their infant is not perfect, it is the infant with the intersexed condition that is the patient not the parents who have an intersexed child. Thus, under the principles of informed consent there is no therapeutic privilege to withhold information from the parent. There is a greater duty to inform the parents, as the child's proxy, of all the information. This includes, *inter alia*, all the risks, alternative treatments, and the probability of success if the child does not receive the suggested treatment.

Therefore, if the legal system strictly enforced the requirements of informed consent they would find it a violation of informed consent whenever a physician provides less than complete information to parents. If the required information is provided, it will reduce a great deal of the confusion that parents suffer through and much of the medical isolation and dependency that results from a lack of information.

## *2. Parental Requirement to Decide in Child's Best Interest*

Parents inherent ability to provide proxy consent for their minor children stems from the belief that the "natural bonds and affection lead parents to act in the best interest of their

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<sup>149</sup> See *supra* notes 20, 114-15 and accompanying text.

children.”<sup>150</sup> Parents must therefore keep the best interest of their children at the forefront of any medical decision. As discussed earlier, when the parents are unable to make medical decisions in the best interest of their children, the state can and does intervene.<sup>151</sup>

In situations involving the birth of an intersex child parents may be under too much emotional strain to render an adequate best interest analysis. To the extent mentioned earlier, parents may mourn the loss of their perfect child and as many as fifty percent may be unable to ultimately bond fully with their “abnormal” child.<sup>152</sup> These reactions contravene the presumption that parents are bonded with their child when exercising proxy medical consent. Thus, counseling should be offered to parents immediately. This will assist them in overcoming the shock and any feelings of loss they may have to promote the parent child bond. The counselor will also be able to determine if the parents are ultimately unable to accept the child, or remain in an emotional state that interferes with their ability to engage in adequate best interest analysis regarding their intersex child. If the counselor finds they are not currently capable of providing best interest informed consent decisions for the child, the state has the ability to intervene and protect the child from potential harm. A guardian ad litem can be appointed to make these determinations for as long as the parent remains incapable of fulfilling this responsibility.<sup>153</sup>

### C. Manifestation of Informed Consent Best Interest Analysis: Acknowledging Rights and Recognizing Personal Interests of Minors

As society continues to recognize more constitutional rights for minors they gain a stronger hold on individual self-determination. Particularly significant for intersex minors, Justice O’Connor pointed out that “a child, in common with adults, has a liberty interest in not

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<sup>150</sup> Parham v. J.R., 442 U.S. 584, 602 (1979).

<sup>151</sup> See *supra* notes 96-97, 102-05, 131 and accompanying text.

<sup>152</sup> See *supra* notes 68-70, 120-23 and accompanying text.

<sup>153</sup> See *supra* notes 102-05 and accompanying text for a discussion of when state can intervene on behalf of children.

being confined unnecessarily for medical treatment.”<sup>154</sup> Therefore, if the benefits of surgeries performed on intersex genitalia are primarily cosmetic, minors have a significant liberty interest in not being confined for these treatments unless they are capable of providing at least some input in the decision.

Currently, sex assignment surgery is recommended before the child reaches the age of two.<sup>155</sup> This is based on the premise that if they are performed early enough the sex and gender of the child can be shaped by the gender of rearing.<sup>156</sup> This not only ignores the individual self-determination of the intersex minor, but is a direct assault aimed at eroding it away. Therefore, a wait and see approach that places the highest level of importance on which sex the child identifies with is more in line with a best interest and individual self-determination of the child. This will also prevent cases where children have rejected assigned genders but have already undergone surgery. If the child has already undergone surgery, reassigning a sex is an onerous task.<sup>157</sup>

Permitting children to age will allow parent to see if they identify with one sex or another. Counseling will play a crucial component. They will be able to smooth the progress of children as they develop and find their place in the world. The psychologist will also be able to assist the parents in determining which sex their child identifies with, and determining when and if a sex assignment surgery is in the best interest of their child. For some children this could come before puberty to prevent mixed hormonal signals. For other children it may be their best interest to never have a genital surgery. This takes the decision away from a medical bright line

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<sup>154</sup> *Cruzan v. Mo. Dept. of Health*, 497 U.S. 261, 288 (1990) (O’Connor J., concurring) (citing *Parham* 442 U.S. at 602).

