

From Intersex to Disorders of Sex Development:
A Foucauldian Analysis of the Science, Ethics and Politics
of the Medical Production of Cisgendered Lives

by

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Abstract

This dissertation takes up the revised treatment model for intersex conditions introduced in 2006, which controversially reclassified them as Disorders of Sex Development (DSDs). It provides a critical Foucauldian analysis of the science, ethics, and politics underwriting medical efforts that aim at securing cisgendered futures for patients unable to provide informed consent. These include not only pediatric management strategies for intersexed children, but also certain efforts used to treat children diagnosed with Gender Dysphoria (GD). Motivated by critiques of both the DSD treatment model, and of the arguments issued by those intersex activists and feminist academics who strategically endorsed it, I review the entangled histories of clinical medicine, feminist scholarship, and intersex activism that constitute the background out of and against which this revision in treatment model and nomenclature emerged in 2006. Those who strategically endorsed DSD had hoped to bring about a reduction in the frequency with which genital normalizing surgeries were performed by rhetorically shifting both clinical and parental focus on to properly medical issues of “health and human flourishing,” and away from cultural concerns regarding gender and identity, the latter of which were seen as motivating and justifying these surgeries. Unfortunately, this strategy appears to have failed and almost a decade after the adoption of DSD, it is accepted within the literature that the genital normalization of intersex infants occurs as frequently as it did before. I diagnose the failure of DSD, situating it in the biomedical model itself, and the binary nature/culture logic underwriting the objectivist account of pathology it appeals to. This logic paved the way for further problematic binaries—most importantly sex/gender and impairment/disability—as well as the adoption of a sovereign or juridico-deductive account of power. This conceptual scheme misrepresents the ways in which medical knowledge/power functions to render certain lives

unliveable, and obscures the historical constitution of sex/gender and impairment/disability as binaries under biopower. Through a review of the DSD nomenclature and clinical recommendations, I conclude that insofar as the primary aim of intersex management is securing a cisgendered future for the intersex infant, the core pathology of intersex conditions is constituted in terms of Cisgendered Function—that is, the function of one’s physical sex characteristics are presumed to perform insofar as they are taken to provide a stable ground upon which reliable predictions about one’s future gender identity, behaviors, and preferences or desires can be made. I go on to reconstruct and then critique the most compelling philosophical answers to the question that clinicians tacitly believe has a self-evident response, and which partially determines both the biopolitical correctness and ethicality of the use of efforts to secure cisgendered futures for those unable to provide informed consent: Is being gender variant or non-cisgendered a pathology? I then defend the position that pathologies of Cisgendered Function are not only socially constituted, but primarily *bureaucratic* in nature, licensing the medical normalization of certain populations with regards to gender, and the withholding of such forms of normalization from others. For those diagnosed intersex or trans* children unable to provide informed consent, this normalization defaults towards the production of cisgendered lives, and where this cannot be achieved, such efforts aim at the production of lives that can *pass* as such. Finally, I consider the implications of these conclusions for ethical medicine and political resistance in the aftermath of DSD. Using a Foucauldian account of ethics and freedom, I defend a moratorium on medical efforts to secure cisgendered futures for those unable to provide informed consent, and timely and affordable access to medical forms of gender-confirming normalization for those trans* and intersex individuals who can.

Preface

This thesis is original work by Catherine Clune-Taylor. A version of arguments presented in Chapter Two and Chapter Three were previously published in Clune-Taylor, C (2010). From Intersex to DSD: The Disciplining of Sex Development. *PhaenEx: Journal of Existential and Phenomenological Theory and Culture*, 5 (2): 152-178.

Dedication

To my parents, Suzanne Clune-Taylor and Lawrence Beauford Taylor, who worked as hard and sacrificed as much as I – if not more – in order to bring this project to fruition. They are the ones who constituted this future as one that was possible for me, and did so against overwhelming odds.

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Glossary of Terms

5- α -Reductase Deficiency: a condition wherein a decrease or loss of 17 β -hydroxysteroid dehydrogenase activity leaves one unable to interconvert testosterone and dihydrotestosterone, leading to atypically low androgen production prenatally. Phenotypic presentation among those with XX chromosomes and 5 α RD2 deficiency can vary, however, the majority present as typically-female at birth and begin to virilize at puberty in response to endogenous testosterone production using other isozymes of the enzyme within the extraglandular tissues (Andersson et al, 1996).

17 β -Hydroxysteroid Dehydrogenase-3 Deficiency: a condition wherein a decrease or loss of 17 β -hydroxysteroid dehydrogenase-3 activity leaves one unable to interconvert testosterone and androstenedione, leading to atypically low androgen production prenatally. Phenotypic presentation among those with XY chromosomes and 17 β -hydroxysteroid dehydrogenase-3 deficiency can vary, however, the majority present as typically female at birth and begin to virilize at puberty in response to endogenous testosterone production using other isozymes of the enzyme within extraglandular tissues (Andersson et al., 1996).

Cloacal Exstrophy: a condition associated with the protrusion of the abdominal organs through the abdominal wall such that infants are born with their intestines and bladder exposed. Cloacal exstrophy is also associated with short-gut syndrome, separated pubic bones, and splitting and/or underdevelopment of the urogenitals, as well as other conditions such as spina bifida and clubfoot.

Congenital Adrenal Hyperplasia (CAH): 90-95% of all cases of CAH are the result of either a decrease or complete loss of 21-hydroxylase activity. As a result, progesterone substrates 21-hydroxylase would typically convert to deoxycorticosterone and 11-deoxycortisol begin to accumulate and are converted by active enzymes in the environment to androgens, leading to an increase in androgen production and the masculinization of XX individuals over the lifespan.

Complete Androgen Insensitivity Syndrome (CAIS): a condition wherein an individual's androgens receptors are completely insensitive to these substrates. As a result XY infants have a female-typical appearance at birth.

