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**The Doctor Will Fix Everything:
Intersexuality in Contemporary Culture.**

Michelle Morgan LeFay Holmes

A Thesis

in

The Humanities Doctoral Programme

**Presented in Partial Fulfilment of the Requirements
for the Degree of Doctor of Philosophy at
Concordia University
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Abstract

This dissertation, The Doctor will Fix Everything: Intersexuality in Contemporary Culture, authored by Michelle Morgan LeFay Holmes, is submitted in partial fulfillment of the doctoral degree in Interdisciplinary Humanities. Using an interdisciplinary approach, this work examines the development of diagnosis and treatment of “intersexuality”. I argue that intersexuality is not a medical condition *per se*, and that standard treatments contravene the ethical and legal standards regarding the treatment and care of minors. I situate medical discourse, fiction and (auto)biography as forms of narrative within a contemporary culture, and I examine how each narrative form respectively creates and contests what it means to be “intersexed”.

Various representations of intersexuality interest me for their ability to shape the category. This dissertation sets out to demonstrate that the scientific narratives are no less *cultural* products than are fictional and personal accounts, and argues that scientific texts are merely specific forms of cultural product. Therefore, I do not structure scientific or medical texts as opposites of personal or fictional ones. Instead, I read each for the ways in which it structures what is possible, knowable, and true about sex, gender and sexuality.

This dissertation weighs the narratives of intersexuals against these cultural and scientific representations to contest standard beliefs and mythological stories about hermaphroditism. The work begins with a historical perspective, moves through narrative and cultural analysis and ends with an ethical discussion of current treatment standards. A glossary follows the bibliography.

Acknowledgements

This dissertation represents only a portion of the work that goes into a doctoral degree, and though it is authored by but one person, many have been involved in its production. I would, therefore, like to thank my programme and my advisors, Dr. Stanley French, Dr. Veronica Hollinger and Dr. David Howes. Each of these people has facilitated the development of my thought in diverse fields which, without their help, I would not have been able to synthesize in this dissertation. To Dr. Hollinger I owe a special gratitude, for she has been with me since my undergraduate degree, providing both academic guidance and personal support.

Some of the work presented in this dissertation has been developed out of specific conference and publication work I have pursued over the past five years. In 1995, I presented work on intersex bodies as queer bodies for the Queer Frontiers Graduate Student Conference held at the University of Southern California, Los Angeles. Derived from that paper, a version of Chapter Three will appear early in 2000 in the University of Wisconsin publication, Queer Frontiers under the title “Queer Cut Bodies”.

In the spring of 1996, I was fortunate enough to begin working with clinical ethicists in both Canada and the United States. The dissertation’s work on consent, the potential autonomy of minors, and truth telling in intersex management build on my presentation at the Intersex panel of the 1996 Canadian Bioethics Society Meetings, held in Montréal that fall. Following from that presentation, I was invited to present preliminary work at the 1998 summer meetings of the McGill University Enhancement Technologies Project coordinated by Carl Elliott and Margaret Lock. My assessment of intersex treatment protocols *vis-a-vis* the concept of “enhancement technologies” which

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appears in chapter four expands on the research was initially produced for that session.

I am grateful for these and many other opportunities to have publicly worked through the ideas that have formed the basis of this dissertation, and I am thankful for the input I received from my various audiences.

My work depends in part on the critical trailblazing theoretical, historical and clinical work produced over the past decade. Without the intellectual commitment and work produced by Alice Dreger, Anne Fausto-Sterling and Suzanne Kessler, this dissertation would not have had a starting point from which to proceed.

Accomplishments are never made without the contributions of our supporters. Thanks go to my family for their encouragement in moments when it was most needed: June Mitzel, Ron Cowan, Eric and Barb Holmes, Maeve and Tony Holmes, and Margaret Druhan. There are some who deserve extra recognition and thanks: my mother, Trudy Cowan, who edited the penultimate draft, and my grandmother, Elsie MacBride, who boosted me over the last financial hurdle. It is a terrible personal loss that my father passed away before the dissertation was defended; he was not always the best teacher, but he instilled in me a fundamental curiosity about the world around me, and for that I am truly grateful. Only a few days before defending this dissertation, I lost a friend and professional colleague, Karol Steinhouse. I am sorry that Karol did not have a chance to see the final product, for she was a great support to me. Then there are those who had to live with me throughout graduate school: I am especially thankful to Trevor, my greatest friend and partner, who I always knew would love me, regardless of whether I finished the dissertation. Finally, were it not for my son, I would not have finished this project; Nicholas, you are my greatest inspiration. Thank you.

Dedicated in memory of

My grandfather,

Gordon Gray MacBride,

and my aunt,

Margaret Marie Bracken.

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Images of Cheryl Chase and Martha Coventry appear with their permission. The portrait of Morgan Holmes by Mary Ellen Mark appears by permission of the artist.

Introduction

This dissertation begins with the premise that there is no such thing as a natural body. This is not equivalent to saying that the body is not a biological organism. Rather, the point of refusing to adhere to a concept of a natural body constitutes a recognition that there is always an interaction between an organism and its environment.¹ There is no way to apprehend the body separately from its constitutive cultural gaze. That is to say, our cultural gaze provides the terms through which we can see or know any body or bodies as such. I use this premise to examine cultural ideas about sex that inform and are informed by medical and biological discourses, and I work to provide a sense of how those cultural perceptions impact on the treatment of intersexuality.

Chapter one maps the concerns of the dissertation, introducing the ethical and narrative questions that I take up in greater detail later. This dissertation accesses intersexuality by way of three major inroads: cultural theory, philosophy and ethnography; all of these are introduced in the first chapter where I begin to discuss ideological commitments, cultural perceptions and precepts, historical shifts in science and medicine and the moral duties of medical care providers.

In chapter one, I map the historical commitments of medical research and consider medicine's investments in establishing itself as a powerful *episteme* that would both shape and be shaped by the political commitments of its cultural context. The chapter introduces theoretical work from a variety of disciplinary perspectives. I discuss Anne Fausto-Sterling's essay "Gender, Race and Nation," on the display of Sarah Bartman in European medical circles as the "Hottentot Venus;" and Nelly Oudshoorn's work debunking the myth of scientific narratives of "discovery" specifically as they relate to

the development of theories about sex hormones. I spend a large portion of chapter one discussing the implications of Alice Dreger's historical work on contingencies of sex and gender and the creation of medical power. Dreger's work focusses specifically on medicine's establishment as a scientific profession, and demonstrates how that process, which effected changes in nineteenth- century diagnosis and treatment of hermaphroditism, is of special importance to this dissertation. Dreger's research and conclusions mark key starting points in my analysis of existing cultural ideologies regarding sexual function and identity, especially as these ideologies relate to the treatment of intersexed persons. The first chapter also serves to introduce the gains and challenges that we can expect to face in the creation of new narratives, new knowledge, and new ethical models for the treatment of intersexed minors.

Media and popular representations of intersex are the subject of the second chapter. I consider reports on and about intersexuality as narrative and examine how the stories of medicine, fiction, and biography try to make sense of what it means to be a "hermaphrodite." I examine some of the tensions between the desire to speak for oneself, and the need to produce a story that contests traditional perceptions. By looking at these venues as different forms of narrative, I consider the ways in which fictions are presented as "truth" and the ways in which these various genres intersect, blurring the lines between truth and fiction. I question the motives of the editors and publishers of Alexina Herculine Barbin's autobiography, and compare textual unease in both Michel Foucault's and Ambroise Tardieu's assessment of Barbin's character, gender and body. I employ Kristeva's theory of abjection to consider the symbolic role of intersexuals or hermaphrodites in modern horror tales from 20/20 to The X-Files. Ultimately, I propose

that all the stories, whether they declare themselves to be medical “fact” or entertainment “fiction,” are symbolic narratives, and that intersexual bodies have a particular symbolic function within those stories.

My third chapter investigates contemporary strategies of resistance used by intersexuals to form a positive identity and community that will affirm intersex, even as they struggle with a culture that has no memory of, or commitment to, positive recognition of intersexuals. I ask what the cultural norms are for sex and gender and discuss some of the attractions and problems present in trying to adopt different cultural models for understanding intersex status. Chapter three also examines various “online” representations of self and community among intersexed persons: on public domain bulletin boards and websites for Turner’s Syndrome and Congenital Adrenal Hyperplasia (CAH), on the Intersex Society homepage, and on the Intersex Voices website. In this section, I examine some of the differences between how parents of young children in the midst of treatment and older patients who have been treated talk about intersex and its medical management. I am also interested in the strategies that people use to resist the medical version of what it means to be intersexed, so I discuss some of the anthropological knowledge of “third gender” categories in diverse cultures and see how that knowledge gets taken up in contemporary intersex identity discourse. I am interested in precisely how these systems of thought are appropriated in the construction of intersex identity in Euro-American circles, and in the potential consequences of adopting other culture’s models for dealing with intersex.

My fourth and fifth chapters work in conjunction to consider specific philosophical and ethical questions about autonomy, children’s rights, and cosmetic

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interventions as distinct from restorative procedures. I consider a number of different ways in which standard medical procedures for the treatment of intersex contradict, bracket, or even violate ethics guidelines.

In chapter four, I explicitly pursue the question of whether cosmetic surgery on intersexed genitals is a “restorative” or an “enhancement” procedure. I argue against its classification as a restoration, showing that it is unclear what, if anything, is lost due to the presence of “ambiguous” genitals; therefore, it is not possible to establish what function cosmetic surgery restores to the intersexed infant. I then consider whether the surgery is an enhancement and determine that, because of poor outcomes commonly reported both in medical follow-up studies and by adults who have been surgically managed, the surgeries fail to enhance function or appearance. I conclude the chapter by challenging the traditional, established view of intersexuality, making preliminary recommendations for change.

In chapter five, I discuss the importance of safeguarding the potential for adult autonomy in intersexed children. I begin by laying out the development of the requirement for informed consent, as opposed simply to consent, in Canada. Whereas prior to 1981 it had been necessary only for doctors to ask permission to perform a procedure, after the landmark Reibl versus Hughs case, doctors were obliged to provide their reasons for proposing any intervention, and were additionally required to provide patients with information regarding risks and benefits of any intervention. I discuss the limitations of consent, given the structure and implications of medical power, and conclude by discussing the importance of autonomy

Recognising that not all readers of this dissertation will have a familiarity with the

medical terms for conditions and procedures associated with intersexuality, I have provided a glossary at the end of the dissertation.

The work of this dissertation is very much a product of its age. It is no less a historically contingent document or representation than anything else I examine within its pages. Therefore, it is necessary to note that two major philosophical developments are crucial both to the ability to conceptualise this work and to develop it. The first is postmodern feminist thought. Without the influence of postmodern theories of sex, gender and knowledge, which enable me to view critically the grand narratives of medicine and science, this project would be impossible. The second is what has come to be known as “queer theory,” as typified by thinkers such as Judith Butler. Butler’s work points out that ideas about what it means to be male and female, heterosexual and homosexual, are ideas always bound up with the privileged term (male, heterosexual). The privileged term’s values are still reflected in, for example, feminist demands for equality, and gay and lesbian demands for liberation/rights. This is because, according to Butler, identity categories such as *woman*, *lesbian*, and *gay* “[...]tend to be instruments of regulatory regimes, whether as normalizing categories of oppressive structures or as the rallying points for a liberatory contestation of that very oppression” (1991, 13-14). The promise, however impossible or imperfect, of using “queer” identity to think about intersex, then, is that it is a slippery category that refuses to be called into the heterosexual/homosexual framework, and defies any neat categorisation of gender or of sexuality, even resisting the notion of a biologically objective *sex*.

The refusal of the binary heterosexual/homosexual structure is important to my own project because doctors try to promise parents that their interventions can effect a

clear and “normal” sexual identity. As Anne Fausto-Sterling points out, the mandate for intersex bodies to be made concordant to singular versions of normalcy informs all the standard procedures, and is carried out without an adequate understanding of its results for the patients:

Almost at once [intersexed] infants are entered into a program of hormonal and surgical management so that they can slip quietly into society as “normal” heterosexual males or females. [...] The aims of the policy are genuinely humanitarian, reflecting the wish that people be able to “fit in” both physically and psychologically. In the medical community, however, the assumptions behind that wish--that there be only two sexes, that heterosexuality alone is normal, that there is one true model of psychological health--have gone virtually unexamined. (1993, 22)

The medical protocols rest on an assumption that, in spite of intersex evidence to the contrary, sex has an immutable character in its normal, healthy state. Thus, although biomedicine recognises that intersexuality is a naturally occurring, statistically stable instance of sexual/anatomical variation, it posits that variation as a pathology, rather than as just another type of body. Annamarie Jagose sums up Butler’s contribution to queer theory’s ability to rethink sex when she notes that

In refusing the commonly assumed distinction between sex and gender, and in dismantling those allegedly causal relations that structure the difference between the two, Butler[...] foregrounds the ‘instability at the very heart of sex’ (1996, 90).

Taking my cue from Butler then, this dissertation argues that intersex bodies are not *the*

site of sexual instability, but rather, that all theories of sexuality have a history, and are imbricated within and by specific cultural and political commitments that seek to deny the very instability of sex. The treatment of intersex, like the treatment of infertility and of women's bodies in general, is therefore only one location among many where biomedicine attempts to solidify the category of sex against the threat of abject dissolution.

CHAPTER ONE

The Creation of Sex: Access to Bodily Knowledge

Western medical practices and technologies have developed within a highly industrialised and mechanistic culture, and have produced metaphors for thinking about and perceiving bodies in ways that far exceed the boundaries of the physical limits of any given body.² It is doubtful, considering the apparent symbolic and interconnected relationship of bodies and artistic or literary representation, that medicine has independently produced these overfull categories; nevertheless, with the predominant position of biomedicine in Western cultures, its particular metaphors of bodies and their “functions” threaten to become, if they have not already, *the only* symbolic and interpretive system mediating our understanding of ourselves. Furthermore, because Western biomedicine is fixated not on a prevention-of-disease model, but on a diagnostic paradigm that sees all bodies as potentially, perhaps unavoidably, defective, these metaphors threaten to produce particularly damaging means of interpreting our selves through our bodies. With regard to the joined interests of medical and political control of sexuality, sociologist John O’Neill states that:

[...]what we are dealing with is an enormous expansion of institutionalised discourse upon sexuality--legal, medical, psychiatric, pedagogic, pornographic--which multiplies the cultural potential of biological sex beyond its intrinsic limits. We need to then ask [sic] in whose interest this expansion occurs and by what specific bodily techniques the various discursive strategies are implemented. (O’Neill, 1985, 136)

Although O'Neill indicates in his work that he does believe in a "natural body," (1985, 118-119, and 133) he does not provide a sense of what the natural body is or might be, or of how we might recognise it. At the end of chapter three, I return to the question of the "natural body" in order to challenge the idea of biological sex. Although I find O'Neill's belief in a natural body to be more a case of wishful thinking than a compelling argument, his work helps to identify the role that current Western biomedicine plays in authoring its own crises, thus giving itself, or taking from culture for itself, an "overstuffed" category (sex in this instance), which it then promises to recontain within objectively quantifiable limits.³ These limits, paradoxically, are, in O'Neill's term overburdened with metaphors and symbolic functions regarding production and reproduction of families, of ourselves through our children, and of our reflected sexualities, inscribed on the bodies of children.

The Medical Story

Scientific practice and scientific theories produce and are embedded in particular kinds of stories. Any scientific statement about the world depends intimately upon language, upon metaphor. The metaphors may be mathematical or they may be culinary; in any case, they structure scientific vision. Scientific practice is above all a story-telling practice in the sense of historically specific practices of interpretation and testimony. (Haraway, 1989, 4)

In her introduction to Primate Visions, Donna Haraway argues that fiction and fact are not as separate as they are frequently taken to be and that they are both the result

of a creative process of human effort; science “proves” certain facts or accomplishments that result from the choices and actions of the scientist. Haraway argues that facts are actively created bodies of knowledge, citing the Oxford English Dictionary definition of “fact” as a past participle of a thing *done*,⁴ that is, effectively created, through interrogation and testimony (Haraway, 1989,3). Haraway is making the point that facts are not already existing passive structures waiting to be apprehended, but “truths” actively demonstrated and brought into being. In this sense, scientific “truths” are as much fictions as the stories of science “fiction.”⁵ Thinking of fact and fiction this way allows us also to understand that the narratives of science fiction may be apprehended as equally “true” as the conclusions of science. It depends on what kinds of stories one is committed to telling.

My introduction states that this dissertation examines particular visions of intersex produced in biomedical, anthropological, and popular media stories, and engages some of the responses that have been made to those visionary commitments. It is also about intersections between stories and, therefore, crosses and combines the discrete disciplinary boundaries informing the ways in which I have come to see, think and write about intersex/uality and the lives of intersexed persons. The purpose for these crossings is twofold. First, it is a mistake to set out a series of chapters that make it appear as though the medical, political, anthropological, community, feminist and ethical stories of intersexuality, the intersexed body and the intersexed community existed thoroughly independently of one another: they do not. Not only do these stories intersect with each other, but at various points they are also occasionally interdependent. Second, it is misleading to suggest that there is only one story told in each “genre,” when, in fact, the

stories of each genre may have multiple and overlapping starting points. The medical story, for example, has in fact been several stories, among the first being the Hellenic mention of girls who, following the progressive evolutionary laws of nature, suddenly turned to boys from too much vigorous exercise and physical stimulation (Pliny, 1942, 531).⁶

Because of a general gap in knowledge production in Medieval Europe, little was contributed to medical knowledge until the reemergence of the Hippocratic and Galenic texts toward the end of the 18th century. This meant that early developments in modern medicine were inclined to echo both classical ideas regarding the biological processes and attributes of sex and generation, and classical social expectations of appropriate behaviours, or gender. Thomas Laqueur, a physician and medical historian, discusses in his Making Sex the inheritance of the classical sex model through the medieval and early modern periods, detailing its impact on how contemporary society conceptualises sex and bodies. Laqueur shows the broad links between social *beliefs* and medical *knowledge*, making it clear that present ideas about bodies, sexuality and gender are linked to past ideas. In so doing, he removes from medicine any claim to be non-ideological, or philosophically neutral.

Indeed, the study of hermaphroditism by medical “experts” operating within socially charged philosophical ideas about the appropriate social place of male and female bodies turned out to be a very important field for medicine’s growing hegemony in the nineteenth century. During its rise from the status of a healing art to a science, medicine used intricate mappings of the different types of intersex to provide itself with the assurance that in the end, an individual had only one “true” sex, and could thus be placed

in his or her appropriate social realm. This approach to the diagnosis and management of intersex persists, and seems to have hit its zenith in the last ten years, along with other technological “advances” in cosmetic surgery.

Within the contemporary medical field, however, there is less universal acceptance of the *status quo* in intersex diagnosis and treatment. Though research in journal articles and medical textbooks suggests that medical professionals have only one story to tell, there are, in fact, rumblings of dissent within association meetings, newsletters and conferences. It seems that younger medical professionals, medical support staff, including paediatric nurses and social workers, and the membership of the Gay and Lesbian Medical Association, are questioning the medical protocol on the treatment of intersex, if not its diagnostic category. The dominant story, then, is far from universally accepted within the field of medicine. In addition, there is no reason to assume a simple one-to-one relationship of medical doctrine to social demands or hermetically-sealed cultural concepts about sex, sexuality and gender identity. That is to say that medicine does not simply respond to and uphold the demand for two clear sexes, but that any culture will have to deal with the anomalies that must, by definition of systemic organisation, occur as ruptures in a system: “Any given system of classification must give rise to anomalies, and any given culture must confront events which seem to defy its assumptions”(Douglas 1966, 39). Western medicine has dealt with anomalous challenges to our sex classifications, not in response to societal demands but *within* the framework of broader cultural perceptions of what is inside and what is outside the system. Mary Douglas argues that

Culture, in the sense of the public, standardised values of a community,

mediates the experiences of individuals. It provides in advance some basic categories, a positive pattern in which ideas and values are tidily ordered. And above all, it has authority, since each is induced to assent because of the assent of others. (1966, 38-39)

The medical system is made up of individuals who are part of a larger culture, and as such, they reside *within* its organisational systems, strategies and values. Physicians, surgeons and endocrinologists, therefore, do not *respond to* demands. The medical system, rather, assents and upholds classifications in conjunction with others in the broader cultural *milieu*. Changes occur either because of resistance or because of dialogue between citizens in a reciprocal relationship of a culture and its values. Therefore, changes in the values of a larger society also form and inform changes in its medical system, but this does not happen as a demand and response pattern; rather, it happens as a conversation necessitated by an overwhelming and converging set of ruptures. These ruptures are then recontained by new stories, and new methods of management that replace the old stories.

To understand and analyse the intersex stories being told, one needs to consider by whom they have been told, and how. Intersex, contrary to the dominant medical story in play now, is a historical phenomenon and not a neutral biological fact. Intersex, as a set of bodily possibilities, has been both an object and product of knowledge for scientists and researchers who have made careers out of first identifying and then “fixing” the “problem.” Whatever else intersex may be at a biological level, at a cultural level, intersex is a category that has resulted from particular scientific and medical commitments, commitments that are linked to larger social means of ordering and organising sexuality.

As an identifying category, intersex is a limited and constrained term imposed on biologically atypical bodies whose one common feature is that their biology in some way confounds the biological differences between males and females. Under the dominant medical gaze, biological differences between males and females are cast as absolute distinctions, and as opposites: males have penises, females have babies (or at least, they *can* have babies). Although the problems with such essentialist ideas about what makes one male or female have been increasingly subject to scrutiny over the past ten years, the reliance upon a presumed stability of such reproductive/genitally-oriented ideas continues to inform the methods for diagnosing one as intersexed. That is to say that one cannot presume intersexuality exists unless one presupposes a strict biological dimorphism between males and females. Thus, the intersexual, as an object of knowledge, is used to prove that when this biological dimorphism is "confused" in a single body, disease is its logical outcome. For the person diagnosed as an intersexual, there may be a doubling effect: first, the individual must struggle to comprehend how s/he could have been labelled as either a "true male" or "true female" while also having been diagnosed as an "intersex." Second, the intersexual who determines not to remain silent is continually forced to work under one of two titles: intersex or hermaphrodite, both being names imposed on one by medical "experts." As we shall see in my discussion of biographical and personal narratives in chapter three, these identifying diagnoses both limit and produce meanings for those caught in their gaze.

"Intersexuality," and its alternate but equivalent term, "genital ambiguity," are used to denote a set of physical conditions commonly referred to as types of "hermaphroditism." Of course, what people understand the term "hermaphroditism" to

mean is both vague and variable, depending on the degree to which one associates it with classical mythology, contemporary “chicks with dicks” pornography, circus side-shows and spectacles, or any combination of these. Briefly stated, intersexuality refers to a physical and/or chromosomal set of possibilities in which the features usually understood as belonging distinctly to either the male OR female sex are combined in a single body.⁷

The term ‘genital ambiguity,’ though commonly used in both medical literature and in the few social-science and humanities papers on the subject, is a misnomer because there are presentations of intersexuality in which the genitals appear quite clearly as one or the other of the two recognised sexes. Furthermore, the use of the term “ambiguous” implies that intersexed genitals do not look like *anything*. This perception enunciates current cultural anxieties regarding sex and sexual identity categories in Euro-American culture. Therefore, I question the idea that intersexed genitalia are “ambiguous.” The fact that they are neither male nor female makes them clearly intersexed rather than confused or incomprehensible. The use of the term “ambiguous” in the diagnosis does not suggest that the intersexed child is somehow a doubled possibility, as is potentially suggested in the “*ambi*” of the term, but rather, a “neither this nor that, and therefore nothing,” in the effective denotation/connotation of the term. In fact, the children are cast as highly unreadable, except through the lens of the combined expertise of genetics, endocrinology and surgery. It is only through the microflouroscope that the ambiguity becomes readable, and then only down to the “one true sex” that the experts have promised to produce for the parents whom they have bewildered with an onslaught of imprecise (mis)information. My conjoined argument, of course, is that it is the prejudice of the expert readers that renders these bodies “ambiguous,” and my point is that intersexed bodies are actually

quite clear in and of themselves, not necessarily a blurry combination of the only two legitimate sexes.

Sexual Identity and Medicine

In medical texts, the body is described and conceptualised as an organism with certain functions to perform; however, the ways humans experience those functions are not explicitly discussed. Sexual pleasures, the experiences of reproduction from coitus and miscarriage through to gestation and birth, and menopause, for example, are described in terms of actions of the body rather than as the infinitely mutable experiences of billions of people. They are, furthermore, discussed principally in relation to their presumed reproductive function. Medical science has no conceptual space or time allotted for the consideration of the infinite possibility of/for bodily experiences. Instead, “the body” is read as a set of signs, and symptoms are described without providing a sense of the larger cultural discourses about bodies and their presumed “proper” functions.⁸ Infertility, for example, is seen as a symptom of an underlying disorder that has impaired the appropriate function of the *reproductive* organs. Similarly, in cases where illness or trauma are present, more attention is paid to organ damage than to quality of life. Indeed, quality of life falls more to the realm of ethicists, while function remains the territory of the medical practitioners, who traditionally overlook their patients’ physical, social, and emotional experiences. The medical/biological presuppositions of appropriate or intended functions of bodies have a deep impact on the management of intersex. For the parents of an intersexed child, when experience is even hinted at in medical literature, an obfuscating set of ideas is presented:

When we talk about the sex organ of the [genetic male] child, we only use the female terms, for example: “The clitoris is too large and will be reduced[...] leaving the top intact; the labia are joined together and will be separated; the vagina is missing and will have to be constructed[...].” We speak only about gonads, not testicles. (Slijper, *et al* 1994, 14)

Not only are these statements outright distortions of the facts about intersexed children’s anatomy, but how such children will experience sexual maturation and/or pleasure is neither considered nor discussed. When medical professionals *do* speak of feelings, it is the feelings of parents that are of concern and the primary consideration is that parents be able to display the child to relatives and friends without feeling ashamed:

A child needs to be assigned a sex as early as possible, and external ambiguities need to be corrected early, preferably during the first weeks of life, say the Hopkins doctors[...] “Otherwise, every time the mom, dad or auntie changes the diaper, everybody gets upset,” says Gearhart.

(Hendricks, 1993, 11)

A reduction clitoroplasty is best performed during the neonatal period, as the parents will be anxious to take a [female] child home with no visible evidence of masculinity, thereby avoiding mental anguish. (Edmonds, 1994, 559)

Cosmetic surgeries are carried out in the infancy of the intersexed child to protect the parents, and have the effect of keeping them in ignorance about their child’s actual condition. Why and how did medicine get to this point?

Previously controlled through juridical intervention, at the turn of the century

“hermaphrodites” came under the control of the medical gaze which could, and did, pronounce intersexuality a disease of atavistic perversity and then imposed a disciplinary “cure” to reduce the threat that biological similarities within and between the categories of male and female would be more readily apparent, possibly unravelling the social structures that divided the public *versus* private spheres of men and women.⁹ This interventionist medical response to hermaphroditic bodies emerged concurrently with the beginnings of separate definitions of heterosexuality and homosexuality and hinged upon the development of hormone research that, for political reasons, was especially committed to developing a theory of the incommensurability of two *opposite* sexes, male and female.

Thomas Laqueur argues that the reason neither lesbians nor homosexuals *per se* could have existed prior to the nineteenth century is that there was no “opposite sex” to whom one would be attracted or with whom one would be sexually active (1990, 90-131). For the same reason, the clitoris was seen, *when* it was seen, as a small penis and not at all troubling as such because there was no sense that males and females were opposites; they were merely variations of the same basic form. It is not, Laqueur argues, until the establishment of males and females as opposite sexes that small penises and large clitorises become troubling indications of a number of possible sexual perversions and/or degenerations. Prior to the development of a theory of opposition in the biological and anatomic features of males and females, women were more likely to be diagnosed as nymphomaniacs than as women with masculinised clitorises (Groneman, 1995, 219-249). In either diagnostic paradigm, the ultimate goal was the same: to control the social position of women through simultaneously claiming them to be “[...]normal in [their]

pathology and pathological in [their] normality”(Horn, 1995, 121).

Before hermaphroditism and homosexuality could become identifiable and perverse social/biological identities, science had to establish that men and women were the only logical and correct social expression of the absolute difference of males and females. Homosexuality, when it became an identity *per se*, was considered a social indication of biological degeneracy because it blurred the distinction/opposition of male and female roles. The relationship of homosexuality to intersexuality and to the opposing categories of male and female is an intertwined and interdependent medico-cultural mechanism that, through medical research and cultural mandates, organises bodies into ontological identities and matching political/social roles. Eventually, the physical definitions of the intersexual and the manifold concept of the homosexual were so overlapped that homosexuality was interpreted as a mental form of hermaphroditism and hermaphrodites were deeply disturbing physical entities who presented the threatening possibility of living as *natural* or *auto-sodomites*.¹⁰ All these theories of sexuality, identity, gender and degeneracy relied heavily on the developing field of social evolutionary theory, a set of theories that confused the social and the biological from the very beginning.

It is a peculiarity of present Euro-American medical discourse and practice that any child born with a clitoris measuring as small as .5cm according to some reports (Litwin et al, 1991, 209-212) and .9cm in others (Kessler, 1998,33-38; McGillivray, 1992,365-368) but who has otherwise typically female internal reproductive organs, a complete cervix and vagina and unfused labia, can be diagnosed as a hermaphrodite and submitted for clitoral reduction surgery. Similarly, it is also a historical peculiarity that a male infant with a penis measuring less than .5cm at birth, but who has otherwise typical

male reproductive organs, will be diagnosed as having “incomplete masculinisation,” assigned a female sex, and submitted for “phallus reduction” surgery (Ibid). Like the diagnosis of “true hermaphroditism,” which could not be ascertained prior to the twentieth century unless a post-mortem exam had been carried out, neither “incomplete masculinisation” or “masculinised female” existed as diagnostic categories prior to more far-reaching changes in medical theories of maleness and femaleness developed in the nineteenth century. These medical changes are not the result of progress in “development and discovery,” but rather the result of political and perceptual commitments.

The current diagnosis and treatment of intersexuality, or genital ambiguity, is intrinsically bound to the manner in which males and females previously came to be seen as absolutely different, and principally to the manner in which femaleness has been constructed, both socioculturally and biomedically, as object and ideal. Several medical historians have done detailed research showing that scientific ideas regarding the relationship of bodily appearance or morphology and appropriately female behaviour demanded that women, particularly white, middle-class women, have a refined temperament and be delicately featured, with fine bones and hair, small teeth, and so on. This set of ideals extended to such things as labour and childbirth, sexuality and genitalia. For example, Mary Poovey argues that childbirth was a sufficiently threatening (albeit temporary) loss of femininity that this “indelicate” behaviour, not the alleviation of pain, was the reason for the development of the use of chloroform in delivery (1987, 137-168). In another essay, Margaret Gibson argues that women’s nature and women’s physical appearance were so ideologically intertwined that:

[...]women’s increasing educational and economic power might be

represented by clitoral hypertrophy, and 'cured' by clitoridectomy or other radical treatments. Clearly, the medical preoccupation with gender roles and with the impact of female homosexuality (or even sexuality) on the family structure reflected such social fears. (1997,111)

In yet another manifestation of cultural and medical anxiety regarding female degeneracy, Sander Gilman writes of the common assertion by medical practitioners that clitoral hypertrophy could be sometimes the cause and at other times the symptom of prostitution, itself another sign of female depravity and racial inferiority (1985). In these models, race and class figure such that the shame for a doctor of the middle-class patient in childbirth was that he might witness her behaving too like an animalistic working-class woman (poor and labouring as a natural consequence of her physical/racial inferiority). Meanwhile, the trouble with clitoral hypertrophy was not only that one's patient might be a sodomite--a vague term that could denote almost anything as long as it was *unspeakable*, but also that she would too closely resemble both the Jewess and the African "Hottentot Venus"(Ibid).

These anxieties and diagnoses set a precedent for the diagnosis of "masculinised genitalia in the female," or "female pseudo-hermaphroditism," but are themselves diagnoses of perversity, of both human form and sexual behaviour, rather than of organic disease. It is these anxieties, social values and the growing power of medicine to decide the fate of human bodies and subjects in the late nineteenth century that set the pattern for the diagnosis and treatment of intersexuality.

For those who take sexuality to be a biological phenomenon of "hard-wired" brain-sex toward certain drives, heteronormative definitions of sexual identity categories

pertain primarily to the penetrative sexual activity between males and females which has the potential, and many presume the ultimate if unexpressed goal, to lead to reproduction. Paradoxically, many of the same medical theorists who presume a tautological identity between biology and sexual “preference” are the same theorists and medical practitioners who contradict these same definitions with the assertion that they can make an intersexed child into whatever they say it is (boy or girl) regardless of the child’s chromosomes, reproductive organs or of the parents’ initial perception of the child.

I am not suggesting that chromosomes or internal and/or external genital structures *do* determine one’s sexual or gender identity or behaviour, but rather that studies on intersexuals are flawed, as are other studies of sexuality and gender identity, because they fail to account for the fact that sexual identity does not necessarily cohere neatly and cleanly with sexual behaviour. In addition, gender assignment can no more be judged successful or unsuccessful according to the object-choices of adult intersexuals than it can be judged as successful or unsuccessful according to any individual’s object choice. In essence, although homosexuality has not been considered an indicator of “gender dysphoria” in mental health circles since the third edition of the Diagnostic and Statistical Manual (DSM III),¹¹ the sexual attraction of intersexuals to persons of the opposite *gender* is still used as a central measure of the evaluation of long-term outcomes for the sex and gender assignment of intersexed persons. Thus, in a discussion of whether it is better to assign a male with a micro-penis to a male or female sex, one medical professional argues that they may fail as women, but that

A study of adults with small (or micro) penis has established that sexual function is *normal* in 75%. In 12 men with a small penis from a variety of

causes it was established that all functioned as *normal* men. They had male oriented jobs, hobbies and sports, normal gender identity and *heterosexual* inclinations. Nine men were married or had a regular female partner, usually of long standing. One man had a wife and mistress. (Woodhouse, 1994, 649; emphasis added)

Though Dr. Heino Meyer-Bahlberg and his co-authors have recently proposed that gender reassignment and non-heterosexual orientation are not necessarily indicators of psychosis in patients assigned a female sex (1996, 319-332), the older attitude displayed in the following quote, in which heterosexual orientation and desire for children and marriage are still the most likely criteria for the measure of a successful outcome, still prevails in established practice:

[...]the patients described by Mulaikal *differ from normal women in their degree of heterosexual activity*, frequency of marriage and fertility. These outcomes may reflect an influence of prenatal androgens on the nervous system in a manner or degree parallel to those of androgen influence that h₂s produced a genital abnormality. The inadequate introitus may thus not be so much the cause of the *abnormal psychosexual adjustment* as a parallel reflection of the prenatal androgen exposure. Furthermore, the patients' poor compliance with corticosteroid therapy, which left their post-pubertal androgen levels high, could have been both a reflection of partial masculinization of the brain and a continuing contributor to that state. (Federman, 1987, 210; emphasis added)

The patients in the Mulaikal study are diagnosed as pathological because they are

not engaged in appropriately heterosexual behaviours oriented toward reproduction.

However, the author, Dr. Federman, seems to have difficulty deciding if these patients, whom he suggests are to blame for their progressive “masculinization” because of their “poor compliance” with their prescribed corticosteroids, have a psychosexual abnormality because they are simply poor patients, or because they actually have masculinised brains. The implications of each finding would be wildly different; the first would suggest that closer adherence to a prescribed treatment could have made these girls live more “normal” lives, and the second would suggest that it is futile to attempt to interfere in these cases, attempting to make a woman out of someone whose biology predestines a masculine set of brain functions. In the first case, the “failure” to live like “normal” women is a patient’s fault. In the second case, the medical management team would be at fault for not recognising at an earlier point that patients with CAH would be more likely to think as men because of androgen exposure to the brain.

Both of the above attitudes fail, of course, to see that deciding on which sexual activities are normal and which are abnormal is not a question that can be answered by science, but an attitude inflected with the values of a given culture. Furthermore, judging the success or failure of the procedures based on the fertility and sexual activities of patients continues to focus on the presumed *proper* functions of bodies and continues to fail to ask about the experiences of the bodies and subjects involved. In the absence of a discussion of experience, medical protocols have marched on since the post-World War II period, attempting to guarantee the normalcy of the intersexed person’s adult sexuality. Under what conditions does this happen?

Intersexed persons are assigned a single sex, and have the corresponding surgery,

long before consent to or comprehension of genital “reconstruction” is possible. In the absence of substantive long-term studies on surgical outcomes which can prove any health benefit, and with mounting anecdotal evidence of both physical and mental harm, there is every possibility that the continuance of standard cosmetic surgical procedures which serve no physical benefit, but only a presumed and projected mental health one, violates the current legal code regarding proxy consent and the surgical care of minors in Canada.

History

The treatment paradigm used to manage intersexed infants and children is historically rooted in medico-evolutionary discourses on criminality and degeneracy, and the surgeries are intended to mitigate against the physical markers of degeneracy, a life of crime, or both. The relationships among race, criminality, prostitution and sexual deviance all intersect in the development of treatment paradigms for intersexuals.

An examination of the history of events in medical research and practice shows shifts in diagnostic paradigms which made the inclusion of heretofore unpathologised intersex features possible as diagnostic categories. For example, although an enlarged clitoris now counts as “masculinisation of female genitalia,” placing it within the range of diagnoses of “ambiguous genitalia,” there was much disagreement in the nineteenth century over whether large clitorises signalled hermaphroditism or a corrupt moral character. The long arguments of nineteenth-century physicians over what was and was not a hermaphrodite were highly invested in both creating professional reputations and reducing the numbers of hermaphrodites in order to solidify the notion that, by and large, *humans* were possessed of only one sex. These two investments did not always work

particularly well together, as a physician would have a lot to gain in “discovering” a hermaphrodite, but he might also have much to gain in proving that males and females were absolute opposites with almost no possibility of ever achieving similar biology or, hence, political status.¹² Thus, the discovery and explanation of physical states other than male or female intersected with cultural changes in concepts of sex and gender systems and the explanation became entangled in means of explaining certain possibilities out of existence. Alice Dreger’s historical study, Hermaphrodites and the Medical Invention of Sex argues that the nineteenth century

[...]was not a time when most of these men were interested in seeing sexual boundaries blur[...]. Many men, following in the footsteps of the great Charles Darwin, wrote with confidence and enthusiasm about the natural and profound differences of the male and female types. (1998,26)

Dreger goes on to point out that the discovery of a hermaphrodite was a problem for medical experts because such ambiguous bodies slipped through the gaps among all the attendant political categories that went with being either male or female. Yet the desire to make a name for oneself made the temptation to publish a case of discovered hermaphroditism too great to pass up. Indeed, as I discuss in greater detail in chapter 3, although Michel Foucault credits himself with having discovered the memoirs of Alexina Barbin, Barbin's story had already been published in Ambroise Tardieu’s 1874 publication, Question Medico-Legale de l’Identité. Ultimately, medical professionals managed the political and professional conflict of interests by first discovering an “apparent” hermaphrodite and then publishing on their own expertise in determining the single, “true” sex of the hermaphrodite. In the end, they were able both to make names for

themselves and to prove the distinct separation of males and females. Their proofs rested, of course, on the development of a scientific vocabulary and field of data that would demonstrate the distinctions that scientists and lay persons alike already believed to be true. Not only would these proofs be used to separate males and females, they would also be employed in the service of proving that in the end, although a scientific expert may be needed to discern the sex and coax it out of its ambiguities, even hermaphrodites had only one true sex.

Nellie Oudshoorn reminds readers that nineteenth-century women could not have referred to hormones to explain their lives because the word, and hence the concept of hormonal control of emotions, bodies and sexual behaviour(s), simply did not exist (1994,15).¹³ Oudshoorn therefore asks us to consider how it is that the concept of hormones came to be developed in the early years of the twentieth century: “[...]cultural ideas became embodied in the concept of sex hormones and[...] scientists actively transformed these ideas once they were incorporated in research practice”(Ibid). Like Haraway’s argument about the fictionality of facts and the facticity of fictions, Oudshoorn’s project illuminates the selective process through which scientists decide which truths they will discover. The arbitrary nature of these demands for simple identification is thrown into sharp relief by Oudshoorn, who reminds us that sex hormones, which comprise a large portion of the ‘biological truth’ about sex, are far from passive records of bodily functions and characteristics: “The concept of sex hormones as agents of masculinity and femininity functioned as a paradigm, focusing previously scattered research around a generally accepted theory”(1994,20). One must *force* and *enforce* the cohesiveness of both sex/gender and research practices; the relationship

between them is not an automatic, naturally given “truth.”

Limitations of Contemporary Treatment Paradigms

Intersexed bodies, taken as those which “do not fit” into the symbolic realm of Western culture, have been literally cut, bound and sutured in order to appear, in a most violent paradox, normal if not natural. The constitution of the intersexual body by medical and social discourse raises both material and discursive questions about what, if anything, counts as “normalcy.” It simultaneously forces the (re)consideration of wider horizons of possibility in both sexual desire and any sex/gender identifications that might inhere in the rubric “queer.”¹⁴ While shock treatment for homosexuality has stopped and homosexuality has been removed as a disorder from the American Psychiatric Association’s Diagnostic and Statistical Manual, intersexed bodies continue to be carved, cut and sutured in an attempt to place them within an understandable symbolic realm. Though I have found no article that claims to *cure* intersex conditions, articles do make regular claims of being able to “fix” the outward manifestations of intersexuality. They cannot claim to be able to cure intersex with their surgical or hormonal management strategies because the underlying causes of intersex are not altered. In addition, it is not clear that the underlying causes are pathologies; they might be neutral, relatively simple and benign variations in human development. In the absence of an identifiable disease,¹⁵ this medical and surgical management continues to be performed at all the major children’s hospitals in Canada and is performed in hospitals across the United States. What are the possible long-term implications for children subjected to such forms of treatment? What cultural reasons are given for the standard of early surgical intervention to reshape the

genitals of infants and children with ambiguous or intersexed genitalia? Are these reasons now obsolete in the face of new evidence regarding outcomes?

The various axes of power intersecting the management of intersex patients include the medical and biological scientific authority that dictates what constitutes appropriately sexed genitals, the uneven distribution of knowledge between medical experts and parents, and the juridical and emotional relations between parents and their intersexed children. *Control* is an accurate description of the goals of the social and cultural systems of thought, linguistic constructions of subjects and identities, and of the actual physical interventions used to fashion both sex and gender. That this control is neither purely abstract nor metaphorical is important: it is often a physical and material imposition enforced through violent means. If the operations carried out on intersexed children were carried out on adults without their consent, they would be considered assaults and the surgeons would be subject to penalties under Canadian tort law.

Both sex, as a biological/anatomical description, and gender, as a set of cultural requirements, can be interpreted as violent impositions written onto the bodies of many separate intersexed individuals by surgeons, geneticists and endocrinologists whom patients might never see. Patients may not see these practitioners because anaesthesia keeps them out of the loop and because tissue samples that go to the geneticists do so independently of the patients. There is a greater chance of a child under long-term management getting to know his/her endocrinologists, but for those who are managed at an early age, the endocrinologist will work only in conjunction with pathologists to arrive at a definitive diagnosis. Physical violence, if we understand the surgical removal of healthy tissue from a child who cannot be consulted as merely one of the means employed in this

process of control and intervention, functions as part and parcel of medical *discourse* rather than as isolated surgical *acts*. Indeed, the (f)acts of medicine discussed in this dissertation, from diagnostic categorisation to surgical intervention, may all be interpreted as *inscriptions* onto bodies of particular forms of meaning that create as much as they discover. The material and symbolic management of intersexuality is therefore part of a larger field of cultural discourse and cultural demands.

Although many volumes have been written on intersexuality within medicine and biology, little has been written about it in humanities-based disciplines. Beyond popular media reports, there has been little consideration of long-term outcomes for patients who have been managed under the early cosmetic surgery interventions begun in the 1950s.

The general lack of theoretical writing in the humanities on the subject of intersexuality and a concomitant cultural imperative to erase intersexuality from common knowledge have had two immediate consequences of significance. The first is an overall absence of community for those diagnosed with intersex conditions. This sets intersex apart from most other clinical diagnoses, such as infertility, Alzheimer's, cancers, heart and stroke conditions, and a plethora of congenital diseases or anomalies, which often have support groups, or are part of a more common knowledge base, and sometimes have both these features. Although the above distinction holds, the medical management of intersexuality also shares particular silences that persist in mainstream support groups. For example, although much attention has been paid to the marital and sexual dynamic of heterosexual women diagnosed with breast cancer, little attention has been paid to the social and sexual issues facing unmarried and/or non-heterosexual women (Hart, 1995; Martindale, 1993).

