

A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION” OF INTERSEX PEOPLE



A REPORT OF A PUBLIC HEARING BY THE HUMAN RIGHTS COMMISSION OF THE CITY & COUNTY OF SAN FRANCISCO

**Marcus de María Arana, HRC Staff
Principal Author**

**25 Van Ness Avenue, Suite 800
San Francisco, CA 94102-6033
(415) 252-2500
www.sfgov.org/humanrights**

APRIL 28, 2005



TABLE OF CONTENTS

CHAPTER 1	Page 3
Preface	PAGE 4
Process Summary	PAGE 5

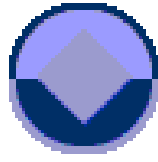
CHAPTER 2	Page 9
A Brief History of Intersex for the San Francisco Human Rights Commission Report: An Essay by Alice Dreger and Cheryl Chase	Page 10

CHAPTER 3	Page 16
Findings and Recommendations	PAGE 17

CHAPTER 4	Page 28
Oral, Written, and Video Testimony:	
People with Intersex Anatomies	PAGE 29
Parents	PAGE 47
Medical	PAGE 50
Academic	PAGE 64
Legal and Ethical	PAGE 67
Public	PAGE 70

CHAPTER 5	PAGE 73
Medical Article Summaries	PAGE 74
Academic, Legal, and Ethical Article Summaries	PAGE 88

Appendices	Page 95
A. GLOSSARY	Page 96
B. WEBSITE LINKS	Page 98
C. PRESS RELEASE	Page 99
D. HEARING SIGNS	Page 100
E. UCSF CORRESPONDENCE	Page 101
F. FURTHER CORRESPONDENCE FROM DR. BASKIN	Page 104
G. LINKS TO COMMISSION MEETING MINUTES RE: DR. BASKIN'S REQUEST TO PROVIDE FURTHER TESTIMONY	Page 110



CHAPTER 1

PREFACE

PROCESS SUMMARY



Chapter 1

PREFACE

On May 27, 2004, the San Francisco Human Rights Commission held a public hearing to investigate the issue of “normalizing” medical interventions being performed on intersex infants and children. The public hearing and this report resulted from requests from people with intersex anatomies for the Commission to explore the question of unwanted, “normalizing” interventions performed on children born with “ambiguous genitalia.” Specifically, the Commission became concerned that homophobia, transphobia, and heterosexism were strong social forces that contributed to the decision-making process for assigning sex and gender to intersex children through “normalizing” genital surgeries and sex hormone treatments.

This report is a summary and compilation of materials, testimony, and information submitted by people with intersex anatomies, parents of children and adults with intersex anatomies, medical providers, academics, legal experts, advocacy groups, representatives of City agencies and departments, and the public. The report is built upon the words and ideas of those who testified at the public hearing, submitted written materials, and/or offered commentary on the content of the findings and recommendations. Every attempt has been made to accurately reflect the information submitted.

In order to be as inclusive and accurate as possible, the organizers of this public hearing and authors of the report agreed to use the term *intersex* to describe people with anatomies that are not considered “standard” for either male or female bodies [definition from Intersex Society of North America/ISNA]. The authors recognize and respect that some people may feel alienated by this definition, some people may disagree with the definition, or some people may object to the use of labels to describe their identities and/or experiences. However, for the purpose of this report, the authors determined that this was the most widely understood definition.

A sincere effort has been made to use the appropriate gender pronouns to refer to speakers and other participants. In cases where pronoun preference is not explicitly stated, there may be mistakes based upon gender assumptions. We apologize for these mistakes. In some cases, no pronoun has been used to avoid such assumptions and mistakes or because of a request from the participant.



PROCESS SUMMARY

Since 1998, the San Francisco Human Rights Commission (“Commission”) has been working with people with intersex anatomies and advocates to identify important issues and to assess the Commission’s ability to respond to concerns about civil rights abuses. After several key educational presentations to the Commission’s Lesbian Gay Bisexual Transgender Advisory Committee (LGBTAC) and to the Commissioners, the LGBTAC created the Intersex Task Force (ITF) in May 2003 to work on intersex issues and concerns within a human rights context. HRC staff and interns, ITF members, and key intersex activists made a detailed educational presentation to the Commission on September 11, 2003, defining the issue and requesting approval for an Intersex Public Hearing. The Commission granted approval for the ITF to plan for a public hearing. Because, to the Commission’s knowledge, no governmental entity in the United States had ever before addressed these concerns as human rights issues, the Task Force worked diligently to ensure comprehensive inclusion of information from as many different sources as would respond to the call for participation. The Commission had specifically asked to hear from doctors, parents, and people with intersex anatomies and to have various medical, academic, legal, and ethical perspectives represented. To this end, the ITF and Commission staff and interns invited people with intersex anatomies, parents, local doctors and medical providers, academicians, legal experts, and ethicists to testify at the hearing and/or to submit written testimony.

Due to a limited and reluctant response to Commission invitations to testify at the hearing from those who perform “normalizing” medical interventions, this report also summarizes video accounts and published interviews as testimony to represent the perspective of some providers. (Several local, nationally known doctors who work in this field of medicine were invited to testify or to submit their written perspective; all but one declined the invitation to directly participate in the hearing.)

LGBTAC members who worked on the Intersex Project, the Hearing, the Task Force, and/or the report include Dora Balcazar, Sally Buchmann, Melchor Bustamante, Chris Caldeira, Scott Campbell, David Cameron, Ben Chan, Jay Dwyer, Julie Frank, Becky Freund, Ted Guggenheim, Jordy Jones, Danny Kirchoff, Aidan Kotler, Nancy “Spyke” Lawlor, Patrick Mulcahey, Ellise Nicholson, Ren Davis Phoenix, Aleem Raja, Jorge Romero-Lozano, Lisa Scheff, Stephen Schwichow, Brooklyne Thomas, Morningstar Vancil, and Lauren Williams. Community members who participated include Blue, Cheryl Chase, Alice Dreger, Betsy Driver, Jamison Green, Thea Hillman, Katrina Karkazis, Emi Koyama, Mani Bruce Mitchell, Eli seMbessikwini, and Peter Trinkl. Former Commissioners Haig Baghdassarian, Alicia Becerril, Shirley Dimapilis, Wilfred Hsu, Martha Knutzen, Johnnie Rollins, Antonio Salazar-Hobson, Theresa Sparks, and Charles Ward participated in the Intersex project during their tenure at the Commission. Marcus Arana was the Commission staff person assigned to the Intersex Project and the Intersex Task Force, and is the principal author and editor of the report; other participating Commission staff included Executive Director Virginia M. Harmon, Larry Brinkin, Toni Delgado,



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

Cynthia Goldstein, Kabir Hypolite, Yong Lee, Hadas Rivera-Weiss, David Treanor, Dominic Viterbo, Tamra Winchester, and Janel Wong. Commission interns Steven Benolkin, Mindy Lee, Ben Lunine, Tara O’Neill, and Mhenaz Saiyeed also participated in the Intersex Project, in the public hearing, and/or in drafting the report.

After the hearing, HRC staff and interns and members of the ITF worked on compiling submissions and summarizing testimonies. Then, the findings and recommendations were drafted based upon the compilations, summaries, and testimonies. The report was unanimously approved by the LGBTAC on January 18, 2005 and forwarded to the Commission. The San Francisco Human Rights Commission unanimously approved the report on January 27, 2005.

Subsequent to Commission approval, Dr. Baskin, a Pediatric Urologist who had testified on behalf of UCSF, wrote to the Mayor’s Office and to the Commission requesting an opportunity to present further medical and research information to the Commission. Dr. Baskin also requested the opportunity to present statements from intersex patients who report experiencing successful outcomes after medical “normalization” interventions. He was given this opportunity on two separate occasions on March 10, 2005 and April 14, 2005. Dr. Baskin did not submit any new medical or research information and did not produce any statements from intersex patients who report experiencing successful outcomes from medical “normalization” interventions.

[***See Appendix F for Dr. Baskin’s correspondence with the Mayor’s Office and the Commission regarding his request to present further information.

After minor amendments requested by the Commissioners were completed, the Commissioners unanimously approved the report in its final form on April 28, 2005. The Findings and Recommendations are based upon the information received from submissions and testimony contained within this report.

PUBLIC HEARING – MAY 27, 2004

The Hearing was conducted on May 27, 2004 in San Francisco’s City Hall. Commissioners in attendance were Chair Malcolm Heinicke, and fellow Commissioners Carlotta Del Portillo, Vernon C. Grigg III, Rabbi Yoel H. Kahn, Faye Woo Lee, Larry Lee, Pat Norman, Ellouise Patton, and Sandra Sohcot. Commissioner Khaldoun Baghdadi served on the Commission at the time of the hearing. Also in attendance were Anna Damiani who represented Assemblyman Mark Leno, and San Francisco City Supervisor Bevan Dufty.

Commission Chair Malcolm A. Heinicke welcomed the public and presenters to the Hearing, thanking the participants in advance for their input into the process. He ex



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

pressed the Commission’s appreciation for being able to create an educational opportunity for the public. Commissioner Heinicke acknowledged that the issue of “normalizing” medical interventions in the treatment of intersex children has not received the “kind of governmental attention it should.” He commended the work of Commission staff, interns, and the Intersex Task Force of the LGBTAC for facilitating the agenda for the hearing. Commissioner Heinicke also commended the work of former Commissioner Theresa Sparks, and expressed gratitude to the staff management team of the LGBTAC for their contributions to the quality of the hearing.

Commissioner Heinicke introduced Ms. Anna Damiani who is a representative from California State Assembly Member Mark Leno’s office. Ms. Damiani apologized for Mr. Leno, who couldn’t be present due to legislative commitments in Sacramento. Ms. Damiani commended the Commission for taking a huge step forward in convening the hearing, noting it was a beginning of a long process. She said that Assemblyman Leno’s office is looking forward to learning how they can help to resolve issues that come up. Commissioner Heinicke introduced Bevan Dufty, a member of the San Francisco Board of Supervisors. Supervisor Dufty thanked the Commissioners and staff of the HRC for devoting time to this issue and for the Commission’s “trailblazing work for the LGBTQI community.” Supervisor Dufty stated that he recognized the passion of intersex people working on these issues and who are waiting to see how society responds to these issues. Supervisor Dufty reiterated that he was appreciative of the opportunity to hear the testimony and was looking forward to the report and recommendations.

Commissioner Heinicke introduced Marcus Arana, the Commission staff person assigned to the Intersex Task Force. Mr. Arana expressed gratitude to the members of the LGBT Advisory Committee and to the Intersex Task Force, including community members, for working for quite some time to make this hearing a reality. By way of background, he noted that people with intersex anatomies had approached the Commission with their concerns and had presented information on a panel of the LGBT Advisory Committee. The Committee then created the Intersex Task Force, which prepared a presentation on the intersex issue to Commissioners given at their September 11, 2003 meeting.

Mr. Arana explained that though the issue came through the LGBT Advisory Committee, intersex is not specifically an LGBT issue. But the connections are there, in that intersex individuals fear that doctors are making sex assignments on infants born with ambiguous genitalia at least partly out of a fear of homosexuality and the desire to re-enforce heterosexuality. Also, there is a desire on the part of doctors to enforce a paradigm of male/female sexuality, assuming a child’s gender identity before the child is able to express it.

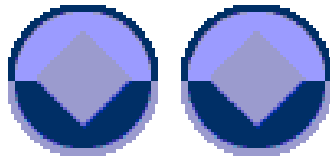
Mr. Arana said that the hearing would include testimony from people with intersex anatomies, parents, doctors and other medical providers, researchers, educators, and psychologists. He explained that additionally, written testimony has been submitted from



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

various parts of the United States and other countries. Mr. Arana explained that he will, with help from Intersex Task Force members, LGBTAC members, and Commission staff, draft a report after the hearing, including the Commissioners’ findings and recommendations, for Commission adoption.

Mr. Arana noted that there is a high incidence of intersex births, with estimates ranging from one in 150 to one in 2,000, and numbers approximately 65,000 intersex births worldwide every year. He reported that according to the University of California, San Francisco, 40 intersex genital surgeries are performed annually in San Francisco. Mr. Arana noted that this hearing is the first by a governmental entity in the United States, and that the issue has never before been addressed as a civil rights issue. He cautioned that the issue is complex and emotional, and asked that participants approach the subject with open hearts and minds. After these opening remarks, the Commissioners heard testimony from experts and the public. ***[See Chapter 4 for testimony]



CHAPTER 2

**ESSAY: A BRIEF HISTORY
OF INTERSEX**



Chapter 2

A BRIEF HISTORY OF INTERSEX FOR THE SAN FRANCISCO HUMAN RIGHTS COMMISSION REPORT

AN ESSAY BY ALICE DREGER AND CHERYL CHASE

“It is justice, not charity, that is wanting in the world.”

Mary Wollstonecraft, *A Vindication of the Rights of Woman*, 1792

Human rights groups believe that what people have in common—their humanity—is more important than how they differ. Organizations advocating for the protection of human rights understand fundamentally that individuals should not be oppressed simply because they are not at the top of the social hierarchy.

The San Francisco Human Rights Commission is the first US governmental agency to recognize that unwanted medical intervention in the treatment of people with intersex is fundamentally a human rights issue. It has been rare even among non-governmental human rights organizations—including those working on “female genital mutilation” and LGBT (Lesbian Bisexual Gay Transgender) issues—to understand why intersex is more than “just a medical issue.” It is assumed that, if medical professionals pronounce that their intentions are good and that intersex anatomies are abnormal, the ethics behind those interventions are beyond discussion.

Thus, in the medical profession, intersex has typically been seen to be a matter of charity, not justice. In rejecting this assumption, the San Francisco HRC has noted that, amidst the variant genes and chemical pathways that constitute intersex, real human beings are asking for more than medical charity.

Beginning in the late nineteenth century, medicine became the primary means for dealing with intersex. Before then, the vast majority of people with intersex conditions went unnoticed by legal, religious, or medical establishments and only a few cases per year came to the attention of authorities. Presumably other people with so-called “abnormal” sex anatomies lived average lives, either because their anatomical variance was undetectable or because it was not considered especially important. When a newborn had a high degree of genital ambiguity, midwives, grandmothers, and other local elders appear to have assigned the sex. In terms of sexual orientation, all people were expected to then have sexual relations solely with those who had been identified as the “opposite”



sex; in many places, violation of this rule was punishable by violent, sometimes lethal, means.

However, by the late 1800s, through the rise of gynecological sciences and military medical examinations, doctors gained a much better sense that “abnormal” sex anatomies were actually quite common. Indeed, late-nineteenth century medical men began reporting dozens of cases a year of “hermaphroditism” and “pseudo-hermaphroditism.” Because most medical experts were politically conservative and wanted to keep sex borders clearly defined, and to contain open homosexuality and the rise of feminism, intersex caused them notable distress. (The conflation of sex, sexual orientation, and gender expression becomes clear in the 1890s use of the term “psychic hermaphroditism” to refer to gay men, and in the common “scientific” claim that university education physically “masculinized” women.) Therefore, biomedical specialists devised a system that would label everyone “truly male” or “truly female,” regardless of the extent of sexual blending.

Medical doctors created an arbitrary standard based on gonadal tissue, which persists in most medical texts today. A person with non-standard sex anatomy and ovaries is seen as a “female pseudo-hermaphrodite”; a person with non-standard sex anatomy and testes is seen as a “male pseudo-hermaphrodite”; and if a person has ovarian and testicular tissue, she or he is seen as a “true hermaphrodite.” Given the technological limitations of the time, Victorian doctors appeared to like this system because they couldn’t easily diagnose “true hermaphroditism” in living people; as a consequence, for the most part, the only “true hermaphrodites” were dead and dissected people.

All other people thought to be intersex, including those considered pseudo-hermaphroditic, were labeled “truly male” or “truly female” and encouraged to act socially and sexually normative in their assigned gender. Over time, however, with improved medical techniques and increased access to healthcare, many more people were being diagnosed with a biological “true sex” that made no sense socially. (In the 1910s as today, women with androgen insensitivity couldn’t practically be labeled men just because they had testes.) And, in a bi-polar gender paradigm, there was no simple social category for those diagnosed with “true hermaphroditism.” So, by the 1920s, experts treating intersex developed a notion of gender (social role) separated from biological sex. And they began to more actively offer surgical “corrections” to bring the biological sex into line with the assigned gender. So the theoretical approaches and surgical techniques evolved bit by bit, though motivation remained the same: keeping sex categories distinct and numbering exactly two.

It should be noted that, in the last half of the nineteenth century, a small percentage of patients with intersex had started to ask for—and some surgeons had started to offer—surgical reconstruction of large clitorises, small vaginas, and hypospadiac penises [the urethral opening does not extend to the tip of the penis]. With the exception of the rare clitorrectomy performed on a child because she had a large clitoris, most of the genital



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

surgeries performed for cosmetic reasons in the nineteenth century were performed on adults at their request.

There is reason to believe that most people with intersex were socially healthy without surgery; they did not disproportionately live as hermits or attempt suicide. Indeed, psychologist John Money studied adults with intersex and found—before the era of standard cosmetic surgical intervention for intersex—that they enjoyed a lower rate of psychopathology than the general population. (The results of Money’s extensive investigation were never published, but they can be obtained by requesting a copy of Money’s Ph.D. thesis from Harvard University.) Nevertheless, like many other realms of biology, sexuality, and psychology, intersex increasingly came under the purview of medicine.

For a small number of people with intersex—namely those at risk for gonadal cancers and salt-wasting—the medicalization of intersex probably improved their health, even saving their lives. Nevertheless, most of the treatment of intersex was motivated not by metabolic health concerns, but by psychosocial concerns; as in the 1890s, by the 1950s, intersex was viewed primarily as a psychosocial problem, one that mixed sex categories in socially uncomfortable ways.

In the 1950s, Johns Hopkins University created a team to deal with intersex, and thus became the first medical center to offer an organized multi-disciplinary approach to intersex, one that sought to essentially eliminate intersex in early childhood. The approach developed there came to be known as the “optimum gender of rearing” model. The basic idea was that each child’s potential for a “normal” gender identity should be maximized by making each child’s body, upbringing, and mind align as much as possible. Because of the belief that it was harder to surgically engineer a boy than a girl, most children with intersex were made as feminine as possible, utilizing surgery, endocrinology, and psychology. A “successful” patient was one judged to be stable and “normal” (i.e., heterosexual) in the assigned gender. (In an era of vice squads raiding gay bars, it is not surprising that homosexuality appeared to most of these professionals an untenable identity.)

Though the early texts from this team advocated truth-telling and consistent psychological support, in practice many patients were deceived and given minimal psychological support. As in most of medicine, doctors made the decisions for patients. There was little investment in the ideas of informed consent or of studying outcomes in a systematic way.

Psychologist John Money provided theoretical support for the Hopkins model, arguing that gender identity was largely mutable early in life, that nurture was more important than nature. His chief support for this claim came from a famous case known as “John/Joan.” The person at the center, David Reimer, was born an identical twin (not intersex) boy in 1965. While performing a circumcision, a doctor accidentally burned off eight-month-old David’s penis. David’s parents consulted with the team at Hopkins, and



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

Money recommended they change the sex and gender of their child and raise David as a girl. For decades Money erroneously touted a successful outcome because the child reportedly had become a normal, female-identified, heterosexual girl. The truth was that David had never felt fully female. Indeed, when his parents told him the truth about what happened to him, he immediately re-assumed the gender role of a boy.

It is unknown why Money—who in 1953 had found a relatively low rate of psychopathology among adults with intersex—thought people with intersex needed to have their sexes and genders surgically and socially engineered to be psychologically healthy. It is better understood why people did not question Money’s controversial theory of nurture-over-nature approach. Surgeons and psychologists liked the theory because it signified that they were providing necessary, good care to “abnormal” children. Many feminists accepted the theory because they preferred the idea that gender - and therefore gender norms - were socially constructed and malleable. Parents may have accepted it because they could be reassured that their queer-bodied children would grow up to be straight-acting adults

But some people didn’t like this system: people who - like David Reimer - felt mistreated at best, and medically assaulted at worst. Nevertheless, most stayed silent, believing they were alone in their experiences. That changed in 1993, when feminist biologist Anne Fausto-Sterling published articles in *The Sciences* and *The New York Times* exposing the basic fact that intersex exists. In response, Cheryl Chase wrote a letter to *The Sciences* announcing the founding of the Intersex Society of North America (ISNA). She founded the group because of her own attempts to recover her history of sex-reassignment in infancy and medically induced shame, and because of the disinterest of most of her former care providers in what had happened to her.

Though ISNA began as a support group, it quickly turned into an advocacy group because its members realized that they had suffered from similar problems. Like many of the early ISNA members, Chase drew on her political consciousness as a lesbian woman to recognize the degree to which intersex had been unnecessarily pathologized. With the successes of the women’s health movement and the queer rights movements as a backdrop, people with intersex began agitating for openness and reform.

Early on, very few medical professionals recognized ISNA’s critiques as legitimate. Many responded that the standard of care was necessary, successful, and justified, even going so far as to actively defend lying to patients about their medical histories. Those at the top simply tried to ignore ISNA. As the leader of the newly formed intersex rights movement, Chase moved rapidly, engaging in dialogue whenever possible, and having group protests when doctors would not listen. With her professional background in computer science, she was particularly adept at using the tools of the Internet to spread ISNA’s message. ISNA also supported the inquiries of researchers like Suzanne Kessler, Anne Fausto-Sterling, and Alice Dreger, and the organization engaged in media outreach as much as possible.



By about 2001, it had become clear to all that the intersex rights movement was not going away. The claims of activists were illustrated in story after story of problematic intersex treatment (from ISNA and from allied groups like the Androgen Insensitivity Syndrome (AIS) Support Group, Bodies Like Ours, and Intersex Initiative), as well as in research that strongly suggested gender identity is not simply a matter of nurture. The fact that medical professionals were still unable to produce an intersex patient satisfied with his/her treatment negated the claims that the advocacy groups solely represented the experiences of a disgruntled minority. Finally, many medical professionals began to respond to calls for outcome data, research, full disclosure of information, and revision of homophobic and sexist protocols.

The intersex rights movement undoubtedly was helped in its success by surrounding trends in favor of LGBT rights, patients' rights, and children's rights. Since 1993, due to the public education fostered by intersex activists, tens of millions of people have learned about intersex. Now medical professionals are less inclined to lie to patients and parents in intersex cases, are less likely to make openly homophobic or sexist remarks, and are more likely to admit uncertainty about the right course of action. A number of teams are engaged in active outcomes research, though opinions still differ about what outcomes should be sought; some think stable gender identity and heterosexuality are the objective; others suggest it should be lack of depression. What type of care an individual or family will receive now varies dramatically; what happens to a child with intersex today appears to depend not only on where she or he is born, but who happens to be on call when she or he is born.

Even today, the goal of many leading teams treating intersex is still to make intersex disappear. Pediatric endocrinologist Maria New recommends Dexamethazone to women who may be carrying an XX child with Congenital Adrenal Hyperplasia (CAH); these treatments do not alleviate CAH, they only make the child's clitoris appear smaller, and practitioners hope that it will decrease the likelihood that girls grow up with masculine behaviors or lesbian sexual orientation. Meanwhile, abortion is routinely offered to women who are likely pregnant with children with intersex conditions, including Klinefelter's Syndrome. Finally, doctors continue constructing vaginas in and performing clitoroplasties on infants and young children, despite arguments by many medical professionals that early genitoplasties fail too often and are unnecessary to begin with.

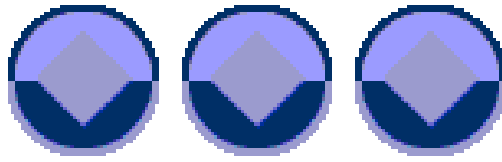
By contrast, as in the women's rights movement, the civil rights movement, and the LGBT rights movements, the goal of intersex advocacy groups is to have people understand intersex conditions as human rights issues. ISNA maintains as its fundamental principle (a principle also fundamental to the women's health movement and the LGBT rights movement) that the fate of a child's sexual anatomy should not primarily rest on the needs of others, but should be left to that individual to decide, barring true medical emergency. This idea may someday cease to be a radical claim, but that day has not yet arrived.



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

Alice Dreger is Associate Professor of Science and Technology Studies at Michigan State University, serves as Chair of ISNA, and has produced three books on intersex.

Cheryl Chase is a scholar and activist and the founder and Executive Director of the Intersex Society of North America.



CHAPTER 3

FINDINGS AND RECOMMENDATIONS



Chapter 3

FINDINGS AND RECOMMENDATIONS

Findings

The Human Rights Commission, having conducted a public hearing on May 27, 2004 on the question of the medical “normalization” of intersex people and the social, legal, and ethical aspects of intersex issues, and having considered verbal and written testimony, hereby finds that:

1. Infant genital surgeries and sex hormone treatments that are not performed for the treatment of physical illness, such as improving urinary tract or metabolic functioning, and have not been shown to alleviate pain or illness (hereafter referred to as “normalizing” interventions) are unnecessary and are not medical or social emergencies.
2. “Normalizing” interventions done without the patient’s informed consent are inherent human rights abuses.
3. “Normalizing” interventions deprive intersex people of the opportunity to express their own identity and to experience their own intact physiology.
4. It is unethical to disregard a child’s intrinsic human rights to privacy, dignity, autonomy, and physical integrity by altering genitals through irreversible surgeries for purely psychosocial and aesthetic rationales. It is wrong to deprive a person of the right to determine their sexual experience and identity.
5. It is as a violation of a child’s human rights to put a child’s body on unnecessary or sensationalistic medical display since there are adequate photographic tools available for teaching purposes.
6. It is ethically wrong to treat people differently or unfairly because they are perceived by others to be “monsters” or “oddities.”
7. Many intersex people experience “normalizing” interventions as a violation of bodily integrity.
8. Patients often experience “normalizing” interventions, secrecy, and medical display (i.e. being touched on the genitals or displaying the patient’s genitals to oth



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

ers) as sexual abuse and may also experience post-traumatic stress symptoms as a result.

