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International Legal Developments Protecting the Autonomy  
Rights of Sexual Minorities: Who Should Decide the Appropriate  
Treatment for an Intersex Child?

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INTERNATIONAL LEGAL DEVELOPMENTS  
PROTECTING THE AUTONOMY RIGHTS OF SEXUAL  
MINORITIES

*Who Should Determine the Appropriate Treatment for an Intersex Infant?*

1. INTRODUCTION

As the essays in this book illustrate, the medical treatment of intersex children is undergoing an intense examination. Doctors, psychologists, psychiatrists, sociologists, historians, ethicists, and intersex activists have all weighed in on the debate about the physical, psychological, sociological and ethical implications of early genital surgery. Before the last decade, the accepted medical protocol granted to physicians almost complete control concerning treatment decisions and the child's best interests. Physicians told parents little about their child's condition and many medical professionals advocated deceiving intersex patients about the exact nature of their conditions to protect them from psychological harm.<sup>1</sup>

During the last 10 years, this protocol has come under heavy attack. Although a number of experts have exposed flaws in the traditional approach, the debate about the appropriate treatment model is far from over. Comprehensive studies addressing this issue do not exist and because of ethical restraints limiting research in this area, the issue is unlikely to be resolved soon.<sup>2</sup>

Those involved in the debate now support three alternative protocols: (1) the model that has existed for the last 40 years, which emphasizes the need for early surgical and hormonal intervention to conform the child's body to societal norms and minimizes the information given to the child and parents to avoid psychological trauma; (2) a "middle ground" approach that emphasizes the need for disclosure of complete information to the parents and deference to the parental decision about whether surgical or hormonal treatment would be in the best interests of their child; and (3) a complete moratorium on all surgical and hormonal treatments that are not medically necessary so that the child, when she reaches the age of consent, can determine whether she wants to elect to undergo any surgical alteration.

Until comprehensive retrospective studies are conducted that clearly establish which approach best protects the interests of the intersex infant, positions are likely to become more polarized. Given the interests at stake and the intensity of the debate, legal institutions will likely be called upon to weigh in on the debate.

Legislatures may be asked to enact statutes<sup>3</sup> and in the absence of legislative action, courts will be asked to intervene. Thus far, no country has enacted controlling legislation and Colombia is the only country where the highest court has rendered an opinion on this issue. Therefore, if courts are asked to resolve the legal, medical and ethical issues surrounding the treatment of intersex children, the outcome is far from clear.

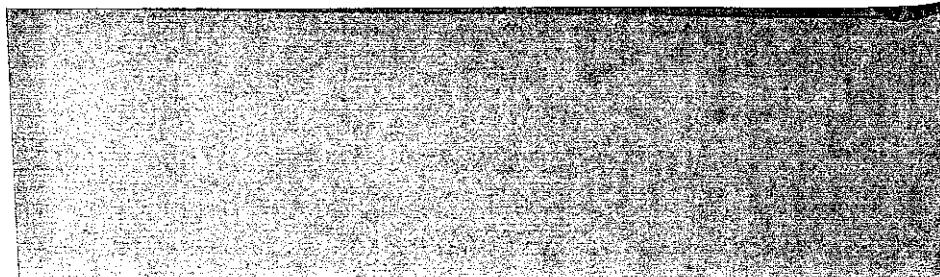
This chapter explores how courts may resolve this issue if they are brought into the controversy. Part I provides a brief summary of the current debates about the treatment model that best protects the interests of intersex infants. Part II describes the doctrine of informed consent as courts have traditionally applied it in medical determinations on behalf of children and others who are not competent to make medical decisions on their own behalf. Part III describes how the Constitutional Court of Colombia, the only high court that has ruled on this issue, applied the law of informed consent in the context of surgical alteration of intersex infants. Part IV explores how courts in Europe, Australia and the United States are likely to resolve this issue if they are asked to intervene. Although no appellate courts in these jurisdictions have been confronted by this precise issue, recent decisions by the European Court of Human Rights, Australian courts, and the United States Supreme Court may shed light on the probable outcome. Part V concludes that the legal arena may not be the optimal forum in which to resolve this complex personal and ethical dilemma.

## 2. THE CURRENT DEBATE OVER THREE ALTERNATIVE MODELS

### 2.1 *The Dominant Protocol*

The dominant treatment protocol developed during the 1950s, due in large part to the influential work of John Money.<sup>4</sup> Money hypothesized that children are born without a fixed gender identity. He believed that children develop a gender identity that conforms to the gender role in which they are raised, as long as that gender role matches the appearance of their genitalia. Therefore, he encouraged physicians to surgically alter infants born with genitalia that do not conform to male or female norms. Money believed that if surgeons sculpted "normal-appearing" genitalia and administered appropriate hormones, and parents raised the child in the gender role that conformed to the surgically created genitalia, the child would develop an unambiguous gender identity, and severe psychological trauma would be avoided. Critical to this protocol is the requirement that intersex children be raised without any ambiguity about their gender. Therefore, physicians traditionally encouraged parents to hide the truth about the child's intersex condition. In addition, to avoid trauma to the parents, physicians often told parents less than the whole truth about the child's condition and guided parents toward the decision the physician believed was optimal.

Until the 1990s, physicians believed that they were uniquely qualified to determine the best interests of the parents and the child. By disclosing selective



information to the parents and advocating support for only one treatment model, physicians controlled the ultimate outcome. As recently as 1995, major medical associations supported the selective disclosure of information to the parents and outright lying to the intersex patient about the nature of her condition.<sup>5</sup> Now, few would advocate in favor of hiding information from the parents or lying to the intersex patient. Changes in bioethical norms have shifted to a model favoring complete disclosure.