The second important consequence of the medical standard for treatment, both for intersexuals and those trying to understand it, is that what little cultural and theoretical material there is provides a sorely incomplete account of intersexuality that risks being taken as wholly representative of intersexuality.¹⁶ At its worst, this has meant that certain collections have used intersexuality as a departure point for a utopian appropriation of the idea of intersexuality as a mascot for sex radicals. Indeed, in their introduction to The Last Sex, Arthur and Marilouise Kroker write that intersexuality is a liberatory state that will free us from the bonds of compulsory heterosexuality, but they fail to include any writings by intersexuals in the collection of essays. Sky Gilbert, in The Whore's Revenge, and Michel Foucault, in his introduction to Alexina Herculine Barbin's autobiography, both write about persons whose bodies function politically as women, yet they force a reading of these women as easy analogues for the struggles and concerns of gay men. This is not to suggest that the works are without merit, but simply that a handful of essays and one autobiography do not constitute an adequate understanding or representation of intersexuality. Who gets to say what intersexuality is and how it should be understood is 'highly contested ground. Traditionally, the very category of intersex has been identified, created, defined and delineated by medical theory and diagnostic practice, both of which have operated in a reciprocal relationship to political and cultural ideas and demands regarding sex and gender. More recently, critical and literary theorists have attempted to rethink intersex, but they too have struggled with the impossibility of seeing intersex except in relation to its medical construction. Finally, in small groups, annual retreats, films and newsletters and in online discussion forums, intersexuals have been struggling with how to define ourselves. There is always a wall of contradiction in not

wanting to accept the medical ideas of pathology that inform the construction of intersexuality as we know it, and yet simultaneously not wanting to admit to our ranks those who are gender anomalous but not officially, that is, medically, intersexed. The saying repeated online is, “If you want to be, you’re not.” This applies well to those who flippantly use intersex to further their own political mandates without having any real appreciation of what intersex is: the Kroker collection stands as a particularly glaring example of this. Yet, the online saying presents a danger because it accepts the medical enforcement of the diagnosis, determining one to be *truly* intersexed only if one meets certain biological and/or anatomical criteria not by design but by birth. Attempting to create an intersex community or identity that is able to challenge the medical dogma of sex and gender is, therefore, no simple feat, and declarations of alterity are complicit in dominant ideologies of typical maleness and femaleness, leaving those categories intact, specifically as bodies that cannot ever *become* intersexed. In this understanding of intersex, male and female remain as stable sex categories, and intersex remains an anomaly rather than a challenge.

Because the physical markers of intersex are surgically removed in early infancy and childhood whenever possible, it is a difficult task to form a political community or set of parameters for intersex identity. This is because each intersexed person is either denied information about his/her condition or is told to keep it secret. As a cultural theorist, I enjoy a special privilege and challenge concerning my subject matter. As one who was diagnosed with a form of intersex in my childhood, I have an interest in telling a particular version of the story. I am not motivated simply by academic curiosity.

Particular challenges are present in any attempt to write about the contemporary

lives of intersexuals, and those challenges limit the scope of this dissertation explicitly to examining only the lives of intersexuals who are “out.” It is difficult to approach others who may be intersexed, or to try to find others. There is a threefold dynamic at work in this difficulty: first, the intersexed person is aware that the other person may be offended to be perceived or included as an intersexual (after all, the surgery is supposed to negate that possibility); secondly, even though the other person may fit a clinical description of intersex, s/he may not be aware of it; third, having been told not to reveal their medical status to others, many intersexuals continue to feel that their conditions are not to be talked about. A final impediment to finding others is apparent in the repeated attempts by different chapters of the AIS support group, the Intersex Society of North America, the Intersex Society of Canada and the Intersex Foundation of Europe to get support groups introduced to the clinical setting. Such attempts have failed because medical practitioners cite patient confidentiality as incompatible with the development of support groups; medical practitioners are actively impeding the ability of intersexuals and our families to know each other.

While intersexuality shares some of the same features of oppression as those faced by transex, transgender, lesbian, gay and bisexual community/ies, it also has distinct features that have rendered problematic any easy alliances with these groups. Unlike the process and options involved in transgender and transsexualism, intersexuals who are operated upon and managed in infancy and early childhood have neither choice nor voice in determining either the course or outcome of their treatments.¹⁷ Additionally, while an intersexed body may confuse the boundaries of sexual orientation for those who hold a biologically grounded definition of it, there are a number of factors that distinguish

intersexuals from gay men and lesbians. For example, left surgically unrevised, an intersexed body could not operate *physically* as only heterosexual *or* homosexual. This is so because if a body is neither clearly male nor clearly female, then there is neither an opposite nor a same sex to which one could be attracted; rather, there would only be bodies that were differently sexed from one's own. This is not to say that intersexed persons don't sometimes *identify* as gay, lesbian, bisexual or transgendered: I have met over 150 intersexuals, in person, by email, by ground mail and by telephone, and all of these sexual and/or gender identifications have been variously put forth, as have the identifications of "asexual" and transsexual as well as heterosexual. I attribute the degree of overlap in the identity categories to the cultural aspect of sexuality; however, attention needs to be paid to the biological definitions of sexuality, for it is the biologicistic models that inform decisions made by specialists who diagnose and manage intersexed neonates and children.

Diagnostic practice concerning intersexuality is linked to the development of two fields in medical science: transsex surgery and endocrinology, including hormone and chromosome research. For example, the medical diagnosis of "genital ambiguity", a 'code term' expressing or denoting intersexuality, includes the presence of one or more of the following features: micropenis or clitoromegaly and hypospadias--a penile urethra which ends somewhere before the tip of the penis. This set of diagnoses is grounded within a functionalist tradition in Western medicine and culture, which presupposes (heterosexual) reproduction as the primary function of human beings.

As recently as fifty years ago, the size of infant genitals was not a primary identifier of intersexuality; this is mostly because there was no established set of surgical

procedures for the “repair” of genital ambiguity. In addition, in the nineteenth century, it was usually a combination of desires and sexual practices or political interests that would lead a subject to a physician for diagnosis in adulthood. For example, Alice Dreger points out that Alexina Barbin might have sought out medical help with the hope of being able to marry her lover by being reassigned as male. Other reasons for seeking the help of a medical professional may have included avoidance of conscription, access to property through inheritance, and a means of making a comfortable living.¹⁸

Even once gonadal sex could be established through advances in surgery and anaesthesiology, and hormones could be measured through urine and blood testing, it remained unfeasible to diagnose genital ambiguity at birth because little could be done to change the appearance of the infant’s genitals. Until after the two World Wars, which were catalysts in plastic surgery developments, and the post-war development of male-to-female transsex surgery to produce an ‘adequate’ female appearance,¹⁹ a child’s sex was assigned primarily according to the appearance of the genitals. In addition to refining their technical abilities, medical specialists had to be able to theorise a set of etiological reasons for the ‘ambiguous’ features of intersexuals and this theorisation relied, until the advent of chromosome analysis, on the *idea* of sex hormones, itself only a very recent development in the scientific conception of ‘sex’.

Many intersex ‘disorders’, having such a wide range of physical features that some persons may never be made aware that they are remarkably different from anyone else, had no diagnostic label until the advent of chromosome analysis in the late 1950s. My assertion that patients have to be forced into “awareness” stands on the grounds that these persons are remarkable only to medical science.²⁰ Indeed, in the course of my

research, I was told the following story by a clinical psychologist who was then completing an internship at the Palo Alto V.A. Hospital:

My supervisor told me about a woman some years ago who was admitted to hospital for appendicitis. The woman and her husband, coincidentally, had been trying to conceive for a number of years, without success. When the appendectomy was performed the surgeons found that the woman had combined gonads [ovotestes] and a dysgenic uterus. Although her clitoris was enlarged, no one had ever found the phallus length particularly remarkable. The surgeons closed and decided to discharge her without telling her about their findings. (personal communication, Dr. S Hart)

Because I am familiar with the etiological processes that would produce such characteristics seen in the above patient, I can accurately guess that the woman was most probably chromosomally “xx” and a “true hermaphrodite”. According to the supervisor, there was no point in telling the woman that she was intersexed; her genital features did not appear to be of concern to her and there would have been no obvious benefit to informing the patient of her gonadal status. This woman did not live her life as a person with “ambiguous genitals” and there was no reason to make her suddenly see herself that way. Yet the case was obviously an interesting example of intersexuality to the medical professionals involved, as the circumstances of the woman’s presentation and the handling of her case were circulated around the hospital as a medical curiosity. Considering the medical concerns associated with the patient’s inability to conceive, and with the risks associated with either leaving the combined gonadal tissue inside, or with removing it, it is difficult to know whether the patient should have been told about her

gonadal status.²¹ One would have to have a solid knowledge of the patient and of her needs, and would have to balance the issue of risk assessment with the patient's sense of herself as a woman. However, if the doctors handling the case were unprepared to inform the patient of their findings fully, then her case should not have been trafficked about as an interesting example of intersex. The medical team handling her case effectively decided that there were two truths about this person: first, she would not benefit from knowing about her condition; second, her condition was nonetheless important enough to be made known to an ever-expanding community of medical professionals. Surely if the doctors in charge of her case decided that the information would be of no interest to the patient, then it would have been more consistent to refrain from making her case a point of relatively public knowledge. The patient was made into an object of scientific "facts," and whatever the patient may have believed about herself, the medical experts decided the "truth" to be something quite different.

In addition to the concrete example above, we may note that many persons with an "XXY" karyotype (Klinefelter's Syndrome) or with congenital adrenal hyperplasia (CAH) or androgen insensitivity syndrome (AIS) could not have been diagnosed as intersexed prior to the late 1950s. CAH and AIS diagnoses both require a conception of hormones and their supposed *appropriate* functions in order to exist as diagnostic labels. This is because the supposed *masculinisation* seen in some females with CAH is attributed to an excess of "male" hormones in the female's body. Likewise, AIS is described as the "failure" of the chromosomally male (XY) body to respond to "male" hormones, and which "fails" to develop the secondary sex features of a male.

Because in their lesser manifestations CAH, AIS and Klinefelter's Syndrome may

result only in lessened or absent fertility--which may never be of concern to some individuals - it would be quite easy to live out one's life without ever being diagnosed. In cases of complete AIS, because the body looks typically female, a diagnosis of intersexuality depends on being able to "see", with the use of technology, the "conflict" between the chromosomes and the bodily appearance. Anthropologist William Beeman points out the intersection of cultural and scientific viewing practices which actively create the ability to see this conflict:

The difficulty in determining clear-cut specification of gender arises because there are at least three ways to define it. Two are biological and one is cultural. The first biological definition defines gender in terms of chromosomes. [...] The second biological definition assigns gender in terms of male and female genitalia. In the third "cultural" definition, males are people who look and act 'male' and females are people who look and act 'female'. Americans generally want everyone to fit the third, cultural definition, even when people have biological characteristics that are not strictly in accord with a two-gender system. (1996, F1)

Beeman's assessment of the biological grounds is somewhat myopic insofar as he takes them as self-evident and unconstructed, but he nonetheless shows the cross-section between demands for and easy means of identifying bodies, persons and behaviours along presumed "appropriate" and "natural" axes.

Structuralist anthropology, which focuses on cultural meaning production as language based, indicates that the above transitions in scientific discoveries--which could have been used to prove the existence of multiple body types and sexes and gender but

were not--are bound by the grammatical limits of he/she, him/her, boy/girl, and man/woman. Medical approaches to the construction of identity are not so much concerned with *practices* as they are with linguistic meaning. This is apparent in medical texts, which provide remarkable examples of entirely *language*-oriented descriptions of bodies. The following excerpts show a complete lack of discussion of what use the genitalia will be to the surgically altered intersex infant. Instead, surgeons merely note procedural directives and provide descriptions of criteria for visual recognition of a sex that is to be 'consistent' with the child's upbringing:

We report a unified approach to phallic reduction that is part of a unified surgical reconstruction applicable to all children with *ambiguous* genitalia who are to be reared as female subjects. [...] Reduction of the diminutive phallus to a normal *-appearing* clitoris is accomplished by making an incision[...] As much erectile tissue as necessary to create an *appropriate* size clitoris is removed via these 2 incisions. (Oesterling *et al*, 1992, 1079)

Comments such as these, combined with Patricia Donohoe's measurements for minimum phallus size (referred to elsewhere in this dissertation) indicate that for the surgeons and other intersex specialists, the visual aspect of what we have come to expect of genitalia is the most important feature in knowing whether we have a boy or a girl and these two categories continue to be the only allowable ones.

Creating and Contesting Stories

Speaking specifically about the Intersex Society of North America (ISNA), Dr. Anne Fausto-Sterling, a geneticist and recognised authority on the biology of sex,

proposes that what the ISNA really needs to do if it is to alter successfully the treatment procedures in current medical management of intersexed infants, is to create a new script for surgeons and pediatricians to use when explaining to parents and to themselves just what intersexuality is (March 15, 1996). In effect, ISNA and any other intersex patient advocacy groups should demand a new paradigm of treatment and of research. This new paradigm would draw attention to the overall health of intersexed children and would highlight the overall perfection of the child's physical appearance. The new mode of treatment should also focus on at least some of the ways that persons experience the functions of their bodies, thereby better assessing the needs of individual patients as they mature both physically and emotionally.

Western culture, of which medicine is a part, is at a crossroads in knowledge production and a number of factors are influencing the direction that could be taken in terms of which knowledge will be valued. The battle is informed by economic and political tides, by funding allocations within medical schools, and by larger scale formations of "common sense" logic within the public realm. All of these combine to produce what Nelly Oudshoorn refers to as "prescientific" concepts (1994). Prescientific concepts are ideas which shape the directions taken in scientific research and practice which Oudshoorn reminds us "[...]always starts from worlds already on hand"(15). For example, culture holds that the sexes are different and dichotomous; science then goes about researching how and why this is so. Scientific research has always taken the idea of an inherent sexual difference as an *a priori* truth and then acted upon that assumption, providing multitudinous studies on the vocational, intellectual and biological differences of males and females, pointedly neglecting studies on similarities between the sexes. As

Anthony Synnott points out in his work The Body Social, the single “x” or “y” chromosome on the 23rd pair is only 1 out of 46 chromosomes and is the only chromosomal difference between males and females, comprising only a 2.17 % difference; in other words, males and females are 98% identical which is nothing at all like being radically different or opposite (1993, 38). Yet it is the commitment to the “opposite nature” of the sexes that informs the biomedical definition of males and females.

Every day in medical science, researchers are engaged in inquiry intended to “refine” diagnostic and treatment procedures; it is the stuff of which medicine is derived and continually recreated. Sometimes technical refinement leads to advantageous end-results, as has been the case with the reduction in maternal and neonatal mortality rates due largely to antiseptic practices on the part of nurses, midwives and physicians.²² More often what happens is, literally, a *production* of knowledge--the effects of which are ambiguous at best.

Decisions regarding research proposals are not objectively based. Harold Brown indicates that the lack of objectivity in research pursuits is papered over in assertions regarding the logic of science, a logic that maintains a sharp line between discovery and research testing methods (1977, 130). Brown goes on to point out that his critical apparatus of dialectical logic “[...]does not deal with relations between isolated or with relatively isolated propositions, but with the role of propositions and questions in so far as they are parts of structured systems of presuppositions and problems” (Ibid). In this sense, Brown is prefiguring Oudshoorn’s notion of the “prescientific” cultural ideas which inform which roads will be taken in scientific research and which ones will be shut down. What Brown does not do is to go very far in indicating some of the effects that

persons experience as a direct result of this sort of scientific methodology.

In Thinking Critically About Research in Sex and Gender, Paula Caplan states that

The first step in *any* scientific study is to decide what you want to find out. Scientists don't randomly choose what they study. Scientists are human and they tend to study what interests them. Often, this means that they have strong needs to prove that something is true or false, and those needs can affect the way they ask the research question: for instance, they might study[...] "Why are women so weak?" rather than "Under what circumstances can people become as strong as possible?"(1994,20)

Caplan is pointing out that because scientists most often approach research on sex and gender from a position which assumes *difference* rather than *similarity* between the sexes, the results of their studies tend to prove the presupposed, prescientific notions of difference which they brought to the study. As a result of the binary structure of difference, combined with phallogocentric hierarchisation privileging the male/masculine in terms of ability over the female/feminine inability, this difference is not a value-neutral, apolitical difference: it is a difference which continues to position the female as an impoverished and impoverishing category.

It is improbable that scientists engage in such studies purposely to oppress women, and it is also unlikely that they carry out their research in full awareness of their biases, deliberately and malevolently insisting that the biases are really only those of the critics of science. Indeed, though some scientists may engage in this sort of behaviour and it does appear that scientific discourse has a built-in escape route which allows a devaluation of critiques of science as "anti-intellectual," there is little grounding to assert

that science is *deliberately* oppressive. However, intention and effects are quite different matters, and though it would be foolish to chase after the intentions of scientific researchers, we can measure and critique their effects and their methods. The goal is not to undermine science, but to encourage it to look differently at the subject matter being investigated and to view critically the conditions under which that investigation takes place. We need a sense of the political and cultural interests that preform the scientific context.

Telling New Stories

A memo released in January of 1983 by the College of Physicians and Surgeons of Ontario to its members sets a reasonably clear ethical mandate for physicians obtaining consent for medical procedures. While the statement is written as a reminder to physicians that their patients have rights to accurate information regarding a procedure and its risks, and rights either to refuse or consent to treatment based on that knowledge, it also instructs doctors on how to avoid law suits on the issue of “informed consent.” The statement conflicts with more recent textbook material advising physicians not to disclose fully an intersexed child's condition or the proposed remedy to the condition. Moreover, the Canadian Medical Association (CMA) recently awarded a prestigious national essay prize to a medical student who proposed that telling a patient the truth about her diagnosis of androgen insensitivity syndrome would not be useful and should be avoided (Natarajan, 1996,568-70). Natarajan’s proposal directly contradicts both the decision of Canada’s Supreme Court in the *Reibl v Hughes* case, and CMA’s ethical guidelines for informed consent. Such examples of medical school teaching and learning

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practice demonstrate that whatever the guidelines may state, and whatever the courts may determine, physicians still perceive themselves to be the final arbiters of who is allowed to have access to what knowledge, and also to judge what knowledge is useful to patients-though they obviously find the knowledge quite fascinating currency within their own professional group.

Because intersexuality is usually treated in infancy and early childhood, any discussion of patient rights is transposed to the rights of parents or guardians. This is because very young children are not generally considered 'capable' of making reasonable decisions regarding personal welfare and/or medical treatment.²³ However, because intersexuality is, if a disorder at all, primarily a cosmetic concern; my proposed resolution to the issue of consent is to delay treatment until the child is clearly capable of making a reasonable decision regarding treatment. In the meantime family members changing baby diapers will have to learn to refrain from exclaiming "My God!" (Dr. John Gearhart, qtd in Hendricks, 1993, 11). The concern is, in most cases, really an aesthetic one and, presumably, sensitive parents and families would not slice off the noses of infants with "unsightly" ones, so why do they so hastily transform the genitals of children deemed "intersexual"?

I believe that, in part, the parents submit their children for surgical revision because intersexuality is cast by the medical profession as a medical disorder, that is to say, as an illness. In this respect, parents of intersexed children are misled. Except in the case of salt-losing syndrome associated with one form of intersexuality, intersexuality is not an illness. Even in the salt-losing form of CAH, the anatomical appearance of the body is not the illness *per se*, but rather, an associated feature. However, instead of

casting the features of intersexuality as 'atypical', the medical profession casts them as a medical condition in which the genitals are malformed or deformed.

The point is to show that this is a medical problem. It's not a horrible curse. We try to demystify the notion of sex differentiation. A hole in the heart is easy to understand. It is an anatomic, structural problem. But a defect of the genitalia touches on so many sensitive issues. (Ibid)

The reason that intersexuality does not have to be thought of as a horrible curse, according to physicians, is that "[...] a child need not grow up with the genitalia he or she was born with" (Ibid). The physicians and surgeons involved in the assessment and treatment of intersexuality make it clear to the parents that their children are "afflicted" with a condition that the medical profession can "cure". This medical "explanation" does not provide parents with an opportunity to view their children as healthy or non-diseased, hence the option of not treating the condition is disallowed from the outset. The explanation also assumes that the child must be either he or she but not both and/or neither. If the medical approach is to work, specialists must restabilise parents' expectation/belief in the face of anatomical, genetic and chromosomal evidence to the contrary, that the sexes are mutually exclusive and that the proper treatment will demonstrate the true and distinct sex of their child.

The question I am posing is whether or not this way of explaining intersexuality constitutes a failure to provide all the necessary information required to obtain consent that is truly *informed*. My second question may be even more controversial as it centres on the issue of minors and their ability to provide or withhold consent. Where minors are concerned, consent to and refusal of medical treatment are difficult issues to resolve. One

of the complicating factors is that determining and defining the intellectual capacity of the minor involved is presumed to be a more difficult task than is determining the intellectual capacity of adults. Yet, the law does recognise the possibility that minors have the potential to provide or withhold consent.

As a general proposition, the common law provides that any person, regardless of age, has the legal authority to give consent to medical treatment if he or she has the mental capacity to do so. [...]The rules for children's informed consent are the same as those for adults. That is, children are entitled to receive the same information about a medical treatment decision and to have their questions answered as would adults. The information must be explained in terms which are understandable to the child. (Sharpe, 1992-93,197-207)

Disagreement and confusion arise over how to assess what terms are indeed *understandable* to a minor, and there is a common attitude that children, as children, are inherently less capable of making decisions that logically correspond to the information they receive about their medical conditions and proposed treatments.²⁴ When the health of the child is seriously at risk, or the life of the child is in danger, or the child is incapable of giving consent because s/he is not conscious, the issue of mental capacity is less problematic. This is because although a child might, for instance, not like the idea of having a major organ transplant and may be afraid of the procedure, the physicians, in order to prove mental incapacity, would merely have to demonstrate that the child does not fully understand the implications of refusing treatment: i.e., death.²⁵ However, with regards to treatment that is done for cosmetic purposes, there is no medical reason that

the procedure(s) could not be postponed until a child was quite certainly capable of deciding whether or not s/he desired treatment. There are no guarantees that intersexed children who do opt in favour of surgical revision would be doing so without coercion toward conformity. This risk could be mitigated, however, if intersexed children were raised in family atmospheres that did not produce and express shame regarding the child's physical body or sexuality. The successful outcome of these suggestions relies heavily on having doctors discontinue their portrayal/characterisation of intersexuality as something that will traumatise anyone who comes in contact with the intersexed person in any way relating to sex or sexuality.

Unfortunately for intersexed children, they are usually managed surgically before reaching a level of linguistic competence that would permit them to indicate the capacity to understand their state(s) or proposed remedy. The justification for treating intersexed infants early is that they can be assigned to a single gender early in their upbringing, avoiding a switch of gender and/or sex later: "Whilst he or she — whichever is to be decided — is still a baby no difficult emotional situation exists for the child"(Dewhurst, 1980(1969), 52). My personal correspondences, however, with ISNA founder Cheryl Chase indicate that none of the early surgeries performed on those she is contact with were able to guarantee an absence of related psychological trauma in later life. This is partly because some individuals required repeated surgeries in order to be brought into line with the assigned sex and partly because it is knowledge of the surgery that produces the trauma:

We have found that genital surgery performed on infants and children who are too young to understand the implications for their sexual future can be

emotionally traumatic. The hidden message is that the child's genitals, although not causing him any physical discomfort, made adults so uncomfortable that they had to be surgically "fixed" before he was old enough to have any say in the matter. (ISNA, 1994, pamphlet: "A Parents' Guide to Hypospadias Surgery")

This leads back to a legal issue, because if the surgery and strict gender assignment practices are not in fact capable of guaranteeing that the child will be unscathed, then why is the treatment carried out? Christopher Dewhurst's text is illuminating on this point: "The parents are deeply involved emotionally, and for a time at least, must suffer such anguish of mind as can scarcely be imagined" (1969, 52). Therefore, it appears that the surgical enforcement of a single sex and gender assignment is carried out not for the sake of the patient, but for the parents — and by extension, for society in general. As noted above, the Hopkins surgeons put it this way:

A child needs to be assigned a sex as early as possible, and external ambiguities need to be corrected early, preferably in the first few weeks of life[...]. 'Otherwise, every time the mom, dad or auntie changes the diaper, everybody gets upset. "' (Dr. Gearhart, in Hendricks, 1993, 11)

Strictly speaking, because the surgery is performed on babies so young that their right to consent is cast as irrelevant and because their condition is understood as a health issue instead of a cosmetic one, the medical procedures are not legally considered as battery. This approach brackets the issue of whether the information required to obtain fully informed consent is ever given to the parents. In fact, current teaching and practice suggest that parents not be made fully aware of the child's condition:

What is to be said to the parents of a newborn of ambiguous sex? The wisest course is something like this: “Your child has been born with an abnormality of the external genitals which make it impossible for us to be sure at this stage whether the child is a boy or a girl. We are quite sure your child will prove to be one or the other and not something in between.”(This is not strictly true, but it should be said to relieve fear). [...]In my view it is more satisfactory to give confident advice to the parents even though this means misleading them to some extent.

(Dewhurst, 1980, 28-29)

Possibly because he is a “founding father” in pediatric gynecological medicine, Dewhurst’s text still circulates widely in medical libraries, and is consistent with the generally accepted medical notion that “[...] the genitalia aren’t finished[...] Nature hasn’t finished the job” (Dr. Berkowitz, in Hendricks, 1993, 10). Berkowitz’s statement suggests that the doctors *can* finish the job, another point that “is not strictly true”(see Dewhurst, above). To equivocate when advising patients or their proxy representatives conflicts with the current laws governing informed consent and with the Ontario College of Physicians and Surgeons’ statement, yet these are the paradigms students are learning from the texts used in local medical schools. The failure of doctors and surgeons to provide accurate information severely limits parental ability to provide informed consent, but further ethical questions arise when we consider how we perceive and treat intersexed infants and children.

Ethical questions concerned with the treatment of intersexed children are not strictly limited to the medical modes of treatment or means of obtaining consent. There

are also larger questions pertaining to societal assumptions about 'appropriate' structures of family. Regardless of whether or not it can be proved that 'informed consent' was properly obtained from a parent or guardian, it remains important to question the commonly held assumption that parents/guardians are actually entitled to speak for their children. Implicit in the doctor's acceptance of, and the parent's granting of, a consenting signature is the unquestioned notion that a parent (or parents) has the right to make decisions about the child, the child's future, the child's body and bodily functions. The issue of consent for medical treatment blurs distinctions between guardianship and ownership. I am pushing the hypothetical question: "If I had an intersexed child, would it be my right to sign over that body for surgical revision?" There is no going back; once a child has had his/her genitals altered s/he can never have them returned to their original state--this is because the surgeries all involve the removal of tissue and once it is gone, it is gone *forever*.

The following exchange indicates that even in the face of evidence that challenges their research and assumptions, surgeons are resistant to changing their attitudes regarding the management of intersexed children.

From: Cheryl Chase

To: intersex-l

Subject: ISNA in Journal of Urology!!!

This letter has just been accepted for publication in the Journal of Urology, a prestigious journal founded by Lawson Wilkins and published at Johns Hopkins, with minor changes in punctuation and clarification of antecedents. The authors made no reply to this letter when it was directed to them personally, and indeed later characterized ISNA as "zealots" to NY Times author Angier. They have, however, provided a reply (enclosed) to be published along with our letter. 30 January 1996

Dr. Jay Y. Gillenwater, Editor

1120 North Charles Street

Baltimore MD 21201-5559

Tel 410-223-4312

RE: MEASUREMENT OF PUDENDAL EVOKED POTENTIALS DURING
FEMINISING GENITOPLASTY: TECHNIQUE AND APPLICATIONS

J. Gearhart, A. Burnett and J. Owen

J. Urol., 153:486-487, 1995

To the Editor,

The authors suggest that—in the absence of long term follow-up—measurement of pudendal evoked potential may confirm preservation of sexual sensation during feminizing genitoplasty on infants with ambiguous genitalia. I caution physicians in using surgery on infant clitorides, because discussions with members of the peer support group Intersex Society of North America indicate that genital surgery can damage genital sensation, and that measurements of evoked potential may have little bearing on the prospect for adult sexual, orgasmic function after clitoral surgery.

Among ISNA members is a woman who underwent complete clitorrectomy as an infant in 1958, before modified clitoral surgery came into fashion. She has no clitoral sensation, and is inorgasmic. She had an electrodiagnostic procedure performed as an adult (enclosed), which demonstrated normal pudendal latencies, similar to the results presented by these authors. In this case at least, normal latency is entirely compatible with complete absence of sensation and orgasmic experience.

Another ISNA member's experience gives rise to further doubt about the meaningfulness of evoked potential. Her 1975 surgery was performed at age 7 by Gearhart colleague Robert Jeffs, a co-author of the surgical technique article referenced by the authors. I Surgical notes (enclosed) indicate that Jeffs used a similar surgical technique on her. Her clitoris is not anesthetic, and she is occasionally orgasmic, so it is doubtful that her pudendal nerve was transected. However, her experience of orgasm is so difficult to reach,

and so rarely attained, that she considers herself to have been clitorctomized, and her sexual function destroyed. Further, there are additional sorts of morbidity which evoked potential measurements cannot eliminate. For instance, another ISNA member, with partial androgen insensitivity, underwent gonadectomy and some sort of clitoral surgery at age 14, in the mid-60's. Because her records are missing from hospital files, it is difficult to know what surgical technique was used. However, based on her report that orgasmic capacity was destroyed for six months, and then returned, I suspect that the surgeon removed a length of clitoral shaft and grafted the glans back onto the stump: after six months, neurological healing allowed her orgasmic function to return. Unfortunately, twenty years later she began to experience intense genital pain, with onset about 24 hours after sexual stimulation. Light touch is painful but bearable, but continued stimulation or orgasm leads to such intense pain on the following day that she avoids sexual activity including masturbation. While her body is somewhat virilized, her testes have been removed, so there is no ongoing virilization, and post-surgical clitoral enlargement is not likely to be a factor.

Respectfully,

Cheryl Chase

Executive Director

Intersex Society of North America

1. Oesterling, J. E., Gearhart, J. P. and Jeffs, R. D.: A unified approach to early reconstructive surgery of the child with ambiguous genitalia. *J. Urol.*, 138: 1079-1082, 1987.

REPLY BY AUTHORS:

Some important points are made in this letter and questions are raised. In our article we clearly stated in the last paragraph that, while this proves that nerve conduction and sensation are retained in these patients, it does not guarantee normal adult sexual function. The aforementioned letter described the experiences of several women born with ambiguous genitalia who underwent surgery between 1958 and 1975. There have been many changes in the surgical approach since 1975. Since the experiences of only 3 women

were described the data are limited. Even with perfection in repair, it must be realized that many anatomical, social and emotional factors are involved in sexual function and orgasmic intercourse. In fact, some women who have never had surgery are anorgasmic. These points and the questions that the Intersex Society of North America raise clearly emphasize the need for careful follow up of a large group of women born with ambiguous genitalia to refine further the surgical techniques in caring for this interesting group of patients.

What the respondents, Robert Jeffs, M.D. and John Gearhart, M.D., fail or refuse to recognise is that their interventions are most likely relevant factors in the sexual functioning of intersexuals who have been subjected to feminising surgeries. The fact that many women are inorgasmic is hardly established as much more than a cultural stereotype regarding female sexuality in general and even if it were unquestionably true, it would still bear little relevance to intersexuals as justification for the treatment they receive. The logic employed by the doctors is similar to telling an abused child that s/he has no right to feel sad or angry because elsewhere in the world children die in wars. Furthermore, as I discuss in my following chapters, what little long-term follow-up the medical community has done on outcomes for girls with clitoral reductions shows that significant damage is done both to their sexual self-image and to their orgasmic potential.

What neither letter in the above exchange begins to consider is the fact that function is not necessarily the only pertinent issue. One of my own questions to each of the authors above would be, "Even if you could guarantee perfect function in feminised patients, how would that make the surgical interventions justifiable?" The point is not only that physical functioning may be impaired, but that all cosmetic surgeries of this kind risk interfering with the self-perception and mental health of the intersexed child. It

is the process of diagnosis and surgical management that creates the anxiety and trauma in all the cases I have come into contact with thus far.

Producing New Knowledge

As I write this section of the dissertation it seems important to note that medical professionals and intersexuals do not have to continue to speak past one another. Since beginning my work on intersex in 1993, I have attended and participated in several medical and bioethics conferences. In all of these settings, there have been geneticists present on the speaking panels, and the audiences have included pediatric surgeons, psychologists and nurses in addition to the expected population of ethicists. In addition, some of the Intersex society's strongest supporters are medical specialists. Dr. Suzanne Kessler, whose book Lessons from the Intersexed was published in 1998, is a clinical psychologist. Dr. William Byne, who sits on the board of Directors of the Intersex Society, is a psychiatrist. Dr. Anne Fausto-Sterling, who has written extensively on biomedical research and gender, and who has a book on intersex forthcoming, is a geneticist. Dr. Milton Diamond, who has just called for a moratorium on intersex surgery, is a psychologist. Dr. Gary Warne published two articles in 1998, calling for physicians and surgeons to listen seriously to the concerns of adult intersexuals who feel that they have been badly cared for by the medical establishment, (1998a, 79-85; 1998b, 3-9). In addition, the response ISNA has received as a group and that my work has received individually by the Gay and Lesbian Medical Association (GLMA) and by the Gay and Lesbian Caucus of the American Psychological Association, has been overwhelmingly positive. "The" medical establishment is by no means unanimous about the efficacy and

value of genital surgery and secrecy for intersex patients.

It is not surprising that many supporters of the present intersex movement, or of those doing critical research on the subject, are in mental health specialties, or come from feminist and/or queer theory backgrounds. The GLMA audience was extremely quick to see that a general, historical homophobia in medical teaching and practice links the management of intersex to a general desire to produce “sexually normal” (i.e. *heterosexual*) adults. Intersexuals who have had their genitals reshaped to conform to a “normal” appearance do not trouble the medical establishment as much as unrevised intersexed genitals do because they remain classifiable, either as successful outcomes or gender-variant outcomes. Conversely, a body type that has no “opposite” is impossible to classify, and this is very unsettling to contemporary medical practitioners and families.

If, as Nelly Oudshoorn’s work demonstrates, scientific discoveries are culturally motivated, and if, as I have argued, the practices of medicine are grounded in prescientific ideas, then it seems that one must first be willing to see what comes eventually to be counted as “knowledge.” It seems, at least in the clinical “management” of intersexuals, that a willingness to see differently is entering the discussion in medical forums around North America. This is due in part to the formation of support groups, and to the willingness of prominent researchers to question the status quo.

This dissertation walks a thin line between listening to the voices of intersexuals and resisting an uncritical valorisation of those voices. Listening seriously and paying proper attention does not mean that one listens passively or naïvely. Furthermore, any voice demanding full respect must be prepared to withstand critical engagement.

I am proposing that the now vibrant and vocal group of intersexed persons, linked

together by internet communications, annual gatherings and joint-project web sites, constitutes enough of a loose community to warrant a preliminary “virtually situated” ethnographic study. By “virtually situated” I mean to suggest that it is impossible to conceive of an intersex “culture” without recognising its virtual context. Intersex community/culture—the exchange of ideas, the formation of identities and language—is being constituted via online venues such as websites and electronic mailing lists. Meetings that take place in person are infrequent and usually attended by only a small number of people, whereas the “virtual community” is a continuously attended forum. Because intersexuals are still largely isolated from each other, and geographically spread apart, it is difficult to claim that they form a community *per se*; however, there is enough cohesiveness in these virtual communities to begin to theorise their benefits and limits.

As an “inside” informant, I find the chance to place intersexuality within the realm of a new critical field thrilling, but also paralysing. As much as I want to make intersexuality understood from the point of view of intersexuals themselves, at the same time I am loathe to pry open their/our lives, allowing yet more voyeuristic, academic curiosity to access intersexuals’ already over-accessed bodies.

The contradictions between the highly public circulation of case histories within medical publishing and conferencing, and the “hush-hush” attitudes encouraged or imposed on families by the medical professional(s) treating their intersexed children, have meant that some of the people I have come into contact with in the intersex movement report having found out about their own cases when they discovered their own photographs in medical journals or textbooks. Writing about intersex without contributing to its commodification is in some ways an impossible task. I hope that readers will

approach my work generously, knowing that my motivation is to resist commodification as much as is possible given the limits of academic research and knowledge production.

¹ Fausto-Sterling, Myths of Gender 2nd Edition, 3-60. Fausto-Sterling's work focuses on the ways in which environmental and cultural factors interact with the development and significance of organism within a cultural lexicon.

² In other words, the phallus is not the only example of the proliferation of symbolic meaning beyond the actual function of a particular organ -- in this case, one that urinates, becomes erect, grows flaccid, and serves as a conduit for seminal fluid, perhaps also serving as a source of pleasure. Brains, breasts, tongues, eyes, ears, brow-lines, hairlines, and so on are all imbued with symbolic meaning beyond the actual space they take up or functions they serve.

³ O'Neill uses the term "overstuffed" where he sees that a category bears symbolic meaning in excess of its physical limits.

⁴ I think here of the linguistic relationship of "fact," "feat," and the French "un fait accompli".

⁵ I return to this argument in chapter two when explicitly comparing medical reporting and the X-Files.

⁶ I do not mean to suggest that the Greeks did not witness something that looked precisely like this type of change. There is, in fact, a condition of "male pseudo-hermaphroditism" in which chromosomally male children with internal (undescended testes) are born looking much more typically female than male. However, at puberty, when testosterone production rises dramatically, these children take on secondary male sex characteristics such as the development of pubic and axillary hair, and rapid growth of the phallus. The condition, now known as 5-alpha reductase deficiency, is explained in my Glossary.

⁷ A detailed account of types of intersex diagnosis is provided in the dissertation glossary.

⁸ In fact, I once had a conversation with a biology teacher who said to me, "But don't you think that a heart *wants* to beat, and that a uterus *wants* to gestate, and that stomachs *want* to be fed, while bowels *want* to void?" [my emphasis] I answered that I saw no logical reason to attribute desires to organs. Yet the dominant conceptual paradigm in medical science that views bodies as machines with functions to perform has certainly led to pronouncements that, for example, women who choose not to have children are over-riding the intended functions of their bodies, and that they jeopardise their health by doing so. This leaves unanswered whose intention gestation, birth and mothering are if not the woman's, and takes the part for the whole, reducing a woman to the sum of her reproductive organs. The fact that the organs are described in our language as the reproductive tract gives an indication of the social bias toward seeing genitals as primarily geared towards the production of offspring. This bias is central to the treatment of intersex because of the continuing adherence to the notion that reproduction should be preserved above all else, particularly in female sex assignments.

⁹ The larger debates around education and voting rights for women depended upon interpreting the sexes as radically different with one suited solely for reproduction and the other suited for public life. Hermaphrodites, if allowed to continue to *choose* their sex, would have threatened the dawning discourse concerning the stability of the distinct separation of male and female. For further work on this relationship see: Oudshoorn, 1997; Fausto-Sterling, 1992; Dreger, 1998.

¹⁰ "Sodomite" and "sodomy" as shown in Vern Bullough's 1972 collection Sex, Society and History, were not specific terms at all, but rather terms that could apply to anyone at any time as long as what was being practised was not reproductive sex. Thus, my use of the term here should not be taken solely to signify a particular set of penetrative or receptive practices, although it *might* actually refer to such practices in some cases. I am simply indicating that the juridical model had no way of interpreting hermaphrodite eroticism as primarily reproductive, assuming as they did that hermaphrodites would not be able to reproduce.

¹¹ The current edition is the DSM IV.

¹² For a longer and more detailed account of professional reputation making, see Alice Dreger's 1998 study, Hermaphrodites and the Medical Invention of Sex.

¹³ I continue this discussion of hormones and research commitments later in the present chapter with a further elaboration of Oudshoorn's work.

¹⁴ As my introduction states, "queer" is meant here to signal the inability for an intersexed body to be classified as either appropriately heterosexual or deviantly homosexual.

¹⁵ That intersexuality is a disease, or set of diseases, is not entirely clear. Although certain pathologies, such as cancer and metabolic malfunction, can arise they are not necessarily linked to intersexed genital

features. For example, a genetic male with congenital adrenal hyperplasia can have salt-wasting even though he will not have remarkable genitals, and to claim that increased cancer risk in testicular tissue proves that androgen insensitivity is a pathology is like saying that increased breast cancer risks for women prove that breasts are pathological tissue.

¹⁶ See for example the work of: Kaplan and Rogers, 1990; Garber, Epstein and Krauss; Herdt, 1994a, 1994b, 1987; Kessler, 1998, 1990; Fausto-Sterling, 1993; Dreger, 1998; Hausmann, 1995; Laqueur, 1992; Barbin, 1979; Gilbert, 1990.

¹⁷ Even if one believes that transex and transgender are conditions that one has no choice about, one still has choice about which treatments to follow or employ in pursuit of one's most appropriate body. It is this set of choices that I am referring to here. I am not suggesting that transex and transgender are themselves choices.

¹⁸ Dreger cites the example of Gottlieb Gottlich (b. 1798) who travelled across Europe and England. Working as a living example of hermaphroditism in medical schools, Gottlich refused surgery because it would remove from him the ability to make a profitable living (1998, 53).

¹⁹ I will return to the inadequacy of the criteria for deciding that the constructed female genitals are adequate by asking the question through the lens of postoperative intersexuals.

²⁰ It is still quite common for intersexuality to be noted only upon autopsy when internal testes in a phenotypic female result in karyotype analysis revealing an "XY" chromosome structure in the corpse.

²¹ There are increased risks of cancer if testicular tissue, combined or undifferentiated gonadal tissue remains inside the body. A patient would have to be made aware of this if appropriate follow-up measures were to be taken. If the gonadal structures were removed, there would be an increased risk for osteoporosis and the patient would have to be placed on hormone replacement therapy (HRT) for the rest of her life, itself a treatment procedure with its own attendant risks, such as stroke and heart-attack, as well as other possible cancers.

²² There are also in-utero diagnostic procedures (amniocentesis, ultrasound, chorionic villi sampling etc.) which may be advantageous to the same end but these are much more controversial as they can relate to sex-selection and questions of eugenics. It is not the mandate of this chapter to examine these questions but they are worth noting here.

²³ The children may make reasoned decisions, but their form of reason is likely to be judged immature and insufficient unless it matches up with decisions that the courts have deemed reasonable.

²⁴ Minors must be proved competent if they are to consent and not be subject to proxy decisions made on their behalf, while adults must be proved incompetent if they are to be subject to proxy guardianship and legal decision making. The law holds that all persons have the potential to make informed decisions, yet the proofs required in the cases of adults and minors presume from the outset that one group is overwhelmingly incompetent, while the other is overwhelmingly capable. As few children have the resources to demonstrate their cognitive abilities in a legal setting, there is unequal access to the official protections offered by the law as it pertains to the issue of consent.

²⁵ I find that even the assumption that a child refusing organ transplant or chemotherapy, for example, does not grasp the permanence of death is not logically consistent with the general acceptance that adults do have the right to refuse treatment, even if that refusal means that their illness will irreversibly progress toward death.

CHAPTER TWO

Representations and Misrepresentations

Fictions and Narrations

This chapter examines some of the ways in which intersexed bodies have been described and produced within ostensibly fact-based scientific research, in autobiographical accounts, and in fiction. My intention in this chapter is to blur the boundaries separating fiction from science. To do this, I examine erotic literature, science fiction, medical news reporting and autobiography.

The sex/gender system is enforced in Western culture in part through the use of surgical measures, which we can see extended in the various “cosmetic” procedures upholding the ideals we map on to typical bodies as much as on to anomalous ones. Thus, for example, future work in the surgical construction of sex might look at the connections between breast surgeries, liposuction, face-lifts, hair transplants, chin implants, etcetera, that typical males and females undergo, and the clitoroplasties, vaginoplasties, hypospadias surgeries, phalloplasties and gonad removals carried out on intersexed infants and children. For what all of these procedures indicate is that the supposedly clear biological distinctions between male and female are constantly blurred, not only in the appearance of intersexed bodies, but in “weak” chins and baldness in males, and in facial hair and “flat-chestedness” in females, to take only some of the most prominent examples of typical anxiety-causing bodily conditions. Yet, as a culture, Euro-Americans continue to maintain an agreed-upon fiction, treating it as a truth, that there are but two clearly

marked, distinct sexes. As Kenneth Kipnis, a psychologist who works with intersexed children and their families has observed:

The conceptual distinction between male and female persons (men/women, boys/girls, ladies/gentlemen, etcetera) is standard cognitive equipment in culture, deeply implicated in self-identification and social ideology.

Particularly in the West, it is taken for granted that humanity comes in two mutually exclusive sexes, and that these are readily distinguishable at birth by the presence or absence of a penis, which in turn, signals a vast array of other permanent physiological and behavioural variations, both present and in the developmental future. (1999, 182)

The ideology that demands interference with the intersexed body is no different from the ideology that coerces interference to maintain the illusion of the mutual exclusivity of typical male and female bodies. As Julia Epstein and Kristina Straub point out in their introduction to Body Guards:

Sex/gender systems as we understand them are historically and culturally specific arrogations of the human body for ideological purposes. In sex/gender systems, physiology, anatomy, and body codes (clothing, cosmetics, behaviours, miens, affective and sexual object choices) are taken over by institutions that use bodily difference to coerce gender identity. (1991,3)

Gender identities are coerced because they serve political goals as a primary means of organising both the expected meaning and function of bodies within a given culture.

