

Shadow Report

**To the 6th National Report of the Federal Republic of Germany
On the United Nations Convention on the Elimination of All
Forms of Discrimination Against Women (CEDAW)**

Compiled by:

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Date

July 2nd 2008

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| Contents | |
| Foreword / Executive Summary | 5 |
| Questions to the German Government | 7 |
| 1. Preamble and Article 1-5 CEDAW | 9 |
| 1.1 Definition - What is Intersexuality? | 9 |
| 1.2 Denial and Ignorance of the German Government | 10 |
| 2. Article 5a 10c (Education) | 11 |
| 2.1 Prof. Dr. John Money`s Gender Theories and their Violations to Human Rights | 11 |
| 3. Article 12 (Health) | 12 |
| 3.1 Problems in Parents - Child Relations | 12 |
| 3.2 Medical Experiments on Human Beings | 13 |
| 3.3 List of Human Rights Violations as a Result of the Treatment according to the “Standards” Developed by Prof. Dr. John Money | 13 |
| 3.3.1 Removal of Gonads (Castration) | 13 |
| 3.3.2 Genital Amputation | 14 |
| 3.3.3 Effective Protection of Rights | 14 |
| 3.3.4 Documentation of Treatment | 15 |
| 3.3.5 Irreversible Genital Surgery of Minors and Adults | 15 |
| 3.3.6 Off–Label Use of Pharmaceuticals | 15 |
| 3.3.7 Consequences of Treatment in Scope of Medical Definition | 16 |
| 4. Article 16 (Marriage and Family) | 16 |
| 4.1 Violation of the Preeminence of the Best Interest of the Child and the Protection of the Identity of the Child | 17 |
| 4.2 Illegal Concealment and Denial of Access to Medical Records | 17 |
| 4.3 Equal Right to Marriage | 18 |
| 5. Special Mechanisms | 18 |
| 5.1 A Possibility of Reconciliation: Truth Commission to Raise Awareness on the Violation of Women`s and Human Rights of Intersex People | 18 |
| 6. Claims and Recommendations | 19 |
| 6.1 The Claims of the Persons Concerned | 19 |
| 6.2 Necessary Aid Programs for Persons | 20 |

| | |
|--|-----|
| Addendum - Case Studies | 21 |
| 1. Case Study “Nella” | 22 |
| 2. Case Study “Christina T.” | 26 |
| 3. Links | 30 |
| 4. Prof. Dr. Milton Diamond / Assistant Prof. Hazel Glenn-Beh: “ An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment on Infants with Ambiguous Genitalia?” | 33 |
| Apendix (German Texts) | |
| 5. The “ Medical Standard“ according to Prof. Dr. John Money | 84 |
| 6. Intersexualität. Die alltägliche Folter in Deutschland. Ein Forschungsbericht, Humboldt University, Berlin | 86 |
| 7. Answer of the German Federal Government to a Parliamentarian question on the issue of intersexuality (dealt with in writing); 2001/2007 | 128 |

Foreword / Executive Summary

On the basis of the beliefs and experiences of the authors, this shadow report is devoted to revealing the denied human rights of intersexual persons as they are standardized in the UN Convention on the Eliminate all forms of Discrimination Against Women (CEDAW), and respectively, in conjunction with Article 3 CEDAW, as well as other UN human rights treaties.

According to the legal point of view of by the authors of this report, CEDAW embraces the protection against discrimination, of all persons who are physically and clearly not belonging to a male gender. Only through this expansive comprehension can it be assured that this protection will be fulfilled for people who have been falsely assigned to a male or female gender. According to the views and experiences of the authors the implementation of an effective protection of persons who have been defined as intersexual or “DSD” (Disorder of Sexual Development) is not given through medical science.

Within intersexual people both, female and male physical characteristics can be found. But next to the variety of their sex chromosomes and/or genitalia, in the majority of cases, no further pathological criteria exist. Despite, in Germany as well as in numerous other countries, intersexual persons are target of irreversible medication and surgery from early childhood on. Consequently, these medical interferences result in life-long obligatory medical treatment.

In the majority of cases, intersexual children will be medically treated in order to visually and mentally adjust them to what is perceived as being “female” in the respective cultural contexts. This is done although a medical indication as well as a quality control is completely absent. There are also cases however in which medical scientists try to adjust intersexual persons to a male gender. This then includes the wrongful extraction of completely intact female genitals and sexual organs, with brutal consequences concerning the possibility of motherhood, selfperception and body image, as well as sexual self determination.

It is a fact that these persons are forced into a gender whereby they loose their natural, individual development potential. The necessity of medical interferences is justified through social aspects, for instance, the concern that the intersexual child without clearly defined sexual characteristics could become a victim of sexual discrimination.

Official estimates classify approximately 80,000 - 120,000 people who live in Germany today, with a medical classification of being “intersexual” (“DSD”, Disorder of Sexual Development).

CEDAW prohibits every form of discrimination on the basis of gender: *“the term ‘discrimination against women’ shall mean any distinction, exclusion or restriction made on the basis of sex”* (Article 1). This poses the duty onto the member states *“to take all appropriate measures to eliminate discrimination against women by any person, organization or enterprise”* (Article 2). Thereby, CEDAW already calls for the contracting state: *“to modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women”*. From the perspective of intersexual persons, this modification to eliminate sexual stereotypes as well as the construction of a binary order in which only women and man exist, is essential for the life and survival of intersexual persons.

The aim of this shadow report is to clarify the physical, psychological and social situation of intersexual people in Germany, with the goal of a full-fledged realization and implementation

of the human rights of all intersexual persons. Germany, as a contracting party to CEDAW, may no longer ignore the massive infringements and violations of human rights of intersexed people. Germany is obliged to undertake “*all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices which constitute discrimination against women*” (Article 2) in order to make sure that women can execute their rights and freedoms.

In its sixth state report to CEDAW the German German Government gives no attention to the concerns of intersexual persons. Therefore, with the shadow report the authors express their hope that CEDAW confronts the German government face to face with the issue, and encourages that they will care for the full implementation of the human rights of intersexual persons (in alliance with Art. 3 CEDAW as well as other human rights norms and treaties of the United Nations).

The intersexual women provide their own shadow report because of the very specific forms of violence and discriminations they are exposed to. Nevertheless, in the preparation process of German shadow reports to CEDAW, the intersexual women were linked to and part of the NGO platform who compiled the main alternative report to CEDAW (the German Women`s Council).

Intersexuality touches on a multitude of universal human and women`s rights. This report concentrates on depicting human rights violations on the basis of lacking implementation of Articles 1-5 (*underlying principles of the CEDAW Convention: Equality, Non-Discrimination and State Obligation*), Article 10 (*Education*), Article 12 (*Health*) und Article 16 (*Marriage and Family*).

All human rights are universal, interdependent and interrelated. Following Article 28 of the Universal Declaration of Human Rights (UDHR), “*every human being is entitled to a social and international order in which the rights and freedoms can be fully realized*”. Also CEDAW stressed in the Preamble, “*...that all human beings are born free and equal in dignity and rights... without distinction of any kind, including distinction based on sex*”. This gives a reason to hope for a recognition of intersexual people who need help and support for the respect, the protection and fulfillment of their rights.

Given the sense of universal and interdependent human rights, the concerns of intersexual people will need to be communicated to other UN treaty bodies [particularly to the Human Rights Committee, the Committee on Economical, Social and Cultural Rights, to the Children`s Rights Committee (CRC) and the Committee Against Torture (CAT)] as well as to the Special Rapporteurs for the protection against torture and violence against women and children.

Questions to the German Government

1. What will the German Government undertake to ensure that the dignity and right to a life free of discrimination (Article 1 in connection with Article 3 CEDAW) also becomes possible for intersexual people?
2. When will the German Government acknowledge the reports of NGOs, representatives of self-help groups and existing research results concerning the living condition of intersexual women / people, and take up a dialog with the affected persons, their associations and self-help groups?
3. In what sort of time frame will the German Government undertake steps to make sure the medical standards of treatment for intersexually born persons are congruent with the requirements of the ratified UN contracts?
4. When will the medical professional societies be asked by the German Government to introduce standards of treatment free of discrimination under active inclusion and participation of the affected persons?
5. When and how will the German Government ensure, that intersexual people are requested to make a decision on which sex / gender they belong to, no sooner than when they themselves are fully able to make this decision?
6. What will the German Government undertake to make sure that in the future no irreversible medical interventions at intersexual people occur without their own *informed decision* ?
7. When and how will the German Government introduce a human rights based treatment of intersexual persons and guarantee it permanently, so that no more discrimination occurs from laws and orders?
8. When will the German Government introduce the concept of the sexual variations in their legislation and ordinances?
9. Which laws will the German Government update, acknowledging the existence of intersexual persons and when?
10. When will the German Government acknowledge the victims of irreversible surgery and medical experiments and grant them legal advice, legal security and an integration within the social order?
11. Will the German Government promote binding laws, free of discrimination, which guarantee the intersexually born the same access to medical achievements as all people?
12. What will the German Government do during the next four years for the construction of specified competence centers and for the education of trained professional staff for the treatment of intersexual people?
13. What will the German Government undertake during the next four years to educate consultation teams with the participation of intersexual people?
14. How will the Government legally regulate the limitation of claims for compensation for damages due to the withholding of medical documents and information?

15. How will the German Government make sure that intersexual persons are admitted an observer status with all scientific studies concerning their minority?
16. Will the German Government during the next four years promote or support a truth commission which contributes to the public awareness and which regulates the compensation (according to Canadian model) of intersexual people injured by medical treatment or non-treatment?
17. In which way and when will the German Government compensate the disadvantages which intersexual people have suffered by the treatments?
18. When will the German Government define which physical and psychological damages due to the false treatment of intersexual people correspond to the degree of impediment / decrease of the capacity to work ?
19. When will the German Government remove the existing discriminations of intersexual persons in civil status law and marriage law?
20. When will the German Government put on new research projects (as e.g., the research group Hamburg) or continue investigating the situation of intersexual adults extensively, and when will these results show clear effects for intersexual persons?

Shadow Report to the 6th State Report of the Federal Republic of Germany to the Treaty of the United Nations to the Elimination of All Forms of Discrimination against Women (CEDAW)

1. Preamble and Articles 1-5, CEDAW

The *Convention on the Elimination of all forms of Discrimination against Women* affirms in its preamble “*the principle of the inadmissibility of discrimination and proclaims that all human beings are born free and equal in dignity and rights and that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind, including distinction based on sex*”. Articles 1-5 comprise the standardized basic principles of equality and anti-discrimination, as well as state responsibilities.

The present alternative report by the Association of Intersexual People (Verein Intersexuelle Menschen e.V.) and its affiliated self-help group “XY-Women” corresponds particularly with these basic principles of equality and the prohibition of discrimination on the basis of sex / gender. CEDAW is enfolded to, “*any distinction, exclusion or restriction made on the basis of sex*” (Article 1) and calls on the member states “*to pursue by all appropriate means and without delay a policy of eliminating discrimination against women*” (Article 2). This is why, according to the legal point of view of the authors, CEDAW is also able to effectively promote the protection of human rights for all people - including intersexual people.

1.1 Definition - What is Intersexuality?

The fact of the matter is irrevocable that nature produces – next to men and women - also persons who do not fit into the binary, culturally grown system of being male or female. The official estimates classify approximately 80,000 - 120,000 people in Germany living with the classification of being “intersexual” (“DSD”, Disorder of Sexual Development).

The concept of intersexuality depicts persons who have sex chromosomes, genitalia and/or gonads which deviate from the culturally motivated norms of sexual constructions. Following birth, some 95% of this group of persons have already had or will undergo genital surgery and various medical interventions to change their fundamental and individual sexual characteristics. These interventions are oriented by the medical feasibilities with the aim to arbitrarily produce “sexual clarity” – albeit their personal rights, their physically and biologically determined construction and, under the absence of evident scientific proof. The intersexual people regard this interference, without their acceptance and without a comprehensive reconnaissance taking place, as a forbidden interference against their autonomy and as an undignified act of violence. The irreversible and extensive psychosomatic and mental damages as well as the preservation of the secondary sex characteristics through medical treatment during the total lifespan, result in an extensive oppression of the persons concerned.

Intersexual people, concerning their biographies, may be classified into two groups. There are on the one hand, those born before 1945 who were essentially victims of the “racial cleansing” of National Socialism. Those who survived this time were hidden by their families. The normality of hermaphroditism had been made a life-sustaining taboo. The second group are the ones that were born after 1946, particularly those, today the majority, who were born after 1950. This report concentrates on the group that was born after 1946, although there are also some intersexual people from the time before 1945 who have survived and are still living

today. Gender assignments in Germany are carried out by state regulation based on regulations that date back to 1937. This regulation, despite the National Socialist background, has always had a continued existence. It has evolved for intersexual people often to grave consequences. These people - totally normal yet endowed with varying sex characteristics, will be classified as intersexual people and their bodily genders considered a variation under the DSD-Syndrome. Nonetheless, the authors of this report are pleased with the mention in the 6th State Report of the Federal Republic of Germany in relation to the new Anti-Discrimination laws (General Equality Law).

It is pivotal to note that intersexual people without surgery and/or medical treatment do, (except for a few exceptions e. g. CAH), not have to apprehend any difficulties or life-threatening physiological diseases due to their specific genital features.¹

1.2 Denial and Ignorance by the German German Government

In the past, two parliamentary requests were submitted to the German German Government with the aim of achieving an official statement about the situation of intersexual people in Germany. The answers of the German Government to these requests are documented in the government printed papers 14/5425 and 16/4322. The answers of the German Government are particularly criticized by the authors in that these originate exclusively on the basis of information of certain medical circles/scientists who have been treating affected persons and, who have an interest in sustaining their previous clinical practice. Intersexual people and their organizations were not heard for this. Also, the available information from independent psychological studies on the situations of intersexual people with disastrous findings have not been included.² The avoiding behaviour of the German Government is clearly documented through the statement: “*We don’t know otherwise, therefore no further measure are necessary.*” The authors fiercely criticize this.

Also, several of the studies conducted on intersexual people, and their metabolic situation, as being treated with paradoxical hormones substitute therapies, in the course of countersexual compulsive allocation, were not taken into consideration.³ So, on a regular basis, intersexual girls and adolescent women are castrated even before the completion of their bodily development. Then following, they are exclusively treated with non-age-based contraceptives or post- or menopausal or even contra-hormonal therapy.⁴ The fatal consequences for the concerned children, girls and women are noticeable even without specialist knowledge and were neither elicited nor found mention in the report of the German Government. For these reasons the Association of Intersexual People cannot accept the ignorance of the German Government.

¹ There are a few exceptions e.g. CAH = Congenital Adrenal Hyperplasia, the clinical pattern is a result of overproduction of the androgen steroid through the adrenal cortex, with or without adrenogenital salt-depletion syndrome. This leads to effects of virilization for persons with XX- chromosomal pattern.

² It is meant here the example of the research group under the leadership of Prof. Dr. Hertha Richter-Appelt, from the Center for Psycho-social Medicine, Institute for Sexology, University Clinic of Hamburg (as well as the Hamburger Study of Evaluation).

³ “Consequences of low level sex hormone substitution in young intersex females”, Clüsserath et.al. 2001; Consequences of sex hormone substitution, out of metabolism regulation,” Clüsserath et.al. 2004; “Intersexuality Disrupted Between Science and Reality” University of Lüneburg, DGSS u. DGSS- Institute, Clüsserath et.al. 2004; “Effects of Testosterone Treatment in a Female Assigned Subject with Swyer-Syndrome after 30 Years - A Self Report” University - Clinic Lübeck Kreuzer/ Kreuzer et.al 2006.

⁴ *non-age-based contraceptives*: minimal dosage of hormones for contraception; *contra-hormonal therapy*: minimal dosage of hormones for treatment of old age symptoms in older women. *Contra-gender hormone therapy* is used to suppress the body's own growth potentials of the secondary sex characteristics (like bodyhair, change of voice, muscle mass etc). However this therapy usually doesn't have the designated effects.

2. Articles 5.a and 10.c - Education

The medical and psychological treatment of intersexual persons orientates itself since the 1950s by the gender theories of Dr. John Money (USA), as well as by particular modern variations.⁵ Money's theories were based on the assumption that if children undergo a sex reassignment surgery at a very early age, combined with the personality changing effects of a hormone therapy, it is possible to (re-) educate a child towards the medically determined sex.⁶

2.1 Prof. Dr. John Money's Gender Theories and their Violations to Human Rights

The theories of Prof. Dr. Money and their variations, whether already, in a horrible way, disproved e.g. through the case of David Reimer⁷, are still utilized today as contents in the medical courses and teaching literature. And so the resulting teaching content for education of doctors still clearly holds on to positions which lead to offences against human rights, followed by other infringements against the law. We, the authors of this report, regard these publications of Prof. Dr. John Money and variations of them as incitement and instructions to the infringement of the law.

Article 10 c CEDAW is committed to the elimination of gender stereotypes in education, particularly in teaching materials. In terms of education and continuing education of doctors, the German Government is obliged to work towards helping doctors to be comprehensively informed and to assure on their part that parents of intersexual children will be informed comprehensively and from various perspectives, including colleagues of other professions and of counsellors of support groups. This way, intersexual people themselves will be enabled to make an informed decision. Appropriate teaching materials on the topic of intersexuality must contain and adequately reflect the experiences of all people concerned.

Furthermore, you often find today in medical text books as well as in other educational materials, a false representation that up until the seventh week of pregnancy every child was phenotypically female. In actuality, all embryos until the seventh week have both internal gender organs of either sexes in their early stages (i. a. Wolffsche Gänge and Müllersche Gänge). Also the external gender organs require up until birth a high complex differentiation towards male or female. However, up to the seventh week of pregnancy all people are intersexual. Only after the twelfth week of pregnancy, will one develop into a bracket of male or female, whereas intersexual individuals remained in an undifferentiated status, more or less. The information about the attributes and condition of people up until the seventh week is of substantial interest to determining all gender-justified discriminations, not only adverse to "intersexual" people.

⁵ The modern variations only aim for a culmination of the inserted medical means.

⁶ "During his professional life, Money was respected as an expert on sexual behavior, especially for allegedly demonstrating that gender was learned rather than innate. Many years later, however, it was revealed that his most famous case was the result of fraudulent reporting on the part of Money. The subject of Money's fraud was his involvement in the sex reassignment of David Reimer, in what later became known as the "John/Joan" case. Money reported that he successfully reassigned Reimer as female after a botched 1966 infant circumcision. In 1997, Milton Diamond reported that the reassignment had failed, that Reimer had never identified as female or behaved typically feminine. At age 14, Reimer refused to see Money again, threatening suicide if he were made to go. Reimer began living as male, and at 15, with a different medical team, he sought a mastectomy, testosterone therapy and a phalloplasty. Later he married a woman who had children from a previous marriage and lived as a man until his suicide at age 38." (Quote from Wikipedia; see: http://en.wikipedia.org/wiki/John_Money)

⁷ http://de.wikipedia.org/wiki/David_Reimer

3. Article 12 (Health)

The human right to health is guaranteed by Article 12 (1) of the UN-Covenant on Economic, Social and Cultural Rights (CESCR) where it says: “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health ”. It is the same imperative from Article 12 CEDAW expressly also for women and from Article 24 (1) on the UN-Convention to the Rights of the Child (CRC). Intersexual individuals must not be disadvantaged with regard to this right. Health relates to the individual, physical and psychological well-being of people. It's not about obtaining complacency within a social order, which can only be achieved through medical treatment with unknown lifelong consequences for bodily integrity. The State is furthermore obliged to take all necessary actions for the wholesome development of children (Article 12 (2) (CESCR)). This includes the protection from dangerous, illegal and unsecured medical treatment.

Still today castrated intersexual women in Germany are refused access to health necessities and hormone therapy adequate to their respective age and bodily condition. The authors know of innumerable intersexual women who are affected by this. Thus female children and young women who had a castration, for different reasons including intersexuality, were substituted regularly with hormone therapies, which possessed neither licensing nor any obvious scientific knowledge.

Children within the first year will have their gonads removed, but due to the lack of age appropriate hormone therapy they won't receive any hormone substitution, up until puberty and beyond. Primarily, this results in a pre-pubertal hormone deficiency during a phase of their development and therein lies largely unexplored associated consequences.⁸ In addition, girls and young women who have been castrated before finishing their bodily development are being treated with non-age-appropriate, contraceptive, or post- or menopausal, or even paradox hormone substitute therapies. This is, according to the experience of the authors, a clearly incorrect treatment. It is often the case, that if well informed women seek an age appropriate therapy, they have to finance it through private expenses.⁹

The studies that intersexual people have conducted themselves demonstrate that the existing medically established practices led to a multitude of secondary diseases in these women, such as affecting metabolism and diseases of internal organs, as well as psychological disorders. Their whole social, psychosocial and psychosexual development was substantially impeded. So, the affected women are trapped in this situation due to their earlier replacement therapy on account of the gonad insufficiency, particularly if the hormone therapy is paradox (of opposite sex). They are not granted any health insurance benefits or they can only benefit from it under high personal financial expenditures. It is generally not possible for parents, for example to insure their newborn intersexual baby or castrated child within the scope of the increasingly requested private insurances / precaution.

3.1 Problems in Parents - Child Relations

The experiences of intersexual people and their partents point to another very important aspect concerning the established medical procedures for the treatment of intersexual children since the 1950s: the problems of parents - especially mothers - in relating to their children.

⁸ Enclosed: Mental, psychosexual-, anatomical, organic, brain-organic, sociological, false development or less development as well as achievement restrictions at school.

⁹ Also moreover personal experiences exist only in the circles of the affected persons, though academically obvious studies are not known.

The “status” of their child often leaves parents in a state of insecurity and dependency to the counselling of doctors that is more or less a form of indoctrination. This medical indoctrination of the parents concerning the gender construction of their child then leads to a form of over-observation for the children and their gender development. From here on out, and after the Money theory, results a form of restrictive upbringing which long-lastingly destroys the “fundamental trust” between parents and child - especially between the mother and child.

Within the framework of a medically claimed, “restrictive gender education”, the natural and normal protection instinct a mother has for her child, is replaced by a “protection” mechanism, which wants to protect the child against his/her own individual sexual development. The natural instincts of the mother to protect the normal life, the survival, and the self-sustainability of the child, are polarized and suppressed by the physician's will to the enforced gender assignment. The reason for this is that doctors make parents think about the sexual development of their children as an “oversized threat”. This is documented by the knowledge of the work by the self-help group of XY-women and their consulting services, as well as psychological studies, which very often reveals the contents of intersexual individuals having distanced relations with their parents.

3.2 Medical Experiments on Human Beings

In the absence of a sufficient quantity of long-term investigations, Professor Dr. John Money's standards has never come out about the experimental stages. The large majority of intersexual individuals in Germany have not given any legal consent concerning the treatment they have been receiving. We, the authors of this report claim that these forms of treatment have been and still are experiments on human beings. Following our legal point of view, a legally binding approval could never come about due to the intentionally wrong clarification about the experimental character of the medical interventions.

Intersexual women are administered drugs for decades beyond their licensing. To the contrary, the impression is given to them, that this type of treatment is based on a medically certified standard. These unlawful measures in Germany remain without consequences, although attempts of treatment without valid approval of the persons concerned are prohibited according to Article 7.2, UN-Convention on Civil and Political Rights (ICCPR). Intersexual women must not be discriminated by exercising this human right (Preamble and Article 3 CEDAW). This is essential, notably also in matters of genital mutilation, genital amputation, genital prosthetics and gonad removal for the purpose of ablative therapy¹⁰, and of dilation.

3.3 List of Human Rights Violations as a Result of the Treatment according to the “Standards” Developed by Prof. Dr. John Money

3.3.1 Removal of Gonads (Castration)

Up till today, the practices recommended and carried out involve the removal of gonads (testicles, ovaries or hybrid forms) of intersexual individuals. Though missing medical indication, instead of regular precaution investigations, healthy gonads are removed still today because of fear that there is an increased cancer risk. Moreover, only the approval of the

¹⁰ The castration is, in the narrower scientific sense, already a hormone therapy. Because it aims at the removal of the hormone-active tissue, as well as its effects on the psychosexuality or the development of the physical arrangement. It is applied, besides to intersexual women, also to sexual offenders.

parents is requested, but is not obtained from the intersexual children themselves; even though these measures concern the right of one's own sex and sexuality, the right of self-determination, and the right of bodily integrity and in respect to a light-hearted childhood.

Parents are recommended these activities from the treating doctors, but an approval by the children is not secured. Their natural development is not waited for. The majority of intersexual individuals and their parents are incorrectly or not at all informed about the consequences of castration and the scientific insecurities of hormone therapy. The castration as well as the inescapably associated paradox hormone therapy for the many people affected, is an interference against basic personal rights. These treatments are, in consideration of the irreversibility and the unknown outcomes, a forced trans-sexualization.

The uninformed castration of intersexual minors and adults, is carried out still today in Germany. In the opinion of the authors of this report, these continued actions offend against the right of the woman to reproductive self-determination (Art. 16.1 lit e, CEDAW). These medical treatments lead to a violation of human dignity (Art. 1 Universal Declaration of Human Rights) and to a violations of the right to health (Article 12 CESCRC and Article 12 CEDAW), as well as of the right to hygienic education and equal access to medical services (Article 10 and 12.1 (CEDAW). For other patient groups – for example, those with supposed increased danger of cancer – it is not the removal of organs but rather the recommendation for precautions and preventative medical checkups routine. These violations so far in Germany have not been tracked. The governmental protection is denied to the women.

3.3.2 Genital Amputation

The medical services claim to have the ability to shorten the clitoris, without loss of sensitivity or destroying the libido. Up till 1986 however, a clitoris classified as being too big was generally amputated, - a practice that resembles female circumcision. This life-destroying procedure is still taking place on children with ambiguous genitals, even though their development is not yet completed, and no one can say with certainty whether this decision is even close to being correct. In addition, although the loss of male glans (head of penis), even in parts, will be assessed as a disability, the loss of sensation due to the clitoris amputation is not seen within that framework. In the opinion of the rapporteurs, this is a violation especially of the human dignity and of the right to health (Art. 12 CESCRC and Article 12 CEDAW), as well as the right to health education and equal access to healthcare (Art. 10 and 12.1 CEDAW).

3.3.3 Effective Protection of Rights

From the point of the affected persons, the application of the methods after the Money model are also a violation the following human rights:

- Article 2 CEDAW obliges the state to guarantee an effective legal protection at the national courts against every form of discrimination against women. For this reason it is forbidden for the courts to put medical standards outside of or above the UN Human Rights Protection System.
- Article 14.1, ICCPR guarantees the equality of every person in front of the law. The enjoyment of this human right may not be denied to people who are subject to a “medical standard”.

The respect, protection and fulfillment of these important women's and human rights is not given in relation to intersexual people in Germany. Regarding past and present medical

practices, intersexual people bemoan the following medical approaches, which are not at all mentioned in the German state report to CEDAW:

3.3.4 Treatment Documentation

- Misinformation and/or false information of persons affected and/or their relatives.
- Deliberate “false clarifications” about diagnostic information.
- Insufficient diagnostic action, by omitting necessary diagnosis procedures.
- Keeping patient's documents, with the intention to let them remain unclear about their true existence.
- Denial of patient documents and files to prevent them from taking juridical steps.
- Neither briefly nor long-term quality control of treatments, nor recordings in a central register, for example, as it is the case with cancer.

3.3.5 Irreversible Genital Surgery Interventions with both Minors and Adults

- Castration without secured indication.
- Castration without consent.
- Castration under default of an inappropriate indication.
- Castration of minors
- Clitoral/Penis amputation as well as clitoris and penal plastic implants without consent.
- Arrangement of neovaginae and neopenis for babies, children and adults without approval.
- Forced enlargement / widening of the artificially invested organs.
- Absence of a medical association which holds a quality education for these interventions.
- Absence of quality control of these interventions.
- Absence of definition of quality characteristics.

3.3.6 Off-Label Use of Medications

- Application of paradox gender hormone substitute therapies (P-HET) without any obvious proof of the effectiveness or the side effects.
- Application of P-HET exceeding the recommended period.
- Application of P-HET without clarification of the side effects.
- Application of P-HET without a compatibility check.
- Application of P-HET without check of the contraindications.
- Application of P-HET without knowledge of chromosomal conditioned interaction with possible other drugs.
- Application of contraceptives as a gender hormone "substitute therapy" without any obvious proof of the effectiveness or the side effects.
- Application of P-HET in particular with children, adolescents and young people at a level adequate for menopausal or postmenopausal women.
- Medications influencing the body growth, e.g., by hypophysis hormones without any obvious proof of the effectiveness or the side effects.

- Application of hormonal drugs to suppress sexual behavior, as they are applied to sexual delinquents.
- Application of personality-changing medication
- Application of other medication to influence secondary sex characteristics, e. g. medications for the treatment of the heart

3.3.7 Consequences of Treatment in the Scope of Action of the Medical Definition

- Lifelong dependence of intersexual persons on hormones substitute therapies and other medical treatments are determined by the legal civil status registration at birth
- In case of the incorrect gender allocation of intersexual individuals medical re-definition of the affected persons now as transsexuals
- Treatment “of intersexual people” according to the treatment of transsexual people.
- Application to the Administration of Justice being based on the bill for transsexuals (TSG – Transsexuellen Gesetz: Transsexual Bill) concerning rights of intersexuals for i.e. individuals pensions, social security and insurance, etc.
- Refusal of medical communities, to undertake the necessary studies on the effectiveness and the metabolic consequences of paradox hormone substitute therapies and other complementary therapies
- The refusal of physicians, who are treating adults, to actively participate in the renewal of the methods of treatment and the disinterest in studies directed at a pediatric purpose. For example, this is clearly documented through the project “Clinical Evaluation Study: Medical and surgical results of treatment, psycho-sexual development and health-related issues affecting the quality of life of patients with problems in their sex/gender development”.

The aforementioned inappropriate behaviours with regard to medical interventions concerning intersexuality are provable and have also been proven publicly by jurisdiction.¹¹ The German Government has been informed provenly informed by affected people and knows about these problems. Hence, it irritates the people affected by this medical and juridical practice of treatment that the German Government pretends to know nothing about these practices.

Aside from a striking intervention in their personal rights, rights to self-determination, and health-related rights, the affected persons claim that these interventions are being carried out only by lifelong restriction of a huge number of other rights. Concerning other rights, especially in the drastic case of lifelong paradox hormone substitute therapy, insurance rights are limited so considerably that intersexual individuals cannot reach the full enjoyment of these rights.

4. Article 16 (*Marriage and Family*)

Article 16 lit. d CEDAW does not only include a basic statement about rights and duties of the parents, but also on the preeminence of the best interest of the child (also addressed in Article 3, CRC), as it says there state parties shall ensure: “*the same rights and responsibilities as parents, irrespective of their marital status, in matters relating to their children; in all cases the best interest of the child shall be paramount.*”

¹¹ Michel Reiter 722UR III302/00 v. 2001; 1 BVR 390/03 v.29.10.2003, Verfahren C.J. Clüsserath; 2 BVR 1833/95, a Transsexual with intersexual background.

4.1 Violation of the Preeminence of the Best Interest of the Child and the Protection of the Identity of the Child

The authors of this report are of the legal view, that after CEDAW Article 16.d, as well as also after Article 5.b, parents are indeed entitled to the right of child education. However, the best interest of the child is always to be taken into consideration with priority. The temporarily uncertainty of the parents about the sexual/physical inconclusiveness of their child must be accepted so that the child's rights can be protected. The authors of this report support the child in having the right to make an informed decision and having his/her identity protected (see Art. 8 (1) CRC). In the opinion of the authors, the uncertainty of parents cannot be placed above the child's health, particularly as the sex-changing medical interventions have irreversible and uncertain results.

According to the article 2 lit. C, CEDAW legal protection is to be guaranteed to every woman. This also counts for children, because following Article 24 (1), ICCPR every child has a legal entitlement to protection by family, society and state against discrimination based on sex/gender.

As far as decisions on medical treatments or surgeries are concerned, which may be postponed to a later point in time (which is the case for sex reassignment surgeries), the right of the intersexual child on informed decision free of discrimination must be also protected against the parents. In Germany this protection is refused to intersexual children. In the opinion of the authors, the State is obliged to protect children against all forms of violence – including also those that were not previously intentional (Art. 19 CRC). Also with regard to this human right there must not be any discrimination based on sex / gender. The application of castration, genital-plastics and medical change of physical developing potentials, during and after the phase of the physical development, are means of promoting "sexual disadvantages" with lifelong devastating effects for the persons concerned. The so-called *Bougieren*¹² is felt by the persons concerned as being a form of sexual abuse. This regularly leads to post surgical pains for years as well as to most dramatic forms of traumatization.

4.2 Illegal Concealment and Denial of Access to Medical Records

Through doctoral advice parents are asked to educate their child according to the "new" sex created by the sex reassignment surgery. In addition, parents are requested to keep the child away from all information about medical interventions and about his / her true condition. The medical grounds for this action lie in the sexual-social security which the child is supposed to develop in his / her newly reassigned gender. In addition, in medical science as well as in technical and teaching literature, it is assumed that intersexual persons have a tendency to be asocial, psychically unstable and often mentally retarded. The intersexual authors of this report regard these generalized statements as not compatible with their dignity as human beings (Article 1, UDHR). The silence towards women, with regard to their earlier intersexual state and the denial of access to their medical records are a violation of the rights on health education and the rights to equal access to health services (Art. 10 lit. h und 12 (1) CEDAW). According to art. 8 (2) CRC, the state is obliged, where the identity of a child has been violated, to give an appropriate support, so that the identity can be restored as soon as possible.

¹² "*Bougieren*" means the forcible widening of the artificially created vagina with sticks to increase the opening and diameter of the vagina for the purpose of making feasible a penetration at a later stage in life.

4.3 Equal Right to Marriage

Article 16 CEDAW guarantees the equal right to marriage. All people under the protection of this convention, must not be disadvantaged in exercising this right. Hence, this counts also towards such intersexual individuals whose gender was wrongly determined and (re-) assigned. Confusion concerning the law related to civil status issues, due to the individual, natural status of intersexual persons and their wrongful determination to one sex, must be solved through special legislation. Nevertheless, for the purposes of healing it is neither possible to apply the German law of same sex partnerships¹³ nor the trans-sexualization.¹⁴ The trans-sexualization of intersexual individuals forbids itself by the different medical-scientific etiology and genesis. The law of same sex partnerships is not acceptable, because it includes disadvantages e.g. in tax law. The wrong allocation of a sex and the domination through external sexual regulations is a violation of the "human right on reproductive self-determination" (Article. 16 (1) lit e, CEDAW).

5. Special Mechanisms

5.1 A Possibility of Reconciliation: Truth Commission to Raise Awareness on the Violation of Women's and Human Rights of Intersex People

The concealment of intersexuality during the Nazi Regime and, later following Prof. Dr. John Money's "Standard", have led to the disappearance of a whole population group from perception and from memory of the majority population as well as from the members of this minority themselves. For the protection of intersexual people it is the utmost priority that these violations become apparent by the general public. The knowledge of human rights violations on intersexual people and their suffering must be included into general education in order to prevent these violations from ever happening again.

Therefore, determined action is needed. The authors of this report find the instrument of a Truth Committee as especially appropriate. According to the model of the Canadian Truth Committee for the processing of the injuries to human rights in the indigenous re-education residential schools, a state driven committee of historians should be set up in close cooperation with intersexual people. A compensation for pain and suffering should be financed via tax means and contributions of the doctor's unions - including the possibility of the fund to claim to get the money back from the actual offenders.

Taking the South African Truth Commission as a model, in those cases where German penal laws have been violated, it must be clear that mitigation of punishment may be guaranteed, but not entire exemption from punishment. The precondition for mitigation of punishment is the entire disclosure of all patient's records towards the respective patients and the publication of all relevant facts towards the state driven committee of historians, as well as the support of restoration of the patients health. Countless physicians have been accomplices, whether in good hopes or in fear, by looking away and by remaining silent. Hence, mitigation of punishment seems to be acceptable if in turn public reconciliation is achieved.

¹³ This means the law on same sex partnerships. In Germany, the same sex partnership has not been granted the same status as marriage.

¹⁴ Trans-sexualization means the false labelling of intersexual people as transsexuals. This labelling is incorrect: Transsexual people make a deliberate choice on the adaption of their sexual phenotype to their gender identity, whereas a sex / gender is enforced on intersexual people.

6. Claims and Recommendations

6.1 The Claims of the Persons Concerned

1. Omit irreversible surgical and medication interventions, so as long as there are no life-threatening indications.
2. Cosmetic interventions only by explicit consent of the person concerned and to be documented under precise written clarification.
3. The treating doctors must voluntarily hand over an entire copy of the individual's medical file to the persons concerned.
4. The treating doctors have, in particular when organ removal is concerned, to clarify all present and future risks of the intervention to the patient.
5. The obligation is to be imposed on doctors to explain the drug therapies resulting from the intervention, concerning their effectiveness and their risks towards the patients, in writing.
6. Establishment of specified education and competence centres focusing on the treatment of intersexual people.
7. Specific vocational training of professionals on intersexuality in all medical disciplines.
8. Establishment of consultation teams for parents of intersexual children, consisting of doctors, psychologists and affected persons.
9. Establishment across the country of counselling and advice centers led by intersexual people.
10. Financial and structural support for intersexual self-help groups.
11. Participation of competent intersexual persons as observers on scientific studies on intersexuality.
12. Comprehensive evaluation of the effects and feasibility of paradox hormone substitute therapies, including an appropriate consideration of the age (if necessary, entry of the indication in the licensing of the respective drug).
13. Comprehensive evaluation of the effects for lifelong chromosomal and age adequate hormone substitute therapies (if necessary, entry of the indication in the licensing of the respective drug).
14. Inclusion of the term "intersexuality" into law.
15. Suspension of the period of limitation concerning (records of) the causal interventions, because it is documented in many cases that medical files have been concealed and victims would be target to further rights violations through fixed time limits.
16. Studies on the situation of intersexual people which serve the interest of promoting their well-being must be set up.
17. For new born children it must be possible to have gender neutral names. It must also be possible to only register their gender preliminarily.

6.2 Necessary Aid Programs for Persons Concerned

1. Establishment of an aid and compensation fund for affected persons (according to the model of the compensation of the victims of Canadian "residential schools").
2. Because intersexual persons are detained from professional advancement through traumatization and hormone treatment, they need a financial support to increase their pension contribution to the average level.
3. Specialized pension regulations for intersexual people and special regulation for victims of sex reassignment surgeries.
4. Establishment of a rehabilitation plan and a medical center for the restoration of physical health (as much as restoration is still possible)
5. Exemption from surcharges and any additional payments in health insurances.
6. Establishment of an index to verify the degree of disability through treatment, non-treatment or wrong treatment of the persons concerned.
7. Opening and economic enabling of special access for victims to participate in educational programmes and further vocational training for the purpose of balancing the suppression intersexual people have suffered from concerning their social and professional competences (Rehabilitation).

Addendum - Case Studies

Content

- 1. Case Study “Nella”**
- 2. Case Study “Christina T.”**
- 3. Links “Intersexuality”**
- 4. Prof. Dr. Milton Diamond / Assistant Prof. Hazel Glenn-Beh: “An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment on Infants with Ambiguous Genitalia?”**

Apendix (German Texts)

- 5. The “ Medical Standard“ according to Prof. Dr. John Money**
- 6. Intersexualität. Die alltägliche Folter in Deutschland. Ein Forschungsbericht, Humboldt University, Berlin**
- 7. Answer of the German Federal Government to a Parliamentarian question dealt with in writing**

1. Case Study “Nella”

Judged, Assigned and Administrated: A Life as a Medical File

No Chance from the Beginning

I was born in 1965 with a bad heart defect and ambiguous genitalia. Due to the heart defect, I was given an emergency baptism only a few days after my birth, as the doctor said I would not survive much longer. Consequently, they kept me in the hospital and would not allow my parents to take me home. My father had to work, but my mother traveled into the city as often as possible from our small town, though she was only allowed to see me through windowpane. When my parents were finally able to take me home after three months, I was affected by the aftermath of Hospitalism.¹⁵ I had been in such a bad condition ("just eyes and nostrils"), that my mother – as she always told me – was ashamed to take me for a walk through our village. The doctor justified all this with high risks of infections due to the heart defect. According to the medical file however, during these three months the various treatments took place due to my ambiguous genitals, whereas it was detected that I had abdominal testis and a male chromosome status. The report of my outer genitals:

“At first glance, the appearance is just like CAH¹⁶: The penis is 2cm long, the scrotum is not developed, but presently forming between two labia majora. No urogenital sinus; the perineum is situated at the mouth of the urethra. This is not stenotic, but is showing an unattractive cicatrice scar. “

In September 1965, being 2.5 months old, I was castrated despite to my life-threatening heart defect. This operation was incomprehensible for two reasons: first it was very risky because of my severe heart defect. Second it made no sense because of my presumed low life expectancy. It is also likely that the doctors had accepted that I could die when under anaesthesia, but the “experiment” was considered more important. The performed castration was carried out without the informed consent of my parents, and was subsequently to be kept secret. However the doctors then made a different decision (17. September 1965):

1. *“Against the former decision not to tell the parents about the genital situation, we decided to tell the parents the truth about the facts of this case, especially because it cannot be asured that controlled re-inspections over the next 20 years will take place. (...)*
2. *Their child is a girl and this gender is determined now and forever.*
3. *During the operation the following conditions were found: No uterus exists, the gonads are malformed and had to be removed. The vagina is short.*
4. *During puberty or at around 10-11 years old, it is necessary that the child must be strictly monitored so that hormone therapy will be introduced at the right time.*
5. *After puberty further corrective operations have to take place (meaning a vaginal prosthetic, details have naturally not yet been discussed with the parents).”*

Another passage states (and of course it is the common monologue of ovaries and not testicles):

¹⁵ Hospitalism or *anaclitic depression* was a pediatric diagnosis to describe infants who wasted away while in the hospital. The symptoms could include retarded physical development, and disruption of perceptual-motor skills and language. It is now understood that this wasting disease was mostly caused by a lack of social contact between the infant and its caregivers. (<http://en.wikipedia.org/wiki/Hospitalism>)

¹⁶ Congenital Adrenal Hyperplasia (CAH) refers to any of several [autosomal recessive](#) conditions... Most of these conditions involve greater or lesser production of [sex steroids](#) and can alter development of [primary](#) or [secondary sex characteristics](#) in affected infants... Only a small minority of people with CAH can be said to have an [intersex](#) condition... (http://en.wikipedia.org/wiki/Congenital_adrenal_hyperplasia)

“Discussion with the parents: Contrary to the earlier decision that was agreed upon, that the parents must indeed say that the child will be castrated and that there must be rigorous monitoring during puberty. The follow-up monitoring is not assured as the mother is Italian, and it might be possible that she will run off to Italy.”

Later the castration will be declared as a mistake:

“7. Further procedures: Directly after the cystoscopy¹⁷, I discussed the case with Prof. (...) again. In his view a male gender with Hypospadias¹⁸ is given. Although he was present at the earlier discussion and castration, retrospectively he believed that a mistake had already been carried out. The situation is now forcing us to continue this way and the small patient must be made a girl. Concerning the vaginal prosthetic he meant that this should be carried out as soon as possible and as long as the child is not aware what happens to him.”

Conclusion: I was barely older than 2.5 months and in spite of a life-threatening heart defect, being castrated without the acceptance of my parents. And, this castration was later defined as a mistake!

Lies and Frauds

The doctor did not tell my parents the truth about me but advised them how to educate me:

“The child is a girl and will stay one as the entire educational upbringing has been arranged. Only between parents and doctor (...) the question of gender should be discussed.”

My parents had not been told that I have male chromosomes and that my testicles were removed. Of course they had not been informed about the mistakes. Continually wrong information was given to my parents:

“The parents certainly asked whether the girl would be able to have children, and they were told, that this was doubtful.”

