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Medicalizing Gender:

From Intersex to DSD,

From the Laboratory to Patient Groups

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PhD candidate: Daniela Crocetti

Coordinatore Dottorato

Prof. Giuliano Pancaldi

Relatore

Prof. Roberto Brigati

Prof. Marta Cavazza

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Il tuo modo di “essere tra” toccava chi ti incontrava. Poiché quando si è rari non si è mai rari in una sola cosa, ma in tante, ogni tuo gesto, ogni tua parola, ogni tua azione, continueranno a vivere nell’altro.

A.B. referred to as Anna

To AISIA

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Acknowledgments

This doctoral project started three years ago in the beginning of 2008. However, certain relationships, academic and non, started a few years earlier as I begun my Italian masters degree in Bologna.

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Introduction

MEDICALIZING GENDER

I.1 *DSD as a shifting object*

The subject of this research, the medicalization of the gendered body, is a shifting object. It has changed its medical name from Intersex to DSD (Disorders -or Divergence[1]- of Sex Development) since the beginning of this research project. Loosely speaking it addresses the gendered components of the body, and their subsequent consideration. Drawing closer, it addresses how modern medicine treats people who manifest variations of one of the gendered components of the body, inserting their bodies into pathological categories now called DSD. This shifting terrain of different modes of viewing the gendered body has grown to include many variations, no longer solely interested in the mythical hermaphrodite. The locus of this investigation is in the interaction between these patient groups and doctors in Italy.

In 2006 medical terminology shifted from Intersex to DSD, erasing the eighteenth century category of pseudo-hermaphrodite. I intend to place the contemporary history of Intersex/DSD in Italy into the historical context of the medical disciplines that define and speak about these bodies as pathological. If DSD is a health issue and Intersex is an identity issue as the new terminology claims, the fields that will come to dominate DSD treatment will be endocrinology and genetics. We find ourselves still in the midlands of this development, where corrective surgery and psychological musings about gender identity are still prominent in the care models in clinical practice.

This research adheres to the interdisciplinary model of Science, Technology and Society, drawing specifically from the mentoring of scholars in anthropology, history of science and moral philosophy. One will find historical development, ethnographic enquiry and bioethical considerations throughout the course of the work. However, all of these considerations are influenced by one of the axes of STS investigation, intended as the interactional influences that science, technology and society mutually perform on each other. In this light, contemporary ethnographic investigation must be informed by a historical inquiry into the development of the scientific disciplines evoked, in this case in DSD treatment.

[1] In chapter three we will further address this shift in terminology, including the Disorder/Divergence disagreement. Disorder is the official term implied in DSD, while patient groups and academics, including myself, support Divergence.

In specific I would like to examine how the linked use of genetic technology and clinical endocrinology have effected DSD treatment, starting from a historical view of the treatment of these disciplines. This exploration of the historical treatment looks beyond DSD to the construction of the molecular vision of gender, and the effects of said technologies on how we envision the gendered body. Adhering to the Foucaultian paradigm that new knowledge and technology creates new paradigms and possibilities of choice, the DSD pathological paradigm emerges anew within the confines of the molecular gender model.

This work is therefore divided into two parts, a historical section, and an ethnographic contemporary section. The first part contains three chapters, the first of which treats the development of hormonal and genetic investigations of the gendered body. The second chapter provides a long-term overview of biological gender categories up until the twentieth century, and the third chapter treats the developments of the twentieth century, including the shifting terminology from pseudo-hermaphrodite to Intersex to DSD.

Building on the foundation laid by the historical examination of the molecular gendered body, we arrive through ethnographical investigation at the contemporary experience of being diagnosed with one of the DSD syndromes. We will examine the evolution of treatment protocols in DSD treatment, paying attention to the multiple scope of the medicalization, from societal gendered issues, to molecular variation and the fabric of the body. The terrain of medical treatment will be drawn through the experiences of patient groups and their interactions with the doctors and institutions involved in DSD care in Italy.

The second section focuses on the three syndromes that have active patient groups in Italy, and their interaction with the Italian health system. The first chapter of the second section, chapter four, presents the most active group, AISIA (Associazione Italiana Sindrome di Insensibilità agli Androgeni), the closest representative of a pan-Intersex group. Chapters five and six present Klinefelter's syndrome and Congenital Adrenal Hyperplasia (CAH). The seventh chapter treats the interactions of the groups with Italian medical institutions, with special treatment of AISIA's negotiation with Hospital A.

The history of the medicalization of sex is riddled with ethical concerns, social beliefs and dynamics, and technological innovation. This complex web of history weaves itself around individual experience. The history and philosophy of science increasingly points to the need to examine the interaction of factors that lead to social practices. In these arenas that are so intricately woven into our life histories such as sex, gender, and the body the raging debate on authority of knowledge is constantly lurking.

I.2 *Syndrome and syndromes*

What is DSD? As we have already indicated, it is a multiple object, which considers the biological and social factors of the gendered body and outlines what is considered pathological versus normal. The syndromes within the category of DSD therefore manifest divergences in the development of one of the many components that are considered gendered in the body. The multiple nature of DSD surfaces not just in the juxtaposition of social and biological factors, but also in the numerous layers of biological factors, medical and scientific disciplines that are involved, and the ambiguous nature of how pathology is defined.

Anne-Marie Mol indicates that disciplinary boundaries inform their own research object, that is, how it is defined, manipulated and put into practice (Mol 2002). Mol refers to the discipline-specific practices as the ontology of the disease category. In her research on vascular leg disease, she found that different disciplines not only described and diagnosed differently, but also performed and manipulated the body differently.

For DSD it is no different: surgeons talk about diagnostic norms for the genitals from aesthetics to function; endocrinologists talk about hormone levels, glands and their genetic correspondents; gynecologists talk about reproductive organs and sexual function; genetic counselors talk about genetic markers and symptom probability; psychologists talk about psychosocial health and gender; patients and their families talk about treatment and consent; social scientists talk about medicalization of gender and physical variance, which now includes the role of technology in seeing and manipulating these categories. Obviously these are neither exhaustive nor closed categories, or paradigms.

Sometimes when I say, “I study Intersex syndromes.”, others respond, “Oh, you mean people who change gender”, referring to Transgender experiences. While Intersex and Trans issues are informed by similar theoretical considerations, surrounding norms of gender and the body, and the medical techniques used in treatment have run a parallel development course, they are far from similar experiences. Transgender individuals may choose to alter their physical make-up to greater conform to their idea of their desired gender presentation, reflecting some degree of individual choice. The unraveling thread in DSD treatment has been imposed choice, either through authority, lack of communication or lack of presentation of options.

DSD’s are generally called syndromes, not diseases, although this precision in terms is subtle enough to often be lost, leading to a discoursive interchangeability of syndrome and disease. It is the nature of syndromes to beg the discussion of pathological read as wrong,

versus pathology read as difference. Georges Canguilhem (1991) was one of the first to bring attention to the increased tendency in medicine to define illness by following statistical norms. These statistical norms were to provide that basis of the difference between the pathological and the normal, focusing on difference as the origin of illness instead of discomfort.

Canguilhem published in the wake of the Eugenics movement, which had specifically linked difference and illness to moral and social deviance (Davis 1997). Therefore when considering the difference in terminology between syndrome and disease, we must also consider the historical stigma that was associated with the term disease. In the genomic age we now debate the difference of syndrome and disease in relationship to identity (Rose 2006), and highlight the difference between *having* a syndrome and *being* diseased (or vice versa).

In medicine and psychology, a syndrome is the association of several clinically recognizable features, signs (observed by a physician), symptoms (reported by the patient), phenomena or characteristics that often occur together, so that the presence of one feature alerts the physician to the presence of the others. The term syndrome derives from its Greek roots (σύνδρομος) and means literally “run together”, as the features do. It is most often used to refer to the set of detectable characteristics, when the reason that they occur together (the pathophysiology of the syndrome) has not yet been discovered. A familiar syndrome name often continues to be used even after an underlying cause has been found, or when there are a number of different primary causes that all give rise to the same combination of symptoms and signs.

A disease, similarly, is an abnormal condition affecting the body of an organism. It is also construed to be a medical condition associated with specific symptoms and signs. It may be caused by external factors, such as infectious disease, or it may be caused by internal dysfunctions, such as autoimmune diseases. In humans, "disease" is often used more broadly to refer to any condition that causes pain, dysfunction, distress, social problems, and/or death to the person afflicted, or similar problems for those in contact with the person.

Therefore, in most disciplines, the concept of disease departs from the concept of syndrome based on two axes: the expression of pain and suffering by the patient (or family members in the case of mental illness) and the relationship of the biological variance to biological dysfunction. A syndrome may contain biological variances that do not specifically lead to dysfunction or suffering for the individual. However, this does not free the individual from the social stigma attached to differences in the body.

Mary Douglas (1966) indicates that all cultures, in her words, “fear impurity”, and create

social rituals and norms that clean the social structure of all that might threaten it, from different bodies to different behavior. However, this anthropological insight also indicates how various cultures and time periods *see* different differences, marking some differences as dangers to be eradicated, disappeared or fixed, while other differences escape recognition. Bio-technology has given us new instruments to *see* differences in the body, re-framing the parameters of the pathological. One could argue, however, that the genomic era is pulling away from the negative definition of biological difference.

Ellen Feder brings these considerations of the normal body and the normal in society to that of the consideration of medical normalizing techniques in DSD treatment. Citing Foucault she addresses how in modern times "medical power is at the heart of the society of normalization" (Foucault in Feder 2009 pg. 231), therefore an institutional regulating body that also influences societal norms of the body. Foucault observes a transition in medicine from being "a set of techniques for curing ills and the knowledge they require." (Foucault 1963 pg.34) to embracing "a knowledge of *the healthy man*, that is, a study of a *non-sick man*, and a definition of a *model man*" (Foucault 1979 pg. 182-3; Feder 2009).

Whereas Douglas and anthropologists might disagree that medicine was ever just a set of techniques used for curing, they would definitely agree that medicine has been used as regulatory tool to clean the social body. Feder indicates through Foucault's argument, that DSD has become such an intense medical concern due to a historically located pathologization of anything related to sex, and specifically modern definitions of homosexuality. Feder discusses an aspect that is one of the key theses of this work, that the emphasis on the social gender aspects of DSD has, until recently, obscured treatment for other physiological issues.

The debate surrounding medicalization and normalization leads to a consideration of disability politics, which questions the social background of stigmatizing language used for physical differences. Disability politics also, however, addresses the difficulty of negotiating for desired medical techniques and against normalizing ones. Feder cites noted disability politic theorist Lennard Davis while writing,

> Whether conspicuous or not, we must reckon with the fact that "there is no area of contemporary life in which some idea of a norm, mean, or average has not been calculated." (Feder 2009 pg. 231; Davis 1995 pg. 23).

These parameters of the expectations of contemporary society regarding the body are part of the package within which DSD treatment lives. DSD syndromes disrupt the assumption

that ones biological sex will manifest not only in the matching gender identity, but the same genitalia and secondary sex characteristics. The fact that generally people associate one's sex with the X and Y sex chromosomes is evidence of how quickly genetic knowledge has penetrated public debate about sex and gender. In western societies that allow for only two social/legal gender categories (male and female), the general modern trend has been to medicalize individuals diagnosed with DSD through surgical, and endocrinological intervention towards less ambiguous gender representation.

Contemporary DSD diagnoses are all based on a genetic definition of sex.

This is a brief outline of how the syndromes are medically broken down into syndrome, chromosome, gonads, hormones, reproductive duct development and genital appearance:

	Chro moso mes	Gonads	Testo-sterone	Dehydro-testo-sterone	Wolffian ducts	Mullerian ducts	External genitalia
46, XY	XY	testes	+	+	+	-	Male
Klinefelter Syndrome	XXY	testes	+, low	+	+	-	Male Small
XYY	XYY	testes	+	+	+	-	male
46, XX	XX	Ovaries	-	-	-	+	Female
Turner Syndrome	XO	Streak	-	-	-	+	Female
Congenital Adrenal Hyperplasia	XX	ovaries	+ from adrenal gland	+/- from adrenal gland	-	+	ambiguous
Complete Androgen Insensitivity Syndrome	XY	testes	+ but not responsive	+ but not responsive	-	-	female
Partial Androgen Insensitivity Syndrome	XY	testes	+ but not responsive	+ but not responsive	+/-	-	ambiguous
5alpha-reductase	XY	testes	+	-	+	-	Female/ ambiguous
17beta HSD	XY	testes	+	-	+	-	Female/ ambiguous

(Cohen-Kettenis and Pfafflin, 2003, pg. 23)

These charts are generally designed to outline the components of the gendered evoked in the syndromes definition, which facilitates gender assignment and treatment of gendered presentation. As you may observe, these charts rarely reference any of the physiological or

developmental issues that may arise in these syndromes.

The most common DSD diagnosises are (with available rough statistics for the USA): CAH (congenital adrenal hyperplasia) 1:13,000; AIS (androgen insensitivity syndrome) complete 1:13,000; partial 1:130,000; gonadal dysgenesis (which implies a mix of chromosomal material) 1:150,000; hypospadias (in which the urethra does not exit at the tip of the phallus or other variation) 1:700; XXY (Klinefelter syndrome, in which there is an additional sex chromosome) 1:1000; Rokitansky (vaginal or uterine agensis) 1:6,000; Turner's syndrome (X,O, in which there is a missing sex chromosome) and 5-alpha reductase deficiency (Blackless, Fausto-Sterling, et Al.. 2000). There are other variances in chromosomal make-up or other gendered components of the body that either go unnoticed (without genetic testing) or until recently were thrown in other categories.

ISNA (the Intersex Society of North America) estimates that one or two in a thousand children received genital "normalizing" surgery from the 1950's until recently[2]. However this figure includes children with cloacal exstrophy (1:250,000, not considered a DSD), a condition with functional issues in which much of the abdominal organs (the bladder and intestines) are exposed. It often causes the splitting of both male and female genitalia (specifically, the penis and clitoris respectively), and the anus is occasionally sealed.

Individuals with both fully developed ovaries and testes may still be referred to with the older term hermaphrodite. Many find this term a relic of medical stigma. What most people diagnosed with DSD experience at some point in their lives, is being told their genitalia or hormone levels are inconsistent with their sex, or their chromosomes, and that this needs to be fixed, based on the language the doctor chooses. This is some of the information that can be found on the web site of the Italian Ministry of Health.

> Le comuni manifestazioni delle anomalie di differenziazione sessuale che si manifestano in età neonatale sono
>
> • ermafroditismo
>
> • disgenesia gonadica mista
>
> • criptorchidismo/ipospadia
>
> • pseudoermafroditismo (maschile e femminile) (Mattioli and Jasonni 2004)

As seen in this recent article by a research team from the University of Genoa, many terms refuse to die. Hermaphrodism and pseudo-hermaphrodism are more commonly described

[2] http://www.isna.org/faq/frequency

respectively by the presence of partial or complete duel reproductive system, and the presence of a singular reproductive system that does not conform to the expected chromosomal sex. The same article reports the following statistics (unclear if they are from the Italian population):

Mosaicismo cromosomico 1/1,666

• S.di Klinefelter (XXY) 1/1,000

• S.da insensibilità androgenica 1/13,000

• S.da insensibilità androgenica parziale 1/130,000

• Classica iperplasia surrenalica congenita 1/13,000

• Agenesia vaginale 1/6,000

• Idiopatico 1/110,000

• Iatrogenico (farmacologico) Non valutabile

• Deficenza 5-a-reduttasi Non valutabile

• Disgenesia gonadica mista Non valutabile

Le forme più frequenti di anomalie dei genitali in pazienti con genotipo XY sono l'ipospadia ed il criptorchidismo con le quali vi è una relativa alta incidenza associativa con i genitali ambigui/Intersex. Questa elevata frequenza associativa rende l'esame obiettivo fondamentale per sospettare anomalie sessuali maggiori:

tipo di criptorchidismo	incidenza di intersesso
unilaterali	30%
bilaterali	32%
palpabili	15%
non palpabili	50%

tipo di ipospadia	incidenza di intersesso
Anteriore	8%
Media	5%
Posteriore	65% (Mattioli and Jasonni 2004)

One can already note the ambiguity of definition as to when to include hypospadias in the category of intersexuality. The conceptual change to DSD (disorders of sex development)[3] in some way neutralizes the emphasis on gender ambiguity, transferring the emphasis to norms of development, in a way that renders the inclusion of hypospadias and micro-phallus more "natural".

The term Hermaphrodite historically refers to a person with both sets of reproductive organs but was also used to refer to people who were ambiguous or mixed in either the gender presentation or their genitalia. Pseudo-hermaphrodite was introduced in the 17th century as medical interest in defining biological sex grew. "True hermaphrodites" make up 0.007% of the population, but Intersex individuals or people diagnosed with DSD can make up 0.1% because the category has expanded to include many more forms of variation.

In western society hermaphrodism has conceptually moved from being a philosophical construct, a monstrosity associated with evil or danger, a biological anomaly representing social deviance, a physical disease category, to a set of syndromes representing biological variance. Yet consistently throughout the change in approach, the choice of the civic gender category has been considered one of the most pressing issues, not the functional aspects. The conceptual difference between disease and syndrome lends weight to policy decisions on the urgency of normalizing DSD bodies to conform to set standard of sex. Whereas a disease indicates a biological variance that necessarily disturbs the functioning of the organism, syndromes indicate simply the manifestation of this variance (especially on the symptomatic level) without implicating functional variation. The use of symptom terminology instead of disease terminology unveils the imperative to act medically on the manifest difference.

I.3 *From the Laboratory to the clinic: the construction of knowledge*

One salient issue in STS studies is the construction of knowledge, and the construction of authority in respect to said knowledge. Sociologists and Anthopologists such as Bruno Latour (1987; 2005), Michel Callon (1987), and John Law (1999) have advocated the Actor Network Theory (ANT) as a tool for analysis. This method tracks the web of communication from the site of investigation to the use of the information, as it becomes a "scientific fact". We place "scientific fact" in quotations in order to highlight the aspect of the construction of information. Latour (1979) also argues that for an empirical event or application to be considered fact, the researcher must convince in some manner the social structures that will

[3] DSD specifically refers to syndromes, not diseases.

use this information, that this information is useful and valid. Foucault in turn indicates that one of primary aspects of bio-power is how it delimitates the options of what is biologically "true" and therefore the possibilities for action.

For our purposes, the site of investigation is both the laboratory (hormonal, genetic and anatomic) and the clinic (patient data, surgical experience). The site of application is the clinic, which includes clinical laboratories. Throughout the course of this work, we will look at the history of ideas (Foucault 1969), as they are utilized in the laboratory and the clinic. The research institutions in question negotiate with the scientific community through publications and scientific conferences in order to convince their knowledge community that their ideas are valid. They negotiate with government institutions for funding and the possibility to implement new practices. But they also increasingly negotiate with patient groups regarding the establishment of correct terminology and care.

Mol's emphasis on the ontology of medical knowledge highlights another aspect of the construction of the scientific fact; practice. Medicine has the express purpose of translating biological data into practices, which should favor the life and experience of the organism. A scientific fact is translated into a social fact, given meaning through its insertion into a practice. The density of a hydrogen molecule has social meaning that is expressed by how we utilize this information. The "reality" of the physical world is irrelevant for humanity until we have tools to talk about it, visualize it or utilize it. The construction of "scientific facts" is a translation of the observable into a language we can understand and utilize. The translation of an empirical phenomenon, in fact, usually happens through a related practice and tool set. Each discipline in science and medicine adapts a set of practices that privilege certain investigational tools over others and certain scientific facts over others (Daston 2000).

DSD diagnosis and treatment involves several knowledge sets and visualization technologies. As we will see in chapter one, descriptive models developed in research laboratories are adapted to practices in the clinic. The knowledge set from a lab that researches hormones are translated to fit the needs and the social environment of the clinician. The commercial adaptation of certain hormonal therapies such as those used for birth control has lead to the use of that type of hormonal compounds for many different situations, including DSD.

The first section of this work focuses on the progression of the dominant scientific beliefs about the gendered body up into the twentieth century. A more detailed historical work would indicate the other currents of scientific thought that were contemporary to each phase, that fell into disfavor, or were less widely accepted. Unfortunately we have space only to consider the

theories that have lead to what is currently considered scientifically true. Historian Simon Schaffer (1986) indicates that history is usually a history of the winners, and therefore of the scientific theories that came to be considered fact.

I have tried in chapter two (of the first part) to construct a progression of the main scientific theories of the gendered body that have lead to the current paradigm. One must consider that this history reflects primarily canonic and academic reflections on the gendered body, not popular belief. As we will see in chapter two, doctors often saw "hermaphroditic" patients posthumously, and express surprise and dismay that these "differences" were not noted in life. This gives us little information onto the lived experience of these individuals, and how their society or microcosm viewed (or perhaps didn't see) their biological variance.

A society indicates its points of contention by creating rules and structures to govern them, as Adriana Destro (2005) notes in her anthropological analysis of the Talmud. While Destro is primarily addressing the length of the text referring to menstrual regulation, she indicates that commonly accepted social practices might not have been included in the list of social regulations, because without conflict these points become invisible, without need for comment. We may ask ourselves about the silence of popular commentary on the hermaphroditic body throughout history, and if this might indicate that specialists, and not the general population, primarily noted these physical variations. If this is true, then the premises that DSD bodies create social stigma, and therefore need to be "fixed", is in part contemporarily medically constructed. Instead of constructed we could say exacerbated: there are certainly observations of social stigma against Intersex individuals in non-medicalized contexts, such as in the eastern African Pokot tribe[4]. We have relatively little personal record of people who might have had DSD syndromes outside of the medical description up until the twentieth century. Histories outside of the medical context appear primarily when sexual orientation is the focus of contention.

The second part draws away from a purely scientific perspective and investigates three syndromes directly, followed by an examination of the interactions of patient groups and medical institutions. These ethnographies paste together medical knowledge with tacit knowledge, the experience of the people diagnosed. What emerges is a contemporary aspect

[4] Edgerton's (1964) research indicates that in this African context an intersex person is excluded from the socially acceptable sexual sphere, and from the dual gender system, thereby highlighting social stigma in non-medicalized arenas. However scholars such as Ong and Peletz (1995) question the influence on colonial structures in the creation of a global construct of gender norms.

of the construction of knowledge, the practices of the people outside of the traditional boundaries of institutional knowledge and authority.

Steven Epstein states:

> In recent years, as questions of health and illness have been recast as thoroughly political matters, more and more ordinary citizens, often organized into patient advocacy groups or broader social movemnts, have demanded a say in how scientist and health professionals go about their work, tossing aside the presumption that technical matters are best left to the experts (Epstein 2007).

Italian patient groups are identified as experts to some extent, analyzing the cutting edge of scientific production on their syndrome, comparing it to actual clinical practice and then adding their own tacit knowledge that comes from living daily with DSD. Some people arrive well into adulthood before discovering the syndrome. This has caused patient groups to question the nature of the medical emergency.

To question the nature of the medical emergency is to question the development of scientific beliefs surrounding DSD and the gendered body. In the first section of this work I hope to unravel the practices that lead to the current treatment paradigm, from the lab to the clinic to the patient.

I.4 *Bioethical concerns*

DSD treatment has come out of the dark, becoming a bioethical issue since the 1990's. This is due to the rise of bioethics as a discipline, and the actions of the first DSD patient group, ISNA. In 2010 the Italian National Bioethics Committee (Comitato Nazionale per la Bioetica/CNB) treated the issue, offering an official position on DSD treatment in both Italian and English.

> It is a delicate matter of considerable bioethical and bio-juridical interest as it places at the centre of reflection the sexual identity of the child (the different physical, mental and social components), the complex decisions of intervening on the body and psyche by the physician, the manner of providing advice for parents and the children themselves when they reach a sufficient level of awareness, the personal, social and legal implications for those affected by these pathologies.
>
> The Opinion, after placing the problem within historical and clinical framework, highlights the principle elements of international bioethical guidelines, in order to grasp the problematic issues in bioethical and juridic terms, and reach some important shared recommendations. Including: each medical intervention in DSD cases must have the objective to harmonize elements of disharmony

in physical, psychological and social terms; the physician must pay particular attention on a diagnostic level to each objective sign (from the stage of prenatal development) to prearrange any possible therapeutic instrument; any intervention on the body must be guided by the principle of the best interest of the child, avoiding any unnecessary mutilation (such intervention should be implemented only in emergencies, as it is preferable to wait until the individual reaches a maturity which allows the expression of consent); the family and the child himself/herself (if able to understand) should be given adequate psychological support and the communication must be careful and gradual, with the provision of appropriate counseling.[5]

The CNB's position focuses on three key internationally recognized issues, correct diagnosis, full informed consent, and the complex nature of surgical intervention and the "best interest of the child". However two crucial points are left to some extent to interpretation; how one harmonizes the physical, psychological and the social terms, and what are the guidelines for acting in the best interest of the child? Until recently, following the model of John Money, it was considered in the best interest of the child to conceal everything and operate early so that they would "not remember anything".

"The best interest of the child" has been a controversial issue within bioethics due to the individual juridic vacancy filled by the child's legal guardian, often a fretful parent. To this respect the Hastings Center commissioned a collaborative research that resulted in the 2006 book, Surgically Shaping Children. This research focused on the different arenas of genital surgeries for DSD, cleft palate and limb lengthening surgeries. It grew out of a project that addressed enhancement technologies, which soon came to realize the fuzzy line between enhancement technologies and corrective surgeries. This fuzzy line is the statistical or contemporary social and medical norm of the body.

> We weren't talking about advantage-seeking social climbers. Instead we were talking about parents and children, who hoped a more normal appearance would improve psychosocial functioning…it forced me and the working group to face one of the deep tensions at the root of many if not all of the debates regarding what we might call "self-shaping technologies." Parents have two fundamental obligations. One is to let their children be, to let them unfold according to their own desires and capacities. The other parental obligation is to shape children, to promote their flourishing or psychosocial functioning (Parens 2006 pg xiv).

[5] Italian National Bioethics Committee, 25 Feb 2010, Minor's Sexual Differentiation Disorders: Bioethical Aspects pg. 3; http://www.governo.it/bioetica/eng/opinions.html; Italian http://www.governo.it/bioetica/pareri.html

Through the comparison of the opinions on the differing techniques, not only of doctors, but also of patients and parents, a common picture emerges. Parents feel a lot of pressure from their social environment and the doctors they encounter to give their children the tools to be not only normal, but also competitive. Rarely did someone speak out against cleft palate interventions, due to the low risk and the relationship of facial aesthetics to social interactions. However, what emerged was that generally the self-esteem of the child was damaged if they were not involved in the decision making process, that being "fixed" left a lingering identity of "not good enough".

Even in the case of cleft palate, a child does not identify their physical difference as social significant until it is indicated to them. Cassandra Aspinall relates how she came to the awareness of her difference as her grandmother tried to explain to her that it was OK.

> Though her grandmother was worried about the harmful and wrongful reaction of others, Aspinall got the impression that something was wrong with *her*…What are the costs to the child when the surgery's primary purpose is not to make the child feel better, but to make others feel better about the child (Parens 2006 pg xvii)?

As we will see in the ethnographic sections, there are many emotional complications in having irreversible decisions made for you that shape your body. Informed consent is a concept that is applied to able-minded adults, not children, therefore the bio-ethical concern becomes predictive, what will be the best interests of the future adult? Though ambiguous in their wording, "avoiding any unnecessary mutilation", the CNB cites the Columbia court ruling that dictates that parents cannot choose genital surgeries for their children as they do not represent functional emergencies. In this ruling the age of consent for surgical procedures is lowered to an elastic age around puberty in which the child can be involved in the decision making process.

Informed consent itself is a sticky issue, due to the problems in construction of knowledge and authority over knowledge addressed earlier. Doctors propose techniques and therapies, addressing DSD as a medical emergency (that implies functional problems) rarely counseling the family that they can wait, or decide not to intervene at all. The Hasting's center project, instead, arrives at a similar message as ISNA's patient centered care model:

> If children with atypical bodies are assured of their caretakers' unconditional love, if those children understand the facts about their bodies, and if, whenever possible, they are included in decisions about the treatment of their own bodies, they will be fine (Parens 2006 pg. xvii).

This consideration on informed consent can be extended to the debate surrounding pre-

natal genetic testing. If an individual is given all of the information about a syndrome, not just stigmatizing stereotypes, they will be prepared to make an educated choice about risk possibility, instead of being advised to end a pregnancy with a "genetically diseased child". As we will see in chapter seven, informed consent changes across disciplinary lines, because the informational object itself changes as technology changes.

The CNB's guidelines indicate the arrival of bioethical consideration of DSD in Italy. However, these guidelines have no real legal weight and are affected by a similar academic affliction found in many Italian disciplines: almost all of the textual research cited is foreign, and no Italian doctors or patient groups were consulted. It is possible that due to the lack of literature on DSD in Italian, this document will gain persuasive weight in coming years.

The patient group's themselves have led the direction of the attention that we will pay to certain bio-ethical concerns over others. While irreversible childhood surgery (often performed without informed consent) was the first bio-ethical concern to put Intersex on the map, it is not always the main focus point of Italian DSD groups. The Italian DSD groups, either because they are syndrome oriented and not pan-intersex, or because they are less confrontational about the demands of social conformity6, focus less on the ethics of "corrective" genital surgery and more on total body health problems.

At the beginning of my ethnographic research, at the end of a long discussion, American Intersex Activist Emi Koyama reminded me that Intersex syndromes can cause health problems due to endocrine variances. Koyama indicated that these health concerns are often overlooked due to the morbid focus of medicalizing genitals. These comments and the orientation of the Italian patient groups lead me to focus more on endocrinology and genetics, instead of surgical procedure. The ethical quandary of "surgically shaping children" remains an open chapter in Italian DSD care. However, as we will see, particularly in chapter seven, full body care that includes the endocrinological and genetic developments discussed in chapter one, is increasingly being put into action.

I.5 *A note on methods*

Due to the interdisciplinary nature of both STS as a discipline and DSD as a medical object, there have been several academic theories and methods utilized in this research. On a broad level these methods were historical and ethnographic, yet as we have touched upon

[6] The severity of the Italian "gaze" as a form of enforcement of social norms of presentation was noted in popular literature at the turn of the century (Dalton 1909)

earlier, both of these aspects are influenced by an STS perspective that would like to investigate the creation of knowledge.

The historical research, therefore, becomes a dance between primary and secondary sources. STS and Anthropology often rely on secondary sources that already have a layer of theory applied to them for historical information. In order to create a broad picture of both laboratory research on the gendered body and a historical picture of DSD, I have greatly relied on the research of others. However, observations from my advisors from the history of science quickly indicated certain discrepancies between the generalized pictures painted by theoretical secondary sources as opposed to the detailed work of historians.

This discrepancy is most notable in respect to theories regarding the progression of thought surrounding the gendered body, and Laqueur's (1990) one sex/two sex model. In order to circumnavigate this theoretical debate, it was necessary to yet again, primarily address the history of "winners" in research arenas. The picture that emerges focuses on the history of ideas about gendered components of the body, and gender in society, but not a conclusion to the debate about gendered bodies in society.

Secondary sources represent the first and third layer of the historical components of this project. The first layer addresses the evolution and separation of the gendered body into components, causes and social theory. Through this separation of components the gendered body becomes infinite, composed throughout history of many diverging theories and even designs on what lays inside of us. The primary research of others is invaluable in creating a picture that leads to our contemporary complex molecular theories.

These secondary sources highlighted the shift to an internal visualization of the body and how that relates (or doesn't) to contemporary DSD care and conception. This influenced the emphasis on endocrinology and genetics in our first chapter.

The second level of the historical research focused on primary sources, some indicated in the secondary sources. The work in the first and second chapter indicates this dance back and forth between secondary and primary sources. The third chapter, instead, contains research with primary sources that have little support with secondary sources. The work on Taruffi and other Italian anatomists grew out of the desire to contextualize the Italian medical academic development. These primary sources are generally published work, although letters help construct some of the background of the medical figures, that might not emerge in these pages.

The other concentration of primary sources appears in the ethnographical section. I had tried to indicate when medical data and research is international or Italian production. While

this work addresses DSD in an Italian context, it proposes no broad theories about how Italian society might specifically view biological gender difference. Italian contemporary medical practice acts primarily in the international bio-medical arena, erasing any context specific aspects in Italian medical publication, which is often in English. Even the historical work of Taruffi indicates a strong dialogue with the European medical community. In certain cases, what emerges is the timing and placement of certain discussions, such as either the recent inclusion of DSD in some Italian pediatric textbooks, or the concentration of recent Italian medical research papers on physiological issues as opposed to gender assignment. However doctors and patients alike informally wonder if the Italian gender and familial structure lends itself in theory to the reconstructive surgical model. One can find very differentiated gender stereotypes in Italian media (Zecchini 2005) and an emphasis on conformity in familial structure.

The overlap of ethnography and history in STS has led to much debate on how to treat all this information together, and specially how to analyze it without imposing an artificial constructionist model. Thomas Kuhn (1962) was of the first to popularize the idea that scientists are not objective regarding their own research, and that this subjectivity is relevant to the history of science. In addition to this he addresses what he calls scientific revolutions, or the changing of paradigms that open space for new ways of thinking and working with a problem. The shift to a molecular model of the body is certainly one of these grand paradigm changes.

Bruno Latour, Micheal Callon and John Law developed the Actor Network Theory as a model for analyzing how these paradigm shifts come about. ANT proposes an analysis of how scientist/doctors/patients/actors negotiate with institutions/social networks in order to transform their observations and opinions into scientific facts. Sociology and Anthropology of Medicine adopt a version called Situational Analysis (Clarke 2005) that maps the interactions between actors in the creation of meaning in a given context. Situational Analysis adds a representative tool to ANT, in which symbolic maps are drawn as part of the research process that visually indicate the power and significance of the actors and networks involved.

In this project the Actors are doctors (from multiple disciples), patients (representing different syndromes) and laboratory researchers (from anatomists to molecular genetists). The Networks are professional conferences and associations, governmental regulatory structures, and ever increasingly, the Internet. The first part of this work concentrates on the transformation of laboratory research into clinical practice. The second part addresses the entrance of a new subjectivity into medicine, the negotiational power of the patient.

The ethnographic component of this doctoral thesis is primarily qualitative, in that manner following an anthropological model more than a sociological one. The research period spans from 2006 to 2010 and consists of participant observation, in-depth interviews, focus group interviews, and internet forums from both patients and medical professionals. All of the names have been changed or are left as initials.

The participant observation has had two aspects, the extended period and a concentrated period, both in Italy. Through the entire research period, I attended medical conferences, medical lectures and meetings on DSD (n=9), as well as the meetings of AISIA (n=8). From Jan 2010 to July 2010, I frequented the molecular genetic lab of Hospital A, with occasional encounters with other members of the DSD team.

After much debate about how to protect the privacy of, not just, the patients I interviewed, but also the doctors and the institutions, I have coded the hospitals that I have interacted with A, B, C, D, E, F. The more in-depth research was performed at Hospital A. I adapt Anne-Marie Mol's explanation in the preface of *The Body Multiple* (2002), that the practices of Hospital A are neither exemplary nor unique to the Italian context. However, seeing as Hospital A seeks to represent itself as a primary DSD center, it is a good model.

> By starting from such a well circumscribed site, I try to move philosophy away from formats that carry universalistic pretensions, but that in fact hide the locality to which they pertain. However, the idea is not to celebrate localism instead of universalism. Instead, it is to keep track as persistently as possible of what it is that alters when matters, terms, and aims travel from one place to another (Mol 2002 pg. viii).

Mol raises another of the many issues at the heart of this research: how important is it to punctualize the cultural context? I have followed Mol's model also with regards to this issue, hoping to let practice reveal what might be interesting about contextual specificity such as cultural influences without elaborating cultural specificity as the object itself. Like her, I write in English for the purpose of communicating to a larger academic community. English, however, is my native language, while not the language in which I have lived my life for the last seven years.

Most of the interviews were conducted in Italian (apart from the handful in the USA) and both quotations and translations have remained faithful to the actual words said or written. The quotations have been checked for minor grammatical errors that might have occurred in transcription. The in-depth interviews cover the entire research period and have been repeated with the same people over time, with patients (people n=17, interviews n=33) and medical

practitioners (people n=12, interviews n=20). From 2008 to 2010 there were 4 occasions in which part of the AISIA meetings involved a focus group interview session.

The Internet is the primary home to many of the patient groups. It also provides a rich ethnographic resource that is, however, questionably reliable. I have cited forum discussions primarily when they express a commonly repeated sentiment in the group. I more liberally site information or stories from the group websites when it is clearly indicated that these statements are part of the official presentation of the patient group or hospital team.

DSD treatment in Italy seems to be changing rapidly, if not only in regards to full disclosure of diagnosis. This work hopes to capture this fleeting moment between the paradigm of treatment formed in the 1950s, which is informed by centuries of research and philosophy of gender and the body, and the treatment model to come.

Part One

THEORY

DSD (Disorders/Divergences of Sex Development) is a composite object that has been constructed over time through the mutation of scientific disciplines and attitudes surrounding the body and gender. DSD currently exists in a social reality full of overlapping contradictions, as in any historical time period. We search for biological causes for social dynamics, such as behavior, and social explanations for biological phenomena such as the moment death occurs, while rarely suggesting theories that interweave both logics. Bruno Latour suggests we have never achieved the pure separation of categories we believe to be part of the modern logical process, such as the Cartesian mind body split and other black and white categories (Latour, 1993). Latour hypothesizes we have never been modern, continuing to contaminate "pure" categories such as the mind with physical processes (the body), the natural with the social, science with culture as so forth.

The biological theories that address the gendered body often claim to be "pure" science or to "just" address the phenomenon of physical processes, however this is categorically impossible. The twentieth century has sought to dismantle the idea of the "pure" scientist who lives in hermetically sealed box, deaf to the messy problems of social theories and debates. Historians and social theorists have pulled apart this image piece by piece, inserting science in a social context and treating science as the process in which observations are translated into theories and objects permeated with social significance. Scientific facts are brought back to the realm of social performance and expectations.

Anne-Marie Mol draws attention to this dynamic by addressing medical practice, describing the doctor-patient interface, but also the interaction between doctors and machines, doctors and the body, doctors and explanatory models. In particular Mol draws our attention to how the scientific object shifts from site to site throughout the body, acquiring symbolic significance and losing it again, even when discussing the same syndrome category, based on the discipline of the observer. A syndrome can be described by means of a genetic marker, a hormonal level, a physical difference or an impairment to how one's life expectations.

It is precisely when the scientific object must be put into action, made to do something in and for human society, that it is revealed to be a symbolic signifier much like any cultural artifice. The processes endocrinology describe in the body, for instance, do not lose their

relation to the real, physical world, what science describes is certainly easy to document. However, when a hormonal theory is applied to a cure, or even the description of a developmental process, it steps into the realm of social interaction and symbolic meaning.

This first section presents a theoretical look at DSD, seeking to display some of the explanatory models that make up the current terminology. The second section turns to the human experience, attempting to look at the syndrome categories from the perspective of those diagnosed and thrown into the world of hospitals, doctors and scientific theory. Both sections are in themselves informed by many theories and perspectives. The primary disciplinary slant is that of STS (Science, Technology and Society studies), that aims to analyze the social, cultural and political factors that contribute to the creation of scientific facts and data.

STS is inherently interdisciplinary and is itself informed by certain principals found in anthropology and history which shatter the nature/culture explanatory divide. Since the arise of increased technology that can "visualize" the inside of the body and its intimate molecular components such as chromosomes and genes, there has been a flood of research that claims to have found a biological explanation for complex social behaviors, including gendered behaviors. At this point the anthropologist often steps up and says, "But that's impossible; behavior is culturally constructed." However, people began to be nervous about turning everything into a culturally-constructed phenomena, pointing out that, even historically, there have been tendencies for humans to behave in certain ways. Human reality is embodied, influenced by experience mediated by the body, including similarities and difference with other bodies.

Marcel Mauss discussed body techniques, ways in which we create symbolic meaning through our bodies and embodied actions. Mauss wrote of physical activities that are coded as female activities or male activities, based on the cultural significance of said activities, regardless of actual individual physical attributes that might make one better at any given activity. Anthropologists have documented how for instance childrearing activities are gendered differently from temporal culture to temporal culture. Mauss' considerations of body techniques turned in another direction as well, to consider how the morphology of the body effects individual experience. From this perspective we can begin to also look at biological theories surrounding the gendered body, that imply experiential differences based on a biological precedent.

The twentieth century has seen the separation of sex and gender, separated at the hip in order to create ways to talk about the practical aspects of living in a gendered body in any

given society (Butler 1993). Sex has come to refer to biological objects such as genes and hormones, and gender to social aspects such as identity and behavior (Fausto-Sterling 1985; 1993). The word gender has given us an important tool to think about what was assumed to be natural or embedded in the body. We have come a long way from the end of the nineteenth century when anatomists claimed that women and certain races were naturally inferior to European men based on their brain size and other biological components (Reis, 2009).

Gender has given us a way to address disparity and prejudices by removing them from the body and placing them in the realm of social interaction where they best belong. However, this has often allowed the biological "facts" of sex to remain black boxes, un-scrutinized, accepted as they are. I would propose that the biological "facts" of the gendered body are involved in a circle game where embodiment helps create ideas about gender, and ideas about gender also help create what we think about the material of the body itself.

Sex as a biological compound object is informed by a legacy of laboratory research on each of the individual aspects that are considered related to the reproductive system, from gonads to hormones, but also performative aspects of gender roles. The biological object of, say, the gonads, is translated from its empirical components to a participatory member in the sexual system of the body, where it gains symbolic meaning informed by the social demands on the gendered body.

In the first introductory chapter we addressed not only research methods, but many of the practical and theoretical concerns surrounding DSD. In the second chapter we will be looking at what the biological vision of the gendered body is. The gendered body is parceled out into chromosomes, genes, gonads, ducts, genitals, hormones, hormonal receptors, secondary sex characteristics and the murky arena of the brain and behavior. In order to address contemporary methods in DSD treatment we will look in further depth at endocrinology, anatomy and genetics, in an attempt to address the shifting locus of biological sex. We will try to mainly address the construction of biological sex, however social theories about gender role and behavior invariably enter the scientific picture.

In the third chapter we will fill in some of the background story of the historical mutation of not only the gendered body, but the then-called hermaphroditic body. Addressing primarily the western world, we will quickly follow the shifts in perspectives regarding the gendered body, arriving at the contemporary medicalized discourse that delimits the normal and pathological. The fourth chapter addresses the interventionist methods of the twentieth century, and the creation of Intersexuality. In this period from the 1920s to the present, attempts are made to create a uniform medical protocol to treat differences in the gendered

body. Towards the end of the twentieth century, the patients voice is finally heard, creating the space for much needed reflection on the medicalization of the gendered body. The fifth and final chapter of this first part brings us to current terminology and treatment methods of DSD. In this chapter, we will discuss the relevance of terminology in light of the historical changes the category has undergone.

The second part of this thesis addresses several aspects of what Nikolas Rose (2006) and Paul Rabinow (1999) propose as bio-sociality. While directly referring to social mechanisms organized around biological objects such as syndromes or genetic markers, it also addresses the interaction between technology and experience of the body. Visualizing bio-technologies makes us aware of genetic markers and "potential" illnesses (Rose and Novas, 2000), as well as increased levels of biological variation. By shifting the attention to the individual who is transformed into patient, we are witness to the struggle for authority in treatment and syndrome definition. The origins of this struggle are contained in Kleinman's analysis of Disease and Illness, disease being the bio-medical explanatory model, and illness consisting of the individual experience of sufferance. However, despite cries that the masses are not scientifically literate, recent history has seen the rise of patient movements that struggle for legitimacy, utilizing scientific language and research. The second part, therefore, follows the interaction of patients and doctors in the establishment of scientific meaning and care protocol.

Chapter 1

TECHNOLOGY AND BIOLOGICAL CONSTRUCTION OF SEX

1.1 *Biological theories of sex, and the search for the locus of identity*

The examination of the passageways that transform laboratory investigation into scientific fact is one of the considerations central to STS. In this chapter we will look at the historical formation of some of the biological arguments central to DSD treatment. DSD treatment is primarily informed by theories of biological sex differentiation, which in the twentieth century are increasingly informed by the biological disciplines of genetics, endocrinology and embryology. DSD treatment is also informed by an overlapping of biological theories onto social theories, such as hormonal imprinting, that investigate how biological factors might contribute to social practices such as identity formation and behavior.

Therefore, before we look at DSD treatment and the clinic, we will look at the laboratory and consider how research questions are framed. We have come a long way from the end of the nineteenth century, and the scientific claims of the biological inferiority of women and certain races (Reis, 2009). However, the assumption that there are binary biological differences underlining the categories of man and woman still inform research questions in different branches of biological research disciplines. On one hand this contributes to a naturalization of social gender differences, on the other, this contributes to the gendering of biological components that participate in the formation of the gendered body.

The twentieth century has encouraged the conceptual and practical separation of the terms, sex and gender, so as to have better tools to address what are considered biological factors versus social factors. The biological construction of sex has delved deeper into the body, beyond the mere genitals, to expose not only reproductive organs and gonads, but molecular components such as hormones, chromosomes and genes. Since the scientific "discovery" of the sex chromosomes, XY and XX have become quickly adopted as canonic markers of biological sex, while at the same time it has been conceded that biological sex does not produce uniform gender identity or gender behavior. However, it must be also conceded that chromosomal sex does not produce uniform biological sex. The premise is that sex as a binary notion is a factor of the social interpretation of the reproductive system. In this chapter we will be looking at some of the components of the biological construction of sex, such as hormones and molecular genetics.

Before we address the specifics of laboratory research and clinical practice that have contributed to the landscape of biological sex, it is important to note that even biological sex has both identity-related, form components and otherwise considered, functional components. The form components refer to the processes with which the body is formed, or rather the material of the body, that create aspects that are linked to gender performance such as genitals and reproductive organs. The functional components are related to reproductive processes, but also, the elimination of bodily waste and as we shall see throughout the chapters, to non-gendered physiological processes such as cardiac health and bone density.

For our purposes in this chapter we will be addressing mainly biological paradigms related to form, as this is what medicalization of the gendered body has primarily focused on. To do this we will be first looking at the development of endocrinology and molecular genetics, primarily in the laboratory.

The second section of this thesis, chapters four, five, six and seven, focus on patient groups and clinical practice. Those chapters highlight the interesting struggle of the patient groups for useful medicalization. By useful medicalization, we mean therapy that treats the disturbances presented by the patient that are in the sphere of the functional components, as opposed to normalization of identity or form related aspects. The patient groups themselves are increasingly interested in hormones and genetics. However, in this chapter we will be looking primarily at the biological theory that comes before medicalization.

In order to approach the daunting task of dissecting what is meant by biological sex, we find ourselves searching for the locus of identity, or the locus of sex. In order to do this, we must temporarily put to the side musing on what "actually" makes a man or a woman in any given historical culture. What, instead, is the biological component that is considered to "really" define sex? In a reductionist model one points initially to the sex chromosomes. The contemporary phenomenon of DSD syndromes is described as a deviance from XX-female and XY-male development.

However, the sex chromosomes were only discovered in the beginning of the twentieth century and are therefore not applicable to the long history of the regulation of the "deviant" gendered body. The sex chromosomes provide a causal framework for all of the other biological components of sex that had been up for discussion for centuries. The reductionist chromosome model of sex, however, breaks down in two directions, the past and the present. Looking at past knowledge, we would have to ignore the sex chromosomes that had not yet been discovered, and consider all of the biological components that contribute to the gendered body, regardless of whether they are considered to be caused by the sex chromosomes.

Looking instead at the present state of knowledge, more and more molecular anomalies, or genetic markers, are discovered that direct development in the various biological processes related to sex, complicating the one-to-one model of chromosomal sex.

So where is the biological locus of sex? Frank Lillie, a pioneering hormone researcher referred to biological sex as merely a name for our total impression of the differences in male and female bodies (Rechter 1997 pg 121). This is certainly true on a taxonomical level, but can it be true when referring to reproductive processes? This begs the question of how important reproductive processes are to our consideration of biological sex. Reproductive sex certainly is a crucial element in defining biological sex, however sterility does not negate other gendered biological components of the gendered body. No one would say a sterile man or woman is no longer a part of those gender categories. Let's try to break down roughly what are the biological elements that contribute to our overall impression of the gendered body and assess their relegated importance to the locus of sex.

Starting with the elements considered to be gendered, that is, either male or female, before the sixteenth century we have the genitals (although often considered to be of the same material and function); certain reproductive organs such as the womb; certain secondary sex characteristics such as facial hair and body fat/ muscle ratio; and heat and humoral property. The gonads were “discovered” to have gendered properties in the eighteenth century and through the twentieth century the reproductive ducts, hormones, chromosomes, certain physiological processes such as bone density and genetic markers were given gendered attributes. The end result of contemporary biological properties of the gendered body can seem to follow a directional model similar to Watson and Crick's Central Dogma of genetic expression.

In contemporary biological models of sex there is debate and controversy over the developmental pathways of biological sex, and the locus of sex (that is: the factors that are considered to be most important in swaying the gendered body to develop in one way or another).

However the pieces of the puzzle of biological sex have been generally agreed upon: from chromosomes; to molecular genetic markers; reproductive ducts (Wolffian and Mullerian); gonads; hormones; reproductive organs (function); genitals (form and function); puberty (secondary hormonal flux); reproductive functions (including but not limited to seed production, insemination, gestation); and secondary sex characteristics (hair growth patterns, fat/muscle ratio, mammary growth, voice, etc…).

The twentieth century has also seen the development of visualization technologies that

have assisted the creation of these complex biological theories. Whereas at the end of the nineteenth century, hundreds of theories of sexual differentiation could be documented, by the 1920's all theories would take into account the well-documented sex chromosomes and sex hormones (Maienschein, 1984 pg. 457).

Jane Maienschein addresses how the three main research approaches of the 19th century, which she identifies as externalists, internalists and hereditarians were to some extent absorbed into the dominant genetics program as specialties, all having fundamentally different research questions at the center of their interests, from external environmental factors to cellular environmental factors to molecular factors (Maienschein, 1984 pg. 458, 480). The unit of heredity, the gene, became a central factor in the consideration of development, while what is still much discussed is how important a role other biological factors play in sex differentiation.

So, returning to our previous list of biological factors, where is the biological locus of sex? As we have seen earlier, the "sex chromosomes" seem the first candidate. But this is precisely what DSD syndromes belie. The sex chromosome will not correspond to assumed gendered aspects of the body in a larger portion of the human population than that which has blue eyes. These biological variations will be shuffled into one of the DSD syndrome categories. Therefore, sex chromosomes cannot be relied upon as the biological locus of sex.

One might want to instead point to the genitals, and for centuries this was probably the primary physical marker of sex. But this too does not necessarily correspond with contemporary biological understanding of sex. It does, however, indicate one of the primary biological sites to be manipulated in either cases of biological variance such as in DSD or social variance such as in the case of Transgenderism. The action and attention of surgeons to the form of the genitals belies beliefs about the social functions of the genitals. Eric Plemmons indicates how in the discourse surrounding genital surgery, form is often privileged over functional issues[7].

For different reasons, authors such as Dreger and Sengoopta point to the rise of the gonadal model: Dreger in direct reference to the development of pseudo-hermaphrodite categories, and Sengoopta in reference to the discipline of gynecology. Sengoopta cites Rudolf Virchow as he addresses the conference of the Berlin Society of Obstetrics in 1848:

> The female is female because of her reproductive glands. All her characteristics of body and mind, of nutrition and nervous activity, the sweet delicacy and roundedness of limbs ... the

[7] Discussions with Eric Plemmons, UC Berkeley Doctoral Student

development of the breasts and non-development of the vocal organ, the beauties of her hair and the soft down on her body, those depths of feeling, that unerring intuition, that gentleness, devotion and loyalty — in short, all that we respect and admire as truly feminine, are dependent on the ovaries. Take the ovaries away and we get the repulsive, coarsely formed, large-boned, moustached, deep-voiced, flat-breasted, resentful and egoistic virago (Mannweib in Sengoopta 2000 pg.4).

Virchow is not addressing the primacy of reproductive functions in defining gender, but the presumed role gendered anatomy has on "innate" female characteristics. It seems important to note that women were not allowed to study the new discipline of obstetrics in most countries in 1848, therefore did not appear in the audience of this lecture, yet were still allowed to practice the non-certified profession of midwifery.

The hormones will provide a causal model that will link the gonads to not only gendered behavior, but also the secondary sex characteristics. We cannot consider hormonal levels to be in and of themselves the locus of sex either. Is the biological model of sex the total impression of the differences in male and female bodies as Lillie believed? By taking a closer look at biological research questions, we can unravel some of the binary boundaries implicate in biological and social discourse. Binary boundaries between nature/culture, man/woman and even the lab and the clinic represent symbolic boundaries within systems of knowledge and practice. In fact, the history of knowledge has shifted the locus of sex all over the body.

Therefore, let us take a closer look at the biological models of some of these differences, especially those that claim central roles, such as the chromosomes, the gonads and hormones.

1.2 *Chromosomal Sex and Molecular Variation*

In high school biology, we are taught that the XX chromosomes indicate a female individual and XY a male. We are told that the maternal egg contributes an X and the paternal sperm contributes either an X or a Y, which then decides the sex of the developing tissue. Chromosomes are our first stop in investigating the biological platform of the gendered body, and we are immediately transported from contemporary science to ancient Greek philosophical theories about the gendered body, which translates female as passive and male as active.

The sex chromosomes were conceived to be the physical site of the units of heredity, the genes. In the 1920's, as research developed on hormones, researches asked themselves how chromosomes contributed to the formation of the gendered body. However, they continued to use the Aristotelian model of active male formation. Ingrid Holmes indicates:

> …in the early years of the 20th century mammalian and avian sex determination and development was seen as determined by the presence of the testes. As a result researchers interested in sex prioritised the inheritance factors that were linked to testis formation. In 1927 the Danish geneticist Øyvin Winge proposed that there existed a 'testis determining factor' on the Y-chromosome, which was linked to the development of the male phenotype (Holmes 2007 pg. 152).

The research question in molecular development research up until the 1990's was "how is the male fetus formed?" or "what is the testis determining factor?".

Evelyn Fox Keller (2002) indicates that from the beginning of the twentieth century the study of inheritance split into two separate studies, genetics (transmission/inheritance) and embryology (development). Historians such as Garland E. Allen (in Ankeny and Parker pp. 11-13) maintain that many contemporary uses of the term "gene" in both scientific and lay usage mirror many of the same connotations and implications of the original Mendelian concept. He links this to the attempt to redefine biology as a "hard" experimentally-based science and the adherence to a philosophy of mechanistic materialism in the development of the discipline itself.

Peter Portin divides the history of genetics into three periods.

1. the period of the 'classical gene,' based on Mendel's original … (1900-1930);
2. the period of the biochemical or developmental gene… (1930-1955); and
3. the period of molecular genetics, beginning with the discovery of the structure of DNA and continuing through the Human Genome Project (HGP) …concerned with the molecular structure of the gene and its functioning in the transcription and translation (1955-present) (Portin, 1993)

One could add a fourth period of Evo-Devo (Evolution-Development) and Epigenetics (environmentally influenced), both of which re-shift the focus of genetic study to embryonic development, and the impact of internal and external environment factors (such as environmental changes) on gene expression (Allen in Ankeny and Parker 2002).

In the era that Mendel's research was rediscovered, we see biology shift from a descriptive discipline that is concerned with comparative anatomy and taxonomy to an experimentally based science. At the same time, there was the paradigm shift from evolution by special creation to Darwin's theories of natural selection. Allen maintains that the shift toward experimental biology was facilitated by younger researchers' interests in embryological differentiation and development (Allen in Ankeny and Parker, 2002, pp. 15-17).

Yet he also maintains that this attempt to remodel biology as a "hard" experimental discipline was modeled not after the experimental physics of the early twentieth century, but after the classical positivist model that was canonized, at the time, in textbooks. He states that

this encouraged adherence to an atomistic, mechanistic model as opposed to a holistic model. He defines these new trends in biology, especially in the United States, through a summary of mechanistic materialism in which; 1. Parts are distinct from the whole, 2. The whole must be studied through a break down of its parts, 3. There are no "emergent" properties in the whole that come from the association of its parts, and 4. Systems change over time only due to external factors. He sums it up by stating: "Finally, the mechanistic worldview is basically atomistic, viewing phenomena in terms of a mosaic of separate, interacting, but ultimately independent parts" (Allen in Ankeny and Parker, 2002, pp.16-17).

In 1911 Johannsen introduced the analytic separation of genotype and phenotype, which as we have seen is at the crux of defining gender in intersex cases. Although criticized as an oversimplification, this model provided a rigorous basis to evolutionary theory. Allen points out the imbedded contradictions in the paradigm by stating:

> …that embryologists have know for virtually a century that development is not a mere unfolding of invariant form.
>
> …the Mendelian paradigm involved raising a variety of genotypes under the same, or controlled environmental conditions but did not consider it necessary to do the converse-…This "oversight" would seem to be no accident, but rather the result of a strong commitment to the mechanistic view of the gene as a stable unit (like the chemist's atom) that invariably produces the same effect regardless of conditions (Allen in Ankeny and Parker, 2002, pp 34-35).

Other historians such as Douglas Allchin, Manfred D. Laubichler, Sahotra Sarkar among others have addressed how the development of terms such as "dominance", "penetrance" and "expressivity" seek to reconcile the mechanistic materialist model with the variance in actual genetic expression, or the phenotype.

Allen states that the mechanistic model paralleled the economic needs of the time, especially within the capitalistic agricultural model of the United States. Breeding new strains, following the capitalistic paradigm of market expansion, became the new frontier of agricultural profit. This helped to focus research on genes and heredity instead of development. Holmes indicates the continuation of the mechanistic model within the shift to the 'molecular' phase of genetics.

> The 'molecular' phase of genetic research was initiated by the 'discovery' of the structure of DNA in 1953 (Watson and Crick 1953). The structure of DNA gave rise to the idea that there was a one to one relationship between the gene (DNA sequence) and protein (amino acid sequence). This, Rheinberger argues, brought about molecular genetics which "transformed its boundary

object, the gene, into a material, physiochemical entity" which was given "informational qualities" (Rheinberger 2000, p.221). The particular view of genes located at definable positions on the chromosomes led researchers to use linkage and physical mapping as a research technology to locate the two genes. This discussion highlights that as with other genes, the technology used to 'locate' the genes led to the view that there was an actual physical DNA sequence identifiable as a gene 'for' the specific phenotype of interest (Holmes 2007 pg. 155).

Dominant medical theory selectively adheres to the gene "for" model. The Y chromosome contains a gene, the SRY, which was believed to suppress Mullerian structures and female internal development, allowing for the creation of Wolffian structures and male development (Thomas, 2006)[8]. In this model female development is still seen as the default, while male development requires active intervention on the molecular and hormonal level.