Unlike “sexy” theory proposing that the coercion can be ended through a valorisation of ambiguity, I am not about to embark on a project proclaiming that all bodily differences should be celebrated for their transgressive potential. Such an attitude can easily operate as little more than a fetishisation of ambiguity that risks losing a sense of the political realities that inhere in sex/gender systems, and turns people against each other. This potential is borne out in Kate Bornstein’s popular writing on gender ambiguity, which Patricia Elliot and Katrina Roen critique for assuming that “gender conformists,” those whose lives and appearance are unremarkable,

[...]necessarily support dominant assumptions about the origins or stability of gender or that [gender outlaws] necessarily contest them. The opposition that Bornstein constructs for the purpose of privileging the outlaws denies the complexity and fluidity of identity she hopes to affirm and denies the possibility of a sexual politics that might find support in either group. (1998,239)

Valorisation of ambiguity risks erasing both the privileges and disadvantages that accrue within the sex/gender system. An analysis of the coercion of sex/gender identity should maintain a sense of where power resides. In the case of intersex, power resides along an axis of a masculinist scientific discourse which privileges the phallic presence of the penis over all else, making intersexuals and females into equivalently defective bodies. Because females and intersexuals are perceived as equally deficient, and therefore more similar to each other than intersexed bodies are to male ones, intersexed children are almost always assigned a female sex and *as females* continue to live out their lives in a

pathologised and impoverished sex/gender.

As one category among many, bodies are vehicles of cultural meaning; they both signify and are subject to the ideological narratives of any given culture. As such, bodies are not neutral biological facts that can be perceived in and of themselves as entities separate from a culture, its values and expectations. This is not only true of the role of bodies in fine arts such as dance, film, painting, photography, literature and so on, but also of their role within the biomedical sciences. Disciplines such as biology, chemistry, anatomy, psychiatry and psychology all produce narratives to describe the appropriate places, roles and appearances for bodies to maintain and represent. Thus, these fields are as involved in discourses that produce and maintain gender roles and sexual identity as any other field of representation (such as film, literature, theatre, fashion) is. The ability of the biomedical sciences to produce certain types of bodies by maintaining some as diseased and others as ideal is a political field as much as a scientific one, and as such is highly regulatory or disciplinary. As Michel Foucault argues in Discipline and Punish,

[...]the body is also directly involved in a political field; power relations have an immediate hold upon it; they invest it, mark it, train it, torture it, force it to carry out tasks, to perform ceremonies, to emit signs. (1995,25)

Foucault's own theoretical blind spot, for which he has been criticised by feminists such as Nancy Hartsock, is his inability to understand how the body signifies differently according to gender. In particular, the cultural subjectivity and disempowerment of women is not paid adequate critical attention in Foucault's work on bodies and their meanings. It is not that Foucault's *theory* is inadequate for the job of

gender analysis, but that his emphasis on a non-gendered, abstract, judicial system of domination and power has “[...]room only for abstract individuals, not women, men or workers” (Hartsock, 1990, 169). Later in this chapter, I demonstrate how this abstraction results in a distortion of gender-specific constitutions of desire and sexuality in Foucault’s reading/interpretation of Alexina Herculine Barbin’s autobiography. For now, it is simply necessary to note that the disciplinary production of sex effected through medical management is not unidirectional. Rather, if medicine effects sex, and hence normative gender as well, then it does so at the behest of a culture that demands to see the mutual exclusivity of male and female, masculine and feminine, borne out. Thus, Robert Crouch argues that “[...]the reaction to the intersexed child reveals less about *intersexuality* than it does about a social and medical *discomfort with intersexuality*,” (1999, 34 [emphasis in original]). Furthermore, as Suzanne Kessler has argued, physicians produce gender because society demands that they do so, and in the process of production, through assurances that every individual has but one true sex, the demand is hidden (1998, 75, fn3).

This chapter asks its audience to think about one of the prevalent “common sense” areas of cognition operating in Western culture: the division not just of persons into two dichotomous and opposing genders (man and woman) but of bodies into two dichotomous and opposing sexes (male and female). Although many disciplinary theories over the last 30 years have produced a critical framework which commonly acknowledges that gender is a culturally specific, arbitrary, and unfixed category, sex remains a supposedly fixed biological category uninfluenced by cultural values or precepts. Whatever most people will make of gender, they assume that one is a man *because* he has

male genitals and reproductive organs, and that one is a woman *because* she has female genitals and reproductive organs. I refer to this as “genital determinism.”

Genital determinism allows people who have just entered a nightclub filled with people to immediately cut from their list of possible sexual partners anyone who does not perform the gender which they assume correlates to a specific genital type. Thus, for example, heterosexual men go to a bar and rule out other men as sexual partners. Heterosexual women are similarly able to rule out other women as partners. And lesbians would rule out men and gay men rule out women. Of course, this is an over-simplification and it is well known that under certain circumstances some people, regardless of declared sexual identities, will have sex with persons who would not usually be within their field of desire. However, the simplification does not negate the fact that people, for the most part, have an expectation that genitals correspond to gender as its founding principle. This chapter is also about narration, both in fiction and in “fact based” reporting. What interests me, and what joins all of the following sections together is how intersexed and non-intersexed people tell stories about bodies that defy categorisation into one of the two accepted, genitally based, identifiers: male and female. When bodies defy categorisation on the genital/sex axis, a variety of responses are possible and in the following narrations the responses range from fetishisation in Anaïs Nin’s erotica, and morbid fascination in the X-Files, to distortion in both Tardieu’s and Foucault’s readings of Alexina Herculine Barbin’s autobiography, to faith in medicine on 20/20 and back to fetishisation in OUT magazine. All these responses, I argue, make it difficult for intersexed persons to create counter-responses, or to even control how our lives will be

represented once we enter into a public realm, be it through autobiography, interviews, or public speaking.

Narrating Difference in Anaïs Nin's Erotica

“Moufaka,” I said, “What are you? Are you a man or a woman? Why do you live with these two girls? If you are a man, why don't you have a girl of your own? If you are a woman, why don't you have a man occasionally?”

Moufaka smiled at me.

“Everybody wants to know. Everybody feels that I am not a boy. The women feel it. The men don't know for sure. I am an artist.”

“What do you mean Moufaka?” “I mean that I am, like many artists, bisexual.”

“Yes, but the bisexuality of artists is in their nature. They may be a man with the nature of a woman, but not with such an equivocal physique as you have.”

“I have an hermaphrodite's body.”

“Oh, Moufaka, let me see your body.”

[...]She took her shirt off first and showed a young boy's torso. She had no breasts, just the nipples, marked as they would be on a young boy. Then she slipped down her slacks. She was wearing women's panties, flesh-colored with lace. She had a woman's legs and thighs[...] Then she slipped

down her panties. And I saw below the delicate curled pubic hair, shaped like a woman's, that she carried a small atrophied penis, like a child's. She let me look at her--or at him, as I felt I should now say.

"Why do you call yourself by a woman's name, Moufaka? You are really like a young boy except for the shape of your legs and arms."

Then Moufaka laughed, this time a woman's laugh, very light and pleasant. She said, "Come and see." She lay back on the couch, opened her legs and showed me a perfect vulva mouth, rosy and tender, behind the penis.

"Moufaka!" (1978,42-43).¹

Hermaphrodites are such elusive creatures! Just when one thinks one has the creature pegged, s/he goes and changes, perversely enjoying causing confusion in the poor unsuspecting or naive viewer. Is it any wonder then that medical researchers, sexologists, taxonomists, physicians and fiction writers have tried so hard, and for so long, to pin down the hermaphrodite's body, making it into only one thing once and for all?

In the passage above, the narrator demands to know whether Moufaka is a man or a woman and then decides the issue for himself no less than 3 times, once through the initial use of the pronouns "she" and "her", then in the decision after seeing the "penis" to inform Moufaka, "you are really a boy," and finally in the reversion to the use of the pronoun "she" in the passage describing the exposition of a "perfect, rosy and tender" vulva. Ultimately, in spite of his attempt to authoritatively inform Moufaka of what she *really* is, the narrator stumbles on his own suppositions about what signifies sex.

This story by Anaïs Nin is interesting because it refuses to grant the authority of vision to the narrator; however, the writing is also troubling because it envisions the hermaphroditic body as deliberately and wilfully confusing, and as a source of spectacular pleasure for Moufaka who seems to enjoy confounding others. There are also obvious echoes of nineteenth-century sexology in the banter regarding the “nature” of Moufaka’s bisexuality, which Nin, the author, locates in the physical body, and which Moufaka locates in the realm of desire and artistry. The tension in the text and its inability to untangle the overlapping categories of inversion, bisexuality, and hermaphroditism indicates a crisis at the nexus of desire, fascination and horror, manifest in both scientific and fictitious descriptions of these sexually “ambiguous” bodies. Ultimately, the crisis results in representation reflecting the perspective of the voyeur, but not that of the “hermaphrodite,” who is but a recreation constituted via the perception of the fiction writer. Furthermore, whether Nin ever encountered an hermaphrodite, or whether she created Moufaka wholly out of an imagination supplemented by forays into sexology, is not clear. Either way, the character of Moufaka is a fictional representation and as such does not represent hermaphroditism nearly so well as the character illuminates a common cultural perception and construction of hermaphroditism.

Nin’s fictional account of hermaphroditic pleasures might be more ironic than oppressive had the collection of stories not been written in the 1940s, temporally proximal to discussions in medicine linking confused bodies to neurotic or criminal minds and behaviours. Such discussions produced findings used to justify the measures historically taken to control actual bodies similar to Moufaka’s fictional one, first through

juridical intervention and then through surgical intervention.

Like the studies on Sarah Bartmann, the “Hottentot Venus,” whom Anne Fausto-Sterling argues was both an object of scientific fascination/disgust and of sexual/specular pleasure,² the hermaphrodite, Moufaka, is both a source of frustration and attraction to Mallard, the narrator. It appears that, in fact, many accounts of hermaphroditism suggest such a doubled relationship of fascination and disgust on the part of the observers and/or record keepers.

Tragic Births

In the Winter 1993 issue of Johns Hopkins Magazine, medical writer Melissa Hendricks published the article “Is it a Boy or a Girl?” The piece details the surgical prowess of a team of doctors in the urology unit at Johns Hopkins, Dr. John Gearhart, Dr. Robert Jeffs, and Dr. Gary Berkovitz. Hendricks describes Gearhart’s surgical techniques on intersexed infants as “artistry”(10), claiming that he “[...]can carve a large phallus down into a clitoris, create a vagina using a piece of colon, mold labia of what was a penis”(Ibid).

I want first to address the incredulous tone of Hendrick’s title and introductory paragraph, a tone which we will see repeated later. Hendricks provides the following narrative of the birth of a child:

The first sound a new parent awaits is the newborn’s cry. When the mother hears it she is relieved. Then the first question is always, “Is it a boy or a girl?” Sometimes, however, the question cannot be answered.

Celia and Larry Smith know how heart wrenching that experience can be.

Celia recently delivered a healthy baby at her hometown hospital. “You have a baby girl,” announced the obstetrician. But when the doctor and nurse took the baby over to the examining table, they started speaking in hushed tones. The child appeared to have a small penis. The doctor came back and told the Smiths, “We have to do chromosome studies. We don’t know the baby’s sex.” (10-11)

It is important to note that Hendrick’s introduction is a speculative fiction. Her narration of delivery-time events is an extrapolated conjecture and no matter how prevalent the scenario may be, it is an overstatement to claim that the parents’ first question *always* demands to know the sex of the child. For example, adoptees who are new parents may be more curious about resemblance than about sex, and parents who have had difficult deliveries or pregnancies may be more concerned about the health of the child than anything else. Even in Hendrick’s own work it is only a syntactical arrangement that permits her to identify the first “question” as one of sex; she constructs relief at a baby’s healthy cry as a *statement*, and skips the anxious, if unvoiced, *question* implicit in the sigh issued by the mother. It is also important to note that the account of the Smith baby’s birth is a reconstruction of events which focuses attention on the drama of the doctors’ approach to atypical genitals rather than on the health of the child. Finally, it is interesting that in the narration, chromosomes are held up as the guarantors of sex when the external sex is held as an “ambiguous” signifier insofar as the doctors suspect that there is a conflict between the anatomy of the child and its sex.

The wisdom here is that genitals should correspond to chromosomes as clear signifiers which articulate the entire social, sexual and reproductive future of the child. In Bodies that Matter, Judith Butler argues that

Gender norms operate by requiring the embodiment of certain ideals of femininity and masculinity, ones that are almost always related to the idealisation of the heterosexual bond. In this sense, the initiatory performative, “It’s a girl!” anticipates the eventual arrival of the sanction, “I pronounce you man and wife.” Hence, also, the peculiar pleasure of the cartoon strip in which the infant is first interpellated into discourse with, “It’s a lesbian.”(1994, 232)

Butler’s remarks regarding the appeal of the comic strip pronouncement apply as well to the kind of pleasure an intersexed person might derive from speculating on a joyful delivery room exclamation, “It’s an intersexual!” What makes both pronouncements appealing is that they subvert the presupposition of the pronouncement of a couple’s status as “man and wife,” a statement that carries with it all the cadences of ownership of women by men, of men’s status as men and of women’s status as marital objects. Of course, I do not think that the simple utterance of new birth pronouncements would automatically overturn these heterosexist and masculinist points of privilege and limitation, and Butler is clear that she does not think such pronouncements will magically overthrow dominant systems. For Butler, the task of liberating bodies from tyrannical pronouncements of imperative sexuality is more complicated than just claiming or reclaiming an identity, because the imperative function of sex

[...]means that a subject is addressed and produced by such a norm--and the regulatory power of which it is a token--materializes bodies as an effect of that injunction. [...]And further, this imperative, this injunction, requires and institutes a “constitutive outside”--the unspeakable, the unviable, the nonnarrativizable that secures and, hence, fails to secure the very borders of materiality. [...]those exclusions haunt signification as its abject borders or as that which is strictly foreclosed. (1993, 187-188)

However, in a similar move to those being made by communities demanding that their queerness not be considered a tragic aberration,³ learning to conceive of intersexuality as something other than a tragedy is a project that I believe to be worthwhile, even if it is bound by certain imperative limitations, even if it remains constrained by the tension of being simultaneously rejected and created within Western medicine. For while the process of teaching parents, families and the general public not to be appalled by the birth of an intersexed child promises to be a long one, the years since 1993 (when Fausto-Sterling’s pivotal article “The Five Sexes” asked scientists and lay readers alike to reconsider their attitudes toward sexual ambiguity) have produced a marked shift in the way that general audiences and younger medical practitioners, and hopefully families too, perceive the very same birthroom event that, as we see in the following section, 20/20 anchor Hugh Downs declared to be one of the worst possible outcomes of a pregnancy.

The following narrative is a transcript taken from 20/20, a popular television “news magazine” hosted by Barbara Walters and Hugh Downs. The show often features

specialised reporters for specific fields; their medical reporter is Dr. Timothy Johnson. The interchange below is excerpted from their introduction to a feature on congenital adrenal hyperplasia (CAH).

Hugh Downs: (introducing the evening's feature) *Now, perhaps the most shocking illness a newborn can have.* Baby girls who are born with their sex organs looking like baby boys. And tonight, thanks to several courageous families, you'll learn about this strange and potentially deadly disorder that is more common than even most doctors realise. And there's good news with it. Timothy Johnson will show you *the extraordinary medical advance that can spare parents a great deal of anguish in the delivery room.* (Emphasis my own)

Timothy Johnson, M.D.: (Voice over, the scene is a hospital delivery room) It is a fact so central to our existence that it is the first thing every new parent wants to know: "Is it a boy or is it a girl?" What few parents realise is that the answer to that question, surprisingly enough is not always that simple. (Sloan; ABC, Feb. 1996)

Johnson's prelude to his report on CAH overlooks the fact that sex is not so central to our existence for it to be the first thing *every young child* wants/demands to know about his/her world. Rather, children want to know why the sky is blue, why we have to eat, what we did with our days before we had them, why babies pick their noses etc. It is parents, not children, who *demand* a sex category for their children. Although information about one's own gender may become necessary at some point, I am not

convinced that the information needs to be either/or for it to be satisfactory. And while I would not advocate withholding information about a child's (inter)sexuality, there are other things that if withheld, would do much more harm. For example, it has been fairly well established in developmental psychology that infants require physical affection right from birth if they are to "thrive," that is, to gain weight, grow appropriately and develop their cognitive abilities to their fullest.⁴

Glenn Gordon: (with a still photo of himself holding the newborn)

I told the waitress at the restaurant that I just had a baby and she said "Oh, did you have a boy or a girl?" and I just started to cry right there in the restaurant because I couldn't answer the question (another still photo is shown of Gordon and his wife, smiling and holding their newborn).

Timothy Johnson: Glenn and Elizabeth Gordon couldn't answer because their daughter was born with an unusual genetic disorder known as CAH. (Cut to Dr. Johnson in what is meant to look like a typical medical examination room) Congenital Adrenal Hyperplasia, a condition that can be *startling* in newborns. In the severe form of CAH, girls are born with ambiguous genitalia--that is, external sex organs that look so much like a boy's that not even a physician can visually determine the sex of the child. (cut to Dr. Maria New) Dr. Maria New, chief of paediatrics at New York Hospital, Cornell Medical Centre, is the country's leading expert on the disorder; she described for me how these girls can look at birth. (The camera zooms in on slide-photographs of neonate genitals of CAH babies).

(Ibid)

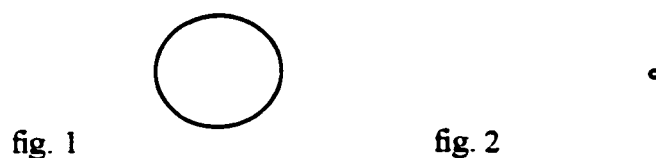
It is important to note that the babies in the photographs used to demonstrate the appearance of genital anomalies are neonates; one has a blackened umbilical stump and the other looks to be just over two or three weeks old. The programme does not point out that the genitals of newborns are often peculiar looking, seeming out of proportion to the infant's body, being swollen and darkened from maternal hormones still present in the infant's body.

Maria New, M.D.: Instead of having a normal vaginal opening, *the clitoris is too large*, consequently, the baby is born and there is a risk that the obstetrician will look at this baby with ambiguous genitalia and say, "It's a boy."

Timothy Johnson: *So How do the external genitalia of a girl become so abnormal?* During pregnancy, CAH triggers an extensive male hormone level that masculinises the external genitalia, even though her internal sex organs, the ovaries and uterus remain normal. Boys can have the syndrome too but because their external genitalia are already male-like, any changes are not noticeable. *But when girls are born with male-like genitalia it can be very shocking for parents and take all the joy out of what is otherwise a joyous event.*

At this point in the segment, 20/20 provides a computer enhanced graphic animation sequence to accompany the commentary of New and Johnson. The animated sequence shows a diagrammatic representation of clitoroplasty; it is an extremely neat and

tidy representation. 20/20 and ABC News have denied me permission to use still shots of the computer graphic in this dissertation, claiming that they never give out permission to use graphics. Therefore, I am forced to provide the following description of the approximately 15 seconds of tape shown on 20/20 to represent a typical surgical “reduction” of a clitoris and creation of a vagina and introitus. The graphic is tinted in a sepia-pinkish colour and is void of sharp lines; the clitoris appears to shrink as if by magic and the introitus appears to grow of its own volition. There are no scalpels, no probes or catheters, no stitches, no blood and no scars in this representation. The clitoris in the sequence appears as an enormous fleshy circle, about 15mm in diameter on my 12 inch screen (fig. 1), and is shrunken down to something appearing not larger than the head of a pin (fig. 2) with a measurement of 1mm diameter:



The dimensions of these circles were used on the 20/20 episode to represent the degree of reduction required to make an inappropriate clitoris into an appropriate one. The voice-over accompanying these computer-produced images “informs” viewers that the excess *skin* of the clitoris is removed. This claim is seriously misleading for, it is, in fact, the *corpora* of the clitoris, including vascular nerves, which is excised--not simply reduced. It is only the glans which in “modern” techniques is recessed onto the remaining stump. The following is a post-operative report of a typical clitoral recession surgery:

With pen and ink a U-shaped dorsal incision was marked out on the clitoris with the apex at the base of the pubis. With the glans and clitoris under tension, the U-shaped incision was carried out around the dorsal aspect of the clitoris to the glans. The dorsal hood of skin was then removed and heavy dexton sutures were placed through the base of the crura of the enlarged clitoris. The redundant corpora was then excised dorsally. The glans was then recessed into the infrapubic area[...] and then the skin approximated as a new clitoral hood. (M.M.C., personal medical file, March 18, 1975, Hospital for Sick Children, Toronto)⁵

The measurements of the organ removed in the above operation measured 2 cm x 1 cm preparatively in 1973, two years before the surgery; there is no notation of post-operative size but the pathology report indicates a specimen measuring 1.5 cm X 1 cm x 1 cm was removed. The scale of reduction in the above surgery is then approximately 2:1. The reduction shown in the 20/20 segment is from 15mm D to 1mm D, a scale of 15:1. 20/20's representation, by showing such equine proportions, encourages the perception that such surgeries are necessary. The mother's commentary accompanying the 20/20 diagrammatic representation is accidentally ironic:

Elizabeth Gordon (mother): These are little girls who have (pause) *a little too much*. And the idea is to, *to just give them what they should have had*.

Timothy Johnson: Dr. New routinely treats children like Allison. (cut to Dr. New).

Dr. New: The genitalia are corrected surgically, and the baby will grow up

to be a fine woman[...] and with the capacity for motherhood.

Elizabeth Gordon: Luckily there are wonderful surgeons who can fix this and do a good job. And *we were lucky to find those people.*

(Emphasis mine)

In order to stress the point of how lucky the Gordon family was to find the surgical experts they did, Johnson goes on to tell the sad tale of a baby, Christopher Russo, who died because he was not diagnosed with CAH and, therefore, was not treated for his severe salt-losing syndrome. Johnson's commentary confuses the issue of genital appearance with the frequent inability of CAH babies to retain fluids. Regardless of what a child's body looks like, or what the sex of the child is presumed to be, a child who fails to thrive should be assessed for endocrine and metabolic functions; genital assessment and chromosomal profiles have nothing to do with the death of baby Russo. The narrative makes it seem as though the appearance of the child's genitals was directly related to the death of the infant when, in fact, it was the failure of medical professionals to assess the child's ability to retain fluids that was the cause of death. The child could quite easily have been raised without surgical interference until s/he was able to choose whether to have surgery, and the adrenal function of the body could have been efficiently managed with cortical hormone treatments.

What makes parents such as the Gordons accept the idea that their children are being given "what they should have had"? A partial answer may be found in Pierre Bourdieu's work on the *habitus* which details the culturally specific organisation of bodies and their uses.⁶ One needs to contextualise the circumstances surrounding the birth

of the child who is diagnosed with some form of intersexuality if one is to understand what motivates parental decision making.

Even though sexuality and sexual behaviours are highly variable, it is part of the Western *doxa* to maintain the idea that heterosexuality is natural while homosexuality is unnatural. We make such pronouncements in the face of the knowledge that all humans are, simultaneously, highly enculturated *and* organic. The idea of one form of sexual expression being more or less natural than any other is absurd; it makes no sense because, if humans are natural organisms, then everything we do must be “natural,” yet, if we are products of culture, then all that we do must be informed by culture. Finally, there has to be a recognition that we are organisms steeped in culture--there is no way of separating the cultural from the natural and attempts to wrench them asunder are doomed to failure. However, the idea that “the natural” is conceptually indivisible from “the cultural” is not what the language or *habitus* of either “common culture” or “science” in Western society renders visible. Rather, the opposite seems to be true.

Thus, when a child is born with “ambiguous genitalia,” management of not only the child but also the parents begins. Instead of trying to teach parents that their intersexed children are atypical but healthy, the medical experts use their authority to first declare the child anomalous and then to reassure parents that they can provide the technical expertise to finish what “nature” has left incomplete. This leaves undisturbed the cultural values claiming that people have bodies with “natural” intended purposes and functions to fulfil, and simultaneously upholds the ability of science to realign any bodies or subjects who accidentally stray from their intended paths. Even though the intersexed

child's bodily features are apprehended and explained as a medical emergency requiring speedy, *technical* intervention and/or correction, the idea that the "natural" is *not* being tampered with through the use of surgical interventions is maintained. Why is it that parents tend to respond as the Gordons in the 20/20 segment did? What makes them accept the idea that the surgery is simply the completion of a natural process?

Susan Gal provides us with a partial response to these questions when she indicates that "the 'meeting' is a speech event ubiquitous in American bureaucratic, corporate and academic life" (Gal, 1991, 186). Gal goes on to indicate that in America--and here I take Canada to be similar enough that we are included in this particular formation of power structures--we accept the "meeting" as a place where those in authoritative positions inform those below them of which course(s) of action are to be taken in order to produce the best end results (Ibid). No matter at what level the meeting takes place, there is always a power imbalance in which some defer to others to provide answers. In the case of the intersexed child's birth, the physician who delivers the child calls in "experts" in the field who then hold a meeting with parents to inform them about their child's condition and explain how they are going to make it all better.⁷ That is the present. What records are available to show us typical case-management in the past? One story stands out from all others as that of perhaps the most well-known hermaphrodite in history.

Alexina Herculine Barbin

Originally encountered in Ambroise Tardieu's 1874 publication Question médico-

légale de l'Identité, Alexina (Herculine) Barbin is described by Tardieu as a tragic and pitiful creature who suffered terribly because *his* true sex was not properly disclosed, and because the needs of his body eventually lead too late to a proper (male) sex assignment, and ultimately to suicide:

On va voir la victime d'une semblable erreur, après vingt ans passés sous les habits d'un sexe qui n'est pas le sien, aux prises avec une passion qui s'ignore elle-même, avertie enfin par l'explosion de ses sens, puis rendue à son véritable sexe en même temps qu'au sentiment réel de son infirmité physique, prenant la vie en dégoût et y mettant fin par la suicide. (Tardieu, 1874, 61)

We shall see the victim of a similar [civil] error [of recording sex], who lived for more than twenty years in the habit⁸ of a sex that was not his own, caught by a passion of which she herself was unaware, until finally informed by the explosion of his senses and returned both to his true sex, and a full realisation of his physical infirmity, and, taking an acute distaste for living, decided to end it all in suicide. [translation mine]

Translating this passage was particularly difficult because of Tardieu's refusal to declare a sex for "the victim," employing passive structures or relative nouns to refer to Alexina B, as he refers to Barbin, until the following paragraph when he unequivocally declares Alexina to be "ce pauvre malheureux," (Ibid) a clearly male subject. Tardieu's difficulty with Alexina is similar to that of Mallard in Anaïs Nin's "Moufaka," and similarly, each narration refuses to grant an authoritative voice to the object under

scrutiny. Yet such anxieties and refusals may not be obvious in translations. Richard McDougall's English translation of Foucault's collection of Tardieu's dossier translates the same passage thus:

We are about to see the victim of such an error, who, after spending twenty years in the clothing of a sex that was not his own, at the mercy of a passion that was unconscious of itself until the explosion of his senses finally alerted him about the nature of it, had his true sex recognized and at the same time became really aware of his physical disability, whereupon, disgusted with his life, he put an end to it by committing suicide. (Barbin, 122)

This translation reads rather more elegantly than my own, but over-rides Tardieu's initial ambiguity and pronounces Alexina to be male, illustrating rather clearly that Barbin's sex was ultimately determined, at least for the translator, not by appearance or anatomy, but by *desire*.

I am opening this discussion of Alexina (Herculine) Barbin's life with these troubling pronouncements and translations to show the disjuncture between the identifications and desires that Barbin illustrates in the memoirs, and those made by publishers of the memoirs. The difficulty one faces in interpreting the memoirs is compounded by the fact that they are available only via these third-party medical (Tardieu) and academic (Foucault) publishers. I have, nonetheless, decided to proceed with the English translation of Barbin's memoirs as my source, for one needs to begin with something--but I have tried to read Barbin's story with an awareness of its limitations as a translation across time and disciplines as well as language.

First, I am skeptical about the validity of neatly adopting a male identity when referring to Barbin. Simply because s/he lived his life finally as a man, does not mean that s/he thought of himself as one.⁹ Barbin certainly draws attention to his physical differences from the other girls, but I am not convinced that difference from females is equal to maleness in Barbin's eyes; Barbin writes:

According to my civil status, I was henceforth to belong to that half of the human species which is called the stronger sex. I, who had been raised until the age of twenty-one in religious houses, among shy female companions, was going to leave that whole delightful past far behind me, like Achilles, and enter the lists, armed with my weakness alone and my deep inexperience of men and things. (1980, 89)

At the very least, it appears that Alexina felt himself radically unprepared to live in the world of men, as a man. And indeed, within a few years of having his civil status changed, Alexina did kill himself, though not without first leaving a record of his life behind:

I am twenty-five years old, and, although I am still young, I am beyond any doubt approaching the hour of my death.

I have suffered much, and I have suffered alone! Alone! Forsaken by everyone! My place was not marked out in this world that shunned me, that had cursed me. Not a living creature was to share in this immense sorrow that seized me when I left my childhood, at that age when everything is beautiful, because everything is young and bright with the

future.

That age did not exist for me. As soon as I reached that age, I instinctively drew apart from the world, as if I had already come to understand that I was to live in it as a stranger. (1980,3)

This passage, from Foucault's publication of Barbin's memoirs, was written shortly before Barbin's death in 1864 and was initially published by Ambroise Tardieu in 1874; it serves as Alexina Herculine Barbin's first introduction of himself to his reader(s). However, though s/he had written his own personal introduction, there is another that serves to set the stage for the reading of her story; it is the formal, academic introduction by Michel Foucault. The introduction, if one should read it before reading Barbin's own account, inclines readers to interpret every kiss, caress, and affectionate glance between Herculine, his student-peers and his teachers as a thinly veiled desire for and of the "puny Achilles hidden in their boarding school" (Intro, viii). Certainly the back cover synopsis, which characterises Barbin's memoirs as an "erotic journal," reduces the complexities of Barbin's story to its most marketable description. Of course, if one should read Barbin's own personal introduction first, then one may be inclined to read his solely as a homeless, unwanted victim of fate. Nonetheless, there are long periods of time in his own written account, where, in fact, Barbin fits in quite well at his girls' school, first as pupil and then as school mistress; furthermore, Barbin's life is not without passion or physical love between himself and his lover, Sarah. Thus, in some ways, neither Foucault's nor Barbin's introduction to the case provides a coherent understanding of Barbin's life. This may be, in part, a limitation of attempting to record a life on paper, in text; it is also a limitation of

both memory and hindsight.¹⁰

Foucault, in setting the context of Barbin's memoirs, describes the period of the 1860's to 1870's negatively as "[...]one of those periods when investigations of sexual identity were carried out with the most intensity, in an attempt not only to establish the true sex of hermaphrodites but also to identify, classify and characterise the different types of perversions" (xi-xii). Yet, in spite of his misgivings regarding this medical characterisation and classification of sexual types, Foucault's own view of Alexina's sex is mostly concordant with the findings of the medical "experts" who oversaw Alexina's case. Foucault, for example, seems to be amazed that no one in the convent "[...]was aware of his [sic] somewhat graceless body, which became more abnormal in the company of those girls among whom he [sic] grew up"(Ibid). In his acceptance and use of the masculine pronoun to refer to Alexina, Foucault accepts the very medical "truth" sought/produced regarding Alexina's sex that his introduction claims to question. In addition, Foucault suggests that only a repressed desire on behalf of the teachers and students in the convent could have produced what Foucault *presumes* to have been a "fascination that misted over their eyes and stopped every question on their lips"(xii), keeping Alexina's peers from *really* looking at her and seeing her for what she was. Foucault here assumes that there *was* indeed something obviously different to be seen in Alexina's form, that the hermaphrodite body is visible and recognisable as such, and posits, without providing proof, that the nuns of the convent desired Barbin for his masculinity, not for his femininity or other qualities (for example, the combination of curiosity and intellect s/he displays).

Admittedly, Alexina himself notes his own difference from the other girls, but as s/he does so many years *after* his juridically imposed change of sex, his attention to his own difference is hardly surprising. It is impossible to tell from a memoir what a person may have thought about him or herself in the moment that recounted events were happening. Thus, it is impossible to know for certain if Alexina thought of himself as obviously different from his peers *while* s/he was still in the convent, *before* s/he had been diagnosed as abnormally different. The types of variations Alexina describes, a general thinness and more visible body hair being the most apparent, have been common enough throughout medical literature to indicate that although people sometimes found such differences remarkable, they were traditionally considered as nothing beyond variations within the norm. Where such variations become deviations is at precisely the time of Alexina's diagnosis in concurrent scientific examinations of race and degeneracy.¹¹ When Foucault accepts the "obviousness" of Alexina's difference, partly because of what is borne out in the memoir, he forgets that Alexina accepted his own "obvious" difference from the perspective of having been assigned male, and only as far the evidence can show, in hindsight.

In his introduction, Foucault characterises the medical investigations into Alexina's case as zealous searches for deviance, and the convent gazes as those of an innocent albeit repressed form of longing, but nonetheless falls on the side of the medical system that would declare Alexina to have had a sex that was at least *more* masculine, and unmistakably so, if not *truly and solely* male.

In his incredulous assessment of the convent population's inability to see Barbin

for what s/he was, Foucault apparently forgets that the Catholic church is a site of permanent adoration of the female body. An argument could also be made that the Catholic church is a site of permanent vilification of the female body, which does not undermine my point, but only illustrates that Catholicism spins on an axis of virgins and whores, with each end of the spectrum (Mary, mother of God and Mary Magdalene) representing a possible site for miraculous intervention. It is, thus, not unusual for Barbin to have been the recipient of fond kisses and caresses from her peers or from particularly fond teachers. It only seems a little remarkable because the memoirs of the other girls, who surely enjoyed the caresses and kisses bestowed by their own admiring teachers, are missing from the record. The probability that Barbin was not the sole recipient of such fondnesses is not purely speculative as the entire culture of the convent would have promoted such “innocent” practices. Mary, mother of God, for example, has been ceaselessly adored in Catholicism, and the young women, Novices, Sisters and Mother Superior in Alexina’s convent would all have been well accustomed to kissing and caressing the figure of Mary. That is to say that certain kinds of admiration are actively promoted within devout Catholicism.

By commenting on Alexina’s physical interactions with her superiors and her peers, without noting the context of religious adoration of the female body, Foucault over-invests in any possible sexual current of the interaction. This is not to say that there is neither sexual desire nor other form of eroticism in such practices, or particularly in Alexina’s case, but they do not have to result from the “truth” of her sex. That is, what eroticism there was did not have to occur because Alexina was truly male, or masculine of

heart. In addition to any probable lesbian context for Alexina's more private activities, there is plenty of broader eroticism in the Catholic church that might contextualise the more general displays of affection between Alexina and hir peers. There is an erotic context for the conception of Christ, and also for his death, and the simple fact that every mass is presided over by a mostly naked, beautifully formed man on a cross suggests that a current of sexual desire runs throughout Catholic ways of seeing and interacting. None of this erotic context, however, leads to a necessary desire for Alexina *as a male figure* in the convent, and it does not lead to a necessary suggestion that Alexina was an object of desire *to everyone*, rather than only to hir girlfriend.

Barbin's own narrative is itself complicated by the fact that it was written close to the time of hir suicide, long after the point at which s/he had been reassigned male by the courts, and had taken up a life as a male railway worker. Thus, like Foucault, when s/he recounts stories of hir desire, modesty about hir body, or erotic feelings for other girls or vague *sensations* of amorphous desire, Alexina also lays the weight of hir masculine assignment onto the past. It is thus difficult to know if s/he thought of himself during hir time in the convent as any more or less modest, or as any more or less feminine, than her peers. What is clear is that the picture itself was muddled for Alexina, at least over time and by the juridical pronouncement of hir "true" sex (male). Whether or not it is remarkable that a young woman¹² who had lived hir entire life in a convent, and who was well aware of romantic idealisations of adolescence, femininity and youth in general, should have felt desire at what *appears* to be every turn is open to question. The problem with autobiography is that it does not tell of the days, weeks, perhaps months when

nothing happened. Thus, it is rather futile to try to determine Alexina's lived experiences from the conventions of an autobiographical account.

Certain physical questions of sex could well have been unspoken questions for Barbin who alludes to a "*certain absence*" that science had been unable to explain, and which was cause for a general anxiety amongst her peers (Barbin, 1980, 39). The certain absence s/he is hinting at could be a lack of breast development, but I believe it refers actually to the absence of menstruation. My suggestion is evidenced by Barbin's attribution of this "certain absence" to "[...]the kind of languor in which [s/he] was wasting away"(Ibid). This statement does not reflect medical concerns regarding sex or gender, or even physical anatomy, so much as it indicates medical anxieties regarding the disciplined balancing of desire with activity evident in appropriate body fluid production. It would not have been unusual for the absence of menarche to cause anxiety in one's peer group as the nineteenth century was, after all, a point at which the Hippocratic doctrine of humours was being used as a primary source for medical teaching and that source maintained that an absence of menarche could be *fatal* (Littré, 466-70). For the Hippocratics, the sex of a body was not evidenced by the genitals, but signified in the metaphorical relationship of fluids (blood, milk, sperm, urine) to the actions of the body. An absence of one form of fluid could indicate an overindulgence in activities such as thinking, eating, and sexual activity. In a worldview that, according to Thomas Laqueur, had only one sex, but two genders, these activities would metaphorically signify gender by the fluids a body would emit:

...because men were hotter and had less blood left over, they did not

generally produce milk. ... Conversely, women menstruated because they were cooler than men and hence more likely at certain ages to have a surplus of nutriment. (Laqueur, 1992, 36)

The need to discipline bodies arose because men who took on the activities of women might, for example, begin to signify womanliness through the production of milk. And women who laboured too long or too hard might cease to signify womanliness in an absence of menstrual production (Ibid).

Alexina's memoirs retrospectively attribute anxiety over her health to a general recognition that she was really a man, a truth that no one wanted to confront, but the anxiety is at least as likely, if not more so, to have been over her own health and a fear of a morbid sexuality, than over a suspected inappropriate gender. As Michel Foucault points out, threats to one's physical, moral and mental health lay in wait everywhere for the nineteenth-century sexual subject:

...there emerged the "nervous" woman, the woman afflicted with "vapors"; in these figures the hysterization of woman found its anchorage point. As for the adolescent wasting his [or her] future substance in secret pleasures, the onanistic child who was of such concern to doctors and educators from the end of the eighteenth century to the end of the nineteenth... was in danger of compromising not so much his physical strength as his intellectual capacity, his moral fiber, and the obligation to preserve a healthy line of descent... (Foucault, 1978, 121)

It is unfortunate that the general dearth of first-person accounts of living as/with

intersex have left Barbin's story vulnerable to those who would make of his life whatever they will. What I have worked to do in this section is read Barbin's narrative with the aim of resisting the production of over determined-declarations of his true sex.

The X-Files

For its 1994 season opener on September 23, The X-Files aired The Host, an episode featuring a hermaphroditic humanoid monster living in an underground sewer system, coming up through toilets and processing plants to find human prey that it would use as reproductive hosts for its larvae. The episode speculates that the hermaphroditic creature, which has human DNA but looks like a giant earth-worm with limbs, is a genetic mutation caused by radioactive fall-out from Chernobyl. The episode concludes with the agents under the mistaken impression that the creature has been terminated but the audience has the last gaze down into the sewer system where the worm-face is seen in the shadows. Clearly this mutant, monstrous human/non-human remains as a threatening spectre in the X-Files universe.

Why a hermaphrodite? Why not just some kind of tragic gene mutation which makes humans like to live in sewers? Like the 20/20 representation of CAH as a tragedy that undoes the birth-room accomplishments of parents, the X-Files hermworm is presented as "perhaps the worst tragedy a [human] can imagine." The fact that the worm is neither male nor female adds another dimension to the X-Files stories that fascinate because they are bizarre. Indeed, in the scene in which Mulder argues about where to process the case with Skinner, Skinner asks where they ought to put the hermworm if not

in a forensic psychiatric institution:

Mulder: There's no way you'll prosecute this.

Skinner: The Justice department has asked that the subject be transferred to an institution for a full psychiatric evaluation.

Mulder:(emphatically) This is not a man. It's a monster. You can't put it in an institution.

Skinner: (exasperated) What do we do with it, agent Mulder? put it in a zoo?(Fox, Sept. 23 1994).

The history of fetishisation and spectacle around hermaphrodites as monsters in sideshows is obviously linked into the X-Files narrative, but how and why?

Making sense of the function of these types of spectral narratives, including the 20/20 coverage of CAH, and of the hermworm in particular, requires an understanding of the binary function served by their creation. The types of creatures shown on the X-Files are appealing because they shore up meaning in the category of "humanness." Although the non-human, or "humans-gone-bad," characters of the X-Files are meant to be horrific, they offer the possibility of a crisis in meaning that can be resolved. Like the surgeons in the 20/20 report, Mulder and Scully are able to find the cause of the anomaly and to effect reasonable limits on the possibility of creating yet more monsters. "The Host" episode of the X-Files is a cautionary tale about the effects of pollution and nuclear fallout;¹³ the 20/20 episode ends by assuring its audience that through preventive screening measures, including genetic testing and prenatal drug and gene "therapy," we can greatly reduce the numbers of children born with genital anomalies. These stories

then, have the ability to counter the anxiety produced by the intersex or hermaphroditic bodies in Nin's fiction, and in Barbin's memoir.

I shall argue that monstrous representations of hermaphrodites function, in a Kristevan sense, as abject categories. I am pushing psychoanalytic boundaries here because I am taking a model based on the psychotopography of the individual and applying it to the creation of meaning for the much broader category of a general audience. However, taken as abject spectres, these representations of hermaphroditism, including both the 'fictional' and 'factual' cases discussed herein, parallel, on a broad level the function of the abject within the single subject.

Kristeva argues that while the *object* "other" functions to "settle [...]the fragile texture of a desire for meaning, which[...] makes me ceaselessly and infinitely homologous to it, what is *abject*[...] is radically excluded and draws me toward the place where meaning collapses"(1982,2). Abjection is a crisis of meaning in which the ego, the grammatical "I," is threatened with its own dissolution. Furthermore, the law and order of the superego are threatened with the possibility of not being able to form or contain the subject because of a threat to the unconscious topos. The most obvious crisis for the subject is death. Thus the abject confronts us at the borders of our bodies: in the tears, blood, mucous and other fluids that escape us, and which are nonetheless a part of us, both I and not I simultaneously. The struggle between the superego (law and order) and the abject is struggle for meaning in which the superego must rescue itself from those borders of meaning to continually support and contain the ego.

Kristeva's point about the superego being the portion of the psyche that has to

confront the abject is that the law and order of the superego are shown to be fragile, and this fragility is deeply unsettling. How does this relate to the ways in which we perceive and narrate intersexed or hermaphroditic bodies?

Western culture, but not all cultures, teaches that human beings come in two biologically and anatomically distinct sexes. Intersex states confront this construction with a direct contradiction. The term “ambiguous” and any of its variants as applied to intersexed genitalia still imply that the categories of male and female are stable, clear and self-present (c.f. chapter one, above). This, as we shall see in my discussion of self-(re)presentation is a problem even for intersexuals. The term “ambiguity” indicates that it is not only in clinical terms that intersexed births provoke anxiety. Because our culture teaches us to perceive ourselves as either male or female, and because these are learned, developed and refined gender categories, it is apparent that they are a function not of ego (the I) but of superego (law and order). The failure to be able to claim a sex for oneself is to fail to have access to the only two available on-ramps (male and female) to meaning, law, order and subject-hood. One must be able to say either “I am male,” or “I am female,” not “I am I.” This latter statement does not even make sense, is not even thinkable without the implication of sex. At least, that is the threat and the fear.

So what is to be said of our monster in the toilet? Why not just have a creature that would live in the sewers and eat people? Why a hermaphrodite? The intentional answer might be that the writers simply wanted to have a logical means of explaining the ability of one mutant to reproduce and become more than one. However, this line of reasoning still leaves unanswered the “unintentional” or unconscious motives behind the

creation of the monster. And this leads us back to the abject.

According to the Kristevan model, if it is the superego which is threatened by the abject, that is, if it is the part of the unconscious which allows the articulation of the “I,” that requires an adherence to the ordering law of the subject, then that which throws the ordering into chaos is doubly threatening. Thus, my own bodily fluids and not those of others are the things which are “properly” abject.