Although some recent comments indicate that many doctors are questioning the traditional protocol,<sup>6</sup> the most recent by the American Academy of Pediatrics (AAP) official publication supports this model.<sup>7</sup> Supporters of this treatment protocol believe that living with ambiguous or anomalous genitalia would lead to ostracism from peers, the potential weakening of the bond that parents are able to form with their child, and severe psychological trauma for the intersex child.

During the last decade, the traditional treatment model has been challenged by a number of intersex adults and researchers studying gender identity formation and the consequences of genital surgery. Intersex adults who were treated in accordance with the dominant model have asserted that the standard protocol often results in physical and psychological harm. They assert that genital surgery may result in a loss of reproductive capacity, a loss or diminishment of erotic response, genital pain or discomfort, infections, scarring, urinary incontinence and genitalia that are not cosmetically acceptable. In addition to physical complications, the dominant treatment protocol may exacerbate an intersex person's sense of shame by reinforcing cultural norms of sexual abnormality.<sup>8</sup> A number of researchers who are studying gender identity formation also believe that surgical alteration should not be undertaken on the assumption that infants are born with the ability to develop either a male or female gender identity. Some recent studies indicate that gender identity is not completely malleable and may be influenced or controlled by prenatal factors.<sup>9</sup>

Based upon these concerns, opponents of the dominant model have proposed two alternatives. One approach calls for a complete moratorium on all genital surgeries that are not medically necessary. The other model supports an approach that emphasizes the importance of providing complete information to the parents of the intersex child and deferring to parental decision making.

## *2.2 Complete Moratorium on all Surgeries that are not Medically Necessary*

Some intersex activists and experts have called for a complete moratorium on all infant intersex surgeries, except for those that are truly medically necessary, until retrospective studies prove that the benefits of such surgeries clearly outweigh the potential risks. Supporters of a complete moratorium believe that the traditional model results in stigma and trauma. They believe that under the current approach, which emphasizes the "normalization" of the infant's genitalia, parents will experience guilt and shame over giving birth to an "abnormal" baby and the intersex child will experience a sense of rejection. Those who support a moratorium, question the traditional assumption that concealing or downplaying the existence of

the intersex condition will help the family lead a "normal" life. In addition, they believe that relieving the parents' anxiety over the birth of their intersex child should not be accomplished by surgically altering the child to fit societal norms. Instead, they emphasize that parents should be educated, provided with complete information about their child's condition, and offered appropriate professional counseling and peer support. In addition, this group believes that children, when they reach the appropriate age, should be provided complete information and the option to decide for themselves whether they want to undergo surgery. Those calling for a moratorium believe that medical treatment of a child's intersex condition should be limited to treatment of conditions that pose an actual risk to the child's physical health.<sup>10</sup>

Those who support a complete moratorium recommend that: (1) experts assess the likely gender identity of intersex infants; (2) intersex children be raised in the recommended gender identity; (3) parents be educated and put in touch with people who can provide counseling and support; and (4) surgical intervention be delayed until the children reach an age when they can decide for themselves whether they want any surgical alteration.<sup>11</sup>

### *2.3 The "Middle Ground" Approach*

Others have called for a "middle ground" approach.<sup>12</sup> Those who support a compromise position believe that the dominant model defers too much to the treating physicians, but a complete moratorium would not be in the best interests of all intersex children. This group believes that physicians should not be making life-altering decisions for their patients that may affect their ability to reproduce and achieve sexual satisfaction, and potentially lead to physical and emotional complications. This group rejects the call for a complete moratorium, however, because they are concerned that the untreated intersex child may suffer psychological trauma that is more detrimental than the potential risks of surgery. This group believes that parents who are fully educated about all the risks and benefits of the different protocols are in the best position to assess what is in their child's best interests.<sup>13</sup> Therefore, they believe that parents, and not physicians, should have the complete authority to determine the appropriate treatment for their children. In other words, this group supports the parents' right to decide, as long as the parental decision is based on a true informed consent. This approach is supported by the British Association of Paediatric Surgeons.<sup>14</sup>

## 3. THE DOCTRINE OF INFORMED CONSENT

The informed consent doctrine preserves patients' rights to make medical decisions on their own behalf. The doctrine requires that patients be fully informed of all the material risks associated with the proposed medical treatment before their consent to a procedure is considered valid. The doctrine protects individuals' rights to bodily integrity and self-determination. In the case of incompetents or minors who are too

young to understand and balance the risks and benefits of a particular medical choice, informed consent is required of a surrogate, typically the minors' parent(s).<sup>15</sup>

Parental decisions on behalf of their children are generally accorded great deference to protect family privacy and parental authority. Typically, courts are not involved in medical decisions involving children, so long as the parents and the physicians agree on the appropriate treatment. Court intervention in parental decisions is rare because legal institutions generally presume that parents will make decisions that will be in the best interests of their children.<sup>16</sup>

In some circumstances, however, when parents are seemingly unable to make a decision based solely upon the best interests of their child and the potential gravity of the consequences of the medical treatment are particularly severe, courts may carefully review parental consent to the treatment of their child. The classic case requiring close scrutiny is the involuntary sterilization of a minor or incompetent adult. Sterilization, without the patient's consent, involves a significant invasion into the patient's right to autonomy. In addition, parents may be motivated by their own concern about having to care for a grandchild should their incompetent child become pregnant or father a child. Therefore, courts will carefully scrutinize these decisions to ensure that the best interests of the child are being protected.<sup>17</sup>

Genital surgery on an intersex infant involves similar autonomy issues. These surgeries may result in involuntary sterilization, decreased capacity to achieve sexual satisfaction, and serious long-term medical complications. Therefore, these surgeries have the potential to permanently and dramatically infringe upon the intersexual's right to bodily integrity and self-determination. In addition, because parents may be making decisions at a time when they are suffering distress about giving birth to and raising an "abnormal" child, it is difficult for parents to objectively determine the treatment that would be in their child's long-term best interests. Therefore, if courts are asked to determine whether parents should have the ability to consent to surgical alteration of their intersex children, they will need to resolve complex ethical issues.