With absurd frauds they were fobbed off:

“Both parents are incidentally well oriented about the situation. They know that Daniela is a girl and that she will remain being a girl. They know that the malformed ovaries had to be taken out, cause otherwise the danger of virilization¹⁹ would have been given (...)” (3.2.1972)

First of all, I never had ovaries. Second of all, one cannot adopt male characteristics with ovaries! Permanently being told lies and these absurd statements I was 'tranquilized':

“21.8.1979 Daniela is concerned due to the absence of menstruation and whether this may cause problems. Explained that the uterus is too small for menstruation. It is not harmful if women do not experience menstruation.”

¹⁷ [Endoscopy](http://en.wikipedia.org/wiki/Endoscopy) of the [urinary bladder](http://en.wikipedia.org/wiki/urinary_bladder) via the [urethra](http://en.wikipedia.org/wiki/urethra) (<http://en.wikipedia.org/wiki/Cystoscopy>).

¹⁸ Hypospadias is a [birth defect](http://en.wikipedia.org/wiki/birth_defect) of the [urethra](http://en.wikipedia.org/wiki/urethra) in the [male](http://en.wikipedia.org/wiki/male) that involves an abnormally placed [urinary meatus](http://en.wikipedia.org/wiki/urinary_meatus) (opening). Instead of opening at the tip of the [glans](http://en.wikipedia.org/wiki/glans) of the [penis](http://en.wikipedia.org/wiki/penis), a hypospadiac urethra opens anywhere along a line (the *urethral groove*) running from the tip along the underside (ventral aspect) of the shaft to the junction of the penis and [scrotum](http://en.wikipedia.org/wiki/scrotum) or [perineum](http://en.wikipedia.org/wiki/perineum) (<http://en.wikipedia.org/wiki/Hypospadias>).

¹⁹ Virilization refers to the biological development of [sex differences](http://en.wikipedia.org/wiki/sex_differences), changes which make a [male](http://en.wikipedia.org/wiki/male) body different from a [female](http://en.wikipedia.org/wiki/female) body (<http://en.wikipedia.org/wiki/Virilization>).

Genital Correction and a Heart Operation

I would eventually get older than initially expected. At the age of seven the doctor decided to carry out the operation on my heart, whether the prognosis was good or not:

“The atrioventricular septal defect operation is still very difficult and shows a high rate of mortality i.e. from around 50% with the entire profile. In this case, survival in addition to the hypoplasia²⁰ of the left side and the probability of the mitral stenosis²¹, is what can still change the chances of operation to the worse. (...) The whole prognosis also considering the pseudohermaphroditism and the severe malformation doesn't look very good. Though from experience, no indication of continuity can be given. But we do not believe that the girl will reach adulthood.”

In 1972 I was in the hospital for the heart operation pre-examination. Because of an infection however, the preexamination was not able to be conducted. Being there the chance was used to correct my genital. The following abstract was documented from my patient file:

“Due to the reoccurring cardio logical Streptococci infections, the scheduled intracardiac catheter must be delayed. We used the opportunity to carry out the genital correction originally planned in 1965.

From the record of the operation on February 2nd, 1972:

“Important for the doctor on the weekend shift: In case the parents want to get information about the child, it is very important to know which information the parents already got by the “medical clinic”. This information is documented in ‘Discussions with the Parents’.

Post. Op.: “The child is showing the after-effects of a shock. Secondary haemorrhage. PPL Lsg will be infused. The child vomits. First signs of recovering of a heavy bronchitis can be noticed. Severe haematoma on both sides of the clitoris. Right sided black and blue discoloration. Development of a necrosis?”

14.2.1972: Both sides of the haematoma on the clitoris are fluctuating. Over night the child was bleeding again, deep quick?. The child still has a violent cough. Basal on the left side, in particular, dry sounds can be heard. No fever.”

Sister “Annemarie” was responsible for the surgical dressing and the “fixing of both hands over night”.

Nine days later or “how it went on”:

“Today (19.2.1972) Daniela will go back to the child doctor, hoping that in the course of next week, the heart catheterise could be performed. If the trauma of the operation heals without further complications, the surgery, which has to be done inguinal, can be carried out.”

Conclusion: I was operated on twice for ambiguous genitalia, in spite of my life-threatening heart defect! No more talking about the risks of dangerous infections! The doctors sited their power of definition over my life!

²⁰ Hypoplasia is underdevelopment or incomplete development of a tissue or organ (<http://en.wikipedia.org/wiki/Hypoplasia>).

²¹ Mitral stenosis is a [valvular heart disease](http://en.wikipedia.org/wiki/Mitral_stenosis) characterized by the narrowing of the orifice of the [mitral valve](http://en.wikipedia.org/wiki/Mitral_valve) of the [heart](http://en.wikipedia.org/wiki/Mitral_stenosis) (http://en.wikipedia.org/wiki/Mitral_stenosis).

Reprisals and Self-Protection

As I found the document of this operation in my medical file, I first thought that this could only be an error i.e. another persons file. I had completely erased the memory of the operations;²² I remembered absolutely nothing. Alongside this realization that I had passed such a massive surgery, I was shocked that I had suppressed my memories because it all had been so scary. I protected myself in constructing alternative memories basing on the saying of my mother “that it had only been a little piece of skin which had to be removed ambulantly”.

On July 20th, 1972 I had a heart operation. In the same year, the doctors saved my life and at the same time turned it up-side-down by destroying it irretrievably.

At the age of 18 I wished to have vaginal prosthetic and underwent a surgery, because they had told me that I would not be able to have a boyfriend remaining "this way". But I have sworn that it should be the last surgery and that I never want to see a doctor again. Today only in case of emergency I am going to a doctor, but I am completely avoiding seeing any gynecologist.

The Lost Years

Today I am 42 years old, still living (tenacious like a cat, my father always says) and so far I have had no specific health problems, compared to the experiences others had gone through. I am now starting to think about my chromosomes and the paradox hormone therapy including the possible damages caused thereby. The consequences of the wrongful treatment are beginning to show: For about two years I have increasingly joint pain (back, left hip, knee and foot) after an one hour walk with my dog (before long walks did not cause any problems). My legs often feel as heavy as lead and I feel dizzy nearly everyday. Increasingly having hot flashes and being fatigue. I also lost much weight. Two years ago early stages of osteoporosis had been diagnosed. Today I an certain to have osteoporosis. I know I have to see a doctor!

I was able to clear most of my psychological problems in a psychoanalysis during the last seven years. I will however still suffer throughout my life, living with the torture of this inhuman treatment. I am neither a man nor a woman, but above all, I am no longer a hermaphrodite. I will remain the patchwork created by doctors, bruised and scarred. If I want to keep living, I must discover myself anew.

Today I am thankful that I have found my inner peace throughout psychoanalysis over the past few years. I am able now to allow closeness and love into my life. Nevertheless, it is still difficult. I feel like someone who has woken up from a 40-year coma, realizing how time has past and how little life has had for me. My original body is irretrievably lost. My identity and my dignity were taken away from me. I am starting now to get it back once and for all!

²² Dissociation is a state of acute mental [decompensation](#) in which certain [thoughts](#), [emotions](#), [sensations](#), and/or [memories](#) are [compartmentalized](#) because they are too overwhelming for the conscious mind to integrate. This subconscious strategy for managing powerful negative emotions is sometimes referred to as "[splitting](#)", as these thoughts, emotions, sensations, and/or memories are "split off" from the [integrated ego](#).

2. Case Study “Christina T.”

Masculine Gender Allotment and Forced Castration by Congenital Adrenal Hyperplasia (CAH) with 21-Hydroxylase-Defect and XX-Chromosomal Sex

I arrived in the world as the second youngest of seven children of an architect and a housewife. The midwife at my birth was at first unsure, whether I was a boy or a girl, until she classified me as a boy because of the findings with regard to the genitals. So I have been announced as a boy at the birth registry office, although there have been notesticles, thus been registered as a male, and been raised as a boy. Actually, what the midwife had regarded to be a male genital, was an unusually elongated clitoris, at whose underside was the discharge of the malformed urethra, which has been de-scribed as a hypospadias.²³ This designates for male children and adolescents the situation of having the opening of the urethra not at the tip of the penis, but anywhere before. Actually, I had and have a so-called adrenal congenital hyperplasia (CAH) with *21-Hydroxylase-Defekt*, with XX chromosomes and, formerly, unequivocally healthy and complete gonads.

I am thus genetically and biologically completely unequivocally a woman respectively of female sex, who, however, suffers from deficiency of the enzyme *21-Hydroxylase*, which results in a deficiency of the essential hormones *Cortisol* and *Aldosteron*. This, in turn, results in the exceeding production of androgens, which effects the virilization of the clitoris.

After a appendix operation, I have been, for the first time, urologically investigated, and have been operated at the Cleves Urology Clinic because of a supposed undescended testicle. After the operation, I have been, as a 17 years old person, informed about my genital findings by the family doctor of my parents as follows:

“You are not a man. You are also not a woman. You are a hermaphrodite. There are cases like yours only one of a million births every year around the world. This cannot be healed. No one can help it. You must live with this.” He began to laugh scornfully, “In former times, people like you have been exposed at the fun-fair, to make money of them. You can try that. There, you are a sensation, an oddity!”

This inhumane and extremely brutal discussion of the findings plunged me into a deep depression and created feelings of suicide in me. With help of my older sister, who was living at Co-logne at that time, I then got in November 1976 into the clinic Cologne-Merheim, where I stayed from November, the 29th to December, the 20th of 1976 and from July, the 25th to August, the 23rd of 1977. Already in the urology department and the Cleves hospital, there were no testicles or spermatic cords detectable, neither externally nor from the right inguinal canal to the bladder, but a ovary-like shaped object with Fallopian tubes, also the investigation in the pathology, at the instigation of the Cologne-Merheimer, detected, that in the tissue samples, there has been no tissue of testicles, but of Fallopian tubes, epididymis, and ovaries. The women's clinic of the university of Cologne has carried out a chromosomal analysis, whose result, at December, the 12th of 1976, detected a normal female constitution (46 XX).

Although the internal specialist had registered for a “laparatomy”, for an urological investigation, a “testovarectomy because of pseudohermaphroditism” was, according to anaesthesia report, carried out on August, the 12th of 1977, by the senior physician of the surgery, who, at

²³ <http://en.wikipedia.org/wiki/Hypospadias>

the same time, was the head of the urological department of Cologne-Merheimer hospital, about whose course has been noted:

“Laparotomy on Friday, August 12th, of 1977... normal, female anatomy with a prepuberal uterus, normally sized ovaries, and the vagina ends closed... removal of the all the intraabdo-minal sexual organs... So there is no hermaphroditism. The cause for the virilization is either CAH or a tumor of the cortex of the suprarenal gland.”

The pathological department reported to the above-mentioned surgeon on the findings of the removed organs:

“6 x 3 x 2 cm big uterus with a smooth portio, a narrow endometrium, and a myometrium. The corpus part of the organ is hypoplastic. On both sides attached on both sides each an ovary in the size of a plum and with ... cysts.”

The senior physician of the surgery and, at the same time, head of the urology, has removed my normal female sex organs, when I was 18 years old and thus major with regard to law, without any reason, without information, without my explicit signature or consent, and thus without any authorization. I have never been informed about the outcome of the operation, but have been left with the illusion, that degenerated gonadal tissue, respectively a kind of tumor, had been removed.

With complete and correct education and with reasonable therapeutic treatment of the congenital adrenal hyperplasia, I, who also would have needed psychological support (This psychological support has been been, intentionally, withheld from me by the senior physician of the psychosomatic department of the University Clinic in Cologne-Lindenthal, psychosomatic exploration, August 3rd, 1977.), I would have been able to experience a fulfilled female sexuality, the life of a woman and mother. All this destroyed to me by the genital mutilation respectively by the provenly enforced castration.

The omitted education, the missing consent, the secrecy, the medical policy of ignorance (which is unlawful against any patient right), and the miseducation, also come to light by a letter of the senior physician of the hospital Cologne-Merheim, who was treating me at that time, to the district recruiting office of Krefeld. At the date from June 5th, of 1979, it is, inter alia, noted:

“The patient is genotypically female, and the normal female inner organs have been surgically removed. I ask for the absolute consideration of the fact, that Mr. V. has not yet been completely informed about the degree of the sickness. The above mentioned diagnoses may not in any case be shared with him.”

By this writing, also the deliberate “non-information” by the doctors of that time comes to light, with regard to the at that time already existing possibility of hormonal as well as surgical assignment to the female gender. This has had the result, that, in the following, I have undergone totally unnecessary urethra constructions, respectively that I have got a surgical-urological and hormonal (female to male) sex reassignment by the physicians, who had treated me that time. The essential and life-long hormonal substitutional therapy (with cortison and testosterone) has started no earlier than two years after the diagnosis of my CAH and of my unlawful castration. Therefore, the deliberate denial of my vital medicine for two years by the doctors, who were treating me at that time, provenly constitutes an attempt of murder. So, for the physicians of that time, I have been a medical-human experiment with the question: For how long does a body with CAH manage to survive without cortison?

The urethra constructions, the foisted upon female-to-male sex reassignment, and the wrongful removal of my healthy female organs / my forced castration had the following consequences:

- I suffer from nearly chronic urinary tract infections, which are resistant to antibiotics, with constant painful problems emptying my bladder, and with a residual amount of urine in the bladder.
- So-called eunuchoid fat developed at my female body.
- My naturally female body has been virilized by the loss of the body's hormone production and by the use of testosterone.
- The originally female voice has been virilized.
- By the time, there developed a distinctly strong male receding hairline, a strong loss of hair, and especially the growth of a beard.
- My skin developed a typically male production of acne.

Starting as nearly healthy young woman, who had, until the age of majority, erroneously been raised as a boy (The age of majority had been reduced at the 01.01.1975 from 21 to 18, Federal Law Gazette I 74, 1713), I have been reconstructed into a significantly "defective" man, by means of a provenly unlawful surgical intervention, an enforced castration, which violates every patient's right and the Basic Law of this country, respectively by the unlawful medical policy of the deliberate secrecy and false information, and by a proven denial of assistance.

From 1977 to 2006 and for longer, I, as a woman, have been forced to live a false life, namely the life of a man. This way, a fulfilled partnership, fulfilled sexuality, my right to motherhood, and the possibility to build up a family, have been taken away from me and been destroyed. No sooner than by my inspection into my hospital documents in November 2006, which had required urgently for the future of my hormonal and surgical treatment, the whole truth has become obvious, respectively the severe and dangerous physical injury (§224 and §226 Criminal Code), the permanent violation and infringement against valid patient's law, the violation of the law with regard to castration, and the massive infringements against the Basic Law of this country and against the human rights, by the doctors, who were treating me that time.

From now on, at age 48, I am beginning to be the woman, I have always been by nature. This cannot bring me back the lost youth and the life of a woman at the age of 20 or 30. It can also never be compensated, what I have suffered at the hospital at the age of 17 and 18:

- the measurement of pelvis and skull capacity as well as arm and leg length without any information about the reasons,
- the public presentation for medical students with the demand to entirely disrobe,
- enforced photographs of my whole naked body,
- close pictures of my intersexual genital, of distorting operation scars on my entire underbelly and intimate areas,
- enforced exploration by the senior physician of psychosomatics at that time of the university clinic Cologne-Lindenthal, to investigate my sexual orientation and behaviour, as well as his unlawful forwarding of my most intimate details to third persons (infringement against the law on privacy) up to today.
- enforced testing of my intelligence by the above-mentioned psychosomatical physician to investigate the influence of my illness and of the effect of the androgens to my brain
- indignities and still today psychological traumata because of most deeply hurting, inhumane and totally stupid and characterless comments by of the doctors of that time

- loss of my bodily integrity by purposeful violation of my basic rights and by the enforced castration.
- loss of my psychological integrity by means of the above named measures, resulting in the object-like experience of my body, which I experience as separated from my self:

The permanent violation of my most intimate private sphere and the permanent sorrow, that my intimate and physical data including photographs possibly can be found at diverse publications and internet fora, have deprived me of any naturalness in the contact with other people. I am suffering until the rest of my life from the resulting psychological isolation and from the inability to make deep social contacts.

It is very hard to me, to reach an appropriate compensation for all the pain inflicted to me, for all the crimes against me, which have been committed by the institution medicine, because full compensation is impossible, e. g., my healthy sexual organs (ovaries and uterus) cannot be reimplanted. To calculate the compensation, one will have to compare with cases of severe changes of personality because of damages to the brain.

Appendix 3: **Links - Intersexuality**

Associations and Self-Help-Groups:

www.intersexuelle-menschen.net
www.xy-frauen.de
www.swyer.de
www.ags-initiative.de
www.bodieslikeours.org
www.intersex.ch
www.101intersex.de
<http://hometown.aol.de/Querkreuzer/000inhaltsverzeichnis.htm>
<http://web.archive.org/web/20010710070555/http://home.t-online.de/home/aggpg/chron.htm>
www.hermaphroditos.de
<http://genderfreenation.de>
<http://blog.zwischengeschlecht.info>
http://www.intersexualite.org/Deutsch-Index.html#anchor_640

Christiane Völling

<http://blog.zwischengeschlecht.info/post/2008/02/07/Sieg-fur-Christiane-Volling://www.sueddeutsche.de/panorama/artikel/930/156517/>
<http://www.faz.net/s/Rub8E1390D3396F422B869A49268EE3F15C/Doc~EDF4E310F3A40486F8D5016D4CDBCA912~ATpl~Ecommon~Scontent.html>
<http://www.3sat.de/3sat.php?http://www.3sat.de/kulturzeit/themen/123354/index.html>
<http://www.ruhrnachrichten.de/nachrichten/nrw/art1544,137587>
http://www.focus.de/panorama/welt/prozess_aid_229141.html
<http://oii-usa.blogspot.com/2008/02/press-release-congratulations-to.html>
http://www.rbb-online.de/polylux/druckversion/index.jsp?key=rbb_beitrag_mini_7179468
<http://www.spiegel.de/spiegel/0,1518,517983-3,00.html>
<http://www.tagesanzeiger.ch/dyn/wissen/medizin/838827.html>

Bundestag

<http://209.85.129.104/search?q=cache:nU48w9BTA6IJ:dip.bundestag.de/btd/14/056/1405627.pdf>

Research and Sciences

www.forschergruppe-intersex.de
www.netzwerk-is.de
www.nichtdnet.psych.psu.de
www.uke.uni-hamburg.de
www.forschergruppe-is.uk-sh.de

Law:

http://www.zerp.uni-bremen.de/deutsch/pdf/plett_intersexualitaet.pdf
http://www.justiz.nrw.de/nrwe/lgs/koeln/lg_koeln/j2008/25_O_179_07grundurteil20080206.html
http://www.netzwerk-is.uk-sh.de/is/fileadmin/documents/publikationen/Kipra505_UdeKoeller.pdf
<http://de.indymedia.org/2007/11/199653.shtml>
<http://www.lobby-fuer-menschenrechte.de/Intersexualitaet02.php#top4>
<http://www.lobby-fuer-menschenrechte.de/Intersexualitaet02.php#top21>

<http://edoc.hu-berlin.de/miscellanies/menschenrechte-27763/5/PDF/5.pdf>

Reports, Films, Texts:

http://images.zeit.de/text/2000/40/200040_intersexneu.xml

<http://www.die-katze-ist-kein-vogel.de/intersex/nur%20INTERSEX.pdf>

<http://www.das-verordnete-geschlecht.de/portrait.htm>

Truth Commissions

South Africa:

www.doj.gov.za/trc/legal/act9534.htm

www.doj.gov.za/trc/media/1999/9903/s990304k.htm

www.fxj.org.za/archive/Linked/update/9510/html5.htm

www.csvr.org.za/papers/papr2r2.htm

www.csvr.org.za/papers/papr2r1.htm

www.info.gov.za/gazette/bills/2003/b34-03.pdf

www.info.gov.za/gazette/bills/2003/b34b-03.pdf

www.lrc.org.za/Focus_Areas/TRC.asp

Wikipedia-Enzyklopedia:

http://en.wikipedia.org/wiki/Truth_commission

Canada:

www.irsr-rqpi.gc.ca/english/truth_reconciliation_commission.html

www.hiddenfromhistory.org

Liberia:

www.ictj.org/static/Africa/Liberia/liberiatract.eng.pdf

East-Timor:

http://de.wikipedia.org/wiki/Wahrheits-_und_Freundschaftskommission_%28Osttimor%29

Sierra Leone:

www.sierra-leone.org/trcbook-TRCAct.html

Peru:

http://de.wikipedia.org/wiki/Kommission_f%C3%BCr_Wahrheit_und_Vers%C3%B6hnung_%28Peru%29

und www.cverdad.org.pe

Fiji:

http://en.wikipedia.org/wiki/Reconciliation_and_Unity_Commission_%28Fiji%29

Argentina:

http://en.wikipedia.org/wiki/Comisi%C3%B3n_Nacional_sobre_la_Desaparici%C3%B3n

http://www.nuncamas.org/english/library/nevagain/nevagain_001.htm

Marocco:

http://en.wikipedia.org/wiki/Equity_and_Reconciliation_Commission_%28Morocco%29

<http://www.ier.ma/>

Guatemala:

http://en.wikipedia.org/wiki/Historical_Clarification_Commission

Chile:

http://en.wikipedia.org/wiki/Rettig_Report

Appendix 4

An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment on Infants with Ambiguous Genitalia?²⁴

By Hazel Glenn Beh²⁵ and Milton Diamond²⁶

Table of Content

I. Introduction

II. The Remarkable Case of Joan/John

III. The Development of a Surgical Standard of Care

A. Standards of Care Within the Medical Community

B. The Surgical Standard in Treatment of Ambiguous Genitalia

C. Standard Care and Malpractice Claims

IV. Parental Consent to Genital Surgery and Sex: Reassignment on Behalf of Children

A. The Doctrine of Informed Consent

B. Consent and Parental Decision Making on Behalf of Infants

C. The Problems of Informed Consent and Infant Genital Surgery

V. Learning from the Past: What Should the Future Hold?

VI. Concluding Thoughts

Endnotes

I. Introduction:

This article discusses the development of a surgical approach to treating intersex[1] infants and others with genital anomalies that began in the late 1950s and 1960s and became standard in the 1970s. Although professional literature has recently questioned the surgical approach to the treatment of infants, controversy surrounding treatment persists and the medical community has divided. How surgical treatment including sex reassignment surgery for intersex infants became a routine recommendation of practitioners and how parents were persuaded to consent to such radical surgeries on their infants provides a cautionary tale that is relevant both for medicine and law.

²⁴ This is a prepublication version prepared for the Internet. Publication occurred in the Michigan Journal of Gender & Law, Volume 7 (1): 1-63, 2000. This version may be different than the published version. www.hawaii.edu/PCSS/online_artcls/intersex/intersex00_00.html

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Over the past four decades, early surgical intervention for infants who are born with ambiguous genitalia[2] or who suffer traumatic genital injury often has been recommended as standard procedure.[3] Surgical advances in this century have made it possible for physicians to choose a gender[4] for the child and then to sculpt gender appropriate genitalia to an approximation of normal-looking appearance. For the most part, when choosing surgical treatment, physicians have opted for a female form because it is easier to fashion female genitalia than male.[5] Relying on a nurture-based theory of gender identity, physicians advised parents to surgically alter their intersexed infant and to raise the child in a manner consistent with its surgically altered genitalia without regard to the gender identity that might have otherwise naturally developed.[6] The same advice has been offered for any male infant whose penis was considered significantly small or had been severely mutilated by trauma. Clinicians have assured parents that the surgical potential for normal-looking genitalia should dictate the gender of rearing and that any innate gender propensity of the child can be changed by careful upbringing.

Medical literature since the 1970s to the present, despite a paucity of confirming evidence, promoted this treatment based largely on a body of published reports initially extrapolated from studies of intersexed [7] individuals and then the incredible case of a single infant that was widely reported in the professional medical, psychiatric and popular literature. In 1997, the medical community was reacquainted with the patient who had been long lost to follow-up.[8] Only then did the medical community finally discover that the outcome of this single case was not as first reported and the bases on which this treatment rests began to crumble.

Part II of this article discusses the remarkable case of Joan/John (J/J), a male infant whose penis was destroyed by a surgical accident and who was then intentionally castrated and surgically transformed into a female-looking infant. [9] Touted as a success, this case report became the foundation of standard care for treatment of certain intersex conditions, micropenis, and accidental penile amputation in infancy. Unfortunately, the outcome of the case was never fully reported until 1997.[10] Had the true facts been revealed earlier, or its premises been subjected to more rigorous scientific inquiry, the medical standard that developed probably would have been different.

Part III of this article discusses generally how medical standards of care develop and how a poorly grounded standard of care became entrenched through anecdotal reporting and without scientific validation. This part concludes by discussing and ultimately questioning tort law's self-imposed impotence in cases where a negligent standard of care develops because treatment has not been subjected to scientific inquiry. While under ordinary negligence principles, juries can find liability based on a profession's collective negligence in establishing their customary practices, many jurisdictions accord more deference to medical standards. In jurisdictions holding physicians to a standard of care based on the medical standards in the community rather than on ordinary principles of negligence, claims based on the assertion that medical practice collectively has deviated from common sense and the rigors of science will not succeed. Ultimately, this section argues with respect to standard care, that this legal standard promotes professional inertia, and when treatment standards are not validated by scientific studies, a deferential tort standard is not appropriate.

Part IV explores the role of the informed consent doctrine, particularly with regard to parental decision-making responsibilities for cases of ambiguous or traumatized genitalia. This section suggests that the aura of confidence the medical community projected concerning treatment, the practice of providing limited and simplistic information based upon a desire on the part of practitioners to shield and protect parents, and the sense of urgency physicians communicated to parents compromised the ability of parents to give their proper informed consent. Even more fundamentally, decision makers failed to consider the child's future potential for self-

determination in the decisional calculation. Compounding these already formidable informed consent obstacles, clinicians also held the belief that children would only accept the gender of assignment if they were raised in the selected gender without equivocation, and so enlisted parents as accomplices to medical secrecy.

Part V offers the recommendations for change endorsed by critics of early surgery, including both medical ethicists and the Intersex Society of North America (ISNA). These recommendations give guidance to physicians and parents who must make very difficult medical decisions on behalf of their child which has lifelong implications on his or her sexual and gender identity and erotic and reproductive potentials.

II. The Remarkable Case of Joan/John:

The contemporary medical model for dealing with cases of ambiguous or traumatized genitalia, started some four decades ago, but became firmly established when the case of John/Joan,[11] was reported in the pediatric literature.[12]

In the early 1970s, John Money, a psychologist at The Johns Hopkins' Hospital, reported the case of an identical twin who lost his penis at the age of 8 months through a surgical mishap during phimosis repair.[13] Along with psychologist Anka Ehrhardt, Money reported that following counseling, the parents consented to sex-reassignment surgery (castration, removal of the scrotum and initial fashioning of a vulva) and thereafter raising their once-son, John, as their new-daughter, Joan.[14] This case is now known in the psychological and medical literature as the John/Joan case.[15]

The parents were counseled to raise the child as a girl and to provide the child only limited information:

They were broadly informed about the future medical program for their child and how to integrate it with her sex education as she grows older. They were guided in how to give the child information about herself to the extent that the need arises in the future; and they were helped with what to explain to friends and relatives, including their other child. Eventually, they would inform their daughter that she would become a mother by adoption, one day, when she married and wanted to have a family.[16]

The parents were further instructed to keep J/J's original sex a guarded secret. In fact, the parents later reported that in order to foster the secrecy they were advised at the time to move from their present locale to settle in a distant city.[17]

Since the children's family did not live close to The Johns Hopkins Hospital where Money had his office, the day-to-day care of the twins was left in the hands of a local psychiatric team following Money's direction. Once a year the twins were brought to The Johns Hopkins for evaluation and insuring adherence to the treatment plan.[18] As subsequently reported by Money, Joan was satisfactorily developing as a girl in marked distinction to the other twin who was now developing as a normal boy.[19]

During the child's preadolescent years, Money reported that the parents were successfully raising the now-female child as a girl who appeared typical enough although with some "tomboyish traits." [20] Money did not report on J/J's refusal to cooperate in his counseling [21] and was apparently untroubled by some conduct that, in hindsight, would prove prescient, such as her persistence in standing to urinate despite her mother "teaching her how little girls go the bathroom." [22]

Besides tomboyishness and standing to urinate, other warning signs developed as the child matured, and these did not appear contemporaneously in the medical literature. Starting from the age of twelve, Joan was given estrogens to stimulate breast growth, widening of hips and other features of typical female pubertal development. These changes were not welcome and Joan was openly showing signs of rejecting her female assignment.[23] The local psychiatrists attending to the child indicated their belief that Joan was a definite tomboy and expressed doubt she would develop into an acceptable and content female.[24] Subsequently, although Money had followed J/J until this point and after, these findings of the child were not reported upon and Joan was seemingly “lost to follow-up.”[25] Actually, due to the discord Joan felt at the counseling she was receiving in Baltimore, at the age of nine she began to object at returning. Parental “bribes” were used to induce her to return for periodic check-ups. In one dramatic gesture of displeasure and defiance at her treatment, at age 13, she ran away from the hospital and was found hiding on the roof of a nearby building.[26] Joan thereafter refused to return to The Johns Hopkins.[27]

Although the case had been widely reported and cited in the medical literature,[28] the rejection of the assigned gender that the child exhibited did not appear in the literature[29] when it might have had an impact on the developing standard of care.[30] Instead the significance of the early reports of J/J’s supposed successful sex change confirmed the apparent efficacy of this treatment as a “standard of care” for certain infants and contributed to its wide acceptance.[31] Skepticism regarding its theoretical scientific base[32] prompted one critic’s prolonged search to find the “adult” J/J to see how she had actually developed and matured.[33] In 1994 both J/J and Dr. H. Keith Sigmundson, the psychiatrist in charge of J/J’s “local” care, were located and the child’s life subsequently reintroduced to the professional literature in 1997.[34]

Suffice to say, the outcome was not as had been reported or predicted. At the time the twin was located again he was a married man, the father of three adopted children. The twin had, of his own initiative, at the age of fourteen, given up life as a girl and vowed to thereafter live as a male, John.[35]

Family members recollected that J/J, while yet quite young, showed extreme male-like behavior and rejection of femaleness. Joan refused “girl” toys, had little interest in girl activities and refused to wear dresses. She preferred to “play army” and often stole her brother’s trucks and other toys to play with. In the prepubescent pre-teen years, Joan “thought I was a freak or something” and eventually “Figured I was a guy” but I “didn’t want to wind up opening a can of worms.”[36] She was constantly teased at school because of her girl clothes and “boy looks and contemplated suicide.”[37] “At the age of 14 years, she was caught standing to urinate in the girls’ bathroom so often that the other girls refused to allow her entrance.... Joan would also sometimes go to the boy’s lavatory to urinate.”[38] Throughout all of these years, despite all of the medical and psychiatric contact Joan endured, and despite expressing “strong fears that something [had] been done to her genital organs,” no one told her the nature of her condition.[39] Indeed, they were advised not to.[40]

After years of “fruitlessly trying to implement Dr. Money’s plan,” gradually the local psychiatric team had a change of heart. They had noticed Joan’s preference for boy’s activities and refusal to accept female status, including her contemplation of suicide, so they had already discussed among themselves the possibility of accepting Joan’s change back to male. They knew doing so would be against the accepted standard of care within the medical community.[41]

Joan’s turning point occurred at the age of 14, when she, on her own initiative, began living as a boy, John. John recalls how soon thereafter he finally learned the truth, “In a tearful episode

following John's prodding, his father told him of the history of what had transpired as an infant and why. John recalls: 'All of a sudden everything clicked. For the first time things made sense and I understood who and what I was.'"[42]

Ultimately, John, underwent a mastectomy to remove the estrogen-induced breast growth and requested phalloplasty to construct a penis. The orchiectomy (removal of the testicles) in infancy necessitated life-long male hormone replacement.[43] Following the transition, John's life dramatically changed.

After the surgical procedures [female to male sex re-assignment surgery], John adjusted well. As a boy he was relatively well accepted and popular with boys and girls. At 16 years, to attract girls, John obtained a windowless van with a bed and bar. When occasions for sexual encounters arose, however, he was reluctant to move erotically. When he told 1 girlfriend why he was hesitant, that he was insecure about his penis, she gossiped at school and this hurt John very much. Nevertheless, his peers quickly rallied around him and he was accepted and the girl rejected.[44]

John later married a woman and adopted her three children. He has bonded with them as a father.[45] Coitus is occasional with his wife. They mostly pleasure each other with a great deal of physical affection and mutual masturbation. John can have coital orgasm with ejaculation."[46]

Notwithstanding John's present level of social acceptance and success as a male, he is bitter and angry over his treatment and his lost childhood. These dramatic and significant events in John's adolescent and adult life, were not entered into the professional literature and thus did not counter the positive reports on this case nor impact the standard of care as it had developed since the 1960s, until the Diamond and Sigmundson publication in 1997.[47]

III. The Development of a Surgical Standard of Care

The following sections explore, using the situations attendant to the treatment of genital trauma or ambiguities as a model, how standard medical practice sometimes develops from case reports, word-of-mouth and the gradual clinical acceptance of innovative therapy without true scientific inquiry into its effectiveness. The article then describes how the surgical standard for treatment of these cases moved from innovation to standard practice largely as a result of a single case report. Although the long-term results of J/Js surgery would not be known for many years, surgery became accepted treatment as the case was recounted in the literature. The article next explores how medical standards of practice are judged by the law and questions the premises surrounding traditional judicial deference to medical standards of care.

A. Standards of Care Within the Medical Community

Medical standards of care are always evolving, they are often neither static nor clearly delineated.[48] A product of medical science's evolutionary character is that not all patients receive standard care. For example, some medical treatment can involve research and experimentation. Medical experimentation typically means that physicians treat patients according to a protocol designed to test an hypothesis and contribute to the body of medical knowledge.[49] Medical practice, on the other hand, involves treatment by accepted therapies, typically considered "interventions that are designed solely to enhance the well-being of an individual patient or client and that have a reasonable expectation of success." [50]

Innovative therapy is neither experimental nor standard practice; it involves treatment that is “‘designed solely to enhance the well-being of an individual patient or client’ but has not been tested sufficiently to meet the standard of having ‘a reasonable expectation of success.’”[51] Because innovative therapies are not sufficiently tested, “the potential benefits and risks of innovative therapies are less well known or predictable.”[52] Thus, innovative therapies, while formulated with the best interests of the patient in mind, nevertheless expose patients to “a greater likelihood that the balance of benefits and risks may be unfavorable due either to the therapies being ineffective or entailing greater, possibly unknown risks.”[53] In order to minimize the number of patients exposed to the attendant unknown risks of innovative therapy, “[r]adically new procedures ... should ... be made the object of formal research at an early stage in order to determine whether they are safe and effective.”[54]

Unfortunately, scientific assessments of innovative surgical procedures is not the norm within the practice of medicine.[55] “Most innovations have become accepted as “standard procedures” without ever having been subjected to the rigorous testing for efficacy of a [randomized controlled trial].”[56] “[I]f rigorous assessment [of medical innovations] occurs, it takes place quite late in the “career” of an innovation, after it has been reported anecdotally, adopted by professionals, medical organizations, public advocates, and third party payers, and accepted as ‘standard practice.’”[57] Commentators note that physicians often display a premature eagerness to adopt innovative therapy before adequate studies are conducted.[58] In actuality, fewer than ten to twenty percent of medical practices have been subjected to randomized clinical trials.[59] Instead, medical standards often develop in an ad hoc fashion, as physicians try new techniques and share early reports of their experiences among their colleagues.[60] Thereafter, clinicians often become entrenched in following particularly therapies and resistant to adopting superior therapies.[61] They are also reluctant to publish reports of unsuccessful procedures or treatments.[62] Lastly, in regard to treatment outcome, the goals are still not universally accepted. There are those who think an intersexed child’s acceptance of the gender of rearing is the goal while others see the child’s comfort as an adult as the goal.[63]

B. The Surgical Standard in Treatment of Ambiguous Genitalia

Since innovative therapy often becomes standard therapy through informal acceptance and use,[64] it should come as no surprise that the practice of recommending early surgical intervention in cases of genital ambiguity became standard prior to rigorous study of treatment outcomes.[65] The treatment, first promulgated by Money, was based on a nurture theory of development derived from his analysis of clinical cases of intersexed individuals rather than from experimental investigation. It essentially began when his reports, based on studies of hermaphrodites, claimed it made no difference if such intersexed children were raised as either boys or girls; they would equally adapt to either gender assignment.[66] The only caveats that Money expressed regarding sex reassignment was that it be done as early as possible, preferably before the 18th to 24th months of life; that no ambiguity be allowed in the gender of the child’s upbringing; and that it is best for the infants’ genitalia to be reconstructed to match the gender of assignment.[67] Money’s theory essentially held that if a child is raised as a boy it will develop as such and if raised as a girl that is the gender that will obtain. And since it would be easier to surgically repair the genitals with female-like anatomy, that would be the preferred method of management.[68]

The initial reports of the J/J case,[69] particularly as reported in the 1972 book *Man & Woman, Boy & Girl*,[70] and its purported success spread rapidly and was frequently recounted in the professional literature.[71] It was thus that the theory that an infant’s sex could be successfully reassigned had a profound influence on the standard of care for infants

born with ambiguous genitalia, a micropenis or those losing their penis by trauma or accidental amputation.[72]

Cases of infants born with ambiguous genitalia are not common but neither are they rare.[73] Of the 3 to 4 million children born annually in the United States, approximately 1 in 2000 are born with ambiguous external genitalia (thus approximately 1,500 to 2,000 such children yearly) and an estimated 100-200 pediatric surgical sex reassignments are performed in the United States annually.[74]

As the J/J case exploded into the literature, the prevailing treatment view became that when amputation or birth defects result in ambiguous genitalia, or genitalia are seemingly incompatible with male sexual functioning (standing to urinate as a child and adolescent and inserting a penis into a vagina as an adult), such males were better off to undergo sex reassignment to assure satisfactory adult sexual function as a female.[75] Incorporating the theory that individuals are psychosexually neutral and would accept their gender of rearing, this proposal offered a relatively simple solution to what was seen as a difficult situation.[76] This view came to dominate pediatric literature.[77] Since then medical wisdom in these cases has remained largely based on hypothetical “surgical potentials” rather than on data from studies or even the long-term outcome of these surgeries.[78]

Surgical intervention became the standard of practice to the extent that, as recently as 1996, the American Academy of Pediatrics published these guidelines:

Research on children with ambiguous genitalia has shown that sexual identity is a function of social learning through differential responses of multiple individuals in the environment. For example, children whose genetic sexes are not clearly reflected in external genitalia (i.e., hermaphroditism) can be raised successfully as members of either sex if the process begins before the age of 2 years. Therefore, a person’s sexual body image is largely a function of socialization.[79]

Remarkably, the only references to support this proposition were to the decade old or older works of John Money; no other corroborating work was cited.[80]

Not all neonatal surgical interventions for infants born with ambiguous genitalia involve sex reassignment.[81] The surgical alteration of any female born with a clitoris larger than one centimeter is also recommended.[82] Keeping with a component of the psychosexual neutrality-at-birth theory that says acceptance of the gender of rearing is contingent on having gender congruent genitalia, an enlarged clitoris was seen as needing reduction or removal to prevent psychosexual ambiguity and to promote parental bonding and affection.[83] The efficacy of even these more modest surgical interventions to normalize genitalia have also lacked validation.[84]

Unfortunately, like the practice of female genital alteration (“mutilation”) for cultural reasons,[85] these surgical interventions can reduce or destroy the girl’s potential for sexual satisfaction in adulthood and limit later surgical alternatives should the male gender manifest itself at adolescence.[86] Interestingly, the effect of the 1996 Criminalization of Female Genital Mutilation Act,[87] on medical treatment on infant females with enlarged clitorises is unknown. While congress intended the act to curb the cultural practices of “members of certain cultural and religious groups within the United States,”[88] it broadly bars circumcision, excision and infibulation of “the whole or any part of the labia majora or labia minora or clitoris of another person who has not attained the age of 18 years”[89] unless it is “necessary to the health of the person on whom it is performed.”[90] It remains to be seen whether a court might view surgical treatment to achieve normally appearing female genitalia as necessary to the health of infants.[91]

Although surgical intervention became “standard care” for intersex infants, rather than considering it a proven treatment protocol, it would have been more appropriate to characterize it as “innovative” therapy all along, because the treatments have not been adequately grounded in long-term studies.[92] To this day, the recommended surgical management practices for ambiguous genitalia that have been promoted by the American Academy of Pediatrics[93], remain invalidated by long-term study.[94] The appropriateness of early surgical intervention was never well supported by scientific investigation, and, in fact, some of the recent research refutes its efficacy.[95] While J/J’s case may have initially suggested a positive outcome was possible, the true test of the treatment’s success could not be known until the patient reached adulthood.[96]

Since the latest reports on J/J’s case were revealed in 1997, the medical community has itself divided on this issue.[97] Critics of the traditional standard of care challenge the premises that purportedly supported surgical intervention. First, they argue that there is no established body of evidence that normal infants are born sexually neutral. The original beliefs were predicated on reports of hermaphrodites, not average males and females. And these by a single investigator. In particular, critics note that the last decade has produced genetic, neurological and biological studies that support a premise that humans are, in keeping with their mammalian heritage, predisposed and biased to interact with environmental, familial, and social forces in either a male or female mode.[98]

Second, critics point to evidence that persons born with genitalia that fall outside our normal expectations can achieve a satisfying psychosexual adjustment without surgical intervention[99] and argue that the imperative to create normal genitalia is of overrated significance.[100] Notably, recent case studies of young males suffering accidental, traumatic loss of the penis (such as J/J’s) suggest reattachment or surgical reconstruction of the penis will yield better psychosexual results than sex reassignment.[101]

Third, critics point to transsexuality,[102] a condition in which individuals develop a sexual identity at odds with both their normal genitals and socially and sexually appropriate rearing. The lives and comments of such individuals provide evidence that gender identity is not solely linked to either the physical appearance of the genitalia or the socialization occurring in child rearing.[103] If the normal appearance of the genitals and unequivocal rearing are determinant, then there could be no explanation for incidences of transsexuality.