How is conceiving the relationship of anxiety, horror and flight between the subject, the “I,” and the abject, the “not-I,” relevant in unravelling the impetus to erase intersexuality? The idea that things are abject when they threaten the boundaries of subjectivity by refusing “binary hierarchization” indicates at least one aspect of the cultural anxiety pertaining to intersex states. Elizabeth Grosz suggests:

corporeality is potentially infinite in form, no mode exhibiting a prevalence over others. However, within our social and signifying systems, this plenum is divided and categorized according to binary pairs[...] which reduce ambiguous terms not amenable to binary hierarchisation, back into this polarised structure ([...]there is no possibility of adopting a sexual position that is neither male nor female).(1990, 72)

How then does an Other, the hermaphrodite, come to function as an abject in the case of the X-Files monster? I hold that because this creature is supposed to have mutated from a human form, though it is not clear in the story if this happened to an adult or if the creature was born this way, it translates into a possibility of something the “I” might become. If the superego is the realm of the law and order, and humans are ordered

into only two possible subjects entitled to call themselves “I”, then the possibility of becoming hermaphrodite represents a possibility of becoming not “I.” in effect, nothing and non-being. The X-Files operates by combining story-lines that push the borders of the viewers’ senses of their own limits and containing that threat under the rubric of fiction. In this way, both the X-Files and the 20/20 episode on CAH are similarly structured: although one programme tells what are supposed to be “facts” while the other is about “fiction,” each show conjures up a crisis which threatens to become ‘internal.’ That is, anyone of us may find ourselves unable to reproduce “appropriately-sexed” beings because of either teratogenic poisons or genetic mutations. However, each programme, one through reliance upon the medical and the other through the explicit construction of fiction, manages to contain the threat and move it back to the sphere of the external which cannot harm us.

My commentary on the narrative structure of 20/20 and the X-Files presumes that I am not speaking to intersexed viewers. One assumes a certain specular pleasure would be present in facing the crisis and then moving beyond it. But what if you *are* the crisis? First of all, one’s viewing experience may be completely pleasureless. Members of the Intersex Society who saw both the X-Files and the 20/20 segment were outraged. Particularly enraged was the member whose email signature reads: “Kiira (Don’t quote Ovid to me) Triea.” For days after each programme aired, there was a flurry of activity on the various intersex electronic discussion lists, and letters to the programming directors at Fox and ABC were sent off by the dozen. The intersexuals I know, myself included, have a real problem with representations of hermaphrodites as monsters who live in toilets and

eat people, or with characterisations of intersexed births as tragedies that can only be resolved if surgeons come in and rescue parents and families from the questions of waitresses. What do you do if you have the conviction that your medical treatment, as opposed to your birth, was an impediment to both your well-being and, in many cases, that of your family? The first and most obvious answer has been to talk back.

Problems in Self-Representation

One reason why the canonical hermaphrodite texts, *Symposium*, Foucault's introduction of Alexina Barbin's autobiography as the memoirs of a "nineteenth-century *hermaphrodite*," Ovid's poems, and so on, offend some intersexuals is that they mythologise and exoticise hermaphroditism, creating serious misconceptions about what a hermaphrodite is. This mythologisation is one of the principal reasons that the Intersex Society does not identify as the Hermaphrodite Society. People may not understand the term "intersex," but at least it does not conjure up images of people with both male and female sex organs, four arms, four legs and two faces. The refusal of the identity "hermaphrodite" is one strategy for bringing our experiences into discourse and has the added bonus of also meeting the medical establishment head-on. In addition to this strategy, the Intersex Society has also worked at producing "real" images of intersexed persons. However, we have had a small problem with this strategy: few have been willing to "come out" and be public. There is still only a handful of intersexuals who are "out," participating in interviews and permitting pictures of themselves to be published. Of

course, there are some very good reasons for being cautious; my own position as the ISNA poster-child left me vulnerable to both death threats and offensive messages in my email. These threats, combined with a disagreement with Cheryl Chase over how my image, activities and personal history could be used for ISNA purposes in press releases, lead to my decision in the fall of 1996 not to do any further publicity related to ISNA.¹⁴

Questions of personal safety and politics aside, there are enormous difficulties in controlling the signifier, even when that signifier is one's own body. This problem has been obvious to me since, after a talk that touched upon the issue was given at my undergraduate university in 1990, I came out publicly about my surgery only to have someone who overheard my conversation walk over and say, "Cool!" I assured her that there was nothing at all "cool" about being clitorectomised at age seven.

This section of the chapter focuses on the pictorial representation of intersexuality in a selection of images of intersexed people and takes note of where those images have appeared and what has been said in accompaniment with them. The first image, a simple family album snapshot of myself with my son, appeared in the San Jose Mercury News' WEST MAGAZINE supplement, in an article written by Donna Alvarado in the summer of 1994. The article was the very first popular news report on Intersex and, more specifically on the Intersex Society of North America. The interview for this article took place in April of 1994, about one hour after I had presented my first conference paper. A reporter came to San Diego to hear what I had to say and wrote a story about the nascent Intersex Society. When the story was ready to go to press, they asked for a photo; they couldn't co-ordinate a photographer in Toronto so I sent them

the only picture of myself that I had that was current. One of the things I liked about the image was that it was boring; it is just a photo of someone who could be your neighbours on their way out to a birthday dinner. In fact, in my own neighbourhood, I am “just a neighbour”--not an activist, not a highly visible intersexual. This is because few, if any, of my neighbours read the kinds of publications in which my work has appeared.



This photo has appeared twice since then, most recently in Leslie Feinberg's Transgender Warriors. It is in Feinberg's "Warrior gallery" that this same image becomes

both more interesting and more troubling. In this version, the photo appears beside a portrait of Pauline Park, who is identified in the book as a Korean-American transvestite.

The question raised by the use of the two photos side-by-side is whether or not transgender projects are always and simply progressive. The two photos are of people who consider themselves to be confounding traditional gender norms in some way or another, but as a surface, visual image, what is visible is simply two people, ostensibly women, with dark hair of similar length, straight bangs, wide set eyes, pale skin and dark clothing. The images are turned a quarter turn toward each other so that it appears as though the two may be turning to address each other. Is this possibly a visual space where the mythologisation of the intersexual and the exoticisation of the “oriental” meet? I have no ready answer, but the question is worth asking. In fact, at a conference in 1998 held at Cornell University, I had the opportunity to discuss with Pauline Park the layout of our photos side-by-side. While she had not previously considered the exoticising potential in the editorial layout of the pictures, she did think it was a possibility, certainly of reading, if not of intent.

The photos below are still shots from video footage taken at an ISNA symposium in 1996 at Mt. Sinai Hospital in Manhattan. The descriptions that follow the photo stills below were written by Anne D’Adesky, medical writer for OUT magazine in an article that was to provide information on the activities of the Intersex Society in educating medical professionals and providing a community for intersexuals. D’Adesky’s article provides readers with a visual description of each of us on that day. Still shots taken from video shot at Mt. Sinai Medical centre are reproduced here for comparison with

D'Adesky's text. The stills show Cheryl Chase, followed by Martha Coventry and Morgan Holmes, respectively.



“At age 40, with her clothes on, and dressed in corporate drag--a flashy green dress, hose and heels--Chase looks more like a soft butch lesbian than a hermaphrodite.



“Coventry, is tall, pretty, and soft-spoken, looking school marmish and a bit like a

drag queen minus the make-up in a long dark skirt and sensible shoes



“Plucky Holmes, a doctoral Candidate who wrote her master’s thesis on intersexuality at York University in Toronto, is doing the dyke-femme number in a stylish violet skirt-with-jacket, killerhose and heels. (D’Adesky, 106+)

The most important question to demand of D’Adesky’s descriptions, all of which purport to provide accurate representations of real, live intersexuals is: “What does a hermaphrodite look like?” Like Foucault’s treatment of Alexina Barbin, D’Adesky’s commentary presumes that there is some identifiable, quantifiable difference about intersexuals that would be visible. Having now met more than 40 intersexuals in person, I can safely say that intersexed persons are not easy to pick out in a crowd; although intersexuality is as common as albinism, it is not as visible because its markers are either covered or removed. Yet, if 1.7 per cent of live births are intersex births, then there is a very good chance that we see “hermaphrodites” all the time. Does D’Adesky expect intersexuals to come with some kind of sign? Her descriptions seem to presume that one

can tell the sexuality and genitals or body type of a person by looking at his/her/hir choice of heels. It is precisely this kind of assumption that makes “queer-bashing” possible. In a personal email to me, Martha Coventry points out, furthermore, that D’Adesky would not be likely to make comments about drag and the appearance of her subjects if she were commenting on persons she presumed to be “normal”(Personal communication, July 23, 1999).

The visual representation of intersexuality in the OUT illustration is nothing short of a tragicomedy. By the time the OUT magazine article was being published, I had become much more comfortable with print than with visual representations of myself and had learned that even the dullest photo could be made to seem sensational. However, when the magazine was just about to go to press, the artistic editors contacted ISNA and said that because it was OUT magazine, the people in the story should not remain visually anonymous, but should be prepared to be *OUT*. As I had already done the West magazine piece, and because within the academy my status was relatively well known already, it was agreed that I had the least to lose by having my picture published to accompany the story. This would allow Cheryl Chase continued cover, and would protect Martha Coventry, herself a journalist/writer, allowing her to remain anonymous within the business. Although each had good reasons to want to avoid having her photos published, the OUT illustration turned out to be so unsatisfactory to all of us that I believe it motivated both Coventry and Chase to try to take more control of the images of intersexuals that would circulate. Both have since allowed photographs of themselves to be published in major publications such as Newsweek and On the Issues. Like the earlier

photos of me in West, their photos have shown them as children, or going about their normal lives, playing with their animals, and families, and carrying out “business as usual.”

After I agreed to be the one whose picture would appear to accompany the article, I offered OUT the same photo that had been printed in other news articles before, but they told me that they had selected a well-known and respected portrait artist, Mary-ellen Marks, to do the photo, and that I would be flown back to New York to have the picture done. Before I left for New York, Ms. Marks contacted me by phone and asked what I was most comfortable wearing; I told her that I wore black jodhpurs and a jacket, or some kind of suit-dress to most professional engagements. She told me to bring what I felt I looked best in, so I took precisely those things: a black frock coat, a white shirt, and black jodhpurs. Because it was a very hot July Fourth weekend, I removed my frock coat on the plane and forgot it. However, I arrived at the shoot with all my other clothes on, though they were promptly rejected by the “wardrobe” assistant who quickly ushered me into the bathroom to put on boy’s briefs, a camisole and size 8-1/2 7-inch spike heels. Apparently, my “killer heels,” really a pair of loafers with a moderate, stacked heel, just did not convey the plucky image they were after. I was very uncomfortable with the idea that this would be the image of “Morgan Holmes, PhD student” that went out in an international publication, but without the photo, the article would have been pulled from the issue, and there was not time to consult or negotiate: there were 5 hours in which to finish the project.



The photo is supposed to be of “me,” but it is a representation over which I had no control and the visual representation of a hermaphrodite as someone with a female top and a male bottom is, at best, facile and sensational. As is typical in large publications that bring in guest writers, editors or artists for an article, a brief biographical “blurb” appears beside a photo of Ms. Marks, the photographer, who is fully clothed with her hands together in a mantis/monkish posture. The biographical brief describes her as a “world renowned documentary photographer and Guggenheim fellow”(OUT, Sept. 1996, 12). Ms. Marks comments on her artistic perception of her subject and the choices she made for the photo’s composition: “She [Morgan Holmes] was kind of sexy, and I wanted it to be sexy. It’s really about the person, not me” (Ibid). In one breath Marks claims both that the picture is about its subject, and that it reflects an image she wanted to create.

Like many of the representations of intersexual people created by those who are not themselves intersexed, this image is filled with contradictions, including claims for the respect of the subject under scrutiny and an authoritative tone that purports to have done the very best by the object of the spectator’s fascination. The only control I ended up having over the shoot was to demand that I not be represented in the leopard print skivvies but in the more clinical, white draped setting. For me, it was the lesser of two evils, but the art department at OUT still managed to print a small version of the leopard and lace costume on the contents page.

These representations provide a record of a struggle for signification similar to that of the Les/Bi/Gay rights movement, which continues to struggle over how the public

should perceive persons who do not fit into the categories of male and female, heterosexual. There is a central concern over whether we should present ourselves as “normal” people, just the same as everyone else with nine-to-five jobs and houses in the suburbs or if we should be insisting upon our creative and flamboyant, absolute difference from the straight community. Early attempts to obtain media attention meant that as a group, intersexuals were willing to present ourselves as flamboyant, so long as the story of our objections to standard medical treatment made it into the press. However, as there are certainly people who have suffered tissue and nerve damage as well as emotional or psychological stress from surgical intervention, but who do not identify themselves as members of any sort of “queer” community, flamboyant or otherwise, our efforts have probably failed them on a variety of levels.

It is problematic to represent hermaphrodites or intersexuals as sexually exotic, as we have seen in Nin’s fiction and D’Adesky’s “reporting”; as tragedies which destroy otherwise joyous events, as depicted both by Melissa Hendricks and the news anchors on 20/20; as monsters in toilets, with nuclear fallout to blame as in the X-Files universe, but there are some positive aspects inherent in the representations. Ambiguous representations can disturb and push the envelope of sexual meaning. Sexual exoticisation of the sort in OUT at least combats the reports claiming that intersexuals have no ‘sexual feeling,’ an inaccurate description commonly used to denote the lack of genital sensation that many surgically altered intersexuals experience. The gross distortion of birthroom events in Hendricks’ work and on 20/20 helped to politicize ISNA’s members and spurred many into action. But most of all, any discussion, however odd or disturbing, is

better than silence. At the very least, even wildly inaccurate or sensational reporting by popular media makes it possible to respond, to make corrections, and to challenge the misconceptions that prevail regarding intersexuality and its implications. Without these popular representations, intersexuals would still be stuck in the medical void of diagnosis, erasure and silence.

In fact, in the years since the rise of internet communications, all kinds of responses and challenges to these representations and more have been raised in forums that can be accessed via computer from anywhere in the world. This has meant that intersexed people have been able to share their outrage at these representations in on-line discussion lists, and have been able to mobilise to create organised responses challenging the popular perception of intersexuality. Furthermore, since the 1990 publication of Suzanne Kessler's groundbreaking essay "Intersexuality and the Medical Construction of Sex," the first to question the wisdom of surgical management of intersexed infants, and the inherently misogynist practice of assigning as female anything that could not "pass" as an "adequate" male, more and more patients and medical professionals have begun to think critically about these protocols too. This questioning is possible, in part, because there are popular representations available, making it easier to point out to broad audiences that the prevailing standards are questionable even if they are not ill-intentioned.

¹ When the stories in *Delta of Venus* were written, Algeria was still a French colony and French artists of the period were well known for their sexual tourism/fetishisation of black men in Algeria. Nin's story participates in this fascination/fetishism with her construction of Moufaka as an African hermaphrodite.

² What Fausto-Sterling actually writes is that "[...]the soap opera drama about Bartmann that played in contemporary Paris suggested that French men, despite their 'civilisation,' actually desired such women: civilisation kept European women under control, decreasing the danger of rebellion, but thwarting male desire. Minute scientific observation converted the desire into a form of voyeurism, while at the same time confining it to a socially acceptable location" (1995,41).

³ I use this variant of the term "queer" here for its nonspecific inclusion of sexual practices and identifications even though I recognise that there is a fear that the category "queer" threatens to elide the specific political needs, work and contributions of lesbian and gay persons. For more on this concern, one may consult Annamarie Jagose's 1996 publication, *Queer Theory: an Introduction*. I retain the use of "queer" because sometimes the need to include multiple possible identifications and practices, encompassing more than just the triad of lesbian, gay and bisexual is required to counter the hegemonic position of heterosexuality as the definition of sexual normalcy. "Queer" in this deployment of it then is meant to indicate any sexual behaviour or identification that could prompt one's parents, family, friends or colleagues to reject, or try to "cure" one's tragic (read: embarrassment to acquaintances and/or family) disease.

⁴ This dissertation is not intended to look closely into developmental psychology, but the need for physical affection has been demonstrated in studies comparing, for example, children in foster care awaiting adoption, children who are otherwise healthy but who are neglected, feral children and children who are more resistant to childhood diseases, perhaps taller than their general peer group, and who are adventurous.

⁵ This surgery, though performed in 1975, is identical to current surgeries except for the use of electric impulse nerve stimulators. The stimulators are now used to measure "evoked potentials" and surgeons consider this to be a significant difference in the procedure although they have no long-term knowledge of how well an "evoked potential" will be borne out in the sensory function of adult women who have had the procedure. One of the impediments to maintaining the evoked potentials (sensory response) is that during surgery, there is no scar tissue build up to interfere with nerve responses.

⁶ I discuss these points further in chapter 3, taking up Bourdieu's work on the *habitus* in his 1976 *Outline of a Theory of Practice* to demonstrate that the actions, activities and uses of bodies always takes place within a cultural context. The *habitus*, according to Pierre Bourdieu, is the social structure that simultaneously informs and is informed by the conditions in which people live, and understand the symbolic conditions of their lives. The *habitus* creates and is created through the material conditions that render the conditions of one's life thinkable, and the *habitus* functions as a regulating force through the collective agreement of a culture's members. Agreement does not always have to be conscious, and it is because agreement is not necessarily total or identical across time or between subjects that there is change in a culture. Neither capitulation nor resistance in the *habitus* is necessarily overt, yet both create and alter the *habitus* through the production of the orthodoxy of rules and predictability and the heterodoxy of challenges and change.

⁷ See Dewhurst 1980, 1992, Overzier 1963, Emans 1990, Hendricks 1993, Donohoe, Hyun-Ju Lee 1994 etc. for numerous examples of how best to manage the parents.

⁸ I believe this to be an allusion by Tardieu to Barbin's life in the convent.

⁹ Because, ultimately, Barbin's body is marked in the memoir as different, I have chosen to use bipotential pronouns when referring to hir. This strategy may frustrate readers, but to appease readers at the cost of deciding, without hir assent, what the "truth" of Barbin's body "really was" is a risk I am not prepared to take. I do not mean to indicate with the use of these pronouns that Barbin was confused, or that hir body was confusing, but only that the narrative s/he wrote is elliptical on the point of hir sex.

¹⁰ This limitation extends as well to more modern personal and clinical accounts of the lives of intersexed persons who may over attribute feelings of non-belonging to their physical difference from their peers.

¹¹ However, it was not the variation alone that caused Alexina to be reassigned as a male; rather, it was hir sexual behaviour -- hir love affair with a girl at the convent-- which coincided with medical and scientific inquiries into the "nature" of the sexes and their inversion that prompted hir reassignment. For Alexina's

reassignment accomplished two things: first, like other reassignments, it asserted that a person could have but one true sex and second, it did away with the troubling problem of lesbianism by showing that Alexina was really a man.

¹² In choosing to refer to Alexina as a "woman," I mean to draw attention to the political space in which s/he grew up: a cloistered, all female environment.

¹³ I do not mean to suggest that nuclear waste and other pollutions are unimportant issues, but I am suspicious of attempts to move people to action that rely on reports, for example, of hermaphroditic whales, birds and fish as though the hermaphroditism were the proof that we ought to tidy up our act. We ought, of course, to tidy up our act, but not because we might otherwise become like the herm-worm.

¹⁴ My decision not to continue as the "poster child" turned out to be a good one for the movement as a whole. Since my departure from the media end of activism, more and varied voices and faces have taken the place where there used to be only one "reliable fall back" person. Sometimes, having one person whom people are aware will do the work, means that, indeed, only one person does the work, but when that person is no longer available, people find out that they can represent themselves, or do the work for themselves. The number of "out" intersexuals does, however, continue to be quite small, with the same dozen or so turning up in publications by the same authors: Alice Dreger, Suzanne Kessler, Anne Fausto-Sterling, and myriad media spots.

CHAPTER THREE

Bodies, Knowledge and Identity

Bodies of Knowledge

In chapter one, I argued that intersex is historically contingent, culturally bounded, and a founding crisis for medical hegemony (c.f. pp 15-16). Through diagnosis and assignment, then, others have constituted intersex subjectivity.

A common response to this situation, and one that I have participated in, has been to declare that whatever “true sex” surgeons declare intersexuals to be after sex assignment and, most often, genital surgery have been effected, one is *still* intersexed. Cheryl Chase, founder of the Intersex Society of North America, states:

My body is not female; it is intersexed. Nonconsensual surgery cannot erase intersexuality and produce whole males and females; it produces emotionally abused and sexually dysfunctional intersexuals. If I label my post-surgical body female, I ascribe to surgeons the power to create a *woman* by *removing* body parts; I accede to their agenda of “woman as lack”; I collaborate in the prohibition of my intersexual identity. (Chase, 1998, 214)

Compelling as her argument in favour of resisting collaboration is, Chase’s response is also problematic because it presumes that sexual dysfunction and emotional abuse persist as problems in *all cases*. While I agree that one might be able to conceive of oneself as being intersexed post-surgery, I am less inclined to want to cast that identity

solely as one permanently abused and dysfunctional.¹ However, Chase's response is a logical outcome of having been cast as pathological; it is her argument that she has only become pathological as a result of the surgery and her family's silence regarding the issue. Chase responds to the medical treatment protocols as one who is simultaneously both object and subject, but the subject position that she tries to claim as her own, intersex, is, ironically, an identity forced upon her by the medical diagnostic system.

Now as objects of my own study, various intersexuals are asked to "speak" as subjects through their writing, and yet they are also forced to remain as "objects" of knowledge by the very fact that it is *my study, and my theory* that seeks to explain what intersex is, has been and could be.²

Intersexuals have been forced to serve as "native informants" to the medical profession in Euro-American culture, and to anthropologists in New Guinea, the Dominican Republic and in North Africa. But intersexuals who have resisted the medical characterisation of intersex as a set of diseases have been denounced, not simply as naive, but as dangerously ignorant. Dr. John Gearhart, a Johns Hopkins urologist, has declared that present day intersex activists are "zealots" (Angier, 1996,np) and has accused the intersex movement of "a giant, giant misrepresentation" for its assertion that genital surgery is tantamount to genital mutilation (Coventry, 1998, 20). To these statements, intersex activists have responded that the supposed *medical* reasons for genital surgeries on intersexuals are, like traditional female circumcision practices, in fact motivated by *culture* and out of a desire to have children who appear the same as all the other children of their "true sex." Martha Coventry, an intersex activist and journalist, writes that "[...] in hospitals just down the street in any big American city, five children a day are losing

healthy, erotic parts of their bodies to satisfy a social demand for ‘normalcy’”(1998, 60).

Because of the brevity and popular media venue of her article, Coventry does not address what motivates the social demand for normalcy, and the links between social demands and medical protocols are not made clear in her article. Therefore, some consideration of these issues is in order.

Alice Dreger concludes her book, Hermaphrodites and the Medical Invention of Sex with the observation that:

The hermaphrodite was and continues to be a person whose body gets caught up in cultural ‘border wars’ --wars over the borders separating males and females, men and women, boys and girls, borders separating the acceptable heterosexual and the disfavoured homosexual, borders separating those with authority from those without.(1998a, 198)

Of course, that such wars or struggles have been and continue to be carried out shows that the categories themselves are not stable, and this applies also to the issue of those who have power and those who do not. Although Dreger invokes Foucault’s chastisement of contemporary Westerners as “other Victorians,” she does not engage Foucault’s complications of the terms of debate, or of the operations of power in discourses on sexuality (Ibid).

Foucault argues in the first volume of The History of Sexuality that power is not a simple case of an opposition of those who have it against those who do not. He contends that neither the state nor the legal system is the source of regulatory power, in this case as it applies to sexuality, but rather that each is a terminal point of power, or, in other words, a point at which multiple deployments and articulations of power become

regularised and reified (1978, 92-93). Foucault argues that in fact, power is the result of negotiations and negations, of confrontations and transformations in relations of force that are always coming into being, but never actually stable (Ibid). As this applies to Dreger's observation, it is a mistake to think that in the border wars over sex and gender women are the powerless and men, particularly medical men, are the powerful. Of course, the medical men established for themselves the ability to declare and demonstrate certain truths; however, they did not do so in a simple act of professional tyranny over the uneducated masses. Rather, Foucault's idea suggests that what truths medicine, or the state, or the law could invoke were the result of contestation, struggle, argument and transformation in "immanent relations of force," shared between different bodies of power (Ibid). In other words, what medicine said to be true about sex was, and continues to be, roughly concordant with the will of society as a whole.

Of course, Foucault's argument is likely to infuriate those who, as infants or children, were diagnosed, isolated and altered against the will that they declare or claim for themselves in the adult present.³ The experience of these individuals, myself included, is that they were completely powerless, and that parents and doctors decided for them and imposed upon them their own ideas about what bodies are for and what they should look like. It is critically important not to forget that the bodies I am writing about are not metaphors for political struggles, but rather, the terrain of the struggle; still, Foucault's point remains valid to this project because little can be gained by thinking of the medical system and its practitioners as an all-powerful entity cordoned off from the rest of an exploited society of sex and gender neophytes.

Though the infant's or child's intersexed body is a material fact, and a

phenomenological source of knowledge for the child, this is true of any body. We do not need to deny that the surgeries can cause very real traumas and pain to these bodies and psyches in order to recognise also that, in fact, there is a sense in which intersexed bodies, like all bodies, *are* metaphorical. That is to say, part of the reason why intersexed bodies are surgically manipulated to appear as much as possible as only one sex is that the bodies are metaphorical representations of the parents' bodies, and of their sexual identity/ies. In this sense, sex, and the genital markers of sex are over-burdened and over-stuffed categories, forced to carry multiple significations or meanings of gender, class, race, sexual identity, and sexual practice, not only of the individual to whom they belong, but of his/her parents, extended family, and culture. And these meanings, significations and metaphors do not emanate from the science laboratory or surgical theatre, but rather from the larger cultural web of which the lab and surgery theatre are only parts. To understand what happens there, we need to understand the will or social hegemony that guides dominant ideas about sex, genitals, gender and sexuality. One such instance of social hegemony is the medical "gaze." For Foucault, (--) "[...]the gaze that sees is a gaze that dominates[...]" (1975, 39).

The "gaze" of Foucault's archeology is not the poetic, benign and passive gaze of longing; rather, this is the gaze described by psychoanalytic thought, an intentional *looking* which creates as much as or more than it *sees* meaning(s) and their boundaries. This is the medical gaze which *creates* as much as, or more than, it *describes* pathology.⁴ It is also a gaze *within* a gaze as the medical is, as I have already argued, only a part of a larger whole. In recognising what the medical gaze creates, or reifies, as a result of its being a cultural nexus point, there is also the possibility of taking up another part of the

Foucaultian project: recognising where and how resistance happens.

By understanding that power is deployed from multiple positions, and that in addition, where there is power there is also resistance, we do not undercut the fact that “real” bodies are sometimes oppressed. Indeed, what we gain by noting the different points from which power emanates is the ability to develop a strategy of resistance that, in its contestation and struggle with hegemonic ideas, creates a new set of power relations, and hence, new truths about sex, sexed bodies, sexualities and genders.

The consequences of Research Gaps

This section seeks to determine what has been said about particular kinds of bodies within discourses of science, anthropology, and to some extent, to examine the meta-analyses of these fields in historical and theoretical works pertaining to intersexuality. As such, the section plays a part in this chapter’s interest in examining how culture enforces norms regarding both the signification and the appropriate uses of bodies. How does one acquire the ability to signify, both *to be* and *to bear* meaning through the body in culture? How and why is this *acquiring* not simply a process in which a subject is free to choose the ways in which s/he will embody a subject position. Specifically, I want to know how it is that bodies that “do not fit” are brought into the symbolic realm in Western culture, and I want to explore the limits of this confinement. How does medical observation, diagnosis and management bring some bodies into being while refusing others? Anne Fausto-Sterling, in her discussion of exactly this process as it relates to the management of intersexuality states:

The treatment of intersexuality in this century demands scrutiny.

[...]Society mandates the control of intersexual bodies because they blur and bridge the great divide; they challenge traditional beliefs about sexual difference. Hermaphrodites have unruly bodies. They do not fall into a binary classification: only a surgical shoehorn can put them there. (1993b, 25)

While it is true that it is the surgical shoehorn which engenders the intersexual, it operates in accordance with a larger ideological shoehorn of a sex and gender binary. What the treatment of intersexed children underscores is that we are all forced to conform to specific, binarised, heteronormative gender roles. Although this dissertation explores a specific medical enforcement of signification through the gender assignment and medical management of intersexed children, the force being exposed is merely a more deliberate force than that to which all persons are subjected. It is different in degree rather than in kind. The surgical violence to which intersexed infants and children are submitted may be likened to the torture device in Franz Kafka's "The Penal Colony". Kafka illustrates that the body itself does not learn from punishment but those who witness it learn that the punishment for non-conformity is extreme. In the case of "The Penal Colony," punishment results in death of the body; in the case of intersexuality, many intersexuals assert that their surgical treatment/punishment has resulted in a death or paralysis of their souls. Yet, as even medical professionals are beginning to acknowledge, there is a "[...]conspicuous lack of [...]longitudinal data and appropriate longitudinal analysis [on intersex patient outcomes]"(Reiner, 1997, 224). Outside of the medical specialities involved, there has been only a handful of ethics essays devoted to the issue of management, and there is an overwhelming absence of cultural work on intersex in

humanities disciplines. I want to address this absence by considering why so little is known about intersexuality in fields outside medical and surgical practice.

A search within cultural anthropology for the terms “intersex” and “hermaphroditism” and their variants yields a wealth of articles and full-length studies on communities of 5-alpha reductase deficiency in Africa, New Guinea, the Dominican Republic and on the question of whether Native Indian “berdache” and Hindu *hijra* are biological intersexes or examples of more fluid gender paradigms within a biological sex system. What is pointedly missing is an anthropological study of intersexuality *within* Euro-American cultures. In fact, on the issue of domestic cases of intersex, Margaret Mead, in a somewhat vituperative tone, claimed that “We [anthropologists] do not make detailed studies of the patients who come into our city clinic with such deep structural abnormalities that it is impossible to tell to which sex they belong” (Mead, 1977, 29). Her interest in domestic cases of intersex is limited by her discipline’s historical tendency to look *outside* one’s own culture. What is peculiar about Mead’s tone is that as a relativist, part of her goal in looking outside her culture is to learn more about the cultural *constructs* of sexuality in her own culture. Thus, it is somewhat surprising that, given the latitude and flexibility of biological sex categories and cultural expectations in the Samoan system that Mead herself remarked upon and studied, she remained so wedded to the notion that intersexed bodies are instances of deep structural abnormality. Nonetheless, Mead clearly omits any study or interest in North American conceptualisation of intersex, and if intersex failed to capture Mead’s attention as an area worthy of examination, then it can hardly be surprising that it has not fallen into any other major research or publishing projects.

The general omission of intersexuality from domestic study is symptomatic of anthropology's early tradition of looking outside its own culture for "basic human truths" that have become obscured by the complications of life in the "developed" world. There is also a history of political domination making it no accident that anthropology has traditionally been undertaken by European, British and American scholars who have done research and field work in the service of that domination (Ingold, 1994, xiii). Mead, for example, wrote of her discipline's reasons for studying the sexuality and bodies of other peoples, stating:

When we study exotic peoples whose whole way of life has been built up differently, [...]we have an opportunity to follow the body through its growth, watch adults and children communicate through the way in which the child's body is treated, and yet keep our own clothes on. Without direct reference to our own selves, far enough removed from the uplift bras and the way Grandfather looks when Granddaughter wears one of them, the ways of the body may be followed in delicate, far-away out-line, and perhaps some new understanding of what human beings are and have the power to be may be learned as no stripping to a tingling and sensitive skin could ever teach us at home. (1977, 80)

Mead's potentially critical view of the anthropological "distance" in the study of "exotic" peoples is not one that she works to its fullest in her own practice.⁵ The tradition of looking outside one's own culture--for the sake of expediency and personal comfort as an "observer," and because of certain disciplinary and ideological commitments to an idea of a pure state of human being in "primitive" peoples--makes it no surprise that

understandings of and approaches to domestic intersexuality were paid little attention by early anthropologists.

That domestic instances of intersexuality are missing from more recent work in medical anthropology is somewhat more surprising, given more recent shifts toward ethnological research into domestic knowledges of local peoples. As a continental pursuit that has translated first into studies of disappearing native populations in North America, however, the slow application of ethnography to North American (Western) culture is, perhaps, predictable. Unfortunately, the omission of the Euro-American context for the medical construction of intersexuality has meant that since new surgical management protocols were implemented in the post World War II period, there has been no one to offer any insight into intersexuality outside the medical framework. Furthermore, there has been little interrogation of how this framework has influenced the ways anthropologists have approached ethnographic research where they encounter intersexed persons in non-Western cultures.

These oversights, in accordance with larger Euro-American social perceptions, have failed to challenge the idea that medical professionals alone have the authority to distinguish what the truth of intersex is. Until quite recently, and only through popular media⁶ which are as likely to distort as to illuminate the issues, intersexuals themselves have not been looked to as sources of authoritative information about what the *truths* of intersexuality are, or could become.

Third Sex? Third Gender?

For intersexuals looking for affirmation of their intersexuality, the lack of attention

to Euro-American cases of intersex has meant that there has been little choice but to “step outside Western culture, [to] where there are examples of third gender social roles, many of them assigned to those with intersexual bodies” (Nussbaum, 1999, 51). Emily Nussbaum, who has summarised this approach in her article “The Sex that dare not speak its name,” reads Gilbert Herdt’s work on third sex and third gender models as telling a primarily positive story about how different cultures deal with anatomical and gender variance in their populations and claims that, “parts of Sambia, a province of New Guinea, and the Dominican Republic have high proportions of 5-AR [5-alpha reductase deficiency]; these cultures accept that at adolescence a few of these seeming girls will develop masculine genitals and grow hairy and muscular”(Ibid.). Nussbaum’s summary is highly selective, however, and does not note that Herdt reminds readers that *recognition* and welcoming *acceptance* are not the same at all:

Note again how the *kwolu-aatmwol* [the Sambia word for those with 5-AR] exists in a culture of extraordinary gender differentiation, with sexual dimorphism marked in humans and in nature according to the Sambia worldview. That such a categorical alternative [*kwolu-aatmwol*] exists at all is a true accomplishment, a partial victory of nature over culture--not as complete as the American transsexual who uses the wonders of medical technology to do so, but still rather impressive--such that *we might be inclined to see it* as a triumph of the third sex. And yet, in the Sambia scheme of things, no classificatory distinction is so tenable that separates sexual nature from sexual culture when it comes to these persons.

“Thirdness” in nature exacts its social cost; like the hijras, this form of

thirdness *is not* admired, and any evidence that persons would cling to the categorical position must cause us to take notice. (Herdt, 1993, 68-69. My emphasis)

Herdt's point is that the *kwolu-aatmwol* hold on to their categorical positions in spite of intense negativity and social stigma, that place them, like the *hijra*, in a marginalised position. Yet Nussbaum takes no notice of this complexity, and this may result from the fact that much of her article relies on the direction of Cheryl Chase to provide *the* intersex point of view. Chase, who publishes the ISNA newsletter, Hermaphrodites with Attitude, has welcomed contributor articles that compare American intersexuality and transsexuality to the *hijra* as a positive social position that intersexuals might take up:

In South Asia intersexed people are often, perhaps usually, handed over to transgendered adults to raise. They grow up in a family and community of people who say, "We are neither men nor women," and whose genitals, by birth or by choice, resemble neither male's nor female's. They call us Hijras. [...] We go from house to house to dance and sing and bless infants at their birth. This ensures their fertility. We also bless couples at their wedding to ensure their fertility. We are paid for doing this, and this is how we earn our living. (Ogborne, 1994,3)

The picture thus painted for intersexed persons receiving the Hermaphrodites with Attitude newsletter is that we could simply look at other cultures where a "third" sex or gender category exists/ed and transpose that model onto a Euro-American context. The portrait given here of *hijra* is positively glowing, but its omissions are extreme. Anne

Ogborne claims that *hijras* are paid for their services and looked upon as spiritually integral to the Indian culture, omitting from his account any sense that *hijras* are less than revered by some members of Indian culture. A professional colleague from India once told my partner that the *hijra* are considered “a general pain in the ass” because they show up unbidden at weddings, births, house warmings and so on, and *demand* money for services that people do not necessarily want. Ogborne’s totalising portrayal of Indian culture and the place of *hijra* within it has contributed to the trend of people in the intersex community sometimes expressing the idea that other cultures can provide viable models of refiguring and reconceptualising intersexuality. In these accounts there may be no sense that such a move requires a necessary translation from the “third gender” categories of other cultures to the “intersex” category of Euro-American culture. Thus, some intersexuals have declared themselves not just similar to “two-spirit” people, but as actual two-spirits. Raven Kaldera, who has CAH writes:

How do I manage? Well, I’m a shaman, a pagan priest(ess) of the Dark Goddess and the Lord of the Dead. Thousands of years ago, I might have been seen to be a shaman at puberty, been acknowledged and valued for the living, breathing, magical, mythical beast that I am. Those of us in the gender community who consider ourselves shamans[...]are starting to move. We want our birthright back. (Kaldera, 1998, 227-232)

Looking to other cultures for spiritual guides or leaders who will restore this “birthright” elides the specific differences in cultures that are temporally and/or geographically distant. The line between learning or appreciating a different way of conceptualising intersex and simply appropriating other cultures’ attitudes risks being

crossed when people search for tattoo artists and “New Age” spiritualists who will valorise their intersexuality as an integral element of the spiritual universe. When intersexuals attempt to adopt other cultures’ cosmologies, they risk abandoning more practical concerns, and turn other cultural systems into commodities. Native writer Beth Brant cautions white people that they cannot just “go native” because whites can never understand the experiences or contextual elements that make a native cosmology make sense and that when whites do this they are effectively stealing native peoples’ spirit(s) (1994, 52).

If the potential misuse or appropriation of another culture is not enough to cause one to worry, there is at least one further problem in looking outside Euro-American cultures to make sense of intersex. On the Intersex Voices website, Raven Kaldera writes that s/he is committed to both Transgender and Intersex political goals. Kaldera is not specific about what those goals are, but makes a claim to being uniquely capable of understanding these distinct identities because s/he is a “Shaman, Walker Between Worlds” (www.qis.net/~triea/raven.htm). I am interested in Kaldera’s use of terms like “shaman” and “walker between worlds” not out of any simple objection to their use, but because their adoption continues to place intersex identity *beyond* the frame of Euro-American culture and does not challenge that culture on its own grounds, within its own framework. Such an approach not only risks appropriation of another culture, but also its distortion, for the debate over the function of recognisable third sex and third gender categories in traditional cultures is far from settled. Walter Williams, for example, takes Native third gender⁷ categories to be a positive recognition of “the different skills and insights of a class of people that Western culture has stigmatized and whose spiritual

powers have been wasted” (1992, 3). At the same time, Gilbert Herdt worries that “alternate or ‘deviant’ third-sex and third-gender roles are[...] typically displaced to the illicit, immoral or illegal margins of society” (1993,47). The existence of third sex and gender categories does not necessarily reflect a social reality in which a culture *welcomes or celebrates* third sex or third gender persons. Herdt’s interest in third-sex and third-gender categories provides a corrective insight to traditional anthropological assumptions that these “excess” sex and gender categories represent a confused or impure state indicating a lack of sophisticated culture. His Third Sex, Third Gender collection offers complex views of the ways in which sex and gender categories function. Herdt’s point is not that third-sex and gender categories necessarily signify a *better* or more liberating and positive means of organising bodies, but rather that such categories are not evidence of a more “primitive” culture.

This appreciation for the cultural complexity of recognised third-sex and third-gender categories is missing from Ogborne, Kaldera, and Nussbaum’s deployments of third-sex models. As a result, Western cultural distinctions between being lesbian or gay, having bodies that are neither male nor female, and having a transgendered identity are elided in their work. Ogborne omits inconvenient details, while Kaldera sutures or perhaps even compresses many different concepts together, and Nussbaum glosses over the anthropological research so that the Euro-American conceptualisation of intersex appears “backward” in comparison with smaller tribal cultural attitudes. None of these writers is an academic, and the writing of both Kaldera and Ogborne is of the personal testimonial sort rather than being theoretical or analytical. Nussbaum’s writing, while not testimonial, is not theoretical but journalistic, and follows the formula of telling two sides

of a story in opposition to one another. Nussbaum mentions third-sex or third-gender models being adopted by some members of the intersex society as though that were the primary focus and best strategy for responding to the medical model. Though one may wish for more illuminating detail from Ogborne regarding the spiritual sanctity of the *hijra*, or on what Kaldera intends to claim by stating himself to be a shaman and a walker between worlds, such clarity or specificity is not available. Both Ogborne and Kaldera write their statements as though they were self-evident and true, suggesting that one can become something simply by claiming it.

Such uses of other sex/gender paradigms, whether accurately or inaccurately, have made the modern intersex movement appear ridiculous to medical practitioners, who typically respond that third-sex or third-gender models do not work because one cannot possibly say, “Boys get in this line, girls get in that line, and all the little hermaphrodites get in this other line” (Nussbaum, 1999, 51). Dr. Walter Meyer, who made this comment, misses the point that current social dicta are not so inclined as they once were to line people up according to sex; there is at least a liberal pretence to declaring one’s sex irrelevant to determining the doors through which we will walk. Instead, Meyer fixates on this one approach taken by some active and vocal intersexed people, and applies it in a broad stroke to discount a whole movement. Meyer’s characterisation of an entire movement as ridiculous because of the comments made by a few show that his approach is both opportunistic and inclined to sensationalism, but it seems unwise to leave the movement vulnerable to charges like the ones he makes. For at the very least, Meyer’s comment indicates that, in many very real ways, one’s sex does remain relevant, and that as a culture, we are far from accepting or welcoming a third category. It makes little

difference to medical practitioners that only a few intersexuals are calling for a *bona fide* third sex or gender category, while most are simply stating that intersexed children should be assigned a gender that corresponds with the dominant body features they will develop as they mature physically, and surgery should not be used to enforce any assignment until the children can provide consent and make choices for themselves.

Declarations of thirdness call attention away from ethics-oriented proposals, appropriating and romanticising “Other” cultures, sometimes ignoring the far from ideal lives that recognised sex or gender “variant” people endure in those cultures. The proposal that intersex persons be recognised as a third sex, furthermore, sets up a sex category that is likely unworkable for a majority of intersexed persons; unlike intersexuals in the smaller populations of the Dominican Republic, Pokot, and Sambia, the Euro-American population of intersexuals is so dispersed that they would remain isolated in any “third” category. Those claiming a third sex or gender status for themselves have not adequately noted the distinction between deciding *for a child* that s/he is a third sex or third gender and making that decision *for oneself* as an adult. I am not contesting the validity of claiming a third sex or third gender for oneself, and demands for such self-identification possibilities to be included on official certificates such as driver’s licenses, census reports, and voting registries would be one effective means of recognising intersexed persons. What I am not proposing is that we assume from the outset either that a child needs surgery to effect a clear social gender, or that a child should be identified as a third sex or third gender at birth because of having intersexed anatomy.

My goal then is to try to rethink, as much as is possible from an internal position, the Euro-American sex and gender system as it relates to intersexuality and its medical

management. The point, however, is not to place intersexuals on display; nor is it to construct largely esoteric theories of how intersexuals might release all of Western civilisation from our bondage under the binary sex/gender system. I am not opposed to such projects, which have been taken up in the work of Marjorie Garber, Julia Epstein, Deborah Findlay and Suzanne Kessler, all of whom draw links between the misogyny and sex-phobic attitudes of scientific research on sex and gender and the medical management of intersexuality.

For the most part, I have chosen not to include photographs of intersexuals in this document. In refraining from using clinical photos, and using only very few photos and video images of intersexuals, it is my goal to frustrate the potential desire of readers to “see” what an intersexed person looks like. I have also chosen whenever possible to use the words of intersexuals themselves to describe their experiences. While intersexed persons are not necessarily better informed on all aspects of intersex, they do have perspectives that have not been granted enough serious consideration. Intersexuals have been placed on display in enough medical textbooks, and esoteric theories that have not listened to or invited the commentary of intersexuals have proliferated in the past several years.⁸ At the same time that I seek to listen to the available voices of intersexed persons, my intellectual commitments require that I not regard their comments as *a priori* more valid than the voices of non-intersexuals who have contributed to debates on the significance of intersex to theories of masculinity, femininity, sexuality and subjectivity, and embodiment in the West.

Though I once believed that intersexuals alone were uniquely qualified to discuss intersex identity and experience, I no longer believe this to be absolutely true, partly

because I no longer believe that “experience” can be accurately retold, or that it is as unified or unifying as narratives of experience claim to be. As Joan Scott points out in her article simply titled “Experience,” claims that experience are critical in identity formation often edit out certain kinds of experience while highlighting others. In the intersex community of the present, for example, there is an emphasis on experiences of medical management and a general absence of narration about other experiences, such as school life, family interactions, involvement in day-to-day activities, religious or spiritual background, class background, etcetera. This means that it is difficult to know what the intersecting factors may be, if any, that make some outcomes better than others. Future research on intersexed children and their families should do qualitative analysis of family dynamics and situations to assess how they can influence outcomes. Thus far, medical specialists have maintained that families merely need to believe that their children have had their sex firmly established, but my work here shows that this is not necessarily sufficient in many cases.

Caveat

Writing about the intersex community presents challenges to a cultural theorist attempting an ethnography of the group. An ethnographic study would customarily be of a group of people who share a common political and cultural history or ancestry, and, for the most part, a common language. Yet the “community” about which I am writing is primarily “virtual,” that is, it exists mostly online in email discussion groups and personal and organisation websites. Intersexuals represented or representing themselves in these forums come from geographically dispersed and distant locations, from many religious

systems and spiritual beliefs, from disparate educational backgrounds and from many different language backgrounds and ethnicities.⁹ There are participants from Germany, England, Spain, Japan, the United States, Canada, New Zealand and Australia, all of whom write regularly, and many of whom have pages within various intersex websites.