#### 4. INFORMED CONSENT FOR THE SURGICAL ALTERATION OF AN INTERSEX CHILD: THE COLOMBIA DECISION

Only one high court has directly ruled on whether the traditional protocol is legally acceptable.<sup>18</sup> Because of a Court decision in 1995, doctors in Colombia were concerned about potential liability for performing genital surgery on intersex infants. Therefore, in two cases in which the physicians recommended genital surgery to the parents, the physicians refused to proceed without a court order. The parents of the two children sought court authority for the procedures to occur.

The Constitutional Court of Colombia considered the evidence supporting the traditional model as well as evidence that critiqued this model and supported a moratorium on infant intersex surgeries. The Court concluded that the contrary opinions put the law at an impasse: to prohibit surgeries until the children reach the age of consent would be engaging in social experimentation, but to allow the

surgeries to continue under the standard protocol would not ensure that the best interests of the children are protected.

To overcome this impasse, the court settled on a compromise approach. The Colombia court allowed parents to continue to consent to surgeries, but the court insisted that procedures be developed to guarantee that parents are consenting solely based upon their child's best interests and not their own self-interest. The court suggested that legal and medical institutions develop informed consent procedures that guarantee that the child's interests are the only concern. To ensure that the consent is truly informed, the court required that it be "qualified and persistent" and any procedures developed must meet the following requirements:

(1) The consent must be in writing.

(2) The information provided must be complete. The parents must be informed about the dangers of current treatments, the existence of other paradigms, and the possibility of delaying surgeries and giving adequate psychological support to the children.

(3) The authorization must be given on several occasions over a reasonable time period to make sure the parents have enough time to truly understand the situation.

The Colombia Court decided that surgical modification of intersex infants must be treated differently from other types of parental consent cases because the traditional model does not ensure that parents are in the best position to make a decision on behalf of their intersex children. The Court was concerned because parents typically lack information about intersexuality, intersexuality is viewed as a disease that must be "cured," and treating physicians convey a false sense of urgency to provide a quick cure. The Colombia court recognized that under these circumstances, parents could not easily distinguish their own fears and concerns from considerations of the "best interests" of their child.

The Colombia court decided that protecting the human rights of the infant required it to strike a balance between allowing parents full autonomy to consent to surgical alteration on behalf of their intersex infants and barring all intersex surgeries. Therefore, the court called upon legal and medical institutions to establish "qualified and persistent" informed consent procedures that protect the rights of the intersex child until comprehensive studies clearly establish the course of treatment that is in the child's best interests.<sup>19</sup>

## 5. INTERNATIONAL LEGAL DEVELOPMENTS

Colombia is the only jurisdiction in which the highest court has addressed the issue of parental authority to consent to surgery on behalf of an intersex child. Given the paucity of cases and legislation on point, it is impossible to predict with certainty how the courts of other nations would resolve this issue. Recent trends, however, indicate that international institutions are calling for greater protection of children's legal rights and greater respect for everyone's right to autonomy. In addition, legal institutions are generally enhancing the protections provided to other sexual minorities. None of these developments provides direct evidence of how courts in nations other than Colombia would rule if they were asked to resolve this issue. The

international trend toward greater protection of the rights of children and sexual minorities and a more expansive interpretation of the right to privacy and autonomy, indicate, however, that other courts may adopt an approach similar to the approach adopted in Colombia.

International recognition of the need to enhance the legal protection provided to children is reflected in the *Convention on the Rights of the Child*, which was adopted by the General Assembly of the United Nations on November 20, 1989.<sup>20</sup> This convention recognizes that children, because of their vulnerability, need special care and protection and reaffirms a child's special need for legal safeguards. The dominant medical management protocol for intersex infants practiced in many nations today does not ensure the protection of an intersex infant's fundamental human rights as defined in the Convention. Current medical practices regarding intersex infants may violate Articles 2, 3, 12, and 16 of the Convention.

Article 2 requires that children should not be discriminated against on the basis of sex. Current medical practices may violate that obligation. The current protocol emphasizes the need for males to be able to engage in satisfactory sexual intercourse over their potential desire to procreate. An XY infant, who is born with a phallus that is considered to be too small for penetrative sex in adulthood, is assigned the female sex. The genitalia are altered to appear "female" and the testicles are removed, even though such removal results in the sterilization of an otherwise fertile male. For XX children, the need to procreate, rather than the ability to engage in satisfactory sexual intercourse, is emphasized. An XX infant, who is capable of reproducing, typically is assigned the female sex to preserve her reproductive capability, regardless of the appearance of her external genitalia. If her "phallus" is considered too large to meet the guidelines for a typical clitoris, it is surgically reduced, even if the reduction reduces or destroys her capacity for satisfactory sex. In other words, males are being defined by their ability to penetrate and females are being defined by their ability to procreate. This protocol treats XY and XX children differently based upon gender stereotypes about the proper roles from men and women and could be considered a violation of Article 2.

