INTERSEX EDUCATION, ADVOCACY & THE LAW: THE STRUGGLE FOR RECOGNITION AND PROTECTION

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When he first received the assignment to do a program on intersex issues, Steph Watts said he was "excited to be doing a show on Internet sex." The director of "Size Matters," an episode of "In the Life,"[1] revealed his initial ignorance about the existence and treatment of intersex children before showing his piece to an international audience of activists, lawyers and educators at Benjamin N. Cardozo School of Law, Yeshiva University on February 22, 2005. A theme that would be repeated throughout the symposium, Intersex Education, Advocacy and the Law, Mr. Watts' reaction to the word intersex is not uncommon: few people are familiar with the conditions and experiences of intersex people. Originally used as a term to refer to bisexuals in the late 19th century, the word intersex has since replaced the antiquated term hermaphrodite to refer to individuals born with chromosomal or genital variations that differ from what is considered standard male or female. As many as 65,000 children worldwide are born with an intersex condition each year, some estimating that between 150 and 300 are born in the United States alone. Many, if not most, of the children born with genital variations are subjected to what the medical literature calls sex assignment surgery. These surgeries can range from a reduction in the size of a female's clitoris to full reconstruction of the genitals and a change of gender.

Intersex activists and advocates argue that these surgeries are generally cosmetic, that they are emotionally, psychologically and physically scarring, and that they are unnecessary for the healthy development of the intersex child. Traditionally, however, the medical community has insisted that the surgeries are a necessary step toward stabilizing gender development, normalizing the child, and allowing parents to properly bond with their child.

In the first gathering of its kind, the *Cardozo Women's Law Journal* and Bodies Like Ours,[2] an intersex support and advocacy group, brought together panelists from six different countries and participants from around the country and

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[1] More information on "In the Life: The Gay and Lesbian Newsmagazine on Public Television" and copies of the video can be requested at http://www.inthelifetv.org.

[2] *See* http://www.bodieslikeours.com.

the globe. The goal of the two-day symposium was to continue a dialogue begun a decade ago by adult intersex patients seeking to change the way the medical community and society as a whole treats children born with intersex conditions through educational efforts, advocacy work and legal remedies.

INTERSEX ON FILM

Mr. Watts introduced his news segment "Size Matters" by saying that anyone who has ever been made to feel ashamed or abnormal can relate to the plight of intersex individuals. The episode follows the personal stories of intersex adults and parents of intersex children and shows interviews with doctors and scholars familiar with the issue. Betsy Driver, the director of Bodies Like Ours, a leading activist, and the news segment's producer, is an intersex adult who was born with an enlarged clitoris who shared the story of her childhood. At three months old, doctors performed a clitorectomy, removing her clitoris "to the nub" and destroying all sensation.

In contrast to Ms. Driver's experience, the segment shows an interview with Lisa, the mother of a little girl born with congenital adrenal hyperplasia, or CAH, who opted to forego genital surgery on her daughter upon the advice of her physician. Intersex children born with CAH are unable to properly make cortisone and instead their adrenal glands produce excessive amounts of virilizing hormones which can cause a female's genitals to appear masculine. Although Lisa initially felt strongly that her daughter should undergo genital normalizing surgery because that was the only way she thought her daughter "could have a good life," her opinion changed after learning more about the experiences of adult intersex patients. "Who has the right to do that to anybody else's body?" she said. "Doctors, parents—anybody?"

In the episode, Mr. Watts also discusses the San Francisco Human Rights Commission's hearings on the treatment of intersex patients in May 2004 and shows clips of testimony from parents of intersex children. One parent, struggling to maintain her composure, is shown telling the Commission that her eleven-year-old daughter has tried to commit suicide twice because she feels so ashamed of her body. Ms. Driver emphasizes that the Commission drew patients, parents, medical ethicists, scholars and more, all advocating overwhelmingly against the current medical protocol, and expresses optimism at the potential effects such a recommendation could have on the current medical approach to intersex births.

The next film, *Is It a Boy or a Girl?*, a Discovery Channel documentary, also follows the stories of intersex individuals, all of whom underwent surgery as children, while also giving prominent placement to Dr. Kenneth Glassberg, the Director of Pediatric Urology at Children's Hospital of New York. As Linda Edwards, a Ph.D. student at the University of Rochester, pointed out in her discussion after the showing, this film brings to light the clashing perspectives of intersex activists and the medical community. Dr. Glassberg is a proponent of early genital surgery and provides a very different perspective from the intersex

activists shown in the film, one directly aligned with the traditional medical protocol.

At the center of the piece, though, is the story of Cheryl Chase, the founder of the Intersex Society of North America[3] (ISNA) and arguably the driving force behind the early intersex rights movement, who was born with a very large clitoris that resembled a penis. Doctors kept her away from her parents for three days after her birth before diagnosing her with male micropenis and undescended testes and releasing her. After a year and a half, her parents' continued concern over their child—then named Charles—drove them to seek out a specialist who conducted chromosome testing and determined that Charles was XX, or female. The specialist told Charles' parents to raise her as a female, have her enlarged clitoris removed, change her name to one that sounded similar to Charles, move to a different town and destroy all evidence that Charles ever existed. They did.

It was not until the age of 19 that Cheryl sought out her medical records and after three years discovered her condition. It took another 16 years and suicide contemplation for Ms. Chase to discuss her condition with anyone. When her feelings of hopelessness shifted to anger, she says, she decided she would no longer be ashamed of her body. She sought out other intersexuals and eventually founded ISNA.