It was observed that up until 7 weeks of gestation, the fetus appears to develop female characteristics. However at 7 weeks the fetus will have only started the formation of Mullerian structures associated with female reproductive development. Are Mullerian structures then to be taken as the locus of biological sex? After 7 weeks the Mullerian structures will either continue developing or transform into Wolffian structures, thereby marking the beginning of a sexual differentiation process. The transformation into Wolffian structures is often described as the deterioration of the Mullerian structures. Both Wolffian and Mullerian structures provide the material that will develop into the reproductive ducts, both requiring transformation as part of the developmental process.

There are three ways to interpret this data: 1. The fetus has no gender until 7 weeks, 2. All humans have some "female" structures until 7 weeks, or 3. The default human model is female and the male model requires action and special work to form.

The dominant interpretation of this contemporary data has been the latter, and it is imbued with the Aristotelian value paradigm[9]. This value paradigm privileges active processes over passive ones, transcribing spiritual significance onto action, as the creation of material. The female is seen as the passive, the default, implicitly tied to matter and lacking social value.

Another interpretation of this scientific data says that the fetus has bi-potential until 7 weeks, much like a stem cell is effectively construed as a multi-potential structure. This research investigates multiple factors that contribute to Wolffian processes or Mullerian processes, often with the aim of investigating DSD syndromes. In this model there is less

[8] Consistent explanatory model at DSD medical conferences

[9] Italian and American text books

value emphasis placed on Aristotelian active/passive paradigms. The emphasis is put on divergences from the statistical norm of gendered development.

Authors from Simone De Beauvoir to Judith Butler have explored the implications of the Aristotelian paradigm in naturalizing the image of female gender role as inferior to the male. Butler poses the heterosexual binary as inherently hierarchical, and insists that the search for the gene for sex (like the chromosome for sex) imposed a gender binary on the research question from the start (Butler 1990). Holmes states:

> The search to find this 'gene for' sex spanned close to 65 years in which, I will argue, researchers undertook a process of scientific creation. In similarity with many, if not all, genes the SRY gene was brought into existence through a process of negotiation between societal and scientific forces. While I do not argue against the existence of the DNA sequence found, the portrayal and characterisation of the gene was clearly shaped by social forces, as not only are scientists members of society who hold social goals and values, but they also exist within a social community of researchers. Nonetheless, with the announcement that the SRY gene had been located in 1990 it seemed as if the gene for sex had been defined. Its place as the 'master gene' for sex was further secured by the creation of an XX male transgenic mouse in 1991 (Holmes 2007 pg. 100).

Research in the 1990's also proposed a new research question, the active process of female differentiation. However, as indicated by Holmes, the genetic markers associated with female development are presented in conjunction with an epi-genetic model. The SRY gene, instead, in the complicated course of its conception, and "discovery" is discussed as a "Testis Determining Factor" and a "master gene for sex". The genes implicated in active female development, such as DAX-1 and WTN4 are instead conceptualized in a "cascade" or interactive model (Nef, 2009; Biason-Lauber, 2006).

> The search for DSS/DAX-1 is similar to that of TDF[10]/SRY in two ways. It was based on a research paradigm which hypothesised its existence, in this case as a dose sensitive site (DSS), prior to the identification of any related DNA. And also the research was based on intersex conditions with ill-defined phenotypes. However it is also different in occurring after the SRY had been crowned the 'master gene' of sex determination and within the knowledge of the wider genomic context. As noted … throughout the 1980s and 90s a few researchers did not follow the standard 'male active development' view of sex determination and sex development. These researchers considered the process of sex development to be multi-factorial, including time and gene dosages. The impact of such genomic factors became increasingly incorporated in the

[10] Testis Determining Factor

construction of DSS/DAX-1.

The meta-analysis that Holmes presents indicates the flux of explanatory models in sex differentiation up until 2005: naming tendencies in research periods as the search for DSS, ACH and DAX-1 (1994-1998); the rise and fall of the female sex determining gene (1998-2002); dynamic patterns of gene expression (2002-2003); and not one, but two genes (2004-2005). Holmes indicates the persistence of the antagonistic sex development model that poses sex determination genes as either negating or antagonising the other, at the same time as research that proposes interactive models. The relationship of DAX-1 to female development was confused by the role it seemed to have to spermatogenesis and therefore, also male development, giving further support to an interactive model.

> While DAX-1 was not considered critical to spermatogenesis, it was understood that its product would be likely to have different impacts depending on the stage of development. This interest in expression profiles led another research group to explore large-scale screening. In an article, simply entitled '*Large-scale screen for genes involved in gonad development',* the researchers found 72 genes which, "may play a role in gonad or sex duct development and /or sex determination" (Wertz and Herrmann 2000, p.51).

However, Holmes indicates that the research question was still often framed as to whether DAX-1 was an "ovarian determining gene" or "pro-testis"/"anti-testis".

The theory of sex antagonism was first utilized as a social theory by figures such as William Blair-Bell[11] (Fausto-Sterling 2000 pg. 158), at the end of the twentieth century, in relation to the effects 'internal secretions' had on masculine and feminine minds and bodies. The internal secretions were then sexed themselves in the 1910's as mutually antagonistic in biological-hormonal theory by British physiologist Walter Heape and Viennese gynaecologist Eugen Steinach (Oudshoorn 1994 pg. 23).

Evelyn Fox-Keller indicates the importance of these metaphors, such as antagonistic or interactive, to creating research questions. Holmes concludes:

> Following Keller's research it is clear that shifts in metaphors can indicate a shift in underlying concepts, and the impact of genomics on the two genes, SRY and DAX-1 was seen in the introduction of new metaphors. During the hunt for the TDF and DSS researchers had used the metaphor of pathways. However as more was known about these genes a new idea was developed, that of the reproductive axis. The change in focus from defining sex in terms of the testes towards the entire reproductive axis also brought new metaphors, specifically of genetic cascades (Holmes

[11] Founder of the London Royal College of Obstetricians and Gynaecologists

2007 pg.166).

Psychologist Vernon Rosario proposes that new metaphors may give way to a concept he calls 'quantum sex'. Rosario points out "there may be thirty-five variations of the WT1 gene (WT1 genotypes), each of which conveys certain statistical odds of particular anatomical and physiological outcomes (phenotypes)" (Rosario in Morland (Ed) 2009, pg. 279). As indicated by epi-genetic research, these genetic markers are increasingly understood as time and environmentally sensitive in their role in sex differentiation. Highlighting the increased attention to genetic markers in DSD treatment, Rosario presents us with a chart of some of the markers involved in diagnosis:

Gene	Chromosomal location	Putative function	Phenotype of mutations
SF-1	**9q33**	**Transcription factor**	**XY gonadal dysgenesis and adrenal insufficiency**
WT-1	**11p13**	**Transcription factor**	**Denys-Drash and Frasier syndromes**
SRY	**Yp11.3**	**Transcription factor**	**Feminized XY and gonadal dysgenesis**
DAX1	**Xp21.3**	**Transcription factor**	**Duplication: XY gonadal dysgenesis Mutation: adrenal hypoplasia congenital**[12]
SOX9	**17q24**	**Transcription factor**	**Duplication: masculinizied XX Mutation: campomelic dysplasia with XY gonadal dysgenesis**
M33	**17q25**	**Transcription factor**	**Feminized XY**
Fgf9	**13q11-13**	**Signaling molecule**	**Feminized XY and gonadal dysgenesis**
DMRT1	**9p24.3**	**Transcription factor**	**Deletion: feminized XY, gonadal dysgenesis, microcephaly, mental retardation**
AMH	**19p13**	**Signaling molecule**	**XY persistent Mullerian duct derivatives**
DHH	**12q13.1**	**Signaling molecule**	**Mutation: XY gonadal dysgenesis with neuropathy**
ATRX	**Xq13**	**Helicase**	**Feminized XY, mental retardation, α-thalassemia**
WNT-4	**1p35**	**Signaling molecule**	**Duplication: XY gonadal dysgenesis Mutation: masculinizied XX**
Gdf9	**5p11**	**Signaling molecule**	**Ovarian follicular failure**

[12] Frequency/International: Congenital adrenal hypoplasia is rare. Although the frequency has been estimated in Japan at 1 case per 12,500 births, clinical experience indicates that this disease is not as common as congenital adrenal hyperplasia due to 21-hydroxylase deficiency (incidence is approximately 1 per 10,000-15,000 births worldwide). Mortality/Morbidity: Congenital adrenal hypoplasia is a lethal disease unless promptly recognized and appropriately treated. With proper medical treatment, patients do well unless they are also affected with Duchenne muscular dystrophy. Glycerol kinase deficiency, if present, does not result in morbidity but results in hyperglycerolemia. This may be recognized by factitiously elevated serum triglyceride concentrations. Thomas A Wilson, MD, Professor of Clinical Pediatrics http://emedicine.medscape.com/article/918967-overview

FOXL2	**3q23**	**Transcription factor**	**Premature ovarian failure and eyelid defects**

(Rosario in Morland (Ed) 2009 pg. 275)[13]

We may asks ourselves why a psychologist has developed such an intricate knowledge of genetic research, however, the answer is simply embedded in DSD treatment. The psychologist has the institutional role of helping the patient navigate not only diagnosis definition and external perception, but also the aftereffects of invasive and stigmatizing treatment. Rosario introduces the story of one of his patients who presents a WT-1 mutation with XY chromosomes, clitoral reduction and gonadectomy, a female gender identity and female sexual orientation.

> At age three-and-a-half her kidneys failed, and within a year she required cadaveric kidney transplant. As a teenager she was placed on "female" hormones (Premarin and Provera), in addition to the immunosuppressant medications required to sustain her transplant.
>
> It was only at fifteen that she learned of her underlying diagnosis. Unfortunately her mother had revealed this during a fight after discovering love letters for a girl to Helen. Maybe she liked girls her mother blurted out, because she had been born a boy! (Rosario in Morland (Ed) 2009 pg. 269)

Rosario's patient, Helen, did not betray gender identity issues, while her mother certainly did. However, it would be difficult to reconstruct the information the mother had been given about Helen's condition. At the same time, it is also evident that the anxiety, on the part of the mother, about gender identity is provoked by the fear of homosexual behavior. Rosario addresses identity as a multiple object, informed by biology and experience.

> Helen's experience of her sex, gender and sexuality is intimately tied to her sense of her body-to what is evident on the surface, to what she understands to be her internal anatomy, to her lost genital and gonadal flesh, and to her genetic make-up…she will have to construct for herself a new experience of her body that allows for sexual intimacy, erotic pleasure, and a fulfilling relationship with women, men or both (Rosario in Morland (Ed) 2009 pg. 280).

Molecular variation adds another factor to both individual identity and biological constructs. Individuals who are diagnosed with DSD are bombarded with added external perceptions, and external interpretations. As we will see in chapter seven, the molecular marker sometimes supplants the chromosomes in the deterministic model of sex.

[13] Adaptation of multiple medical charts put together

The human species is extremely varied, and XX individuals are not always biologically female or XY individuals biologically male. While any of these divergences are put into the DSD category, as disorders, what is meant is that the gendered development of these individuals deviates from a statistical norm. These divergences do not necessarily indicate potential health problems or psych-social syndromes such as gender dysphoria[14]. Most individuals who fall into the DSD category have consistent gender identities, but may suffer from the stigma of the medical treatment they receive in childhood.

So what is biological sex then, if not chromosomes and genes? And how is it related to gender identity? (Jabolonka and Lamb, 2005). In the neo-Mendelian model, as we have seen, one gene determines one trait, therefore the genotype directly codes for the phenotype. This model was embraced by Watson and Crick, famous for "co-discovering" the double helix chromosomal form and but also for establishing the Central Dogma of genetics which states that development is unidirectional and mechanistic. In this simplistic model, DNA creates RNA which creates protein, and then, the organism itself.

Following this central dogma, it should follow that an XY chromosome will always produce a body with all the physical components which are associated with the male body: Wolffian structures, testicles, testosterone, penile structures with an urethra that exits at the tip, facial hair, lower fat to muscle ratio, not to mention all of the behavioral components that are associated with maleness. A direct link between XY chromosomes and male identity or behavior is certainly not always the case, and neither is the direct link between XY chromosomes and the development of a "male" body with all of the previously mentioned components. It now seems there is also not a direct link between molecular markers and binary development.

One of the primary problems with the binary sex model is that it also attributes binary sex to all of the aforementioned biological components, which create what Lillie referred to as our overall impression of the differences between men and women. Developmental models and epi-genetics address this discrepancy between what is considered the genotype, the genetic material and the phenotype, referring not just to how a body looks, but also to its functional components (Jabolonka and Lamb, 2005). Epi-genetics departs from the mechanistic model

[14] Gender dysphoria is a medicalized term for transgenderism, individuals who live a different gender role than the one assigned them at birth. The medicalization of said gender dysphoria allows people to access medical resources such as hormone replacement therapy, but unfortunately stigmatizes Transgender experiences as a mental disease category for people who are not mentally ill.

primarily in that biological components are not seen as separate from the whole as in the Central Dogma[15] (Allen 2004). In these newer biological models the development of the body is seen to be highly influenced by the functions and processes of development, not just genetic material. Epi-genetics draws on early Drosophila fly experiments that showed how flies would be born with different eye color and different wing types based on the environmental factors such as heat or humidity in which they were conceived (Ankeny and Parker, 2002).

One of the important factors of this research for our interest in the gendered body is that the experiments produced flies that showed how varied the results of genetic material can be, without producing non-functional or impaired bodies. The language of genetic illness relies on predictive diagnosis, which relates biological variation to functional problems relying on a statistical measure. Variations in the biological manifestation of the gendered body as is the case of DSD are believed to be 1 in 2000 people (Dreger 1999). This statistic continues to increase based on increased knowledge (and increased genetic testing that reveals molecular variation) about the body that expands our knowledge of physical variance.

DSD are often considered medical emergencies when they manifest what are considered either "ambiguous" genitals or genitals that don't conform with the assigned gender. Genital appearance is intensely private but also highly relevant to how we think about the gendered body. The surgical manipulation of children's genitals to conform to social expectations is still a highly contested part of DSD treatment.

Generally when talking about DSD we are not talking about bodies that have functional problems, but bodies that are different in their gendered components. Genetic technology has "discovered" many more of these differences that don't fall in the realm of the social anxiety provoked by the genitals. As genetic testing increases, however, certain biological systems failures, particularly of the kidney, can be associated with variances in genetic markers related to sexual differentiation. If these syndromes are inserted into the DSD paradigm, the medical category will grow even further.

In Italy the two most visible patient groups deal with two syndromes that have less to do with genitals and more to do with hormones and genetics. Androgen Insensitivity Syndrome (AIS/Morris' syndrome) and Klinefelter's syndrome were both "discovered" in the 40's (Caffaratto 1963). Without the chromosomic information, many of the people with these

[15] The central dogma of molecular biology deals with the detailed residue-by-residue transfer of sequential information. It states that information cannot be transferred back from protein to either protein or nucleic acid. (Crick 1958; 1970)

diagnoses would not have any idea that they were different from any other man or woman. The main functional problem they experience is sterility. However, the gendered body is made up of many different biological components besides just its reproductive capabilities.

AIS is a syndrome in which the XY chromosomes do not produce a male person. As the body develops, Wolffian structures and "male" gonads form internally, while externally "female" genitals and secondary sex characteristics develop. Clinically it seems that 1 in 120,000 people have AIS (Blackless 2000), although it also seems possible that there are many more who have not been diagnosed. Testicles are differentiated from ovaries through the function they perform in reproduction and their tissue differences. However having "male" gonads does not make a person a man, especially when other female biological components are present. When doctors discover AIS they often recommend the removal of the gonads, claiming they want to avoid identity problems in the woman diagnosed.

However, the identity problems reported by patients are based on the language the doctors choose[16]. If the doctor believes chromosomes dictate sex and gender, the doctor might tell the patient they are biologically or genetically a man, but physically a woman. However, as we have seen, chromosomal material is not the primary determining factor in the gendered biological body. The gendered body has may different components from gonads to genitals to timbre of the voice. The vast majority of people with AIS have female gender identities, while some XX individuals raised as women do not.

In Klinefelter's syndrome individuals have three sex chromosomes, XXY, with the primary symptom being infertility. There are certain mutations that can have cognitive developmental issues. However, with the increase of genetic testing, Klinefelter's syndrome is now estimated to result at 1 in 700 people, increasing the amount of cases that do *not* have symptoms that disturb the person diagnosed. The Klinefelter body has been seen as feminine, with breast growth, or with an increased body fat/muscle ratio. Doctors recommend hormone replacement therapy, that does not affect cognitive development or sterility, but that can masculinize the appearance of the body and affect mood and behavior. We will talk more about this aspect in the next section on hormones.

Klinefelter's syndrome reveals how common genetic variety can be, but specifically it also reveals that this variety in the biological gender generally still produces a healthy body. The variety in the physical manifestation of gender becomes a problem when it is measured against an idealized norm of the gendered body. There are still not very much data about other

[16] Interviews with patients

health aspects related to Klinefelter's syndrome that are not in some way related to gendered expectations.

Genes are no longer seen as Mendelian discrete entities, but they have been given material structure, at first simplistic, now interactive. Allen summarizes the co-existence of the "classical" mechanistic model with new theory:

> Today, we have ample evidence for the actual interaction of genes and gene products, various "genes" or DNA segments coding for several domains of a single protein (Portin, 1993, p.207), along with a variety of regulatory mechanisms, so that an understanding of how genotype may be transformed into phenotype appears more attainable than at any time in the past.
>
> However, the old mechanistic materialist notions of the gene still persist in a variety of ways in both the professional scientific, and especially popular, literature about heredity. And nowhere is this more prominent, and perhaps more dangerous, than in research on the genetics of human behavior and personality traits that has increased in frequency and boldness of assertion on the coattails of the Human Genome Project (HGP) (Allen in Ankeny and Parker).

In DSD research the determining function of the sex chromosomes is believed to be de-classed by the influences of genetic markers. Disability theory claims that it is the interpretation given by the social environment as negative, that then marks these divergences from the norm as disabilities, problematic medical categories. Not all DSD syndromes have a corresponding genetic marker, but it is increasingly believed that the divergence from chromosomal sex is to be found in molecular markers. It is still too early to see where molecular research will place the locus of biological gender. We can instead look further up in the chain of development from chromosomes to molecular markers to Mullerian and Wolffian structures to the gonads and hormones.

1.3 *Bi-sexual gonads and heterosexual hormones*

The "discovery" of gender difference in the gonads is perhaps a crucial historical moment in the study of the development of the gendered body. Laqueur states that it wasn't until the mid eighteenth century in Europe that term "testicle" came to mean only the male organ, no longer qualified as male or female testicles, or stones (Laqueur 1990 pg 161). The manipulation and study of the gonads in the nineteenth century eventually lead to the "discovery" of hormones as chemical reactions, and therefore the establishment of a new physiological paradigm. Up until the twentieth century, however, it was believed that the nervous system regulated body functions, not chemicals such as hormones transported through the circulatory system.

Following Fox-Keller's theories on scientific paradigms, historian Merriley Borell states:

> Until specific physiological responses were identified as needing explanation by other than nervous causation, physiologists simply did not realize that chemicals were capable of provoking physiological events in the same manner as nervous stimuli (Borell Merriley 1985 pg. 10).

The gonads represent the first palpable member of internal biological sex. Through minimally invasive techniques, doctors could feel around in the body for the gonads and, in some cases, examine the gonadal tissue and determine if it was a testicle or an ovary[17]. This shifted the medical gaze from external characteristics such as the genitals and body form to an internal force directly related to reproduction. The gonads that had been primarily associated with aforementioned reproductive functions moved into a central position in the biological construction of sex.

Medvei argues in his *History of Clinical Endocrinology* that the relationship of the testicles to reproduction and sexuality was well known since antiquity (Medvei, 1982 pg 43). The varying cultural roles of eunuchs throughout the centuries indicate a complex understanding of the effects of gonadal removal. Medvei points out that despite the high status of eunuchs in different cultural periods, stigmatization of sterility was the more common social more, highlighting the social link between gonads and personhood. While this knowledge was put into use in animal husbandry, much of functional speculation about gonadal function came through experimental evidence of damaged gonads (as in early cognitive/brain region research). It was not until Berthold's experiments in 1849, in which he reinserted gonads back into the bodies of castrated chickens, that one could begin to speculate on what the gonads actively do (Medvei, 1982; Dreger 1998).

For much of the eighteenth and nineteenth century, the gendered gonads floated in limbo, their specific internal processes still relatively unknown. In this period, after it was decided that the gonads were bi-sexual, that is, belonged to one of two gender categories, experiments focused on reproductive behavior. Reproductive behavior refers to the practices and actions that a given animal goes through in the act of mating, not the internal processes involved in fecundation and gestation. However, Berthold's experiments showed that gonadal removal and replacement affected not only reproductive capacity and mating behavior, but also bodily form.

Berthold's chickens showed gendered differences in what are now considered secondary sex characteristics, which are primarily esthetic non-functional markers of the gendered body.

[17] First surgical procedure for sex determination

In the case of chickens what humans observe are based on the waddle and the crest. Obviously what humans observe in each other as secondary sex characteristics is much more complex. Gendered physical traits such as body hair and fat/muscle mass ratio vary enormously in the human species, requiring different social groups to develop esthetic gendered coding systems that may require reinforcement through clothing, make-up, plastic surgery etc.

Whereas secondary sex characteristics continued to have social significance in clinical sex determination, laboratory experiments attempted to unravel how the gonads acted on the material of the body. Historians such as Victor Cornelius Medvei focus on the testicles as the key to early endocrinological experimentation. The twentieth century has witnessed an extreme switch in which the female reproductive system is highly medicalized, while andrology has made few advances from the nineteenth century premise. However, in the nineteenth century the male testicle was a new site for therapeutic promise.

Early research into sex hormones focused on what is considered a positive trait of the male domain; sex drive. Charles-Edouard Brown-Sequard was initially ridiculed in 1889 when he addressed the Société de Biologie stating that he had injected himself with animal testicles as an experimental therapy to renew vigor and mental clarity (Oudshoorn 1994 pg 18). However, soon afterward there was a rash of therapies and treatments that treated mostly men, but also women, with gonadal mixtures. These mixtures claimed rejuvenation properties in a manner that linked sexual prowess with energy and intellectual prowess (Oudshoorn 1994; Sengoopta 2000).

Despite the astounding evidence in Berthold's experiments, that showed there was something in the gonadal material that could manipulate the material of the gendered body, the clinical application of gonadal research focused on a performative concept of maleness, high sex drive and energy. Gonadal therapy sought for the most part to treat what can be considered Andropause in aging men. The most extreme example of these therapies is seen in the work of Serge Voronoff, who established a farm in the Italian Riviera, where he raised monkeys for their testicles (Hamilton 1986).

Voronoff experimented with organotherapy primarily for male rejuvenation, along the same theoretical lines as the modern day viagra, that sexual vitality is linked to vitality in general. However, he made many other theoretical associations that formed part of the dominant model of gendered biology at the time, such as a connection between biology and sexual orientation. He claimed to have cured several patients of homosexuality by means of testicular implants, based on the inversion theory of homosexuality that overlapped categories

of sexual orientation, gender identity and behavior. He also linked the gonads to "dementia praecox", the mental illness known today as schizophrenia, based on the assumption that the gonads and aging were interlinked (Hamilton 1986).

Voronoff fell into disrepute, after having performing hundreds of testicle implant surgeries throughout the 20s. It is important to note that Voronoff was first applauded by the international congress of surgeons in 1923, before falling out of favor by the 40s. Voronoff's work was dismissed as unscientific, for failing to experimentally establish results, occurring at the same time as the chemical structure of hormones were instead isolated in laboratory research. Voronoff himself believed that eventually the active property of the gonads would be isolated and be applied to therapy in a simpler manner. The social theories that linked testicles to male domain behaviors such as physical energy/rowdiness, high sex drive (hetero-sexual orientation) and intellectual achievement did not instead fall into disrepute, but were simply attached to the hormone model.

Eventually, the chemical structure of hormones was identified and gonads were no longer a causal material in themselves, but a secreting organ working in the endocrine system. The experiments from Brown-Sequard to Voronoff in gonadal organotherapy, combined with discoveries and experiments with adrenal and thyroid extracts, lead back to the speculation that these glands produced internal secretions, a term coined by Sharpey-Schaefer (Medvei 1982 pg 159). The conceptual model of glands and secretions that would make up the endocrine paradigm indicates an interactive model, in fact referred to as the endocrine system. Developmental models sought to represent the interactions of the different glands, however, the gonads often remained isolated to sexual function.

Dreger links the rise of modern medicalization of DSD to the establishment of Kleb's 1876 gonadal model of “True” sex that we will see in the next chapter. In Kleb's model, that was widely applied until Money's model in the 1950s, the gonads achieved primacy in indicating the biological sex of the individual.

> In late nineteenth century biomedical texts on sex differences, reproductive difference was most often cited as *the* fundamental difference between Man and Woman, the thing that was in turn the source of all their other difference (Dreger 1998 pg151).

This link between gonads, reproduction and gender will be impossible to remove from the hormonal model that followed, despite the systemic model of endocrine function. At the end of the nineteenth century science was itching to delve further into the body. The biological model was shifting, but technical practice could not yet investigate the functional tissue of a

live body. Following Klebs model that aligned all bodies into male or female categories based on gonadal material, British researchers Blacker and Lawrence used Kleb's model in 1896 to analyze and dismiss past cases of alleged hermaphroditism using gonadal material[18]. Their case studies show no data about the individual, only slides of the gonadal tissue make up (Dreger 1998 pg. 148). Scientific affirmation about the Hermaphroditic body often focused on posthumous information. Dreger points out that this "truth", represented by gonadal material, was still invisible in the live patient.

While Berthold's experiments indicated the morphological potential of gonadal material that would soon be understood as hormonal, disciplinary boundaries sent laboratory interest in different directions. Dreger is quick to point out not only that functionality was not the research focus,

> Indeed, in 1896 Blacker and Lawrence had made it absolutely clear that they were unconcerned with functionality, writing that true hermaphroditism was to be "taken to mean merely the presence of different genital glands in one individual, without reference to the presence or absence of their functional activity."

But also that biological variation in the gendered body confused the internal secretion model.

> Moreover, hermaphroditism seemed to defy the very core of internal secretion theory, because some spurious hermaphrodites with testicles displayed entirely female secondary sex-characteristics, and vice versa (Dreger 1998 pg 152).

At the same time that gonads were being implanted in men, gynecology was about to see the controversial rash of ovary removal that spanned from the 1890s to the 1910s. Sengoopta attributes the rise of the procedure to Edourdo Porro's[19] expanded caesarean section, which included the removal of the uterus and ovaries in 1876 (Sengoopta 2000 pg 435). The expanded caesarean had the initial purpose of preventing future pregnancies, however, women with osteomalacia were often seen to improve after the procedure. The technique was adopted as a cure not only for osteomalacia, but also breast cancer, hysteria and other female behavioral disturbances.

They were confusing times. A woman was a woman because of her ovaries and their

[18] Kleb's model is also present in Taruffi 1898 (Professor of pathological anatomy, University of Bologna)

[19] Porro also investigated the hermaphroditic body

reproductive functions, yet she was often better without them. A man, on the other hand, might need an extra set of gonads to boost his "natural" inclinations. In charting the history of the ovary Sengoopta points out:

> Schäfer's own career attested to this momentous transformation: in 1895 he had remarked that the gonads exerted their influence on the body "without doubt ... through the nervous system" but in 1907 he considered it "highly probable that it is to internal secretions containing special hormones that the essential organs of reproduction — the testicles and the ovaries — owe the influence that they exert on the development of the secondary sexual characters ..." (Sengoopta 2000 pg 425).

In 1880 the gynecologist (and primary advocate of healthy ovary removal) Hegar advocated for a "sex determining-force" that directed the development of the secondary sex characteristics and the gonads, while anatomists were arguing that the gonads were this determining force. While Hegar[20] based his theory on the neural model (Sengoopta 2000 pg 435), his postulation was not far from the model that hormone theory would present in the 1920s. Oudshoorn affirms:

> The acceptance of the hormonal theory in the biological sciences was facilitated by the fact that it fitted into a major debate among biologists about the sexual development of organisms. In the 1910s, the topic of sexual development was controversial, particularly between physiologists and geneticists. Physiologists at that time suggested that the determination of sexual characteristics is affected by environmental and physiological conditions during the development of the embryo. Geneticists suggested however that sex is irrevocably fixed at conception by nuclear elements, the sex chromosomes.
>
> With the introduction of the concept of sex hormones, sex endocrinologists claimed they had found the missing link between the genetic and the physiological models of sex determination (Oudshoorn 1994 pg. 21).

In the 1920s the chemical structure of certain hormones was identified, and the search for the source to mass-produce them began. The first striking discovery was that large quantities of oestrogenic hormone (estrogen) were found not only in pregnant mares (but not in non-pregnant females) but also in stallions. Estrogens and progesterons were thought to be directly linked to the female reproductive process, therefore there was no good explanation for its appearance in male horse urine (Oudshoorn 1994 pg 25; Gaudillière 2008). In the 30s "male" hormones were also found in female animals. So strong were the beliefs that hormones were

[20] Hegar lost 1/3 of his surgical patients to infection, indicating his concern for his patients well being Laqueur 1990 pg 181

gendered that researchers began looking for causes outside the body for the presence of "heterosexual" hormones, such as in food sources or environmental factors (Oudshoor 1994; Rechtor 1997).

In the late 1930s, Lillie labs was commissioned by the Rockefeller Foundation to perform a thorough research on hormones and sexuality (meaning reproduction more than behavior) (Rechtor 1997). Part of Frank Lillie's theories were founded on earlier experimental research with freemartins, pairs of calf twins, one XX and one XY, in which the XX calf often developed male and female genitals. This lead him to believe that in complex organisms, sex development is "taken over" by hormonal influences (Oudshoorn 1994 pg 21). However the explosion of hormone research continued to blur the clear link between male and female hormones and their corresponding sex hormones. Hormones were shown to have multiple effects on the body, regardless of gender, on fat ratio, cardiac health, bone density, etc. The Amsterdam school started pushing for a change in terminology that would remove sex and the gendered labels from hormones (Oudshoorn 1994 pg 34; Sengoopta 2006).

Lillie's affirmations about the role of hormones in sex development served to dismantle social affirmations regarding the dual sexed deterministic nature of the gonads. But in the 1930's he now gave the hormones a determining role that was also linked to the brain. Lillie was opposed to de-sexing hormone terminology. Julia Rechter explains Lillie's complicated rationale as a mystical understanding of sex: insidious when applied carelessly (Rechter 1997 pg 121), sex becomes merely a name for our total impression of the differences in the gendered body.

Whereas the early history of hormone research focused on male sexuality and rejuvenation, from the thirties onward the focus turned on the female body, no longer through ovary removal but by hormonal therapies. Pre-Menstrual Syndrome was defined in the thirties and debated in its causes through the fifties. The idea of PMS, however, was never liberated from the early hypothesis of hormonal intoxication and the pre-scientific image of the biologically irrational female. Oudshoorn states that hormones became drugs looking for diseases (Oudshoorn 1994 pg 108), and in fact, female reproduction now has hormonal products for everything from not having babies to increasing fertility.

So what happened to the debate surrounding the gendered nature of hormones and hormonal effects on non-reproductive systems? Well, it remains slightly hidden behind socially influenced conceptions about the gendered body. In the medical clinic one talks about male hormones and female hormones, and theories such as hormonal imprinting, but in practice doctors use experimental data as best they can to help people, which often means

liberating “sex” hormones from their obligation to create absolute male and female bodies.

One highly influential social idea about the gendered body is that behavior, intelligence and the brain have biological gender difference. This is certainly true in part, but not in ways that mean one gender will have behaviors or abilities that the other will not. Following Marcel Mauss’s (1936) theories on techniques of the body, we can contemplate how having different body material, more/less muscle, or more/less body hair, effects of relationship to the world around us. Experience is shaped not just by internal factors in the body, but also by our body in the world, as captured by theories on embodiment. However, in the 70s it was discovered that androgens are converted (aromatised) to estrogens before they interact with brain tissue, (Callard, Petro, Ryan,1978) pulling away from a chemical explanation for cognitive difference. Since then, researchers have proved and disproved gendered brain differences many times over.

The hormonal imprinting theory states that gender identity is formed in-uterus during time-specific hormonal production, yet this too remains theory. As we will see in chapter 6, this has lead to pre-natal hormone treatment of CAH, to block masculinization of the XX mind and body. However, what we will also see is that male stereotyped behavior such as high energy is often confused with male gender identity. If hormonal imprinting were universally plausible, all XX CAH patients would have male gender identities, not the slightly higher probability that manifests. People who have hormone replacement therapy certainly report changes in mood, energy and sexual desire, but rarely changes in cognitive performance or ability, or their own gender identity.

Hormones certainly shift what we consider secondary sex characteristics, the physical traits that we see as male and female. Hormonal therapy can make a person feel and look more like their actual gender identity, however hormonal therapy will not change a person’s idea of who they are. Hormones are instead, catalysts for physical, mood and energy changes. These theories about hormones are put into practice in different arenas. For Transgender people, hormones help adjust their body to fit their identity. The relationship of androgens to mood and depression has been explored in psychology, and androgens have been used to treat depression in women, obviously without the hormones having any effect on their gender identity.

“Male” and “Female” hormones are not only found in all bodies, but are necessary for all bodies. We saw earlier that in Androgen Insensitivity Syndrome, doctors often wanted to remove the patients' gonads, so as not to threaten their gender identity. Unfortunately, patients report disastrous results with having their autonomous hormone production removed,

especially before puberty. As the syndrome name implies, people with this syndrome are insensitive to androgens, however their body still utilizes and needs them, not for reproductive functions, but for all the other processes in which hormones are involved, such as bone density, heart regulation, endocrine regulation, metabolism, mood and energy to name a few. Because these patients are women, they are prescribed female hormone replacement therapy to help their body function. Researchers are increasingly proposing a mix of “male” and “female” hormones, so as to better replicate what bodies actually produce. In some countries, however, woman have a hard time accessing therapies based on “male” hormones, and are forced to use only estrogens and progestrogens.

In Klinefelter's syndrome one can see the physical effects of low testosterone levels. Certain physical traits can seem “softer” and “feminine” based on fat/muscle ratios. It is still unknown what part of the syndrome causes cognitive issues, although it has been localized to be more severe in 2 specific molecular markers. Hormone therapy for Klinefelter's syndrome focuses on the gendered presentation of the body and behavioral components that are considered masculine, such as high energy, assertiveness and high sex drive. The hormone therapy does not affect the person’s gender identity, or sexual orientation, but many individuals express it makes them feel more like themselves.

The expectations of what a female body and a male body are supposed to do and feel like, are based on concepts that adapt social gender roles to biological markers. One of the main targets of hormone therapy in the male body continues to be sex drive and energy, continuing straight from Brown-Sequard's experiments on himself. The object of hormone therapy in the female body ranges from reproductive activity to “chemically induced” mood swings. These expectations of what hormones should do for the biological body are placed on the social body, in a manner that disregards the variety of biological gendered components. Rarely will a woman be advised to take hormone therapy to increase her sex drive, because a high sex drive is not considered a desirable component of femaleness.

Celia Roberts states that hormones came to be seen as messengers of sex, active components that shaped the gendered body (Roberts 2007). The social message that is attached to this concept is that these hormones also shape gendered behavior, identity and sexual orientation. This may be true in some aspects of fetal development, but as we have seen, it is not true in the course of ones life. Oudshoorn points out that this presumed link between reproduction and gendered identity, in turn, causes people to think of hormones themselves as having sex, belonging to either the male or female body. However, while hormones regulate reproduction and influence secondary sex characteristics, they also

perform many important tasks in the body, regardless of their gender or the body's gender.

In this chapter I link the discussion of chromosomal sex to hormonal sex primarily because of the observed link in medical practice. In DSD syndromes, the body is explained and treated through a picture that sees chromosomes, genes and hormones as overlapping causal agents that create the gendered biological components of the body. Genetic material and hormone levels are analyzed along with the material of the body to diagnose and decide on treatment.

Sometimes, the hormonal treatment has the aim of pulling the body in line with gendered expectations of esthetics and performance. Sometimes, it is to remedy the health effects of the removal of otherwise healthy gonads. The right hormone therapy will also help regulate other important non-gendered biological systems.

The myths surrounding chromosomes and hormones link the biological to the social. Chromosomes indicate the body toward a certain developmental path, which contains many variants. These variants are sometimes considered pathological, or part of a disease category, because they are not as common, and they disrupt an image of pure male and femaleness. However the symptoms of these variations are related to assumptions surrounding the gendered body, not actually functional problems. Many people who do not have genetic variations will still have a varied gendered body, behavior and identity.

Hormones help regulate gendered components in the reproductive system, but do not have sex themselves, nor do they only act on the sexual system. Much is left to be discovered about these regulatory systems and what they imply for our overall health. A colleague once said to me, “Isn't it sciences' job to investigate differences,” in this case gender differences, “in the body?”[21]It is important to understand how the social image of scientific information is being used when addressing the gendered body. Is it being used to help people, or rather to establish a biological/natural rational for discrimination? The idea that there are sex differences in hormones for example, can block a potential therapy from being used. The gendered body is created through a complex network of interactions, and it will only be when we investigate all of our assumptions of what male and femaleness are, that we will be able to see how biological sex really works.

1.4 Framing the question, contemporary application of biological theories to the social

[21] In reference to the Dorothy Sayers quote: The first thing that strikes the careless observer is that women are unlike men. They are “the opposite sex” (though why “opposite” I do not know; what is the “neighboring sex”?). But the fundamental thing is that women are more like men than anything else in the world. In Laqueur 1990

Physical aspects of the gendered body can be directly linked to molecular and chemical processes reflected through laboratory research. However, it bears mentioning two other processes that are described as natural or biological, and tied to hormones and genes, that are nonetheless contaminated by the performative and social constructs: behavior and cognition (ability).

These categories bear mentioning because as we have seen in the previous section on laboratory research, social conceptions of gendered behavior and ability often contaminate otherwise biological categories. Gendered behavior refers not only to gender role, identity and corresponding sexual orientation, but also to the category that is observed in non-human animals and in consequence defined as natural or instinctual. The theories of *natural* gendered behavior, often refer to performative acts that tend to be performed more by one gender such as certain childcare activities (within a western context), as being biologically driven, even though they are not performatively the same across cultures. Natural/Biological theories of behavior will often compare humans with the rest of the animal kingdom, which does not necessarily have even the same biological reproductive stratagem, (Ellegren 2000; Meyer 2000) let alone similar social behavior.

Evolutionary Psychology, in specific, attempts to explain contemporary gender roles through an evolutionary model. Utilizing evolutionary theory to address behavior, hunting and gathering gendered activities practiced centuries ago (the gendering of which is, yet again, not uniformly distributed throughout temporal-geographic cultures) would explain the statistical probability that in contemporary cultures a rapist is a man, and women instead display "nurturing" behavior and so forth based on biological imperative (Pinker 2002). We have practically no documentable evidence on gendered rape activity or childcare in pre-historic times, but we do have evidence that these behaviors have greatly varied over time and location.

Cognitive functions, such as memory, perception, or language, are considered as adaptations, that is, as functional products of natural selection or sexual selection. Adaptationist thinking about physiological mechanisms, such as the heart, lungs, and immune system, is common in evolutionary biology. Evolutionary psychology applies the same thinking to psychology. Unfortunately the intellectual result of these theories is to biologically rationalize gendered stereotypes and the resulting social inequality, instead of offering a scientific understanding of the biology of difference. The idea that these higher cognitive functions have developed differently across gender lines is also statistically unproven.

Cognitive Linguist Steven Pinker, who promoted the idea of the language instinct in the

1980's, continues to promote a well-documented argument for a long-term development throughout human history of gendered cognitive differences. Political theorists such as bell hooks[22] imply that colonial history has emphasized gender differences among white dominant cultures, obscuring power divides between other marked social categories such as poor, non-white etc…hooks implies that therefore gender is over-emphasized and naturalized (given a "natural" biological basis) while power structures are ignored. In direct debate with Pinker about the under-representation of women in science, psychologist Elizabeth Spelke argues that ability and achievement are socially constructed objects that have been measured differently across time and place. Spelke argues that discrimination and social forces have shaped women's presence in science more than intrinsic aptitude or motives[23].

Much research funding has also been allocated to find performative differences in cognitive ability between the two social genders. One must ask what social function this serves, and what "therapies" these researches might encourage. In meta-analysis, cognitive tests show greater performative variance in gender than between genders, the bell curves of median male and female behavior overlapping (Goldstein 2001 Chpt 3). There is little research on the extreme difference of men to other men, and women to other women, which is not based on investigating socio-economic differences that imply social disadvantage.

While in the nineteenth century anatomists "naturalized" female social disadvantage through first cranium and then brain size, the twenty-first century looks at neuro-imaging. While Evolutionary Psychology explains gendered behavior through an evolutionary model, neurological research has looked for gendered difference in cognitive performance and gendered neurological location in task performance. Neurology has replaced the ancient western assumption that women aren't good at math (and therefore paradoxically shouldn't be allowed to study it) with spatial rotation tests, implied to be essential for higher math computation (Dehaene,, Spelke,, et Al., 1999; Huguet et Al, 2009. However, evidence shows female math performance is increasing rapidly as more women actually study math (Gallagher and Kaufman 2005).

Neurologist Catherine Vidal indicates that in 2010, of 10,000 articles in neurology, 3% displayed gendered differences in either cognitive location or performance (Vidal 2010). Vidal elaborates that in the examination of these articles one will find minimum levels of

[22] bell hooks specifically uses lower case letters when referencing herself.

[23] Pinker, Spelke 5.16.2005 debate: http://www.edge.org/3rd_culture/debate05/debate05_index.html

standard deviation and often small sample sizes. Vidal indicates that research that shows difference is more likely to get published than research that shows no difference, which is seen therefore as having no result. There are no publications on DSD cognitive performance, except when extreme cognitive deficiencies are also present[24].

Vidal's position is in direct opposition to Evolutionary Psychology, and is based instead on Neuro-plasticity research (Vidal, 2004). Neuro-plasticity research states that most of brain diversity happens after birth. Neuro-imaging shows that thickening of brain regions (correlated to physical or mental tasks) is proportional to the years spent performing that task, and that regions will shrink when the task is no longer performed. Therefore, Vidal proposes that complex behavior that involves variant social codification, such as cognitive ability but also gendered behavior, is most likely a product of reinforced behavior, not instinct or ancient gendered tasks.

We have followed this minor digression into psychological theories about sex differences due to the position certain theories take that gendered behavior and ability have a biological basis. And of course they do; the mere fact of being embodied or differently embodied has impact on the experience of being human. However, these theories place biological differences directly onto the definition of the gendered experience, whereas gendered experience is simply too heavily influenced by social factors, which include the elaboration of social value of certain physical traits over others. We have followed this digression also because the "naturalization" of social processes crop up time and time again in the description of biological gendered processes in ways that deserve to be put under the microscope.

[24] There are neuro-imaging publications such as Intersex And Gender Identity Disorders: Neuroimaging Differences in Spatial Cognition between Men and Male-to-Female Transsexuals Before and During Hormone Therapy (Schöning, S., et Al. 2010) that correlate hormone and gender to spatial cognition tasks, their research question implies a gender bias applied to spatial cognition.

Chapter 2

HERMAPHRODITISM AND THE SOCIAL THREAT, A WALK THROUGH HISTORY UP UNTIL THE 1900'S

2.1 *Social object*

Hermaphrodite \Her*maph"ro*dite\, n. [L. hermaphroditus, Gr. hermaphródītos]

so called from the mythical story that Hermaphroditus, son of Hermes and Aphrodite, when bathing, became joined in one body with Salmacis, the nymph of a fountain in Caria: cf. F. hermaphrodite.] (Biol.) An individual which has the attributes of both male and female, or which unites in itself the two sexes; an animal or plant having the parts of generation of both sexes, as when a flower contains both the stamens and pistil within the same calyx, or on the same receptacle. In some cases reproduction may take place without the union of the distinct individuals. In the animal kingdom true hermaphrodites are found only among the invertebrates (Webster 1993).

The term "hermaphrodite" has its origins in Western discourse in the Greek philosophical and biological tradition. Plato (*Symposium,* 189e) pondered the hermaphrodite as the philosophical origin of humankind before its subsequent division into the sexes. For Aristotle, the hermaphrodite was a useful philosophical concept in considering the social placement of man in the world; at the same time, the hermaphrodite was also considered one of the many possible physical variables of the human species (Ross 1912). The history of the discourse surrounding hermaphroditism has implications for changing conceptions of social gender roles and their flexibility. Changing views of the taxonomy of the gendered body play a parallel role.

The terms Hermaphrodite, Intersex, and DSD do not mean the same things and cannot be used interchangeably. However, in common language one may be used to describe another. The medicalization and separation into syndromes, such as in DSD, describes a different object than what hermaphroditism was meant to represent. In this chapter we will follow the unfolding of hermaphroditism as a social object until the eighteenth century, when it starts to mutate to its present categorization as a medical object. Hermaphroditism can be seen to be a social object precisely in that its ordering and management was covered by the social authorities of state and religion. On the one hand, what we encounter is a history of words, on the other hand what Foucault refers to as a history of bodies, which are moved in and out of

social categories.25

Many in the current era might not have heard of Intersex or DSD, but everyone has an idea of what hermaphroditism is, correct or not. The medicalization of Intersex/DSD and the legacy of secrecy in medical protocol have hidden it from common discourse. In casual conversation even among academics, the terms Intersex and DSD can erroneously evoke the image of someone who lives in or legally adopts a different gender category than the one they were assigned at birth, such as in the case of transgenderism or transexuality. One may appeal to the detailed explanation of anomalies of development of gender and sex to key the listener into the subject at hand. Or, in laziness, one can drop the word hermaphrodite and instantly your listener is at least closer to a shared definition.

Why is "hermaphrodite" a commonly understood term whereas "Intersex" and "DSD" are not? Part of the reasoning comes from early twentieth century medical practice that emphasized secrecy and adopted the term Intersex. Later twentieth century identity politics rendered transexuality and transgenderism commonly understood categories, but not Intersex. But perhaps more convincing is the evidence of centuries of medical interest in the taxonomy of gender and sex that continued the use of a terminology based on the key word hermaphrodite. As we will see further on, modern day syndrome categories from the eighteenth century on, were contained in the categories of "spurious" and "pseudo" hermaphroditism.

Patient groups generally find the term "hermaphrodite" offensive, because it is inaccurate in most syndromes, but also because of the legacy of social stigma that it still carries. "Hermaphrodite" referred classically to an individual with both female and male genitalia, coming from a period where there was little investigation into the internal nature of reproductive organs. In practice, the category morphed to include people who had mixed sexual traits or what is still called ambiguous genitals.

Before medicalization, this mixture or ambiguity simply disrupted the social order in societies where privileges and/or social roles were dictated by gender category. This was particularly the case in what can be referred to as the Judeo-Christian paradigm that has strongly influenced what we commonly consider as the western world. Anthropology reveals societies and historical contexts in which birth order or social status was a more influential determining factor than gender role.

Social stigma surrounding hermaphroditism seems to be higher in societies that have

[25] See Celia Roberts' discussion of Foucault in Roberts, 2007, pp. 19-20

problems with homosexuality. Classical Greece had a rigid dual gender system, without much stigma surrounding homosexuality or hermaphroditism.[26] One of the many exports of British colonialism was legislated homophobia. Laws against homosexual activity in ex-colonial nations often still use the same (ex-British) penal code number (Ong and Peletz 1995). The majority of the historical information we have about the medicalization of hermaphroditism comes from European cultures.

In considering the history of Hermaphroditism27 one notices varied aspects of historical social reality in action, from daily gender role and legal sex status, to biological definition of taxonomy and function. Before genetics were involved in sex and gender determination, there were obviously other methods, from behavior to genital aesthetics, which established social gender. Needless to say, gender determination has significant legal and social implications. Most of the records we have of live "hermaphrodites" up until 17th century are from social-legal disputes surrounding their legal gender status, allowing or disallowing them rights to marry, attain property, becoming priests and all the other gender-based rights of citizenship.

The social legal disputes surrounding the "deviant" gendered body are performatively similar to that of regulation of cross-dressing. We have many accounts of women[28], who were not considered biologically ambiguous, that were prosecuted for cross-dressing as men. As in cases of "dubious sex", rulings from either church or social-legal authorities are extremely various. The fact that some of these women were put to death for assuming a male social status (Joan of Arc, etc), underlines the social gravity of maintaining gender differences. As we will later, however, punishment was usually reserved for those discovered in presumed homosexual relationships (Crompton, 2006 pp. 473–475; Krimmer, 2003, p351).

Different cultures and historical periods have developed laws and social codes to handle the biosocial phenomena of sex and gender variation. In *Purity and Danger*, anthropologist Mary Douglas discusses social organization stating that, anything that threatens the social fabric of the group is considered unclean and must be either removed or cleansed through social ritual (Douglas 1966). The diverse social regulation developed in different time periods

[26] Observation from Roberto Brigati: "Classical Greece had a horrifyingly dual gender system, male homosexuality was straightaway encouraged, and i don't think there was much persecution/stigma of heramphroditism, not more than in later times"

[27] I use the term "hermaphrodite" when used in historical context.

[28] Catalina de Erauso (1592–1650)/ Antonio de Erauso given permission by the Pope to wear men's clothes; Erauso, 1996

in connection to hermaphroditism indicate the level at which gender differences threatened the social fabric of the time.

Delving further into history, we can observe two pillars of Western society, the Judeo-Christian tradition and Greek, science and philosophy. Varying interpretations of the Old Testament give different interpretations of gender variance and roles. Biologist Anne Fausto-Sterling comments: “Early biblical interpreters thought that Adam began his existence as a hermaphrodite and that he divided into two individuals, male and female, only after falling from grace.” (Fausto-Sterling 2000).

Biblical scholars question the various interpretations of the ancient Hebrew version of Genesis.

> A point made by Trible and others is that at the time of creation in Genesis 2:7, *ha-'adam,* which has been conventionally translated as “man”, “the man” (*ha* read as the definite article “the”), or “Adam”, had no gender (Trible, 1973, pp. 30-48). Gender comes into existence only with the creation of woman in Genesis 2:22, following which, in 2:23, the “earth-creature” or “groundling” (suggested alternative translations of *ha-'adam*) is sexually differentiated as “man” (*ish*), and woman as *ishah.* A note can be added here on the word “rib”. Sarah Roth Lieberman points out that the Sumerian word “ti” means both “rib” and “to make alive” (Lieberman 1975). The double meaning may explain why Eve, who is called “mother of all living” in Genesis 3:20, was created from Adam's rib (an otherwise very odd piece of male anatomy to chose). Unfortunately, in the Bible, the association is lost because the Hebrew words for “rib” and “life” are two different words with unrelated roots (Witcombe 2000).

Whereas this contemporary historical linguistic debate illuminates the origins of biblical interpretations of gender, modern society has been conditioned by the later Christian translations from Greek. In 1 Timothy 2:11-13, we see that the early un-gendered version is erased, and that gender difference is used to support gender dominance. This mirrors Judith Butler's theory that sex distinction is key to gender inequality (Butler 1993). In this case Adam is redefined as the first male being, and is considered superior to woman because he was created before Eve.

Jewish religious texts reflected their contemporary cultural preoccupations about gender by outlining practical guidelines and regulations. The Talmud and the Tosefta discuss modes of conduct and inheritance of intersex people, reflecting female guidelines in some cases (non-inheritance of their father’s estate) and male in others (prohibition of shaving) (Fausto-Sterling 1993). Yet again, this does not directly imply that intersexed people had a comfortable position in ancient Hebrew society, but it suggests that there might have been a

social position allowed for physical gender variation which is lacking in modern legal structure. We must keep in mind the distinctions between social regulation through legal structure, regulatory social practices that dictate behavior, and the process of medicalization which describes and philosophizes not only the role of the body in society, but the right of certain bodies to exist in society.

We are familiar with the reoccurring mythical image of hermaphrodites in ancient Greek history, yet it would be safe to say it is unlikely that the rate of intersexuality was higher, or that they had a more comfortable place in society.

> In tracking the history of medical analyses of intersexuality, one learns more generally how the social history of gender itself has varied, first in Europe and later in America, which inherited European medical traditions. In the process we can learn there is nothing natural or inevitable about current medical treatment of intersexuals. Early medical practitioners, who understood sex and gender to fall along a continuum and not into the discrete categories we use today, were not fazed by hermaphrodites. Sexual difference, they thought, involved quantitative[29] variation. Woman were cool, men hot, masculine women or feminine men warm. Moreover, human variation did not, physicians of this era believed, stop at the number three (Fausto-Sterling, 2000, p. 33).

Aristotle defined hermaphrodites as a sort of twin in which there wasn't enough material to produce the second child, yet he argued that the heat of the heart determined which of the two possible sexes was represented. Both Aristotle and Plato were interested in the primordial myth of Hermaphrodites, separated to create the two genders. However, Aristotle was much more concerned with the "natural" superiority of the masculine quality than the possibility of ambiguity.

> The female always provides the material, the male that which fashions it, for this is the power we say they possess, and this is what it is for them to be male and female […] While the body is from the female, it is the soul that is from the male (Ross 1912).

The female did not contribute form to generation, but only matter.

> Here is the indication that the female does not discharge semen of the same kind as the male, and that the offspring is not formed from a mixture of two semens, as some allege. Very often the female conceives although she has derived no pleasure from the act of coitus... (Aristotle in Aughterson 1995 pg 45).

[29] In this case quantitative refers to number of reproductive chambers, whereas it could be argued that the heat model represents qualitative difference.

In this model there is not a mixture of material, male and female remain separate, distinct categories. Aristotle saw the actual hermaphroditic body as physically aberrant, a male or female body that contained extra, non-functional material, much like a tumor. While aberrant, the hermaphroditic body has no added moral weight, outside of the well-developed hierarchical philosophy of gender in the body.

The *Corpus Hippocraticum* discussed generation in a different matter, addressing the variety of factors that contribute to creating the sex of the child, as opposed to the factors that create the natures of the sexes. In the Hippocratic model, there are three factors in generation, a left and right side dichotomy, the timing in the cycle, and the strength of the seed, equally potent factors in both the male and female contribution.

> This treatise[30] suggests that there are three kinds of men, and three kinds of women. If both parents secret female seed, for example, the child will be beautiful and highly feminine (thelukotata) girl; if the woman produces female seed and the man male seed, and the female seed is stronger, the child will be a girl who is bolder, but still behaves within the bounds of modesty. If the man produces female seed and the woman male seed, and the female seed dominates, then the child will be female, but 'masculine' (1.29, Loeb IV, 268-70; Follinger 1996:44). In Greco-roman antiquity, both sexes are equally fragile; all bodies consist of 'hard parts' and 'soft parts' (Gen. 3, L 7.474)... (King, 1998, pg.9).

Hippocratic medicine was directly concerned with the difference of the female reproductive body, creating a gendered body of knowledge that is reflected in the formation of gynecology. Hippocratic texts refer to the womb as mobile and related to overall womanness, a discourse that is replicated in the medicalization of hysteria. Helen King refers to the Hippocratic woman as being represented by the archetype of Pandora, which presented a negative metaphorical reading of female anatomy.

> For the Greeks of the classical period it is Pandora, the separate creation who is the origin of the 'race of women', who makes gynaecology necessary. She is a womb-jar, insatiable in her appetites, lustful, deceitful, but fertile. Hippocratic gynaecology states female difference in terms of structure and function. Structurally, women have an entirely different texture of flesh from men, being wet, soft and spongy (King, 1998, pg 39).

The transitional periods in the aging process, such as puberty and old age, were used as part of the explanation of masculinization or feminilization across an individual's life.

[30] On the nature of Man

Aristotle had compared the female body to that of a boy's (King, 1998, pg.10). Hippocrates described masculinization in women as a response to changing fluids linked to aging and environment. Helen King speculates that this discourse may have explained the modern day category of late on-set Congenital Adrenal Hyperplasia (CAH) syndrome[31] (King, 1998, pg 10).

Attitudes towards gender role and hermaphroditism vacillated through different periods somewhat independently of biological visions of the body. The pre-republican Roman state (1000-500 BCE) viewed intersexuals as a negative prophetic sign and often had them put to death. Fausto-Sterling notes that later on, in imperial times, it seems that intersexuals were de-stigmatized and achieved the right to marry (Fausto-Sterling, 2000 p. 33).

Galen followed the tradition of Hippocrates, in the 2nd century CE. His anatomical texts and medical treatise, like Hippocrates', remained a mainstay of western medicine well up into the 18th century. For our concerns, the most significant aspect of his biological theories, that prevailed well into the 17th century, was that the female genital anatomy was simply the inverse of the male.

> For the parts were formed within her when she was still a foetus, but could not because of the defect in heat emerge and project on the outside, and this, though making the animal itself that was being formed less perfect then one that is complete in all respects (Galen in Aughterson, 1995, pg. 47-48).

Galen, like those who came before him, was interested in a biologically-based explanation for the difference between the male and female body, which in turn has supernatural origins and moral implications.

> Indeed you ought not think that our creator would purposely make half the whole race imperfect and, as it were, mutilated, unless there was some great advantage in such mutilation (Galen in Aughterson, 1995, pg. 48).

He compiled much of the knowledge obtained by previous writers, and furthered the inquiry into the function of organs by performing sections and vivisection on animals. His collection of observations, based on animal anatomy, became canonic anatomy for 1,500 years. Hampered by religious restrictions similar to those that anatomists experienced under the Catholic Church, which prevented the dissection of human bodies for centuries after him,

[31] Masculinization of the female body around menopause due to the degree in estrogens or prior increase in androgens.

Galen assumed that anatomical structures in animals were the same as in humans.

The uterus was seen to have seven reproductive chambers, three each respectively producing either a male or female, one of which produced a hermaphrodite (Fausto-Sterling, 2000 p. 34). Some versions of these Hippocratic-Galenic theories allowed for gradations of sex and gender, due to the mixture of male and female seed (Borris, 2004, pg. 116). Caelius Aurelianus of the 5th century CE believed that this mixture of seed not only passes on a mixture of physical traits, but also a mixture of sexual desires hinting at biological theories on bisexual and homosexual behavior (Borris 2004 pg. 116).

Lorraine Daston and Katharine Park indicate that there are important nuances that are different between the Aristotelian and Hippocratic models.

> This model expressed the characteristic Aristotelian interpretation of sexual difference, which presented male and female less as points on a spectrum, in the Hippocratic manner, than as polar opposites admitting no meaningful mediation. Thus from the Aristotelian point of view, hermaphroditism was a condition only of the genitals-the product of the excess of matter and imbalance of male and female principles-rather that of the entire organism. There could be no true hermaphrodites in the sense of the Hippocratic model; the animal was either male or female, and the other set of genitals was always inoperative, resembling in that respect a tumor or growth (Aristotle 1953, bk. 4, ch.4; 772b26-35).

> Although both the Hippocratic and the Aristotelian accounts were purely naturalistic, they differed greatly from each other in their sexual implications. The Hippocratic model was sexually charged; allowing for a spectrum of intermediate sexual possibilities, it posed a potential challenge to the male-female dichotomy. The Aristotelian model, on the other hand, had none of these resonances; the sexual ambiguity of the hermaphrodite was never more than superficial, leaving the bipolar sexual order intact (Daston and Park in Fradenburg, and Freccero (Ed), 1996 pp.119-120).