Finally, critics remind those who adhere to the surgical standard that, “after some three decades of these surgeries, there is still not a single report of a non intersexed male having been successfully raised as a contented androphilic woman.”[104]

Another important new factor prompting reevaluation of the surgical standard is the emergence of criticism by former patients. Many of the individuals who have been subjected to sex reassignment or clitoral surgery are calling for an end to such practices.[105] The Intersex Society of North America, founded in 1993 and operated by intersexuals, has issued recommendations that call for avoiding unnecessary infant surgery and postponing irreparable surgical interventions.[106] They challenge the efficacy of surgery, pointing to their own cases as evidence.[107]

Nevertheless, many clinicians continue to evaluate male infants for sex reassignment based on the size or functionality of the penis and females for surgical alteration based upon clitoris size[108] and continue to perform surgical procedures to alter genitalia which forecloses later choices for patients. So great is the fear of psychosexual maladjustment,[109] proponents of surgery identify phallus size as a key determinant of whether a genetic male should be

surgically reassigned,[110] even over male reproductive capacity.[111] As Money explained for infants, “‘Too small now, too small later’ is a useful working rule with regard to construction or reconstruction of a penis.”[112]

C. Standard Care and Malpractice Claims

In medical malpractice cases, courts often hold physicians to a standard of care that differs from ordinary principles of negligence.[113] In general negligence law, a jury’s view of “reasonable prudence” can override a deficient standard of care in a particular profession or industry.[114] As Judge Learned Hand explained,

[I]n most cases reasonable prudence is in fact common prudence; but strictly it is never its measure; a whole calling may have unduly lagged in the adoption of new and available devices. It never may set its own tests, however persuasive be its usage’s. Courts must in the end say what is required; there are precautions so imperative that even their universal disregard will not excuse their omission.[115]

While “[w]hat usually is done may be evidence of what ought to be done,”[116] Judge Hand reminds us that no profession is so collectively infallible that custom alone should establish reasonable prudence in every instance.[117]

But in medicine, the prevailing view has held that “[t]he law generally permits the medical profession to establish its own standard of care.”[118] A physician must exercise “the degree of knowledge, skill, and care used by other physicians practicing in the same specialty.”[119] “[A] physician is negligent when the physician does an act which a reasonably careful physician would not do or fails to do an act which a reasonably careful physician would do.”[120] Physicians are not guarantors of positive outcomes, absent their own express promises;[121] there is “no presumption of malpractice from the mere fact of injury.”[122]

Allowing the medical community to abide by its own established standard of care means that when the profession “unduly lags” or adopts a negligent standard of professional care, tort law’s deference to those standards will preclude liability.[123] Ordinarily, expert testimony is essential to establish the medical standard of care, and a jury is seldom allowed to substitute its own evaluation of the reasonableness of that standard.[124]

There are a few notable cases that reject this extraordinary deference to an unassailable medical-community-based standard, most notably, *Helling v. Carey*.^[125] In *Helling*, a 32 year old plaintiff suffered vision loss as a result of glaucoma.^[126] The plaintiff asserted that the ophthalmologist was negligent for not conducting glaucoma screening. At the time the plaintiff suffered injury, the standard practice was to test persons over the age of 40 because glaucoma increased with age and was uncommon in younger persons.^[127] However, glaucoma testing was also inexpensive, simple, and posed no appreciable harm to patients.^[128] Relying on Judge Learned Hand’s formulation of reasonable care in the *T.J. Hooper* case, the Washington Supreme Court held that physicians could be held negligent as a matter of law even when they conformed their treatment to the standard practice of the medical community.^[129] The court explained that “irrespective of its disregard by the standards of the ophthalmology profession, it is the duty of the courts to say what is required to protect patients under 40 from the damaging results of glaucoma.”^[130] Notably, *Helling* resulted in a legislative attempt in Washington to clarify and retreat from the ordinary negligence standard in medical malpractice cases as it was articulated by the Washington court.^[131]

Helling is generally regarded as a minority view^[132] and has been extensively criticized by legal scholars.^[133] As one commentator remarked, “In all other areas of tort law, the jury retains the power to find that the entire industry has ‘unduly lagged;’ in malpractice cases -- and these alone-- the jury is typically deprived of this power.”^[134]

Usurping the autonomy of the medical profession and creating judicially-decreed, faulty or costly standards of care may be the price of applying ordinary negligence principles, however there is also a cost to deference.^[135] As one commentator noted, “[t]he legal malpractice framework may actually serve to entrench poor standards into mainstream practice, as adherence to custom is one benchmark by which a physician’s procedure is measured.”^[136] One common expression echoing the same idea is: “You will seldom be sued if you do what your teacher taught you.”

Because medical standards evolve, a secondary issue regards the standard of care when opinion in the medical community is fluid. While standard care requires that physicians “keep abreast” of “customary practice” as it develops and changes,^[137] few cases actually find liability based on the failure to keep pace with changing professional standards.^[138] More commonly, rather than failing to keep abreast of medical advances, the situation arises where physicians hold divergent opinions and the medical community divides because of the evolving nature of medical care. In fact, disagreement among practitioners is a common occurrence, “[o]n many matters the medical community is divided as to the preferred method of therapy or treatment.”^[139] Generally, malpractice law protects those within a divided medical community; a physician following one of two schools of thought will enjoy freedom from liability even if the treatment chosen proves ineffective.^[140] While there are exceptional cases,^[141] the general rule is that so long as the medical community remains divided, malpractice law offers little protection to patients caught in the middle of an evolving standard of care.

Surgical treatment of ambiguous genitalia in infancy exemplifies an instance where prevailing medical wisdom, in an area of immense significance to individuals and their families, developed without any conclusive evidence that surgical intervention was appropriate. Because surgical care developed without sufficient scientific inquiry and validation of its long-term success, the premises behind judicial deference toward the medical community, at least in the types of cases presented herein, are not particularly compelling.^[142]

The basic reason why professionals are usually held only to a standard of custom and practice is that their informed approach to matters outside common knowledge should not be “evaluated by the ad hoc judgments of a lay judge or lay jurors aided by hindsight.” In the words of a leading authority, “When it can be said that the collective wisdom of the profession is that a particular course of action is the desirable course, then it would seem that the collective wisdom should be followed by the courts.”^[143]

Deference is accorded to the medical community by courts based on the assumption that medical standards are a product of collective wisdom and not of collective ignorance.^[144] Courts presume that standards of care are developed as a result of scientific inquiry and validation, not on ad hoc treatment based on mere anecdotal evidence. But such is not always the case,^[145] and was not so in the case of infant genital surgery where despite a lack of research it became “fairly common to recommend to the parents that they raise a male baby with micropenis as a girl[.]”^[146] and “fairly common to remove the enlarged, masculine-looking clitoris” of female hermaphrodites.^[147] When courts reject ordinary negligence principles in malpractice cases in those instances where treatment is not based upon collective wisdom but something much less, courts insulate the medical professional from liability for its collective shortcomings.

Moreover, the deferential standard reinforces professional inertia. Others have observed that slowness to change even after new information comes to light is not uncommon:

Perhaps more troubling [than adopting a standard without rigorous testing] is that even when trials are conducted, and the results published, physicians may not change their behavior, particularly when the trials report negative findings. Studies of the impact of [randomized controlled trials] on the practice of medicine, from the 1960s through the 1980s, have consistently found that [randomized controlled trials] have little direct impact on physician's practice.[148]

Where judicial deference allows the medical community to establish its own standards of care the court surrenders its power to "say [in the end] what is required,"[149] and allow the profession "to set the measure of its own legal liability, even though that measure might be far below a level of care readily attainable through the adoption of practices and procedures substantially more effective in protecting others against harm than the self-decreed standard of the profession." [150] This is particularly so when the profession has not even abided by its own recommendations for the evaluation of a standard or set of guidelines for the management of some specific clinical problem.[151] By allowing the medical community to set the standard by which negligence is determined and by protecting the divided medical community, tort law renders itself impotent to promote change within the medical community.[152]

IV. Parental Consent to Genital Surgery and Sex Reassignment on Behalf of Children

This section explores the informed consent doctrine and the challenges of actualizing informed consent in the context of infant medical care. This section also confronts the question of how and why parents consented to radical, life-altering treatment of their intersex infant, and why the safeguards of informed consent seemingly failed. The article suggests that an atmosphere of urgency, partial and inaccurate disclosure of the condition and risks, a sense of secrecy and shame all impeded true informed consent. Worse, both the parents and doctors failed to include the child's right to an open future, the right to self-determination, into the decisional calculus.

A. Doctrine of Informed Consent

The informed consent doctrine[153] preserves a patient's right to make medical decisions on his or her own behalf.[154] It protects "the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law." [155] Two key interests are particularly at stake: bodily integrity and self determination.[156] "The law of informed consent is predicated on notions of patient sovereignty and serves to safeguard the patient's right of choice." [157]

Informed consent requires physicians to disclose relevant information concerning a proposed treatment to patients. [158] Generally, informed consent includes an obligation to provide information concerning alternatives to the proposed treatment, including "material risks incident to abstention from treatment." [159]

Although some courts continue to follow an older "physician-oriented" standard and measure the adequacy of disclosure with reference to the custom and standard within the medical community,[160] over the past two decades, the decisional trend for judging the adequacy of informed consent is toward a "patient-oriented" standard, with reference to "what a

reasonable person objectively needs to hear from his or her physician to allow the patient to make an informed and intelligent decision regarding proposed medical treatment.”[161]

The modern trend of judging informed consent by a “patient-oriented” standard stands in stark contrast to a physician-based standard for judging the standard of medical care.[162] Under the patient-oriented standard of informed consent, “what the medical community believes the patient needs to hear in order to make an informed decision is insufficient, without more, to resolve the question of what an individual patient reasonably needs to hear in order for that patient to make an informed and intelligent choice regarding the proposed treatment.”[163] The modern, patient-oriented standard does not shield physicians just because their disclosure conforms to the established custom of their peers if that standard is inadequate to meet the needs of the particular patient.[164] Thus, in jurisdictions employing a patient-oriented standard of informed consent, patient autonomy rights prevail over medical-community standards.[165]

The trend toward judging the adequacy of disclosure from the patient’s vantage is justified because the patient-oriented standard “better respects the patient’s right of self-determination and affixes the focus of the inquiry regarding the standard of disclosure on the motivating force and purpose of the doctrine of informed consent -- aiding the individual patient in making an important decision regarding medical care.”[166]

Under either a patient-oriented or physician-oriented standard, physicians do not need to disclose information when the physician determines that the risk of disclosure poses a threat “of detriment to the patient as to [make disclosure] become unfeasible or contraindicated from a medical point of view.”[167] Commonly known as the “therapeutic privilege,” this exception to disclosure protects physicians from claims when the physician determines that disclosure would carry risks to the patient.

The classic therapeutic privilege case concerns a patient with peculiar apprehension or nervousness that suggests to physicians that full disclosure might pose additional health risks.[168] Then, “[t]he medical standard... [is] that a competent and responsible practitioner would not disclose information which might induce an adverse psychosomatic reaction in a patient highly apprehensive of his condition.”[169] In practice, few cases actually rely on the privilege as an excuse for nondisclosure.[170] Importantly, commentators and courts recognize that liberal invocation of the privilege nullifies the general obligations of disclosure and respect for patient autonomy and self-determination and should therefore be discouraged.[171]

B. Consent and Parental Decision Making on Behalf of Infants

While children and incompetents possess bodily integrity and self-determination rights in theory,[172] finding a practical framework that allows others to make decisions and yet assures the correctness of those decisions for that patient presents a legal and ethical challenge.[173] The primary obligation for making medical decisions on behalf of children resides with the child’s parents and the obligation to disclose information about treatment runs to them.[174]

While the standard by which courts judge surrogate decision-making on behalf of incompetents is a “substituted judgment standard,”[175] for infants the standard is better viewed as a “best interest standard” since an infant has no prior judgment from which decisionmakers might draw.[176] Parental determinations of the child’s best interest are accorded deference in order to protect family privacy and parental authority and autonomy;

this authority, once based on a notion of “children as chattel,”[177] is now premised on the belief that “the natural bonds of affection” motivate parents to act in the child’s best interest.[178] The law presumes that “family members are generally most concerned with the welfare of a patient.”[179]

The authority of parents to make medical decisions, however, is not unbridled and the state may intervene where parental decision making seemingly fails to adequately protect the interests of the child. [180] Usually, conflicts between physicians and parents draw the state into medical treatment controversies.[181] It is unusual that anyone champions the interests of the child when the treating physician and parents agree on treatment, even though the child may have conflicting interests.[182]

One notable exception to the general rule that no judicial review is necessary when parents and doctors are in accord is with regard to involuntary sterilization decisions.[183] Even when doctors and parents agree, significant statutory and common law oversight of the decision to involuntarily sterilize incompetents has developed in most states to prevent hasty involuntary sterilization of the mentally impaired,[184] especially in childhood.[185] “Any exercise of state power to order the non-consensual sterilization of an individual must be scrutinized carefully because of the individual’s rights and interests that are at stake.”[186] Appellate courts caution lower courts that, “because sterilization necessarily results in the permanent termination of the intensely personal right of procreation, the trial judge must take the greatest care to ensure that the incompetent’s rights are jealously guarded.”[187]

The general rule of careful judicial scrutiny in involuntary sterilization cases notwithstanding, the ethical issues surrounding genital surgery on the intersex child has not drawn much attention until very recently, although such surgery poses serious risks to the intensely personal rights related to identity and erotic and possibly reproductive potential.[188] Critics of surgical intervention on these infants contend that ethical considerations in the treatment of intersex children warrant more judicial and ethical attention than currently received.[189] Requiring physicians and parents to establish the necessity of such surgery by “clear and convincing” evidence might well be justified because of the life-long impact of the surgery on crucial and substantive aspects of life.[190]

In surrogate decision making other than compulsory sterilization, judicial involvement is not the norm unless parents and physicians are not in accord.[191] However, it remains useful to consider how courts evaluate cases in which parents and physicians disagree. Parental decisions to deny medical treatment for religious[192] or other reasons[193] may be challenged by the state and set aside by court if those decisions are deemed not in the child’s best interest. While “parental autonomy is constitutionally protected,” the state, as “guardian of society’s basic values” sometimes has an overriding duty to protect children.[194] When opinions on the advisability of treatment conflict between parents and physicians, ethicists often advise weighing three factors in evaluating whether to interfere in parental decision making: 1) the decisional capacity of the minor; 2) the burden and risk of treatment; and 3) the effectiveness of the treatment.[195]

While the first factor, decisional capacity, is seemingly inapplicable in considering medical treatment for infants, when decisions can be postponed, the infant’s future decisional capacity should be protected. Protecting that potential decisional capacity remains a relevant consideration when weighing irremediable medical intervention such as the destruction of reproductive and erotic capacity or infringement on gender options.[196] Under a trust-model of decision making that seeks to preserve a child’s “right to an open future,”[197] parents should attempt to safeguard a child’s right of autonomy.[198] and be “constrain[ed] from

consenting on the child's behalf to that which may impair the enjoyment of autonomy at maturity.”[199]

As to the second factor, consideration of the risks and burdens, includes weighing both the possibility of a positive outcome as well as the “human costs of getting there.”[200] When the burden and risk are great, treatment may carry too high a price to be justified.[201] Some critics liken parental consent to genital “mutilation” which might permanently impair adult function as a form of child abuse that should be prohibited.[202]

Finally, as to the third factor, decisionmakers must “consider whether the treatment is likely to be effective in securing some significant and subjectively valuable benefit for the child.”[203] “Demonstratively effective” treatments should be weighted of more value than “experimental or investigational” treatments.[204] The burden should be on proving the enhancement of the quality of life rather than the absence of harm.

C. The Problems of Informed Consent and Infant Genital Surgery

In order to weigh the risks, benefits, burdens and effectiveness of treatment parents need information concerning the proposed treatment. However, perhaps acting in part out of an ill-conceived concept of therapeutic privilege, parents have sometimes been deprived of key information.

Importantly, the effectiveness of informed consent must be tested by both what is disclosed and how it is disclosed.[205] This section questions how parental informed consent was secured in cases of genital surgery. In particular, this section explores five grounds for criticizing the consent obtained by some practitioners in these cases:

1. the false aura of urgency;
2. the failure to impart complete and accurate information;
3. the oppressive secrecy in which parents were advised to not discuss the situation with others and to particularly hold all information even from the child;
4. the failure to reveal the uncertainty of the outcome; and
5. the failure to appreciate the child's right to an open future in the decisional calculation.

1. The Aura of Urgency

Clinicians have long imparted a sense of medical urgency to parents upon the birth of an intersex child.[206] Although the intersex state is typically not life-threatening, parents are counseled to act quickly in order to establish a sex of rearing that is unequivocal.[207] Many medical texts classify this decision making process as a medical emergency.[208] Clinicians develop a treatment plan to facilitate conforming the child to that sex within days of birth.[209] Money counseled parents to act quickly and to delay announcing the sex of a child born with ambiguity to avoid the trauma and embarrassment of a “reannouncement” of the child's sex and name.[210]

Despite the impression of “urgency” that clinicians create, surgical treatment of the genitals is essentially cosmetic and not medically urgent.[211] Instead, the message of urgency is based upon social and psychological considerations, including stigmatization and the nurture assumption.[212] Compassion for the parents and concern that they would not bond[213] also prompted urgency, “the medical team will recommend that surgical therapy begin early in

order to spare parents the trauma of seeing their child as intersexed each time they change the infant's diaper.”[214]

Critics argue that none of the core premises on which early surgery was based justify urgency. First, the theory that children raised unambiguously with normalized genitalia would accept the gender of rearing was untested by reliable studies.[215] In truth, physicians could not confidently assert, based on data, that surgery performed at any age would be any more or less successful.

Second, the stigma clinicians feared would befall a child in the locker room could be mitigated through less drastic alternatives than through immediate surgical alteration.[216] When Diamond and Sigmundson first recommended a moratorium on most cosmetic infant genital surgery, they nevertheless supported the early decision to socially assign the child to boy or girl classification.[217] They merely opposed taking the irreversible surgical step of removing body parts, while still recommending children be raised with a clear gender status based on which gender will likely develop.[218] They wrote, “In rearing, parents must be consistent in seeing their child as either a boy or a girl; not neuter. In our society intersex is a designation of medical fact but not yet a commonly accepted social designation.”[219]

Finally, recommending prompt surgery based on the fear of parental rejection and failure to bond is premised more on medical opinion than fact.[220] Importantly, recommending surgery based on a concern for the sensibilities of parents and others is never appropriate, as only the best interest of the child is relevant.[221] Critics contend that while “Money has presented some data that having a child with ambiguous genitalia causes parental stress, ... support for the second part of that hypothesis, that the stress on the parent (and presumably on the child) is alleviated by surgical correction, is entirely absent.”[222] As Alice Dreger commented, even if physicians were motivated by a singular desire to alleviate psychosocial problems of both the family and the child, “it is not self evident that a psychosocial problem should be handled medically or surgically. We do not attempt to solve the problems many dark-skinned children will face in our nation by lightening their skins.”[223] Further, parental anxiety and distress can be enhanced by this medical attention rather than reduced. Parental tension and stress can be reduced by managing the intersex condition as a normal variation and imparting to the parents the knowledge that the genital variation can be dealt with at a later age.

2. Imparting Incomplete Information

Clinicians treating children with congenital birth defects sometimes fail to impart accurate and complete information for a variety of reasons.[224] The problem of inadequate disclosure during neonatal medical crises is not confined to the intersex infant:

The information available to the family in a medical crisis is quite often inadequate. Some have suggested that this problem is rooted in the complete dependence and lack of power of the patient and family. All information of both the particular and general medical type, is held by the hospital staff.... Physicians have a propensity not to admit the limitations of their professional knowledge and ability. Additionally, the use of medical jargon during counseling clouds the ability of parents to be fully informed[225]

Intersexed individual, Howard Devore, a practicing psychologist who counsels other intersexed persons has himself had 16 surgeries to repair a severe case of hypospadias. He has been quoted as saying;

“[In regard to surgery] There’s going to be scarring and stricture formation and loss of sensation. No scar tissue is as flexible as skin. There’s no way they can deny that. The ‘informed consent’ they give parents to sign is totally unrealistic. One of our [intersexed persons] main issues is that parents are told after a few surgeries, their children will have ‘normal genitals.’[226]

In the case of intersexuality, Money contended that in counseling, “parents need to have the necessary medical information, albeit somewhat simplified, in order to be able to explain their dilemma to themselves, before explaining it to other people.”[227] However, full and complete disclosure about the condition was generally not advised by professionals. Instead, counselors were advised that in counseling parents, the counselor should explain to parents that the child was “sexually unfinished.”[228] The concept that these children are “unfinished” is particularly deceptive because it implies that 1) with more gestational time unambiguous sex organs would have developed and 2) that physicians are not “changing” something fundamental about the child but are merely “finishing” the child’s incomplete anatomy.[229] [230] In doing so, as Suzanne Kessler points out, clinicians are suggesting to parents that it is the genitals that are ambiguous and not the gender.

The message ... is that the trouble lies in the doctor’s ability to determine the gender, not in the baby’s gender per se. The real gender will presumably be determined/proven by testing, and the “bad” genitals (which are confusing the situation for everyone) will be “repaired.” The emphasis is not on the doctors’ creating gender but in their completing the genitals. Physicians say that they “reconstruct” the genitals rather than “construct” them.... The fact that the gender in an infant is “reannounced” rather than “reassigned” suggests that the first announcement was a mistake because the announcer was confused by the genitals. The gender always was what it is now seen to be.[231]

When clinicians emphasize the incompleteness of the genitals and suggest to parents that surgery can make the genitals match a correct gender, they fail to help parents appreciate that the gender of the intersex child is not clearly established, not merely that the genitals have uncertain sexual characteristics. Indeed, it is the ambiguous nature of the genitals that signal the ambiguous nature of the child’s future sexual identity and preferred gender, and that innate ambiguity cannot be masked by surgery.[232] Parents require detailed information about the condition, the efficacy of treatment and the alternatives in order to weigh the burdens of surgically assigning a child to a gender, risking reproductive and erotic possibilities, necessitating future surgeries and lifelong medical and hormonal treatment.[233]

3. Perpetuating Secrecy

Secrecy is probably the most unusual and harmful aspect of the medical treatment prescribed for intersex conditions.[234] Money contended that the sex of rearing must be unequivocal and as a result the treatment necessarily justified deception as the children matured. But, as the children grew older, this secrecy has had the added consequence of preventing their participation in later treatment choices.[235] Parents were counseled to raise these children without equivocation as to the child’s assigned sex and to withhold information from the child so that the child would feel secure in his or her gender.[236]

The medical community’s zeal to raise intersexed babies or those sexually reassigned without ambiguity is necessarily deceptive,[237] because, after all, despite the dogma, the child’s genitals were not rendered by surgery unequivocally typically male or female.[238] Secrecy persists even today, as one physician explained, “If they have an excellent outcome and they look perfect “I would downplay it [the original ambiguity] as much as possible.”[239]

In a revealing case study debated in the Hastings Center Report, ethicists considered whether either a sixteen-year-old female or her parents should be informed when the teen seeks treatment for failure to menstruate.[240] Upon discovery that the “girl has an XY genotype, a genetic abnormality called testicular feminization”[241] and “[possible] precancerous testes that require surgical removal” and will need vaginal surgery to have intercourse, the question arises whether the child or parents should be told the genetic information or the fact that she is “really a guy.”[242] The treating doctor asks whether he can withhold the information until the child is twenty-one. Two authors suggest that the physician’s concern is justified.[243] They accept that the child’s parents might become “emotionally distraught” and come to regard her as a “freak” or might at some point divulge the harmful information to her. The authors conclude that if “the functions of guardians to secure the wishes and welfare of minors ... can [not] be secured by disclosing [the patient’s] genetic identity to her parents, then there seems no sound ethical reason to disclose this information in these circumstances.”[244] Addressing two fundamental questions, the authors reason:

“Would a typical physician act differently from Dr. P [the hypothetical doctor withholding information]?” The answer is “No!” Some, of course might inform her, but disclosing the information is by no means customary within the profession.... “Would a hypothetical reasonable person want this information revealed to her at this time?” Probably not. What reasonable person would needlessly choose to make a bad situation worse?[245]

The authors suggest that a loosely constructed “therapeutic privilege” applies to justify long-term deceptions toward both the patient and the teen’s parents based merely on a belief that reasonable patients would not want to know such matters. Yet, contrary to this position, the judicial construction of the informed consent doctrine assumes patients want to know what is relevant and material to their condition.[246] As the Canterbury court cautioned when fashioning this therapeutic privilege to withhold information from the patient,

The physician’s privilege to withhold information for therapeutic reasons must be carefully circumscribed, however, for otherwise it might devour the rule itself. The privilege does not accept the paternalistic notion that the physician may remain silent simply because divulgence might prompt the patient to forego therapy the physician feels the patient really needs. That attitude presumes instability or perversity for even the normal patient, and runs counter to the foundation principle that the patient should and ordinarily can make the choice himself. Nor does the privilege contemplate operation save where the patient’s reaction to risk information, as reasonably foreseen by the physician, is menacing. And even in a situation of that kind, disclosure to a close relative with a view to securing consent to the proposed treatment may be the only alternative open to the physician.[247]

In intersex cases, physicians both marginalized the participation of parents and then enlisted parents in maintaining a wall of secrecy that persisted into the child’s adulthood[248] without contemplating the actual risk of disclosure to the patient based on the unproved premise that unambiguous genitals and unequivocal child-rearing practices paired with a lack of information as to the nature of the original condition would benefit the child. What was left out of the equation that might militate in favor of full disclosure are the social and psychological costs in addition to the medical damage that secrecy can promote.[249]

A last cost of secrecy should be mentioned. Typically, patients eventually discover their condition from an inadvertent family slip, community gossip or personal investigation into puzzling aspects of their lives. The patient thus learns anyway what she or he was never supposed to have found out. Even more disturbing than discovering the secret, the former patient also discovers that his or her deformity is unspeakably shameful in the minds of parents and physicians. This revelation, usually coming without support, can be

devastating.[250] They wonder why they were not accepted and loved as they were. This makes manifest the fear of romantic/erotic relations and reduces the pursuit of intimate contacts. Last, the former patient learns that she or he has since childhood been systematically deceived by the very people who should have been the most trustworthy; parents and physicians. All this is damaging and needless.[251] The solution is for complete honest and early disclosure of the situation with appropriate counseling and support.[252]

4. Failing to Disclose The Uncertainty of the Long-term Outcome[253]

Parents consenting to these surgeries might have responded differently had they understood the innovative nature of the treatment, and certainly it was the obligation of clinicians to so inform them.[254] However, because the J/J case, as originally presented, had become “a classic for the academic and medical community”[255] clinicians probably projected more confidence in the procedure than it deserved.[256] Clinicians asserted the potential for successful “normalization” because the literature suggested such, when, in fact, insufficient data existed to support their premises.[257] Indeed, clinicians were advised as recently as 1994, to project confidence in the treatment recommendations when counseling parents:

This [simplified medical] knowledge will help [parents] feel convinced that what is being done is correct and that it is their own decision as well as that of experts. Otherwise, they might easily feel that they are acquiescing to an intervention based on trial and error, which might prove to be all error.”[258]

As to treatment of micropenis in particular, Money counseled:

It is fairly common to recommend to the parents that they raise a male baby with micropenis as a girl. This is, of course, a very difficult decision for parents to make, and they must be given all the information possible to understand the rationale and consequences of the decision. First and foremost, they [parents] need to know that gender identity and role are not preordained by genetic and intrauterine events alone, but that their differentiation is also very much a postnatal process and highly responsive to social stimulation and experience. Thus, they need to be reassured that their baby can grow up socially as a girl and fall in love as a female.[259]

The reassurance that counselors were urged to convey concerning the effectiveness of the treatment and that the treatment was not based on trial and error was not accurate because the only experience which clinicians could report was actually drawn from anecdotal and incomplete case reports that were appearing in the medical literature.[260]

5. Ignoring The Child’s Right to an Open Future

Surgical intervention has been promoted as a way to offer the intersexed child a more “normal” life. Remarkably, proponents of surgical treatment ignore the possibility that the child might one day have a different concept of “normal” and want to choose a different course of treatment, or none at all.[261] Surgical proponents discount the possibility that the intersexed adult might desire to participate in their treatment decisions as a countervailing justification to delay surgical interventions.[262]

A relevant rule extrapolated from the ethics surrounding the genetic testing of children is emerging that would accord more weight to the child’s autonomy and right to an open future when making elective medical decisions. Recently, Laurence McCullough, medical ethicist at Baylor College of Medicine “Center for Medical Ethics and Health Policy” recommended:

When genetic conditions for which a child is at risk do not have biopsychosocial consequences until adolescence or adulthood, genetic testing for such condition should be postponed until later when the child can engage in informed assent as an adolescent or informed consent as an adult. Intersex conditions that neither are life-threatening nor involve chronic morbidity should be managed under this rule. Intersex conditions that are chronic and that involve manageable psychosocial consequences until adolescence or adulthood should be managed under this rule.[263]

Thus, he recommends that in balancing the desirability of normal-appearing genitalia with the foreclosure of the child's ability to later consent, the scales tip in favor of delaying treatment.

IV. Learning from the Past: What Should the Future Hold?

There are increasing doubts among some in the efficacy of early surgery and an acknowledgment by many more that more study is needed.[264] Given the current state of medical knowledge, ethical considerations suggest the course of treatment should change. Medical uncertainty coupled with the infant's inability to consent to this life-altering treatment and the child's right to an open future, suggest to critics, including the Intersex Society of North America, that a "moratorium" on infant surgery is the best course when surgery is solely intended to cosmetically change ambiguous genitals.[265]

These critics argue that parents of children with ambiguous genitalia would be better counseled to manage the psychosocial consequences of genital differences in childhood rather than opting for a surgical response. Nonsurgical approaches such as individual and family counseling to mitigate the stigma and develop coping strategies[266] preserves a child's right to self-determination.[267]

Those who have already undergone surgical treatment present current ethical dilemmas in light of the revelation that there are those who daily struggle with gender confusion and medical questions and remain uncertain what surgical procedures were performed on them when they were an infant. There is no rationale reason why secrecy surrounding the early treatment should persist into adulthood. The incomplete or inaccurate medical information can result in mistaken assumptions about the actual health risks the individuals actually bear.[268] For example, gonadectomy, exposes patients to a definite risk of osteoporosis and creates a need for life-long hormone replacement.[269] Adult intersexed individuals report that their attempts to obtain a clear diagnosis and understanding of the treatment undergone as an infant are often frustrated.[270] Therefore, some critics suggest that patients treated as infants and whose treatment was cloaked with secrecy should be recontacted so that they can be provided with complete medical information.[271] Importantly, to the extent that new knowledge of J/J's case suggests that ongoing medical and psychological risks exists that can be alleviated or lessened by more medical information, practitioners may have continuing ethical and legal duties to their former patients.[272]

V. Concluding Thoughts

In 1998, a young man, barely twenty, whose story mirrors J/J's, contacted Milton Diamond and described his encounter with both the medical profession and the legal profession as he came to terms with his medical history.[273] He explained that after years of feeling he was an "it" or "alien" and not fitting in as a girl and considering himself more a boy,[274] during family therapy as an adolescent, his mother, for the first time, revealed to him that he had significant genital surgery as an infant. Although not entirely sure of the significance of her

revelation at that time, he eventually came to understand the full import of the surgery performed on him as an infant through persistent medical detective work. He discovered that his healthy testicles had been removed when he was an infant and he was raised as a female because of a significantly small penis noted at birth.[275] At the age of seventeen he decided that he could no longer live as a female and, like J/J, reclaimed his male identity.[276]

Remarkably, although he once did, he now holds no anger toward his parents given what they were advised at the time;[277] he was pleased that his parents assisted him in his transformation to male as a young adult. He believes now that they did the best they could, both in permitting surgery and then in accepting him when he shed the female identity. However, the young man felt that someone should account for the surgical removal of his testes and the sex reassignment performed on him as an infant that had scarred him so deeply.[278] He sought legal advice as to whether to pursue a claim against the doctors who treated him; he said he was referred to the “best” malpractice firm in his state. The law firm considered his case at some length, but finally advised him that his case was weak and not worth pursuing. They explained to him that doctors had followed the “standard of care” at the time of his treatment.[279] As a result, he abandoned the notion of filing suit; in his last contact with the attorneys they cautioned him that the statute of limitations, once tolled by his minority, was about to run.

What would a jury’s reaction be to a story like J/J’s if it were judging the standard of care that clinicians employed in these cases? In jurisdictions rejecting *Helling v. Carey* and the application of ordinary negligence principles to malpractice actions, tort law renders itself impotent to hold the medical community accountable for decisions based on failed medical standards or to be itself an agent for change. These jurisdictions presume the medical profession’s own internal safeguards sufficiently protect the public and that the standards so developed deserve judicial deference. Jurisdictions rejecting *Helling* presume that the medical community’s standard of care springs from collective wisdom and not from collective ignorance. It is in these circumstances that the wisdom of Judge Hand’s words ring most true.

The informed consent doctrine has more potential to change collective practices, however. Especially in those jurisdictions that have adopted a patient-oriented standard to judge informed consent, the counseling approach clinicians employed in the past is not defensible. The informed consent doctrine requires physicians to reveal material data including risks, efficacy, and alternatives to patients, or their parents, in order to allow them to make informed decisions. The patient-oriented standard leaves little room for the inaccuracy and secrecy formerly employed in advising parents and patients. Providing parents with a fuller explanation of the risks, including the recently reported failures of treatment as well as information on the successful adaptation of individuals raised without surgery, may well curb parental consent. After all, few parents would probably consent to such extensive treatment if physicians reveal that there is no scientific evidence supporting the premise on which treatment is based and the child may ultimately reject the treatment and be left worse off for having gone through it.

Finally, a fuller airing of the ethical dimensions of treatment and the duties of informed consent may prompt a more cautious approach to surgical intervention.[280] Importantly, recognizing the child’s right to an open future as part of the decisional calculation may yield a more measured approach in these difficult cases. The child should have the final say in how it wants to live. As it has been often stated: the most important sex organ is between the ears rather than between the legs.[281]

Endnotes

- [1] Intersexed individuals are those that are born with biological features simultaneously typically male or female. For instance they might have one ovary and one testes or gonads that contain features of both ovarian and testicular tissue, they can have chromosomes of XXY, XO or other configurations. There are more than 1 dozen categories of intersex.
- [2] Ambiguous genitalia are those that are not clearly identified as male or female. Usually detected at birth they are a frequent sign of intersex.
- [3] See infra notes ____.
- [4] Gender as used in this paper is a social term representing the social conditions of boy and girl and man or woman. This is contrast to the biological terms of male and female. It is thus obvious that a male can live as a girl and woman and a female can live as a boy or man.
- [5] See infra notes ____.
- [6] See infra notes ____.
- [7] See John Money, et al., An Examination of Some Basic Sexual Concepts: the Evidence of Human Hermaphroditism, 97 BULL. JOHNS HOPKINS HOSP. 301, ____ (1955) (“In place of a theory of instinctive masculinity or femininity which is innate, the evidence of hermaphroditism lends support to a conception that psychologically, sexuality is undifferentiated at birth and that it becomes differentiated as masculine or feminine in the course of the various experiences of growing up”); John Money, Cytogenetic and Psychosexual incongruities with a note on space form Blindness. 119 AM. J. PSYCH. 820, ____ (1963) (“It is more reasonable to suppose simply that, like hermaphrodites, all the human race follow the same pattern, namely, of psychological undifferentiation at birth.”). In the early days intersexed individuals were known as hermaphrodites and pseudohermaphrodites.
- [8] One of the authors of this article, Milton Diamond, was one of the two researchers who reintroduced the patient to the medical literature in 1997.
- [9] See infra notes ____.
- [10] See infra notes ____.
- [11] For recent accounts of the John/Joan case, see Milton Diamond & H. Keith Sigmundson, Sex Reassignment at Birth Long Term Review and Clinical Implications, 151 ARCHIVES PEDIATRIC ADOLESCENT MED. 298 (1997) [hereinafter Sex Reassignment]; Milton Diamond & H. K. Sigmundson, Management of Intersexuality: Guidelines for Dealing with Persons with Ambiguous Genitalia, 151 ARCHIVES PEDIATRIC ADOLESCENT MED. 1046 (1997) [hereinafter Management of Intersexuality]; Milton Diamond & Kenneth Kipnis, Pediatric Ethics and Surgical Assignment of Sex, 9 J. CLIN. ETHICS 398 (1998) [hereinafter Pediatric Ethics]. Colapinto provides the most thorough examination of J/Js life. See John Colapinto, The True Story of John/Joan, ROLLING STONE, Dec. 11, 1997, at 54. See also John Colapinto, 2000 (In Press). AS NATURE MADE HIM: THE BOY WHO WAS RAISED AS A GIRL. Harper Collings, New York. [hereinafter As Nature Made Him]. Professor Greenberg discusses the case in a critique of law and medicine’s rigid, binary approach to sex and gender. See Julie A. Greenberg, Defining Male and Female: Intersexuality and the Collision Between Law and Biology, 41 ARIZ. L. REV. 265 (1999).

[12] See SUZANNE J. KESSLER, LESSONS FROM THE INTERSEXED 6 (1998) (commenting, “virtually all academic writing on sex and gender refers to a case first described by sexologist John Money in 1972”); Alice Domurat Dreger, “Ambiguous Sex” -- or Ambivalent Medicine? Ethical Issues in the Treatment of Intersexuality, 28 HASTINGS CENTER REP. 24, 26 (1998) (describing establishment of surgical standard).

For references to the surgical standard, see, e.g., JOHN MONEY & ANKE A. EHRHARDT, MAN & WOMAN/BOY & GIRL (1972) [hereinafter MAN & WOMAN]; P. K. Donahoe et al., Clinical Management of Intersex Abnormalities, 28 CURRENT PROBLEMS IN SURGERY 517, 527 (Aug. 1991); LOWELL KING, UROLOGIC SURGERY IN NEONATES & YOUNG INFANTS 369-70 (1988); Alan D. Perlmutter, Intersex, 2, 15, in UROLOGICAL SURGERY IN INFANTS AND CHILDREN (Lowell R. King, ed.) (1997); Timing of Elective Surgery on the Genitalia of Male Children with Particular Reference to the Risks, Benefits, and Psychological Effects of Surgery and Anesthesia, 97 PEDIATRICS 590 (April 1996) (also available as American Academy of Pediatrics 1997 Policy Reference Guide) [hereinafter Timing of Elective Surgery]; C. R. J. Woodhouse, Ambiguous Genitalia and Intersexuality -- Micropenis, in PEDIATRIC UROLOGY 689, 690 (Barry O’Donnell & Stephen A. Koff, eds. 1997).

[13] The child’s penis was “ablated flush with the abdominal wall” during an electrocautery procedure which burned the entire penis, causing it to eventually necrose and slough. MONEY & EHRHARDT, MAN & WOMAN, supra note __, at 118. Penile amputation occurs by surgical or other childhood mishaps. They are not common but are not rare. See, e.g., Bernardo Ochoa, Trauma of the External Genitalia in Children: Amputation of the Penis and Emasculation, 160 J. UROLOGY 1116 (Sept. 1996) (reporting seven case studies); Tracy Thompson, Two Atlanta Physicians Get Reprimand Over Babies’ Burns Suffered During Circumcisions, ATLANTIC J. & CONST. November 8, 1986, at B1 and Joan McQueeney Mitric, Merits of Circumcision A Subject of Dispute Disfigurement Leads to Two Lawsuits in Atlanta, WASH. POST, Oct. 23, 1986, at Z9 (reporting that two babies, on the same day, were burned during circumcision and one underwent sex-change surgery because of the severity of tissue destruction).

[14] The plan was developed as follows, “The parents agonized their way to a decision, implementing it with a change of name, clothing and hairstyle when the baby was seventeen months old. Four months later, the surgical first step of genital reconstruction as a female was undertaken, the second step, vaginoplasty, being delayed until the body is full grown. Pubertal growth and feminization will be regulated by means of hormonal therapy with estrogen.” MONEY & EHRHARDT, MAN & WOMAN, supra note __, at 118-19. The child underwent an orchiectomy (surgical removal of testicles) and preliminary surgery before age two. Diamond & Sigmundson, Sex Reassignment, supra note __, at 298, 299.

[15] The names are pseudonyms, Sex Reassignment, supra note __, at 299; Colapinto, supra note __. Kitzinger writes: “The John/Joan case is still amongst the most widely cited studies in social science textbooks on gender issues. Its popularity with textbook authors is due, in part to the . . . nature of a case [which seems better suited to science fiction than science]. Celia C. Kitzinger, Gender, Sex and Knowledge: The construction of the John/Joan Case in Social Science Textbooks (In press).

[16] MONEY & EHRHARDT, MAN & WOMAN, supra note __, at 119.

[17] Diamond & Sigmundson, Sex Reassignment, supra note __, at 302. Interestingly, in a book published in 1968 Money had written: “. . . it used to be commented in passing that

when a new announcement of sex was necessary, the parents should move to a new town, find a new job, sever all connections with the past, and start life anew. I have found that this formula is completely untenable.” JOHN MONEY, SEX ERRORS OF THE BODY: DILEMMAS, EDUCATION, COUNSELING” 61 (1st ed. 1968) [hereinafter SEX ERRORS 1968] at 61.

[18] See Colapinto, supra note ___, at 68.

[19] See Colapinto, supra note ___, at 55.

[20] Money reported: Regarding domestic activities, such as work in the kitchen and house traditionally seen as part of the female’s role, the mother reported that her daughter copies her in trying to help her tidying and cleaning up the kitchen, while the boy could not care less about it. She encourages her daughter when she helps her in the housework.

MONEY & EHRHARDT, MAN & WOMAN, supra note ___, at 121. However, he continued, “[t]he girl had many tomboyish traits, such as abundant physical energy, a high level of activity, stubbornness, and being often the dominant one in a girls’ group. Id. at 122.

[21] See Colapinto, supra note ___, at 68.

[22] MONEY & EHRHARDT, MAN & WOMAN, supra note ___, at 120. The mother noted times when the girl had “penis envy” on seeing her twin brother’s penis in the bath. Id. at 121.

[23] P. Williams & M. Smith, Open Secret: The First Question. Science Series, BBC Television Production; Milton Diamond, Sexual Identity, Monozygotic Twins Reared in Discordant Sex Roles and a BBC Follow-up, 11 ARCH. SEXUAL BEH. 181 (1982) [hereinafter BBC Follow-up].

[24] BBC Follow-up, supra note ___, at 183.

[25] Colapinto writes that Money did have further contact with the twins but this was not reported upon. See Colapinto AS NATURE MADE HIM at 149.

[26] Diamond & Sigmundson, Sex Reassignment, supra note ___; Colapinto, supra note ___, at 71.

[27] Diamond & Sigmundson, Sex Reassignment, supra note ___, at 300.

[28] See infra notes ___.

[29] More remarkably, it now appears that prior to the J/J reports in the 1970s, data were available suggesting that intersex individuals left to develop without surgery, nevertheless, generally made satisfactory adjustments. Significantly, these data gathered in the 1950s by John Money went unreported in the professional literature. Had they been reported it most likely would have mitigated against the adopted surgical method of treatment. See John Colapinto, AS NATURE MADE HIM at 227-229.

[30] After the widely publicized report on the J/J case by Diamond and Sigmundson in 1987, Money, in 1998, acknowledged the failure of treatment but theorized that other variables including surgical delay may have caused the child to reject the assigned gender. See MONEY, SEX POLICE, supra note ___, at 314-319. Colapinto reported that in 1975

Money knew that Joan had sexuality fantasies about girls, her father reports that Money asked him “how they felt about raising a lesbian,” yet this “clinical finding was not in his next report on the twins which appeared in 1975.” Colapinto, *supra* note __, at 70. According to Colapinto, despite the child’s refusal to have any further corrective surgery in adolescence and admitting attraction to the female figure, Colapinto described Money’s 1975 article as a “more glowing report than the one from three years before.” *Id.*

[31] See *infra* notes __.

[32] Diamond had challenged Money’s theories since the 1960s, but Money would not be dissuaded by critics. MONEY & EHRHARDT, *MAN AND WOMAN*, *supra* note __, at 154 (citing and criticizing works of Diamond (among others) who challenged correctness of early surgical intervention). Money continues to defend his work. See JOHN MONEY, *SIN, SCIENCE, AND THE SEX POLICE: ESSAYS ON SEXOLOGY AND SEXSOPHY* 314-323 (1997) [hereinafter *SEX POLICE*] (responding to critics, including Milton Diamond).

[33] In 1994, co-author of this article, Milton Diamond, located the twin with the assistance of H. Keith Sigmundson, a psychiatrist with the Ministry of Health in Victoria, British Columbia. Sigmundson had treated J/J under Money’s supervision. It took Diamond some dozen years to locate and contact Sigmundson.

[34] Although initially reluctant to cooperate with Diamond in following up this case, Sigmundson was finally convinced that to do so was in the greatest interest of medicine. Sigmundson confesses that he knew of Diamond’s persistent attempts at contacting him, “but I couldn’t bring myself to answer it.” Colapinto, *supra* note __, at 92. He admitted to being “shit-scared of John Money.... He was the big guy. The guru. I didn’t know what it would do to my career.” *Id.* John, now a married man, agreed at Sigmundson’s and Diamond’s urging to cooperate after he learned of his textbook fame “as a success”, in his own effort to stop this form of treatment on others. *Id.* at 94.