The stories of other intersexuals in the film closely mirror Ms. Chase's experience of shame and dissatisfaction with the treatment they received. Dr. Glassberg, however, says that the healthy psychological development of intersex children requires sex assignment and normalizing surgery before 15 months of age. Like many doctors who support early surgery, Dr. Glassberg feels surgery is important for the parents of intersex children, too: "If the parents have a child with a very large phallus that looks like a penis, can that parent feel comfortable training that child as a female?" Dr. Glassberg also raises questions about what parents would tell the babysitter, family members, and even the child, him—or herself.

These questions weighed heavily on Rick and Tina, a couple with a small daughter who was born with CAH. It took nine days for doctors to determine that baby Katrina was a girl, after which she was placed on female hormones and early surgery was recommended. Katrina had an enlarged clitoris and urinary tract problems as a result of the CAH. Tina says that during those nine days she was bombarded by phone calls and messages from family and friends wanting to know the sex of the baby and was concerned about what to put on the birth certificate.

While Tina acknowledged that the decision was a difficult one to make, she and Rick decided to go ahead with surgery to address the urinary tract problems and reduce the clitoris. When the time came for surgery, Dr. Glassberg, the treating physician, decided reduction of the clitoris was unnecessary because the female hormones had already made it smaller.

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[3] *See* http://www.isna.org.

Though intersex activists would likely consider this situation a partial success—the medical condition of the urinary tract was treated but the sensation was retained in the clitoris—Linda Edwards noted that Katrina's clitoris was still deemed too large and "had" to be reduced. That it was done so by hormones or by surgery does not change the essential characterization of the enlarged clitoris as unacceptable.

Adding yet another perspective to the mix, the film features a mother and son in the Dominican Republic where there is known to be a cluster of children born with 5-alpha reductase, in which the body cannot properly process testosterone. This causes XY male children to develop physically and socially like XX female children until puberty, when their bodies masculinize and their gender identities shift to male. The contrast between the community in the Dominican Republic, which accepted and adjusted to Roberto's shifting sex as he became a man, and one in the United States, where that same child may have been surgically assigned a female sex and raised as a girl, is stark.

After the film, Ms. Edwards, a Ph.D. student in the Visual and Cultural Studies Program at the University of Rochester, brought attention to the different perspectives shown and how they impact the debate over the treatment of intersex children. She noted, for example, that in the film Dr. Glassberg spoke in terms of "we," bringing the weight of the medical community, while the intersexuals spoke in personal terms, highlighting their own experiences and placing the focus on the individual patient. Ms. Edwards also noted that while the scientific perception of genitals seems to focus on conformity in size and shape and as a way to distinguish between boys and girls, for intersexuals interviewed, genitals represent the capacity to experience pleasure and passion.

While several adult intersexuals in the film expressed and seemed to accept the sense that they do not feel wholly male or wholly female, rather somewhere in between, for Dr. Glassberg and others who share his perspective, Ms. Edwards said, intersexuals are simply not "fully male or fully female;" they are lacking and depend on the medical community to provide them with an answer. The irony, she points out, is that even with 65,000 intersex births a year, doctors are still remiss to have real answers to the questions raised by intersex births.

CLASSIFYING GENDER: CULTURE IMPERATIVES AND LEGAL CONSTRAINTS

The first panel discussion of the symposium focused on the social construction and legal definition of gender and how that informs the intersex rights movement. Moderated by Dr. Chris Straayer, Chair of the Department of Cinema Studies at New York University, each panelist discussed their current papers or projects and then took questions from the audience to facilitate discussion.

Jo Bird, a Ph.D. candidate and member of the faculty of law at the University of Melbourne in Australia, presented her thesis work on bioethics and human rights. "A requirement of citizenship is sex," she said. "To be considered as completely human by the law, one must have a recognizable, classifiable sex." It is

the medical intervention that gives the intersex child its humanity in the eyes of the law, she said.

Ms. Bird told of a case involving a 13-year-old child in Australia named Alex who identified as transgendered. When Alex's parents sought to have hormones administered to help Alex's body more closely conform to her gender identity, the government intervened and the case went to court. In its ruling against the parents, the Australian court said that Alex was not mature enough to provide consent to such treatment. The law, Ms. Bird stressed, treated this 13-year-old's choice as one so grave that a court order was required to authorize the treatment. She explained that even adults who seek to legally change their sex are required to jump through certain hoops, she said, to determine that they are truly transgendered before a sex-change operation can be performed. In contrast, intersex children are legally subjected to sex assignment surgery before they can even talk or express an opinion on the matter.

Ms. Bird advocated that the first step in rendering intersex legally visible is to focus on language. Before true legal recognition can occur, the language used to discuss intersex must be changed. Australia, she pointed out, is the first country to legally recognize intersex as an identity; it defines intersex as "a person who, because of a genetic condition, was born with reproductive organs or sex chromosomes that are not exclusively male or female." This, Ms. Bird believes, is a step towards legal recognition of intersex.

Ms. Bird derided the opinion offered by many health care providers that surgery is necessary to help the parents adjust to the child's condition. Under the Convention on the Rights of the Child, a child's rights should be the primary consideration. She pointed out that parents do not have a right to be comfortable with their newborn baby, and surgery to that end is a form of eugenics to "erase human indifference."

Dr. Natasha Gruber, a Professor of Philosophy and Gender Studies at the Universities of Vienna and Innsbruck in Austria, focused her presentation on the interrelation of sex and gender and its impact on sexual identity. Dr. Gruber explored the theories of gender and sex that other scholars, such as Anne Fausto-Sterling, Judith Butler, and Michel Foucault, have developed and promoted for further discussion of a more fluid understanding of gender.