These discrepancies are important because they remind us of the flux of ideas throughout the centuries. Different social theories are extrapolated in a combination of canonic texts that best mirror the prevailing dogma. Daston and Park state that the Hippocratic model dominated writing throughout the early Middle Ages, with an Aristotelian revival starting in the thirteenth century. While the Aristotelian model of generation dominated, Galen and Hippocratic theories mixed in, creating a less rigid gender model. The rise of anatomy from the sixteenth century was linked to the return of the Galenic and Hippocratic models. These Greek models replicated themselves as the primary source of knowledge throughout the centuries.

From the fall of the Roman Empire to the sixteenth century, the cultural center of the

western world moved to the Islamic empire. The main anatomical texts available in Europe up until Vesalius were reproductions of Galen and Avicenna. Abd Allāh ibn Sīnā, also known as Avicenna, rediscovered Galen and Aristotle, creating a medical system that combined Greek, Persian, Islamic, and Ayurvedic knowledge. The islamic empire kept Greek knowledge and tradition alive while Europe drifted through what is referred to as the dark ages. Avicenna's *The Canon of Medicine* ('Qanun fi-l-Tibb), written around 1020 was translated into Latin in the middle ages (Sarton, 1948; Sarton 1951).

Abd Allāh ibn Sīnā is credited with the elaboration of the concept of syndrome in disease diagnosis (Goodman, 2003, p. 155). A syndrome is organized around similar symptomology or similar characteristics, as opposed to causal factors. This departs from occult understanding of disease in which bad acts are direct causes of physical ailments. This concept becomes fairly important in the study of pathological anatomy, and is highly relevant to modern day DSD categories which are termed as syndromes, not diseases.

Ibn Sīnā description of the hermaphroditic body remains genital centered:

> Chapter 43. About the Hermaphrodite.
>
> In a person who is a hermaphrodite, there is neither a male member nor a female one alone. Some of them have both, but one member is rather less visible or weaker, while the opposite is true for the other. There are some in which both members are equal. And it occurs to me that some of these take the active role and some the passive role, but there is little evidence concerning this. Often they are cured by cutting away the less visible member, and then by medical management (regimen) of the wound (Borris, 2004, pg130).

Ibn Sīnā follows the Aristotelian model that envisions the hermaphroditic member as a surgical problem, an unnecessary addition to the body to be dealt with accordingly. His position is mirrored in contemporary concerns in DSD management, genital correction and the correlation between gender identity and sexual behavior, in which only two "true sexes" exist. Ibn Sīnā discusses homosexuality at much greater length than hermaphroditism throughout his texts, associating the male homosexual with effeminacy and bad moral conduct. He addresses the theory, promoted by the pseudo-Aristotelian *Problems*[32], that desire for anal penetration is due to the placement of nerve endings, but sides with the social model of homosexuality. Kenneth Boris states:

> Avicenna defines the role and means of sexual pleasure in heteroerotic copulation, ignoring the clitoris. Wives sexually unsatisfied by their husbands take lovers; their ambiguous gender and

[32] Assembled from 350BCE to approximately 500CE

> Avicenna's stress on rubbing suggest tribadic possibilities. Relative to his comment on anally receptive males, Avicenna's discourse here is at least morally neutral, though elliptical (Borris, 2004, pg 129).

Ibn Sīnā does not directly address the role of the clitoris in sexual pleasure, or its size being related to homosexual behavior in women. He does, however, continue to link female pleasure with the release of female seed and the potential for generation.

The consideration of the hermaphroditic body was part and parcel of speculation surrounding biological origins of homosexuality. As highlighted in Foucault's, *The History of Sexuality*, homosexuality refers to different acts and behaviors in different cultural epochs (Foucault 1998). In the fourteenth century, the pseudo-Aristotelian *Problems* is rediscovered and becomes the new source for the idea that the male homosexual is biologically different from the heterosexual male, similar to a woman or a hermaphrodite (Borris, 2004, pg130). Later, as we will see in both the works of Taruffi and Bianchi, the large clitoris will become a fundamental rationale for the biological origins of lesbianism.

The late middle ages saw the aforementioned mixture of Greek paradigms, mediated by Avicenna's writing. While Avicenna is morally neutral respect to hermaphroditism, thirteenth century writers such as Albertus Magnus begin to apply the negative associations of the effeminate homosexual to the hermaphrodite body. The clear two-sex Aristotelian model is blurred with the Hippocratic model, with the result that the hermaphroditic body becomes sexually and morally charged.

> The result was to compromise the sexually neutral Aristotelian model of hermaphroditism, and to give it a vague aura of moral and sexual disreputability; Albertus described hermaphrodites, viragos and effeminate males as liars, whose bodies and behaviors mislead (Cadden, 1993, pp. 212-213).

The thread of the hermaphroditic body as deceptive increases as the Aristotelian division is blurred. No longer is there an erroneous extra part, but some underlying cause that has various moral consequences. It is important to remember that up until the eighteenth century, we are still referring primarily to an external, genital-based phenomenon. Most of contemporary DSD categories would not have fallen under the public gaze.

The hermaphroditic body is not in itself a medical object, subject to cures and therapy, but a socially relevant scientific object. The hermaphroditic body would also come to be seen as physically aberrant. Evidence of hermaphrodites in the middle ages comes to the fore also through the debate on baptism, in which a child with deformities was considered monstrous

and could not be baptized (Shildrick, 2005, pp. 30-46). Genitalia difference was seen as the direct result of fornication with the devil. Physical difference, that could be seen as disability, was associated and muddled with deviance and departure from a moral code. Medieval Christian moral doctrine, particularly, was active in merging the moral and the anatomical-biological points of view concerning "monstrosities", and up through the Renaissance era, the Church continued to have final authority in issues of medicine and science.

Foucault writes:

> No doubt this should be examined more closely, but broadly speaking we can accept, or at least people will tell you, that from the Middle Ages to the sixteenth century, and until at least the start of the seventeenth century, hermaphrodites were considered to be monsters and were executes, burnt at the stake and their ashes thrown to the winds. Suppose we accept this. In fact, in 1599, for example at the very end of the sixteenth century, there is a case of the punishment of someone being convicted as a hermaphrodite apparently without anything else being involved other than the fact of being a hermaphrodite. It was someone called Antide Collas, denounced as a hermaphrodite. He/she lived in Dole and, after examining him/her, the doctors concluded that this individual really had both sexes, but that he/she could only have both sexes because he/she had had relations with Satan and it was this relationship that had added a second sex to his/her original sex. When interrogated the hermaphrodite confessed to having had relations with Satan and was burned alive in Dole in 1599. It seems that this is one of the last cases in which a hermaphrodite was burnt for being a hermaphrodite (Foucault, 2003, pg. 67).

The view of the hermaphroditic body as monstrous, links physical difference to moral deviance, (fornication with the devil is called into play). However, what is punished is the aberrant body, not the sexual act. The hermaphroditic body is posed as a different sort of rift in the social fabric, not in respect to gender roles and social-sexual norms, but in respect to the health of the social body that the "monstrous" body threatens. While the social object shifts from potential homosexuality to physical difference, there is still lacking the attention and detail of classification that medicalization will bring. In the nineteenth century, we will see a return to the moralization of the aberrant body, but medicalization will bring theory much deeper inside the body, no longer resting on surface issues such as genitals.

Thomas Laqueur argues that despite the inclusion of a third sex in debates about the physical nature of man, the dominant model in the western world up until the eighteenth century was a "one sex model", not male and female, but male, with any exemption organized around it. This model is utilized in political gender theory, which states that the white-European male body is still used as a normative, with all other bodies being marked, or un-

normalized to some extent. The "discovery" of difference of the gonads in a precise quality (type of tissue, productive cycles, although not yet hormonal secretion) shifted the arena of the discourse from external to internal.

> Sometime in the eighteenth century "testicle" could stand alone to designate unambiguously the male gonad; it no longer carries the modifier "masculine" or "feminine". "Ovary", not "female stones" or "testicle feminine", came to designate its female equivalent. Moreover, the overtly political language of some earlier anatomical descriptions – Zacchia's description of a *beneficium*[33] of the clitoris as leading to a false diagnosis of hermaphrodism, for example – gave way to the more clinical, organ-centered language of nineteenth century medicine […] (Laqueur, 1990, p. 161).

Laqueur has been criticized for ignoring anatomical texts from previous centuries that directly discussed the difference of female anatomy (Laqueur, 2003, pp. 300-306; Isis discussion 2003). These texts arise from the Hippocratic model, mentioned earlier, that located the uterus as the focus of the female body. Daston and Kathrine indicate that there were different influences of the Hippocratic and Aristotelian models throughout different historic periods and places.

What Laqueur seems to be addressing is the hyper-focus on the physical differences and a naturalization of psychological differences that became so pertinent in the eighteenth century.

> Both Schiebinger and Laqueur have argued that it was not until the late eighteenth century that the sexuality of the body was thought to extend to all its parts, including the mind (Schiebinger 1989: 189). Only then did the uterus cease to be an internal analogue of the penis, becoming an organ with no male counterpart. Sexuality came to be seen 'as penetrating every muscle, vein, and organ attached to and molded by the skeleton' (Schiebinger 1989: 191; cf. Laqueur 1990: 4-5). (King, 1998, pg 11).

Helen King argues, instead, that this model also existed in classical Greece. What is original to the eighteenth century is the intersection of the changing political-social infrastructure and this scientific emphasis on the differences between the male and female body that, for our interests, increases the scientific obsession with the hermaphroditic body. Daston and Park assert that up until the sixteenth century, medical discussion of the hermaphroditic body focused on generation and genitalia. Thereby, it did not have the same impact on legal and political discussions, and was not yet associated with sexual ambiguity (Daston, Park, 1995, pp. 419-438).

[33] *beneficium* means enlargement

During the middle ages, the conceptual model of the continuum of the similarity between male and female anatomy prevailed. Whereas female reproductive structures were often still conceptualized as internalized male organs, and described through comparison with male anatomy, we begin to see an increased precision in terminology, the beginnings of a gendered biological discourse, with a focus on the distinction of the functions of the reproductive organs.

The return of attention to generation and the Hippocratic vision in the sixteenth century is a precursor to the explosion of medicalization the hermaphroditic body will soon receive. The gradient model was filled with moralization. In this re-reading the hermaphroditic body is associated with same-sex desire, regardless of belonging to a fixed-gender category. The male body was the model of normality for all bodies, and male heterosexual behavior the norm for moral behavior. However, throughout the centuries, concern over the hermaphroditic body shifts back and forth between concern over different bodies and parts (that can erroneously contribute to same-sex sexual activity) to concern about the innate moral nature of behavior embedded in different bodies. Foucault claims that from the seventeenth century onward, same-sex sexuality may be punished, but the hermaphroditic body itself is no longer the direct social object. However, it becomes a medical object.

2.2 *The medical object, from the Sixteenth Century*

The internal distinction between the male and female body, up until the sixteenth century, was vague at best. The social perception of the hermaphroditic body was, to some extent, a public event up until the "discovery" of the gonads. By public event I mean, the interpretation of gender based on external genitalia and behavior, instead of internal organs and/or genes. These events also played out in the public sphere, such as courthouses and local gossip, as opposed to behind the closed doors of medical examination rooms. The subsequent medicalization brought investigation inside the body to discover the individual's "true sex". Genitals in western societies were not for public viewing, but were rendered public through court cases or debates about ambiguity. Medical authority (independent of religious authority) over the body grews from the sixteenth century as Foucault (1963) elaborates in *The birth of the clinic*.

In 1543 Johannes de Andreas Vesalius published the anatomical text, *De Humani Corporis Fabrica*, that was to become the canonic text for centuries (Porter, 1997). This text represents a lightening of the Catholic Church's ban on dissection, and the rediscovery of Greek knowledge that was awakening throughout Europe. Vesalius's text was a challenge to Galen's

comparative methods, advocating for direct observation of the human body as opposed to animal dissection. Despite this critical eye, Vesalius's work basically took part in reinforcing the Greek tradition as a primary source of knowledge.

The conceptual model of Greek anatomy as a basis for medicine, returned to Europe through Vesalius's adaptation of Galen, and became the mainstay of the discipline. Vesalius taught at the University of Padua, and from sixteenth century on, Italy became a center for the study of anatomy. The rise of the study of anatomy is linked to the rise of empirical medicine. However, there was still quite a lot of reliance on the classical texts, which lead to a particular consideration of the body. Empirical medicine, in combination with classical texts, forms the basis for debate on the hermaphroditic body up through the eighteenth hundreds.

Before science made its way into the exploration of the interior of the body, it began to stake its claim as the authority on the body. The growing association between the hermaphroditic body and the homosexual body was on slippery moral ground since the re-popularization of the Hippocratic model in the sixteenth century. Theories on the physical difference of homosexuals, nerve placement in men, and large clitorises in women returned to the surface. The hermaphroditic body could be seen as a mask for the homosexual body.

The concept of monstrosity, to a large extent, disappears through the negation of two simultaneous sexes, or the hermaphroditic body. The medical object becomes the establishment of true sex. Foucault references Antide Collas as the last hermaphrodite killed for the simple fact of having a hermaphroditic body, indicating in later cases the crime becomes homosexual behavior. The medicalization of hermaphroditism is complicated, negating its existence while attempting to better classify and categorize it.

Foucault refers to the case of the hermaphrodite of Rouen and the doctor Jacques Duval in 1614, to indicate the shifting climate.

> The first case was known at the time as “the Rouen hermaphrodite.” It concerned someone who was baptized as Marie Lemarcis and who gradually became a man, wore men's clothes, and married a widow who was already a mother of three children. There was a denunciation. Marie Memarcis, who had taken the name of Martin Lemarcis, came before the court and the first judges called for a medical examination by a doctor, an apothecary, and two surgeons. They found no signs of virility. Marie Lemarcis was sentenced to be hung, burned and her ashes scattered in the wind. His wife, or the woman who lived with him or her, was sentenced to witness the execution of her husband and be thrashed at the town's crossroads. Because it was a capital penalty, there was the right of appeal that took place at the Rouen court with a new expect opinion. The new experts agreed with the first experts that there was no sign of virility; only one, Duval, recognized signs of

virility. The verdict of the Rouen court is interesting because it releases the woman, orders her to wear woman's clothes, and prohibits her from living with anyone of either sex, “on the pain of death.” (Foucault, 2003, pg 68).

The disagreements between Duval and the other medical professionals, directly target the debate between the monstrous body and the emerging clinical, detailed approach to anatomy and sexuality. Duval combines Hippocratic and Aristotelian models to describe a body that may have mixed traits, but belongs to one sex, citing that it is a doctor’s responsibility to investigate further to ensure the happiness of the patient. Kathleen Long addresses Duval's treatment of the case of Marin/Marie le Marcis, which he claims is the inspiration for all his work. Duval is called to testify as Marin/Marie's case drags on for years, risking the death penalty.

For Duval, the condemnation to death of someone who does not fit neatly into the constructed categories of male and female is a violation of the sanctity of life, and patent absurdity, since none of us fits neatly into those categories. While his fellow doctors shrink from the contamination they might endure from contact with the hermaphrodite's body, Duval condemns their deadly negligence...This difference of opinion and approach also marks the confrontation between empirical forms of medical investigation (including dissection and invasive internal examination) and more traditional forms of observation based on ancient tradition. (Long, 2006, pg83).

Duval insists on considering all of the signs of the body, and categorizing them into male and female categories. Therefore every physical aspect has an either male or female quality, but an individual is the sum of its parts. Duval, in his final opinion, sides on the side of masculinity for Marin, because of his sexual inclination and the presence of the phallus, highlighting the need to incorporate the physical with the social.

Duval justifies his project of establishing the parameters of sexual difference by arguing that it is necessary to understand and recognize the genitalia of either sex in order to determine such cases. He claims that his work is a legal manuel for surgeons involved in deciding cases of sex, sexuality (defloration), birth, etc. Thus, from the opening pages of this treatise, sexuality is strictly linked (even in the case of Marin) to the question of reproduction within marriage (Long, 2006, pg 84-85).

Genital ambiguity was increasingly linked to sexual deviance, as not only homosexuality but also cross-dressing became a crime. In the seventeenth century, England, France and the Americas adopted specific laws that punished both male and female transgression of civic gender category. Elizabeth Reis cites cases in 1652 and 1677 in New England where women

were punished for wearing men's clothing until a specific law was developed in 1696 in Massachusetts (Reis, 2009, Pg 15).

Valerio Marchetti (2001) refers to the seventeenth century as the period in which bi-sexuality was invented as a juridical category. Using the term "invention" Marchetti alludes to the bio-politics of the legal regulation of gender and the negation of the hermaphroditic body. Marchetti also wants to indicate a break from the past, which would never allow the hermaphroditic body to exist again legally. Paolo Zacchia's (1657) *Questionum medico-legalium*, addresses the legal problem of the hermaphroditic body, by redefining it as an object that is either really male or really female. This version of the medicalization of the gendered body, steps away from the discourse of monstrosity by erasing the reality of gender duplicity, establishing medicine as the central authority in these disputes.

> As Riolan put it in 1614: "it belongs to the physician to know the sex of hermaphrodites, and to judge that [sex] which suits them, without giving them the option to elect and choose the sex they would like" (Fradenburg and Freccero, 1996, pg 125).

The social questions are the same, sex assignment and gendered sexual behavior, but there is a shift towards medical authority. Joseph Bajada indicates that Zacchia's real concerns rest on the question of marriage. In Zacchia's early taxonomy of the hermaphroditic body, there are four main categories, three male and one female.

> In his opinion, therefore, hermaphrodism as such does not impede the individual from performing the sexual act. As long as one sex prevails the ability to marry is not lost (Bajada, 1988, pg 100).

Laqueur indicates that Zacchia argues that hermaphrodites are not dangerous, but a medical object, and that science can determine the true nature of the individual by weighing the biological facts. However the medical object remains slippery,

> The clinical and professional tone of the Questionum-case histories, taxonomies, learned reviews of the literature on various points- would lead one to assume that organs will be treated as the sign of something solidly corporeal, something that thoroughly informs its subject and determines identity. But Zacchia, like Montaigne, treats organs as if they were contingent certificates of status: "members conforming to sex are not the cause that constitute male or female or distinguish between them...Because it is so, the members of one sex could appear in someone of the opposite sex." (Laqueur, 1990, pg.140).

Paula Findlen highlights, however, that anatomist in this period "were often reluctant to give up these older Galenic descriptions of female reproductive anatomy as a mirror of the

male body." (Findlen, 2008, pg. 224). This would still create a slippery slope between the dichotomy of the male and female body. Medicalization in this period is still taxonomical, important especially for social purposes, namely marriage. Medicine is not yet interventionist. Zacchia concedes annulment of marriage when the sex act cannot be performed, because medical intervention could be life threatening (Bajada, 1988, pg 100).

Elizabeth Reis indicates that doctors were called to testify at court cases, and to investigate the anatomical "truth" (Reis 2009). According to Reis, doctors often choose to designate a definitive gender assignment that guaranteed heterosexual behavior. The genital standard of biological sex could confound the growing belief that homosexuality itself was a biological aberration. Reis highlights that treatment was not uniform, but in most cases, a doctor would do what he could to establish the patient as a heterosexual body. A heterosexual body, to borrow from Foucault, is a "useful body" to society, which produces legitimized social products.

As the hermaphroditic body slips from being a socially-relevant taxonomical object related to generation, to a medical object subject to medical authority, the authority of the individual slips away.

A body that begins to be associated with moral impurity is not a body that can be trusted, nor an individual that can be trusted to tell the truth about themselves.

> Thus far, the Renaissance medical and legal treatment of hermaphrodites accorded in practice with medieval norms, despite the pressure of a new, theoretical understanding of hermaphroditism. The novelty of sixteenth-century legal practice lay in its increasing reliance on outside testimony to determine the hermaphrodite's predominant sex. Prior to this period, it had been widely assumed that the mature hermaphrodite could be depended on to know and choose which sex predominated, for it was one's "nature" that spoke in the urgent tones of attraction to the "opposite" sex, and what possible motive could there be to dissimulate (Fradenburg and Freccero, 1996 pg 124)?

In the case presented earlier, it is due to the medical testimony of Duval that Marie/Marin was saved from the punishment of death. Daston and Park indicate that the law and medicine were allies that disqualified the hermaphrodite's own testimony, due to the climate created by "the new fear of sexual fraud and malfeasance surrounding all forms of sexual ambiguity..." (Fradenburg and Freccero, 1996, pg 125). The consolidation of medical authority over the body belies the continued debates and lack of certainty as to the true nature of the gendered body.

What is clear is that biology is increasingly linked to identity-category boundaries. Reis argues that the medical obsession with the hermaphroditic body as fraudulent, runs parallel to

colonial paranoia surrounding race (Reis 2009). Reis appeals to the Foucaultian position that argues that the new political structure of democracy helps create the notions of population and citizenship. Reis cites medical and newspaper accounts that denounce people who "passed" for white, or male or who "changed" from black to white or from male to female in the course of their life. The biological patrimony of gender and race both provided distinct privilege and participatory status in birthing democracies, and therefore it was important to identify which authority would regulate these boundary-lines.

There are obviously different considerations to make in countries where participatory democracy was still evolving, and in colonial settings. Renato Mazzolini relates the intricate social stratification developed in the Americas in the nineteenth century, based on parentage and race (Mazzolini, 2007, pp. 349-373). Within the picture that Mazzolini gives us is embedded the neo-Mendelian fear of racial regression, in which the socially undesirable biological material, such as dark skin, can return in following generations. However, in Europe, and Italy in particular, one can assume gender played a larger role in social position than race[34].

How can gender fraud be avoided when medical authorities are still in disagreement over exactly which body parts hold the key to this biological identity category? While Riolan insists that only a doctor knows a person's true sex, he disagrees with Duval over the determining nature of body parts. Kathleen Long indicates the ambiguity of Riolan's classifications, representing hermaphrodites as "overly lustful women:"

> So this part called the clitoris, mimicking by its form and its composition the male rod, can grow and thicken like a finger in libidinous and lustful women, and they can abuse it to give themselves pleasure, by living with each other (Long, 2006, pg 106).

The classification of the hermaphroditic body slides into the model of the biological lesbian. Long states:

> Riolan destroys all certainty of what is masculine, what feminine. If the penis grants manhood, then the phallic woman is also a man; if the penis can be taken away, then manhood based solely upon it is easily lost (Long, 2006, pg 107).

[34] The Racial Laws (Legge Raziale) were a part of Fascist Italian identity propaganda, however this part of the fascist program was aimed at unifying an Italian identity within the national boundaries against a mythical external threat (particularly the African man), not policing or stratifying multi-ethnic society.

Gabriele Falloppio, one of Vesalius's students, began in-depth investigation into the internal female reproductive system, for which the duct in which the egg travels from the ovary still carries his name. His extraordinary production of anatomical investigation helped establish Italy as intellectual center for empirical medicine in the sixteenth century. He contributed to prophylactic campaigns against syphilis, stating that of the 1,000 men he had equipped with a pink-ribboned condom, none had been infected. He also claims to have named the vagina and been the first to anatomically describe the clitoris.

> In the sixteenth century, the clitoris became the object of a famous Renaissance turf war between two preeminent Italian anatomists, Gabriael Fallopius and Renaldus Columbus. Each claimed to have "discovered" the clitoris (Chalker, 2000, pg 79).

Laqueur points out that the clitoris has been rediscovered throughout history. He claims it regains importance in the Renaissance in function of the consideration of the similarities between the male and female body.

> In a popular midwifery manual published in 1671, the English midwife Jane Sharp argued that the penis and the clitoris were nearly identical in structure and function. "The clitoris," she notes, "will stand and fall as the yard [penis] doth and makes women lustful and take delight in copulation." (Laqueur in Chalker, 2000, pg 79).

However, the clitoris begins to mark the boundary lines between the female and male body. The hypertrophy of the clitoris is increasingly linked to immorality and biological lesbianism, or Tribadism. In his 1898 compilation, Cesare Taruffi (Professor of Pathological Anatomy of the University of Bologna), cites many cases from the late fifteen hundreds to the late eighteen hundreds in which the clitoris is part of the explanatory structure of medical interest in female homosexuality (Taruffi 1898).

The anatomist Giovanni Bianchi posthumously examined a young person who had confessed to being a woman right before their death. Catherine Vizzani had lived for eight years as a man, but had been mortally wounded in 1743 after trying to elope with a woman. The objects of medical investigation were the hymen (certificate of virginity), gendered physical attributes such as fat distribution and clitoris size.

> This young woman did not have a clitoris greater than others, as it was written from Rome that she had, and as they say that all those women whom the Greeks called Tribades, or who follow the custom of Sappho have. Rather, it can be said that hers was very ordinary and should be placed among the small instead of large or medium ones (Bianchi in Findlen, 2009, pp. 222-223).

Paula Findlen contextualizes Bianchi's findings as part of the larger debate on "medical

sexology" in the Enlightenment. Bianchi's statements about body fat, height and hip width also belie the increase of taxonomy of the gendered body. Findlen states:

> Medical interest in the clitoris first emerged during the midsixteeth century, when Italian anatomists, beginning with Realdo Colombo35, identified it as the seat of desire. Within a few decades, physicians agreed that, under the right circumstances, it might grow large enough to make a woman a tribade, a woman attracted to other women, and possibly even transform her into a male...Bianchi's treatise appeared at a moment when anatomists were actively debating the nature of this singular female part (Findlen, 2009, pp. 223-224).

The link between a hypertrophied clitoris and tribadic or immoral behavior continues to some extent in contemporary DSD discourse, even as the eighteenth century anatomists attempted to disprove it. As we will see in later discussion of individual syndromes, there are different medical expectations for the social-sexual production of the gendered body, leading to hormone therapy to increase sex drive in the male identified body, and reduction of the clitoris in the female identified body.

Findlen's analysis contains a subtext that is important to note, that consists in the English perception of Italian morality, gender and sexuality in the age of the Grand Tour. Findlen claims that the English of this period were obsessed "with the alleged homosexuality of the Italians" (Findlen, 2009, pg. 30). This on one hand reflects the English anxiety about sexuality, but on another is a reaction to the unique social climate of the period, which, in Italy, produced female intellectuals (*filosofesse*), male companions for married women (*cicisbei*), castrated men (*castrati*), "femininely" dressed men (*macaroni*), etc. In this period, Italy also emerges as the center of knowledge production in pathological anatomy, fostering much of the work that would create the demarcation of the gendered body.

2.3 *From Hermaphrodite to Pseudo-Hermaphrodite: Moving inside the body. Nineteenth Century*

Alice Domurat Dreger (1998) defines the period between 1870 and 1915, "the Age of Gonads", because of the increased medical interest in establishing everyone's "true sex". The new century saw the abandonment of the term "natural philosopher" in favor of "scientist" (Schaffer, 1986, pp. 387-420) and biology began to define itself as a study in its own right, independent of the larger categories of the natural sciences or philosophy. The paradigmatic shift of the nineteenth century is marked by three significant factors, the establishment of

[35] Gabriael Fallopius and Renaldus Columbus both claim "discovery" of the clitoris.

medical experts of biological sex, the introduction of the qualifications "pseudo-" or "spurious" to hermaphrodite terminology, and the beginnings of an experimental-causal link between the reproductive system and the genitals.

Anatomy had finally made its way into the body and was developing models based on the human body, instead of the animal models of Galen, that had been the guidelines for the western world for more than a millennium. And importantly, obstetrics (and then gynecology) was establishing itself as a specialized medical discipline (to the exclusion of female midwife practitioners) (Porter, 2001, pg. 222).

Up until this period, the term "hermaphrodite", coupled with cases of "mistaken sex", had dominated the conceptual market. As we have seen earlier, social structures dictated that one adopt a gender role and stick to it. In addressing the new medical interest in hermaphrodites, one must remember that despite the enormous advances in identifying the uterus and ovaries, little was still known about their functioning. If the understanding of normal anatomy contributes to the understanding and definition of the pathological, and vice versa, we must wonder what the conceptual models were for defining normality.

We have seen that, while the term hermaphrodite continued to dominate medical texts, there was a medical investment in the negation of the hermaphroditic body. Medicine had taken the strong position that there was a way to put all bodies in one category or the other. As Dreger states, the sexualization of the gonads, and investigation into their function in reproduction, added a biological piece to the puzzle. The gonads were envisioned as having a deterministic role in the creation of the sexed body, which in its substance is the predecessor of hormonal theory. As mentioned in chapter one, the gonads themselves were used as medical material before the chemical components were identified.

The age of the gonads, references a conceptual shift from that of the Greek biological model, which saw the female and other bodies as divergences from the ideal male body. While there had always been particular attention paid to the female reproductive system, there had not been a experimental correlation between the reproductive system and the genitals. The gonads provided the tool Zacchia and others had been looking for to elaborate the taxonomy of gender.

Isidore Geoffroy Saint-Hilaire coined the disciplinary term "teratology" (Dreger, 1998, pg. 33), the study of anomalies, or pathological anatomy in the early nineteenth century. In 1833 Saint-Hillarie presented his classification model for sex determination based on the sexual organs. The French anatomist sought not only to establish himself as an authority on sex classification, but to explain anatomical anomalies as deriving from normal forms. This

lexicon indicates growing speculation on the development of the human body, in which the abnormal is no longer monstrous, but pathological, and reflects the natural order of things, removing once and for all the super-natural attributes. Elizabeth Grosz indicates that the nature of transforming monsters and freaks into abnormal pathologies, makes diversity analogous to sickness (Grosz, 1996, pg. 58).

Saint-Hilaire's model mirrors the Aristotelian model, in which the hermaphroditic body presents an excess of material. He divided the sexual body into three zones, the profound portion relating to the gonads, the middle portion which refers to the other internal reproductive components and the external portion representing the genitals. If the parts corresponded, the individual was a normal male or female, whereas the presence of mixed material constituted hermaphroditism. Saint-Hilaire speculated that it was the profound portion which characterized sex (Dreger, 1998, pg. 142).

In the same period, the English doctor James Young Simpson introduced the concept of a spurious or true hermaphrodite. Despite the fact that Simpson was less taxonomically precise than Saint-Hilaire, he established for the next century what medicine had already been attempting, the medical subordination of "true hermaphroditism". Centuries of speculation on the hermaphroditic body are thus re-ordered due to the anatomical negation of the hermaphroditic body as a real possibility. Everyone will now have a binary biological sex category. Marchetti indicates the origin of legal bi-sexuality as centuries earlier, but with this shift in terminology comes the naturalization of this social fact (Marchetti 2001).

On one hand, the hermaphroditic body disappears into the realm of mythology. But, on the other, the quantity of bodies that depart from the norm of a canonic male or female body explodes, carving the way for the modern syndrome categories. Many more bodies can be included into the spurious category, moving beyond a genital-based system.

The nineteenth century established tissue difference between the ovary and testicles, establishing a biological sexualization of the gonads. It also saw great discoveries in the developmental model and internal anatomy. Researchers Wolff, and then Müller, further refined ideas about developmental pathways and ducts in the determination of the gendered embryo, which was largely delineated by the development of ovaries or testicles[36]. The deterministic role of the gonads in development was then applied to the taxonomy of the hermaphroditic body. Dreger delineates this historical change:

> The classification system for hermaphroditisms presented in 1876 in the *Handbuch der*

[36] Wolffian and Müllerian ducts; (Wolff 1759); (Müller 1830)

pathologischen Anatomie by Theodor Albrecht Edwin Klebs (1834-1913) functioned something like a constitution for the Age of the Gonads. Klebs's taxonomy, apparently the first of its kind, codified the belief that the true sex should be based exclusively on the nature of the gonads.

I. True hermaphroditism (presence of ovaries and testes in one individual):

1. True bilateral hermaphrodism: one testicle and one ovary on each side of the body.

2. True unilateral hermaphrodism: on one side an ovary or a testicle, on the other an ovary and a testicle.

3. True lateral hermaphrodism: (also called alternates hermaphrodism) an ovary on one side, a testicle on the other.

II. Pseudohermaphrodism (spurious hermaphrodism; "doubling of the external genital apparatus with a single kind of sexual gland"):

1. Masculine pseudohermaphroditism: presence of testicles and evident development of the feminine genital parts.

2. Feminine pseudohermaphroditism: presence of ovaries with some predominance of the masculine genital parts.

Note that one of the most significant results of Klebs' system was that a being could appear almost entirely feminine internally and externally and still be considered a true male by virtue of the possession of testicles and lack of ovaries (Dreger, 1998, p. 145).

The case of Herculine Barbin, made public through the publication of her memoirs by Michel Foucault, was well known and much commented on by medical practitioners of the period. Adelaide Herculine Barbin was born in 1838, changed her civil gender status from female to male in 1860 and committed suicide in 1868. In her diary Adelaide describes a break with her happy youth when she was diagnosed as a male pseudo-hermaphrodite. This is compounded by the loss of her female lover, the change of civil status and the social hardships of being alone and unaccustomed to the male working world. In contemporary practice, Adelaide would probably have been allowed the choice to continue to live as a woman, and lesbianism is no longer a criminal act in France.

In his *Question Médico-légale de L'identité dans ses Rapports avec les Vices de Conformation des Organes Sexuels*, presiding medical practitioner Auguste Tardieu reports:

The extraordinary case that remains for me to report indeed furnishes the most cruel and painful example of the fatal consequences that can proceed from an error committed at the time of birth in the establishment of civil status. 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 (Foucault, 1980 p. 122).

The account of both the doctor and Barbin are riddled with the social difficulties of gender identity, and social condemnation of possible homosexual behavior. The doctor attributes Herculine's unhappiness to the original gender assignment, whereas one can reasonably postulate Adelaide/Herculine's unhappiness originates in being forced to change civic gender category. However, homosexuality is still indicated as a marker of potential mistaken gender assignment in the treatment of DSD.

Bianchi's account of Catherine Vizzani, as we saw above, is part scientific, part literary. While it was used in Italy to further his career and underline his authority in anatomical issues, it was published in English as a titillating medical account. Throughout the eighteenth century stories of hermaphrodites captured a certain sector of the educated public's imagination. Medical cases are filled with personal information and anecdotes, as well as a certain level of moral commentary. The hermaphrodite as a medical object is infused with social concerns that reflect considerations of the role of the individual in society. Duval's case history is considered sensationalist even by some of his contemporaries.

At some point the individual hermaphrodite disappears from the story. The story of the hermaphrodite shifts towards body parts and rudimentary explanations of their processes. The Foucaultian medical gaze supplants the social object. Dreger shows how faces disappear from medical reports, replaced by genitals and gonadal diagrams. However this does not indicate that the nature of identity disappears from the debate, quite the opposite.

The nineteenth century is riddled with the posturing of medical certainty that gives way to a multitude of positions, combining what Reis defines as medical mistrust of the individual, moral positioning on marriage and sexual behavior, and theories on the biological locus of gender identity. These various positions give rise to an ambiguous mid-period where deviant bodies are subject to medical speculation and rules, deemed not to be hermaphrodites, yet not easily placed in a normative social category (Reis 2009).

In May 1802 the medical commission of Mantua decides that Giacoma Foroni is neither woman nor hermaphrodite. Giacoma is assigned to the male legal category, but is legally denied the right of matrimony.

...che realmente la Giacoma Foroni non sia donna, non sia ermafrodito di nessun genere, ma un uomo bizzaramente dalla natura nel pudendo mal conformato. Che se il Governo ha mostrato

intersse a questo giudizio, ben e' giusto, che gli sia noto per quegli oggetti, che interessano la di lui vigilanza, che quest'essere infelice, quantunque riconosciuto assolutamente spettante alla specie maschile, non e' capace di matrimonio. Non puo' essere moglie, perche escluso dal rango di donna, ed ha la fatalità per il bizzarro difetto de' suoi organi di non poter essere mai legalmente marito: par quasi nato per verificare in qualche modo, quanto alla negazione di tutti i privilegi d'un sesso, il favoloso destino di Salmace (Celli, 1998 pg 30).

The report reveals that Giacoma identifies as a heterosexual woman, but due to her testicular material, lack of menstruation and "ambiguous" genitals she is deemed biologically and thereby legally male. Her belief in her female nature is deemed to be induced by her upbringing and her ignorance about the body.

L'uomo considerato nel puro stato di natura non conosce altro, fuori della tendenza alla riproduzion di se stesso, e quindi anche abbandonato a se medisimo si accoppia ad individui di sesso diverso senza aver acquistata da altri alcune preventiva idea della differenza de'sessi, e di quello a cui un'tale individuo appartenga (Celli, 1998, pg 20).

For much of the nineteenth century the term "hermaphrodite" will slip out of the taxonomy of the body and into the taxonomy of the self, and become analogous to the new term homosexual. Same-sex sexual behavior and opposite sex dressing, things we associate with the contemporary category of homosexuality, were increasingly subject to punitive jurisdiction after the sixteenth century. However, the nineteenth century initiates the naturalization process of sexual behavior, rendering same sex relationships a biological object.

Sexual behavior and sexual orientation came under scientific scrutiny in their own right. Pioneering activist Karl Heinrich Ulrichs, defined uranism in 1870 as a biologically-based difference of sexual orientation or a third gender (Taruffi, 1898, pg 30/330). Ulrichs contributed to the conception of homosexuality as sexual hermaphroditism, on one hand identifying same-sex desire as a third gender/sex, and on the other, rendering the study of homosexuality scientific with biological roots. Sexual inversion was used to describe the deviance from the gender of the genitals and the object of desire. Ulrichs' objective, however, was to de-criminalized homosexual behavior (specifically in Germany) by giving it a "natural" place in the biological schema[37]. Biological hermaphroditism provided a framework in which the physical aspects could be analyzed in conjunction with desire, and in

[37] "The Urning, too, is a person. He, too, therefore, has inalienable rights. His sexual orientation is a right established by nature…"; Ulrich 1970

fact, gender and sexual behavior remain at the center of medical interest in hermaphroditism (Taruffi 1898).

Biology and behavior were already increasingly confused, the contemporary categories of homosexual, transsexual, transgender, and hermaphrodite overlapping, as the scientists involved attempted to develop increasingly precise classification systems for both social and biological aspects of sex and gender. Ulrichs' move to render uranism a biologically-based category, was an attempt to transfer same-sex desire from moral theory to scientific theory, where it would hopefully be subject to less stigmatization and punishment[38].

Psychiatrist Richard von Krafft-Ebing in the late nineteenth century, attempted to classify deviant and normal sexual behaviors much in the same way anatomists of his era attempted to classify deviant bodies (Krafft-Ebing 1886 pp. 185–192; Taruffi 1898). Krafft-Ebing localizes these behaviors in the body, identifying a distinction between the sexual impulse and the sexual organs. He was the first to utilize the terms homosexual and heterosexual (1886).

Krafft-Ebing's theories rest on the nervous system, which was one of the dominant conceptual models of the inner mechanisms of the body in the nineteenth century. As we have seen in chapter one, endocrinology, in the early twentieth century, struggled against the static model, affirming that chemical secretions that circulate through the body, instead of electrical impulses, regulate the organs. In his theory same sex desire involves a congenital disturbance of the nervous centers that communicate between the sexual organs and the sensory organs, which form the idea of what being male or female is.

In these models, there is a relationship between experience that is grounded in the body, and identity formation. Certain identities that transgress the heterosexual identity and body are still, at this point, considered in themselves pathological. The liberation of presumed sexual deviance from moral territory, by placing it firmly in a biological context, is part of a long cultural shift that will eventually deconstruct sexual behavior as a natural category. The scientific categorization of the deviant body, separate from a moral framework based implicitly on sexual behavior, on the other hand, is just getting started.

2.4 *Bologna, Nineteenth Century*

At the end of nineteenth century Cesare Taruffi completed his third edition of his treatise

[38] Magnus Hirschfeld frequently cited Ulrichs' theories of biological homosexuality in Homosexuality of Men and Women (Hirschfield 1922), seeking again to combat German law paragraph 175 with the campaign "justice through Science"

on Teratology, entitled *Ermafroditismo ed Agenosoma*. Taruffi was the first professor of pathological anatomy at the University of Bologna, and the director of the anatomical museum, which still hosts many of the renowned anatomical wax models he collected that contributed to the development of the discipline of anatomy. The establishment of this university position marks the consolidation of the discipline. In fact Taruffi is as much a historian of the theories of pathological anatomy as a practitioner.

Taruffi's compilation highlights the theories that were canonic, and those that were still subject to debate at the beginning of the twentieth century in Italy. The subjects that he treats indicate increased attention to the biological nature of woman, not surprisingly, considering the contemporary establishment of gynecology. This was also an era that sought to establish a biological hierarchy not only between the sexes, but also races. Luigi Calori, one of the many illustrious men of Europe, who sustained that women and Africans were inferior to white men based on their biology (especially their skulls), was director of the faculty of Medicine at the University of Bologna (Anatomy Professor for 52 years) while Taruffi was professor (Ruggeri 2007)[39].

In *Ermafroditismo ed Agenosoma*, hermaphroditism is an ambiguous, negated category. Taruffi outlines the development of categorical models, siding with Klebs' model, which establishes the gonads as the center of gender differentiation. In this model the only true hermaphrodite is a person with mixed gonadal tissue, all other deviant bodies can be organized back into the male and female categories. However Taruffi sees the pathological category as expanding.

> Abbiamo inoltre avvertito che rispetto alla sede ed al numero dei Pseudo-Ermafroditi vi sono altre deformità, non raccolte nelle nuove classificazioni, che erano già cognite e talora incluse forzatamente nelle vecchie sintesi, mentre a nostro avviso hanno diritto di appartenere ai Pseudo-Ermafroditi. Tale diritto è loro concesso al fatto che i caratteri sessuali non si limitano ai segmenti già ricordati, ma si estendono a tutto il corpo animale; sicché quando questi sono talora in disaccordo coi precedenti caratteri costituiscono nuovi generi rispetto all'Ermafroditismo, e già principiano ad essere riconosciuti: difatti Krafft-Ebing ha chiamato Ermafroditismo psichico la sconcordanza degli istinti sessuali colla forma ordinaria degli organi della fecondazione; e Schneller ha chiamato Pseudo-Ermafroditismo la presenza della barba in una fanciulla con alcune deformità negli organi generativi (Taruffi, 1898, pg. 26/720).

[39] Prof. Ruggeri is the director of the museum of Pathological Anatomy of Bologna, that hold Taruffi's collection and Calori's skull collection

By the twentieth century the true-hermaphrodite will all but disappear, but the category of pseudohermaphroditism is in constant expansion even through the shift to Intersex terminology. Taruffi includes many topics that will become part of later syndrome categories, however, with a predisposition for "female disorders". It is unclear if this is a reflection of a growing trend in the medicalization of the female body, or a continuation of the one sex model of Laqueur, which marks all non-male bodies as deviant.

Taruffi separates his observations into anatomical and clinical sections. The anatomical observations outline the taxonomical models we have seen earlier that allocate the body into female and male categories. He gathers 84 case studies into bio-metric data, that attempt to indicate the frequency of certain phenomena (Taruffi, 1898, pg. 61/705). His tables or "*specchi*" (mirrors) represent the 15 factors he sees as relevant: civil status, dress, penis, clitoris, scrotum, testicle location, male urethra, anatomic sex, menstruation and amenorrhoea, inguinal hernia, sex change, sexual inclination, heredity, feminine organs and variety (Taruffi, 1898, pp. 62/706-81/725). Not all of the examples contain all of the information. Four of the fifteen categories: civil status, dress, sex change, and sexual inclination, are specifically social.

The clinical observations focus primarily on issues related to homosexuality and the female body. The clinical sections treat feminized men, gynecomastia (male breast growth), and masculine women. The section on masculinized women is the most developed, divided into seven chapters; general traits, macrosomia (abnormal height), body hair, elephantiasis of the clitoris, psychological masculinization, sexual inversion, and tribadism.40

Taruffi's treatment of this confluence of the female body, anatomy, morality, sexual behavior and teratology is ambiguous. While the anatomical section attempts to firmly root hermaphroditism in a biological taxonomical structure, the clinical section belies anatomical knowledge and focuses on social manifestations of gender and sexual behavior in which the hermaphroditic body disappears. As a historian, he evidences predominating theories and preoccupations on the biological nature of gender behavior without clearly stating an individual position. The predominant treatment of female behavior within an anatomical construct indicates a marked historical anxiety surrounding female social position. Taruffi identifies the exceptional Italian intellectual women who left such a strong impression on the

[40] Invirilismo (femmina con alcuni caratteri maschili): 1. Caratteri generali 2. Macrosomia femminile 3. Ipertricosi nella donna 4. Elefantiasi della clitoride 5. Invirilismo psicologico 6. Inversione sessuale 7. Tribadismo in Taruffi

British imagination as having psychopathic masculinization.

> Concedendo che l'intelligenza femminina non superi quella dell'uomo ed ammettendo che essa però gareggi e talora s'avvicini all'altra, non ne risulta che questo fatto, sempre eccezionale, si colleghi regolarmente coll'aumento di volume e di peso del cervello da avvicinarsi al virile (Taruffi, 1898, pg 27/327).

Taruffi returns the social speculation on female intelligence to the body and brain weight. In other observations, he dismisses that this social characteristic is tied instead to other physical attributes such as height and masculine traits. The tribadic or lesbian body is also localized, although in the clitoris and not in the brain, and is not necessarily associated with other masculine attributes. In the numerous chapters dedicated to this social phenomena, Taruffi ponders the relationship of the clitoris to hysteria, same sex-desire and masculine behavior.

While Taruffi is primarily interested in taxonomy, or teratology, his ample use of case studies draws out two interesting aspects of the coming interventionist era. The first aspect reflects the transformation of the medical gaze and authority. The second refers to certain discrepancies between what the legal-medical paradigm sees as a problem, and what individuals actually lived. One begins to see a clinical picture in which the body can be thoroughly examined and manipulated. Doctors have full liberty to examine the genitals of 6000 Parisian prostitutes (Taruffi, 1898)[41]. There is a delicate moment when full examination is no longer a choice and when surgical manipulation of the genitals becomes standard.

Taruffi examined 40 year old Virginia Mauri in 1896 (Taruffi, 1898, illustration added after pg. 64/758). His account follows the contemporary style, including personal information relevant to sexual activity, and detailed reference to gendered physical attributes. A detailed drawing is commissioned that portrays Virginia reclining with her legs apart, naked except for a string of pearls, feminine boots and thigh stockings, with her expressionless face slightly turned to the side. The striking difference from pornography of this era is that this medical diagram is much more graphic, photographically detailing the contours of the vaginal entrance and the hypertrophied clitoris. There is no mention of why Virginia is being examined, what her interests might be, or what the outcome of the examination is.

Instead we read about the doctors' hands that palpate and penetrate, seeking internal indications of sex, such as the mouth of the uterus, or internal testicles. Virginia does not allow a rectal exam, thereby setting the limit of negotiation of authority and morality on her

[41] Research on clitoral length and sexual behavior in France

body. Taruffi classifies but does not operate. He refers to surgical manipulation of the genitals in a handful of paragraphs, whereas 50 years later, surgical techniques will dominate medical literature.

In this case study, Taruffi refers to the artificial dilatation of Faustina's urethra during sexual practices (by Faustina's husband) in order to indicate that certain surgical manipulations have been attempted. He indicates he would primarily like to discuss two new interventions, one to compensate for the defect of the organ, and one to diagnosis the "true sex".

> Il tentativo fatto dal marito di Faustina ci conduce a ricordare alcune operazioni chirurgiche per riparare certa anomalie congenite delle parti generative, le quali risguardano alterazioni singolari come l'ipospadia, l'amputazione della clitoride, i restringimenti congeniti della vulva e della vagina, e le fistole retto-vaginali. Le cure ed i processi operatori sono gia entrati nella pratica, e questi non hanno diretta attinenza con gli effetti delle psicopatie sessuali, per cui limiteremo il nostro racconto soltanto a due ardite e nuove operazioni; una per supplire il difetto dell'organo, l'altra per diagnosticare il sesso dell'inferma (Taruffi, 1898, pg. 36/680).

In Taruffi's 84 case studies, he only directly reports one surgical manipulation of the genitals, the amputation of the clitoris and the creation of an "artificial vagina". In this case the surgical intervention is at the request of the woman, performed even though she is found to have testicles. Cases such as this one confirm Reis's theory that despite efforts to canonize anatomical knowledge surrounding gender, such as the determining nature of the gonads, clinical treatment was often ambiguous and individual. Klebs' model dictated that a person with testicles was a man; however, practitioners often sided on the gender expressed by the individual.

> La ragazza desiderando maritarsi, non esito' l'A. a fare una vagina artificiale e ad amputare la clitoride. Non dice poi se riescia sentire il collo dell'utero; racconta pero' che dopo 8 mesi dall'operazione la ragazza si marito' e compieva il coito senza difficolta, ma quando l'A. scrisse essa non aveva prole. (L'A. tace sulla distanza di tempo, e sullo stato interno delle parti).[42]

The only other surgical interventions Taruffi reports are clitorectomies; one performed by Mason in New York in 1868 on a 5 year old girl[43] (a precocious predecessor to Money, as we

[42] Coste de Marseille. Amputation d'un psuedo-penis chez une juene fille. Journal des connaissances medicales. Paris 1835-36 Vol. III, pag. 105 in Taruffi 1898 pg. 51/695

[43] Mason. Elephantiasis of clitoris. New-Yorck med. Record. 1868. May 1. Amputo' coll'ecraseur una clitoride ipertrofica in una fanciulla di 5 anni, che era lunga 4 pollici, e groos pollici 4 ½ in Taruffi

will see in chapter three) and the infamous legacy of Baker Brown. Brown in his 1866 work *Surgical Diseases of Women,* claimed that clitoral irritation could lead women to "abuse solitary pleasures" that would eventually lead to a decline in their physical health, hysteria, nymphomania and even mania. The cure (as in line with other British medicalization of the female body) was to remove the offending organ, in this case the clitoris. Brown eventually lost his position due to a bioethical scandal that claimed he performed clitorectomies without the women's prior knowledge and consent (Clark 2006 in Simonton, pg. 66). We have already seen that the clitoris is a site of much contention in the gendered body. Taruffi sides against clitorectomies for behavioral issues, yet condones them in congenital conditions.

> Ma tale consiglio curativo, dopo aver dato luogo a molte questioni, e', per il fine suddetto, totalmente abbandonato, sicché l'amputazione rimane indicata solo per tutte le alterazioni già cognite, e da ultimo Pozzi afferma senza fornire prove, che l'ipertrofia della clitoride si verifica spesso nelle donne dedite all'onanismo col solo cambiamento delle dimensioni delle medesima (Taruffi 1898 pg. 21/321).

Taruffi's contemporary Edoardo Porro reports on the use of diagnostic surgery, also mentioned in Taruffi's text. The idea that internal evidence can be obtained from a live body is relatively new, in fact Porro comments:

> A quanto mi consta e' questo il primo caso di operazioni chirurgiche istituita per constatare indubbiamente il sesso (Porro, 1883, pg. 23).

Porro reports that the patient T.G. had requested a medical examination because he wanted to be legally declared a man. T.G. had lived 22 years as a woman, but at 18 he had already had one medical examination that legitimized his desire to live as man. T.G. was examined internally by at least six doctors in one sitting, including the rectal exam that other patients often refused. Porro proceeded to the surgical examination of the gonads, because none of the other examinations clearly indicated whether the gonads were ovaries or testicles. Taruffi comments on this case stating not only that he considers these cases of "doubtful sex" frequent, but often due to hidden testicles. This surgical intervention appears to be a technique to put the family at rest as to the true nature of their child's gender. These sentiments mirror the interventions in the era to come, which puts its faith in the revelation of internal biological factors that indicate the true sex of the individual.

These medical cases give us a clear picture of the intellectual debate that covered the

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1898 61/361.

gendered body at the end of the nineteenth century. It is perhaps less clear what was happening in the general population, and how many of these types of cases went un-noticed by those directly involved. A handful of cases shed a bit of light on this ambiguity between what doctors, scientists and legislators saw as serious issues, and what was relevant to those who fell under this medical gaze. While doctors and scientists searched ever deeper into the body to identify the biological locus of gender identity, individuals usually had no problem identifying the gender category that they felt they belonged to. Problems could arise when the gender identity conflicted with their sexual object, rendering them performative homosexual and therefore deviant.

Moving beyond the correlation to homosexual behavior, how relevant was genital appearance in heterosexual relationships? This question is extremely relevant to the rise of the interventionist model. Obviously doctors and anatomists had precise ideas about what the male and female body was supposed to look like. However, we have seen that performatively the heterosexual act was defined by penetration by one partner of the other. The case studies refer to many individuals who were "discovered" post-mortem to have had ambiguous sexual attributes. Specifically we see cases of individuals self- and socially defined as married heterosexuals, later diagnosed as having incongruent genitals. In these cases the genitals are problematic in a medical context, but not always in a hetero-normative social context.

> Ernesta N. stimata ed educata per una femmina, a 16 anni sentì una grande affezione per un giovane, ed a 17 anni e mezzo sposò un giovane del suo paese, con cui visse per 12 anni in buona intellegenza, sebbene i rapporti sessuali non potessero mai compiersi regolarmente. Rimasta vedova le inclinazioni sessuali si modificarono, ed ebbe molti amanti con cui i rapporti sessuali si compievano normalmente, ma dopo poco tempo si ammalò e mori. Alla necroscopia si trovò un pene simile a quello di un fanciullo di 12 anni affetto di ipospadia...[44]

The medical investigation of "mistaken sex" in life generally occurs when the individual begins same-sex activities. Earlier in the section, Taruffi refers to the case of Faustina Mauro, who after 10 years of marriage falls in love with a woman (who unfortunately is her brother's wife) and asks for her marriage to be annulled (Taruffi, 1898, Osservazione 66 pg. 58/702). Faustina is brought to trial in 1870 on charges of adultery with a married woman and later, in 1884 granted divorce and legal status as a man[45]. When the sexual object does not change,

[44] Magitot E. 1881 Sur un nouveau cas d-ermaphrodisme. Bulletins de la Societe d'Anthropologia. Pag. 487 in Taruffi 1898 pg. 67/367

[45] Unclear if this ruling is based on medical or Faustina's testimony.

individuals (and their lovers) are not interested in changing their gender status.

At the beginning of the nineteenth century, Vincenzio Chiarugi (1819) reports several cases of women who either "lived in happy matrimony even at her death" 46 (Chiarugi 1819 pg. 14) or were unhappy at being declared medically of the opposite sex (like Foucault's Herculine Barbin). Commenting on a French girl who was unhappily forced to change sex after medical examination, he states: "But it's inconceivable how she could have believed, to be of the female sex…(Chiarugi 1819 pg. 13)"47Chiarugi states that these cases should put experts of the art of health ("periti nell'Arte Salutare") on their guard against imposters and attempts to deceive. Taruffi's 1898 work indicates a century full of experts "on their guard".

As the medical field moves towards the twentieth century, we see hermaphrodites as deceivers replaced by medical confidence, as if a patient can only deceive when the terrain is unsure. Taruffi imparts a vision of the end of the nineteenth century that is instead sure of its diagnostic tools, hoping to reveal the hidden nature of gender under the skin, regardless of how invasive these physical exams might be.

By the beginning of the twentieth century, we can freely state that what was once called the hermaphrodite, has become fully medicalized and disappears from the social radar.

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46 "visse in tranquillo matrimonio perfino alla sua morte"

47 "Ma e' inconcepibile come abbia potuto ella credere, d'essere di sesso femminile...

Chapter 3

Intersex

3.1 *Erasing hermaphroditism, phenotype and genotype*

As the possibility of the hermaphroditic body to exist disappeared, leaving only male and female as valid medical categories, technological advances changed the direction of medicalization of gendered body. Advances in surgery finally provided the technical prowess to satisfy the desire to mold the body into its presumed ideal form (a claim of prowess that is contested by patients, even with contemporary surgical techniques; Morland 2009 pp. 285-312). Advances in endocrinology provided the technological possibility to modify the secondary sex characteristics. Advances in genetic theory would soon impose themselves on the taxonomical model and "discover" new syndromes.

In the 1990s Intersex became a term that reflected identity politics and the fight for certain bodies to exist in an increasingly medicalized world. Like many political identity categories, it is a reclaimed term, which came into being in a different context in the early twentieth century. Intersex as a medical and scientific term represents the incorporation of a genetic model of development with new interventionist technology. This paradigm conceptualizes the medical object, which shifted from hermaphroditism to pseudo-hermaphroditism to Intersex, as something that can be fixed by new theories and technologies. In 2006, yet a new term was coined, DSD (Disorders of Sex Development), in combination with a new patient care model (Feder 2009 pp. 285-287; Koyama 2006).

Many contemporary doctors and scientists who work with DSD, adopt the linguistic separation of sex and gender, along theoretical lines developed by feminists and identity politic theorists, in which sex has a biological/genetic origin and gender has a social performative role. This is one of many clear indications of how social debates have affected the development of medical theory and practice.[48] However, preludes to the social distinction between sex and gender may be found within the beginnings of genetic theory on development.

In 1911 Wilhelm Johannsen introduced the analytic separation of genotype and phenotype

[48] This linguistic distinction between sex and gender is not always present in other branches of medicine and biology. Furthermore the adoption of such terminology does not indicate an awareness or agreement with the social theories that lead to the change in terminology.

(Johannsen, 1911; Jabolonka and Lamb, 2005), which is at the crux of defining gender in Intersex cases. As we have seen in Chapter one, the beginning of the twentieth century is ripe with conceptual change. The mechanisms of the body are in a constant state of re-visualization. However, one can find strikingly different models across disciplinary boundaries, such as the developmental model found in embryology versus the atomistic model found in molecular chemistry. All of the various models however, culminate in a vision of the body as an increasingly plastic entity.

While the atomistic vision of the body may interpret the interaction between genotype and phenotype as a Mendelian one-to-one interaction, the phenotype was still seen as possibly subject to modification. The potentially unstable nature of biological gender and race were under constant scrutiny (Reis 2009, Mazzolini 2007). The fear of biological impostures, those who could pass as white or male to obtain increased rights of citizenship, would dissolve (only to some extent) as voting rights were extended to women and non-whites. This consideration is slightly altered in the Italian context where the concept of the democratic citizen went through other restrictive mutations under Fascism until the end of WWII.

Body modification in Intersex care management will become medical protocol around this time, the 1950's, whereas up until Taruffi's time it was only an experimental possibility. What we see in the shift from Hermaphrodite terminology to Intersex terminology (which still incorporates the pseudo-hermaphrodite taxonomy), is a shift from 'the intention to define' to 'the intention to intervene'.

Intersex as a word was used throughout the nineteenth century to refer to a biological construction of what is now considered homosexuality. Intersex implied 'between the sexes', where hermaphroditism could be connotated to mean 'having both sexes'. The biomedical use of the term Intersex appears first in Richard Goldschmidt's 1917 article "Intersexuality and the Endocrine Aspect of Sex" (Dreger, 1998, pg. 31). Intersexuality worked well with the rising bio-chemical development model of sex.