[35] Diamond & Sigmundson, *Sex Reassignment*, *supra* note, at 300; Colapinto, *supra* note at 92.

[36] Diamond & Sigmundson, *Sex Reassignment*, *supra* note, at 300.

[37] *Id.*

[38] *Id.*

[39] Colapinto, *supra* note __, at 70.

[40] Colapinto, *AS NATURE MADE HIM* at 54.

[41] Colapinto, *supra* note __, at 72, 92.

[42] Diamond & Sigmundson, *Sex Reassignment*, *supra* note __, at 300.

[43] *Id.* at 301. The testicles are the prime source of androgens (male hormones). These substances are needed for normal male development and every-day processes.

[44] *Id.* at 300.

[45] *Id.* at 302.

[46] *Id.* at 301. (While J/J's testicles were removed, he still retains his accessory glands -- prostate and seminal vesicles-- and these, more than sperm, contribute the bulk of semen.)

[47] Diamond & Sigmundson, *supra* note __.

[48] See generally Mark A. Hall, The Defensive Effect of Medical Practice Policies in Malpractice Litigation, 54 SPG- LAW & CONTEMP. PROBS. 119, 126-29 (1991).

[49] See NATIONAL COMMISSION FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAVIORAL RESEARCH, THE BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH 3 (1979) [hereinafter BELMONT REPORT]. The Belmont Report remains a cornerstone of the National Institutes of Health's guidelines of human subject research. See PROTECTING HUMAN RESEARCH SUBJECTS INSTITUTIONAL REVIEW BOARD GUIDEBOOK xxi-xxiii & Appendix 6 (DHHS 1993) [hereinafter HUMAN RESEARCH SUBJECTS].

[50] BELMONT REPORT, *supra* note __, at 3.

[51] Dale H. Cowan, Innovative Therapy Versus Experimentation, 21 TORT & INS. L.J. 619, 621 (1986) (quoting NATIONAL COMMISSION, REPORT & RECOMMENDATIONS: RESEARCH INVOLVING CHILDREN (DHEW Pub. No. (OS) 77-0004, 1977). See also Dieter Giesen, Civil Liability of Physicians for New Methods of Treatment and Experimentation: A Comparative Examination, 3 MED. L. REV. 22 (1995). See also BARRY FURROW, et. al, 1 HEALTH LAW § 6-5, at 386 (1995) (discussing medical innovation).

[52] Cowan, *supra* note __, at 621; Giesen, *supra* note __, at 33.

[53] *Id.* at 622.

[54] BELMONT REPORT, *supra* note __, at 3; Giesen, *supra* note __, at 33. When experimentation follows innovation, institutional review boards provide an early airing and review of ethical issues. No such review occurs when innovative therapy becomes standard in an ad hoc fashion.

[55] Others have noted this phenomenon with regard to medical practices that become standard before validation. For instance D. H. SPODICK, 1973. The surgical mystique and the double standard. AMERICAN HEART JOURNAL, 85:579-583. found, after reviewing 70 reports in specialty journals appearing in 1971, 9 of 16 medical treatment studies were controlled; none of 49 studies of surgical intervention involved a controlled study. Consider:

There follows a period during which the innovation (having received professional and public support and legitimization through state endorsement and third-party coverage) achieves the privileged status of a "standard procedure." For a period of time it becomes generally accepted by interested parties as the most appropriate way of proceeding with a particular problem or situation. It is probably incorrect to refer here to the activity as an "innovation" ... since at this stage it has graduated from being just another promising performance (something new with great potential) to the position of being an established and respected activity. Although there is a bias against reporting unsuccessful or untoward performances, they certainly occur but are usually dismissed as infrequent, the result of having poor material to work with, public misunderstanding, and so forth. So entrenched has the activity become that it takes rare courage for any individual or group even to question its effectiveness or

desirability. To do so, as we shall see, is to invite retaliation from professional organization interests, public indignation, and even in rare cases sanctions from the state (at 387-388).

John B. McKinlay, *From Promising Report to Standard Procedure: Seven Stages in the Career of a Medical Innovation*, 59 *MILBANK Q.* 374, 87-89 (1981). See also Margaret Lent, Note, *The Medical and Legal Risks of the Electronic Fetal Monitor*, 51 *STAN. L. REV.* 807 (1999). Lent explains that fetal monitoring to avoid hypoxia during delivery became standard care in the 1970s before scientific validation of its efficacy. *Id.* at 812. Over the years, use has expanded beyond high risk deliveries so that this technique is now used for 83% of all American births. *Id.* Now, in twelve randomized control studies, with one exception, none suggest that electronic fetal monitoring decreases fetal mortality. *Id.* at 813. Moreover, in one study, the fetal monitored group actually suffered an increase in neurological disorders. *Id.* In sum, the overwhelming scientific studies dispute its efficacy. *Id.* at 814-15. Nevertheless, routine fetal monitoring with its attendant increased cost in time and effort remains an entrenched practice in delivery, perhaps out of fear of legal liability for abandoning an established standard, *id.* at 822-23, or “professional inertia.” *Id.* at 808.

[56] Nancy M.P. King & Gail Henderson, *Treatments of Last Resort: Informed Consent and the Diffusion of New Technology*, 42 *MERCER L. REV.* 1007 (1991). Grimes, D. A. 1993. *Technology follies: the uncritical acceptance of medical innovation.* *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 269: .”The need for ongoing assessment of both new and old medical technologies is undisputed. Nevertheless, much if not most, of contemporary medical practice still lacks a scientific foundation.” at ____.

[57] *Id.* at 1013; see also McKinlay, *supra* note __, at 376.

[58] See McKinlay, *supra* note __, at 381 (1981); Donald E. Kacmar, *The Impact of Computerized Medical Literature Databases on Medical Malpractice Litigation: Time for Another Helling v. Carey Wake-Up Call?*, 58 *OHIO ST. L.J.* 617, 631-32 (1997) (noting that “comments, articles and reports” about a treatment often “snowball into consensus” without validation, and cautioning, “[t]his cycle can impede the adoption of new, better policies and continue adherence to traditional ones”).

[59] See King & Henderson, *supra* note __, at 1021 (citing OFFICE OF TECHNOLOGY ASSESSMENT, 98th Cong., 1st Sess., *THE IMPACT OF RANDOMIZED CLINICAL TRIALS ON HEALTH POLICY AND MEDICAL PRACTICE: BACKGROUND PAPER* (Aug. 1983). See Lent, *supra* note __, at 811-13.

[60] See McKinlay, *supra* note __, at 376; Kacmar, *supra* note __, at 642 (commenting “doctors tend to look to informal information sources, such as other colleagues, for answers in lieu of looking outside their own medical circles for new studies, data, or procedures”); King & Henderson, *supra* note __, at 1022-24 (identifying this phenomenon as part of the conceptual conflict “at the heart of medicine, Is medicine essentially science or essentially treatment?” *Id.*

Some argue that all medicine should be subject to evidence-based practices rather than anecdotal transmission of procedures. See D.L. Sackett, D. L., et al., *Evidence-based Medicine: how to practice & teach EBM* __ (1997).

[61] See Kacmar, *supra* note __, at 631-32; Wilson & Reiner, *supra* note __, at 367 (commenting, “As with many clinical paradigm shifts, in the absence of data, adherents of each protocol become increasingly dogmatic that their preferred approach is better for the patient, and that it would be unethical to subject the patient to the other ‘less acceptable’

treatment. Individual clinicians' attachment to specific treatment regimes result in the ongoing polarization of paradigms.”).

[62] McKinley, *supra* note ____, at 379.

[63] MILTON DIAMOND, 1998. *Intersexuality: Recommendations for Management*. ARCHIVES OF SEXUAL BEHAVIOR, 27:634-641. at 638.

[64] See SACKETT, *supra* note ____, at ____ (“Contemporary medicine is increasingly calling for practice to follow data and research rather than anecdote and past practices for the sake of tradition ”).

[65] The kinds of surgeries performed on infants with genital anomalies are numerous. Sex reassignment is the most radical, but other surgeries also have erotic and reproductive ramifications. See KESSLER, *supra* note __, at 40-64 (discussing surgical interventions); Diamond & Sigmundson, *Management of Intersexuality*, *supra* note __, at 1047-48 (discussing nonsurgical options); MONEY, SEX ERRORS, *supra* note __, at 52-55 (discussing surgical interventions).

[66] John Money, et al., see note _____.

[67] Diamond & Sigmundson, *Sex Reassignment*, *supra* note __, at 298-99. In his most recent book, Money contends that other researchers early on misstated his contention that sex could be changed up until the age of two; that he had always asserted that “the crucial age is somewhere around eighteen months.” MONEY, SEX POLICE, *supra* note __, at 313. However, he was less clear in his original writings, “the critical period is reached by about the age of eighteen months. By the age of two and one-half years, gender role is already well established.” *Id.* at 312 (quoting his work from 1955). He now contends that J/J’s disastrous outcome could be the result of parental delay in surgery until 22 months (among other possibilities). *Id.* at 319. However, he also notes that J/J’s “social reassignment” had occurred at seventeen months. *Id.* at 315.

[68] Dreger, *supra* note __, at 29 (noting that it is easier to surgically construct a “functional” vagina than a penis).

[69] The J/J case might be considered the “ground zero” case for justifying this standard of care.

[70] MONEY & EHRHARDT, *supra* note __.

[71] See, e.g., KESSLER, *supra* note __, at 6-7, 13-14 (“According to all of the specialists interviewed, management of intersexed cases is based upon the theory of gender proposed first by John Money, J.G. Hampson, and J.L. Hampson in 1955 and developed in 1972 by Money and Anke A. Ehrhardt” that “gender identity is changeable until approximately eighteen months of age.”).

[72] See generally DREGER, *supra* note __, at 181-82; Dreger, *supra* note __, at 27; KESSLER, *supra* note __, at 6.

[73] Traumatic injury, especially to male infants, although less common than intersex births, occurs with sufficient frequency to appear in the literature as well. See *supra* note __.

[74] Diamond & Kipnis, *Pediatric Ethics*, supra note ___, at 401; Dreger, supra note ___, at 29 (reporting on estimates of 1 in 500, 1 in 1,500, and an even larger group of children with “cosmetically ‘unacceptable’ genitalia possibly subjected to repair in infancy”); cf. W.H. Kutteh, et al., *Accuracy of Ultrasonic Detection of the Uterus in Normal Newborn Infants: Implications for Infants with Ambiguous Genitalia*, 5 *ULTRASOUND OBSTETRICS GYNECOLOGY* 109 (Feb. 1995) (estimating 1 in 5,000).

Kessler notes and discusses the difficulty in determining the number of infants with intersex conditions and genitalia anomalies. *KESSLER*, supra note ___, at 135 n. 4.

At any rate, J/J’s unusual case is certainly not alone in medical literature. In another case study not lost to follow-up, a child lost his penis through trauma. The child underwent sex reassignment but “in adolescence the patient refused to continue hormonal medication and requested sex reassignment as a boy.” Ochoa, supra note ___, at 1116. See also Cowley, supra note ___, at 64 (reporting biographies and discussing changing standard of care).

[75] Dreger explains why males were surgically turned into females whereas females were left as females: clinicians treating intersex children often talk about vaginas in these children as the absence of a thing, as a space, a “hole,” a place to put something. That is precisely why opinion holds that “a functional vagina can be constructed in virtually everyone” -- because it is relatively easy to construct an insensitive hole surgically. Dreger, supra note ___, at 29; see also Diamond & Sigmundson, *Sex Reassignment*, supra note ___, at 298 (citing medical literature). While there was no evidence that the constructed female genitalia would be a better substitute, the simplistic thinking at that time, was that to be a satisfactory sexually functioning woman meant only to have a female appearing pudenda and a vagina suitable to accept a penis.

[76] See Wilson & Reiner, supra note ___, at 362-63 (describing the treatment protocol of early surgery).

[77] See *KESSLER*, supra note ___, at 136 n. 10; Diamond & Sigmundson, *Sex Reassignment*, supra note ___, at 298 (citing medical texts). See e.g., P.K. Donahoe, et al., *Clinical Management of Intersex Abnormalities*, 28 *CURRENT PROBLEMS IN SURGERY* 517, 527 (Aug. 1991); KING, supra note ___, at 369-70 (reporting prevailing view, “Up to approximately 18 months of age, sexual identity is not established and gender reassignment may be well tolerated by the child”); *Timing of Elective Surgery*, supra note ___; Woodhouse, *Ambiguous Genitalia*, supra note ___, at 689-90 (reporting on prevailing view to reassign gender in cases of micropenis of less than 2 cm).

[78] *KESSLER*, supra note ___, 12-32 (commenting that physicians refute recent critics “with nothing more than generalities No documentation (anonymous or otherwise) have been offered of adult intersexed who are pleased with their treatment.”); Diamond & Sigmundson, *Sex Reassignment*, supra note ___, at 298; Dreger, supra note ___, at 27; Wilson & Reiner, supra note ___, at 367. See also Diamond, *PEDIATRIC MANAGEMENT* at 1025 calling for review of sex reassignments done over the past decades. DAVID E., SANDBERG, HEINO F. L. MEYER-BAHLBURG, GAYA S. ARANOFF, JOHN M. SCONZO, AND TERRY W. HENSLE. 1989. Boys with hypospadias: A survey of behavioral difficulties. *JOURNAL OF PEDIATRIC PSYCHOLOGY*, 14:491-514 at 510. These authors studied boys with hypospadias and found a higher degree of gender-atypical behaviors than in a group of other boys that had various hospital surgical procedures. However, they also report their findings: “indicating that the penis may be of less significance in the process of gender development than previously thought, does not stand alone. Several studies of normal child development have demonstrated that nonanatomical characteristics, such as hair style and

clothing, are critical in children's classification of other individuals (and presumably themselves) according to sex." This study did not compare those with hypospadiac surgery with those individuals with hypospadias not having any surgery.

[79] Timing of Elective Surgery, *supra* note __, at 590 (supporting this proposition with four works authored or co-authored by Money and dating between 1957 and 1987: Money et al, *Imprinting and the Establishment of Gender Role*, 77 *ARCH. NEUROL. PSYCH.* 333 (1957)); MONEY & EHRHARDT, *MAN & WOMAN*, *supra* note __; John Money & B.F. Norman, *Gender Identity and Gender Transposition: Longitudinal Outcome Study of 24 Male Hermaphrodites Assigned As Boys*, 13 *J. SEX MARITAL THERAPY* 75 (1987)).

[80] Suzanne Kessler has written of Money's dominance in the field: Almost all of the published literature of intersexed infant case management has been written or co-written by one researcher, John Money Even the publications that are produced independently of Money reference him and reiterate his management philosophy.... Even though psychologists fiercely argue issues of gender identity and gender development, doctors who treat intersexed infants seem untouched by those debates Why Money has been so single-handedly successful in promoting his deas about gender is a question worthy of a separate and substantial debate.

KESSLER, *supra* note __, at 136 n. 10. See also Diamond & Sigmundson, *Sex Reassignment*, *supra* note __, at 298 (describing Money's dominance); DREGER, *supra* note __, at 181-82 (describing dominance of Money in developing the standards of care for intersex infants); Kitzinger, *supra* note __ (discussing Money's dominance).

Money's views have changed somewhat although he still approves sex reassignment even in cases of traumatic amputation of the penis. See MONEY, *SEX ERRORS OF THE BODY AND RELATED SYNDROMES*, 1994 , at 84 (writing of total loss of penis: "All in all, it is a difficult situation, regardless of the sex of rearing[,]") and on reassignment generally: "the most expeditious rule to follow is that no child, after the toddler age, should have a sex reassignment imposed on the basis of a [physician imposed] dogmatically held principle.")
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[81] See William Reiner, *Sex Assignment in the Neonate With Intersex or Inadequate Genitalia*, *AMER. J. OF DISEASES OF CHILDREN* 1044 (Oct. 1999) (discussing problem that children will reject the sex of rearing and commenting "surgical reduction of an enlarged clitoris can at times damage sensation and thus reduce orgasmic potential and genital pleasure and, like ablation of the testes is irreversible."); Dreger, *supra* note __, at 28.

[82] AARONSON, I. A. 1992. *Sexual differentiation and intersexuality*. In P. Kelalis, P., L. R. King and A. B. Belman (eds.), *CLINICAL PEDIATRIC UROLOGY*, pp. 977-1014, at 1005, 1007, W. B. Saunders, Philadelphia. KESSLER, *supra* note __, at 49; Dreger, *History*, *supra* note __, at 349 (commenting on standard care for clitoral surgery, "If her clitoris is longer than 1 centimeter stretched at birth, surgeons will seek to surgically reduce it because they think that it will bother the child's parents and interfere with bonding and gender identity formation.").

[83] See Wilson & Reiner, *supra* note __, at 363; Sherri A. Groveman, *The Hanukkah Bush: Ethical Implications in the Clinical Management of Intersex*, 9 *J. CLINICAL ETHICS* 356, 357-59 (1998). See also MONEY & EHRHARDT, *MAN & WOMAN*, *supra* note __, at __; MONEY, *SEX ERRORS*, *supra* note __, at __. There is no evidence presented by Money et al. that parents of children born with physical handicaps are any less bonded or otherwise protective or loving to their children. KESSLER, *supra* note ____, at 91, on the other hand,

presents cases where the parents accept the intersex condition if it is presented well or have severe misgivings for giving in to the physicians' urging for surgery. There also are studies that show that children might be aware of the appearance of their own or peer's genitals but don't consider them crucial for classification of gender until about the age of 9 (RONALD GOLDMAN, AND JULIETTE GOLDMAN. 1982. CHILDREN'S SEXUAL THINKING: A COMPARATIVE STUDY OF CHILDREN AGED 5 TO 15 YEARS IN AUSTRALIA, NORTH AMERICA, BRITAIN, AND SWEDEN. Routledge & Kegan Paul, London, England.)

[84] See Reiner, *Sex Assignment*, supra note __; Dreger, supra note __, at 32 (noting a lack of long-term follow-up on females undergoing clitoral surgery); Diamond & Sigmundson, *Management of Intersexuality*, supra note __, at 1047; Cowley, supra note __, at 66 (reporting on study of female pseudohermaphrodites (genetic females born with masculinized external sex organs) wherein five of twelve surgically reduced clitorises "had withered and died" as a result of surgical intervention). Annie Green, writes: "Thirty-two years have passed since my clitoris was taken from me. Though I was too young to be able now to recall the event, I feel that I will be grieving the loss for the rest of my life." Annie Green, *My Beautiful Clitoris*, 2 *CHRYSALIS* 12 (1997). And Cheryl Chase, an advocate for the intersexed, warns that better clitoral surgery is not the proper response to an enlarged phallus. Cheryl Chase, *Surgical Progress Is Not the Answer to Intersexuality*, 9 *J. CLIN. ETHICS* 385, 386-87 (1998). Physicians practicing today acknowledge the surgical techniques of just a decade ago on clitoral surgery yielded poor results. The comments of Associate Professor of Urology and Pediatrics Laurence Baskin in response to a visit by ISNA members to the University of California, San Francisco medical school is revealing:

Baskin admits that surgical technique in the past was not optimal. "The surgery was done ... by very well intended physicians, but we didn't understand the nerve supply well. We started to understand the nerve supply [to the clitoris] 10 years ago."

Althaea Yronwode, *Intersex Individuals Dispute Wisdom of Surgery on Infants*, *SYNAPSE*, March 11, 1999, available at <<http://itsa.ucsf.edu/~synapse/archives/mar11.99/yronwode.html>>. [from *TRANSGENDER TAPESTRY*, 1999:18-21, 32.

Kenneth Glassberg continues to perform clitoral surgery for cosmetic reasons while calling for long-term studies to evaluate the importance of the clitoral tissue in preserving clitoral orgasm. GLASSBERG, 1998. *The intersex infant: Early gender assignment and surgical reconstruction*. *JOURNAL OF PEDIATRIC AND ADOLESCENT GYNECOLOGY*, 11:151-154. at 153.

[85] See generally Joanne A. Liu, *When Law and Culture Clash: Female Genital Mutilation, A Traditional Practice Gaining Recognition as a Global Concern*, 11 *N.Y. INT'L. L. REV.* 71 (1998); Joleen C. Lenihan, *A Physician's Dilemma, Legal Ramifications of an Unorthodox Surgery*, 35 *SANTA CLARA L. REV.* 953 (1995). Both Kessler and Dreger liken the surgical treatment of ambiguous genitalia for cosmetic and cultural reasons to female genital mutilation. See KESSLER, supra note __, at 80-83; Dreger, supra note __, at 33-34.

[86] Milton Diamond, *Pediatric Management of Ambiguous Genitalia and Traumatized Genitalia*, __ *J. UROLOGY* __ (1999); Chase, *Surgical Progress*, supra note __, at 386; Kipnis & Diamond, supra note __, at 402-03. Meyer-Bahlburg has written: "Some female-assigned patients with a history of clitoromegaly will end up changing their gender to male, and in those cases, a history of clitorrectomy or clitoral resection with the reduction of loss of a penile organ altogether causes great regret. In my clinical experience, also some patients

who live as lesbian women would prefer if their enlarged clitoris had been left intact." HEINO F. L. MEYER-BAHLBURG, 1998. Gender assignment in intersexuality. *JOURNAL OF PSYCHOLOGY & HUMAN SEXUALITY*, 10:1-21 at 12.

[87] See Criminalization of Female Genital Mutilation Act, 18 U.S.C.A. § 116.

[88] Congressional Findings, at Pub. L. No. 104-208, § 645(a) (2), 110 Stat. 3009-708.

[89] 18 U.S.C. § 116 (a).

[90] 18 U.S.C. § 116 (b)(1). See KESSLER, *supra* note __, at 81-82 (commenting on ISNA position that the language is sufficiently broad to cover some intersex surgeries); Dreger, *supra* note __, at 34. Some suggest that the act violates the equal protection because it protects females but not males from the customary practice of circumcision. See Ross Povenmire, Do Parents Have the Legal Authority to Consent to the Surgical Amputation of Normal, Healthy Tissue from Their Infant Children?: The Practice of Circumcision in the United States, 7 *AM. U. J. GENDER SOC. POL'Y* 87, __ (1999).

[91] Congresswoman Patricia Schroeder has written against the practice of genital mutilation. Schroeder, 1994. Female genital mutilation-- a form of child abuse. *THE NEW ENGLAND JOURNAL OF MEDICINE*, 331:739-740.

[92] For elaboration on the distinctions between innovation, practice and experimentation, see BELMONT REPORT, *supra* note __, at 3; Cowen, *supra* note __; King & Henderson, *supra* note __; Karine Morin, The Standard of Disclosure in Human Subject Experimentation, 19 *J. Legal Med.* 157, 167 (1998).

[93] *Pediatrics*. 1996. Timing of elective surgery on the genitalia of male children with particular reference to the risks, benefits, and psychological effects of surgery and anesthesia. *Pediatrics*, 97:590-594.

[94] Cowley, *supra* note __, at 66 (noting scarcity of both medical and psychological studies); Ochoa, *supra* note __, at 1119 (calling for more study); Woodhouse, *supra* note __, at 692 (questioning wisdom of sex reassignment surgery in children with micropenis and lack of long-term study); Diamond & Sigmundson, Sex Reassignment, *supra* note __, at 303 (noting lack of validating studies and need for long-term follow-up); Kipnis & Diamond, Pediatric Ethics, *supra* note __, at 402; William Reiner, To Be Male or Female -- That is the Question, 151 *ARCHIVE OF PEDIATRIC MEDICINE* 224, 225 (1997) (calling for more research and cautioning, "It may well be said that conclusions about sex reassignment as described in much of the literature are erroneous secondary to the conspicuous lack of such longitudinal data and appropriate longitudinal analysis."); Justine Marut Schober, A Surgeon's Response to the Intersex Controversy, 9 *J. CLIN. ETHICS* 393, 394 (1998) (noting lack of long-term studies regarding psychological adjustment); Wilson & Reiner, *supra* note __, at 367; Diamond, *PEDIATRIC MANAGEMENT*, *The Journal of Urology* 162 (1999) at 1026.

[95] Reiner, To Be Male or Female, *supra* note __, at 225; Ochoa, *supra* note __, at 1119; Woodhouse, *supra* note __, at 692; William George Reiner, Case Study: Sex Reassignment in a Teenage Girl, 35 *J. AM. ACAD. CHILD & ADOLESCENT PSYCH.* 799 (1996) [hereinafter Teenage Girl]; Reiner, Sex Assignment *supra* note __ (noting his own studies with "18 children who are 46, XY males with totally inadequate phalluses but normal testes that were sex assigned to female, demonstrate that parents tend to be uncomfortable with sex reassignment and children do not behave as typical little girls.").

[96] See Diamond & Sigmundson, *supra* note __, at 302 (noting “cases of infant sex reassignment require inspection after puberty; 5- and 10-year post sex reassignment are still insufficient”).

[97] The medical community has become polarized on treatment issues. The *Journal of Clinical Ethics*'s symposium issue on intersexuality reported, “The parties in this discussion have become increasingly estranged. Alice Domurat Dreger, guest editor of this special issue ... informs us that she invited some of those who have acted as proponents of infant surgery to present their arguments, but none accepted.” Edmund G. Howe, *Intersexuality: What Should Careproviders Do Now?*, 9 *J. CLIN. ETHICS* 337, 338 (1998). See also Wilson & Reiner, *supra* note __, at 367.

[98] Wilson and Reiner note that there is “considerable support for the theory that there may be a neurobiologic component to many gender identities” and that gender may be influenced by hormone levels in the brain “prenatally or immediately postnatally” and conclude, “[c]ertainly gender identity involves more than the behaviors of the parents in rearing children.” Wilson & Reiner, *supra* note __, at 364. See also Milton Diamond, *Biological Aspects of Sexual Orientation and Identity*, in *The Psychology of Sexual Orientation, Behavior and Identity: A Handbook* 48 (Greenwood Press, Westport, Connecticut) (L. Diamant & R. McAnulty eds., 1995); M. Hines, *Abnormal Sexual Development and Psychosexual Issues*, 12 *BAILLIER'S CLIN. ENDOCRINOLOGY & METABOLISM*, 173, __ (1998) (nevertheless, Hines is reluctant to recommend change in the “standard of care”); S. LeVay, & D.H. Hamer, *Evidence for a Biological Influence in Male Homosexuality*, *SCIENTIFIC AMERICAN* 44-49 (May 1994); D. Hamer, & P. Copeland, *LIVING WITH GENES: WHY THEY MATTER MORE THAN YOU THINK* (1998); LeVay, S., *QUEER SCIENCE* __ (1996).

[99]

Diamond and Sigmundson explain: Most intersex conditions can remain without any surgery at all. A woman with a phallus can enjoy her hypertrophied clitoris and so can her partner. Women with AIS or virilizing CAH who have smaller-than-usual vaginas can be advised to use pressure dilations to fashion one to facilitate coitus; a woman with partial AIS likewise can enjoy a large clitoris. A male with hypospadias might have to sit to urinate without mishap but can function sexually without surgery. A person with a micropenis can satisfy a partner and father children.

Diamond & Sigmundson, *Management of Intersexuality*, *supra* note __, at 1049. See also Dreger, *supra* note __, at 29-32; A. Lev-Ran, *Gender Role Differentiation in Hermaphrodites*, 3 *ARCHIVES SEXUAL BEHAV.*, 391-424 (1974) (describing numerous cases where individuals adapted to gender atypical genitalia).

[100] See KESSLER, *supra* note __, at 105-32; Dreger, *supra* note __, at 94.

It is, unfortunately, only recently that it has been revealed that a study of more than 250 intersexed individuals who received no surgical intervention as babies was conducted prior to 1952 but left unpublished in the professional literature. The review by John Money found: “Far from manifesting psychological traumas and mental illnesses, the study showed, the majority of patients rose above their genital handicap and not only made an ‘adequate adjustment’ to life, but lived in a way virtually indistinguishable from people without genital difference.” See JOHN COLAPINTO, at 227. One can only conjecture as to why this study was never mentioned nor considered by its author after its presentation as a senior dissertation at Harvard (available by written application to the Widener Library at Harvard University).

[101] Ochoa, *supra* note __, at 1118-19.

[102] See generally HARRY BENJAMIN, *THE TRANSSEXUAL PHENOMENON* __ (1966); Milton Diamond, *Self-Testing Among Transsexuals: A Check on Sexual Identity*, 8 J. PSYCH. & HUMAN SEXUALITY 61, __ (1996).

[103] See Bockting, W. O., and E. Coleman. 1992. *GENDER DYSPHORIA: INTERDISCIPLINARY APPROACHES IN CLINICAL MANAGEMENT*, The Haworth Press, New York; Bullough, B., V. L. Bullough, and J. Elias. 1997. *GENDER BLENDING*. Prometheus Books, Amherst, New York.; Devor, H. 1989. *GENDER BLENDING: CONFRONTING THE LIMITS OF DUALITY*. Indiana University Press, Bloomington, Indiana.

[104] Diamond, *Ambiguous and Traumatic*, *supra* note __ at 1023. See also Reiner, *To Be Male or Female*, *supra* note __, at 225 (reporting on his ongoing research and stating that he is following fifteen 46 XY children who were castrated at birth due to genital anomalies, stating that although reared as females the patients “do not appear to be classically male or female but display masculine characteristics that are in many cases quite striking”); A recent article reports of one individual who was sex reassigned and, at the age of 28, remains living as a woman. She, however, has a male-identified job and is ambisexually oriented and presently living with a female sexual partner. See Susan J. Bradley, et al., *Experiment of Nurture: Ablatio Penis at 2 Months, Sex Reassignment at 7 Months Psychosexual Follow-up in Young Adulthood*, 102 PEDIATRICS 1 (1998) (full text available at <<http://www.pediatrics.org/cgi/content/full/102/1/e9>>).

[105] Reports of adverse outcomes have been met with ambivalence in the medical community. More recently, surgeons have been criticized because they have not accorded enough weight to patients’ reports of adverse outcomes. There is a psychological reason that careproviders may ignore reports of adverse outcomes: if the claims are true, surgeons would have to acknowledge that performing surgery was a mistake. This would be exceedingly painful. The only way to avoid this pain would be to deny that these claims are true. Howe, *supra* note __, at 338.

[106] ISNA, *Recommendations for Treatment Intersex Infants and Children*, available at <<http://www.isna.org/recommendations.html>>(last visited April 2, 1999) [hereinafter ISNA Recommendations]. Money reserves particularly harsh criticism for ISNA, labeling the organization as “militantly activist” in advocating raising the intersex child as an “it,” which he regards as a step backward. MONEY, *SEX, SIN*, *supra* note __, at 320-21. ISNA has never advocated raising children as “its.” They advocate sexual assignment but without any surgery. So too does Diamond, advocate raising the child in a clear gender but without cosmetic genital altering surgery. UROLOGY at 1025. Kenneth Glassberg, on the other hand, argues “There are no data to support the benefits of delayed assignment or treatment of these infants and I can’t imagine any parent, without whose wholehearted cooperation any treatment program will fail, accepting such an approach.”KENNETH I. GLASSBERG, 1999. Editorial: Gender assignment and the pediatric urologist. THE JOURNAL OF UROLOGY, 161:1308-1310. at 1308.

[107] See, e.g., Groveman, *supra* note __, at 356; Chase, *supra* note __, at 385.

[108] See Diamond & Sigmundson, *supra* note __, at 298 (discussing and citing medical literature recommending sex reassignment based on surgical potential); see also KESSLER, *supra* note __, at 108-109 (discussing criteria for surgery in females and males); Donahoe,

supra note __, at 527 (commenting, “[g]enetic females should always be raised as females, preserving reproductive potential, regardless of how severely the patients are virilized. In the genetic male, however, the gender of assignment is based on the infant’s anatomy, predominantly the size of the penis”); Newman, supra note __, at 645 (commenting, “In practical terms, regardless of the genotype, most children with ambiguous genitalia are best suited for the female role.”).

[109] See KESSLER, supra note __, at 34-35; MONEY, MAN/WOMAN, supra note __, at 178-79; MONEY, SEX ERRORS, supra note __, at 82.

[110] See, e.g., Donahoe, supra note __, at 527 (“[I]t cannot be overly stressed that the 46 XY [genetic male] Karyotype does not dictate rearing the child as a male if the phallus is inadequate in size.... If the phallus length is less than 2.0 cm and certainly less than 1.5 cm, we are quite concerned....”); Lowell King, supra note __, at 369.

[111] Some but not all intersex and ambiguous conditions impact reproductive capacity. Standard care encourages preservation of female reproductive capacity but decisions as to males is based on penis size, not reproductive capacity. See Patricia K. Donahoe, *Clinical Management of Intersex Abnormalities*, 28 CURRENT PROBLEMS SURGERY 517, 527 (Aug. 1991).

[112] MONEY, SEX ERRORS, 2nd ed, supra note __, at 66.

[113] See generally FURROW, supra note __, at § 6-2, at 361; Sam A. McConkey, *Simplifying the Law in Medical Malpractice: The Use of Practice Guidelines as the Standard of Care in Medical Malpractice Litigation*, 97 W. VA. L. REV. 491, 496-97 (1995).

[114] *The T. J. Hooper*, 60 F.2d 737 (2d Cir. 1932).

[115] *Id.* at 739.

[116] *Texas Pac. Ry. v. Behymer*, 189 U.S. 468, 470 (1903) (Holmes, J.).

[117] 60 F.2d at 739.

[118] *Toth v. Community Hospital at Glen Cove*, 239 N.E.2d 368, 373 (N.Y. App. 1968); FURROW, supra note __, at 359-62.

[119] *Gorab v. Zook*, 943 P.2d 423, 427 (Colo. 1997) (en banc).

[120] *Id.* (quoting Colorado Jury Instruction 15:2).

[121] See *Turner v. Children’s Hosp., Inc.*, 602 N.E.2d 423, 427 (Ohio App. 1991).

[122] *Id.* at 427.

[123] See *Harris v. Groth*, 663 P.2d 113, 115 (Wash. 1983) (en banc); See generally Hall, supra note __, at 126-27 (noting distinction between “garden-variety tort cases” where jury is “ultimate arbiter” and medical malpractice where “jurors are instructed to judge physicians not by the jury’s sense of what is right, but by the custom that prevails in the profession”); Gary T. Schwartz, *Medical Malpractice, Tort, Contract and Managed Care*, 1998 U. ILL. L. REV. 885, 890.

The existence of a uniform standard of care is probably more of a legal fiction than medical profession fact. See Hall, *supra* note ___, at 121 n.10, 128-30 n. 38 (commenting “the law has always presumed the existence of that which does not exist -- established, concrete professional standards”).

[124] Craft v. Peebles, 893 P.2d 138, 147 (Haw. 1995) (“It is well settled that in medical malpractice actions, the question of negligence must be decided by reference to relevant standards of care for which plaintiff carries the burden of proving through expert testimony.”). See also FURROW, *supra* note ___, at 361 (commenting that “[t]he standards for evaluating the deliver of professional medical services are not normally established by either judge or jury”).

[125] Helling v. Carey 519 P.2d 981 (Wash. 1974) (citing The T.J. Hooper, 60 F.2d 737 (2d Cir. 1932) (holding that irrespective of medical standards, reasonable prudence would require providing inexpensive pressure tests to all ophthalmological patients where the test is inexpensive and simple).

[126] *Id.* at 982.

[127] *Id.*

[128] *Id.* at 983.

[129] *Id.*

[130] *Id.*

[131] In Harris v. Robert C. Groth, M.D., Inc., 663 P.2d 113 (1983), the Washington Supreme Court recounted the professional and legislative reaction to its decision in Helling v. Carey, 519 P.2d 981 (Wash. 1974). Harris, 663 P.2d at 115-16. Notably, Harris held that even following the legislature’s purported overruling of Helling, Washington continues to hold to a “reasonably prudent” physician and that “the degree of care actually practiced by members of the profession is only some evidence of what is reasonably prudent, it is not dispositive.” *Id.* at 120. See Lent, *supra* note ___, at 829-30.

[132] FURROW, *supra* note ___, at 361 (“Most jurisdictions ... have been reluctant to follow Helling in replacing the established medical standard of care with a case-by-case judicial balancing.”). Cases in apparent accord with Helling include: United Blood Services, Div. of Blood Systems, Inc. v. Quintana, 827 P.2d 509, 520 (Colo. 1992) (en banc) (“If the standard adopted by a practicing profession were to be deemed conclusive proof of due care, the profession itself would be permitted to set the measure of its own legal liability, even though that measure might be far below a level of care readily attainable through the adoption of practices and procedures substantially more effective in protecting others against harm than the self-decreed standard of the profession.” but holding that expert testimony is necessary to establish that one school of practice’s standard of care is unreasonably deficient); Nowatske v. Osterloh, 543 N.W.2d 265 (Wis. 1996) (denying that traditional malpractice standard differs from ordinary negligence); Townsend v. Kiracoff, 545 F. Supp. 465 (D. Colo. 1982) (citing The T.J. Hooper, 60 F.2d 737 (2d Cir. 1932) (“even if the defendant’s affidavits and evidentiary materials could establish that the hospital acted in accordance with the standard of care and custom of the community of Colorado hospitals, the plaintiff would still be entitled to prove at trial that the entire community’s custom is negligent”); Turner v. Children’s Hospital, 602 N.E.2d 423, 427 (Ohio App. 1991) (stating, “although customary practice is

evidence of what a reasonably prudent physician would do under like or similar circumstances, it is not conclusive in determining the applicable standard required.”).

[133] See, e.g., *Osborn v. Irwin Memorial Blood Bank*, 7 Cal. Rptr.2d 101, 125-126 (Cal. App. 1992) (rejecting *Helling v. Carey*, and noting that most commentary and case law has been critical of the case); Schwartz, *supra* note __, at 890; Clark Havighurst, *Private Reform of Tort-Law Dogma: Market Opportunities and Legal Obstacles*, 49 *LAW & CONTEMP. PROBS* 143, 159 n. 45 (1986). But see Dan Dobbs, et al., *Prosser and Keeton on the Law of Torts* § 33 at 30 n. 53 (noting “increasing number of courts rejecting customary practice standard in favor of reasonable care or reasonably prudent doctor standard” and citing cases) (5th ed. 1988 pocket part); Theodore Silver, *One Hundred Years of Harmful Error: The Historical Jurisprudence of Medical Malpractice*, 1992 *WIS. L. REV.* 1193,1212-1219 (arguing for a return to negligence principles).

[134] Schwartz, *supra* note __, at 890.; see also Gary T. Schwartz, *The Beginning and the Possible End of the Rise of Modern American Tort Law*, 26 *GA. L. REV.* 601, 663-64 (1992) [hereinafter *Modern American Tort Law*] (noting that *Helling v. Carey* has not garnered support, “[malpractice] conservatism has largely survived the 1980s”); cf. Richard E. Leahy, *Rational Health Policy and the Legal Standard of Care: A Call for Judicial Deference to Medical Practice Guidelines*, 77 *CALIF. L. REV.* 1483, 1502-06 (1989) (arguing that courts and juries have too much independence to establish and judge the medical standard of care and proposing judicial deference to professionally promulgated guidelines).

[135] See Kacmar, *supra* note __, at 631-32 (noting in malpractice actions there is substantial reliance on the medical profession to define its own standard of care and lack of incentive to keep abreast); Silver, *supra* note __, at 1212-19; Leahy *supra* note __, at 1495-97.

[136] Kacmar, *supra* note __, at 643.

[137] See *Rooney v. Medical Center Hosp. of Vermont*, 649 A.2d 756, 759 (Vt. 1994) (“To practice the profession of medicine, a physician is not required to be possessed of the extraordinary knowledge and ability that belongs to the few practitioners of rare endowments. But the physician is required to keep abreast of new techniques and knowledge and to practice in accordance with the approved methods and means of treatment in general use [in his field].”). See also Kacmar, *supra* note __, at 641.

[138] *Id.* (citing Angela Roddey Holder, *Failure to “Keep up” as Negligence*, 224 *JAMA* 1461, 1462 (1973)).

[139] Schwartz, *American Tort Law*, *supra* note __, at 664.

[140] See *Hood v. Philips*, 537 S.W.2d 291, 294 (Tex. App. 1976) (holding “a physician is not guilty of malpractice where the method of treatment used is supported by a respectable minority of physicians, as long as the physician has adhered to the acceptable procedures of administering treatment as espoused by that minority”). See also Schwartz, *American Tort Law*, *supra* note __, at 664-65 (commenting that traditional tort law has held that “when intelligent doctors can disagree, the defendant cannot be found guilty of malpractice”); Joan P. Dailey, *Comment, The Two Schools of Thought and Informed Consent Doctrines in Pennsylvania: A Model for Integration*, 98 *DICK. L. REV.* 713 (1994).

[141] An alternative view is possible, one in which the two schools might be measured against one another. One court reasoned that where two schools differ, “plaintiff should be permitted to present expert opinion testimony that the standard of care adopted by the school

of practice to which the defendant adheres is unreasonably deficient by not incorporating readily available practices and procedures substantially more protective against the harm caused to the plaintiff than the standard of care adopted by the defendant's school of practice." *United Blood Services v. Quintana*, 827 P.2d 509, 521 (Colo. 1992) (en banc).

[142] Furrow notes that "clinical innovation allows physicians to vary standard treatment to suit the needs of a particular patient, where the patient presents a particular problem or desperate situation." FURROW, *supra* note ___, at § 6-5, at 385. However, he notes that courts rarely allow such a defense except in instances "when conventional treatments are largely ineffective or where the patient is terminally ill and has little to lose by experimentation with potentially useful treatments." *Id.*

[143] *Osborn v. Irwin Memorial Blood Bank*, 7 Cal. Rptr.2d 101, 125-26 (Cal. App. 1992) (citations omitted).

[144] In the case of surgical treatment for cases of ambiguous it is probably more a matter of "following the leader" rather than ignorance.

[145] See *supra* notes ___.

[146] MONEY, SEX ERRORS, 1st ed., *supra* note ___, at 48.

[147] MONEY, SEX ERRORS, 1st ed., *supra* note ___, at 93.

[148] King & Henderson, *supra* note ___, at 1021; see also Lent, *supra* note ___, at 808.

[149] *United Blood Services v. Quintana*, 827 P.2d 509, 520 (Colo. 1992) (en banc) (quoting *The T.J. Hooper*, 60 F.2d 747, 740 (2d Cir. 1032)).

[150] *Id.*

[151] See Sackett et al, *supra* note ____ at 115-116. Four guides were offered for the evaluation of a proposed medical guideline: 1) Were all important decision options and outcomes clearly specified?; 2) Was the evidence relevant to each decision option identified, validated and combined in a sensible and explicit way?; 3) Are the relative preferences that key stakeholders attach to the outcomes of decisions (including benefits, risks and costs) identified and explicitly considered?; 4) Is the guideline resistant to clinically sensible variations in practice?

[152] See Kacmar, *supra* note ___, at 633-39.

[153] See generally RUTH R. FADEN & TOM L. BEAUCHAMP, *A HISTORY AND THEORY OF INFORMED CONSENT* (1986) (tracing history and discussing moral underpinnings of informed consent doctrine in medical tradition).

[154] See Susan D. Hawkins, *Protecting the Rights and Interests of Competent Minors in Litigated Medical Treatment Disputes*, 64 *FORDHAM L. REV.* 2075, 2093-94 (1996)

[155] *Cruzan v. Director, Mo. Dep't. of Health*, 497 U.S. 261, 269 (1990) (quoting *Union Pacific R. Co. v. Botsford*, 141 U.S. 250, 251 (1891)).

[156] See Hawkins, *supra* note ___, at 2094-2102 (other interests include privacy, to be free of unwanted physical invasions, and preservation of life); James Bopp, Jr. & Richard E.

Coleson, A Critique of Family Members as Proxy Decisionmakers Without Legal Limits, 12 ISSUES L. & MED. 133, 134-35 (1996). See also *Fiori v. Pennsylvania*, 673 A.2d 905, 909-10 (Pa. 1996) (commenting, “[t]he right to refuse medical treatment has deep roots in our common law.... [f]rom this right to be free from bodily invasion developed the doctrine of informed consent”).