Dr. Gruber drew on Judith Butler's theory of gender as performance, as a reflection of society's demands on each of us to perform our respective gender in specific ways. Intersexuals, she said, undermine the gender binary by highlighting the fact that nature produces many varieties of sexes and bodies, but those variations are subsumed into two—and only two—sexes. Dr. Gruber discussed with approval the proposal by Anne Fausto-Sterling that we work towards expanding sex categories to either five different sexes or even a continuum.

There are almost more questions in the debate over how to address the gender binary than there are answers, Dr. Gruber said: How would an open gender culture impact sexuality and desire, which are also generally treated as binary? How do we

develop a new concept of sexuality not centered around penetration? And what kind of training and culture would be necessary to develop a society with a gender continuum?

Dr. Gruber's presentation was followed by Jessica Knouse, Esq., an Appellate Court attorney at the New York State Supreme Court, Appellate Division, Third Department in Albany, NY, who discussed her paper entitled "Intersexuality and the Social Construction of Anatomical Sex." Identity, Ms. Knouse said, is a product of five components: anatomy, sexual orientation, personality, behavior and desire. According to Ms. Knouse, two cultural presumptions influence identity. The first presumption is that each of these components operates in a binary system. The second is that all of the components will be congruent.

Unlike the cultural presumptions, Ms. Knouse said that biology tells a very different story about identity. An individual's personality can be, and often is, a conglomeration of traits traditionally associated with male or female. As the existence of intersexuals demonstrates, anatomy can be a conglomeration as well. And, she said, it is clear from the existence of homosexuals that one can have a female anatomy and a male sexual orientation. Ms. Knouse argued that even though anatomy itself is complex and goes beyond genitalia, the external morphology, or external markers of sex, is privileged above all others.

The law uses sex for three primary purposes, Ms. Knouse said: for official documents, for marriage, and for interpreting anti-discrimination provisions. In all three cases, the law accepts both the presumption of a binary system and that of congruity of components. When the law uses sex for government documents, it is generally based solely on external morphology at birth. For purposes of allowing marriage, Ms. Knouse explained that the law again relies on genitalia, and sometimes chromosomes, at the time of birth. When cases involving transgendered individuals arise, most courts base the sex determination on immutable characteristics, such as chromosomes. When sex is used to interpret anti-discrimination legislation, Ms. Knouse said courts have defined sex discrimination broadly. The Supreme Court, she explained, has recognized that anatomy is not the only factor in discrimination, but that an individual can suffer discrimination for failing to conform to the gender binary.

Ms. Knouse points out that traditional avenues of legal redress for patients are unrealistic as applied to intersexuals: Lack of informed consent is difficult to prove and often barred by statutes of limitations, and medical malpractice suits are typically unsuccessful because doctors are not departing from the existing medical custom. She argues that a complete ban is the most effective way to address the issues raised by intersex surgeries.

In addition, Ms. Knouse proposes that the law be stripped of legal sex categories. She notes that legislation already shows a trend "towards diminishing the influence gender has on the law and society," and she visualizes a three-phase change in the way the law deals with sex. In Phase One, the law would recognize

intersex as a discrete sex, as Australia has. This, she said, would promote recognition and acceptance of human ambiguity. In Phase Two, she advocates for categories of "absolute" and "ambiguous": male and female are absolute, intersex is ambiguous. Initially, she recognizes, those in the ambiguous category may be a minority, but in Phase Three, she envisions more people feeling comfortable with the idea of being ambiguous. Incongruity and ambiguity, she argues, would naturally grow to include more than just physiology and the number of people identifying as ambiguous would eventually make it the majority.

THE PERSONAL BECOMES POLITICAL

Betsy Driver kicked off the second day of Intersex Education, Advocacy and the Law with a moving speech about the personal impact of the current medical protocols. Ms. Driver began with her own story growing up intersex and subjected to the indignities of medical intervention. Waking up in the wee hours of the morning with men in white coats standing above her, Ms. Driver recalls the doctors telling her they just wanted "a little look-see" to see what she looked like "down there." Her mother, she said, told her that she was the only one with this kind of condition, but that by allowing the doctors to study her, she was helping to make sure this never happened to anyone else. Of course, that was not true, but it is the story doctors told her mother to justify making her what she called "an object of spectacle" for the physicians.

Ms. Driver emphatically condemned the practices some doctors, such as those who oversaw her care, employ in order to gain consent from parents. Ms. Driver said she has met hundreds of adult intersexuals and parents of intersex children, and has heard stories of doctors threatening to call social services agencies with allegations of child neglect if the parents do not consent to treatment, in addition to the more common claims that if they do not perform surgery the child is more likely to become a homosexual, have life-long gender identity disorders, experience traumatic teasing, and possibly even commit suicide.

Ms. Driver said that there is no research indicating surgical intervention improves even basic quality of life for an intersex patient. "New research does show, though, myriad negative side effects: damaged self-esteem, painful and unexplained scarring, inability to orgasm, repeated surgeries, adults identifying as the gender they were prior to medical intervention," and still more. More than the physical consequences, Ms. Driver emphasized, the real trauma of medical intervention and sex assignment surgery stems from the secrecy that surrounds it and the shame that comes from knowing one's genitals and sex are so embarrassing that it isn't even acknowledged. "It's the lies told to us by our parents and caregivers because they were told those lies."

Despite her experience and that of thousands of others just like her, Ms. Driver expressed optimism and hope about the hearings held last year by the San Francisco Human Rights Commission, expected to release recommendations favorable to intersex advocates this year. Those hearings marked the first time

intersex issues have been considered by a legislative body anywhere in the United States, she said, and along with increased media coverage and incorporation into academia, it makes this an exciting time to be involved in the intersex movement. "It's a great start," Ms. Driver said. "But at the end of the day, we need to remember it is only the beginning."