At the beginning of the twentieth century surgery, is no longer a life-threatening procedure, which allows for the entrance of genital surgeries en-mass into treatment of the "deviant" body. The new bio-chemical models of development envision bodily tissue as increasingly plastic and modifiable. Whereas medicalization from the sixteenth century onwards sought to establish itself as the final authority in gender determination, the body itself becomes subject to manipulation. It is not only the person who must adhere to one gender role or the other, but all of the mechanisms of the gendered body, from the secondary sex characteristics to the genitals.

The medical approach in the period that spans from Klebs' taxonomy in 1876 to John Money's interventionist protocol in the 1950's is ambiguous at best. On one hand, Dreger (1998) affirms that many practitioners assumed the gonadal model as a marker of true sex and attempted to conform their patients to their gonadal sex. However, Reis (2009) states that in the US, many doctors intervened primarily to help their patients attain a heterosexual body. There were no straightforward agreed-upon norms. Our understanding of a consolidated clinical model begins with John Money in the 1950s in the US.

3.2 *John Money and the Optimal Gender of Rearing*

Until the 2005 Chicago Consensus convention, where Intersex activists, academics and medical practitioners met in official guise for the first time to address Intersex care, John Money's Optimal Gender of Rearing model was the standard of treatment, liberally cited by Italian physicians as the standard of care until 2006[49]. While criticism of Money's model entered the public arena in the 1990's, the Consensus Convention in 2005 shook international waters, and it was no longer possible to blithely follow Money's protocol (Dreger and Herndon, 2009, pg. 206). Money's OGR protocol, which requires uninformed early childhood intervention, is in the process of being dismantled due to the trauma un-informed medicalization creates. However, at its time, the OGR offered a revolutionary approach.

Money began his research on the psychology of hermaphroditism[50] in his doctoral thesis. Money's research conclusions essentially agree with Dreger's gonadal hypothesis, that most gender assignments were still based on gonadal tissue, and that this was an inadequate measure of human gender identity. His conclusions also concurred with Reis' heterosexual hypothesis, stating "Lurking in the background, there also seemed to be a moralistic horror at the possibility of errors of sex leading to marriages between persons of the same sex" (Money (I:8) in Karkazis, 2008, pg 48). We are now aware of the irrevocable psychological damage caused by Money's model, largely due to the stigma of medical stigmatization (medical stripping/invasive exams/lack of informed consent/family secrecy), and irreversible surgical interventions (inconsistent with gender identity/destruction of sex pleasure/scarring). Money's original research, however, was committed to questioning assumptions about the biological determination of sexual orientation and gender identity, but also to some extent questioning the social prejudice attached to Intersex.

[49] Interviews Hospitals A, B, C, 2006

[50] Money's term at the time of his dissertation; Karkazis 2008

Bioethicist Katrina Karkazis shed interesting light on Money's model in her recent research, specifically by looking at his earliest findings in his doctoral thesis in which he examined 248 case studies (from 1895 to 1951) and conducted in-depth interviews with ten individuals diagnosed as hermaphrodite (Karkazis 2008, pg 49). His research questions focused on the causes of libido and sexual orientation. He determined that while hormones had profound effect on sex drive, they did not necessarily impact sexual orientation or gender identity. He found that the majority of individuals developed heterosexual behavior based on their sex of rearing, not their gonadal material. This caused him to criticize theories on the biological origins of homosexuality, and begin considering the importance of upbringing in gender identity and sexual orientation.

However, if Money had paid closer attention to one of his original findings, some of the future errors could have been avoided. In particular, one notices the low incidences of psychoses and neuroses in the Intersex cases he investigated, cases in which generally there hadn't been early childhood intervention. Money correlated these findings to his observation that the individuals who suffered most were those who had the largest differences between their physical gender, sexual orientation and their assigned gender. He decided the locus of the psychological disturbance was the differing physical gender, particularly the genitals. In hindsight, after 50 some years of early childhood genital surgery, we might ask ourselves why Money ignored the evidence that many of his case studies were not modified physically, and yet were evaluated to be psychologically healthy.

These case studies, by definition, refer to people who were in some way examined (some post-mortem), but not necessarily medicalized, indicating an invisible statistic of those not diagnosed. The most common medical rationale for the lack of follow-up research in Intersex care, is that a patient who disappears has healthily integrated into society. One could assume, using the same logic, that the statistically "invisible", non-medicalized Intersex individual, is also living a happy life out there somewhere.

Instead, attacking the gonad-centered biologically deterministic model of gender identity and sexual orientation, Money decided that changing the body (genitals) of the infant would assure future psychological health. The key issue in Intersex care continued to focus on gender assignment, but now technology was given a greater role. Johns Hopkins University instituted a multi-disciplinary team, guided by Lawson Wilkins, who had recently linked cortisol to virilization and salt-loss in CAH (Karkazis, 2008, pg.51). This team included gynecologic surgeon Howard Jones, urologist William Scott and two other psychologists besides Money, the Hampsons.

In 1955 and 1956 Money and the Hampsons published a series of articles that outlined the OGR based on the theory that children are psychosexually neutral at birth. This generally involved hormonal and surgical interventions, ideally before two years of age, which would create a uniform gender presentation. Future critics Milton Diamond and Keith Sigmundson sum up Money's second axiom, that healthy psychosexual development is dependent on the appearance of the genitals (Diamond and Sigmundson, 1997, 298-3040).

Money and the Hampsons' early papers suggested that age-appropriate information should accompany treatment (Money, Hampson and Hampson, 1955, pp. 284-300). However this position was eventually obscured by paternalistic arguments to keep patients in the dark "for their own good". Money's own interpretation of age-appropriate information still involved obscuring biological precision, by referring to Y chromosomes as a broken X chromosome[51], and using the gender-neutral term, gonads, instead of testes or ovaries. Karkazis argues that "Money and his colleagues advocated both honesty and concealment- a fact that lead many clinicians to assume that given the option, concealment might prevent more harm and engender less confusion". Dreger cites one of numerous papers in the 80's that argued "that a physician could justifiably withhold information from a sixteen-year-old AIS patient and/or her parents if he believed that the patient and/or family was likely to be incapable of handling the fact that she has testes and an XY chromosomal complement" (Minogue and Taraszewski in Dreger, 1998, pp. 24-35).[52]

In the same article Dreger analyzes one of the strange side effects of the OGR and technology on Intersex treatment:

> One of the troubling aspects of these protocols are the asymmetric ways they treat femininity and masculinity. For example, physicians appear to do far more to preserve the reproductive potential of children born with ovaries than that of children born with testes… Similarly, surgeons seem to demand far more for a penis to count as "successful" than for a vagina to count as such. Indeed, the logic behind the tendency to assign the female gender in cases of Intersexuality rests not only on the belief that boys need "adequate" penises, but also upon the opinion among surgeons that "a functional vagina can be constructed in virtually everyone [while] a functional penis is a much more difficult goal". So, for example, in a panel discussion of surgeons who treat

[51] While there are scientific theories that identify the Y chromosome as an evolutionary degraded X-chromosomes, in these cases the Y-chromosomes is simply inaccurately portrayed to hide the truth.

[52] See also Natarajan A, 1996, Medical ethics and truth telling in the case of androgen insensitivity syndrome, pp. 568–570 and the response Kemp B.D. et Al., 1996, Sex, lies and androgen insensitivity syndrome.

> Intersexuality, when one was asked, "How do you define successful intercourse? How many of these girls actually have an orgasm, for example?" a member of the panel responded, "Adequate intercourse was defined as successful vaginal penetration." (Dreger, 1998b, pp. 24-35)[53]

In the majority of cases the OGR became the optimal construction of a girl. It was said "you can make a hole but you can't build a pole." (Hendricks, 1993, pp.10-16). A phallus is seen as having to be at least 8cm. Anne Fausto Sterling explains:

> Since 1980, we have known that the average clitoral size of newborn girls is 0.345 centimeters. More recent studies show that clitoral length at birth ranges from 0.2 to0.85 centimeters. One prominent surgeon in the filed of sex reassignment surgery, when interviewed in 1994, seemed unaware that such information existed. He also thought the measurements irrelevant, arguing that for females "overall appearance" counts rather than size. Thus despite published medical information showing a range of clitoral size at birth, doctors may use only their personal impressions to decide that a baby's clitoris is "too big" to belong to a girl and must be downsized, even in cases where the child is not Intersexuals by any definition (Fausto-Sterling, 2000, pg. 60).[54]

The main difference between a phallus and a clitoris, besides the recommended length, is the meatus, the erectile tissue, which is the other concern in surgical processes in either direction. There is also evidence that penile size at birth does not correlate to size after puberty.

This combined with the lack of full disclosure and follow-up care and research has lead to the traumatic mess the medical profession is currently trying to clean up.

3.3 *Money's evidence, Joan/John and the rhetoric around "experimenting on children"*

Money's model was quickly adopted as the new cure protocol in Intersex cases from the first publications in the '50s. Psychology professor Suzanne Kessler indicates that Money's model was uniformly adapted with surprising consensus, stating "even the publications that are produced independently of Money reference him and reiterate his management philosophy" (Kessler, 1998, pg. 136). It was the first uniform model to be proposed since Young's 1917 and Taruffi's 1900 works. Karkazis argues that Money's protocol filled the previous vacuum with a detailed guide backed up by empirical evidence.

In the 70's Money's work began to receive widespread attention. To some extent, this was due to the overall push to investigate subjectivity, social conditioning and social prejudice,

[53] See also comments of John P Gearhart in Bailez M. M., et Al., 1992, p. 684

[54] See also Riley and Rosenbloom 1980, Oberfieled et al. 1989; Lee 1994 pg.59

into which Money's theories about social conditioning and gender neatly fit (Kessler, 1998, pg 7).

Most agree that we cannot learn what is best for a child by putting them in potentially harmful situations and observing what happens. Intersex activists, who criticize genital normalization surgery through the language of gender politics, request that children be allowed to decide their gender for themselves, later in life. They are, in turn, criticized as wanting to perform social experiments on children, ignoring the serious implications of social rules surrounding gender. These activist do not claim that modern society is elastic enough not to damage children who have differences or have no fixed gender, they simply do not believe gender assignment necessitates the creation of "ideal" genitals in children.

Unfortunately, part of the rational for performing early childhood genital surgeries is based on Money's social experiment with a male child, "John", who had had his penis obliterated in a circumcision accident.

John's parents saw Money on TV and contacted the Johns Hopkins clinic after a long search for some sort of solution for their child. They had repeatedly been informed that phallic reconstruction surgery was not entirely successful. Money's proposals were revolutionary and seemed to provide hard evidence that gender identity was not biologically determined.

The family agreed to let the Hopkins clinic adapt their child's body and followed their suggestions in raising, now Joan[55], as a female. Money's reports on the case seem unanimously successful, reporting Joan as interested in a series of stereotyped female activities. At some point Money lost contact with the family, but continued to found much of his theories on the success of this non-Intersex experiment. Money and the Hopkins team adhered to the theory that a patient that disappeared was a patient who had re-integrated well into society. Further Intersex treatment would be based on the reputation the Joan/John case established.

In the meantime, in the 1970's, Psychology was just about to de-pathologize homosexuality but had not yet elaborated deeper theories on gender. The Hopkins clinic continued to promote a stereotyped idea of gender identity for their patients, and negatively associate a-typical gendered behavior with homosexuality. While homosexuality was being de-pathologized for the general population, for Intersex cases it is often still interpreted as the result of wrong gender assignment or treated through hormone therapy.

[55] John and Joan are not the real names, they are instead the first names of the Hampsons.

Activist Kiira Triea irreverently questions her experience with the Hopkins's clinic:

> I've wondered why researchers at Johns Hopkins were so concerned with the genitals of a barely teenaged hermaphrodite from a family of absolutely no standing or financial resources. My experience at the PRU [Psychohormonal Research Unit] leads me to believe that a need to express and preserve androcentric control is at the root of the medical-industrial complex's fascination with my (our) genitals. The amount of medical resources that were brought to bear against a 14-year old Intersexed kid are pretty amazing, considering that life-saving surgery and treatments are routinely denied people at Hopkins (Triea in Dreger 1999, pg. 141).

Discourses surrounding the use of medical resources are obviously different in Italy's state-supported health system. However, until recently, in Italy as well, Intersex treatment was highly genital-focused and elaborately stereotyped gender-identity images. Kiira indicates that medical-social expectations for the male crossed the boundaries from surgery to psychology in a similar manner to that which Dreger outlined earlier. Kiira continues:

> Doctors act as enforcers of genital and behavioral conformity for the Penis Club. As high priests of the biological technocracy, and as privileged possessors of "secret" knowledge, they wield their power to ensure that only owners of medically approved, "viable" penis are granted membership in the Penis Club. All others are by default granted membership in the Vagina Club (Triea in Dreger 1999, pg. 141).

The definitional power of medicine is evident in the Transgender political/legal struggle in regards to who can access the right to have the genitals they prefer. Transsexual experiences are generally the opposite those of Intersex children in that one group actively seeks genital surgery, and the other is seen as necessitating genital surgery. In both cases on an international level, until recently, it was an outside authority to make this decision for the individual, evaluating whether this person fit in one gender category or another, independent of what they themselves felt.

Kiira indicates that the scientific measures of gender identity, at the time, highly sexualized the already stereotyped assumptions.

> Hopkins doctors view themselves as compassionate, helpful people who save lives and alleviate suffering. They assumed since I was raised as a boy, I must want to become a member of the Penis Club. They attempted to utilize technical means to alleviate my suffering as a "defective male"…when I first arrived at the PRU, I was evaluated by John Money. He assumed that I had a male gender and, being 14 years old, knew the "facts of life". He asked me if I wanted to fuck someone or if I wanted to be fucked by someone else. Since I didn't completely understand what he was talking about, he showed me a pornographic movie, in which a guy with an immense penis had

> rough, almost violent, penetrative sex with a woman, Money had drawn another blank, as the movie did nothing but frighten me (Triea in Dreger 1999, pg. 142).

Many activists address the inappropriate way the treatment of DSD hyper-sexualizes children. Dilatation techniques as well as repeated genital medical examinations, not to mention genital surgery, draw the child's attention to their genitals, often without giving them the emotional tool to understand why so much attention is being paid to parts of their body they have come to understand as private. The average five-year-old already associates their genitals with embarrassment and varying levels of shame in Western societies. Activists call this experience medical stripping in regards to the attention paid to their bodies, and medical rape when touching is involved.

The medical 'gaze' and the objectification of the body are imperative to the discussion of the construction of pathology as external to lived experience, and therefore especially relevant to discussions of medicine and children.

> What was fundamentally invisible suddenly offered to the brightness of the gaze, in a movement of appearance so simple, so immediate that it seems to be the natural consequence of a more highly developed experience. It is as if for the first time for thousands of years, doctors, free at last of theories and chimeras, agreed to approach the object of their experience with the purity of an unprejudiced gaze (Foucault, 1963, pg195).

Foucault uses poetic irony to depict his version of the medical idealism of the time. There is the intersection of medicine finally entering the body, and the illusion of an unprejudiced gaze. All of the medical accounts of hermaphrodites, except one, come to us from medical journals in which the doctors speak for the patients. The depictions of the patients and the colored language of the doctors paints only a vague picture of the experience of the patient.

The medical journals and subsequent modern texts on DSD are full of pictures. Pictures of genitals with hands that position them to show better their distinctive qualities. Pictures of people half undressed to highlight the secondary sex characteristics that render them ambiguous, occasionally with bags over their heads. Within the text, the process by which the depth of the vaginal canal is ascertained is described, leading one to imagine the amount of palpating the patient must experience. This combined with the discussed fear of inadvertently 'creating' homosexuals through incorrect gender assignment, and continual reference to the patient as abnormal and/or the fact that they are not what they think they are.

Dreger (1999) makes a poignant visual point on the cover of *Intersex in the Age of Ethics*, by representing all of the individuals, Intersex or not, fully clothed in normal comfortable

positions. She instead is in the center, naked with the medical measuring board behind her, with her eyes covered to 'hide her identity'. The medical eye, instead, goes inward to the internal anatomy of the patient, and perhaps leaves their humanity undefended on the outside.

> In 1992, Lisa Blumberg broke a secret surrounding a medical procedure she termed public stripping. What she is referring to is a common but mostly unspoken practice of making children with rare disabilities and birth conditions take off clothes so that they can be displayed to a large number of medical professionals and students. Children are ordered to take different poses to expose different body parts and angles and are sometimes photographed. While some may argue that such practice is sometimes necessary for research and educational purposes, but there is little evidence that medical professionals involved paid efforts to minimize and repair the psychological damages from the experience. Many of these children were deeply traumatized by this experience into their adulthood, and yet could not speak out about it because of shame and isolation (Koyama 2006).

What is created then, with the birth of the clinic is a certain authority of knowledge, and with that knowledge, a certain authority over the body that renders the individual invisible. As we have seen in the brief discussion of the development of surgery, many of the first patients were not in a position to negotiate their treatment, the pain involved or the risk to their life. As we move towards the age of lawyers and informed consent, one would expect the individual to reappear. The examination process generally focuses on providing scientific information on which to base gender assignment or the need for eventual treatment. However in the search for evidence, the needs of the patient are lost.

> Like earthlings faced with the arrival of some sensitive and mysterious alien, the PRU psych squads continued their attempts to divine the hermaphrodite creature's "true sex." Not having the sensitivity or intelligence to obtain this information by asking, they decided to inject me with testosterone and observe the results… My reaction to testosterone was considered a litmus test for my eligibility for the Penis Club, and it was a test I failed completely. At this point they reconsidered their labeling of my gender. Money now decided that I was a "failed male," i.e., female…Since I had declined membership ("failed") as a Penis Club initiate, it was of paramount importance to make me a member of the Vagina Club as soon as possible…As a member of the Vagina Club I was treated differently at the PRU. Money no longer talked to me of fucking and being fucked…I don't remember hearing the words "orgasm" or "lesbian" the entire time I was there, over three years…I seriously doubt that Dr. Howard Jones, who performed genital surgery on me, paid any consideration at all to that function. I have no clitoris at all…The object was to make the hermaphrodite fuckable (Triea in Dreger 1999, pg. 142-3).

Triea's testimony is important also because she was treated directly by Money, who to a large extent set the standard not only for DSD management, but the type of interaction the professional was to have with the subject. Members of the Italian DSD patient groups observe similar patterns in the consideration of the intersection of sexual pleasure and male and female identity. Where this now seems obvious, in the case of clitoral reduction or clitorectomy, we will see it also emerge in techniques that evaluate post-operative sexual satisfaction and in the medical object of hormonal therapies.

We have observed that many of the technologies involved in DSD treatment are fruit of little more than a century of scientific investigation. This, at times, makes it difficult to draw the line between whether a given clinic is using experimental techniques or experimenting on children. Since 2000, a Canadian surgical group has been developing a technique that would potentially be reversible, cutting down on scar tissue and embedding tissue in the body instead of removing it (Pippi 2006). They claim to have developed this technique in order to save healthy tissue, when the parents insist on early surgery. Attempts to develop surgery that would both eliminate social anxiety by reducing the clitoral size and yet maintain clitoral sensation can be found from the 1960's onward (Stringer and Oldham, 2005, pg. 597).

On the other hand, a Cornell research project has come under attack for experimenting with similar surgical procedures that would reduce the clitoris without sensation loss. The researcher verified his results by stimulating the clitoris of the child (from five years old) in front of her parents in repeated exams (Dreger and Feder, 2010 pp.1598-1601). This was in 2007.

Intersex treatment continues to be marked by a strange lack of scientific process, such as long-term research projects and the application of ethical standards in patient care. The Canadian group's research indicates clitoral enlargement as one of the main factors in timing the clitoroplastic intervention (Pippi 2007 pg. 26), however it remains unclear to whom clitoroplasty is important: doctors, parents or patients?

The large clitoris was one of Taruffi's obsessions, barely disguised as the investigation of the biological bases of immoral behavior, female promiscuity and homosexuality. Dreger and Feder indicate the misplacement of scientific process in regards to theories about the clitoris and female sexual health.

> For over a decade, many people (including us) have criticized this surgical practice. Critics in medicine, bioethics, and patient advocacy have questioned the surgery's necessity, safety, and efficacy. We still know of no evidence that a large clitoris increases psychological risk (so is the surgery even necessary?), and we do know of substantial anecdotal evidence that it does not

increase risk. Importantly, there also seems to be evidence that clitoroplasties performed in infancy do increase risk – of harm to physical and sexual functioning, as well as psychosocial harm.

But we are not writing today to again bring attention to the surgeries themselves. Rather, we are writing to express our shock and concern over the follow-up examination techniques described in the 2007 article by Yang, Felsen, and Poppas…Here more specifically is, apparently, what is happening: At annual visits after the surgery, while a parent watches, Poppas touches the daughter's surgically shortened clitoris with a cotton-tip applicator and/or with a "vibratory device," and the girl is asked to report to Poppas how strongly she feels him touching her clitoris. Using the vibrator, he also touches her on her inner thigh, her labia minora, and the introitus of her vagina, asking her to report, on a scale of 0 (no sensation) to 5 (maximum), how strongly she feels the touch. Yang, Felsen, and Poppas also report a "capillary perfusion testing," which means a physician or nurse pushes a finger nail on the girl's clitoris to see if the blood goes away and comes back, a sign of healthy tissue. Poppas has indicated in this article and elsewhere that ideally he seeks to conduct annual exams with these girls (Dreger and Feder 2010).

Returning to the case that made John Money an icon in the 70's, we find that the John/Joan experiment does not have a happy ending. The family lost touch with the Hopkins' clinic on purpose. Their child, around the age of puberty, had been told about the original incident and expressed the desire to live his life as a male. He had a second reconstruction surgery and went on to marry. Other popular media circumstances put him in touch with Milton Diamond, an endocrinologist who attacked Money on two fronts, social determinism and early childhood surgery. John then went public with his life story, which in turn, lead to the book in 2000, *As Nature Made Him,* by John Colapinto, a Rolling Stones Magazine reporter.

Diamond's endocrinological training led him to be critical of Money from the start, damaging Diamond's career to some extent (Fausto-Sterling, 2000, pp. 67-71). He disagreed not only with Money's psycho-sexually neutral model, but also with the idea that genital appearance was essential to gender identity. Diamond therefore became, indirectly, the first substantial critic of early genital surgery. Karkazis points out, however, that unfortunately, Diamond's criticism follows the same assumptions as Money, that stereotyped behavior indicates gender identity, simply shifting the biological indicator from genitals to hormones, replicating the older biologically deterministic model (Karkazis, 2008, pg.74). Bernice Hausman discusses the confusion in the overlapping biological and social models:

Diamond and Sigmundson assume that gender both precedes and follows from sex-the male predisposition to 'act like a boy'-but it and the 'actual behavior' of the boy need reinforcement 'in daily interactions.'[They thus maintain] their claim about gender's innateness at the same time they

acknowledge gender as the result of social focus (Hausman in Karkazis 2008 pg 74).

Regardless of whether biological factors such as hormones, or social factors such as family environment, have more influence in forming gender identity, gender itself is a culturally bound practice. The reoccurring biologically-influenced model would at first continue to promote a confusion in terms, combining gender identity, gendered behavior, and sexual orientation.

John eventually committed suicide. While John's case helped push the scales back to the biological model of gender identity, the locus of the pain that lead him to suicide seems to lie elsewhere. John's gender identity and role was accepted by those around him, remaining largely undisputed. In the article that Money wrote in response to Diamond's attacks (Karkazis, 2008, pg 75), he lists the potential reasons for John's rejection of a female gender identity, that seem to be instead indicators of the trauma that might have lead John to suicide: the trauma of silence, shame and surgery. Money himself wondered if the social stigma surrounding lesbianism lead the family to help John reclaim a male identity. Both sides of the nature/nurture debate continued to get lost in the maze in which sexual orientation is linked to gender identity.

3.4 *From biological determinism to social determinism and back again*

The debate about gender assignment was then back on the table, and the popular trend was returning to a biological model. Karkazis indicates the rise in that period, of articles in which individuals who had been "made female" in childhood, later asked for gender reassignment. Urologist-turned-child psychologist, William Reiner started in the 1980's to promote hormonal imprinting theory, which placed prenatal hormone levels as the locus of gender identity (Karkazis, 2008, pp. 77-79). Hormonal imprinting was mentioned by Money's team in 1957, but they instead sided with social influences as being primary in gender identity formation (Money et Al., 1957, pp. 333-336). Reiner's version of hormonal imprinting was still referenced in Italy in 2006, while up until that time they also utilized Money's protocol of interventionist Intersex management[56].

Hormones certainly have a role in shaping the gendered body, and Reiner believed they also shaped gender identity independent of the form of the body. Yet again, gender identity in research was reflected through sexual preference and stereotyped behavior, instead of focusing on expressed identity. Karkazis notes that "desire for females is seen as conclusive

[56] Interviews 2006 Hospital A

evidence of a male gender identity". Much of biologically-based gender research looked at the stereotyped behavior and worked backwards, assuming a hormonal prenatal origin, that had never actually been measured.

However the terrain was changing from the 1980's to the 1990's, by means of the cultural shift to recognize transexuality and homosexuality. This has lead to the separation of the concepts of sexuality, gender identity and gendered behavior, but also to a deeper analysis of the causal model. Meta-analysis indicates that human cultures generally recognize male and female as primary gender categories. However, in different historical periods and different territories, the cultural practice of embodying these categories changes drastically. Some cultural practices allow for a continuum of gender expression, or gender categories that are feminine or masculine without being defined in the same way as male or female, representing a third or fourth gender category.

Anthropologist Gilbert Herdt reads the concept of gender as essentially social and highlights how gender is always tied to practice. "In short, the emergence of a historical category of the gendered self was gradually attached to sex roles, leading to more explicit sexual-dimorphic ideas crystallized in the scientific and technological (in Foucault's sense) discourse of ancient Greece." (Herdt, 1994, pg. 54). Scientific knowledge about the model impacts on those same concepts and practices. Gender remains, in Mauss's terms, a technique of the body, as embodied action, not a biological entity.

Finding what behavior may indicate which gender category, is a slippery object, where every rule has at least ten exceptions. From talking more, to talking less, to mathematic ability, to rough play, the only thing that remains consistent across cultures is the attachment of a ranking value system to behavior that is considered gendered. The cross-cultural studies of linguist Deborah Cameron support the theory that "both sexes' behavior is influenced by the power structures of the wider society." (Cameron, 2007, pg. 78). Cameron indicates that, in a male dominant society, the stereotype of female communication will correspond to what is less prestigious or valued by that society. This can be seen in culturally specific racial stereotyping as well, where the outside group will come to embody what is already seen as negative for the self-identified indigenous group. As we have seen in Reis's work, both gender and race were given biological explanations tied to negative stereotyping from the 18th century onward.

We have hinted before that the pathological category of Intersex was expanding; more bodies were to be included in the deviant category. Advances in visualization bio-tech increased the possibility to speculate over hormone levels and new found genetic markers.

The return to a biological causal-model through endocrinology was able to ignore the culturally-relative aspect of gendered behavior because of the amazing discoveries of what hormones actually seemed to do. Some prime examples were to be seen in the treatment of transgender individuals, Congenital Adrenal Hyperplasia (CAH) and 5-alpha reductase. While originally used to support a hormone centered causal model, the inconsistencies in the same model would instead lead to something else entirely.

Reiner formed part of his hormonal imprinting theory on his experience performing phalloplasty on a non-Intersex fourteen-year-old, born female, who had a male gender identity (Reiner 1996 in Karkazis 2008 pg. 77). Reiner decided that this person must have had a high androgen pre-natal environment, because their male gender identity, which he correlated to their behavior and sexual orientation, was so obviously male to him. He also observed multiple cases of non-Intersex (although often considered in the category of DSD), phallic abnormalities as seen in cloacal exstrophy that had been assigned the female gender at birth. In these cases, he observed that of 33 patients, 19 had re-assigned to a male identity (Karkazis, 2008, pg. 78). In self-identified males, he describes unanimously male behavior primarily based on stereotyped play behavior. There was no testing of pre-natal hormone levels in these cases. However there was consistent male gender identity without the presence of male genitals.

Anthropologist Harold Garfinkel was among the first to observe the arbitrary nature of genital structure in identity formation. He observed Transsexual women who passed as heterosexual women, acquiring what he termed “cultural genitals” though the practice of living as a woman (Herdt, 1994, pg. 59). What has emerged through increased awareness of the transgender experience, which is increased subjective testimonials, is that in these cases hormonal therapy has effects on the body, libido and mood, not gender identity, gendered behavior, or sexual orientation. A transgender person will spend some amount of time in their life convincing a medical authority of precisely this, that they have always felt to be a different gender from the one assigned at birth, that their sexual object will remain the same even if their legal gender category changes, that their gendered behavior is already consistent with their gender identity. Hormonal therapy serves to shift their body presentation, but often also has the emotional effect of making people feel “more like themselves”.

Reiner moved on to observe Intersex cases, finding in the CAH diagnosis actual evidence of high pre-natal androgen levels. He, among others, promoted the theory that girls with CAH developed male identities and lesbian sexual behavior based on this pre-natal hormonal imprinting. Even at first glance one can see the contradiction in terms. If they have a male

gender identity and are attracted to girls, they are betraying heterosexual behavior, not lesbian — to be a lesbian, one must identify as a female. The Italian CAH patient group (ISC), repeatedly insists in their communications that their children do not show increased tendency to lesbian behavior[57], while they do observe more aggressive play behavior in their female identified CAH children. Therefore, they have an a-typical gendered behavior with an unvaried gender identity. There are people with this diagnosis, (as well as XX people without), who instead have a male gender identity. Karkazis relays other clinical observations:

> As Dr. T (a clinician and researcher I spoke with informally) wryly observed, "If Reiner was so right, *all* 46,XX infants [with classical CAH] would declare themselves male by age two, irrespective of gender assignment." (Karkazis, 2008, pg. 82).[58]

Activist Thea Hillman was medicalized hormonally for CAH, diagnosed due to early onset puberty[59]. As her political involvement in the Intersex movement grew, she began to question the normalization of the female appearance of her body through hormone treatment, and slowly stopped taking what had always been considered necessary medicine. This had effects on her moods, and her body, but not on her sexual orientation, or her gender identity. She doubts that her sexual identity is related to CAH, noting the variance of hormonal levels in both heterosexual and homosexually identified non-DSD individuals. She states what was medicalized in her body was simply her gender presentation.

Karkazis justly observes "These are not simply academic arguments: treatment hinges on these theories. As a result, debates over gender assignment do not concern all Intersex conditions, but primarily those exhibiting gender-atypical prenatal androgen exposure." (Karkazis, 2008, pg. 80). The primary empirically-consistent effect of these androgen levels is genital form and size. As we have seen, beliefs about technical limitations had generally lead to feminization of the Intersex body. The clinical debate continued to focus on gender identity, shifting from a genitally-based to a hormonally-based theory.

Genetic testing gave a new name, 5-alpha reductase deficiency, to a cultural experience in which a female child experienced physical virilization at puberty. This experience had been witnessed in Dominican Republic and among the Sambia of Papua, New Guinea where the genetic marker has been found to have high frequency (Herdt, 1994, pg. 420). The syndrome

[57] This observation is also invariably influenced by the homophobia exhibited by the parents in the group.

[58] *all* my emphasis.

[59] Phone interview 11/2009, Hillman, 2008

5-alpha reductase is linked to a deficiency of the 4-steroid 5-alpha reductase enzyme, which impairs the metabolism/transformation of testosterone to dihydrotestosterone (DHT). DHT mediates some of the prenatal genital differentiation, and the infant with this syndrome will have a female genital appearance, that will masculinize at puberty's hormonal onslaught.

Ethnographic data in the Dominican Republic and Papua, New Guinea indicate that most of the people with this syndrome are raised as females, and most at puberty change to the masculine gender role. Since the discovery of the genetic marker, case studies in the US and Italy have correlated this data regarding adult gender identity (Imperato-McGinley Julliane et al., 1974; 1979).

The male gender identity outcome of the syndrome was often interpreted as the triumph of nature of socialization. However, the passing from the female social gender category to the male was enabled by physical changes, not the individual expression of gender identity. Herdt indicates that in the cases in the Dominican Republic, there are several factors that have been overlooked: the local frequency of the syndrome, the local recognition of the syndrome as a third biological sex (possibility within a bi-gender system), the local gender hierarchy, and the evidence that not all individuals with the syndrome assume a male gender identity.

Herdt argues that these factors point to a strong social pressure for these individuals to assume the socially advantageous male gender role, while still being subject to the social label of third sex. Herdt highlights a case in Papua New Guinea where a heterosexual male identity was assumed only after the individual had been married as woman, exposed as kwolu-aatmwol (local name for 5-alpha reductase), physically threatened by her then husband and humiliated (Herdt, 1996, pg. 437). These cases serve as a reminder that gender is an interactional performative social category, the interpretation of which is highly influenced by biological factors.

Bio-medicine decided, based on American research in the late 70's, that this syndrome indicated a male gender identity. The bio-medical causal explanation was the hormonal prenatal imprinting of testosterone, uninfluenced by the absence of DHT. In the end, it is possibly not crucial to decide whether this syndrome generally leads to male gender identity because of hormonal imprinting or a variation of social conditioning. The biomedical verdict indicated that it was better to raise these children as males, which caused a small revolution.

Seeing as phalloplastic techniques were still considered (even now) to be inferior to vaginoplasty, a handful of doctors began to council against early childhood genital surgery for this one syndrome. As we will discuss in further detail in chapter 8, this has had interesting ramifications in the clinic, in Italy starting with the introduction of routine DSD genetic

testing in 2000. Increased genetic testing has added another factor to the puzzle of biological influence on gender identity, often revealing the multileveled process of development. The emergence of new syndromes, new technologies, and the acceptance that gender identity, gendered behavior and sexual orientation are independent factors, has lead to the need for an interactive model. But, possibly more important, the emergence of an Intersex activist movement in 1993 highlighted the need to listen to what the patients were actually experiencing.

3.5 *Towards a Patient Centered Care Model, from Intersex to DSD*

We can already see that the terms Hermaphrodite and Intersex refer to a gender-based, that is, socially-defined identity while DSD is very specifically worded as a medical category. In their diagnostic wording however, DSD syndromes often refer to the same social issues such as gender role and gender presentation. This focus on gender role highlights legal and social issues in Western society. Although homosexuality is no longer a pathological category in psychology, gender dysphoria is, and we can still find many papers that indicate heterosexuality as indication of correct gender assignment in DSD cases. In the United States and Italy, homosexuals are not allowed full citizenship rights such as marriage and the ability to give citizenship to a life partner[60], so we could say it is still socially advantageous to be heterosexual.

One of the particularities of Intersex and now DSD discourse is the separation into individual syndromes. The twentieth century has seen an increased level of medicalization, advances in surgical techniques, and endocrinology, breaking away from Hermaphrodite and pseudo-hermaphrodite terminology to that of Intersex and individual syndromes. Definitions such as male pseudo-hermaphrodite become: the Syndrome of Morris and later Androgen Insensitivity Syndrome.

The switch to DSD was initiated in 2005 and has been advancing rapidly even though it is not universality accepted. Emi Koyama of the Intersex Initiative writes:

> DSD is an acronym for "Disorders of Sex Development." Defined as "congenital conditions in which development of chromosomal, gonadal, or anatomical sex is atypical," DSD was designed to replace archaic terms "true hermaphrodite" and male and female "pseudo-hermaphrodite," as well as the imprecise term "Intersex." However, DSD is not simply synonymous with "Intersex." While

[60] Same-sex marriage is available in some US states as of 2010, but does not apply to national regulation that allows for sponsoring of a spouse for US citizenship.

"hermaphrodite" and "Intersex" both clearly refer to the whole person (despite attempts to use clever derivatives to name conditions rather than persons, such as "Intersex condition" or "hermaphroditism"), "DSD" is specifically construed as a medical condition. In other words, "Intersex" is often about who one is; "DSD" is a condition she or he may have (Koyama 2008).

The first Intersex patient group to make a large impact on medical policy was ISNA (Intersex Society of North America), founded by Cheryl Chase in 1993. ISNA closed its doors in 2008 (while still maintaining the internet platform), and in the same year, the Accord Alliance was established using DSD terminology. Two members of ISNA participated along with medical practitioners in the DSD Consortium and the Consensus convention in which the new terminology of DSD was agreed on. Emi Koyama, formerly of ISNA, now of the group Intersex Initiative, indicates that both terms are useful in different arenas. Instead OII (Organization International Intersex) is strongly opposed to DSD terminology stating that it only increases medicalization, continues stigma through the use of the term 'disorder' and reinforces the homophobia, transphobia imbedded in the treatment of Intersex/DSD. ISNA states its position:

> Over the past year, we have begun to use the term "disorders of sex development," or DSD, in place of "Intersex" in these contexts. It's not our intention to make Intersex an entirely medical issue. But we are addressing people working in a medical context. We have found that the word DSD is much less charged than "Intersex," and that it makes our message of patient-centered care much more accessible to parents and doctors. Our aim is to meet them where they are.
>
> What is a "disorder"?
>
> Intersex itself is not a disorder, rather a variation. But Congenital Adrenal Hyperplasia, for instance, is an inherited disorder affecting adrenal function. Many women with Androgen Insensitivity Syndrome have become comfortable with the term AIS, which is based on "syndrome." But "syndrome" is a pattern of symptoms indicative of some disease or disorder. "Disorder" refers to the underlying cause, not Intersexuality itself, and certainly not to the whole person.
>
> What about "Intersex"?
>
> That said, there is so much more to Intersexuality than the medical context. ISNA certainly doesn't mean to tell Intersex adults or support or activist groups what language they should use. If "Intersex" is working for you, by all means use it![61]

[61] Why is ISNA using "DSD"?, Submitted by ISNA on Wed, 05/24/2006

Many advocate for a less stigmatizing term, Divergence of Sex Differentiation (Reis, 2009, pg. 153), arguing that the term Disorder continues to promote prejudice. Many groups that organize around individual syndromes, as opposed to the Intersex identity terminology, are more inclined towards DSD in that it speaks to medicalization issues instead of gender issues. The controversy of terminology exists within and without the syndromes. The first Intersex passport was awarded in Australia in 2003 to Alexander MacFarlane, diagnosed with Klinefelter syndrome (Butler 2003). Members of an Australian CAH group instead requested not to be required to use the Intersex category, stating that CAH does not always manifest in gender variance. The CAH group's position betrays the continuing fear of stigmatization through terminology. However, in Australia Intersex categorization is far from mandatory, and it is still difficult to obtain a gender-neutral passport[62].

The reclamation of stigmatizing terminology was important to the original US patient movement. The first groups liberally used the terms Hermaphrodite and Intersex to expose the social normalizing practices involved in the care model. The first patient groups, ISNA and Hermaphrodites With Attitude, were in turn directly supported by gender-politic groups and the Trans movement. This identity-politics alliance asked, why force on children genital surgeries that are denied to consenting adults? The first line activism of the groups was antagonistic, holding protests at medical conventions and publicly giving voice to the aspects of Intersex care that had been intentionally kept secret.

Within less than ten years, however, ISNA and other groups had found medical allies and shifted from a purely antagonistic model to one of collaboration. As reflected in Steven Epstein's work on HIV activism, at some point the activists gained expert status and negotiating power. This process has occurred as well in Italy, very rapidly. However the Italian patient group process does not follow the same progression. The Italian groups do not seek alliances with gender identity politics, and as we will see, focus specifically on medicalization.

The Italian groups generally formed in the dark, completely deprived of accurate information about the syndrome. An individual with a Klinefelter diagnosis might be told they wouldn't live past 40, and an AIS woman might be told not to have sex. Therefore their first line actions were focused on full disclosure and promoting research on care options. The AIS

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http://www.isna.org/node/1066

[62] There is no substantial evidence that passports would be easier to falsify if gender was removed from the descriptive categories.

group encountered doctors in esteemed DSD care centers in Rome, who did not know about vaginal dilatation techniques. The group members quickly became scientifically proficient and experts, in order to help distribute accurate information. After studying care options for 5 years, certain Italian groups are beginning to more aggressively criticize early childhood surgery. Whereas not initially critical of a normalizing care protocol, the awareness that there are other less harmful options, has redirected their position.

The American (and French/Canadian) groups started by attacking the surgical fix and the subsequent shame and secrecy. In the end, the groups reflect the same concerns. ISNA states:

> The Intersex Society of North America (ISNA) is devoted to systemic change to end shame, secrecy, and unwanted genital surgeries for people born with an anatomy that someone decided is not standard for male or female. We have learned from listening to individuals and families dealing with Intersex that: Intersexuality is primarily a problem of stigma and trauma, not gender. Parents' distress must not be treated by surgery on the child. Professional mental health care is essential. Honest, complete disclosure is good medicine. All children should be assigned as boy or girl, without early surgery.[63]

The Italian groups concentrate on full disclosure, hoping to shift the decision process from the health care provider to the parent. They are generally less critical if the parent decides on normalizing surgery, however, they often indicate that that decision is forced on parents through misinformation and heavily stigmatizing medical communication. Taking these factors into account, the Italian groups collaborate with doctors and push for useful medicalization. Activist Emi Koyama elucidates the shift from the gender identity paradigm to a critique of medicalization:

> The discourse surrounding useful medicalization is represented by the disability politics discourse. Disability politics identifies the pathologization process as a medical expression of social stigma.
>
> While most people understand the word "disability" to refer to a list of physical characteristics that cause difficulties or inconveniences to people who possess them or those around them, and from that point of view one could argue that Intersex has nothing to do with disability because it does not cause any difficulties or inconveniences on its own. But to a disability theorist, disability is not simply a characteristic of one's body, but the product of social institutions that divide human bodies into normal and abnormal, privileging certain bodies over others.

[63] http://www.isna.org/index.php accessed 21/10/10

In this view, the physical condition that necessitate the use of a wheelchair in order to move about is not itself a disability; social and architectural structures that deprives a wheelchair user of full participation in the society is what disables her. Similarly, Intersex activist Esther Morris's observation that "not having a vagina was not my problem; having to get one was," can be paraphrased to say: not having a vagina was not a disability; the social expectation that she needed to get one in order to live happy and productive life marked her body disabled (Koyama 2006).

In an overview study of the history of the Intersex rights movement, Alice Dreger and April Herndon indicate that by 2004 the terrain has drastically shifted.

Since about 2004, there has been a marked increase in interest among clinicians to reform practice. For example, thanks to the initiative of the feminist academic sociologist Monica Casper, who served as ISNA's executive director in 2003, ISNA developed a medical advisory board of approximately twenty-five people, most of them clinicians[64], something that seemed a distant dream as late as 1998. In 2004, at the American Academy of Pediatrics Section on Urology meeting, many clinicians were clearly agonizing over the choice of treatment in Intersex cases. Even surgeons who had historically been ardent defenders of the OGR model were publicly expressing serious reservations. In October 2005 the highly influential Lawson Wilkins Endocrine Society and the European Society for Pediatric Endocrinology held a consensus meeting in Chicago that resulted in a hopeful degree of movement toward providing more psychosocial care, peer support, truth telling, informed consent, and outcomes data.[65]

In the same period another working group formed to put into writing a new care model. This group was formed of Intersex patients, parents and clinicians. Their indications are called a Patient Centered Care model, which are outlined in both a parent handbook and a clinicians handbook. The PCC model seeks to replace the optimum gender of rearing (OGR) model developed by John Money and his colleagues at John Hopkins University in the 1950's (Money 1955). As we have seen the OGR focuses on fixing gender assignment through surgical intervention, reinforcing gender identity as the primary concern in Intersex disorders. The patient-centered care model seeks to address some of the controversy created through a non-informed surgery model, as well as reorienting the medical focus towards physiological issues such as cardiac health and bone density. The principles outlined in the patient-centered care model are representative of the lines of conflict indicated by patient support groups:

[64] The Italian group AISIA formed a scientific committee in early 2010, including a surgeon who had earlier been an advocate of early childhood surgery, who had recently changed position.

[65] Dreger and Herndon in Morland 2009 pg. 205-6; Dreger in Huisman, Harley (Ed.) 2004 pp. 390-409,

(1) Provide medical and surgical care when dealing with a complication that represents a real and present threat to the patient's physical well-being.

(2) Recognize that what is normal for one individual may not be what is normal for others; care providers should not seek to force the patient into a social norm (e.g., for phallic size or gender-typical behaviors) that may harm the patient.

(3) Minimize the potential for the patient and family to feel ashamed, stigmatized, or overly obsessed with genital appearance; avoid the use of stigmatizing terminology (like pseudo-hermaphroditism) and medical photography; promote openness (the opposite of shame) and positive connection with others, avoid a "parade of white coats" and repetitive genital exams, especially those involving measurements of genitalia.

(4) Delay elective surgical and hormonal treatments until the patient can actively participate in decision-making about how his or her own body will look, feel, and function; when surgery and hormone treatments are considered, health care professionals must ask themselves whether they are truly needed for the benefit of the child or are being offered to allay parental distress; mental health professionals can help assess this.

(5) Respect parents by addressing their concerns and distress empathetically, honestly, and directly; if parents need mental health care, this means helping them obtain it.

(6) Directly address the child's psychosocial distress (if any) with the efforts of psychosocial professionals and peer support.

(7) Always tell the truth to the family and the child; answer questions promptly and honestly, which includes being open about the patient's medical history and about clinical uncertainty where it exists. (Intersex Society of North America 2006)

It is still early to tell if the change in terminology from Intersex to DSD is accompanied by a change in treatment as is hoped. Terminology is not deterministically linked to social paradigms. One would expect the terminology of pseudo-hermaphrodite to reflect social mores of the 17-century and DSD to reflect progressive 21century gender and disability politic but this is not always the case. For example, a research paper from Hungary that raised contemporary bioethics issues on how pathology is communicated for Klinefelter's syndrome didn't use DSD but the outdated and stigmatizing male pseudo-hermaphrodite terminology (Göllü, 2007).

In 2006, an international medical conference on Intersex was held in Rome, frequented by doctors from a wide range of countries, where simultaneous translation to English was provided. The newly formed AISIA (still in unofficial form) had a table with their poster

presentation. Participating physician Dr. Ian Hughes presented the consensus consortium's clinical guidelines for a new model of patient-centered care and the new DSD terminology (Hughes 2006). AISIA in 2009 translated and published on their website the Italian version of the parent handbook. In the future they hope to edit the handbook to reflect the Italian context, from negotiating the public health system to information sharing. Public health can often mean standardization that impedes individual care while at the same time providing free help. Many AISIA members do not get free hormonal replacement therapy, because they would have to use the stigmatizing health code of pseudo-hermaphrodite.

Parallel to the presentation of these guidelines at the 2006 convention, one of the main DSD treatment centers in Rome presented its newly formed treatment team, composed of a psychologist, surgeon, endocrinologist and geneticist, highlighting a desire to follow the consensus convention guidelines. However, these half-day presentations, were followed by a day and a half of presentations of new surgical techniques. Overall, there seemed to be a disparity between the new clinical patient-centered model and the time devoted to surgical technique. However, one cannot expect a paradigm shift to be enacted in a day. In chapter seven, we will more closely examine the concrete changes in DSD treatment since the formation of patient groups.

Part Two

Ethnography

As I began to research Intersex in 2006, several things were mutating in ways that would have a large impact on what was happening in Italy. First was the international change in terminology to DSD, which took root immediately. The second was the formation of DSD patient groups also in Italy, which would demand the introduction of a new era of DSD care. I first met members of what would become AISIA (Associazione Italiana Sindrome da Insensibilità agli Androgeni) at the International conference on Intersex in Rome in May 2006. While we sat through three days of primarily surgical presentations, we talked about their experiences and what they hoped to see change in the future.

As is the case at the beginning of most research projects, I had a simplified idea of what was the discourse surrounding DSD and what were the various positions of those involved. In my direct research period, from 2006 to 2010, I have seen these positions shift, particularly those of the medical practitioners, probably due to the increased dialogue between practitioners and patients. These positions are complicated and individual, not part of a hegemonic scheme to medicalize and normalize the gendered body. However, the end result has often appeared to be such. As Katrina Karkazis (2008) suggests in *Fixing Sex*, even the doctors who appear to be the bad guys, are still generally trying to help patients in a complicated playing field. Determined to get a full picture, I began to interview practitioners from the medical fields interested in DSD, endocrinologists, surgeons, psychologists, geneticists, in both adult and pediatric departments, as well as following the patient groups.

In 2010 AISIA formed a scientific board *(comitato scientifico*) consisting of a surgeon, two endocrinologists, a psychologist and a patient who is also a medical student. This collaboration represents the primary difference in the development of DSD politics in Italy and other contexts. As we have touched on earlier, Intersex identity politics are dominated by the English language and have origins in a specific US context that include queer and gender theory in the greater discourse. The Italian DSD discourse is dominated by the analysis of medicalization, localizing its methods in disability politics, while this is not directly explicated.

The Italian patient groups are not pan-Intersex and do not engage directly in a gendered discourse or an anti-normalizing platform. Their first line agendas are de-stigmatization and

useful medicalization. One of the key aspects that has come out of my work with AISIA and KIO (Klinefelter Italia Onlus) in Italy, is the use of collaboration with hospitals and doctors to subvert the dominant care model. In directing attention towards physiological health concerns, they redirect attention away from gender assignment and genital surgery.

There are multiple ways that supports groups have been regarded in anthropology and science studies, from Nikolas Rose and Carlos Novak's (2000) *Genetic risk and the birth of the somatic individual* that addresses the socialization of genetically probable syndromes to Steven Epstein's (1998) *Impure Science: AIDS, Activism, and the Politics of Knowledge* that addresses how patients and their allies contribute to the redirecting of research and care protocol. This has lead to the conceptual framework of bio-socialities, which addresses the socialization around a medicalized category. Support groups have often been looked at with suspicion by medical practitioners, not only because of their occasionally antagonistic role in requesting changes in care protocol, but also because of their request for an authoritative position in addressing the syndromes. Support groups have sustained accusations of promoting an external sick role or being representative only of unsatisfied patients.

In this section we will be looking at the fabric of the treatment of DSD syndromes, starting from the experiences of the syndrome-based patient groups. Chapters four, five and six discuss some of the bioethical concerns each syndrome faces, the work of the patient groups, as well as the medicalized perspective of the syndrome. In Chapter seven we move into the complicated world of treatment, where theory meets practice. The clinical situation represented is perhaps idealistic, a university hospital that seeks to establish itself as a specialized care center. However, it is within this context that new care guidelines are potentially being written for all of Italy.

Chapter 4

AIS and AISIA, Syndrome and Situation

Androgen Insensitivity Syndrome, as we have seen in the previous chapter, would not have been recognized in the categorization systems associated with hermaphroditic terminology. Yet since its “discovery” in 1953 (Caffaratto, 1963, pg 42), the syndrome has been the site of multiple forms of medicalization. AIS, Klinefelter's syndrome and CAH (Congenital Adrenal Hyperplasia) are the most “seen” and manipulated of the DSDs. AIS, once-upon-a-time under the skin, unseen until recent technology, emerged as a syndrome in need of “fixing”, a process now under scrutiny by those themselves diagnosed with AIS.

Ten plus years after the formation of the first Intersex patient group (INSA in 1993), a dialogue had been started between patients, academics and the medical community, and things started to shift from the hegemonic “don't ask don't tell” neo-Money model. The Chicago Consensus Conference in October 2005 involved the participation of patient group members from the US, UK and Germany. In April 2006, Rome held the International Meeting on Anomalies of Sex Differentiation. Within half a year of the Chicago Consensus conference, the new DSD terminology was being used in the scientific circuit.

In 2004 a small Italian group started forming around Androgen Insensitivity Syndrome (AIS). By the time of the 2006 conference in Rome, the group had grown, created a website and were on their way to being an officially recognized patient group. In July 2010 the group AISIA had the first Italian version of a consensus conference, in direct dialogue with the medical team that seeks to be the primary center of DSD care in Italy. Changing terminology and creating dialogue move much faster than actual policy change, but in five years of activity, there have been several notable changes.

AISIA continues to operate as a patient group organized around AIS, but tends to lend itself also to the role of a pan-DSD group, hoping to work on many different levels of the medical and social issues involved. Many of the issues involved in the medicalization of AIS overlap in other DSD categories. The primary concerns usually fall around informed consent and communication of the diagnosis, stigmatization, hormonal therapy, and surgical interventions.

The bio-political paradigm in which AISIA operates is complex, part institutional and part personal. Italy has not seen the “minority rights revolution” (Skrentny 2002) or the explosion

of identity politics envisioned in territories that define themselves through multiculturalism. However, since 2001 Italy has a national network that handles rare diseases, which enables a certain level of action on the institutional level. However, there remains a strange wall of ignorance and silence around DSD in the public sphere.

4.1 *AIS, technology and the locus of sex*

Androgen Insensitivity Syndrome could be considered a post-molecular phenomenon, revealed in the twentieth century by bio-imaging technology. Since the 1990s, AIS is not only associated with XY chromosomes and female phenotypic development, but also with a handful of genetic markers believed to be directly related to the lack of androgen receptors. Imaging technology lays out in charts and numbers, chromosomal material, molecular genetic markers, gonadal material and hormonal levels, otherwise invisible to the naked eye. In the case of CAIS (Complete Androgen Insensitivity Syndrome) the naked eye sees what was always seen, a female individual, before technology gave a window to the inside.

Visualization technology snakes through the telling of what is seen as "normal" gendered fetal development. Following the central dogma of Watson-Crick genetics, one starts from the XX or XY chromosomes, to the molecular genetic markers that code for RNA, and then proteins which lead to structure formation. As we have seen in chapter one, there are competing models of development, some more complex than others. The SRY gene found on the Y chromosome is believed to induce testicular formation, the genes responsible for ovary development are not as well characterized, but recent research points to the role of the WTN4 gene (Baison, et al., 2003). The WTN4 gene has caused much debate because it debunks the former, Aristotelian-tinged script that indicates male formation as an active process, and female as a default.

At this point, development gets more complicated and deviations in developmental theory come to the surface. However, a canonic representation of general medical texts will state:

> Once differentiated, the ovaries produce estrogen, and testes produce testosterone. These two hormones provide crucial signals for the differentiation of other sex-related characteristics, including an important set of primitive ducts. Early in development, every fetus has both sets of ducts. One set, called the Wolffian ducts, has the capacity to develop into the male vas deferens and accessory structures, which store, nourish, and ejaculate sperm. The other set, called the Müllerian ducts, has the capacity to become the female fallopian tubes, uterus, cervix, and upper vagina. Normal sexual development is governed by presence or absense of testosterone and AMH. A second hormone made by the testes, called antiMüllerian hormone (AMH), induces the Müllerian

ducts to undergo apoptosis, causing them to degenerate. In males, degeneration of the Mullerian ducts is triggered by AMH. Development of the Wolffian ducts is triggered by testosterone. In individuals with androgen insensitivity syndrome, AMH acts but testosterone does not.[66]

A more complex model indicates that the gonads produce different levels of hormones in time-sensitive windows of development. DSD researcher Ieuan A. Hughes indicates:

> Sex determination is defined as the commitment of the indifferent gonad to a testis or an ovary, a development that is genetically programmed in a critically timed and gene dosage-dependent manner (Hughes 2001).

Molecular research in DSD points to a more complex picture, shifting the focus from hormone production and the "action", to hormone receptors, timing, environmental influences and genetic markers. Researchers Amanda Swain and Robin Lovell-Badge point out the research context and the increasing complex picture:

> Our knowledge of mammalian sex determination is based on two main areas of study. First, the characterization of the biological events that determine the sexual development of the individual, including patterns of gene expression, and second, the study of genetic mutations in humans and mice that lead to abnormal sexual phenotypes... Serendipity has also played a hand, where in several cases targeted mutations in mouse genes, being studied for other reasons, have led to unexpected sex reversal phenotypes. The collection of molecular candidates implicated in sex determination is now quite extensive. We are not able to fit all of these into simple pathways, where one gene acts on the next and so on in a linear fashion, as seems possible in the invertebrate model organisms, Caenorhabditis elegans and Drosophila. In part this is due to gaps in our knowledge, as we are clearly missing several key components, but it is looking increasingly likely that the system is much better described as a network of factors. In fact, the story so far is like some partly recovered script for a play. Thus some gene products are main characters with roles at several different stages, some act as a chorus, in a combinatorial fashion with others, whereas a few play a critical role in one scene and then disappear. The mechanism presumably evolved to be delicately poised to respond to the initial trigger to be male or female and then to amplify this decision while avoiding development of intersex phenotypes. It is therefore likely to be a system full of back-ups and functional redundancy. The complexity may also follow from the relatively late embryonic stage at which the decision is reached. This means that events occurring in one cell lineage have to be coordinated with others in the context of a developing organ and eventually the whole organism (Swain and Lovell-Badge 1999).

[66] http://medicine.jrank.org/pages/1888/Androgen-Insensitivity-Syndrome-Sexual-Development.html

Bio-imaging techniques give a lot of power to the diagnostic process and render the medical object scientifically real (Ettore 2002; Rapp 2000). Invisible genetic markers are given names and positions in the body. However, it often remains unclear where the problematic object lies in DSD syndromes. We still know little about the long-term health effects of DSD syndromes, or of their therapies such as hormone replacement therapy or gendered body modifications. Molecular research provides an invaluable tool in increasing our understanding of the developmental process. It can show us the myriad of options of physical expression. However these myriad modes of expression exist within a medical model that defines deviance from the norm as pathological, subject to investigation and remedy.

Within the AIS spectrum there is also a form called PAIS (Partial Androgen Insensitivity Syndrome), which is more likely to have found its way into historical medical literature. PAIS is much less common than CAIS, estimated respectively as 1:130,000 to 1:13,000 births (Blackless 2000). People with PAIS have often "ambiguous" genitalia at birth and therefore are likely to be treated with surgery at a young age. The gender choice of the doctors in the case of PAIS is usually female, based on the opposite rationale from CAH: that is, aesthetic rather than reproductive, privileging form over function. In the case of "ambiguity" the aesthetic will be assisted by plastic surgery, the down-sizing of the clitoris, creation of a vaginal passage and occasionally of labia. A doctor may see a different need for surgical reduction depending on whether they use the rigid statistical average of 0.345 centimeters for infant female clitoris length or the more elastic average of 0.2 to 0.85 (Fausto-Sterling 2000). The surgical reduction of the clitoris usually has the long-term effect of reducing sensation and rendering the future adult non-orgasmic (as discussed in cases of female genital mutilation in some societies).

Since the discovery of the sex chromosomes, the primary scientific issue AIS presented was a direct conflict with chromosomal sex determinism. Before sex chromosomes, it was the conflict with the gonadal material. Before the discovery of gonadal material one can assume the presumed conflict went unnoticed. The medical management of AIS often reflects pre-scientific assumptions about the gendered body, regardless of the genital form. Most individuals, at the moment of their diagnosis, will have to sort through this information. Doctors have been known to state that AIS women are "really" or "genetically" men, referring to patients irreverently as "*donne con le palle*[67]", or using mixed, confused, gendered language such as male-ovaries or female-testicles, instead of using the gender neutral term,

[67] Interview material, "*Women with balls*"

gonads.