However, aside from this electronic contact, intersexuals meet each other only rarely in person. In 1996, the Intersex Society of North America (ISNA) held its first retreat in Sonoma, California, and video-taped portions of the retreat have been released as “Hermaphrodites Speak,” a 30-minute information video that is now distributed to instructors in medical schools and sexuality studies programmes. In 1997, ISNA held its second retreat, this time in North Carolina; this retreat was not filmed. In 1997, members from around the world gathered in England to attend the Androgen Insensitivity Syndrome Support Group United Kingdom (AISSGUK) conference in England, and another meeting took place in August of 1998 in Chicago. Beyond these meetings, intersexuals from the online groups sometimes arrange to meet each other while travelling.

I have met Max Beck, Cheryl Chase and Martha Coventry through these kinds of arranged meetings. I have also met several intersexed persons in Canada this way. Intersexuals on the discussion lists often liken these meetings to finding lost siblings; however, for the most part, the community and its meetings are textual. To write, then, about the development of an intersex community or network is necessarily to write about texts, and it becomes apparent in this process that intersex is as much about intertextual relationships as it is about “community.” Furthermore, this intertextual set of relations is not only between individuals, but also within individuals who see themselves identified through their medical records, or in the absence of those, in the information they can find

in medical textbooks and case studies. Intersexuals, who report again and again that they grew up surrounded by a conspicuous silence about their bodies, sometimes even find out about their own cases in medical journal and textbook publications.

Community

As a participant/observer in the modern Intersex movement from 1993 through 1998, I have had a particularly close relationship to my field of study. However, aside from occasional questions regarding spirituality, body image, political goals and strategies, my participation on electronic discussion lists for intersexuals and in group activities such as meetings or demonstrations has not been pointedly academic. Being an intersexual on a discussion list for intersexuals is no more or less focussed than being an academic on an academic list. There are long periods of silence, occasional flame-wars, a proliferation of messages that have nothing to do with the ostensible purpose(s) of the list, and all the digressions from there that one can imagine. What does distinguish intersex discussion lists from the others organised around some form of political or identity affiliation is that while contributor-/members can choose to be feminist on the feminist studies list, and choose to be queer identified on the queer studies list,¹⁰ members on the intersex lists did not choose to be intersexed. The narratives told indicate that intersexuals writing on the lists are very much aware of themselves as *produced* subjects who may capitulate *to*, or resist medical interventions and cultural presuppositions.

This particular record of the experiences of intersexuals is very much aware that, as Joan Scott points out, experience is not something that an individual has, but rather a systemic process that actively produces and differentiates subjects as individuals (1992,

25-28). This project is an account of intersex that does not simply render the intersexuality visible, but that also renders visible the system that produces the intersexual. Unlike a traditional ethnography, this work does not take the objects of its study simply as the subjects who know, based on their experience(s). This project draws attention to the available narratives about intersex, but it also asks under what conditions such narratives have been made possible, not only by the medical system that produces intersex as a pathology, but also by a current of gender politics that has produced and is producing intersex as an identity.

What I am proposing here is a kind of doubling that questions both the narrative of intersex as a terrible deformity best covered up with surgery and silence, the story put forth in the discourse of medical texts, and the narrative proposing that one take pride in one's intersexuality to reclaim it as a subject-identity as legitimate as typical maleness and femaleness in contemporary society, the Intersex Society story.

Because "intersex" is a medical diagnostic label, list members spend a lot of time trying to understand the mechanisms¹¹ through which we have been both diagnosed and "cured," although we were not actually sick.¹² This is the tricky task of reclaiming as "normal" something that has been cast as pathological. Sally Gross, a theology student from England, looks to *Torah* to consider hir intersexuality and argues that although "As a brute physical phenomenon, the bodiliness of people like us who are born intersexed challenges cherished assumptions about sex and gender made by many people within Western society" (http://www.qis.net/~triea/IS_and_scripture.html), intersexuality may perhaps have been God's original design for humans. In a discussion of Genesis 1:27, Gross provides the following translation "So God created Man [the Hebrew is "Adam"]

in his own image, in the image of God he created him; male and female he created them”

(Ibid.) and comments that:

[...]there is a syntactic ambiguity in Genesis 1:27 which led Jewish commentators to suggest our species was originally created androgynous. The syntactic ambiguity and this particular Rabbinical gloss were later seized upon by some of the philosophers of the Renaissance, who viewed hermaphroditism as a mark of wholeness which was subsequently lost. (Ibid.).

Kiira Triea, who was assigned male at birth but reassigned female at age 14 when she experienced a feminising puberty, writes that:

[...] it was exactly my “treatment” and how it was inflicted upon my being which really damaged me more than anything else and prevented me from having what I think of as “normal” happiness. That damage caused me to live in fear and loneliness, running from every person who might have been attracted to me, for most of my life. This is how I know that what was done to me was not for my well being; how I know that I was simply a creature to be utilized as a research subject in one of the largest medical teaching hospitals in the world.

Like Sally Gross, Kiira Triea locates her troubles in other people’s perceptions of her sexuality and gender rather than in the condition of her body. Another member, Toby Sinclair, who rejects either a male or a female gender and prefers a “neuter” designation, provides a humorous account of the medical establishment’s push for Toby to assume a male assignment after having previously refused a female one:

Presenting oneself as a male can be difficult if one is five feet two inches tall, has a high voice and no facial hair [...] But the Experts were confident that these difficulties could be overcome with the simple addition of a penis, or a reasonable facsimile thereof. Since I did not have such an appendage, the Experts (who had obviously never tried it themselves) recommended wearing a jockstrap with a rolled up pair of socks in it to produce a strategically placed bulge. (Sinclair, 1997.

<http://www.qis.net/triea/>)

In the end, after discovering that the socks did all kinds of unpleasant and ridiculous things when one engaged in such typical activities as walking to school, riding a bike, or sitting down, and that no one could see the bulge anyway, Toby decided that the experience had “[...]taught me as much about the Experts as it did about the proper use of socks” (Ibid.).

Sometimes, the response of intersexed person to the medical experts is actively to produce a different kind of intersex subject--one not principally defined as a patient. Like current movements in the gay, lesbian, and queer communities, contemporary intersexuals have picked up the mantle of PRIDE. Diane Anger, who has since left ISNA and started her own Christian-based support group, has written of her decision to appear on Jerry Springer, disclosing her AIS: “It was not only liberating to tell the whole world my big, dark secret, but it was also liberating to finally admit to myself that, YES, I am an INTERSEXUAL” (1997, <http://www.qis.net/~triea/>).

I have organised and participated in this approach through my contributions to quarterly ISNA publications, and participation in the 1996 and 1997 Toronto Pride

Parades; however, when I look back on those activities, one of the things I realise is that the pride discourse only works as a response to the idea of shame, and as its obverse, does not do enough to challenge the category. The problem with approaches that simply posit new identity categories and set out to legitimate them is that they

[...]take as self-evident the identities of those whose experiences are being documented and thus naturalize their difference. They locate resistance outside its discursive construction and reify agency as an inherent attribute of individuals, thus decontextualising it. (Scott, 1992, 25)

Using experience as a legitimate ground for the production of knowledge is attractive and useful because, as the feminist axiom “the personal is the political” demonstrates, experiential knowledge contests the values and uses of the requirement for “objectivity.” Scott points out in her article, however, that the drawback to this use of experience is that it often universalises the experience of one, or of a few, and takes them as representative of the many. Experience, then, can function as a kind of synecdoche in which only certain kinds of experience count when it comes to the representation of a whole diverse group of people.

In the case of the intersex movement, which has become not just a few voices crying foul in the medical wilderness, but a slick media-driven and consumer/lobby *movement*, the part that has come to represent the whole is genitally oriented and is based on a politics of queerness. Like the mainstream culture that created the diagnostic category, this use of intersex as an identity category retains the synecdochic sign of genitals that cast women as those who lack, or who *are* their reproductive capacity, and men as those who possess the phallus. The signification of the subject through presumed

genital attributes, whether one accepts this as real or symbolic, remains unchallenged in the current signification of the term “intersex.”

Scott’s point that a politics based on experience does not dismantle the terms of its construction is borne out in the contemporary intersex movement: like the surgeons and other medical specialists involved in the treatment of intersex, the Intersex Society, which is by far the loudest of the support groups and the one with the most media coverage,¹³ leaves intact the terms upon which the category of intersex has been constructed; one of those terms is genitals. I am proposing that understanding the emergence of the intersex movement, and furthering the serious attention it deserves requires understanding that this identity is not transhistorical, something that has always been here just waiting to be properly apprehended. It also requires understanding that what it means to be intersexed will change. Whether the identity and diagnosis will become obsolete is something that I cannot predict, but the neat alignment of genitals with identity in both the diagnostic practice and the creation of the contemporary intersex movement faces a serious and productive challenge for “[...]the appearance of a new identity is not inevitable or determined, not something that was always there simply waiting to be expressed, not something that will always exist in the form it was given by the particular political movement in the particular historical moment” (Scott, 1992, 33). This understanding of the variability and contingency of identity has not yet been fully realised by the intersex movement’s representative voices.

Even though the current intersex movement challenges the mainstream to reconsider its view of genital anomalies as a negative set of conditions, the movement has actually reified intersex as a category of physical conditions that threatens the terms of

maleness, femaleness and heterosexuality.

The mapping that I do of intersex culture, which is also necessarily a consideration of dominant ideas regarding sex, sexuality and gender in Euro-American culture, results from four years as a participant member on three different electronic, intersex discussion lists and in various political actions, and “grass-roots” organisations. Early in this period, our email discussion groups were quite small, with as few as four discussants on the now defunct discussion list, *isna-l*. Since then, on-line membership has grown to include as many as 30 participants each on a handful of different lists run by members or former members of the *isna-l*, which no longer operates. These electronic forums are private, open only to intersexuals, and upon occasion to partners on an invitational basis. When it happens, partners are included because it is generally hoped that they are genuinely interested in the specific issues that intersexed people pointedly worry about, and because it is a general supposition that intersexuals pose a peculiar set of challenges to those who would dare have us.¹⁴ For the most part, however, partners do not seem to have had much to say and have remained mostly silent. A number of points may be drawn from this silence. First, “partners” are sometimes not around for the long haul and they leave the list when the relationship ends. This has happened in a few cases, often with the intersexed person attributing the break-up to his intersexuality.¹⁵ Second, partners may hesitate to “speak” on-line, feeling it is their primary role to listen and observe. Third, it may be that over time, intersexuals, contrary to their own perceptions of themselves, prove no more or less challenging than any other partner, leaving little need for our companions to speak or require support in handling our “special” intersex needs.

The fear that our partners would be/must be faced with particularly difficult

lovers often came up in early questions over whether partners of intersexuals might need their own electronic support group. In the end, such a group never materialised. Much of the initial call for such a group may be attributed to the fact that many members were new to the internet and eager to belong to as many discussion groups as possible. Perhaps in the end it was simply not necessary to have such a list. Perhaps it would have been a good idea to have such a list, but was not badly enough needed for anyone to actually set it up.

I am interested in the discourses produced in these electronic forums, and in media releases because I am concerned with the position *inside* the temporal and cultural space in which they formed. They do not exist as a challenge external to a culture's ideology of gender, but also act within the allowed discourses of individuality, production and resistance that constitute a living culture. According to Pierre Bourdieu the *habitus*--that is the defining features, rules and regulations by which a culture organises itself--is ever changing. Bourdieu posits the habitus as something akin to a discourse that "[...]feeds off itself like a train bringing along its own rails," (1995, 79) implying a static reproduction of the same, yet he also notes that:

[...]generation conflicts oppose not age-classes separated by natural properties, but habitus which have been produced by different *modes of generation*, that is, by conditions of existence which, in imposing different definitions of the impossible, the possible, and the probable, cause one group to experience as natural or reasonable practices or aspirations which another group finds unthinkable or scandalous, and vice versa. (ibid, 78)

In spite of its apparently static formation, Bourdieu's account of the habitus can

be identified as “post-structural” for its clear emphasis on the discursive production of meaning, including both ruptures and continuities in that production. The task at hand is to examine the ruptures and continuities of our ever-changing *habitus* such that a critical appraisal of the twentieth-century idea of “intersexuality” can be brought into focus, showing both the limits and uses of the category “intersex(ual)” and of its medical categorisation and treatment as a disease.

All cultural systems are constructed means of *making* sense of the world, and this making sense is accomplished by dividing both concrete and abstract phenomena into categories. As products of culture these systems and categories are both necessarily forced and enforcing codes. This does not mean that all systems are morally suspect but it does imply that to think of them as “natural” would be a mistake.

The *habitus* of an intersexed person in Euro-American culture is in many ways no more or less conflicting than is the *habitus* of any other citizen in the realm, although some have claimed otherwise. In response to a question over whether intersex is related to sexual identity, Cheryl Chase responds:

We'l, I wouldn't say it has absolutely nothing to do [with sexual identity or preference]. ...they are extraordinarily, subtly interwoven in complex ways, and intersex people are far more likely to grow up with, um, same-sex sexual orientation and complex gender identity--simply male or female--than are other people. So they *are* related.¹⁶

Chase's comments are media savvy insofar as they certainly grab a listener's attention; however, it is by no means determined that intersexed people are far more likely than anyone else to grow up to have same-sex desires. Chase's repeated assertion

that queerness is the *modus operandi* of intersexuality is suggested in statements that “[...]a disproportionate number of ISNA members are gay, lesbian or bisexual.”¹⁷ Her claim, however, is based on her association with the population that comes to ISNA,¹⁸ and no formal study has been done on either this population, or on the wider long-term outcomes.¹⁹

Chase is frequently interviewed on the issue of how many intersex births there are every year, and on what happens to intersexuals in adulthood; her responses include the very widest possibility for intersex diagnosis, including groups such as Turner’s Syndrome (45X) and Klinefelter Syndrome (47 XXY), and she reports that the adult population of intersexuals is overwhelmingly “queer.” Her reasons for doing this are legitimate enough, if one considers that the medical profession includes Turner and Klinefelter in diagnoses of intersex, and her assertion that intersexuals are very much more likely to grow up to be queer subverts the assertion by doctors that surgeries can effect a normal adult sexuality, and that parents should be told in no uncertain terms that “[...]their child will not grow up with abnormal sexual desires, for the layman gets hermaphroditism and homosexuality hopelessly confused” (Hill, 1977, 810-814).

However, if the genetic sciences estimate that 1/2000 live births is an intersex birth, then with only a few hundred people from all over the world in regular contact with the Intersex Society, Chase’s claim for an exceedingly high rate of non-heterosexual identity in the intersex population is theoretical speculation at this point. It may be that her hunch is correct, if only because the category of queerness is broadening. More anecdotal evidence is indeed cropping up in queer studies suggesting that few heterosexuals are exclusively heterosexual in the sexual practices they engage in over a lifetime. Yet the idea that one is

intersexed confounds the notion of “same-sex orientation,” so what Chase is really discussing is whether intersexuals more frequently have sexual orientation more towards people of their own assigned gender.

Without a doubt, the population on the isna-l discussion list, and many who have contacted the group by mail or phone have identified as bisexual, gay or lesbian, and sometimes as transgendered or transsexed, but this could simply be an effect of such people already being more accustomed to speaking about their sexual difference(s). This possibility is at least as likely as Cheryl’s hypothesis that the larger portion of intersexed persons identifies as homosexual and has simply learned not to discuss any questions they may have about their diagnoses or treatments. Information from various Androgen Insensitivity, Klinefelter, and Turner Syndrome support groups suggests that a large number of intersexed adults identify as heterosexual; issues of marriageability and raising families figure as prominent concerns in the ALIAS newsletter.²⁰ Concerns about fertility, marriage and heterosexual intercourse are also central in discussions on the Turner’s Syndrome Society web page bulletin board, where hundreds of women and girls with Turner’s Syndrome talk about their efforts to conceive, their desires for comfortable, heterosexual relationships even if they cannot have children, and their desires to experience pubertal changes that are at least similar to those of their peers in terms of growth and the onset of menstruation.

Resisting sex and gender

One of the greatest leaps taken in feminist analysis since the 1960’s has been the separation of the concepts of sex and gender. By distinguishing the two, feminists began

analysing how cultural perspectives of women had been mapped onto biology, and pointed out that so-called “biological destiny” was little more than the expression of a cultural set of expectations for female and male behaviours. This eventually made it possible for scientific preconceptions about male *versus* female intellectual ability to be called into question, and it illuminated the ways in which oppressive functions of culture sought to manage female sexuality, mobility and personal freedoms by declaring women biologically unfit or unsuited to a particular job or public position -- medicine, law, higher education, physical labour, independent living, etcetera. The limitation of separating sex, as a biological category, from gender, as a social category, however, has turned out to be that the category of “sex” has remained relatively unchallenged; whatever one might say about the cultural variability of gender, it remains true that at some level, people still believe in the idea of a biological sex that is free of cultural preconceptions and that this “sex” serves as the ground-point for all those arbitrary cultural expectations about gender.

Recent theories of gender, sex, and sexuality, of which Judith Butler’s Bodies That Matter and Suzanne Kessler’s Lessons from the Intersexed stand out as the most groundbreaking, have proposed that it is time to give up on the concept of sex altogether. What this means is that there is no conversation we can have about sex that is not about gender. Like the Foucaultian argument that if there is a “true nature” we will never get there because we will always see through the eyes of culture, these more recent works argue that if there is such a thing as “sex” we will never know what it is beyond the scope of the cultural framework of gender. Perhaps what we need to do is jettison the hinge-pin of “sex” altogether, recognising that when we discuss bodies and their functions in terms of “sex” we are really articulating presupposed, prescribed notions of what given bodies

should do, and that as soon as we enter into discussions of appropriate activity, or behaviour, and challenges to those prescriptive notions, we are talking about *gender*. This means discussions that make claims to being grounded in biology, not ideology, such as those about “brain sex,” are in fact highly ideological discussions about gender. As such, they are still investigations into what constitutes “appropriate” behaviour and thought for men and for women and how it can be identified or verified. The ideological commitments of such research become apparent when women or men do not think or perceive the way that they are expected to. Reasons for those “deviations” are sought out and recontained as normal responses to specific conditions.

The feminist emphasis on the idea that gender is a culturally contingent construct, has, rather ironically, made it fairly easy for psychologists such as John Money and the generation trained under him to propose that human beings are “psychosexually neutral at birth” (Diamond and Sigmundsen, 1997, 298). Following from that idea, Money and his colleagues proposed that whenever it was necessary, either because of ambiguity or accident, then children should always be assigned a female sex and raised to have a feminine gender because “it is simpler to construct a vagina than a satisfactory penis, [and therefore] only the infant with a phallus of adequate size should be considered for male gender assignment” (Perlmutter *et al* 1992, qtd in Diamond and Sigmundsen, 1997, 238). The premise was that *anyone* could be made female, as long as the messages received about one’s gender were consistent from an early stage of childhood. Money, following the theory that the development of subjectivity begins in earnest at the point of language acquisition, recommends in his Sex Errors of the Body that, whenever possible, surgeries to reassign the sex of a child with traumatised or ambiguous genitals be carried out before

the age of eighteen months. Money's theory is that, whenever possible, one needs to act prior to the age the child has acquired language, and never later than at three years of age, by which time he presumes gender/identity/language to be firmly established.

Surgeons, for their part, have pushed Money's recommendation back to do surgeries to "finish" or "correct" the genitals of intersexed infants within 72 hours of birth whenever possible, hoping that the need to ever inform the child of his or her surgery would not come up.²¹ Regardless of when the medical teams actually carry out the surgical enforcement of a child's sex assignment, their actions are motivated by the idea that sex assignments will be successful as long as everyone believes in them.

The protocol presumes that in some sense, this is what anyone's gender identity hinges on: that we believe we are what we have been told we are, or as I heard one panelist at a recent transgender conference observe about birth announcements circulating in her office, "Everyone takes the doctor's word for it [the sex of the infant]." From there, we continue to believe and enforce both the sex and gender of the child, whom it is supposed will grow up to perform social roles consistent with the assigned sex/gender.

In fact, the logic for categorising transsexualism and gender identity disorder as "disorders" rests on the premise that people in the person's life "failed to believe": that such individuals have either been given conflicting messages about their sexualities (often the mother is blamed for this, especially in the case of "sissy boys"), or that they have just failed to believe the appropriate story about themselves, their sexuality and their gender.

This construction and use of gender wildly distorts the point that feminists were trying to make when they split sex from gender: that girls and boys, men and women, did

not like or dislike trucks, certain professions, particular exercises because of biology but because of subtle social messages about what it was appropriate for a person of a given sex to do, think, or feel. The weak point in the socialisation theory is that it failed to address the ways in which ideas about *biology*, and not just the manifestation of identities, are socially constructed. It is ironic that a culture that clings to biology as the ground of gender has developed the ability to surgically construct sexed bodies to match gender identities, either as they are expressed by adults in the case of transsexuals who choose for themselves, or as the presentations hoped for by adults who decide for intersexed children what bodies match the identities they will be assigned. Yet, for all this technical interference, scientists and laypersons alike have failed to note that these are only extreme examples of the techniques²² employed to bring all bodies into line with gender.

Clearly, the continued enforcement of restrictive and binarised gender categories is not what feminists were hoping would result from the push to understand gender as a social construct. Unfortunately, however, that push has taken place within a cultural context where many cultural assumptions regarding the neutrality of science have remained in place. In the realm of sex and gender assignment, the push to see gender as a manifestation of social expectations took hold in subspecialties where men still dominate the fields: urology, obstetrics and gynecology, and endocrinology. Their premise that anyone without a penis of minimum size could not function adequately as male, but could easily be taught to believe in herself as female, took hold and is only just beginning to be challenged. There is one major reason for this: the children who were managed under this paradigm are finally old enough to make their voices heard, and they are contesting

reports that their management was successful.

In the case of John/Joan, the identical male twin, after suffering the loss of his penis when it was seriously burned during circumcision, was reassigned as female at 18 months of age by Johns Hopkins psychoendocrinologist John Money. Money and his colleague Anke Erhardt reported in their 1972 collection Man and Woman/Boy and Girl that John had fully accepted his female sex assignment and showed an appropriate feminine gender role:

Although the girl [John] is not yet a woman, her record to date offers convincing evidence that the gender identity gate is open at birth... and that it stays open at least for something over a year after birth. (1972, 98)

However, in 1997 psychologists Milton Diamond and Keith Sigmundsen broke the news that by age 14 John had rejected his assigned sex and, after learning that he had been born and raised as a boy for the first year and a half of his life, had demanded reassignment back to male. As Joan, John did not exhibit the behaviours that people expected from a girl, and the medical team in charge of his care was very distressed by his adamant refusal of his female sex assignment. In fact, though Dr. Money was aware that John had rejected his assigned sex, Money never published a retraction of his article proclaiming the unqualified success of the reassignment.²³ That job was left to Diamond and Sigmundsen; Money remains silent about it to this day. But if Money's assertion that we can make anyone into any gender so long as we begin early enough, and his concomitant silence on the final outcome of John's case are disturbing, then Diamond and Sigmundsen's assessment of the case is equally disturbing. Diamond and Sigmundsen argue that the reason John rejected his female assignment is that he thought like a man,

and that his thinking, in turn, was a result of swimming in prenatal androgens that stimulated certain areas of the brain to take on “male” characteristics, desires, and behavioural tendencies. Diamond and Sigmundsen do not mention in their follow-up work on John the probable significance of several key factors in John’s childhood:

- John was born healthy and his parents quite reasonably expected that their son would grow up to be a healthy adult male.
- John had an identical twin brother who did not suffer the loss of a penis and was not, therefore, reassigned female. The brother then would provide a mirror image of John as a boy, both to the family and to John himself.
- John’s mother expressed extreme apprehension about reassigning her child as female, and accepted the assignment only as a last resort.
- John lived for the first 18 months of his life as a boy, and had likely acquired at least some of the traits expected of boys in the time period (mid 1960’s).

Diamond and Sigmundsen overlook all of these cultural influences in John’s life possibly because the commitment motivating research into brain sex is the desire to determine what makes males and females radically *different*, rather than what makes them overwhelmingly similar. Diamond and Sigmundsen use their research to draw conclusions similar to those I make in this dissertation: that adults should not take it upon themselves to impose sex assignments on children surgically. Nonetheless, I take issue with their research because one of its premises is that there is nothing we can do about “brain sex.” Therefore, they argue, we should not fight the tomboyish tendencies of females with high androgen levels (CAH), and we should not worry about chromosomal males with complete androgen

insensitivity (AIS) developing masculine behaviours that conflict with their bodily appearance. They argue that the girl with CAH will “naturally” have more masculine behaviours because her brain is constantly exposed to high levels of androgen, stimulating “male” cognitive development, and that the brains of people with AIS will never “masculinise” because the tissue cannot respond to androgens. If there were not geneticists trying to figure out how to prevent future CAH and AIS, as well as other intersex births, then I would not be so worried, but such research and medical commitments do exist and are being acted upon, and the premise that there is “nothing we can do about an intersex brain” plays into the hands of those who will say that if we cannot fix intersex then we should just get rid of it altogether.

Instead of worrying about finding the biological key that will ensure “normal behaviour,” I am suggesting that we stop thinking about sex as the natural foundation onto which “gender” gets mapped. Sex is not an “everyday truth” that is both obvious and self-evident as a biological fact, but is a strange, constantly changing expression of ideological discussions about bodies and their appropriate places in the world. Sex, then, is not “normal”--though it is normative. Sex is normative *as an actively produced concept*. Sex is a cultural law, and, as such, it is an eternally shifting expression of the values in a given time and place. Sex is not “natural,” though it gets naturalised in discourse about functions and structures of bodies and anatomy.

The attitude that bodies have certain intended functions is so pervasive that the popular media and its readers have uncritically accepted as “fact” that the “failure” to bear children leaves women at a significantly greater risk for developing breast cancer. One implied message of the popular press is that women can choose a career over motherhood,

but that by failing to allow their bodies to fulfil their intended reproductive function they leave themselves at risk of developing a potentially terminal illness: have babies (and nurse them for a minimum of one full year say some reports) or pay the price. It seems that, when all other tactics fail to move women back into the domestic sphere, scaring them *to death* is considered a viable method to try.

The idea that breasts' intended function is to nurse infants overlooks the fact that not all women have, or desire, children. Anatomical discussions about the function of the breast place it squarely on the bodies of females and does so in imperative terms of the responsibilities women have to the children that they *should* bear. In other words, a social presupposition about roles gets mapped onto a discussion of biology, and there are few discussions about female anatomy and biology that do not end up being discussions about what women *should or should not do* with their bodies. The social imperative to become mothers, to engage not only in mothering, but also in the idea of motherhood, gets naturalised on the surface of the body, such that the cultural imposition of a role is erased and made to seem as though it is just something one was built to do. This attitude is so pervasive that the popular media and its readers have uncritically accepted as "fact" that the "failure" to bear children leaves lesbian women at a significantly greater risk than heterosexual women for developing breast cancer.

For example, an increasingly popular statistic is that the risk for lesbians to develop breast cancer is one in three. This contrasts sharply with the well-known statistic reported in the medical literature that one in eight women (presumably straight), will develop breast cancer in their lifetime. This one in three statistic for lesbians was posited by Susanne Haynes of the

National Institute of Health at the 1992 National Gay and Lesbian Health Conference and at the 1992 American Public Health Association Conference. However, Dr. Haynes did not base this number off [sic] of solid epidemiological data that she collected among lesbians. Instead, she examined several studies, some of which included lesbians, some of which did not, and found that nullparity (not bearing children) was a risk factor in developing breast cancer. She suggested that since the majority of lesbians do not have children, lesbians thus had a greater risk of developing breast cancer compared to heterosexual women. However, no solid data are available on rates of child bearing among lesbians. (Hart, 1995, np)

Our use of anatomy to naturalise culturally specific concepts about gender can also be demonstrated in language use itself, such that, for example, it is unnecessary to distinguish the female breast from the male breast as there is, indeed, only one breast and it *is* female.²⁴ It is equally absurd to distinguish the penis as *male*; the penis *is* male and does not, therefore have to be qualified as such. Yet the material that makes up both breasts and penises is present on/in both female and male bodies, so it *should not be* obvious that the breast is female and that the penis is male. Is it just a matter of size? Perhaps, but it is also more than that, for the terms also presuppose an appropriate use and placement of any particularly “sexed” organ. I am not suggesting that bodies have no material limits, that they are not bound by flesh, but the material reality of the body needs to be rethought

[...]as the effect of power, as power’s most productive effect. And there will be no way to understand “gender” as a cultural construct which is

imposed upon the surface of matter, understood either as “the body” or its given sex. Rather, once “sex” is understood in its normativity, the materiality of the body will not be thinkable apart from the materialization of that regulatory norm. (Butler, 1994, 2)

Judith Butler argues that sex is not a biological fact, but rather, a phantasm, and is neither something one is, nor that one has (1994, 3). This does not mean that there are no material bodies. Clearly, as Judith Butler’s work points out, bodies *do* matter; they live, die, love, take risks, mourn, suffer and, potentially, inflict suffering too. But Butler’s point, and mine, is that the means of perceiving, understanding and setting our material bodies into practice and motion are highly enculturated events--not biologically neutral phenomena. Sex is an agreed upon illusion, and the gender that gets mapped onto sex is just another illusion, perhaps slightly more contested than sex, but still maintained within an ideological framework in which some are “born” to dominate, and others to submit/obey.

This power imbalance is organised according to a binary structure of male/female, dominant/obedient and is upheld through discourses of expectation and ideology mapped onto the “cultural surface” of bodies (Epstein, 1995, 21). Julia Epstein argues that when bodies do not meet up with social expectations, regardless of how normal their variation may be within “nature,” they have traditionally been perceived by families and physicians as *profoundly unnatural* and absolutely intolerable; furthermore, patients are diagnosed and managed with the specific goal of making their bodies match “normal social categories” (Epstein, 1995, 80). The goal of medical intervention in cases of atypical bodily appearance, then, is not to make bodies more natural, but to make them provide a

cultural surface that coincides with larger cultural ideals and expectations. This is especially, though not exclusively true with intersex, which medicine has recognised for several centuries as a natural variation, but for which law and culture have no room.

¹ In the past, I have cast the issue of intersex in terms of an erased but ever-present identity, but I think that it is more complicated even than that. It may be that awareness of one's surgery produces those feelings, or that family reactions to the diagnosis and its management create the context for those feelings to develop. Certainly those feelings do develop, probably for as many varied phenomenological reasons as there are different intersexed people, but I do not think that it needs to be cast in terms of a psychological pathology. Indeed, framing the issue in terms of a permanent problem leads down a dangerous path of saying that nothing can be done to make an intersexed person's life any better, and if the medical establishment latches onto that idea, then we could see the widespread use of in utero diagnostics for the purposes of terminating any person with an intersex condition. This would both push back the clock on when gendered subjectivity begins to count in terms of the question, "Is it a boy or a girl," and it would threaten to narrow the boundaries of the "normal" human body yet again, in the same way that barr-body and chromosome tests have already done.

² I am indebted to Gayatri Spivak's article "Who claims alterity?" for its critical analysis linking the subject and the object of knowledge together.

³ In this chapter, I use the term "infant" to denote a child of less than 2 years old, and "child" or "minor" to refer to anyone between age 2 and the age of majority. However, in my later chapter on consent and medical ethics, "infant" is used in its legal sense to denote anyone under the age of majority.

⁴ Emily Martin's Woman in The Body, as whole text, describes how medical metaphors of production and efficiency posit the female body as one which is an essentially faulty machine in need of medical interventions that will bring it into efficient production.

⁵ This chapter is not intended to either condemn or examine Mead's work, but this section is intended to indicate a conservative tendency in anthropology that is prevalent enough even to be apparent in the work of someone considered particularly nonjudgemental in her approach to the study of sexuality. My criticism is not intended to discount the valuable changes that Mead brought about in Western perceptions of sexuality, sexual expression and sexual health, but merely to point out some of the repercussions of anthropology's early disciplinary limits.

⁶ I am omitting recent theoretical work on intersex from recognition here because although it forms a useful means of considering Western approaches to intersex, it does not study contemporary cases of intersex, but rather is rooted in historical records such as the story of Herculine Barbin, or turn of the century sexology and discourses of sexuality in medicine in general.

⁷ I have chosen here to avoid the use of the term "berdache" because as a term derived from the Persian, it has little to do with Native Cultures. It is however, important to note that there is a general linguistic problem in trying to designate such categories and that "third gender" is also problematic. Therefore, in any specific context, I refer to the tribal name given, for example: *winkte*, or *nodle*.

⁸ In particular, The Last Sex, a collection edited by Arthur and Marie Louise Kroker, Julia Epstein's Either/Or, Neither/Both, and Marjorie Garber's Spare Parts all omit the voices of intersexuals from their texts, either because they have chosen to highlight other concerns, or, as in the Krokers' collection, because the work is just a careless use of intersexuality as a departure point for sensational, or paranoid, or fetishist ideas about hermaphrodites.

⁹ All of these differences notwithstanding, there is one factor that we have in common: we have been labelled, diagnosed, or forced into this community by a shared medical and technological system that has defied borders, political parties and language differences to proliferate with confidence its particular version of the body (as machine) well beyond its initial Euro-American post-enlightenment surgical theatres and anatomy classes.

¹⁰ While there is debate around whether or not one chooses to be homosexual, there is less debate about the choice to identify as "queer" because queer signifies so many possibilities, many of which have as much to do with thought as with sexuality. One premise, for example, in choosing to identify as queer is to refuse the comfort of being presumed to be heterosexual, thereby undercutting the hegemonic privilege granted to those who are presumed heterosexual. By using the term "queer" in an affirmative sense, people refuse the cultural demand for sexual "normalcy". Further reasons that people may choose to identify as queer are that the term does not operate within a binary of hetero/homo oppositionality, that "queer" includes more possibilities than any of the other identity markers (gay, lesbian, bi). In effect, to claim queerness is to refuse to be pinned down, to refuse to allow others to get too comfortable with assumptions about one's sexual desires, or practices.

¹¹ Recognising that the diagnostic and treatment protocols are mechanisms has led to several list participants referring to the medical profession as the MIC, or "medical industrial complex".

¹² It is necessary to remind readers here that although there can be medical considerations in some intersex presentations, they are not related to the cosmetic concern of genital appearance. Though genital appearance may prompt the diagnosis, for example, of salt-wasting in CAH, it is possible for a genetically male child to have salt-wasting CAH and show no genital anomaly at all. Throughout this thesis then, I distinguish between medical concerns, which are health related, and cosmetic concerns, which are culturally based.

¹³ As of June 1999, the ISNA website lists 30 separate interviews, television and print news reports and editorials involving ISNA. See <http://www.isna.org/isnainnews.htm>

¹⁴ Of course, everyone, as an individual, probably has the sense at one time or another that his or her baggage is more than any other human soul should have to endure; however, within the intersex group, members often express a feeling of being uniquely and exponentially undesirable as a partner because of their intersexuality. While it is quite valid to observe that all people probably experience similar feelings of undesirability, few have had the concrete experience of being deemed so physically abhorrent that they *require* surgical alteration in childhood. Also, few people will have to respond personally to the assertion of medical experts that without surgery to "correct" us, neither parents nor society at large will be able to accept us.

¹⁵ Whether such break-ups are over-attributed to intersexuality because of the structure of the lists as support venues for intersex problems, or because of the population who arrives at such lists in the first place remains unclear. It is probable that a combination of such factors influences these assessments, just as it is possible that at least in some ways, a person's intersexuality may influence the state of his relationship(s), just as any other set of emotional or physical challenges might.

¹⁶ John McMullin and Chelle Mileur, Hangin' OUT, National Public Radio, NPR, San Francisco, 3 November 1997.

¹⁷ Cheryl Chase's position is summarised in Nancy Murrell's 1998 article, "Intersex group raises questions about genital surgery."

¹⁸ In her 1998 essay "Surgical Progress is not the answer to intersexuality," in the November issue of Clinical Ethics, Chase lists the population she has talked with at approximately 300.

¹⁹ Furthermore, Chase's claim that the net result of intersexuality is queerness assumes a certain stability of identity that, like both the medical establishment and identity based politics, does not take into account that what people identify as and what they actually do often do not match evenly. Certainly this fact has greatly complicated the ability of epidemiological attempts to track and predict the spread of HIV, for example.

²⁰ ALLIAS is the newsletter of the AIS support group based in the U.K.

²¹ At the Mt. Sinai continuing medical education seminars where I delivered a paper in May of 1996, two surgeons objected to my argument that a failure to inform a child of the nature or reason for genital surgery formed part of the resulting emotional trauma, and they suggested that the entire problem could be avoided by perfecting their surgical techniques and carrying them out before a child could have any memory of the event. Their idea was that the children could best be served by keeping them in complete and permanent ignorance regarding their diagnoses and surgeries.

²² I am deliberately alluding to the root word *techné* which in its original Greek usage denoted both an artistic and scientific approach to a question or methodology.

²³ Rolling Stone Magazine exposed John Money's deliberate suppression of John's rejection of his female sex assignment in the December 11 1997 issue.

²⁴ Conceptual frameworks such as this have severely negative implications for the health care of men who *do* get breast cancer. Breast cancer in men is poorly understood and rarely addressed in public forums, meaning that there is a general cultural ignorance regarding male risk for developing breast cancer, and regarding treatment procedures and outcomes for males with breast cancer.

CHAPTER FOUR

New Methods for managing intersex

Intersex Management: Treatment or Enhancement?

The pressing question in this chapter is not whether the surgical “correction” of genital ambiguity is socially motivated. Theorists, researchers and clinicians including Alice Dreger, Anne Fausto-Sterling and Suzanne Kessler have convincingly argued this point already, and medical journal articles openly declare that “Proper gender assignment to a neonate born with ambiguous genitalia is a social emergency of the newborn period” (Coran and Polley, 1991, 812), and that intersexed neonates “[...]present the staff and parents with the unique problem of indeterminate sex and should be considered a neonatal psychosocial emergency” (McGillivray, 1992, 365). The critical point under consideration here is the set of conditions under which the sex/gender assignments of intersexed children are enforced.

An intersexed child needs a gender assignment as much as any other child does; I do not dispute this point. But why do doctors insist that the gender assignment of intersexed infants and children has to be *sutured* down surgically in cases where there is what they diagnose as “masculinisation of female genitalia” and “incomplete masculinisation of male genitalia”? To answer this concern, I propose considering the distinctions made regarding treatments and enhancements in Parens’ 1998 article “Is Better Always Good?” Before launching into that discussion, however, some clarification of my use of terms is in order.

My use of the term “cosmetic surgeries” is quite specific because I do not want to suggest that there are no circumstances under which genital surgeries should be performed on infants. For example, if the proposed surgeries are meant to alleviate or remedy physical pain, or if they are to correct a functional impairment, such as the ability to void one’s bladder, or if there is an organ exstrophy (meaning that the organs are external to the body, which happens only exceptionally rarely), for example, then surgeries would certainly be indicated on health grounds.

I refer to intersexuality as a range of conditions, but I use the term “condition” only in the sense that being typically male or typically female are conditions or states of being; I do not mean “condition” in its medically euphemistic sense of “disorder”. I reserve the use of terms like “disorder” to describe actual health problems that can be present in some types of intersex conditions: salt-wasting in CAH, for example. I also use the term to describe the socially threatening “disorder” that intersex conditions appear to represent to normative conceptualisations of embodiment within a binary sex and gender schema.

I do not include sterility or reduced fertility within the category disorders, because reproduction is a highly personal issue, not an automatic medical crisis. That is to say, while for one person the inability to reproduce may be a condition seen as a malfunction, to another person it may be a condition seen as a blessing. While fertility clinics would probably argue this point with me, their perception of infertility as a failure is directly related to the fact that they see clients who self-select for disappointment in not being able to reproduce. The perception of reproduction and fertility is an important issue in

the treatment of intersex, however. For the sex assignment of genetic females presupposes both reproduction and heterosexuality as the goals of “successful” assignment (Edmonds, 1994, 535-66). Is the surgical management of intersexuality then “restorative”, as medical professionals maintain? or, as a primarily aesthetic set of procedures, are surgical interventions on intersexed children “enhancements,” procedures that mollify parental and social concerns?

Surgery is not an enhancement technology

To determine whether or not the cosmetic surgeries on intersexed genitals are medical treatments or enhancements, we need to ask what the goals of the surgeries are. We also need to ask whether the declared goals are the same as the actual goals. Most write-ups in surgical and pediatrics journals declare, for example, that the surgery is meant to effect a clear sense of sexual and gender identity for the child, and to protect him or her from a potentially hostile and uncomprehending world:

That a newborn should have a deformity [affecting] so fundamental an issue as the very sex of the child[...] is a tragic event which immediately conjures up visions of a hopeless psychological misfit doomed always to live as a sexual freak in loneliness and frustration. (Dewhurst and Gordon, 1969,52)

While more recent recommendations for managing intersexed infants may lack the florid imagination of Dewhurst and Gordon, the same basic principles are repeated or demonstrated in the current literature.¹ What becomes apparent in these discussions

regarding treatment protocols is the central concern for parents which is expressed in the frequent cautions that the greatest care be taken in managing the parents and assuaging their anxieties about both the child's true sex and the long-term outcome that can be expected.

As enhancements, intersex surgeries to assign a solid sex/gender identity to the child are procedures in which the anxiety of the parents is treated by proxy via the body of the intersexed child. Social/clinical psychologist Dr. Suzanne Kessler argues that it is not only in textbook recommendations but also in practice that intersexed children are being used as a conduit to manage parental and societal anxiety about the stability of sex and gender:

Lest there be any doubt about whom the genitals are for, one team of researchers justifies doing surgery by saying that it "relieves parental anxiety about the child with relatives and friends." Another surgical group is even more explicit in concluding that "for a small infant, the initial objective is an operation to feminize the appearance of the baby to make it acceptable to the parents and family."

(Kessler, 1998, 55)

Are we then treating the wrong patients? Are we in fact *treating* them at all?

At the same time that their case studies promise to ameliorate parental anxieties, surgeons also claim they are trying to guarantee that intersexed children will grow up to perceive themselves as seamless, singularly sexed and gendered persons. To what degree is this an achievable goal? It presumes that "typical" men and women feel completely at home in their bodies and gender identities, and that typical men and women do not

experience crises regarding their own phenotypic appearances. Yet there are many physical crises of sex identification that commonly confront perfectly typical men and women: whether one has too much body or facial hair to be a *properly feminine* woman, or whether one has perhaps too much fat on the hips, or not enough hair on one's head, face or chest to be a *properly masculine* man. A cursory inventory of the availability of products and services to combat such bodily "shortcomings" and "failures" indicates that at multiple points people feel that they are not the "real" men and women they are supposed to be. Yet surgeries done to effect a cosmetic appearance of definite sex are offered to parents as guarantees that their intersexed children will grow up to be complete and whole men or women. Is this not an impossible promise to keep?

Is cosmetic surgery on intersexed genitals a treatment, or an enhancement? Eric Parens considers Norman Daniel's differential definitions of "treatment" and "enhancement" in the context of asking which services are necessary medical interventions that should be covered under insurance programmes and which ones are not necessary and, therefore, should not be covered (Parens, 1998, 1-15). To be considered a treatment, a procedure must restore a specific or potential ability for a person to be able to compete at a roughly equal level with his/her peers. An enhancement is a technology that would permit an individual to perform in excess of reasonable expectations, or to compete from a superior position.

However, the terms of the competition are far from clear in the case of intersex. How can we determine what the potential ability being restored is? What is it that unaltered intersexed persons are being denied the ability to compete for if left alone? If we

extrapolate from the medical procedures and extend the argument, the suggestion is that the terms of competition have to do with sexual identity and behaviour and that doctors are trying to guarantee, or at least seriously limit, a particular outcome for parents to expect. That parental expectations are clearly part of the equation is evident in follow-up reports where the success of procedures is frequently measured according to parental satisfaction with the cosmetic appearance of the child's genitals as "normal."

Parens raises questions regarding the use of the terms "normal" and "equal" when assessing function and ability. Parens is not certain that these terms are at all clear, but I would argue that their clarity is not really the point; even if we could all agree on set meanings for these terms, would that necessarily mean that anything outside the "normal" and the "equal" would be useless, or meaningless, or sick? Even supposing, for example, that normal were universally understood *only* to indicate statistical norms, and we therefore labelled homosexuality as "abnormal," it would be ridiculous to claim that being homosexual would be a life not worth living; yet this is precisely what the present handling of intersexuality implies: it is not normal and we should do everything we can to prevent people from even knowing about it, never mind understanding it or living it.

Surgical and pediatric journals repeatedly state that surgeries to correct ambiguous genitals are "necessary," but they do not always state why. Perhaps it is presumed self-evident that one cannot claim the sex of a child to be certain if the genitals remain in a state that defies so singular an assignment. If that is so, perhaps it is unwise to make a final pronouncement about the sex of the child at such an early age.² However, given that refraining from making such pronouncements is not likely, it is necessary to work

backward to the ideas informing the imperative to treat ambiguous genitals and ask to what extent these concepts validate conceptualising cosmetic surgery on infant genitalia as “restorative.”