THE CULTURAL [IL]LOGIC OF "NORMALIZATION" SURGERY

Dr. Suzanne Kessler, Dean of the School of Natural and Social Sciences at Purchase College, SUNY, and author of "Lessons From the Intersexed," moderated the first panel of the day. The discussion began with historical perspectives on the development of the current medical protocols for intersex children.

Dr. Geertje Mak, a Visiting Scholar from the Netherlands at the New York University Centre for the Study of Gender and Sexuality, focused exclusively on adult hermaphrodites in the late nineteenth and early twentieth centuries. She began with the story of a young woman who appeared at her doctor's office with her father to demand that he remove all vestiges of masculinity. The doctor found that she was mistakenly identified as a girl at birth, but was really a man. The young woman was adamant that she would not be able to marry unless the doctor performed surgery. Concerned about allowing fraud in a marriage, the doctor refused to help her. However, he suggested she change the sex on her birth certificate. When the young woman and her father refused, arguing that she would become a pariah in the community, the doctor contacted the authorities to request a civil sex change on her behalf. He was told that the law does not require the birth certificate to be accurate and that a change could only be made at the behest of the individual herself.

Dr. Mak's story demonstrated that at the turn of the last century, it was the doctor who resisted surgical intervention, not the hermaphroditic patient. The 250 cases she studied from Western Europe and the United States from the nineteenth century show that the medical community gained its power of intervention in this way. Not all doctors were as socially concerned as the aforementioned doctor. Dr. Mak also spoke of a doctor who exploited his patient's desperation to marry in order to gain her "consent" to a very dangerous and uncommon surgery for his own research. But contemporary critics decried the use of the surgical process employed and stressed that a doctor's duties are to help the patient. Some doctors, she said, even promoted allowing the hermaphroditic individual to choose their sex according to their "inner psychological disposition."

Exploring this history and the interactions earlier intersex patients had with medicine is important to understand the development of the current medical model of treatment. Dr. Mak stated, "If we want to understand how sex was normalized in this new constellation between doctor and patient, we have to understand how these translations back and forth took, and take, place, and how they are negotiated."

A discussion of the history of intersex medical intervention in the 20th century continued with Dr. Alison Redick, an Andrew W. Mellon Postdoctoral Fellow at Wesleyan University's Center for the Humanities. Her presentation, entitled "What Happened at Hopkins," focused on the period between 1916 and 1955, when the current treatment protocols took shape. Dr. Redick's analysis of over 100 case studies from that period determined that in the case of an intersex birth, doctors would make an approximate sex assignment, but would then wait until puberty to determine if contradictions in sex developed. Those contradictions, she said, were accepted as "inevitable consequences of intersex conditions," and were not considered social or medical emergencies.

That all changed in 1955, when the theories of Dr. John Money, a researcher at Johns Hopkins University, were implemented. Those theories, known as the Hopkins Protocol, provided the framework for surgical intervention and surgical "normalizing" surgeries practiced today. Dr. Redick suggested that Dr. Money's theories were revolutionary because he argued that the sex of rearing was a more reliable factor for determining psychological sex and sexual orientation than gonads, which had previously been relied on. "The protocols were built on the notion that perfect genders can be achieved in intersex subjects as long as all evidence of contradiction was eliminated . . . . [They] are contingent upon a dangerously normative conception of gender according to which people should always conform to a masculine or feminine ideal." But, she noted, if you take away the ideal or reveal it as impossible, "the whole enterprise falls apart."

Shifting away from an historical analysis, Dr. J. David Hester, a Fellow at the Centre for Rhetorics and Hermeneutics at the Alexander von Humboldt-Stiftung Foundation in Germany, offered a rhetorical perspective to the issues faced by intersexuals. Dr. Hester's work "analyzes the ways in which medicine creates and reinforces rhetorical contexts and the resultant effects upon participants, treatment paradigms and outcomes."

Dr. Hester identified several consequences of the rhetorical contexts employed by the medical community in response to intersex. First, the medical community rejects empirical evidence that indicates science uncovers a multiplicity of possible genders. Rhetorical invention, he said, necessitates medical intervention. Doctors speak to other doctors in a way that reinforces the status quo and the current protocols, Dr. Hester said, but speak to parents of intersex children in a way that will socialize them to the status quo. "Can one be said to have freely given consent in a rhetorical context that selects and interprets data concerning, represents its findings about, and employs treatment for overcoming intersexuality *as* a pathology?" he asked. In order to legitimize surgical intervention, the medical community has developed a rhetorical framework for its necessity: the social emergency.

Another consequence is that the patient enters a lifetime of medical management because it is impossible to heal. Dr. Hester asked, "What happens when we discover that medical intervention, usually thought of as the primary

means by which people heal from disease, not only fails to heal but creates a context antithetical to healing?" So, he said, the intersex community has found and developed its own, alternative forms of healing. Ironically, Dr. Hester said, the healing is not from the underlying medical condition but from the harm caused by the medical community.

Dr. Katrina Karkazis, a cultural anthropologist and Research Associate at the Center for Biomedical Ethics at Stanford University, has participated in medical meetings and conducted interviews with clinicians, patients and parents of intersex individuals as part of her research. Dr. Karkazis began her presentation by noting that the treatment of intersex conditions has shifted over time, and that justifications for continued surgical intervention have even changed, in response to confrontations with adult intersex patients and evolving medical knowledge. "[But] what I want to suggest," she said, "is that this picture is necessarily incomplete and obfuscates a cultural logic which assumes a certain connection between genitals, gender and sexuality that makes these surgeries seem necessary, even inevitable." She continued, "[i]t is these connections, not arguments about techno-scientific capabilities, that enable feminizing genital surgeries on females to continue."