9. Feminizing genitoplasties performed on intersex people can produce physical and emotional outcomes similar to those of female circumcision or Female Genital Mutilation (FGM).
10. “Normalizing” interventions performed to alleviate a parent’s social discomfort about their child’s intersex anatomy violate the patient’s human rights.
11. “Normalizing” medical interventions performed on an intersex child to address the discomfort of doctors, relatives, and anyone other than the consenting patient is a violation of the child’s human rights.
12. Another governmental entity, the Constitutional Court of the Country of Colombia, recognized the need to protect people with intersex anatomies from “normalizing” interventions, by “significantly limiting the ability of doctors and parents to surgically alter the genitalia of intersex children because “normalizing” interventions have no evidential basis as being “necessary, safe, or effective” and there is a lack of evidence demonstrating that an early decision on “normalizing” interventions is urgent.
13. Another governmental entity, the Constitutional Court of the Country of Colombia found that the State assumes that parents will act in the best interests of their children. However, the court found that parents are more likely to make decisions based upon their own fears and concerns rather than what is ultimately best for the child in the case of intersex infants, and that this is especially true when parents are being pressured by others to choose quickly.
14. “Normalizing” interventions violate most medical standards of informed consent including the standards put forth by the United Nations’ Commission on Human Rights, the American Convention on Human Rights, and the American Pediatric Association’s standards.
15. The American Academy of Pediatrics’ policy on informed consent includes specifications on best practices concerning a child’s right to assent to (or refuse) medical treatments. A patient’s input is particularly crucial when the proposed intervention is not essential to their welfare and/or can be deferred without substantial risk.
16. Parents have the right to provide informed consent for medical treatments that are necessary for the physical health of an intersex child, and not for “normalizing” procedures.



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

17. Many parents choose "normalizing" interventions for their intersex children based on misinformation and/or coercion from the doctors. Because of this, some parents' consent is not truly informed consent.
18. Deceiving patients makes informed consent impossible, and surgeries and treatments performed under deceptive circumstances are therefore performed without patient approval.
19. Without the patient's consent, parents sometimes choose "normalizing" interventions for adolescents who had not been surgically or hormonally "normalized" as infants or children.
20. No evidence indicates that intersex children benefit from "normalizing" interventions. Existing data suggest that the long-term consequences of "normalizing" genital surgeries are quite negative. Many intersex adults report dissatisfaction with the sex hormone treatments and/or the surgeries they were subjected to as infants and children. Reported dissatisfaction includes physical appearance, scarring, pain, and diminished or absent sexual function, as well as psychological problems such as depression, poor body image, dissociation, sexual dysfunction, social anxiety, substance abuse, suicidal ideation, shame, self-loathing, difficulty with trust and intimacy, and post-traumatic stress disorder.
21. There is little positive follow-up data from patients who have been subjected to clitorectomies or clitoroplasties during the last ten years. Specifically, there are no data that reflect patient satisfaction with the surgical outcome, suggest that the reconstructed genitals are structurally and functionally "normal," or indicate quality of life has been improved.
22. The definition of a "successful outcome" differs greatly between medical providers and patients. Questions in follow-up studies tend to focus on heterosexual sexual behavior as being the standard for success, as opposed to fertility or pleasure. It is more common to ask a patient if she or he is married than to ask if that patient has a pleasing sexual life, is able to procreate, or has the ability to achieve orgasm.
23. Most intersex people have not been asked to participate in follow-up studies. Such participation would require a level of disclosure by doctors that many intersex people have been denied, because traditional approaches encourage concealment of intersex status, and a person may not know they have an intersex anatomy having been "protected from" this information by doctors.
24. Doctors who claim positive surgical outcomes have no data to support this. The emotional impact of "normalizing" medical interventions has not been studied by clinicians that assign sex and gender to intersex people.



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

25. Most intersex people who have been subjected to nonconsensual surgical and/or sex hormone treatments and who have been asked state that they would have preferred to have their bodies left intact. Most intersex people who have not had surgery are grateful and do not wish to undergo medical procedures to “normalize” their genitals.
26. There are few long-term follow-up studies on “normalizing” genital surgery performed on intersex children. Most follow-up studies focus on acceptance of gender assignment and have not adequately addressed quality of life issues for intersex adults.
27. Research is not a suitable substitute for immediately ending “normalizing” interventions.
28. There is no medical consensus regarding whether “normalizing” genital surgeries are advisable or beneficial.
29. There is great inconsistency among doctors and medical associations regarding the medical treatment of intersex children. There is no written standard of care, and decisions to “normalize” genitals are based upon subjective standards and cultural prejudices.
30. The American Medical Association, American Association of Clinical Endocrinologists, and the American Urological Association no longer have official policies on the management of intersexuality, and state that they defer to the “decisions of individual doctors and membership associations.”
31. The American Association of Pediatrics, American Medical Association, and American Urological Association have called having ambiguous genitals a “social emergency” that necessitates an immediate medical response.
32. The American Academy of Pediatrics (AAP) has concluded that treating “ambiguous” or “abnormal” genitalia requires urgent medical attention, and recommends that “normalizing” interventions happen very early in life – between the ages of six months and eighteen months.
33. All surgery carries the risk of death, and that risk increases in younger patients. All surgery carries the risk of infection; healthy intersex children have had their good health impaired or permanently compromised as a result of “normalizing” interventions.
34. Most infant genital surgeries are performed with a treatment goal of “normalizing” the visual appearance of an intersex child. The subjective determination of what appears “normal” is left to individual physicians.



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

35. Genital surgeries performed on intersex infants and children are essentially irreversible.
36. Performing infant genital surgery for “normalizing” purposes can destroy or limit reproductive capacity, eliminate options for expression of gender and sexual identity, and diminish or destroy sexual function and pleasure. Genital surgery also can lead to long-term physical pain.
37. Clitoral surgery can have negative outcomes: it risks a reduction or loss of sensation in the genital region; it may create painful sensations upon arousal or erection; it may not be consistent with the child’s gender identity [a person’s own sense of self in terms of being masculine and/or feminine].
38. Vaginoplasty can have negative outcomes: it can cause infertility; vaginal dilation is often painful and humiliating; the constructed vagina can smell like bowel; it can necessitate constant use of sanitary napkins; it frequently requires repeated surgical revisions; and it is usually created or deepened for the expressed goal of accommodating a penis, rather than for the satisfaction of the patients; vaginal dilation is painful and can be experienced as sexual abuse; there is no medical need for a preadolescent girl to have a vagina.
39. Hypospadias “repair” (surgically moving the urinary opening to the end of the penile shaft) often involves many, often painful, surgeries. As the body tissue used to reconstruct the urinary tract lacks the beneficial properties of real urinary tract tissue, it can require ongoing medical intervention.
40. Adult men with small phalluses can and do learn to be sexual in ways that satisfy both themselves and their partners. Most adult men with small penises would not want to have them removed and would prefer to participate in such decisions.
41. Adult women with large clitorises can and do learn to be sexual in ways that satisfy both themselves and their partners. Most adult women with large clitorises would not want to have them removed or resized, and would prefer to participate in such decisions.
42. Adults with atypical genitalia usually would not choose the procedures to which intersex infants and children are subjected, such as the removal of a small penis or the removal, reduction, or recession of a large clitoris.
43. Ambiguous genitalia can be a sign of metabolic concerns that may need urgent treatment; however, ambiguous genitals themselves do not need urgent surgical or hormonal treatment to “normalize” or “correct” their appearance.



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

44. Most medical interventions performed on children are available to young adults when they are able to give consent. It is easier to operate on larger anatomy and results are more likely to be seen by the patient as positive. Early childhood surgeries often necessitate revisions to accommodate body growth. Increased frequency of surgery also increases surgical risk.
45. Parents often are not advised that they will have to dilate their child's newly constructed vagina or that the child may need multiple surgeries. Medical providers often tell parents that there is something wrong with the child. Parents of intersex children report feeling shame, fear, horror, humiliation, regrets, and ongoing doubt about the choices they may have made for their children.
46. Because genital surgery affects one of the most sensitive parts of the body, it can hinder sexual response. Since these “normalizing” procedures often are experienced as a violation, they also can damage a person’s capacity for physical and emotional intimacy.
47. Historically, preservation of sexual pleasure and orgasmic capacity has not been prioritized as a surgical goal, or even taken into consideration. In recent years, clinicians have recognized the importance of preserving sensation — yet preserving sensation is not the same as preserving pleasure. Many intersex people report sensations of pain rather than pleasure. In addition, it is virtually impossible to cut tissue without causing nerve damage. This is particularly true for tissue that is as densely innervated as the genital and pelvic area.
48. Intersex adults report undergoing sex hormone treatments even when there is evidence that such treatments may harm their general health. Future negative effects of sex hormone treatments may not be disclosed to intersex individuals before the treatment is started, and the negative effects of those treatments are not adequately medically addressed.
49. The preponderance of evidence suggests that gender identity cannot be surgically assigned. The outcomes of such surgical assignments can be devastating to the patient, and to their family.
50. Most intersex children can live happy and healthy lives without surgical intervention.
51. Rationales for “normalizing” medical interventions are based upon social mores and norms and are not evidence-based.
52. Current treatment protocols are homophobic in that they use heterosexuality as the measure of a successful gender assignment. Homosexuality is considered an undesired or unsuccessful outcome.



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

53. Parents often are made to believe that their intersex children will be homosexual and/or suicidal if they do not undergo “normalizing” genital surgery.
54. Prejudice against people with nonstandard genitals is culturally determined, and this negative bias does not exist in every culture.
55. Intersex people are subjected to “normalizing” medical interventions that are intended to reinforce gender assignment.
56. “Normalizing” interventions cannot create or change a person’s sex, gender, sex identity, or gender identity.
57. Gender identity is not intrinsically tied to physiology in a predictable way. The most accurate way to identify a child’s gender is to allow them to assert it.
58. Although many intersex people identify as either male or female, some do not.
59. Sometimes patients are assigned a gender that is incongruent with their own gender identity. When that assignment has been reinforced surgically and/or hormonally, transitioning to an appropriate gender is problematic. It is essentially impossible to completely reverse “normalizing” procedures. Intersex people who were assigned a sex and gender that is wrong for them face the additional hardship of transitioning to their actual sex or gender identity.
60. Intersex people’s legal identities are compromised when their gender assignment doesn’t match their chromosomes. This could cause complications for intersex people who are legally married or desire to marry. It is also problematic when legal identification appears inconsistent with gender expression.
61. Parents often are led to believe that intersex is unique and rare. This becomes a barrier to acquiring vital information and support from other parents that will help them care for their intersex children.
62. Approximately 1 in 2000 children is born with so-called ambiguous genitals. Additionally, some people are discovered to have some type of intersex condition later in life.
63. In the United States, approximately five “normalizing” surgeries are performed on infants each day.
64. Due to their experiences, many intersex people fear medical providers and clinical settings and are therefore reluctant to seek routine, necessary, or emergency medical attention.



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

65. The practice of utilizing “normalizing” interventions and concealment fosters shame and secrecy. Clinicians often do not tell intersex children anything about the intersex aspects of their bodies or about the surgeries and/or sex hormone treatments to which they were subjected, even after the patient becomes an adult. Often, intersex people and adults are told lies to cover up the true nature of their bodies and medical interventions, and this system of deception is recommended to the family members of the intersex person.
66. While access to accurate information and peer support helps people accept intersexuality as normal - secrecy, lies, and withholding patient information can produce a sense of “freakishness” about intersexuality. Intersex children often discover partial truths about their bodies and medical histories, and they do not always get this information from appropriate sources in appropriate ways. Further, they are not routinely offered professional therapeutic support along with this information.
67. Biology curricula reinforce theories of human sexual dimorphism. Students are taught that human bodies always fall into one of two opposite categories: male or female. However, the definitions of male and female anatomies do not include intersex anatomies.
68. Medical and mental health care providers are not being adequately trained in human sexuality. This inhibits most health care providers from understanding their patients’ particular needs and offering them the most appropriate care.
69. There are insufficient numbers of medical and mental health providers who are adequately trained in providing appropriate intersex care and treatment. Currently, there are not enough medical and mental health professionals trained to help manage intersex births.
70. Some teaching institutions recently have begun to create appropriate curricula to teach comprehensive intersex studies to medical and mental health providers.
71. Because of increasing controversy regarding “normalizing” interventions, concerned clinicians are questioning the traditional “concealment model” of intersex treatment. Some are working to advocate for a “patient centered” treatment model.
72. Before 1993, no intersex people were on record acknowledging their experience with “normalizing” practices. Because of the growing patient advocacy movement, some intersex people are now able to speak publicly about these issues.
73. Peer support and advocacy groups like the Intersex Society of North America (ISNA), Bodies Like Ours, and Intersex Initiative are working to improve the lives of intersex people.



74. The Internet is one of the primary vehicles intersex people use to gain information about their conditions and find community support. Low-income people, including many intersex people of color, are less likely to have access to email, the Internet, or other technological resources.

RECOMMENDATIONS

In response to the issues and needs of individuals affected by the medical “normalization” of intersex people and the social, legal, and ethical aspects of intersex issues, and found upon consideration of verbal and written testimony of the May 27, 2004 public hearing, the Human Rights Commission hereby recommends that:

1. “Normalizing” interventions should not occur in infancy or childhood. Any procedures that are not medically necessary should not be performed unless the patient gives their legal consent.
2. 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 make informed consent.
3. Infant genital surgeries that are undertaken to improve the underlying physical health of an intersex child should be performed within that patient-centered model. All recommendations for any genital surgery should be evidence-based.
4. Medical professionals should give a full disclosure of the condition, and all treatment options, including non-treatment, to the patient, family, and/or parents: Parents should be told that most cases are not medical emergencies and do not require “normalizing” interventions. Parents should be given access to studies that support any medical recommendations. Parents should be told that current practice of early surgery is criticized by many intersex adults, by some parents of intersex people, and by some physicians, and is therefore highly controversial. Providers should acknowledge that there are no data supporting the belief that “normalizing” interventions are beneficial or necessary to the psychosocial health of the patient, and should provide parents with information about current and future benefits, potential complications, potential side effects, and all treatment alternatives, including non-intervention.



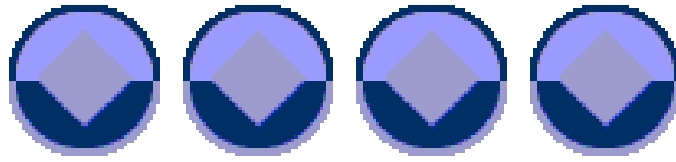
A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

5. All information regarding the risks of sex hormone treatments, including cancer risks should be provided to the patient and the parents.
6. Full, informed consent should be enforced.
7. Ethics review boards, which include intersex people, should be established to consult with doctors on appropriate treatment protocols for intersex conditions.
8. Doctors should receive approval for any intersex interventions from an outside entity, and an ethics review board which includes intersex people, that is separated from medical peer-based review, in order to ensure accountability on intersex treatment.
9. Genital surgery and hormonal treatments should be available to fully informed and consenting patients.
10. Providers should provide parents with access to peer support and appropriate mental health services.
11. Mental healthcare providers and educators should offer ongoing mental health support and age-appropriate information to intersex people.
12. Medical record keeping should be mandated, and that medical records and photographs should be kept for life, and that all patients should be given access to their records.
13. The problem of social discrimination should be addressed rather than offer hormonal or surgical intervention.
14. Intersex children should be encouraged to think positively about their bodies even if those bodies are different in some ways from others.
15. An intersex child should be raised as male or female without “normalizing” interventions, accepting that their gender may change as the child’s own sense of gender identity emerges.
16. Local, state, and federal legislators should investigate the question of necessity for having gender markers as a requirement for legal identification.
17. Local, state, and federal entities should investigate the need to include intersex as a protected category in anti-discrimination laws.



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

18. Medical and mental health providers should be educated on various intersex concerns, e.g., how to create safer medical settings for intersex people, on Lesbian Gay Bisexual Transgender (“LGBT”) cultural competency so that being LGBT is not seen as a negative outcome, and how to responsibly talk to parents about intersex.
19. School staff and administrators should be educated on intersex issues in order to increase safety in schools for intersex students.
20. Adequate funding should be provided for services that support and protect intersex people, particularly youth, in suicide prevention, peer support, coming out, counseling, and housing services.
21. Public health educators should help end shame, secrecy, and isolation imposed on intersex people by providing factual and affirming information to the public, including children, that variations in anatomy are normal, natural, acceptable, and not necessarily a medical problem.
22. The City and County of San Francisco should sponsor annual public education events on Intersex Awareness Day (October 26th) by collaborating with intersex groups, public health administrators, and human rights groups to raise public awareness of intersex issues. The City and County of San Francisco should urge other governmental entities to do the same.
23. The City and County of San Francisco should dedicate appropriate funds to support the work of community-based organizations that specifically serve the needs of intersex people.



CHAPTER 4

ORAL, WRITTEN, AND VIDEO TESTIMONY



Chapter 4

ORAL TESTIMONY – PEOPLE WITH INTERSEX ANATOMIES

THEA HILLMAN

Thea Hillman described herself as a person with an intersex condition, congenital adrenal hyperplasia (CAH). She is an advocate for patient centered care for people with intersex conditions based on the standards set forth by the Intersex Society of North America. Intersex means people born with sex anatomy someone else considers non-standard male or female. In her definition she includes large clitorises, small penises, and hypospadias.

She said that infants and intersex people are discriminated against by physicians who are fearful and ignorant of sexual difference. At four years old, Thea started growing pubic hair. She was given medication to slow down her rate of maturation. She wore a special bracelet. She was proud of her differences but the social and emotional aspects of her development were difficult. The androgens in her brain accelerated her social and mental development beyond her age group. She took medication to forestall this but no counseling or psychological support was offered to her.

Frequent medical examinations left her with some emotional scars akin to those of a sexual abuse survivor. Intersex treatments made her feel like a freak or abnormal. Today she believes her parents did the right thing for her but wishes that she had been informed of the social repercussions of being intersex. Had she known her condition was OK she would have been spared a lot of grief and soul searching as a youth. Today she has found comfort and self-awareness from her contact with other intersex individuals.

Ms. Hillman stated that intersex is as common as cystic fibrosis. It is not a rare abnormality as the current medical model asserts. Every day five (5) children in the US are subjected to the model which wrongly states that intersex is pathological and a psycho-social emergency. Last year the Journal of Pediatric Health claimed that “next to perinatal death, genital ambiguity is likely the most devastating condition to face any parent of a newborn.” The model asserts that intersex children cannot possibly develop into healthy adults as they are. It recommends emergency sex assignment reinforced by early genital surgery. It assumes parents and children cannot handle the truth about intersex status. Parents and providers are encouraged to be less than honest about the child’s status and care options. It assumes that genitals capable of heterosexual sex are the highest priority. It does not include quality of life issues, such as happiness, successful relationships or sexual health. Nor does it include the concept of a person being gay, lesbian, bisexual or transgender as an acceptable outcome.



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

Patient-centered care focuses on the child as the patient and not the parent or society. Surgery is not a means to treat the distress of the parent. Patient-centered care promotes openness and honesty while advocating for mental health care for both parent and child. In a patient-centered model, surgery for normalizing is not viewed as medically necessary or essential. It allows for the child to determine their own gender and to advocate for themselves at an age when they are old enough to do so.

Doctors must be required to receive sex and sexual function education so that they will understand how their actions affect a child’s future. They must also receive sensitivity training about gay, lesbian, bisexual and transgender issues so they do not fear these people as the worst outcome or as failed treatment. Hospitals must account for treatment of intersex to a panel outside of the urology or endocrinology departments. Hospitals should have a response team that includes a social worker and a psychotherapist. Their response protocol should differentiate between “medically necessary” and “cosmetic.” Simply arguing that the surgeries are better now is beside the point because the surgeries are medically unnecessary.

The High Court of Colombia mandated a new kind of informed consent focused on the child’s long-term interests. San Francisco can be the first city in the nation to adopt a patient centered care model for intersex people.

[In response to the question why activists and UCSF endocrinologists differ in perspectives:] “First, the medical establishment is changing and beginning to listen to the problem. Treatment varies across the country, but the current standard of care is still emergency sex assignment and surgery. Doctors are afraid of this issue because of legal ramifications of their actions. The older pediatricians, endocrinologists and urologists set the standard and they are not changing. At conferences doctors say they don’t do clitorectomies any more. They just do clitoral reductions. But the problem is that clitoral reduction isn’t necessary and hypospadias surgery isn’t necessary in most cases.”

Secondly, [UCSF Pediatric Urologist] Dr. Baskin’s notion of what is included in intersex and how those anatomies are treated is limited. [Ms. Hillman’s] definitions include any type of sex anatomy abnormality that receives unnecessary medical intervention (i.e., that will not save the child from illness or pain).

[In response to a question regarding the nature of hypospadias surgery complaints:] “All of the people I know who have had repair wish they had not.”

[In response to a comment about why society isn’t more aware of the phenomenon and what positions the religious communities take on the subject:] “More isn’t known because of society’s fear of the subject of sex, genitalia, and children’s genitalia in particular. The current model tells the parents as little as possible, tells the child nothing of their intersex condition, promotes surgery, and keep silent about their sexual ambiguity so that the child will accept their gender assignment.”



[In response to a question regarding the availability of written medical procedures:] “I don’t think there’s a list of that kind of thing. They just follow the American Academy of Pediatrics. It’s happening doctor by doctor. But the people traumatized by the medical treatment they received are often lost to follow-up.”

BETSY DRIVER

Ms. Driver was born with an intersex condition congenital adrenal hyperplasia (CAH) in the 1960’s. Initially, doctors were unable to determine whether she was a boy or a girl, but later they decided she was a girl because she had a uterus and ovaries. So her enlarged clitoris was amputated to ‘feminize’ her. Her parents were told that without the surgery she would grow up with gender problems, become a lesbian or commit suicide.

At three months Ms. Driver underwent a total clitorrectomy despite the absence of disease or any medical condition. The doctors opined that it was a social emergency. Throughout her childhood she had many more hospital routine stays. Medical student groups frequently dropped by to examine her. Today she views these group examinations as institutionalized sexual abuse.

During her teens more surgeries followed, each with more group examinations. One surgery left Ms. Driver incontinent. Through another she acquired a venereal disease. All of the surgeries and attention taught her that her body was unacceptable and something of which to be ashamed. As a young adult she was unable to form bonds or a relationship. After years of therapy with misguided therapists she learned the truth about her medical history and genital mutilation. In her late 30s, she read about someone else with an intersex condition that was treated at the same hospital and shortly thereafter met another person with CAH for the first time in her life. Her healing began. Ms. Driver eventually started the intersex peer support organization, Bodies Like Ours.

Ms Driver stated, “To this day, parents are not being referred to peer support. They are bullied into having surgery done on their children and told they are alone. The shame, secrecy, and deceit continue to be perpetuated by the medical establishment. An effort to bring parents or intersex people together would be helpful. Yet hospitals do not take such steps. Whenever we hear from parents we do a geographic search by email to find someone else in their area. Many people also connect through our public message forms. We are also on the Internet but a parent must be fortunate enough to have Internet access. Hospitals could support this effort. Just yesterday a mother with a two-year-old baby found our organization on the Internet. It was the first time she had spoken to another person with CAH. But we do not reach out to hospitals yet. We are underfunded and not ready.”



HIDA VILORIA

Ms. Viloría described herself as a person with XX chromosomes, female reproductive organs, and ambiguous genitalia, and unlike many other speakers at the public hearing, she did not undergo surgery or hormonal treatments. Ms. Viloría stated that her father was a doctor from Colombia where such treatments were not the standard. Ms. Viloría became an activist after hearing that doctors believed that intersex people would be unhappy if they did not receive “normalizing” treatments and she wanted to voice that she was very happy she did not receive such unwanted procedures.

Ms. Viloría stated that medical protocols are based on the misperception that being intersex is detrimental and a deformity or abnormality. Ms. Viloría pointed out that doctors do not operate on abnormally intelligent or attractive people to reduce the variance from the norm. She never saw her own body as abnormal and did not suffer any abuse or emotional trauma as a result of being intersex, and pointed out that many people who are not intersex have surgery because they are unhappy with the appearance of their bodies. Ms. Viloría reported that she never had any confusion with her gender identity as a female, nor has she had any difficulties with intimate sexual relationships. She credits her family’s support as being important to her positive self-esteem because being intersex was never portrayed as shameful.

Ms. BLUE

Ms. Blue describes being targeted for sexual abuse on the basis of genital difference. She understands this abuse as “symbiotic” with concealment-based and surgical medical treatments of intersex because these foster shame and secrecy. She is grateful to be genitally intact, emphasizing that she loves her body as is, and was deeply disturbed by nonconsensual hormonal interventions in her youth. She has yet to be told her diagnosis or of any legitimate medical concerns underlying this treatment. Her experience with doctors is that they withhold information while exhibiting inappropriate interest in her intimate parts. This hinders her access to healthcare. She argues against early genital surgeries, often presented as prevention for abuse like hers, claiming “I would *not* have been better off mutilated! I wasn’t hurt because my body was different. I was hurt because people hated and feared that difference.”