Article 3 requires that in all actions concerning children, the best interests of the child shall be a primary consideration. The traditional medical protocol emphasizes the need to "normalize" the child. One of the motivations for "normalizing" the child is to ease the psychological discomfort of the parents and enhance their ability to bond with their child. Surgical alteration of a child that may result in involuntary sterilization, diminished capacity for sexual satisfaction, and a gender assignment that may be contrary to the child's gender identity does not ensure that the best interests of the child are a primary consideration and thus the traditional protocol may violate Article 3.

Article 12 protects children's rights to have their opinion taken into account in any matter affecting them. The traditional protocol ensures that children do not have input into decisions that have a profound effect on their lives, including their ability to procreate and achieve sexual satisfaction, because these decisions are being made when the child is too young to participate in the decision making process.



Article 16 protects children from interference in their right to privacy. Procreative decisions are considered a fundamental privacy right under the United States Constitution and the laws of many other nations. A court could potentially find that surgeries that result in involuntary sterilization infringe on the child's fundamental right to privacy under Article 16.

The *Convention on the Rights of the Child* provides enhanced safeguards to protect the rights of children. If the medical treatment of intersex infants is eventually litigated, courts may refer to the terms of the Convention and determine that surgical alteration of intersex children, as practiced under the traditional model, improperly infringes on the rights of children.

In addition, other legal developments in Australia, Europe, and the United States, in cases involving other sexual minorities, including transsexuals and homosexuals, indicate that these jurisdictions may be more likely to provide enhanced protection to intersex children. Just as the rights of children are being recognized, sexual minorities, who historically have been subjected to discriminatory treatment, are now being accorded greater legal protection.

### 5.1 Australia

The courts in Australia have not been asked to determine whether parents have the ability to consent to genital surgery on behalf of their intersex infants. The Family Court of Australia has addressed, however, the rights of intersex persons in other related areas. The most recent decisions by the Family Court indicate that if it were asked to resolve the issue of infant genital surgery, it would likely place significant emphasis on the intersex infant's right to autonomy.

In 1979, *In Marriage of C. and D. (falsely called C.)*,<sup>21</sup> Australia issued a decision that provided the least respect for the rights of intersex persons when it ruled that, an intersex person was neither a man nor a woman for purposes of determining his ability to marry. In this case, a wife sought an annulment of her marriage of 12 years claiming that her husband was not legally a man. The husband was a true intersexual with an XX chromosomal pattern and a combination of male and female biological aspects.<sup>22</sup> The husband had undergone a number of surgeries to modify his external sex organs and to remove his breasts so that his external appearance would be male. The court granted the wife's petition for annulment on the grounds of mistake because she believed she was marrying a male. Although the husband had male gonads and genitalia, he had the chromosomal configuration typical of a female. Therefore, the court concluded that he was neither a male nor a female.<sup>23</sup>

In 2003, in *Attorney General v. Kevin*,<sup>24</sup> the court rejected its decision in 1979 and greatly expanded the rights accorded to intersex and transsex persons. In determining that a female-to-male transsexual was a male for purposes of marriage, the court recognized that changes in social attitudes, advances in medical research, greater respect for the rights of children and international expansion of the right to privacy supported a finding that transsexuals are entitled to marry in their self-identified sex role.

In addition, Australian courts have been asked twice to determine the court's role in decisions by teens to undergo medical treatment that would physically alter their sex attributes to bring their bodies more into conformity with their gender identity. The judges in each case found that the teen's decision must be reviewed by a court, even if all the parties involved in the treatment decision are agree. The judges required court supervision because they found that there was a significant risk of making the wrong decision and the consequences of a wrong decision would be particularly grave.<sup>25</sup> The courts were concerned about the biological, social, and psychological consequences of the proposed intervention.

In its most recent decisions, the Family Court of Australia has followed the international trend of providing enhanced protection to sexual minorities and greater respect for the rights of children to privacy and autonomy. In addition, the court has indicated that it requires some type of judicial oversight of surgical or hormonal treatment that would alter a person's sex attributes because of the potentially grave consequences. Therefore, if Australian courts are asked to determine the appropriate treatment protocol for intersex infants, they are likely to follow the same approach as the Colombia court and require some type of oversight of the decision.

## 5.2 Europe

Although the European Court of Human Rights (ECHR) has not directly addressed the autonomy rights of intersexuals, it has resolved a number of disputes between member states and their transsexual<sup>26</sup> citizens seeking legal recognition as their self-identified sex. Recent ECHR decisions involving transsexuals illustrate the evolving expansion of the rights accorded to persons who fail to conform to sex and gender norms.

Transsexuals have made claims for decades that countries that refuse to grant transsexuals legal rights that comport with their self-identified sex violate Articles 8 and 12 of the *Convention for the Protection of Human Rights and Fundamental Freedoms (CPHRFF)*.<sup>27</sup> Article 8 relates to privacy and Article 12 relates to the right to marry and found a family.