Dr. Money's theory that sexuality and sexual orientation are an integral part of one's gender role, she said, is still present in the way clinicians think of intersex patients. Dr. Karkazis described a conversation with one doctor who emphasized the need to ensure proper "sexual function" in one of his female intersex patients. By sexual function, though, the doctor was referring to sexual intercourse. The assumption that other sexual acts that provide pleasure are consistently subordinated to *the* sexual act, she said, demonstrates that intercourse is still seen as the "meat and potatoes" of sex and that heterosexuality is the norm upon which all considerations of sexual function is based.

Dr. Karkazis emphasized that this assumption acts to deny the sexual experiences of people with atypical genitals. "In a culture that requires discrete and binary gender divisions," she said, "bodies that threaten those divisions threaten the whole system upon which binary gender rests."

The final presenter on the panel was Dr. Sharon Preves, a professor of Sociology at Hamline University in St. Paul, Minnesota, and the author of *Intersex and Identity*. Her book is based on life-history interviews with several dozen intersexuals from North America, most of whom had genital surgery as a child.

Dr. Preves joked that one comment from an interviewee named Sherri probably sums everything up better than the whole book:

> If doctors really want to do something for their intersexed patients, I would say the first thing is [to] put the intersex person in touch with other people who are intersexed. Number two is see number one. And number three is see number one. That's it. Doctors think that you're going to kill yourself if you find out the truth. People kill themselves because they feel alone and isolated and helpless; that's why they kill themselves. When doctors

> don't tell their patients the truth, they're cutting them off from the opportunity of incredible support.

Intersex, Dr. Preves said, is a social problem, not a medical problem; it is considered a social deviance. Dr. Preves mapped out the process of identity negotiation she developed from her interviews with adult intersexuals. This process involves three stages: the stigmatized self, a product largely of being under the medical gaze and exploited by doctors for research; the search for the "authentic" self, engaging in personal archaeology and piecing together one's medical past; and the renegotiated self, which often comes from participating in intersex support and activism.

In all her interviews, Dr. Preves said, there were three consistent messages intersexuals received about themselves that cut across diagnosis, gender and sexual identity lines: they are objects of medical interest and treatment; they were not to know what was wrong with them and why they were receiving such treatment; and such procedures were in their best interest and should remain uncontested.

INFORMING CONSENT: WHOSE 'BEST INTEREST' IS AT STAKE?

Dr. Ed Stein, a professor of Law at Benjamin N. Cardozo School of Law, moderated the next panel, which focused on the legal consequences of the informed consent doctrine as it relates to intersex surgeries. Dr. Stein is the advisor for the *Cardozo Women's Law Journal* and the author of "The Mis-Measure of Desire: The Science, Theory and Ethics of Sexual Orientation," among other publications.

The first speaker was Dr. Hazel Glenn Beh, a professor of Law at William S. Richardson School of Law, whose presentation was entitled "Informed Consent and Parental Authority." Dr. Beh began by articulating the defects in the way informed consent is gained in the case of genital surgeries: a false sense of urgency is communicated, information is tightly controlled, patients are surrounded by secrecy, parents are given limited or inaccurate information about the condition and possible outcomes of the surgery, information is presented in the context of the binary imperative, and the law presumes that parents will act in the child's best interest.

Legally, parental authority is not unlimited, Dr. Beh said. She discussed several areas where parents' rights are curbed by the state, such as where the parent has a conflict of interest, where questions of sterilization arise, and even where non-therapeutic experimental therapies are suggested for the child, among others.

Although the law has traditionally seen parental rights as fundamental, Dr. Beh said there are important justifications for such intrusions on parental rights. It is important, she said, to preserve the child's right to an open future and autonomy. Additionally, such intervention may serve to preserve fertility, sexual and reproductive choices. And the Supreme Court has long held that parents are not free to make a child a "martyr" for their own cultural or religious beliefs.

Finally, Dr. Beh questioned the assumption that parents can be counted on to act in their child's best interest. She cited one article where parents were asked if

they would consent to surgery even if a reduction in sexual sensation or responsiveness were *certain*. Ninety-five percent said yes.

Dr. Marie Fox, professor of Law, and Dr. Michael Thomson, Head of the School of Law, both at the Keele University School of Law in England, presented a paper they have been working on together entitled "Cutting It: Surgical Intervention and Sexing Children."

Dr. Fox explained that they have come to this issue in the context of researching male circumcision issues, but also the process of sexing children in general. While correlations have been drawn between female genital mutilation and intersex surgeries, Dr. Fox noted that a similar correlation exists with routine male circumcision. In both cases, external morphology plays a central role in determining sex, focus is on the size, aesthetic and function of the genitals, and there are similar arguments about normalizing and creating a sense of belonging in a particular social group. Likewise, she said, both types of surgery limit the range of choices for adults who are subjected to such procedures.

The history of routine male circumcision reveals that all manner of justifications have been found for male circumcision. Dr. Thomson told the story of a doctor in 1870 who placed the blame for a child's paralysis squarely on his penis, which was "tightly imprisoned in a contracted foreskin." In other cases, he said, the foreskin was blamed for irritability in children, alcoholism, curvature of the spine, clubfoot, masturbation and even mental retardation. More recently, physicians have identified the foreskin as "a piece of prehistoric culture," and "a reservoir for infection," Dr. Thomson said. "Circumcision has always been a procedure searching for a justification," he noted.