DAVID CAMERON

David describes himself as an androgyne, and intersex person who prefers not to be labeled as a man or a woman. David has XXY sex chromosomes and an intersex condition called Klinefelter's Syndrome. As a child, David did not develop like other boys, developed breasts in his 20's and was told he was sterile. He sought medical attention for a low sex drive. Without receiving any emotional counseling, his doctor prescribed high doses of testosterone injections and was told he'd have to take it the rest of his life. His doctor told him he might gain weight and his shoulders broaden and to consult a medical library for other information. The doctors offered breast reduction surgery and



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

testicular implants but David refused. David reports that his gender identity was never discussed, and as a result of the testosterone his body changed in ways that altered his sense of self. David went through puberty again in his 30's. He became extremely sexually active and contracted the AIDS virus. Had he known any of these side effects before hand, David would have settled for a low sex drive.

David states that he heard about a support group for people with Klinefelter's Syndrome but found that the leaders of the group and their doctors believed that the condition could be "cured" with testosterone treatment. David believes that it is crucial for intersex people, of all gender identities (especially those with gender variations), to know and be informed of the negative side effects, including cancer risks from sex hormones through appropriate counseling and support groups for intersex persons. David states that he felt that he had been deceived by his own doctor even as an adult and that individuals must be allowed to make an informed decision on whether to use sex hormones or not.

PETER TRINKL

Mr. Trinkl is an intersex person. Mr. Trinkl was born with a vaginal opening, but lacked female internal organs. Cosmetic surgery was performed on him to close the opening.

He notes that he knew he was intersex from an early age but that his family was very secretive about this. However, some people in Mr. Trinkl's school and community learned that he was intersex and he was subject to bullying and abuse because of this. He had his head slammed against a metal gate and at the age of seven was denied membership to the Cub Scouts. Mr. Trinkl did not complain about the constant bullying due to the shame and secrecy surrounding intersex people.

Mr. Trinkl wishes that the genital surgery had not been done on him. He believes that it is shortsighted to believe that intersex people can be treated through genital surgery. Mr. Trinkl is opposed to genital surgeries that are not medically necessary and are performed without the informed consent of the patient. Mr. Trinkl believes that many surgeries performed on intersex people are for the purpose of sexual assignment and visual normalization of the appearance of genitals.

Mr. Trinkl explained that he was made to feel like he was the only intersex individual and that the loneliness and isolation he felt in his life stemmed from the systematic denial of the reality of intersex lives. He notes that today there are organizations such as Bodies Like Ours, the Intersex Society of North America, and the Intersex Initiative that are working to break the cycle of shame and secrecy surrounding intersex lives.



ELI seMBESSAKWINI

Ms. seMbessakwini described her experiences growing up and being made to feel that her body was wrong and something to be ashamed of. She explained that her parents and doctors had lied to her for thirty years.

Ms. seMbessakwini’s clitoris was operated on: once when she was less than a year old and again as a ten-year-old in order to reduce its size. These operations affected the most sensitive parts of her body “connected to pleasure and sex and relationships” before she was old enough to discover them for herself.

Ms. seMbessakwini was born with testicles in a body that looked like a baby girl’s. If her testicles had not been removed she would have looked like a man after puberty. The removal of Ms. seMbessakwini’s testicles instead took away the chance of fathering a child which is something she wants very much and also stopped the production of hormones her body had been naturally producing. As a result she is now paying for doctor visits and pills that are known to have harmful health effects and are destroying her liver.

Ms. seMbessakwini is upset that her perfectly healthy body was invasively and irreversibly operated on and that she was castrated and sterilized for no good reason. She explains that these operations robbed her of her childhood and caused shame, confusion, depression, anorexia, anxiety, insecurity, panic attacks, low self-esteem, explosive anger, lack of trust and feeling of safety, and strained and broke many of her relationships". She feels that the integrity of her body and her trust was taken from her when there was never anything wrong with her body.

SUEGEE TAMAR MATTIS

Ms. Tamar Mattis introduced herself as an intersexed parent and medical student. As an intersex person, Ms. Tamar Mattis has experienced discrimination and objectification such as when she went to the UCSF emergency room with a severe eczema outbreak. “At least 20 doctors” came into her room, opened up her gown and looked at her entire body but not one offered any medical help.

Ms. Tamar Mattis advised the Commission that while it is illegal to abort a male or female “child” based on parental preference for gender, it is legal and common to abort an intersex child based purely on intersex status. Further, medical treatment should be based on scientific evidence and there is no research to demonstrate that intersex babies benefit from cosmetic genital surgeries.

Two years ago, Ms. Tamar Mattis received a call from a pediatric nurse who was caring for a newborn intersex baby. The parents were told that the baby needed to have genital surgery but not that the surgery was purely cosmetic. The nurse wanted to inform the parents of other options but in doing so would risk her job for contradicting established



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

protocols. About to embark on her clinical training, Ms. Tamar Mattis fears a similar dilemma and that speaking up could end her career. She stated that the job of protecting intersex babies should not fall on isolated nurses and medical students.

Ms. Tamar Mattis believes the Commission has the power and urges it to implement anti-discrimination laws that would stop the “unnecessary mutilation of intersex babies, at least here in San Francisco.”

JIMMY BRUCE

Jimmy Bruce is an intersex person who was born with a phallus, undescended testes, and XY karyotype. Mr. Bruce’s father, an attending pediatrician, and an urologist determined to raise Jimmy as a female instead of a male with a small penis. The doctors removed his perfectly healthy phallus and testes, and the surgeon counseled his parents to conceal the fact of the surgery to reinforce the gender assignment of female.

Mr. Bruce’s mother told him that he would soon have to start taking pills (which he later discovered to be female hormones), and that he was infertile. He believed that his parents lied to him by omission and that they were removing his self-determination by telling him what gender to be. At age 18, he underwent surgery to create a vagina from his bowel, which was covered by his insurance plan. Mr. Bruce stated that the procedure was “inflicted on me without my educated and/or informed consent. And with zero discussion, they sent me off to school.”

At age 19, Mr. Bruce obtained his medical records and felt great emotional devastation at his discovery. Feeling manipulated and abused by his parents, Mr. Bruce was estranged from them for many years. Six years later, he is suffering the physical and emotional consequences of the choice of surgical gender assignment that his parents made out of fear: minimal sexual function, depression, and severe osteoporosis. Mr. Bruce recommended a moratorium on surgery in San Francisco, at the very least.

SEAN SAIFA WALL

Mr. Wall stated that he and several family members have intersex anatomies. He reported that the ROTC rejected the membership of his older sister because she is intersex. Mr. Wall spoke out specifically as an intersex person of color, and from a demographic that does not have access to email, Internet, or technological resources to learn about intersexuality or to meet peers.

He reported that his mother lives in fear that her children will be mistreated if anyone learned of their anatomy. Mr. Wall reported that his undescended testes were removed when he was 13, and that he was given estrogen to feminize his body. He states that psychotherapists asked him if the hormones had “altered my attraction to women or changed my presentation as male.” Mr. Wall described having his genitals examined



and enduring rectal explorations searching for his scrotum without any explanation from the examining doctors as to the reason.

He recommended that children be allowed to develop with their own gonads before initiating hormonal treatments. Mr. Wall suggested that education should begin in middle and high school health classes to educate young people about sexual diversity instead of reinforcing male/female gender binary.

WRITTEN TESTIMONY – PEOPLE WITH INTERSEX ANATOMIES

ANJA

Anja reports that she is part of a group of intersex people who are living as women in Germany. She outlined certain aspects particular to Germany.

“Ovarian donation” is forbidden in Germany.

A person must decide for a sex male or female before law, even though some people do not identify as either just one sex or the other. Dress codes mandate that females, and those living as females, have to wear a dress or a skirt in some companies. Some of the group members don't want to simply be put in the group "woman".

Intersex people are not allowed to join the Olympic games. To join as women, they are told that they have the wrong chromosomes, and for the men are told they have the wrong body. But there is no intersex group at the Olympic games and for the Para-Olympics, intersex people are not seen as being handicapped enough.

Some insurance carriers send an intersex person away for just being intersex and without checking psychological points of the individual.

MICHAEL BORRIELLO

Mr. Borriello describes himself as an intersex person and is a staff member of the New York Association for Gender Rights Advocacy (NYAGRA). He submitted his testimony on their behalf. He reports that NYAGRA is the first statewide transgender advocacy organization in New York as well as the first statewide transgender advocacy organization in the United States to hire an openly intersexed person as a paid staff member.

NYAGRA strongly supports the San Francisco Human Rights Commission's initiative to “educate parents on the issue of intersex genital mutilation (IGM).” As an organization,



NYAGRA fully committed to “ending unnecessary surgery and the physiological and psychological trauma that IGM produces.”

Speaking as an intersex person, Mr. Borriello believes in the importance of educating people that being born intersexed is a natural phenomenon. Like variations in hair, eye and skin color, male and female anatomies come in different shades, “different, yes; but not harmful or shameful.” He stated that cutting off or hiding these differences does not make them go away, as evidenced by the five children born each day with intersexed bodies. It is the shame of misinformation, unnecessary surgery, and isolation that does the harm. Mr. Borriello pondered how many expectant parents today are aware of the possibility that their child may not be a boy or a girl, but a little of both?

Mr. Borriello opined that the births of intersex people should be addressed with education, not operations. He stressed that society must acknowledge that 'either/and' is just as real a possibility as 'either/or.' He asked for compassion for all those who have come and will come into this world in intersexed bodies, and acceptance of intersex physical conditions. He stated that surgery would not change who one becomes – “Taking the wings off a butterfly does not turn the butterfly into a beetle. Removing the parts of our anatomy that made our parents or doctors uncomfortable did not make us comfortable - in our bodies, or in a society barely able to admit that we exist.”

MAURO ISAAC CABRAL (also known as I.A. Grinspan)

Mr. Cabral stated that he was born in Argentina in 1971 and raised as a female. He discovered his intersex anatomy at 13 during a medical examination where doctors determined that Mr. Cabral did not have a vagina, fallopian tubes or uterus. He stated that the doctors promised that “they would turn me into a ‘real’...a ‘true’ woman –a woman with a vagina, a woman capable of having the love of a man: penetrative love.” Mr. Cabral had a male identity and told his family and doctors that he did not desire this surgery. Mr. Cabral reported that because his father and medical team expressed horror at his gender identity, at age 16, Mr. Cabral was forced to have genital surgery.

CHERYL CHASE

Ms. Chase is the founder and Executive Director of the Intersex Society of North America (ISNA) and a person born with an intersex anatomy. Initially, Ms. Chase was assigned a male gender and named “Charlie.” Before she was old enough to remember, Ms. Chase was subjected to a clitorrectomy and reassigned to a female gender. She states, “Because there had been early surgical sex assignment and secrecy thereafter, I did not know that my sex had ever been in question, nor that my body was different from that of other girls.”

Ms. Chase stated that the family dynamics of her parents’ experience of fear, trauma, and shame from her birth and early medicalization affected her ability to be socially interactive. She believes that, because her parents were not free to communicate the



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

fear, shame, and grief, they “developed anger toward me, the proximal cause of their suffering. Ms. Chase did not perform well in school despite high intelligence, and was the constant object of teasing by other children at school. And, behaviorally, she was different than girls, stating, “I was not a girl. I did not feel or act like a girl – or a boy.” She spent most of her youth socially isolated, playing with boys when she did interact, and have romantic crushes on older girls and women.

Ms. Chase believes that her parents suffered from huge guilt over their decision to re-assign her as female and that they worried that she would eventually confront them about their decision. Her parents therefore increased their scrutiny over her sex-typed behavior and she responded with rebellion against all authority. She reports being subjected to abdominal surgery when she was eight, and subsequent annual visits to endocrinologist. No one told her the truth about what was happening to her. “No adequate explanation was given to me, and some of what was told to me was pure invention.”

Ms. Chase reports years of psychiatric therapy, and being blamed by her parents as the only unruly child in the family. Years later, the counselor told her that she had seen Ms, Chase because “you were still identifying as a boy.” Despite therapy, Ms. Chase remained as “withdrawn, friendless, unhappy, and incapable of voicing feelings when I left her care as when I entered it.” She was told that she left counseling “because you were better.” Ms. Chase thinks it was due more to her parents’ frustration with her lack of progress – “however that might be defined.” After she began menstruation at twelve, the endocrinologist visits ceased.

Beginning when she was nineteen, Ms. Chase made repeated attempts to access her medical records. Her mother dodged the request. Her gynecologist promised to obtain the records and was successful but told her there had been no response from the hospital. Years later, after failed relationships and suicidal thoughts, Ms Chase finally obtained a three page summary from another gynecologist, seeing the word “hermaphrodite” and the details of her genital surgery. Though she left the office in shock at this discovery, that same doctor sent a letter to the hospital reporting that Ms. Chase was doing very well in her “true sex, i.e. female” and that they should be proud of their work.

After thirteen more years, and more failed relationships, Ms Chase returned to learning about her past. She asked intersex clinicians for help but “most ignored me.” One clinician told Ms. Chase that she had received “really excellent care.” Ms. Chase was shocked by this reaction and realized that “intersex clinicians had no understanding of sexual function, and therefore no advice to offer me on that score. They were unable to refer me to any therapist with experience or knowledge of intersexuality. Though...they agreed to introduce me to other intersexed adults, none ever did. One acknowledged that, although she had met a number of adults who had been given clitoral surgery as infants under her care, she had never inquired about their sexual function.”



After realizing that intersexuality was fairly common, and that adults are suffering and that “doctors that specialize in intersex had nothing to offer these people,” Ms. Chase founded ISNA in 1993, with the idea to end shame and secrecy and unwanted medical intervention on intersex people. To date, the organization has received hundreds of grateful letters, emails, and telephone calls thanking ISNA and declaring how “contact with ISNA has dramatically changed their lives for the better.”

CILIO

Cilio described herself as a “young orphan born pseudohermaphrodite” from Africa (23 years old). She reports though the doctors could not determine her actual sex, Cilio states that she “passed all [her] childhood as a woman” but knowing that she was different from her peers. In 1999, she “learned that [she] was actually a man...” and wanted to make her identity officially female, but she lacks resources for psychological evaluation and surgery in France. Cilio reports that she is seen both as a “medical urgency” in France and as a “monster” in Africa. She reports living in “insulation” and feels “invaded by the shame” and feels rejection because of the appearance of her “body and situation.”

DANA

Dana reports being born 54 years ago, and did not have a clear understanding of her medical history until 2 years ago. Dana stated that she was “forcibly raised male.” She recalled being “tormented, beaten, and sexually abused by classmates, a gym teacher, and my step-father for being a freak of nature.” Dana reports that her stepfather harassed her about her penis when she was a child, calling it “little worm” while her mother watched passively and silently.

Her vague memories include, receiving “butt shots” and yet having a female-shaped body and breast development during puberty. She reports trying hard to fit in as a male but lived in “fear and self-loathing” and hiding “aspects of myself.” According to Dana, the result of the shame and secrecy was “3 nervous breakdowns, lifelong insomnia and constant wondering: about what I am.” After a lifetime of emotional pain, Dana decided to transition to female. During an exam, Dana learned that the shots she had been given as a child were actually testosterone. She was diagnosed with a “micropenis” and a type of hypogonadism called “primary testicular failure.”

Dana reports feeling relieved to understand her past, but is frustrated by the discrimination she experiences being seen as a transsexual woman. She states that because of the effects of testosterone, she is “forever branded by the gender they wanted me to be, not my real one... It is wrong to force a child into something without considering that child's real self and of altering the body through hormones and/or surgeries when the child is not sick.”



ESTHER

Esther stated that she was diagnosed with “sexual dysfunction” as a teenager because she had no reproductive organs. “I was devastated by my sudden sterility and not at all concerned with being sexually active. I had also discovered sexual function through masturbation so I didn’t understand what everyone was upset about.” Esther stated that the focus of her care was to create a vagina so that “I could have a normal sex life with my husband when I got married.”

Esther states she was diagnosed with MRKH syndrome and did not know that for 35 years, and that other associated health problems had a connection with the “sexual dysfunction.” She reports being alarmed by the medical language in her reports, stating “Phrases like ‘accommodate a penis’ and ‘sexual dysfunction’ are distressing.” Esther stated that many women had to endure multiple vaginal surgeries, have vaginas that smell of the bowel from which they were constructed, and must wear pads 24/7 because of their “bowel vagina.” She reported that some women have not seen a doctor since their surgery because “they do not trust their doctors or their condition is too hard to explain to new doctors.” She disagreed with the testimony of Dr. Baskin, Pediatric Urologist at UCSF. “Contrary to Dr. Baskin’s remarks [see pages 49-51], a quiet patient is usually a distrusting patient, a mistreated patient or a severely depressed patient.” Esther addressed her perspective of intersex as a civil rights issue: “I see intersex as a civil rights movement still in the stage of breaking the silence.”

JANE GOTO

Jane Goto described herself as an intersex person diagnosed with Androgen Insensitivity Syndrome (AIS). She reports that as a toddler in 1959 she underwent 2 hernia surgeries. Though this procedure is a common way that AIS expresses itself no tissues were removed and her parents were not told about her condition. Ms. Goto reports that at age 17 she learned about her intersexuality when she visited her family doctor to get birth control (though she has no menses). At her doctor’s recommendation, she underwent exploratory surgery at age 18, where doctors found no uterus and “abnormal” ovaries – the fact that she had testicular tissue was withheld from her at this time. The doctors gave her mother a dire (and erroneous) prognosis - “My mother recently told me that my GP discussed the surgery with her without my knowledge and told her ‘the poor child will never be able to have intercourse.’”

Ms. Goto became happily married, and subsequently had an orchidectomy to remove to remaining testicular tissue. She began hormone therapy and was berated by the pharmacist for getting such a large prescription (she was given a year’s supply) – “. Didn’t I know it was extremely dangerous to have that much of any drug in my home?” In 1978, Ms. Goto was finally told about her chromosomal makeup, “the dreaded 46,XY karyotype” (usually associated with male sex and gender). “I remembered skulking back to the lab where they had taken a cheek scraping for a buccal smear and asking the timid technician “Was it male?” She nodded “Yes” and then turned pale as if realizing that



she should not have revealed such combustible information. I drove home in a state of shock and by some miracle did not run over anyone.”

She had an emotional response to the ramifications of years of deceit by her doctors - “I initially took the news very well but completely fell apart when I got home. I wailed from such a primal place. It was as if all the grief, horror and pain in the world poured out of me.” Following the removal of my gonads, I fell into a 25-year spell of deep denial. My intersex condition was not something I would permit myself to think about. In fact, I have experienced times of paralyzing depression. Over the last 25 years, the shame and secrecy about AIS has fueled feelings of inadequacy and low self-esteem.” Ms. Goto reports becoming an overachiever, using humor as her defense mechanism. Yet, nothing she did was ever enough – “In my work-life I have garnered heaps of approval and recognition in the field of public relations and as a corporate trainer (none of which convinced me I was a worthy).”

Ms. Goto states she is highly selective in making friendships. She also has avoided seeking medical attention, “much to my detriment.” Eventually, she found a competent doctor who helped her put her intersex experiences into perspective. The doctor pointed out how the shame she felt was negatively affecting her life and referred her to resources for meeting other women like her. Ms. Goto states, “This prompted me to reach out to other AIS women and start to put the shame away for good. Since making this decision and meeting dozens of AIS women, I feel energized, renewed and kind of ‘NORMAL’ for the first time in my life.”

LYNN EDWARD HARRIS

Mr. Lynn Edward Harris reports that he was born in Orange County California in 1950, and was named Lynn Elizabeth Harris. “Due to ambiguously-formed genitalia at birth,” Mr. Harris was assigned female by his mother and pediatrician and remained in that gender role until age 29. He was diagnosed at age 23 “as possessing a rare, complex, congenital condition known as ‘True Hermaphroditism’ - with undescended, sub-sized ovotestes i.e. ‘gonadal mosaicism’ found in approximately 1-in-25,000 births.”

After puberty, Mr. Harris' anatomy had “developed clearly along non-female lines, i.e., no breasts, no milk glands, no child-bearing hips, no menses, sterility; early beard growth, male vocal chords, male skeletal structure, male musculature, male libido, male genetic patterning.” Beginning in February 1979, Mr. Harris felt “justified to live full-time in the male social gender role.” For the following four years (1979 to 1983) he lived in a sexual legal limbo, still carrying the original-and-only, valid female I.D. On numerous occasions when asked for proof of identification, he “was accused of strangely utilizing a ‘counterfeit’ or ‘stolen’ I.D. card belonging to some woman.” Desire for a permanent legal remedy to rectify all I.D. disputes, thus making it consistent with his outward persona, had become crucial, so Mr. Harris petitioned the Superior Court of California to change his birth certificate.



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

After some struggle with the Bureau of Vital Statistics, the gender marker was finally changed in 1983. Mr. Harris described this action as being socially significant – “This case, which the Vital Statistics Branch [sic] could never define in their terms as having ‘an opposite sex’ has gone uncontested and unchallenged by other bureaucratic, legal, and medical authorities.” Subsequently, Harris is presumed to have set the landmark or legal precedent in California of one's obtaining a legal sex revision without benefit of any cosmetic or reconstructive "sex reassignment-type surgery. “

Mr. Harris advocated for “a moratorium on surgeons' gratuitous, so-called ‘corrective’ or ‘normalizing’ genital operations” and stated that “Genital modification is not a panacea. It could facilitate one's ‘apparent’ social sex (re)classification on paper; but it could never automatically revamp ones ‘actual’ or ‘true’ (often inconsistent and conflicting) chromosomes, genes, gonadal composition, glandular / hormonal output, overall brain circuitry and, in turn, one's inherent gender identification and sexual proclivity.”

ELI HOBBS

Eli Hobbs reports having lived a “normal life” as an “androgynous” female in Indiana. At 13, Mr. Hobbs began to masculinize and began to be harassed in locker rooms by being called “girl-boy” and being told “No one wants to be with a girl that looks like a boy.” Eli reports being kicked out of women’s bathrooms and being sent to therapy at 15 to be taught “how to be a girl.” Mr. Hobbs did not discuss the harassment at school due to feelings of hopelessness and humiliation.

Mr. Hobbs states that no one would discuss what was going on and his troubles were “brushed under the rug” and that the solution to his suffering was to try to appear as normal as possible.” He reports learning shame about his body, which affected his intimate relationships, and diminished his self-esteem.

When Mr. Hobbs was 22, an endocrinologist informed him that his medical records stated that his “body is ambiguous” and that he could not tell what sex Mr. Hobbs was. Mr. Hobbs reported that the doctor could not explain much, and he has not learned much from other doctors he has consulted. He states that he has developed self-acceptance through peer support and by speaking about his experiences. He expressed the belief that he would have avoided “a lot of agony and pain” when he was younger if he had only spoken with other people like himself. Mr. Hobbs reports having spent years in drug and alcohol dependency trying to deal with his childhood trauma.

BRIN HOP

Brin Hop self-described as being born in 1970 with ambiguous genitalia. According to Mr. Hop, his father told the doctor to “do whatever it takes to make him normal.” Mr. Hop reported that the doctor assigned him as male, and that he has had “an ocean of health”



problems since that time. He stated that he would have preferred to have “grown up the way I was born.”

LYNELL STEPHANI LONG

Lynell Stephani Long describes herself as an “Intersex woman, activist & educator.” She states that although intersex births are statistically common, doctors still insist on “fixing” intersex bodies surgically because “no one will understand.” But, Ms. Long questioned the right for doctors to make such determinations, “Unfortunately, no one asks the child what would make him or her happy. At least no one asked me.” She reports that she was subjected to genital surgery at 2-days-old. At 8-years-old, her mother took her to a specialist who put Ms. Long on a growth hormone program. By age 14, she was injecting herself with growth hormone, and then testosterone. Ms. Long reported being subjected to display and humiliation as a child. “The most horrible experience I remember is laying in bed with IV’s in both arms, having my doctor and at least fifteen student doctors stare at my genitals, and leaving without pulling down my hospital gown. I laid there exposed for over an hour until the nurse finally came in to change the IV bag.”

Despite being given male hormones, her body seemed to feminize, which pleased Ms. Long, who had a female gender identity. Yet, if her mother caught her engaging in feminine activities, she was beaten. So, Ms. Long learned quickly to hide her gender identity to keep her mother’s favor. The hormone shots made her ill, but Ms. Long continued the interventions, despite the illness and the humiliation by the doctors. “To me the doctors were God, and I believed them. Even though the injections were making me sick I still took them. “

Ms. Long endured a lifetime of harassment for appearing androgynous. She states that “no one knew if I was a boy or girl unless they asked me. When asked, I said I did not know for sure. When my mother overheard me saying that at the age of 15 she whipped me and told me I was an embarrassment to her.”

In 1997, she was finally diagnosed with Partial Androgen Insensitivity (PAIS) and began estrogen therapy after years of feeling suicidal. That year, she also learned about the work of ISNA after seeing Cheryl Chase on television, and became an activist herself. She described her personal sense of gender identity. “Being intersex is in the brain. It’s something that even though I couldn’t point a finger on it I knew existed from the age of eight. I’ve never felt like a male, and I’m not sure what it feels like to feel like a female because I’m neither. I am Intersex, and today that’s OK.”

MIKE

Mike identified as a person with an intersex anatomy and said that it was important that people learn that being born intersex occurs naturally, like other conditions. Mike



pointed out that intersex is different but not harmful or shameful. He stated that it is the shame of misinformation, unnecessary surgeries, and isolation that does the harm. Mike requested that everyone be compassionate to all those who have come and will come into this world in intersex bodies.