Before its decisions in *Goodwin v. United Kingdom*<sup>28</sup> and *I v. United Kingdom*<sup>29</sup> in 2002, the ECHR consistently held that denying transsexuals the right to be legally recognized as their self-identified sex did not violate the *CPHRFF*. In 1986, the Court, by a 12-3 margin, decided in favor of the state.<sup>30</sup> Although the Court continued to rule in favor of the state and against transsex claimants, over time, the number of justices ruling in favor of the state diminished. In 1990, the margin was reduced to 10-8,<sup>31</sup> and in 1998, in an 11-9 decision, a sharply worded dissent indicated that based upon societal and scientific developments, the court might soon reject its earlier decisions. In 2002, the ECHR unanimously rejected its earlier decisions and ruled that states that deny transsexuals the right to be recognized as their self-identified sex violate Articles 8 and 12 of the *CPHRFF*.<sup>32</sup> In 2004, the European Court of Justice made a similar ruling.<sup>33</sup> In 2004, Great Britain, which for decades has been one of the countries that provided sparse protection to

transsexuals, joined other European countries and passed sweeping legislation to provide transsex persons expansive legal rights that recognize their self-identified sex.<sup>34</sup>

### 5.3 *United States of America*

Two recent developments in U.S. courts indicate that the U.S. may be moving towards providing greater legal protection to sexual minorities. First, the U.S. Supreme Court has expanded its conception of the right to liberty under the U.S. Constitution. In addition, recent decisions involving discrimination against gays, lesbians, and transsexuals indicate that the courts are now unwilling to allow discrimination based upon stereotypes of what constitutes a man or a woman.

The Supreme Court's decision in *Lawrence v. Texas*, in 2003, indicates that the court is willing to expand its conception of the right to liberty, which is protected by the Fifth and Fourteenth Amendments to the U.S. Constitution.<sup>35</sup> These amendments apply only to actions by the government, so the *Lawrence* decision would not apply directly to a parental decision to consent to surgical alteration of their intersex child. The reasoning and language in this decision indicate that the court supports the view that autonomy rights, especially regarding issues of sex must be protected. Because of ambiguous language in *Lawrence*, it is difficult to determine the exact implications of the decision. It is possible, however, that *Lawrence* portends a trend in the U.S. to acknowledge the importance of sexual self-determination.

In *Lawrence v. Texas*, the state of Texas adopted a statute that criminalized sodomy between two people of the same sex. The Supreme Court declared the statute to be unconstitutional because it unduly burdened an individual's right to liberty. According to the Court, a person's right to liberty is implicated because:

These matters involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment. At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life.<sup>36</sup>

The state's right to criminalize same-sex sodomy is clearly distinguishable from the parental right to consent to genital surgery on behalf of their intersex child. But, by using expansive language to define the liberty interest and by overruling precedent that had narrowly defined the liberty interest, the Supreme Court indicated its willingness to provide greater protection to choices that are central to dignity and autonomy, including issues related to sexuality.

Another line of cases in the United States, involving statutes that prohibit discrimination because of "sex," have also greatly expanded the rights of sexual minorities to be free from discrimination based upon sex stereotyping.<sup>37</sup> Before the last decade, U.S. courts consistently ruled that "sex" discrimination statutes did not protect sexual minorities, such as homosexuals and transsexuals, from discriminatory actions.<sup>38</sup> Recently, courts are determining that discrimination based

upon sex stereotyping about the proper roles for males and females constitutes unlawful "sex" discrimination.<sup>39</sup> None of these statutes specifically apply to intersex genital surgery, but the underlying rationale of these cases could be used by intersex persons if they are being surgically altered to conform their bodies to male and female stereotypes.

As previously discussed, the underlying basis for the dominant treatment protocol is in part based on inappropriate sex-role stereotypes because XY and XX infants are treated dissimilarly. For a male, the dominant concern is that the XY male have an "adequate" penis so that he can engage in intercourse. For an XX infant, the dominant concern is reproductive capability, rather than the capacity to engage in satisfactory sex. In other words, males have been defined by their ability to penetrate and females have been defined by their ability to procreate. This penetration/procreation gender stereotype is further reinforced by the medical community's emphasis on the need for a female to have an acceptable looking clitoris over her need for sexual satisfaction. Creation of a sensitive clitoris and a vagina that properly lubricates during sex is not the primary concern during female genital modification surgery. A successful surgical modification of a female is not defined as one that will likely result in her ability to achieve sexual pleasure; instead, it is defined as one that results in the creation of a proper sized clitoris (that may not be as sensitive as the unaltered clitoris) and a vagina that will allow penetration by a male's penis. Thus, the dominant model is based upon sex stereotypes.

Nothing in current U.S. legislation or case law specifically prohibits the continued use of the traditional treatment protocol. Recent cases regarding homosexuals and transsexuals, however, have indicated that U.S. jurists believe that sexual minorities should receive greater protection under the U.S. Constitution and some federal and state statutes. These cases could portend a trend to provide greater protection to intersex infants and could be used as persuasive authority to convince legislatures to adopt statutes or courts to rule in favor of providing greater protection to intersex children.

## 6. WHO SHOULD DECIDE?

The major difference between the alternative proposals turns on whether the ultimate decision makers should be physicians, parents, the intersex child, when she reaches the age of consent, or the courts. Until comprehensive studies are conducted that clearly indicate whether early genital surgery typically results in the potential for greater benefit or harm to the child, the decision cannot be left to physicians or delayed until the child reaches an age where she has the capacity to consent. Therefore, the remaining choices are granting the authority to parents to decide or requiring some type of review of parental decisions. Some experts believe that parents are uniquely qualified to make this decision, while others believe that it will be impossible or difficult for parents to divorce their self-interest from the child's best interests. Therefore, until studies more clearly indicate the model that is most

beneficial for the intersex child, some type of oversight of parental decisions is desirable. The question remains, however, whether it is in the best interests of the child to have the courts provide this review or whether the oversight should be undertaken by an institution other than a court.