De La Chapelle or XX Male Syndrome: a condition wherein an individual has chromosome that has acquired material from a Y chromosome in a crossing-over event. If this material includes the "sex determining region on the Y" (SRY) gene, XX infants will generally have a male-typical appearance at birth and be sterile, however, they may occasionally present with undescended testes and hypospadias. The phenotypenof those XX infants who lack the SRY gene (or are SRY-negative) can rang from male-typical to ambiguous.

Gender Identity Conversion Efforts (GICE): a term coined by Drescher (2010) referring to those efforts that aim at securing cisgendered futures for children diagnosed with gender

dysphoria (or previously, Gender Identity Disorder). Practically, GICE include “promotion of same-sex peer relations; encouragement of gender-typical and ‘neutral’ activities; limit-setting of cross-gender behavior; and dialogues on gender” between both the physician and the child, and the parents and the child (Zucker, 2008, p. 360).

Gender Identity Disorder (GID): diagnosis for those whose gender fails to cis-align with their sexed body, the core construct of which is a combination of 1) the identification with the other gender and 2) “a sense of inappropriateness, if not rejection, of one’s assignment to the natal gender, with the key specifiers of age (in terms of some age-specific criteria), gender (including some gender-specific criteria for childhood), and sexual orientation (for adolescents and adults)” (Meyer-Bahlburg, 2010, p.462). GID was first introduced by the APA in DSM-III (1980) under the diagnosis “Transsexualism” and redefined as GID in DSM-IV (1994).

Gender Dysphoria (GD): diagnosis introduced by the APA to replace GID in DSM-V (2013) in order to narrow the diagnosis to those who are both gender variant and experience dysphoria as a result of that gender variance (as opposed to those who are merely gender variant).

Gonadal Dysgenesis: general term referring to atypical development of the gonads.

Hypospadias: a condition in which the opening of the urethra does not extend to the tip of the penis. In its mild form, the urethral opening is located on the head of the penis (or the glans penis), whereas the urethral opening is located along the shaft of the penis in cases of moderate hypospadias. Finally, in the cases of severe hypospadias, the urethral opening is located below the penis, on the body wall.

Intersex Society of North America (ISNA): the first specifically intersex activist organization founded by Cheryl Chase in 1993 in response to Anne Fausto-Sterling’s article “The Five Sexes: Why Male and Female Are Not Enough.” In 2008, the ISNA dissolved and formed as the Accord Alliance, a medical lobby group that eschews the term (and identity) “intersex”.

Karyotype: refers to the number and appearance of chromosomes in the cell nucleus.

Klinefelter Syndrome: a condition wherein an individual has 47 XXY chromosomes as the result of a nondisjunction event during meiosis, characterized possibly impaired fertility; development of feminine secondary sex characteristics at puberty. These individuals generally appear typically-male at birth.

Micropenis: a condition wherein one’s penis is smaller than 2.5 standard deviations below the mean.

Müllerian Ducts (or Paramesonephric Ducts): paired ducts that run laterally down the side of the urogenital ridge in the developing fetus and terminate at the sinus tubercle in the primitive urogenital sinus. In XX fetuses, these ducts typically develop into the fallopian tubes, uterus, cervix, and upper 1/3 of the vagina. In XY fetuses, these ducts typically regress.

Non-XX or non-XY Sex Chromosome DSDs (excluding Turner and Klinefelter Syndromes): a condition wherein an individual has an atypical number of sex chromosomes as a result of nondisjunction events during meiosis that are not 45 X0 or 47 XXY (for example, 47 XYY, 47 XXX, 48 XXYY, etc). This category also includes those with a chimeric karyotype, such as 45 X0/46 XY. The majority of these patients are phenotypically male or female are thus go undiagnosed, however, there can be variability in phenotype.

Optimal Gender of Rearing (OGR): treatment model for intersex conditions first introduced by John Money and his colleagues Joan and John Hampson at John Hopkins Medical Center in the 1950s based in part on Money's doctoral research. This treatment model emphasized early surgical and hormonal assignment of sex and unambiguous gender rearing in accordance with assigned sex. It was via this model that Money introduced gender as a category distinct from sex.

Partial Androgen Insensitivity Syndrome (PAIS): a condition wherein an individual's androgens receptors are partially insensitive to these substrates. As a result, XY infants can exhibit a range of phenotypes at birth depending on their level of androgen insensitivity, from a male-typical appearance to a female-typical appearance.

Sexual Orientation Conversion Efforts (SOCE): a term used to refer to any and all management strategies that aim at securing heterosexual futures for individuals with same-sex desires.

Turner Syndrome: a condition wherein an individual has only one X chromosome (45 X0) as the result of a nondisjunction event during meiosis, characterized by undeveloped ovaries, short stature, lack of secondary sex characteristics. These individuals appear typically-female at birth.

True Hermaphroditism: a condition defined by the presence of both ovarian and testicular tissue.

World Professional Association for Transgender Health (WPATH): know as the Harry Benjamin International Gender Dysphoria Association until 2009, WPATH is an interdisciplinary association that formed in 1979 in order to create the first Standards of Care (SOC) for treating trans* patients. Both the American Medical Association and the Endocrine Society have officially endorsed WPATH's SOC as the official treatment model for patients with GD, however, the APA has yet to do so. In 2011, WPATH published the 7th version of the document.

Introduction

My introduction to feminist and bioethical critiques of the medical management of intersex conditions came in an undergraduate course on the philosophy of gender and sexuality at the University of Western Ontario. At the time, I was in my second year of a four-year Honors Bachelor of Medical Sciences program, specializing in Microbiology and Immunology. My plan was to go eventually to medical school and specialize in high-risk obstetrical care, as I had been particularly interested in both embryology and reproductive immunology. I took the philosophy of gender and sexuality course with Dr. Helen Fielding as my elective that year because, in addition to fitting within my lab schedule and satisfying my essay requirement, it sounded like something I might find personally interesting as an out and active member of the LGBTQ community on campus, and as someone who identified as a feminist (though in an admittedly naïve way, without knowing much about the history of feminism itself). The medical management of intersex conditions was the very first topic we covered in the class, reading Anne Fausto-Sterling's "The Five Sexes: Why Male and Female Are Not Enough," Suzanne Kessler's "The Medical Construction of Gender: Case Management of Intersexed Infants," Robert A. Crouch's "Betwixt and Between: The Past and Future of Intersexuality," and excerpts from Michel Foucault's *History of Sexuality, Volume One*. These four readings by a feminist biologist, a feminist sociologist of medicine, a bioethicist, and a critical social-political philosopher not only disrupted my best laid plans to become a physician (much to my parents' chagrin), but further, motivated and inevitably set the tone for this dissertation. These authors represent the intellectual lineages out of which this project and the arguments presented herein emerge, and with regards to which it seeks to intervene.