MANI BRUCE MITCHELL

Mani Bruce Mitchell is a psychological counselor and native New Zealander. The doctors initially assigned her as “male” and then reassigned Mani after performing a laparotomy. Reassignment was kept secret from Mani, and the local community decided at a meeting to act as if Mani had always been female. Mani expressed that the most emotional damage was inflicted by thoughtless attitudes of others. She reported that constant trips to the doctor were physically painful, intrusive, and humiliating. Mani states that the topic was never discussed in the family so no explanation of being intersex was ever discussed or disclosed.

When Mani was 8 years old, her parents left her at a hospital. In an operating room theater, Mani was exposed to observation by strange doctors and subsequently was forced to endure “normalizing” surgery which left her scarred, in pain, and with diminished sexual functioning as an adult. Mani recalls that her legs were tied to the bed and her arms were restrained with a straight jacket. She reports that she suffered horribly because she was insufficiently medicated for pain control.

Mani states that the shame and secrecy were the most devastating aspect of the treatment, and that her body was simply different and not damaged or diseased and therefore did not need “fixing.” Mani also commented on how the legacy of shame and secrecy made her an optimal target for sexual abuse, as she had been conditioned to endure sexually inappropriate touching from the doctors.

ROBYN S. ROBBINS

Robyn identified as a person with an intersex anatomy and emphasized the plight of intersexed individuals. She stated that the secrecy surrounding her treatment added to her sense of anger and rage for being assigned the wrong sex. Robyn stressed that intersex individuals want most a sense of self-determination. She further stated that she believes that is “tantamount to severe abuse that an individual has to undo what was once done in the name of medical science...the assignment of the wrong sex or the mutilation of genitalia.”

Robyn advocated for intersex people to have informed consent over their medical treatment as a basic given medical right. She wanted most of all to not be “treated like oddities, but as feeling human beings with the same rights as anyone regardless of birth circumstance.” She stated that “...our desires are not extreme, our wishes not unrea



sonable, our dreams not uncommon. Thank you for giving us this avenue for our self expression.”

FR. SPENCER ST. JOHN

Fr. Spencer St. John identified himself as intersex. He stated that after he was born, his father and the doctors spent much time behind closed doors, excluding his mother from the decision-making process. After a month in the hospital, Spencer was sent home. He described becoming aware that he was not the “sex” that others had told him he was at three years of age. Fr. Spencer recalled being forced to wear a pink, frilly dress and he quickly “ripped it to pieces” on the playground. He reports having a very isolated childhood, where he was regularly teased as being homosexual even though he had no knowledge of sex whatsoever. Fr. Spencer attributes his mother’s strong love and support as the reason that he did not commit suicide – “Suicide was often in my thoughts and would have been the easy way out.”

Fr. Spencer developed a solitary style of survival, avoiding people and relationships, preferring the peace and quiet of the wilderness. He joined the scouts where “It was easy to pretend things were as they should be...because the subject of sex was never mentioned...” Fr. Spencer avoided school, which he saw as a place of “punishment and alienation” and spent most of his time in nature and away from school. When he did make a friend, the child’s parents would quickly forbid contact with Spencer. After a solitary childhood and puberty, Fr. Spencer entered into an even more lonely adulthood, lacking in intimate relationships.

By age forty, Fr. Spencer discovered that his caring nature provided healing for others, and after ten years of worry and study, he was finally ordained as a Catholic priest. The celibacy required by the church provided respite from expectations of sexual intimacy. There, no one questioned his masculinity and he was “warmly welcomed into an ecumenical monastic community.” Fr. John expressed his wish that no other intersex children face ridicule and the “fear of rejection.” He expressed concern that “[s]exual reassignment at birth leaves closed hospital records and emotionally broken adults in its wake.”

VIDEO TESTIMONY – PEOPLE WITH INTERSEX ANATOMIES

“XXXY” – STANFORD UNIVERSITY DEPT. OF COMMUNICATIONS - 2000

HOWARD DEVORE: “As a child, it is really scary to be in a hospital and not know why, other than there’s something wrong with what is between your legs.”



HOWARD DEVORE: “My father said it most clearly. He didn’t think that he was being offered a choice. And, I think that most parents have this experience.”

JIMMY BRUCE was born in 1976, and was initially assigned as male. Then the doctors changed their determination. They removed his undescended testes, and subsequently performed a clitorrectomy on Jimmy. Jimmy’s father stated, “They said they could correct the problem and that we could raise her as a girl. They [the doctors] thought that was the best way to handle it.”

HOWARD DEVORE: “I would go back to school sometimes maintaining this plastic tube coming out of my genitals for up to six weeks, draining into a sack that I had strapped to my leg underneath my jeans. I thought they were trying to make me look more like a boy and they were trying to make it so that I could stand to pee.”

JIMMY BRUCE: After enduring a vaginoplasty that created a vagina from bowel tissue, Jimmy started to notice that it was pushing out of his body. Working as a bicycle messenger, Jimmy described the discomfort he experienced to his doctor. “I was told at the age of fourteen or fifteen that I would have to wear a maxi-pad for the rest of my life...[Expressing his horror at the thought] Jimmy exclaimed, “I am not a girl!”

HOWARD DEVORE: “It’s horribly unfair that one’s sexual feelings, one’s ability to be able to feel like you can couple in an intimate way with another human being is literally destroyed by some doctor’s idea of how genitals are supposed to look.” “I don’t know one intersexed individual who is happy with the treatment they have received from the physicians that they have consulted with over the years – not one! Not one! I have spoken with people internationally, more than a thousand of them. I’m eager for the medical society to present these successful cases, because I can’t find one.”

HOWARD DEVORE: “I am doing the best I can to educate enough people to see that this practice is stopped – that there will be no cosmetic surgery on the genitals of infants anymore – that it is okay to raise intersexed people. And, if they choose later to have the surgery, if they are given the chance to make the choice between the natural genitals they were born with and genitals that may look more like this or more like that. If they have the chance to do that...If I had the chance, I would not have gone through quite so horrible an adolescence and quite so difficult an identity formation as an adult.”

SEX UNKNOWN – 2001 – NOVA

“Explore the fateful consequences of gender reassignment”

(This program told the story of David Reimer, who was surgically assigned as female when he was eight-months-old after his penis was destroyed during a circumcision. Psychologist Dr. John Money used this case as a way to validate his now discredited theory that all small children are psychosexually neutral. David Reimer committed sui



cide in May 2004. His family believes that the reason for David’s suicide was his life long depression stemming from the incorrect gender assignment recommended by Dr. Money.)

DAVID REIMER: “You don’t wake up saying, ”I’m a boy today, you know? It’s in you. Nobody has to tell you who you are.”

ORAL TESTIMONY – PARENT PERSPECTIVES

FREEMA HILLMAN

Ms. Hillman reported that, as a second grade teacher, she heard the term “virilized adrenal hypoplasia” years before she recognized the symptoms in her own 4-year-old daughter. Due to the lack of an enzyme, Ms. Hillman’s daughter had an overactive adrenal gland which produced an excess of testosterone and made the child prone to advanced bone age, early puberty, stunted growth, facial and body hair, lesbianism and “other masculine characteristics.”

Ms. Hillman states that she gave her daughter hormone medications because she wanted her daughter to look normal and fit in. For years, the two fought the effects of hormonal imbalance. Ms. Hillman stated: “In retrospect, I was always trying to hide the evidence of who she really was inside. But she always knew.” Ms. Hillman is grateful that she “didn’t have to face the option of genital surgery to achieve that look of normalcy ... because it is very clear now that my daughter would not have chosen it for herself.”

Ms. Hillman reported that as a parent, her only resource was a hospital library and the information she obtained there was limited and frightening. Her husband was unwilling to talk about their daughter’s condition and Ms. Hillman was ashamed and embarrassed to talk about it with friends. Had there been more public awareness and better communication, the Hillmans could have been spared the misunderstandings, loneliness, fear and shame.

WRITTEN TESTIMONY – PARENT/FAMILY PERSPECTIVES

DEBBIE HARTMAN

Ms. Hartman resides in Sweetborough, New Jersey and submitted written testimony. She is the single mother of a 10-year old intersex child, Kelli. Kelli was surgically re-assigned female at the age of 11 weeks and has had 4 genital surgeries to try and



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

make her genitals look female. Ms. Hartman emphasizes that Kelli’s genitals still do not look female and she has endured unnecessary pain, confusion and severe emotional and physical scarring. Ms. Hartman also suffered emotional trauma as a mother.

She states: “My child has tried to commit suicide twice in her 10 little years because she says she hates her body. She constantly asks me why they ... cut up her genitals.” Ms. Hartman quotes Kelli as follows: “They thought I was no good, Mom.”

Regretfully, Ms. Hartman reports that she was not given enough information to make an informed decision. Ms. Hartman would have liked to be told of the option to raise her child as he/she was born and let him/her decide. Also, she says she repeatedly asked to speak with others in her situation and was told, “There is no one.”

Ms. Hartman believes that an intersex child must be raised male or female but that it should not include physical alteration. Ms. Hartman recommends surgery only in case of a real medical emergency.

RUTH TANG

Ms. Tang lives in Victoria, Australia and provided written testimony. She is the mother of a child who, at age one, was medically labeled a “true hermaphrodite”. Ms. Tang recounts shock, worry, and no access to information or peer support. She and her husband relied on doctors who decided that the child should be raised as a girl and that surgery was necessary “to make her into a girl.”

As a result of surgeries and hormones, Ms. Tang’s child suffered a great deal of trauma, confusion, and shame. Secondary to her child’s pain, Ms. Tang lives with the guilt of “putting her child through the most horrendous emotional and psychological traumas for so much of her life.” Ms. Tang states: “I now know that she should not have had any surgery or hormones until she was old enough to make her own choice based on her own feelings. ...Without a doubt her rights have been violated.”

ANONYMOUS FOSTER PARENT

The foster parent asked that she and her foster son remain anonymous. The foster parent stated that she got her son when he was 17. At that time, he was not aware of being intersex and that he had been raised female. He had thought that he was a lesbian since he had been raised female and was attracted to females. After “many” years, they learned that intersex existed and that he seemed to “fall under that cap.” As a parent, the foster mother urged everyone to be accepting of humans for who they are and not because of “what is or what is not between their legs and who they decide to share themselves with.”



ANONYMOUS

The writer stated that they are a family member of an intersex person, and expressed pride that San Francisco is the first City to hold a public hearing on intersex issues as human rights issues. They clearly separated intersex from transgender issues, stating appreciation that the Commission “is interested in learning about the unique medical, social and human rights issues for intersex people as separate from those of the trans community.”

The writer stated that LGBT organizations often rush to include intersex people in their activities without understanding the issues facing intersex people, and that often creates a greater sense of isolation for intersex people without serving their unique needs – “And the intersex people who are most in need of support are small children who have just been surgically mutilated or are at risk of that happening. “

The writer expressed deep concern for intersex children – “Each year thousands of babies and young children, including in San Francisco, face the likelihood of having their genitals mutilated.” The writer also expressed concern that people are not getting important information or are being coerced – “In addition to the inability of a child to know what is going on and to fully understand the way their body will be affected for the rest of their life, doctors routinely deny their parents accurate information and railroad them into choosing in favor of surgery.”

The writer stated that their intersex family member and others like her experience a wide range of injustices: medical records are denied or destroyed, doctors provide misinformation, the patient is denied consent to procedures performed on them, and specialists do not inform the patient or their parents about the risks of surgery or hormone treatment. They expressed concern about their intersex family member’s ability to access sensitive and informed health care. They report that she suffers the physical and mental health consequences of how she was treated for being intersex.

The writer noted the lack of education and resources – “There is a lack of information about intersex conditions in the general public, and very few resources for intersex adults to gain support and information.” They concluded with a strong and urgent recommendation to stop the “normalizing” interventions – “...it is the necessity of legislation outlawing medically unnecessary genital mutilation on intersex infants and children here in San Francisco. In this progressive city of ours, there is nothing to keep surgeons from performing these unnecessary and damaging procedures, and no program to provide supportive resources to parents so they can learn how they can raise a happy, healthy intersex child without this type of medical intervention.”



ORAL TESTIMONY – MEDICAL PERSPECTIVES

DR. LAURENCE BASKIN - Department of Urology, University of California, San Francisco (UCSF)

Dr. Baskin described himself as a pediatric urologist at UCSF. He disagreed with the figure of 40 intersex surgeries at UCSF every year, stating the figure actually is one-per-year. He said that at UCSF they do not do surgeries to establish a diagnosis or to give hormones, unless the child is “missing” hormones.

Dr. Baskin said that there are births in which you cannot tell the parents whether the child is a boy or a girl, and that presents a crisis because of our culture, in which “basically two sexual identities are accepted at birth.” Dr. Baskin said he and other doctors try to figure out the gender as best they can, based on genetics and the presence of XY or XX chromosomes. He described another group of patients that present later than the newborn period, when their bodies start to change. They may initially look like a girl, and then start to look like a boy. He said that is confusing for the parents, who then seek medical care.

Dr. Baskin said that another group of patients is diagnosed pre-natally, through ultrasound. Sometimes, the fetal chromosomes are XY, indicating a boy, but at birth, the child looks like a girl. He described those children as “intersex per se.” He said the environment becomes important because “it’s not what’s between your legs, it’s what’s between your ears” that counts. He described San Francisco as a great place to live given local cultural mores, unlike other cultures where one’s appearance determines whether you are treated as a male or female. He gave as an example Saudi Arabia, where being a boy is more valued.

Dr. Baskin said that 15 or 20 years ago intersex births were considered a social emergency and that within 24 hours the parents needed to know whether the newborn was a boy or girl. He said that things have changed and now doctors realize that sex and identity evolve, and that assignment does not need to take place on an emergency basis. He said that it happens at UCSF up to six times a year, where an intersex diagnosis is very clear. He said they have excellent long-term follow up for these patients. He said sex and gender assignments are made with very careful input from an endocrinologist, a pediatric neurologist, himself, clergy, the family, etc. He stressed the importance of genes and chromosomes in making these determinations, and that each patient must be treated individually.

Dr. Baskin stated that infants without a phallus used to be deemed to be girls, but that he and other doctors have stopped doing that. He said that his medical group “lets the sex evolve.” He said that intersex children are less than one percent of his practice, and that the operative rule regarding surgery is “if you can’t put it back don’t take it out;” in other words, stay away from irreversible surgeries.



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

Dr. Baskin described the condition known as “hypospadias” where a child may look like a girl but then produce more male hormones at puberty, ending up being a boy. He also described a “third sex” where reproduction is possible. Dr. Baskin said that in the past too many surgeries were performed, and that today irreversible surgeries are rare. He said, however, that 99 percent of the surgeries that are done are “very straightforward.” He noted that when there are chromosomal anomalies, such as XX XY XO, treatment is complex.

Dr. Baskin said that, in patients with ambiguous genitalia, the diagnosis is congenital adrenal hyperplasia 85 to 90 percent of the time, and is a relatively common condition. He described the progress of fetal development in which without the influence of testosterone the fetus is a girl. But with the “enzyme defect,” even though their chromosomes may be XX (female) and they may internally have a uterus and ovaries, the girls end up “looking like a male” due to clitoral hypertrophy (enlargement). He said that historically surgery was done to make the clitoris smaller or even to remove it, but that is rare now. He said that in the “rare” case when clitoral surgery is performed, erectile function is preserved. He explained that the problem is that these little girls have urogenital sinus, in which there is no separate vaginal opening and that surgery separates the vagina from the urethra so they can be “normal.” He said that these girls grow up normally and can have children, though they must take hormones. He said that some babies born with a missing hormone controlling water balance will die within two weeks.

Dr. Baskin explained that in the case of a newborn with ambiguous genitalia, a good deal of testing and meetings occurs. If an exact diagnosis comes up, they present it to the family with options. Surgery is recommended if there is no vagina, or if gonadal tissue is somewhere in between a testicle and an ovary as that is risky for cancer. He said that if it’s not that clear, nothing will be done until puberty when gender identity has been established. Dr. Baskin said that ambiguous genitalia result in surgery about one percent of the time. He also maintained that the condition of hypospadias is not an intersex condition, and that it, like a cleft palate or an extra arm, would always be “fixed.” Dr. Baskin discussed the condition in which males are born with a tiny penis (microphallus). Those children do grow up to have “normal” sex and have kids. He said that in the past that wasn’t accepted because of the need to have penile-vaginal penetration, but now it’s accepted that there are other ways to have sex. He said converting a baby with a tiny penis to a female would be “a disaster.” He said, though, that to make parents feel better, the child would be given male hormones.

Dr. Baskin said that these issues are discussed at pediatric conferences, and that the issues are not settled. He said that “we’ve made great strides with just the concept that sex can evolve” and that it’s not always necessary to make an emergency sex assignment. He predicted that at the next pediatric endocrinology/urology conference there will be continued discussion of intersex conditions and the question of when to do surgery and other treatments. He concluded by mentioning that doctors hear very little from patients with successful surgeries, but mostly hear from patients who have had problems.



He singled out Cheryl Chase, founder of the Intersex Society of North America, as having been especially helpful.

[Editor’s Note: After the Commissioners unanimously approved the report on January 27, 2005, Dr. Baskin asked the Mayor’s Office and the Commission for an opportunity to present further information to the Commission, specifically to present statements from intersex patients who report experiencing successful outcomes from medical “normalization” interventions. Despite repeated Commission invitations, Dr. Baskin did not provide further medical or research information or any statements from intersex patients who report experiencing successful outcomes after medical “normalization” interventions. ***See Appendix F for further correspondence between the Commission and Dr. Baskin.]

NOTE: Dr. Baskin reported to the Commission that normally UCSF performs one “intersex” surgery annually. He also indicated that clitoral surgeries are no longer performed at UCSF. The Commission requested information from UCSF regarding the number of genital surgeries performed each year at their facility. UCSF’s Health Information Management Services provided different figures than those given by Dr. Baskin, as follows:

SURGERY STATISTICS FROM UCSF 2000 THROUGH 2003

UCSF provided the following information in response to requests regarding the number of genital surgeries performed each year at their San Francisco facilities:

Number of Clitoral/Vaginal/Vulvar surgeries performed at UCSF from 2000 through 2003:

2000	5 surgeries (ages 1 day, 5 mos., 14 mos., 5 years, 13 years)
2001	6 surgeries (ages 1 day, 1 day, 8 mos., 9 mos., 12 mos., 17 years)
2002	6 surgeries (ages 1 day, 3 years, 3 years, 4 years, 10 years, 13 years)
2003	6 surgeries (ages 3 mos., 3 mos., 6 mos., 6 mos., 13 years, 17 years)

(Diagnoses: Congenital Anomaly of Cervix/Vagina [6]; Cervix/Female Genital Anomaly [5]; Androgenital Disorders [7]; Indeterminate Sex/Pseudohermaphroditism [4] Anomaly of labia [1]; Hypertrophy of labia [1])

Total: 23 clitoral, vaginal, and/or vulvar surgeries performed on children under 17 years of age – 15 patients were under 4 years of age – 12 of those patients were under 1 year old



Number of Hypospadias Repairs:

2000	65 (under 12 years of age – 53 were under 2 years of age; + 4 adults)
2001	71 (under 13 years of age – 57 were under 2 years of age; + 6 adults)
2002	82 (under 15 years of age – 69 were under 2 years of age; + 6 adults)
2003	74 (under 13 years of age – 62 were under 2 years of age; + 3 adults)

Total: 292 procedures on children under 17 years of age – 241 of those were under 2 years of age – 151 of those patients were under 1 year of age; + 18 procedures on adults = **307 surgeries**

UCSF notes that the Hypospadias repair figures contain “20 repeat patients who had 2 procedures each, and 7 repeat patients who had 3 procedures each,” indicating that 27 people underwent 61 procedures.

GRAND TOTAL: From 2000 through 2003, doctors at UCSF performed 315 genital surgeries on children with ages from 1 day to 17 years:

- **241 procedures were performed on children under 2 years of age**
- **164 patients were under 1 year of age.**

DR. KATE O’HANLAN

Dr. Kate O’Hanlan is a gynecologic cancer surgeon. She began her presentation by placing concepts of sexual orientation, gender identity and intersexuality on a female-male spectrum and stating that every place within the spectrum, including ambiguous genitals, is normal. Dr. O’Hanlan made the following points:

Practical Considerations:

- The rationale for infant and child genital surgery is speculative and psychosocial. Such surgery alleviates no pain or illness; it is cosmetic and medically unnecessary.
- Surgical clitoral reduction risks future urinary function and reduction or loss of sensation. Vaginoplasty can cause infertility.
- All genital surgeries performed on children are also available to young adults when they are better able to give consent.
- It is easier to operate on larger anatomy and results are more likely to be guaranteed.
- Genital surgery is irreversible. If a person born with a large clitoris is initially raised female and becomes male at puberty or desires gender reassignment after puberty, that person will be glad that the clitoris was not cut or carved on.
- Sexual identity is formed in the brain during the first 12 weeks of pregnancy and genital development doesn’t always correlate with what happens in the fetal brain.



Available Research/Peer Review Literature and Needed Data:

There is no proof of long term benefit from infant genital surgery and there is evidence of harm.

- Currently, to perform new or innovative surgery, one has to request approval from an institutional and investigational review board. Historically, experimental genital surgeries have been performed without panel review or follow up.
- We are lacking positive follow up data from adults who have had clitorectomies or clitoroplasties in the last ten years. Specifically there is no data that reflects satisfaction with surgery results, data that the genitals are structurally and functionally normal or that quality of life has been improved.
- Many adult intersexuals report dissatisfaction with treatment and surgeries they received as infants and children. People complain about appearances, scarring, pain, and diminished or absent function.
- In peer review literature, results of clitoroplasty are very disappointing. Young girls with vaginoplasty require repeat surgeries over and over again to fix an organ that they would not use until mid teens at the earliest.
- Adult women do not complain about having a large clitoris.
- Adult men do not want to have their microphallus removed and be raised a girl. They still declare themselves to be a boy within two to four years and then have to transition as transgender once they have autonomy. Adult men with small phalluses can and do learn to be sexual in ways that satisfy both themselves and their partners.

Ethical/Human Rights Considerations:

- It is unethical to disregard a child’s intrinsic human rights to privacy, dignity, autonomy, and physical integrity by altering genitals through irreversible surgeries for purely psychosocial and esthetic rationales. It is wrong to deprive a person of the right to determine their sexual experience and identity.
- We condemn female genital mutilation among African tribes though it may be culturally essential.
- Pediatric urologists who perform infant genital surgery believe they are helping children by making them look more normal but “they have been stunningly slow to recognize this really important human rights issue of the child.”
- Infant genital surgery violates every medical standard of informed consent. It violates UN Commission on Human Rights, American Convention on Human Rights, and American Pediatric Association’s standards. The Nuremberg Code of Ethics states you may not do anything to a human being in your charge that is not medically necessary particularly if it’s irreversible and potentially harmful.

Regarding the discrepancy between standards of informed consent and infant genital surgery:

- The standard is malleable according to priorities. Surgeons who think that the most important thing for a toddler is to have a vulva or phallus that looks more like the



other kids in the classroom will attempt to provide it. Surgery is an attempt to calm parents by creating a short-term favorable picture.

- Intersex surgery began with good intentions, but the data doesn't support it.
- The trend is away from surgery, even among those who perform it, but the trend is not going far or quick enough.

General Recommendations:

- Adopt observational management style of helping the child, helping the family and then letting the child, after puberty, decide what surgery they may want or need.
- Do not operate on an infant's clitoris or remove a phallus. Do not remove a potentially functional gonad. Do not perform a vaginoplasty on a child until requested after puberty.
- Every institution that credentials surgeons to perform pediatric genital surgery should create an ethics panel to review current literature and to generate a policy on intersexual issues based on available literature.

If surgery is offered:

- Apply standards used in all other surgeries. Provide parents with information about current and future benefits, complications, side effects and alternatives.
- Prohibit genital surgery on any child without prior ethics panel review.
- Require follow up studies on all intersex children who have had genital surgery.

Recommendation for the Commission:

- The Commission should prohibit genital surgery without formal ethics panel review in all hospitals under City auspices.
- Dr. Baskin made reference to “abundant follow up data” that supports the performance of clitoral reduction on little girls or vaginoplasty. However, this data does not exist. The Commission should require that Dr. Baskin produce it.

MARY MC GHEE

Mary McGhee described herself as a labor and delivery nurse at San Francisco General Hospital where she has worked for the past 12 years. Ms. McGhee explained that she was the person most likely to place the newborn on the mother's chest and to announce the sex of the child. She pointed out the irony because she has never received any training on the issue of intersex births.

Ms. McGhee indicated that she was not taught what to say to parents or how to address their needs with sensitivity. She was uncertain how well informed the social workers are at SFGH. Ms. McGhee recommended that resources be developed for nursing and social work staff. She urged a legislative response to ensure intersex issues in curriculum of social work and nursing programs, medical schools, psychology programs, and continuing professional education courses.



WRITTEN TESTIMONY – MEDICAL PERSPECTIVES

AMERICAN ACADEMY OF PEDIATRICS (AAP)

The American Academy of Pediatrics responded to the Commission’s inquiry about AAP’s official policy on the treatment of children born with ambiguous genitalia by sending two articles to illustrate their position. The first article, *Evaluation of the Newborn with Developmental Anomalies of the External Genitalia* offered the some guidance: Surgeries should be performed as early as possible. Depending on the procedure, this will range from 6 months to 18 months of age. The article states that “The birth of a child with ambiguous genitalia constitutes a social emergency.” In their response to the Commission’s inquiry, the AAP offered the article as “the best way to address the questions you posed originally regarding treatment of children with intersex conditions and methods for approaching families of children born with these conditions.” The article recommends an immediate medical response to change the appearance of ambiguous genitals: “their diagnosis and treatment require urgent and immediate medical attention.” Physicians must acknowledge the psychological stress this may place on the family and parents. Thus, open communication between the families and the doctors is crucial.