When faced with this issue, the Colombian court wisely decided that new decision models must be created to protect the rights of the children. It did not, however, mandate judicial oversight of these matters. Instead, the court encouraged legal and medical institutions to develop informed consent procedures that would result in a consent that is "qualified and persistent." The court set minimal requirements for a qualified and persistent consent and required that: (1) the consent be in writing; (2) the parents receive full information about all the uncertainties involved in the alternative treatment protocols; and (3) the parental authorization must be given on several occasions over a reasonable time period.<sup>40</sup>

Judges are not experts in this area and some may not have heard of intersexuality, much less have a thorough understanding of the complex physical and psychological consequences that may accompany the different treatment models. Although some recent court decisions indicate a trend towards greater respect for people's right to control their gender identity and sexuality, a number of other decisions illustrate that courts may choose to ignore experts and rely on their own prejudices in sensitive areas involving sexuality and gender.<sup>41</sup> For example, some courts presented with scientific evidence about the nature of transsexuality have chosen to ignore the scientific evidence in favor of sources such as Webster's dictionary.<sup>42</sup>

The case that best illustrates the problems that may arise if this issue is litigated in the courts is a 1993 decision from the family court of Australia. *In re A* involved an intersex child with Congenital Adrenal Hyperplasia (CAH), who had been raised as a girl.<sup>43</sup> At puberty, A began to virilize and he self-identified as a boy. When A was 14 ½ years old, he sought surgical treatment to bring his physical appearance in line with his gender identity. No one opposed the procedure. A's desire was supported by his parents and the medical treatment team, which included a surgeon, an endocrinologist, a psychiatrist and a psychologist. Because the procedure would result in the sterilization of A, court approval was sought.

The court determined that although A had a general understanding of the problems involved with the proposed surgery, the court was not convinced that he was sufficiently mature to fully appreciate and objectively assess the various options. The court also decided that the parents did not have the power to consent on behalf of their child and the treatment decision required court supervision. The court decided that court authorization was necessary as a "procedural safeguard" because it was not clear which decision would be in the child's best interests and an incorrect decision would yield particularly grave results.

Although the court decided that granting A's request was the correct decision, the court seriously considered denying the petition. The court stated:

It is clear on all the material that the various treating experts regard this...as being highly desirable in A's interests. I had nevertheless considered the possibility of rejecting the application on the basis that it is only another three and a half years until A attains 18 years and at that stage it would be open to him to make his own decision.<sup>44</sup>

The court ultimately relied on the psychologist's evidence that delaying the surgery for three years posed a significant risk that A would commit suicide or suffer severe and irreparable psychological trauma. This possibility caused the court to grant A's petition. It is unclear how many other judges would have substituted their own judgment for that of the affected parties. Given that the judge in *In re A* was "sorely tempted," this possibility cannot be ignored.

Because judges are unlikely to have the knowledge to decide these issues and these requests may force judges to confront their own stereotypes about sex and gender, allowing one judge to determine the appropriate treatment for an intersex child is not ideal. Therefore, a fourth treatment protocol may be the best alternative to follow until comprehensive studies clearly indicate whether early genital surgery results in the potential for greater harm or good for the child. Instead of allowing a doctor, the parents, or a judge to control the outcome, a fourth alternative is to require the formation of committees to advise parents on alternative treatment options. These committees should consist of experts from all the relevant disciplines, including endocrinologists, paediatricians, psychologists, and sociologists as well as intersex adults who have experienced the different treatment protocols and parents who have been faced with this decision. These committees can serve four critical needs:

- They can provide guidance to the parents;
- They can ensure that any parental consent is qualified and persistent;
- They can gather data on the outcomes of different treatment models; and
- They can provide continuing education to intersex persons, parents, and treating physicians.<sup>45</sup>

By working together, advocates of each treatment model will be able to accomplish at least some of their goals. Those who support the traditional model will be able to continue to treat those patients whose parents consent, but physicians will no longer have to be concerned that they may later be sued because they failed to provide enough information for the consent to be truly informed. Those calling for a moratorium will not be able to halt to all surgeries, but they will know that a number of surgeries that would have otherwise been performed will not occur and that those that are performed will provide enhanced safeguards for the child. Those who call for parental control of these decisions will be satisfied that the decision still rests with the parents. Finally, all will be reassured that the ultimate decision will not be rendered by judges who may or may not be knowledgeable about these issues and who may render a decision based upon their own prejudices or stereotypes.