The gynecologist Morris (who also experimented with ovarian grafts before the advent of hormones) in 1953 described 82 cases of testicular feminization, using the eighteenth century terminology of male pseudo-hermaphrodite (Morris 1953). As the relationship with the partial forms was identified in the 1980s, physicians began to prefer the less confusing and more comprehensive term, Androgen Insensitivity Syndrome. From the 1990s patient advocacy groups also supported abandoning the terms "testicular feminization" and especially pseudo-hermaphrodite, which is now considered inaccurate, stigmatizing and archaic.

The biological visualization technologies, especially molecular imaging, are important in identifying the level of androgen insensitivity, and potentially arrive at other diagnoses such as 5 alpha-redutace, Reifenstein syndrome or PAIS. The level of androgen insensitivity is relevant for issues such as reproductive possibilities, bodily changes at puberty and gender identity.

Gender identity, as we have seen, has been the primary historical preoccupation in the medicalization of DSD. However, most women diagnosed with CAIS do not have an ambiguous gender identity, possibly even statistically less then XX women. In the case of so-called “ambiguous” genitals, a decision must be made of how to raise the child, and in the past, following the OGR, how to modify the genitals. The medicalization of CAIS belies other concerns, in the absence of external genital issues. One day, one “discovers” a medical problem and is confronted with a series of decisions that highlight the gap between a medicalized molecular vision of the body and the concerns of those who live with this diagnosis.

In the next section we will confront some examples of diagnosis communication and the subjective experience of entering the medical arena.

4.2 *CAIS, negotiating diagnosis, hospitals and desires*

> L: noi l'abbiamo saputo abbastanza presto perché aveva un'ernia. Allora ci hanno detto di farla operare. Siamo andati in ospedale pensando che sarebbe stata una piccola cosa di due tre giorni. Dopo, quando è tornata dalla sala operatoria, c'ero solamente io, mi ha chiamato il medico e mi ha fatto capire che dovevamo parlare di qualcosa di grave. E mi ha chiesto “Lei sa cos'é l'ermafroditismo?” Io ho detto si, ma non ero sicura che fosse una cosa che esiste veramente o fosse una cosa mitologica. Il medico ha detto “No, no, esiste. E guardi che sua figlia ha questo problema e può darsi che abbiamo sbagliato, che non è una bambina, potrebbe essere che deve cambiare sesso, perché abbiamo trovato dei testicoli. E quindi non abbiamo più operato abbiamo lasciato tutto com'era, bisogna fare le indagini, e così vediamo se è un maschio o una femmina. E da lí é

cominciato tutto. (Mother, AISIA)

The discovery of an inguinal hernia or an inguinal lump are among the most common circumstances that lead to a AIS diagnosis in childhood. In many cases the discovery of a DSD is treated as a medical emergency, while a hernia repair is seen generally as a minor procedure. Twentieth century DSD treatment is riddled with miscommunication, and the diagnosis was often hidden from the patient and even the family. The medicalized language of DSD, as opposed to hermaphrodite, seeks to remedy some of the social anxiety produced by the diagnosis.

The presence of testicular tissue in a girl child can disturb the doctor, who communicates this disturbance to the parents. This is compounded by the fact that many practitioners, despite medical training, are unfamiliar with DSD and the variety of biological material. Description of the various syndromes has found its way into some Italian pediatric textbooks from the late 1990, increasing medical awareness, and providing new pathways for treatment (Bertelloni 2007; Zappulla 2005).

The Italian AIS patient group has a marked dividing line between those diagnosed since 2000 and those before, which rests in the communication of the diagnosis. Trude, diagnosed and operated on in the 1990s describes how she was told about her diagnosis accidentally.

> com'è venuto fuori? è venuto fuori che… (ride)… praticamente sono andata all'ufficio del ASL, del mio paese, con la cartella clinica, per richiedere l'esenzione dal ticket. Praticamente per avere farmaci gratis e esame del sangue gratis, e le visite, alcune visite così gratuite…e…quando il dottore…ho visto il dottore e gli ho detto…guarda sono stata operata a 15 anni, ho avuto un tumore all'utero e così via, lui ha guardato la cartella clinica e mi ha detto, ma perché le hanno detto che ha avuto un tumore? E ho detto perché e' così che mi hanno detto…ma non me lo hanno detto subito, me lo hanno detto a 19 anni perché pensavano che fosse troppo, un colpo troppo forte per me a 15 anni. Fa, "adesso quanti anni ha?" e gli ho detto 25, 24. Fa, "grande abbastanza a sapere che non ha avuto un tumore, e' un pseudo-ermafrodita". Così, secco. E io, lo presa bene, nel senso, gli ho riso in faccia, perché comunque avevo gia visto un documentario ero gia informata e…(patient, AISIA)

Or misdiagnosis, as the case may be. Terminology is not only an indicator of up-datedness of information, stigmatization and care but also becomes a factor in access to care.

In 1968 Italy reorganized its health and hospital system, creating a form of public health care free to the general public. In 1978 this system was converted to a national health service (*the Servizio Sanitario Nazionale, SSN*), which is similar to the UK National Health Service (Cosmancini 1994). It is publicly run and funded mostly from taxation: some services require small co-pays, while other services (like emergency care and the primary care physician) are

completely free of charge. Like the UK, there is a small parallel private health care system.

Like the UK, in order to regulate a state-run and paid health care system, diseases and syndromes are given codes that outline the type of exams and medicines that will be paid for by the state. There is some degree of regional autonomy, and codes and coverage can vary from region to region. There is currently no code for CAIS in most regions, which means doctors are forced to give the code for either pseudo-hermaphroditism or PAIS in the case of a CAIS diagnosis.

This means, those diagnosed under the older non-disclosure model will not know their diagnosis and either: access hormonal therapy and be erroneously informed that they are a pseudo-hermaphrodite, or not have access to the treatments related to the various interventions they might have had as children. Access to treatment is determined by the coding system which relies on out-dated terminology. The most common interventions they might have had in early age are gonadectomy or vaginal canal replacement surgery.

Informed consent and diagnosis communication are perhaps at the top of the list of the bio-ethical concerns in DSD treatment. As we saw in chapter three, the Money OGR model came to advise *not* informing the patient and some times even the parents, based on the rationale that this would facilitate not only gender stability but also acceptance of potential difference. Money's team hoped to help parents and patients avoid thinking of themselves or their children as deviant or monsters. The avoidance of stigmatization through non-disclosure, however, is probably only possible in a non-interventionist model. When someone has instead been medicalized in childhood, they already know something is going on, without knowing why there have been so many hospital visits. The onus of silence can weigh heavily in the family. The parent handbook, one of the results of the consensus convention, advises doctors to focus on communication that facilitates acceptance, emphasizing that differences between people is normal, and not treating the syndromes as an emergency.

Parents and older patients indicate that the sensation ‘that something horrible has gone wrong’ was communicated by the medical team. This is combined with a hurried stress to make an (interventionist) decision about treatment.

> L:...ti devono scioccare (il genitore), ti fanno venir paura in un modo scioccante. E’ poi ce un totale mancanza di rispetto e discrezione. Ci e’ successo una volta che il dottore e’ uscito nella sala di attesa e’ ha detto: “ chi e’ la madre del intersessuato?” (Mother, AISIA)

The Money model stresses the urgency and the need for early intervention in order to instill mental health, a positive self-esteem and a stable gender identity. However, many later

state they wish the doctor had told them it wasn't a big deal, not life threatening, and that it could be dealt with calmly in time. Many patients indicate the late discovery of their diagnosis, combined with the surgical and/or examination process in early childhood, to be the very source of their emotional issues within the diagnosis.

> Anna: ah sì sì.. gliel'ho sempre rinfacciata a mia madre.. ho litigato..ride...fino a ..verso 25, 26 anni litigavo sempre perché.. io sono stata molto male.. non tanto per quello che avevo quanto perché i miei genitori non mi hanno detto niente.. un po' per come mi ero stata trattata.. per questo.. però adesso.. mia madre un po' ha capito.. ha cambiato atteggiamento..adesso sono più grande.. e quindi.. abbiamo fatto un po' pace fra virgolette..

Anna learned about her diagnosis in her twenties, connecting the dots between something she came across in a medical text, her childhood experience, and the hormonal therapy she had taken since her operation, but gaining most of her information from the Internet. Her experience can be seen as a template for many treated and diagnosed into the late 1990s. After a childhood hernia, her mother was informed of the diagnosis. Anna had a second hernia at 17 and at that time they also gave her a gonadectomy and her parents were advised not to tell Anna anything because learning that she had XY chromosomes might make her feel bad or threaten her gender identity.

Unfortunately for Anna, the doctors did not emphasize the side effects of gonadectomies. Gonads produce hormones that are important for many different health systems in the body. It was believed that AIS gonads had a high cancer risk, due to statistical risk found in patients with mixed (mosaic) gonadal material. However, this is not confirmed by scientific research, and often doctors will state that early gonadectomy is generally performed for psycho-social reasons. Anna's parents refused further treatments, and as Anna did not know about her diagnosis, she did not seek any either and went years without natural or artificial hormones.

Anna muses about other family members that she is sure also have AIS, but are older and have never been medically diagnosed. They have never menstruated or had children, they have little body hair, but they have had none of the problems that medicalization assumes one will have with AIS. Many are married and healthy, some well into their 80ies. None of them have had gonadal cancer or marital problems due to vaginal length.

> io ho scoperto da mia madre ..che hanno.. ad un anno.. fui operata al ernia.. gli avevano detto che avevo un.. sindrome.. ma mia madre non aveva proprio capito niente.. e neanche loro mi hanno detto niente.. mi hanno detto che in Italia si chiama la sindrome delle belle donne.. non so sei..ride..pero non e' cosi nel mio caso..perché non si viene mai l'acne insomma neanche le rughe in teoria..però mia madre non ha voluto sapere niente.. e poi dopo ho scoperto che nella mia famiglia

che ne sono tantissime..e praticamente.. due sorelle della mia nonna.. eguale hanno questa sindrome.. e tante cugine di mia nonna.. le nonne di miei nonni.. le zie della mia nonna.. le sorelle della nonna.. insomma un po' tutti.. sono tutte nella zona delle Marche..

Anna suffered various physical and emotional problems until she got a hold of her diagnosis and started searching for a hormone replacement therapy (HRT). She is now involved in an experimental program, establishing through the collaborative work of AISIA, that uses androgens instead of a estrogen/progesterone mix. Finding the right hormonal therapy can be another causality of the health code system, which gives gender to hormones and therefore blocks cross-gender hormone therapy.

Anna suffered from the misinformed medical stigmatization also in her personal life. With the diagnosis finally in the open, she got a full examination and was (mis)informed by the doctor that she could never have a normal sex life, because she had a short vaginal canal, and in fact, he advised that she shouldn't have sex. She was dating someone at the time, and the combined shock of the erroneous information and the stigmatizing attitude of the doctor threw her into depression. Medicalization of the vaginal canal is another aspect we will look at closer later.

Diving deeper into the intricacies of the Money diagnosis and non-disclosure model, we continue to hear similar stories of family rupture and conflict after the diagnosis has come to light. Franco D'Alberton, an Italian DSD team psychologist highlights the importance of full disclosure at the moment of diagnosis and when decisions are being made.

> Knowledge about one's medical condition is a basic human right...However, optimal communication about DSD is easier said than done; it demands 'advanced communication skills' from the clinician (Liao et al., 2010). Even then, our restrictive, binary language of sex and gender may render the task too emotionally challenging for some clinicians and parents...Care givers' feelings of safety and integration can positively influence care recipients' sense of safety and capacity for integration...Some say that far from being a risk to their psychic equilibrium, the moment when they were clearly told about their diagnosis was the moment when some of their experiences began to make sense. Full disclosure is most important when it involves people in decision-making, not when 'the die is cast' and a door is closed. Without full disclosure, a person receives surgical procedures performed under a false pretext. To be deceived in this way is to be pulled along the path of rage sorrow and regret (D'Alberton 2010).

Clara since 2007 has been investigating her molecular diagnosis, but she knows that when she was a child, they diagnosed her as PAIS. Her father took everything into his own hands and denied her the truth. Clara was born at home, in Sicily in 1960, and when she was nearly

two, her mother noticed her labia were more united than her sister's had been, and said something to Clara's father. This began a series of medical visits hidden from the mother, leading to conflicting diagnoses of CAIS or hypospadias, in which the former usually leads to a female gender assignment and the latter to a male. To give the doctors credit, they advised postponing surgical intervention until after puberty. Clara's father instead found a private hospital, and at 11 years old they removed 90 percent of Clara's clitoris and her gonads. She took 7.5 mg a day of estrogen (an extremely high dose) until she was 26 without knowing why.

At 26 she went to a gynecologist because she had never been able to have complete penetrative sex and was told she didn't have a vagina. She called her father who denied everything and then her father in secret asked her doctor to call the gynecologist and lie to her (revealed to her later). After ten years hospital records were destroyed, so there was nowhere to look for them. The doctor at the time suggested vaginoplastic surgery but her father still denied everything. He only answered, "because it was better that way"[68]. Later, a doctor told her "you need to find yourself a good widower who already has kids"[69]. Clara states: "In Sicily only prostitutes have (sexual) pleasure…and then, a lesbian is the same as a prostitute…bad news…"[70].

After thirty she left Sicily and her life began to change. She had a few more experiences with men, one of whom told her that her vagina was "too tight". She went to a psychologist who helped her accept the idea that she might be lesbian. And then she went to San Francisco where for the first time in her life she saw what it could be like to be gay without stigmatization and problems, and it all became much easier. She told her mother right away, who was overcome with guilt. Her mother was convinced Clara was lesbian because she was XY, and that Clara had AIS because she and her husband were third cousins.

Unlike the hetero-normative narrative of the otherwise well-written and interesting novel *Middlesex*, (Eugenides 2002) which brought Intersex/DSD to the mainstream in 2002, Clara does not agree with her mother that she is gay because she is XY, and that she would have been happier as a man. The first years after learning about the diagnosis, she fantasized about what it would have been like to be a man. She had always envied the freedom men had in Sicilian society, while women had so many more rules to follow. She had always been

[68] "perche era meglio cosi".

[69] "devi trovarti un bravo vedovo con gia dei bambini"

[70] "In Sicilia godono solo le puttane...e poi lesbica eguale a puttana, poco per bene..."

targeted socially for being tall and masculine, some of which seemed to come from her mother's northern features. Clara, ultimately, is happy as a lesbian woman, socialized as a woman to be sensitive, "convinced that she prefers female sisterhood"[71]. She jokes that being a man in Italian society has many privileges that she envies, but that most women would like more freedom and possibilities. Maybe she would have been happy as a man, but she is happier to be the person she is with her complex varied experience.

Clara points out that the medicalization of DSD often denies unproblematic sexuality to both heterosexual and homosexual patients: telling them they are 'the only ones', or that there are no solutions, or performing surgeries that remove sensation or make people paranoid about their genitals. She laughs, saying, "It is really hard for me to achieve orgasm" (due to the removal of tissue and scaring), "but at least (other) women are more willing to have patience and have sex longer". But, one of the worst thing for her was having been told she was one in a million, that there was practically no one else in her position.

> Come si permettono a toglierti la speranza? Negandoti l'oppurtunita di informazione e interazione?...Negavano una sessualità affermativa, che ci sono altri, che ci soffre... [72]

The last ten years has not just given light to patient groups that socialize information and negotiate medical authority. It has also seen the entrance of a new way of communicating diagnosis. New members of AISIA often have less traumatic stories of family conflict, because they are told right away in less stigmatizing terminology.

Melanie is one of the younger members of AISIA, and she is studying to be doctor in northern Italy. Her experience is similar to Viviana's from Puglia, however, who was also diagnosed in the last ten years. They both went for gynecological exams, after going through puberty years earlier, without the onset of menstruation. After a series of exams, the CAIS diagnosis was reached and explained as a variation, more common than known. Both were advised to have gonadectomies and counseled on hormone replacement therapy. Both feel protective towards their families, glad they know, but wanting them not to be burdened.

In this case the burden is no longer anger over miscommunication, uninformed surgeries, or stigmatization surrounding gender identity. The burden, which we will deal with in greater depth later, is the inability to become pregnant. Viviana indicates that this is probably the biggest problem for her mother. She told her husband immediately, but she is from a small town, and you don't talk about sex often. Viviana confesses her hormone therapy has never

[71] "convinta che preferiva la sorellanza femminile"

[72] Interview 08/09

really gone right,[73] but she hopes the more people talk about AIS and DSD, the less stigma there will be, and the more hope there will be for good treatment.

Melanie is not studying a DSD related branch of medicine, but nonetheless is very informed about the details of the syndrome and interested in promoting more detailed research. Her eyes lighted up when she told me about how she found a girl in Canada who had the same genetic marker as she does. When she talks about the discovery of the Y chromosome she says, anyway, "*sono la stessa di un mese fa*", she's the same as she was a month ago, the Y chromosome means little to her identity.

This, of course, is true unless you have the bad luck to be diagnosed by a doctor who insists that the Y chromosome means masculinity. Doctors once insisted that telling a woman that they have a Y chromosome would damage their gender identity. However, it would be more precise to say that telling a woman that having a Y chromosome means they are not a woman, or not who they think they are, is the real root of potential damage.

4.3 *Not talking about surgery*

Marina is a slight pale girl who seems shy in many situations, but she says she often doesn't speak in certain situations, because she is too angry to speak. She is still searching for a solution for the vaginoplasty she had at ten years old that gives her numerous problems. Her situation, like that of Clara's and the negative consequences of her clitoral reduction, is the result of a lack of communication between doctors, parents, and patients. But Marina's situation is also correlated to the discrepancy between what surgery can actually do technically, and the usefulness of the results for the patient. The debate about the "success" of surgical procedures walks down a thorny path, which weaves between constantly improving technology and the ability to modify the body, and the impossibility to un-do most interventions. This is exacerbated by the historic lack of dialogue between patients and surgeons, that might shift the debate from technical prowess to patients' desires and long-term experience.

We have not covered the historical development of surgery, apart from its relation to the study of anatomy, for some of the reasons mentioned in the introduction. One simply cannot debate the skill of a technique or a surgeon from outside the discipline, irrespective of the fact that the irreversible long-term physical and psychological effects of certain surgical

[73] Hormone Replacement Therapy (HRT) can cause bloating, mood swings, digestive problems among other symptoms.

interventions remain one of the most heated bioethical issues in DSD treatment. DSD treatment and patient interest seems to be shifting, not only towards full disclosure, use of non-stigmatizing terminology and informed consent, but also towards useful medicalization.

I use the phrase, useful medicalization, in reference to what is considered useful for the patient, in terms of the whole body and health, as apposed to normalization techniques. This is the line followed by the PCC (patient centered care) model seen in chapter three. One motivation, therefore, for not discussing the development of surgical techniques in greater depth, is that part of the useful medicalization strategy is seeking alternatives to surgery. This is done not by avoiding medicalization, or labeling all medicalization of the gendered body as stigmatizing or normalization. Instead, many patient groups are lending themselves to research that focuses on endocrinological issues and genetic investigation.

A diagnosis of AIS traditionally implied two different possible surgical interventions, gonadectomy and vaginoplasty. Both are problematic for different reasons. Vaginoplasty because it generally requires repeated interventions, dilation, can lead to unpleasant secretions, pain, shame and preoccupation, all the while not necessarily providing the possibility to have penetrative sexual relations. Gonadectomy is problematic for the reason outlined in chapter two, relating to the necessity of hormones for overall health.

Marina was operated on when she was ten years old, not young enough to not remember (as recommended by Money), nor old enough to be sexually active. She is unclear what her parents understood about the operation, but is sure that they were told that it would "fix everything" and have no side effects. She was told nothing. She experienced all of the emotional trauma of medical stripping (Dreger 1999; Parens 2006), related to repeated medical attention to her genitals, with the consensus of her parents. American activists refer to this type of experience as similar to being molested with your parents' consent. Other patients, but also parents relate similar experiences:

> T: io vorrei fare causa, essere visitate in continuazione, visite senza spiegazione. Tutti quelle visite mi facevano male e comunque non sapevo niente ancora. Non conoscevo, era traumatico. (Patient, AISIA)

> L: a nostra figla hanno fatto le foto quando era piccola, prima degli interventi. Hanno detto che la sua clitoride era ingrandita ma di non preoccuparci. Ma a 7 mesi hanno fatto il primo intervento. (Mother, AISIA)

Marina does not blame her parents, because she explains that their power was taken away from them. They were repeatedly told they were doing what was best for their daughter. She

more recently found letters from the medical team that eventually operated on her, insisting that her parents bring her in for the operation, that they (the parents) would destroy their daughter's life if they didn't. Marina received a neo-vagina created from intestinal tissue. This type of intervention requires maintenance, repeated dilation to maintain the diameter and length. Unfortunately, scar tissue can form internally that is rigid, and will block any manual attempts at dilation. In addition, the use of intestinal material can release unpleasant-smelling vaginal secretions at random moments (particularly after eating).

Marina has experienced severe bleeding when she has had penetrative sex. She is frustrated and angry that she had no say in the decision, but also that there seems to be no remedy. Sitting on a street corner, she spoke with Gioia who had had a similar operation and side effects. They both were afraid that their sexual partners could "really tell" that they weren't "normal", which interfered further with their self-esteem and comfort with sex.

Iain Morland refers to his own experience with a post-surgical body:

> Certainly genital surgery can render strange anatomies that would otherwise have passed without comment. For instance, when I was about eleven, in the school locker-room (that fabled location on which some surgeons base judgments about the fate of intersex people who don't receive surgery) I was teased *not* because of the intersex characteristics that remained after surgery but specifically because of the scars *caused* by surgery (Morland in Morland, 2009, pg. 301).

AISIA has provided a space where people who have had surgery can talk with people who haven't. DSD treatment is riddled with contradictions, one of which is the lack of scientific process, in the form of long-term follow-up research. Most surgeons can only claim their operations successful in the immediate time period after the intervention. Patient groups, seen in certain contexts as critical and antagonistic to medicalization, can provide a wide data base for long term research. Far from representing "only dissatisfied patients", many groups are seeking greater collaboration with medical institutions.

Alternatives to vaginoplasty, such as manual and surgical dilation, have entered into the mainstream of Italian DSD treatment, largely through the investigative and strategic work of AISIA. Two of the founding parents explain how the doctors told them to look around, inform themselves.

> M: ...e mentre poi l'hanno operata, per la cosa che sapevo, insomma, per questa cosa, durante l'operazione, è venuto fuori il medico, dalla sala operatoria, sempre questa scena terribile, c'è, ne avremmo potuto forse parlare anche dopo, comunque nel momento eravamo veramente tanto tanto,
>
> F: ansiosi,

M: tesi, e dice " il problema non era sicuramente quello dell'apertura, la vagina non ha la dimensione assolutamente, non può avere rapporti sessuali"… ha detto che doveva affrontare sicuramente un intervento chirurgico, quindi, la vaginoplastica, a quel punto, poi noi siamo ri-andati il giorno dopo a parlare con calma con lui, per farci spiegare meglio, pero non è che ci hanno dato nessuna indicazione, "informatevi, vedete dove la fanno, ci sono tanti metodi diversi, informatevi voi…" lui ha anche, era anche disposto a provare lui, questo qui, e, insomma, lui poteva provare ma certo, poi questi interventi si devono fare nel momento in cui una vuole avere rapporti sessuali perché se si fanno prima, e poi una non ha rapporti si atrofizza, tutto quanto, per cui noi siamo entrati proprio nel panico ancora di più, intanto che dobbiamo spiegare a lei, perché lei stava dormendo quando ce lo hanno detto, no? E poi a dargli una prospettiva, e li in quel momento abbiamo deciso di non dirglielo immediatamente ma prima darci… un pochino guardarci intorno, e vedere cos'era possibile, ma, almeno per poterle dire cosa si poteva fare, (Parents, AISIA)

The problem of dilation after surgery represents itself. Does a girl who is not yet sexually active need to have a penetrable body? The parents in question took the matter into their own hands, contacted the AIS group in England, and were put in touch with Sarah Creighton's gynecological team. They then physically went to Creighton's clinic, and here learned about dilation techniques. The clinic emphasized the use of graduated dilators and medical support. On their return they tried to talk about this alternative with their doctor.

Noi quando abbiamo saputo che c'era questa cosa siamo andati da diversi medici, prima di dirlo a lei, a sentire se era una cosa accettata, e ci hanno detto che erano leggende, favole, sogni, cose del genere, che non l'avevano mai sentito nominare, non è che hanno detto che "ok adesso mi informo", ci hanno detto "no, non state a chiedere a questa cosa,". Quindi a non riconoscere questa cosa, se non sanno delle cose, ce...io capisco, potrei non saperlo io, e che non ci sono molti che si sono interessati a questo problema, il medico può anche dire "non l'ho mai sentito", però, potrebbe anche dire, "va bene, adesso Lei mi sta dicendo questa cosa, mi informo". Qui, ci hanno lasciato molto fare da noi, andare a cercare persone, etc…e poi non c'è questa cosa di lavorare insieme, aiutarti, ognuno diceva una cosa diversa, e una non sa più che cosa deve fare, perché veramente, l'informazione che, uno dice una cosa, e poi un altro ne dice un'altra, voglio dire che anche i genitori se lo passano maluccio. Ti fanno male, quando devono decidere le cose, perché poi una delle ansie che uno ha quando i bambini sono piccoli è che, uno è obbligato a fare qualche decisione, o fai una cosa o non lo fai, comunque, hai preso una decisione. (Mother, AISIA)

In 2009 AISIA was asked to participate in a medical conference on AIS, part of the changing DSD attitudes, and they in turn invited Naomi Couch from the Creighton clinic. Couch presented dilation as the first line of intervention, especially since it does not create

irreversible tissue damage. She explained the need to delay any intervention until after puberty, when the patient can be a direct protagonist in decision making. She implied that while pediatric surgeons view infant tissue as easier to manipulate, the body goes through repeated changes throughout development that might facilitate care later than sooner. Couch also indicated that many patients may still choose vaginoplasty instead of dilation, due to the time commitment, but that the experience is different when individually motivated.

Several months before, AISIA had contacted me asking if I had come across in my research, any doctor in Italy who actually had experience practicing dilation. I was put into contact with the gynecological clinic of the university hospital A, where I had originally been observing the pediatric department. The head gynecologist informed me that they had experience with dilation for Rokitansky syndrome (Mayer-Rokitansky-Kuster-Hauser syndrome/ MRKH)[74] or vaginal or Mullerian agenesis.

MRKH is a DSD marked by the lack of vaginal canal and often uterus in a XX person with ovaries and female phenotype. Type II is associated with renal problems (25-35%). The Milan Center for Rokitansky syndrome (*Centro per la Diagnosi e il Trattamento della Sindrome di Rokitansky, Fondazione Ca' Granda Ospedale Maggiore Policlinic,o Milano*), estimates a MRKH frequency of 1:4000 XX individuals. The Milan clinic seems to have established a MRKH hospital-run patient group in 2009, emphasizing the role of non-stigmatizing psychological support. Both AIS and MRKH patients must affront sterility. The Milan clinic's medical literature indicates that they use the Vecchietti (first performed in 1965; Vecchietti 1965) modified laparoscopic procedure, which can be described as surgical dilation.

Intersex activists argue that, until there is a social shift that includes a change in the medical discourse surrounding physical variation, it will continue to be hard to live as Intersex, not because of the syndromes themselves, but because of how they are treated and interpreted.

The university clinic was interested in exploring other options, and already had had success with the Vecchietti technique. They sent one of their doctors to the 2009 AIS conference and

[74] The earliest references to vaginal agenesis and proposed therapy can be found in Hippocrates' work on "*The Nature of Women*". Other references can also be found in the Roman and Greek eras. The first contemporary description was in 1781.The description of congenital absence of the vagina with incompletely developed uterine remnants or a completely absent uterus as a specific syndrome can be traced to the work of four individuals. They were Mayer (1829), Rokitansky (1838), Kuster (1910) and Hauser (1961-1973). Provided by MRKH UK support group http://www.mrkh.org.uk/mrkh.html

met with Noami Couch and AISIA. In 2009 and 2010 the university clinic sent a handful of its staff to the Creighton clinic and started providing follow-up care for many women, who had previously been followed primarily by their pediatrician. The clinical line for dilation versus surgery was said to be 3cm vaginal length. Reports from AISIA members have shown that some members were able to dilate to a desired dimension from less, and many had been operated on in childhood with 3cm or more.

Marina is angry because her experience, at an esteemed DSD treatment center in the late 1990s, is in contrast with most of the medical recommendations. She had 3cm to start with, she was too old to "not remember" or not have been traumatized by the repeated genital attention, and way too young to be sexually active or maintain dilation. And none of her family were informed that there were other options. Gioia is not angry, but as she meets other AIS women, she starts to question things she had earlier accepted. The fact is, her vaginoplasty has not resolved her problems either, and has numerous side-effects. The idea that she was not informed of other options, reopens a wound that seemed healed.

4.4 *Towards useful medicalization, gonads and hormones*

> C: Cosa avrei voluto? Avrei voluto che lasciassero a me la possibilità di decidere in futuro, quando avrei raggiunto la maturità per farlo, sicuramente. Avrei voluto che lasciassero, avrei voluto scegliere io. Come effettivamente io avrei voluto scegliere se operarmi oppure no. (patient, AISIA)

In 2009 at a DSD medical conference in Turin, a leading doctor in a DSD team (Hospital C) ingeniously stated what was the state of the art, the shifting territory between new and old models. Through the course of his presentation, he stated that research now indicates that early gonadectomy is not only not necessary (not supported by scientific data as to increased cancer risk), but potentially harmful due to the importance of hormones, especially through puberty. He ended by stating that his clinic still performs them in early childhood when diagnosed early.

Most pediatric centers in Italy seem to continue early intervention; gonadectomies, vaginoplasty, urethra repositioning, clitoral reduction, penile reconstruction etc. Clinics mirror the affirmations of Polly Carmicheal who states that parents request these early interventions, and the doctors acquiesce to ensure acceptance of the child on the part of the parents.

In 2010, however, the Italian National Bioethics Committee came out on the side of the 1999 Colombia decisions:

The constitutional ruling recognizes that parents can give consent to treatment as long as it is guaranteed to be based only on the interests of the child and not on their own self-interest. To ensure this, it is necessary that informed consent is "qualified, clear, explicit and based on full recognition of the consequences of the treatment and alternative treatments" (with reference also to the possible postponement of intervention) and that it is "persistent" (in other words, repeated over time) to guarantee the interests of the child (with appropriate psychological support). Only medical intervention that is necessary can be carried out, namely, those interventions justified on the grounds of protection of the physical integrity and health of the child, also as regards the physical pain resulting from the burden of the operation and the associated risks: no operation can be carried out only for psychosocial reasons (emotional non-acceptance by parents of undefined sex; the parents' need for biological normalization for social acceptance). For intervention for which there is no data on the benefits or the potential danger for the child (both physical and psychological) or that is irreversible, the consent of the actual subject is required (when informed consent must be gradual and based on the maturity of the child). It is on this basis, therefore, that the constitutional ruling limits the capacity of physicians and parents to intervene surgically altering children with such pathologies, considering parental consent invalid if not motivated by the best interests of the child.[75]

At the 2006 conference in Rome, early gonadectomy was presented in a similar light, unnecessary, yet, done. The territory once shifting, left unresolved spaces. Various members from the audience asked for facts, follow up data. This provoked one English doctor to respond "you criticize us for being too invasive, isn't making a patient return for continued controls invasive?" This is the hidden mask of the stigma talking. If DSD were treated as a condition like any other, such as other endocrine-related conditions, overall health monitoring would be assumed. And if gonadectomies aren't performed for health reasons, then why do them?

Doctors will cite Money's protocol and state that they remove the gonads, so as to promote a stable gender identity. However, patients don't express gender-identity difficulty. There can be serious side effects instead, due to the lack of hormone production, and the difficulties in equilibrating hormone replacement therapy. There is the possibility that androgens could masculinize the body at puberty, and therefore are removed to avoid later ambiguity. However in these cases it is possible the masculinizing effects will be welcomed by the patient. Some DSD medical teams have sought to hormonally delay puberty, avoiding

[75] Minor's Sexual Differentiation Disorders; Sentencia SU-337/99, May 12 1999, and T.551/00, Aug. 2 1999. Cf. also sentencia T-477/95 (www. isna.org/Colombia)

gonadectomy, until the patient expresses a clear gender identity[76].

The road towards useful medicalization is marker by the shift away from the identity-politics framework that directly attacks the normalization of gender to a disability-politics framework that necessitates dialogue with the organizing force that deems ones body "in need of fixing". Emi Koyama of the Intersex Initiative notes:

> Intersex activist Esther Morris's observation that "not having a vagina was not my problem; having to get one was," can be paraphrased to say: not having a vagina was not a disability; the social expectation that she needed to get one in order to live happy and productive life marked her body disabled (Koyama 2006).

Italian DSD groups tend to turn away from directly addressing gendered discourse publicly. Individuals within the groups might have an Intersex and/or queer identity, as Trude indicates, a positive difference:

> io sono, sono convinta che, in natura, in natura non esistano solo maschio e femmina, esistano intersessuati, cioè... se nei fiori, negli animali, negli uomini, gli essere umani, c'è, esiste…esistono tre sessi. E quindi non vedo perché, possiamo definire che ci sia un terzo sesso per i fiori, un terzo sesso per gli animali e non ci sia per, per gli esseri umani. C'è… io non dico che magari sulla carta d'identità dovremmo scrivere intersessuata anzi che maschio o femmina, però già riconoscere che esiste… un'altro tipologia di genere, mi sembra importante. È importante soprattutto per la dignità della persona, la paziente. Perché comunque si sente definito, si sente qualcosa, non si sente una via di mezzo, tra: sono maschio o sono femmina? No, si sente… intersessuata. Non è una parola brutta, è una parola che ci descrive la perfezione.

In dialogue with doctors the request is often to pay less attention to gender identity and more to health issues. As the parent handbook indicates, early stable gender assignment is important, no one should ignore the social pressures and prejudice surrounding gender. However, the possibility for change must be provided by avoiding irreversible surgery. If you do a quick search in medical journals for Intersex and DSD, you will find most articles address gender assignment and surgery.

AISIA collaborates with three university medical centers in Italy (Hospitals A, B and F) that are creating genetic databases and expanding research on hormones. The projects focus on different health aspects from bone density, cardiac health, molecular markers, to hormonal mixtures. Research center B shows higher bone density and better cardiac health in those who have not had early gonadectomy, regardless of the type of hormone replacement therapy. This

[76] DSD Clinical Guidelines http://www.dsdguidelines.org/htdocs/clinical/methodology.html

research center is rapidly diluting the concentration of medical papers on surgery and gender assignment, replacing them with research on cardiac health, bone density and other hormonal health concerns. Their collaboration with AISIA has given them an authoritative voice in that their database is bigger than other Italian hospitals, and has given AISIA an authoritative voice in realigning treatment protocol.

Sexualized ideas about hormones, the national health coding system, and hormone marketing obstacle some of the attempts to shift endocrine treatment. As within many patient groups, when AISIA members meet, there are often discussions about therapies and treatments, administering medicine, doses, what brand etc... Others' experiences can be more authoritative than doctor recommendations, especially in an experimental field such as endocrinology. Those who have not had gonadectomies do not need hormone replacement therapy and are not usually in endocrine care. They generally don't have the symptoms associated with hormonal imbalances.

The national health system will cover estrogen and progesterone therapy for women and androgen therapy for men. These drugs are then available in doses relevant to their most commercial uses, respectively female birth control and sports doping. Estrogens, progesterones and androgens are hormonal categories, not three fixed hormones, and with each category there are slightly different chemical components, actions and results[77].

Seeing as hormone therapy can coincide with the communication of the diagnosis, it is sometimes hard to unravel what is a chemically-induced mood swing and what is due to experience-provoked emotions. Much of the long-term experimental evidence of hormone therapy comes from the use of chemical birth control and menopause hormone therapy (Oudshoorn 1994). Women often can indicate a higher level on mood swings while taking chemical birth control (Lark, 1996, pg.21). In the late 1990s this mood effect was attributed to progesterone, and the progesterone ratio was lowered, leading to the development of the mini-pill and other birth control formulas.

Willard Myron Allen co-discovered progesterone with his anatomy professor George Washington Corner at the University of Rochester Medical School in 1933. He gave it the name Progesterone derived from Progestational Steroidal Ketone (Allen 1970). Progesterone is a steroid hormone involved in the female menstrual cycle, pregnancy (supports gestation) and embryogenesis of humans and other species. It is also prescribed for menopausal women

[77] For more information on the commercial development of hormones see Oudshoorn 1994; Roberts 2007; Gaudillière 2008

in order to prevent endomitrial or uterine cancer, and excess bleeding in transition (due to estrogen therapy).

So what would the role of progesterone be for a woman who does not have a uterus? This is the question to be raised in treating the whole body, not just sex-related aspects. A quick review reveals that progesterone, like all hormones, has many regulatory effects, from the gall bladder function to stem cell regulation[78]. However, it is also produced by the adrenal gland, not just the ovaries. Estrogen is also associated with mood swings (Douma et Al., 2005), but in AIS treatment it is indicated primarily for bone mass and cardiac health. The Women's Health Initiative suspended hormonal menopausal treatment trials due to the rapid increase in cancer rates (Congressional Hearings USA 2004). The results of their US congressional hearing was that perhaps "natural" hormones (found in plants) instead of synthesized did not have the same level of side-effects.

Patients have trouble sifting through all this conflicting information, in the same measure that doctors try to stay up-to-date with cutting edge research. AISIA and other DSD patient groups seem to have decided that the only way to get better medical care is to collaborate with hospital research groups. In this manner, instead of directly attacking gonadectomy procedures, they are lending themselves to scientific research that will give clearer answers for their overall health. One of these research projects questions the gendered-hormone model in DSD treatment, proposing androgen therapy instead of estrogen or estrogen/progesterone mixes.

The idea would be that an AIS person would normally produce higher levels of androgens than estrogens and progesterones. The physical health of individuals who have not had gonadectomies would indicate that it is only the sex-related systems that are insensitive to androgens, that instead the androgens continue to have effect on other regulatory systems. If that is the case, maybe a higher testosterone mix would be beneficial in AIS treatment.

At the woman's health medical convention in Bologna in 2010, AISIA was able to invite a gynecologist to talk about treating AIS women in gynecological contexts. In the hallway

[78] Progesterone raises epidermal growth factor-1 levels, a factor often used to induce proliferation, and used to sustain cultures, of stem cells, increases core temperature (thermogenic function) during ovulation, reduces spasm and relaxes smooth muscle. Bronchi are widened and mucus regulated. (Progesterone receptors are widely present in submucosal tissue.), acts as an antiinflammatory agent and regulates the immune response, reduces gall-bladder activity, normalizes blood clotting and vascular tone, zinc and copper levels, cell oxygen levels, and use of fat stores for energy. (Hould, et Al. 1988; Chumacher et Al. 2004)

amongst coffee and pastries, Anna (of AISIA) asked the English doctor what he thought about testosterone therapy for AIS. He said he hadn't seen much difference in his patients, and that there were long term risks for the liver with androgen therapy. Afterwards Anna told me, “I don't care, I'm going to try it”.

Four months later Anna was, well, hilarious. She was happy and irreverent as always, but now she was joking about the return of her sex drive. Generally suspicious of deterministic models, she was not sure if she wanted to attribute how she felt to the change in hormones, or other events in her life, including all the positive results that have come out of the group’s activities. The problem was, however, that she would have to pay for the androgens herself, because she is a woman. There are certain regions, such as Piemonte, that will cover androgen therapies for women, but most don't. She contemplated how she could get them from another region, if she would have to set up a fake residence.

As it is, she often leaves town to get medicine. She doesn't want to have to deal with her small town pharmacist seeing the code for pseudo-hermaphrodite to get hormones; she doesn't accept the terminology at all. She says, first I'll try this, then, we can see if we can use treatment that uses both androgens and estrogens. However the androgens are costing her over 50 euros a month.

Since I first wrote this chapter, Anna has died of heart attack, nine months into the experimental androgen treatment. It turns out, she had gotten frustrated with the lack of progress with Hospital F’s program and had gotten Testosterone prescribed to her father, which she then took herself. Anna had had heart and other health problems since she was little. She had had a check-up for her heart right before she started taking the androgen therapy. From there on out, no doctor was following her through her switch in hormonal therapy. The two main health risks related to androgen therapy are liver damage and heart complications.

One of my first meetings with Emi Koyama ended with her telling me about Intersex activist Max Back’s death to Mullerian cancer. Emi implied that Max had not gotten the full initial care they needed for three Intersex related complications: avoidance of doctors after traumatic childhood medical events, medical visits that concentrated on the gendered body and not overall health, and lack of correct medical attention due to medical bias/inaccuracy surrounding gender in the body. Max had been assigned female at birth, receiving the mutilating surgeries that the 1960’s required to create a girl child. As an adult Max began to remember their childhood experiences, suffered major depression and then went through the medical-legal process of gender reassignment (Alexander in Dreger 1999).

It is possible that Anna's death had nothing to do with the androgen therapy. However, it would also seem likely that she should have been monitored regularly, while shifting to a Hormone Replacement Therapy (HRT) that could negatively affect a pre-existing condition. The Italian health care system can isolate patients with DSD by offering them care only through stigmatizing nomenclature, or stigmatizing behavior on the part of the medical practitioners. Anna's medical points of reference were in cities far from where she lived, and betrayed no concern or no knowledge about her decision to change HRT. I myself had forgotten her heart issues when she told me how well she was doing with the new HRT. The world has lost one of its points of light.

There are many negative side effects in clinical practice caused by the social anxiety that DSD seems to provoke: from gendering hormones and other biological components, to not treating the full individual. The road to useful medicalization is complicated, but collaboration seems to be growing in every direction.

4.5 *Biosociality, hidden in the shadows and out in the light of day*

In 1934 Marcel Mauss brought the body and the biological into the social sphere by addressing what he referred to as 'techniques of the body' (Mauss 1936). In this lecture Mauss highlighted how the body is the instrument with which we negotiate culture society and interactions. Bodily actions and appearances are codified and gendered by society, from how we walk, to who is expected to open a door. However, how we are embodied also affects how we will interact with this world and its mutable expectations.

Disability politics addresses physical difference and subsequent medicalization through this perspective, indicating that it is the expectation of what the body must be or look like, that marks it as disabled, pathological or in need of fixing. In seeking useful medicalization strategies, AISIA adopts the theoretical platform of disability politics, often leaving identity politics to personal discussions. The organization of a social group around a biological category is an aspect of what Nikolas Rose considers in his interpretation of bio-sociality. Rose (2004; 2006) contemplates biological citizenship, also represented by genetic disease categories in which the individual is 'potentially unwell'.

DSD syndromes and AIS in specific, reflect many considerations within biosocial, disability and biological citizenship discourses. The diagnosis is generally based on biological chromosomal material that represents a rupture with expectations of the gendered body. By inserting biological variation into a medicalized, pathology framework, the expectations of being potentially unwell are projected onto the AIS body. In turn, AISIA members socialize

around the diagnosis, in search of useful medicalization, to challenge stigmatization, and to share their experiences and problems with people in a similar situation.

AISIA started in 2005 as a social network that operated as a non-expert medical research team. Members attended medical conferences and sought medical information and options. This lead quickly to collaboration with the Creighton clinic, but also three Italian university hospitals (A, B and C) that had different therapies, research and options to offer. In 2006 AISIA became an official group and began to fill its website with scientific articles and personal testimonies. By 2008 there were more than one hundred contacts, and the group began to participate more directly in medical conferences.

AISIA performs several specific functions; a reference site for medical care and research projects, personal interaction and information, bi-yearly group meetings that also provide group therapy sessions. AISIA currently collaborates with two hormone research projects (bone density/cardiac health, testosterone therapy), a genetic database project, a psychological assessment project (including research on full disclosure) and a DSD team.

The group meetings often serve as a sounding board for the concerns of AIS women. These concerns rotate around negotiating medical care, and the social impact of related issues such as sexual activity, lack of menstruation, and sterility. The bio-sociality of the group provides a forum for the members to meet and speak openly with other people who may have otherwise affronted many difficult life moments alone.

Members talk about what they do and don't tell people outside the group, their fears and expectations. They swap stories about either pretending to have their period, or avoiding talking about it.

> T: A 10 anni ho avuto una perdita enorme, mi hanno fatto festa dicendo che sono diventata signorina, pensavo quando non è più venuto che forse mi si è rotto l'imene. Comunque nel mio paese si parla sempre, tutti vogliono sapere se ti è venuta la prima mestruazione, quindi me la sono inventata.

But as one gets older, interactional issues, such as sex and children, supplant menstruation as a primary concern. AIS patients' sex lives can be affected by the length of their vaginal canal. However, it is often also affected by the stigma of medicalization and surgical traumas, emotional and physical. Several group members report having had relationships that were interrupted or disturbed by events related to their diagnosis. Within the group, many of those who have had surgery have continued problems with penetration. As we have seen earlier, these surgical outcomes are compounded by the fear that "someone can tell", or the stigma

attached to having a body that “needed to be fixed”.

Other group members who learned of their diagnosises later in life, or through more recent, non-stigmatizing communication have had varying experiences in relationship. Most found their partners supportive and understanding. Two group members have been able to adopt, another complicated issue due to Italian law. Hanna, years later, still fills with emotion when she talks about going to Russia to meet her youngest child. National Italian adoption, available only to married heterosexual couples, is so slow that even many married couples seek other channels. Hanna describes the pain of waiting even weeks when they had already meet their youngest, leaving their oldest at home.

Other members thank Hanna for being in the group, for being a positive example for the future. Hanna is very self-assured, she is older and has been able to overcome her biggest obstacle within the diagnosis, having children. Tara, on the other hand, has never been able to get over the idea that she cannot have biological children, or that she would have to get married to adopt. Being able to vent her frustrations in the group is a big help for her. She wonders, out loud, if it is right to blame the syndrome for not being able to have children, when so many people can’t have them. The group provides an environment where everyone can express their fears and insecurities, talk and laugh about dilators, vibrators and everyday issues without censoring themselves or risking insensitive bigotry.

The group members bring back stories from their friends who don't have AIS, who also have problems with sex and relationship. Melanie jokes that she is often the one to give advice to her female friends, since the diagnosis has made her more aware of her body. Anna works in an academic environment where many of her colleagues are conservative Catholics. She isn't out about her diagnosis, and says she is asked if she is a lesbian when she talks about the importance of respecting difference. She finds the idea that being against discrimination must imply that you are part of the discriminated group, humorous, while she herself is heterosexual. She wonders what her colleagues would think about AIS. Anna, like most of the group, reads difference as positive, and despite the problems gonadectomy and diagnosis have given her, she is sure that AIS and AISIA have brought her a richer experience.

In May 2010, the group instituted a scientific committee within the group, fruit of collaboration with individual doctors and medical institutions. The committee consists of a psychologist, a pediatric endocrinologist, a surgeon, and a medical student diagnosed with CAIS. This committee increases the group’s role as a non-professional authority in AIS care. In July 2010, the group met with the pediatric team of one of the major DSD centers in Italy, a hospital where many had received treatment. The event was similar to a mini-consensus

convention, a historical first in which patients and doctors shared experiences and frustrations. In chapter seven, we will look in further depth at the particularities of the DSD team and their collaboration with patient groups.

Chapter Five

Klinefelter's syndrome

5.1 *Klinefelter's syndrome as a multiple object*

Klinefelter's syndrome is one of the syndromes that may be revealed through pre-natal chromosomal testing, due to the presence of a third sex chromosome, XXY. It is also one of the intersex/DSD syndromes that probably would *not* have been included in the teratology of the hermaphrodite. In fact many Klinefelter's syndrome support groups, like several CAH groups, do not consider the diagnosis as Intersex[79]. Child Psychologist Leonard Sax[80] (2002), in fact, challenges Fausto-Sterlings' 1.7% figure for Intersex frequency, stating that the "term should be restricted to those conditions in which chromosomal sex is inconsistent with phenotypic sex, or in which the phenotype is not classifiable as either male or female". According to his statistics, which remove the diagnoses of Klinefelter's syndrome, Turner's syndrome and late-onset adrenal hyperplasia, Intersex has a prevalence of 0.018%.

However, DSD terminology reaches further into the body and is more encompassing in that it refers to processes and development. The reference to development allows Klinefelter's syndrome to be more clearly included in the pan-DSD category. That said, Klinefelter's syndrome had become one of the most noted Intersex syndromes since the discovery of sex chromosomes, due to the fact it was revealed to be fairly common. Sax is inaccurate in his affirmation "that most clinicians do not recognize as Intersex, (conditions) such as Klinefelter('s) syndrome" (Sax, 2002, pg. 174). It is more likely that, in fact, most clinicians do not recognize and therefore do not *diagnose* Klinefelter's syndrome, while once diagnosed, it is firmly considered within the DSD (and once-called Intersex) classification scale.

Klinefelter's syndrome highlights Canguilhem's (1943) considerations of the normal and

[79] When individuals with Klinefelter's syndrome do identify with Intersex identity politics they maintain strong positions, as in the case of the individual in Australia who obtained a non-gendered passport, and Lallo of Rome who has a queer Klinefelter group that I do not discuss here because he is the only member of the group.

[80] Sax is more well known for his popular work which affirms biological gender determination and follows Robert Bly and others who declare the need for more "ancient" social rituals to "teach" girls and boys to be "well-adjusted" men and women, and for his work advocating single-sex schooling in order to promote female achievement and self-esteem.

the pathological. The syndrome is currently defined diagnostically by its third sex chromosome. While some may come upon the diagnosis while seeking care for related symptoms such as infertility, others may “discover” the syndrome through chromosomal testing before it presents any variation in quality or experience of life. Where are the boundaries of disease (implying discomfort), in a pathological category primarily linked to structural variance?

In Mol's (2002) discussion of multiple objects, she addresses how ontological categories shift due to their manipulation in practice. Each medical discipline lays out its boundaries of observation based on its disciplinary focus, “seeing” different aspects of the body. This aspect of medicine repeats itself across all of the DSD diagnoses. Technology has revealed Klinefelter's syndrome, drawing out patterns of DNA and marking the statistically uncommon. Klinefelter's syndrome starts as chromosomes, and is then unraveled into different symptomological categories based on the disciplinary focus.

This syndrome was described for the first time in 1942 based on the symptomology, by doctor Klinefelter along with his colleges Reifenstein and Fuller Albright. The symptomology that the Endocrinologist Klinefelter noted as problematic focused on the combination of mammary growth, and low or no sperm production in a group of patients. Working with Albright, he described the nine men as having "gynecomastia, aspermatogenesis without aleydigism, and increased excretion of follicle-stimulating hormone" (Klinefelter et Al. 1942). At first he assigned these symptoms to endocrine dysfunction and postulated the presence of a second testicular hormone (X-hormone; British Medical Journal 1957), but later recognized the chromosomal link (Klinefelter 1986).

Through the 1950’s there was some debate about testing for this chromosomal material, and the correlated chromatins[81]. Murray Llewellyn Barr discovered (with graduate student Ewart George Bertram) in 1948, the "Barr body" (Barr and Bertram 1949), soon to be understood as a chromatin indicator for the number of X chromosomes of an individual. There is one less Barr body than the number of X chromosomes: an XY or an X,O have no Barr bodies, an XX or an XXY individual has one Barr body, a XXX two Barr bodies and so forth.

[81] Chromatin is the combination of DNA, histone, and other proteins that makes up chromosomes. It is found inside the nuclear envelope of eukaryotic cells. The functions of chromatin are to package DNA into a smaller volume to fit in the cell, to strengthen the DNA to allow mitosis and meiosis, and to control gene expression and DNA replication. http://en.wikipedia.org/wiki/Chromatin

Typically an XY male is chromatin negative and an XX female chromatin positive. However the DSD sex-chromosome syndromes, such as Turners (X,O) and Klinefelter's disturbed this chromosomal binary. In 1945 Heller and Nelson showed that gynecomastia wasn't present in all cases, especially in those with less testes development (British Medical Journal, 1957, pg. 1294). These cases (considered rarer, but perhaps less often identified) were then correlated to a female sex-chromatin pattern, confusing the clear picture in early chromosome testing. It was even postulated that Klinefelter's syndrome was a genetic sex-reversal.

> There is not much doubt that these individuals are examples of a sex reversal carried to a stage which had not hitherto been considered possible in man, since it affected not only the general bodily appearance (the "phenotype") but also the gonads. Furthermore, since in some cases spermatogenesis has been demonstrated in some of the testicular tubes, it follows that the process of sex reversal has involved even the germ cells (British Medical Journal 1957, pp. 1294-5).

In 1956 Nelson began to separate what he considered "true" Klinefelter's syndrome, chromatin positive from "false" cases that were chromatin negative, which would soon establish the chromosomal link to the syndrome. The "false" cases mainly presented problematic sperm production and testicular function, without the developmentally related variations (Leydig cells, etc…).

> Nelson suggests that a more reasonable nomenclature would be to abandon the term Klinefelter's syndrome altogether and call the chromatin-positive types "female pseudo-hermaphrodites with gonadal dysgenesis" and the chromatin-negative types "early testicular atrophy due to tubular fibrosis." (British Medical Journal 1957, pg. 1295)

What Nelson had really come upon was the chromosomal link. Soon thereafter, "early testicular atrophy" and other sperm-production-related testicular dysfunctions were removed from the Klinefelter's syndrome category in favor of the chromatin-positive diagnostic factor. Far from not recognizing Klinefelter's syndrome as Intersex, the presence of a Barr body in a male phenotype with male reproductive organs raised all sorts of questions about development and so-called "sex reversal". Klinefelter's syndrome would certainly not be currently considered female pseudo-hermaphroditism.

By the 1960's other bio-imaging techniques were available and Klinefelter's syndrome was firmly associated with the 47, XXY chromosomal structure[82]. However, in the clinic there often remained some confusion about what it meant to be genetically male or female, was it

[82] Standard development implies 46 chromosomes.

the chromosomes, or was it the Barr bodies? These researchers attempt to clarify the nomenclature:

> The same argument applied to Klinefelter's syndrome (XXY, etc.), in which patients should be described as "chromatin positive" rather than "of female genetic sex." They are just as likely to be males (XY) with an extra X as they are to be females (XX) with an extra Y. Clinically, of course they are males who are usually sterile (Gordan, Dewhurst; response to Gray 1965).

Due to its chromosomal nature, Klinefelter's syndrome has a direct link to the eugenics debate. In Italy the syndrome is included in standard prenatal testing for women over 35, like other chromosomal variations. As we shall see, however, prenatal testing does not directly imply a eugenics platform. The eugenics platform is induced by a more complex relationship between information, communication and the creation of medical authority. Media cases can give a good example of the lack of public knowledge about Klinefelter's syndrome and DSD.

At the beginning of February 2008, Klinefelter's syndrome hit the Italian press, without indicating what the syndrome consisted of. On February 11th, in Naples, there was an anonymous call from within the hospital denouncing infanticide. A judge was called, a court order issued and seven policemen stormed into the hospital ward where a perfectly legal late term abortion had just been performed. They interrogated the woman who had just come out from under anesthetic and the two operating physicians. Italian law 194 stipulates the right to access late term abortion for health motives including psychological health. The woman, being over 35 years old had been advised to have prenatal genetic screening. The paper reported that the fetus had been diagnosed with what was called a "serious genetic illness", Klinefelter's syndrome, and therefore the patient had decided to terminate the pregnancy.

The articles that followed mainly rehashed the abortion debate, the use of late term abortion for psychological reasons, and the aggressiveness of the police intrusion in the hospital. I found no use of the terms Intersex or DSD, or differentiation between syndrome and disease. There were a few attempts to clarify how Klinefelter's syndrome can manifest. There was also an embarrassing episode in which an anti-abortion Italian politician, Giuliano Ferrara, had himself tested for Klinefelter's syndrome because he has small testicles (which he photographed), announcing that he had prayed in church for positive results.

Genetic testing and our understanding of what genetic disease actually means obviously have strong ethical implications as far as what could be seen as a eugenic programs that eliminate difference through abortion. However, approaching the issue by attacking a woman's right to choose continues a discourse that interferes with individual, especially

female, autonomy. The abortion discourse hides the larger social issues of the medicalization of variance, or the elimination of variance, referenced by disability politics.

The lack of public knowledge, and the ambiguity of expert knowledge has lead to Klinefelter's syndrome being referred to as a "grave genetic illness", as in this media case in Naples. What is it about Klinefelter's syndrome that frightens people enough to call it a grave genetic illness? What creates the medical emergency? Once, it was primarily associated with sterility, however, once the chromosomal structure was identified, there was a rash of research to find other possible symptoms. Klinefelter's syndrome currently has the following possible taxonomical and symptomatic attributes:

1. XXY, chromatin-positive Male
2. Discrepancies surrounding cognitive implications: described as possible retardation or possibly lower IQ than family members.
3. Osteoporosis due to long bone growth caused by low androgen levels.
4. Low androgen levels for an XY male
5. Sterility and smaller testicles
6. Feminine appearance through either breast growth or increased fat/body mass ratio
7. Increased possibility of homosexuality
8. Possible shyness.

Referring back to our earlier discussion of the differences between syndrome and disease, we can clearly identify Klinefelter's as a syndrome, in that it lacks clear manifestation of functional problems besides those in the reproductive system. While reproduction is considered one of the primary rights and/or functions of humanity, it is not necessary to the function or survival of the organism.

Attribute number 1, seen in the list above, is the defining point of the syndrome, referring to material and or developmental variation, not symptomology. Attribute number 2 starts to unravel Klinefelter's syndrome as a social object. Once it was clarified what the parameters of the syndrome were, chromosomal variation, the research object shifted to cover behavior and cognition. This perhaps seemed like a logical leap considering that an additional chromosome had severe developmental effects in Down syndrome. This research object was also facilitated by increased institutional chromosomal testing, revealing data about asylum and prison populations that was not otherwise readily available (Price et Al., 1985, pg. 330).

Much of Klinefelter's symptomology was developed before the syndrome was known to be as common as it actually is. It is now estimated that one in seven hundred males have this chromosomal anomaly. The Klinefelter's cases that were brought to medical attention were

for hypogonadism, gynaecomastia, fertility. More and more cases trickled in as genetic testing expanded to other arenas.

It could also be speculated that it was a chromosomal anomaly in search of symptoms. The same Barr who named the Barr bodies conducted research in mental institutions, looking for a higher prevalence of the chromosomal anomaly (Barr et Al. 1960). Klinefelter's thus came to be viewed as a syndrome of cognitive development like the other chromosomal DSD's, XYY and Turner's syndrome (0,X).

Looking for biological differences in populations already removed from normative society, such as in the asylum or prison implies a belief that these behavioral variations might have a biological base. Chromosomal anomalies provide an example in which the correlation between behavior, and developmental and hormonal variations can be observed. However, when the frequency of the anomaly is unknown in the general population, it is impossible to determine if there is instead an increased frequency in these institutional settings.