The second article, *Timing of Elective Surgery on the Genitalia of Male Children with Particular Reference to the Risks, Benefits, and Psychological Effects of Surgery and Anesthesia* focuses primarily on the timing of genital surgeries. “Due to concerns surrounding a child’s body image, which is generally derived from social interactions, genital surgery should be performed while the child is still young. A child with external birth defects, including hypospadias, is at risk of developing distortions of body image that reflect other people’s subtly communicated evaluations of the child’s body.” Because body image develops early in life, the sooner one can perform corrective genital surgery the better. This will decrease the chance of psychosocial and behavioral problems. Furthermore, improvements in anesthesia have minimized the risks associated with surgery on infants and risk of death is minimal. Ultimately, due to technical improvements in medicine, undescended testes or hypospadias operations can be performed at earlier ages; even as early as 6 months of age. Yet, The AAP also acknowledges that there is increased risk for complications and death in young patients that may outweigh the perceived gains. The younger the child is the higher the risk-benefit ratio becomes.

AMERICAN ASSOCIATION OF CLINICAL ENDOCRINOLOGISTS (AACE)

The American Association of Clinical Endocrinologists (AACE) responded to the Commission’s inquiry regarding AACE’s official policy on the treatment of children born with so-called ambiguous genitalia: “The AACE does not have any standards of care and preferred procedural recommendations regarding the treatment of children born with ambiguous genitals.” The AACE referred the Commission to materials already provided by the AAP (*Evaluation of the Newborn with Anomalies of the External Genitalia – July*



2000). This article recommends that “Surgeries should be performed as early as possible. Depending on the procedure, this will range from 6 months to 18 months of age.”

AMERICAN MEDICAL ASSOCIATION (AMA)

The American Medical Association (AMA) responded to the Commission’s inquiry regarding AMA’s official policy on the treatment of children born with so-called ambiguous genitalia: The AMA does not have its own official policy regarding the treatment of children born with ambiguous genitalia. The AMA states that it usually defers to the national medical specialty societies to develop specific practice standards. The AMA referred the Commission to seek that information from the American Academy of Pediatrics and the American Psychiatric Association.

AMERICA UROLOGICAL ASSOCIATION (AUA)

The American Urological Association (AUA) responded to the Commission’s inquiry regarding AUA’s official policy on the treatment of children born with so-called ambiguous genitalia: “At this time, neither the AUA nor the Urology sections of the American Academy of Pediatrics has an official policy or guideline regarding the care and treatment of children with ambiguous genitalia. Indeed, it’s a very complex problem and there is a divergence of opinions among respected professionals. Many of the physicians who treat these young people feel that early reconstructive surgery is appropriate for ambiguous genitalia secondary to hormonal stimulation.

However, there is a body of opinion shared by an increasing number of physicians dealing with the problem who feel that, in the case of ambiguous genitalia due to chromosomal abnormalities, delaying reconstructive surgery until the individual is able to participate in the decision making process, is appropriate. This opinion is not shared by all and, indeed, there are those who feel that early intervention is reasonable when the parents know all the facts and are able to provide informed consent. All of the professionals agree that there should be a ‘team’ approach to treating these patients and informing them and/or their families, in an objective fashion, of the advantages and disadvantages of early reconstructive surgery versus delayed reconstructive surgery. The team includes a Pediatric Urologist, Pediatric Endocrinologist, and Pediatric Psychiatrist. As you can see, there is continued scholarly discussion and investigation of this condition but, as noted, there is no official policy embraced by the AUA at this time.”

DR. RONALD BACHMAN, Chief of the Department of Genetics, Kaiser Permanente, Oakland, CA

Dr. Bachman reports that he is the Chief of the Department of Genetics at Kaiser Permanente Hospital in Oakland, California. He reports that he is involved in making “the correct diagnosis in children with ambiguous genitalia, it is our pediatric endocrinologist who follows the patient.” Due to this reason, he states that he does “not have the exper



tise to comment on the treatment of intersex conditions to the Human Rights Commissioners.” Dr. Bachman declared that, while he favors the “patient-Centered model of care,” he believes that “each case needs to be individualized.” He recommended a team approach that includes “parents, the primary care physician, and the specialists involved in the diagnosis and management (may include geneticist, genetic counselor, pediatric urologist, pediatric endocrinologist, and a representative of the Intersex Society [of North America]).” He further opines that “It is important that the specialists have expertise in the diagnosis and management of intersex disorders.”

DR. WILLIAM BYNE, Department of Psychiatry, Mount Sinai School of Medicine, New York, NY

Dr. Byne describes himself as both a researcher into sexual differentiation and a clinical psychiatrist who has provided care for people with intersex conditions. He stated that “The goal of treatment of intersex should be to optimize the quality of life of the patients.” Dr. Byne believes that the traditional model of concealing the intersex condition from the patient has inflicted damage on the patients – “Tremendous psychological harm has been inflicted by the shame resulting from this shroud of secrecy and deception.”

Dr. Byne reports that intersex people do not express being overly concerned with their different anatomy, but instead describe deep feelings of shame and isolation due to their parents’ and doctor’s reluctance to discuss the difference. He states that many intersex people felt betrayed when they learn that their parents and doctors kept the truth from them about their bodies. This erosion of trust is a major barrier in establishing therapeutic relationships with medical and mental health care providers. He further states that it is difficult to work toward a successful mental health outcome when the intersex patient experiences ongoing deception from their doctor.

Dr. Byne recommends honesty and full disclosure to the parents, including discussing all treatment options and weighing the benefits against the risks. He urges care providers to realize that intersex is not necessarily urgent or life threatening, and that cosmetics should not be the sole criteria for genital surgeries on infants. Dr. Byne further recommends better education so that parents understand the full and complex scope of gender role behavior, emphasizing the broad range of such behaviors and the large amount of overlap between them. He cautions parents from being “overzealous in their attempts to reinforce gender appropriate behaviors.”

Dr. Byne recommends discerning between gender assignment and genital surgery, noting that a gender role can be assigned without surgery. Dr. Byne stated that, “In spite of the fact that textbooks seem to all agree that intersex is a psychosocial issue, medical care providers still tend to treat it as if it is ‘curable’ with surgery...Of course, intersex is a lifelong condition that does not go away with surgery. But, cosmetic genital surgeries on small children are still often used to try [to] assuage parents’ fears and concerns.”



DR. DORA GOLDSTEIN, Stanford University, Stanford, CA

Dr. Goldstein is a member of ISNA’s Medical Advisory Board and a member of the Board of Directors of PFLAG (Parents, Family, and Friends of Lesbians and Gays). She states that her experiences with PFLAG expanded her understanding of the “distress of people who feel left out of the general society.” Dr. Goldstein notes that she understands how the many variations of human sexual development can lead to a confusing gender assignment at birth. She also expressed sympathy for families who are “confronted with an infant with an ambiguous sex...” and stated that she understood doctors’ “urge to do something to correct the perceived abnormality.”

Dr. Goldstein urged doctors to understand that genitals do not necessarily conform to gender role expectations, and that all people are born with “an inborn knowledge of what gender they are, even if their anatomy does not agree.” She stated that there is nothing shameful about this discrepancy and that such anatomies are actually quite common. Dr. Goldstein suggests that society needs to be more open and accepting about gender roles. She recommended that full and accurate information needs to be promptly disclosed to the parents, and that surgical interventions should not be done on children who are too young to participate in the decision.

DR. PHILIP A. GRUPPUSO – Professor of Pediatrics, Brown University, Providence, RI

Dr. Gruppuso is the Director of Pediatric Endocrinology at Brown University and the Hasbro Children’s Hospital in Providence, Rhode Island. In addition, Dr. Gruppuso is a Professor of Pediatrics at Brown, and has been involved in the care of many children born with ambiguous genitalia. During the first 15 years of his practice, Dr. Gruppuso followed the established practices regarding ambiguous genitalia. Then, he became involved in the care of a young teenager who had been surgically assigned as a female at birth, and had been forced to take estrogen. This person was in the process of changing to a male gender and Dr. Gruppuso assisted him in obtaining male hormones, insurance approval for a mastectomy, and a referral for surgical reconstruction of the young man’s genitals.

Dr. Gruppuso stated that he believes that the standard of surgical gender assignment is based upon the controversial work of Dr. John Money. Dr. Gruppuso reflected, “The result of this was...irreversible cosmetic surgery on babies in order to support gender assignments. It has become apparent through recent reports and retrospective clinical analyses that gender assignment in the newborn period is an uncertain process. Gender surgery on newborn babies, necessarily performed without their consent and often performed without a full understanding for the implications on the part of the parents, can have serious, lifelong consequences.”

Dr. Gruppuso stated his analysis – “I believe that appearance-altering surgery on newborn babies for the purpose of gender assignment is wrong. It is often undertaken with



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

out full disclosure to the parents of potential consequences. It creates shame and can result in irreversible modification of the genitalia that may not correspond to the patient’s ultimate gender. I believe that physicians should adhere to the principle of doing no harm and that resources should be made available so that patients may benefit from long-term psychological intervention rather than being subjected to surgery.”

DR. WILLIAM REINER – Department of Urology, Division of Pediatric Urology, Department of Psychiatry, Division of Child and Adolescent Psychiatry, University of Oklahoma Health Sciences Center, Oklahoma City, OK

Dr. Reiner is a physician who trained in child and adolescent, and adult psychiatry after 18 years of adult and pediatric urological training and surgical practice. Dr. Reiner’s particular area of interest has been psychosexual development in children and adolescents with congenital genital anomalies. He addressed the "optimum gender policy" or "optimum gender of rearing policy" in children born with intersex conditions.

Dr. Reiner noted that the phrase "ambiguous genitalia" is subjective and begs the question: "Ambiguous to whom?" Based upon his clinical experience, Dr. Reiner states that "... ambiguity is in the eyes of the adult looking at the child – but I have never seen, met, or assessed a child or adolescent with anomalous genitalia who stated that their genitalia were ambiguous, "in-between," "male-and-female," and so forth.”

Dr. Reiner notes that the expression "optimum gender policy," or "optimum gender of rearing policy" misleads people to believe that identity can be externally assigned - "Identity is peculiarly internal – and is quite naturally, therefore, intuitive." He reports that 1/3 of the children he has seen that have XY chromosomes and functioning male hormones and hormone receptors and who have been assigned as females have “legally have transitioned to male sexual identity spontaneously.”

Dr. Reiner concludes that “we cannot arrive at an optimum gender policy because we have no idea what gender – that is, what sexual identity – any child or adolescent or adult has or could have unless and until that child or adolescent or adult tells us.” He states that “I also have learned from my work that if we assign the incorrect sex to a child – and especially if we do not remove any part of that child's anatomy without their consent – then the child always has the prerogative to correct us and at whatever time or age seems appropriate to the child.”

DR. NINA WILLIAMS - Robert Wood Johnson Medical School, Institute of Psychoanalysis and Psychotherapy of New Jersey, Highland Park NJ

Dr. Nina Williams reports that she is a licensed doctoral psychologist in private practice, and occasionally works with a person who has an intersex anatomy, or to help a woman who is pregnant, or a mother with a child who has ambiguous genitalia. Dr. Williams teaches human sexuality at Robert Wood Johnson Medical School and includes intersex panels to educate the second-year students.



As a mental healthcare provider, Dr. Williams states that she was taught nothing about intersex conditions, much less how people with these conditions are treated. When she encountered a 19-year-old with vaginal agenesis ten years ago, she and her supervisor (an eminent researcher and practitioner of sex therapy) never even discussed whether or not the patient could choose to refuse a vaginoplasty. “My assignment was merely to “prepare” her to accept the surgery. I was discouraged from raising this topic in the therapy, and when I gingerly mentioned “all your choices” in a session about her treatment, the patient never returned.” Five years later, Dr. Williams tried a different approach - “When another young woman client ... told me about her distress over her unusual-looking genitals, I decided to do something different, to listen to her and learn about her experience and of the options for treatment.”

Dr. Williams believes that the goal of intersex treatment is to protect the development of a healthy identity and that genitalia is not the most important component contributing to gender identity development. She sees secrecy and unwanted medical interventions as being most destructive to trust and security. “We all need the experience of being accepted as we are, of belonging, and ‘the peace that comes with the acceptance of what one seems to be made to be.’” [Second quotation by Erik Erikson]

Dr. Williams believes that helping families to support this acceptance is the ultimate goal, best achieved through steady psychological support, honesty, and respect for the child and parents, and postponing cosmetic genital surgeries until the child reaches the age to give truly informed consent. She also stressed the need for financial resources and health insurance for parents and children in order to obtain appropriate treatment.

Dr. Williams offered an opinion about why infant genital surgeries happen – “We react with an uncanny preoccupation with those who don’t conform to our fantasies about people fitting smoothly into two sexes. Our desire to eliminate evidence to the contrary makes us believe that surgically assigning sex to babies with ambiguous genitals will help people who are intersexed to fit in. But why don’t we think about a less intrusive and potentially destructive intervention? An alternative means is to accept the presence of a wider variety of bottoms than we’re used to admitting, then moving on.”

VIDEO TESTIMONY – MEDICAL PERSPECTIVES

“XXXY” – STANFORD UNIVERSITY DEPT. OF COMMUNICATIONS – 2000

DR. JORGE DAABOUL (Children’s Hospital, Oakland): “Physicians, presumably in the best interest of the child, would take upon themselves the burden of the information and make decisions as to the gender, sex of rearing, gender of rearing, in a way completely



independent of the parents.” “...I hope we can make amends to the individuals we have harmed over the years, and I think our profession should do that in a formal way.”

SEX UNKNOWN – 2001 – NOVA

“Explore the fateful consequences of gender reassignment”

(This program tells the story of David Reimer, who was surgically assigned as female after his penis was destroyed during a circumcision. Psychologist Dr. John Money used this case as a way to validate his now discredited theory that all small children are psychosexually neutral. David Reimer committed suicide in May 2004. His family believes that the reason for David’s suicide was his life long depression stemming from the incorrect gender assignment recommended by Dr. Money. The bulleted statements are derived from the video’s narrative text.)

- MALES WITH SMALL OR UNFORMED PENISES ARE STILL ASSIGNED FEMALE GENDER THROUGH SURGERY. SUCH GENDER ASSIGNMENTS ARE A TENET OF TRAINING AT JOHN HOPKINS. DOCTORS MAY QUESTION OTHER TENETS BUT NOT THE SURGICAL AND HORMONAL ASSIGNMENT OF GENDER TO INTERSEX INFANTS AND CHILDREN WITH “AMBIGUOUS GENITALIA” WHICH IS BASED ON MONEY’S WORK.

DR. PHILIP RANSLEY (Great Ormand Street Hospital): [Regarding an XY male diagnosed with a “microphallus”] “ This child would have gone through childhood with an extremely tiny phallus and would have had a very small phallus in adult life. The psychological burden he would have carried as a male would have been enormous. There was no difficulty in this case in everyone agreeing that the appropriate sex of rearing was female. And, she was gender assigned female.”

- “NORMALIZING SURGERY” HAS BEEN THE STANDARD PRACTICE UNTIL RECENTLY. SURGEONS WOULD CALL IT BEYOND DEBATE. YET, THERE HAVE BEEN VIRTUALLY NO LONG TERM FOLLOW-UP STUDIES TO MEASURE THE SUCCESS OF THEIR SURGICAL GOAL OF “NORMALIZATION.”

DR. WILLIAM REINER (Johns Hopkins): “There probably are cases where a child has been helped by surgery, but we don’t know them. The fact is that the medical community has been enormously remiss in not doing long term follow up studies, and as long as those long term follow up studies are not done, then their claim that there are ‘happy customers’ rings kind of hollow.”

DR. RANSLEY: “The scientific data that we’d love to have [would] tell us whether the decisions we were making in infancy were correct or not. This data does not exist. Therefore, in this field of medicine there has to remain a mixture of science and art.”



- AFTER DR. MONEY PUBLISHED A LIST OF WHY IT MIGHT HAVE FAILED, DR. GRUMBACH COMMENTED THAT IT WAS TOO LITTLE TOO LATE.

DR. MELVIN GRUMBACH: “This led to major disaffection. What hurt a lot of us is that there had been no word that was not working out. We had been let down by somebody we respected.”

- DR. JOHN MONEY’S THEORY REGARDING THE PSYCHOSEXUAL NEUTRALITY OF INFANTS IS OVER 40 YEARS OLD AND HIS EXPERIMENT WITH DAVID REIMER FAILED IN EVERY WAY.

DR. GRUMBACH: “In the 21st century, what we can say is that the theory of gender neutrality was wrong...that there are important biological factors that play a role. What the mixture is between environmental and biological factors is going to take us a long time to sort out.”

DR. MILTON DIAMOND: “He [David Reimer] was forced to live a life that was not his own, was not of his making, not of his choice, in which every time he tried to assert himself, he was thwarted by the two forces which are supposed to be most helpful in our lives – our parents and our physicians.”

ORAL TESTIMONY – ACADEMIC PERSPECTIVE

DR. JOAN ROUGHGARDEN

Dr. Joan Roughgarden is a Biology Professor at Stanford University and teaches pre-med students. She has recently published a book called *Evolution’s Rainbow*, which addresses the biology of intersexuality. She states that biologists are doing a bad job at teaching biology by misrepresenting nature as being limited to the male/female binary. Dr. Roughgarden described the vast physical diversity found among vertebrates, including primates. Sex is not even based upon chromosomes, as many species have males without the Y chromosome.

Dr. Roughgarden recommended that all doctors study diversity in gender, sexuality, and body types in order to practice in San Francisco. Also, she recommended creating a list of surgical and hormonal procedures that San Francisco hospitals are authorized to conduct. Finally, require that practicing doctors receive remedial education on diversity in gender, sexuality, and body types.

DR. NAOMI O’KEEFE

Dr. Naomi O’Keefe is a licensed clinical psychologist, specializing in treating sexual dysfunction, and is a professor of psychology at Argosy University teaching courses in



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

human sexuality and sexual dysfunction. Well-meaning parents and doctors keep surgical treatments a secret from the child to reinforce gender identity even though that identity may still be undetermined to the patient.

According to Dr. O’Keefe, most professional psychology trainings do not adequately address the frequency of this sexual diversity. Therapists need to be better informed about the prevalence of the natural occurrence of genital diversity, and the suffering that shame and secrecy cause to intersex people and their families.

In most cases, variation in genital appearance is not a medical emergency but is treated as a social emergency. Physical and psychological trauma can be the result of the surgeries: poor bladder and bowel functioning, scarring, disfigurement, and many intersex people have no sexual arousal or orgasmic ability, which can be devastating to the individual and their partners.

Dr. O’Keefe recommended the following: Train providers to respond to intersex anatomies as being natural and not needing surgical repair in most cases. Train providers to address the emotional needs of the parents and extended family of the intersex person regarding the elimination of shame and secrecy. Mandate that all hospitals in San Francisco provide counseling referrals to the family that includes peer support from other parents and intersex children. Prohibit all unnecessary infant genital surgery and mandate consensus from a decision-making team, including the pediatrician, parents, counselor, and professional patient advocate from the intersex community to determine if the procedure is medically necessary.

JOY O’DONNELL

Joy O’Donnell is the Director of Training for the National Sexuality Resource Center, which is a project of the Human Sexuality Studies Program at San Francisco State University. During a presentation by the Intersex Society of North America (ISNA) at a 2003 summer institute, students, doctors, nurse practitioners, social workers, teachers, therapists, researchers, and other experts were shocked to learn of the surgical treatment of intersexuality and dismayed at their own ignorance of the topic.

Medical students and doctors in particular expressed feeling alienated by the fact that they had not learned anything about the topic during their education. Few attendees were aware of the damage sustained by many survivors of intersex infant surgery. This workshop was listed as one of the most important and influential aspects of their time at the institute. Forty-four percent reported that they wanted intersex issues included in the curriculum, especially for those who will work to change the practice. One student wrote, “Besides the emotional trauma and mutilation to these individuals, I learned that there is such a thing as medical rape, which goes tolerated and unpunished.”



The lack of proper training on intersex issues within the framework of sex education contributes to the continued acceptance of these surgeries. Ms. O’Donnell recommended that the City of San Francisco halt the surgeries immediately. As well as intersex people, medical providers suffer when they discover that their well-intended treatments have caused greater harm than good, which was experienced at the institute. Medical professionals and medical students should be required to take courses on intersex issues from a social and psychological perspective before being allowed to practice medicine. SFSU expects to have the first semester-long course on intersex issues offered by Fall 2005.

DR. KATRINA KARKAZIS

Dr. Katrina Karkazis is with the Center for Biomedical Ethics at Stanford University. Her doctorate is in cultural and medical anthropology and she has a Masters degree in Public Health. Dr. Karkazis has been conducting research on the controversies over the medical treatment for intersexuality since 1997. Dr. Karkazis conducted over 50 interviews with clinicians (pediatric urologists and endocrinologists from Brown, Dartmouth, University of Michigan, Columbia University, University of Chicago and others, many of whom are top in their field) as well as intersex adults of diverse diagnoses and parents of intersex infants and intersex adults. Dr. Karkazis reported that her interviews show that “normalizing” genital surgery is still widely viewed as appropriate treatment and performed on intersex infants at increasingly earlier ages, “often within the first few weeks of life,” according to those clinicians and parents she interviewed.

Dr. Karkazis reported that her interviews with clinicians and parents demonstrate that parents are often not given proper informed consent: They are frequently not told about the risks, complications, outcomes, or potential for more surgery later in life. They are also not told about the recent controversies about surgical interventions. Some of the parents who initially refused genital surgery for their infants reported that they were pressured to consent to surgery for the infant. She also reported that both clinicians and parents knew of several instances where parents consented to only one genital surgery and clinicians performed additional genital surgery without the parents’ knowledge or approval.

Dr. Karkazis acknowledged that there are very serious medical concerns for some infants born with intersex diagnoses that require urgent care; the rush to surgery, however, is not an emergency. Rather, she said, these debates are about cultural issues not medical ones. Dr. Karkazis reported that in some cases it was the parents who pushed for surgery because of their fears about the difficulty of their child living with atypical genitals. Some parents she interviewed were able to overcome this fear and did not choose genital surgery for their children. She said this evidence suggests that parents need time to absorb the news about their child’s diagnosis and anatomy before making non-urgent treatment decisions, such as surgery.



Dr. Karkazis explained that her research shows that determination of ambiguous genitals is subjective and often does not entail physical measurement, particularly for clitoral enlargement. She stated this is important because infants could receive very different treatment dependent upon the treating clinician.

Dr. Karkazis stressed that she interviewed several clinicians who no longer advocate many types of genital surgery, such as clitoral reduction and vaginoplasty for microphallic males (because it is increasingly felt these infants should have a male gender assignment), while others advocated a “wait and see” attitude. These attitudes reflect change in medical thinking and practice. These voices are an important minority but are not representative of the majority of clinicians at this point.

Dr. Karkazis stated that evaluative studies lag behind surgical techniques and that surgical procedures can never properly assess patient satisfaction because this would require interviewing adults. At the point these studies could take place, the surgical techniques may no longer be used, supplanted by another non-validated method. She also pointed out the problem with ascertaining sexual function and satisfaction in infants, via intermediate measures such as blood flow, rather than adults who have become sexual. Dr. Karkazis stated that the question “Are the surgeries successful?” is the wrong one. Rather, we should ask “Is this a medical issue or a cultural one?” She suggested the cultural issues drive the idea of a medical imperative, and that these need to be addressed to remove the sense of urgency.

WRITTEN TESTIMONY - ACADEMIC, LEGAL, AND ETHICAL PERSPECTIVE

AMERICAN CIVIL LIBERTIES UNION (ACLU)

The ACLU submitted their legal opinion on the issue of genital modification surgery (“GMS”) on children, stating that they support the right of intersex people to control decisions to alter their bodies through hormones and/or surgical treatment. They further state that GMS is unlawful under California and Federal statutes.

The ACLU states that because the surgery has high risk, and such treatment can be deferred without substantial risk, “several bodies of law require that doctors wait to perform genital modification surgery until children have the capacity to decide for themselves what procedures, if any, to undergo. They state that parents have “no legal authority to consent on behalf of their children to unnecessary, invasive, and potentially harmful medical procedures.” They state that several of the surgical techniques used on intersex children are prohibited under laws that prohibit genital mutilation, that international norms established by the UN in 1996 condemn genital cutting, and that cosmetic procedures imposed on infants violate their civil rights under the California Constitution.



ACLU states that “performing genital surgery for cosmetic purposes can destroy or limit reproductive capacity, constrain options for expression of gender identity, and diminish or destroy sexual function. Conducting elective medical procedures that may forever restrict intersex people’s ability to make fundamental decisions affecting their destiny is a serious invasion of the right to privacy.” The ACLU urged the Commission to issue findings consistent with the forgoing legal principles.

DR. ROBIN HOBURG

Dr. Hoburg lends expertise as a clinical psychologist and behavioral health services researcher. She urges banning early cosmetic genital surgeries on intersex children, citing their potential to harm psychological and physical functioning. She states that she is “astounded by the lack of rigorous, systematic research in this area.” She has particular concern given that studies of intersex people suggest these procedures contribute to trauma, substance abuse, and other psychological and behavioral health problems.

She emphasizes the high stakes of current protocols, citing the recent suicide of David Reimer. She argues that intersex people, like people with disabilities or lesbian, gay and bisexual people, will gain social acceptance and diminish their stigma through visibility—not through being hidden or “normalized.” Dr. Hoburg calls for clinicians to “explain the scientific knowledge based on the psychological, behavioral, sexual and other effects of medically unnecessary surgeries before another intersex child is subjected to potentially harmful medical procedures.”