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## NOTES

- <sup>1</sup> Alice D. Dreger, "Ambiguous Sex—or Ambiguous Medicine? Ethical Issues in the Treatment of Intersexuality," *Hastings Center Report* 28 (1998): 27; Suzanne J. Kessler, *Lessons from the Intersexed* (1998).
- <sup>2</sup> Sharon Sytsma, "Ethical Dilemmas in Retrospective Studies on Genital Surgery in the Treatment of Intersexual Infants," *Cambridge Quarterly of Healthcare Ethics* 13 (2004): 394.
- <sup>3</sup> South Africa has considered whether to legislate in this area. *South African Press Association*, "Legislation Mooted to Regulate Intersex Surgery," 2004 WL 99626478. The city of San Francisco has also held hearings on this issue. "Historic Intersex Human Rights Hearing in San Francisco." [www.intersexinitiative.org/news/000119.html](http://www.intersexinitiative.org/news/000119.html)
- <sup>4</sup> John Money, "Hermaphroditism: Recommendations Concerning Case Management," *Journal of Clinical Endocrinology and Metabolism* 4 (1956): 547-556; John Money, Joan Hampson, and John Hampson, "An Examination of Some Basic Sexual Concepts: The Evidence of Human Hermaphroditism," 97 *Bulletin of Johns Hopkins Hospital* 97 (1955): 301-319.
- <sup>5</sup> Alice D. Dreger, *Hermaphrodites and the Medical Invention of Sex* (1998).
- <sup>6</sup> Martin T. Stein, David E. Sandberg, Tom Mazur, Erica Eugster and Jorge J. Daaboul, "A Newborn Infant With a Disorder of Sexual Differentiation," *Pediatrics* 114 (2004): 1473.
- <sup>7</sup> American Academy of Pediatrics Policy Statement, "Evaluation of the Newborn with Developmental Anomalies of the External Genitalia," *Pediatrics* 106 (July 2000): 138.
- <sup>8</sup> Intersex Society of North America. <http://www.isna.org/library/recommendations.html>
- <sup>9</sup> William G. Reiner and John P. Gearhart, "Discordant Sexual Identity in Some Genetic Males with Cloacal Exstrophy Assigned to Female Sex at Birth," *New England Journal of Medicine* 350 (2004): 333.
- <sup>10</sup> Alyssa Connell Lareau, "Who Decides? Genital-Normalizing Surgery on Intersexed Infants," *Georgetown Law Journal* 92 (2003): 129; Hazel Glenn Beh and Milton Diamond, "An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment on Infants with Ambiguous Genitalia?" *Michigan Journal of Gender and Law* 7 (2000): 1; Bruce E. Wilson and William G. Reiner, "Management of Intersex: A Shifting Paradigm," 9 *Clinical Ethics* 9 (1998): 360; Kenneth Kipnis and Milton Diamond, "Pediatric Ethics in the Surgical Assignment of Sex" *Journal of Clinical Ethics* 9 (1998): 398; Milton Diamond and Keith Sigmundson, "Management of Intersexuality: Guidelines for Dealing with Persons With Ambiguous Genitalia," *Archives Pediatric Adolescent Medicine* 151 (1997): 1046; Cheryl Chase, "Surgical Progress is not the Answer to Intersexuality," *Journal Clinical Ethics* 9 (1998): 385; <http://www.isna.org/drupal/agenda>
- <sup>11</sup> <http://www.isna.org/drupal/agenda>
- <sup>12</sup> Jorge Daaboul and Joel Frader, "Ethics and the Management of the Patient with Intersex: A Middle Way," *Journal of Pediatric Endocrinology and Metabolism* 14 (2001): 1575.
- <sup>13</sup> S. F. Ahmed, S. Morrison, I. A. Hughes, "Intersex and Gender Assignment; the Third Way?" *Archives of Disease in Childhood* 89 (2004): 847.
- <sup>14</sup> British Association of Pediatrics Statement, *Statement of the British Association of Pediatric Surgeons Working Party on the Surgical Management of Children Born with Ambiguous Genitalia*. <http://www.baps.org.uk/documents/Intersex%20statement.htm> (July 2001).
- <sup>15</sup> American Academy of Pediatrics, Committee on Bioethics, "Informed Consent, Parental Permission, and Assent in Pediatric Practice, in Policy Reference Guide," *Pediatrics* 95 (1995): 314.
- <sup>16</sup> *Parham v. J.R.*, 442 U.S. 584, 602 (1979).
- <sup>17</sup> *In the Matter of Romero*, 790 P.2d 819 (Colo. 1990); *Estate of C.W.*, 640 A.2d 427 (Pa. Super. 1994).
- <sup>18</sup> Sentencia No. SU-337/99; Sentencia No. T-551/99.
- <sup>19</sup> *Ibid.*
- <sup>20</sup> 1989 *Convention on the Rights of the Child*.
- <sup>21</sup> (1979) 35 F.L.R. 340.
- <sup>22</sup> *Ibid.* 342.
- <sup>23</sup> *Ibid.* 345. The court stated: "I am satisfied on the evidence that the husband was neither man nor woman but was a combination of both, and a marriage in the true sense of the word...could not have