I am not sure exactly how or when I decided I was going to become an MD, but that dream had been with me for as long as I can remember. Even as a young child, it is the only response I can ever recall giving when asked what I wanted to be when I grew up, and my parents enjoyed producing photographic evidence of this desire from earlier, murkier periods of childhood that I can't remember (see fig. 1 below).



Fig. 1. My father and I, age 3.

Going to medical school is a fairly common dream, particularly among children of precarious class and/or racial status given the social and class stability/mobility it promises, so perhaps my univocal focus was (and is) unsurprising. However, I can also point to many things in my personal history that surely guided the development of this desire. In truth, the specter of medicine has been a fairly constant presence throughout my life. A Bahamian immigrant with diabetes, high blood pressure, and all of the co-morbidities that accompany those diagnoses (such as diabetic neuropathy and nephropathy), my father's health and complex medical needs have been an active concern that has structured much of my family's daily existence since before I was born. One of my earliest memories of childhood is of my

mother and I visiting my father in the hospital during a stay in which his specialists attempted to rejig his cocktail of medications. Until I was six, my mother worked by babysitting my three younger cousins and I in our apartment during the day, one of whom—Nicholas—had been born with what I think was eventually determined to be a Y-linked chromosomal anomaly and that had presented at birth in the form of a missing eye. After failing to thrive, physicians reassured Nicky’s mother Franny that he was likely developmentally delayed, but that he would catch up with appropriate rehab therapies. However, by the age of two, Nicky had undergone at least four major surgeries to close a hole in his heart, to untangle/resect portions of his digestive system, and eventually to insert a permanent G-tube when these latter surgeries failed. Nicky was with my mother when he had his first seizure and she took him to the emergency room where it was discovered that he was missing his corpus callosum, meaning the left and right hemispheres of his brain were unable to connect. A sweet, joyful boy who was quick to laugh, he remained at the cognitive level of an infant until his death in December 2014 at the age of 28. When my mother stopped babysitting, she began to work as a teaching assistant to children in what was then called an “MH” for “Multiple Handicap” class. Until my parents bought their first house in Scarborough when I was 14, we lived in a co-operative housing unit split fairly equally between low-income families and people with disabilities. And beyond my surroundings, I have had a lot of my own health issues both as a child born prematurely and as a teen—for example, I spent a week in the hospital when I was 4 years old to treat the severe childhood asthma and environmental allergies I had likely developed as a result of a lengthy incubator-stint in infancy. After a series of severe ankle sprains, which tore all of the already congenitally-lax ligaments in both of my feet, I was diagnosed in my late teens with a mild, bilateral case of congenital *talipes equinovarus*, better known as clubfoot. I underwent my first

surgery to debride, reconstruct, and modify all of the ligaments in my right ankle when I was 18 and will require a minimum of three further surgeries to maintain my ability to walk, two of which will likely need to occur within the next three years.

These experiences, I am certain, not only contributed to my fairly steely-eyed focus on becoming a physician, but further, normalized living among and in relation with those with at times fairly serious medical needs, as well as living as a medicalized subject with them. In this sense, though I rarely if ever call on my own experiences in the course of this project—and indeed, as a cisgendered woman without a diagnosed intersex condition writing about intersex and trans* individuals, why would I?—my experiences do nonetheless color the ways in which I think and write about not only intersex specifically, but pathology and medicine in general. For this reason, I felt it important to acknowledge explicitly at least some of these early and more personal experiences of and with medicalization, for they lurk in the background of not only the path to medical school I was on when I first stumbled into philosophy and the topic of intersex, but the arguments and analyses presented herein.

At the time of my first encounter with Fausto-Sterling, Kessler, Crouch, and Foucault, the majority of choices that I had made in my life had been done in service of my master plan of becoming an MD. I went to the University of Western Ontario for undergrad specifically because I could do my degree there through the Faculty of Medicine rather than the Faculty of Science, making it the closest thing to a “pre-med” undergraduate program in Canada at the time. My parents and I agreed that attending a private high school instead of our local Scarborough high school would greatly increase my odds of getting to med school and so my father increasingly took his construction cleaning company on the road to the United States in the 90s so that we could afford tuition at one of the cheapest of Toronto private schools, taking advantage of lucrative government contracts to clean the plethora of

supermax prisons that began popping up across the nation like weeds during this time. It was soon clear that I needed a part-time job in order to help out with school tuition (and for spending money of course—I was a teenager after all), and so I got a job filing results at the busy family practice in midtown Toronto run by four women GPs who all did low risk obstetrical care. Not only did it pay better than a grocery store, but I could also learn things there and lock down my reference letters for medical school before I even got to undergrad—and from four members of the faculty of Medicine at the University of Toronto no less.

The four doctors I worked for all knew about my dream of becoming a doctor and encouraged this in me, teaching me about things during downtime between patients. As staffed turned over I was promoted to secretary, working there part-time during the school year and full time during the summer, even returning to the position from UWO during for my first two summers of undergrad. The doctors taught me to administer flu shots to help deal with the deluge of patients during flu season, and would explain abnormal results to me—what they might indicate, what further studies they required, and various treatment options. One took me incognito in scrubs as their “student” to see deliveries and C-Sections up close. I was with them through the summer of SARS and restocked their vaccines following the blackout. When a locum filling in for a doctor on mat leave commented that I would breeze through medical school and residency right into my own practice, I prided myself on my focus and my preparation, on how strategic I had been.