In presenting her thesis paper, "Hacking the Gender Binary Myth: Recognizing Fundamental Rights for the Intersexed," Sara Benson proposes that intersexuals should receive Constitutional protections against discrimination. Ms. Benson, an LL.M. candidate at the University of California-Berkeley School of Law (Boalt Hall), argued that genital surgeries violate the fundamental right to personal bodily integrity and the unrecognized rights to personality and gender identity.

Ms. Benson recognized that there are two hurdles that must be overcome for Constitutional principles to be applied in intersex cases: the state action doctrine, and the "somewhat nebulous" character of fundamental rights jurisprudence.

While the Constitution does not apply to private actors unless the state was involved in the action to such an extent that it amounts to state action, Ms. Benson argued that the "permission theory" should apply in intersex cases. That theory, she said, holds that when the government is complicit in the behavior and permits the action, it may be imputed to the state itself. This is the case with intersex surgeries, she said.

Fundamental rights jurisprudence is based on rights "implicit in ordered liberty" and "deeply rooted in the history and traditions" of the nation, Ms. Benson said. The right to bodily integrity stems from the right to privacy under the

Fourteenth Amendment and protects the right to refuse treatment, have an abortion or plan a pregnancy. Ms. Benson believes this right already offers some protection to intersex children, especially where fertility is implicated. In addition, the invasions caused by a parade of doctors, forced dilation of the vagina, lifetime surgical requirements, long-term medical side effects and other circumstances may implicate the right to bodily integrity.

Ms. Benson also advocates a right to personality, previously unrecognized by the Supreme Court, stemming from the First Amendment right to expression and the right to privacy and liberty under the Fourteenth Amendment. She says the right to personality has been recognized by Germany in the case of transsexuals and in Columbia, where intersexuals' potential adult choices may conflict with parental decisions. In the end, Ms. Benson hopes that such Constitutional protections would create a right to choice for intersexuals and a right to re-define the gender spectrum.

INTERSEX AND INTRASEX DEBATES: BUILDING THEORIES AND ALLIANCES TO CHALLENGE SEX DISCRIMINATION

The keynote address was delivered by Julie Greenberg, the Associate Dean and professor of Law at Thomas Jefferson School of Law. Ms. Greenberg is also the Chair of the American Bar Association International Sub-Committee on issues related to Sex, Gender and Sexual Orientation, and is a nationally recognized expert on those issues. Ms. Greenberg's address focused on two issues particularly controversial within the intersex movement in the hopes of starting an explicit dialogue about then. The first issue she raised was whether intersex activists should insist on a full moratorium or support a parental consent model that ensures the best interests of the child are paramount.

Under what she terms the Moratorium Model, doctors and parents would assess the gender identity that the child would likely form, and raise the child as such without surgical intervention. A moratorium on cosmetic surgeries would stand, she said, until it is proven that they are beneficial. Educational and psychological support components would be in place for parents and patients. And finally, children would be allowed the flexibility to decide the avenue of treatment when they reach the age of consent.

The Middle Ground Approach, Ms. Greenberg said, recognizes that there may be some surgeries that are in the best interests of the child. Like the Moratorium Model, proponents of this model advocate assessing and assigning a gender, and providing education and psychological support. Unlike that model, however, proponents of the Middle Ground model would allow parents to decide, but would create a system that ensures parents are in a position to make that decision based on the best interests of the child, although Ms. Greenberg did not elaborate on what kind of system would be necessary to effect such protections.

Ms. Greenberg suggested that activists look at other social movements for guidance and noted that there has been significant backlash in other movements for "pushing to the limit." She said that sometimes it is more advantageous to take "baby steps" toward the end goal in order to garner more support.

The second issue Ms. Greenberg addressed was whether intersex activists should form alliances with other groups or movements, such as the LGBT, anti-female genital mutilation, or feminist movements. She warned that there can be negative consequences to forming such alliances. For example, she said, when a group's interests become so diverse that they cannot adequately advocate for each sector's needs, someone inevitably gets left behind. Similarly, the issues of a particular movement can get "watered down by numbers." In addition, there are concerns among intersexuals about being associated with the LGBT movement because most intersexuals do not identify as gay, and homophobia could serve to keep some people from the movement.

Ms. Greenberg suggested "using a comprehensive theory of sex discrimination to build alliances" with such groups. The success of "sex stereotyping" cases, where an individual argues that he or she has been discriminated against because he or she failed to meet the expectations of the sex stereotype, may prove useful for intersex cases. Performing genital "normalizing" surgery on intersex infants, Ms. Greenberg argued, is discrimination based on a failure to live up to the stereotypes associated with male and female genitalia.

NEW CRITICAL FRAMEWORKS: THE COLUMBIA DECISION AND SAN FRANCISCO'S HUMAN RIGHTS COMMISSION REPORT

Moderated by Emily Grabham, a Research Fellow at the Centre for Law, Gender and Sexuality at the University of Kent in the United Kingdom, this panel gave analysis and updates on two of the most recent legal developments involving intersex rights.

Ben Lunine is a member of the San Francisco Intersex Task Force of the San Francisco Human Rights Commission. He presented some of the recommendations, still in draft form, which the LGBT Advisory Committee developed last year. Activists from the Intersex Society of North America first approached the Committee in 1998, he said, asking them to examine the issue of intersex surgeries. It wasn't until the summer of 2003 that the decision was made to create a task force. In September of that year, the initial presentation was made to the Commissioners and, just eight months later, the Commission held the first-ever public hearings on intersex issues. In January 2005, a report based on those hearings was voted on and approved by the LGBT Advisory Committee for presentation to the full Commission, which took place later that month. Mr. Lunine said that the Commissioners have voted to adopt the report, but emphasized that the information is still in draft form and the final version will be released in the coming months.