Nonetheless, in 1960 Barr looked for Klinefelter's syndrome in the asylum population and found it. In a similar manner in the 1960's researchers looked for XYY individuals in prison populations (Jacobs et Al. 1965; Casey et Al 1966; Goodman et Al., 1967) and found them. This prison/XYY research continues to find its way into other bodies of bio-social research that correlate testosterone to violent behavior. The prison research results, however, only reveal aspects of the prison population, not the population at large. In the 1970's the tables turned again, away from biological determinism to social determinism, and it was shown that there are more XYY individuals outside of prison than in (Walzer and Park 1975), thereby undermining the previous correlation.

Klinefelter's syndrome is often still linked to severe cognitive difficulties in medical communication. Medical reports are varied in their results. A ten-year Australian review shows 22 of 32 patients "with an identifiable pattern of disorder, including marked lack of insight, poor judgment and impaired ability to learn from adverse experience. Use of long term replacement testosterone treatment reduced episodes of behavioral indiscretion." (Simm and Zacharin 2006).

Another Dutch team indicates research shows an increased presence of XXY individuals having psychiatric disorders such as anxiety, depression, conduct disorder and schizophrenia (Boks 2007). Their sample was 31 consenting patients from a 51-member Klinefelter's syndrome patient group that were not informed about the psychiatric scope of the survey. Ten members had current psychiatric diagnoses, primarily depression, with two instances of psychosis. The researchers themselves indicate this is not statistically significant for psychosis

in such a small sample size. Almost all of the psychiatric disturbances showed family history, in all of the cases of depression (five on the mothers' side and one on the fathers' side) and in one of the psychosis cases (one on the fathers' side). The conclusion of the article, then, is a possible X chromosome link to psychiatric disturbances in XXY individuals. In a different research environment, the conclusion might have been that XXY individuals present psychiatric disturbances only when there is family history.

The only large-scale research (from hospital discharge diagnosises, conducted by the Danish team that also performed one of the few research projects on XXY overall health) indicates that there is an overall 69% increase of XXY hospital admissions for any diagnosis (Bojesen et Al., 2005). This means that from a thirty-year population span of 832 XXY and 4033 XY individuals, 85% of the XXY population had been hospitalized for another condition and 70% of the XY population. This research presents its finding very conservatively, indicating that perhaps only 25% of XXY individuals are diagnosed, and therefore the XXY sample population is precisely that which has already been medicalized and will continue to receive more medicalization. Regarding psychiatric diagnosises they indicate an overall 17,4% of the XXY population versus 5,7% of the XY population. They have tried to analyze the evidence for tendencies in hospitalization before diagnosis, however this is difficult from only hospital records. These percentages break down into: psychosis 02.6% XXY, 00.7% XY; personality disorder 11.1% XXY, 03.5% XY; retardation 04.2%, 00.1% XY. This shows an increased risk factor that, however, is still too low to be a defining factor of the syndrome. These statistics are part of the inherent "risk" factor of genetic diagnosis.

It is now believed, instead, that cognitive differences for Klinefelter's syndrome are not as severe as once depicted. It can be said that they are revealed to be different in comparison to other family members, but not necessarily noticeable when the individual is compared to the general population.

Returning to the symptom list, points 3 through 6, osteoporosis, low androgen levels and sterility, refer to biological markers. These research objects have helped endocrinologists understand the relationship of hormones to developmental processes. Throughout the development of endocrinology, it has been noted that "sex" hormones have a role in many different physiological systems. Testosterone helps tell the body when to stop long bone growth. Therefore lower androgen levels can lead to increased long bone growth, which also increases the risk of osteoporosis. This is the arena in which many patient groups would like to direct research, the resolution of hormone-related physiological issues.

Points 7 and 8 indicate the continued, conjectured, correlation between hormones, genes and behavior. Presumed homosexuality is attached to the stigma of the diagnosis. The stories of those involved in patient groups reveal a more delicate interaction between the syndrome, physical manifestation and behavior. The associations between what is a feminine body, the increased fat/muscle ratio, or what is feminine behavior, a lack of energy, become a complex mixture of personal experience. These factors bend around the body and identity, often distancing from a direct correlation to what is considered homosexuality.

The sensationalist media case in Naples reveals the ambiguities in what is communicated and understood, when genetic anomalies are detected. Whereas the media case highly publicized the abortion debate, a woman's right to choose has legal consensus in Italy, pre-natal genetic testing raises different ethical issues. What was missing from the media debate was the delicate nuances of disability politics that frame the discussion regarding normality and pathology. For what is really significant in a discussion of pre-natal testing and abortion, is how "genetic disease" is defined.

Tom Shakespeare (1998; 1999), and Lennard Davis (1995; 1997), among others, have defined disability as socially and environmentally specific. Following this logic, disability is viewed as a consequence of the incongruence between the individual and the environment (intended as both natural and social factors). Disability politics' contributions to the genetic testing debate have centered around whether the genetic marker marks something considered biologically problematic, or socially problematic. Adele Clark (2003) addresses bio-medicalization in a similar manner, posing the problem of how many new medical categories new technology is "seeing" as in need of fixing. The social stigma attached to Klinefelter's syndrome marks it as a biological anomaly with social implications.

Due to the lack of clarity surrounding subjective dis-ease (Klineman 1985) in Klinefelter's syndrome, I would like to outline what Klinefelter's is like for those diagnosed. This will lay a bit of a foundation to readdress the use of prenatal genetic testing.

5.2 *KIO, biosociality*

Klinefelter Italia Onlus is one of the 3 main DSD patient groups active in Italy. It was founded in 2004 after the first Klinefelter's patient group, founded in 2002, was taken over by doctors[83]. It is active throughout Italy, with spokespersons in Livorno, Ferrara and Naples.

[83] The founder of KIO complained about professional and monetary interests interfering with the first group, where the primary physician involved used the patient group to get paying clients in an

Like many groups, it operates as an informational Internet platform that is supplemented with annual meetings and activities that include medical conferences and other collaborations.

Both Rabinow (1999) and Rose (2006) discuss bio-sociality from different angles. Rabinow, as an anthropologist and historian of Foucault, highlights the creative nature of the socialization of information. This perspective is also reflected in Epstein's (1998) work on the politics of patient support groups. Bio-sociality generally refers to a social category that is created around biological information. Rose adds to this discourse by extending the field of consideration to how new technologies create new biological categories to be part of. Rose elaborates that a new category of biological citizenship in which the members are potentially un-well is thus created.

Members are diagnosed to be potentially un-well through the revealing powers of new technologies. The Italian support group, KIO, weaves its experience through both perspectives of bio-sociality, negotiating the political power of information, and handling the impact that diagnosis can have on one's identity.

The founding member of KIO, Marcello, spoke to me about his relief, when he finally got an accurate diagnosis and description of Klinefelter's syndrome. The diagnosis came several years before the accurate description. He had first been diagnosed after years of trying to have a child and only his wife was being examined for infertility. He insisted that he also be tested for infertility and was found to have low testosterone production and then Klinefelter's syndrome. At this first step, the syndrome was primarily manifest in infertility, a non-life-threatening disturbance. Another doctor he consulted about the syndrome told him he wouldn't live past 40 and that there was no treatment available.

Years later, he went on hormone therapy. He talked about the changes he felt when he began testosterone therapy; more active, more energy, more libido, like he had finally become himself. He seemed very happy with the masculinization of his body (less body fat ratio) and the effects of the testosterone on his personality. Some of this discourse was framed in what could be interpreted as a masculinization of personality as well, in reference to the energy levels and libido. In his narrative, he spoke of the subsequent separation with his wife, indicating that she was not happy with him as a more assertive person. However, he is clear to state that he has always had a male gender identity and heterosexual behavior. The hormones opened something in him that lay dormant, something that is seen as being more masculine—however, there was never a point in which he didn't identify himself as a man.

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otherwise state subsidized health care system.

However, as I continued to talk to Marcello, it turned out that what had sent him back to the doctor and lead to the hormone therapy was not his gender presentation, but debilitating headaches that had been going on for years. He tried to locate the first doctor who had diagnosed him, without success, not wanting to return to the doctor who had negatively sensationalized the syndrome. When he finally located the doctor, he was told that more research was coming out, and that he could try hormone replacement therapy. The direct result was the alleviation of the headaches, the rationale for which is difficult to find in the medical literature on Klinefelter's syndrome.

For the group founder as well as medical researchers, the exalting point of hormone replacement therapy is its effect on personality and behavior. Many of those involved in KIO replicate the satisfaction of having a diagnosis, and the results of subsequent therapy. The points of contention remain the stigmatization of the syndrome and the general lack of information and research on long-term-health effects. Little is known about the long-term effects of androgen hormone replacement therapy. Accurate communication is increasingly available, the younger group members often having a more positive experience at diagnosis.

Another group member, Franco, describes his experience:

> A 21 anni (2001), quasi 22. avevo un varicocele, e ho voluto fare degli accertamenti da un urologo. L'urologo mi mandò dall'endocrinologo. L'endocrinologo, credeva ci fosse un mosaicismo, ma il cariotipo ha confermato klinefelter 100% 47XXY. Mi disse che ero una persona normale, che non avevo nulla di diverso da un altro maschio. Mi spiegò con un disegno il sistema delle ghiandole. E' stata una comunicazione positiva. Mi sono accettato subito.[84]

Information translates into personal empowerment, but also a secret knowledge that someone already knew about themselves. In this case, bio-sociality confers special-ness and explanation.

> Ero felice all'idea di non poter avere figli, era come una rivelazione che gia' sentivo in precedenza. Sentivo, quando non lo sapevo, che essendo poco forte, non avrei dato alla luce un figlio forte. Sono stato appassionato di scienze naturali alla scuola, e sentivo la volontà di estrarmi dalla riproduzione, per non indebolire la specie. Quando seppi dell'infertilità, mi venne da sorridere pensando a questo mio sogno. La gente mi dice che non è bello pensare questo. Ma io sono felice. Ora che ho una compagna, la preoccupazione e per lei, ma io continuo a rimanere felice di essere infertile.
>
> Mentre il sapere che avrei presto iniziato una terapia con testosterone, mi ha dato un po di

[84] Email interview 17/07/09

preoccupazione iniziale. E' sempre una terapia, e avevo paura degli effetti collaterali. Anche il comunicare la mia diagnosi agli altri mi dava felicità, perchè permettevo alla gente di conoscere il sistema endocrino maschile e di evitare di ghettizzare le persone che nascono con una malattia genetica. Ho sempre ammirato la semplicità dei ragazzi con sindrome di Down, sapere della mia sindrome mi faceva sentire un uomo piu semplice.[85]

The genetic data of the third sex chromosome occurs in a context where this group member has already felt stigmatized in some way, seeing himself as (genetically) weaker even before the diagnosis. This message is mixed however with appreciation of difference, admiration for the emotional expression of people with Down's syndrome and the hope that by communicating his diagnosis, people will have more information about genetic illness. He hints that before the diagnosis, his idea of himself was negative, whereas the diagnostic information gives not only tools for action and self-determination in the body, but a place in a biological framework of identity.

La diagnosi della sindrome mi ha portato solo una vita piu ricca e felice...Era come avere una cultura in piu'. Era come ricevere una spiegazione ai miei atteggiamenti introversi.[86]

However, it is not the diagnosis alone that connects the dots in the biological understanding of the self, the groups provide expert knowledge that doctors cannot always access. The group provides context:

Un ulteriore conoscenza di me stesso specchiandomi negli altri, sono stato molto felice, ho appreso informazioni in piu' che i medici avevano tralasciato.[87]

The group also provides a context in which to discuss the social interpretation of the diagnosis. Marcello expressed his frustration with the stigmatization, the association of the syndrome with homosexuality, and therefore femininity and weakness. But he was quick to state that that was all prejudice, what would it matter if people weren't homophobic? Franco states the image of Klinefelter's syndrome is “that they are effeminate, crazy and fat”[88].

Marcello seemed to dismiss homophobia as a problem indirectly related to Klinefelter's syndrome. As if homophobia were just a facet of the spectrum category of bigotry not to be considered, not founded on real information or solid social values. He stated that the group had probably about 10 percent homosexual members, as does the population at large. What

[85] Email interview 17/07/09

[86] Email interview 17/07/09

[87] Email interview 17/07/09

[88] dicono che siamo effemminati, pazzi e grassi Email interview 17/07/09

emerged was that due to the syndrome, all of the group members had been indirectly subject to homophobia, having been imagined to be homosexual due to the syndrome, and therefore there was no room for homophobia in the group.

Italian government institutions show some hostility to homosexuality, while not directly criminalizing it. The Italian Equal Opportunity Minister, Carfagna, in 2007 removed all links to gay political and support groups from the ministry website, and in the same year, questioned the choice of holding gay pride in Rome[89]. Many right wing party members attended the Catholic Church sponsored "Family Day" gathering in Rome in may 2007, which rhetorically positioned the "family" as being threatened by homosexual couples[90]. Italian politics often respond to debates provoked by the positioning of the Catholic Church. An Italian men's group organized around a biological phenomenon, that is not a gay or queer rights group, which has an anti-homophobia policy is probably unique.

However, homophobia in not the only stigmatizing social factor surrounding Klinefelter's syndrome. The stigma of un-wellness, disease, or mere biological difference can reveal the moral structures underlying health concepts even in present day understanding. Franco explains how he used to tell everyone about the diagnosis, to combat the afore-mentioned stigmatization, but has had a handful of negative surprises that has lead him to be more selective.

> Raccontavo sempre a tutti fino al 2007, poi solo alle persone che hanno i mezzi per ricevere il messaggio. Ad esempio, alcuni miei soci hanno fondato un gruppo sportivo chiamato Klinefelter footbol club, dove i giocatori indossano la maglietta della squadra con sopra scritto, Klinefelter, uno dei giocatori, non vuole indossare quella maglietta, dicendo "io non gioco con un tumore sulla schiena". In base alla cultura della persona si deve dare un messaggio diverso e a volte non darlo. Un altro caso e' stato di una famiglia di Milano, la quale quando hanno ricevuto la diagnosi di loro figlio, il padre ha lasciato la moglie, dicendo "ti lascio perchè mi hai fatto un figlio gay".[91]

The message hidden in many of the DSD group discourses is the veil of possible prejudice due to culturally ingrained ideas about gender and the body. Here he states, depending on the

[89] In 2010 Prime Ministry Berlusconi made international scandal by stating "that is better to have a healthy obsession with beautiful women then to be gay" in reference to his paying for sex and female attention. In response another Minister stated that everyone knows no one wants their child to be gay.

[90] Then out of office Berlusconi attempted to speak, but was thrown off the stage due to his second marriage and extra-martial activities.

[91] Email interview 17/07/09

person's knowledge structure (*cultura*), one must communicate a different message. This difficulty surrounding communication is mirrored in the Parent Handbook designed by ISNA and translated to Italian by AISIA. The Parent Handbook attempts to communicate to those who might hold the most fear and prejudice, new parents.

5.3 *Medicalization, hormones, gender and health*

Hormone replacement therapy in Klinefelter's syndrome care was prescribed for gender presentation (feminine-seeming fat/muscle ratio), sex drive and homosexuality. Hormones and Chromosomes have become the 20th century emblem of biological gender. Even though homosexuality is no longer considered pathology, in and of itself, it is still often utilized as a symptom in Intersex syndromes linked to hormone imbalances. This is one of the myriad of the ambiguities of what is being medicalized in DSD. Is it the social expectation of gender-related issues such as physical gender presentation, gendered behavior and even reproductive issues, or is it the physiological health complaints such as headaches and osteoporosis? This ambiguity within endocrinology has run the course of my research, touched upon in previous chapters.

KIO members express a positive relationship with the medicalization of the syndrome in its guise as hormone replacement therapy, a frustrated one in the guise of prenatal testing. This mixed experience is a product of the same factor of lack of accurate information and research. In a discussion of research directions in endocrinology, it becomes immediately evident that the female reproductive organs and secretions have been a more active locus of interest and manipulation. Marcello believes Andrology to be an underdeveloped field[92], which like many other disciplines, does not communicate with pediatric endocrinology (which is, instead, more in contact with other DSD cases). The medicalization of menopause has lead in 2004 to a congressional subcommittee hearing in the USA on health risk of primarily "female" hormone replacement therapy (Congressional Hearings (USA) 2004). Research on "male" hormones has often had the stigma of pseudo-science, evoking the experiments of Brown-Sequard and the monkey gonads of Voronoff (Oudshoorn 1994). "Male" hormone research initially investigated longevity and virility, leading to modern day remedies such as Viagra. However, these research attempts were among the first investigations which would form the basis for modern day endocrinology.

[92] Historians indicate its establishment as an independent discipline in the 1960's, the first andrology journal published in 1969 (Social Studies of Science 1990).

KIO members would like to promote more research in andrology. Their hope is that research move beyond secondary sex characteristics and behavior toward fertility, cardiac and bone density issues, the long term effects of hormone replacement therapy and so forth. Having been framed medically, the group seeks useful detailed medicalization.

> Vorrei raggiungere tutti i pazienti Italiani e far si che tutti i giovani uomini ricevano una visita andrologica di controllo all'età dai 12 ai 14 anni. Quindi il gruppo servirà a tutta la popolazionae maschile.[93]

Some international activists question the motives of medicalizing in the first place, even on the hormonal level, calling into question Klinefelter's syndrome's biological versus cultural aspects. The US context often appeals to the lexicon of gender-identity politics. Yet again we see an ambiguity in Intersex terminology, not used by the Italian group. Intersex can represent, even to the patient, an extra stigmatization. Or Intersex can represent an aspect of the diagnosis and the subsequent medicalization that leads to self-identification with a political category. North American activist D. Cameron writes:

> It is only fairly recently that I have discovered the term “intersexed” and how it relates to my body. I like the term because I prefer more choices than male or female...it wasn't until I was 29 years old that a label was put on my physical differences, differences I never quite understood. I had large nipples on smallish breasts, peanut size testicles, and cellulite type hairless fatty tissue over most of my body. I was told at an infertility clinic that I had an extra X chromosome and a karotype of XXY-47. This is commonly known as Klinefelter's syndrome. I was informed that I was genetically sterile and that my “sex glands” produced only 10 percent of what was considered normal testosterone levels for a male. I was advised to immediately start testosterone therapy. I was told my “sex drive would increase,” I would “gain weight and my shoulders would broaden,” and that I would have to do this every two weeks for the rest of my life. The medical journals called my condition “feminized male.”...This reality was not evident at my birth...Not having any other information or knowledge about my situation, at the advice of the doctor at the fertility clinic, I faithfully got my 300mg. injections of testosterone every two weeks. I soon found myself going through puberty all over again-in my early thirties (Cameron in Dreger 1999 pp. 91-92).

He describes the trails and tribulations of 20 years of hormone replacement therapy (HRT), his attempts to use patches and even going cold turkey at one point. Cameron wonders what the medicalization is doing to his identity, and his feminine side.

> During this period (1976-1981), I did not have any counseling for emotional issues. My main

[93] Email interview 17/07/09

support came from my life partner, Peter, who I met in 1978...It was an overwhelming time of confusion, yet the confusion was mixed with discovery. I didn't understand why I had been chosen to have this experience in my life, and wondered whether I should instead have stayed who I was. In the end, because I was so tall, I decided to proceed, in order to find out what being "male" was like. I often regret that decision...For the next ten years I became quite strong and trim...In 1991, my sex drive began to diminish significantly. I feared that my testosterone replacement therapy had failed. I started to think of testosterone as a poison in my system. I started to get back in touch with my female side-and realized that I had never completely lost her. Emotionally and spiritually I have always felt more feminine, and I began to doubt the correctness of the decision I had taken, in 1976, to find out what being male was like. My sexual orientation had not changed-I was still attracted to men. I considered lowering my hormone dosage, but doctors advised against it. There would be serious side-effects they told me. But could the side-effects be anymore painful than the fear of prostate, breast, or testicular cancer by continuing the injections, I wondered? Why wasn't I told any of this when I started hormone therapy? (Cameron in Dreger 1999 pp. 93-94).

Cameron initially had a positive experience with HRT, despite his questions about whether he really wanted to masculinize his body. While all of the Italian group members I talked to identify as heterosexual, they indicated that HRT wouldn't have changed their sexual orientation. HRT had instead satisfying effects on their energy levels, sex drive and body form. Androgen therapy in Italy is increasingly administered by means of a gel that is otherwise commercialized for sports performance (doping). Cameron explains the complications with continual use of the therapy:

For two or three years, my doctor raised my testosterone dosage to 350 to 400 mg. Every two weeks to see if that would improve my sex drive. My sex drive was unchanged, but I started having more prostate and urinary problems. I was put on another drug to compensate for the side-effects of the testosterone... In December 1995, I decided to stop my injections as they had become painful and I needed a rest after 19 years. (When I stopped the injections, I was up to 350 mg. every two weeks.) Some side-effects occurred within five weeks: fatigue, mood swings, depression, more difficulty urinating...I realized I could not return to where I was in 1976, before the testosterone injections, and decided that it was best to stay on the journey I had started... In January of 1996 I returned to testosterone therapy, with one androderm patch a day. My energy improved but flattened out in two weeks...My sex drive was still absent even with the patch, and so I wondered how unfortunate all this hormone replacement therapy had been, since my lack of sex drive was the main reason I had originally started on the hormones...On Father's day I decided that I had had enough of the patches. I decided to return to the injections and wait and see if the medical community would even come up with an acceptable alternative. I injected 200 mg of testosterone

into my glutes. It actually felt good!...My energy level has returned as has my sex drive, and I generally feel very good...There are many courageous intersexed people on our planet, not just males and females. Our sex hormones define us or set us free from categories. When others look at me they probably see a big, hairy, bearded man. But I know the TRUTH... I am a unique blend of my female and male essences, and I expect to continue evolving at that level. (Cameron in Dreger 1999 pp. 95-96).

The Klinefelter's diagnosis at the chromosomal site reveals what we cannot see, but sometimes suspect about ourselves. The medicalization of the syndrome, like most hormonal therapy, is an experimental procedure, exercising effects on the physical body, but also on the subtle dynamics of mood and energy. Cameron reiterates throughout his narrative that his sex drive was one of his primary concerns. He was not interested in becoming a more masculine, or heterosexual individual.

Is lack of sex drive problematic only in a male body? Or is it only medicalized in a male body? As we will see in the medicalization of CAH, high sex drive in the female body, associated with clitoral hypertrophy, has been medicalized in the opposite direction[94]. Since Brown-Sequard's announcement to the Société de Biologie in 1889, despite the negative reaction of the scientific community, endocrinology of the male body has largely focused on sex drive, vigor and mental clarity (Oudshoorn 1994 pg. 18). These form part of the images of the male social role that Oudshoorn claims persist in the understanding of the sex hormones. One could postulate that these pre-scientific ideas contribute to the image of men with Klinefelter's syndrome as effeminate and partially male, despite the fact that the majority of XXY individuals have male gender identities.

Cameron, and many of the KIO members welcome the positive effects of hormone replacement therapy. Cameron also addresses the unknown in hormonal cure, and questions if it is possible to return to the experience of body one had before therapy started. Cameron cites normal testosterone levels for the adult male body as ranging from 400 to 1,100, a fairly wide range. The normal range for the female body is 2 to 60. This discussion obviously does not take into account hormone receptors. There is still much to be discovered about the complex effects of hormones on development and the body. Androgens have been used as an

[94] Taruffi retained and cited other research that indicated that large clitorises lead to immoral behavior such as lesbianism or prostitution. Victorian cures for nervous disorders associated with "frigidity" continued to remove female sexual subjectivity and individual sexuality from female choice and instead placed it in darkened medical rooms. What we are addressing here are the medical expectations for the female body, not individual female expectations for their own body.

experimental cure for depression for all genders.

The founder of KIO spoke about the need to create a network of medical allies, outlining the complications of political alliances. As DSD treatment centers form in the major hospitals of Italy, the groups test and seek out doctors that seem to respond to their needs. It was pointed out that Klinefelter's is generally diagnosed in adulthood, or in pre-natal screening. Therefore the allies are often not the same for KIO as for syndromes that are diagnosed in early childhood. As we will see in the next section, many of the interactional issues with the medical community revolve around the accurate communication of the diagnosis.

Canonization of the symptomology can lead to stigmatization of the syndrome category, but can also interfere with individual autonomy. Looking out at the harbor after several hours of explaining the dynamics of being diagnosed with Klinefelter's syndrome, Marcello touched again on gender identity, stating that the group had one member who identified as a woman. While many Klinefelter men are tagged as effeminate, there is generally a consistent male gender identity. Marcello described the absolute resistance of the doctors to suspend androgen therapy in favor of facilitating this person’s gender choice. He himself had argued with the doctors who insisted that a XXY individual is always a man, stating, but even XY men sometimes feel they are really women.

He wondered why it couldn't be possible in the rare case that the XX of the XXY triad outweighed the XY. As in the case of 5-Alpha reductase, as we will see in chapter seven, sometimes the statistical evidence a specific DSD syndrome presents regarding gendered identity binds that genetic marker to one gender identity. This in turn can blind clinicians to the variety of gender identity in the general population regardless of their biological makeup.

The Italian state health care system facilitates the choice of XY individuals raised as males (or XX individuals raised as females) to change their civic gender category to that of their choosing and obtain hormone replacement therapy. This is not to say that transgenderism and transexuality are not stigmatized. They are defined medically as gender dysphoria, in which case the medicalization of diverging gendered experience facilitates the access to state-sponsored body-modification technologies. Within the boundaries of DSD syndromes, the genetics of the syndromes dictate the cannon, perhaps assuming a more rigid standardization than that applied to the non-medicalized population.

5.4 Prenatal testing

I genetisti dovrebbero essere assistiti da un andrologo quando fanno le consulenze genetiche alle famiglie.

> Per me il test genetico prenatale, è sbagliato. Perchè serve solo ad alimentare l'industria dell'aborto, è una mossa politica. I test andrebbero fatti alla nascita, infatti quelli prenatali sono a volte falsi-positivi. L'informazione genetica è carente, si dovrebbe dire che ogni caso è a sè e che il fenotipo dipende soprattutto dall'ambiente.[95]

KIO mobilized an information campaign around the highly publicized prenatal testing/abortion case in Naples in 2008 in which Klinefelter's syndrome had been described as a "grave genetic illness". They focused on actual experiences of Klinefelter's syndrome, and the new statistics directly informed by the increase in prenatal testing indicating a Klinefelter's frequency of 1 in 700. By this point however, the media had lost interest, and the intervention of the group was barely covered.

Emi Koyama of the Intersex Initiative commented on this case by writing:

> My response to this sort of case is that we need to build a society where children born with various disabilities and deformities would not face such harsh lives, and where families with such children are well supported96.

The support group's experiences highlight the relation of knowledge to power, as in Foucault's (2003) discourse on medical control and body norms. Prenatal testing has a Janus face in the contemporary history of DSD. On one hand, there is the risk of eugenic practices. A KIO member states that prenatal testing has only abortion to offer in response to the early diagnosis. It is in this vein that Margaret Locke (2005) calls genetic testing the new divining, providing possible outcomes one-step earlier in the game. The KIO member highlights a pertinent aspect of this new divining, that genetic testing indicates a range of possibilities, not certainties. Klinefelter's syndrome can *possibly* lead to an increased health risk.

As we have stated before, there is actually little research on the overall health of Klinefelter patients, making it hard to construct the picture of genetic risk.

> The mortality and causes of death in KS patients are largely unknown; only two epidemiologic studies have been conducted. Swerdlow et al. (2001) reported a significantly increased mortality from all causes (relative risk, 1.63), with increased risk of dying from lung cancer, breast cancer, diabetes mellitus, circulatory diseases, nonischemic heart disease, cerebrovascular disease, respiratory disease, and vascular insufficiency of the intestine. Price et al. (1985) reported a significantly overall increased mortality (relative risk, 1.50), with increased risk of dying from circulatory and cerebrovascular diseases. Both studies only examined the primary cause of death.

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95 Email interview 17/07/09

96 Email, 17 February 2008

The same Danish study states that probably only 25% of Klinefelter cases are diagnosed, implying that the difference of 2.1 yr median survival age is in itself a partial statistic.

On the other hand, genetic testing shows the commonality of genetic variation. The increase in genetic testing (in the case of Klinefelter's syndrome, prenatal chromosome testing) has revealed the frequency of what were once considered extremely rare anomalies. This, in theory, changes the perspective of the pathological category. If one in 700 men have the Klinefelter chromosomal anomaly, one must assume many of these individuals have not had negative symptomology and are unaware of their diagnosis. The frequency of the syndrome, combined with the variety of symptomology also indicates that Klinefelter's syndrome is probably not a grave genetic illness.

Earlier I mentioned the shift from an Intersex identity-politics paradigm to a DSD disability-politics paradigm. As long as the medical protocol continues to focus on the gender identity aspects of DSD, a critical reminder of gender theory is imperative. The negotiation of body and behavioral norms in DSD is often linked to the societal stigma surrounding gender roles. However, disability theory applied to DSD has created the option to directly address the medical pathways of establishing and enforcing embodied and behavioral normalization. The hope is to put further light on the function and definition of pathology, statistical norms, symptomology and the medical fix. The concept of disability is dictated by the expectations of the environment in which one acts.

Within the disabilities-politics framework, and not only, it has become increasingly important to think about genetic technology (Shakespeare 2005), what it does performatively, and what it implies for personal identity. At the current moment, the association of genetic markers with a pathological category has primarily diagnostic relevance. Although the public understanding of genetics is still linked to the Mendelian model (one gene: one trait), current research points to the complex interaction of development, and intercellular interaction in gene expression (Jabolonka and Lamb 2005).

Klinefelter's syndrome is read as a disability or a serious illness in the context of how information about the syndrome is communicated. A London-based clinical research indicates that termination rates are higher in Klinefelter's prenatal diagnosis when the test results are communicated by a gynecologist as opposed to a genetic counselor. A genetic counselor is perhaps more likely to indicate the probability factor in genetic testing and have more detailed information about the symptomology surrounding these diagnosises. As in the 2008 Klinefelter case in Naples, one can see the direct correlation between genetic testing and the eradication of difference. The communication of accurate diagnostic information and risk

calculation is often missing. However the Klinefelter's group promotes genetic research because they feel it will show how common and diverse the syndrome is.

Yet again, we read of the moral ambiguity introduced by the new technology. On one hand, the prenatal reading of genetic code stimulates a eugenic discussion, and the possible erasure of a certain type of person from the population, due to social stigmatization of their individual traits. Is prenatal testing ethical for an individual morally or religiously opposed to abortion? This is a salient question in a country with strong ties to the Catholic Church and faith. In secular society instead, the question becomes if a possible health risk with social implications is reason enough to terminate a pregnancy. This individual choice will be driven by the information provided by the medical practitioners. The technology has not yet arrived that provides therapeutic options based on this anticipated knowledge.

On the other hand, it is generally the specialists in the diagnostic field of genetics who perform the role of detailing the nuances of the syndrome category. Genetic counselors and technicians are less likely to communicate a Mendelian deterministic model of genetics. The training they receive includes in-depth knowledge of the myriad of factors involved in genetic expression. The scientific object for geneticists is the genotype, which is then linked to the possible phenotype. A genetic technician at an Italian DSD center expressed her frustration that test results are given to the parents by pediatricians. She stated that parents often then called her directly, scared by the initial information, later comforted by a more detailed description of the probable syndrome.

In this century of the gene, as described by Fox-Keller (2000), technology has revealed another layer of biological understanding that has quickly become a metaphor for determining factors in the individual. The gene has become a commonly use metaphor for heredity and individual aspects of personhood. This metaphor therefore carries with it a large amount of symbolic weight. This weight presents itself in the initial impact of the communication of a genetic anomaly. It is as if one is being told their very structure has gone awry.

Klinefelter's syndrome was born in the context of genetic investigation, revealed as an anomaly in bodies that were most likely historically not medicalized. As more research is conducted, the focus will most likely shift, as it does in many DSD categories, towards holistic endocrinological research that treat the long-term health concerns of those diagnosed. It will be in that context that the ramifications of genetic technology will become more transparent. Then we will see if the technology pushes us to be better than well (Elliot 2004); selecting for the mythical ideal human, or if it will show us the great variety of human manifestation.

Chapter six

Congenital Adrenal Hyperplasia (CAH)

6.1 *What is CAH?*

Congenital Adrenal Hyperplasia (CAH), Iperplasia Surrenale Congenita (ISG), and Sindrome Adrenogenitale (SAG), are the medical terms that connote one of the most frequently occurring of the DSD syndromes. ISG was adopted in Italy instead of SAG in May 2008, a direct translation of the English CAH terminology that also removes the word *genitale* (genital). This passage of terminology reflects many of the decisions embedded in the move from Intersex to DSD. ISG moves from the pathological wording of SAG that directly reflected social anxiety such as concentration on genital form, to a terminology that speaks not only of morphology but also of molecular processes in the body.

As the term Congenital Adrenal Hyperplasia implies, there is more to the diagnosis than divergences in sexual development. The adrenal gland has a complex function in hormone management. The Australian CAH patient group has argued against including CAH as an Intersex category, stating that it is an endocrine imbalance[97]. However it is within the ISG/CAH diagnosis that the controversial clitoral reduction surgeries in early childhood are most often performed. Clitoral reduction surgeries can reduce or remove completely the possibility for the patient to achieve orgasm in adulthood.

American Intersex activist Thea Hillman (2008), instead, argues for the correlation of CAH experience to Intersex identity. Hillman was diagnosed CAH due to early on-set puberty. She states that she began to consider herself Intersex because her gendered body was medicalized in childhood, despite having avoided genital surgery. The hormone replacement therapy delayed her early on-set puberty, but it also acted to feminize her physical, gendered appearance.

CAH refers to an autosomal recessive condition, believed to result from mutations of genes for enzymes that mediate the biochemical steps of the production of cortisol from cholesterol by the adrenal glands (steroidogenesis). Most of these conditions involve excessive or deficient production of sex steroids and can alter development of primary or secondary sex characteristics in some individuals. Research indicates approximately 95% of cases of CAH are due to 21-hydroxylase deficiency (White and Speiser 2000). In the less severe, late-onset

[97] http://www.congenitaladrenalhyperplasia.org/mb/controversy/0030760281

form of CAH, prenatal virilization does not occur. The milder enzyme deficiency was termed non-classical 21-hydroxylase deficiency (NC21OHD) in 1979 and was later found to be the most common autosomal recessive disorder in humans. Disease frequency of NC21OHD varies between ethnic groups with the highest ethnic-specific disease frequency in Ashkenazi Jews at 1/27 (New 2004).

The expansion of the medical category to include milder forms of adrenal imbalance further distances the diagnosis from its association with the historical category of hermaphroditism. The primary medical health concern in CAH is salt-wasting (rapid reduction of necessary body salt levels) which can quickly lead to death if not caught immediately. In the XY individual this may be the only potential concern, as virilization of the genitals is not an issue. For this reason many parts of the world, including Emilia-Romagna, Italy, perform neo-natal screening for the syndrome. The other possible concerns are: virilization, ambiguous genitalia, early puberty, advanced bone age, cystic acne, failure of puberty to occur, infertility and metabolic variance (New 2006). A rough literature review of CAH alternately focuses on: endocrinological developmental issues, the relationship of hormones to gender identity, and genital norms and their modifications.

Reflecting the exquisitely specialized nature of contemporary medicine and science, CAH breaks down into many different points of interest and investigation, becoming a different object for endocrinologists, geneticists and surgeons. CAH itself is not just one diagnosis, but different fluctuations of the endocrine system that interacts with and affects other bodily systems such as sexual development. It was at the specialized clinic at Johns Hopkins that Lawson Wilkins in the late 1940's identified that the hyperplasia and overproduction of adrenal androgens resulted from impaired capacity for making cortisol (Bishop 1966). This discovery pulls CAH further into the category of endocrine disorders.

As early as 1865 the first image of CAH emerges in Luigi DeCrecchio's post-mortum investigations of "true sex" (Bostwick and Cheng 2008). Later, DeCrecchio investigated patients with genital ambiguity that died after episodes of vomiting and diarrhea, though these symptoms remain secondary to the establishment of the sex of the individual.

As in all of the DSD diagnostic categories, different stories unravel in different periods, highlighted by the changes in terminology. Embedded in the changing terminology, the biological dogma of the period, (in this case, of DSD), such stories are often related to debates about which system indicated sex and gender best in the body. In the course of time, the location of interest has moved from genitals to gonads to molecular processes. The choice of vocabulary can indicate the paradigm of the practitioner or the research environment that they

are involved in. As we have seen, there has been much debate about the use of the word "disorder" in DSD terminology. Strangely enough, the less severe form of CAH, NC21OHD, is comfortably referred to as a disease. NC21OHD lacks the uncomfortable association with genitals and sexuality; it primarily addresses deviation in biological function.

NC21OHD is a condition revealed to exist by technology. The unraveling of DSD syndromes is also a history of technology that shapes understanding and definition of the syndromes. The technologies that appear in the history of DSD reveal syndromes and act upon the body. Digging into the history of what is now called CAH, one can see the diagnosis change as different aspects of the body are revealed through technology. We also see how DSD becomes increasingly a medical object as technologies develop to modify and "fix" the symptomology deemed pathological.

Current CAH treatment touches many arguments such as the ethics of early genital surgery, informed consent and the medicalization (and genetization; Lippman 1991) of the sexual body. It unravels our expectations of what medicine can do for us, as far as regulating our reproductive development and guaranteeing our bio-social right to reproduce (Ettore 2000). It also exposes a continued anxiety surrounding the construction of normal genitalia. In its history as a diagnostic category, it might have been referred to as spurious or pseudo female hermaphroditism, fodder for 18th century debates of where one's true sex lay, in the gonads, genitals, secondary sex characteristics or behavior (referred to as costume).

The introduction of hormones and developmental theory contribute to the intermediary categories of De Crecchio's syndrome (De Crecchio 1832), Fibiger-Debré syndrome (Fibiger 1867, Debré 1882), Gallais' syndrome, Pirie's syndrome and Wilkins' disease (Lawson Wilkins 1948). However, medicine was interested in variations of the sexual body before it had the knowledge to identify and modify these endocrinological systems. Before endocrinology, the medical object was therefore simply the sex of the individual.

6.2 *Before endocrinology*

Luigi De Crecchio (the founder of the institute of forensic medicine in Naples) is referred to as being the first to describe a CAH case in detail in 1865 (Bostwick and Cheng 2008).

> Pertanto con la narrazione di questo caso io mi propongo di dimostrare, come sia taluna volta difficilissima, ed anche impossibile, la determinazione del sesso, durante la vita; (…) In uno dei teatri anatomici dell'ospedale degl'Incurabili capito' nell'ultimo gennaio un cadevere che in vita fu il corpo di certo Giuseppe Marzo, (…) L'apparenza della fisionomia era decisamente maschile, (…) per la giacitura di tutti i lineamenti costituiti di linee recise, appezzate ad angoli e non

dolcemente curve come nelle femmine e massimamente per la barba (…) Onde il petto era per tali caratteri assolutamente virile. (…) Gli arti inferiori, nei quali vi era qualche carattere riferibile al sesso femminile, nel loro assieme e nel maggior numero delle loro parti erano tutt'altra cosa che tali. (…) Il monte di venere era molto rilevato sul pube; e cio' mi colpi' profondamente. Nel sito proprio dove si rincontra l'asta virile vedevasi il pene, che alquanto ricurvo in sotto, nello stato naturale raggiungeva la lunghezza di 6 centimetri; e disteso senza molto forza, perveniva a 10. (…) L'apertura dell'uretra non cadeva al suo giusto sito in punta all'asta, ma bensi per ipospadia di primo grado (…) e' da dire che in questo soggetto, nel quale l'apparecchio urinario e parte del genitale erano manifestamente virili, si e' rivenuto della femmina la vagina, l'utero, le ovaja, le trombe, i legamenti larghi ed utero-ovarici, ed altre cose che andro' notando e che mi sembrano di non facile interpretazione circo il loro significato sessuale. (De Crecchio 1865 pp. 151-160).[98]

De Crecchio discovered posthumously that in this patient, there were internally: a fully developed uterus, fallopian tubes and ovaries. This ability to reveal in death what is hidden in life was the key to the new discipline of forensics. However, one must trace backwards, to recreate the actual life of the individual. Giuseppe had died after an episode of vomiting and diarrhea, indicating possible salt-wasting. These are the symptoms that give us the indication that this person possibly had CAH. However these symptoms are not yet the medical object. De Crecchio was interested in a different type of diagnosis.

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[98] Hence with the narration of this case I propose to demonstrate, how it is sometimes extremely difficult and even impossible, sex determination, during life. In one of the anatomical theaters of the hospital of the Incurables toward the end of January arrived a cadaver which in life was the body of a certain Giuseppe Marzo (...) The appearance of the physiognomy was decidedly male, (…) for the fall of all of the lines were made up of sharp lines, well placed at angles and not sweetly curved like in the feminine (body) and especially because of the beard (…) So that the chest was for those characters absolutely virile. (…) The lower limbs, in which there were some characters referable to the female sex, put together and in greater number were anything but that (feminine). (…) The mons pubis was very apparent on the pubis; which struck me profoundly. On the place where you see the virile shaft you could see the penis, that was curved posteriorly in its natural state measured 6 cm, and stretched without much force, came to 10. (…) The urethral opening did not fall on the right part of the shaft, but rather as in first grade hypospadias (...) it must be said that in this subject, in which the urinary structure and part of the genitals were clearly viril, became feminine in the vagina, uterus, ovaries, tubes, large ligaments and uterus-ovarico, and other things that I will explain as I go and that seem to me not easy to interpret regarding their sexual significance.

> É di molta importanza per la determinazione del sesso lo studio delle abitudini, delle tendenze, delle passioni, del carattere morale in genere: lo che nel caso in esame mi pare che non si potesse meglio che col tessere la storia della vita; ed io lo faro' il piu completamente che mi sia possible, studiandomi di prendere a fondamento di una tale narrazioni di fatti meglio accertati, e spogliarli di tutto l'esagerato ed il favoloso che nei giorni successive alle sezione si e' sparso dalla voce delle donnicciuole che lo conobbero in vita, e che, dopo morto, sono venute a notizia del caso strano (De Crecchio 1865 pg. 169).[99]

De Crecchio proceeded to interview those who knew Giuseppe in life, establishing that the patient/cadaver had a male gender-identity and heterosexual behavior. Giuseppe had been baptized as a female, but from the age of four was raised as a boy. De Crecchio speculates that Giuseppe lets his potential marriage fall apart because he is afraid that his fiancé would find out that in the church records he was listed as a girl. De Crecchio, based on the internal organs, refers to this as "a case of masculine appearance in a woman" (De Crecchio 1865 pg. 151).

Dreger refers to the eighteen hundreds as the "Age of the Gonads" (Dreger 1998), because of the tendency in this period to assign "true sex" base on gonadal tissue despite all other evidence. This was obviously influenced by the relatively recent discovery of the tissue and function differences between ovaries and testicles. Redick however, refers to this period as the "era of idiosyncrasy" (Redick in Reis 2008, pg. 85). This is more obvious in cases where physicians are attempting to attribute "true sex" to a live patient that already has a firm gender identity, sometimes following the gonadal standard, sometimes following external indications such as genitals and behavior.

Reis indicates that in either case, in the eighteen hundreds, doctors were relying increasingly on their *own* data and analysis of the individual. Reis states "In their zeal to achieve sexual certainty, doctors did not hesitate to judge their patients' gender performance as mistaken, if not deliberately fraudulent." (Reis 2009 pg. 29). As we have seen earlier in the historical discussion of DSD (chapter 3), Reis is highlighting the shift from monstrosity paradigm to the hidden truth paradigm. In Reis's discussion of practices in the United States,

[99] It is very important for sex determination the study of the habits, the tendencies, the passions, and the general moral character: in reference to the case at hand I believe that you could not do it better than by drawing out the life history; and I will do this as completely as it is possible for me, careful to get at the base of this narration of facts that are best checked, and stripping them of all the exaggeration and the fantastic which in the days after the dissection circulated by the voices of gossiping women who knew him in life, and once dead, came to know of the strange case.

she sees social anxiety regarding the establishment of "true sex" as linked to social anxiety surrounding race as a biological paradigm. In both cases many privileges could be obtained by "passing" for a different sex or racial category.

De Crecchio however displays his own uncertainties about "diagnosing" Giuseppe post-mortem. De Crecchio indicates that he disagrees with the affirmations of his colleague Professor Tesorone; that if Giuseppe had been better examined in life, medical professionals would have decided Giuseppe's genitals (implying also his gender) were female due to the anatomical positioning of the mons pubis and the perineum (De Crecchio 1865 pg. 182). De Crecchio believes that based on Giuseppe's behavior and un-disputable sexual activity with women, in life he would have been diagnosed as a man with absent testis (cryptorchid).

De Crecchio belongs to the period where true hermaphroditism no longer exists, and he dismisses the relevance of overly detailing the three categories he refers to as *Androginia* (a male with female appearance), *Ginandria* (female with the inverse) and *Misto* (full female and male reproductive structures) (De Crecchio 1865 pg. 178). The primary categories are defined by the presence of the gonads, and De Crecchio agrees with Tesorone that Giuseppe's "true sex" is female.

However, De Crecchio returns at the end of his musing to question both the role of the male gonads in shaping the form of the masculine body, and the relevance of hidden biological information in medical-legal issues like gender (and therefore marriage). He indicates that Giuseppe was so externally masculine, that obviously this shaping of (male) form, so to speak, had to come from some other process in the body besides the gonads. He decided that Giuseppe's case was singular, deciding from medical journals that most other *Ginandri* in some way "betrayed" themselves as females. He muses that Giuseppe could have been allowed to marry, but without biological reproductive possibility. He declares the impossibility of establishing sex in this case; for in life, they would not have been able to perform internal exams. In this manner it is unclear whether De Crecchio gives primacy to behavior or the reproductive organs, he simply abstains from a final ruling. This case, accompanied by the salt-wasting symptoms, will lead to the endocrinological understanding of CAH.

Taruffi's studies affirm the idiosyncrasy of Italy in the eighteen hundreds and before. The majority of the cases Taruffi cites refer to adults with various degrees of genital ambiguity with no reference to salt-wasting or other signs of endocrinological disturbance. In certain cases, the medical authorities reserve the right to force a civic gender change, in others the desire of the individual prevails. Given the technology of the period, testicular tissue was

easier to access than internal organs. Therefore in a live patient, it was easier to diagnose what might have been AIS, based on testicular tissue in a female body. The discovery of internal organs such as ovaries and the uterus usually occurred posthumously. In all of the cases, however, homosexual behavior is seen as indication of erroneous gender assignment, a presumption that prevails in current diagnosis.

Before the discovery of the endocrinological component of this diagnostic category, those with severe salt-wasting simply did not survive to adulthood, while less severe cases such as Giuseppe's weren't recognized as salt-wasting. The object of medical investigation in De Crecchio's examination is clearly reduced to genital appearance and reproductive organs. Gonadal tissue was a precursor to chromosomal sex, as in CAH, XX chromosomes correspond to ovaries with varying degrees of genital development. In many of the medical histories, it is nearly impossible to discover why the patient ends up under medical observation, if not for "pure scientific curiosity". It is difficult to penetrate past the medical gaze to discover the interests of the patient.

Virginia Mauri, mentioned in chapter one, is depicted graphically by Taruffi's artist mostly naked, wearing boots, long stockings and a set of pearls, reclined on an easy chair, legs spread with knees bent for her 1896 visit to Bologna. The stockings and pearls, one can imagine, are included to indicate her female clothing.

> Virginia Mauri, nata in Roma nel 1859, raccontava quanto segue. Ella aveva due sorelle viventi ed a 16 anni era già mestruata. Da prima sentiva inclinazione verso il sesso maschile in guisa che rimase incinta due volte quantunque il coito le riescisse doloroso, ma la gravidanza non giunse a termine interrotta ogni volta per aborto. Raccontava inoltre che in seguito le si manifesto' anche l'inclinazione per il sesso femminile.
>
> All'età di 20 anni la Virginia era alta 138 centimetri; aveva le gambe corte e sproporzionate rispetto al tronco(...)Le mammelle poi e la voce erano maschili.
>
> Quando la Virginia giunse a Bologna nel 1896 aveva la barba nera ed assai folta; i capelli di ugual colore, molto lunghi. Un fatto molto importante si fu che il Dott. Ravaglia verifico' la mestruazione, durante il suo soggiorno in città.
>
> La Virginia aveva sotto il pube un cilindro sporgente carnoso, che allo stato flosioso misurava cm. 5 ½, fornito di glande e di prepuzio, con indizio del frenulo (vedi Tavola). Il Dott. Ravaglia seppe che in origine il glande aderiva inferiormente colla cute del suddetto cilindro e che un chirurgo recise trasversalmente il tessuto retratto in corrispondenza della sede del frenulo; in tal guisa le parti si poterono allungare, e si riconobbe la mancanza del canale uretrale rimanendo soltanto un solco con un superficie liscia e con alcune lacune a fondo cieco.

Sotto il cilindro carnoso apparivano le grandi labbra, fra cui si riconoscevano anche le piccole labbra, ed in alto l'orificio uretrale. Fra le medesime labbra si penetrava facilmente in vagina e si raggiungeva col dito il collo dell'utero; ma coll'esplorazione non si riusci a scoprire ne i testicoli ne le ovaia, sia nelle grandi labbra, sia nell'inguine. Non fu permesso l'esame per l'intestino retto (Taruffi pg66/760).[100]

Like many of Taruffi's case descriptions, there is a thorough anatomical description with some hints at the patient's behavior and lifestyle, without mention of the interests of the individual, the reason for examination or any potential health risks. One can hazard the present day diagnosis would be non-salt wasting CAH.

We can wonder about Virginia's experience. How does she react to this medical stripping? Is it uncomfortable for her to be so exposed in front of men, or does the fact that they are doctors make it socially acceptable in her eyes as well? She has the liberty to refuse an anal

[100] Varginia Mauri, born in Rome in 1959, narrates the following. She had two living sisters and at sixteen she had already menstruated. From the beginning she felt inclined towards the male sex because of which she got pregnant two times albeit coitus was painful to her, but the pregnancy never came to term interrupted every time by abortion. She said in addition afterwards she also felt inclined towards the female sex.

At twenty years old Virginia was 138 cm tall. ; she had short and disproportioned legs (…) The breasts then and the voice were maschile.

When Virginia arrived in Bologna in 1896 she had a thick black beard; hair of the same color, very long. A very important fact was that Doctor Ravaglia verified her mestration during her stay in the city.

Virginia had a protruding meaty cylinder under her pubis, that in limp state measured 5 ½ cm, furnished with the gland and foreskin, with the indication of the frenulum (see Illustration). Dr. Ravaglia knew that originally the gland was attached to the lower skin of the cylinder and that a surgeon transversally severed the retracted tissue to correspond to the seat of the frenulum; because of that the parts can lengthen, and you can recognize that absenze of the urethral canal that remains just an indentation with a smooth surface and some dead end gaps.

Under the meaty cylinder the labia majora appeared, between which you could recognized the labia minore, and above the urethral orifice. Between the same lips you could easily penetrate into the vagina and arrive at the neck of the uterus with the finger; but you could not find with exploration testicle nor ovaries, neither in the labia majora nor in the groin. An intestinal rectal exam was not permitted.

examination, yet she supports a vaginal exam that penetrates up to the neck of the uterus. There is no follow up report to indicate changes in Virginia's civil status, health status or medical intervention. In another of Taruffi's cases, there is evidence of at least 8 doctors performing a vaginal examination in the same visit, but the woman is permitted again to refuse a rectal exam (Taruffi pg66/760). However, in one of Edoardo Porro's cases in 1882, six doctors perform a rectal exam on a 22-year-old woman (Porro 1883 pp. 21-23). None of these cases mention the future-gender-identity of the individual or their health status. Currently, however, neo-natal screening for CAH is specifically justified for its salt-wasting component. The diagnosis in a "virilized" female will often lead to clitoral reduction surgery.

The history of medicalization of hysteria reveals the heightened tendency in the eighteen hundreds to link female body parts to the essential nature of femininity and morality (Sengoopta 2000). It also reveals the dual nature of professionalization, in which social mores surrounding nudity and genital touching are absent in the clinical setting. Foucault (1963) analyzes the anonymity of the medical gaze in *The Birth of the Clinic*, that allows for this breach of social coding and authority over the body. In Sengoopta's (2000) work *The Modern Ovary*, we see the development of links between morality and the ovaries in otherwise non-pathological female bodies.

Taruffi speculates in his monograph covering Tribadism that *ipertrofia del clitoride* (a large clitoris) can be linked to immoral behavior such as lesbianism, prostitution and nymphomania. Taruffi introduces his chapter on *inversione sessuale* (sexual inversion) by stating that "*L'amore fra le donne come fra gli uomini (pederasti) e' un fatto avvenuto in tutti i tempi...*"[101] (Taruffi 1898 pg. 33/333), however, nonetheless defines it pathology. He refers to his contemporaries, Ulrichs, Westphal and Krafft-Ebing, in describing the taxonomy, terminology and research into the biological origins of homosexuality. The work of Ulrichs and Krafft-Ebing contrast biology with individual autonomy. Taruffi states "this diagnosis often has great importance, on one hand to establish the plan of care, and on the other to recognize the level of responsibility of the infirm regarding the cause of the disease."[102] So, in his view biological origins can remove the responsibility of the individual for their actions.

As in the 19th century, even current literature can erroneously confuse gender identity,

[101] "Love between women as between men (pederasts) is something that has happened in all eras…"

[102] "questa diagnosi spesso ha grande importanza, ora per stabilire il piano di cura, ed ora per riconoscere il grado di responsabilità dell'infermo in quanto alle cause del morbo."

gendered behavior, genital appearance, and sexual orientation as mutually dependent. As we will see in the following sections, Italian CAH groups are unhappy about the emphasis on the increased probability of lesbianism in medical literature on CAH[103]. Obviously the declassification of homosexuality as a mental illness in 1974 has done much to alleviate the correlated stigma, as well as a deconstruction of gender stereotype behavior and gender identity. However, some of these features of the relationship between social attitudes and scientific literature, that link sexual orientation to gendered biology, do not seem to have changed much in the last hundred years.

In this very light, Taruffi's section on tribadism was significant in that it highlighted the sexualized nature of medical concern over clitoral hypertrophy that continues to be an aspect of medical discussion of CAH. Before endocrinology, clitoral hypertrophy would have been the primary indicator of CAH. However, moral concern surrounding the clitoris was not limited to homophobia. Baker Brown, among others, referred to the elephantiasis of the clitoris, stating that physiological irritation of the clitoris provoked masturbation, which would degrade their physical health, leading to hysteria, nymphomania, and even mania (Taruffi pg. 20/320).

Parent Duchatelet in 1837 observed the genitals of 6000 prostitutes in Paris, and found only 2 enlarged clitorises (Taruffi pg. 20/320), thereby dismissing the theory that the clitoris enlarged when "abused" often. Taruffi was skeptical and wonders what Duchatelet meant by enlarged clitoris. Instead Charpy in 1872 claims that of 800 prostitutes, he found many cases of enlarged clitorises "especially those who lived in brothels and often among Tribades" (Taruffi pg. 20/320)[104]. Here the object of research is the connection of immoral behavior and clitoral hypertrophy, not just of lesbianism and hypertrophy, although tribadism is mentioned. As we can remember from chapter two, Bianchi received heavy sanctions from the Catholic Church for claiming that lesbians did not all have a biological indicator such as the large clitoris. One might consider the morality of conducting 6000 genital examinations, without medical justification or the offering of medical services, in an underprivileged female population[105].

Historical evidence of ambiguous genitalia before 1800 is largely related to cases

[103] Forum discussions

[104] 'specialmente in quelle che vivono nei bordelli e spesso tre le *tribadi*,"

[105] These genital exams were part of the French state hygiene program for registered prostitutes that primarily sought to protect clients from disease.

surrounding marriage disputes or presumed homosexual acts. In a large number of the cases, a marriage is petitioned for annulment based on difficulties in performing coitus (Taruffi 1898). The complaint is invariably linked to the act of penetration, either in the act of being penetrated or penetrating. While it may be noted for the record that the wife in question also has a clitoral hypertrophy, divorce seems to be granted only on the occasion of impenetrability. It is therefore historically difficult to establish how important clitoral/phallus size was to the general population, whereas it becomes very important to the medical debate.

What emerges is the preoccupation of the biological origins of not just "true sex" but also morality and social status. This is reflected throughout the century by studies on prostitution, homosexuality, hysteria, racial inferiority and the eugenic dogma that linked abnormality to something that weakened the health of the social body (Davis 1995). This historical analysis provides us with a looking glass as to the origins of the social mores that influence the surgical aspect of DSD treatment. In the historical framework, genital surgery is framed as the bio-power of medicine enforcing normality. It is a step beyond the claims of medical authority in establishing an individual's gender.

Medical discourse claims that the locus of social enforcement of normality in not generated by the medical gaze, but by the population at large. At the 2006 Intersex conference in Rome, a London psychologist insisted it was the parents, particularly in the context of multi-culturalism (the psychologist's affirmation), who requested genital-correction surgery. However, medicine provides the means and technology to not only recognize the genetic anomaly, but also modify the genital appearance. As we addressed in chapter three, Money's Optimal Gender of Rearing model advocates early surgery to protect the psychosocial health of the future adult. This rational draws from two significant historical changes: the medicalization of childhood and birth (Whitaker 2003), and the increase of public nudity.

The majority of cases up into the early twentieth century do not consider the physiological health aspects of DSD, instead focus on genital aspects and "true sex", represented by adult or postmortem cases. It is only with increased medicalization in early life that CAH cases are recognized before puberty, creating the environment for the possibility, not only of intervention, but of debates on forming the future psycho-social health of the individual. The doctor no longer imposes a biologically determined model on an adult individual with fully formed opinions and identity, but reads biological data that statistically indicate one of the two gender identities. Money's OGR model attributes hardship and suffering to growing up with an atypical body, specifically in the realm of the genitals. Money's doctoral research and other historical anecdotes indicate relative mental stability in individuals who grow up with

genital ambiguity.

Taruffi at the turn of the 19th century, in fact, describes Virginia as sexually active, having gotten pregnant twice. Taruffi refers us to a French case from 1881 in which a widowed woman, postmortem, is found to have a phallus the size of a twelve-year-old boy (Taruffi pg. 67/367). The widow Ernesta N. had been happily married for twelve years, after which she had many lovers, which leads to the conclusion that the greater society did not find fault with her "ambiguous" genitalia.

As we have seen up until the twentieth century, many cases are discovered postmortem, leading to the belief that the individuals' life was otherwise unmarked by difference. Other cases come to medical attention due to marital discrepancies or individuals wanting to change their civic sex category. These cases, such as that of Herculine Barbin (republished by Foucault 1980), that end in suicide and melancholy are generally ones in which a gender change is imposed by a medical authority or a homosexual relationship is punished.

The majority of CAH cases would simply have remained undiagnosed, lacking significant genital ambiguity. DSD terminology expands to include even the mild hormonal variances that escape the taxonomical language of the eighteen hundreds and before.