The argument that a medical need is defined by what must be done to restore species-typical functioning breaks down in assessing the care and needs of intersexed persons because it is difficult to define in any precise terms what the function of genitalia is. There is a multitude of potential functions for genitals, only some of which pertain to appearance and not all of which are required at all times, or even separately, in order for the other terms derived from genital sex to be stable. That is to say, one could have intersexed appearing genitals and still be fertile, for example, but the potential to have a typical looking appearance concordant with one’s sex assignment and to retain both sensation and fertility is rarely possible within the current management paradigm, oriented only toward making visually acceptable, usually female external genitalia.

Parens conceives of a procedure as being restorative if it returns a typical body function that is a basic requirement for independence and relative autonomy; some examples that Parens does not include but which could be considered as treatments are those to restore language cognition and expression to stroke victims, mobility to persons with spinal cord injuries, and the ability to speak and eat to children with severe cleft palate, and so on. But not all examples are so clearly restorative. Cochlea implants blur the definition of restorative procedures, depending on the degree to which one recognises sign as a language and culture that is normal and the Deaf community as a “normal” community.³ The surgical alteration of intersex genitals is at least as troubling to this

concept of restoration because it is extremely difficult to ascertain what has been lost to the intersexed person that is specifically a problem of genitals. I suspect that no matter what biological functions we try to settle on as having been lost, they will prove slippery and mobile. Are genitals simply a means toward a reproductive end? In that case, much intersex cosmetic surgery is counter-productive or at least self-contradicting. Are genitals primarily signifiers of one's sex and gender identifications? In which case the sheer plurality in form and size in the general population confuses the issue. Are genitals primarily meant to function as pleasure zones? In which case, the documented failure rates in appearance and sensation of about 20%--30% in many long-term follow up studies indicate that pleasure cannot be the function surgeons are trying to restore. It is not at all clear which are the biological functions of genitals and which are the cultural ones, and I have yet to discover what opportunities typical genitals afford that atypical genitals do not.

If the only goal of the surgery is to convince parents, family and caretakers that the child is "really" of a certain sex, then the surgery can be defined as purely cosmetic. In this case then, and for all the reasons I have already discussed, such surgeries cannot logically be considered treatments. But are they, therefore, enhancements? To be an enhancement, a procedure must provide the patient with some unusual advantage, or a quality that one could not logically expect from his or her genetic background. According to this line of reasoning, is it an enhancement to perform a partial clitorectomy on a child who has no known family members with an enlarged clitoris? A number of problems present themselves with this question: how would we know whether the child's great

grandmother or grandmother had large clitorises? What counts as large? What about unusually small or absent inner labia? And the same types of questions would apply to mild hypospadias, penile curvature (chordee) and micro-penis.

Most importantly, shouldn't an enhancement, if it is really to be one, actually *work*? Is an enhancement really an enhancement if it risks making a patient feel worse about him/herself?⁴ If procedures are treatments that restore an equal footing to these "diseased" children, can these treatments be said to be the most effective means of management available if they risk both the psychological health and the physical operation of the child's body? How much risk is too much for us to consider these interventions as a viable set of technologies?

The cosmetic diagnosis of "ambiguous genitalia" is a diagnosis without a disease. There are many physical genital or secondary sex characteristics that we might associate with *families* instead of with intersex. For example, inverted nipples may be observed as an inherited trait through several generations, but they can become pathologies in the eyes of a plastic surgeon, or even a family practitioner who may ask, "Are you certain you don't want me to refer you to someone who can fix that?" Indeed, plastic surgeons sometimes go so far as to pathologise people, and women in particular, who do not want to alter their appearance surgically. In this framework those who opt in favour of cosmetic surgery are valorised as 'go-getters,' while those who opt out are derided:

It's hard to say why one person will have cosmetic surgery done and another won't consider it, but generally I think people who go for surgery are more aggressive, they are the doers of the world. It's like make-up. You

see some women who might be greatly improved by wearing make-up, but they're, I don't know granola-heads or something, and they just refuse.

(Dr. Ronald Levine qtd. in: Morgan, 1991,26)

The attitude of the cosmetic surgeon's comment shows how easily doctors are able to use liberal individualist valorisations of assertive behaviour to convince women that we do ourselves no service by refusing technology which can "greatly improve" us. Dr. Morgan points out in her article that this particular surgeon does not mention the *surgical* nature of his proposed interventions; instead, he likens plastic surgery to the wearing of make-up, thus effectively papering over the fact that *cosmetic* surgery is nothing like *cosmetics* at all.

In effect, the same promises, derisions and glossing are at work in the treatment of the "cosmetic" features of intersexuality. Parents who resist surgery or who question it risk being labelled "difficult" or may be accused of not making the best choices for their children, and they are told that the surgery will secure their children's sexual futures. There is little to no discussion about the invasive *surgical* nature of the procedures and the risks of nerve and tissue damage are routinely minimised.

Surgeons who cut out the "redundant corpora" (MMC, personal medical file, March 1975) of clitorises that are "too big" and of penises that are "too small," assuming that this is indeed the right way to make a child recognisable as the sex doctors proclaim it to be, have inherited Freudian theories of mature vaginal sexuality *versus* immature clitoral sexuality and evolutionary theories positing that more evolved races demonstrated more distinct differences between males and females. Though these theories may be

loudly disavowed now, that disavowal only takes place when the theories are laid out in the open. Had it not been for the political and discursive concerns of the late nineteenth and twentieth centuries and the concomitant research enterprises I discussed in Chapter One, we would not have even begun to develop either the diagnostic or management strategies that we have for dealing with intersexuals.

So, is the intersexed child being treated or enhanced? Given that there is a scientific recognition that we come in more than two biological sexes, then it is within the natural range of human possibility that we can be born and live as subjects other than male or female. Variances in sex may be no more biologically significant than variances in height. However, unlike the ways in which height patterns are reproduced in families, few intersexed children are born to parents who are themselves intersexed; therefore, we do not *expect* that any given parents will produce an intersexed child.⁵ That is to say that a family expects that their child will be of either one sex or the other, like their parents, and that the child's only combined traits will be facial features, mannerisms, *et cetera*, not genitalia. Thus, the surgical revision of the child's genitalia is perceived as a restoration of that which the child could reasonably be expected to have had, given the family history. But we would also have to ask what it is that the family expects as the logical outcome of the child having only one sex, and then we are likely to find that expectations run to sexual maturation as a socially, if not biologically, heterosexual subject who will eventually marry and reproduce or adopt children.

Therefore, if we accept the management of intersexed children based on family norms and expectations, as well as an ability to compete in the marriage market, then we

see that parents would also be completely within their rights and obligations to take their newborns in to be tested for a gay hypothalamus, or a gay gene, or to have their gay adolescents forced into treatment to become heterosexuals. Yet we have already acknowledged that families have no *a priori* right to expect that their own sexual identities or behaviours will be reproduced in their children, and acknowledge that homosexuality occurs throughout the world at approximately the same rate, and therefore can be said to be a perfectly human and natural part of the sexual spectrum. We now recognise that although it may make family relations strained, and that although there may be difficulties encountered in terms of competition for benefits, employment, and personal safety, non-heterosexual persons cannot be forcibly subjected to "treatment." Of course, if the homosexual person is unhappy in his or her identity, then s/he is welcome to seek treatment for gender revision, or for a number of relationship and personality issues, but these need not be hermetically linked to the homosexual identity as heterosexual people are also welcome to enter into treatment of these types at their own request.

A New Ethical Approach

When I began the research for this dissertation and made preliminary proposals for its structure, it was still necessary to persuade not only doctors but also bioethicists that the standard of care for intersex management was in need of serious reconsideration and revision. The more established generation of medical specialists remains largely committed to the standard of care developed in the post-World War II period, with only a few theorists and medical scientists publicly and guardedly calling for a reassessment of

current practice. Yet the job of convincing the ethicists that change is needed has been successful enough that an entire issue of The Journal of Clinical Ethics has been devoted to reexamining the current standard. This work has been accomplished through the efforts of groups like ALIAS, ISNA and H.E.L.P., and the long-term research of clinicians like Suzanne Kessler, Milton Diamond and Jocelyn Schober, and through the historical work of Alice Dreger.

Thus, the task at hand is no longer to convince ethicists that a new approach to patient care is required. Instead, this chapter segment examines why this new approach is, in fact, the most appropriate paradigm to formulate and follow. In essence, the tenets of this “new” paradigm are not actually *new*. Insofar as the tenets adhere to commonly held beliefs that one has a moral duty to respect the autonomy and integrity of individuals, this “new” paradigm is actually quite conservative. That is to say, the proposals for revising the standard of care in intersex management are merely attempts to bring intersex management up to speed with already established ideas about freedom of choice and individual autonomy. The approach that many intersex patients are now calling for does not seek to subvert the notion of the individual and it does not challenge or question the limitations on choice or free will; rather, it extends those ideas and sets them into practice in intersex management by distinguishing the need for medical care and the demand for an “appropriate” cosmetic appearance.

This argument is, therefore, not a discussion of solid and incontrovertible principles that can be said to be good in and of themselves. Rather, my discussion focuses on agreed upon fictions and principles that have been created in a symbiotic relationship

of philosophical and political ideals. These ideals are shared over a fairly broad segment of the Euro-American world, and yet the specific ways in which they play out are quite varied and in no sense do they form a hermetic system. Thus, the terms of this debate are not self-identical in all geographic regions and, therefore, the specifics of my own argument are meant to apply only to a Canadian context. Because of the similarities in the fictions to which people, nations, and political systems adhere, however, there are ways in which my arguments may be amenable to interpretation, or have implications in discussions taking place elsewhere.

Fictions though they may be, the principles of liberal democracy are integral to a larger context through which a subject comes to know what it means to be a person in the world. Some of these fictions are:

- that each of us is an individual
- that individuals are autonomous
- that the autonomy of individuals should be protected
- that individuals have the right to measure what is right for themselves when deciding the course of their lives

This chapter is then about the illusions of choice and beneficence as they apply within a contemporary rights discourse. I recognise that the new proposals for the treatment of intersex are being launched to serve the needs of a specific group, and that any argument for a greater good, in terms of sex and gender liberation projects for example, is only adjunct to the main goal. This chapter also recognises that there are differences between doing something for one's own interest while claiming beneficence,

doing something in the interests of a claimed scientific neutrality--which is one way of looking at the current treatment paradigm for intersex management--and doing something for one's own interests that *might* also benefit others.

Current medical protocols serve primarily to create subjects who will not challenge the *status quo*, subjects who will indeed choose only one of the two available boxes to identify themselves. The scientific/medical approach may claim to provide a neutral and merely descriptive view of intersexuality, but the classification of difference as disease is not, in fact, a neutral activity; it is an ideologically-loaded choice because gender and sex norms function in the service of larger political demands. Teresa de Lauretis reminds us that "a sex-gender system is always intimately connected with the political and economic factors in each society" (1987, 5). By this, de Lauretis means to indicate that the social and political functions a subject will perform and the responsibilities a subject will fulfil are first determined by the sex-gender system of the social web into which one is born. This is no less true for intersexuals, who definitely present a challenge to that organisational structure. As a challenge to the system, intersexuality has always required management to place it firmly back within recognised ideological structures. Whether this has happened through juridical or medical measures, the concern seems always to have been to make certain that particular subjects were not enjoying rights, privileges or status to which they were not truly entitled. This is the "real" meaning of "true" sex: the truth lies not in one's anatomy or biology, but in what one is actively entitled to claim as one's own, be it inheritance, property, suffrage or autonomy. In this sense then, the feminist truism that "the personal is political" which de

Lauretis argues illuminates how the public and private spheres are not separate realms but interconnected and multiple spheres of economy, reproduction and production, sexuality and family, work and so on, is also a truism for intersexuals. For intersexuals, whom medicine casts as deficient and thence by default best assigned female in most cases, like “true” women, traditionally come up on the short end of the ideological stick. Just as women have traditionally been denied full autonomy, intersexuals continue to be denied full autonomy. But if certain subjects are able to make gains *as women*, securing rights, responsibilities and privileges as full citizens, intersexuals are not yet able to do these things *as intersexuals*.

Intersexuals must first perform what Elizabeth Spelman argues is an impossible task; we must separate the male or female part of us from the intersexed part of us, and must declare that singular sex as the principal definition of who we are. It is not that this is uniquely impossible for intersexuals, but that it is a fictitious action that all subjects are forced to perform: to separate the sex of the self from the race of one’s body. And as Spelman argues, because we can only choose one box, or one door to walk through at a time, then if sex is the most fundamental starting point, we separate ourselves from others who may be more similar to us by virtue of belief, class, race, religion, education, and so on. We must first choose one or the other of the available boxes, and by then irreversible medical interventions have compelled, coerced or forced the box that will be marked. As an ideological function, this checking of the box is no more or less a compelled, coerced or forced function than it is for any other subject, but it is a critical difference that as a physical reality only intersexuals *must* lose or gain (or sometimes both) parts and gaps in

our bodies during infancy and childhood so that we can check the appropriate box.

Because of the metonymic use of genitals to signify the totality of the subject, medicine is able actually to locate the intersexed *part* of the body, in the same way that it locates male and female parts. However, unlike the case of identifying the male and female parts that will represent the whole man or woman, once the intersex part has been identified, it must be removed from the body. In place of the intersexed part, surgeons create the (usually) female part that will represent the whole. Yet, this representation is bound to be insufficient, for as Spelman points out in her discussion of what it means to be a woman, “[...]pointing to the woman part of me would be no mean feat: being a woman is not the same thing as, nor is it reducible to, being a ‘female.’ ‘Women’ are what females[...] are supposed to become” (1988, 134). Spelman’s point is that biological femaleness is no guarantee that one will be considered a “proper woman”, whatever that signifies in one’s own culture. My point is that biological femaleness is not even a requirement for one to become a proper woman, and that this is so because femaleness is a category of lack. As long as one is not male, anyone can become a woman, and it is clear in the medical framework that intersexuals are not male.

It is only now with the rise of an intersex movement that people are realising that it is no more possible to locate the intersex part, which is separate from the black self, or white self, or woman self than it is to separate out any other “part” which makes up the whole that is the social phenomenon of subjectivity. Intersexuals may, in fact, grow up to look typically female, and to experience the political and social world as women, much the same way that typical females experience the world as women, but there are parts of

an intersexed woman's past that must not be addressed, thought of, or mentioned--even to oneself--if one is to walk in the world as a woman. While there may be secrets that all females must harbour in order to live as women, the secrets of intersexuals are significantly less common.

Yet, medical practitioners assume that they can create subjects who will not think about their diagnoses, or their surgeries to remove or create body parts, and who will identify quite seamlessly and simply as female, or, in rare cases, as male. Surgeons and clinicians claim that most patients are happy as adults, and that they live as typical men and women, but the medical experts overlook that even these supposedly happy patients would, in fact, have to negotiate a set of bodily experiences unlike those that any of their typically sexed peers will encounter. None of my supposed "peers"--outside the intersex movement--ever had her clitoris removed. None of our non-intersexed peers had the procedures that we take for granted as part of our history:

- Repeated pelvic examinations through infancy and childhood.
- Repeated chromatin body tests in the form of buccal smears.
- Repeated hormone analysis in the form of regular blood and urine samples.
- Yearly photographs of our bodies (unclothed, with eyes blacked out) and our genitals.
- Chromosome testing in the form of skin samples.
- Regular measurement of one's hairline, as doctors search for "male" or "female" hair growth patterns.
- Regular bone-age x-rays to determine one's stage of sexual maturation.

Medical experts have seriously neglected the psychological aspects of having to recognise that as intersexuals, we are not “just like the other women,” even when we have male partners and children who are biologically “our own.” In the wake of this neglect, standard medical advice for the management of intersexuality in infants and children continues to recommend surgery as early as possible, the preservation of fertility in all genetic females, and not mentioning the words “intersexuality” or “hermaphroditism” because doing so “[...]creates an atmosphere in which parents want to know answers” (Mazur, 1983, 419). Of course, Tomas Mazur, who authored this statement, has forgotten that by law, patients or those providing proxy consent such as parents or guardians are entitled to ask questions; they are entitled to the information that would prompt those questions and they are entitled to accurate answers to their questions.

Unfortunately, too many physicians follow standard text-book advice, such as the following, which maintains that “[...]it is more satisfactory to give confident advice to the parents even though this means misleading them to some extent” (Newman *et al*, 1991, 655). Though this statement is somewhat dated, the attitude persists in present practice. In an on-going email communication, one Ontario parent reported that her family doctor and the specialists attending to her child’s care refused to provide a final diagnosis of her child’s condition. She wrote to me:

The doctors told me that my daughter had a scrotum, and that she had “xy” chromosomes, but they have only told me that she has a “biosynthetic enzyme defect,” and that is just a bunch of words to me, and they are not a diagnosis. They mentioned AIS very early on, but never said

anything else about it. The surgeon advised her surgery to remove any reminders of what was wrong with my child. (S.M. personal email, Jan. 99)

The lack of information given to this parent was clearly distressing, prompting her to contact me in search of more information. In addition, once her daughter's surgery was done, this parent was left on her own to worry about what to expect, what the implications of her daughter's unclear diagnosis might be, and what her role as a parent should be in this case. She wrote in a later email that she was apprehensive about buying a truck for her daughter because it might damage the child's identity as a girl. It was not until we discussed how we had both had trucks as children and that we had grown up probably the happier for it that this parent was able comfortably to go out and purchase a new Tonka truck that her daughter had been asking to have.

The treatment this family has received in the two years since the child's birth in Southwestern Ontario reflects a highly unified standard of care that remains largely unquestioned in the medical profession. Only in the last three years has this protocol come under increasing scrutiny, and even then only from a margin of younger medical students and residents, a very select number of health professionals, and one medical association, the Gay and Lesbian Medical Association (GLMA).

Part of the reason that the approach to managing intersexuality is so singular is that it has a very limited epistemological genealogy. The paradigm was set by a very small number of experts in the field and they have trained those who work as senior staff in teaching hospitals now. Thus, most of the psychological theory about the assignment of

gender and the necessity for doing so as early as possible can be traced to John Money and Johns Hopkins University. The surgical techniques used in the management of intersex can be traced to Christopher Dewhurst, in England, and a group of surgeons, of whom J.M.E. Slijper is one of the most prominent, in the Netherlands.

As we have seen, it is standard in the medical literature to express concern primarily for the parents of intersexed infants. Many sources indicate that the presentation of a child with ambiguous genitalia is the most shocking and tragic situation that a parent can face.⁶ Management of the child is often predicated on this assumption and promotes the idea that the only way to alleviate the parents' anxiety is to assign a sex early and quickly affix it surgically. Because surgeons still insist that girls are easier to make than boys, these surgeries are overwhelmingly of the feminising kind: a full 90% are assigned female (Newman *et al*, 1991, 655). There is a well-known statement used to justify the prevalence of female sex assignment: "It is easier to dig a hole than build a pole." Dr. John Gearhart, a surgeon at Johns Hopkins, has had this statement attributed to him in print, and I have since heard it mentioned that he deeply regrets having made it; however, as unfortunate a statement as it may have been for him to make outside the operating theatre, it would be a mistake to think that he was either the first or the only person to say it, and we may be thankful that he did say it in public because it illuminates just how misogynist the assignments of intersexed children are.⁷

Common Treatment Outcomes

Many of ISNA and AIS support group members report feeling deeply ashamed

and abused by their medical treatment. Kiira Tria, who was born in the mid-sixties and assigned male, but was diagnosed with progesterone-induced female pseudo-hermaphroditism and treated in the mid-through-late seventies by John Money and his colleagues at Johns Hopkins, writes:

I was an interesting lab rat. I call myself a lab rat because that is how intersexed kids are treated. Tested, photographed, tested again, photographed some more. [...]it was precisely my treatment and how it was inflicted on my being which really damaged me more than anything else and prevented me from having what I think of as “normal” happiness. [...]I never uttered a peep about being intersexed to anyone, not a word. Ever. It was something that I seemed completely incapable of doing. It was unthinkable to even think about doing such a thing. Talking means death. Intersexed people don’t talk. (Tria, 1997, <http://www.qs.net/~triae.htm>)

Diane Anger, a woman with complete AIS, was born in 1964 and writes of her treatment:

[..]then of course the many horrible, tense visits to the pediatric endocrinologist to have my genitals gawked, fondled and stared at by hordes of what I perceived to be nasty, despicable men, had me questioning my own existence as a person, male or female. (<http://www.qs.net/~triae/diane.htm>)

For many patients with AIS, as well as those with CAH, early surgery to “feminise” the appearance of the genitals can include vaginoplasties to lengthen a short

vagina or create one where there was none. Research on early vaginoplasty (the creation of the hole) for children with salt-losing CAH indicates a low success rate and it is not much better for those without the salt-losing syndrome. Azziz *et al* note that only 34% of vaginoplasties before age four may be considered to have favourable outcomes (Azziz, 1986, 1012). Furthermore, the same authors note that 40% of CAH women in their study did not engage in heterosexual relations and 38% were not able to achieve comfortable coitus. A more recent article suggests a higher rate of heterosexuality but with a sample size of 9 patients and 5 of those aged 20 and under, it is worth remaining skeptical about their reports that the patients had turned out to be heterosexual and that they were overwhelmingly orgasmic (Newman *et al*, 1992, 181). Their findings are questionable because young women who are not orgasmic often report otherwise and it is common for lesbians to report having been heterosexually active in their early adult years.⁸

Because the rate of non-coital sexual activity is quite high in the CAH group, the risks of early vaginoplasties outweigh the potential benefits. In addition, because of the probability of repeat surgeries and pelvic examinations being performed, it would be difficult to carry out such procedures on a child without making her feel sexually abused and/or monstrous. Furthermore, an infant or young child has no requirement for a vagina and parents are often uncomfortable with, and do not use, the vaginal inserts needed to keep the constructed vagina from collapsing; this could obviously account for the low success rate in outcomes for early intervention. Yet surgeons continue to believe that by perfecting their techniques, they will be able to effect successful outcomes. This approach totally overlooks the emotional aspect of dealing with intersex, evaluating outcomes

solely on physician and parental satisfaction with the post-operative appearance of the child.

Newman *et al* report that “We have used a number of different methods to reconstruct the vagina, including chronic dilation, perineal flaps, pedicle flaps from the inner thigh, and molded stent grafts. None of these methods has proven fully satisfactory” (Newman *et al*, 1991, 648). As a result of inadequate or “unsatisfactory” procedures, children are frequently subjected to repeat surgeries. Newman and his colleagues report being at work on the use of transplanted colon but the long-term success of this highly invasive surgery remains undetermined. It is critical to understand that what is being proposed in this particular method is opening the abdomen of a perfectly healthy child and removing a piece of healthy colon. The procedure risks impairing the ability of the digestive tract to function properly and leaves the child at risk for invasive infections. The likelihood that the constructed vagina will be satisfactory to the patient is something researchers do not know at present. Surgeons expect that the outcomes will be very good, but this has always been the expectation with each new procedure.

What does this leave us to propose? Because the degree of masculinisation in CAH individuals with the salt-losing syndrome is greater than in those without, and because many such persons experience ongoing virilisation, a female gender assignment is not necessarily appropriate and may, in fact, be quite harmful. As the percentages from the studies quoted here indicate, fertility and heterosexual coitus do not appear to be *primary* concerns for persons for whom long term outcome data are available. A new approach to management is the proposal that chromosomally female (46 XX) children

with severe salt-losing CAH be assigned a male sex. A chromosomal female with salt-losing syndrome assigned the male sex will not require vaginoplasty to create or deepen a vagina, will not be stigmatised by having a lower voice, a muscular build or by being “hirsute.”

While some may question the wisdom of a male sex assignment in a chromosomal female, there is evidence that it can work out much better than a female sex assignment. Dr. Maria New of New York Hospital writes of a patient with a 46 “xx” karyotype and 21-hydroxylase deficiency that “[...]he had lived all his life as a male. He had had many female lovers before he married. His wife was entirely satisfied with their sexual relationship” (New and Kitzinger, 1993, 6). Although Dr. New writes that this individual’s monthly bleeding indicated the probability of fertility as a woman, the case demonstrates that the medical imperative to preserve such fertility is not necessarily the only, or the most appropriate, route to follow. In fact, a male sex assignment would require less surgical intervention as the genital development would look quite typically masculine. At puberty, patients managed in this way would have to choose if they wanted to continue in a male assignment, and would have to choose whether to have their internal reproductive organs removed. If they chose not to remain in a male assignment, patients would have to weigh for themselves what course of action to take with regard to their genital appearance, but the benefit of waiting until the early stages of puberty would be that nothing irreversible would have been done without the child’s explicit consent.

Why is it more difficult to maintain a female sex assignment in a chromosomal female with CAH? When primary care-givers focus on the potential fertility of

chromosomal females with CAH, they overlook equally important social and medical concerns. Because the hormones used to control ongoing virilisation are unpleasant to take, involving painful injections, and must be used for life, many individuals at ISNA and on CAH support groups report inconsistent use of the drugs, or frequent changes in drug therapy from one set of hormones to another, and have experienced progressive virilisation and/or unpleasant side-effects as a result. One individual came to ISNA for support after new hormones to control her ongoing virilisation caused her to gain 100 pounds in three months. Had she been assigned a male sex at birth, she would not have had a partial clitorrectomy, would not have suffered the stigma of being hirsute and she would still weigh the 112 pounds that she had prior to the change in her hormone medications to inhibit virilisation.

In addition to the ongoing virilisation associated with CAH, the reasons that constructed vaginas are inclined to high failure rates warrants consideration. A constructed vagina is susceptible to stenosis and internal adhesions, lacks the nerve sensation of a congenitally present vagina, cannot lubricate adequately if at all, and does not have the elastic quality of a congenitally present vagina. Often coital success is measured only in terms of the ability to insert a penis into the vagina and no consideration of other factors is made. Only these oversights in perception enable the view that vaginoplasties are more successful than phalloplasties. When held to the same physical response standards as phalloplasties, however, even the “successful” outcomes of vaginoplasty appear less than adequate. By comparison, Mulaikal *et al* report that of nine genetic females in their study who were born between 1938 and 1957 with CAH and assigned a male sex at birth, all

were functioning as males and “gender reversal was considered inappropriate” (Mulaikal *et al* 1987, 189).

Refraining from imposing irreversible procedures in the name of achieving sexual normalcy would not impede the ability of those who do grow up to identify as heterosexual to have surgeries early in adolescence or puberty to effect a physical appearance consistent with their sexual identities. Instead of trying to guarantee “sexual normalcy,” something which parents understand to mean “heterosexual” and which many doctors mean to imply, families of intersexed children and the intersexed children themselves would be likely to benefit more from open discussions on sexuality, facilitated by qualified child psychiatrists and family counsellors and/or sex educators. The objective of the counselling should be to allow the child to explore sexuality issues including orientation and gender identity in a supportive atmosphere. The goal should not be to counsel the child exclusively toward sexual behaviours which will meet parental expectations of weddings, baptisms, christenings and so forth. The idea of ‘sexual normalcy’ should be restated in terms of a desire for the child to be sexually happy and comfortable with her/himself -- not for the focus to be, as it has been, on parental satisfaction with cosmetic results or with the child’s reaction to “gender-appropriate” toys, for example.

The cost burden of counselling can be alleviated somewhat by accessing and utilising the support of groups like ISNA, A.II.aS. an AIS support group with chapters in the U.S., England and Canada, several websites for families dealing with CAH, and H.E.L.P (Hermaphrodite Education and Listening Post), run by Helena Jackson-Smith, a

parent of an intersexed child. There are now a number of such groups around the world in countries including Japan, New Zealand, Germany and Australia; many of them are specifically oriented to one particular type of intersexuality, and many have the ability to provide broad support and information. Although there are fewer of these groups in Canada, paediatricians and endocrinologists could facilitate the formation of more local groups by putting parents and patients in contact with one another.

One of the things which parents and patients alike suffer from is standard medical practice which inadvertently, or deliberately in some cases, imposes severe isolation of patients and their families. Many people who come to ISNA tell how their parents were advised to move far away and not discuss their child's history with anyone. I regularly receive emails from families and patients alike who describe isolation and embarrassment that are exacerbated by standard medical care. At 42 years of age, one woman writes about her treatment:

I [...]live in Sydney Australia (don't hold that against me). I was born with CAH - not actually diagnosed until I was 5. At 7 I had a clitoridectomy because of an enlarged clitoris. The Drs have told me that I will need further surgery if I am to have sexual relations however to this date I have not even had a boyfriend let alone a sexual relationship. I feel that the reason that I have not had the relationship is that I probably feel embarrassed [sic] about it, I also feel that I have been cheated of something and that males don't want only half a female. I also feel more male than female. (personal communication with F.P., July 8 1999)

This woman suffers because she is afraid to discuss her feelings about her body, and in 36 years of medical management, nothing has been done to help her. This failure on the part of her care givers is clearly linked to the emphasis that current practice places on appearance and the appropriate way to have a sexual relationship. The medical standard claims that surgery can produce sexual normalcy, but fails to account for how much sexuality has to do with perception and feelings, rather than with heterosexual penetration. So this particular woman, like many others with intersex diagnoses, describes feelings of being too male, or not female enough, and she has no appropriate channels for discussion within the medical treatment paradigm. This woman's case is particularly interesting because she is not associated with ISNA or any of its offshoots, yet the feelings she describes about her self-image reflect the feelings of many others who have been treated under the same protocols. This reflection suggests that it is the discourse and treatment of intersex that produces these feelings, and not a preexisting identity framework at ISNA. This is an important point because, as I have indicated at various stages in the dissertation, established medical professionals often discount the testimony of ISNA members in particular as the loud complaints of a disgruntled few.

Many of the problems faced by intersexed persons and their families could be ameliorated by welcoming more rather than less conversation on the subject. There would be obvious benefit to patients if care givers were to provide them with close, psychological counselling, helping them to understand their bodies' specific processes, needs and changes. Surgeons and endocrinologists, who have little or no training in mental health care, are not qualified to carry out this counselling and support; they are more like

technicians in the field and the mental and social support should be left to mental health experts and peer support groups similar to those formed by AIDS and breast cancer patients.

There is considerable merit in changing the script used to explain intersexuality to parents. The model doctors traditionally use states that “this child was born with unfinished genitals. We can surgically correct the error by completing the genitals. The patient will then be a normal male or female” (Hendricks, 1993, 11). Clinical psychologist Suzanne Kessler suggests instead that the overall health of the child should be emphasised, as should the overall appearance of the child so that parents are assured that they have healthy and beautiful new babies. In addition, she advises that doctors should stress that the child can choose cosmetic surgery at some future date but that there is no need for early cosmetic intervention and that a “wait and see” approach would be most appropriate (Kessler, 1998, 129). Kessler remarks that, in fact, this kind of script is precisely what many parents are ready to hear:

If one looks, one can find some examples of parents ready to hear a new philosophy. There are the parents of a young girl who, when told about her XY chromosomal pattern, her absent vagina, and her diagnosis of AIS responded: “Wow--how interesting! She’s really special. Let’s see what we can find out about this.” In a sample of boys and men with micropenises, those able to make the best adjustments had parents who thought the appearance of the penis was satisfactory and conveyed this to their sons. (Kessler, 1998, 130)

Surgical management as the primary and final solution to intersex genitals

perpetuates the notion that bodies have to look a certain way to be acceptable, and it does not allow parents to develop a more accepting attitude toward their children. It is also important to understand that for many intersexuals, not only are their surgeries damaging to nerve structures--something one might possibly suffer for the sake of being rendered visually normal--but the surgeries actually fail to deliver a normal and complete appearance. Many adults who have had “corrective” genital surgeries report that the surgery damaged their appearance as well as their function/sensation, leaving them with just masses of scar tissue (see intersex organisations’ print and website material in works cited). This fact, combined with the stigma of silence that most families dealing with intersex face, can be extremely emotionally damaging. This set of experiences and outcomes often prevents intimacy and jeopardises the comfort and confidence of the individual with him/herself.

Intersex Society representatives have also proposed encouraging parents to realise that surgery cannot simplify or correct the complex emotional and psychological aspects of intersexuality. The ISNA is not naive about its call for change, and is quite clear that in a culture where having one clearly defined gender with a body to match is of paramount importance, intersexuality risks being perceived as freakish. The point being argued by various intersex support groups is that surgical intervention has not been a successful means of combating the perception of intersexuality as a form of monstrosity. This is probably because the surgery is motivated by the perception of intersexuality as a monstrous condition, and is therefore bound to contribute to that perception, even though

the goal is to produce a child who feels totally “normal.” Providing patients and families with the support to mitigate such perceptions and the feelings they produce may seem like a daunting and unfeasible task, but with an increasing number of peer support and information groups, this call is becoming much more practical. Neither intersexuals nor their families have been well served by the standard medical approaches that have isolated them and hindered their efforts to contact others dealing with the same or similar issues. The fears and problems, and the successes of families and patients, remain unaddressed, with each successive family facing the diagnosis going through the process very much alone.

¹ Reiner, W.G. 1997; Edmonds, 1994; Roselyn et al 1983.

² It may indeed be that there is a false sense of security in declaring the sex of any child directly from birth, and based solely on genital appearance. After all, it is because boys and girls are expected to grow up to do certain things that leads to parental dismay over having gay children, and also leads Monique Wittig to argue that lesbians are not women, and Judith Butler to argue that all queers threaten our concepts of the relationship of genitals to sexual identity.

³ There is a small but growing body of fascinating and valuable work on the Deaf community and how deafness is perceived by the hearing world. Much of the premise in this work is that the Deaf community, being those who have fluency in Sign, and who live in a Deaf world, see their language not as an approximation of English, or French, for example, but a language unto itself, with valuable contributions to make in cognitive theory, cultural production, and phenomenological understandings of what it means to think, communicate and feel. Some members of the Deaf community argue that cochlear implants rob those who are deaf from entering the community of the Deaf, and from making the contributions that should have been theirs to make as an opportunity of birth. For more on this, see Lennard Davis, 1995. Enforcing Normalcy: Disability, Deafness and the Body, Verso Press: London and New York. In fact, Davis draws parallels between the devaluation of the deaf community and of intersexuals, pointing out that both groups, among many others considered "abnormal" have been the targets of eugenics movements that devalued "disabled" bodies. In addition, see Oliver Sacks, 1989. Seeing Voices: a journey into the world of the Deaf, Harper Collins: New York. Sacks discusses the conditions at Gaudellet College in Massachusetts, conditions which have made a community viable within itself and as contributors to the larger North American culture.

⁴ See the summer 1998 issue of Gay and Lesbian Quarterly, Chrysalis and the ISNA web site <http://www.isna.org> for multiple reports of patient dissatisfaction with outcomes.

⁵ While intersex conditions may be prevalent in some families, the reproductive couples may not expect to have intersexed children, while inherited forms of intersex (AIS, CAH) will mean that the intersexed family members themselves will be sterile or have reduced fertility.

⁶ See the comments made by Hugh Downs quoted in chapter two.

⁷ I do not want to belabour the point of misogyny in the assignment and management of intersex infants and children. I have argued this point extensively in my Master's Thesis (1994, York University) and in various other publications (Holmes, 1994b, 1999).

⁸ The body of knowledge on these issues is too broad to cite, and includes everything from film documentaries, popular culture, lesbian autobiographies, and books such as Our Bodies/ Our Selves, among many others.

CHAPTER FIVE

CONSENT AND AUTONOMY

What are the limitations of consent?

If medical teams, parents and other care providers are to set out a new approach to treating intersexuality, what considerations will we need to make with regard to consent? For if parents are still to function as proxies for their children's medical care, and we are also going to ask that parents not make irreversible decisions in that care, then certain official challenges are almost certain to arise.

In the past quarter century, perhaps because of the threat of malpractice suits which are more common in the United States than in Canada, the American medical establishment has seen an increasing necessity for and value placed on the idea of producing an informed patient who then provides consent for a physician to carry out medical treatments. At least since the decision of the Supreme Court of Canada in the case of *Reibl v. Hughes*, medical professionals and bioethicists alike have come to understand that simply obtaining consent for medical therapies and/or procedures is not sufficient to proceed with any proposed course of treatment. Since the case was decided on October 7th 1980, it has been necessary to obtain *informed* consent from a patient before proceeding with any proposed treatments or therapies. Yet the standard approach to the medical and surgical management of intersexed infants and children, as I have already argued, obviously ignores the legal and ethical guidelines for producing and obtaining informed consent. An extremely paternalistic approach to informing both

parents/guardians and patients prevails in the management of intersex cases, and assumes that full disclosure of the patient's diagnosis and/or treatments would be more traumatic than families and patients could bear. This chapter argues that full disclosure is no less a requirement in intersex specialities than it is in any other medical field, and that it should be patients rather than families whose feelings, thoughts, questions and so forth are considered to be of primary importance.

Whether or not one agrees with the principles of informed consent law is not the issue, for the law has already determined that informed consent is a basic requirement of appropriate treatment. The law is intended to safeguard the autonomy of patients and their fundamental right to make reasonable decisions specific to their own lives and circumstances. When physicians and surgeons ignore the law, which they do as a matter of course in the treatment of intersexuality, they are not just being paternalistic; they are *breaking* the law. Whether they think themselves justified in doing so is not for them to decide, for it has already been decided by the courts that the decision is not up to them. Informed consent laws do not apply any less to the treatment of intersexuality than to any other field.

Why is it a physician's duty to properly inform patients and their families of an intersex diagnosis? The needs of the patient must be considered and patients who find out the truth about their diagnoses in isolation are often ill-equipped to cope with the information. One woman with AIS writes about her own discovery of the truth in response to Dr. Anita Natarajan's justification of deceptive practice:

[...]learning the truth about having AIS is traumatic. But learning it alone and scared in the stacks of a library is shockingly inhumane. When doctors

and parents abdicate their responsibility to speak the truth, they not only allow this to happen, they virtually ensure it will. It is almost inevitable that that patient will learn the truth. The real question is how, and when, do we want her to do so. When I discovered I had AIS, the pieces finally fitted together. But what fell apart was my relationship with both my family and doctors. It was not learning about XY chromosomes or testes which caused enduring trauma; it was discovering that I had been told lies. I avoided all medical care for the next 18 years. I have severe osteoporosis [sic] as a result. This, Ms. Natarajan, is what lies produce. (Anonymous [US representative], 1996, 7)

I am not simply arguing that obtaining informed consent is all that a medical care giver is obliged to do before proceeding with a patient's course of treatment. Providing adequate care should be the same thing as providing the *best* care. The idea that once one obtains *informed consent* one has fulfilled a fundamental duty to the patient and can then proceed with the agreed upon treatment is contested as insufficient in some discussions of the matter. Margøret Sommerville, for example, argues that simply obtaining informed consent to carry out a treatment does not guarantee that either the conditions of treatment or the treatment itself are either moral or ethical (Sommerville, 1980, 11). This is an argument I will return to later in this chapter, for it is an important consideration in the treatment of minors.

For consent to constitute a valid act requires not only the right to give permission to proceed, but also the right to informed refusal. That is to say that unless I am equally free to refuse to do something, or to have it done to me, then I am not truly free to

consent. This point is very important in the study of experimental procedures on prisoners, children, and mental health patients who may not have full access to the right of refusal. A prisoner, for example, might “choose” a treatment in return for better overall medical care. In such a case, the validity of his or her choice becomes questionable; therefore, prisoners can no longer be offered special privileges in return for submitting to experimental procedures or other studies. Instead, the overall condition of prisons, including health care for prisoners, is supposed to be both improved and equal for participants and non-participants alike. These measures are intended to encourage the development of conditions under which prisoners can give true consent. This is a fairly new development in the general treatment of prisoners and has required an adjunct change in the general perception/belief that prisoners, by definition, have forfeited their right to autonomy as payment for the crime(s) they have committed.

Even elderly patients with certain diminished mental faculties remain full subjects under the law, entitled to make their own decisions unless they have given power of attorney to a proxy representative.¹ In cases where a patient presents a danger to him/herself or to the public, treatment can be compelled as a matter of public policy, and is not handled according to usual patient care guidelines. Compelled treatment can also be applied in the management of highly communicable diseases such as tuberculosis, in which case a diagnosed patient *must* submit to treatment; otherwise the general public is at risk of contracting the disease. However, in certain cases, even compelled treatment is contestable because the threat of certain diseases to the general public may be unclear, and there may be more hysteria than fact involved in assumptions about transmission rates and how a given disease is passed and spread.

Treatment/management of intersexuality is not compulsory, but the conditions under which it is carried out are coercive. Proxy representatives are sought to give or refuse consent because minors are believed to have, *de facto*, a diminished mental capacity to make decisions. Challenges to this perception and manipulation of children's rights and faculties are being raised by ethical committees and governing bodies, but their conclusions are not always implemented in practice.

Thus, for example, the American Academy of Pediatrics' (AAP) committee on bioethics authored a paper on medical decision-making and the treatment of children. In the paper, they argue that patients have both a legal and ethical right to make their own decisions regarding their health care unless "[...]the patient has diminished decision-making capacity or must undergo legally authorized 'involuntary' treatment. Respect for competent patients' autonomy ordinarily extends even to the refusal or discontinuation of their own life-sustaining treatment" (Committee on Bioethics, 1995, 314-317). The same essay also cautions that proxy consent is highly problematic because the health care providers "[...]have legal and ethical duties to their child patients to render competent medical care based on *what the patient needs*, not what someone else expresses" (Ibid. Emphasis mine). Yet, the AAP does not always apply these conclusions or follow the guidelines set out in the article.

I witnessed what happened when the academy was faced with unhappy intersexed patients who held a demonstration at the annual AAP convention in Boston in 1996. The AAP issued a press release stating that they were aware of and sensitive to the needs of intersexuals, though they had refused to meet with intersexuals present at the convention. Furthermore, in the face of challenges made by the first generation of

surgically altered intersexuals to have reached adulthood, their press release refused to reconsider the presumed wisdom of early genital surgery and deflected attention from its cosmetic function, couching it once again as a set of procedures meant to protect the future psychological well-being and sexual identities of patients. The following 5 points make up the main body of the AAP statement:

Intersexuals are individuals who are born with anatomical characteristics of both males and females.

The academy is deeply concerned about the emotional, cognitive and body image development of intersexuals, and believes that successful early genital surgery minimizes these issues.

Research on children with ambiguous genitalia has shown that a person's sexual body image is largely a function of socialization, and children whose genetic sexes are not clearly reflected in external genitalia can be raised successfully as members of either sexes [sic] if the process begins before 2 1/2 years.

Management and understanding of intersex conditions has significantly improved, particularly over the last several decades.

From the viewpoint of emotional development, 6 weeks to 15 months seems the optimal period for genital surgery. (AAP, news release, Oct. 29 1996)

The AAP press release's rhetoric is highly deceptive. It does not, for example, indicate that the reason doctors recommend early genital surgery is that one goal of the surgical intervention is to avoid ever telling the child about it, or about the intersexuality.

The hope in the field is that their techniques will become so advanced that there will never be any need for the child to know of his or her diagnosis or treatment. Judged on its own grounds, this is irresponsible medical practice, for it thwarts the ability of patients to give accurate medical histories to future practitioners, which can lead to serious complications.² The claim that the child can be raised with equal success in either sex erases the practice of overwhelmingly assigning intersexed children to the female sex, and masks the extent to which the medical establishment values a visually appealing penis over a “functional” introitus. What the academy does not appear to appreciate is that “minimizing the issues” is not the same thing as providing good care, and that they are going to have to be accountable to adult intersexuals who do not want their emotional and body image issues *minimised*. I realise that this is a turn in my text toward a more malevolent sense of minimisation, but I am attempting to draw that aspect of implicit discourse out of the more benevolent claims made by medical practitioners in the field.

The AAP press release was intended to counter the arguments of intersexuals who were asking the convention’s attendees to reconsider their policies regarding the standard course of treatment in intersexuality. Similar to arguments made by female health care consumers that doctors should stop perceiving and treating menstruation and pregnancy as pathological states, the ISNA representatives at the demonstration were asking doctors to realise that ambiguous genitals were not diseased genitals, and that a patient’s potential to consent to or refuse surgery at a later date should not be ignored, but protected as a right. Representatives were also calling attention to the lack of appropriate information given to parents. None of these concerns was ever addressed by the AAP, and their press release simply ignored the issues, couching their position in a claim of professional

dedication that concluded with an appeal to the strength of numbers: “The American Academy of Pediatricians is an organization of 51,000 pediatricians dedicated to the health, safety and well-being of infants, children and young adults” (Ibid).