I recount all of these awkwardly personal details in order to make clear both the magnitude with which my encounter Fausto-Sterling, Kessler, Crouch, and Foucault in that casually chosen elective disrupted my life plans and how deeply unprepared for it I was. In his 2011 book chapter “Intersex Treatment and the Promise of Trauma,” intersex scholar

Iain Morland challenges the common critique that intersex clinical management is traumatic by targeting the identification of trauma with the unintentional failure to do something. These critiques generally argue that intersex management in general, and genital normalization in particular, unintentionally traumatize the intersexed patient both physically and psychologically, and thus fail to avoid the trauma that purportedly awaits them as an individual with ambiguous genitalia. Instead, Morland draws on sociologist Kai Erikson's articulation of individual trauma as "a blow to the psyche that breaks through one's defenses so suddenly and with such brutal force that one cannot react to it effectively" to forward a definition of trauma as something that suddenly and permanently changes an individual "in a way that forecloses the possibility of conscious reaction and contemplation" (qtd. in Morland, 2011, p. 158-160). Trauma, according to Morland, overwhelms; our inability to react to it effectively leaves us forever changed and forecloses certain ways of living and being in the world. Equipped with this new definition, Morland elegantly argues that intersex clinical management "specifically in its aim to construct gender, [is] *traumatic by design*" [emphasis added]; its goal to "fix" the intersex child in one gender and foreclose ways of gendered living (p. 158). This is why sex assignment must be done in infancy, while children are still considered malleable and unable to react, and thus still *traumatize-able* with regards to gender.

Though I did not realize it at the time, this first encounter with these authors and the critiques they raised was *traumatic* according to Morland's definition, for not only was I unequipped to react to the critiques they raised, I can now look back on that time and see that it was the moment when certain possible futures and ways of living in the world became impossible for me—most importantly, those futures in which I went to medical school and became a physician. Externally, my response to this literature and to the critiques of the

science, ethics, and politics of the medical management of intersex conditions it raised was fairly indistinguishable from that of the rest of my classmates: I was horrified by the heteronormativity of the treatment model; by the lack of evidence supporting it; by the blatantly unethical performance of medically unnecessary genital normalizing surgeries on those unable to consent for the sake of “society” and the fiction of dimorphic sex; and by the legacy of physicians withholding information and outright lying to patients and their surrogates these authors detailed. Further, I was unsettled by the short excerpts of the *History of Sexuality, Volume One* we read and the questions it raised for me about medicine’s objectivity and beneficence.

I am sure that it is only because I intended to join the ranks of those being critiqued in these readings that I remained preoccupied with intersex after the class moved on to the next topic on the syllabus. I think that at first I was motivated by a desire to, if not prove these authors wrong, then at least establish a hidden complexity to the issue: there must be more to this story that they are missing. I’m sure that I hoped to redeem medicine for myself in some way, prove that the science couldn’t, in fact, be that bad, that our practices couldn’t, in fact, be so baseless and that clinicians could not, in fact, be so unreflective and engage in such obviously unethical behavior. As I progressed through the remainder of my Microbiology and Immunology Degree, intersex stayed with me and continued to emerge as a theme throughout my studies (for example, I did my major research project for my class on the Biochemistry of Genetic Disease on the intersex condition, Congenital Adrenal Hyperplasia). I also began to take more philosophy courses—as many as I could, really. When I was advised that the conditions of my BMSc program would not allow me to double major, I took a heavy course load, such that by the time I finished my degree in

Microbiology and Immunology, I had enough philosophy credits to complete my BA in the area in one more year (which I did).

The more engaged with philosophy I became, the more I researched intersex conditions and their management, and (perhaps most importantly) the more Foucault I read, the more alienated I became from my dream of going to medical school. To put it bluntly, the idea started to really creep me out. I had begun to reinterpret and reframe some of my past experiences with medicine in terms of my own medicalization as a patient, and that of those close to me, as a patient's advocate and proxy decision-maker (my father signed a set of uniquely designed documents waiving his rights to confidentiality and granting me the ability to act as his proxy decision-maker without the necessity of a formal competency assessment when I was 22), and as an employee who worked for six years in a family practice. Most importantly, I had begun to reflect on the patients with intersex conditions who had come through the practice and the way in which they and their families had been managed. My research along with these reflections had disturbed much of what I thought I understood about medicine and its role in society. That is, it challenged what I thought I knew about what medicine was *about* in terms of the roles it played in society and the effects it had both society and individuals. Thus, by the time I had finished my undergraduate degrees, I found myself at something of a loss. It was suddenly time for me to write the MCAT and apply to medical school and do the thing that my whole life had supposedly been leading up to, and I found myself feeling uncertain about and wary of a future in medicine in a way that I never had before, and could never have imagined even three years earlier. This unease was only compounded by the fact that I had initially been interested in reproductive medicine and embryology and realized now I could end up as a specialist called upon to manage intersex patients prenatally.

Having never really considered any other possible futures, I had no idea what to do next. Some of my professors at UWO—most notably Samantha Brennan, Tracy Isaacs, Helen Fielding, and Carolyn McLeod—encouraged me to consider graduate school in philosophy, so that I might continue to pursue my research and concerns about intersex conditions. In all honesty, I took their advice and enrolled in the MA program in philosophy at UWO not because I was sold in any way on the idea of professional philosophy as a career, or because I felt like I had found my “true calling.” It simply seemed like a productive way to spend a year while I figured out what to do “for real.” Completing my MA, however, only left me feeling further adrift; the courses I took and the research I did only served to put me even further off a future in medicine. Moreover, as the child of working-class parents neither of whom advanced beyond secondary school (and one of whom never completed elementary school), being an academic in general, let alone a philosopher, wasn’t anywhere on my radar. Finding myself with three degrees at 25 and unsure of what to do next, I decided to take a year off and was lucky enough to be offered two year-long courses to teach at UWO, experiences I enjoyed far more than I expected. During this time, Tracy, Carolyn, Helen, and in particular Sam, encouraged me to consider seriously a career in philosophy and to apply to the University of Alberta to work with Cressida Heyes, the Canada Research Chair in Philosophy of Gender and Sexuality. I submitted to their coercion largely because I really enjoyed Cressida’s work; I knew I wasn’t quite done learning, thinking, and writing about intersex and medicine more generally; and frankly, I still wasn’t sure what else I was going to do if I didn’t go to med school and I didn’t want to leave Canada. The PhD program in Philosophy at the University of Alberta was the only one to which I applied.