DR. MILTON DIAMOND

Dr. Milton Diamond is a professor at the University of Hawaii, Minoa. He submitted brief written comments along with several articles related to the treatment of intersex individuals. Dr. Diamond made several recommendations: No surgery should be done to any person without that person’s informed consent, all individuals should be treated with full honesty, and all persons should be fully informed of their condition and all the options for their treatment.

DR. ALICE DREGER

Dr. Dreger provides definitions of intersex, clearly marking it as distinct from transgender while noting some overlap in these populations. She posits that intersex, like race, “is best understood as a political category that reflects biological variation.” She notes the arbitrary judgments in what constitutes intersex, paying particular attention to clinicians’ inconsistencies. For example, a boy without a discernible penis is always considered intersex, while a girl without a vagina is not. She clarifies that while ambiguous genitals constitute intersex, not all forms of intersexuality involve ambiguous genitals, and may involve only internal organs.



She recognizes that some intersex conditions signal underlying metabolic concerns, though the most common challenge they pose is not loss of health, but social stigma. Dr. Dreger notes that people with intersex are treated as a shameful problem that must be “fixed” to alleviate social discomfort.

Dr. Dreger states that there is current controversy among health care providers regarding treatment of people with intersex conditions. She objects to “unfortunate trends like the selective abortion of fetuses suspected of having intersex conditions and attempts to define gender as simply chromosomal in cases of gay marriage.” However, she is encouraged by projects providing widespread education on intersex issues, believing that this is the key to further progress.

SHANE SNOWDON - Director, University of California at San Francisco LGBTI Resources

“I appreciate the opportunity to describe the intersex-related educational work that has been undertaken at UCSF since 2000. That work has been very well-received, and it is our hope that increasing numbers of health care institutions will join UCSF in bringing to current and future health care providers the experiences, perspectives, and recommendations of intersex individuals.

In 2000, UC students and staff members brought intersex-related materials to me and asked that I join them in providing intersex-related education at UCSF and throughout the University of California system, since I was already engaged in similar work around the needs and concerns of lesbian, gay, bisexual, and transgender (LGBT) individuals. After reviewing the materials and meeting with health care providers and intersex health educators, we designed formal and informal educational efforts, which have been very well-received.

Our ongoing work, detailed below, has shown the critical importance of dialogue between intersex individuals and health care providers so that responses to intersex conditions are sensitive, knowledgeable, well-considered, and informed by the experiences of intersex patients and their families. On the basis of this work, we highly recommend that institutions providing health education and health care familiarize themselves with the perspectives and experiences of intersex people and their families, utilize the educational and psychosocial support materials produced by intersex groups, and review their educational and clinical practices related to intersex.

At UCSF, intersex-related educational activities have included:

- Infusion of intersex education into the formal curriculum of the School of Medicine and the School of Nursing, including class sessions devoted to intersex and syllabus-featured additional sessions on intersex (2001 onward)
- Frequent co-curricular presentations attended by a wide variety of students, faculty, and staff at both noontime and 5pm (2000 onward)



- Presentations on intersex in grand rounds of the Departments of Pediatrics and Psychiatry (2002 onward)
- Full sessions on intersex within the for-credit, student-organized LGBT health elective serving the Schools of Medicine, Nursing, Pharmacy, and Dentistry (2002, 2003, 2004)
- Inclusion of intersex in 40+ lectures on LGBT health in the four schools noted above (2000 onward)
- Inclusion of intersex in continuing education and grand rounds for nursing staff (2002 onward)
- Distribution of educational materials to medical social work staff (2003 onward)

Other intersex-related activities in which UCSF LGBTI Resources has been involved include:

- Facilitation of UC participation in the National Medical Student Survey on Intersex
- Collaboration with the Editor of Kaiser Permanente’s national ethics newsletter on an influential edition devoted to intersex
- Coordination of intersex education tracks at the National LGBTI Health Summits in 2002 and 2004
- Presentations on intersex throughout the University of California system, resulting in the expansion of the UC LGBT Association of faculty, students, and staff to include “Intersex”
- Information and referrals for intersex people and technical assistance to intersex education efforts

I hope you will not hesitate to contact me if I can provide any additional information about these wide-ranging intersex education efforts, which have been extremely well-received. As mentioned above, we believe it is critical that health care institutions become more broadly aware of intersex experiences and perspectives, review clinical and educational practices, and make use of the informational and support materials recently developed for providers, patients, and their families.”

ORAL TESTIMONY - PUBLIC

MORNINGSTAR VANCIL

Ms. Vancil stated that she did not have an intersex anatomy but has survived “female circumcision.” She stated that only recently has a medical provider asked her about the “circumcision” and that the only other person she has told is her partner. Ms. Vancil reported that she had ongoing physical problem resulting from the “circumcision” and the conditions under which it was performed. She stated that intersex people have been forcibly surgically assigned gender and it was mutilating, much like the “female circumcision” endured by Ms. Vancil.



WRITTEN TESTIMONY - PUBLIC

MICHAEL ALTERMAN & PAUL QUICK, M.D.

The writers are members of the San Francisco Lavender Greens, and state that “The Green Party considers this to be an issue of fundamental human rights.” According to the writers, the Green Party recently adopted a platform plank supporting “the right of intersex and transgender individuals to be free of coercion and involuntary assignment of gender or sex,” and opposing “involuntary medical or surgical treatment--including the involuntary treatment of children--to assign gender identity or sex.”

The writers emphasized that the same ignorance and fear around sexuality and gender affect intersex people with the same issues that “have long led to discrimination against and persecution of Gay, Lesbian, Bisexual and Transgender people.”

The writers mention that electroshock therapy was once used to try and “cure” homosexuality.” The writers state that, although the attitude of the medical establishment toward LGBT people has improved in recent years, “the continued practice of performing surgeries on children to “normalize” genitalia, or providing hormonal treatments when there is no urgent medical need to do so, is a glaring exception.” They acknowledge that doctors who perform “normalizing” interventions believe they are acting in the best interests of their patients, yet they believe that “ignorance and fear around gender and sexuality have taken precedence over sound medical judgment and compassionate care.”

DONALD CAVANAUGH

Mr. Cavanaugh commended San Francisco for once again taking the lead in attempting to understand the needs of a minority population. He states that, as a gay journalist, “. I have been appalled to learn that the medical industry has seen fit to take upon itself decisions regarding the gender and sex of infants.”

Mr. Cavanaugh states that doctors “frighten parents into thinking that something is wrong with their children and then co-opt them into making irreversible decisions that lead to multiple surgeries, pain, and confusion and often turn out to have been wrong in the first place.” He recommended protecting children from “normalizing” interventions and strengthening informed consent – “Gender/sex (re)assignment surgery should be the decision of the person undergoing the procedure, not the decision of arrogant doctors and frightened parents.”

Mr. Cavanaugh states that gender identity and sexual orientation are not the same and that erroneous gender assignment can be devastating if that person later decides to transition to another gender. He urged providers to “stop the surgeries and to provide education to parents so they may do the right thing and let their intersex children grow



up to be adults capable of making their own choices regarding how they sexually present their genders.”

JORDY JONES

University of California Chancellor’s Fellow Mr. Jordy Jones writes that normalizing surgeries on healthy intersex people are performed to the patient’s detriment for the purpose of serving an ideology. Mr. Jones further outlines the eugenic implications of such practices, such as forced sterilization in the 19th Century.

Mr. Jones noted modern trends and expressed concern that they may be used to eliminate intersex births, writing that “Genomic mapping and DNA sequencing promise to allow medicine to locate and eliminate selected genes and to prevent ‘defective’ children from ever being born.” He stated that intersex births are not a medical emergency, and urged the Commission to “extend their inquiry into the implications that genetic selection and reproductive counseling can have for a new, prophylactic eugenics.”

MICHAEL PINKERTON

Mr. Michael Pinkerton draws on his experience of circumcision as a violation of his bodily integrity to decry the practice of unnecessary genital surgeries (and other normalizing procedures) performed on intersex youth without consent.

SELBSTHILFE INTERSEXUALITÄT

This is an intersex support group from Switzerland. The writers expressed gratitude to the Commission for the human rights work on intersex issues. They outlined the goals of the organization:

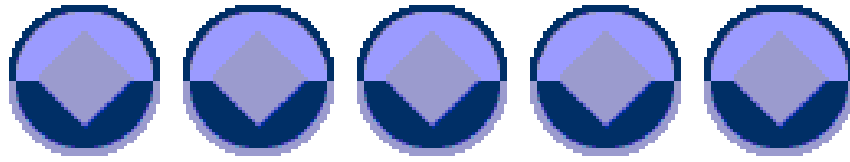
- Creating an exchange of experiences and interests between parents and concerned children and adults as well as interested circles.
- Facilitating cooperation and understanding with/by important organizations in the whole area of health care (as for example psychologists, physicians, surgeons, etc.), media, other support groups, intensification of international contacts.
- Stopping secrecy and lack of information that leads to shame and traumas, and urging social acceptance of human diversity. Opposing the idea that difference equals disease.
- Formulating political requirements concerning gender or sex construction in our society (legal regulations regarding acceptance of several third sexes and official acceptance in registry offices in Switzerland).



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

- Promoting education and trainings (e.g., for midwives, teaching staff, psychologists, physicians, others).
- Furthering activities that support concerned children and adults, their parents.

The group states that “the autonomy and the right to self determination of persons with an intersex condition are violated by any surgery-oriented model, and that “Intersexed genitals are not a medical problem, “but simply a difference in anatomy. They urge that “treatments which aren’t very essential in the medical sense may wait until the person with an intersex condition can consent,” and that “Counselling should begin as soon as the possibility of intersex arises or as soon as the family needs this kind of help by the public society.”



CHAPTER 5

**MEDICAL, ACADEMIC, LEGAL,
AND ETHICAL ARTICLE SUMMARIES**



Chapter 5

MEDICAL SUBMISSION SUMMARIES

Evaluation of the Newborn with Developmental Anomalies of the External Genitalia

American Academy of Pediatrics (AAP), Committee on Genetics, Section on Endocrinology, Section on Urology, PEDIATRICS, Vol. 106 No.1 July 2000, Pages 138-142

There are a number of considerations that will affect the decision as to the appropriate sex of a baby born with ambiguous genitalia. (1) Fertility: Females with Congenital Adrenal Hyperplasia (CAH) may have the potential of fertility, most other intersex infant's fertility will be reduced or absent. (2) Capacity for normal sexual function: In cases of a micro-phallus, there may be potential for development of the penis in puberty. A series of testosterone injections may result in increased size; only then should the infant be raised as a boy. (3) Endocrine function: Depending on the gonadal function, hormone supplements may be necessary. (4) Malignant change: The possibility of malignant degeneration of gonads must be considered. For XY patients, undescended testes are easily brought down into the scrotum. However, biopsies should be performed to determine if they are malignant. (5) Testosterone imprinting: Because testosterone imprinting in the fetus can affect the sexual orientation of the child, caution should be used when a decision to rear the child as a sex that differs from their karyotype. (6) Timing of surgery: Surgeries should be performed as early as possible. Depending upon the procedure, this will range from 6 months to 18 months of age.

According to the AAP, the diagnosis and treatment of intersex children requires urgent medical attention. “It is important to arrive at a definitive diagnosis so that an appropriate treatment plan can be developed.” Physicians must acknowledge the psychological stress this may place on the family and parents. Thus, open communication between the families and the doctors is crucial.

Timing of Elective Surgery on the Genitalia of Male Children with Particular Reference to the Risks, Benefits, and Psychological Effects of Surgery and Anesthesia

American Academy of Pediatrics, Section of Urology, PEDIATRICS Vol. 97 No. 4 1996, Pages 590-594

The authors have determined that, due to concerns surrounding a child's body image, which is generally derived from social interactions, genital surgery should be performed while the child is still young. “A child with external birth defects, including hypospadias, is at risk of developing distortions of body image that reflect other people's subtly communicated evaluations of the child's body.” Because body image develops early in life,



the sooner one can perform corrective genital surgery the better. This will decrease the change of psychosocial and behavioral problems. The article asserts that “...children whose genetic sexes are not clearly reflected in external genitalia...can be raised successfully as members of either sex if the process begins before the age of 2 ½ years. Therefore, a person’s sexual body image is largely a function of socialization.”

The article states that improvements in anesthesia have minimized the risks associated with surgery on infants and risk of death is minimal. Therefore, in order to avoid psychological, post-surgical trauma seen in children between the ages of 1 and 3 years, surgery is recommended for children between the ages of 6 weeks and 15 months. Ultimately, due to technical improvements in medicine, undescended testes or hypospadias operations can be performed at very young ages. However, the younger the child is the higher the risk-benefit ratio becomes and it is essential that young patients receive treatment at facilities that specialize in pediatric care and support, “particularly in the areas of anesthesia, urology, and nursing, who are sensitive to the special needs of children.

Biology and Epidemiology of Testicular Dysgenesis Syndrome

BJU International, Official Journal of the British Association of Urological Surgeons, Vol. 93 Supplement 3, May 2004, Pages 6-11.

C. Asklund, N. Jorgensen, T. Jensen, & N.E. Skakkebaek

Testicular Dysgenesis Syndrome (TDS) generally occurs in the fetal stages and in the most severe cases can lead to hypospadias, undescended testicles, testicular cancer, and poor semen quality. Because of the prevalence of testicular cancer in TDS patients, there may be a genetic link between TDS and testicular cancer. Biopsies should be done early on to determine if a person is at risk for testicular cancer and the CIS cells can then be eradicated through low-dose radiotherapy.

Abnormalities of Sexual Determination & Differentiation

Smith’s General Urology, Sixteenth Edition, Chapter 41, Pages 639-677

L.S. Baskin, Pediatric Urology, UCSF Children’s Medical Center, University of California, San Francisco, CA

According to the author, surgery on intersex individuals should only be performed if the diagnosis is clearly established and the long-term outcome for the diagnosis is favorable. The article acknowledges the consequences of making a hasty gender assignment, stating “Unfortunately, a prompt but inappropriate assignment, although timely and comforting for family, physicians, nurses, and staff can lead to more complex problems in the future.” Full clitoral or phallic amputation should be avoided. However, surgical recession may be necessary. For patients with an XY genotype, phallic reconstruction, although highly problematic, and sex hormone therapy may provide the best overall outcome. The author states that “Clitoroplasty is presently a controversial topic. No studies exist to clearly document whether androgen stimulation resulting in a large clito



ris requires reduction or can be left intact.” The article points out the controversy in the timing of vaginal construction, noting that “...the presence of a vagina is not necessary until puberty and initially only to allow the passage of menstrual fluids. Later, the vagina is necessary for vaginal penetration, fertility, and, in most females, a healthy female sexual identity.” The author recommends that vaginal reconstruction should not occur until the “patient is ready to assume appropriate care of the newly constructed vagina.”

The author notes that several surgeries and procedures are needed when operating on the smaller bodies of infants and children, and that the patient most likely will require additional procedures in adolescence and adulthood.

Anatomical Studies of the Female Genitalia: Surgical Reconstructive Implications

Journal of Pediatric Endocrinology & Metabolism Vol. 17, No. 4 2004, Pages 581-587
L.S. Baskin, Pediatric Urology, UCSF Children’s Medical Center, University of California, San Francisco, CA

According to the author, children with ambiguous genitalia should undergo reconstructive surgery in early childhood, similar to those children with facial deformities, to diminish possible negative outcomes – “When indicated, surgery should be performed in infancy to minimize psychological trauma and surgical complications from scarring.” Previous methods of clitoral reduction and reconstruction resulted in reduced sensation among patients. Clitoral recession also has side effects and the clitoris can become enlarged and feel painful during stimulation after puberty. Ultimately, clitoral reconstruction at early ages is preferable in severe cases. According to the author, clitoral reduction is recommended in the most severe cases of genital masculinization.

Anatomical Studies of the Human Clitoris

The Journal of Urology Vol. 162, September 1999, Pages 1015-1020

Baskin, Erol, Li, Liu, Kurzrock, and Cunha, Departments of Urology and Anatomy, University of California School of Medicine, San Francisco, CA

The authors stated that surgical correction for “masculinized” female genitalia “requires a clear understanding of normal female anatomy.” The authors state that their approach to reduction clitoroplasty is based upon information obtained during anatomical dissection [on cadavers]. They stress that anatomical understanding “should benefit” their idea of reconstructive surgery. The writers state that the historical treatment of “feminizing genitoplasty has evolved from clitoral amputation to clitoral preservation.”

The authors recommend aggressive procedures for “severe cases of masculinization,” such that the erectile bodies of the genitals should be removed by amputation. The outcome is unclear – “To our knowledge, the long-term effect on sexual function of removing this erectile tissue is unknown.” They recommend clitoral recession as a compromise method to “maximize sensation and, hence, sexual function.” The article concludes with a discussion:



Dr. Charles Flack: “My concern is in regard to changing techniques that we already know are working well. If we [made strategic incisions] we would preserve most of the nerves. How important is it to preserve every nerve? These are not peripheral sensory nerves, which we cut all the time. We make incisions and they grow back. Are they not ultimately going to re-sensitize the clitoris if you leave the majority of the major branches?”

Dr. Laurence S. Baskin: “I do not think that we have any data on the outcome of these procedures. I think that we should design them and leave the maximum amount of nerves possible. You have touched on a subject that is rampant on the Internet and [among] our patients. We need to be careful of judging the outcome of our procedures when we do not have any data.”

Diagnosis and Management of Ambiguous External Genitalia

Endocrinologist Vol. 13, Number 3, Pages 260-268, June 2003

F. Conte and M. Grumbach

The authors state that the treatment of intersex babies is quite controversial. However, recent studies show that gender identity is a product of both genetics and environmental interactions. Though long-term follow up data is not available, early surgery and treatment is still recommended. However, most 46,XY babies should be raised as males, unless they are completely androgen resistant, and all 46,XX babies should be raised as females. According to the authors, corrective and reconstructive surgery should be performed by six months of age. If rudimentary testes are present, they should be removed at the time of initial repair. Long-term psychosocial support will be crucial for success and stability of the child.

The authors recommend initiating “plastic repair of the external genitalia by 6 months of age.” They state that “Function is more important than the cosmetic appearance of the external genitalia. Skillful genitoplasty is essential in children raised as females in whom the clitoris is greatly enlarged.” Finally, the authors recommend an integrated approach in the absence of outcome studies. “In sum, the physicians and consortium concerned with the diagnosis, selection of sex of rearing, and management of the infant with intersexuality must be prepared to address the complex ethical, cultural, social, religious, clinical, and surgical issues presented by the intersex patient in the face of incomplete outcome data.”

Changing Attitudes to Sex Assignment in Intersex

BJU International Vol. 93, Pages 659-664

S.M. Creighton and L-M Liao, The Middlesex Clinic, Elizabeth Garrett Anderson and Obstetric Hospital, University College London Hospitals, London UK

This article synthesizes disparate perspectives on intersex management in order to provide a broader view, and provides historical perspectives by examining the theoretical



basis behind traditional surgical treatments - the “optimal gender policy” (otherwise known as the “nurture” argument). The authors note that patients lacking knowledge of their conditions cannot participate in research studies with full consent. “Follow-up reports,” therefore, “have tended to be based on a few frequently cited cases using problematic methods.” Meanwhile, “few non-surgically assigned patients have been available for comparison.”

The authors note flaws in assuming that boys with small penises are better off being raised as girls, yet this practice has been preferable “because of the poor outcome of penile reconstructive surgery,” though the authors note promising advances in tissue engineering. Yet, significant doubt exists about whether female gender assignment is preferable. Studies of men with (non-reconstructed) micropenis have “failed to find the predicted high levels of sexually-related emotional and behavioral disturbance.” Further, they remark, “The authors question if re-assignment of boys with micro or absent penis to girls constitutes cultural practice or evidence-based medicine.”

Vaginoplasty is often performed in the first two years of life, even though “the child is not expected to menstruate for at least ten years (if she has a uterus) and will not be sexually active for even longer. Given the lack of data suggesting that early infant vaginoplasty has a better long-term anatomical, cosmetic and functional outcome than...delayed surgery, [this practice] is then chiefly to create a reassuring appearance for significant adults.” They cite the lack of studies rating patient satisfaction, though noting that doctors have reported “unsatisfactory or poor cosmetic results in 28-46% of patients.” There is frequent need for multiple surgeries, and parents pursuing these procedures may fail to “appreciate that a one-off surgical fix to ‘normalize’ genital appearance now looks unlikely.”

The authors evaluate the sexual difficulties created by early surgical sex assignment - “women with CAH report more sexual difficulties than their counterparts.” They cite a study comparing “women with ambiguous genitals who had undergone feminizing surgery with [those] who had ambiguous genitalia with no surgery” which found that both groups reported poor overall sexual function when compared with a control group.

However, “those who had undergone clitoral surgery were significantly less likely to report experience of orgasm than those who had not had surgery.” Further, “[s]ubsequent research using objective testing of genital sensory thresholds in a pilot sample of women with CAH found that those who had undergone clitoral surgery had marked differences from normative values.” The authors assert that, “any incision to the clitoral glans, corpora or hood could risk damage to the dense innervation. Past confidence amongst pediatric surgeons in unimpaired sexual function after clitoral surgery seems no longer tenable.”

They cite a report which argues that since “the outcome expectancy [of surgery is] largely psychological...surgery needs to show a positive effect in psychological and me



chanical terms.” Psychologists recommend that “clinicians are best to avoid a panicked insistence that... ‘something must be done’” and to “discuss the possibility that the desired genital appearance even if achievable (and even if those involved willingly risk physical damage to achieve this) may not realize for parent or patient their gender aspirations [for the child].”

The authors acknowledge the unknown psychological impact of surgical sex assignment on intersex patients, noting that while stories found on the ISNA website may not be exhaustively representative, they do represent a significant proportion of patients with serious concerns. And, the psychological impact on parents is unclear at best; there is no evidence that early surgical intervention pacifies parental anxieties over their child’s sex. They report psychologists’ concerns that “physically traumatizing procedures, and the repeated intrusive examinations that they necessitate” may be more traumatizing than the potential social problems of nonintervention. Additionally, there are concerns that the “unquestioned insistence that ‘something must be done’ about the child might negatively influence parental feelings and attitudes” and affect “the child’s identity development and overall psychological well-being.” Though they acknowledge that a child with unaltered genitals may face psychological problems common to people who are socially perceived as different, they argue that “surgery is not the only answer to social intolerance” and that it “does not necessarily protect patients from having to confront their difference.”

The authors criticize the idea that “normalizing” genitals normalizes psychological and sexual development - “The extent to which gender development arises specifically from genital anatomy is far from clear.” They addressed the inconsistency in medical standards, “It is no wonder that this area of research is confusing, with each investigator trying to tie the outcome to their favorite...theory, ignoring variables that do not interest them.” They note the messy complications of sexual orientation and gender identity in all people, stating that these are often oversimplified “to preserve a sexually dimorphic ideology, that of two fixed, discrete but complementing sexes.”

The authors outline the role of fertility considerations in sex assignment, describing new medical technology advances that further shift these considerations. They acknowledge the complicated moral and ethical implications involved, arguing that “delaying gonadectomy until adolescence where appropriate at least allows the patient a voice in this discussion.” The authors document criticisms of current protocols that recommend assigning sex without irreversible surgeries. They note, however, that most clinicians continue to practice and recommend “genital sexing on infants and young children.”

The authors describe medical advances that have improved understanding of the etiology of intersex conditions. They note that the significances attributed to intersex anatomies are socio-political in origin. They declare, “The extent to which health professionals have a role in the lives of people with nonstandard genital characteristics may have to be negotiated in the future, rather than taken for granted as in the past.”



They believe that ending genital surgeries is unlikely, as “[t]here will always be parents who choose surgery for their children despite full information about potential risks” as well as patients who opt for surgery themselves. “However,” they maintain, “a more realistic appraisal of the benefits and risks, a stronger sense of personal control, and a collaborative relationship are likely to lead to improved patient satisfaction and reduced risk of concomitant psychological distress.”

In conclusion, they point out the cultural mandate driving all affected parties in the debates over proper care. They note that, while alternatives to early surgery are called experimental, surgical sex assignment “also represents an experiment involving invasive, risky and irreversible intervention. We are unsure how the absence of rigorous evaluation of the intended outcome could have ever been justified in interventions with such grave consequences...” They remark, “The clinician’s choice is stark; to share the diverse opinions with patients and parents and assist them to develop their own responses, or pretend to certainty and intervene before they learn what questions to ask.” They conclude - “It is not for the medical profession itself to decide behind closed doors on behalf of society how to seal the fate of persons with nonstandard genitals.”

Long-Term Outcomes of Feminization Surgery: The London Experience

BJU International Vol. 93 Supplement 3, May 2004, Pages 44-46

S.M. Creighton, Elizabeth Garrett Anderson and Obstetric Hospital, University College London Hospitals, London UK

Proponents of feminization surgery state that the procedure provides a more stable gender development, superior psycho-sexual and psycho-social outcomes, relieves parental anxiety, and allows for normal sexual intercourse in adulthood. However, there is not sufficient evidence to establish a link between infant feminization surgery and improved psychosocial outcomes. According to Creighton, most studies are done by the original surgeons, and many intersex adults continue to live in ignorance of their own diagnosis, because of standard policies of nondisclosure. Yet, there are no standard methods for cosmetic assessment.

According to the author, there is no evidence that such surgeries promote a stable gender identity, or that the child will identify with the assigned gender. Long-term data on this area of medicine is necessary; however, such data has not yet been published. Ultimately, surgery may relieve parental concerns; however, the results of surgeries in post-pubescent stages is less-than-satisfactory and may require many revisions - she also lists physical complications, including urinary infection, fistulae, clitoral pain, incontinence and strictures of the urethra.