Mr. Lunine said the following findings have been adopted in the draft report, among others:

- Intersex surgeries and therapies are generally not medically necessary.
- The current protocol allows individual physicians to determine what is "normal."
- Performing infant genital surgery for normalizing purposes can destroy reproductive capacity, eliminate options for expression of gender and sexual identity and diminish or destroy sexual function and pleasure.
- There is no evidence that intersex children benefit from "normalizing" interventions. On the contrary, many report dissatisfaction, pain, depression, sexual dysfunction, shame and even post-traumatic stress disorder.
- Normalizing interventions done without the patient's consent are an inherent human rights abuse.
- The most accurate way to determine gender is to allow the child to assert it.
- The current protocols are homophobic, in as much as they use heterosexuality as the standard upon which all decisions are made.
- Relieving parents' discomfort by surgery on the child is a human rights violation.

The Commission also approved some recommendations, and Mr. Lunine shared some of them:

- Normalizing interventions should not occur in infancy or early childhood.
- Any procedures that are not medically necessary should not be performed unless the patient gives their legal consent.
- A patient-centered treatment model should be implemented, which emphasizes peer support, access to information, openness, treating the child as the patient, honoring the person's right to make informed choices about their own bodies, and delaying treatment until the patient can give informed consent.
- Medical record keeping should be mandated, medical records and photographs should be kept for life and patients should be given access to their records.
- Local, state and federal anti-discrimination laws should be amended to include intersex as a protected category.
- An intersex child should be raised as male or female without genital "normalizing" intervention, accepting that their gender may change as the child's own sense of gender identity emerges.

Following Mr. Lunine, Dr. Morgan Holmes, an Assistant Professor of Sociology at Wilfrid Laurier University in Waterloo, Ontario, Canada, provided some insight into the 1999 Columbian Constitutional Court decision on intersex

surgeries on children. While many have touted the decision as a step forward for intersex rights, Dr. Holmes is more reserved in her enthusiasm and pointed out some of the limitations of the decision.

The holding of the case is that parents have no *a priori* right to alter intersex bodies, she said, but only if the surgery belies a prejudicial attitude and interferes with the developing autonomy. The Court recognized two important social changes as necessary precursors to this decision: the development that children are not the property of parents, and the shift in social perception of intersexuals from stigma to awareness. The Court held that the state has an obligation under the United Nations Convention on the Rights of the Child to protect children from all forms of discrimination and that human beings have the right to autonomy and dignity of their person, including bodily integrity.

Under the Convention, Dr. Holmes said, the state shall assure the child the right to express their views freely and the child shall have the opportunity, either themselves or through a representative, to be heard in any administrative or judicial proceeding affecting him or her. While these are positive developments, Dr. Holmes says her hesitancy comes from the more nuanced limitations of the decision. The Court specifically limited its decision to this case because the child involved was mature enough, in the court's view, to make such decisions on his or her own. In that sense, the decision rests on the notion that the child in question already has self-awareness, drawing a distinction between a child with a developing autonomy and a child with a developed autonomy. "The right of the child to safety and to the protection of the develop*ing*, rather than the develop*ed*, autonomy falls closely in line with the general Western ideology that claims that each of us has a right to self-actualization." Dr. Holmes continued, "[w]hatever the limits of that ideology, at least protecting children in ways consistent with it would not perpetuate the legal perception and social treatment of children as a subclass, but rather as developing subjects."

In addition, she said, the decision does not question the authority of medical knowledge: a requirement of the decision is that a medical team makes the determination whether a child has sufficient autonomy to make such decisions. Dr. Holmes also stresses that the decision does not recognize intersex as a minority group; it recognizes that some intersexuals under some conditions might constitute a minority group. "The rights to protection of autonomy, or of developing autonomy," she says, "do not depend on minority status, and the court is misguided in relying on that argument to secure its ruling."

THE POLITICS OF INTERSEX

Noa Ben Asher, Esq., a J.S.D. candidate at the New York University School of Law, moderated the next and final panel of activists and allies to address the politics of the intersex movement. Betsy Driver began the discussion by saying that one of the biggest issues intersex activists have to confront is that of homophobia and how to address it within and outside the movement.

While Ms. Driver encourages non-intersex allies to advocate for intersex rights, she said when she recently got a letter from an LGBT organization asking whether they should add an "I" to their name, she advised against it. A desire to be inclusive and politically correct, she said, will not help to solve the travesty of genital mutilation against intersexuals. Organizations who wish to take on intersex issues, she said, need to first ask themselves, "What are we going to *do* about it?"

Ms. Driver reminded the audience that the media can be a powerful tool for education and breaking down barriers, and encouraged activists to use it to their benefit whenever possible. She stressed that it is important to get the message out that intersex is not a white issue, a class issue, nor a religious issue, especially because a popular perception of intersexuals is that they are associated with liberal politics or with homosexuality. Traditional lines of division do not apply to intersex issues, she said.

Nancy Ehrenreich, a professor of Law at the University of Denver Sturm College of Law, said that the intersex movement could potentially be closely aligned with many social movements beyond LGBT groups, such as patients' rights, disability rights and children's rights. The author of the forthcoming Harvard Civil Rights/Civil Liberties Law Review article, "Intersex Surgery, Female Genital Cutting and the Selective Condemnation of Cultural Practices," Ms. Ehrenreich explored the ways the intersex movement and the anti-female genital cutting (FGC) relate and why anti-FGC activists have been unwilling to embrace intersex issues.