6.3 *Associazione Famiglie Iperplasia Surrenale Congenita*, (Family Association CAH)

The language of DSD and CAH propose the syndrome as an adrenal developmental issue, indicating the immediate health risks of salt-wasting and the potential health risk associated with early on-set puberty. The literature for parents also generally contains a part that refers to genital anomaly and subsequent corrective surgery. These concerns weave together, presenting themselves in some cases and not others. Early genital surgery, implicitly non-consensual, has been a mobilizing point for international intersex activists, who push for a moratorium on irreversible intervention until a patient can make independent decisions.

This push against early genital intervention is not present in the Italian patient group AFISC, which largely represents collaboration between doctors and parents. AFISC serves as a point of reference for parents and patients who are encountering the syndrome for the first time, or who are in search for more information. The focus of the group is providing mutual support and negotiating medicalization. There is a tendency to discuss different types of medicalization, posing the questions of when and how, as opposed to *if* it should be done. The group has bi-annual meetings, collaborates with the growing care centers, and hosts a website with an active discussion board. I was not able to directly interview group members, therefore

their activities and interests emerge from the forum debates and website material. The framework of Italian CAH care protocol is informed by interviews with doctors involved in the DSD care centers.

The concerns of parents, patients, and doctors rotate around different issues, the first two actors often trying to negotiate and translate information of the last. Doctors seek to identify CAH through neo-natal screening, molecular genetic and hormonal exams. Based on the presented symptoms, and when the diagnosis is made, they balance individual variables against standards in endocrine treatment and genital variance. Increasingly patients are sent to the specialized DSD centers that will pass on information about the patient group to the parents. The majority of the group's discussions focus on pharmaceuticals and parenting.

> Buongiorno, ho una bimba di 4 anni affetta da sag forma non classica, alla quale è stata prescritta terapia con idrocortisone da somministrare 3 volte al giorno (h.8 16 e 24) Ovviamente la bimba non è in grado di assumerla autonomamente ed in particolare l'orario delle 16.00 coincide con l'uscita dall'asilo, inoltre se dovessi lasciarla più a lungo non saprei come darle la terapia!! In più i compagni che la vedono prendere tutti i giorni la siringhetta iniziano a chiedere se è ammalata... So che non è un problema "grande" ma mi piacerebbe confrontarmi con qualcuno che lo condivide. Grazie. M[106]

Many parents seek advice and solidarity on how to administer medicine to small children several times a day, worried about the reactions of the other children. Parent's tacit knowledge of medicine administration is more authoritative and useful than the initial medical impact.

> Salve a tutti ho 35 anni e vengo da V provincia di M, sono mamma da 3 mesi di uno splendido bambino di nome S, dopo il parto e i consueti giorni di ricovero siamo venuti a casa e sembrava tutto a posto fino a che S non è stato male e portato d'urgenza all'ospedale è stato ricoverato perchè dallo screaning delle malattie metaboliche è risultato positivo alla SAG forma classica con perdita di sali. E' stato in ospedale 40 giorni finché i medici non sono riusciti a trovare il giusto dosaggio dei farmaci FLORINEF e IDROCORTISONE. Appena saputo di cosa soffriva mi è caduto il

[106] Good morning, I have a four-year-old girl who is affected with the non-classic form of CAH, for which she was prescribed hydrocortisone three times a day (hours 8, 16, 24) Obviously she is not able to take them herself and in particular 4pm coincides with when she gets out of nursery school but otherwise if I had to leave her there longer I don't know how I would give her the medicine!! What's more the other kids see her with the little syringe every day and are starting to ask if she is sick… I know it isn't a "big" problem but I would like to compare with someone who has the same experience. Thanks. M

mondo addosso, non avevo la più pallida idea di che cosa si trattasse, i medici mi hanno spiegato che è una malattia rara ed è ereditaria si trasmette con due genitori portatori sani del fatto che con la perdita di sodio il piccolo va in schok e che per questo si deve aggiungere sale nel latte. Visto che conosco così poco questa sindrome, e ho scoperto questo forum volevo sapere se il piccolo S potrà avere una vita del tutto normale, sapendo che dovrà continuare a prendere i farmaci prescritti per il resto della sua vita. Ringrazio tutti coloro che vorranno rispondermi.[107]

The bio-socialization of the syndrome usually begins with the parents. In some cases CAH is portrayed as an inherited and therefore genetically bound syndrome. At first contact, parents wonder what kind of life their child will be able to have, if it will be "completely normal". They seek patient authority and life stories.

Ciao A, sono E sono una mamma di un bambino di 9 anni affetto da SAG nella sua forma classica proprio come il tuo piccolo S e come tante mamme posso comprenderti perchè abbiamo passato anche noi quello che tu stai provando in questo momento. Se vuoi quando vuoi puoi farmi tutte le domande anche le più banali (email)!!!!! Per il momento ti dico che i nostri figli faranno una vita normalissima, faranno sport, si sposeranno e potranno avere figli e saranno felici.....ma per fare ciò saremo noi mamme a dover prima di tutto accettare la situazione e non far vivere ai nostri figli l'ansia o la paura!!!!! Scrivimi quando vuoi sarò felice di sentirti.....9 anni fà conoscere persone anche adulte affette da SAG è stato un sollievo!!! Un abbraccio E[108]

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[107] Hello to everyone I am 35-years-old and I'm from V province of M, I am the mother since 3 months to a splendid child named S, a fter the birth and the following recovery days we came home and everything seemed fine until S started to get sick and we urgently brought him to the hospital and he was admitted because based on the metabolic screening he resulted positive for CAH classical form with salt wasting. He was in the hospital for 40 days until the doctors were able to find the right doses for FLORINEF and HYDROCORTISONE. As soon as we learned what his illness was everything fell apart, I didn't have any idea what it was the doctors told me it is a rare disease and that it's hereditary transmitted by two parent carriers the fact that with the loss of sodium the child goes in shock and for this you need to put salt in the milk. Seeing as I know little about this syndrome and I learned about this forum I wanted to know if the little S will have a normal life knowing that he must continue to take the prescribed medicine for the rest of his life. I thank everyone who wants to answer me.

[108] Dear A, I'm E I'm the mother of a 9 year old boy with CAH classic form just like your little S and like many mothers I can understand you because we have also gone through what you are feeling in this moment. If you want when you want you can ask me all of your questions even the most simple (email)!!!!! For the moment I can tell you that our sons will have normal lives, play sports, marry, have children and they will be happy…….but to be able to do that it will be us mothers to have to

AFISC handles all of the forms of the syndrome, therefore the primary-life risk, salt-wasting, is one of their main interests. Members rely on each other to provide real life pictures of the progression of the syndrome that medical textbooks cannot provide. Medical articles about CAH often, instead, focus on genital issues.

> Sono un papà di un bambino SAG di 9 anni. Posso confermarti tutto ciò che ha detto E: faranno una vita normalissima. L'unico problema, anzi diciamo fastidio, è che dovrà fare almeno 4 controlli del sangue all'anno, perchè la terapia dovrà essere sempre somministrata al giusto dosaggio. Infatti fino a circa 14-15 anni i valori ormonali saranno abbastanza "ballerini", ed è fondamentale saperli per "aggiustare il tiro", cioè dare la giusta terapia. Se vuoi scambiare altre info: email Ciao.[109]

The idea of a normal life is compromised by the guarantee of a medicalized life, at least four times a year in the hospital to adjust the therapy. However, the parents use the group to discuss their fears and not put them into the lives of their children. The bio-sociality around CAH redefines medicalized as normal.

> SALVE A TUTTI, PUR TROPPO O NO ANCHE MIA FIGLIA E' AFFETA DA SAG. OGGI MENTRE GLI STAVO DANDO IL QUARTINO DI HYDROCORTISONE(LA PASTIGLINA DEL PM) MI HA GUARDATO E MI HA DETTO "MAMMA MI SONO STUFATA DI PRENDERE SEMPRE QUESTA CHICCA", COME LA CHIAMA LEI, "LA DEVO PRENDERE ANCORA PER MOLTO?","PERCHE' MIO FRATELLO NON LA PRENDE? E TU E PAPA' LA PRENDETE?", IO HO RISPOSTO DI NO. E LEI HA RIBATTUTO DICENDO "NON E' GIUSTO". ERA TUTTA IMBRONCIATA. GLI HO DETTO CHE LA DEVE PRENDERE PERCHE' A LEI MANCA UN ENZIMA E CHE SE NON LA PRENDE I DOTTORI SI ARRABBIANO E POI DOBBIAMO ANDARE ALL'OSPEDALE A FARE LE PUNTURE. GLI HO SPIEGATO CHE SE CI PENSA BENE ALLA FINE NON E' CHE POI SIA UN PROBLEMA COSI' GRAVE PRENDERE QUALCHE PASTIGLIA AL GIORNO SE LA FANNO STARE BENE E CHE ALLA FINE PUO' LO STESSO FARE UNA VITA NORMALE COME TUTTI

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first accept the situation and not make our children live in anxiety and fear!!!!! Write me when you want and I will be happy to hear from you…9 years ago I met others even adults with CAH and it was a relief!!! A hug E

[109] I am the father of a 9-year-old boy with CAH. I can confirm everything that E said: they will have a very normal life. The only problem, well let's say irritation, is that he will need to have at least 4 blood tests a year, because the therapy needs to be always given at the right dose. In fact until around 14-15 years old the hormone levels will be fairly "up and down", and it's important to know they to "hit the mark", that is give the right therapy. If you want other information: email Bye.

GLI ALTRI BAMBINI DELLA SUA ETA'. ORA SI E' CALMATA MA SICURAMENTE TORNERA' ALL'ATTACCO, HA 5 ANNI E HA UNA LINGUA LUNGA.[110]

When the condition is life-threatening, management of the pharmaceuticals is part of the life-changing event. Biological language can help justify actions to the under-age patient. Within the model of bio-sociality, parents become experts in judging doses and recommending doctors as well. The majority of the discussions introduced by parents refer to how to administer medicines and which doses might be appropriate in which situations. As we will see in the next section, genital surgery remains a black box.

6.4 *CAH and genital surgery*

The surgical and endocrinological intervention for virilization in the AFISC remains a given, black box. The fact that is consistently referred to by group members indicates that it is considered an important issue. Yet genital surgery it is not up for discussion, it is not posed in the realm of decisions. When the condition presents virilization, the parent discussion about the virilization itself becomes less direct, using euphemisms instead of precise terms. Or genital surgery is introduced by patients themselves. CAH will be referred to as a disease by the parent, and the genital surgery masked by reference to the hormonal pathology.

Ciao sono la mamma di una bimba di cinque anni affetta da Sag e vorrei sapere a quale età può essere più indicato (per non traumatizzarla) iniziare ad informarla della sua malattia e dell'intervento che ha dovuto subire a pochi mesi dalla nascita.[111]

Genital surgery is referred to as “the operation”. Usually substantiated by “had to have”.

[110] Hi to everyone, unfortunately or not, also my daughter has CAH. Today while I was giving her the quarter of hydrocortisone (the PM pill) she looked at me and said “Mamma I’m fed up with always taking this gum”, as she calls it, “do I have to keep taking it for long?”, “why doesn’t my brother take it? Do you and papa take it?” I responded no. and she responded saying “it’s not fair”. She was all sulky. I told her she had to take it because she was missing an enzyme and if she didn’t take it the doctors would get mad and then we would have to go to the hospital to get a shot. I told her if she thought about it in the end its not that big a deal to take a few pills a day if they help you stay well and in the end she can have a normal life like all the other kids of her age. For now she’s calm but surely she’ll start up again. She is 5 and has a big mouth. (All capitals in original)

[111] Hello I am the mother of a five-year-old girl with CAH and I would like to know at what age it could be indicated (so as not to traumatize her) to began to inform her about her illness and the operation she had to have only a few months after birth.

Salve L, mi chiamo N e sono una mamma di una ragazzina affetta da sag. anche la mia ha subito l'intervento da piccola, le posso dire che è stato del tutto naturale informare mia figlia del suo stato: aspettavo che fosse lei a chiedermi e le rispondevo sempre dicendole la verità, naturalmente cose che poteva capire. A me non sembra che mia figlia l'abbia presa a male. Comunque se vuole parlare con me basta che mi lasci un suo rec. e la chiamo oppure può scrivere al mio indirizzo di posta: email oppure può rivolgersi all'associazione a lei più vicina. spero di esserle stata di aiuto. cordiali saluti n[112]

The group website indicates its position on genital surgery by citing the hospital-produced handbook:

LA TERAPIA CHIRURGICA

La terapia medica non è sufficiente a correggere le anomalie dei genitali esterni prodotte nella femmina dall'eccesso di androgeni in epoca fetale. E' necessario pertanto intervenire chirurgicamente per ridurre le eccessive dimensioni del clitoride e per correggere l'aspetto della vagina separando lo sbocco delle vie urinarie dall'apertura vaginale. Generalmente l'intervento viene fatto precocemente, nel primo anno di vita, per evitare che la bambina risulti psicologicamente disturbata dall'alterazione dei genitali. Il più delle volte l'intervento viene fatto in un tempo unico, con un'eventuale "revisione" durante la pubertà. Lo scopo è duplice: correggere l'alterazione anatomica (aspetto estetico) e permettere di avere dei normali e soddisfacenti rapporti sessuali da adulta (aspetto funzionale). [113]

Other international groups, instead, question the *necessity* of reducing the clitoris,

[112] Hello L, my name is N and I am the mother of a girl with CAH. Also my daughter had the operation when she was little, I can tell you that it was totally natural to tell my daughter about her situation: I waited until she asked me and I answered telling her the truth, naturally things she could understand. It doesn't seem to me that she felt bad. Anyway if you want to talk with me just leave me your information and I'll call you or you can write my email: email or you can write the association nearest you. I hope I was helpful. Sincerely n

[113] THE SURGICAL THERAPY

The medical therapy is not sufficient to correct external genital anomalies produced in the female by excessive androgens in the fetal stage. It is necessary therefore to intervene surgically to reduce the excessive size of the clitoris and correct the appearance of the vagina separating the point of the urinary opening from the vaginal opening. Generally the operation is performed early, in the first year, to avoid that the child is psychologically disturbed by the alteration of the genitals. Most of the time the operation is done all at once, with eventual "revisions" during puberty. There are two reasons: correct the anatomic alteration (esthetic aspect) and permit normal and satisfying sexual relations as an adult (functional aspect).

highlighting that this is an esthetic decision and perhaps better left to the individual (child/infant). The handbook refers to both the esthetic and functional aspects of the interventions. In this case function refers to normal female sexual satisfaction. However, normal female sexual satisfaction usually involves a fully functioning clitoris, as opposed to only penetration.

Pediatricians tend to advocate for early intervention, citing pliable tissue and John Money's OGR model. The OGR model maintains that interventions must be performed before the third year when the child forms its gender identity. The OGR model directly correlates genital form with gender identity, but also hopes that surgery performed in early childhood will be a less traumatic, forgotten event.

Gynecologists and adult practitioners often advocate postponing genital surgery until puberty or later for a number of reasons. The primary practical reason is to prevent the need for repeat intervention. As we see in the Italian handbook, a “revision” at puberty can be necessary. A repeat intervention at puberty or later in life greatly diminishes the benefits achieved by performing surgery before strong memories are formed.

In addition to these technical issues, there is the consideration of individual autonomy. The tendency toward early surgery in pediatric clinics indicates the level of pressure parents are faced with to actively create a healthy environment for their child. In this case the environment is the child's body itself. The bioethical investigation sponsored by Johns Hopkins, Surgically Shaping Children, investigates the difficult territory of deciding what is best for children's bodies, when the object is esthetic as 0pposed to functional. Ellen K. Feder's research in the US speaks to the parental concerns also in the Italian context:

> But, as doctors made clear to all the parents with whom I spoke: What sort of parents would subject their child to life as a hermaphrodite?...the job of any parent -is not only to protect one's child, but also to accommodate her to the world in which she lives. If in the case of intersexed children, cosmetic genital surgery is presented to parents as a necessary adjustment, it is only too easy to understand why parents would consent to its performance (Feder in Parens, 2006, pg 205).

Pediatricians in Italy responded to the question, 'do you even have parents who oppose the suggested treatment?' surprised, repeating the truism “every parent wants their child to be normal.” Feder indicates the concerns of adult practitioners, also addressing the ambiguous terrain of emotional support.

> While parents are expected to be attuned to their children, such identification is discouraged in the parents of intersex. Parents are not given the chance to imagine their children's lives in anyway

except as in need of immediate correction. Despite the fact that doctors know, for instance, that later surgeries are less dangerous and more likely to produce the desirable results-both with respect to appearance and the preservation of sensation-they nevertheless promote surgery. Children, they claim, will experience less trauma if they are spared the memories of removal of gonads or the excision of phallic tissue. Doctors understand the eventual necessity of painful vaginal dilation in the case of the (majority of) children assigned female. The likely prospect of additional surgeries or other traumatic procedures in subsequent years goes unmentioned, as does the option of delaying surgery until the child is older (Feder in Parens, 2006, pg 205).

Communication can become difficult in the family, due to the stigma of medicalization. However, the support groups normalize, creating a space where the difference is the common bond.

Ciao sono una ragazza di 23 anni e sono affetta da sindrome adrenogenitale che e' stata riscontrata all' eta' di 10 anni in seguito alla nascita di mia sorella anche lei affetta dalla stessa patologia. Sono seguita all'ospedale Regina Margherita a Torino al reparto di endocrinologia; un reparto ottimo con personale molto qualificato sia gli infermieri che i medici in particolar modo la Dott.ssa Eineudi che ha preso in cura sia mia sorella che me: una persona professionale e molto umana. All' inizio non e' stato facile e non lo e' tutt' ora sia per me stessa che per la mia famiglia che ha reagito molto male alla notizia. Ci si e' tuffati in un silenzio dal quale soprattutto i miei non riescono ad uscire. Sono molto contenta della scoperta di questo forum e mi piacerebbe avere informazioni su eventuli incontri o novita' e magari la possibilita' di poter parlare con persone affette dalla mia stessa patologia. grazie e ancora complimenti per il forum.[114]

As we have seen, support groups become in themselves expert groups, sources of information. As an expert group they also regulate which arguments are up for discussion, canonizing information and practices. The forum is composed largely of discussions surrounding reproduction by adult patients and pharmaceuticals by parents. Parents mention that their children have had corrective surgery in a manner that implies that there have been

[114] Hi I am a 23-year-old girl and I have CAH that was discovered at 10 after the birth of my sister who has the same pathology. I was cared for at Queen Margaret Hospital in Turin in the endocrinology ward; an excellent ward with very qualified personnel both nurses and doctors in particular Doctor Eineudi who cared for both my sister and me: a professional person and very human. In the beginning it wasn't easy and it still isn't neither for me or my family who reacted badly to the information. We fell into a silence that especially my parents cannot get out of. I am very happy to have discovered this forum and I would like to have information about encounters and news and hopefully the possibility to talk with someone with my same pathology. Thanks and complements for the forum.

no problems surrounding the issue. Of the adults, only four mention their experience of early genital surgery. Two indicate that they are happy with the choice their parents made for them to operate early, two instead are not. Most are silent. One discussion in which an adult reported to be traumatized by their early genital surgery (that unfortunately I did not save earlier) has been removed from the forum. The one that remains is fairly heated.

> Mi chiedevo se c'è qualcun altro che, essendo affetto da SAG, si ritiene per questo motivo intersessuale e, se sì, come si relaziona con gli altri e con sè. La mia domanda ai genitori è la seguente:
> La maggior causa di intersessualità è la SAG, e sebbene non tutte le bambine affette da SAG siano intersessuali, alcune lo sono. Ritenete davvero una cosa saggia far operare le vostre figlie neonate/bambine affette da SAG? Non pensate che rischiano di essere infelici perché mutilate a vita (non esistono ricostruzioni in questo senso), e che invece gli eventuali traumi d'infanzia si possono superare e che possono scegliere da sè di operarsi in futuro? Spero davvero che qualcuno mi risponda.[115]

> Com'è che tutti si preoccupano tanto per le loro figlie e nessuno risponde a me? Se avessero scritto dei genitori avreste solo risposto "a me non è capitato" o "spero non mi succeda"? Mah...[116]

This post asks two questions, is there anyone in the group who identifies as Intersex, and why is no one talking about genital surgery.

> Ciao, io sono una mamma di una ragazzina di 17 anni, operata per la correzione dei genitali all'età di un anno. non ho mai avuto dubbi se operare o meno mia figlia, semplicemente perchè lei cromosomicamente è una femmina ed ha solo un disturbo ormonale che ha interferito sulla formazione dei suoi genitali. Adesso che ha 17 anni è una bella ragazza, molto femminile e ha tutte le caratteristiche fisiche di una donna. Io non vedo perchè tu ti ponga questi problemi. Tu sei affetta

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[115] I was wondering if there is anyone else, because of CAH, defines themselves as Intersex for this reason and, if yes, they relate with others and with themselves. My question to parents is this: The most common cause of Intresexuality is CAH, and even if not all of children with CAH are Intersexed, some are. Do you really think it is wise to operate on your newborn girls with CAH? Don't you think that they risk unhappiness because they have been mutilated for life (reconstruction doesn't exist in this sense), and that instead the eventual traumas of infancy they could get over and that they could decide to operate themselves in the future? I really hope someone answers me. 16/05/09 Re: SAG + IS, e relativa domanda ai genitori

[116] How is it that everyone is so worried about their children but no one answers me? If parents had written they would have only answered "it didn't happen to me" or " I hope it doesn't happen"? Whatever. 20/05/09 Re: SAG + IS, e relativa domanda ai genitori

da sag? Ti hanno operata e non sei contenta? Non credo di aver mutilato mia figlia, anzi, credo di averle ridato un qualcosa che, per motivi che ben conosciamo, era nella sua natura. Ho sentito altre persone che si ponevono le tue stesse domande, ma loro, hanno un motivo in più per interrogarsi sugli interventi di ricostruzione dei genitali, ci sono tanti casi dove si nasce cromosomicamente maschio ma fisicamente femmina. Se avessi avuto una figlia/o con questa patologia, allora credo proprio che avrei dovuto tener presente del suo patrimonio genetico. Per finire ci sono diverse forme di isc, mia figlia ha quella classica. Come vedi ti ho risposto e mi piacerebbe che adesso fossi tu a rispondermi. ciao n[117]

The answer comes from a mother who was involved in the 2007 discussion about genital surgery that was removed from the forum by 2009. In 2007 the group was younger and perhaps less experienced with a varied point of view regarding genital surgery, due to its close ties to medical establishments. In the 2007 discussion, N asked the individual who criticized early genital surgery, how they dared questioned the right of a parent to try to do what is best for their child. The discussion was very heated and oppositional.

In this response N understands the question to be about gender identity first, surgery as a consequence. That is, why not delay surgery so someone can decide later, if they identify instead as a man? N gives primary importance to the chromosomes regarding the make up of the gendered body and identity, even when she is referring to AIS. Statistical and historical evidence indicates that there are more XX individuals with CAH who identify as men, than XY individuals with AIS who identify as men. CAIS individuals primarily have female gender identities. The chromosomal material does not indicate gender identity specifically in

[117] Hello, I am the mother of a 17 year old girl, operated at one year for genital correction. I never had any doubts about operating on my daughter or not, simply because she is chromosomally female and only has a hormonal disturbance that interfered with the formation of her genitals. Now she is 17 and a beautiful girl, very feminine and has all of the physical characteristics of a woman. I don't understand why you are asking yourself this. Do you have CAH? Did they operate on you and you're not happy? I don't believe to have mutilated my daughter, the opposite, I think I re-gave her something that, for motives that we know well, was in her nature. I have heard others ask your same questions, but they, have an added reason to ask themselves about genital reconstruction, there are many cases where one is born chromosomally male and physically female. If I had a daughter with this pathology, then I think I would have to take into account her genetic makeup. In conclusion there are different forms of CAH, my daughter has the classic form. As you see I have answered you and I would like that now you answer me. Bye n.

28/05/09 Re: SAG + IS, e relativa domanda ai genitori

the case she is talking about. The effects of clitoral reduction for a girl who identifies as female is not up for discussion.

> Ciao N, grazie di avermi risposto. Io sono affetto da sag classica, avrei preferito che i miei genitori non facessero niente e lasciassero che le cose facessero il loro corso da sole. Ora ho i documenti nuovi al maschile, ma per averli ho dovuto faticare non poco e fare un percorso che avrei potuto in parte risparmiarmi (oltre che avere risultati molto migliori di quelli che tristemente ho) se i miei genitori non avessero deciso di operarmi. Credo che sia più semplice gestire questa cosa senza tante operazioni da bambine, e che sia una scelta che possiamo prendere per conto nostro da grandi. Chiaramente in molte si opererebbero, ma visto che si tratta di cose irreversibili, non si dovrebbe tenere conto di chi potrebbe vederla come una mutilazione? Di chi potrebbe starci male?[118]

The post, in fact, avoids debating the validity of clitorectomy for someone who identifies as female. It speaks to their individual struggle to change legal gender and attempt to surgically reconstruct what had been previously eliminated.

> Ciao, mi piacerebbe avere una conversazione con te, anche telefonica, se vuoi mi puoi scrivere il tuo rec. al mio indirizzo privato: email Voglio farti una domanda: secondo te, le bambine che nascono con i genitali non perfetti, ma questo non significa che sono dei maschi, si possono lasciar crescere senza intervenire? E quale sarebbe la loro crescita? Tu sai che i bambini confrontano il proprio sesso con gli altri bambini, semplicemente solo per conoscersi e capire la differenza che c'è tra loro. Pensa solo per un'istante, come si sentirebbero queste bambine? Io sono una mamma, mi piacerebbe mettermi nei panni di chi la vive personalmente anche perchè questo mi aiuta a capire meglio e magari a consigliare meglio. A volte si fanno degli errori semplicemente perchè non si conosce.... Ciao e a presto N[119]

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[118] Hello N, thank you for answering me. I have classic CAH, I would have preferred that my parents didn't do anything and let things develop by themselves. Now I have new male documents, but to get them I had to work hard and follow a path that I could have in some way avoided (other than having results much better than those I sadly have) if my parents had not decided to operate on me. I think it is much easier to handle this thing without so many operations as a child, and that it's a decision we can make on our own when we're older. Clearly there would still be many operations, but seeing as its irreversible, don't you think we should think about who might see it as mutilation? Who could be hurt? 29/05/09 Re: SAG + IS, e relativa domanda ai genitori

[119] Hi, I would like to have a conversation with you, maybe on the phone, if you want you can write your information to my private email. I want to ask you a question: in your opinion, girls who are born with non-perfect genitals, but this does mean that they are boys, can one leave them to grow

Here N asks what it would be like to raise a girl with a large clitoris. This is the fear of every parent that is communicated by the doctors. No one wants to "experiment" on their child. However, N seems to move from her absolute position of just a few years before. Patient groups canonize information in the same process of discipline building that happens in the medical profession. However, support groups are built on the foundation of communication, and authority is accrued by subjective experience.

> M se puoi contattami ho la tua stessa situazione, se puoi lasciarmi tua mail così ti scrivo. ciao ciao A[120]

After following the discussion another person appears who is in the same situation. In Florence a small movement is gaining momentum that inserts Intersex into the queer movement. The Arcigay center there has a meeting place where people can come and talk about their experiences, gender identity, sexual orientation and the medicalization of Intersex. One of the founding members is also in the same situation as M, assigned female at birth, operated on, and identifies as male. As we have addressed earlier in the Introduction, Trans experiences is quite different from Intersex, due to early age medicalization. However, some Intersex individuals (also in the Italian context) find peace in the queer/trans movement after early genital surgery in the opposite direction of their gender identity. The queer/Trans reality (such as the group in Florence) and the DSD patient groups do not dialogue at this time in Italy.

> Mia cara M, sono una mamma di una ragazza affetta da SAG. La tua e-mail mi ha riempito di tristezza e mi ha ricordato i tanti dubbi che ho avuto al momento dell'operazione. La pensavo come te, non avrei voluto operarla; ma forse tu non ti rendi conto dei pregiudizi della gente...Quali problemi avrebbe potuto avere una bambina che candidamente si sarebbe potuta trovare a mostrare in pubblico i genitali (ricordo che la mia piccola in spiaggia voleva sempre togliersi il costume bagnato e i miei sforzi per farlo il più discretamente possibile e come le altre mamme la incitassero

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up without doing anything? What would their childhood be? You know that children compare their genitals with each other, simply to know themselves and understand the difference between them. Think just for a moment, how would these girls feel? I am a mother and I would like to put myself in the shoes of those who live this directly because this helps me understand and hopefully give advice better. Sometimes you make mistakes simply because you don't know…Bye and hear from you soon N

04/06/09 Re: SAG + IS, e relativa domanda ai genitori

[120] M if you can write me I am in the same situation as you, if you leave me your email I'll write you. Bye bye A 20/07/09 Re: SAG + IS, e relativa domanda ai genitori

a toglierlo e a restare anche senza..) e come sarebbe stata marchiata e isolata da compagni e dai loro genitori che avrebbero visto in lei un "diverso", un pericolo per la giusta sessualità delle loro figlie.. L'operazione gliel'ho fatta fare quanto prima, perchè non fosse puntata a dito, ma le dilatazioni non ho voluto fargliele fare, questo lo avrebbe scelto lei da adulta. Tu sei molto arrabbiata, ma se un genitore ha una figlia dai genitali ambigui che però è geneticamente femmina, cosa dovrebbe fare se non aiutare a correggere ciò che la natura ha sbagliato? Sei sicura che anche tu non avresti fatto la medesima cosa? Vorrei tu non fossi così astiosa soprattutto coi tuoi genitori, io so come si saranno ingiustamente sentiti in colpa e quanto avranno sofferto per te. Ti sono vicina, a tutto c'è rimedio! Se vuoi parlarne ulteriormente puoi contattarmi, la mia e-mail è email Ti saluto con affetto. N E[121]

There are many psychosocial factors involved in the choices that parents make, with a very limited set of information on the end results. Activist Iain Morland retains that surgically modified genitals are marked and subject to stigma and shame in a similar manner as simply different genitals are. However the fear of bullying and the social pressure to have a normal child must be agonizing for a parent. It is important to remember that at the beach in Italy, children are often naked until 3 or 4 years old (this tendency seems to be changing however and many parents will cover their young children when they change them in public places).

The AFISC web site posts a conference document[122] on the positive long-term results of

[121] My dear M, I am the mother of a CAH girl. Your email filled me with sadness and reminded me of all of the doubts that I had at the moment of the operation. I thought like you do, I didn't want to have her operated on; but maybe you don't realize how prejudiced people are…what problems a girl could have who candidly could have found herself showing her genitals in public (I remember at the beach my little girl always wanted to take off her wet bathing suit and my trouble to do it as discretely as possible and how the other mothers encouraged her to take it off and be without it..) and how she would have been marked and isolated by the other kids and their parents who would have seen her as "different", a danger to the right sexuality of their daughters.. I had her have the operation early, so she wouldn't be pointed at, but I didn't want to let them do the dilation, that she could decide as an adult. You are very angry, but if a parent has a daughter with ambiguous genitals that is however genetically female, what should they do if not correct what nature messed up? Are you sure you wouldn't have done the same thing? I wish you weren't so mad especially with your parents, I know how they would have felt unjustly at fault and how much they have suffered for you. I'm close to you, there is a solution for everything! If you want to talk about it further you can write me, my email is (email) I say goodbye with affection. N E 28/07/09

[122] http://www.iperplasia.it/ RISULTATI A LUNGO TERMINE DELL'INTERVENTO DI GENITOPLASTICA FEMMINILE CON VECCHIO E NUOVO METODO (A. Bocciardi, A.

genital surgery that directly contradicts other findings.

> Attualmente sono a disposizione numerose tecniche di genitoplastica. Noi abbiamo scelto la tecnica introdotta nel 1987 dal Prof. Passerini-Glazel. Tra il 1988 ed il 2007, all'Istituto San Raffaele di Milano, abbiamo eseguito circa 100 interventi di questo tipo, costituendo la più ampia casistica europea...Anche i risultati a distanza di tempo sono buoni, infatti a circa 10 anni dall'intervento tutte le ragazze e le loro mamme si dicono soddisfatte dell'aspetto estetico dei genitali esterni[123].

However, another document from the same conference reveals a break in consensus on the positive psychosexual results of early surgery.

> I risultati indicano nella sfera sessuale importanti differenze tra i due gruppi; le ISC mostrano un ritardo e talvolta un'assenza nelle tappe dello sviluppo affettivo e sessuale: Le adolescenti che hanno subito l'intervento di correzione vaginale negli ultimi 10 anni hanno espresso nei colloqui con la psicologa disagio sia per le visite preliminari che per le medicazioni successive. Soprattutto sono state vissute con sofferenza l'inserimento dell'intruso e le manipolazioni per mantenere la dilatazione vaginale.
>
> E' risultato evidente che ciò che rendeva penoso questi interventi non era la sofferenza fisica, in se stessa molto limitata, ma il fatto che venissero eseguiti in quella zona, che è avvertita come particolarmente sensibile e delicata, che nel tempo, soprattutto per gli adolescenti, acquisisce un particolare significato emotivo collegato al pudore ed all'affettività.
>
> Questi dati ci inducono ad ipotizzare che i risultati della ricerca, soprattutto per quanto riguarda i limiti e i ritardi nei comportamenti sessuali, possano essere determinati in larga misura dagli interventi medici nell'area vaginale.[124]

Lesma)13/11/2007 Convegno ISC del 10/11/2007 a Bologna

[123] There are actually many types of genitalplasty. We have choosen the technique introduced in 1987 by Prof. Passerini-Glazel. Between 1988 and 2007, at San Raffaele in Milan, we have performed around 100 operations of this type, forming the largest European sample…Even the results after some time are good, in fact around 10 years after the operation all of the girls and their mothers say they are satisfied with the esthetic aspect of their external genitals.

[124] The results indicate a important difference in the sexual arena between the two groups; the CAH show a delay and sometimes the absence of the affective and sexual developmental steps: the adolescents that have been operated on for vaginal correction in the last 10 years have expressed in meetings mental health issues both for the initial visits and the successive medicalization. Especially the insertion of the penetrative object and the manipulations to maintain vaginal dialation were

This report refers not only to the psychological damage of medical stripping, but also to the possible psychological damage of having your genitals medically manipulated. How is a parent supposed to decipher this range of information, when it seems that certain fixed positions are taken in different disciplinary arenas? Adult practitioners, such as gynecologists, advocate waiting until after puberty, while pediatricians vary in position, but often advocate early surgery. Italian psychologists who collaborate with DSD teams reject the aspect of the OGR model that insists on silence. As we have seen, parents who advocate early genital surgery, now based on doctors' advice, also communicate the diagnosis with the child as they grow.

The creation of DSD teams is providing an environment in which real long-term research can be conducted. Previous affirmations of patient satisfaction were generally based on un-scientific speculation that believed a patient that did not return was a satisfied patient who had integrated into the community. Dr. Ian Aaronson of the Medical University of South Carolina proclaimed that doctors 'should stand in shame' at the lack of follow-up studies on the cosmetic genital surgeries on Intersex children they have been performing for decades[125].

Early genital surgery is criticized because it increases attention and stigmatization to the genitals, and because it can reduce sensation. Iain Morland questions the ability for surgery to make someone feel normal, as opposed to altered and scared. CAH interventions can include clitoral reduction, which can reduce sexual sensitivity. Naomi Crouch has indicated how the importance of the clitoris to female sexuality has been overlooked, emphasis being placed on vaginoplasty and penetration. A Milan research report highlights this ambiguity, stating that 5 of 10 women who had had genital surgery had satisfactory sex lives, whereas only 3 of the 10 had orgasms. Their conclusion was that "performing early feminizing genitoplasty could lead

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suffered.

It seems evident that what was difficult about the operation wasn't the physical pain, in itself fairly limited, but the fact that it was performed in that zone, that is felt as particularly sensitive and delicate, that in time, especially for adolescents, acquires a particular emotional meaning connected to shame and affection.

This data forces us to hypothesize that the results of the research, especially regarding the limits and delays in sexual behavior, can be largely determined by medical intervention in the vaginal area.

http://www.iperplasia.it/ Risvolti psicologici a lungo termine dalle donne affette da ISC/CAH sottoposte a interventi chirurgici plastici Palma Bregani 13/11/2007 Convegno ISC del 10/11/2007 a Bologna

[125] http://www.intersexinitiative.org/news/000114.html

to a stable psychosexual development." (Lesma et AL 2006).

However, due to fear of bullying, early surgery is still standard practice, particularly for CAH "masculinization", otherwise known as hypertrophy of the clitoris. No one in the Italian CAH group is talking about clitoral reduction, leaving one to surmise it is either taboo or not a problem. A greater understanding of this issue would require a more in depth look at the construction of female sexuality in Italy, particularly in relation to the right to sexual pleasure, than this research has had time to allow for.

6.5 *Overlapping gender identity and sexual orientation*

There is little discussion of psychosexual repercussions of genital surgery in the AFISC forum, if not in one discussion that touches on another aspect of CAH diagnosis, preoccupation about potential homosexuality. The clinic of John Money firmly established homosexuality as one of the potential symptoms of CAH. However homosexuality was often confused with other categories such as gender identity and gendered behavior. There is still consensus that there is a tendency in CAH girls to display non-gender stereotyped behavior, that is, rough-play and interest in machinery. However, there is disagreement in how this corresponds to the general population. As in Klinefelter's syndrome, as the syndromes become better known, and recognized as more frequent, the subsequent focus on potential homosexuality seems to wane. It is possible that this is also a result of the declassification of homosexuality as a mental disorder.

However, Italy institutionally still condones many forms of homophobia, rendering the social life of homosexuals problematic. Many homosexuals are not public with this information in some aspect of their life, and cannot have their relationships recognized by the state. This level of secrecy contributes to the idea that homosexuality is not normal, and not accepted. Given the difficulties involved, many parents would prefer heterosexual children, so that they can participate in normative social and family practices. No one thinks they are going to have a homosexual child given the 1 to 10 odds. However in the CAH literature, one is informed that their child might have an increased possibility to become lesbian, which puts the idea (and/or fear) in the parent's head.

It would be impossible to ascertain how much of the 19th century theories listed by Taruffi on the correlation of clitoral hypertrophy and lesbianism influence present day theories in the CAH diagnosis. However, as in Klinefelter's syndrome, homosexuality is correlated to differences in secondary sex characteristics and theories of hormonal "imprinting" that would affect both gender identity and sexual identity.

Vi sarei grato sapere se ci sono genitori con figlia maggiorenne affetta da sag e se sta procedendo tutto normalmente o stanno avendo e/o avuto problemi sia psicologici sia livello di identità sessuale,vi chiedo questo perche con mia figlia di 18 anni stò avendo problemi a livello della sfera sessuale, allora volevo capire se tutto questo è dovuto a quello che comporta la patologia (interventi chirurgici,alterazioni ormonali, ecc.) e in ultimo il fatto che per un po' di anni ha dovuto eseguire delle dilatazioni all'ostio vaginale per evitare che si verificasse di nuovo il suo restringimento e quest'ultima pratica non era altro che un fac-simile del rapporto sessuale,e quindi tutto questo abbia influito psicologicamente su mia figlia fino a portarla ad una tendenza omosessuale o tutto ciò è dovuto a tutt'altro. P[126]

The medicalized discussion that links biomarkers such as genetic markers and hormones to gendered behavior and sexual orientation is all over CAH medical literature. However P seems to be asking instead another question we find in CAH research literature; has all this invasive medicalization of her genitals led my daughter to reject heterosexuality? The question unfolds in many layers: does CAH medical stripping cause psychological problems, does it cause psychosexual problems, is homosexuality a psychological problem (bad object choice in sexual desire), are instead the bio-markers involved in homosexuality, is the development of homosexuality an unrelated event?

Caro p, io ho una ragazza di 17 anni ed è una ragazza molto femminile, non ha tendenze omosessuali.

Ti dirò, mia figlia è stata operata ad 1 anno di età ed è stato un intervento risolutivo e non ha avuto bisogno di altre manipolazioni. Dimenticavo: mia figlia è affetta dalla forma con la perdita dei sali! Quando abbiamo saputo di questa tecnica siamo rimasti increduli, come assoc. siamo un po' contrari a queste tecniche proprio perchè sappiamo che posso dare degli effetti sulla sfera psicologica. Personalmente non posso dirti altro se non che, visto che si può, certe tecniche andrebbero evitate il più possibile. Rivolga questa domanda al suo endocrinologo oppure rivolgiti

[126]I would be happy to know if there are parents with an adult girl with CAH and everything is proceeding normally or if they are having or have had problems either psychological or on the level of sexual identity, I ask this because my 18-year-old daughter is having problems in the sexual sphere, so I wanted to understand if all this is because of what the pathology entails (surgery, hormonal alteration, etc.) and lastly the fact that for years she has had to perform dilation to the vaginal opening in order to avoid it contracting and this last practice wasn't anything but a simulation of the sexual act, and therefore if all this had a psychological influence on my daughter so as to bring her towards homosexual tendencies or if that is because of something totally different.

10/03/09 re: figli adulti affetti da sag

allo psicologo che segue queste ragazze. ciao n[127]

N indicates the association is opposed to certain techniques, although this is not found in the group's literature. We can assume she is referring to medically assisted dilation, or prolonged medical intervention as implied by her comments.

Ciao p io sono una ragazza di 26 anni affetta da sag classica e ti posso affermare che la nostra non patologia non influisce sulla nostra sfera sessuale, io ho sempre vissuto e mi sono sempre comportata come una ragazza normale. Comunque se hai dei dubbi o se tua figlia ne ha e volete farmi qualche domanda mi farebbe piacere rispondervi, ti lascio la mia mail: email a presto!v[128]

Ciao P, io sono una ragazza di 34 anni affetta da sag (senza perdita di sali). Non ho avuto bisogno di nessun intervento correttivo in quanto il mio deficit è lieve. Anche io come V mi sono sempre comportata come una ragazza normale. Posso capire che tua figlia sia stata traumatizzata da queste tecniche invasive che sicuramente segnano una bimba e che anche io non approvo. Avendo letto altre discussioni nel forum in cui ci sono persone affette da sag "omosessuali", mi stà a cuore dire che non c'è nessun studio che dice che questo nostro deficit comporti omosessualità. Non nego che in caso di tecniche correttive invasive non adeguate ci possano essere problemi psicologici, ma questo non è causato dal fatto che una bimba in realtà si senta maschio, semmai dallo shock che possa avere nel sentirsi "violata intimamente". Secondo me se un individuo ha tendenze omosessuali ed anche la sag non vuol dire che quest'ultima sia la causa della prima. Nel mondo ci sono milioni di gay, ma questo non significa che siano tutte persone affette da sag! Sono stufa di sentire che sag sia per forza sinonimo di omosessualità. Forse, nel tuo caso sarebbe opportuno (se non l'hai già fatto) sentire uno psicologo competente. Comunque sia, ti auguro ogni bene per tua

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[127] Dear P, I have a 17-year-old daughter and she is a very feminine girl, she does not have homosexual tendencies. I can tell you, my daughter was operated at 1 years old and the operation was decisive and she didn't need any other manipulations. I forgot: my daughter has the form with salt wasting! When we learned about this technique we were incredulous, as an association we are a bit against these techniques because we know they can have psychological effects. Personally I don't know what else to tell you apart from, seeing as you can, certain techniques should be avoided as much as possible. Pose this question to your endocrinologist or to a psychologist that follows these girls. Bye N

13/03/09re: figli adulti affetti da sag

[128] Dear p I am a 26-year-old girl with classic CAH and I can contest that our pathology does not affect the sexual arena, I have always lived and I have always acted as a normal girl. Anyway if you have doubts or if your daughter does and you want to ask me some questions I would be happy to answer, here is my email: email talk to you soon! v

17/11/09 re: figli adulti affetti da sag

figlia. Ciao[129]

ISNA's parent handbook attempts to address both surgery and possible sexual orientation prejudices by stating that the parent's first responsibility is to accept and support their child in which ever physical and psychological form they appear in. The discussions mark homosexuality as "not normal" and "caused by" or related to a "psychological problem". At the same time they distance the syndrome from homosexuality, in a manner that also renders homosexuality "normal" or within the normal range of possible events. It struck me that on one hand, questions about sexual orientation provoked much more response and discussion than questions about genital surgery. And on the other hand, that even in this discussion, surgery remains: a vague unmentionable, a "single resolution" or "multiple invasive techniques", without really mentioning if these were clitoral reductions, vaginoplasty, or surgical dialation.

> Ciao P, penso che non dovresti essere te a scrivere su questo forum ma tua figlia, ormai ha 18 anni e credo che sappia cosa le sta succedendo, poi se vuole confrontarsi con altre ragazze che hanno il suo stesso problema sta a lei decidere, e comunque ci sono sempre sempre gli psicologi che possono aiutare molto.V[130]

However, the adults with CAH on the forum aren't talking about their sexual orientation,

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[129] Dear P, i am a 34-year-old with CAH (without salt wasting). I didn't need an operation as my deficiency is slight. I too like V have always lived as a normal girl. I can understand that your daughter was traumatized by these invasive techniques that surely mark a child and that I don't agree with them. Having read other discussions in the forum in which there are other "homosexual" people with CAH, I take it to heart to tell you that no research says that this defiency causes homosexuality. I don't deny that in cases of these unsuited invasive corrective techniques there can be psychological problems, but this is not because a girl really feels masculine, if anything it's for the shock they can feel in feeling "intimately violated". I think that if someone has homosexual tendencies and CAH it doesn't mean that the later is the cause of the first. There are millions of gay people in the world, but this does mean they all have CAH! I am fed up with hearing that CAH is necessarily synonymous with homosexuality. Maybe, in your case it would be opportune (if you haven't already) to talk to a competent psychologist. Anyway I wish the best for your daughter. Bye.

27/11/09 Re: figli adulti affetti da sag

[130] Dear P, I don't think it should be you to write to this forum but your daughter, now she is 18 and I bet she knows what is happening to her, then if she wants to talk to other girls that have her same problem she can decide, and anyway there are always psychologists that can help a lot. V

03/04/09 Re: figli adulti affetti da sag

their surgical or medical experiences or their sexual lives. This sharing is reserved to private conversation. Concerns about homosexuality and the traumatic effects or surgery remain to some extent encapsulated in the realm of parental responsibility and fear (also as reported by medical professionals). The most vocal concerns of the adult women with CAH seems instead to be another aspect of sexuality, neither pleasure nor penetration nor genital form but reproduction (as also for many AIS women).

6.6 CAH and reproductive rights

The adult patients on the forum are invested in their reproductive rights, having animated discussions about how to moderate the pharmaceuticals, which can include the birth control pills. Many of the individuals with CAH already have a somewhat medicalized existence, but in the attempt to have children, medical information and authority needs to be renegotiated. Many who have found a therapy they are satisfied with for themselves, find themselves back on-line, asking advice and seeking answers. The transition from pediatric CAH specialists to adult care can leave many without information.

> Ciao mi chiamo K ho 36 anni sono affetta da SAG. Il 26 febbraio 2007 è nato mio figlio D un bel bambino che ora ha 8 mesi per quasi 9 chili di simpatia. Io non ho la forma classica infatti mi è stata diagnosticata la SAG a 9 anni, ho avuto gli interventi correttivi e sono in terapia sostitutiva con idrocortisone e florinef. Sono seguita presso l'Ospedale San Raffaele di Milano dal dott. Russo endocrinologo. Per la mia gravidanza mi ha seguito la Dottoressa Castiglioni, ginecologa, che ha fatto nascere D con cesareo programmato alla 38esima settimana. Anche il dottor Russo mi ha seguita e consigliato la terapia da prendere. La gravidanza è stata x me un periodo bellissimo, sinceramente avevo dei dubbi e delle preoccupazioni, che comunque sono scomparsi quando alla prima ecografia ho visto e sentiro il cuoricino di D battere.... Durante la gravidanza i medici che mi hanno seguita mensilmente, oltre ai controlli standard da farsi in gravidanza, mi hanno consigliato di eseguire le analisi del sangue x vedere i livelli ormonali che effettivamente non erano sempre nei limiti. E infatti la terapia è stata corretta strada facendo. Ci sono stati poi i mal di schiena, le gambe gonfie, la stanchezza ma tutto poi si dimentica e passa quando vedi l'esserino che ti dava tanti calci nella pancia per la prima volta. Spero che anche tu possa provare quest'esperienza, questa gioia che è indescrivibile. Un caro saluto K[131]

[131] Hi my name is K I'm 36 and I have CAH. The 26th of February my son was born a beautiful baby that now is 8 months old and almost 9 kilos. I don't have the classic form and in fact I was diagnosed at 9 years old, I had corrective surgery and I take Hydrocortisione and Florinef. I am followed by San Raffaele Hospital in Milan by doctor Russo endocrinologist. During the pregnancy I

Individuals who have grown up with CAH are thrown into the medicalized world of childbirth with often both the experience of having grown up "different" and the expectations of what medicine can and cannot do to change this. Elizabeth Ettorre (2002) in her work on reproductive genetics, gender and the body discusses genetic technology's impact on reproduction, indicating that an increased possibility to diagnose and manipulate alters the moral landscape. In Ettorre's framing of the argument, having a healthy baby becomes a moral responsibility made possible through technology. In vitro and artificial insemination technologies reveal the work behind getting pregnant and having a healthy baby, but as Charis Thomson (1998) observes in her work, they also highlight the social expectation to perform that work, and to make the sacrifices necessary to have a healthy baby.

> Ciao a! volevo aggiornarti dopo la visita dal ginecologo. E' stato molto gentile, mi ha detto che capisce che il mio non può considerarsi un normale caso di infertilità vista l'irregolarità del ciclo; mi ha comunque consigliato di fare l'isterosalpingografia (che farò il mese prossimo); in seguito ai risultati di questo esame contatterà anche la mia endocrinologa e insieme cercheranno di aiutarmi. Speriamo bene! Continuerò a tenerti informata sull'evoluzione della situazione. Un bacio e mi raccomando sii forte e fregatene delle male lingue! Purtroppo persone stupide ce ne sono a bizzeffe!!! Un caro abbraccio![132]

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was followed by Doctor Castiglioni, gynecologist, who birthed D with a cesarean planned in the 38th week. Doctor Russo also followed me and advised what therapy to take. The pregnancy was a wonderful time for me, sincerely I had doubts and worries, but anyway they disappeared when at the first the ultrasound I saw and heard D's heart beat…. During the pregnancy the doctors followed me monthly, besides the standard controls that one does in pregnancy, they advised me to take blood tests and see the hormonal levels and effectively they weren't always in the limits. And in fact the therapy was corrected as we went along. There was a bit of back pain, swollen legs, tiredness, but then you forget everything and you get over it when you see the little being that kicked you so much in the stomach for the first time. I hope that you can also have this experience, this joy in indescribable. A kind goodbye K

[132] Hello A! I wanted to put you up to date after the gynecological visit. He was very nice, he told me that he understand that mine can not be treated as a normal case of infertility given the irregularity of my (menstrual) cycle; he advised me anyway to have a hysterosalpingography (that I'll have next month); following the results of this examination he'll contact my endocrinologist and together they'll try to help me. Lets hope for the best! I'll keep you up to date about the situation. A kiss and please be strong and don't care about those that say bad things! Unfortunately there are tons of stupid people!!! A sweet hug!

Besides the normal pressure and insecurity of pregnancy, CAH women have the burden of a genetically-linked syndrome and the stigma and discoursive responsibility that implies.

> Salve a tutti. Mi chiamo L. Ho 31 anni e sono affetta da SAG. Una marea di medici mi aveva consigliato di farmi chiudere le tube o comunque di non provare mai a rimanere incinta. Io però mi sentivo donna a metà. Volevo un figlio a tutti i costi, ma dopo due anni di tentativi, niente. Mi sentivo una donna inutile, poi mi sono detta che se Dio non voleva rendermi madre era perchè forse avevano ragione i medici. Poi, la mattina del 12 settembre 2005, dopo due soli giorni di ritardo, ho fatto il test di gravidanza: ero sicura che qualcosa in me stava accadendo e infatti ero incinta. Un ginecologo mi consigliò di non aspettare e di fare il raschiamento: troppo rischioso far nascere quella creatura, mi disse,ma io non mi arresi. Feci la villocentesi all'undicesima settimana, ma era certa che in grembo ci fosse P e che fosse sano: avevo già sofferto io abbastanza: Dio non poteva far entrare altro dolore nella mia vita. Il responso della villocentesi: P....SANO...SANISSIMO!!!! La gravidanza è stata dura, ma poi tutto è finito bene. Ho dovuto fare il taglio cesareo. Sono anche affetta dal fattore di leyden nella forma grave e in seguito ad un'incidente ho un piastrino al titanio che tiene unite le vertebre cervicali. Mio figlio ha quasi due anni e dagli accertamenti lui non risulta essere neanche portatore sano della SAG. Il mio messaggio? NON ARRENDETEVI MAI. SPERATE, PREGATE, CREDETE IN VOI STESSE. NON DOVETE LASCIARVI INTIMORIRE E FIDATEVI SOLO DI MEDICI CHE REALMENTE CONOSCONO I PROBLEMI LEGATI ALLA SAG. DI CIARLATANI IN GIRO CE NE SONO TANTI!!!![133]

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[133] Hello to everyone. My name is L. I am 31 and I have CAH. A sea of doctors advised me to close my tubes or at least never try to get pregnant. I however felt half-a-woman. I wanted a child at all costs, but after two tries, nothing. I feel like a useless woman, and then I told myself if god did want to make me a mother maybe it was because the doctors were right. Then, the morning of September 12th 2005, after only two days late, I took a pregnancy test: I was sure something was happening to me and in fact I was pregnant. A gynecologist advised me not to wait and to have an abortion (curettage): too risky to give birth to that creature, he told me, but I didn't give in. I had the Chorionic villus sampling (CVS) in the eleventh week, but I was sure that P was in my womb and that he was healthy: I had already suffered enough. God couldn't have made other suffering enter my life. The results of the CVS: P….healthy…super healthy!!!! The pregnancy was hard, but everything ended well. I had to have a cesarean, I am also affected by the Leyden factor in the serious form and after an accident I have a titanium plate that holds my cervical vertebrae together. My son is almost two-months-old and based on the tests he isn't even a healthy carrier of CAH. My message? DON'T EVER GIVE UP. HOPE, PRAY, BELIEVE IN YOUR SELF. DON'T LET YOURSELF BE INTIMIDATED AND ONLY HAVE FAITH IN DOCTORS WHO REALLY KNOW THE PROBLEMS RELATED TO

As in other DSDs, a lack of information can heighten stigmatization. Doctors who are not in collaboration with specialized DSD centers can replicate historical paradigms that relate to pathology as monstrosity. This level of stigmatization is more common in the stories of AIS treatment up into the 1990's; however medical pressure to not reproduce can be present also in the CAH diagnosis. Individuals with CAH, when seeking to have children, face not only the medicalization of childbirth, but also the stigmatization of a genetically linked syndrome.

> Ciao E, sono L. Sono felice che tu abbia letto il mio messaggio. Io so che cosa vuol dire vivere tutta la vita con l'angoscia di non essere uguale agli altri. So anche che mio figlio è un caso particolare. Ma so anche che non si può non tentare. Per tutta l'adolescenza mi sono sentita derisa, umiliata, offesa. L'irsutismo era evidentissimo e i miei coetanei non perdevano occasione di deridermi. Per me è stato devastante. A 19 anni pesavo 38Kg: mi rifiutavo di mangiare. Poi grazie ad un'estetista e al mio pediatra, il professor E B, che mi ha sempre aiutato e stimolato a continuare a cercare la cura più giusta, ho visto i primi risultati. A 21 anni ho conosciuto il mio attuale marito. Innamorami e sentirmi ricambiata mi ha dato più fiducia in me stessa. Non volevo un figlio per un senso di riscatto. Volevo un figlio perchè avevo tanto amore da dare, tutto quell'amore che da ragazzina non sono mai riuscita a trasmettere a nessuno...Neanche nei miei sogni più belli ho immaginato la gioia che provo quando P mi abbraccia o mi viene incontro sorridendo, o quando mi chiama di notte perchè vuole essere coccolato. Come si può lasciare vincere la paura e rinunciare a tutto questo? So che è difficile, ma non si può smettere di sperare.[134]

The risk factors of being a carrier of CAH are discussed, often in the context of having a certain level of intimacy with the syndrome. The object of discussion reveals the social-moral pressure of reproducing within the framework of genetic pathology. However, discussion also

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CAH. THERE ARE LOTS OF CHARLATANS AROUND!!!!

[134] Hi E I am L. I am happy that you read my message. I know what it means to live your whole life with the pain of not being the same as everyone else. I also know that my son in a particular case, but I also know one can't not try. For my whole adolescence I was made fun of, humiliated, offended. The Hirsutism (hairiness) was very evident and my peers didn't miss a moment to make fun of me. It was devastating. At 19 I weighted 38kg: I refused to eat. Then thanks to a beautician and my pediatrician, professor EB, who always helped me and stimulated me to seek the best cure I had the first results. At 21 I met my actual husband. Falling in love and feeling it mutual gave me more confidence in myself. I didn't want a child to get back at someone. I wanted a child because I had so much love to give, all that love that as a girl I wasn't able to give to anyone…not even in my best dreams did I imagine the joy I feel when P hugs me or comes towards me smiling, or when he calls me in the night because he wants to be cuddled. How can you let fear win and renounce all of this? I know it's difficult, but you can't stop hoping.

reveals the possibility of choice and lack of medical protocol that directs said choice in one direction or another. The fear of eugenic practice in prenatal testing is a focus point for disability politics. The stories of CAH patients as potential parents reveal a lack of medical pressure not to have children (with the one exception we saw a few pages back who had a healthy son anyway) within this expert knowledge group made up of patients. This exposes, yet again, the role accurate information has in possible eugenic practice in prenatal testing.