[157] *Turner v. Children’s Hospital, Inc.*, 602 N.E.2d 423, 431 (Ohio App. 1991).

[158] *Carr v. Strode*, 904 P.2d 489, 493 (Haw. 1995).

[159] *Wheeldon v. Madison*, 374 N.W.2d 367, 375 (S.D. 1985) (citing *Canterbury v. Spence*, 464 F.2d 772, 787 (D.C. Cir. 1972)).

[160] See generally Annotation, Modern Status of Views as to General measure of Physician’s Duty to Inform Patient of Risks of Proposed Treatment, 88 A.L.R.3d 1008, §§ 3, 6-7; William J. McNichols, Informed Consent Liability in a “Material Information” Jurisdiction: What Does the Future Portend?, 48 OKLA. L. REV. 711, 716-17 (1995) (describing state trends); Richard A. Heinemann, Pushing the Limits of Informed Consent: *Johnson v. Kokemoor* and Physician Specific Disclosure, 1997 WISC. L. REV. 1079, 1082-86 (discussing patient-oriented standard and describing trends).

[161] See *Carr v. Strode*, 904 P.2d 489, 490 (Haw. 1995) (tracing evolution of standard and overruling prior case adopting physician-oriented standard). The seminal case rejecting the physician-oriented standard and adopting the patient-oriented standard is *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972). See also *Congrove v. Holmes*, 308 N.E.2d 765 (Ohio 1973); *Arena v. Gingrich*, 748 P.2d 547 (Or. 1988); *Corrigan v. Methodist Hosp.*, 869 F. Supp. 1202 (E.D.Pa. 1994); *Wilkinson v. Vesey*, 295 A.2d 676 (R.I. 1972); *Shadrick v. Coker*, 963 S.W.2d 726 (Tenn. 1998); *Stripling v. McKinley*, 746 S.W.2d 502, *aff’d*, 763 S.W.2d 407 (Tex. 1988).

[162] See *Gorab v. Zook*, 943 P.2d 423, 428 n. 5 (Colo. 1997) (en banc) (noting evidentiary differences between patient-oriented informed consent doctrine and medical community standard of care).

[163] *Id.* (emphasis in original). Physicians must provide information concerning “material risks” and, at least in some jurisdictions, they must provide information about alternative treatments. See *Doe v. Johnston*, 476 N.W.2d 28, 30-31 (Iowa 1991).

[164] *Cooper v. Roberts*, 286 A.2d 647, 650 (Pa. 1971) (“As the patient must bear the expense, pain and suffering of any injury from medical treatment, his right to know all material facts pertaining to the proposed treatment cannot be dependent upon the self-imposed standards of the medical profession.”).

Cobbs v. Grant, 8 Cal 3d 229, 104 Cal. Rptr. 308, 611 P.2d 598 (1993) (“A medical doctor, being the expert, appreciates the risks inherent in the procedure he is prescribing, the risks of the decision not to undergo treatment and the probability of a successful outcome of the treatment . . . The weighing of these risks against the individual subjective fears and hopes of the patient is not an expert skill. Such evaluation and decision is a nonmedical judgement reserved to the patient alone.”) This language explicitly requires physicians to explain the probability of success and requires the physician to tell the patient what he means by success. GEORGE J. ANNAS, 1994. Informed consent, cancer, and truth in prognosis. THE NEW ENGLAND JOURNAL OF MEDICINE, 330:223-225, at 225.

[165] GEORGE J. ANNAS, 1994. Informed consent, cancer, and truth in prognosis. *THE NEW ENGLAND JOURNAL OF MEDICINE*, 330:223-225, at 225. (“Of course, the doctrine of informed consent is based on the recognition that people are not all the same and that physicians must let patients decide about treatment options so that they do not treat them “always the same way for everybody alike.”)

[166] Carr, 904 P.2d at 485.

[167] Canterbury, 464 F.2d at 789.

[168] See *Nishi v. Hartwell*, 473 P.2d 116 (Haw. 1970), overruled on other grounds, *Carr v. Strode*, 904 P.2d 489 (Haw. 1995) (patient’s fear and apprehension justified not telling him of “collateral hazard” of paralysis associated with diagnostic procedure regarding aneurysm).

[169] *Nishi*, 473 P.2d at 121.

[170] See *McNichols*, supra note ___, at 728-79 & n. 97 (noting scarcity of decisions based upon therapeutic privilege defense). Compare *Roberts v. Wood*, 206 F. Supp. 579, 583 (Ala. 1962) (finding disclosure adequate and noting, “Doctors frequently tailor the extent of their pre-operative warnings to the particular patient, and with this I can find no fault. Not only is much of the risk of a technical nature beyond the patient’s understanding, but the anxiety, apprehension, and fear generated by a full disclosure may have a very detrimental effect on some patients.”) with *Cornfeld v. Tongen*, 262 N.W.2d 684, 700 (Minn. 1977) (rejecting therapeutic privilege defense where doctor testified that “he did not want to concern her with what he regarded as a foregone conclusion”);

[171] See *Canterbury*, 464 F.2d at 92; *McNichols*, supra note ___, at 728.

[172] *Rosebush v. Oakland County Prosecutor*, 491 N.W.2d 633, 636 (Mich. App. 1992) (commenting, “[t]he right to refuse lifesaving medical treatment is not lost because of incompetence or the youth of the patient”); *Custody of a Minor*, 393 N.E.2d 836, 844 (Mass. 1979) (stating that incompetent persons enjoy the same panoply of rights and choices of competent persons).

[173] See generally Committee on Bioethics, American Academy of Pediatrics, *Informed Consent, Parental Permission, and Assent in Pediatric Practice*, POLICY REFERENCE GUIDE 496 (1997) (also available at 95 PEDIATRICS 314 (Feb. 1995)); Joseph P. McMenamin & Karen Iezzi Michael, *Children As Patients*, in *LEGAL MEDICINE* 396 (American College of Legal Medicine, ed., 4th ed. 1998); Bopp & Coleson, supra note ___; Dena S. Davis, *Genetic Dilemmas and the Child’s Right to an Open Future*, 28 RUTGERS L.J. 549 (1997); Leslie P. Francis, *The Roles of the Family in Making Health Care Decisions for Incompetent Patients*, 1992 UTAH L. REV. 861; Leonard H. Glantz, *Research with Children*, 24 AM. J.L. & MED. 213 (1998); Marcia Gottesman, *Civil Liability for Failing to Provide ‘Medically Indicated Treatment’ to a Disabled Infant*, 20 FAM. L.Q. 61 (1986); Louise Harmon, *Falling Off the Vine: Legal Fictions and the Doctrine of Substituted Judgment*, 100 YALE L.J. 1 (1990); Hawkins, supra note ___; Robert J. Katerberg, *Institutional Review Boards, Research on Children, and Informed Consent of Parents: Walking the Tightrope Between Encouraging Vital Experiments and Protecting Subjects’ Rights*, 24 J.C. & U.L. 545 (1998); Ann MacLean Massie, *Withdrawal of Treatment for Minors in a Persistent Vegetative State: Parents Should Decide*, 35 ARIZ. L. REV. 173 (1993); Andrew Popper, *Averting Malpractice By Information: Informed Consent in the Pediatric Treatment Environment*, 47 DEPAUL L. REV. 819 (1998); Elyn R. Saks, *Competency to Refuse Treatment*, 69 N.C. L. REV. 945 (1991); Robyn S. Shapiro & Richard

Barthel, *Infant Care Review Committees: An Effective Approach to the Baby Doe Dilemma?*, 37 HASTINGS L.J. 827 (1986); Walter Wadlington, *Medical Decision Making For And By Children: Tensions Between Parent, State, and Child*, 1994 U. ILL. L. REV. 311; Amy Elizabeth Bruskey, *Comment, Making Decisions for Deaf Children Regarding Cochlear Implants: The Legal Ramifications of Recognizing Deafness as a Culture Rather than a Disability*, 1995 WISC. L. REV. 235; Rachel M. Dufault, *Comment, Bone Marrow Donations By Children: Rethinking the Legal Framework in Light of Curran v. Bosze*, 24 CONN. L. REV. 211 (1991); Elizabeth J. Sher, *Note, Choosing for Children: Adjudicating Medical Care Disputes Between Parents and the State*, 58 N.Y.U. L. REV. 157 (1983).

[174] Conceptually, the parent's duty to make decisions is sometimes characterized as a parental right. When the law views the parental obligation to make decisions as a parental right, then the child's rights might be subordinated to their parents. See RICHARD H. NICHOLSON, *MEDICAL RESEARCH WITH CHILDREN: ETHICS, LAW, AND PRACTICE* 132 (1986). Whether viewed as a right or duty, parental decisions are cloaked in deference arising out of the right to privacy and the right to parental autonomy under the Fourteenth Amendment. See, e.g., *Wisconsin v. Yoder*, 406 U.S. 205 (1972).

[175] The judicial decision maker "must 'substitute itself as nearly as may be [possible] for the incompetent and ... act upon the same motives and considerations as would have moved' the incompetent." Dufault, *supra* note ___, at 221-22 (quoting *City Bank Farmers Trust Co. v. McGowan*, 323 U.S. 594, 599 (1945)).

[176] "The fundamental difference between the use of substituted judgment and the 'best interests of the child test' under such conditions lies not in the decision reached, which may be the same, but in the vantage from which the decision is reached." *Id.* at 227. See *Rosebush v. Oakland County Prosecutor*, 491 N.W.2d 633, 639 (Mich. App. 1992) (discussing difference and commenting that preference in surrogate decision making is to use a substituted judgment standard and best interest standard where a preference was never stated or is otherwise unknown). See also Catherine L. Annas, *Irreversible Error: The Power and Prejudice of Female Genital Mutilation*, 12 J. CONTEMP. HEALTH L. & POL'Y 325, 337 n. 123 (1996).

[177] Dufault, *supra* note ___, at 214-215.

[178] *Parham v. J.R.*, 442 U.S. 584, 602 (1979); *In re. L.H.R.* 321 S.E.2d 716 (Ga. 1984) ; see also *Hawkins*, *supra* note ___, at 2081; *Sher*, *supra* note ___, at 171-72; Dufault, *supra* note ___, at 218-19.

[179] *Fiori v. Pennsylvania*, 673 A.2d 905, 912 (Pa. 1996) (acknowledging right of mother to order removal of life support of adult son in persistent vegetative state).

[180] See *In re Doe*, 418 S.E.2d 3, 7 n. 6 (Ga. 1992) (commenting that parents do not have an "absolute right to make medical decisions for their children"); *McMenamin & Michael*, *supra* note ___, at 397; Dufault, *supra* note ___, at 212-15 (tracing historical perspective of parental right to make medical decisions); NICHOLSON, *supra* note ___, at 133-34 (discussing limits of parental authority). See also *Povenmire*, *supra* note ___, at ___.

[181] 1992) See *Rosebush v. Oakland County Prosecutor*, 491 N.W.2d 633, 637 (Mich. App. 1992) ("We hold that the decision-making process should generally occur in the clinical setting without resort to the courts, but that courts should be available to assist in decision making when an impasse is reached.").

[182] See Sher, *supra* note ___, at 168-69 (noting that the courts resolve conflicts between the state and the parent and “few courts recognize that children have an interest to articulate independent of their parents or the state”).

[183] See generally ROGER B. DWORKIN, *LIMITS: THE ROLE OF THE LAW IN BIOETHICAL DECISION MAKING* 54-60 (1996) (approving the increasingly adopted judicial case-by-case approach in involuntary sterilization cases); Povenmire, *supra* note ___, at ___.

[184] See generally Roberta Cepko, *Involuntary Sterilization of Mentally Disabled Women*, 8 *BERKELEY WOMEN’S L.J.* 122 (1993) (describing statutory and case law approaches to sterilization of mentally disabled); Elizabeth Scott, *Sterilization of Mentally Retarded Persons: Reproductive Rights and Family Privacy*, 1986 *DUKE L.J.* 806, 818 (noting “most laws ... embody strict procedural and substantive requirements that create a strong presumption against sterilization”).

[185] DWORKIN, *supra* note ___, at 58; Scott, *supra* note ___, at 848 n. 140. See Haw. Rev. Stat. § 560:5-602 (“[p]ersons who are wards and who have attained the age of eighteen years have the legal right to be sterilized [I]n no event, however, shall wards be sterilized without court approval unless sterilization occurs as part of emergency medical treatment”).

[186] *In the Matter of Romero*, 790 P.2d 819 (Colo. 1990) (en banc) (denying guardian’s request to sterilize brain-injured adult).

[187] *Estate of C.W.*, 640 A.2d 427, 428 (Pa. Super. 1994) (affirming mother’s request to sterilize adult mentally retarded daughter).

[188] See Dreger, *supra* note ___, at 28-29 (noting medical tendency to preserve female reproductive capacity but not male reproductive capacity).

[189] See KESSLER, *supra* note ___, at 77-104, 132; Dreger, *History*, *supra* note ___, at 353; Kipnis & Diamond, *supra* note ___, at 406-07. See also Povenmire, *supra* note ___, at ___ (arguing for a heightened ethical evaluation in male circumcision cases as well).

[190] Povenmire proposes this standard for evaluating male circumcision decisions, causing parents to weigh the medical justifications for the procedure against the procedure’s irreversibility and the child’s inability to consent. See Povenmire, *supra* note ___, at ___.

[191] See, e.g., *Rosebush v. Oakland County Prosecutor*, 491 N.W.2d 633, 637 (Mich. App. 1992) (reviewing jurisdictions and holding that no judicial application is required prior to removing life-support from minor in persistent vegetative state); *In re L.R.H.*, 321 S.E.2d 716 (Ga. 1984) (accord, holding that no prior judicial approval is necessary prior to termination of life-support of minor).

[192] See, e.g., *In re Sampson*, 317 N.Y.S.2d 631 (Fam. Ct. 1970), *aff’d*, 323 N.Y.S.2d 253 (1971) (ordering surgery to correct facial deformity despite only psychosocial risk for nontreatment alternative and surgical risk to health); *State v. Perricone*, 181 A.2d 751 (1962); *Jehovah’s Witnesses v. King County Hosp.*, 278 F. Supp. 488 (W.D. Wash. 1967), *aff’d*, 390 U.S. 598 (1968); see generally Sher, *supra* note ___, at 161 notes 19-23 (collecting cases).

[193] See, e.g., *A.D.H. v. State Dep’t of Human Resources*, 640 So.2d 969 (Ala. App. 1994) (ordering AZT treatment for AIDS); *In re Petra B.*, 265 Cal. Rptr. 342 (Cal. App. 1989)

(ordering medical treatment for burns where parents are treating child with herbal remedies); *Custody of a Minor*, 379 N.E.2d 1053 (Mass. 1978) (holding that child's best hope for recovery required chemotherapy despite and over parental concern for discomfort and parental pessimism); *In re Vasko*, 263 N.Y.S. 552 (1933) (ordering surgical removal of cancerous eye despite parental objection); *In re Rotkowitz*, 25 N.Y.S.2d 624 (N.Y. Misc. 1941) (ordering operation on foot to correct progressive deformity); but see *In re Seiferth*, 127 N.E.2d 820 (N.Y. 1955) (upholding right of parent to decide not to treat cleft palate and harelip); *In re Tuttendario*, 21 Pa. Dist. 561 (Pa. 1911) (holding parents could decide to withhold surgical intervention for deformity caused by rickets because they feared possible outcomes).

[194] *Petra B v. Eric B.*, 265 Cal. Rptr. 342, 346 (Cal. App. 1989) (quoting *In re Philip B.* 156 Cal. Rptr. 48 (Cal. App. 1979)).

[195] See generally Kenneth Kipnis, *Parental Refusals of Medical Treatment on Religious Grounds: Pediatric Ethics and the Children of Christian Scientists*, in *LIBERTY, EQUALITY AND PLURALITY* 268, 272-73 (Larry May, et al., eds. 1997); *Protecting Human Research Subjects*, supra note ___, at 6-19 (discussing considerations when children are subjects of research); Karine Morin, *The Standard of Disclosure in Human Subject Experimentation*, 19 *J. Legal Med.* 157, 189-90 (1998). See also *Petra B*, 265 Cal. Rptr. at 346 (state may intervene upon consideration of the "seriousness of the harm," "the evaluation for the treatment by the medical profession," the "risks involved in medically treating the child," and the "expressed preferences of the child").

[196] See *Scott*, supra note ___, at 849 n. 142 (noting the difficulty in assessing "how someone will function or act in the future").

[197] See Joel Feinberg, *The Child's Right to an Open Future*, in *WHOSE CHILD? CHILDREN'S RIGHTS, PARENTAL AUTHORITY, AND STATE POWER* 124 (William Aiken & Hugh LaFollette, eds., 1980) [hereinafter *WHOSE CHILD?*].

[198] *Id.* at 126, 151 ("if the child's future is left open as much as possible for his own finished self to determine, the fortunate adult that emerges will already have achieved, without paradox, a certain amount of self-fulfillment, a consequence in large part of his own already autonomous choices in promotion of his own natural preferences."); *Dufault*, supra note ___, at 218-19.

[199] *NICHOLSON*, supra note ___, at 131.

[200] *Kipnis*, supra note ___, at 273.

[201] *Id.*

[202] Patricia Schroeder, 1994. *Female genital mutilation-- a form of child abuse*. *THE NEW ENGLAND JOURNAL OF MEDICINE*, 331:739-740. See also K. Rossiter & S. Diehl. *These nurses consider it child abuse if the parents do not allow surgery on their intersexed infants*. 1998. *Gender reassignment in children: Ethical conflicts in surrogate decision making*. *JOURNAL OF GYNECOLOGIC AND NEONATAL NURSING*, 27:59-62.

[203] *Kipnis*, supra note ___, at 273

[204] *Id.*

[205] Morin, *supra* note ___, at 191

[206] Reiner & Wilson, *supra* note ___, at 368 (commenting, “[i]t is interesting to note that ambiguous genitalia are essentially the only congenital anomalies viewed as a surgical emergency for cosmetic reasons.”).

In the John/Joan case, the child’s parents recalled how rushed they were to make the agonizing decision, they received a letter from Money suggesting they were “procrastinating.” They polled their family and their pediatrician all who counseled against the surgery. But, they were persuaded by “Dr. Money’s conviction that the procedure had every chance for success.” Colapinto, *supra* note ___, at 64.

[207] KESSLER, *supra* note ___, at 17-21; Cowley, *supra* note ___, at 66.

[208] Dreger, *supra* note ___, at 30 (quoting Patricia K. Donahoe, et al., *Clinical Management of Intersex Abnormalities*, 28 *CURRENT PROBLEMS IN SURGERY* 515, 540 (1991). Actually only the “salt-losing” category of CAH requires immediate attention. In rare conditions, gonads are prone to development of malignant tumors and may be removed prophylactically. Diamond & Sigmundson, *Management of Intersexuality*, *supra* note ___, at 1047.

[209] KESSLER, *supra* note ___, at 21-24; Dreger, *supra* note ___, at 27 (“In an effort to forestall or end any confusion about the child’s sexual identity, clinicians try to see to it that an intersexual’s sex/gender is permanently decided by specialist doctors within forty-eight hours of birth.”).

[210] MONEY, *SEX ERRORS*, 2nd ed., *supra* note ___, at 65-66; KESSLER, *supra* note ___, at 17 (quoting a urologist, “One of the worst things is to allow them [the parents] to go ahead and give a name and tell everyone, and it turns out the child has to be raised in the opposite sex.”) (alteration in original).

[211] See Dreger, *supra* note ___, at 30 (stating the clinicians view intersex states as a “social emergency”); Diamond, *Management of Intersexuality*, *supra* note ___, at 1047 (cosmetic clitoral and sex reassignment surgery should be postponed until “the patient is able to give truly informed consent”); Wilson & Reiner, *supra* note ___, at 368.

One might argue, as has psychologist Meyer-Bahlburg that the adult actions and beliefs are predicated on what happens starting from infancy and therefore neonatal surgery is beneficial and not “merely” cosmetic since it will facilitate adjustment to the assigned gender. H.F.L. Meyer-Bahlburg, *Gender Assignment in Intersexuality*. 10 *J. PSYCH. & HUMAN SEXUALITY*, 1, __ (1998). However, no controlled study supports this thesis. The premise is quite dubious: parents must consent to emergency surgery on their infant’s genitalia to prevent psychosocial harm at a later date.

[212] See *Timing of Elective Surgery*, *supra* note ___, at 590 (expressing concern that these congenital defects “may influence the mother’s attitude toward child” and noting disadvantage of “prolonging the child’s ‘defective’ status and crystallizing any disruption in family relationships that the child’s condition may have produced”); Cowley, *supra* note ___, at 65 (reporting view that physicians view “creating a normal appearance” as urgent). Instead of “normalizing” the sex organs, Diamond urges clinicians to counsel parents “that appearances during childhood, while not typical of other children, may be of less importance

than functionality and postpubertal erotic sensitivity.” Diamond & Sigmundson, *Management of Intersexuality*, supra note ___, at 1047.

[213] See MONEY, *SEX ERRORS*, 2nd ed., supra note ___, at 82 (cautioning that parents of children with birth defects of sex organs “may despise, criticize, and avoid the pathology in their child who, in turn, feels despised, criticized and avoided as a person.”); see also American Academy of Pediatrics, *Timing of Elective Surgery*, supra note ___, at 590.

[214] Reiner & Wilson, supra note ___, at 363 (citing Heino F.L. Meyer-Bahlburg, *Gender Assignment in Intersexuality*, 10 *J. PSYCH. & HUMAN SEXUALITY* 1-21 (1998)).

[215] See Diamond & Sigmundson, *Management of Intersexuality*, supra note ___, at 1048.

[216] Dreger, supra note ___, at 32-33; Kessler, supra note ___, at 128-32. Moreover, the haste and secrecy produces its own shame and stigma. See Robert A. Couch, *Betwixt and Between: The Past and Future of Intersexuality*, 9 *J. CLIN. ETHICS* 372, 375 (1998) (noting that discomfort with intersexuality is culturally constructed); Preves, supra note ___, at 415 (noting that surgery compounds shame rather than erasing it, and that parents might have been taught to deal with their different child rather than misguided attempts to “normalize” them through radical surgery); Wilson & Reiner, supra note ___, at 364 (commenting that silence produces “significant feelings of shame”). There is increasing recognition that gender exists along a continuum, much as medicine and society desire a binary gender construct. See KESSLER, supra note ___, at 132; Terry S. Kogan, *Transsexuals and Critical Gender Theory: The Possibility of a Restroom Labeled “Other,”* 48 *HASTINGS L.J.* 1233, 1238 (1997). See also Brynn Craffey, 1997. *Showering “Sans Penis”*. *CHRYSALIS: THE JOURNAL OF TRANSGRESSIVE GENDER IDENTITIES*, 2:55-56.

[217] Diamond & Sigmundson, supra note ___, at 1047; cf. KESSLER, supra note ___, at Cowley, supra note ___, at 66 (reporting on recommendations of Intersex Society of North America and biologist Anne Fausto-Sterling).

[218] Diamond and Sigmundson’s views are supported by ISNA, an organization of and for adult intersexuals. ISNA, supra note ___. See Chase, supra note ___, at 385.

[219] Diamond & Sigmundson, *Management of Intersexuality*, supra note ___, at 1047.

[220] See KESSLER, supra note ___, at 74-76. In regard to the effect on parents, Money et al. have written: “More than one-half of the parents (8/14) underwent only a short-lived, minor degree of crisis precipitated by having a micropenis baby [that that they were told would need to be reassigned as a girl]. None had an extreme degree of crisis.” JOHN MONEY, TOM MAZUR, CHARLES ABRAMS, AND BERNARD F. NORMAN. 1981. *Micropenis, Family Mental Health, And Neonatal Management: A Report On 14 Patients Reared As Girls*. *JOURNAL OF PREVENTIVE PSYCHIATRY*, 1:17-27.

[221] See *Estate of C.W.*, 640 A.2d 427, 428 (Pa. 1994) (quoting *Matter of Mildred J. Terwilliger*, 450 A.2d 1376, 1382 (Pa. 1982)) (“[I]n making the decision of whether to authorize sterilization [of incompetent adult], a court should consider only the best interest of the incompetent person, not the interests or convenience of the individual’s parents, the guardian or of society.”); *Wentzel v. Montgomery Gen. Hosp., Inc.*, 447 A.2d 1244 (Md. 1982) (“in considering the best interests of an incompetent minor, the welfare of society or the convenience or peace of mind of the ward’s parents or guardian plays no part”); *Mack v. Mack*, 618 A.2d 744, 759 (Md. App. 1993).

[222] Wilson & Reiner, *supra* note ___, at 367.

[223] Dreger, *supra* note ___, at 30.

[224] Bopp & Coleson, *supra* note ___, at 144 (discussing studies demonstrating tendency of physicians to withhold information or not to admit the “limitations of their professional knowledge and ability”).

[225] *Id.* at 141-42.

[226] Althaea Yronwode, 1999. Wisdom of Surgery on infants. *TRANSGENDER TAPESTRY*, 1999:18-21, 32. at 21.

[227] *MONEY, SEX ERRORS*, 1st ed. at 62-63.; 2nd ed., *supra* note ___, at 67.

[228] [A] pediatric endocrinologist at Children’s Memorial Hospital in Chicago, would draw a pair of X’s. This, he would say, was what a normal female’s sex chromosomes looked like: XX.

Id. A physician candidly recalled to a reporter how he and his colleagues counseled parents of intersex children: Then, with the heel of his hand, he would erase the leg of one X. That, he would say was what happened to one of their daughter’s X chromosomes. It was incomplete, unfinished. This was why her sexual organs hadn’t developed the way they should, why her breasts would not grow, why she couldn’t ever have children. What he did not say is that the incomplete X was not an X chromosome at all. It was a Y chromosome, the genetic marker for a male. The child they were talking about was not a girl, at least not so far as her genes were concerned. She was a boy. Kiernan, *supra* note ___, at 1 (interviewing Jorge Daaboul).

[229] See *KESSLER*, *supra* note ___, at 21-24 (describing information provided to parents during diagnosis and noting deceptive and incomplete information imparted); Dreger, *supra* note ___, at 31 (recounting anecdotal reports of parents and adult patients being misinformed and deceived about the nature of the condition and the treatment); anecdotal cases are also discussed in Colapinto, *supra* note ___, at 95; Cowley, *supra* note ___, at 64, 66.

[230] Not infrequently the concept of “more time in gestation” having been needed leads to feelings of maternal guilt; e.g. “If only I had taken more time. . . ”

[231] *KESSLER*, *supra* note ___, at 23.

[232] Intersex is not merely a condition of the genitals, but of a sexually dimorphic brain. See William G. Reiner, Case study: sex reassignment in a teenage girl, 35 *J. AM. ACAD. CHILD & ADOLESCENT PSYCH.* 799 (1996) (noting the complexity of intersex conditions and uncertainty as to causes). See also Milton Diamond, 1976. Human sexual development: biological foundation for social development. In F. A. Beach (ed.), *HUMAN SEXUALITY IN FOUR PERSPECTIVES*, pp. 22 - 61. The John Hopkins Press. at 38-39.

[233] In the context of involuntary sterilizations generally, one court commented, “An individual’s right to procreate is fundamental.... Sterilization involves a surgical invasion of bodily integrity. It destroys ‘an important part of a person’s social and biological identity,’ ... can be traumatic for the individual, and can have ‘long-lasting detrimental emotional effects.’” *In re Romero*, 790 P.2d 819, 821 (Colo. 1990) (en banc) (citations omitted) (upholding right of incapacitated mother of two to refuse sterilization where she expressed desire to have additional children).

In *ARATO V. AVEDON*, 5 CAL. 4TH 1172, 23 CAL. RPTR. 2D 131, 858 P.2D 598 (1993) the Court concluded: “a physician is under a legal duty to disclose to the patient all material information -- that is, information which would be regarded as significant by a reasonable person in the patient’s position when deciding to accept or reject a recommended medical procedure-- needed to make an informed decision regarding a proposed treatment.”

[234] A recent prize-winning essay student essay advocates deception in the case of androgen insensitivity syndrome (AIS) discovered at adolescence. AIS patients are genetic males who, for lack of receptors necessary to masculinize, will grow up looking like females but possessing an underdeveloped vagina and lacking ovaries. The condition is sometimes overlooked until adolescence when it is discovered because the child fails to menstruate. The medical student argues that both the parents and the adolescent child should be shielded from knowledge of AIS. Since, “[t]he only services the physician can provide are surgical reconstruction of the vagina and counseling on adoption,” she suggests that if the “patient is completely comfortable with her female sexuality” then “physicians who treat AIS patients are justified in not disclosing the information that the patient is genetically male.” Anita Natarajan, *Medical Ethics and Truth-Telling in the Case of Androgen Insensitivity Syndrome*, 154 CANADIAN MED. ASS’N J. 568-69 (1996).

[235] See Colapinto, *supra* note __, at 95. J/J resisted hormone treatment and four years of unyielding pressure and deception by both Dr. Money and her local treatment team to undergo vaginal reconstruction. *Id.* at 70-71. See also Sherri A. Groveman, *The Hanukkah Bush: Ethical Implications in the Clinical Management of Intersex*, 9 J. CLIN. ETHICS 356, 357 (1998) (discussing life with AIS, recounting surgery and ongoing medical treatments, and stating that doctors “implored my parents never to tell me the truth” and describing finally discovering diagnosis on her own at age 20 through medical detective work).

[236] William Reiner, an Assistant Professor of Child and Adolescent Psychology at Johns Hopkins University, describes the rationale for secrecy: At the time of initial gender assignment, to protect the child’s psychosocial development from potentially hurtful comments, physicians have generally counseled families not to discuss any of this with other family members or friends. Further, based on the theory that any doubt may undermine development of gender identity concordant with the assigned sex of rearing, they also advise the family not to discuss the child’s condition with the child. Wilson & Reiner, *supra* note __, at 363. Wilson and Reiner explain that as medical records become more easily obtainable, secrecy is increasingly unrealistic, out of step with current views of patient rights, and patient autonomy. *Id.* at 364. See also Diamond, *Management of Ambiguous Genitalia*, *supra* note __, at __ (“Parents and clinicians have often concealed aspects of surgery and treatment from the child and excluded maturing children from medical management decisions.... Adults who have had these procedures in childhood are now presenting at clinics quite ignorant of their history.”); Dreger, *supra* note __, at 27, 30-32 (“Clinicians treating intersexuality worry that any confusion about the sexual identity of the child on the part of relatives will be conveyed to the child and result in enormous problems, including potential “dysphoric” states in adolescence and adulthood.”); Groveman, *supra* note __, at 357 (commenting on receiving AIS diagnosis and infant surgery, “the sole instruction my parents received ... was one of “damage control,” calculated to confirm a solid image that I was their daughter in the same breath that doctors enjoined them that they should not disclose my true diagnosis to anyone, least of all me”).

Money suggests that displayed ambivalence to the gender assigned is fatal to success. See MONEY, *SEX ERRORS*, *supra* note __, at 66 (“If a change must be made [in the announcement of sex] then it should be made only once and forever, with no delay or

vacillation.”); MONEY, SEX POLICE, supra note ___, at 319 (raising the effect “about hearing of one’s infantile medical history from the children of adult members of the community grapevine” as a possible explanation for the failure of J/J’s case). But Money’s idea of a success if for the sex-reassigned person to accept without question the imposed gender switch. This is independent of whether the individual him or herself would make that gender decision given all the facts.

Elsewhere, however, Money has written that “The withholding of information can be extremely traumatic, as the patient will soon realize that things are being withheld and will resort to inferential guesswork. . . . When they grew up, several of these [hermaphroditic] patients confronted me with the folly of this policy, for they had known all along that they had been dealt with insincerely. In the majority of instances, they also knew exactly whnformation was being withheld. . . .” JOHN MONEY, 1983. Birth defect of the sex organs: telling the parents and the patient. BRITISH JOURNAL OF SEXUAL MEDICINE, 1983:14.

[237] In a prize winning essay, Natarajan urges physicians keep secret the male status of women with androgen insensitivity. She reasons that the knowledge will be too psychologically damaging for them and so justifies the ethics of deception. Natarajan, supra note ___, at 570.

AIS women themselves, on the other hand, express a desire to know the truth of their condition. See: B. Diane Kemp,.1996. Letter to the Editor (re: Sex, Lies and Androgen Insensitivity Syndrome). 154 CANADIAN MEDICAL ASS’N J. 1829-33.; Sherri A. Groveman, Letter to the Editor. 154 CANADIAN MEDICAL ASS’N J. 1829, 1832 (1996). Anonymous. 1996. Letter to editor. 154 CANADIAN MEDICAL ASS’N J. 154:1832. This is supported by the present research of Diamond among 35 women with AIS.

[238] See Dreger, supra note ___, at 28, 31. Moreover, when patients are not given complete information, they sometimes do not appreciate the continued sex-related risks of their former sex that plague them. Id. at 31-32.

[239] Cowley, supra note ___, at 66 (quoting Dr. Antonne Koury, chief of pediatric urology at Toronto’s Hospital for Sick Children).

[240] Brendan P. Minogue & Robert Taraszewski, Commentary, The Whole Truth and Nothing But the Truth? 18 HASTINGS CENTER REPORT 34 (Oct./Nov. 1988) and Sherman Elias & George Annas. Commentary, The Whole Truth and Nothing But the Truth, 18 HASTINGS CENTER REPORT 35-36 (Oct./Nov. 1988).

[241] Current sensitivity to the effect on the patient of labeling the condition “testicular-feminization” the condition has been relabeled “androgen insensitivity syndrome” (AIS). The person’s body tissues can not respond to androgens which are needed for typical virilization.

[242] Minogue & Taraszewski, supra note ___, at 34.

[243] Minogue & Taraszewski, supra note ___, at 34.

[244] Id. at 35. The authors suggest the information is not “relevant” since nothing can be done and all “immediate problems can be addressed without revealing the information about her genetic abnormality.” Id. at 34.

A contrary position that full disclosure rather than deception to both parents and child is also presented. See Elias & Annas, supra note ___.

[245] Minogue & Taraszewski, *supra* note ___, at 35.

[246] A physician bears the burden of producing evidence that the therapeutic privilege negates the duty to disclose, and only then, “the patient has the ultimate burden of proving the nonexistence of the exception.” *Bernard v. Char*, 903 P.2d 676, ___ (Haw. App. 1995), cert. granted and clarified on other issues, 903 P.2d 667 (1995).

[247] 464 F.2d at 789 (footnotes omitted). See also McNichols, *supra* note ___, at 728 (applauding narrow scope of therapeutic privilege crafted by Canterbury).

[248] The J/J case, communications from former patients, and ISNA discussions share a striking common theme that information, even in adulthood, was desperately wanted but difficult to obtain. See *supra* notes ___, ___. These stories suggest a deviation from the so-called common view: [A] physician has a fiduciary duty to inform a patient of abnormalities in his or her body. The basis of this duty is that the patient has a right to know the material facts concerning the condition of his or her body, and any risks presented by that condition, so that an informed choice may be made regarding the course which the patient’s medical care will take. The patient’s right to know is not confined to the choice of treatment once a disease is present and has been conclusively diagnosed. Important decisions must frequently be made in many non-treatment situations in which medical care is given, including procedures leading to diagnosis.... These decisions must all be taken with the full knowledge and participation of the patient.... The existence of an abnormal condition in one’s body, the presence of a high risk of disease, ... are all facts which a patient must know in order to make an informed decision on the course which future medical care will take. *Gates v. Jensen*, 595 P.2d 919, 922 (Wash. 1979) (en banc).

[249] See Sharon E. Preves, *For the Sake of the Children: Destigmatizing Intersexuality*, 9 J. CLIN. ETHICS 411, 414 (1998).

[250] It has been reported that Cheryl Chase, Director of the Intersex Society of North America, “At the age of 35 . . . had a nervous breakdown. Although she had been able [with difficulty] to access her medical records in her early 20s, . . . the years of secrecy, unexplained surgeries, and sexual dysfunction caused by removal of her clitoris had taken a huge toll on her. ‘Until I was 35, I was ashamed and terrified that people would find out that I was different than a woman. Like many, supposedly happy and successful patients, I was silenced.’” Yronwode, *WISDOM OF SURGERY ON INFANTS* note ____ at 19.

[251] See Kipnis & Diamond, 1998 at 407; Diamond, 1999 at 1026.

[252] See Diamond & Sigmundson, *supra* note ____ at 1048.

[253] See Kipnis & Diamond, 1998 at 407; Diamond, 1999 at 1026.

[254] See FURROW, *supra* note ___, at § 6-5 at 386-87 (commenting, “courts seem willing to tolerate clinical innovation so long as a patient is properly informed as to the innovative and untested nature of the procedure”).

[255] Diamond & Sigmundson, *supra* note ___, at 298.

[256] Kipnis & Diamond, *Pediatric Ethics*, *supra* note ___, at 406 (“it is not possible for a patient’s parents to give informed consent to these procedures, precisely because the medical profession has not systematically assessed what happens to the adults these infant patients become.”).

[257] See Dreger, *supra* note ___, at 32. Diamond, *Ambiguous and Traumatized*, *supra* note ___, at ___.

[258] MONEY, *SEX ERRORS*, 2nd ed., *supra* note --, at 67 (emphasis added).

[259] *Id.* at 54 (emphasis added).

[260] Indeed, the American Academy of Pediatrics, in its 1996 recommendations on timing male genital surgery, stated “a person’s sexual body image is largely a function of socialization” referencing only the decade-old and older work of John Money. *Timing of Elective Surgery*, *supra* note ___, at 590. Yet, to date, there has not been a single report of a sex reassigned nonintersexed male successfully living as an androphilic woman. (Diamond, *supra* note _____, at 1023.)

[261] There is no doubt that doctors are choosing treatments based on social or personal value judgments, consider the following quote concerning clitoral surgery that favors appearance:

The clitoris is not essential for adequate sexual function and sexual gratification ... but its preservation would seem to be desirable if achieved while maintaining satisfactory appearance and function.... Yet the clitoris has a relation to erotic stimulation and to sexual gratification and its presence is desirable, even in patients with intersexed anomalies if that presence doesn’t interfere with cosmetic, psychological, social and sexual adjustment.

KESSLER, *supra* note ___, at 37 (quoting Judson Randolph & Wellington Hung, *Reduction Clitoroplasty in Females with Hypertrophied Clitoris*, 5 *J. PEDIATRIC SURGERY* 224, 230 (1970)).

[262] Wilson and Reiner comment: [T]he right of the individual to determine what happens to his or her body has been increasingly asserted. Patients and families are demanding a voice in the issue of sex assignments and therapies. After all, the child’s sex-of-rearing and gender identity are profoundly important to that child’s lifelong development and adjustment. Although parents may give consent for surgery, there is increasing movement toward obtaining a child’s assent to procedures, particularly those which, like most genital “reconstructive” procedures, are elective from a medical viewpoint. This means delaying surgery until we can take into account the affected individual’s determination of his or her own gender.

Wilson & Reiner, *supra* note ___, at 364. See also Schober, *supra* note ___, at 394 (“For the best long-term outcomes, we need to consider that surgical treatment methods do not ‘cure’ intersexuality, and that a procedure such as vaginoplasty should address a consenting and requesting patient’s needs and desires, not parental and societal comfort.”).

263] Laurence McCullough, “The Ethics of Gender Reassignment,” Presentation at conference 1999 Pediatric Gender Reassignment: A Critical Reappraisal Wyndham-Anatole Hotel, Dallas, Texas, April 30, 1999. See also Dena S. Davis, *Genetic Dilemmas and the Child’s Right to an Open Future*, 28 *RUTGERS L.J.* 549, 575-81 (1997) (noting and approving of trend against conducting genetic tests to predict late-onset diseases and suggesting that parents who opt for testing “preclude the child’s right and opportunity to make that decision for himself in adulthood”).

[264] See *infra* notes ____.

[265] KESSLER, *supra* note __, at 74; Kipnis & Diamond, *Pediatric Ethics*, *supra* note __, at 405-406; Diamond & Sigmundson, *Management of Intersexuality*, *supra* note __, at 1047; Reiner, *Sex Reassignment*, *supra* note __, at 1044. Diamond, *J. Urology* at 1025-1026. Kipnis and Diamond and Diamond also recommend the moratorium remain in effect until the positive value of the surgery is documented with adequate follow-up study. See Meyer-Bahlburg, *supra* note __, at 15 and Glassberg, *supra* note ____, at 152-153 (both defending cosmetic surgery). While suggesting that surgery continue on ambiguous genitalia, Glassberg, *supra* note ____ at 1309, is also open to change: ". . .we must learn from patients who resent how they were treated and those who are satisfied. If data become available to prove that a given approach should be changed, we should do this promptly. Today with valid, unbiased followup data, and genetic, pharmacological and surgical tools, we should be able to produce a satisfying outcome for nearly all children born with this potentially devastating problem."

[266] Preves, *supra* note ____.

[267] See Diamond & Sigmundson, *Sex Reassignment*, *supra* note __, at 303; Dreger, *supra* note __, at 30, 33-34.

[268] Preves, *supra* note __, at 415 (reporting on fear of cancer as a result of incomplete medical history); Groveman, *supra* note __, at 357-58.

[269] See ISNA, *Frequently Asked Questions, Hormone Replacement and Osteoporosis*, available at <<http://www.isna.org/faq/htm>> (warning that persons who have had their gonads removed in childhood are at exceptionally high risk of osteoporosis), last visited July 15, 1999.

[270] Morgan Holmes, *Is growing up in silence better than growing up different?* 2 *Chrysalis: The Journal of Transgressive Gender Identities* 7-9 (1997/1998) (describing mental disturbance and suicidal ideation); Cowley, *supra* note __, at 66 (discussing case of Cheryl Chase, ""not only was [she] denied information as a child but was lied to by doctors when she later tried to obtain her medical records"); Colapinto, *supra* note __, at 95 (recounting incidents of secrecy and resulting psychological pain and suffering).

[271] Kenneth Kipnis, and Milton Diamond. 1998. *Pediatric Ethics and the Surgical Assignment of Sex*. *THE JOURNAL OF CLINICAL ETHICS*, 9: at 406-407. Milton Diamond, 1999. *Pediatric Management of Ambiguous and Traumatized Genitalia*. *JOURNAL OF UROLOGY*, 162: at 1026.

[272] See, e.g., *Blaz v. Galen Hospital Illinois, Inc.*, 982 F. Supp. 556 (N.D. Ill. 1997) (noting that where there is a continuing duty the cause of action does not accrue until the defendant "had sufficient facts to understand that its treatment had placed the plaintiff at risk"); *Mink v. University of Chicago*, 460 F. Supp. 713, 720 (N.D. Ill. 1978) (citing *Canterbury v. Spence*, 464 F.2d 772 (D.C. App. 1972)) (recognizing ongoing duties to notify women of cancer risks related to treatment with DES discovered after treatment); *Schwartz v. United States*, 230 F. Supp. 536 (E.D. Pa. 1964) (holding that veteran's hospital has duty to inform patient of newly discovered risks associated with prior treatment); *Tresemmer v. Barke*, 150 Cal. Rptr. 384 (Cal. App. 1978) (holding that doctor had continuing duty to warn of later discovered risks associated with Dalkon Shield and statute of limitations was inapplicable); *Reyes v. Anka Research Ltd.*, 443 N.Y.S.2d 595, 597 (N.Y. Sup. Ct. 1981) (noting that cause of action for failing to notify patient of recall of IUD "continued up to the time of reasonable discovery"). But see *Schendt v. Dewey*, 520 N.W.2d 541 (Neb. 1994) (holding that there is no

duty to warn of cancer risks from radiation following termination of the physician-patient relationship). See generally Lori B. Andrews, *Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks*, 29 HOUS. L. REV. 149, 169 (1992) (discussing on-going duties to warn where genetic testing later reveals other as-yet-unknown links to diseases and carrier states); Andrea G. Nadel, Annotation, *Duty of Medical Practitioner to Warn Patient of Subsequently Discovered Danger From Treatment Previously Given*, 12 A.L.R.4th 41 (1981 & 1997 supp.).