From Intersex to DSD

During my MA (2006-2008) and the early years of my PhD (2008-2011) I was fairly busy working on fulfilling my degree requirements and the majority of my focus during that time was on coursework and comprehensive exams. As a result, I didn't keep up to date with scholarship on intersex and news out of the intersex activist community in quite the same way I had during my undergraduate years. By the time I began my dissertation research in earnest, it was as though the universe I had been busy preparing myself to enter had been flipped upside down, or had lost gravity. The feminist academic and intersex activist critiques that had challenged me out of my life plans and inspired me into new ones had given way to the Consensus Statement and its Disorders of Sex Development (DSD) nomenclature, the dissolution of the Intersex Society of North America (ISNA), and arguments from former critics of the pathologization of intersex conditions that used Foucault in order to argue for their "repathologization." It was like I had entered a type of academic slumber in the age of intersex and woken in the age of DSD.

Like many, I was shocked to learn about the adoption of the Consensus Statement and the DSD nomenclature, as well as the ISNA's role in its production and their subsequent dissolution and reformation as the Accord Alliance. I was appalled by the endorsement of the DSD nomenclature and treatment model by the very same intersex activists and feminist academics like Cheryl Chase and Alice Dreger whose scholarship and activism had inspired my own scholarship and academic reorientation. And, like many others, I couldn't quite make sense of what had motivated this about-face. Furthermore, I was very concerned by the way in which those who were either involved in the adoption of DSD or endorsing it were engaging—or more specifically, failing to engage—with what seemed to me to be valid concerns about DSD that had been raised by critics, especially

those *with intersex conditions*. The internet was awash in vitriol for feminist academics without diagnosed intersex conditions like myself for meddling in the lives and affairs of those with them. And while I fully support not feeding the trolls (and indeed, much of this took the form of offensive ad hominem attacks), many of those who were angry raised important questions about the DSD treatment model and nomenclature: about the lack of transparency surrounding not only the DSD treatment model's development and adoption, but also the ISNA's role in it; about the ethical role feminist academics without diagnosed intersex conditions can and should play within an activist movement and identity politics which does not represent them; and most importantly about the potentially negative effects that the DSD treatment model and its nomenclature might have for those with intersex conditions in terms of intersex as an identity and identity politics.

Though I was deeply disturbed by the move to DSD, I want to acknowledge explicitly that as a cisgendered woman without a diagnosed intersex condition, the move to DSD has little direct effect on me, as I am spared the specific forms of normalization that target those deemed intersex. This is not to say I am not affected by or implicated in the shift to DSD. As sexed, gendered, and sexualized subjects under biopower, we are all affected by the move to DSD insofar as it represents a shift in the contemporary constitution of the heterosexual matrix and the particular ways in which normal and abnormal sex, gender, and sexuality are conceptualized within those biomedical regimes of truth that define them. However, as someone who has not been deemed abnormal with regards to these norms of sex, gender, and sexuality—at least, not clinically, and not yet—while I may be subjected to (and subjectivized via) these same norms, I do not bear the brunt of their weight. It is important to me that I explicitly frame my concerns about, and critical engagement with, the move to DSD as that of yet another feminist academic without

a diagnosed intersex condition—particularly given how uncomfortable with and deeply problematic I find the way in which others such as myself have engaged with and been complicit with this shift. For example, I was and remain deeply disturbed by feminist academics without diagnosed intersex conditions policing the boundaries of intersex identity in terms of who does or does not count as intersexed, or denying the existence of an intersex identity in the face of those who identify as such—even if for strategic reasons and with the best of intentions.

Finally, like many, I was heartbroken when it became clear that this change in nomenclature and treatment model had done nothing to change medical practice regarding the performance of medically unnecessary genital normalizing surgeries on infants and children: as far as we know, they continue to be performed on infants and children unable to consent as frequently as before (Karkazis, 2009, p. 133 and pp. 156-161; Feder, 2014, p. 140). Admittedly, tracking the performance of these surgeries on intersex patients is difficult given that there is no specific registry either nationally or internationally (Karkazis, 2009, p. 23). That being said, it is generally accepted within the literature that physicians continue to see medically unnecessary genital normalization as an essential component of intersex management, and that it continues to be performed as frequently post-DSD as it was pre-DSD. Due to the lack of hard stats that a registry or formal tracking system might generate, we are forced to rely on the assertions of clinicians practically engaged in intersex management, and such evidence has begun to accumulate. Feder (2014) concluded that the frequency with which genital normalizing surgeries are performed had continued unabated under DSD on the basis of interviews with 12 pediatric specialists in intersex care performed between 2010-2011. This finding confirms those of sociologist Georgiann Davis on the basis of sixty-five in-depth interviews she performed between October 2008 and April 2011 with

medical intersex experts, individuals with intersex conditions and parents of intersex children. Fascinatingly, Davis found that despite the fact that physicians were more hesitant regarding surgery since the publication of the Consensus Statement—with one physician she interviewed imploring her colleagues to please “[not] do surgery”—“medically unnecessary surgical interventions continue . . . even after the publication of the professional stance against such practice” (Davis & Murphy, 2013, p. 138). Even physicians working in clinical contexts they identified as “progressive” emphasized that surgical practice had not changed post-DSD, with one of Davis’ interviewees remarking that “surgical intervention is still quite common, even in a relatively enlightened place like this one” (p. 137). This final point echoes my own experiences with clinicians engaged in intersex management. In late 2013 and early 2014, I had the opportunity to present two Pediatric Grand Rounds sessions at the University of Alberta Hospital on the clinical and ethical issues associated with intersex management with a pediatric urologist who performs feminizing and masculinizing surgeries. This urologist generally saw himself as “progressive” (particularly in comparison to his father and grandfather, who had also been pediatric urologists) because he acknowledged that in many cases there had been no clear “right choice” with regards to sex assignment. In these cases, the urologist would acknowledge this uncertainty to the parents and let them decide whether they wanted a boy or a girl, performing the normalizing surgeries of their choice. While not doing surgery—or, “doing nothing”—is likely presented as an option, the sense I got from our conversations was that it was never a serious one. The assumption remained that some surgery (or surgeries) would necessarily be done—it was really just a question of *which* surgeries.