Managing Parents

In relation to its application in the treatment of intersex patients, the right to informed refusal should apply both to parents and to older intersex patients. This means that the goal of intervention should change from its current imperative to have parents consent to *early* genital surgeries and associated interventions, to a goal of educating parents about treatment options and their probable long-term outcomes. In present management protocols, the goal of medicine is to teach parents how to see intersex from the medical and surgical perspective. Thus, for example, I have already discussed an email dialogue with a new mother regarding the misinformation she received about her daughter’s condition; in a more recent conversation, this same mother was adamant that whatever was wrong with her child had not been visually apparent, and that the child was already several days old when the mother had to manually palpate the labio-scrotal folds of the child’s genitals in order to demonstrate to the father what the doctors had already shown her: that the child had partly descended testes (personal communication with S.M., February 7 1999). The point here is that the parents were actively taught by the medical management team to see their daughter as genitally ambiguous. Suzanne Kessler argues that this is precisely what many management teams do; they actively teach parents to see their children as anomalous, and then declare that the child’s ambiguity, while a neonatal emergency, can finally be fixed, and a solid sex assignment firmly established:

[...]physicians normalize the intersex condition and keep the infant's gender from being problematic[...] by first teaching parents to see the genital ambiguity and then by teaching them to see the ambiguity as not important. It is merely a genital ambiguity, and a correctable one at that. (Kessler, 1998, 93)

In the model I am proposing, the goal would be to educate parents about a *variety of possibilities*, allowing them to determine what medical services their children, and not they themselves, might need to access at a future point. In the first case, which is the current *modus operandi*, the medical establishment is imposing an intervention for a condition that the parents may not even perceive as troubling,³ while in the second case, it would be offering a set of possible services that people would be free to either accept or refuse upon reaching an age at which they could decide for themselves.

As it stands, parents who refuse treatment for intersex conditions risk being read as irresponsible or naive. In some cases, it is conceivable that the need for cosmetic intervention to stabilise the sex assignment of the child could be perceived as so necessary by social workers or medical staff involved, that parents could face criminal prosecution for refusing such surgeries.⁴ At a session on intersex management at the 1995 SSSS⁵ meetings, Dr. Heino Meyer-Bahlberg suggested that early cosmetic surgery was critically important to prevent bonding failures that might lead to child abuse and reported an anecdote of a father who had tried to rip the enlarged clitoris off his daughter's body with his bare hands, causing serious damage to the surrounding tissue. A representative of the Intersex Society has suggested that, instead of seeing the surgery as a measure that might have prevented such abuse, one should see the surgery merely as a medically "safe" version of the same enactment of hatred and non-acceptance. The argument is that

refusing surgery is neither a negligent act, nor an act that leads to abuse, and that, in fact, the current protocols do not ask parents to learn to accept and love their children as they are, but only to avoid having to face their children as they are. Medical practitioners exacerbate parental and societal ideas about the unacceptability of intersex conditions, contending that there is a risk of suicide in cosmetically unaltered children with intersex conditions. They argue, therefore, that cosmetic intervention is actually a life-preserving measure. By simply extending this argument, which has no verifiable data to substantiate it, medical practitioners could work with social workers to charge a parent with negligence for refusing treatment, or even with a failure to provide the necessities of life.⁶ How did doctors come to have this much authority to determine which decisions are valid, and which are not?

Medical Power

Medical literature frequently expresses concern for parents of intersexed infants; many sources indicate that the presentation of a child with ambiguous genitalia is the most shocking and tragic situation that a parent can be faced with. Management of the child is often predicated on this assumption and promotes the idea that the only way to alleviate the parents' anxiety is to assign a sex early and quickly affix it surgically. Without long term follow-up on the outcomes for these assignments and procedures, it is somewhat surprising that medical practitioners are so willing to advise parents in ways that seem so certain of positive outcomes. Given that this is how cases are currently being managed, what are the outcomes that we are aware of and are those outcomes being well accounted for in advice given to parents?

The reasons for the authoritative position of medical practitioners in relation to patients are many and discussing them here is well beyond the scope of this chapter. It is, however, likely that the heightened position of doctors as figures of authority has much to do with the rise of science throughout the 18th and nineteenth centuries and with the fall of religious authority. That is to say, the rise of the medical professional coincides roughly with the fall of the centrality of religion in the day-to-day lives of typical people, and also with the general rise of science in the 18th and nineteenth centuries.⁷

Jay Katz has proposed that the authority of the doctor as “knower” constitutes a very powerful relationship of *faith* between patients and their medical practitioners. It is a faith that he claims practitioners are convinced would be undercut by admitting the uncertainties inherent in any course of treatment or procedure:

Learning to live more comfortably with uncertainty[...] has been impeded by other strongly held, although largely unexamined professional beliefs: that patients are unable to tolerate awareness of uncertainty, and that faith in professionals and their prescriptions makes a significant contribution to the treatment of disease. In the light of these and other problems it is not surprising that doctors are most reluctant to share authority with patients and instead insist that patients follow doctors' orders. (Katz, 1984, xvii)

The rise of science has not meant that the faith vested in religions and their leaders has disappeared; rather, that faith has merely shifted ground and the doctor has replaced the priest, rabbi or minister as the authority over life and death. Patients who refuse to acknowledge medicine as the new authority and who may refuse to follow ‘doctor’s orders’ are, at the very least, considered foolish. Religious faith is cast as illogical and

emotional, while faith in science is cast as “reason.”⁸ In some cases, the reason and faith of a patient may be completely overridden. The right of refusal is foreclosed upon and consent by the patient is considered irrelevant. Patients can be forced by legal orders to obey or submit to treatment(s) regardless of their individual beliefs or reasonable objections to treatment:

Compulsory treatment legislation is based on public policy determination.

In effect, a value judgment has been made that it is far better to deprive one individual of his right to refuse or to authorise care than to risk the spread of a serious disease. *A patient with a communicable disease may be quite willing to submit to treatment. The law does not care whether the patient is or is not willing[...]* It compels therapy in order to maintain good order, public welfare and health. (Rozovsky and Rozovsky, 3, emphasis mine)

The force does not end with communicable diseases; minors can be *compelled* by legal interventions to undergo medical treatment. In the United States minors who refuse to undergo life-prolonging therapies have been forced by court orders to submit to treatments: “[...]Lee Lor, 15, fled Fresno after police dragged her from her home and forced her to undergo chemotherapy for ovarian cancer, contrary to her fears and her Hmong family’s suspicion of Western Medicine. Two months later doctors relented and a judge lifted the order” (Perkins, np). It is also possible for medical practitioners and judiciary forces to intervene even in cases which are not primarily health related but ‘aesthetic’:

Jane Doe[...]was removed from her father’s legal guardianship[...]because she weighs 350 pounds. A thin aunt was pressuring Jane’s father to put

her on a diet [and] reported him to the child welfare system when Jane failed to lose weight. [...] Since she has not lost sufficient weight to satisfy the court, she now faces a more serious threat to her physical and emotional health: the judge plans to put her in a hospital-based 800-calorie weight-loss program under court order to lose 5 pounds per week with the stipulation that she[...] not be released until she has lost 150 pounds.

(Atkins, 1995, 8)

The cases of Jane Doe and Lee Lor demonstrate that, as it stands, the right to refuse treatments is only minimally exercised in the United States. With many American or American trained physicians and medical experts in Canada, it is not surprising that our own ethical textbooks are only just beginning to consider the right to refuse treatment as a valid right that could be substantiated by reason. Due to a perception that it would be economically and judicially unfeasible to consider consent and refusal on a case-specific basis, and because of prejudices which favour “life” and thinness at all costs, it appears that the rights of minors and their guardians, like the rights of those with communicable diseases, can be easily overridden. Similarly, in the case of intersex treatments, medical practitioners are likely to consider it absurd to invoke the right to refuse treatment in cases where “cosmetic” alteration of the child’s genitals is recommended to “repair” an intersex appearance.

As David Valentine points out in his article “One Percent on the Burn Chart,” genitals account for only 1% of the total body surface, yet carry an enormous burden of signification in terms of who a person is, and what s/he does. One prevailing fear, often expressed by doctors who treat intersexed patients, is that without early cosmetic

surgery, this signification process will be muddled, resulting in a confusing and confused sexual identity for the intersexed child. For this reason, the thought that parents might refuse cosmetic treatment leads medical experts to conclude that such a decision would be both ill-informed and irresponsible. What is often over-looked in this medical perception is that intersex patients who have had all the requisite surgeries have begun, in significant numbers, to declare that the early interventions did nothing to prevent identity crises, and may have actually caused or exacerbated identity crises.

Consent is, overwhelmingly, the desired and presumed conclusion sought from patients; intersex management is not a special case in this respect. The medical community does not popularly entertain the idea that a patient could legitimately opt to withhold his or her consent once having been thoroughly informed of the benefits and risks of a proposed medical therapy or diagnostic procedure. The only unique aspect of intersex treatment is that we are dealing with consent-by-proxy, rather than the direct consent of the patient. However, whether we are discussing the present ability of parents to refuse certain procedures, or the future possibility of adult intersexuals to refuse proposed procedures, the validity of the refusal as it is perceived by medical professionals remains the central and unchanged issue. Jane Coy argues that a patient's refusal to follow a physician's orders or to grant consent constitute "noncompliance", a situation toward which doctors have four intersecting views: all cases of noncompliance are problems which require solutions, the solution to noncompliance is compliance, all instances of compliance are *non problematic* and, finally, it is the patient who is the source of trouble in cases of noncompliance (Coy, 1989, 826-827).

In a world where science and 'reason' appear to have taken the place of God, at

least in determining how our laws are made, upheld and executed, it is easy for conflicts of the sort detailed above to come about. It is a world in which having a communicable disease causes one to lose his or her rights just as a convicted offender loses his or her rights, in which the use of alternate therapies may result in criminal convictions, and in which traditional values from non-Western cultures may result in highly charged conflicts, between not only doctors and patients but between patients and social services and courts as well.

I am not proposing that a return to the authority of religion would be advisable; the mere fact that diverse religions would easily come into conflict with each other implies that this would be unworkable. My point, rather, is that the authority of science/medicine is not necessarily a desirable alternative to God or religious institutions as our central source, measure and establishment of authority. And, indeed, it is advisable that, whatever the moral, religious or ethical considerations of the attending physicians, respect and consideration for differing patient values regarding life, death and spirituality be upheld.

I have already indicated that the principle of *informed* consent, as a requirement, is a relatively recent development in medical practice. In what is called 'paternalistic' medical practice, doctors presume, indicate and, indeed, assert that they know what is best for a patient. This model had been the dominant *modus operandi* of the medical establishment well into the age of civil rights activism.⁹ In the paternalist model of medical practice:

[...]the physician-patient interaction ensures that patients receive the interventions that best promote their health and well-being. [...]At the

extreme, the physician authoritatively informs the patient when the intervention will be initiated. (Emanuel and Emanuel, 1995, 163-164)

Although Emanuel and Emanuel assert that physicians rarely advocate the implementation of paternalistic approaches to physician-patient interaction,¹⁰ it is also true that many senior, respected and established practitioners currently in practice would have been trained through the sixties and seventies, before the advent of a patient-based model of care: "Prior to the 1970s, the standard for informed consent was 'physician-based'. Since 1972[...] however, the emphasis has been on a 'patient-oriented' standard" (Emanuel and Emanuel, 1995, 170).

The fact that many of today's practitioners were trained in a period of physician-based practice, or by medical practitioners who were indoctrinated during the paternalistic model's heyday, may account for the murky evaluations and perceptions of the purpose of providing a patient with sufficient information to make an informed decision about his or her proposed medical treatments. It is also quite possible that a pretence to 'patient-centred' care could paper over a paternalistic approach to treatment.

But there are problems other than the approach of physicians which impede the effective implementation of informed consent as a directive and operative method of interacting with patients. Studies have shown that *both* patients and doctors have a tendency to believe that consent, informed or not, is a formality intended to satisfy a bureaucracy and protect doctors against law-suits. Cassileth *et al* found in a study of 200 cancer patients that 75% of their subjects believed that consent forms were legal documents designed to protect doctors and 28% believed that they "were obligated to sign a consent form if they received one" (Cassileth *et al*, 1980, 898-899). The editorial

comment on the Cassileth study states that

The ordinary patient[...]cannot possibly make a reasoned decision without being told what the physician intends to do and why, what the alternatives are, and what the probabilities of success and risk may be. [Yet] physicians[...] assume that the idea of truly informed consent even for an ordinary elective procedure is a delusion, and that it is cruel[...] to reveal all the major hazards to the patient[...]" (Drummond, 1980, 917)

A study by two cardiac surgeons in 1976 showed comparable results to the Cassileth study and noted that surgeons attributed patient inability to make reasonable decisions to a failure on the part of patients: "Each of the twenty patients failed to recall major parts of the interview" (Barber, 82). Barber argues, however, that patient recall may be influenced by the standard prejudice that physicians have against "[...]providing full information in the belief that well-informed patients will refuse to consent to necessary procedures" (Barber, 83). Howard Brody, in his 1989 essay "Transparency: Informed Consent in Primary Care," makes it clear that "benign paternalism" was still the most common mode of approach taken toward patients by physicians. Ten years after Brody published the essay, as I have seen in my professional interaction with physicians and surgeons at conferences and interdisciplinary settings that doctors still presume that patients do not have the ability to understand medical information or proposed interventions. Medical professionals assume themselves to be the only people capable of determining how much information a patient requires or can handle emotionally. Given that this is so, it is not at all surprising that patients, as well as practitioners, have muddled understandings of the purpose of informing a patient and obtaining consent

based on that information.

It is significant that the most common experience of medical care occurs at the primary care level, that of the family physician and patient. This is important because what we are most accustomed to can easily set or strongly inflect the manner in which patients come to expect medical experts to behave. Thus, the notion of “informed consent” can easily be undermined via a primary care mode in which Brody states “[...]respect for patient autonomy is almost completely absent” (Brody, 1989, 5). Primary care practitioners perceive the autonomy of patients as irrelevant to “routine” exams and do not often bother to explain why tests may be ordered; they may behave in ways that make it difficult for patients to feel entitled to read their own medical files

The ‘transparency model’ which Brody ultimately lays out is intended to make clear that the point of informed consent is not “a bureaucratic legalism [but a] part of patient care” (Ibid). Furthermore, Brody asserts that the transparency model will aid in ensuring patient autonomy and in reducing the poor recall and comprehension results, like those of the Cassileth study, which are well known to him.

Brody has chosen the primary care setting as the place to instigate the transparency model because he recognises the tendency of ethical questions to be posed only in terms of extremes:

The models of informed consent discussed[...] typically take as the paradigm case something like surgery for breast cancer or the performance of an invasive and risky radiologic procedure. [...]Primary care medicine, however, fails to fit this model. [...]Indeed, in primary care it is much more likely for the full process for informed consent to treatment[...] to occur

over several office visits rather than at one single point in time. (Brody, 1989, 5-6)

Brody's statement about paradigm cases is well taken. I have noticed that current trends in bioethics writings indicate that most of the questions circulate around life and death issues rather than specifically around care issues. In the chapter on Consent in Health Care Ethics in Canada, two of the four subsections deal with terminal illness, a third deals with the *Reibl v Hughes* case, arguably a life/death case in terms of the severity of illness (arterial sclerosis in the brain) and results of the surgery (a paralysing stroke), and the final subsection deals with a case in which a woman was paralysed on the left side of her face by a largely unnecessary surgery to restore partial hearing impairment. Chapter eight, "The Case of Baby L" deals with the treatment of a terminally ill infant, Chapters ten, eleven, and twelve deal with genetics, abortion and reproductive technologies while all of Chapters thirteen and fourteen deal with end-of-life medical care, including the very sensational Sue Rodriguez case.

I have no doubt that life and death issues are worth exploring. However, by making them the primary focus of texts on bioethics and in discussions of ethical questions, we overlook all the more commonplace instances in which informed consent is required and sought, however inadequately that may happen. And we overlook the power of the primary care setting to influence the way in which patients and doctors approach each other in other settings.

The Necessity of Informed Consent

To this point in this chapter, I have described some of the ways in which

patients' concerns, interests and rights are overlooked in standard medical practice. At its most extreme, standard medical practice and the law can move so far as to be not only ignorant of patients' concerns, interests and rights but absolutely unconcerned with them to the detriment of both patients and their families. However, admittedly, what I have done this far is posit a personal *a priori* that individuals have a right to informed consent, and concomitantly, to informed refusal without justifying or explaining why this ought to be an imperative under which we all should operate.

Therefore, in this section of the chapter I shall do three things: provide a definition of "informed", provide a structure through which to recognise both consent and refusal and, finally, engage these combined terms in a discussion of the influences of a social ideology of "the individual" in which one is necessarily wronged if not recognised as a cognizant, reasonable and capable individual in his or her own right.

Let me begin by posing the question: What is implied in the search for and deliverance of consent, informed or not? I propose that this question lands us squarely in a discussion about freedom. And it is not merely the personal or individual freedom of the person providing consent which is at stake; I propose that, indeed, the freedom of all individuals is at stake in each and every instance in which consent is sought. Why? Because the opposite of consent is refusal, or in the terms of existential struggle: revolt. But what is the relationship of refusal to the freedom of others?

Nothing is decided in advance and it is because man [sic] has something to lose and because he can lose that he can also win. Therefore, in the very condition of man there enters the possibility of not fulfilling this condition.
(de Beauvoir, 1976, 34)

What I take de Beauvoir to be saying is that all human existence is a negativity, not in the sense of right and wrong *per se*, but rather, in the sense of a negative image which holds a potential to be turned into a positive image through *process*. The integrity of the process is then guaranteed not by the docile submission to preestablished laws, for this is what de Beauvoir describes as infantile behaviour (1976, 35-39). Instead, one must enter into a conversation with the prescribed laws and customs, and from there, either act in accordance with them or refuse them. But the sincerely entertained potential to refuse is what grants freedom to the act of compliance.

By this measuring stick then, the blind compliance of the 28% of patients in the Cassileth study who believe they must sign consent forms if they are received, throws the freedom of all individuals into question. Furthermore, the paternalism of doctors who believe that patients are incapable of responding well to uncertainty also jeopardises the freedom of all persons, including their own, because their paternal behaviour forecloses upon the possibility of anyone really choosing the direction of his or her medical treatment, and by extension, of his or her life: "The drama of original choice is that it goes on moment by moment for an entire lifetime, [...]that freedom is there as if it were present only in the form of contingency" (de Beauvoir, 1976, 40-41). de Beauvoir's point is that our freedom is never total, and that at any/every moment I must reconfirm my freedom and that of others by deciding.¹¹ If our freedom is only a contingency, then it is negated in moments in which we either refuse to permit others to make a free choice, or refuse ourselves the ability to make a free choice and each of these possibilities acts in a reciprocal relation to the other.

Thus I ask the question, is choice implied in consent? Yes, there must necessarily

be a choice made in order to present a valid consent. But what is it that makes the choice valid? To this I respond that it is knowledge, the very type which physicians fear will undermine a patient's confidence, which constitutes the validity of a choice.

The patient must be informed so that he [sic] will know what he is getting into, what he may expect from the procedure, what his likely alternatives are--in short, what the procedure (and forbearance from it) will mean, so that a responsible decision on the matter may be made. (Freedman, 1975, 34)

It comes to this: if one is not free then none can be free. If a doctor refuses to allow the possibility of a patient's refusal and does all that s/he can to force compliance, then not only have the rights of the patient been hindered, but so have the rights of the physician who has effectively forced him or herself into a position wherein s/he has no choice except to treat a patient, regardless of how uncertain or ineffective the diagnosis or prognosis may be. By taking a paternalistic approach and *deciding for* the patient what the patient needs, the physician fails in his moral duty to assure the "[...]right which each of us possesses to be treated as a person, and in the duty which all of us have, to have respect for persons, to treat a person as such, and not as an object" (Freedman, 1975,32).

The physician has failed to comply with 'the golden rule' of treating others as one would want to be treated him/herself, and has thus jeopardised his or her own right to be properly informed and granted the possibility of choice in other situations which may require his or her consent. For if you devalue individual freedoms in one realm, then you may easily limit other freedoms of choice, for example: political, cultural, and economic. If you state that only the physician knows what the patient requires, then you are only a

very short distance from a totalitarianism which states that a dictator knows best what the occupants of his domain require. One cannot be a citizen in one arena while only 'existing' or having the possibility of coming into 'being'¹² denied in another. Then the physician may not expect his/her banker to explain what is to be done with the physician's money or why; the teacher of his/her children will not have to explain what the children are to be taught or why; the physician is not an expert in those fields and cannot be expected to fully understand the reasoning provided by those who are experts.

This discussion leads to my promised definition of the "informed" portion of "informed consent". The term "informed" in itself, is not difficult to understand, however, the question of its application has been cause for significant consternation to physicians, court judges, lawyers and patients. It, therefore, seems clear that in spite of the relatively simple idea that to be informed means that one has "much information, knowledge, or education" (Webster's New World Dictionary, College edition), the definition does not translate into a clearly shared meaning or application.

How does providing information to a patient influence his or her freedom of choice? What are the requirements of adequate information? Physicians complain that it is impossible to completely inform patients of every risk involved in any given treatment. However, the courts disagreed with this complaint, and decided that the arguments made by physicians distort the concept and intent of informed consent, arguing not that patients would have to be familiar with every possible risk, or with every minute detail of any proposed procedure, but that they would have to be given adequate information to form a rational decision regarding their course of treatment. In the *Reibl v Hughs* case, which set the new Canadian standard for ensuring a *valid informed consent*, the judgment

made it explicit that:

[...]a consent is sufficiently informed if and only if the explanation provided to the patient included that amount of information that the average, reasonable patient in the patient's position--as the doctor knew it, or should have known it--would require" (Baylis *et al*, 1995, 205).

In the United States, the approach is more explicitly oriented toward ensuring the *civil rights* of the patient: "To deny the possibility of informed consent is to ensure that it will never be achieved--an attitude that is immoral, and, in hospitals in states that have adopted the Patient's bill of Rights, illegal" (Drummond, 1975, 917-918). Although each model takes an explicitly different approach to the issue of informed consent, they both share a moral position that it is the physician's duty to properly inform a patient of what is indicated in all proposed procedures or treatments.

Thus far I have not explicitly responded to the physicians' charge that it would be both impossible and cruel to fully inform a patient. I believe that the decision in the *Reibl v Hughs* case, combined with the positions of Jane Coy and Howard Brody will be instructive here.

We know from the Cassileth study, that as it stands, patients have a poor ability to recall the information given to them at the time of providing consent. The authors in the Cassileth study propose that this is a failure of the means of providing information and not a failure on behalf of the patient. To remedy the retention problem, the authors advise that the

Barriers[...]imposed by the difficulty of the material and by the legalistic and other negative connotations of the consent document[...]need to be

removed if[...] patients are to function as the informed consumers that many[...] wish to become. (Cassileth *et al*, 1980, 899-900)

The transparency model proposed by Howard Brody indicates that physicians should take their patients through the diagnostic process with them. That is, they should not simply write down the symptoms of a patient, do some preliminary tests and then make a pronouncement about the next diagnostic procedure. They should, instead, get to know the relevant histories of their patients, find out what issues are important to their patients and have a full dialogue relationship between patient and physician so that patients will be aware of how a physician proceeds from one assessment to the next.

Brody's model is implied in the judgment of Justice Bora Laskin in the *Reibl v Hughs* case. The physician (Hughs) should have, as a simple matter of course, known that his patient (Reibl) was only one and a half years away from retiring with full benefits from the Ford motor company and weighed that against the foreseeable improbability of a stroke over a four to five year period in the patient's life. Based on that knowledge the surgeon should have advised postponing surgery until after the patient's retirement. Why? Because the physician was quite aware of the significant risk of stroke that could result from the neurosurgery to tie off a vascular bundle which was causing the patient troublesome, but *not immediately dangerous*, head-aches. Instead the surgeon led the patient to believe that the risk of a stroke, due to his condition, *in an immediate sense* was greater than the risk of stroke due to the surgery. In the court proceedings, it is indicated that the physician clearly knew that this was not the case. It was decided that a reasonable person in the patient's position would have delayed surgery until after his retirement, thereby obtaining his full pension and not exposing himself to a serious risk of

stroke before that time (Dominion Law Reports, vol 114, pp34-35).

If Dr. Hughs, who had been Reibl's surgeon, had worked through a transparency model, he would have known more about Reibl's situation and needs than just what was medically advisable, and would have been able to more accurately weigh the potential risks and benefits of the proposed surgery. There is more to the effective treatment of a patient's symptoms, diseases or complaints than just knowing what is medically relevant to oneself as a practitioner. One must also know what is relevant, both medically and personally, to the patient.

Jane Coy follows the position of Drummond, and by extension, of de Beauvoir, that self-determination is an essential feature of providing care that is not merely *adequate*, but *good*. For Coy, good care has a moral value: "When the Principle of Autonomy serves as the moral foundation of informed consent, consent is required 'simply' because it helps protect and enhance a patient's right to self-determination" (Coy, 1989, 827). Coy makes it clear that this right to self-determination is not limited to choosing only to consent to procedures which will produce good medical results. She asserts that there are other results which need to be considered with regard to the patients' individual evaluations of goodness. Coy furthermore maintains that to treat a patient otherwise is to treat that person merely as a means to a medical end which goes against one of Kant's categorical imperatives: all persons must be treated as ends in themselves.

Kant's categorical imperatives do not extend from any external command or sense that one must do good to others, and one does not treat another person as an end in him or herself because that would be a self-evident good, or that a moral act can be determined from the good it produces. Rather, laws are moral when they tell us "[...]to act in ways

which we could rationally agree to have everyone act” (Schneewind, 1991, 151). Thus, Schneewind argues that according to a Kantian moral framework, when I think through a course of action, I can determine its moral permissibility by asking if I will raise a contradiction to the demand that everyone act as I would act (Ibid). If we apply this line of reasoning to medical ethics, then the question becomes: if I deny a patient the potential to decide for him or herself, am I then setting a standard in which any person’s ability to decide, including my own, may be discounted and ignored? And if I deny that refusal is a necessary component of consent, do I then risk jeopardising all people’s, including my own, right to refuse what I do not want? If the answer to questions such as these is yes, according to Kantian moral philosophy, then my proposed course of action is not morally permissible.¹³ It is, therefore, immoral to deny patients the capacity to refuse as much as it is immoral to maintain that they cannot possibly be adequately informed.

Setting such a moral imperative into action has been contested as an impossible task, with medical professionals arguing that it would require a medical education for a patient to be truly informed. This debate rages quickly into a case of *reductio ad absurdum* with doctors claiming that they could never attend to all the risks of any proposed treatment. This, however, is not the point of treating all persons as ends in themselves, and informing them of every possible risk down to the last millionth of a percentage point is not the goal. The point is not to take a standard of information derived from a medical education, but to consider what each patient, with his or her own values and needs, requires in order to have enough information to make his or her own decision.

When it comes to the management of intersexed minors, this proposal requires that physicians take a “wait and see” approach to the cosmetic management of their

patients. It may turn out that each individual case is highly unique and that even those patients who do opt for cosmetic surgery will not opt for identical procedures. In a case of identical presentation of masculinised female genitalia, one person might, for example, opt for quite dramatic clitoral reduction surgery while leaving elongated labia alone, and another person might do the opposite. Yet another person might decide to have both the labia and clitoris altered, but only moderately. Another might choose radical reduction of both labia and clitoris. The possibilities are, presumably, limitless insofar as they are unique to each person's needs.

Regaining Autonomy

Is it possible for all patients to simply regain control within a medical environment? I remain doubtful about this. I have some very specific resources: a familiarity with medical texts, and understanding of basic procedures, access to information through a variety of sources that many do not have (internet, World Wide Web, medical and academic libraries) and several friends and colleagues in the medical field. The great majority of patients do not have access to such information, and some are disinclined to search after it. If that is a particular patient's inclination, then we must accept that as his or her right, for to demand that they seek out greater knowledge may be to ask them to seek something they are not emotionally capable of handling even if they do have the mental capacity to do so. This returns to ensuring a fundamental respect for the autonomy of individuals. However, doctors must be trained to enter into conversations with their patients, helping them to determine for themselves what the limits of their required knowledge are. For intersex patients, then, respect for their

autonomy means that any cosmetic interventions should be withheld until the patient is old enough to engage in such conversations with his or her health care providers.

Even if we could get to a point where there could be an *absolute* guarantee that there would be no nerve or tissue damage resulting from any cosmetic procedures, the moral permissibility of allowing parents or guardians to provide proxy consent for minors would continue to be questionable. The problem arises out of a failure to ensure the creation and maintenance of conditions under which a subject can exercise his or her own moral and ethical autonomy. When a parent makes a decision early in a child's life in order to prevent having the discussion at a later date, they foreclose on the potential for the child to decide for him or herself.

If we do not question the ability of parents to provide proxy consent for cosmetic procedures then we must accept, for example, that any consent they provide that is aware of the risks involved is valid. This includes having parents provide consent to a procedure that they are aware their child may not appreciate in the future. Their moral and ethical duty may be fulfilled in statements to the effect that they will take responsibility for their child's dissatisfaction, *should it come up*, at a future date. Of course, they hope that their children will not be unhappy, but they accept the risk and weigh it against the benefit of having a child with acceptable appearing genitals. Most conclude that the risk is acceptable. In an open forum bulletin board for CAH families, two parents write about their young daughter's recent clitoroplasty and vaginoplasty:

Hi. Cara is on her 3rd day of post-op and is doing very well. We feel that we have made the right decision in regards to this surgery. Every case is different and in waiting for maturity could have resulted in more

complicated matters in the future. We basically had a choice of a vagina or no vagina. Should I ask my daughter that question now[...]or wait a few years? [...] We feel that we have made the best decision[...]Cara may feel different in the future, but we can only hope and pray that she understands it. (Bridson and Bridson, July 10 1999, <http://elevenoclock.com/CAH/>)

The parents' willingness to accept any risk involved in their daughter's surgeries, including the risk that she may not like the outcome, is all that is required under current informed consent laws. But the duty not to remove someone else's ability to exercise moral and ethical autonomy, which is part of a set of social responsibilities, is threatened in such cases. In fact, insofar as early surgeries reduce the need for potentially unnerving, open conversations with older children, this form of risk acceptance threatens the parents' own ability to fulfil their moral duty to ask and answer difficult questions. Parents assuage their own fears about discussing sexuality and sex-related issues with their children by erasing their children's physical differences at an age where conversation is impossible.

In the viewpoint of many patients of the generation subjected to invasive genital surgery as children, this attitude amounts to moral cowardice. It is cowardice because it displaces responsibility in the form of "understanding" onto the shoulders of the child/adolescent/adult whose body has been altered. At a certain point, it becomes tiresome to continually act as an apologist for beleaguered parents who--we are supposed to believe--did the best they could under difficult circumstances. Many intersex adults, myself included, face familial admonishment if we "fail" to understand our parents'

decisions. Medical professionals and families cast us as “difficult” or “ungrateful” if we do not express gratitude either for having the very best procedures that surgeons could provide, or for our parents wishes that we be “normal” looking. Comments such as those made by the Bridsons cast understanding in a rhetoric of compliant (good) behaviour, and suggest that those who do not understand their parents’ decisions are ungrateful (bad) children. A significant number of the intersexed activists I know have become estranged from their families since seeking accountability from their parents and doctors.¹⁴

There are, of course, risks in refusing surgery and if they are to fulfil their moral obligations to their children, and to society in general, then parents will have to be willing to accept those risks as well. However, in cases where the proposed surgical interventions serve cosmetic purposes, the risks would be limited to the children not being satisfied with their appearance, and that is a risk that could be treated successfully by providing surgery to the child at his or her request. Rather than leave that risk simply hanging in the air, it is worth considering what knowledge is available regarding long-term outcomes for those who did not have cosmetic surgery in infancy or childhood.

As I have already indicated, the great majority of intersexed infants and children are assigned a female sex in infancy. A small percentage of individuals with intersex diagnoses are, however, considered too medically fragile, perhaps because of asthma or prematurity or other medical conditions, to endure elective surgical interventions in infancy or childhood, and have, therefore, not had their genitals altered. Some have conditions that did not become apparent until adulthood, and, therefore, did not have cosmetic genital surgeries. Some choose as adults to have their genitals altered, while others choose to remain as they are. An older woman with progesterone-induced clitoral

hypertrophy, whose clitoris was not reduced told me that she feels grateful not to have been surgically managed and that her clitoris has never been bothersome either to her or to her lovers. These cases are examples of two separate groups of patients: those who opted for surgery in adulthood and those who have never had surgery. Though their decisions are quite different, each of the people I have talked with in these groups has reported greater satisfaction with her body than have those who had no choice in the matter. Where I have seen adults express anxiety about genital appearance, it is important to note that negative attitudes are likely rooted in the attitudes of others, rather than in the reporting individual herself.

A woman who contacted me through the internet was diagnosed with late onset CAH when she was 43 years old. For much of her adult life she had been shuffled from doctor to doctor, each of whom gave only a partial and inaccurate diagnosis such as PCOS (polycystic ovarian syndrome), infertility, hormone imbalance and so on. As a result, this woman has only very recently, with her proper diagnosis, received adequate hormone management for her endocrine and metabolic functions. She writes of her experience with CAH, however, that her body's physical differences, which began to develop in her adulthood, never made her feel less womanly or less feminine, and had not been a problem in her marriage, although her fertility concerns had been unsettling. Rather, it was appalling treatment by two doctors who damaged her self-perception with ignorant and insensitive accusations and statements:

What made me feel unfeminine, less attractive, odd, or whatever expression you want is two experiences with two different gynecologists. My first accused me of masturbating so much that I was red and large. I had not

been masturbating. That was "my normal" sized clitoris. Needless to say, I never went back to him. The second time with another gynecologist following a D&C, he said that he needed to send me to an endocrinologist for testing because "you don't want to be like that", referring to the size of the clitoris. So the people who were supposed to help me were the ones who hurt me terribly which made me feel odd, unfeminine, etc. At the time, I had very unhappy feelings about myself and as yet had no diagnosis - a very trying time. (personal communication, S.M.D., July 9 1999)

Obviously, the opinions of medical practitioners need to change if they are going to be able to provide appropriate care to patients. The attitude of the doctors treating the above patient would definitely improve with some education about the natural variability of female genitals, and about the difference between superstition and reality regarding masturbation. It is difficult to believe that the statements they made to this patient are contemporary and not from nineteenth-century tracts on propriety in marriage and sex, but the legacy of discourses about female bodies, deviance, and sexuality obviously continue to hold sway in the treatment of both women and intersexuals.

Medical discourse and practice continue to see intersexuals and women as approximately the same thing: imperfect and incomplete forms of human embodiment. Discourses of disease and deviance overlap in the treatment of women and intersexuals. Misogyny clearly underwrites the diagnosis of an "intersex disorder" in any woman with a large clitoris--so long as it falls under the gaze of the medical establishment. There is also misogyny in the proposal that it is easier to make intersexuals into women because

they only need to have a hole dug out. The sex negative attitude of the doctor who accused S.M.D. of masturbating echoes Lambroso's hypothesis of the relationship between criminal sexuality (prostitution), onanism, tribadism and large clitorises. This framework simultaneously casts female bodies as imperfect in their lack, and deviant in their excess. But there are other dangers as well.

The medical treatment paradigm I have outlined sets up a situation in which the full right to moral and ethical autonomy for women and intersexed children is discounted and jeopardised. The liberation of each into a fully autonomous state is intertwined in ways that this dissertation has only just begun to map out. Feminists who write that women with AIS are impostors, as Germain Greer does in her newest book, and those who ignore the treatment of intersexed children as a medical exception, as Fran Hoskin does, risk perpetuating perceptions of bodies that imperil not only the autonomy of intersexed persons, but also of women in general. For as long as we do not challenge the conceptualisation of women as "lack," then female sex assignment, including clitorrectomy and vaginoplasties, the removal of healthy tissue and phallocratic fixations on genital size, will prevail.

Many of the long-term studies I have discussed in this dissertation have significantly smaller adult participants than infant and child subjects. The studies usually remark that patients "x, y, and z" were "lost to follow up. What becomes clear from having spoken with many intersexed persons is that practitioners actively fail to pursue knowledge of long-term research on how intersexuals fare as adults. Several intersexed persons I know have contacted their surgeons, offering to be interviewed for the purpose of providing long-term data, but as with John/Joan, clinicians have refused to listen to

what adult intersexuals have had to say. The few existing studies presume that as long as the initial cosmetic features of our intersexuality have been “corrected” then there is nothing wrong with us, or that if there is, then it must be our fault, or the fault of our families, and not the fault of the medical system. Although the system promises that surgeries will effect clear gender identities for intersexed children, and a “perfectly normal” adult sexuality, when those outcomes do not happen, the medical system does not question either its management paradigm or its promises; instead, it defers responsibility to families and patients.

It seems, then, that when one’s body is “offensive” in its difference, that it belongs to the state, and that the state can impose whatever corrective measures it sees fit, but when one’s body is “normal”, even if one remains seriously distressed, then the body belongs to the individual and it is his/her/hir problem to resolve. When a body is distressing, as in the case of intersex, the state is free to interfere, but when a subject is distressed, as many older patients are about their experiences of treatment and its outcomes, they are coerced into silence and paralysis

¹ The role of persons with power of attorney for elderly patients and those with psychiatric disorders is larger than the scope or mandate of this body of work. I mention proxy representatives not as uncontested or infallible means of ensuring that a patient's best interests are served, but only as an example of when proxies are called upon in the care of those who have reached adulthood.

² If, for example, a patient does not tolerate anaesthesia well as is often the case in patients with metabolic disorders, or will require hormone therapy/ies in adulthood, it can be difficult for practitioners to know how to proceed, and can lead to a need to go through diagnosis all over again.

³ My concern here is specifically with the cosmetic concerns with intersex. I am not suggesting, for example, that parents should not be taught how to measure their children's adrenal levels in order to administer medicines to control adrenal crises.

⁴ This is the possibility that worries Anita Catlin, and which she discusses in her 1998 article, "Ethical commentary on gender reassignment: A complex and provocative modern issue." *Ped. Nursing* 24(1):63-65+.

⁵ Quad-S is the S.S.S.S., or the Society for the Scientific Study of Sex, an interdisciplinary academic association of psychologists, sexologists, biologists and lay persons.

⁶ Admittedly, bringing a charge of failure to provide the necessities would be an extreme case scenario; however, it is a logical extension of the argument that early cosmetic intervention is a life-preserving measure, and it is this justification of early cosmetic surgeries on intersexed genitals that permits these elective surgeries to be covered by public health insurance while, for example, adult genital surgeries are not covered.

⁷ In Chapter one, I discussed the importance of professional status making efforts in the nineteenth Century.

⁸ To declare faith openly as a crucial element of the treatment would, by logical extension of Katz's insights, seriously undercut its function within the relationship. To declare the relationship between doctors and patients as one of reason casts some patients as "good" and others as "difficult", thereby serving a very coercive function as well.

⁹ Jay Katz places informed consent as a development of the early sixties. *The Silent World of Doctor and Patient* See p. 2.

¹⁰ This argument is extended in "Four models of the physician-patient relationship," p. 172.

¹¹ Whether one's choice is right or wrong, whether its consequences are positive or negative, deciding is the same as making a commitment to uphold my freedom and that of others. This sense of deciding runs throughout de Beauvoir's existential work and is particularly important in her novel, *Le Sang des Autres*. Agonising over the potential outcome of a decision paralyses the soul and leads to inaction, thus threatening both my own freedom and that of others.

¹² I use 'exist' here in the existentialist sense of a stasis which is both morally and developmentally a weakness. In simple existence there is no will and no struggle; there is only a passive compliance in which neither the master who commands nor the slave who obeys can progress into 'being'. My point of departure is a specifically de Beauvoiran discussion of the Kojevian interpretation of Hegel's master/slave dialectic, see: de Beauvoir *The Ethics of Ambiguity*.

¹³ What makes Kantian moral philosophy appealing is that it adheres to principles of autonomy rather than taking the position that moral laws are given by God for humans to follow. This means that we can, through reason, come to determine moral codes of conduct that would apply regardless of religious belief, or lack thereof. In culturally diverse societies, and in ones where religions have less power to determine the actions of citizens, a moral code based on reason guarantees a measure of predictability and agreement across these differences.

¹⁴ This is akin to situations of physical or sexual abuse committed against children who are scapegoated for divulging "family secrets". In such situations, instead of punishing the abuser, families punish those who come forward to bear witness to the abuse.

Conclusion

In a society where it seems that the final concern is for appearance, does it make sense to think of particular cases as more or less intersexed? If, for example, a genetic male with a micropenis is assigned female and has the phallus removed, is he any less intersexed than he would have been had he been assigned male? If one of the diagnostic criteria for intersex is that a patient have genitals that “conflict” with his or her chromosomal sex, then it seems that in fact, genetic males with micropenises are *made into* intersexuals, rather than corrected.

What about a genetic female with “classic” congenital adrenal hyperplasia? Is she any less intersexed if she is assigned a male sex?

The answer in cases like those above must be that the patients are not any less intersexed, but that, in fact, they may more closely adhere to particular diagnostic criteria in their “fixed” state than in their “unfixed” one (because virilisation is not confined to CAH and there are many women who have muscle bulk, facial hair and large clitorises who are not diagnosed as intersexed, and because boys with micropenises have been known to grow up to be typical males, some of whom continue to have penises of smaller than average but still “acceptable” size, and some who have penises of average size). Thus, it becomes apparent that the diagnosis of intersex is really about what the culture sees on the body’s surface, and that surgical “corrections” are really intended only to fit patients into a visually acceptable mold.

The point here is not to question whether sex assignments belie the ability of medicine to actually “fix” intersexuality, but to indicate that the medical approach to intersexuality is structured and contained by a form of story-telling. The narrative

begins with diagnosis, hits a crisis in dealing with parents and families and has its ending tacked on in the form of surgeries and sex assignments. But disturbing questions arise out of this narrative.

What makes a genetic female with isolated clitoral hypertrophy any less female than a newborn whose clitoris measures only a few millimetres less? Is anything accomplished in the recommended clitoral recession to make the patient *more* female? Although medical texts and post-operative reports suggest that the surgery can “restore a normal feminine appearance” (MMC, Personal Medical File, March 1975), they make no claim that the surgery restores any lost *femaleness*. A reverse version of these observations would also apply to chromosomally or genetically male children who are diagnosed with an intersex condition, usually indicated by some form of “incomplete masculinization.” The suggestion of my dissertation is that the procedures used to assign such children the female sex—including the removal of the phallus and testes and the surgical construction of a vagina, introitus and external “female” genitals—do not make them any less intersexed, but perhaps actually more intersexed, for after their surgical management they have bodies which are more rather than less at odds with their chromosomal and/or genetic sex. By its own standards of diagnosis then, the very medical procedures that are meant to fix the intersexuality are actually only measures to render it invisible to the public eye.

This leaves only two possible conclusions: either a child is still intersexed after having surgery, or the child never was intersexed in the first place. This set of examples is meant only to be illustrative of the contradictions inherent, first in the diagnosis, and second, in the treatment of intersexuality; it is not the limit of possible

cases with which we might demonstrate this. In a sense, the “disorder” is nothing more than an ever shifting phantasm in the collective psyche of medical culture.

In essence, I am suggesting that no one is truly intersexed and that we are all intersexed. This is so because no two males are identical in morphology or phenotype and neither are any two females, and when we begin to note that at a certain point the border between intersex and not intersexed is a millimetre, then the whole category becomes absurd.

This is not to say that there are not certain health concerns that should go undiagnosed, or that conditions like adrenal metabolic crises are phantasmic in nature. Clearly, there are some health risks and there are certain fertility complications in CAH. However, the fact that a woman can grow up with CAH and never know it until she has difficulty conceiving, or has an onset of severe acne in her thirties or forties, and will not be diagnosed with an intersex disorder, but simply with mild or late-onset CAH indicates that CAH itself is not an intersex disorder. This is equally true of partial androgen insensitivity (PAIS), which is diagnosed as intersex in cases where there is micropenis, but not where there is infertility in the grown male. Although some might argue, for example, that complete androgen insensitivity constitutes an intersex disorder because the chromosomes “conflict” with the person’s anatomical appearance, it remains worth pointing out that for most of the world, chromosomes are irrelevant determinates of who we are; thus it seems absurd to make them the determinates of a person’s “true” sex in CAIS. Likewise, with cases of true hermaphroditism, a category that is quite thoroughly questioned in Alice Dreger’s historical work, there is no reason to determine that our gonads are the first source

and final site of subjectivity, or that in the absence of “coherent” gonads surgery is the most appropriate course of action. The fact that we perceive it as more accurate to use surgery to accomplish the subjectification of the person is a culturally contingent, historically specific phenomenon. This is only the most recent method of dealing with intersex. I have argued throughout this dissertation that it is not necessarily the best way, and it is my hope that it will not be the final way.

Throughout this dissertation I have argued that intersexuality is an historical and cultural construction rather than a biological phenomenon. The creation of the category “intersex” has had much to do with the development of professional power and prestige. In addition, I have mapped out the relationship of the categorisation of intersex to ideological commitments that structure the categories of sex and gender. I have argued, furthermore, that any body is a historically contingent body, and that “sex” is as much a symbolic system of organisation as gender is. Though my project resists Foucault’s neglectful reading of the particularities of Alexina Herculine Barbin’s life, my work is inflected with the Foucaultian premise that Euro-American culture is not sexually repressed, but sexually obsessed.