[273] Name withheld. Tape recorded interview on file with author.

[274] He explained, for example, that his best childhood friend was a boy. As he matured, he had few friends, but generally he preferred male friendship. He could act like a girl, “but it didn’t feel right.” He played with Ninja Turtles rather than Barbie and preferred to act like a boy.

[275] From his description and subsequent interview, he probably had micropenis and possibly a hypospadias. He was XY 46, [normal for a male] but he didn’t discover that (nor did his parents) until he was an adult undergoing sex change back to live as a typical male.

[276] He now takes injections of testosterone but his external genitalia, even now after reconstruction, remains “deficient.” Unfortunately, his testes were removed at the same time as his penis was amputated. Earlier estrogen treatment forced the development of breasts but three years previously he had a mastectomy.

[277] For a long time I felt, “how could you do this to me? ... If they had known I was born as a boy, they wouldn’t have raised me as a girl.” He also explained, “When I was ten, I asked my mother if God makes mistakes.” “My mother was left in the dark as much as I was [about my condition].” The doctors told his parents his testes were cancerous (although they were not). His parents were not clear at the time that he was born a boy, although genetic tests at the time revealed he had a normal 46 XY karyotype and he had normal testes.

[278] In addition to hygienic problems with urination there are the scars from surgery and the need for life-long medical treatment. Most crucially there is also the hesitation in social interactions with the knowledge he will not function as a typical male nor be fertile. He has as yet to engage in any erotic social activity with a partner.

[279] He explained, “the conclusion was that the doctors at the time of my birth did the best they knew how to do.”

[280] KESSLER, *supra* note __, at 75-76; Kipnis & Diamond, *supra* note __, at 405-407; Diamond & Sigmundson, *Management*, *supra* note __, at 1047; Dreger, *supra* note __, at 34; Catlin, *supra* note __, at 65.

Unfortunately, Dreger notes that ethicists have historically not been included in this debate. See Dreger, *supra* note __, at 26 (noting the scant attention to the ethical issues until now). Times are changing, as evidenced by the devotion of an entire issue on this topic in the *Journal of Clinical Ethics* in 1998.

[281] Reiner, *Sex Assignment*, *supra* note __ (reminding readers “the brain is the most important sex organ”).

Appendix 5

Der “ Behandlungsstandard“ nach Dr. John Money und die damit verbundenen Verstöße der Bundesrepublik Deutschland gegenüber der Verpflichtung zum Einschreiten gegen diskriminierende Gepflogenheiten

In den späten 1950er Jahren begann die experimentelle chirurgische Geschlechtsangleichung „intersexueller“ Kleinkinder auf Grund der von dem Psychiater Prof. Dr. John Money von der Universität Baltimore entwickelten “Zeitfenster-Theorie”, wonach die Geschlechtsidentität bis zu einem bestimmten Alter, welches irgendwo zwischen 6 Monaten und 2 Jahren nach der Geburt liege, unbestimmt sei und daher anerzogen werden könne, wenn das körperliche Erscheinungsbild innerhalb dieses Zeitfensters eindeutig chirurgisch dem weiblichen oder männlichen Geschlecht zugewiesen werde.

Anfang der 1970er Jahre wurde die Geschlechtszuweisung in sowohl in der damaligen DDR als auch in der Bundesrepublik Deutschland zum medizinischen Standard erklärt, obwohl keine wissenschaftlichen Beweise erbracht wurden, durch die Berühmtheit des Falls eines einzigen Jungen (unter dem Pseudonym “John/Joan-Fall”). Dieser war eindeutig männlich geboren und hatte durch einen Unfall im Kleinkindalter seinen Penis verloren. Auf den Rat von Dr. John Money erhielt er keine männliche Rekonstruktionsplastik, sondern er wurde zum Mädchen umoperiert einschließlich der Entfernung seiner gesunden Hoden und entsprechend erzogen. Aufgrund positiver Kurzzeituntersuchungen dieses einen Falls entstand der Standard zur operativen Geschlechtszuweisung für intersexuelle Kleinkinder und für Jungen mit unfallbedingtem Penisverlust im Kleinkindalter.

Da nur ein einziger Fall die Grundlage von dessen Durchsetzung bildete und nicht eine ausreichende Zahl von Langzeitexperimenten, ist er über das Experimentierstadium nie hinausgewachsen. Selbst dieser eine Fall hat sich als Misserfolg herausgestellt. Im Jahr 1994 fand der Sexualwissenschaftler Prof. Dr. Milton Diamond (Universität Hawaii) heraus, dass der damals ohne seine eigene Einwilligung umoperierte Junge seit 1980 wieder in der männlichen Rolle lebte, und auf eigenes Drängen, soweit es medizinisch noch möglich war, wieder zum männlichen Geschlecht angeglichen worden war. 1997 wurde die Wahrheit über seinen Fall der Weltöffentlichkeit vorgestellt. Im Jahre 2000 begingen erst der normal aufgewachsene Zwillingbruder und dann der damals unter dem “John/Joan-Fall” berühmt gewordene Mann Selbstmord.

Dr. John Money hat in seiner “Zeitfenster-Theorie” die Geschlechtsidentität (welchem Geschlecht sich jemand zugehörig fühlt) mit dem Geschlechtsrollenverhalten verwechselt. Das Rollenverhalten, also ob sich jemand so verhält, wie es für einen Jungen oder ein Mädchen typisch ist, kann anerzogen werden, nicht aber die Geschlechtsidentität.

Nach dem „Standard“ von Dr. John Money muss die Herstellung eines geschlechtlich eindeutigen Aussehens innerhalb des “Zeitfensters” erledigt sein. Viele medizinische Texte stufen den Entscheidungsfindungsprozess der Eltern bzgl. deren Einwilligung zu geschlechtszuweisenden Operationen an ihren Kleinkindern als medizinischen Notfall ein. Money befürchtete, dass die Eltern traumatisiert sein könnten, wenn sie ihr Kind mit intersexuellem Genital sehen und es dann nicht annehmen würden. Oft werden den Eltern nach diesem Standard unvollständige Informationen über die genaue med. Beschaffenheit des Kindes vermittelt. So wurde empfohlen, den Eltern mitzuteilen, ihr Kind sei geschlechtlich unvollständig auf die Welt gekommen, und die Medizin könne es vervollständigen. Diese „Lehrmeinung“, die keine ist, hält sich hartnäckig bis zum heutigen Tage, obwohl es sehr wohl andere Lehrmeinungen gab. So vertrat bereits 1957 und 1961 Prof.Dr. Overzier, das die

Entfernung der Gonaden z.B. bei AIS unnötig, ja sogar schädlich sei. Die Bundesregierung sieht keinen Handlungsbedarf.

Die Berichterstatterinnen bemängeln die Verstöße der Bundesrepublik Deutschland gegenüber der Verpflichtung zum Einschreiten gegen diskriminierende Gepflogenheiten. Der Staat kommt seiner Verpflichtung nicht nach, mit allen geeigneten Mitteln unverzüglich eine Politik zur Beseitigung der Diskriminierung der Frau zu verfolgen (Art. 2 Uno-Frauenrechtskonvention). Zu diesen Mitteln gehören "gesetzgeberische und sonstige Maßnahmen". Dazu gehören auch Maßnahmen zur Änderung oder Aufhebung von "Gepflogenheiten" (wie z. B. med. Standards) und "Praktiken" (Art. 2 f Uno-Frauenrechtskonvention). Die Bundesrepublik Deutschland wäre nach Ansicht der Berichterstatter verpflichtet, durchzusetzen, dass Dr. Money's med. Versuch durch einen besseren Standard ersetzt wird, der die Frauenrechte nicht mehr verletzt.

Intersexualität

Die alltägliche Folter in Deutschland

Ein Forschungsbericht

Humboldt-Universität zu Berlin
Philosophische Fakultät III
Zentrum für transdisziplinäre Geschlechterstudien
Forschungsbericht zum Hauptseminar 53 898
Zur Neuerfindung von Geschlecht in Biologie und Medizin
(Naturwissenschaftsforschung)
Dozentin: Bärbel Mauss
Sommersemester 2004

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„Unser verstümmeltes Geschlecht ist ein medizinisches Konstrukt, also Theorie. So schob man uns von einem Nichts in das andere Nichts: Unser Geschlecht, wie es uns angeboren wurde, hat keine gesellschaftliche Existenz. ... Nun ist fraglich, welche psychischen Auswirkungen sich bei intersexuell Diagnostizierten, jedoch nicht Operierten, konstatieren lassen ... Vermutlich wären wir AUCH durch alle Kategorien durchgefallen. Aber mit Sicherheit hätten wir etwas EIGENES entwickeln können, hätten z. B. unser sexuelles Potential entdeckt und unseren Körper kennengelernt“

- Michel Reiter²⁷

²⁷ Heldmann, Anja, Jenseits von Frau und Mann, Intersexualität als Negation der Zweigeschlechtlichkeit, in: Differenz und Geschlecht: neue Ansätze in der ethnologischen Forschung, Berlin, 1998, S. 61.

Inhaltsverzeichnis

| | | |
|------------|--|--------------|
| 1. | Einleitung | S. 5 |
| 2. | Zum Begriff der Intersexualität | S. 7 |
| 3. | Wie wurde historisch mit Hermaphroditen umgegangen? | S. 9 |
| 3.1 | Die drei Phasen des Umgangs mit Hermaphroditen | S. 9 |
| 3.2. | Michel Foucault und der Fall Herculine | S. 9 |
| 4. | Das Geschlechterbild der modernen Medizin | S. 13 |
| 4.1. | Wie legitimiert die Medizin Operationen an Intersexuellen? | S. 13 |
| 4.1.1. | Medizinische Quelle 1 (Schweiger) | S. 13 |
| 4.1.2. | Medizinische Quelle 2 (Pelz, Dittmann) | S. 15 |
| 4.1.3. | Medizinische Quelle 3 (Leitsch) | S. 18 |
| 4.2. | Intersexualität in Schulbüchern | S. 20 |
| 4.3. | Zum Verhältnis von sex und gender bei Intersexualität | S. 22 |
| 4.4. | Die medizinische Zurichtung zu heterosexuellem Begehren | S. 23 |
| 4.5. | Die medizinische Herstellung der Zweigeschlechtlichkeit | S. 25 |
| 4.6. | Der Arzt als Überwacher der Geschlechterordnung | S. 28 |
| 5. | Der westliche Diskurs über Genitalverstümmelung | S. 31 |
| 5.1. | Von rassistischem Sprechen und Schweigen | S. 31 |
| 5.2 | Verweiblichung oder Vermännlichung? | S. 33 |
| 6. | Zur doppeldeutigen „Konstruierbarkeit“ des Geschlechts | S. 35 |
| 6.1. | Ausblick in die Vielgeschlechtlichkeit jenseits fester Identitäten | S. 39 |
| 7. | Politisch-strategischer Teil | S. 41 |
| 7.1. | Zur Instrumentalisierung von Intersexuellen | S. 41 |
| 7.2. | Diskussion um den Opferbegriff | S. 41 |
| 7.3. | Zur Differenz zwischen Homo- / Transsexuellen und Intersexuellen | S. 42 |
| 7.3.1. | Konzept des Dritten Geschlechts führt zu Pathologisierung | S. 43 |
| 8. | Politische Forderungen | S. 45 |
| 9. | Resumee | S. 47 |
| 10. | Bibliographie | S. 50 |

1. Einleitung

Die folgende Gemeinschaftsarbeit dokumentiert unseren ein Semester lang laufenden Forschungsprozess zum Thema Intersexualität. Da es sich hierbei um einen Forschungsbericht und nicht um eine herkömmliche Hausarbeit handelt, widmen wir uns in diesem Text verschiedenen Fragekomplexen, die unsere Diskussion bestimmt haben. Wenn sich deshalb einige Argumente in verschiedenen Passagen des Textes wiederholen sollten, trägt dies dem Umstand Rechnung, dass dieser Forschungsbericht von drei Personen gemeinsam verfasst wurde.

Der hegemoniale biomedizinische Diskurs beruht auf dem „Imperativ der Zweigeschlechtlichkeit“: Von der biologischen Reproduktion aus gedacht gibt es genau zwei Geschlechter, die sich heterosexuell fortpflanzen. Am Rande dieses Diskurses treten jedoch Widersprüchlichkeiten auf, wie beispielsweise bei Geschlechtsbestimmungen. Der medizinische Umgang mit Intersexualität zeigt auf, wie die angesprochenen Uneindeutigkeiten über Pathologisierungen in das System der Zweigeschlechtlichkeit reintegriert werden und als das Außen des Normalitätsdiskurses konstruiert werden. Diesem Geschlechterbild der modernen Medizin ist die folgende Arbeit gewidmet.

Im ersten Teil befassen wir uns mit dem Begriff `Intersexualität`, seiner Herkunft und seinen Beschränkungen und fragen nach den Selbstdefinitionen der Betroffenen. Anschließend widmen wir uns der Frage, wie mit Hermaphroditen historisch umgegangen wurde bzw. welche Entscheidungsmöglichkeiten sie hatten und führen dies am Beispiel von Herculine Barbin und der Theorie Michel Foucaults exemplarisch aus. Im Folgenden wenden wir uns dem Geschlechterbild der modernen Medizin zu und befragen drei medizinische Quellen danach, warum Intersexuelle geschlechtlich eindeutig gemacht werden. Warum wird operiert und wie legitimiert die Medizin einen sozial kategorisierenden operativen Eingriff? Anhand von vier Schulbüchern zeigen wir im Anschluss daran, wie diese medizinische Geschlechterideologie populärwissenschaftlich vermittelt wird. Nach diesem Quellenstudium untersuchen wir, wie das herrschende Verhältnis von sex und gender durch die bloße Präsenz Intersexueller in Frage gestellt wird. In den folgenden zwei Abschnitten arbeiten wir heraus, wie sich die medizinische Profession als Vollstreckerin von Zwangsheterosexualität und Zweigeschlechtlichkeit profiliert. Dementsprechend befasst sich das folgende Kapitel mit dem Arzt als Überwacher der Geschlechterordnung. Hier kommen wir erneut auf die Frage zu sprechen, weshalb Operationen an Intersexuellen innerhalb des herrschenden Geschlechtermodells unumgänglich sind. Der nächste Abschnitt befasst sich dann mit der Frage, warum Genitalverstümmelungen in afrikanischen Ländern im westlichen

Mediendiskurs verurteilt werden, während die Verstümmelung Intersexueller im Westen verschwiegen wird. Einem weiteren Paradoxon spüren wir im nächsten Kapitel nach: Einerseits spricht der postmoderne Feminismus von der symbolischen `Konstruktion` der Geschlechter, andererseits `konstruieren` Ärzte das materielle Geschlecht bei Intersexuellen. Um die scheinbare Nähe der beiden Positionen zu widerlegen, befragen wir die Texte Judith Butlers. Anschließend wagen wir einen Ausblick in eine vielgeschlechtliche Zukunft. Zum Abschluss berichten wir von unseren Diskussionen um den Begriff des `Opfers` (medizinischer Maßnahmen) und die Instrumentalisierung Intersexueller in Debatten der Gender Studies. Außerdem stellen wir die Unterschiede zwischen der traditionellen Emanzipationsbestrebung Homo-, Bi- und Transsexueller auf der einen Seite und dem Kampf Intersexueller gegen Folter auf der anderen Seite heraus. Zu diesen politisch-strategischen Überlegungen gehört auch die Beschreibung der Pathologisierungsfahr, die im Konzept des `Dritten Geschlechts` liegt. Dieser Abschnitt mündet dann am Schluss in eine Auflistung politischer Forderungen, denen wir uns anschließen möchten. Nun wünschen wir aber viel Spaß beim Lesen!

2. Zum Begriff der Intersexualität

Das Roche Lexikon Medizin definiert Intersexualität als „Störung der Geschlechtsdifferenzierung mit Widersprüchen in der Ausbildung der allgemeinen äußeren geschlechtlichen Erscheinung (Intersextyp; s. a. Geschlechtsmerkmale), der Keimdrüsen bzw. Geschlechtsorgane (s. a. Gonadendysgenese) sowie des chromosomalen Geschlechts; s. a. Hermaphroditismus, Pseudohermaphroditismus, Feminisierung, Virilisierung; vgl. Transsexualismus.“²⁸ An dieser Definition wird sehr deutlich, dass `Intersexualität` ein medizinisches Kunstwort für verschiedene `Syndrome` ist. In unserer AG-Diskussion stellten wir uns die Frage, welchen Begriff wir bevorzugen: Intersexualität, Hermaphroditismus, Zwitterigkeit? Uns fiel am Begriff Intersexualität auf, dass er mit dem Konzept eines `Dazwischen` eine dennoch gültige Norm voraussetzt, `zwischen` deren Polen etwas seinen Ort hat.²⁹ Darüber hinaus kommt dieser Begriff aus der Medizin. Weiter fiel uns auf, dass der Begriff `Hermaphrodit` zwar nicht aus der Medizin kommt, jedoch männlich konnotiert ist, während Intersexualität als Begriff geschlechtsneutraler ist. Der Begriff des Zitters wird wiederum eher abwertend mit Assoziation zum Tierreich gebraucht und kommt auch aus der Medizin. Reiter schreibt hierzu, der Begriff `Zwitter` sei schon im 9. Jahrhundert entstanden

²⁸in: Roche Lexikon Medizin, 4. Auflage; © Urban & Fischer Verlag, München 1984/1987/1993/1999, <http://www.gesundheit.de/roche/ro17500/r18377.html> (Stand: 9. Juli 2004).

²⁹ Protokoll unserer AG-Sitzung vom 8. Juni 2004.

und bedeute „Lebewesen mit männlichen und weiblichen Geschlechtsmerkmalen“, aber auch „außereheliches Kind“ oder „Bastard“.³⁰

Zentral war für uns an diesem Punkt die Frage, welche Begriffe / Selbstdefinitionen Intersexuelle verwenden. Es stellte sich heraus, dass Betroffene den Begriff oftmals selbst verwenden, ihn aber trotzdem sehr kritisch sehen. Reiter schreibt etwa, `Intersexualität` sei ein Anfang des 20. Jahrhunderts geprägter medizinischer Begriff für „sozialeliminatorische Vorhaben“.³¹ Andere KritikerInnen heben die traumatische Erfahrung hervor, die als `intersexuell` bezeichnete Personen eint: So bemängelt Georg Kluda am Begriff der Intersexualität, es sei „geradezu absurd, aus den zahlreichen Geschlechtsuneindeutigkeiten, die von der Medizin als Krankheiten und Missbildungen verunglimpft werden, ein zusammenhängendes Phänomen zu basteln: 'Turner-Syndrom', 'Klinefelter-Syndrom', 'androgenitales Syndrom' sowie 'Androgen-Resistenz-Syndrom' sind nicht miteinander verwandt, sondern haben vollständig andere biologische Hintergründe.“ Das Einzige, was Personen verbinde, die mit dem „Kunstwort Intersexualität“ bezeichnet würden, sei vielmehr die „Erfahrung von Pathologisierung, Verrat der Eltern und körperlicher Verstümmelung.“³²

Zum Schluss stellte sich die Frage nach Alternativen zu den unterschiedlichen geschlechtskonstituierenden Begriffen. So sollte eher ein Kontinuum von Geschlechtern angenommen werden, als von nur zwei eindeutigen Geschlechtern ausgegangen werden.³³ Als Ausweg wurde die amüsante, aber dennoch ernst gemeinte Bezeichnung „Hurra, es ist ein Hurx!“ für etwas nicht eindeutig zu Bezeichnendes ins Spiel gebracht.³⁴ Der erfundene Name entgeht durch seine vage Aura der Falle, wieder eine klare, ein- und ausschließende Definition zu liefern.

3. Wie wurde historisch mit Hermaphroditen umgegangen?

3.1. Die drei Phasen des Umgangs mit Hermaphroditen

Georg Kluda macht historisch drei Phasen aus, in denen Hermaphroditen mit sehr unterschiedlichen Politiken konfrontiert waren/sind: Bis zum 19. Jahrhundert hätten sich Hermaphroditen bei Volljährigkeit für das eine oder andere Geschlecht entscheiden dürfen,

³⁰ Reiter, Michel, Theoretische Differenz, symbolische Nähe, in: Gigi Nr. 6, März / April 2000, S. 20.

³¹ Reiter, Michel, „Ein normales Leben ermöglichen“, in: Gigi Nr. 8, Juli / August 2000, S. 8 und Reiter, Michel, Medizinische Intervention als Folter, in: Gigi Nr. 9, Oktober / November 2000, S. 15.

³² Kluda, Georg, Fürsorgliche Belagerung, in: Out of Dahlem, Nr. 1, Dezember 2000, S. 42.

³³ Protokoll unserer AG-Sitzung vom 8. Juni 2004.

³⁴ Protokoll unserer AG-Sitzung vom 1. Juli 2004.

erst danach habe sich der medizinische Apparat formiert und das „authentische Geschlecht“ anhand der Gonaden bestimmt. In der zweiten „Phase der Medikalisierung von Hermaphroditen“ Anfang des 20. Jahrhunderts sei es dann der Diskurs der Degeneration gewesen, der sie als monströs und missgebildet dargestellt habe. Im Rahmen der medizinischen Fotografie seien sie zur Schau gestellt worden. Die dritte Phase setzte in den 50er Jahren ein: Nun wurden hormonelle und chirurgische Interventionen propagiert.³⁵ Auch Reiter betont, dass die chirurgische Korrekturbestrebung noch sehr jung ist: Erst seit ca. 50 Jahren würden Intersexuelle operiert.³⁶

3.2. Michel Foucault und der Fall Herculine

Eine Veröffentlichung des französischen Philosophen Michel Foucault gibt über diese historischen Phasen etwas genauere Auskunft, er teilt die Geschichte allerdings etwas anders ein. Foucault entdeckt 1978 die 1860 veröffentlichten Memoiren des Hermaphroditen Herculine Barbin. Foucault kommentiert den Text und veröffentlicht ihn neu. Hinzu nimmt er medizinische Gutachten und Presseberichte, wodurch er einen Diskurs um das „wahre Geschlecht“ nachzeichnet.

Herculine wird bei ihrer/seiner Geburt als Mädchen kategorisiert und dem entsprechend erzogen. Während der Adoleszenz in Klosterschulen muss er/sie die geschlechtliche Differenz gegenüber den anderen Mädchen verschweigen, was einer Tabuisierung gleichkommt. Sie/Er wird sich ihres/seines Anders-Seins langsam bewusst, sucht dies jedoch zu verbergen. Ihre/Seine Umwelt wiederum verbalisiert nicht, was sie eventuell erkennt. Durch ihre/seine Ausbildung zur Lehrerin wird Herculines weibliches Geschlecht in der Bahn einer ‘typischen Frauenbiographie’ fortgesetzt. In einer späteren Liebesbeziehung zu einer Kollegin an ihrer Schule verstärken sich ihre/seine Identitätsprobleme. Die Unmöglichkeit, sich einer Geschlechtskategorie zuzuordnen und das Verbot der Homosexualität drängen Herculine dazu, ein Geständnis abzulegen. Aus diesem resultiert die Bestimmung einer männlichen Geschlechtsidentität mittels klerikaler und juridischer Institutionen. Der Wechsel der Geschlechtsidentität spitzt sich während ihrer/seiner Arbeit als Eisenbahnarbeiter in Paris zu. Schließlich scheitert Herculine jedoch im eigenen Kampf mit der Identitätsproblematik und nimmt sich das Leben.

Im Essay, den Michel Foucault den Memoiren einleitend voranstellt, fragt er: „Brauchen wir *wirklich* ein wahres Geschlecht?“ und ergänzt: „Mit einer Beharrlichkeit, die an Starrsinn

³⁵ Klauda, Georg, Fürsorgliche Belagerung, in: Out of Dahlem, Nr. 1, Dezember 2000, S. 43.

³⁶ Reiter, Michel, Ein perfektes Verbrechen, in: Gigi Nr. 2, Juni / Juli 1999, S. 16.

grenzt, haben die Gesellschaften des Abendlandes dies bejaht.“³⁷ Im Anschluss an die Frage skizziert er diese abendländischen Diskurse um Geschlecht und zeigt den Wandel auf, dem sie unterliegen: Im Mittelalter ist es qua Rechtssprechung legitim, zwei Geschlechter zu haben. Der Vater oder Pate bestimmt mit der Namensgebung ein Geschlecht, welches der Hermaphrodit an der Schwelle des Erwachsenenalters gegebenenfalls einmalig wechseln kann. Weitere Wechsel während des Lebens gelten jedoch als Straftaten.

Mit dem 18. Jahrhundert werden den Individuen Entscheidungsmöglichkeiten genommen: Die notwendige Definition des eindeutigen Geschlechts obliegt der biologischen Sexualtheorie / Medizin, Justiz und den Formen administrativer Kontrolle in den modernen Staaten. Geschlechtervermischung gilt als „Verkleidung der Natur“³⁸, und Hermaphroditen werden ‘Pseudohermaphroditen’ genannt. Die Medizin diskutiert diverse Fälle von Hermaphroditen mit dem Ziel, das wahre Geschlecht herauszufinden. Im 19. und 20. Jahrhundert sind die Diskurse des 18. Jahrhunderts in gewandelter Form wirkungsmächtig. Zwar wird eingeräumt, dass ein Geschlecht angenommen werden kann, das nicht dem biologischen entspricht, dagegen implizieren jedoch Psychologie, Psychiatrie, Psychoanalyse und öffentliche Meinung, es müssten „zwischen Geschlecht und Wahrheit komplexe, dunkle und wesentliche Beziehungen bestehen.“³⁹ Dies führt dazu, dass Abweichungen von den Normen des sexuellen Begehrens und von der Zweigeschlechtlichkeit nicht unbedingt pathologisch oder kriminell, jedoch ein ‘Irrtum’, eine Ausgeburt der Phantasie sind.

Die Geschichte Barbins ist für Foucault von besonderem Interesse aufgrund ihrer zeitlichen Verortung und indem sie sich vielfältigen Identifizierungen entzieht. Alexina Barbins Tagebuchaufzeichnungen zeugen davon, wie ein Individuum im neunzehnten Jahrhundert von Medizin und Justiz hartnäckig zu seinem wahren Geschlecht befragt wurde. Zunächst wurde sie/er als Mädchen erzogen, dann von Medizin und Justiz als ‘wahrer Junge’ erkannt und scheiterte schließlich an dieser neuen Identität. In der Zeit zwischen 1860 und 1870 wurde „die Suche nach der Identität in der Sexualität sehr intensiv betrieben“.⁴⁰ Vor diesen Identitätsdiskursen ist Alexina hinter den Klostermauern der Mädchenpensionate, in denen sie/er aufwächst, geschützt. Begehren ist dort nicht an sexuelle Identität geknüpft. Erst durch die institutionelle Befragung seitens der Religion, der Medizin und der Justiz, vermittelt durch Männer, wird Herculines/Alexinas sexuelle Identität eindeutig gemacht. Eine besondere Wendung nehmen diese Diskurse mittels der „discretion“⁴¹, in deren doppelter

³⁷ Foucault, Michel, Brauchen wir wirklich ein wahres Geschlecht?, in: Schäffner, Wolfgang, Vogl, Joseph (Hg.), *Herculine Barbin. Michel Foucault. Über Hermaphroditismus*, Frankfurt am Main 1998. S. 7.

³⁸ ebd. S. 9.

³⁹ ebd. S. 10.

⁴⁰ ebd. S. 12.

⁴¹ ebd. S. 13.

Wortbedeutung ihre zweischneidige Wirkungsmacht geborgen liegt (Verschweigen: in den klösterlichen Diskursen – Unterscheiden: in den institutionellen, Identität stiftenden Diskursen).

Bemerkenswert ist für Foucault, dass Herculine in ihren/seinen Memoiren, die sie/er nach Änderung ihres/seines Geschlechtsstatus verfasst, die glückliche Vergangenheit der Nicht-Identität und des Anders-Seins als Trost heraufbeschwört. Trost daher, weil sie/er zwar durch normative Verunsicherung nach Eindeutigkeit verlangte, die neue Identität jedoch nicht ihrer/seiner Person entspricht. So wird der Text zum literarischen Dokument der Nicht-Identifizierung. Der deutsche Psychiater Panizza schrieb, basierend auf den in Frankreich wenig rezipierten Memoiren, eine antiklerikale Romansatire. Der Schwerpunkt dieses Buchs liegt auf dem skandalträchtigen der Geschichte, wodurch die Person Herculine nur mehr undeutlich zu erkennen ist: „Panizza wollte aus ihr ein bloßes Schattenwesen ohne Identität und ohne Namen machen, das sich am Ende der Erzählung auflöst, ohne eine Spur zu hinterlassen.“⁴² Foucault hat diese beiden Texte zusammen mit Arztberichten und Zeitdokumenten zu Herculines Leben herausgegeben: „weil sie zu jenem Ausgang des 19. Jahrhunderts gehören, das so heftig vom Thema des Hermaphroditen heimgesucht wurde – etwa wie das 18. Jahrhundert von dem des Transvestiten.“⁴³ Für uns war dieser Text sehr spannend, da er deutlich macht, wie Hermaphroditismus historisch behandelt wurde. Ab dem 19. Jahrhundert war schließlich eine Vermischung der Geschlechter verboten. Dabei kristallisierte sich für uns die Erkenntnis heraus, dass gesellschaftliche Diskurse auch gewalttätig zum Offenbarungseid zwingen können, ohne dass eine aktive Person, ein Täter verantwortlich sein muss.⁴⁴

4. Das Geschlechterbild der modernen Medizin

4.1. Wie legitimiert die Medizin Operationen an Intersexuellen?

Medizinische Quelle 1 (Monika Schweiger „Zur Chirurgie der Intersexualität“):

Nachdem nun geklärt wurde, was Intersexualität eigentlich bezeichnet und wie in der Geschichte mit intersexuellen Menschen umgegangen wurde, wenden wir uns der heutigen, medizinischen Praxis zu, die geschlechtlich vereindeutigende Operationen an Intersexuellen

⁴² ebd. S. 18.

⁴³ ebd. S. 18

⁴⁴ Protokoll unserer AG-Sitzung vom 8. Juni 2004.

vornimmt. Besonders beschäftigt hat uns die Frage, warum Intersexuelle geschlechtlich eindeutig gemacht werden. Warum wird operiert und wie legitimiert die Medizin einen sozial kategorisierenden operativen Eingriff?

Um diesem Punkt näher zu kommen, haben wir die einschlägige medizinische Fachliteratur durchgearbeitet. In der Dissertation von Monika Schweiger finden sich beispielsweise sehr voraussetzungsvolle Annahmen zu der Frage, weshalb Intersexuelle operiert werden müssen. Zunächst erläutert sie, wie es zur Zugehörigkeit zu einem Geschlecht komme. Sie schreibt, die Sexualentwicklung werde zum einen von festgelegten biologischen Faktoren wie dem chromosomalen, gonadalen und zerebralen Geschlecht beeinflusst. Zum anderen spielten das morphologische Geschlecht, das „nach der Geburt zugewiesene, bürgerliche Geschlecht und biologisch begründete geschlechtsspezifische Erziehungstendenzen“ eine wichtige Rolle.⁴⁵ Schweiger behauptet: „Das Wechselspiel dieser Kräfte“ bewirke die „Geschlechtsidentifikation des Kindes im Alter von etwa 2-3 Jahren. Die Entwicklung geht später über in die sexuelle Orientierung und Partnerwahl, in die Übernahme der psychosozial bestimmten Geschlechtsrolle bis hin zur Sexualität als Teil des Welt- und Menschenbildes.“ Bis hierhin entspricht ihre Beschreibung den gängigen Erklärungsmustern. Nun kommt aber das ‚Phänomen‘ Intersexualität hinzu. Zur Frage der medizinischen Legitimation von Operationen an intersexuellen Menschen schreibt Schweiger im Anschluss nur kurz: „Eine geschlechtsspezifische Erziehung ist jedoch nur möglich, wenn morphologisches Geschlecht und zugewiesenes Geschlecht übereinstimmen. Ist dies nicht der Fall, werden die Eltern verunsichert und eine psychosozial normale Entwicklung des Kindes ist nicht gewährleistet. Aus diesen Gründen ergibt sich die Notwendigkeit einer möglichst frühzeitigen Geschlechtszuordnung und damit eines frühen Operationstermins. Beides sollte vor dem Beginn des Geschlechtsbewußtseins des Kindes geschehen.“⁴⁶ Diese Art von Präventionsdenken fiel uns immer wieder in den Denkmustern medizinischer Texte auf. Die heutige Gewaltausübung sei notwendig, damit das Kind in Zukunft ‚normal‘ und somit glücklich sein könne. Die Behauptung zukünftig zu habenden Glücks legitimiert durch eine solche Argumentation heutiges Leid.⁴⁷ Im Weiteren widmet sich Schweiger verschiedenen Operationstechniken. In diesem Kontext spricht sie erneut sehr genau aus, was das Ziel der Operation ist: „Mit der operativen Korrektur soll die Angleichung an einen normalen weiblichen bzw. männlichen Phänotyp des äußeren Genitales erreicht werden.“⁴⁸ Des Weiteren betont sie die prioritäre Kontrollmacht der Ärzte über die Penetrationsfähigkeit des

⁴⁵ Schweiger, Monika, Zur Chirurgie der Intersexualität, Dissertation an der Ludwig Maximilians Universität zu München, München 1982, S. 6.

⁴⁶ ebd., S. 8.

⁴⁷ Protokoll unserer AG-Sitzung vom 1. Juli 2004.

⁴⁸ Schweiger 1982, S. 87.

weiblichen Körpers: „Entscheidend ist, daß die Kinder, bei denen eine Vaginalkorrektur durchgeführt wurde, in ärztlicher Kontrolle bleiben bis sie ausgewachsen sind, also etwa bis zur Pubertät. In diesem Alter sollte man sich bei einer abschließenden Untersuchung vergewissern, daß die Scheide weit genug ist und keine narbigen Verengungen zeigt, so daß ein Koitus von der anatomischen Situation her problemlos möglich ist.“⁴⁹ Die Betonung der Koitusfähigkeit des Organs zeigt noch einmal in aller Deutlichkeit die Funktion der Operation: Sie soll einen penetrierbaren weiblichen Körper erschaffen, ohne den die heterosexistische Ordnung nicht überleben kann. Krass ausgedrückt: Frauen sollen von Männern gefickt werden. In der Zusammenfassung hebt Schweiger erneut die Wohltätigkeit der chirurgischen Maßnahmen hervor: „Falsche oder zu späte Behandlung kann für das Kind lebenslang schwere psychosoziale Probleme nach sich ziehen.“⁵⁰ Weiter wird deutlich, dass der biologische Körper für soziale Normen passend geschneidert wird: Sie schreibt, ein „wichtiger Faktor, der zur Geschlechtsidentifikation des Kindes führt“, sei „die geschlechtsspezifische Erziehung. Diese zu verfolgen kann den Eltern aber auf die Dauer nur gelingen, wenn das äußere Genitale im Phänotyp dem bürgerlichen Geschlecht entspricht.“⁵¹ Deutlicher lässt sich kaum formulieren, dass sex für gender zurechtgeschneidert werden muss, das soziale Geschlecht also das biologische erschafft.

Medizinische Quelle 2 (Intersexualität im Kindesalter, Tagung an der Universität Jena):

Während die Arbeit von Monika Schweiger Auskunft darüber gab, wie die Medizin Operationen an Intersexuellen legitimiert, lässt sich aus der folgenden Quelle zusätzlich erfahren, welche Vorstellung von Geschlecht in der Medizin wirksam ist: Aus der gleichen Zeit wie Monika Schweigers Dissertation stammt das Themenheft: „Intersexualität im Kindesalter“.⁵² Hierbei handelt es sich um eine Zusammenstellung von Beiträgen, die auf einer Tagung an der Universität Jena gehalten wurden.⁵³ Wie aus dem Vorwort des Sammelbandes hervorgeht, befasste sich die Tagung vor allem mit diagnostischen Methoden und deren Verbesserung. Am Rande war der Themenkomplex „Entscheidungen über Geschlechterrollen, Bedeutung von rechtlicher Zuordnung des juristischen Geschlechts und die psychische Situation der Menschen“ von Interesse. Das Vorwort lässt - wie bei Schweiger - keinen Zweifel darüber entstehen, dass die MedizinerInnen die - im Bezug auf

⁴⁹ ebd., S. 91.

⁵⁰ ebd., S. 95.

⁵¹ ebd., S. 96.

⁵² Hoepffner, W., Hesse V. (Hg.), Intersexualität im Kindesalter, Arbeitstagung der AG Pädiatrische Endokrinologie, Jena 1984.

⁵³ Ein Ost-West-Vergleich bezüglich des Umgangs mit Intersexualität kann allerdings nicht gezogen werden, da bei der Tagung Fachkundige aus der DDR und der BRD zusammenkamen.

Geschlechterkonstruktion unreflektierte - Auffassung vertreten, mit ihrer Forschung und der daraus resultierenden medizinischen Praxis die Lebensqualität ihrer PatientInnen zu verbessern. Daran zeigt sich, dass medizinische Diskurse nicht berührt werden von (wissenschaftlichen) Diskursen, welche die Geschlechterkonstruktion kritisch hinterfragen. Diese einseitig ignorante Trennung der Denkstrukturen lässt zwei in Bezug auf Geschlecht gänzlich gegensätzliche Wahrnehmungsrealitäten entstehen.

Dieser Umstand zeigt sich auch in dem Beitrag „Bemerkungen zur rechtlichen Regelung der Geschlechtszuordnung“ von L. Pelz⁵⁴. Die Zweigeschlechtlichkeit wird als naturgegeben vorausgesetzt. Begründet wird dies damit, sie sei bei allen höheren Lebewesen vorherrschend. Legitimierend für die Entscheidung der Medizin, ein Geschlecht herzustellen, ist eine historische Herleitung dieser Praxis. Da die Entscheidung von jeher alternativ gewesen ist (Beispiel aus dem Jahr 1738), soll das auch künftig so sein. Außerdem liegt die Entscheidungsgewalt eindeutig bei der Medizin. Die Anpassung an ein Geschlecht muss vor allem aus Gründen der Integrierbarkeit der Individuen in das soziale Leben geschehen: „Darüber hinaus würde eine solche Regelung [Einführung des `genus neutrius`] nicht der gesellschaftlichen Integrierung, sondern der öffentlichen Brüskierung von Patienten mit intersexuellen Organbildungsfehlern dienen. Das kann nicht unsere Aufgabe sein und darf niemals zu unserer Aufgabe werden.“⁵⁵

Der umfangreichere Beitrag von R. Dittmann⁵⁶ stützt seine Argumentation auf Forschungsergebnisse aus Tierversuchen (wobei eingeräumt wird, diese seien nur bedingt auf Menschen übertragbar⁵⁷) und Experimente mit intersexuellen Kindern und Jugendlichen.⁵⁸ Dittmann gibt eine Definition: „Mit dem Begriff Geschlechtsidentifikation (bzw. Geschlechtsidentität) wird ein typisch menschliches Phänomen beschrieben und als grundlegende Identifikation eines Individuums mit dem einen oder anderen Geschlecht

⁵⁴ Pelz, L., Bemerkungen zur rechtlichen Regelung der Geschlechtszuordnung, in: Hoepffner, W., Hesse V. (Hg.), Intersexualität im Kindesalter, Arbeitstagung der AG Pädiatrische Endokrinologie, Jena 1984, S. 232–S. 235.

⁵⁵ ebd. S. 235.

⁵⁶ Dittmann, R., Psychosoziale Aspekte bei der Wahl der Geschlechtsrolle für intersexuelle Patienten, in: Hoepffner, W., Hesse V. (Hg.), Intersexualität im Kindesalter, Arbeitstagung der AG Pädiatrische Endokrinologie, Jena 1984, S. 236-249.

⁵⁷ „Je höher eine Spezies ausgebildet ist, umso entscheidender scheinen Umweltbedingungen für die Ausprägung von Verhaltensweisen zu sein.“ (ebd., S. 237).

⁵⁸ „Folgende Bereiche fanden dabei in der Literatur besondere Berücksichtigung: 1. Sport und Spielaktivitäten im Freien, 2. Aggressivität im sozialen Kontakt, 3. Mutter- und Kind-Spiele/ `Mutterschaftsverhalten`, 4. Spielkameradenpräferenz, 5. soziale Zuweisung spezifischer Rollen im Verhalten (z.B. als `Tomboy`), 6. Einstellung zur Kleidung und Körperpflege.“ (ebd., S. 237). Hieran lässt sich überdeutlich erkennen, wie Rollenstereotype zur Basis von Forschungsfragen werden!

definiert, deren Entwicklung weitgehend von Lernprozessen abhängt.“⁵⁹ Die Zuweisung der Geschlechtsidentität wird also auf Sozialisation beruhend geschildert. Dieser müssten von medizinischer Seite Eingriffe wie „chirurgische Korrekturen und postnatale Hormontherapie“, sowie „eine frühe Ausräumung elterlicher Zweifel“⁶⁰ vorangehen. Hier wird die unreflektierte Erkenntnis der Geschlechterkonstruktion in einer relativistischen Wendung missbraucht. Es scheint zweitrangig, welchem Geschlecht ‚geschlechtlich uneindeutig‘ geborene Menschen zugewiesen werden, von Bedeutung ist vor allem, dass dies geschieht. Weiter bleibt die Argumentation, wie auch im untersuchten Beitrag von Monika Schweiger, im hegemonialen System der heteronormativen Zweierbeziehung verhaftet: „Ziel aller korrigierenden Operationen, auch eventueller späterer Vaginaloperationen, für die intersexuellen Patienten sollte die Erreichung der Kohabitationsfähigkeit sein. Dieser Gesichtspunkt sollte bereits bei der Wahl der sozialen Geschlechtsrolle im Säuglingsalter gründlich mitbedacht werden.“⁶¹

In dem Prozess der Geschlechtsbestimmung ist die Einbeziehung der Eltern von Bedeutung. Da sie in der Erziehung auf die Geschlechtsidentität ihrer Kinder hinwirken und hinwirken sollen, müssen sie ein eindeutiges Geschlecht als Ziel haben. Die Entscheidungsgewalt liegt hier beim ExpertInnenwissen der Medizin und Psychiatrie. „Eine intensive begleitende Aufklärung und Beratung der Eltern sollte dazu führen, dass diese die fachliche Empfehlung auch zu einem eigenen Entschluss entwickeln und diesen dann überzeugt mittragen können.“⁶² Außerdem soll den Eltern⁶³ durch fachlich kompetente Beratung die Angst vor Diskriminierungen genommen werden. Der Handlungsbedarf der Medizin wird nochmals begründet: „Abwartende und bagatellisierende Haltungen von behandelnden Ärzten und

⁵⁹ ebd., S. 239; hierbei bezieht Dittmann sich auf Untersuchungen von Money: vgl. Money, J. und A.A. Erhardt: Männlich – Weiblich. Die Entstehung der Geschlechterunterschiede. Reinbek, 1975.

⁶⁰ Dittmann, R., Psychosoziale Aspekte bei der Wahl der Geschlechtsrolle für intersexuelle Patienten, in: Hoepffner, W., Hesse V. (Hg.), Intersexualität im Kindesalter, Arbeitstagung der AG Pädiatrische Endokrinologie, Jena 1984, S. 239-240.

⁶¹ „Für die klinische Praxis in der Behandlung und Betreuung von Patienten mit intersexuellem Genitale bedeutet dies zusammengefasst also, dass 1. die Festlegung des sozialen Geschlechtes möglichst früh und 2. erste operative Korrekturen vor Ende des 2. Lebensjahres erfolgen sollten, diese 3. am Phänotyp der äußeren Geschlechtsorgane orientiert sein müssen und 4. eventuelle auch durch weiter operative und medikamentöse Maßnahmen eine spätere Kohabitationsfähigkeit erzielt werden sollte sowie 5. für sozial männliche Kinder auch eine stehende Urinierposition.“ ebd., S. 241.