> Ciao a tutti. Sono il padre di due bimbe: la prima ha 4 anni e mezzo ed è affetta. La seconda ha 2 anni e mezzo e ANCHE lei è affetta. Non abbiamo ancora escluso il terzo bimbo anche se cominciamo ad essere un po' "vecchiotti". Non è facile, ma con il secondo è tutto molto più normale. Credo che il grosso problema sia scoprire la malattia nel primo bimbo e gestire quel vortice di emozioni che ti travolge e ti scuote fin nel profondo. Nella seconda gravidanza si è molto più preparati da subito. Anche quando abbiamo scoperto che la seconda era affetta, ci siamo un po' arrabbiati (ancora, sempre a noi, ...) ma è durato poco: la vista della prima bimba era una gioia immensa. Oggi siamo felicissimi delle nostre bimbe e delle nostra famiglia. Dal punto di vista tecnico non è molto più complesso: le portiamo alla visita assieme, il farmaco lo prendono assieme (dosaggi diversi ma ...), all'ospedale prendiamo i farmaci per entrambe. La piccola, imitando la più grande, ha imparato a prendere le pastiglie per via orale a 18 mesi: è bastato mostrargli la mano con la pastiglia come alla sorella e la piccola l'ha presa e mangiata senza nessuna difficoltà. Auguro a tutti che il secondo nato sia sanissimo, ma se anche fosse affetto, credo che la gioia che porta in famiglia sia molto maggiore dell'impegno che la sua sindrome comporta. Se pensate al secondo figlio OVVIAMENTE bisogna essere PIU' ATTENTI perchè la madre deve fare la terapia in utero DA SUBITO (meglio entro la 4/5^ settimana) per evitare disfunzioni ai genitali nel caso di femmine (nel caso di un maschio la si interrompe dopo l'esito della villocentesi (11^ settimana) e la si riprende direttamente sul bimbo appena nato). Se avete ulteriori curiosità o domande potete anche contattarmi all'indirizzo email Ciao G[135]

[135] Hello to everyone. I am a father of two girls: the first is 4 and a half and has (CAH). The second is 2 and a half and she is ALSO (CAH). We haven't given up the idea of a third even if we are starting to get a little "elderly". It's not easy, but with the second everything is more normal. I think the biggest problem was learning about the disease of the first child and handling that vortex of emotions that sweeps you up and shakes you to your core. In the second pregnancy you are much more prepared from the beginning. Even when we learned that the second had it, we were a little bit angry (as always, at our selves…) but it didn't last long: seeing the first child was a immense joy. Today we are really happy with our girls and our family. From a technical point of view its not that much more complicated: we bring them to (medical) visits together, they take the medicine together (different dosages but…), at the hospital we get medicine for both of them. The smaller one, imitating the

In Italy prenatal CAH treatment with dexamethasone or similar hormones to counteract virilization has been available since the 1980's. Prenatal treatment is only offered to those known to have a family history of CAH. It is therefore unclear, also in Italian medical literature, how often it is actually used. Abortion is not offered for CAH, as it is for Klinefelter syndrome or occasionally AIS[136]. The prenatal treatment has the scope of treating virilization in female children and thereby avoiding genital surgery. It is suspended if the child is male and will not affect eventual salt-wasting. Recent long-term studies on prenatal dexamethasone treatment have indicated possibly negative effects, "Effects on cognition, especially memory, have been observed (Lajic et Al. 2008)."

The lack of discussion surrounding certain arguments hints at the lack of choice. Foucault postulates that the nature of bio-power and control is creative, in that it can create possibilities and impossibilities. Bio-power frames what is normal and within the context of technology, what is to be strived for. The deconstruction of DSD treatment often seeks to highlight the ambiguity of *necessity* in care protocol. One of the faces of the power dynamic between doctors and patients is how therapeutic options are presented as optional or not. In the CAH group dynamic the "given" or "not optional" seem to be early genital surgery and pharmaceutical intervention. CAH as a debilitating syndrome, a child to abort, or a genetic illness that must not be passed on, is not part of the group's discourse. Practical problems are dealt with by comparing stories, advising clinics, and doctors, or offering tacit knowledge. Yet nowhere within the group is there even the hint that these pregnancies, past or future, should be avoided.

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bigger, learned how to take the pill orally at 18 months: it was enough to show her the hand with the pill as we did with her sister and the smaller one took it and ate it without much difficulty. I wish for everyone that the second born is born very healthy but even if they have it, I believe that the joy they bring to the family is bigger then the work the syndrome implies. If you think about a second child OBVIOUSLY you need to be more careful because the mother needs to take in-uterus therapy RIGHT AWAY (better within the first 4/5 weeks) to avoid the dysfunction of the genitals in case it's a girl (in the case of a boy you stop at the results of the CVS (11th week) and you restart with the newborn). If you have other curiosity or questions you can contact me at the email address email Bye G

[136] XXY, due to its chromosomal nature is part of routine prenatal genetic testing, whereas CAH and AIS related genetic markers would need to be targeted on request. However, AIS is sometimes identified prenatally when the sonogram genital appearance does not match the chromosomal information.

Chapter 7

Collaboration, evolving care in the Italian clinical landscape

7.1 *Shifting landscape*

In 2006, as previously mentioned, there was an international medical convention on Intersex in Rome. As part of the changing landscape, the conference used the term Intersex, while introducing the new DSD terminology. The reports of the consensus convention and the proposed change in care model, arrived just as the Italian patient groups were forming. The founding members of AISIA were at the 2006 conference to present a poster, with an information table that represented what would become the official group.

It was a nebulous moment, full of tension, where health care providers were still ambivalent, on the fence between Money's model and the possibility of postponing early surgery, full disclosure, and performing follow-up research. Several moments in the course of the conference indicated that these were the key issues in the process of evolution. One of the English doctors on the panel agitatedly stated; "You criticize us saying that our techniques are too invasive, and then you criticize us saying there is no follow-up care or data. Isn't the act of gathering follow-up data invasive?"

A member of the audience replied that, if the diagnosis communication was less stigmatizing (and care less traumatizing), routine check-ups would be like those after heart surgery or any other medical procedure. One of the focuses of the new therapy guidelines is specifically communication-oriented, hoping to treat DSD "as a syndrome like any other, instead of a syndrome like no other" (Feder and Karkazis 2008). This, of course, implicates informing patients so that they can have an active role in their own care.

The English clinic announced they were suspending early gonadectomy procedures because they had confirmed that the lack of the gonad was actually harmful (due to the complexities and side-effects of hormone regulation). Early gonadectomy is one of the many sex-bias interventions, as we have seen, and it is performed on women with AIS largely for psychosocial reasons. There has never been any statistical evidence, live or post-mortem, that DSD gonads (without mixed chromosomal tissue) have a higher cancer risk. The positioning of the gonads in AIS patients does make monitoring more complicated. Another comment came from the audience, "but then you've never had evidence that AIS gonads posed cancer risk?" To which the doctor responded, "No, we've never had the medical evidence, high

cancer risk is only present in gonadal dysgenesis (mixed chromosomal tissue).” Part of the erosion of trust in patient/doctor relationships is based on this form of procedures, performed without medical evidence.

In informal discussion, I encountered an English psychologist who claimed that parents from more traditional cultures would not accept their child if it was different (despite the evidence that early childhood surgery arose in the United States only in the 1950’s, thereby “traditional” cultures did not use surgical modification) and that it was the parents who insisted on early genital surgery, not doctors. We were accompanied in this discussion by a Canadian surgeon who had recently developed the “reversible” surgical clitoral reduction technique (that we addressed in chapter six); in the case the child assigned female developed a male gender identity later in life. Both medical professionals seemed to be at a loss as to how to remedy parents’ fears and expectations against the problems surgery could cause for their children in the future. Patient groups such as ISNA state that parental fears for their children should not be medicalized in the form of “corrective” surgery. As we have seen in previous chapters, parents indicate that their fear is of how a bigoted world will treat their child[137].

I followed the founders of AISIA throughout the conference, who gave me in depth interviews in the free moments. They were a mother and father in their fifties, a woman in her thirties and a woman in her twenties. All of them had been subject to the medicalizing aspects of DSD before there were any patient support groups in Italy. They all indicated that the doctors they found weren’t very interested in helping them talk to other people in their situation. Lorre (mother of an adolescent with CAIS) indicated that it seemed strange to her that in a center that dealt specifically with DSD, there weren’t ever other mothers she could talk to.

I had begun my interview process only a few months earlier, with the head of hospital A. From my first phone call with him, it was clear that he needed some convincing as to why a social scientist would be interested in DSD. On the phone, he asked me why I wanted to interview him, stating that at his hospital they did the same things they do in the USA. At the conference again he asked me, what is the real reason you are studying Intersex? It seemed,

[137] It remains unclear how much of the image of children being teased in situations of public nudity is mentioned *first* by the doctors or medical literature, reinforcing a parental worry and thereby giving validity to this fear. ISNA maintains that the doctors responsibility should be to emphasize the variety of the human body and acceptance of difference. However doctors may encounter parents who have no interest in accepting difference, in any aspect of their lives.

given the debates and his obvious awareness of patient group antagonism at the conference, that he either assumed I wanted to criticize the doctors, or that I was a patient myself.

Neither and both were partially true. As I spoke with Lorre (mother, co-founder of AISIA) about her agonizing experience before and after her child had surgery, I remembered, as one does, my own childhood medical experiences: two doctors holding me down and sticking me with needles as I screamed and cried, and my mother standing by watching, also crying. In the end the two doctors, who were just trying to get a blood sample, gave up and gave me some raisins instead of the lollypop they had promised me. I more remember leaving the hospital and walking down the stairs to the subway with the box of raisins (which I hate), than I do the failed blood draw which instead, my mother talked about periodically throughout my childhood as having traumatized her.

The blood draw was a pre-surgical procedure. I, like many young girls, had had a vaginal track infection, and in the early 80's doctors proposed urethra track enlargement for young girls with repeated problems with infections. The experience of the failed blood draw seemed to have cured me however, and my infection cleared up and never came back. Reading the literature on hypospadia, it appears I narrowly avoided a similar procedure, which can lead to more infection and scarring then it cures. I told Lorre about this experience originally to share a similar moment where my mother had suffered watching me have an procedure I barely remembered. However, it leads us to wonder what is the logic behind surgically manipulating young children, for aesthetic reasons, who can't really make sense of the painful event. I became aware of the personal nature of the opinion I was already forming against uninformed irreversible childhood surgery.

Already in 2006, an endocrinologist from hospital B approached Lorre and offered himself as a patient advocate. He expressed himself in similar terms as Dreger's request: that DSD be treated as a medical condition like any other. Endocrinologist B indicated that he would be interested in screening the AISIA members, and that he was working on research that focused on the endocrinological health aspects of DSD, not gender assignment. He was the first Italian doctor to publicly advocate against early gonadectomy.

As previously indicated, the bulk of the conference was dedicated to surgical techniques, from phalloplasty to clitoral reduction to urethra re-positioning. The English psychologist I had spoken with informally, announced in her presentation that patient groups only represent unsatisfied patients, the satisfied patients having disappeared into "normal society", a position which she herself has retracted in more recent years. At the end of the last day when all the surgeons had left, a man from the NYC hypospadias group spoke, after a panel in which there

had also been a medical law professor from Rome. He was not surprised that there was so scarce an attendance of the only patient's presentation.

The law professor's official presentation advised doctors to not perform surgery without informing patients of the risks, in order to avoid lawsuits. In an informal interview she informed me that it is much more difficult to sue over lack of informed consent in Italy than in the United States. She stated that there is not one specific law, but a series of laws that imply the need for informed consent. According to her, the only case that had succeeded when a medical repercussion had been discovered years later, was a case of a hemophiliac who contracted a disease from a blood transfusion.

7.2 *What was, what is. Shifts in practice from 2006 to 2010*

DSD treatment reflects many aspects of the contemporary landscape, from the medicalization of social issues such as gender, to the bio-ethical debate that repositions the patient as protagonist. Adele Clarke notes that not only are differences in the body increasingly medicalized, but bio-medicalized, requiring bodies to fit within not just a natural standard, but a standard of the body that can be achieved through technological intervention (Clarke et Al. 2003). Carl Elliot (2004) treats this theme by hypothesizing that technology and modern culture push us to expect to be better than well. Elliot indicates that in several arenas, such as dental appearance, one may be socially sanctioned if they do not utilize the aesthetically corrective procedures now commonly available.

Peter Conrad (2005) instead looks at what he calls the shifting engines of medicalization, attempting to find the locus of where medicalization develops and comes from. While appreciating the availability of medicalizing technology as a motivating factor, he indicates that one of the major factors that has changed the medicalized landscape is the entrance of consumers into the field in the role as experts. In the twentieth century history of DSD treatment, one can clearly see the progression from the paternalistic model where the patient is kept in the dark, to the oppositional period where patients contested this medical form of regulation of difference, to the phase we are now entering, where patients become experts who negotiate and evaluate the available technology and care options.

This process in Italy seems to have been on fast-forward. In 2006 the patient support groups were either controlled by doctors, such as the ISC group (then SAG), or labeled as being representative of only disgruntled patients. Aided by the Internet and International networking, they went from being uninformed patients to experts. This rapid shift to patient empowerment in Italy (and their criticism of previous DSD care protocol) very quickly

reflected a potential career threat for those doctors who might want to advance beyond a local level, apply for European grants, etc. In 2010, several Italian university medical centers that vie for national and international funding sought alliance with the DSD patient groups, actively promoting their continuation. Up into the 1990's Italian DSD patients were often told not to seek out other patients, or that there weren't others. As we have seen in chapters four and five, in Italy diseases considered rare are allocated special funding for the creation and maintenance of specialized centers, to which patients from all of Italy would be referred.

The process of transformation to a patient-centered model is complicated however. At the 2006 conference, hospital D presented its new psychologist who would be an active part of the new model of team management. It was unclear who would communicate the diagnosis to the patient and/or family, but at least there would be someone to handle the effects of the communication. Despite the positive atmosphere, several of AISIA's members were suspicious about the possibility of real changes at Hospital D. Their suspicions were based on their own experiences regarding diagnosis communication, diagnosis information, and treatment choices.

In this section I present three sites of change in perspective concerning Italian protocol: vaginal dilation, gonadectomy, and diagnosis communication. In the following section, where I address the molecular genetics lab, we will see other subtle changes in approach regarding early surgical intervention but also in the relationship between difference, disease and stigma.

AISIA had a long struggle convincing Italian practitioners that vaginal dilation was a viable alternative to vaginal reconstruction surgery, and that it didn't need to happen before a patient was old enough to want to have vaginal penetration. This process started with patient operative experiences at hospital D, finding its way to hospital A and hospital E (competing with hospital D). This issue was anticipated by more serious problems, not only by a lack of diagnosis communication, but also a lack of treatment options. The group members who were treated at hospital D have complaints that range from diagnostic inaccuracies to insensibility from nurses who called out into a crowded waiting room "who is the mother of the hermaphrodite?" to informing adult patients (in one case to a woman with a non-modified medically "normal" length vagina) that they should not be sexually active.

After the 2006 conference, two AISIA members separately returned to hospital D and confronted the doctors who had treated them. These doctors present themselves at medical conferences as supporting full-disclosure and avoiding unnecessary early childhood surgery, while in early practice their actions were quite different. The AISIA members indicated that their own personal interests mattered less to them than the possibility of change. They wanted

to investigate behind the rhetoric to see if it was safe to send new members to hospital D, or advise them to travel further to hospital B or hospital A.

Lorre and Federico had made the decision to operate on their child at hospital D under extreme pressure and what they described as scare tactics.

> Mi ha chiamato il medico e, mi ha fatto capire che dovevamo parlare di qualcosa di grave. E mi ha detto, "Lei sa cos'è l'ermafroditismo?" e io ho detto, mah! Sì, ma non ero sicura che fosse una cosa che esistesse veramente o fosse una cosa mitologica, così. Ha detto "No, no, esiste. E guardi che sua figlia ha questo problema e può darsi che abbiamo sbagliato, che non è una bambina, potrebbe essere che deve cambiare sesso, perché abbiamo trovato dei testicoli. E quindi non abbiamo più operato, abbiamo lasciato tutto com'era. Bisogna fare delle indagini, e così vediamo se è un maschio o una femmina." E da li e' cominciato tutto. Accertamenti, analisi, e poi le operazioni. Operazioni perché più avanti hanno fatto una laparoscopia per esplorare all'interno, e quando hanno visto che c'erano i testicoli ci hanno chiesto di operare. Perché lei non ha la forma completa, ha la forma incompleta, la PAIS, e questa forma effettivamente, può, durante poi la pubertà, dare ulteriori cambi. Non so, la peluria, la voce. Ci hanno consigliato che era molto più semplice allevarla come una femmina perché, era probabilmente più, come si può dire, adatta, al suo aspetto esterno. E alle fine non abbiamo avuto dubbi, l'aspetto esterno era femminile insomma, abbastanza. C'era qualcosa che non andava, però era un aspetto femminile, e quindi era la strada veramente più semplice. Però c'era il discorso della pubertà e il suo effetto contraddittorio, e quindi abbiamo deciso di fare l'operazione. E poi ancora dopo abbiamo fatto un altro intervento perché, ci hanno detto, che aveva un forma genitale… Era poco diciamo … L'unica apertura in cui si apriva una piccola vagina…[138]

[138] The doctor called me and, led me to understand that we needed to talk about something serious. And he said to me, "Do you know what hermaphroditism is?" and I said, uh, yes, but I wasn't sure that it was something that really existed or something mythological, like that. He said "no, no, it exists. And look here your daughter has this problem and its possible that we are wrong, that she's not a girl, its possible she needs to change sex, because we found testicles. And therefore we didn't operate we left everything how it was, we need to do some tests, to see if she is a boy or a girl." And everything started from there. Certainly, tests, and then an operation, operation because later on they did a laparoscopy to explore inside and when they saw that there were testicles they asked us to operate, because she doesn't have the complete form, she has the incomplete form, PAIS, and this form, effectively, can, during puberty, bring other changes, I don't know, hair, the voice, they advised us that it was much easier to raise her as a girl because, it was probably more, how can I say it, suited, to her external appearance, that in the end we didn't have any doubts, the outside appearance was female in the end, enough, there was something not quite right, but it was a female appearance, and therefore

They are a middle class couple with a high level of college education, which perhaps gave them the resources to continue to inform themselves and help found the patient group, however it did not help them confront the initial lack of information and the rhetoric of a "medical emergency". Lorre wonders if she would have let them operate on her daughter if she knew all she knows now.

Dreger and INSA insist that the genital aspects of DSD are not medical emergencies but potential sources of social anxiety. As indicated earlier, there is no scientific evidence that delaying genital surgery will have negative ramifications for the child, yet there is evidence that rushing surgery can irreversibly damage the body. Surgery is often proposed as a one-time fix.

> e quindi e' stata detto, "adesso e' tutto fatto, nel senso che ora, ha una piccola vagina che poi crescerà, e quindi quando avrà 10 anni dovrà prendere degli ormoni"

However, one cannot anticipate how the body will grow. Many women who are not diagnosed with DSD do not have "optimal" vaginal length when they become sexually active, rendering the penetrative act painful, regardless of the state of the hymen.

> L: E poi verso i 15 anni, ero un pochino ansiosa perché pensavo che non era sicuro questo fatto della vagina che fosse cresciuta, così come era cresciuta lei, e allora facevo un po' domande ai medici e alle fine l'hanno fatto una visita e hanno visto che effettivamente,
>
> F: che non era cresciuta…
>
> L: sì che effettivamente non era così, buona, la situazione con la crescita, invece lei aveva 16 anni. E allora, ci ha detto che effettivamente bisognava fare un piccolo intervento di, ingrandire un pochino, l'apertura
>
> F: quella vaginale…
>
> L: e mentre poi l'hanno operata, per cose che sapevo, insomma, per questa cosa, durante l'operazione, e' venuto fuori il medico, dalla sala operatoria, sempre questa scena terribile, ce, ne avremo potuto forse parlare anche dopo, comunque nel momento eravamo veramente tanto tanto,
>
> F: ansiosi,
>
> L: tesi, e dice (il medico) " il problema non era sicuramente quello dell'apertura, la vagina non ha la dimensione assolutamente, non può avere rapporti sessuali" ha detto che doveva affrontare

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it was really the simplest choice but there was the issue of puberty and its opposite effects and so we decided to have the operation and then after we had another operation because, they told us, because she had a genital form, it was a little let's say, the only opening in which a little vagina opened…

sicuramente un intervento chirurgico, quindi, la vaginaplastica, a quel punto, poi noi siamo ri-andati il giorno dopo a parlare con calma con lui, per farci spiegare meglio, però non e' che ci hanno dato nessuna indicazione, "informatavi, vedete dove la fanno, ci sono tanti metodi diversi, informatevi voi…" lui ha anche, era anche disposto a provare lui, questo qui, e, insomma, lui poteva provare ma certo, poi questi interventi si devono fare nel momento in cui una vuole avere rapporti sessuali perché se si fanno prima, e poi una non ha rapporti si atrofizza, tutto quanto, per cui noi siamo entrati proprio nel panico ancora di più. Intanto che dobbiamo spiegare a lei? Perché lei stava dormendo quando ci hanno detto, no? E poi a dargli una prospettiva, e lì in quel momento abbiamo deciso di non dirglielo immediatamente ma prima darci, un pochino guardarci intorno, e vedere cos'era possibile, ma, almeno per poterle dire cosa si poteva fare,

Lorre and Federico searched the Internet after the initial impact and contacted the English AIS group. They were torn between the doctors who told them not to worry about it, and the psychologist who told them to tell their daughter everything and let her decide. They were frustrated at the lack of information, unclear what were the options they could give their daughter. They were informed at hospital C about the Vecchietti technique, surgical dilation, which seemed slightly less invasive. They visited the Creighton clinic in London, and received detailed information about vaginal dilation techniques, from the positive aspects: it avoids permanent internal scarring, it's non-surgical, it's not irreversible; to the negative: it needs to be a self-initiated process to be followed over months, it requires more time. The Creighton center specifically focuses on the interaction of two factors for dilation success, the desire of the patient and relaxation through de-stigmatization.

Noi quando abbiamo saputo che c'era questa cosa siamo andati dai diversi medici, prima a dirlo a lei, a sentire se era una cosa accettata, e ci hanno detto che erano leggende, favole, sogni, cose del genere, che non l'avevano mai sentito nominare, non e' che hanno detto che "ok adesso mi informo", ci hanno detto "no, non state a chiedere a questa cosa,"

They repeatedly encountered obstacles to their informational search, from doctors who were willing to "try" techniques they knew little about; to others who negated the existence of techniques they did not themselves practice. However, the alliance with the English group and clinic gave them at first self-assurance, and later a negotiating position of authority. Lorre and Federico's daughter was followed by the Creighton clinic and in a matter of months had resolved the lack of possibilities they had been confronting for years. Lorre acknowledges that part of the success probably came from cutting the parents out of the process; their daughter had entered into a direct relationship with the clinic.

In 2009 AISIA collaborated with hospital E (competing with hospital D where Lorre's

daughter, and other AISIA members were treated in the 80s and 90s), which organized a medical conference specifically on AIS. They invited a gynecologist from the Creighton clinic and the psychologist from hospital A, who was working on a study that addressed the benefits of full disclosure. The Creighton gynecologist presented four growing international perspectives; waiting until the age of consent to perform any non-life threatening interventions, the use of dilation as a first line intervention, the role of the clitoris in female sexual satisfaction and the need to de-stigmatize genital difference. She indicated that dilation could be performed with a vibrator, in order to transform a potentially embarrassing procedure into a normative use of sex related objects.

The psychologist from hospital A presented his work on full-disclosure as a comparison of the trauma, confusion and betrayal expressed by patients who had only been partially informed about their diagnosis. At the end of the conference, three members of AISIA related part of their experiences, also focusing on the need for non-stigmatizing, complete, diagnosis communication.

In 2008 Lorre had asked me if I knew of any doctors who had experience with dilation techniques, and another researcher put me in touch with a lead gynecologist at hospital A. In the end, her team had little practical experience with AIS, but some with Rokitansky syndrome where there is a congenital absence of either the vaginal passage and/or the uterus in a XX woman. The gynecological team of Hospital A sent one of their doctors to the conference in Rome, which lead quickly to not only a relationship with AISIA, but a training exchange between hospital A and the Creighton center.

The pediatric psychologist and the gynecologist from hospital A had never met, even though they work on the same syndromes in the same hospital. Another pediatrician at hospital A confirmed that many of their DSD patients remain in their care until 30 years of age. This is a significant indicator of the lack of follow-up adult care.

The lack of information and follow-up care has an extremely negative impact in the case of endocrine therapy, from hormonal replacement therapy in Klinefelter's syndrome and CAH, to gonadectomy in AIS. As we have noted earlier, often DSD patients are cured less for these aspects of the syndrome, that are obscured by the excessive attention paid to gender related issues.

In the past few years more and more attention has been paid to early gonadectomy, and, as we saw earlier, several international clinics have reversed their policies. As we saw in chapter four, the lack of full disclosure can bring about inconsistent hormone replacement therapy, as in Anna's case, while Melanie, who received more recent treatment has been able to follow

her own care.

There are other members of AISIA who are starting to question the need for gonadectomy even after puberty. Carine feels like she was rushed into it at 17, only months before she could have legally made the decision herself. She has yet to find a hormonal therapy that makes her feel healthy as she did before the gonadectomy. Anna returned to her doctor at hospital D years later and confronted him on his paternalistic decisions to remove her gonads and not inform her. His response was dismissive and AISIA has not pursued collaboration with their center.

After the 2006 conference AISIA and the pediatric department of hospital B began collaboration on an endocrinological health project that continues today. Many AISIA members receive most of their DSD-related care at hospital B that has continued to investigate hormonal doses and the option to not perform gonadectomy. KIO has also increased their referrals to Hospital B. The adult endocrinological section of hospital F is in the process of implementing an experimental research on the use of androgen therapy for AIS patients.

Hospital B has been increasing its authority in the field through the production of research with the larger patient base provided by collaboration with the patient groups. Hospital A has written a national project requesting to be assigned as the primary DSD treatment center in Italy, but hospital B is the only Italian institution collaborating with the European DSD initiative. Hospital B focuses on physiological health concerns, redirecting attention away from morbid concerns over gender regulation. Hospital A has a longer history of treating all aspects of DSD care, including the controversial childhood surgeries.

Throughout the years between 2006 and 2010 there have been several Italian medical conferences on DSD. I have witnessed several strange presentations, that began by citing international research that indicates it is better to wait until puberty before performing any irreversible surgery, and end with the presenter stating, but when we perform these surgeries in early childhood we find x. These presentations indicate the influence of international research on the national discourse, while also indicating that it has not yet penetrated to national practice. That said, as we have seen in chapter six, clitorectomy has not entered the national discourse outside of queer politics. The patient groups for the syndromes that would be subject to this intervention do not question its necessity and rarely do the doctors.

In 2009 AISIA published and started distributing their translation of the consensus convention's parent handbook. The parent handbook has been criticized by international activists as not being aggressively anti-early childhood surgery, yet it very specifically

redefines genital variation as *variation*, not a medical emergency, indicating that a parent's discomfort should not result in medicalization of the child. AISIA concurs that the aim of the parent handbook is to inform and outline care options, assuming the target audience to be those who need more help overcoming stereotypes, misinformation, and prejudice.

In four years AISIA established a network of trusted allies, and is now, more likely to be invited to speak at medical conferences. While they primarily represent AIS, they are trying new strategies to help those who have come to the group with other diagnosises. One family has decided to raise their child as a boy, after an imprecise PAIS diagnosis that generally leads to female assignment. They are still lacking a clear diagnosis, but their child's early personality led them to go against the doctors' recommendations. They moved to the country (following clinical advise regarding childhood gender change) and suffered many emotional trials, but have now returned to the city and come to peace with the outcome of their choices. The whole family, including the two older siblings, attended the last AISIA retreat. They find the group to be a useful tool in "resetting their anxieties". One of the mothers in the group, Lia, told me, "You never stop questioning yourself and it's good to have people who are instead on your side…the doctors make you feel like if you don't do what they say, it's all your fault even when they can't give you clear answers."

7.3 *2010*

In 2010 AISIA established a medical advisory board, composed of a pediatric psychologist, pediatric endocrinologist, surgeon and a member who is a patient and a medical student. The surgeon in question, was once an adamant advocate of the success of early childhood surgery, who has changed position, while still promoting less invasive surgical techniques such as the Vecchietti or Davidoff (surgically assisted dilation). AISIA has grown themselves as a group to be increasingly opposed to any surgical intervention without the direct consent of the patient.

In the meantime, the pediatric department of hospital A continued to work on its national proposal to be designated as the primary DSD treatment center, assisted by the psychologist and the molecular genetic lab that see themselves as patient advocates. AISIA continued to develop their relation to the gynecological department of hospital A, which had sent several of its members for training at the Creighton clinic.

AISIA members, and associate members with other diagnosises, report success with the dilation techniques performed with the assistance of hospital A's gynecological staff. One associate member reports the success based on the attention and care. Chiara had been told

she had no vagina and absolutely needed some sort of surgery, however, in a sitting with one of the gynecologists trained at the Creighton clinic, and accompanied by another AISIA member, she was able to dilate to 3cm, indicating every possibility of reaching "optimal" length through non-surgical means. Chiara praised not only the staff, but the group (AISIA), stating that she probably would have never come alone. Members will often coordinate to accompany each other to visits.

On an institutional level, changes can be witnessed in textbooks and didactic tools. A pediatric manual produced by hospital A now contains a chapter on DSD, which, however superficial, introduces the possibility of DSD to the health care student in their basic training. Many doctors react inappropriately, due to lack of official training on the material. The gynecological courses at hospital A now cover vaginal variation and its treatment, emphasizing not only non-invasive treatment, but indicating several times throughout the lesson that these procedures cannot be performed without the consent of the patient.

These procedures are still performed without the consent of the underage patient in pediatric care. Therefore the gynecological department is seeking to create an alliance with the pediatric department, a move that could strategically place them as the only Italian hospital to provide both pediatric and adult DSD care. In January 2011 there will be the first DSD conference to combine both disciplines and patient groups, however it is still unclear if it will have national participation.

Throughout the course of my contact with hospital A, doctors from different disciplines would refer to shifts in hierarchy protocol since 2000 as the previous generation of department heads went in retirement. In the pediatric ward, it was repeatedly indicated that two figures had dominated the DSD care process, an endocrinologist and a surgeon, and that all of the current discipline heads had made their careers under these masters. It was indicated that previous department heads had been paternalistic in their methods, often taking full control of decisions they would not necessarily even share with other doctors, let alone patients. Their former pupils clearly sought to defend the reputations of their masters' while moving instead towards a collaborative model.

In July 2010 AISIA had its first Italian version of a consensus convention with the pediatric department of Hospital A. The patient group component has become a decisional factor in medical authority in DSD treatment, and by opening its doors to criticism, hospital A was sure to gain credibility also at the international level. One of the organizers was the same doctor who had been skeptical of social research in clinical settings.

This endocrinologist opened the discussion by stating that many things had changed in the

course of his career, in the medical discourse in general, but also in the consideration of DSD. He mentioned the discovery of genetic markers and new syndromes. In particular he also referred to the increased possibility of assigning the male gender in cases where one would have universally gone in the female direction.

The primary issues for the group were diagnosis communication and early childhood surgery. The initial discussions indicated that the clinic had already adapted a full-disclosure policy. The previous director of the clinic, perhaps like Money, was revolutionary in his interests in "curing" DSD. However, he had a reputation of being paternalistic even with his staff, not interested in discussing his decisions on gender assignment and surgical intervention. The clinic is presently attempting to contact older patients and have them return for check-ups, especially in cases where it is unclear what treatment was followed.

Throughout the initial discussion, which focused on clear non-stigmatizing diagnosis communication, the surgeon either spoke on or played with the telephone. He had declared at the beginning that he would need to leave shortly. He was the successor of the surgeon who had repeatedly written Marina's[139] parents that they needed to return to the hospital and "correct" her problem.

The group presented the request that there be more follow-up research on overall health issues. The endocrinologist referred to problems in following patients and obtaining accurate information about compliance. Anna highlighted the fact that until the 1950s no one received gonadectomy, therefore there was really a wealth of knowledge to be found about people with DSD who actually had no apparent health problems or interventions.

When Anna opened the discussion about vaginoplasty, stating that based on the group's statistical experience, the members who had used dilation were more satisfied then those who had had surgery, the surgeon finally placed his telephone in his pocket and engaged in the discussion. He was instantly on the defensive, stating that he valued his sleep and therefore he was sure he had never done anything wrong because otherwise he could never sleep at night. Anna asked if he had the follow-up evidence to back up this statement, trying to indicate she wasn't attacking him and his procedures.

The surgeon cited 7 cases, however, one of them was Marina who was sitting in angry silence. Anna cited that in the group's experience, even women with only 2cm had had success with dilation techniques. The surgeon responded that he had never operated on anyone with more than 3cm. Yet again, Marina sat silent, but Anna spoke for her saying that

[139] Marina received vaginoplasty at age ten, as we saw in chapter four

instead, a member of the group had been operated on by his team starting from 4cm, and that this person now could not dilate due to internal scarring.

At this point, he claimed that it was ridiculous that the group expect so much from the surgical techniques, that it was incorrect to call the operation *neo-vagina simuldea*, (simulation new vagina), because surgeons could not replicate nature, they could only simulate or approximate. Anna replicated that the group was in agreement, and was requesting that surgeons wait until puberty. Anna also indicated that in Marina's case, it was the surgical team that insisted on the perfection of the surgical results. The surgeon then began to attack the specific way Anna stated her position, no longer attempting an exchange of information.

The endocrinologist intervened, trying to reduce the tense atmosphere, by stating that he really appreciated the information that the group was sharing, considering that it was so difficult to keep track of patients after the transition to adulthood. At this point the surgeon attempted to be charming, saying that the group members were strong and courageous, calling them "women with balls" in some sort of play on words that, unfortunately, is fairly offensive.

The members of the molecular lab took this opportunity to interrupt, stating that they were very happy to work with the group to trace potential genetic markers. One of their younger members stated that their research was showing that development was a continuum, and that more intricate processes indicate gender than simple chromosomes. The endocrinologist, who had once asked me, "Don't all parents want their children to be normal?", diplomatically reaffirmed the importance of the group's evidence to the entire team.

7.4 *And then there was genetics: practicing DSD diagnosis*

In 2009/2010 part of my ethnographic work played out in the molecular genetics lab of a main university pediatric clinic, hospital A. My research lead me to the molecular lab for two reasons, my interest in genetics and the increasing presence of genetics in DSD discourse, but also due to the roadblocks I encountered trying any other type of ethnography in the pediatric clinic, for obvious ethical and privacy reasons.

The work of the genetics lab touches two important aspects of DSD, communication of the diagnosis, and the relationship of pathology to difference. At the time I began my research Hospital A was shifting to a full-disclosure policy, assisted by the house psychologist. The first communication of the diagnosis was generally given by an endocrinologist or a surgeon, often in consulting rooms with other children and families. Hospital A is in the process of

implementing private consultation rooms for DSD cases. On one hand they treat DSD as a medical emergency with psychosocial implications, on the other they have to deal with the spatial limitations of the clinic.

Standardized communication is not part of the Italian health care systems priorities, and they do not generally produce pamphlets or informative flyers[140]. However, hospitals A and C have put out a pamphlet on SAG (CAH), which addresses the developmental and functional aspects of the syndrome, in a reassuring manner. The social factor of genital surgery is downplayed, simply referred to as something you *need to do* if the clitoris is *too large*. AISIA and KIO have made their own pamphlets, including an Italian translation of ISNA's parent handbook, however there is no guarantee that they are passed on to patients and families. Therefore the majority of the responsibility of communication falls on the clinicians.

The second level of communication, after the impact of the diagnosis, involves functional decisions and an understanding of what the diagnosis means. The geneticist at hospital A told me that many parents call her directly asking for further information, yet she does not have an official role in diagnosis communication. As we have seen in chapter one, there is often an understanding gap between popular conceptions of Mendelian genetics (one gene: one trait), and molecular genetics that relies to some extent on a developmental model.

The geneticist must explain two factors that have emerged in molecular genetics, the complex model of development that goes beyond the chromosomes, and the difference between a genetically-based syndrome and being un-well. Molecular genetics represents the genomic paradigm, in which the performance of the genes and their interaction with non-genetic factors are the objects of research. The genomic concept has difficulty mapping directly onto the dualistic social model that now finds itself represented by chromosomal sex. This philosophical issue can be instrumental in helping parents understand and accept a previously unheard of difference.

The work of the genetics lab plays out in various practical ways: diagnosis communication, statistical evidence of development and molecular markers, implications for postponing early irreversible interventions. Molecular testing is generally performed after birth, thereby the bioethical debates such as fear of eugenic elimination practices can be limited to chromosomal prenatal diagnosis and not molecular genetic testing as of yet.

[140] A comparable socialized health system, in England, focuses on reducing costs by educational prevention campaigns. In addition their diagnosis system is highly standardized, to the extent of limiting the doctor's individual decision-making power.

Currently pre-natal testing is for the most part chromosomal, thereby detecting syndromes such as Klinefelter's and Down's but not AIS or CAH. However, in the case where there is a family history of CAH, pre-natal testing can be recommended. In Emilia-Romagna where CAH is the most common DSD, there is a neo-natal screening program, primarily to prevent salt-wasting. As we have seen in chapter six, the proposed pre-natal therapies for CAH masculinization can have severe cognitive side-effects.

Nikolas Rose (2004) discusses the nuance of genetic diagnosis as being "potentially unwell", highlighting the link between the predictive nature of genetics and identity. In a similar manner Margaret Lock (2005) refers to the increase of genetic testing as the new divining, a new diagnostic tool that indicate probabilities, much like the ancient Greek oracles. Pre-natal testing reflects not only our expectations of what technology, or bio-medicalization, should be able to do for us (Ettore 2000), but also the expectation that we reject a perceived imperfection (Rapp 1999). Ryna Rapp postulates that this "modern divining" incurs social pressure *to do something* about this advanced knowledge. Rapp indicates that potential mothers will be shamed or held accountable for choosing to continue a pregnancy where prenatal testing has revealed a genetic variance associated with syndrome categories.

In a London research, a radical difference was found in pregnancy termination in case of Klinefelter's syndrome diagnosis, based on whether a gynecologist or a genetic counselor communicated the chromosome test results (Hall et Al. 2001). Pregnancy termination rates were higher when the diagnosis was communicated by a gynecologist. These results have been repeated in several other countries (Yon-Ju et Al. 2002, Mezei 2004). Authors explain their findings by proposing that a genetic counselor is more likely to explain genetic indicators as representing a varied spectrum of development as well as having more updated information about genetically-linked syndromes. The Klinefelter's group promotes genetic research *because* they feel it will show how common and diverse the syndrome is.

The geneticist of hospital A expresses a similar opinion, stating, "Parents call me asking, 'they've found this genetic marker, what does it really mean?'". Genetic counselors are appearing in certain medical fields, such as cancer, but ironically not in the sensitive arenas where adults/parents must make decisions for children/patients. The statistical data on DSD and other genetically-linked syndromes can be more up-dated in research fields that specifically treat these issues. This makes all the difference in communication, as we have seen in the case of Klinefelter's syndrome, from portraying the syndrome as a serious genetic illness to a genetic variation.

The other implication of molecular testing is in gender assignment, the focus of so much of DSD medicalization. Molecular testing provides much greater accuracy in diagnosis, even though even the geneticist indicated that many people diagnosed with DSD do not have any of the established genetic markers[141]. However when the genetic marker is present, it will distinguish the diagnosis from the once catchall category of PAIS. Historian and biologist Ingrid Holme wonders:

> Yet as the historical analysis of the shift between the one sex to two sex model indicates (Laqueur 1990), it remains to be seen whether the social sphere will respond by incorporating this new evidence into the tacit, everyday understandings of sex or seek to maintain the binary and fixed relationship(s) between men and women by governing them as males and females (Holme, 2007, pg. 2).

At hospital A they test for 6 genes that are implicated in CAH, AIS and 5-alpha reductase. They receive samples from all over Italy, doubly anonymous through a coding system. Molecular testing became routine for DSD at hospital A in 2000. Since then they have been expanding their research based on the other health factors implicated with the genetic markers. At this point however, molecular testing primarily supports diagnosis accuracy and corresponding gender assignment.

In a recent case, molecular testing revealed a 5-alpha reductase genetic marker, changing the original PAIS diagnosis. As noted by Gilbert Herdt, in the context of bio-medicine, 5-alpha reductase is now given a male gender assignment, but this has not been the universal outcome across time and culture. PAIS was generally assigned the female gender, but as we have seen in chapter three, this was largely due to the perception of genital surgery outcomes (easier to create female genitalia than male).

In the recent case of 5-alpha reductase a cautious model was invoked. The parents were counseled to raise the child as a boy with a micro-phallus and postpone surgical intervention. They had wanted to continue raising the child as a girl. In the meantime the clinicians would see if the child's phallus responded to topical testosterone treatment. Due to faith in the implications of genetic markers, irreversible surgery was avoided. The parents dis-ease (Kleinman 1986) with a non-standard body was medicalized through therapy instead of through the manipulation of the body of their child.

The child had been informed about what was going on since a DSD was suspected; however it was a long process. As the family moved towards a gender change, the

[141] Interview 8/3/10

psychologist indicated that the child was aware of the extended liminal state and showed a lot of tension, clenching their jaw and asking which bathroom to use. The child markedly relaxed when the male choice was made, probably indicating an end to a period of instability. As indicated in the parent handbook, children pick up on the preoccupation of the parents and doctors, and often feel themselves to be at fault. The release from the stressful environment relaxes the child, not changing their body to conform to an ideal.

The belief in Western biomedicine that 5-alpha reductase indicates a male gender identity directly shifted care protocol in two key manners: the proposed acceptance of a boy child with a micro-phallus, and the advice to postpone intervention until the patient is self-determining. The locus of gender identity dived even deeper into the body to the molecular genetic marker.

Micro-phallus and hypospadias are often considered psychosocial medical emergencies, implicating childhood interventions. Patient groups, however, insist that this should also be an individual adult decision, indicating that doctors exaggerate the "locker-room" bullying and ignore the trauma associated with surgery and the post-surgical body.

Vernon Rosario (2009) hypothesizes that the complexity of genetic expression promoted by molecular research will lead to an equally complex model of sex and gender that he calls quantum sex. However, as we have seen in chapter one, historian Garland Allen (2002) references his own difficulty in relaying a non-mechanistic or non-deterministic model of genetics in teaching upper-division college students. One gene-one trait model is inaccurate, but easier to understand. The professional use of genetic counselors may help in the diffusion of a non-deterministic model.

Molecular diagnosis, however, is a highly mechanical process, not a philosophical experiment on human variation. The laboratory procedure tries to isolate the molecular component that is associated with the diagnosis they are leaning towards. I accompanied different technicians through the steps that lead to the isolation of the genetic marker, who were clearly experts in laboratory procedure, not necessarily in gender theory. I was shown how to extract, purify, determine the concentration of, and then amplify the DNA. The DNA is then read and analysed for the specific marker that is being looked for.

One blood sample will go through the same procedure several times, to test for the different suspected markers but also to guarantee the accuracy of the result. In the amplification process different enzyme primers are added to a standardized chemical mixture in a process called the Polymer Chain Reaction, which multiplies the chain to seem infinite[142].

[142] 3/9/10

The entire process was infinitely standardized, not necessarily by medical protocol, but by the machines themselves and the companies that provided the chemical mixtures designed for the machines. The chemical compounds came in boxes with instructions as detailed and fairly identical to those followed in the lab. Names of processes were often parallel to the name of the machines, such as the Amplification PCR System 9700 Applied Biosystems.

There were glass jars everywhere, like a glassmakers workshop, but everything was sterile with surgical plastic inside. Disposable products place the responsibility of sterility on the manufacturer, removing it from the lab. My first informant had been with the lab for 30 years, from before the time in which you needed a specialized degree to be a molecular lab technician, and he was a local. He explained to me the progression of techniques and abandonment of certain techniques from radioactive processes to siphoning chemicals like one does with gasoline. They searched for sex hormones and growth hormones, now they look for genetic markers.

Non so per che cosa, so fare le cose[143].

He told me, I don't bother with why they do things; I know how to do things. But this was obviously ironic, he had little things to say about everyone, he had perhaps been there as long as anyone, mastering the techniques as they changed. He implied that he always handled the extraction due to his tacit knowledge, the others left things a mess, an obstacle to accuracy.

It was like returning to college chemistry: titration (drip), and centrifugation. Every step used different droppers with differing levels of accuracy, and different centrifuges for differing sample sizes. The extraction process broke the cells to extract the DNA, which were then purified with a Wizard ® genomic DNA purification kit. We followed the instructions from the kit, however, every step had its own non-written tacit aspect, agitate like this, it should look like this when it comes off the bottom, etc.

They brought me to the ward where they did the blood draws, four beds in a room, and on the way, we passed the psychiatrist and head endocrinologist, with the family of the 5-alpha reductase diagnosis. They had returned from of another series of tests, primarily because they had agreed to raise their child as a boy. The geneticist indicated that they had always believed the child to be boy, yet it was unclear if this opinion was based on appearance, expressed identity or molecular material. In any of these cases, all of the team members were having trouble convincing the surgeons that they couldn't operate.

It certainly seems like a miracle to render DNA sequences visible, through this cleaning

[143] 3/10

and replication process. It also requires a lot of patience. Throughout the various processes we added chemicals and centrifuged, taking always-smaller samples, rendering what had once looked like blood into a clear liquid like water. For the child diagnosed with 5-alpha reductase, the process of rendering visible the molecular material had changed his life in many ways: from the medicalization techniques he would live through, to the assigned-gender he would grow in.

Yet I heard contradictory comments in other cases, for instance, in the case of an adult, one technician commented, "poor thing she thinks she's a lesbian, but really she's a man", due to the patient's molecular make-up. The patient had an uncontested female identity throughout her life, combined with female sexual object choice. The geneticist will insist that XY chromosomes do not make you a man, that CAIS patients are obviously women, yet sometimes a molecular marker is taken to indicate the same determinacy that chromosomes once did.

In 2006, an endocrinologist of hospital A still referred to hormonal imprinting as the locus of gender identity and resulting sexual orientation. In 2010, this rationale was already breaking up, no longer applied to any diagnosis apart from CAH, and even in CAH the lesbian stereotype had been separated out into gender identity, gendered behavior and sexual orientation. Despite occasional genetic opinions that could be perceived as deterministic, the geneticists generally advocate for a complex, developmental model. This genomic model generally refutes the deterministic language of the 'gene for x social trait', but rather, as Fox-Keller suggests, views genes as processes. New genomic research continues to affirm an increasingly interrelational model of sex development. As Holme indicates:

> The view of the body as an active process is widespread in the discussions of the paradigm shift from studying single genes in genetics to studying genetic networks in genomics (Holme, 2007, pg. 171, Moss 2003).

In the hospital laboratory, however, resources are limited, and individual genes are targeted in order to promote more accurate diagnosis. Previous tests, including those used by sports committees, focused on the chromosomes, Barr bodies and the idea of an "inactive" second X chromosome as the mark of womanhood. As we have seen in the Caster Semenya media debacle, mentioned in the Introduction, genetic testing does not present an accurate picture of a person's gender identity or gendered ability.

The lack of medical attention to potential health risks involved in the differing DSD syndromes implies that the medical problem is still contextualized as focusing on social gender categories.

In 2002 Alex MacFarlane won the battle to gain an Australian passport which did not register sex as male or female, instead recognizing Alex's karyotype as XXY and sex state as being un-determined, not being male or female (Holme, 2007, pg. 185, Bulter 2003). Alex argued that it was impossible to choose to be male or female, and to do so would be committing fraud. Rather than Alex's claim being a drastic challenge to the institutional structure that rests on the idea of a binary 'true sex', I would argue that it was accepted because it was supported by what is seen as a fairly rare karyotype variation (Holme, 2007, pg. 185).

Most individuals in Italy with Klinefelter's syndrome or DSD do not claim transgender identities, often seeking to distance themselves from what they consider a misconception of their experience. However, the legal battles of the twentieth century over the right to change social gender category, or the right of individuals with DSD syndromes to participate in sports (without being harassed or subject to stigmatization), beg the question of what is the societal motivation for regulating legal gender categories so tightly.

One can only hope that the trials and changes that have come about in the medicalization of DSD will lead to greater care for the overall health of the patients involved. Several research institutions in Italy, such as hospital A, B and F are actively involved in projects that move beyond chromosomes and gender assignment, from the invisible genes to collaboration with patient groups.

7.5 *Useful medicalization*

The direct engagement of the patient groups with the medical practitioners reflects disability politics discourse, subverting medical attention towards the explicit needs and requests of the patients. As we have encountered throughout this work, Italian DSD groups do not engage directly in gender politics, accepting the medical category from which they hope to gain something. At the same time, they are attempting to mediate the incorrect stigmatizing images of the individual syndromes, which can lead to medicalization other than that requested.

The tactical maneuver to seek medical collaboration instead of rejecting medicalized labels reflects Rabinow and Rose's considerations of the new bio-socialites, identities and social citizenship/participation organized around a heightened awareness of one's biological material. A medical student in AISIA told me how she found someone in Canada with the same molecular genetic marker as her and that they had become pen-pals. Her biological information was exciting for her, invoking intimacy with otherwise strangers due to a potentially-shared experience of specialized biological information.

A KIO member spoke of his diagnosis as "*una cultura in più*", another culture to be a part of. His chromosomal status introduced him to a group of people who he could understand in a particular way. In addition, we are reminded of Adele Clarks' insistence that there is not only increased medicalization, but bio-medicalization, a conception of the body derived from technology and dependent on technology to achieve a social conception of wellness.

However, the groups' requests, and the larger considerations of disability framework, reassesses the theoretical assumptions of Carl Elliot's work, *Better Than Well*. Instead of adapting to a consumer-driven medical system that creates higher than natural standards for health and wellness, such as straight teeth, the patient groups expect actual care from the medical establishment, which although, is still unclear if it can provide.

At an AISIA meeting an endocrinologist from hospital B confirmed that it is difficult to asseses the right hormone replacement therapy for DSD patients, not only because of the scarcity of research, but also because the hormones available on the market are compounded to regulate the reproductive system, sexual libido and muscle performance. As Ettore (2000) implies in *Doctor May I Please Have a Healthy Baby*, the medical-consumer complex described by Elliot (2004), sometimes communicates a proficiency in not only manipulating the body, but identifying the locus of the *problem* within a pathology that creates expectations that cannot be met.

If Italian DSD groups have quickly won negotiating force within DSD treatment, it is due to several factors together, from collaboration to a subjective navigation of bio-sociality. An AISIA member once told me, "We are the most knowledgeable doctors for ourselves." All of the groups rely on web formats to consolidate and therefore canonize even tacit knowledge.

If instead, many medical centers in Italy continue to perform early genital surgery or other procedures without fully informing the parents or patient of the diagnosis or treatment options, they will soon be doing so in direct opposition to national consensus. Without national enforcement of institutional standards, the individual opinion and hierarchy within the hospital structure will dictate care protocol. DSD is fairly unknown to the average pediatrician. The Italian doctors who are publishing new pediatric textbooks that include DSD are generally the same doctors who advocate de-stigmatization and full-disclosure. The imposition of silence generally leads to shame. If films and public media can be taken as an indicator, it would seem that DSD is about to be unmasked as yet another human variation.

Conclusion

> For decades, sex assignment in children with ambiguous genitals depended more on surgical possibilities than on other criteria. Because children were viewed as psychosexually neutral at birth, there seemed to be no objection against assigning and raising most children (46, XY children included) with intersex conditions or severe genital malformations as girls. Early surgery was considered to contribute to a healthy psychosexual development, because it helped avoid ambiguity in the way children experienced themselves and were experienced by others…
>
> Prenatal brain exposure to sex hormones and perhaps other biological factors probably influence gender development to a greater extent than has long been assumed. Although it is unlikely that biological factors entirely determine gender identity, they should be taken into account when it comes to sex assignment decisions…Considering all parameters and including the opinions of all relevant persons, a decision has to be made. The possibility that the child will later regret the decision cannot be overlooked. If the persons involved keep an open mind and parents are adequately counseled, the consequences of a sex reassignment need not necessarily be a disaster. Though there are proponents of raising such children as third sex, we believe our society is not ready for the acceptance of third gender in children. (Cohen-Kettenis and Pfafflin, 2003, pg. 103)

As we have seen throughout the previous chapters, DSD is a complex object, which can have profound effects on people's lives and bodies. The effect that the DSD diagnosis has on people's lives, however, is moderated by the social interpretation given to the biological information implied in the diagnosis. DSD as a biological object manifests in the laboratory as hormonal levels, chromosomes and molecular genetic markers. In the clinic DSD manifests as a combination of these biological markers along with the genitals, reproductive organs and other indicators of the performative aspects of gender identity.

In the end, DSD diagnosis layers biological markers onto highly personal aspects of identity and gender. The individuals directly involved must negotiate this added information about their gendered biological make-up. In the clinic this added information often implies some degree of pressure, or rational, to modify the physical or chemical material of the body. While the development of genetics and endocrinology as disciplines is intensely interesting, the DSD diagnosis is a subjective experience that steps outside of the confines of the search for empirical knowledge. In fact, the new frontier of DSD care is the communication of the diagnosis. This communication can make the difference between a traumatizing experience and a generalized medical experience.

Understanding of DSD overlaps the evolution of scientific observation of the gendered

body, with the evolution of social attitudes towards gender and the body. The cutting edge of scientific research indicates that not just gender identity, but also the gendered body, are formed by a complex interaction of biological markers combined with environmental and experiential factors. The biological variations involved in many of these cases have more impact on social, gender-related issues than on the function of the body. As Cohen-Kettenis and Pfafflin indicate, however, society is often hesitant to nonchalantly accept these differences.

The complex scientific understanding, of the biological components of the gendered body, must be boiled down in the cauldron and rendered practical, for those who are diagnosed with one of the syndromes or their parents who make the first decisions for them. Individuals and parents must decide where social pressure is more important, and where, instead, autonomy and functionality must come before the social imperative to "be better than well". The affirmation that physical "normality" is necessary for one's socio-mental health says much more about the society that professes such statements than it does about what this "normality" is.

Even a slight investigation into the history of hermaphrodism/intersexuality/DSD reveals a wealth of social constructions sold as empirical observations of biological facts. The concept of the normal versus pathological body has changed and will change based on a given society's need to enforce its definitional boundaries. The consideration of the role of the reproductive organs in the body and their relationship to mental health is a fair example of the political rhetoric of gender roles, and specifically women's place in the social structure.

The first part of this thesis attempts to address some of the evolution of the scientific theories of the gendered body. Our understanding of the molecular interactions in the body is increasingly precise, which leads us to be able to adjust the body with systematic accuracy towards our statistical norms of health. Our increased understanding of the complexity of biological processes, however, also allows us to consider the variety of biological expression possible when developing care protocol in a clinical context.

Gonadal experiments across the nineteenth and twentieth centuries exposed the morphological effects of internal secretions on the gendered body. Contemporary research increasingly explores the complex relation of hormones and genes to many other layers of health and function in the body. We now have ever more accurate knowledge about the developmental processes that shapes the gendered aspects of the body than that which created so much social panic in the nineteenth century understanding of what is now called DSD.

On one hand contemporary research reveals the benign aspects of these molecular

variations, and therefore pacifies the social stigma attached to the gendered variation. On the other hand, the increasing biological data reinforces the boundary-lines between the normal and the pathological in the clinical framework. Hormonal and genetic research, however, reveal a third aspect of variation: the need to investigate the overall health of individuals with DSD. We begin to have a deeper understanding of the role that hormones have in the function of the entire bodily system, other than solely that of the reproductive system. The combination of removing stigma and full body health investigation can lead to a useful medicalization of DSD that strips away the centuries of paternalistic body modification.

DSD has many faces and realities, as we have seen throughout these chapters. It lays inside the body waiting to be discovered, or shows itself as a variation of the body part (genitals) that we generally keep hidden. While Rosario (2009) postulates the arrival of 'quantum sex' in DSD treatment, the mainstream social issues of the gender binary cannot be ignored. However, as we have seen throughout these chapters, DSD is more complicated than gender assignment. In fact, patient groups struggle to draw medical attention towards a larger health program.

The complex interaction of hormones and genes creates a unique individual in every developmental process. As we saw in chapter one, our understanding of these biological processes is still evolving. It is still unclear what of the gendered biological markers are related to gendered traits, or more precisely, to what extent. What is clear from the second part, chapters four, five and six, is that hormonal therapy is more important to the health and quality of life of DSD patients, than it is for the shaping of their gendered identity.

Instead, the previous two centuries of the medicalization of the gendered body focused on genital form and gender identity. Historical analysis points to an emphasis on the creation of a heterosexual body. Scientific understanding of the body, based on biological markers and processes as opposed to divine revelation, combined with technological advances, lays the pathway for intervention and modification of the body.

In chapter two we follow various ideas about the gendered body that would cause a person to be condemned or accepted. In chapter three, instead, we witness the development of an interventionist model in which, through techno-science, every body can be brought back to the "norm". In part two we observe the contemporary struggle, instead, to be brought back to health.

One might ask again, as one of my interview subjects did at the beginning of this project, "Why look at Italy? What is particular to this context?" On a simplistic level, we can consider one of many answers to this question. For instance, the impact of international networking

emerges, bringing about the dissolution of the 'local' in techno-science and biomedicine. Patients as well as doctors use these international networks to create and reinforce an image of authority on a given subject. Yet, inside the negotiation for a position of authority in the establishment of knowledge, the local context re-emerges.

An interesting example is that of the actions of the patient groups. Underage non-consensual genital surgery was the focus point for the original English-language Intersex patient activism. It continues to be one of the key points of debate in many international contexts. Italian groups generally adopt a different strategy that focuses on useful medicalization, avoiding the rhetoric of identity politics that explicitly advocates for de-stigmatizing difference. The Italian groups generally collaborate directly with a hospital research center, and negotiate the final health results, more than the rational behind certain techniques. The end results are often the same, but the strategies are different.

All international AIS groups have come out against early gonadectomy, yet in certain medical contexts, like in Italy, adult gonadectomy is still routine. In group discussions, and medical encounters, however, the overall health effects of these surgeries reveal themselves as problematic. If AISIA changes its position to oppose all not-at-risk (there are higher cancer risks with mixed gonadal tissue) gonadectomies, it will most likely be as a result of endocrine health results. ISNA and other groups already oppose not-at-risk gonadectomy stating that it provides a social cure for a mis-communication of gendered biological information, with serious health ramifications.

DSD care continues to evolve, as does our understanding of the biological mechanisms that contribute to the gendered body. Next week (January 2011), hospital A will have its first conference with presentations from both the pediatric and gynecological staff. The conference will be opened by parent members of AISIA and ARFSAG (Associazione Regionale Famiglie Sindrome Adreno Genitale, old name for AFISC, occasionally still in use), an important first, considering that usually, if patient groups are asked to present, they are placed at the end of the conference when most of the participants have left. In October 2011, hospital A will host a two-day medical interdisciplinary conference that will include non-surgical methods, patient group participation and several panels on diagnosis communication.

In the Foucaultian paradigm, information and the creation of "facts" are directly linked to bio-power and social control. While DSD research continues to create elaborate parameters for which gendered bodies are normal or pathological, the creation of definition and information is no longer solely in the hands of detached experts. The creation of information in DSD definition and care, now also comes from subjective experience.

In this research project I have attempted to undress some of the layers of social belief imbedded in scientific theories about the gendered body. In turn we then observe the experiences related to these scientific theories. In the second part, we can see a new model emerging, in which scientific knowledge begins to dialogue directly with subjective experience in the murky land that is clinical practice.

This new era for DSD will be dictated as much by social customs as by techno-scientific innovations. Dreger states that based on her experience with parents and Intersex patients through ISNA, that "shame is the biggest problem, with secrecy a close second" (Dreger in Parens, 2006, pg. 265). In the last 5 years, Italy has shifted to a full disclosure model, collaborating directly with patient groups to minimize shame and stigmatization. However, DSD language increases the medicalized platform, which inherently lays its faith in the transformative powers of biomedicine. The shift in the quality of care is highly influenced by the shift in the perception of what "needs to be fixed".

Techno-science and biomedicine give us both an increasingly non-stigmatizing understanding of the great variety of bodily manifestation, as well as the tools to continuously manipulate the body. The future of DSD care and comprehension will be dictated by some measure of both perspectives.

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