Because of the conflicting results and evidence for infant genital surgeries, all options should be discussed with parents and family, including the option of no infant genital surgery. A study of 44 adolescents performed at her multidisciplinary clinic “...concluded that repeat procedures were common and could be avoided by deferring



the primary vaginal procedure until adolescence.” She also notes that such deferral would “limit the total number of operations for each individual.” There is no data that supports the need for early surgical intervention, and this study may indicate the opposite is true – “The study suggests that cosmetic surgery to the clitoris does not ensure improved adult sexual function and indeed may cause damage.” The author states, “It is now unacceptable to claim that clitoral surgery does not affect sexual function...In the absence of firm evidence that feminizing genital surgery benefits psychological outcome, then the option of no infant genital surgery must be discussed...”

The Virilized Female: Endocrine Background

BJU International Vol. 93, Supplement 3, May 2004, Pages 35-43

M.G. Forest, M. Nicolino, M. David, & Y. Morel

Department of Paediatrics, Biologie Endocrinienne et Moléculaire, Hôpital Debrousse, Centre Hospitalier Lyon Sud, Lyon, France

The writers state that sexual identity and gender assignment surgeries may have disappointing results. However, they state that the reasonable choice for parents whose children have ambiguous genitalia is to raise them as female, especially in cases where their genitalia have potential for normal female reproduction. Sexual identification and gender identity may be influenced by many factors. The authors recommend a discussion with reluctant parents before treating children with severe virilization of external genitalia”...a ‘collegiate’ discussion, including parents, endocrinologists, biologists, psychologists, and surgeons must precede the final decision. The ‘reality of life’ is not always logical and the sex identification of the child can be influenced by several factors, among which the parents’ views and acceptance are major.”

The Newborn Examination: Part II

Emergencies and Common Abnormalities Involving the Abdomen, Pelvis, Extremities, Genitalia, and Spine

American Family Physician Vol. 65, No. 2, January 15, 2002, Pages 265-270

M. Fuloria & S. Kreiter, Wake Forest School of Medicine, Winston-Salem, NC

This article argues that “abnormalities” in genitals are still defined by the size of the clitoris or the penis. The authors state that “The presence of ambiguous genitalia is a medical emergency. Adrenal and pituitary integrity must be established.”

The Undervirilized Male Child: Endocrine Aspects

BJU International Vol. 93, Supplement 3, May 2004, Pages 3-5

N. Josso, Unité de Recherches sur l’Endocrinologie du Développement (INSERM), Institut de Recherches sur les Cytokines, Clamart, France

According to the author, management of under-virilized male children is difficult and requires close collaboration between pediatricians and the specialized medical teams.



Attitudes of Adult 46, XY Intersex Persons to Clinical Management Policies

The Journal of Urology Vol. 171, April 2004, Pages 1615-1619

H.F.L. Meyer-Bahlburg, C.J. Migeon, G. D. Berkovitz, J.P. Gearhart, C. Dolezal, & A.B. Wisniewski, New York State Psychiatric Institute and Department of Psychiatry, Columbia University (Meyer-Bahlburg), New York, New York, Divisions of Pediatric Endocrinology (Migeon, Wisniewski) and Pediatric Urology (Gearhart), Department of Pediatrics, Johns Hopkins University, Baltimore, MD, and the Division of Pediatric Endocrinology, Department of Pediatrics, University of Miami (Berkovitz), Miami, FL.

According to the authors, the study was conducted via mailed written questionnaire and a subsequent hospital visit and physical examination. It suggests that intersex patients who have undergone certain surgical procedures have generally favorable results. However, there were some adult patients who were dissatisfied with their gender and with their genital status; sexual function was also problematic for some of the respondents. The authors point out the “weaknesses of their own study” and note how with that fact that one-half of the respondents either could not be contacted or refused to participate in the study may have impacted their statistical outcomes.

Analysis of the methodology: [The following is a sociological analysis of the methodology used in this study]

- This study used a small sample; all of the samples were less than 30. The method used to analyze the data was an ANOVA or an analysis of variance between groups. However, no hypothesis was given or null hypothesis to determine why the ANOVA was used.
- They used an F test, and most of the sample groups were large enough for an F test. However, one group was less than 10 individuals, thus, invalidating this statistic.
- The conclusion appears to be based on simple proportions. However, their sample size was too small to draw such conclusion relying on proportional data alone.
- The response to the sample set was poor. Furthermore, the sample was drawn only from people who went to John Hopkins. Thus, no conclusions about the general population can be drawn from this data. One can only make general statements about patients at John Hopkins. This is because medical care, follow up, and regional differences may affect the data in other institutions that would alter the national picture.

Effects of Clitoral Surgery On Sexual Outcome in Individuals Who Have Intersex Conditions with Ambiguous Genitalia: A Cross-Sectional Study

The Lancet Vol. 361, April 12, 2003, Pages 1252-1257

C. L. Minto, L.M. Liao, C. R. J. Woodhouse, P. G. Ransley, & S. M. Creighton Elizabeth Garrett Anderson Hospital, Department of Obstetrics and Gynaecology, University College London Hospitals NHS Trust, London UK (Minto, Liao, Creighton); In



stitute of Urology, Middlesex Hospital, University College London Hospitals NHS Trust, London (Woodhouse); and Great Ormond Street Hospital for Children, London (Ransley)

The authors declare, “Our results indicate that individuals who have had clitoral surgery are more likely than those who have not to report a complete failure to achieve orgasm and higher rates of non-sensuality—in particular, a lack of enjoyment in being caressed and in caressing their partner’s body... Our findings suggest that adult sexual function could be compromised by feminizing clitoral surgery. Infants and young children are powerless to oppose any procedures, so genital surgery for them is not just a medical issue but also a moral one.”

According to the authors, debate over ethics with interested parties should be encouraged and clinicians should advance the debate and help individuals and families to make the best possible decisions by producing reliable information. They expressed concern about the clinical response to the study – “Many surgeons will undoubtedly feel justified in doubting the findings of this study, and will fall back on the traditional response of claiming that current techniques are more advanced than the surgical procedures we assessed. Although surgery has advanced in many ways, this is not a valid reason for complacency. In this study, surgery was performed 8-40 years ago, and most individuals had undergone clitorrectomy. Of the three sexually active participants who had undergone the newer technique of nerve-sparing clitoral reduction, however, two had the worst possible score for orgasm difficulties.”

Current Concepts of Hypospadiology

BJU International Vol. 93, Supplement 3, May 2004, Pages 26-34

P.D.E. Mouriquand & P.Y. Mure

Advocates surgical intervention for hypospadias. Acknowledges that hypospadias surgeries are difficult and that certain factors that weigh into success are currently unknown. Long-term follow-ups are crucial to improving and assessing this area of medicine. Urinal flow often is irregular after such surgeries and collaboration between endocrinologists and pediatricians is crucial for increasing success.

Possible Determinates of Sexual Identity: How to Make the Least Bad Choice in Children with Ambiguous Genitalia

BJU International Vol. 93 Supplement, May 2004, Pages 1-2

P.D.E. Mouriquand

According to the author, gender and gender identity may revolve around more factors than simply what genitals a person has. Several factors seem to affect what a person’s gender identity will become. These factors are genetic make-up, hormonal environment of the fetus, external genital appearance, internal genital organs, and gonads. Ultimately, little is known about what determines sexual identity; however a child born with



ambiguous genitalia seems to be pushed more towards one sex or another depending on a combination of the aforementioned factors.

Clinical and Biological Assessments of the Undervirilized Male

BJU International Vol. 93 Supplement, May 2004, Pages 20-25

M. Nicolino, N. Bendelac, N. Jay, M.G. Forest, & M. David

Department of Pediatrics, , Hôpital Debrousse, Lyon, France

The authors write that, in cases of undervirilized males, it is crucial to keep the parents informed. Furthermore, in the event of a small penis or uncertain degrees of testosterone production, gender assignment should be postponed because further investigations will be needed. In cases like these, a child should be karyotyped to determine their chromosomal sex. In determining the child's sex, a doctor should consult and discuss options with several doctors from varying disciplines. There are generally no perfect choices for sex rearing and the most reasonable outcome should be considered. Ultimately, an undervirilized male presents a unique and difficult problem for clinicians.

Small Penis and the Male Sexual Role

Journal of Urology, Vol. 142, August 1989 Pages 569-571

J. Reilly & C.R.J. Woodhouse, Institute of Urology, St. Peter's Hospitals and the Hospital for Sick Children, London, England

The article details the methods and results of a study of 8 adolescent males and 12 adults males who had been given a diagnosis of “micropenis” based upon a measurement of their phalluses against a “mean” length of the male population. The article offered a standard of desirable male traits: All of the patients reported being heterosexual and that they could achieve erection and ejaculation. All could stand to urinate from the tip of their penises and 6 patients had undergone hypospadias repair. All patients had undergone sex hormone treatments as children to stimulate penis growth, and all but one patient had responded with penile growth.

The authors addressed the consistency of parental concerns. Although all of the parents “...considered their children as normal boys once the child was assigned the male gender” and they thought the appearance of the child's genitals “...satisfactory, but they expressed concern about the size of the penis, wondering if sexual function in adulthood would be a problem.” One patient, who was born with “ambiguous genitalia” and was not assigned to a male role until 6 weeks of age, was “lost to follow-up” before the review was written. According to his mother, he reported embarrassment about his genitalia. The article stated that “His mother attributed the emotional problems to the abnormal genitalia.” The article acknowledged how the attitude of the parents can affect the childhood experience of the patient. “The well informed and open parents, found more often in the younger age group, produced more confident and better adjusted boys. The poorer results in the older group may be the result of uncertain diagnosis and inadequate counseling by physicians.”



According to the authors, the patients reported normal self-perceptions of being male, although some did report teasing by peers and feeling anxious of “voiding or changing in public.” None reported particular problems in adolescence, all “felt male” and “they particularly enjoyed contact sports.” All IQs were in normal ranges. Those who were sexually active reported that they had satisfactory sexual relationships with their partners, and the “group was characterized by an experimental attitude to positions and methods.” In addition, “All patients were happy with their [male] gender identity and they had participated in normal male activities in childhood and adolescence.”

The authors conclude that micropenis may be an indication of a defect in sexual differentiation, which may be a consideration in determining the “sex of rearing.” Despite data supporting that males with small penises can and do have happy and fulfilling lives, the authors conclude that, “A small phallus may indicate a female gender assignment.”

Mixed-Method Research for Child Outcomes in Intersex Conditions

BJU International Vol. 93 Supplement, May 2004, Pages 51-56

W.G. Reiner, University of Oklahoma Health Sciences Center, Department of Urology WP 3150, Division of Pediatric Urology, Department of Psychiatry, Division of Child and Adolescent Psychiatry, Oklahoma City, USA

According to the author, poor communication and lack of data in the area of intersex treatment detrimentally affects that medical community. Little information exists regarding long-term outcomes of children who have received treatment for intersex related conditions; this has further exacerbated the problem. Ethical standards of care must be adhered to and the patient should be informed of all choices and involved in the decision-making process. Further studies on how children cope with intersex conditions are needed to provide full information to patients and their families; in turn, guiding them to the most appropriate decision for their needs and desires.

Sexual Quality of Life in an Intersexual Population: A Needs Assessment

BJU International Vol. 93 Supplement, May 2004, Pages 54-56

J.M. Schober, Hamot Medical Center, Erie, PA , USA

According to the author, genital surgeries may lead to sexual pain, discomfort and urinary disorders; sex hormone treatment can lead to sexual dysfunction. Increased openness about surgery can have both positive and negative impacts upon patients. Ultimately, openness about surgery and sexual variances may lead to unrealistic expectations and increase feelings of inadequacy. Care groups for intersex individuals seem critical to help alleviate many of these problems.



Gender Assignment: Background and Current Controversies

BJU International Vol. 93 Supplement, May 2004, Pages 47-50

D.F.M. Thomas, Department of Paediatric Urology, St. James’s University Hospital, Leeds, UK

The author states that the area of gender assignment and re-assignment poses difficult and contentious ethical dilemmas and this area of medicine has come under increased scrutiny in recent years. Ambiguous genitalia and intersex states can pose serious, life-long implications. However, gender assignment is imperfect and long-term studies have yielded disappointing results. The need for extensive long-term studies is apparent and aggressive, non-necessary early surgeries should be avoided and are unjustified. Yet, leaving a child with uncorrected genitalia may be considered unacceptable to parents.

Intersex Surgery in the Adult

BJU International Vol. 93 Supplement, May 2004, Pages 57-65

C.R.J. Woodhouse, The Institute of Urology and Nephrology, University College London, and the Hospital for Children, Great Ormond Street, London, UK

The former standard of care for intersex individuals was to assign a gender that was deemed “most appropriate” and then persist with it and never inform the child of what had happened to them. In many Western cultures babies were assigned as females because surgical alterations were easier to perform. This may indicate that the baby’s best medical interests were not considered important. Little long-term data is available and the need for follow up studies is great. Other problems like limited knowledge about sexuality plague these surgeries. Many patients’ quality of sexual activity is less than satisfactory. Doctors need to consider the fertility of the child when assigning gender to infants. Clitoral reductions typically result in reduced sensation. Men with small penises can and do have sexually satisfying experiences, despite medical reluctance to allow intersex males remain male. Ultimately, there is little evidence available on the results of raising intersex babies as male and more research is needed.

Rules for the Clinical Diagnosis in Babies with Ambiguous Genitalia

Child’s Health (2003) Vol. 39, Pages 406-413

Y. Low, J.M. Hutson, & Murdoch Children’s Research Institute Sex Study Group, Centre for Early Sexual Development, Royal Children’s Hospital, Parkville (Low, Hutson), Murdoch Children’s Research Institute and department of Paediatrics, University of Melbourne, Melbourne, Victoria, Australia (Hutson)

The authors state, “Next to perinatal death, genital ambiguity is likely the most devastating condition to face any parent of a newborn. Western Society does not, as yet, recognize any person who does not neatly fall into the ‘male or ‘female’ category; and this clinical condition, perhaps more than any other, is attended by a whole myriad of emotional, psychosocial, cultural, diagnostic, and treatment issues.” According to the authors, intersex disorders and ambiguous genitalia are rare. However, when they occur, they must be managed accurately and expeditiously. A systematic and thorough



examination of the infant is required to narrow down the possible diagnosis. A multidisciplinary approach is best; thus, a team of qualified surgeons, pediatricians, endocrinologists and geneticists is key. Early and long-term management of the patient is crucial for proper psychosocial development.

ACADEMIC, LEGAL, AND ETHICAL ARTICLE SUMMARIES

Informed Consent, Parental Permission, and Assent in Pediatric Practice

Pediatrics Vol. 95 No. 2 February 1995, Page 414-317

American Academy of Pediatrics policy paper written by the AAP Committee on Bioethics

This article provides information on how the policy of informed consent has “evolved and become more formal” since its inception. It states that “[p]atients should participate in decision-making commensurate with their development; they should provide assent to care whenever reasonable. Parents and physicians should not exclude children and adolescents from decision-making without persuasive reasons. Indeed, some patients have specific legal entitlement to either consent or to refuse medical intervention. Although physicians should seek parental permission in most situations, they must focus on the goal of providing appropriate care and be prepared to seek legal intervention when parental refusal places the patient at clear and substantial risk.” Cases of serious conflict can require consultative assistance.

The article analyzes the concepts and ethics of informed consent, right to refuse treatment, “proxy consent,” parental permission and child assent. Informed consent is noted to include “fully and accurately providing information relevant to exercising...decision-making rights.” The capacity of the patient or surrogate to make necessary decisions is of key importance. Also crucial is the patient’s freedom to choose among alternatives without coercion or manipulation. Refusal of treatment is explained as a moral and legal right under most circumstances.

“Proxy consent” is understood as a problematic practice. Providers are stated to “have legal and ethical duties to their child patients to render competent medical care based on what the patient needs, not what someone else expresses...[T]he pediatrician’s responsibilities to his or her patient exist independent of parental desires or proxy consent.”

Obtaining assent from minor patients is recognized as important for a variety of reasons: patient empowerment; fostering trust in the physician-patient relationship; helping a patient understand the nature of her or his condition; determining whether the patient



is under coercion to accept or deny treatment; understanding the patient’s views on treatment in order to consider them carefully.

Also, in some situations, a patient’s “persistent refusal to assent may be ethically binding. This seems most obvious in the context of research (particularly that which has no potential to benefit the patient). A patient’s reluctance to assent should...carry considerable weight when the proposed intervention is not essential to his or her welfare and/or can be deferred without substantial risk.”

Ethical conflicts are to be handled with additional medical consultations, counseling, multidisciplinary case management, and consultation with clinical ethicists. Special care is to be taken so that children’s moral status is not diminished by the physicians’ and parents’ abuse of “raw power.”

Some minors are understood as emancipated and granted special status in decision-making. In many states, some situations involving the sexual health of an otherwise non-emancipated minor may be handled with the patient in a full decision-making role. Additionally, non-emancipated minors who “have decision-making capacity” may also be considered “mature minors” and granted this power.

An Emerging Ethical & Medical Dilemma: Should Physicians Perform Sex Assignment Surgery on Infants with Ambiguous Genitalia?

Michigan Journal of Gender & Law, Vol. 7:1, (2000)

H.G. Beh & M. Diamond, William S. Richardson School of Law (Beh), University of Hawai’i (Diamond)

The authors state that David Reimer’s case was used by Dr. John Money to develop the current standard of care for children born with ambiguous genitalia. Initially, Dr. Money reported the case was successful. However, in 1997 it was found that the surgery was far from a success because David, who was assigned the female gender after a failed circumcision, had surgery to reverse the female assignment, was living as a male, and resented the fact that he lost his childhood because of this. The standard of care continues to be surgical “normalization” for infants born with ambiguous genitalia. However, even those who are not assigned a new gender experience problems. Females who undergo clitoral reductions to “normalize” their genitalia often experience decreased or lost sexual satisfaction in adulthood. Many of the interventions that are promoted in the medical field are not supported by long-term studies of patients.

Reimer’s case has divided the medical community and many members now challenge the traditional standard of care that calls for intervention. They point out that no case has been successful where a non-intersexual boy was reared as a girl. Moreover, doctors rarely disclose all of the facts and treatment options to patients; this may violate the informed consent doctrine. Ultimately, physicians should move to a patient-oriented approach that requires them to reveal material data including risks, efficacy, and alterna



tives to patients and/or their parents. Physicians should also recognize a child’s right to be part of this decision and perhaps physicians should encourage parents to wait until their child is old enough to convey their own desires.

“First, Do No Harm” – The Fiction of Legal Parental Consent to Genital-Normalizing Surgery on Intersexed Infants

19 Yale Law & Policy Review 469 (2001)

K. Ford

According to the author, emergency infant genital surgeries are unjustified and based on questionable scientific data. Ambiguous genitalia generally do not pose immediate risks to the child’s health and thus do not constitute a medical emergency. For the procedure to constitute a medical emergency, it must be an action that is “appropriate to protect the life and health of the child, not the psychological welfare of the child’s parents or physicians.” For a parent to be authorized to consent to a procedure for a minor, the procedure must benefit the child. Follows up studies conducted on post-surgical results are rare and they usually focus on the appearance of the child’s genitals.

However, recent studies have demonstrated that long-term results of these surgeries are quite disappointing. Often times, such surgeries result in deformed genitalia, pain, and loss of sexual sensitivity. Moreover, “there is always the possibility that surgeons were altogether wrong about the future gender choice of the infant.” Furthermore, “[S]ociologist Sharon E. Preves noted that “many who had genital surgeries emphasized that the very operations that were intended to assuage feelings of difference only served to highlight their stigma.” Ultimately, these surgeries have not been shown to be beneficial to the patients. Because of the lack of evidence supporting their beneficial nature and their non-emergency status, parents do not have the legal right to consent to such surgeries for their children. According to the authors, a moratorium on non-emergent infant surgeries should be implemented.

Background of Colombia Decisions

J.A. Greenberg and C. Chase

This article explains a recent decision by the Constitutional Court of Colombia to “significantly [limit] the ability of doctors and parents to surgically alter the genitalia of intersexed children.” As noted, “[t]he Court held that intersexed people constitute a minority entitled to protection by the State against discrimination. Surgery may actually be a violation of autonomy and bodily integrity, motivated by parents’ intolerance of their own children’s sexual difference.”

The Court’s decision supports the claim that surgical modification of intersexed infants, though widely accepted as standard medical practice, has no evidential basis as “necessary, safe, or effective.” Also, this ruling recognizes a similar lack of evidence that an early decision is urgent. As noted, “The State assumes that parents will act in the best



interests of their children. In the case of intersexed infants however, the Court found that parents are likely to make decisions based upon their own fears and concerns rather than what is best for the child, especially if they are pressed to decide quickly.”

“The Court required legal and medical communities to establish a new category of consent - ‘qualified, persistent informed consent’ - intended to force parental decisions to take into account only the child’s interest. For children over five, parents cannot consent, because the child has achieved an autonomy that must be respected, and because the child has...developed a gender identity, which reduces the urgency of a decision as well as any potential benefits of surgery.” Also, “[t]he Court held the criticism by intersexed people themselves to be of ‘decisive importance.’”

The article explores a case that built precedent for these decisions. A young man, treated in a similar fashion to the Canadian “John/Joan” case, argued his case against medical hubris before the Colombian high Court and won.” The Court found that “parents cannot give consent on a child’s behalf to surgeries intended to determine sexual identity. The [Colombian] Constitutional guarantee of free development of one’s own personality implies a right to define one’s own sexual identity.”

Finally, the article notes that this Court “has the final word on Constitutional matters, so no appeal is possible. Also, “the Judges noted, of public authorities, the medical community, and ordinary citizens ‘to open a space to these people, who until now have been silenced.’”

[The following is a letter that was part of an amicus brief provided by ISNA at the Colombian Court’s request. The Colombian Court cited this brief in their decision]

This letter from Cheryl Chase, Executive Director of ISNA, to Mr. Uprimny of the Constitutional Court of Colombia, addresses the matter of a six-year-old intersex child facing clitoral reduction and vaginoplasty. She urges the Court to keep with its previous determination that “all choices involving sexual identity must be made directly by the person, and not by the parents,” adding, “To impose surgery is to subject a child to unnecessary risk of irreversible harm, and violate her human rights.”

Ms. Chase points out that recent scholarly work examining medical management of intersex children has resulted in a growing body of surgeons, psychiatrists, psychologists, and ethicists arguing against early genital surgery on these children. She notes, “It would be a pity for the Court to create a precedent insulating doctors from any liability for harm caused by performing non-consensual genital surgery precisely at the moment when scholarly opinion is changing.” She further elaborates on controversy among specialists regarding this medically unnecessary, irreversible, potentially harmful practice.

Ms. Chase explains that clitoral reductions are motivated solely by “the unproven belief that [the surgeries] may enhance psychological well-being.” Similarly, early vaginoplasty



ties are motivated by “the unproven belief that [the surgeries] may ease parental discomfort now or that the decision would be traumatic for the patient to make later...”

Ms. Chase emphasizes that these surgeries are irreversible, and that “there is no medical advantage or benefit to performing surgery now as opposed to later, when the child can make her own choice and when her gender identity is clearly established.” She also explains the benefits of delaying surgery: larger genitals are easier to work on; scar tissue is negatively affected by the changes in size and shape accompanying normal growth and pubescent development; surgical techniques will have had that much more time to advance.

Ms. Chase notes that many people with this child’s condition have been happy living as women with their large clitorises intact, while others develop a male gender identity, and also prefer to have their genitals intact. Further, she explains, while physicians argue that a penis must be of a certain size to be “functional,” this “may mean different things to different people...A small penis is capable of providing sexual arousal, genital pleasure, and orgasm.”

Ms. Chase analyzes surgeons’ argument that the genitals must be normalized to save intersex children from feeling different. She notes, “[P]rejudice against people with unusual genitals is culturally determined...If there is intolerance of physical difference, then the intolerance should not be addressed by using medically unnecessary, irreversible, potentially harmful plastic surgery to try to hide the physical difference without the patient’s consent.” Ms. Chase cites evidence that adults would not choose clitoral surgery for themselves. Also, she mentions that many adult intersex women express regret and anger that surgery was imposed on them as children.

Ms. Chase notes that current worldwide surgical protocols for intersex management have their foundation in the “John/Joan” case, where a baby boy who lost his penis in an accident was reportedly successfully reassigned as a girl. Recently, the truth has come out that the patient never identified as a girl, and resumed living as a male in his teenage years. Reconsideration of the case has caused experts to assert that genital surgery requires the consent of the patient.

Ms. Chase highlights the work of Drs. Diamond and Sigmundson (a sex researcher and a psychologist, respectively) who have used their research into intersex management to provide clear recommendations for how doctors can best serve intersex children. They recommend counseling for parents and the child, as well as full disclosure to be provided in an age-appropriate fashion. They advocate against early genital surgery. They emphasize a focus on the child as the patient. Other experts, including pediatric surgeon Dr. Justine Schober and ethicist Dr. Alice Dreger have similar positions.

Ms. Chase holds that both the Nuremberg Code and basic principles of human rights law prohibit this practice. She remarks on lack of evidence that these surgeries achieve



their sole stated aim: to enhance the long-term psychological well being of the patient. She asserts, “[T]hese surgeries are plainly experimental: (1) They are not medically necessary to alleviate pain or any physiological dysfunction. (2) There is no medical consensus that these procedures are advisable or beneficial...On the contrary, there is growing concern over the efficacy and ethics of these procedures among medical experts in many fields. (3) There are no outcome studies to support the hypothesis that these painful, invasive, and irreversible surgical procedures result in any psychosocial benefit to the child or enhance the child’s well-being in any way. Conversely, an increasing number of adults who were forced to undergo these procedures as children are coming forward to report profound physical and psychological harm, including pain, scarring, urological problems, loss of sexual sensation and functioning, and severe emotional trauma.”