<sup>155</sup> *See supra* notes 7, 23 and accompanying text.

<sup>156</sup> *See supra* notes 17, 20, 22-25 and accompanying text.

<sup>157</sup> *See supra* note 56-61 and accompanying text.

rule and creates an individual evaluation based on each child's individual needs and circumstances.

Keeping with this model also protects intersex minors' right to individual self-determination on another level. By keeping the family in counseling the motives of the parent can be assessed. As discussed above, the parents may be suffering from emotional strain or shock from the birth or news of their intersex minor; however, they may also have conflicting interest from their child. If parents have difficulty considering that the interests of their child may evolve and grow over time with the child, it may be difficult for the parent to fully consider whether surgery is in the best interest of the child.<sup>158</sup> For instance, a normalization surgery may seem more beneficial while the child is an adolescent, as they may feel embarrassed particularly during gym class at school. However, if the surgery comes with the loss of sexual sensation it may not be in the child's best interest when the child becomes an adult and would prefer normal sexual sensation. In addition, as discussed above, some parents may have cultural conflicts that lead them toward surgery regardless of the child's interest.<sup>159</sup> These conflicts can be discovered during the long term counseling. If the parents have interests that sufficiently conflict with those of the child, the state has the ability to intervene and protect the child from potential harm.<sup>160</sup> A guardian ad litem can be appointed to represent the interest of the child, thereby preserving the child's individual self-determination and assuring that the child's best interest is truly accomplished through the rules of informed consent.

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<sup>158</sup> See *supra* note 122 and accompanying text.

<sup>159</sup> See *supra* notes 130 -36 and accompanying text.

<sup>160</sup> See *supra* notes 102-05 and accompanying text for a discussion of when state can intervene on behalf of children.

## CONCLUSION

Though existing informed consent rules are underutilized and improperly applied, strict adherence to the rules of informed consent can protect the rights of individuals born with intersex conditions. The consequences of infant genital surgery can be significant both during childhood and once the child reaches adulthood. The surgery can result in scarring, loss of sexual sensation, and emotional difficulties, including feelings of shame and isolation resulting from the secrecy. In addition, if the assigned sex is rejected the necessary tissue to assign the other gender has already been removed.

Informed consent requires doctors to provide parents with all the necessary information to make informed decisions in the best interest of the child. Instead, parents are given shady information expressed in terms of urgency at a time when they are in shock and under emotional strain. Additionally, the parents may have interests that directly conflict with those of the child. This does not meet the standard for granting informed consent on behalf of a child. Instead, it represents the social trepidation of the child's condition and the rush to correct the problem without regard to any of the principles of informed consent, and a complete disregard for the idea of individual self-determination.

In an effort to stabilize the situation and protect the interest of this minority group the legal system should insist on the strict enforcement of all the principles of best interest informed consent. The parents and the child should undergo years of therapy to understand the situation. The therapy can identify conflicts, determine when, and if, surgery is in the child's best interest, as well as what sex the child identifies with. Parents should be given the tools to give actual informed consent that is truly in the best interest of the child.

The 1969 medical mentality that the infants are “freaks, misfits, curiosities, rejected by society” should be left behind as a remnant of history. A time when society held the birth of a child with a intersex condition as a “social emergency” to be treated with trepidation and urgency. Social trepidation and deceptive research from decades long past ought not control the decision of what is in a child’s best interest. For a society with institutional underpinnings so strongly established in individual self-determination to take the right of self-determination away from an entire group out of fear of their birth is unacceptable. Informed consent is the very embodiment of an individual’s right to self-determination; if the rules do not apply to these individuals then society has judged them less than full citizens by the condition of their birth.