Thus, in addition to taking up the science, ethics, and politics underwriting the DSD treatment model for intersex conditions, this dissertation also takes—much to my surprise—

the form of a critique of the arguments of some of those very same feminist academics who inspired me to give up my dream of medical school in order to keep researching and writing about intersex. In fact, though one goal of this project is to provide theoretical resources for those who might desire to use them in order to resist the oppression experienced by intersex people (medical or otherwise), I am writing here to a specific literature (and set of actions) undertaken by other feminist academics without diagnosed intersex conditions like myself. Indeed, whatever concerns and/or outrage over DSD I have are necessarily defined with regards to my position as a cisgendered woman and feminist microbiologist turned philosopher. Thus, I found myself deeply troubled not only by the arguments offered by these individuals in favor of DSD, but also by their failure to acknowledge seriously and respond to critics of their arguments as well as their practical involvement in DSD's adoption and in intersex activism as an identity politics movement more generally. In particular, I remain deeply concerned by those arguments in favor of DSD that turn on the denial of an intersex identity and intersex community in the face of individuals who identify as such—even as a strategic move, fuelled by the best of intentions. Not only does this strike me as deeply problematic politically, it also fails to take into account the differential positions of privilege between feminist academics without diagnosed intersex conditions and those with them. Subsequently, while I engage with arguments made by these academics about intersex both as a term and as an identity, I offer no positive arguments in favor of either, nor do I make any specific prescriptions regarding what intersex people or activists should or should not do. Rather, my intention here is to contribute a critical voice to a particular literature with the kind of scholarly and political care required in light of the impact this literature can and historically has had for those individuals whom it takes up. Furthermore, this strikes me as the most this project can be as one lacking primary research such that

intersex (and trans*) voices are themselves absent. This is not to minimize the breadth or depth of this project as a critical contribution to the literature, but merely to make clear the specific political and theoretical context out of which it emerges—including its limitations—which constitute and contour its horizon of possibilities as a critical, theoretical, political, and ethical academic engagement.

As a philosophical project examining the DSD treatment model for intersex conditions that draws upon a variety of different literatures in multiple disciplines, this dissertation has obvious implications for scholars of intersex in the humanities and social sciences and for health care professionals engaged in intersex management. It also has less obvious implications for those thinking and working in areas beyond this literature—most notably for feminist theorists, philosophers of science (especially philosophers of biology and philosophers of medicine), and bioethicists.

The history of intersex clinical management and its pivotal role in generating gender as a category distinct from sex is likely well known to any scholar interested in sex or gender in general. I update this history with an analysis of the way in which sex and gender are constituted in the DSD treatment model, outlining the nosological and practical ways in which it continues the project first set out by John Money through the Optimal Gender of Rearing (OGR) treatment model of securing cisgendered futures for intersex infants and thus, of producing cisgendered lives. One effect of the move to DSD has been the emergence of a gap within the literature critically examining the DSD treatment model, particularly with regards to the science underwriting it in terms of both the quality/kinds of scientific evidence it invokes, and the theories of gender and sex development it appeals to. Critical feminist engagement with the science underwriting OGR was a critical aspect of early activist and academic critiques of intersex management, yet is suspiciously absent under

DSD. I argue this lacuna has emerged in the aftermath of DSD because by strategically endorsing a biomedical model of intersex conditions specifically as disorders, those activists and academics who did so reauthorized medical authority over these physical states such that the science—that is, the biosocial model of gender development and the epistemic reliability of the data supporting it—fell out of their purview. The critical philosophical analysis I provide of both the DSD treatment model and its supporting scientific evidence base fill this conspicuous gap in the literature and thus represent some of this project’s most important contributions for scholarship on intersex, as well as sex, gender, and sexuality more generally.

In the course of this critical, feminist study of the science underwriting DSD, I also provide the first clear account of its pathology in terms of cisgendered function, referring to the function the assemblage of physical sex characteristics is taken to perform in terms of providing a stable ground for predictions regarding an individual’s future gender, with gender referring to not only gender identity, but also gendered behavior and non-sexual preferences or desires. Despite both the history of academic and activist work critiquing the identification of intersex conditions *as* pathologies, and their reclassification specifically as disorders, we remain without a clinical account of or justification for their identification as such. By outlining one through examination of the nosological and practical aims of the DSD treatment model, I provide another necessary piece for discussions regarding the ethics and politics of intersex management. Though medical evidence—including evidence regarding the nature of the pathology in question—is not sufficient for ethical medical practice or decision-making, it is necessary for it (Borry, Schotsmans, & Dierickx, 2006). Not only might we think it unethical to engage in the treatment indicated by our evidence base (for example, because we lack informed consent), but further, the nature of the pathology

can also itself determine ethical medical practice, such as in cases where failure to treat can result in death. Thus, the unique account of the pathology of intersex conditions in terms of cisgendered function that I introduce fills a gap in the literature that has gone largely unrecognized.