Ms. Ehrenreich studied literature produced by the anti-FGC movement and tried to apply them to the arguments of intersex activists. What she found was that they map onto each other very well. Anti-FGC activists argue that the practice is harmful, both physically and psychologically—one of the most common arguments in the intersex movement. They also complain of impaired sexual function and the violation of sexual autonomy, like intersex adults. Finally, Ms. Ehrenreich said that anti-FGC activists condemn the practice as being done for cultural, not medical reasons, and tout it as a form of gender subordination used to regulate the sexuality of women. Of course, Ms. Ehrenreich pointed out, all of these arguments can be applied to intersex surgeries and have, in fact, been discussed throughout the symposium.

Why, then, has the anti-FGC movement been so resistant to embrace intersex issues? Ms. Ehrenreich believes there are several reasons, including a fear of how controversy might affect their own movement. Fundamentally, however, "the resistance of mainstream anti-FGC activists is due to their investment in understanding Western, white culture as better than the African societies they are criticizing." As cultural relativism is the most contentious issue within the anti-FGC movement itself, Ms. Ehrenreich argued that including intersex surgeries in the movement's agenda would only serve to combat those critiques. By consistently criticizing genital cutting wherever it occurs, FGC opponents would show that their opposition is based on principle, not cultural intolerance.

Janet Green, co-founder, with Betsy Driver, of Bodies Like Ours, is a member of the Congenital Adrenal Hyperplasia Research, Education and Support Foundation, and was at the symposium representing the International Intersex Organization. "The politics of intersex began as the politics of lying," she said. Keeping secrets and controlling information is a fundamental part of the current medical protocol.

"It is the politics of collusion," she said, as medicine seeks to fulfill religious and societal goals of maintaining a sex and gender binary. "It is the politics of language," as words like intersex, ambiguity, anomaly, abnormal and others carry stigma with them that are immediately associated with the person described by such words. Such language, Ms. Green said, "focuses all of the attention on one part of us—our genitals," detracting from intersex individuals' souls and hearts.

"The politics of intersex is the politics of denial." Intersex surgeries serve to hide the fact that not all bodies are simply male and female. From the moment a baby is whisked away from his or her parents, Ms. Green said, "It is the politics of fear," instilled through isolation and constant examination. "It is the politics of compliance," the way intersex children and their parents understand that if they do not comply with the protocol, they are doing something terribly wrong. "It is the politics of inclusion," she said. But more than any of that, Ms. Green stressed, "the politics of intersex is the politics of change." From where the movement began, Ms. Green said there have been incredible changes—though not enough. Doctors have listened and, although they have not stopped the surgeries, she said the impact of the intersex voice on the treatment of intersex children is apparent.

For Emi Koyama, Founder and Director of Intersex Initiative,[4] there is no contradiction between different social movements and the intersex movement. While there are different priorities for each movement, they do not work against each other. Ms. Koyama comes from an activist and academic background and has done work with the disability rights movement, the feminist movement, in sex-worker rights, with LBGT issues and more. All of this work, she said, informs her work on intersex issues.

Early in her intersex activism, Ms. Koyama studied how Women's Studies professors use intersex in their classrooms and found that most teachers used intersex as a theoretical devise for feminist or queer theory and ignored the individual intersexuals' experiences. One goal for Ms. Koyama is to educate others working in social movements so that when they do address intersex issues, it furthers the goals of intersex activists.

Ms. Koyama began as an intern as ISNA in the late 1990s, but left to start Intersex Initiative, based in Portland, Oregon. Of course, she acknowledged, it is just easier to be your own boss and that influenced her decision. But she also said that it is a great benefit to have three different groups across the country working on different strategies, keeping each other in check. It is important to remember,

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[4] *See* http://www.intersexinitiative.org.

she said, that even within the intersex movement, no single organization can represent all intersexuals' goals. She sees tension between the groups as healthy and says that the friendly conflicts within the movement help to move it forward.

Personally, Ms. Koyama says that her thinking about intersex politics has changed. "At first, I blamed the surgery for everything," she said. "But I don't even remember the surgery." While the surgery created its own difficulties, it was "the secrecy and shame, being on display, the lying and dishonesty" that caused so much pain and confusion in her own life. She still advocates for putting an end to surgeries, but stresses that it is only one part of the problem.

Moonhawk River Stone, M.S. is a psychotherapist and the Board Chair of International Foundation for Gender Education, Inc. His most recent work is entitled "Gender Identity is for Every One: Creating a Paradigm for Change."

Mr. Stone's work focuses on "the newly emerging field of trauma, which plays a critical role in the lives of intersex people." He was introduced to the intersex movement when he read the first publication of Hermaphrodites with Attitude, and was struck by the stories adult intersexuals told. "The trauma they endured was unconscionable to me," he said, and he decided he had to become an intersex ally.

"Ally work is critical because a traumatizing society divides us across a multiplicity of differences and diversities: race, class, ability, disability, sex, gender, sexual orientation and gender identity, religion, expression and even personal characteristics, such as size," he said. "It keeps us from connecting with one another." Mr. Stone said that he believes the sex/gender paradigm traumatizes everyone who culturally comes within that paradigm, but that instances of healing on a societal level are rare. "The society . . . must follow the healing protocol, which means coping with feelings of guilt and shame and helplessness, and taking responsibility for what happened in the name of the paradigm." One example of healing on such a level, he said, is the work by Desmond Tutu in South Africa, struggling to heal from the trauma of apartheid.

Mr. Stone emphasized that allies working to help heal the trauma suffered by intersex people must be diligent in their duties, keeping current with the movement's evolution, acknowledging their own ignorance and bias, and being careful not to convolute the intersex movement with other movements, such as transgender rights.

The symposium was a success in that it was one of the first symposiums of its kind to address these issues and to focus the spotlight on legal issues facing the intersex.