Ms. Chase stated, “It is repugnant and contrary to a child’s basic human rights to allow a parent to consent to medically unnecessary genital surgery for the purpose of dictating the child’s future gender identity or of altering the child’s body to conform to an idealized cultural notion of ‘normal’ genital appearance.” She notes that a wide variety of human rights organizations have recognized this principle in the context of female genital mutilation.

Ms. Chase writes, “Parents have considerable legal control over their children, but they do not have the right to disregard the child’s intrinsic human rights to privacy, dignity, autonomy, and physical integrity by altering a child’s genitals through irreversible surgeries based on an unproven and controversial psychosocial rationale.”

Health Care Professionals and Intersex Conditions

*Archives of Pediatrics and Adolescent Medicine, Vol. 158 May 2004, Pages 426-429
J. Frader, P. Alderson, A Sch, C. Aspinall, D. Davis, A. Dreger, J. Edwards, E. Feder, A. Frank, L.A. Hedley, E. Kittay, J. Marsh, P.S. Miller, W. Mouradian, H. Nelson, & E. Parsons*

This article was prepared by a multidisciplinary group at The Hastings Center in Garrison New York to address medical, psychosocial and ethical issues associated with the care of intersex children. The group “concluded that none of the appearance-altering surgeries need to be performed quickly; families with children with intersex conditions require multidisciplinary care; children with intersex conditions deserve to know the truth about their bodies; families and health care professionals will benefit from rigorous longitudinal studies; and health care professionals need additional training about intersex conditions and sexual health generally.”

The authors state that a surgical “fix” is an inappropriate remedy for “families’ discomfort, guilt, and/or sense of shame.” They emphasize that gender assignment does not require surgery, and that “[medical] test results do not accurately predict later sexual identification.” They note the importance of providing patients with full, sensitive disclo



sure; psychological and social support; and peer contact with adults who have lived with their condition.

Pediatric Ethics and the Surgical Assignment of Sex

The Journal of Clinical Ethics, Winter 1998, Pages 398-410

K. Kipnis & M. Diamond

Recent studies have called into question Dr. John Money’s research that advocated for the assignment of sex to babies born with ambiguous genitalia. Further research has shown that babies born with micro-penises who were assigned as female failed to identify with their assigned gender; rather, they believed they were boys. Concerns over children being ridiculed because their genitals differ in shape or size may be misplaced. Ultimately, there should be a moratorium placed on infant genital surgeries when they are done without the consent of the patient, parental consent should not be considered because many well meaning parents may make decisions that do not end up benefiting the patient. The moratorium should not be lifted unless medical research finds that outcomes of past surgeries have been positive and physicians make efforts to repair some of the damage from past deceptive practices.

Who Decides? Genital-Normalizing Surgery on Intersexed Infants

Georgetown Law Journal, No. 129, November 2003

A.C. Lareau, Georgetown Law Journal Association

The author assesses the benefits of strengthening informed consent as a way to eventually ending “normalizing” interventions. Ms. Lareau questions if parents can legally give informed consent to surgery on their children “that is irreversible, essentially cosmetic, and most often medically unnecessary.” The author argues that until the medical community can separate bona fide medical concerns from “discriminatory mores,” the “known detrimental effects of surgery mandate that it be halted.”

The author questions the argument that children should not be made to suffer without surgery until society is more open to difference, noting that we do not “normalize” other children who may be at a social disadvantage due to race, intelligence, height, or other physical features that deviate from societal norms. In fact, that it is more devastating to subject children to the current standard of intersex treatment, which reinforces a sense of intersex bodies being “freakish.” The author states that “questionable social and psychological concerns regarding the parent and child are not sufficient to justify irreversible medical surgery.”

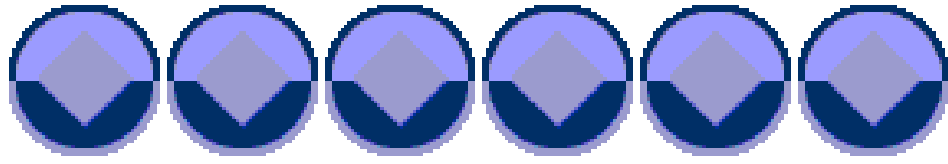
The author points to the social forces creating emotional conflicts that can prevent parents from acting in their child’s best interest. The treatment of intersex children is symptomatic of bias “based on rigid ideas about masculinity and femininity.” The author urges the courts to “scrutinize these decision closely when deciding what is in the best



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

interest of the child and should not give weight to potential psychological benefits that have not been proven.

The author states that strengthening informed consent may be the best incremental step to achieving protection for intersex children until such time as the surgeries can be ceased. The author concludes by urging the legal and advocacy community to continue to push the medical community to investigate whether “normalizing” surgeries are recommended solely for social and psychological concerns. The author expressed concern about full, informed consent under the existing intersex treatment model – “The current inability of the medical community to differentiate between truly medically-necessary surgery and surgery performed for social and psychological reasons renders even the fully-informed parents unable to consent to irreversible and unnecessary cosmetic genital surgery.”



APPENDICES



APPENDICES

A. GLOSSARY

B. WEBSITE LINKS

C. PRESS RELEASE

D. HEARING SIGNS

E. UCSF CORRESPONDENCE

F. FURTHER CORRESPONDENCE FROM DR. BASKIN

G. LINKS TO COMMISSION MEETING MINUTES RE: DR. BASKIN’S REQUEST TO PROVIDE FURTHER TESTIMONY

A. GLOSSARY

AMBIGUOUS GENITALIA

Genitalia that is not easily classified as male or female; genitals that are not readily determined by doctors to be male or female; genitals that have a combination of masculine and feminine characteristics and are not considered “standard” for “male” or “female.”

ANDROGEN INSENSITIVITY SYNDROME (AIS), PARTIAL ANDROGEN INSENSITIVITY SYNDROME (PAIS), or COMPLETE ANDROGEN INSENSITIVITY SYNDROM (CAIS)

Androgen Insensitivity Syndrome, or AIS, is a genetic condition, inherited (except for occasional spontaneous mutations), occurring in approximately 1 in 20,000 individuals. In an individual with complete AIS, the body’s cells are unable to respond to androgen, or “male” hormones. (“Male” hormones is an unfortunate term, since these hormones are ordinarily present and active in both males and females.) Some individuals have partial androgen insensitivity (PAIS).

The extent of androgen insensitivity in 46 XY individuals is quite variable, even in a single family. Partial androgen insensitivity typically results in “ambiguous genitalia.” The clitoris is large or, alternatively, the penis is small and hypospadiac (these are two ways of labeling the same anatomical structure). Partial androgen insensitivity may be quite common, and has been suggested as the cause of infertility in many men whose genitals are of typically male appearance.



CONGENITAL ADRENAL HYPERPLASIA (CAH)

Adrenal hyperplasia is the most prevalent cause of intersexuality among XX people with a frequency of about 1 in 13, 000 births. It is caused when an anomaly of adrenal function causes the synthesis and excretion an androgen precursor, initiating virilization of a XX person in-utero. Because the virilization originates metabolically, masculinizing effects continue after birth. Sex phenotype varies along the full continuum, with the possible added complication of metabolic problems that upset serum sodium balance.

HERMAPHRODITE

The word "hermaphrodite" is a stigmatizing and misleading word. There is growing momentum to eliminate the word "hermaphrodite" from medical literature and to use the word "intersex" in its place. While some intersex people do reclaim the word "hermaphrodite" with pride to reference themselves (like words such as "dyke" and "queer" have been reclaimed by LGBT people), it should be generally avoided except under specific circumstances.

HYOSPADIAS

Hypospadias refers to a urethral meatus ("urinary opening") which is located along the underside, rather than at the tip of the penis. In minor or distal hypospadias, the meatus may be located on the underside of the penis, in the glans. In more pronounced hypospadias, the urethra may be open from mid-shaft out to the glans, or the urethra may even be entirely absent, with the urine exiting the bladder behind the penis. Hypospadias is essentially a cosmetic difference. A person with hypospadias may have to urinate sitting, rather than standing. He may also be prone to urinary tract infections.

INFORMED CONSENT

The doctrine of informed consent is based upon the legal principle of battery, which holds that an offense to personal dignity occurs when one violates another's bodily integrity without full and valid consent. Under this doctrine, a doctor must provide the patient with adequate information about the proposed treatment, including all alternatives to the proposed procedures. The patient's decision must be voluntary and must be made without undue influence or coercion from the doctor. The patient's decision must be competent, meaning that the patient must have an understanding of all of the risks and benefits of the proposed treatments. The doctrine of informed consent is intended to protect the patient's body from unwanted or uninvited procedures and to protect the clinician from liability.



INTERSEX

A person with an intersex condition is born with sex chromosomes, external genitalia, or an internal reproductive system that is not considered "standard" for either male or female.

KLINEFELTER’S SYNDROME

A quite common chromosomal variation - 47XXY. (Other variations include XXXY and XXXXY) The only characteristic that seems certain to be present is small, very firm testes, and an absence of sperm in the ejaculate, causing infertility. Except for small testes, those with Klinefelter are usually born with normal male genitals. But their testes often produce lower than average quantities of testosterone, so they don't virilize (develop facial and body hair, muscles, deep voice, larger penis and testes) as strongly as other boys at puberty. Many also experience breast growth at puberty (or later) and some have a uterus and ovaries as well.

“NORMLIZING” MEDICAL INTERVENTIONS

Genital surgeries and hormonal interventions performed on infants and children that are not performed for the treatment of physical illness, such as improving urinary tract functioning or metabolic health, and have not been shown to alleviate pain or illness.

B. WEBSITE LINKS

These are links to organizations that provide support networks for people with intersex anatomies and their families, as well as bibliographies for further reading on the subject of intersex.

- AIS Support Group UK - <http://www.medhelp.org/www/ais/>
- Bodies Like Ours - <http://www.bodieslikeours.org/>
- Intersex Initiative - <http://www.intersexinitiative.org/>
- Intersex Society of North America - <http://www.isna.org/>
- UCSF Center for Gender Equity - <http://www.ucsf.edu/cge/lgbtr/>
- UK Intersex Association - <http://www.ukia.co.uk/>



C. PRESS RELEASE

NEWS RELEASE

MAY 11, 2004

FOR IMMEDIATE RELEASE

For information contact Marcus Arana at (415) 252-2519

SAN FRANCISCO HUMAN RIGHTS COMMISSION TO HOLD PUBLIC HEARING ON INTERSEX ISSUES

The San Francisco Human Rights Commission has announced that it will hold a public hearing on intersex issues on Thursday May 27, 2004. The hearing, starting at 4:30 p.m., will be held at San Francisco City Hall, 1 Dr. Carlton B. Goodlett Place, Room 416, and is scheduled to end at 7:30 p.m.

Intersex has been defined as anatomies that have a combination of male and female sexual characteristics and is therefore not considered “standard” as male or female. Intersex anatomies may influence chromosomal mosaics, internal reproductive organs, and/or external genitalia. Estimates of the frequency of children born with intersex anatomies range from approximately 1 in 150 to 1 in 2000 births.

The Commission will take testimony on whether infants with intersex anatomies should be surgically assigned gender by doctors who are unable to determine if the child’s sex is male or female, and who do not know what the child’s gender identity is or will be. Commissioners also will consider whether some infant surgeries are truly medical emergencies or are performed solely for cosmetic reasons. Further, the Commission will investigate to what degree parents are given sufficient information to make informed consent and given referrals to appropriate support networks.

Commissioners from the Health Commission also will be in attendance. A report with Findings and Recommendations will be created from the information collected from the testimonies of academics, medical providers, psychiatric providers, parents, family members, and people with intersex anatomies.

###



D. HEARING SIGN

PUBLIC HEARING

ON

INTERSEX ISSUES

**ROOM 416
SAN FRANCISCO CITY HALL**

THURSDAY, May 27, 2004, 4:30 PM



E. UCSF CORRESPONDENCE

01/27/2005 03:52 4154762314

UCSF FTC/PED. SURG.

PAGE 02/02



University of California
San Francisco

School of Medicine
Department of Surgery
Box 0570
San Francisco, CA 94143

Malcolm Heinicke, Chair
Human Rights Commission
25 Van Ness Avenue, Suite 800
San Francisco, CA 94102-6033

06 JAN 27 PM 3:29
S. F. HUMAN RIGHTS
COMMISSION

Dear Mr. Heinicke:

UCSF Children's Hospital is appreciative of the proposed Human Rights Commission report on intersex and congratulates you for your work in this important area. I am grateful for the opportunity to review the report in advance. Much progress has been made in medical responses to intersexuality as the report notes, but much remains to be done. The HRC report is an important step toward bringing this issue to the forefront of the public's consciousness.

We at UCSF are committed to the ongoing study of this issue, in concert with patients, medical professionals, community activists, and others interested in this important work. In anticipation of the work to be done, I have convened an interdisciplinary task force to review the HRC's recommendations. As the report notes, it is clear that education will be a major component of this work, and UCSF is committed to substantial patient and family education along the lines recommended by the report.

Again, we are grateful for the HRC's interest and work in this area, and we look forward to working together on this important issue.

Sincerely,

Diana Farmer, MD
Professor of Surgery, Pediatrics, OB-Gyn & Reproductive Sciences
UCSF School of Medicine
Surgeon-in-Chief
UCSF Children's Hospital

Cc: Virginia m. Harmon, Executive Director
Marcus Arana, LGBTAC Staff member
Lary Brinkin, LGBTAC Staff member

Page 02 of 02
Printed on 01/27/2005
Printed at 03:52:00



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

Body text of an email letter from Kieran Flaherty, Director of Local Governmental Relations at UCSF to Steve Kawa, Chief of Staff, San Francisco Mayor’s Office, regarding the HRC Intersex Report:

“The HRC has informed UCSF that Dr. Larry Baskin sent a letter to Mayor Newsom, dated February 1, 2005, regarding the HRC's forthcoming report on intersexuality. Dr. Baskin apparently feels that the HRC report does not represent a balanced approach in its present form. Dr. Baskin is not writing on behalf of the UCSF Children's Hospital.

I would like to provide some context for you.

- UCSF and UCSF Children's Hospital were not aware that Dr. Baskin was planning to contact the Mayor.
- Dr. Diana Farmer, Surgeon-in-Chief at UCSF Children's Hospital, has convened an interdisciplinary task force to review the HRC's recommendations.
- The task force decided that Dr. Farmer should serve as the UCSF Children's Hospital spokesperson on this issue. Dr. Baskin was present at that meeting and we believe he intends to provide his expertise and viewpoints to the task force, if not participate as a member.

The expected response to Dr. Baskin from the HRC--that they will receive additional information and testimony in addition to that which Dr. Baskin has already provided to them--seems fair and reasonable. In fact, the University is pleased with the HRC's extraordinary willingness to accommodate Dr. Baskin's desire to provide additional information.

The University is genuinely grateful for the HRC's interest and work in this area. The University is committed to substantial patient and family education along the lines recommended by the report.”



UCSF email concerning the creation of an Intersex Task Force

Subject: UCSF Intersex Task Force

March 21, 2005

FROM: Mark Laret, CEO
David Kessler, Dean - School of Medicine

RE: Appointment of UCSF Intersex Task Force

In anticipation of the publication of the San Francisco Human Rights Commission's (HRC) report entitled, A Human Rights Investigation into the Medical "Normalization" of Intersex People due to be released next month, we are inviting you to participate on UCSF Intersex Task Force.

The charge of the UCSF Intersex Task Force shall be to:

1. Review the San Francisco Human Rights Commission (HRC) Report entitled, A Human Rights Investigation into the Medical "Normalization" of Intersex People;
2. Review UCSF's current practices, including the social-emotional support and education resources offered to parents of intersex infants, and surgical interventions performed on infants and children with intersex conditions;
3. Examine current nation-wide practices and trends related to parent support and education and the treatment of infants and children with intersex conditions;
4. Recommend guidelines for the socio-emotional support and education of parents of intersex infants and the treatment of intersex patients at UCSF.

We request that Diana Farmer serve as both chair of the task force and as UCSF's spokesperson on this subject and that Cindy Lima serve as staff.



F. FURTHER CORRESPONDENCE FROM DR. BASKIN

The Commission unanimously approved the report, “A Human Rights Investigation Into The Medical Normalization of Intersex People” on January 27, 2005.

On February 1, 2005, Dr. Laurence Baskin wrote to the Mayor’s Office requesting an opportunity to present further medical and research testimony. Dr. Baskin also wrote to the Commission on March 1, 2005 in response to invitations to appear before the Commission to present further medical and research testimony, including statements from intersex patients who have experienced successful outcomes. The following letters provide a record of Dr. Baskin’s correspondence with the Mayor’s Office and the Commission. Despite repeated Commission invitations, Dr. Baskin did not provide further medical or research information or any statements from intersex patients who report experiencing successful outcomes after medical “normalization” interventions.

CHRONOLOGY OF 2005 CORRESPONDENCE WITH DR. BASKIN:

February 1, 2005: Letter from Dr. Baskin to the Mayor’s Office requesting opportunity to present further medical and research information to the Commission.

February 16, 2005: Letter from Director Harmon to Dr. Baskin with an invitation to testify before the Commission on March 4, 2005 to present further medical and research information.

March 1, 2005: Letter to Director Harmon from Dr. Baskin declining invitation to appear on March 4, 2005.

March 16, 2005: Letter from Director Harmon to Dr. Baskin with an invitation to appear before the Commission on April 14, 2005 present further medical and research information.

April 11, 2005: Letter received from Dr. Baskin to Director Harmon declining invitation to present further medical and research information.



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL "NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

MAY-05-2002 03:03

SF-OFFICE OF THE MAYOR

P.02/02



UCSF Children's Hospital
at UCSF Medical Center

Urology Faculty Practice
Pediatric Urology
400 Parnassus Avenue
Suite 610
San Francisco, CA 94143
tel: 415/353-2200
fax: 415/353-2480
www.ucsfhealth.org/childrens
University of California,
San Francisco

Laurence S. Baskin, MD
Hubert S. Swans, MD
Angel Chen, RN, MSN, CPNP

February 1, 2005

Mayor Gavin Newsom
Mayor's Office City Hall
1 Dr. Carlton B. Goodlett Place Rm. 244
San Francisco, CA 94102-4689

RE: San Francisco Human Rights Commission Report on the
Treatment of Patients with Intersex

Dear Mayor Newsom,

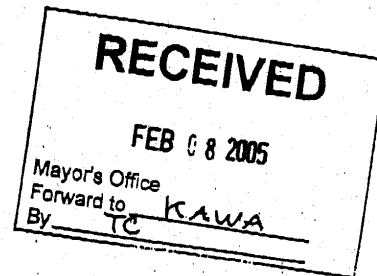
I have reviewed the draft report from the San Francisco Human Rights Commission on the medical treatment of intersex.

This report has the potential to be quite educational. In its present form, however, I don't feel that it represents a balanced approach. I would appreciate the opportunity to respond to inaccurate representation of my practice at the University of California San Francisco in the Department of Urology and Pediatrics prior to the reports publication. I also think it would be useful for the commission to hear from patients who have had successful outcomes by their own admission, which I believe makes up the overwhelming majority of patients that have been treated.

Sincerely,

Laurence S. Baskin, M.D.
Chief Pediatric Urology
Professor of Urology & Pediatrics
Department of Urology

LSB:agl



TOTAL P.02



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL "NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

LAURENCE S. BASKIN, M.D.

PEDIATRIC UROLOGY

400 PARNASUS AVENUE, ROOM 610
SAN FRANCISCO, CALIFORNIA 94143-0330

March 1, 2005

Virginia Harmon
Executive Director
Human Rights Commission
25 Van Ness Avenue, Suite 800
San Francisco, CA 94102-6033
415-252-2500
415-431-5764

Re: Congenital genital abnormalities

Dear Ms. Harmon,

Thank you very much for taking my phone call the other day concerning your letter dated, February 16, 2005. In short, I look forward to meeting with you in person and other commission members concerning the SF Human Rights draft on patients with congenital abnormalities. As mentioned on the phone, I have quite a hectic schedule over the next few months with a number of research project pending as well as clinical responsibilities, and a large grant submission to the National Institute of Health.

I will not be able to respond with such short notice by March 4th as advised in the deadline, but look forward to taking a leadership role in the future on this most important subject.

Sincerely,

Laurence S. Baskin, M.D.
Chief Pediatric Urology
Department of Urology



UCSF CHILDREN'S MEDICAL CENTER

Fetal

Neonatal

Pediatric

Adolescent



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL "NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

S. F. HUMAN RIGHTS
COMMISSION
LAURENCE S. BASKIN, M.D.
05 APR 11 AM 4:39

PEDIATRIC UROLOGY

400 PARNASUS AVENUE, ROOM 610
SAN FRANCISCO, CALIFORNIA 94143-0330

April 4, 2005

Virginia Harmon
Executive Director
Human Rights Commission
25 South Van Ness Avenue, Ste 800
San Francisco, CA 94102-6033
252-2500
431-5764 (fax)

Dear Executive Director Harmon,

I received your letter dated March 16, 2005. Unfortunately, I will not be able to attend the Commission's hearing scheduled for Thursday, April 14th, 2005. I have a prior academic commitment at an international urologic conference.

I was able to review the draft of "a human rights investigation into the medical "normalization" of intersex people" that was put together by the San Francisco Human Rights Commission. Speaking frankly, I am disappointed with the present draft. As I stated in my earlier testimony, patients with genital differences of the sex organs can face major challenges requiring extensive support from families, their community and healthcare professionals. These conditions include anomalies of the chromosomes, gonads, internal reproductive ducts and the external genitalia including malformations like cloacal exstrophy and penile agenesis.

As illustrated in the draft, Chapter 4, oral testimony- people with intersex anatomies, of the 10 testimonies, 5 patients had "normalizing" surgery, 4 did not have surgery and in 1, the



UCSF CHILDREN'S MEDICAL CENTER

Fetal

Neonatal

Pediatric

Adolescent



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL "NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

surgical status is not given. Of these 10 testimonies, it is quite clear that 9 of these individuals have had severe emotional problems, secondary to their status as intersex patients, irregardless of whether they have had surgery or not. Clearly, these are very complex issues and without question, surgery in itself is not the answer to either short nor long-term psychological and physical well being of these individuals. In the one case of the oral testimony where the individual by their admission has had a successful outcome, this is attributed to a loving and supportive family.

I would like to emphasize the importance of family support, acceptance and education in the treatment not only of individuals with intersex, but to all severe medical conditions whether congenital or acquired. As I mentioned in my previous conversations, I would hope that the SF Human Rights Commission would take the opportunity to present a balanced report. Presently, there is no discussion about families and the rights of families to seek the best possible care for their children. Furthermore, I would reiterate the words of thousands of patients with congenital anomalies such as cleft palate, hydrocephalus, pectus excavatum, cochlear agenesis, ventral septal defects, uretero-pelvic junction obstruction, cryptorchidism, hypospadias and congenital adrenal hyperplasia "there is nothing wrong with being normal."

I would like to emphasize the definition of intersex in itself as well as the incidence of patients with intersex remains open to debate and in itself is controversial. For example, in my opinion, the draft includes extensive discussion on individuals that do not have intersex. I also take issue with the concept that sex is assigned by families, doctors, elders or the community. Sexual identity comes from the individual and is self determined by a complex interaction of genes, hormones, environment and many other unknown variables. I would also emphasize that the difference between sexual identity which traditional has been either male or female but can also be both or neither and sexual preference which is not germane to this discussion.

Historically and even in contemporary times, governmental intrusion into the basic rights of families to determine their own healthcare decisions has been a failure. Certainly the treatment of patients with intersex anatomies remains complex, controversial and in need of better evidence based outcome studies. This is illustrated by the myriad of publications, debates, conferences and meetings on the diagnosis and treatment of individuals with intersex. It is my hope that the SF Human Rights Commission can take this opportunity to



UCSF CHILDREN'S MEDICAL CENTER

Fetal

Neonatal

Pediatric

Adolescent



A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL "NORMALIZATION OF INTERSEX PEOPLE – A REPORT OF A HEARING OF THE SAN FRANCISCO HUMAN RIGHTS COMMISSION

encourage participation by all individuals concerned with the health care treatment of patients with complex issues and not create further polarization between the medical community and patient advocacy groups.

Sincerely,

Laurence S Baskin MD FAAP FACS

Laurence S. Baskin, M.D.
Chief Pediatric Urology
Department of Urology

LSB:agi

cc: Malcolm Heinicke
Chair, SF Human Rights Commission

Honorable Mayor Gavin Newsom
City Hall
25 van Ness Avenue
San Francisco, CA 941202



UCSF CHILDREN'S MEDICAL CENTER

Fetal

Neonatal

Pediatric

Adolescent



H. LINKS TO COMMISSION MEETING MINUTES RE: DR. BASKIN’S REQUEST TO PROVIDE FURTHER TESTIMONY

The following links are to the minutes of Commission’s meeting meetings where the issue of Dr. Baskin’s request to present further information, and concerns about the three-month delay in releasing the report were discussed as an agenda item. To review Commission remarks and community member responses regarding this delay, please refer to the following meeting minutes.

www.sfgov.org/sfhumanrights

[February 24, 2005](#)

[March 10, 2005](#)

[April 14, 2005](#)