Beyond this, I provide unique arguments emphasizing the uniquely *bureaucratic* nature of both intersex conditions and gender dysphoria as pathologies of cisgendered function under biopower via bureaucratic forms of government. Administrative demands such as those requiring individuals be sorted in terms of sex on legal identification or those limiting access to health care on the basis of diagnosis are ways in which particular individuals are made live while others are let die under biopower. These arguments are thus of interest to scholars interested in the constitution and government of individuals as members of sexed and gendered populations, as well as locating bureaucratic practices via which we might more effectively resist that government.

The critical analysis I provide of DSD as a system of nomenclature will be of interest to philosophers of science, biology, and medicine interested in questions regarding the goals and abilities of our nosological systems, as well as their relationship to knowledge production in the form of clinical research. My review of the clinical evidence and model of gender development that the DSD treatment model appeals to, as well as the account of the pathology of intersex conditions that I forward will also be of interest to these scholars. Not only will this discussion review important epistemological problems facing evidence-based medicine in general, I will further identify the unique epistemological problems facing research studying the model of gender development appealed to by the DSD treatment model—brain organization theory—and conclude that as a result of these problems, clinicians in this area will never have the kind of evidence base upon which

recommendations could be justifiably made. Moreover, after reviewing contemporary biomedical definitions of both mental and physical pathology, I provide a critique of the dominant biomedical account of pathology—Christopher Boorse’s Biostatistical Theory of Disease—that has implications for not only our identification of intersex and gender dysphoria as pathologies, but for our identification of pathologies in general. Finally, through my Foucauldian analysis of these issues, I emphasize the importance of taking into account the historical, political, and social context of scientific knowledge production and its technological use when reviewing them in terms of traditional topics in these fields like evidence, study design and natural kinds.

This work probably has the most obvious implications for bioethical discussions regarding the medical management of both intersex conditions and gender dysphoria, particularly in children. First and foremost, I add my voice to the chorus of those calling for a moratorium on the performance of unnecessary genital normalizing surgeries on intersex infants, as well as on the treatment of trans* kids with so-called “conversion therapies” which—like childhood management of intersex—aims at securing a cisgendered future for the affected patient, and thus at the production of cisgendered lives. I agree with those who have been arguing since the early 1990s that the use of such medically unnecessary interventions on those unable to consent constitutes a gross violation of their right to autonomy (as well as their right to bodily integrity in the case of the intersex child)—a very widely recognized bioethical principle (Faden, Beauchamp, & King, 2004, p. 5). Indeed, the intransigency of intersex management practices is fairly shocking in light of the clear violation to autonomy they constitute, let alone the anecdotal evidence available indicating their potential to cause harms (and thus, to constitute malfeasance). The fact that “physicians have treated intersex in ways that defy most conventional understandings of ethical medical

practice” is the reason that Feder calls them “disorders like no other” (Feder, 2009, pp. 237, 238).

I go on, however, to provide a series of novel arguments grounding both this moratorium and access to gender-confirming interventions for all those capable of providing informed consent that desire them. Indeed, though autonomy is enough from a bioethical perspective to ground my argument for a moratorium—given its status as one of the four principles of North American bioethics emerging in Beauchamp and Childress’s 1985 book *Principles of Biomedical Ethics* (in addition to beneficence, non-maleficence, and justice)—though perhaps not for my argument regarding ensuring access to care (depending on one’s point of view) I am nonetheless suspicious of traditional conceptions of autonomy and the rights-based discourse via which it is invoked. Following Dean Spade (2011), I argue that rights-based discourse or initiatives problematically appeal to a sovereign conception of power as deductive rather than a Foucauldian account of biopower as productive. Indeed, I argue that focusing exclusively on autonomy and the right to it obscures the ways in which biopower functions and the forms of subjectification, normalization and governmentality via which particular lives are made live while others are let die – all of which have bioethical significance. Thus, rather than relying on traditional bioethical or autonomy-based arguments, I justify these two claims through appeal to a Foucauldian conception of ethics and of the possibilities for freedom available to the subject within the context of biopower. Further, on the basis of these accounts, I argue that both the DSD nomenclature and Gender Dysphoria be jettisoned as diagnoses and that those institutional bureaucracies which administer medical knowledge/power be challenged and radically reconstructed so that those who can provide informed consent can access gender-confirmation in the absence of pathology.

In Chapter One, “From Politicized Intersex Activism and Feminist Critique to Disorders of Sex Development,” I begin with a review of the intimately entangled histories of medicine, feminist scholarship and intersex activism out of and against which the DSD treatment model emerged in 2006, only to be quickly and universally adopted by clinical experts in intersex care internationally. After detailing both reactions to the DSD treatment model among clinicians, intersex persons and feminist academics, as well as various critiques of the DSD treatment model that have been raised, I conclude this chapter by laying out the four most philosophically rigorous arguments that have been offered in favor of it. In a sense, this chapter serves to orient the reader with regards to both the *why* and the *how* of the move to DSD—that is, it makes clear both what motivated former critics to endorse the “repathologization” of intersex conditions as DSDs (and thus, why they did), and the arguments by which they got there.

In Chapter Two, “Diagnosing the Failure of DSD: Medical Power/Knowledge and the Fictitious Unity of Sex, Gender and Sexuality,” I outline an argument for the failure of the DSD treatment model as a strategy meant to bring about a reduction in the performance of genital normalizing surgeries on intersex infants and children. Specifically, I argue that those who endorsed a biomedical model of intersex conditions as disorders of sex development were forced to commit not only to a nature/culture binary, but also to further binaries which follow from it, in particular sex/gender and impairment/disability. Commitment to these binaries has multiple problematic effects, the most important of which are the obfuscation of the larger histories of biopower and of medicine out of which the medical management of intersex conditions first emerged in the 1950s via John Money’s Optimal Gender of Rearing (OGR) Treatment Model, and commitment to a juridico-deductive model of power. I then move on in the remainder of Chapter Two to outline these

specific histories in order to resituate the DSD treatment model and intersex management in general with regards to them. I ultimately conclude that those theoretical and activist interventions which hope to improve the lives of those with intersex conditions must employ analyses that begin from a rejection of the nature/culture binary; that recognize the place of intersex management with regards to the larger history of biopower and the production of gender; and finally, that employ an understanding of power which, unlike a juridico-deductive account, better represents the productive ways in which interrelated networks of knowledge/power actually function. In the remaining three chapters of this dissertation, I examine the DSD treatment model employing just these kinds of analyses.