⁶² ebd., S. 242.

⁶³ Weitere Anleitungen zur Beratung der Eltern: „Dabei wird einleitend versucht, ihnen zu vermitteln, dass die Störung ihres Kindes nur eine von vielen möglichen in der embryonalen Entwicklung eines Menschen darstellt und mit Fehlbildungen anderer innerer Organe vergleichbar ist. Die Befürchtung der Eltern es bestehe ein Zusammenhang zwischen genitaler Fehlbildung und psychischer bzw. psychosexueller Abnormität, kann vermindert werden. [...] Es gelingt so, den Eltern die Störung ihres Kindes als eine Unterbrechung einer normalen Entwicklung von einem undifferenzierten, für beide Geschlechter gleichen Ausgangsstadium zu erläutern. Die medizinischen Maßnahmen, so wird erklärt, sollen dazu dienen, das ‚unfertige‘ Genitale einem normalen Erscheinungsbild anzugleichen. [...] Eine mögliche Lebensplanung ohne eigene Kinder (Adoption, caritativer Beruf, pflegerischer Beruf, Karriere) wird angesprochen.“ ebd., S. 243 „[...] weiter werden die Eltern beruhigt, dass ihre Kinder durchaus kein homosexuelles Begehren entwickeln müssen, wenn die Sozialisation in einer Geschlechtsidentität erfolgreich ist.“ ebd., S. 244.

unzureichende Aufklärung können – wie wir es immer wieder einmal beobachtet haben – zu unzureichender oder verspäteter Behandlung und dann letztlich für die Patienten zu Fehlentwicklungen, Verstimmungen, Verhaltens- und Leistungsstörungen, gestörter Geschlechtsidentifikation und bis zu Suizidideen führen.“⁶⁴ Die zweigeschlechtliche Ordnung wird so stark als Gesamtheit vorausgesetzt, dass eine Nicht-Identifikation lebensbedrohliche Folgen haben kann. Es wird nicht in Erwägung gezogen, diese Ordnung zu kritisieren und zu hinterfragen oder gar als Ursache für Diskriminierungen und Probleme mit geschlechtlicher Uneindeutigkeit zu sehen. Stattdessen wird betont, der betroffene Mensch müsse verändert werden, um leben zu können.

Medizinische Quelle 3 (Dominik Leitsch „Die Intersexualität. Diagnostik und Therapie aus kinderchirurgischer Sicht“):

Eine weitere Dissertation, die wir untersucht haben, ist die von Dominik Leitsch „Die Intersexualität. Diagnostik und Therapie aus kinderchirurgischer Sicht“, die Mitte 1996 an der Universität Köln eingereicht wurde. Seine Arbeit beginnt mit Definitionen von 'Geschlecht' und 'Sexualität': „Unter Geschlecht (Sexus) versteht man die Unterschiedlichkeit der Individuen in bezug auf Anatomie und Funktionen der genitalen Organe. Als Sexualität definiert man die im Körperlichen und im Geistig-Seelischen ablaufenden Verhaltensweisen, welche sich auf Lustgewinn in den Beziehungen zum (normalerweise) anderen Geschlecht richten und der Fortpflanzung dienen.“⁶⁵ Zu diesem offensichtlichen Heterosexismus gesellt sich gleich anschließend eine krasse Pathologisierung intersexueller Menschen: „In der heutigen Zeit umfaßt die Intersexualität eine große Zahl schwerwiegender Störungen im Kindesalter, welche bei fehlender Therapie zu schweren körperlichen und geistigen Schäden des Kindes führen können.“⁶⁶ Ohnehin ist in seiner Arbeit durchweg von einem 'Leiden' der als intersexuell diagnostizierten Kinder die Rede. Konsequenterweise propagiert Leitsch deshalb die umfassende 'Dokumentation' intersexuell diagnostizierter Kinder. Dazu differenziert er zunächst die verschiedenen Formen der Intersexualität in „Fehlbildungen“ des chromosomalen, gonadalen und somatischen Geschlechts. Leitsch hebt die Notwendigkeit einer frühen Entscheidung hervor: „Die Untersuchungen von MONEY und ERHARDT zeigten, daß Kinder bis zum Ende des zweiten Lebensjahres ihre psychosexuelle Identität entwickeln. Erfahrungsgemäß gilt, daß es sich für die psychische Entwicklung negativ auswirkt, wenn das einmal gewählte Geschlecht nach dem dritten Lebensjahr noch einmal

⁶⁴ ebd. S. 242

⁶⁵ Leitsch, Dominik: Die Intersexualität. Diagnostik und Therapie aus kinderchirurgischer Sicht. Dissertation, Universität Köln, 30. Mai 1996, S. 7.

⁶⁶ ebd.

geändert wird. Daraus resultiert die unbedingte Notwendigkeit mit der Diagnostik und der Therapie einer intersexuellen Störung so früh wie möglich zu beginnen, und möglichst vor dem Erreichen des dritten Lebensjahr festzulegen, ob das Kind als männliches oder weibliches Individuum erzogen werden soll.“⁶⁷ Er fordert also individuell angepasstes Verhalten aufgrund eines gesellschaftlichen Zwanges (Zweigeschlechtlichkeit) ein – wobei die Ausführenden jedoch zentral an der Produktion dieses Zwangs beteiligt sind. Flankierend soll eine Psychotherapie den gewünschten Erfolg gewährleisten: „So sollten Kinder mit einer intersexuellen Fehlbildung zusätzlich zu der chirurgischen und pädiatrischen Betreuung durchgehend durch psychologisches Personal betreut werden um evtl. auftretende Diskrepanzen in der körperlichen und psychosexuellen Entwicklung des Kindes festzustellen und in das Therapiekonzept einzubringen.“⁶⁸ Es soll ausgeschlossen werden, dass biologische Geschlecht zwar eindeutig ist, das Kind aber ganz anders empfindet oder begehrt. „Die Therapie in bezug auf intersexuelle Fehlbildungen sollte stets dreigleisig sein. Am wichtigsten hierbei ist zunächst der kausale Therapieansatz, so z.B. die Substitution von Glukokortikoiden bei Kindern mit einem AGS. Der zweite Punkt ist die chirurgisch-plastische Rekonstruktion des äußeren Genitals in Richtung des gewählten Geschlechts mit dem Ziel eines guten kosmetischen und vor allem funktionellen Ergebnisses. Der dritte und nicht minder wichtige Therapiepfeiler ist die psychosoziale Betreuung der Eltern in der frühen Kindheit und später auch zunehmend die Patienten selbst.“⁶⁹ Leitsch benennt vier Faktoren für die Festlegung des kindlichen Geschlechts:

1. „Befund des äußeren Genitals bei der Geburt und seine Ansprechbarkeit auf exogene Testosteron und/oder DHT-Gaben
2. Erfahrung und Können des behandelnden Operateurs sowie Möglichkeiten der Klinik
3. Erfahrungen über die psychische und physische Weiterentwicklung des Kindes in der Pubertät einschließlich der zu erwartenden Fertilität.
4. Ethnologisches und soziales Umfeld der Eltern“⁷⁰

Am Ende seiner Arbeit geht Leitsch auf die männlich-weiblich Verteilungshäufigkeit ein: in Köln ist es eine Rate von 1:2, in der von ihm zitierten Arbeit von LUKS 1:3 und von den 114 dokumentierten `Fällen` aus der Weltliteratur ist es eine Quote von 56:44. Zu diesen Quoten und die Entstehungsbedingungen schreibt er leider nicht mehr. So ist gerade bei letzterer Quote davon auszugehen, dass gerade Vermännlichungen eher schriftlich festgehalten werden, da eine Vermännlichung operationstechnisch schwieriger zu bewerkstelligen ist.

⁶⁷ ebd.

⁶⁸ ebd., S. 43.

⁶⁹ ebd., S. 129.

⁷⁰ ebd., S. 130.

4.2. Intersexualität in Schulbüchern

Beim Blick in Schul- und Lehrbücher, die an Berliner Gymnasien kursieren, offenbart sich das oben skizzierte Geschlechterbild der Medizin in populärwissenschaftlicher Weise. Vier derartige Schriften sollen im Folgenden anhand der Fragen nach Geschlecht, Geschlechterbeziehungen und Sexualität in Kürze vorgestellt werden.

In Corinne Stockleys **„Tessloffs Bildlexikon in Farbe – Biologie“** wird in ein männliches und ein weibliches „Fortpflanzungssystem“ unterschieden, die nebeneinander abgebildet sind. Es wird eine Anleitung (!) zum Geschlechtsverkehr gegeben („[...] Daran schließen sich rhythmische Bewegungen des Beckens an.“). Einen Höhepunkt kann nach Stockley jedoch anscheinend nur der Mann haben: nur von ihm ist die Rede im Zusammenhang mit dem Höhepunkt. Generell wird alles unter dem Aspekt der Fortpflanzung betrachtet.⁷¹

Das **„große Buch des Allgemeinwissens: NATUR“** hält fest: „Wie alle biologischen Eigenschaften wird auch das Geschlecht im allgemeinen irreversibel festgelegt, und zwar genotypisch oder phänotypisch [...] Ein Extremfall liegt bei den zahlreichen zwittrigen Arten vor [...] Bei den Säugetieren [...] liegen die genetischen Determinanten des Geschlechts auf einem Chromosomenpaar, den Geschlechtschromosomen X und Y [...]“. Beim Menschen wird Zwitterigkeit also nicht erwähnt; des Weiteren wird behauptet, dass Geschlecht irreversibel festgelegt ist. Es wird in einen „Geschlechtsapparat“ des Mannes und der Frau unterschieden; der Mensch erscheint bei dieser Formulierung als Maschine. Zur Erotik wird angemerkt: „Der Mensch ist auch biologisch durch seine ständige Paarungsbereitschaft zur Erotik prädestiniert, die ja nichts anderes ist als ein Regelwerk zur Kanalisierung dieser ansonsten überbordenden hormonellen Wallungen.“ Erotik dient diesem Verständnis nach nur der Fortpflanzung, und zwar einer gesitteten. Außerdem wird impliziert, dass Hormone eine elementare Rolle für die Paarung spielen und nur schwer unter Kontrolle zu bringen sind.⁷²

In **„Biologie heute“ für Gymnasialklassen** wird eine „Partnerbeziehung“ dadurch gekennzeichnet, dass in ihr sexuelle Bedürfnisse von Mann und Frau befriedigt werden (müssen), allerdings auch nur dort. Es gibt auch homosexuelle Beziehungen (bei Frauen auch „lesbische Liebe“) und bisexuell lebende Menschen. Das sei jedoch alles „veranlagt“ und es gebe einen „angeborenen Sexualtrieb“. Der „Triebstau“ wird „in der Regel abgebaut durch den Orgasmus“. „Abartige und krankhafte Verhaltensweisen“ sind S/M-Sex. Außerdem gibt

⁷¹Stockley, Corinne, Tessloffs Bildlexikon in Farbe – Biologie. Tessloff Verlag, Hamburg 1987 (Original 1986), S. 88-91.

⁷²Das grosse Buch des Allgemeinwissens: NATUR. Verlag Das Beste, Stuttgart/Zürich/Wien 1996, S. 358 + 805.

es noch „Sittlichkeits- oder Triebverbrecher“, die ihren „Trieb“ an Frauen und Kindern „abreagieren“. Primäre Geschlechtsorgane beim Mann sind Hoden, Samenleiter und Penis, primäre Geschlechtsorgane bei der Frau sind große und kleine Schamlippen, Scheide, Gebärmutter, Eierstöcke und Eileiter. Es wird konstatiert: „An den Geschlechtsorganen lassen sich die Geschlechter bereits bei Neugeborenen unterscheiden.“ Sekundäre Geschlechtsmerkmale sind bei Mann wie Frau Behaarung, Becken, Schultern, Muskulatur, Körperform, Leistungsfähigkeit und Stimmlage. Tertiäre Geschlechtsmerkmale sind Anziehsachen. „Ob es ein Junge oder ob es ein Mädchen wird, bestimmen die Chromosomen.“ Der Chromosomensatz XY produziere einen Jungen, der Chromosomensatz XX ein Mädchen. Alles wird fein säuberlich bipolar unterschieden. Nach all diesen Stereotypen kommt der Clou zum Schluss: „Die Klassifizierung in 'typisch weiblich' und 'typisch männlich' beruht ... vielfach auf einem Vorurteil.“⁷³

In „**Natur – Biologie für Gymnasien, 7.-10. Schuljahr**“ werden die Geschlechtsorgane des Mannes fein säuberlich getrennt von denen der Frau unterschieden. Dies geschieht auch graphisch: die einen auf der einen Seite, die anderen auf der anderen. Der Mann ist aktiv und hat einen Orgasmus, bei der Frau ist davon nicht die Rede. „Der Scheide kommen im Wesentlichen zwei Aufgaben zu: Sie nimmt bei der körperlichen Vereinigung von Mann und Frau den Penis und das von ihm abgegebene Spermium auf, und sie ist der natürliche Geburtskanal, durch den das Kind bei der Geburt herausgepreßt wird.“ Sexualität ist als „natürlicher Geschlechtstrieb“ angeboren. Die Ursachen von Homosexualität werden in „angeborenen Veranlagungen und frühkindlichen Erlebnissen“ vermutet (!). S/M-Sex wird als „Perversion“ und als „abartiges und krankhaftes Verhalten“ bezeichnet. Sexuelle Gewalt wird auf einen „starken Geschlechtstrieb“ zurückgeführt. Schlüsselreize sind angeboren. Das „Weib-Schema“ basiert auf: „schmale Schultern, wohlgeformter Busen, breites Becken, weiche Körperformen und lange Beine“. Das „Mann-Schema“ bedeutet hingegen: „breite Schultern, schmales Becken, muskulöser Körperbau“. „Dieses Mann- bzw. Weib-Schema bestimmt bei uns Menschen unbewusst die Wahl des Sexualpartners.“ Begehren von Uneindeutigem/-n ist so nicht denkbar. Natürlich: „Zwei Chromosomen bestimmen das Geschlecht“.⁷⁴

⁷³Hoff, Peter / Jaenick, Dr. Joachim / Miram, Wolfgang (Hg.): Biologie heute 2G (Gymnasium), Hannover 1995, S. 193-195 + 357.

⁷⁴Claus, Roman / u.a. (Hg.): Natur – Biologie für Gymnasien, 7.-10. Schuljahr, Band 2., Stuttgart/Düsseldorf/Berlin/Leipzig 1991, S. 271-334.

4.3. Zum Verhältnis von sex und gender bei Intersexualität

Fundamentale Regeln heterosexueller Zweigeschlechtlichkeit sind erstens das Kongruenzgebot – Körpergeschlecht und Geschlechtsidentität müssen deckungsgleich sein – und zweitens die Annahme, Geschlecht sei nicht veränderbar: die einmal vorgenommene Geschlechtszuweisung gilt lebenslanglich.⁷⁵ Als dritte Grundannahme kommt hinzu, dass Geschlecht eine körperliche Basis habe. Jede dieser drei Grundannahmen wird durch die bloße Präsenz Intersexueller als ideologische Konstruktion enttarnt. Intersexualität unterbricht die Routine der Geschlechterkonstruktion; Intersexuelle sind Personen, die sich diesem Geschlechterentwurf nicht zuordnen lassen: sie gehören nicht nur einem Geschlecht an, von daher tun sie dies auch nicht ein Leben lang und eine geschlechtliche 'körperliche Basis' ist bei Intersexuellen zwar gegeben, diese passt jedoch nicht in das hegemoniale männliche oder weibliche Körpermodell – somit gibt es bei Intersexuellen keine körperliche Basis für Geschlecht. Diese muss erst hergestellt werden – wortwörtlich. „Der Krieg fängt dort an, wo die Weichen gestellt werden.“⁷⁶ schreibt Michel Reiter.

Von großer Bedeutung für die Entscheidung der Geschlechtsbestimmung ist bei intersexuellen Genitalien die Erscheinungsform des äußeren Genitales, das phänotypische bzw. morphologische Geschlecht, das nach Auffassung von MedizinerInnen sowohl das psychische als auch das soziale Geschlecht nachhaltig prägt. Der Gynäkologe Tscherne schrieb 1987: „Eine normale chromosomale, gonadale und hormonale Geschlechtsdifferenzierung ist Voraussetzung für die normale Ausbildung des Genitales und eine adäquate Sexualentwicklung, also ein zusammenpassendes, chromosomales, gonadales und genitales Geschlecht.“⁷⁷ Es findet also eine Hierarchisierung der 'Geschlechtskomponenten' statt: die Annahme ist, dass sex dem gender vorgängig sei. Mit der Zurichtung des sex, der Genitalien, soll also auch das gender hergestellt werden und damit zusammenhängend (heterosexuelles) Begehren. In dieser (medizinischen) Lesart werden die Kategorien sex und gender auf die Füße gestellt. Sex und Natur werden als natürlich gedacht, wohingegen Gender und Kultur als konstruiert verstanden werden. Dies aber sind falsche Dichotomien. Bei Intersexuellen wird der Sex wortwörtlich konstruiert. MedizinerInnen glauben, dass ihr ExpertInnenstatus sie dazu ermächtigt, die 'Wahrheit' der Natur zu 'hören', die ihnen zuflüstert, welchen Sex ihr/e PatientIn haben sollte. Aber: Die 'Wahrheit' der

⁷⁵Jäger, Ulle / Sälzer, Christian, entweder oder und der rest. transsexualität und transgender, in: diskus, Nr. 3, Frankfurt am Main, Dezember 1999, 48. Jahrgang, S. 29-33.

⁷⁶Zitat von Michel Reiter in: Tolmein, Oliver & Rotermund, Bertram, „Das verordnete Geschlecht“ (Film), Hamburg 2002.

⁷⁷Heldmann, Anja, Jenseits von Frau und Mann, Intersexualität als Negation der Zweigeschlechtlichkeit, in: Differenz und Geschlecht: neue Ansätze in der ethnologischen Forschung, Reimer, Berlin, 1998, S. 58.

MedizinerInnen ist gesellschaftlich und wird in Folge der Operation(en) durch die Unsichtbarmachung intersexueller Geburten erneut hergestellt.⁷⁸ Wir gehen davon aus, dass die Kultur der Zweigeschlechtlichkeit und das gender der ÄrztInnen, JuristInnen, Eltern und anderer Beteiligter die Ursache (!) für die Zurichtung des sex eines intersexuell geborenen Kindes ist und nicht eine wie auch immer herbeihalluzinierte 'Natur'. (vgl. hierzu genauer den Punkt 4.6.: Der Arzt als Überwacher der Geschlechterordnung).

4.4. Die medizinische Zurichtung zu heterosexuellem Begehren

Der Mediziner Dominik Leitsch definiert Sexualität als „die im Körperlichen und im Geistig-Seelischen ablaufenden Verhaltensweisen, welche sich auf Lustgewinn in den Beziehungen zum (normalerweise) anderen Geschlecht richten und der Fortpflanzung dienen.“⁷⁹ Menschen mit uneindeutigem gender und/oder sex sind in dieser Sichtweise offensichtlich nicht begehrenswert. Dies sagt viel über die bürgerliche Geschlechterordnung aus: Da in der heterosexuellen Matrix nur Hetero-, Homo- oder Bisexualität denkbar ist – wobei Homo- und Bisexualität für Leitsch schon unter 'unnormal' fallen –, muss eben nicht nur das Objekt des Begehrens eindeutig sein, sondern eben auch das Subjekt. Anders formuliert: Sowohl die Fremd- wie auch die Selbstidentifikation sind geschlechtlich eindeutig: männlich oder weiblich. Dies betrifft mitnichten nur Intersexuelle, sondern alle Menschen! Ohnehin: es muss begehrt werden, Asexualität ist in dieser Konzeption nicht denkbar. Folgerichtig gibt es parallel zur 'materiellen' Vernichtung von all denen, die aus dieser Ordnung fallen, auch keine symbolische Repräsentation. Es gibt noch nicht einmal offizielle Begrifflichkeiten, die das Begehren von bzw. das begehrt-werden von Nicht-männern-nicht-frauen sprachlich fassen können. 'Die Bewegung' hat hierfür zwar den Begriff 'queer', der aber aus mehreren Gründen für die Anliegen Intersexueller unbrauchbar ist (vgl. hierzu genauer die Punkte 6.: Zur doppeldeutigen 'Konstruierbarkeit' des Geschlechts und 5.1.: Von rassistischem Sprechen und Verschweigen).⁸⁰

Dass sich Intersexuelle jedoch fortpflanzen, scheint nicht angestrebt zu werden. So werden beispielsweise bei einer Verweiblichung die weiblichen Genitalien auf die Scheide reduziert. Die Möglichkeit, auch eine Gebärmutter und Eierstöcke künstlich herzustellen, wird nicht in Erwägung gezogen. Es geht also bei Intersexuellen tatsächlich nur um Kohabitationsfähigkeit.

⁷⁸Fausto-Sterling, Anne, Sexing the Body: How Biologists Construct Human Sexuality, <http://www.symposium.com/ijt/gilbert/sterling.htm> (Stand: 13. Juni 2004).

⁷⁹Leitsch, Dominik, Die Intersexualität, Diagnostik und Therapie aus kinderchirurgischer Sicht, Dissertation, Universität Köln, 30. Mai 1996, S. 7.

⁸⁰Protokoll unserer AG-Sitzung vom 4. Juni 2004.

Das Fehlen der Scheide wird vor allem unter dem Gesichtspunkt der Unmöglichkeit, eine heterosexuelle Beziehung führen zu können, beurteilt. Der Gynäkologe Richter schrieb 1987: „Die gänzlich unerwartete Konfrontation mit einem Defekt, der ihr die Erfüllung ihrer erträumten und anerzogenen Rolle als Frau und Mutter unmöglich macht, stürzt die Betroffene nicht selten in einen Abgrund der Verzweiflung.“⁸¹ Wie selbstverständlich wird von der Frau als „Mutter“ gesprochen. Wenn sie auch aufgrund ihrer „Anomalie“ keinen Beitrag zur Reproduktion leisten kann, so sollte doch wenigstens ihr sexuelles Begehren auf einen männlichen Sexualpartner ausgerichtet und sie deshalb zur Kohabitation fähig sein.⁸² Penetration wird als einzig legitime wie einzig denkbare Sexualität dargestellt. Und dass eben diese nur ermöglicht wird, weil es zur heterosexuellen Ordnung dazugehört, wird deutlich daran, dass die Überlegung des „Lustgewinns“ bei vereindeutigten Intersexuellen nicht als 'Argument' angesehen werden kann: die vielen mittlerweile bekannten Einzelschicksale belegen, dass operierten Intersexuellen eine lustvolle Sexualität oftmals verwehrt bleibt aufgrund (!) der Operation(en).

Anders formuliert: Nach herrschender medizinischer Sicht müssen Menschen geschlechtlich eindeutig sein, da sie sonst angeblich keine erfüllende Sexualität hätten. Von dieser absurden Vorstellung einmal abgesehen, ist hieran interessant, dass Sexualität in dieser Argumentation durchaus sozial gefasst zu werden scheint: die Reproduktion wird nämlich nicht angestrebt. Noch anders formuliert: bei Intersexuellen wird Sexualität sozial gefasst, bei 'Eindeutigen' biologisch. Ob die nicht angestrebte Reproduktion bei Intersexuellen eugenisch motiviert ist, kann hier nur als offene Frage stehen bleiben.⁸³

Von der Idee her werden also aus Intersexuellen einerseits heterosexuell lebende Frauen und andererseits heterosexuell lebende Männer hergestellt. Wenn biologisch 'Eindeutige' jedoch queere oder, um mit Herrn Leitsch zu sprechen, nicht „normale“ Begehrensstrukturen entwickeln, greift erneut ein ganzes Set an Diskursen und Institutionen, die den sex mit dem Begehren in Einklang bringen wollen. Als Beispiel sei hier das 'Syndrom' der sogenannten 'gender identity disorder in children' genannt, welches non-konformes Begehren pathologisiert. Zeigen Heranwachsende geschlechtsrollenuntypische Verhaltensweisen, wird auf homosexuelles Begehren geschlossen, welches dann weg'therapiert' werden soll. So soll z.

⁸¹Heldmann, Anja, Jenseits von Frau und Mann, Intersexualität als Negation der Zweigeschlechtlichkeit, in: Differenz und Geschlecht: neue Ansätze in der ethnologischen Forschung, Berlin 1998, S. 62.

⁸²ebd., S. 59 und 66.

⁸³Protokoll unserer AG-Sitzung vom 4. Juni 2004.

B. die 'Behandlung' des sog. 'sissy boy syndroms' bei sich unmännlich verhaltenden Jungen verhindern, dass aus diesen homosexuell lebende Männer werden.⁸⁴

4.5. Die medizinische Herstellung der Zweigeschlechtlichkeit

Heterosexuelle, zweigeschlechtliche Ordnung meint, dass potentielle Störungen ihrer Evidenz durch entsprechende Umdeutungen, Dressuren oder gewaltsame Eingriffe korrigiert und so gewendet werden, dass ihre Grundannahmen aufrechterhalten und bestätigt werden. Die Geschlechterordnung ist so tiefgreifend, dass auch evidente Uneindeutigkeiten sie nicht aus der Bahn werfen. Mag die Stimme eines Mannes noch so hoch, der Bartwuchs auf der Oberlippe einer Frau noch so stetig sein – diese werden lediglich als Abweichungen einer dennoch gültigen Norm gedeutet. Mann/frau ordnet sich in der Begegnung wechselseitig ein, und auf der Grundlage dieser Zuordnung werden Pässe ausgestellt, Arbeitsplätze vergeben, Sexpraktiken bestimmt und vieles mehr.

Dass nur wenige Menschen die rigide geschlechtliche Norm tatsächlich erfüllen, bleibt ohne Bedeutung, denn es existiert ein breites Spektrum an Interventionen, begonnen bei selektiver Wahrnehmung bis hin zu gewaltsamen medizinischen Praktiken, die die Zweiheit als kulturelle Selbstverständlichkeit sicherstellen. Das Zweigeschlechtermodell legitimiert sich durch die Natur als Stifterin der Binarität. Kinder mit uneindeutigen Geschlechtsmerkmalen müssen dementsprechend als Versagen, Ausrutscher und Versehen der Natur gedeutet werden. In einem solchen Fall erhebt sich die Medizin zur Vollstreckerin der unterstellten Eigentlichkeit einer binären Natur und stellt diese durch chirurgische und hormonelle Eingriffe wieder her. Deutlich wird, dass Geschlecht nicht allein diskursiv oder psycho-sozial hervorgebracht wird, sondern gleichermaßen im direkten Zugriff auf die Körper.⁸⁵ In der Medizin werden Durchschnittsdaten und Grenzwerte festgelegt, um die Trennschärfe gegenüber dem anderen Geschlecht aufrechtzuerhalten. Aus organmedizinischer Sicht ist beispielsweise die Klitoris für die Fortpflanzungsaufgabe der Frau entbehrlich, doch in ihrer Morphologie sollen die Körper eindeutig in Frau und Mann unterschieden werden können – sonst steht die Eindeutigkeit in Frage.

⁸⁴Jäger, Ulle / Sälzer, Christian, entweder oder und der rest. transsexualität und transgender, in: diskus, Nr. 3, Frankfurt am Main, Dezember 1999, 48. Jahrgang, S. 29.

⁸⁵Engel, Antke, ene mene meck und du bist weg – über die gewaltsame herstellung der zweigeschlechtlichkeit; Jäger, Ulle / Sälzer, Christian, entweder oder und der rest. transsexualität und transgender, in: diskus, Nr. 3, Frankfurt am Main, Dezember 1999, 48. Jahrgang, S. 29.

MedizinerInnen gehen zunächst allein von dem äußeren Erscheinungsbild eines Intersexuellen aus. Ihnen und ihren Eltern soll suggeriert werden, dass sich ein eindeutiges Geschlecht zumindest auf der gender-Ebene herstellen lässt, das zunächst unabhängig von ihrem biologischen Geschlecht (sex) zu sein scheint. Gegenüber den PatientInnen wird von Seiten der ÄrztInnen jedoch niemals von 'Anomalie' oder 'Defekt' gesprochen, um die geschlechtliche Uneindeutigkeit zu verschweigen, die aus medizinischer Sicht durchaus pathologisch ist. Nicht das Wohl der Kinder steht demnach im Vordergrund, sondern es gilt, das duale Geschlechterdenken der Gesellschaft zu reproduzieren. Die Medizin ist Teil dieser Zwei-Geschlechter-Kultur, die keine mehr- bzw. uneindeutigen Geschlechter akzeptiert.⁸⁶ Die Medizin kann als kultureller Bereich bezeichnet werden, in dem sich das Körper- und Geschlechtermodell einer euro-amerikanischen Gesellschaft widerspiegelt, das ein 'Wir' auf der Basis der Zweigeschlechtlichkeit konstituiert und damit Intersexuelle als die 'Anderen' definiert.⁸⁷ In unserer Rezeption medizinischer Fachliteratur fiel uns auf, welche Funktion die Definition von 'Störungen' für die diskursive Herausbildung eines medizinisch 'normalen' Körperbildes hat: So findet sich beispielsweise im Kommentarbereich des Bandes „Gynäkologie und Geburtshilfe“ in Kapitel 1 „Die geschlechtsspezifische Entwicklung und ihre Störungen“ als erstes das Unterkapitel „Sexuelle Differenzierung und ihre Störungen“. Dort wird die Intersexualität abgehandelt. Dazu gehörten Menschen, die „Merkmale beider Geschlechter“ aufwiesen. Wie bei der im ersten Kapitel analysierten Definition des Roche-Lexikons werden verschiedene Geno- und Phänotypen unterschieden. Die Gonadenagenese, die Gonadendysgenese, das Adrenogenitale Syndrom, der Scheinzwitter (testikuläre Feminisierung) und der echte Zwitter (Hermaphroditismus verus). Als zweites Unterkapitel wird die „Struktur und Funktion der Fortpflanzungsorgane und der Brustdrüse“ erklärt. Sehr erhellend war für uns hierbei, dass zuerst die Abweichung erläutert wird, bevor die Norm, von der sie abweicht, vorgestellt wird. Dies lässt den Schluss zu, dass erst die Definition der Abweichung die Definition eines „normalen“ Körpers ermöglicht.⁸⁸ Das Normale wird also über das Anormale hervorgebracht. Wenn alles, was im System der zwei Geschlechter nicht aufgeht, als Krankheit definiert wird, kann sich dieses System weiter unbefleckt als ideale Repräsentation der Wirklichkeit darstellen. Dem ist entgegenzuhalten, dass sich auf körperlicher Ebene statt einer binären Struktur ein Spektrum abzeichnet: es gibt ein Kontinuum von Geschlechtern.⁸⁹ Die Realität ist chaotischer, ist komplexer als es uns die

⁸⁶Heldmann, Anja, *Jenseits von Frau und Mann, Intersexualität als Negation der Zweigeschlechtlichkeit*, in: *Differenz und Geschlecht: neue Ansätze in der ethnologischen Forschung*, Berlin 1998, S. 65 und 68.

⁸⁷ebd., S. 56.

⁸⁸ *Gynäkologie und Geburtshilfe, Original-Prüfungsfragen mit Kommentar*, bearb. von Gunter von Minckwitz und Sybille Loibl, Stuttgart/New York 2000, S. 94.

⁸⁹Jäger, Ulle / Sälzer, Christian: *entweder oder und der rest. transsexualität und transgender*, in: *diskus*, Nr. 3, Frankfurt am Main, Dezember 1999, 48. Jahrgang, S. 29 und 32.

Ideologie der Zweigeschlechtlichkeit weismachen will. Intersexualität kann als gut gehütetes Geheimnis betrachtet werden. Diese Unsichtbarmachung Intersexueller reproduziert auf symbolischer wie historischer Ebene Zweigeschlechtlichkeit.⁹⁰

4.6. Der Arzt als Überwacher der Geschlechterordnung

Eine der Antworten auf unsere Leitfrage, warum operiert wird und wie die Medizin einen vereindeutigenden operativen Eingriff legitimiert, lautet: Intersexuelle müssen wegen der Identitätsverlustangst der heteronormativen Umwelt zugerichtet werden. In der entsprechenden medizinischen Literatur findet sich immer wieder der ärztliche Präventionsgedanke: Es wird behauptet, intersexuell geborene Kinder würden, wenn sie nicht operiert und einem der zwei Geschlechter zugeordnet werden, später Probleme in ihrem Leben bekommen. Ohne Operation seien sie unglücklich. In dieser Sichtweise werden Intersexuelle vor der Gesellschaft geschützt, die/der ÄrztIn erscheint als wohmeinende/r HelferIn.

Wie schon zuvor angeführt, ist diese Sichtweise de facto falsch. Folgen der Zurichtung sind psychiatrische Zwangseinweisungen nicht einwilligungsfähiger intersexueller Kinder, oft jahrelange erlebte sexuelle Gewalt, physisch irreparable Schäden, Traumata, die Versagung der Möglichkeiten einer erfüllten Sexualität für alle Zeiten, erlebte Isolation, Unkenntnis der Umwelt und damit die Unmöglichkeit, sich offen zur Thematik auszutauschen. Nahezu alle fühlen sich im 'falschen', da konstruierten Körper. Eine eigene Identität wie eigene Würde wird vorenthalten. Kurz: die Operationen und jahrelange Hormonverabreichungen müssen als Folter gesehen werden. Dies wird durch die erschütternden Erfahrungsberichte operierter Intersexueller immer wieder deutlich. Faktisch findet also ein Deal statt: gedealt wird ein ursprünglicher Körper und Erlebnisfähigkeit gegen soziale Akzeptanz.⁹¹ Hierzu ein Zitat von Michel Reiter, das wir auch unserer Arbeit vorangestellt haben: „Unser verstümmeltes Geschlecht ist ein medizinisches Konstrukt, also Theorie. So schob man uns von einem Nichts in das andere Nichts: Unser Geschlecht, wie es uns angeboren wurde, hat keine gesellschaftliche Existenz. [...] Nun ist fraglich, welche psychischen Auswirkungen sich bei intersexuell Diagnostizierten, jedoch nicht Operierten, konstatieren lassen [...] Vermutlich wären wir AUCH durch alle Kategorien durchgefallen. Aber mit Sicherheit hätten wir etwas

⁹⁰Protokoll vom 24. Juni 2004.

⁹¹Heldmann, Anja, Jenseits von Frau und Mann, Intersexualität als Negation der Zweigeschlechtlichkeit, In: Differenz und Geschlecht: neue Ansätze in der ethnologischen Forschung, Berlin 1998, S. 65.

EIGENES entwickeln können, hätten z. B. unser sexuelles Potential entdeckt und unseren Körper kennengelernt“.⁹² Von daher stellt sich die Frage, die auch unsere Leitfrage ist: was ist der wirkliche Grund der Operation?

Wir denken, dass die Konfrontation der 'Eindeutigen' mit Intersexuellen Angst bereitet: Mann/Frau kann der eigenen Identität als Mann/Frau wie auch Hetero/Homo/Bi verlustig gehen. D.h. sowohl Gender als auch Sexualität stehen auf dem Spiel. Intersexuelle stören – frecherweise – erstens das Gebot, dass Geschlecht nicht veränderbar ist und zweitens die Naturgegebenheit der Zweigeschlechtlichkeit.⁹³ Sie stellen durch ihre bloße Existenz einen permanenten Störfaktor der zweigeschlechtlichen, heteronormativen Ordnung dar. Sie irritieren ihre Umgebung und halten die gesellschaftlich bedingten Maßstäbe nicht ein. In Anbetracht der Tatsache, dass für die allermeisten Menschen jedoch die Kategorien Geschlecht wie Sexualität absolut zentral für ihre Identitätsbildung sind und sie mit der Anerkennung Intersexueller anerkennen müssten, dass eben gerade diese beiden Kategorien nicht natürlich, sondern Ideologie sind und somit ein beträchtlicher Teil ihres Selbst in Frage gestellt wird/werden müsste, erscheint es einfacher und schmerzfreier, die 'Störung', also als intersexuell diagnostizierte Kinder, zu eliminieren. Anders formuliert: Die Sicherheit der eigenen Identität beruht auf der Ausgrenzung anderer Identitäten. Die Konfrontation mit Intersexualität stellt die Stabilität der eigenen binär verorteten Identität in Frage und rückt den Zwang zur geschlechtlichen Vereindeutigung als Mittel zur Aufrechterhaltung hierarchischer Geschlechterverhältnisse in den Blick. Genau darin liegt die Bedrohung für die 'Eindeutigen'.⁹⁴ Entgegen dem eigenen Selbstverständnis schützt der ärztliche Präventionsgedanke also 'die Gesellschaft' vor Intersexuellen, nicht etwa Intersexuelle vor 'der Gesellschaft'. Der medizinische Umgang zeigt den hilflosen Versuch, gesellschaftliches Leiden ersparen zu wollen. Sie erspart westlichen Gesellschaften an der Präsenz Intersexueller 'leiden' zu müssen, indem sie Intersexuelle leiden lässt – durch ihre Elimination. Die medizinischen Verfahren schützen die Gesellschaft vor Uneindeutigkeiten, um sie in ihrem polaren Denken nicht zu irritieren. 'Fehlgeratene' Körper werden in die Norm eingepasst. ÄrztInnen können dementsprechend als HüterInnen der körperlichen Dualität im Sinne unserer kulturellen Vorstellungen über Geschlechter bezeichnet werden. Sie entwickeln Methoden, um körperliche Geschlechterdifferenzen jenseits der Zweigeschlechtlichkeit zu eliminieren. Die Medizin ist Teil unserer Kultur, und die MedizinerInnen handeln den Normen unserer Kultur entsprechend, wodurch sie diese natürlich unterstützen und

⁹²ebd., S. 61.

⁹³Protokoll unserer AG-Sitzung vom 8. Juni 2004.

⁹⁴Engel, Antke: ene mene meck und du bist weg – über die gewaltsame herstellung der zweigeschlechtlichkeit.

reproduzieren.⁹⁵ Zusammenfassend muss die Standardfrage „Was ist es denn? (Junge oder Mädchen?)“ als (krasse) Gewalt begriffen werden. Babies, die sich nicht eindeutig zuordnen lassen, werden in der Medizin durchweg pathologisiert. Sie gelten als `unfertig` und/oder haben eine „Wachstumsstörung“. 'Fertig' in diesem Sinne ist nur ein 'eindeutiger' Junge bzw. ein `eindeutiges` Mädchen, für welchen/welches sich die Eltern dann entscheiden.⁹⁶ Kinder im Säuglings- und Kleinkindalter werden nicht nach ihrem Willen gefragt, über ihre Körper wird einfach verfügt. Institutionen urteilen darüber, mit welchem Körper das Kind aufwachsen wird, mit welchem Geschlecht es seine eindeutige soziale Rolle in dieser Gesellschaft einnehmen soll.⁹⁷ Das ist Gewalt.

5. Der westliche Diskurs über Genitalverstümmelung

5.1. Von rassistischem Sprechen und Schweigen

Von Gewalt ist allerdings im Kontext westlicher Medizin nie die Rede. Gewalttätigkeit wird nach wie vor nur in außereuropäischen Ländern gesucht und gefunden. Wichtig für unsere Überlegungen ist unsere Situiertheit in einem westlich-christlichen Kulturkreis, als weiße Subjekte. Diese Überlegung kommt insbesondere dann zum Tragen, wenn die unterschiedliche öffentliche Aufmerksamkeit für Genitalverstümmelungen an Frauen in Afrika und die Folter an intersexuellen Menschen in Europa gegenüber gestellt werden.

Die verschiedenen Formen der Beschneidung an Mädchen und Frauen, die in afrikanischen Ländern leben, gelten international als geächtete Menschenrechtsverletzung und eklatante Diskriminierung von Frauen. Es dürfte schwer sein, in westlichen Ländern Gruppierungen zu finden, die derartige Praxen befürworten. Dem steht die Genitalverstümmelung an intersexuellen Menschen in der westlichen Welt gegenüber. Diese wird nicht nur nicht als Menschenrechtsverletzung verhandelt – sie wird größtenteils gar nicht beachtet. In dieser Sichtweise gibt es per Definition keine Menschenrechtsverletzungen in der westlichen Welt.⁹⁸ Im Laufe unserer Beschäftigung mit dem Thema ist uns aufgefallen, dass `Intersexualität` im Westen diskursiv sehr stark ausgegrenzt wird: Zwar finden sich laut US-amerikanischen Studien etwa 35% der Gesamtbevölkerung in irgendeiner Weise nicht in der

⁹⁵Heldmann, Anja, Jenseits von Frau und Mann, Intersexualität als Negation der Zweigeschlechtlichkeit, In: Differenz und Geschlecht: neue Ansätze in der ethnologischen Forschung, Berlin 1998, S. 61 und 66.

⁹⁶Protokoll unserer AG-Sitzung vom 24. Juni 2004.

⁹⁷Heldmann, Anja, Jenseits von Frau und Mann, Intersexualität als Negation der Zweigeschlechtlichkeit, In: Differenz und Geschlecht: neue Ansätze in der ethnologischen Forschung, Berlin 1998, S. 61.

⁹⁸Protokoll unserer AG-Sitzung vom 15. Juni 2004.

heterosexistischen Matrix wieder. Während lesbische, schwule und bisexuelle Fragen aber zunehmend öffentlich diskutiert werden (können), fallen transsexuelle oder gänzlich zur Kategorie Geschlecht quer laufende Thematiken weiterhin völlig aus dem Raster öffentlicher Aufmerksamkeit.⁹⁹ Hierbei ist zu beachten, dass der normierende Zugriff der Medizin keine Seltenheit ist: Reiter schreibt, etwa 16.000 Intersexuelle würden jedes Jahr geboren. Es ist zu vermuten, dass er damit das geographische Gebiet Deutschlands meint. Weiter schreibt er, in Deutschland lebten 1,5 bis 3 Millionen Intersexuelle.¹⁰⁰ In einem späteren Text zitiert Reiter eine Studie, nach der von etwa 2% intersexuellen Menschen in der Gesamtbevölkerung auszugehen sei, also etwa 1,6 Millionen allein in Deutschland. „Mindestens jedes 2000. Neugeborene erfährt eine medikalisierte Zuweisung bereits ab der Geburt.“¹⁰¹ Anne Fausto-Sterling geht sogar davon aus, dass ca. 4% aller Neugeborenen intersexuell geboren werden.¹⁰²

Der westlich-abendländische Quasi-Konsens, einerseits die Genitalverstümmelung an Mädchen und Frauen in Afrika zu ächten, andererseits jedoch die Genitalverstümmelung, Folter und sexuelle Gewalt gegenüber intersexuellen Kindern in Deutschland noch nicht einmal zur Kenntnis zu nehmen, muss von daher als chauvinistische und rassistische Abgrenzung gesehen werden. Traditionelle, patriarchale Clansysteme in afrikanischen Ländern, die Frauen und Mädchen unterdrücken und ihnen Gewalt antun, werden einer aufgeklärten, gleichberechtigten, modernen, westlichen Welt mit ihrer präzisen, sauberen Naturwissenschaft bzw. Medizin, die Menschen hilft, gegenübergestellt. Eine derartige dichotomisierte Gegenüberstellung folgt nicht nur einer langen kolonialistisch-rassistischen Tradition und bereitet den Boden für sog. 'humanitäre Interventionen', in dem deutsche und andere Gutmenschen 'den Wilden' ein bisschen Zivilisation bringen. Nein, sie stellt auch Geschlechterverhältnisse vollends auf den Kopf. Zweigeschlechtlichkeit, wie wir sie heute kennen, ist eine westliche Erfindung, ebenso wie die Durchsetzung eines dichotomen sozialen Geschlechts eher in westeuropäischen Kulturen vorherrschend ist. In außereuropäischen Kulturen sind die Rollen der Geschlechter nicht selten offener definiert. Sowohl der Geschlechtsrollenwechsel als auch alternative Geschlechterkategorien bieten akzeptierte Geschlechtervarianten.¹⁰³

⁹⁹ Reiter, Michel, „Ein normales Leben ermöglichen“, in: Gigi Nr. 8, Juli / August 2000, S. 10.