- taken place and does not exist." *Ibid.* As a non-man/non-woman the implication of this court's holding is that he could not marry anyone at all.
- <sup>24</sup> *Attorney General v. Kevin*, Family Court of Australia (2003) 172 FLR 300.
- <sup>25</sup> *In Re A*, Family Court of Australia (1993) 16 FLR 715 (involving a request by an intersex teen who had been raised as a girl but whose body virilized at puberty who sought to further masculinize his body to bring it into conformity with his gender identity); *Re Alex*, Family Court of Australia (2004) 31 Fam LR 503 ¶ 176 (involving a transsex teen who sought sex modification surgery).
- <sup>26</sup> A transsexual is someone whose known biological sex markers are all congruent at birth, but who has a gender self-identity that does not conform to these biological factors.
- <sup>27</sup> *European Convention for the Prevention of Human Rights and Fundamental Freedoms*, signed 4 Nov. 1950, entered into force 3 Sep. 1953.
- <sup>28</sup> *Goodwin v. United Kingdom*, European Court of Human Rights (2000) 35 E.H.R.R. 18.
- <sup>29</sup> *Case of I. v. the United Kingdom*, European Court of Human Rights (2002) 36 E.H.R.R. 53.
- <sup>30</sup> *Rees v. United Kingdom*, European Court of Human Rights (1987) 2 FLR 111.
- <sup>31</sup> *The Cossey Case*, European Court of Human Rights (1991) 2 FLR 492.
- <sup>32</sup> *Goodwin v. United Kingdom*, European Court of Human Rights (2002) 35 E.H.R.R. 18; *Case of I. v. the United Kingdom*, European Court of Human Rights (2002) 36 E.H.R.R. 53.
- <sup>33</sup> *K.B. v. National Health Service Pensions Agency and Secretary of State for Health*, European Court of Justice (2004) Eur. Ct of Justice 0.
- <sup>34</sup> See Gender Recognition Act, 2004, Eliz. II, c. 7 (Eng.).
- <sup>35</sup> *Lawrence v. Texas*, 539 U.S. 558 (2003).
- <sup>36</sup> *Lawrence v. Texas*, 539 U.S. 558, 574 (2003).
- <sup>37</sup> A number of federal statutes prohibit "sex" discrimination. See e.g., Title VII of the Civil Rights Act of 1964, 42 U.S.C. § 2000e-2(a)(1) (prohibiting employment discrimination); Title IX of the Higher Education Act, 20 U.S.C. § 1681 (prohibiting discrimination in education); The Equal Credit Opportunity Act, 15 U.S.C. § 1691 (prohibiting discrimination in by lending institutions).
- <sup>38</sup> See, e.g. *Wrightson v. Pizza Hut of Am., Inc.*, 99 F.3d 138, 143 (4<sup>th</sup> Cir. 1996); *Williamson v. A. G. Edwards & Sons, Inc.*, 876 F.2d 69, 70 (8<sup>th</sup> Cir. 1989); *DeSantis v. Pacific Tel. & Tel. Co.*, 608 F.2d 327, 329-332 (9<sup>th</sup> Cir. 1979); *Sommers v. Budget Marketing Inc.*, 667 F.2d 748 (8<sup>th</sup> Cir. 1982); *Holloway v. Arthur Andersen*, 566 F.2d 659 (9<sup>th</sup> Cir. 1977); *Dobre v. Amtrak*, 850 F. Supp. 284; *Doe v. U.S. Postal Serv.*, 1985 WL 9446 (D.D.C. 1985); *Terry v. E.E.O.C.*, 1980 WL 334 (E.D. Wis. Dec. 10, 1980); *Powell v. Read's Inc.*, 436 F. Supp. 369 (D. Md. 1977); *Voyles v. Davies Med. Ctr.*, 403 F. Supp. 456 (N.D. Ca. 1975), aff'd mem., 570 F.2d 354 (9<sup>th</sup> Cir. 1978); *Grossman v. Bernard's Township Bd. of Educ.*, [1975] 11 E.P.D. (CCH) P10,686 (D. N.J. 1975), aff'd mem., 570 F.2d 319 (3<sup>rd</sup> Cir. 1985).
- <sup>39</sup> See, e.g., *Nichols v. Azteca Rest. Ent. Inc.*, 256 F.3d 864 (9<sup>th</sup> Cir. 2001); *Rene v. MGM Grand Hotel, Inc.*, 305 F.3d 1061 (9<sup>th</sup> Cir. 2002); *Schmedding v. Tnemec Co. Inc.*, 187 F.3d 862 (8<sup>th</sup> Cir. 1999); *Heller v. Columbia Edgewater Country Club*, 195 F. Supp. 1212 (D. OR 2002); *Samborski v. West Valley Nuclear Serv., Co.*, 2002 WL 1477610 (W.D.N.Y. June 25, 2002); *Centola v. Potter*, 188 F.Supp.2d 403 (D. MA 2002); *Ianetta v. Putnam Investments, Inc.*, 142 F.Supp.2d 131 (D. MA 2001); *Jones v. Pacific Rail Serv.*, 2001 WL 127645 (N.D. IL 2001); *Smith v. City of Salem*, 2004 WL 1745840 (6<sup>th</sup> Cir. 2004); *Schwenk v. Hartford*, 204 F.3d 1182, 1201 (9<sup>th</sup> Cir. 2000); *Rosa v. Park West Bank & Trust Co.*, 214 F.3d 213 (1<sup>st</sup> Cir. 2000); *Johnson v. Fresh Mark, Inc.*, 2003 WL 23757558 (N.D. Ohio Jan. 30, 2003); *Doe v. United Consumer Financial Serv.*, 2001 WL 3350174 (N.D. Ohio Nov. 9, 2001).
- <sup>40</sup> Sentencia No. T-551/99.
- <sup>41</sup> See e.g., *In re Estate of Gardiner*, 42 P.3d 120, 124 (Kan. 2002); *Littleton v. Prange*, 9 S.W.3d 223, 226 (Tex. App. 1999); *Kantaras v. Kantaras*, 884 So. 2d 155 (Fla. Dist. Ct. App. 2004).
- <sup>42</sup> *Gardiner*, supra note 38.
- <sup>43</sup> Family Court of Australia (1993) 16 FLR 715.
- <sup>44</sup> *Ibid.*
- <sup>45</sup> These committees must be mindful of the problems that may develop when ethics committees are asked to render decisions about medical treatment. See, e.g., Robin Fretwell Wilson, "Hospital Ethics Committees as the Forum of Last Resort: An Idea Whose Time Has Not Come," *North Carolina Law Review* 76 (1998): 353.