Foucault’s argument against the “repression hypothesis” is that if Western culture were truly sexually repressed, there would be no discussion about sex, yet everywhere one finds that sex is “put into discourse” (1978, 11). The question is not why Westerners repress sexuality, but rather how they produce it, under what circumstances, and why. Foucault argues that sex functions symbolically to provide the means through which subjects become intelligible as selves:

It is through sex—in fact, an imaginary point determined by the

deployment of sexuality—that each individual has to pass in order to have access to his own intelligibility (seeing that it is both the hidden aspect and the generative principle of meaning), to the whole of his body (since it is a real and threatened part of it, while symbolically constituting the whole), to his identity (since it joins the force of a drive to the singularity of a history). (1978, 155-156)

Similarly, this dissertation has not been an examination of intersexuality's absence in culture but rather an examination of its production within culture as a diagnostic category and a pathological body, and as a reclaimed identity.

In chapters one, two and three, I followed Foucault's interest in "...who does the speaking, the positions and viewpoints from which they speak, the institutions which prompt people to speak about it [sex] and which store and distribute the things that are said" (Foucault, 1978, 11). I argued that intersex has been produced, discussed and framed within certain contexts, with particular political goals informing both its creation and treatment. I questioned the medical claim to have the sole authority to produced valid knowledge of intersexuality, and how best to treat it. In addition, I opened the discussion to address the promise and limits of gender studies and the contemporary intersex movement. I have not taken the position that by virtue of their victimisation intersex narratives are therefore "innocent". I have challenged the imperative of identity-based politics to create a unified "community voice" and have shown points of difference as well as similarity in the stories intersexuals have told about what it means to be intersexed. I have discussed the problems that can result when intersexuals turn to geographically and culturally distant models of "third

sex” and “third gender” categories. In my discussion, I asked where the power resides to produce the terms through which intersex enters culture, examining what ends are served by that production.

In sum, intersex is not exactly a repressed category, but an actively produced one that has captured the abject fascination of medical practitioners since their rise as professionals in the nineteenth century. Moreover, popular hearsay suggests that, regardless of whether any given person is aware of the intersexuality, a general anxiety and fascination about bodies that are neither male nor female persists in Euro-American culture. This fascination helps to produce the conditions in and through which intersexuality is both constructed and perceived.

This project has aimed to begin the work of providing different points of articulation from which knowledge and discussion of intersex could emanate. I have accounted for the conditions under which intersexuality is discussed.

My work has also asked to what extent it is possible to create a corrective narrative of intersexuality that could combat the standard medical and mythical stories that have been used to represent intersex conditions to readers, parents, and Euro-American subjects in general. I have worked to return the weight of subjective knowledge of one’s body to intersexuals, and to those who love and care for us, such as our parents, extended family members and partners. Yet, I recognise that the narratives intersexuals weave are constrained by a lack of historical knowledge regarding the production of intersex. The panhistorical and transhistorical narratives which result from this lack of knowledge continue to trouble me, for they elide specific differences and universalise “intersex”. Such narratives fail to note that what

it means to be intersexed in any given culture is both a cause and a product of particular power structures.

Future work on intersexuality might consider fieldwork observing the specific differences between the production of intersexuality in the West and third sex categories in smaller “tribal” communities, though this work may become impossible as those smaller communities become more subject to Western medical and scientific interventions. Other projects might include long-term studies with close follow-up on the patients who are being managed surgically now. We still do not know conclusively whether Chase’s theories of higher rates of “queerness” in intersexuals result from the population with which she has had contact, though I suspect that this is the case. We also do not know whether children being managed now will have better outcomes either because their surgeries are truly “better” than they were twenty or ten years ago, or because the intersex movement might have a positive impact on the conditions under which they mature. It may be that this will present a serious impediment to persuading clinicians that a paradigm shift is in order.

Some may be inclined to argue that, until we know what the outcomes for the current generation are, it would be irresponsible to change treatment standards. This virtually guarantees that for at least another twenty years, surgery on infants’ genitals will continue. Much more dialogue between ethicists and clinicians will be required, and persons working in the field will want to examine the weight of technical advancement against the threat to autonomy. Increasingly, ethicists, intersexuals and their families may ask clinicians to account for their attitudes about sexuality and normalcy. Many clinicians argue that they are merely trying to protect children from

prejudice and cruelty, but future work in this field is already set to examine the degree to which clinical interventions perpetuate and create prejudice, rather than resolve it.

Each of my chapters has begun a project that in itself could be carried much further, but each section has allowed me to develop preliminary conclusions. The project remains a beginning, providing a map of the inroads researchers can follow. Much more work remains to be done on the subtleties of the various intersex communities and support groups that have formed over the last few years. I have presented here only a small sampling of what some of the most vocal intersexed persons have had to say about their treatment. The unique contribution of this work is that it has challenged the scientific/medical claim to neutral production of knowledge and has made connections between political needs, cultural ideas and ideals, and scientific models of discovery and treatment. I have deliberately resisted any drive to provide a total story of what intersex is, and have instead provided a broad sense of its location within western culture. Intersexuality is neither strictly a medical condition, nor simply a new cultural fascination. It is, rather, the result of intersecting and diverging political, cultural and scientific interests, is subject to change, and is not self-identical even to intersexuals working to change the way that it is perceived. It will be very interesting to see how the understanding and construction of intersexuality changes as a result of contemporary political, cultural and ethical challenges.

BIBLIOGRAPHY

- Alvarado, Donna. 1994. Intersex, West Magazine San José Mercury News Sunday Supplement. July 10: 6-11+.
- American Academy of Pediatrics. Press Release Oct. 1996.
- Angelino, Henry and Charles Shedd. 1955. A note on Berdache, American Anthropologist, 57:121-26.
- Anger, Diane. A retrospective view of a male pseudo-hermaphrodite's long road to recovery. Intersex Voices <http://www.qis.net/~triea/diane.htm>
- Angier, Natalie. 1996. Intersexual healing: an anomaly finds a group, New York Times print run 1,209,225. Sunday, February 4.
- Anonymous, (US representative). 1996. Sex, lies and ideology, ALIAS 1(6):7.
- Anonymous. 1994a. Be open and honest with sufferers, British Medical Journal, 308:1041-1042.
- Anonymous. 1994b. Once a dark secret, BMJ, 308:542.
- Atkins, Dawn (ed) 1995. Body Image Task Force Newsletter (BITF) Spring/Summer v.5, p 10. Santa Cruz: CA.
- Atwood, Howard. 1880. Traites des hermaphrodites partie genitales. accouchements des femmes. I. Liseau: Paris.
- Azziz, Ricardo *et al.* 1986. Congenital Adrenal Hyperplasia: long-term results following vaginal reconstruction, Fertility & Sterility, 46 (6):1011-14.
- Bailez, M.M. *et al.* 1992a. Vaginal reconstruction after initial construction in girls with salt-wasting adrenal hyperplasia, J. Urology, 148:680-84.
- _____. 1992b. Vaginal reconstruction after initial construction of the external genitalia in girls with salt-wasting adrenal hyperplasia, J. Urology, 148:680-84.
- Barber, Bernard 1980. Informed Consent in Medical Therapy and Research. Rutgers UP: New Brunswick, NJ.
- Barbin, Herculine (Intro. by Michel Foucault). 1980. Herculine Barbin: Being the Recently Discovered Memoirs of a Nineteenth-Century French Hermaphrodite. Pantheon: New York.

- Baylis, Francoise *et al* (Eds.). 1995. Health Care Ethics in Canada. Harcourt Brace: Toronto and Montreal.
- Beeman, William. 1996. What are you? male, merm, herm, ferm or female? The Baltimore Sun 17 March, print run 39100 editorial section, Perspective: F1.
- _____. 1993. Subtotal de-epthialization and partial concealment of glans clitoris: a modification to improve the cosmetic results of feminizing genitoplasty, J Urology, 150:651-53.
- Bing, Elizabeth and Esselyn Rudikoff. 1970. Divergent ways of coping with hermaphroditic children, Medical Aspects of Human Sexuality (December):73-88.
- Bingham, Caroline. 1971. Seventeenth Century Attitudes toward Deviant Sex, J Interdisciplinary History, 1:447-68.
- Bornstein, Kate. 1994. Gender Outlaw: On men, women and the rest of us. Routledge: London and New York.
- Bourdieu, Pierre. 1995 (1975). Outline of a Theory of Practice. Cambridge UP: Cambridge and New York.
- Brant, Beth. 1994. Writing as Witness. Women's Press: Toronto.
- Bridson, Don and Bridson, Nancy. 1999. Public domain CAH Message Board. <http://www.elevenoclock.com/cah/> July 10.
- Brody, Howard 1992. The Healer's Power. Yale UP: New Haven and London.
- Brown, Harold. '977. Perception, Theory and Comittment: The new philosophy of science. Chicago UP: Chicago.
- Brown, Peter G., ed. 1993. "Initial Conditions." The Sciences Vol. 33-2: 2.
- Butler, Judith. 1994. Bodies that Matter: On the discursive limits of "sex". Routledge: New York.
- _____. 1990. Feminists Theorize the Political. Routledge: New York.
- _____. 1988. Gender Trouble. Routledge: New York.
- Byne, William. 1994. "The Biological Evidence Challenged." Scientific American Vol. 270-5, pp 50-55.

- Caplan, Paula and Caplan J. 1994. Thinking Critically about Research on Sex and Gender Harper Collins: New York.
- Carter, Chris. 1994. The Host, The X-Files Fox Network: Sept. 23.
- Cassiltheth *et al*, 1980. Informed Consent--Why are its Goals Imperfectly Realized? New England Journal of Medicine vol.302, pp 896-900.
- Castro-Magana *et al*. 1984. Management of the child with ambiguous genitalia. Medical Aspects of Human Sexuality, 18 (4):172-88.
- Catlin, Anita J. 1998. Ethical commentary on gender reassignment: A complex and provocative modern issue, Ped. Nursing 24(1):63-65+.
- Chase, Cheryl. 1998a. Surgical progress is not the answer to intersexuality. J. Clinical Ethics 9(4):385-392.
- _____. 1998b. Affronting Reason. Looking Queer Dawn Atkins (ed.). Haworth Press: London and New York.
- Committee on Bioethics. 1995. Informed consent, parental permission, and assent in pediatric practice, Pediatrics 95(2):314-317.
- Coran and Polley. 1991. Surgical management of ambiguous genitalia in the infant and child. Ped. Surg. 26(7):812.
- Coventry, Martha. Personal communication, July 23. 1999.
- _____. 1998. The tyranny of the esthetic. On the Issues. VII(3): 16-20+.
- Coy, Jane A. 1989. "Autonomy-Based Informed Consent: Ethical Implications for Patient Noncompliance." Physical Therapy, vol.69 pp 826-833.
- Crouch, Robert. 1998. Betwixt and between: The past and future of intersexuality. J. Clinical Ethics 9(4):372-384.
- D'Adesky, Anne. 1996. The third sex, Out Sarah Pettit (ed.) New York: 104-108+
- Davis, Lennard. 1995. Enforcing Normalcy: Disability, deafness, and the body. Verso: London and New York.
- de Beauvoir, Simone 1976 (1948). The Ethics of Ambiguity. Citadel Press, New York: NY.

- De Lauretis, Teresa 1987. Technologies of Gender Indiana UP: Bloomington and Illinois.
- _____. 1986. Feminist Studies, Critical Studies. Indiana UP: Bloomington.
- Dewhurst, Christopher John (Sir). 1980. Practical Pediatric and Adolescent Gynecology. Marcel Dekker: New York.
- Dewhurst, Christopher J. and Gordon, Ronald. 1969. The Intersexual Disorders. Baillière Tindall & Cassell: London
- Dewhurst, Christopher J. and D.B. Grant. 1984. Intersex Problems, Archives of Disease in Childhood, 59:1191-94.
- Diamond, Milton. 1997. Sexual identity and sexual orientation in children with traumatised or ambiguous genitalia, Journal of Sex Research 34 (2): 199-211.
- Diamond, Milton and Sigmundsen, Keith. 1997. Sex reassignment at birth: a long term review and clinical implications, Archives of Pediatrics and Adolescent Medicine 151 (3): np.
- Dittman, Ralf *et al.* 1992. Sexual behaviour in adolescent and adult females with congenital adrenal hyperplasia, Psychoneuroendocrinology, 17 (2-3):153-70.
- Domenici and Lesser (Eds.). 1995. Disorienting Sexuality: Psychoanalytic reappraisals of sexual identities. Routledge: London and New York.
- Donohoe, Patrica K. 1991. Clinical management of intersex abnormalities, Current Problems in Surgery, August:546-79.
- Donohue, Emma. 1993. Imagined more than women: lesbians as hermaphrodites, 1671-1766, Women's History Review, 2:199-216.
- Dreger, Alice. 1999. Intersex in the Age of Ethics. University Publishing Group: Hagerstown, MD.
- _____. 1998a. Hermaphroditism and the Medical Construction of Sex Harvard UP: Boston.
- _____. 1998b. A history of intersexuality from the age of gonads to the age of consent. J. Clinical Ethics 9(4):345-355.
- Drummond, Rennie. 1980. Informed consent by 'well-nigh abject' Adults, NEJM vol. 302:917-918

- _____. 1983. The social enforcement of heterosexuality and lesbian resistance in the 1920's, Class, Race and Sex: the dynamics of control, Swerdlow and Lessinger (Eds.). G.K. Hall: Boston.
- _____. 1979. Lesbianism and American history: a brief source review, Frontiers, 4 (3):80-85.
- Edgerton, Milton T. October 19, 1994. Unpublished reply letter to Cheryl Chase.
- Edmonds, D. Keith. 1994. Sexual development anomalies and their reconstruction, Pediatric and Adolescent Gynecology Sanfillipo *et al* (eds.) W.B. Saunders (Harcourt Brace): Philadelphia.
- _____. 1989. Dewhurst's Practical Paediatric and Adolescent Gynaecology 2nd ed. Butterworths: London, Boston, Singapore, Sydney, Toronto and Wellington.
- Elliot, Patricia and Katrina Roen. 1998. Transgenderism and the question of embodiment, GLQ 4(2):231-261.
- Emans, S.J. and D.P. Goldstein. 1990. Pediatric and Adolescent Gynecology 3rd edition. Little Brown & Company: Boston.
- Emanuel, J.E and Emanuel, L.L. 1995. Four Models of the Physician-Patient Relationship. in Health care Ethics in Canada Balis *et al* (eds). Harcourt Brace: Toronto, Montreal, and New York.
- Epstein, Julia and Kristina Straub (Eds.). 1991. Body Guards: the cultural politics of gender ambiguity. Routledge: London and New York.
- Epstein, Julia. 1995. Altered Conditions: disease, medicine and storytelling. Routledge: London and New York.
- _____. 1990. Either/or-Neither/both: sexual ambiguity and the ideology of gender, Genders 7 (spring): 99-142.
- Erhardt, Anke and John Money. 1967. Progestin induced hermaphroditism: IQ and psychosexual identity in a study of ten girls, Journal of Sex Research, 3 (1):83-100.
- Evans-Pritchard, E.E. 1970. Sexual inversion among the Azande, American Anthropologist, 72:1428-34.
- F.P. personal communication, 1999.

- Fausto-Sterling, Anne. 2000. Building Bodies. Basic Books: New York.
- _____. 1998. Unpublished paper delivered at -----, New York.
- _____. Personal communication, March 15, 1996.
- _____. 1995. Gender, race and nation: the comparative anatomy of "Hottentot" women in Europe. Deviant Bodies Jennifer Terry and Jaqueline Urla (eds.) Indiana UP: Bloomington and Illinois.
- _____. 1993a. "The Five sexes: Why male and female are not enough," The Sciences, March/April:20-25.
- _____. 1993b. How many sexes are there? New York Times OP-ED, March 12, 1993.
- _____. 1992 (1985). Myths of Gender 2nd edition. Basic Books: New York.
- Federman, Daniel D. 1994. Psychsexual adjustment in congenital adrenal hyperplasia, NEJM, 316 (4):209-210.
- _____. 1994. Life without estrogen, NEJM, 331 (16):1088-89.
- Feinberg, Leslie. 1996. Transgender Warriors Beacon Press: Boston.
- Findlay, Deborah. 1994. Discovering Sex, Canadian Review of Sociology and Anthropology 32 (1):25-52.
- Foucault, Michel. 1995. Discipline and Punish 2nd ed. Vintage Press: New York.
- _____. 1990. History of Sexuality Vol. 1: an introduction. Vintage Books: New York.
- _____. 1988. History of Sexuality Vol 2: the use of pleasure. Vintage Books: New York.
- _____. 1979. Discipline & Punish: the birth of the prison. Vintage Books: New York.
- _____. 1975. Birth of the Clinic. Vintage: New York.
- Freedman, Benjamin 1975. A Moral Theory of Consent, The Hastings Center Report vol.5(4): 32-40.
- Garber, Marjorie. 1993. Spare Parts: the surgical construction of gender, The Lesbian and Gay Studies Reader, Abelow *et al* (Eds.). Routledge: New York (321-338).
- Gal, Susan. 1991. Between Speech and Silence: the problematics of research on language and gender, Gender at the Crossroads of Knowledge. Michaela di Leonardo (ed.)

University of California: Berkeley.

Gallagher, Catharine and Thomas Laqueur (Eds). 1987. The Making of the Modern Body. U. California P: Berkeley and Los Angeles.

Gearheart, John P. *et al.* 1995. Measurement of evoked potentials during feminizing genitoplasty: Technique and applications, Journal of Urology, 153:486-87.

Geertz, Clifford. 1984. Local Knowledge. Basic Books: New York.

Gelbke, Heinz. 1963. "Plastic Surgery." Intersexuality, Ed. Claus Overzier. Academic Press: London and New York.

George, Sue. 1993. Women and bisexuality. Scarlet Press: London.

Gersh and Gersh, eds. 1981. Biology of Women. University Park Press: Baltimore.

Gibson, Margaret. 1997. Clitoral Corruption, Science and Homosexuality Vernon Rosario (ed.). Routledge: London and New York. 108-132.

Gilbert, David A. *et al.* 1988. Phallic reinnervation via the pudendal nerve, J Urology, 140:295-99.

Gilman, Sander. 1993. Freud, Race and Gender. Princeton UP: Princeton.

_____. 1989. Sexuality: an illustrated history: representing the sexual in medicine and culture from the middle ages to the age of AIDS. Wiley: New York.

_____. 1985a. Difference and Pathology: stereotypes of sexuality, race, and madness. Cornell UP: Ithaca, NY.

_____. 1985b. ----- Race, Writing and Difference Henry Louis Gates (ed.) Chicago: University of Chicago Press.

Glassberg, Kenneth I. and Gobind Laungani. 1981. "Reduction Clitoroplasty," Urology 17.6:604-5.

Groneman, Carol. 1995. Nymphomania: the historical construction of female sexuality, Deviant Bodies Jennifer Terry and Jaqueline Urla (eds.) Indiana UP: Bloomington and Illinois.

Gross, Robert *et al.* 1966. Clitorectomy for sexual abnormalities: Indications and technique, Surgery 59(2):300-308.

- Gross, Sally. Intersexuality and scripture. Intersex Voices
http://www.qis.net/~triea/IS_scripture_.html
- Grosz, Elizabeth, 1994. Volatile Bodies. Routledge: London and New York
- Groveman, Sherri. 1998. The Hannukah bush: Ethical implications in the clinical management of intersex. J. Clinical Ethics 9(4):356-359.
- Gunew, Sneja. (Ed.) 1990. Feminist Knowledge: Critique and construct, Routledge: London and New York.
- Halperin, David. 1990. 100 Years of Homosexuality. Routledge: London and New York.
- Hamer, D. and LeVay S. 1994. "Evidence for a Biological Influence in Male Homosexuality." Scientific American Vol. 270-5, pp.43-49.
- Hampson, Joan G. 1955. Hermaphroditic genital appearance, rearing and eroticism in hyperadrenocorticism, Bulletin of the Johns Hopkins Hospital 97:65-73.
- Haraway, Donna. 1989. Primate Visions Routledge: London and New York.
- Harding, Sandra. 1991. Whose Science? Whose Knowledge? Cornell UP:Ithaca, NY.
- Marmon-Smith, Helena. 1998. 10 Commandments, J. Clinical Ethics 9(4):371.
- Hart, Stacey. 1995. Lesbian healthcare and breast cancer research, Unpublished paper presented at the 1995 Queer studies Graduate Student Conference, Queer Frontiers, University of Southern California.
<http://www.usc.edu/isd/archives/queerfrontiers/queer/papers/hart.html>
- _____. April 20, 1996. Personal Communication.
- Hartsock, Nancy. 1990. Foucault on Power: A theory for women?
Feminism/Postmodernism Linda Nicholson (ed.) Routledge: London and New York 157-175.
- Hausman, Bernice. 1995. Changing Sex: transexualism, technology and the idea of gender. Duke UP: Durham, NC.
- Hendricks, Melissa. 1993. Is it a Boy or a Girl? Johns Hopkins Magazine, November 1993:10-16.
- Herd. Gilbert. 1994a. Mistaken Sex: Culture, biology and the third sex in New Guinea, Third Sex, Third Gender. Zone Books: New York.

- _____. (Ed.). 1994b. Third Sex/Third Gender. Zone Books: New York.
- _____. 1987. The Sambia: ritual and gender in New Guinea. Holt, Rinehart and Winston: New York.
- Herd, Gilbert and Julian Davidson. 1988. The Sambia 'Turnim-man': Sociocultural and clinical aspects of gender formation in male pseudo-hermaphrodites with 5-alpha reductase deficiency in Papua New Guinea, Archives of Sexual Behaviour, 17.1:33-56.
- Hill, Sharon. 1977. The child with ambiguous genitalia, American J of Nursing: 810-814.
- Holmes, Morgan. 1994a. Medical Politics and Cultural Imperatives: Intersexuality beyond pathology and erasure, unpublished Master's Thesis, Interdisciplinary Studies. York University, Toronto.
- _____. 1994b. Re-membering a queer body, Undercurrents, May 1993:11-13.
- Horn, David G. 1995. This norm which is not one: reading the female body in Lombroso's anthropology, Deviant Bodies Jennifer Terry and Jaqueline Urla (eds.) Indiana UP: Bloomington and Illinois.
- Howe, Edmon G. 1998. Intersexuality: what should careproviders do now? J. Clinical Ethics 9(4):337-344.
- Ingold, Tom. 1994. Companion Encyclopedia of Anthropology. Routledge: London and New York.
- Intersex Society of North America. 1994. Brochure: A parent's guide to hypospadias surgery.
- <http://www.isna.org>
- Izquierdo, Gerardo and Kenneth Glassberg. 1993. Gender assignment and gender identity in patients with ambiguous genitalia, Urology, 42(3):332-42.
- Jacobs, Sue-Ellen and Jason Cromwell. 1992. Visions of reality: Reflections on sex, sexuality, gender and gender variance, Journal of Homosexuality 23(4):43-69.
- Kaldera, Raven. 1998. Agdistis' children, Looking Queer Dawn Atkins (ed) Haworth Press: London and New York, 227-232.

- Kaplan, Gisella and Lesley Rogers. 1990. The Definition of male and female: Biological reductionism and the sanctions of normality, Feminist Knowledge: Critique and construct, Sneja Gunew, (Ed.). Routledge: London and New York.
- Katz, Jay 1984. The Silent World of Doctor and Patient. The Free Press (MacMillan): New York, NY.
- Katz, Jonathon Ned. 1995. The Invention of Heterosexuality. Penguin: New York.
- Kessler, Suzanne. 1998a. Lessons from the Intersexed Rutgers University Press: New Brunswick, NJ.
- _____. 1998b. The Meanings of Gender Variability, Chrysalis (Spring): 33-38.
- _____. 1990. The medical construction of gender: case management of intersexual infants, Signs, 16(1):3-26.
- Kipnis, Kenneth and Milton Diamond. 1998. Pediatric ethics and the surgical assignment of sex, J. Clinical Ethics 9(4): 398-410.
- Kogan, Stanley *et al.* 1983. Subcutaneous total reduction clitoroplasty: a safe modification of existing techniques, J Urology, 130:746-48.
- Kristeva, Julia. 1982. Powers of Horror: an essay on abjection Columbia UP: New York.
- Kroker, Arthur and Marie Louise Kroker (Eds.). 1993. The Last Sex. New World Perspectives: Montréal.
- Kumar, H. *et al.* Clitoroplasty: experience during a 19-year period, J Urology, 111:81-84.
- Laqueur, Thomas. 1992. Making Sex: Body and gender from the Greeks to Freud. Harvard UP: Cambridge MA.
- _____. 1990 (1989). Amor veneris, vel dulcedo appeletur, Fragments for a History of the Human Body Vol.3, Michel Feher *et al* (eds.) Zone Books: New York.
- Lattimer, John K. 1961. Relocation and recession of the enlarged clitoris with preservation of the glans: an alternative to amputation, J Urology, 86(1):113-116.
- Lev-Ran, Ayre. 1974a. Sexuality and educational levels of women with the late treated adrenogenital syndrome, Archives of Sexual Behaviour, 3(1):27-32.

- _____. 1974b. Gender role differentiation in hermaphrodites, Archives of Sexual Behaviour, 3(5):391-424.
- Lief, Harold and Lynn Hubschman. 1993. Orgasm in the postoperative transsexual, Archives of Sexual Behaviour, 22(2):145-55.
- Lightfoot-Klien, Hanny. 1989. Prisoners of Ritual. Harrington Park Press: New York.
- Little, James. 1994. The inconspicuous or 'disappearing' penis, Pediatrics, 94(2):240-242.
- Littre, Emile. 1861(1839) Hippocrates Oeuvres Complètes Vol. 1 J.B. Bailliere:Paris.
- Litwin, A. I. *et al.* 1990. Clitoral length assessment in newborn infants of 30 to 41 weeks gestational age, European Journal of Obstetrics and Gynecology and Reproductive Biology, 38:209-12.
- Marcus, George and Michael M. Fischer. 1986. Anthropology as Cultural Critique, Chicago UP: Chicago.
- Martin, Emily. 1992. Woman in the Body revised edition. Beacon Press: Boston.
- Martindale, Kathleen. Winter 1994. Can I get a Witness? MY Lesbian Breast Cancer Story Fireweed, Issue 42:9-15.
- Marx, Karl and Frederick Engels. 1975. Complete Works vol. 6. International Publishers: New York.
- Mazur, Tom. 1983. Ambiguous genitalia: detection and counseling, Pediatric Nursing, Nov/Dec:417-22.
- McGillivray, Barbara. 1992. The newborn with genital ambiguity, Seminars in perinatology, 16(6):365-68.
- McMahon, Robert. 1965. Hermaphrodisim in infancy and childhood, Pediatric Surgery, 59(2):290-99.
- McMullin, John and Chelle Mileur. 1997. Interview with Cheryl Chase. Hangin' Out National Public Radio, San Francisco. November 3.
- Meyer-Bahlberg, Heino. 1996. Gender change from female to male in classical CAH, Hormones and Behaviour 30: 319-332.
- _____. 1994. Intersexuality and the diagnosis of gender identity disorder, Archives of Sexual Behaviour, 23(1):21-40.

- Meyers-Seifer, Cynthia and Nancy Charest. 1992. Diagnosis and management of patients with ambiguous genitalia, Seminars in Perinatology, 16(5):332-39.
- Mittwich, Ursula. 1985. Males, females and hermaphrodites, Annals of Human Genetics, 50:103-21.
- M.M.C. personal medical file. Hospital for Sick Children, Toronto. March 1975
- Money, John. 1991. Biographies of gender in paired comparisons, The Handbook of Sexology, John Money and H. Musaph (Eds.), Elsevier: New York.
- _____. 1987a Gender identity and gender transposition: longitudinal study of 24 male hermaphrodites assigned as boys, Journal of Sex and Marital Therapy, 13(2):75-92.
- _____. 1987b. Psychologic considerations in patients with ambisexual development, Seminars in Reproductive Biology 5(3):307-313.
- _____. 1985a. Gender, history, theory and usage of the term in sexology and its relationship to nature/nurture, Journal of Sex and Marital Therapy, 13(2):75-92.
- _____. 1985b. "Pediatric sexology and hermaphroditism," Journal of Sex and Marital Therapy, 11(3):139-156.
- _____. 1975. Sex education and infertility counseling in various endocrine-related syndromes: The juvenile and adolescent years, Endocrine and Genetic Diseases of Childhood and Adolescence, L.I. Gardner (Ed.). W.B. Saunders: Philadelphia.
- _____. 1968. Hermaphroditism and pseudohermaphroditism, Textbook of gynecologic endocrinology, J.J. Gold (ed.). Hoeber Publishing: New York.
- _____. 1956. Hermaphroditism: Recommendations concerning case management, J. Clinical Endocrinology and Metabolism, 4: 547-56.
- Money, John and Dana Mathews. 1982. Prenatal exposure to virilizing progestins: An adult follow-up study of twelve women, Archives of Sexual Behaviour, 11(1):73-83.
- Morgan, Kathryn P. 1991. Women and the Knife. Hypatia 6(3):25-53.
- Mulaikal, Rose *et al.* 1987. Fertility rates in female patients with congenital adrenal hyperplasia due to 21-hydroxylase deficiency, NEJM, 316(4):178-82.
- Nancy Murrell 1998. "Intersex group raises questions about genital surgery" Miami Herald Wednesday, October 28, 1998. NP.

- Nanda, Serena. 1994. Hijras: An alternative sex and gender role in India, Third Sex/Third Gender, Gilbert Herdt (ed.). Zone Books: New York.
- _____. 1985. The Hijras of India: cultural and individual dimensions of an institutionalized third gender role, J Homosexuality, 11:35-54.
- Natarajan, Anita. 1996. Medical ethics and truth telling in the case of androgen insensitivity syndrome, Canadian Medical Assoc. J. 154: 568-70.
- New, Maria. 1992. Female pseudohermaphroditism, Seminars in Perinatology, 15:299-318.
- New, Maria and ELizabeth Kitzinger. 1993. Pope Joan: a recognizable syndrome, J Clinical Endocrinology and Metabolism, 76.1:3-13.
- Newman, Kurt *et al.* 1992. Functional results in women having clitoral reduction as infants, J Pediatric Surgery, 27.2:180-84.
- _____. 1991. The surgical management of infants and children with ambiguous genitalia: Lessons learned from 25 years, Annals of Surgery, 215(6):644-53.
- Nin. Anais. 1978. Delta of Venus Bantam Press: New York.
- Nussbaum, Emily. 1999. The sex that dare not speak its name, Lingua Franca 9(4): 42-51.
- O'Neill, John. 1985. Five Bodies Cornell UP: Ithaca and London.
- Oberfeld, Sharon *et al.* 1989. Clitoral size in full-term infants, American Journal of Perinatology, 6(4):453-54.
- Oesterling, Joseph *et al.* 1992. A unified approach to early reconstructive surgery of the child with ambiguous genitalia, J Urology, 138:1079-84.
- Ogborne, Anne. 1994. Hijras and intersexuals, Hermaphrodites with Attitude 1(1):3.
- Oudshoorn, Nelly. 1994. Beyond the Natural Body: an archeology of sex hormones. Routledge: New York.
- Overzier, Claus (ed.). 1963. Intersexuality Academic Press: London and New York.
- Parens, Eric. 1998. Is better always good? Hastings Center Report Jan/Feb, S1-15.
- Parmar, Pratibha and Alice Walker. 1994. Warrior Marks: female genital mutilation and

the sexual blinding of women. Harcourt Brace: Troy, MO.

Perkins, Katharine 1995. Kids asserting Rights in Health Care San Francisco Examiner, May 1 1995.

Perlmutter, Alan and Claud Reitelman. 1992. Surgical managment of intersexuality, Campbell's Urology NP.

Phelan, Shane. 1989. Identity Politics: lesbian feminism and the limits of community. Temple: Philadelphia.

Pliny. 1942. Natural History Vol. 2. H. Rackham trans. Loeb Classic Library: London.

Poovey, Mary. 1987. Scenes of an indelicate character, The Making of the Modern Body Mary Gallagher and Thomas Laqueur (eds.) University of California: Berkeley (137-168).

Preves, Sharon. 1998. For the sake of the children: destigmatizing intersexuality. J Clinical Ethics 9(4):411-420.

Raboch, Jiri *et al.* 1987. Sexual development and life of women with gonadal dysgenesis, J Sex and Marital Therapy, 13(2):117-27.

Randolph, Judson *et al.* 1981. Clitoroplasty for females born with ambiguous genitalia: a long-term study of 37 patients, J Pediatric Surgery, 1(6):882-887.

Raymond, Janice. 1994. The Transsexual Empire: the making of the she-male, 2nd edition. Teachers College Press: New York.

Reibl v. Hughs 1980. Dominion Law Reports, vol. 114 (3d).

Reiner, William. 1997a. To be male or female: that is the question, Archives of Pediatric and Adolescent Medicine 151:224-225.

_____. 1997b. Sex assignment in the neonate with intersex or inadequate genitalia, Archives of Pediatric and Adolescent Medicine 151: 1044-1045.

Riley, W.J. and A Rosenbloom. 1980. Clitoral size in infancy, Pediatrics, 96:918-919.

Rosario, Vernon (Ed.). 1997. Science and Homosexualities. Routledge: London and New York.

Roscoe, Will. 1991. The Zuni Man-Woman. U New Mexico Press: Albuquerque.

_____. 1988. Living the Spirit: A gay American Indian anthology. St. Martin's Press:

New York.

- _____. 1987. Bibliography of Berdache and alternative gender roles among the North American Indians, J Homosexuality, 14(3-4):81-171.
- Rose, Jaqueline 1986. Sexuality in the Field of Vision, Verso: London and New York.
- Rozovsky, L. and Rozovsky, F. 1990. The Canadian Law of Consent to Treatment. Butterworths: Toronto and Vancouver.
- Rubin, Gayle. 1993. Thinking Sex, The Lesbian and Gay Studies Reader, Abelow *et al* (Eds.). Routledge: New York (3-41).
- Rubin, Gayle. 1975. The traffic in women, Toward an Anthropology of Women, Monthly Review Press.
- Russo, Mary. 1994. The Female Grotesque: risk excess and modernity. Routledge: New York.
- S.M. 1998-99. Personal email communication series. December--January.
- S.T. 1995. An AIS woman speaks out, Hermaphrodites with Attitude 1(2)np.
- Sandberg, David *et al*. 1995. Gender development in boys born with hypospadias, Psychoneuroendocrinology, 20(6):np
- Sane, Kamud and Ora Hirsch Pescovitz. 1992. The clitoral size index: a determination of size in normal girls and girls with abnormal sexual development, J Pediatrics, 120:264-66.
- Schneewind, J.B 1991. "Modern Moral Philosophy," A Companion to Ethics, Peter Singer ed. (Cambridge, MS: Blackwell, 1991) 151.
- Schober, Justine M. 1998. A surgeon's response to the intersex controversy, J. Clinical Ethics 9(4):393-397.
- Schroeder, Patricia. 1994. Female genital mutilation, NEJM 331.11:739-40.
- Scott, Joan. 1992. Experience, Feminists Theorise the Political, Judith Butler and Joan Scott (eds.). Routledge: London and New York, 22-40.
- Sharma, Satash Kumar. 1989. Hijras, the Labelled Deviants. Gian Publishing: New Delhi.
- Sharpe, Gilbert 1993-93. Consent Law and Minors Health Law in Canada, Vol 13: np.

- Simpson, J.L. 1976. Disorders of Sexual Differentiation. Academic Press: New York.
- Singer, Peter (Ed.). 1993. A Companion to Ethics. Blackwell: Oxford.
- Sinclair, Toby. My definitions, other people's cures. Intersex Voices
<http://www.qis.net/~triea/toby.htm>
- Slijper, F.M.E. *et al.* 1994. Neonates with abnormal genital development assigned the female sex: parent counseling, J Sex Education and Therapy, 20(1):9-17.
- Sloan, David. January 5, 1996. Feb. "It's a Boy...Maybe" 20/20 ABC: New York.
- Sommerville, Margaret. 1980. Consent to Medical Treatment, Law Reform Commission of Canada: Ottawa.
- Spivak, Gayatri. 1989. Who claims alterity. Remaking History. Barbara Kruger and Phil Mariani (eds.) Bay Press: Seattle. 269-292.
- Stecker, John F. *et al.* 1981. Hypospadias cripples, Urologic Clinics of North America: Symposium on Hypospadias, 8(3):539-544.
- Stein, Edward. 1990. Forms of desire: sexual orientation and the social constructionist controversy. Garland: New York.
- Stoller, Robert. 1985. Presentations of Gender, Yale UP: New Haven and London.
- Straub, Kristina. 1991. Sex, gender, and sexual identity in modern culture: male sodomy and female prostitution in Enlightenment London, J History of Sexuality, 2:186-203.
- Synnott, Anthony. 1993, The Body Social: Symbolism, self and society. Routledge: London and New York.
- Terry, Jennifer and Jacqueline Urda, (Eds.). 1995. Deviant Bodies: Critical perspectives on difference in science and popular culture, Indiana UP: Bloomington and Indianapolis.
- _____. 1988. Locating ourselves in the history of sexuality, Outlook, 1(summer):86-88.
- Tong, Rosemary. 1989. Feminist Thought: a comprehensive introduction, Westview: Boulder and San Francisco.

- _____. 1997. Feminist Approaches to Bioethics, Westview: Boulder and San Francisco.
- Toubia, Nahid. 1994. Female circumcision as a public health issue, NEJM, 331(11):712-16.
- Tolen, Rachel. 1995. Colonizing and transforming the criminal tribesman: The Salvation Army in British India, Deviant Bodies Jennifer Terry and Jaqueline Urla (eds.) Indiana UP: Bloomington and Illinois.
- Triea, Kiira. 1997. Intersex Voices: Educational resource website
<http://www.qis.net/~triea/>
- Turner, James G., (Ed.). 1993. Sexuality and Gender in early Modern Europe: Institutions, texts, images, Cambridge UP: Cambridge and New York.
- Van Seters, A.P. and A. K. Slob. 1988. Mutually gratifying relationship with micropenis of the husband, J Sex and Marital Therapy, 14(2):98-107.
- Warne, Gary. 1998a. Advances and challenges with intersex disorders, reprod Fertil Dev, 10(1): 79-85.
- _____. 1998b. Androgen Insensitivity Syndrome in the ear of molecular genetics and the internet: a point of view, J. Ped. Endocrinol. Metab, 11(1):3-9.
- Warner, M. (Ed.). ----. Fear of a Queer Planet: Queer politics and social theory, U Minnesota P: Minneapolis.
- Wendell, Susan. 1996. The Rejected Body: Feminist philosophical reflections on disability. Routledge: London and New York.
- Williams, Walter. 1986. The Spirit and the Flesh: Sexual Diversity in American Indian Culture. Beacon Press: Boston.
- Wilson, Bruce and William Reiner. 1998. Management of intersex: A shifting paradigm. J. Clinical Ethics 9(4):360-369.
- Wittig, Monique. 1992. The Straight Mind. Beacon: Boston.
- Woodhouse, C.R.J. 1994. The sexual and reproductive consequences of congenital genitourinary anomalies, J. Urol 152 (August): 645-651.
- Zucker, K.J. 1996. Commentary on Diamond's 'Prenatal disposition and the clinical management of some pediatric conditions.' Journal of Sex and Marital Therapy, 22, 148-160.

GLOSSARY

Androgen Insensitivity Syndrome (AIS) and Partial Androgen Insensitivity

Syndrome(PAIS):

In AIS/PAIS the cells of an XY individual do not respond to the effects of androgens. Because of a missing or misplaced protein, the cells' ability to bind androgens causes a partial or complete lack of response to testosterone. PAIS can produce effects similar to CAH or progestin induced pseudohermaphroditism in a fetus. With complete AIS a neonate has no visible signs of intersexuality as the external genitalia appear typically female. Internal female structures do not develop, however, because Mullerian Inhibiting Hormone is secreted by the testes, and prevents the development of the oviducts, cervix, uterus, and vagina.

Congenital Adrenal Hyperplasia CAH:

Results when an adrenal function anomaly (21-hydroxylase or 11-hydroxylase deficiency) causes the synthesis and excretion of an androgen precursor, initiating virilization of a XX person in-utero. Because the virilization originates metabolically in the adrenal glands, masculinizing effects can continue after birth. Person's with severe CAH may have difficulty metabolising sodium and can suffer from severe, life-threatening dehydration called "salt-wasting syndrome" however, the metabolic effects of CAH can be counteracted with cortisone. CAH can affect both male and female fetuses but the increased androgen production produces "ambiguity" only in chromosomally female fetuses.

Clitoral recession:

A surgical procedure in which the mid-section of the clitoris is removed and the tip is stitched back onto the base, which is then recessed into the *mons pubis*.

Female pseudo-hermaphrodite:

Individual with 'XX' sex chromosome and ambiguous or masculine genitalia.

Gonad:

Organ which produces gametes (ova or spermatozoa). In the early stages of fetal development, all gonads are undifferentiated, that is: they have the potential to develop into either ovaries or testicles, or possibly, a combination of the two. It is possible for people to have combination gonads and never be aware of it; the presence of the combination tissue will become apparent only during routine autopsy, or perhaps during an appendectomy or other abdominal surgery.

Hir:

This pronoun has entered into the popular and personal writing of transsexuals, transgendered persons and others who feel that their bodies confound any attempt to assign a sex that is strictly male or strictly female. I use the pronoun in cases where a person has actively done so before to describe himself, or in cases where individuals express an ambiguous self-perception, perhaps claiming a "neuter" sex. My use of "hir" in such cases is not intended to decide for hir that s/he is transgendered or transsexed, but to allow the recognition of multiple sex and gender identifications such persons may make.

Hypertrophy:

Literally: excess meat.

Intersex:

The combination, in a single individual, of characteristics of both recognized sexes (male and female). Sometimes referred to as hermaphroditism.

Klinefelter syndrome:

Most males inherit a single X chromosome from their mother, and a single Y chromosome from their father. Males with Klinefelter syndrome inherit extra X chromosomes from either the father or mother. The most common Klinefelter karyotype is 47 XXY, though one may inherit more than just one extra X. The effects of Klinefelter are quite variable, and many men with Klinefelter are never diagnosed. There is, therefore, some question as to whether or not Klinefelter is an intersex disorder. The answer may lie in the degree of masculinisation experienced by each individual. Except for small testes, men with Klinefelter are born with typical male genitals. But their testes often produce lower than average quantities of testosterone, so they don't develop the facial and body hair, muscles, deep voice, larger penis and testes that most boys do at puberty. Many also experience some breast growth at puberty. Physicians recommend that boys with Klinefelter be given testosterone at puberty, so that they will develop in the same way as their peers, and that men with Klinefelter continue to take testosterone throughout their lives, in order to maintain a more masculine appearance and high libido.

Male pseudo-hermaphrodite:

Individual with 'XY' sex chromosomes and ambiguous or feminine genitalia.

Phalloclit:

I have created this term to describe tissue which is not exactly a penis but also not a 'proper' clitoris. As a penis it will be considered too small, as a clitoris, too large.

Doctors usually refer to such an organ as a phallus until it has been pared down to be an acceptable clitoris. Even when present on an 'XY' individual with no endocrine, gonadal or karyotype disorders, doctors will not call it a penis for fear that the parents will resist its reconstruction (amputation) as a clitoris which is the preferred medical course.

Progestin-induced female pseudo-hermaphroditism (or masculinisation):

Patients are sometimes referred to as "progestin (progesterone) induced female pseudo-hermaphrodites." The intersex features are caused by prenatal exposure to exogenous androgens. Progestin is the most common of these and was administered to prevent miscarriage in the 50's and 60's. Progestin is converted to an androgen (virilizing hormone) by the prenatal XX persons' metabolism. This can cause genital virilization with effects ranging from an enlarged clitoris to the development of a complete phallus and fused labia. The appearance of these children is, therefore, similar to that of chromosomal females with CAH; however, unlike CAH, virilization of these children ceases when they are no longer exposed to exogenous progestins. Puberty is exclusively female. Although progestin was declared ineffective at preventing miscarriage in the early 1960's many women continued to have it prescribed to them into the mid 1970's.

Turner's Syndrome:

Turner's Syndrome children are born with an XO karyotype and are phenotypically female and raised as such. Girls with Turner's Syndrome are often placed on growth hormone at an early age because they tend to be of very short stature. Many women with Turner's Syndrome take hormones to induce menstruation and some are using advanced reproductive technologies to attempt pregnancy.

True hermaphrodite:

Individual with both testicular and ovarian tissue. The tissue may be combined in an 'ovotestis' or the gonads may be separate. True hermaphrodites are, most frequently, genetic females with an 'XX' karyotype. It is possible that male genetic information ('Y' chromosome) is attached to the 'XX' chromosomes in amounts sufficient to produce both ovarian and testicular tissue in a single body. However, contrary to speculation which borders on the mythic, it is highly unlikely that such an individual could fertilize him/herself; there is no indication of sperm production in the testis although the ovarian tissue may produce ova. For a longer discussion of the philosophical and epistemological implications of dividing intersexuals into categories of male and female pseudo-hermaphrodites versus true hermaphrodites see Alice Dreger's 1998 book The Medical Invention of Sex.

5-alpha reductase deficiency:

This is a form of partial androgen insensitivity in which XY fetuses do not fully masculinize due to an enzyme deficiency. However, because of increased testosterone

production at puberty such a child could experience masculinizing puberty and genital growth. This particular syndrome has been well documented in the Dominican and New Guinea populations where it is quite common.