¹⁰⁰ Reiter, Michel, Ein perfektes Verbrechen, in: Gigi Nr. 2, Juni / Juli 1999, S. 16.

¹⁰¹ Reiter, Michel, „Ein normales Leben ermöglichen“, in: Gigi Nr. 8, Juli / August 2000, S. 8.

¹⁰² Fausto-Sterling, Anne: The Five Sexes, Revisited, in:

http://www.nyas.org/membersonly/sciences/sci0007/fausto_body.html, (Stand: 14. Februar 2001).

¹⁰³ Heldmann, Anja, Jenseits von Frau und Mann, Intersexualität als Negation der Zweigeschlechtlichkeit, In: Differenz und Geschlecht: neue Ansätze in der ethnologischen Forschung, Berlin 1998, S. 73.

Dadurch, dass über Genitalverstümmelung in der westlichen Welt fast nichts zu hören bzw. lesen ist, werden Intersexuelle nicht nur unsichtbar gemacht, sondern es wird in perfider Weise Zweigeschlechtlichkeit auch noch reproduziert und damit die ganze Gewalt, die immer woanders, niemals aber hier verortet wird. Der Blick auf Genitalverstümmelung in Afrika lenkt von dem Blick auf die eigene Kultur, auf die Menschen in unserer nächsten Nähe ab.¹⁰⁴ Wir schlagen vor, das Problem genau umgedreht zu betrachten: Erst durch die westlich-abendländische Kultur der Zweigeschlechtlichkeit erlangt die Folter an intersexuellen Menschen ihre Legitimation.¹⁰⁵

5.2. Verweiblichung oder Vermännlichung?

Als ab ca. 1940 chirurgische und hormonelle 'Korrekturen' ihren Anfang nehmen, wird der bis dahin geltende Leitsatz 'in dubio pro masculo' durch die inzwischen fortgeschrittene chirurgische 'Korrektur'-Möglichkeit 'it's easier to make a hole than to build a pole' abgelöst.¹⁰⁶ Der Gynäkologe von Terruhn hat dies 1987 auf den Punkt gebracht: „Die Wahl des sozialen Geschlechts erfolgt nach der günstigsten Korrekturmöglichkeit.“ Eine Scheide ist leichter herzustellen als ein Penis mit Hoden. In ca. 90% der Fälle wird eine Feminisierung des Kindes vorgenommen. Das heißt, dass es nach Ansicht von GynäkologInnen „für ein weibliches Individuum mit reduzierter Genitalfunktion leichter sei 'im Leben ihren Mann zu stehen' als für ein männliches Individuum mit verminderter Geschlechtsfähigkeit“. (Bolkenius, 1982) Für eine Frau ist es dieser Sichtweise zufolge leichter, auf eine befriedigende Sexualität zu verzichten als für einen Mann.¹⁰⁷

Diese Form der Verweiblichung trifft jedoch primär auf westliche Gesellschaften zu. So schreibt etwa Leitsch: „So geht die Tendenz bei mohamedanischen Eltern, ungeachtet von der Praktikabilität, oft mehr in die Richtung, ein Kind zu vermännlichen. Dieses erklärt sich daraus, daß in diesen Kulturkreisen ein nicht kohabitationsfähiger Mann höher angesehen wird als eine nicht gebärfähige Frau. Viel wichtiger als eine befriedigende Kohabitationsfähigkeit ist es, das Genital soweit herzustellen, daß das Kind in der Lage ist im Stehen zu urinieren. Dieses ist ein weiterer Grund dafür, daß die Zahl der maskulinisierenden

¹⁰⁴ebd., S. 57.

¹⁰⁵Protokoll unserer AG-Sitzung vom 15. Juni 2004.

¹⁰⁶Das Zitat 'It's easier to make a hole than to build a pole' ist laut Internet (<http://www.bodieslikeours.org/girlfriendsarticle/girlfriends5.html>) von einem Doktor der John-Hopkins University (vgl.: Protokoll unserer AG-Sitzung vom 8. Juni 2004).

¹⁰⁷Heldmann, Anja, Jenseits von Frau und Mann, Intersexualität als Negation der Zweigeschlechtlichkeit, In: Differenz und Geschlecht: neue Ansätze in der ethnologischen Forschung, Berlin 1998, S. 59f.

Operationen in den letzten Jahren stetig zugenommen hat.“¹⁰⁸ Wird also im Westen bei intersexuellen Kindern eher eine Verweiblichung betrieben, wird in anderen Kulturkreisen eher vermännlicht.¹⁰⁹

Nun ist es zwar sicherlich richtig, davon auszugehen, dass es in unterschiedlichen Kulturkreisen auch unterschiedliche männliche und weibliche Existenzweisen gibt. Dass allerdings auch in westlichen Gesellschaften kohabitationsfähige Männer höher angesehen werden und das Stehpinkeln nach wie vor eine Bastion der Männlichkeit darstellt, ist kein Geheimnis. Und so verwundert es nicht, dass MedizinerInnen an operativen Vermännlichungstechniken forschen. Leitsch schreibt: „Ebenfalls entscheidend in bezug auf die Wahl des kindlichen Geschlechts sind das Können und die Erfahrung des behandelnden Operateurs. Galt früher im Zweifelsfalle eher zu verweiblichen, erlangt in der heutigen Zeit die Maskulinisierung mehr und mehr auch bei höhergradigen intersexuellen Genitalien an Bedeutung. So führten verbesserte Operationsmethoden, besonders in bezug auf die Rekonstruktion der maskulinen Harnröhre und die Schaffung kinderurologischer Zentren, zu einer zunehmenden Anzahl von Vermännlichungen bei Kindern mit intersexuellen Fehlbildungen.“¹¹⁰ Interessant an dieser Dissertation von 1996 ist noch, dass verschiedene Kulturkreise („mohamedanische Eltern“) betrachtet werden und dadurch ein kleines Stück weit der medizinische Universalitätsanspruch aufgegeben wird.¹¹¹ (Siehe hierzu auch Kapitel 4.3.: Zum Verhältnis von sex und gender bei Intersexualität).

6. Die doppeldeutige Rede von der Konstruierbarkeit des Geschlechts

Von Seiten kritischer selbstorganisierter Intersexueller gibt es eine scharfe Kritik an den Gender Studies und den sozialkonstruktivistischen Thesen des postmodernen Feminismus. So schreibt Michel Reiter, die Theorie sozialer Konstruktion von Geschlecht klinge wie eine Gebrauchsanweisung für ÄrztInnen, die Intersexuelle umoperieren. „Der als biologisch diskreditierte Humanwissenschaftler ist in Wirklichkeit ein Sozialkonstruktivist.“¹¹² Damit wird die Gemeinsamkeit von biologischen MedizinerInnen und feministischen Konstruktivistinnen hervorgehoben. Weiter kritisiert er, dass „alle feministischen

¹⁰⁸Leitsch, Dominik, Die Intersexualität, Diagnostik und Therapie aus kinderchirurgischer Sicht, Dissertation, Universität Köln, 30. Mai 1996, S. 131.

¹⁰⁹Protokoll unserer AG-Sitzung vom 1. Juli 2004.

¹¹⁰Leitsch, Dominik, Die Intersexualität, Diagnostik und Therapie aus kinderchirurgischer Sicht, Dissertation, Universität Köln, 30. Mai 1996, S. 130.

¹¹¹Protokoll unserer AG-Sitzung vom 24. Juni 2004.

¹¹²Reiter, Michel, Theoretische Differenz, symbolische Nähe, in: Gigi Nr. 6, März / April 2000, S. 22.

Geschlechterdiskurse” auf der Existenz zweier Geschlechter aufbauten. Die ‘Mainstream-Geschlechterwissenschaft’ sei unfähig, den Komplex Intersexualität aufzugreifen. Zu Judith Butler bemerkt er: „Gleichfalls verschwinden aus dem diskursiven Horizont all jene Bereiche, in denen Hierarchie und Gewalt eine Rolle spielen.” Wo die „gewaltsame Herstellung der Bipolarität soziale Praxis ist”, sei es zynisch, sie als bloße Sprechakte zu bezeichnen.¹¹³ Dass der Begriff der Konstruktion von Geschlecht im Angesicht körperlicher Gewalt in einem neuen Licht erscheint, haben wir auch in unseren Sitzungen besprochen.¹¹⁴ Der Knackpunkt ist hier also, dass sich Gender Studies und Medizin in der Behauptung einer Konstruierbarkeit von Geschlecht treffen.

An dieser Stelle bedarf es jedoch einer genaueren Betrachtung der Konstruktionsmodelle, da die Medizin von einer ‘Konstruierbarkeit’ des Geschlechts ausgeht, diskurstheoretische Ansätze - insbesondere der Judith Butlers - aber von einer ‘Konstruiertheit’ (die überwiegend unbewusst abläuft) des Geschlechts. Butler klammert in ihren Ausführungen die Komponente der Gewalt keineswegs aus. Außerdem stellt sie die Frage, wie die Kategorien von ‘Mann’ und ‘Frau’ performativ hergestellt werden. Durch dieses Hinterfragen wird deutlich, dass bei deren Herstellung Ausschlussverfahren mächtig sind, die Menschen ‘anderen’ Geschlechts verschwinden lassen, beziehungsweise wieder unter der neuen Kategorie ‘Intersexuell’ an den Rand des heteronormativen Spektrums setzen.

Ebenso wie die dichotomen Geschlechterkategorien ‘Mann’ und ‘Frau’ muss das so genannte dritte Geschlecht mit den zahlreichen Namen intersexuell, Hermaphrodit oder Zwitter als konstruiert von aktuellen, kulturellen, sowie historisch diskursiven Prozessen verstanden werden.

Das dichotome, heteronormative Geschlechtermodell ist einer der Eckpfeiler der gesellschaftlichen Ordnung. Insofern wird alles in den Bereich des Unnatürlichen, Pathologischen und Anomalen verwiesen, was diese Ordnung in Frage stellt. Menschen, die bei ihrer Geburt nicht eindeutig einem Geschlecht zugeordnet werden können, werden von Medizin und Justiz so lange befragt und begutachtet, bis dies scheinbar doch möglich ist. Diese Praxis tradiert sich über das 20. bis in das 21. Jahrhundert.¹¹⁵ Auf perfide Art und Weise modernisieren sich die medizinischen Diskurse. Die Psychiatrie und Psychoanalyse geben der Herstellung von eindeutigen Geschlechtern neue Befragungsmethoden an die Hand. Medizinische Fortschritte, wie plastische Chirurgie oder Genomanalyse ermöglichen eine

¹¹³ Reiter, Michel, Theoretische Differenz, symbolische Nähe, in: Gigi Nr. 6, März / April 2000, S. 23.

¹¹⁴ Protokoll unserer AG-Sitzung vom 1. Juli 2004.

¹¹⁵ Zum historischen Diskurs über Intersexualität, vgl. Kapitel 3.

schmerzhafte, Menschenrechte verletzende Konstruktion eines so genannten eindeutigen Geschlechts mit dem Skalpell. Das Prinzip bleibt das gleiche wie in den vorangegangenen Jahrhunderten: gesellschaftliches Denken und Politik funktionieren über Identität stiftende Diskurse, die Verwerfungen und Ausgrenzungen in Form von nicht Kategorisierbarem produzieren. Es ändern sich lediglich die Vorzeichen, unter welchen Realität performativ hergestellt wird. So verwundert es nicht, dass im Mittelalter Geschlechterkategorien anders durchlässig sind, da gesellschaftliche Identität vorrangig über die feudale Ständeordnung hergestellt wird. Mit Beginn der bürgerlichen Gesellschaft bedarf es aufgrund der zunehmenden politisch-gesellschaftlichen Relevanz der Kategorie Geschlecht eines statischeren Modells von Zweigeschlechtlichkeit. Folter an geschlechtlich nicht zuordnenbaren Menschen wird in der Gegenwart von medizinisch-psychologischer Seite mit der ansonsten eingeschränkten Lebensqualität der Betroffenen und ihrer Angehörigen gerechtfertigt. Auffallend ist, dass beispielsweise soziologische¹¹⁶ sowie ethnologische¹¹⁷ Texte zu Intersexualität und Geschlechterverhältnissen sich an Judith Butlers These der performativen Konstruktion von gender und insbesondere sex abarbeiten. Immer wieder wird auf die Existenz von zwei real wahrnehmbaren, wenngleich konstruierten, Geschlechtern beharrt, sowie der Aspekt der realen Leiblichkeit betont. Zum einen rührt dies wahrscheinlich von der oft missverstehenden Rezeption Butlers her. Sie wurde fälschlicherweise oft so verstanden, dass performativ hergestellte Realität nicht existent und greifbar oder willkürlich ist. Andererseits ist dieses Festhalten am real existierenden, vergeschlechtlichten Körper nicht nachvollziehbar, betrachtet man beispielsweise eine Anmerkung Butlers zur Performativität:

„Diese [performative] Wiederholbarkeit impliziert, dass die ‘performative Ausführung’ keine vereinzelte ‘Handlung’ oder ein vereinzeltes Vorkommnis ist, sondern eine ritualisierende Produktion, ein Ritual, das unter Zwang und durch Zwang wiederholt wird, unter der Macht und durch die Macht des Verbots und des Tabus, bei Androhung der Ächtung und gar des Todes, die die Form der Produktion kontrollieren und erzwingen, die sie aber nicht, darauf lege ich Nachdruck, im voraus vollständig determinieren können.“¹¹⁸

¹¹⁶ An folgendem Text ist dies exemplarisch festzustellen: Hirschauer, Stefan, *Wie sind Frauen, Wie sind Männer? Zweigeschlechtlichkeit als Wissenssystem*, in: Christiane Eifert und andere (Hg.): *Was sind Frauen? Was sind Männer?*, *Geschlechterkonstruktion im historischen Wandel*, Frankfurt am Main 1996, S. 240-256.

„So findet sich in Judith Butlers postmodernem Dekonstruktionsversuch der Geschlechtskategorien das Postulat, der Geschlechtsunterschied sei eine ‘Fiktion’ oder eine bloße ‘Kopie ohne Original’. Diese Rhetorik der Irrealisierung ist immer noch befangen in der ständigen Abwehr des biologischen Realismus, den wir alle teilen.“ ebd., S. 241.

¹¹⁷ vgl. Heldmann, Anja, *Jenseits von Frau und Mann, Intersexualität als Negation der Zweigeschlechtlichkeit*, In: *Differenz und Geschlecht: neue Ansätze in der ethnologischen Forschung*, Berlin 1998.

¹¹⁸ Butler, Judith, *Körper von Gewicht*, 1997, Frankfurt am Main, S. 139.

Gerade wenn wir, unsere Körper, unsere Leiber, unser Denken, verhaftet sind in einer gesellschaftspolitischen Realität der Zweigeschlechtlichkeit und wenn diese Dichotomie Leid produziert, indem sie Menschen zwingt, sich ihr anzupassen, ist es wichtig, die Prozesse zu hinterfragen, die diese Realität herstellen. Wenn Menschen nur existenzfähig sind, sofern sie einer Kategorie in einer dichotomen Geschlechterrealität zugeordnet werden können, so sollte diese Realität hinterfragt und verändert werden. Da wir jedoch alle in dieser Realität verhaftet sind, ist eine Veränderung nur dann möglich, wenn Herstellungsprozesse zu Bewusstsein gebracht werden.

Aufschlussreiche Gedanken darüber gibt beispielsweise das Verständnis Butlers von Performativität an die Hand. Wenn die ritualisierte Herstellung von Geschlechtern unter dem Zwang, diese herzustellen geschieht, dann hat das zur Folge, dass sie mit allen Mitteln vollzogen wird. Einfacher gestalten sich solche Prozesse bei Menschen, die bei ihrer Geburt gemäß der gesellschaftlichen Konventionen Anhaltspunkte für die Zuordnung zu einem Geschlecht mit sich bringen. Ist das nicht der Fall, werden Verbot und Tabu mächtig. Menschen mit nicht eindeutigen äußerlichen Geschlechtsmerkmalen müssen aus dem ausgegrenzten gesellschaftlichen Tabubereich mit Gewalt herausgeholt werden, um in der gesellschaftlichen Ordnung leben zu können. Die dezidierte Abgrenzung von der Konstruktionsthese Butlers führt zu einer weiteren Spur: Auch ethnologische und soziologische Wissenschaft sind situiert in einem kategorisierenden Denken. Gerade in der Soziologie sind Geschlechterkategorien notwendig, um zu Forschungsergebnissen zu gelangen. Dekonstruierendes – immer zugleich rekonstruierendes – Denken in diesen Disziplinen würde eine Doppelung der wissenschaftlichen Arbeit bedeuten. Es würde bedeuten, Ergebnisse immer gleichzeitig zu hinterfragen. (Konkret würde das beispielsweise bei dem Soziologen Hirschauer, der von der Geschichte der Homosexualität berichtet, bedeuten: es müsste mit gefragt werden, wie die Kategorie Homosexualität mit der von ihm beschriebenen Wissensgeschichte gleichzeitig reformuliert wird¹¹⁹.)

Hier zeigt sich ein weiterer Punkt, dem Wissenschaft Rechnung tragen sollte, interdisziplinäre Geistes- und Gesellschaftswissenschaft sowie medizinische: sie kann den Menschen, den Einzelnen, der Einzigartigkeit nicht oder nur unzulänglich gerecht werden.¹²⁰ Es besteht eine Diskrepanz zwischen wissenschaftlichem Herangehen, das selten den Menschen in seiner Gesamtheit, immer jedoch auch die Herausbildung der eigenen Theorie meint und nur

¹¹⁹ Hirschauer, Stefan, *Wie sind Frauen, Wie sind Männer? Zweigeschlechtlichkeit als Wissenssystem*, in: Christiane Eifert und andere (Hg.): *Was sind Frauen? Was sind Männer?*, *Geschlechterkonstruktion im historischen Wandel*, Frankfurt am Main 1996, S. 240-256.

¹²⁰ vgl. auch Kapitel 7.1.

unzulänglich die Lebensrealität der bestenfalls wissenschaftlich beschriebenen Menschen. Gleichzeitig ist dieser Widerspruch ein diskursiver Zirkelschluss: die Theorie, welche die Zweigeschlechtlichkeit in Frage stellt, gibt so genannten intersexuellen Menschen Denk- und Handlungsmöglichkeiten, gleichzeitig werden diese von eben der Theorie kategorisiert. So gilt wohl die Forderung des Rechts über sich selbst zu bestimmen, über die körperliche Unversehrtheit, sowie die Definition oder Nichtdefinition einer Identität, nicht nur gegenüber der Medizin, sondern gegenüber jedweder wissenschaftlicher Theoriebildung. Dies zusammengedacht mit Michel Reiters Vorbehalten gegenüber der Dekonstruktion führt zu einem Widerspruch der nicht aufzulösen ist. Gemäß der Argumentation, den einzelnen Menschen vor die Theoriebildung zu setzen, darf sein Einwand nicht an Gewicht verlieren, andererseits sollte damit aber auch nicht ein genaues Lesen der Konstruktionstheorie Butlers blockiert werden.

6.1. Ausblick in die Vielgeschlechtlichkeit jenseits fester Identitäten

Anja Heldmann fragt, ob mit der Dekonstruktion der 'Natur der Zweigeschlechtlichkeit' die Entmaterialisierung von Körpern einhergehen muss? Sie verneint dies: „Die psychischen und physischen Narben, die Schmerzen der operierten Körper von Intersexuellen sind so real, dass es als Hohn erscheint, bereits ihre 'ursprünglichen' Körper für konstruierte zu halten.“¹²¹. Intersexualität als Negation der Zweigeschlechtlichkeit bedeutet nicht, mit Geschlechtern in Form einer Maskerade oder Travestie lediglich zu spielen, es erfordert eine grundsätzlichere Veränderung des polaren Denkens bezüglich einer pluralen Geschlechterdifferenz jenseits der Kategorien 'Frau' und 'Mann'. Heldmann fordert nicht einen „selbstmitleidigen Blick“ auf das „schwache Geschlecht“, wie es die feministische Bewegung lange Zeit propagiert hat, sondern auf die gewaltsame Eliminierung sog. zwischengeschlechtlicher Menschen.

Wir befinden uns hier in einer argumentativen Zwickmühle: einerseits muss von Zweigeschlechtlichkeit als Konstruktion und von konstruierten Körpern ausgegangen werden, die dieses Modell bedienen, andererseits muss auf der 'Substanz' von Körpern bestanden werden, um Intersexuellen nicht erneut den Ort ihrer Präsenz zu nehmen. Heldmann plädiert von daher für die Beibehaltung der Kategorien gender und sex. Die vielfältigen Formen der Intersexualität und die Schwierigkeit der Medizin, diese zu kategorisieren, machen deutlich, dass die körperlichen Merkmale intersexueller Körper nicht lediglich als eine Mischung der

¹²¹Heldmann, Anja, Jenseits von Frau und Mann, Intersexualität als Negation der Zweigeschlechtlichkeit, In: Differenz und Geschlecht: neue Ansätze in der ethnologischen Forschung, Berlin 1998, S. 56.

definierten weiblichen und männlichen Körpermerkmale anzusehen sind, sondern jeder Körper für sich eine eigene körperliche Geschlechtskategorie darstellt. Dadurch wird der Begriff der Intersexualität obsolet. In diesem Sinne plädiert Heldmann für andere Begrifflichkeiten. Sie schlägt 'Vielgeschlechtlichkeit' vor; 'Frau' und 'Mann' definierten dann lediglich zwei Möglichkeiten der Geschlechterformen unter vielen.¹²²

Was theoretisch so einfach formuliert wird, gestaltet sich in der Praxis als nicht unbedingt einfach. Das Wissen um den Körper, das u. a. durch die Biologie und Medizin geprägt ist, erlaubt es nicht, Leibeserfahrungen und -wahrnehmungen unipolar zu erleben. Die Menschen in unserer Kultur können nur anhand binär gestalteter Körperdifferenz die Geschlechter 'Frau' und 'Mann' wahrnehmen. In Begegnungen mit Intersexuellen fällt auf, wie dominant dieses binär gestaltete Körperwissen ist. So werden oft in der unmittelbaren Konfrontation mit einem intersexuellen 'Leib' an seinem/ihrem 'Körper' Merkmale gesucht, die sich nur an der Kategorien 'Frau' und 'Mann' zu orientieren scheinen. Durch eigenes Körperwissen wird versucht, den Leib in binäre Geschlechtermerkmale zu strukturieren. Da dies unmöglich gelingen kann, tritt zunächst Verwirrung auf. Erst wenn eigenes Körperwissen vergessen wird, besteht die Möglichkeit, dem Menschen gegenüber gerecht zu werden. Geht es aber andererseits nicht genau darum, dieses Wissen gerade nicht zu vergessen? Geht es nicht vielmehr darum, sich des eigenen Verhaftet-Seins in der binären Ordnung bewusst zu werden? Erst mit einem Bewusstsein für diese Kategorien ist es möglich, mehr als nur den in der Kategorie verhafteten Menschen zu sehen. Durch diesen erweiterten Blick kann es gelingen, geschlechtliche Körper in mehr als zwei Varianten zu erfassen. Durch die Konfrontation mit Intersexuellen ergibt sich aber die viel grundsätzlichere Herausforderung, identitätskonstituierende Prozesse immer wieder zu hinterfragen, um vielleicht irgendwann Identität unabhängig von Geschlecht denken zu können. Eine Differenz der Geschlechter jenseits der Zweigeschlechtlichkeit sehen zu können, bedeutet, sich ein völlig neues Wahrnehmen, Denken und Wissen anzueignen, das die Menschen in ihren vielfältigen Geschlechtern belassen kann.¹²³

¹²²ebd., S. 55-57 und 71.

¹²³ebd., S. 69f.

7. Politisch-strategischer Teil

7.1. Zur Instrumentalisierung von Intersexuellen

In unseren Diskussionen ist uns klar geworden, dass die Gefahr besteht, Intersexuelle zu instrumentalisieren. Es ist bemerkenswert, dass hier die Nicht-Intersexuellen über das Andere sprechen – anstatt über sich, über `Normalität`. Intersexualität wird gerne als Beispiel genommen, um anderen zu erklären, was `gender` etc. ist. Um Zweigeschlechtlichkeit jedoch zu erklären, muss man nicht Intersexualität nehmen, sondern kann auch bei sich selbst anfangen! Ansonsten wird stets das sensationelle, exotische Andere gegenüber gestellt. Mit der umgekehrten Intention wird nachvollzogen, was in den Medizinbüchern passiert, in denen das Normale aus der Anormalität heraus erklärt wird. Die Dekonstruktion kann und sollte aber nicht in den gleichen Bahnen wie die Konstruktion verlaufen.¹²⁴ Intersexuelle sind immer im Fokus der akademischen Apparate: Nach der Medizin werden sie nun von den Sozialwissenschaften als Forschungsobjekt entdeckt.

7.2. Diskussion um den Opferbegriff

Außerdem hatten wir eine Diskussion um den Opferbegriff: Können Intersexuelle als `medizinische Folteropfer` betrachtet werden? Einerseits sind Intersexuelle Opfer des medizinischen Komplexes, weil sie sich als Kinder nicht wehren können. Andererseits ist die Bezeichnung `Opfer` stark vereinfachend: etwaiger Widerstand gegen den Eingriff wird nicht sichtbar. Wenn Intersexuelle diesen Begriff zur Selbstbeschreibung benutzen würden, wäre es vielleicht etwas anderes. TäterInnen gibt es aber ganz klar: MedizinerInnen, JuristInnen, Eltern. Oder? Haben nicht auch diese Personen noch mehr Dimensionen? Was ist mit der Bezeichnung 'Betroffene'? Sie ist weniger schematisch und stellt die gemeinsam gemachten Erfahrungen von Intersexuellen heraus.

Auch in Punkto gemeinsamer politischer Organisation sind zunächst die Besonderheiten der Situation Intersexueller zu analysieren, bevor gemeinsame Interessen behauptet werden:

¹²⁴ Protokoll unserer AG-Sitzung vom 1. Juli 2004.

7.3. Zur Differenz zwischen Homo- / Trans-sexuellen und Intersexuellen

Nachdem uns die verbrecherische Rolle der Medizin deutlich geworden war, diskutierten wir verschiedene Formen des Widerstands gegen diese Praktiken. Eine wichtige Frage war dabei, ob Intersexuelle sich nicht mit der Lesben- und Schwulenbewegung verbünden müssten, um mehr Aufmerksamkeit für ihr Anliegen zu bekommen. Diese Möglichkeit wäre nur dann praktikabel, wenn die entscheidenden Differenzen zwischen diesen Gruppen nicht nivelliert werden, lautet unsere These. Weshalb dies so wichtig ist, erläutert Georg Klauda in seinem - für uns sehr wichtigen - Text „Fürsorgliche Belagerung“: Er schreibt dort, es gebe zwei Modelle, die sich im medialen Diskurs um Intersexualität der „Stabilisierung unseres Wissens über männlich und weiblich“ verschrieben hätten: Zum einen das Krankheitsmodell der ÄrztInnen, das Intersexualität pathologisiert und sie als Entwicklungsstörung darstellt. Auf der anderen Seite nennt er die von Homosexuellen als Minderheit übernommene Praxis, Intersexuelle als „klar abgegrenzte Gruppe von Personen zu definieren, denen die Abweichung von der Norm als ihre besondere Eigenschaft zukommt. Diese Gruppe wird als das Andere konstruiert und trägt so dazu bei, die Norm zu befestigen (...)“¹²⁵ Er kritisiert, dass Lesben und Schwule Transsexuelle ‚kolonialisieren‘, also eingemeinden, und Transsexuelle wiederum Hermaphroditen. Damit werde die Differenz gezeugt, die zwischen den einzelnen Gruppen besteht. Transsexuelle könnten sich nicht als Intersexuelle bezeichnen, weil „genau die Operationen, die Ihnen den Geschlechtsübergang erleichtern sollen, unter Umständen an der Verstümmelung von Hermaphroditen entwickelt wurden.“ An ihnen sei schließlich auf katastrophale Weise versucht worden, ein Geschlecht zu konstruieren. Das „Anerkennungsmodell“ von Lesben und Schwulen könne deshalb nicht auf Hermaphroditen übertragen werden.¹²⁶ Klauda schreibt als Fazit: „wir werden nicht darum herumkommen, unser Zweigeschlechtermodell gründlich zu revidieren, statt es durch das Minderheitenmodell zu reparieren.“ Hermaphroditen könnten nicht unter Zeichen wie ‚queer‘ oder ‚transgender‘ subsumiert werden, kritisiert Klauda.¹²⁷ Die zentrale These, der wir uns angeschlossen haben, ist hier also, dass sich die Problematik von Coming-out und gesellschaftlicher Anerkennung, die für Schwule, Lesben und Bisexuelle entscheidend ist, wesentlich von dem Anliegen von Menschen mit medizinischer Gewalterfahrung unterscheidet, die in erster Linie „medizinische Folteropfer“ seien.¹²⁸ Von daher sind auch die politischen Forderungen grundlegend andere: Transsexuellen geht es um die Anerkennung ihres umgewandelten Geschlechts, während es

¹²⁵ Siehe hierzu auch unsere Diskussion zum Begriff Intersexualität im Kapitel 2 dieser Arbeit.

¹²⁶ Klauda, Georg, Fürsorgliche Belagerung, Out of Dahlem, Nr. 1, Dezember 2000, S. 42.

¹²⁷ Klauda, Georg, Fürsorgliche Belagerung, Out of Dahlem, Nr. 1, Dezember 2000, S. 42.

¹²⁸ Klauda, Georg, Fürsorgliche Belagerung, Out of Dahlem, Nr. 1, Dezember 2000, S. 41.

Intersexuellen um die Anerkennung und vor allem um den Erhalt ihres angeborenen Geschlechts und um die Beendigung einer invasiven Medizin geht.¹²⁹

7.3.1. Konzept des Dritten Geschlechts führt zu Pathologisierung

Klauda weist aber noch auf einen weiteren Punkt hin: Mit der Verwischung der Unterschiede zwischen Schwulen, Lesben und Transsexuellen auf der einen Seite und Intersexuellen auf der anderen Seite werde „das von der Sexualmedizin begründete Konzept des Dritten Geschlechts aus der Anfangszeit des 20. Jahrhunderts neu aufgelegt“. Wenn dann die Medizin unter diesem Oberbegriff wieder unterschiedslos Transsexuelle, Homosexuelle und Hermaphroditen zusammenfassen könne, hätten auch Lesben und Schwule eine „pathologische Medizin wieder am Hals“.¹³⁰

Da die Varianzen geschlechtlicher Differenzen sehr unterschiedlich sind, kann in einem anatomischen Sinne nicht von einem `Dritten Geschlecht` gesprochen werden, hebt auch Reiter hervor.¹³¹ Vor allem aber sei es schädlich, die Grenzen zwischen Transsexuellen und Intersexuellen zu verwischen, weil MedizinerInnen und PsychiaterInnen ihre pathologisierte Klientel dann ausdehnen könnten. Als Beispiel zitiert er den Repromediziner Milton Diamond, der Geschlechter nicht mehr anhand der Genitalien unterscheiden will, sondern anhand von „geschlechtlichen Verhaltensabweichungen“. Die `Abnormalitäten`, die Schwule, Lesben, Transen und Zwitter konstituieren, gelten als „somatisch verortbar – erklärbar mal entlang einer genetischen Mutation, mal nach hormonell veränderter Ausprägung des zentralen Nervensystems bzw. des Corpus Callosum und mal nach normabweichenden Regelkreisläufen zwischen Nebennierenrinde und Hirnanhangdrüse.“¹³² Wohin das führt, zeigt das folgende Beispiel: Klauda erwähnt, dass an der Universitätsklinik Hamburg-Eppendorf sowie an der Uni Lübeck ein `millionenschweres Forschungsprojekt` angelaufen sei, das sich „Störungen der körpergeschlechtlichen Entwicklung und Intersexualität“ widmen möchte. In einem ersten Schritt werde mit einem Umfrage-Bogen ein Daten-Profiling „nicht nur von Hermaphroditen, sondern auch von Transsexuellen sowie Lesben und Schwulen durchgeführt.“¹³³

¹²⁹Heldmann, Anja, Jenseits von Frau und Mann, Intersexualität als Negation der Zweigeschlechtlichkeit, In: Differenz und Geschlecht: neue Ansätze in der ethnologischen Forschung, Berlin 1998, S. 70.

¹³⁰ Klauda, Georg, Fürsorgliche Belagerung, Out of Dahlem, Nr. 1, Dezember 2000, S. 42.

¹³¹ Reiter, Michel, „Ein normales Leben ermöglichen“, in: Gigi Nr. 8, Juli / August 2000, S. 8.

¹³² Reiter, Michel, Hurra - das neue Transschända!, in: Gigi Nr. 11, S. 23.

¹³³ Klauda, Georg, Fürsorgliche Belagerung, Out of Dahlem, Nr. 1, Dezember 2000, S. 42.

8. Politische Forderungen

Gegen Ende unserer Beschäftigung mit Intersexualität drängte sich uns die Frage auf, welche politischen Forderungen sich aus den erarbeiteten Texten ergeben.¹³⁴ Dabei haben wir verschiedene Adressaten unterschieden:

Forderungen gegenüber der Medizin als akademischer Disziplin und operierendem Apparat:

- Anerkennung der Behandlung an Intersexuellen vor Einwilligungsfähigkeit als Straftat und Menschenrechtsverletzung,
- Eine unbedingt zu schaffende gendersensible Medizin muss deshalb diese Operationen und Hormonverabreichungen sofort einstellen,
- Eine Veränderung der Lehrpläne des Medizinstudiums ist dringend notwendig: Es darf nicht sein, dass im Medizinstudium nur medizinisches Fachwissen auswendig gelernt wird, ohne eine Selbstreflexion über das spätere Tun zu erlernen,
- Die Trennung zwischen den „two cultures“, wie J. P. Snow die Bereiche der Natur- und der Geisteswissenschaften genannt hat, muss aufgehoben werden, indem die – in den Geisteswissenschaften teilweise schon lange übliche – Inter- und Transdisziplinarität auch in der Medizin eingeführt wird.¹³⁵

Forderungen an den Staat:

- Kein Eintrag des Geschlechts in den Pass.
- Opferentschädigungszahlungen zur Gewährleistung eines Lebensunterhalts
- Adoptionsvermittlung¹³⁶

Forderungen an die Gesellschaft:

- Es ist eine veränderte Wissensproduktion anzustreben: Das Geschlecht soll für die eigene Identität nicht so wichtig sein. Geschlechtliche Ambiguität ist gegenüber einer Eigentlichkeit hochzuhalten. Identitäten sollen vielfältig, nicht auf zwei beschränkt sein. Dieser multisexuellen Gesellschaft müsste allerdings eine Kulturrevolution voran gehen.¹³⁷
- Bis dahin gilt es, Intersexuelle gesellschaftlich sichtbar zu machen und ihnen einen

¹³⁴ Forderungen von Intersexuellen sind u.a. zu finden in dem Text: Reiter, Michel, „Ein normales Leben ermöglichen“, in: Gigi Nr. 8, Juli / August 2000, S. 11.

¹³⁵ Protokoll unserer AG-Sitzung vom 1. Juli 2004.

¹³⁶ Reiter, Michel, „Ein normales Leben ermöglichen“, in: Gigi Nr. 8, Juli / August 2000, S.11.

¹³⁷ Protokoll unserer AG-Sitzung vom 1. Juli 2004.

Platz in der Gesellschaft einzuräumen. Dazu gehört u.a. eine Änderung der pädagogischen Lehrpläne in der Schule. Zu den Veränderungen in der Schule müsste auch eine Überarbeitung der anatomischen Abbildungen z. B. in Biologie-Schulbüchern gehören. Dazu schreibt Reiter: „Das vereindeutigte und in zwei Kategorien geteilte anatomische Geschlecht, wie es in Lehrbüchern und durch Erzählungen als Kombination aus Eierstock/Hoden, Behaarungstypen, etc. verhandelt wird, existiert überhaupt nicht und seine vorgebliche Natürlichkeit ist eine Farce.“¹³⁸

9. Resumee

Im folgenden möchten wir keine ausführliche Zusammenfassung des Forschungsberichtes geben, sondern die wichtigsten Ergebnisse noch einmal kurz wiedergeben. Folgende Punkte waren für unsere Arbeitsgruppe besonders wichtig: Der Blick in die Geschichte zeigte uns, dass der Wechsel des Geschlechts erst seit dem 19. Jahrhundert verboten ist, nachdem sich der biologisch-medizinische Apparat installiert hat. Dabei kristallisierte sich für uns die Erkenntnis heraus, dass gesellschaftliche Diskurse gewalttätig zum Offenbarungseid zwingen können, ohne dass eine aktive Person, ein Täter verantwortlich sein muss.¹³⁹

Zur Frage, weshalb Intersexuelle operiert werden, haben wir diverse medizinische Texte durchgearbeitet. Zusammenfassend lässt sich festhalten, dass die Sexualmedizin Intersexualität als schwerwiegende Störung sieht. Zweigeschlechtlichkeit und Heterosexualität wird von den MedizinerInnen für normal gehalten. Die MedizinerInnen behaupten, eine geschlechtsspezifische Erziehung sei nur möglich, wenn körperlich-morphologisches und nach der Geburt zugewiesenes bürgerliches Geschlecht übereinstimmen. Wenn dies nicht der Fall ist, sei eine psychosozial normale Entwicklung des Kindes nicht gewährleistet. Es hätte dann keine erfüllende Sexualität. Oberstes Ziel ist dabei die Kohabitationsfähigkeit: Es muss eine Koitusfähigkeit des Geschlechtsorgans hergestellt werden. Menschen mit einem dritten oder neutralen Geschlecht würden diskriminiert werden. Deshalb ist oberstes Ziel, ein eindeutiges Geschlecht zu erzeugen. Entscheidend sei die Leid vorbeugende, bald nach der Geburt vorgenommene Korrektur. Hierbei sei es zweitrangig, ob eine Vermännlichung oder Verweiblichung vorgenommen wird. Um auch das sozial gelebte Geschlecht auf den korrigierten operierten Körper zu eichen, wird im Anschluss eine Psychotherapie empfohlen. Der biologische sex wird also entsprechend dem herrschenden

¹³⁸ Reiter, Michel, Theoretische Differenz, symbolische Nähe, in: Gigi Nr. 6, März / April 2000, S. 22.

¹³⁹ Protokoll unserer AG-Sitzung vom 8. Juni 2004.

gender-Modell geformt, das soziale Geschlecht erschafft das biologische. Es zeigt sich, dass es bei den geschlechtlichen Normierungen keineswegs um die Interessen der Betroffenen, sondern um die Absicherung dichotomer Geschlechterverhältnisse geht.¹⁴⁰ Intersexualität wird mittels der binären Geschlechternorm zugleich hervorgebracht wie verboten.¹⁴¹

Im krassen Gegensatz zu den ärztlichen Konzepten stehen die Erfahrungen der operierten Menschen. Sie sehen die Operationen nicht als Wohltat zur Verhinderung von Leid, sondern als Folter. Ihr Körper wird mit Gewalt gezwungen, ein anderer zu sein, sie werden mit Gewalt in ein kulturelles Raster gepresst, in das sie nicht hineinpassen. Hinzu kommt die sexualisierte Gewalt durch die behandelnden Ärzte, etwa bei der Bougierung (‘Dehnung’) der Scheide. Da die medizinische Selbstlegitimation mit diesen Ausführungen also hinfällig ist, muss es einen anderen Grund dafür geben, dass Intersexuelle zwangsoperiert werden. Wir sind zu dem Schluss gekommen, dass Intersexuelle für die herrschenden Geschlechterverhältnisse eine Bedrohung darstellen. Sie offenbaren die zwangsheterosexuelle Zweigeschlechtlichkeit nur zu offensichtlich als kulturelles Artefakt. Sie stürzen das System in eine Identitätskrise. Demnach schützt der ärztliche Präventionsgedanke also ‘die Gesellschaft’ vor Intersexuellen, nicht etwa Intersexuelle vor ‘der Gesellschaft’. Individuell kann nicht gelöst werden, was nur gesellschaftlich geht.

Von sexueller Gewalt wird in westlichen Ländern nur gesprochen, wenn es um außereuropäische Kulturen, etwa die Genitalverstümmelung in Afrika geht. Damit wird in rassistischer Weise davon abgelenkt, dass auch im aufgeklärten Westen Folter und Verstümmelung durch die moderne Medizin an der Tagesordnung ist. Diese Fakten passen aber nicht zum kolonialen, paternalistischen Blick, den auch manche Feministin auf die „armen Frauen“ in Afrika fallen lässt. Diskursive Ein- und Ausschlussregeln fielen uns auch bei der gesamten Rezeption medizinischer Literatur auf: Medizinische Diskurse können es sich leisten, völlig ohne Bezugnahme auf feministische Diskurse zu existieren, die die Geschlechterkonstruktion kritisch hinterfragen. Naturwissenschaftliche Diskurse weisen allerdings unterschiedliche Durchlässigkeiten auf. In der Biologie ist es beispielsweise üblicher, Kritik aus der eigenen Disziplin heraus zu leisten (siehe etwa Donna Haraway etc.) als im Bereich der Medizin, wo die AutorInnen mancher wichtiger Standardwerke noch nie etwas von feministischer Naturwissenschaftskritik gehört zu haben scheinen und ihre Theorieproduktion seit Jahrzehnten unfassbar hermetisch ist.

¹⁴⁰Engel, Antke, ene mene meck und du bist weg – über die gewaltsame herstellung der zweigeschlechtlichkeit.

¹⁴¹Engel, Antke, ene mene meck und du bist weg – über die gewaltsame herstellung der zweigeschlechtlichkeit.

Als Ausblick steht für uns fest, dass eine grundsätzlichere Veränderung des polaren Denkens in Richtung einer pluralen Geschlechterdifferenz, einer Vielgeschlechtlichkeit jenseits der Kategorien 'Frau' und 'Mann' dringend notwendig ist. Zum Schluss möchten wir noch auf die Gefahr hinweisen, dass Operationen an Intersexuellen aufgrund der zunehmenden öffentlichen Kritik bald durch unauffälligere vorgeburtliche Elimination abgelöst werden könnten. Zur Frage, ob Intersexuelle bereits heute durch ein systematisches pränatales Screening ausgefiltert werden, haben wir keine genauen Angaben gefunden. Es ist aber zumindest klar, dass Föten mit bestimmten, der Intersexualität zugerechneten Syndromen, nach §218a bis zum neunten Monat abgetrieben werden können, „wenn schwerwiegende Beeinträchtigungen des körperlichen oder seelischen Gesundheitszustandes der Schwangeren zu erwarten sind - mit anderen Worten, wenn das künftige Kind als nicht zumutbar gilt.“¹⁴² Michel Reiter schreibt, über Pränataldiagnostik und In-Vitro-Fertilisation werde man „vermutlich schrittweise eine vollständige Elimination anstreben“.¹⁴³

¹⁴² Reiter, Michel, Ein perfektes Verbrechen, in: Gigi Nr. 2, Juni / Juli 1999, S. 16. und Reiter, Michel, Theoretische Differenz, symbolische Nähe, in: Gigi Nr. 6, März / April 2000, S. 22 und Reiter, Michel, Hurra - das neue Transschanda!, in: Gigi Nr. 11, S. 23.

¹⁴³ Reiter, Michel, Medizinische Intervention als Folter, in: Gigi Nr. 9, Oktober / November 2000, S. 14.

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