In Chapter Three, “The Disordering of Sex Development and the (Re)Production of Cisgendered Lives,” I turn to the DSD treatment model, beginning with an examination of the nosological shift from the intersex system of nomenclature to the DSD system of nomenclature before moving on to look at the way in which the pathology of intersex conditions are constituted via clinical practices. By focusing in particular on the few ways in which practice has changed under DSD, I argue that the aim of intersex management under DSD is the same as it was under OGR—specifically, securing a cisgendered future for the intersex infant, and thus the production of cisgendered life. Further, sex remains “gender all along” under DSD with the sex of intersex infants “fixed” on the basis of appeals to brain organization theory and the notion of a hormonally and socially mediated “brain gender.” As a result, I argue that the pathology of the intersex patient is one that is constituted in terms of cisgendered function. Further, I argue that when a cisgendered future cannot be secured for the intersex patient, medicine turns its efforts towards the production of a future which can *pass* as cisgendered, through the use of puberty blockers such as Lupron. Puberty blockers prevent the development of secondary sex characters and facilitate the production

of lives that appear to be cisgendered (even if they are not), by limiting those possible futures where one is visibly or “readably” trans*.

In Chapter Four, “Securing Cisgendered Lives: A Critical Analysis of the Pathologization of Gender Variance,” I reconstruct and then critique the most compelling philosophical answers to the question that clinicians tacitly believe has a self-evident response: Is being gender variant or non-cisgendered a pathology? Clinical evidence (or lack thereof) regarding the nature of a pathology, its prognosis and the various methods for treating it are necessary, but insufficient conditions for ethical medical practice and decision-making. This is particularly true where those unable to provide informed consent are concerned, such as infants or children. Indeed, in cases where failure to treat might result in death, bioethicists agree that health care professionals are morally obligated to care for those unable to provide informed consent (and sometimes against the wishes of their legal proxy decision-makers, such as in the case of Jehovah Witness children and blood transfusions). Thus, while the nature of pathologies of cisgendered function cannot determine ethical clinical practice, it clearly plays a role in such a determination. After drawing on the work of philosopher of biology and critical disability scholar Ron Amundson in order to critique Boorse’s account of pathology, I argue that any attempt to ground the pathologization of intersex conditions as *physical* pathologies is untenable. Subsequently, I turn to examine the pathologization of gender variance as a *mental disorder* within the *Diagnostic and Statistical Manual* (DSM), from the introduction of Transsexualism in DSM-III (1980) until the reclassification of Gender Identity Disorder as Gender Dysphoria in DSM-V (2013). I conclude in this chapter that pathologies of cisgendered function and the three elements of the heterosexual matrix that make these pathologies possible—sex, gender and sexuality—are *socially constituted entities* that function primarily at the level of the *bureaucratic administration*

of medical knowledge/power to justify the submission of particular populations to various forms of gender-confirming normalization, or to withhold those forms of normalization from other populations. Importantly, the way these pathologies function bureaucratically cashes out in ethically distinct ways for adolescents and adults who are able to provide informed consent and children who are not. While adolescents and adults able to provide informed consent are granted the authority regarding their gender such that they initiate the gender-confirming process insofar as it is their distress and social impairment that gender normalization aims to treat, children treated with medical efforts to produce cisgendered lives are denied this authority. Rather, in these latter cases, we initiate normalization in order to relieve the distress and social impairment experienced by society as a result of the apparent mis-alignment between the child's sex and their gender, as enacted through clinicians and proxy decision-makers. Indeed, this must be the case, for it is not clear that children—and in particular, intersex infants—have either a gender with regards to which they might be dysphoric, or an understanding of their body, let alone their body as sexed, to which gender incongruence must be indexed. Thus, I conclude that in the case of those unable to consent, the gender dysphoria and social impairment that medical efforts to secure cisgendered futures treat are those of health care professionals and guardians as the individuals for whom the child's gender incongruence actually registers. These cases then, might be best described as cases of gender dysphoria by proxy, rather than pediatric intersex conditions or gender dysphoria in childhood.

Finally, in Chapter Five, "Ethics, Medical Knowledge/Power and Politics After DSD," I provide a series of uniquely Foucauldian arguments for a number of specific normative recommendations: the above-mentioned moratorium on all medical efforts to secure cisgendered futures for those unable to provide informed consent, and that those

who desire access to medical forms of gender-confirming normalization be granted access to it in a timely and affordable manner. Some might question my ability to issue such normative claims within a Foucauldian framework, and argue that such an act is in tension with the use of the framework itself. Indeed, the liberatory potential (or lack thereof) of Foucauldian analysis is seen by many to be its most problematic characteristic. While genealogy is very useful for revealing the discursive and non-discursive constitution of the subject, there is not an outside of power for Foucault—no natural, or prediscursive, autonomous subject to whom we might return—and thus, no clear possibility for an account of liberation. To issue new norms is to merely redeploy power and call that redeployment liberatory.

I follow Oksala (2011), however, in her optimism regarding the possibilities for freedom available to the Foucauldian subject under biopower, in the domains of ethics, language and the body. I justify my two primary prescriptive claims by cashing out ethical medical knowledge/power in light of both Foucault's account of ethics as the relationship of oneself to the self via which one forms themselves as an "ethical subject," and his prescriptive claims regarding the exercise of freedom in this domain in terms of critically and self-reflexively engaging in practices of the self in ways that stretch the limits of subjectivity and intelligibility (Foucault, 1990b, p. 28). After cashing out the possibilities for freedom available to the Foucauldian subject in terms of the necessarily excessive nature of both language and lived experience such that neither is completely determined by their constitutive elements, I go on to justify three further prescriptive claims: that both the DSD nomenclature and the diagnosis of Gender Dysphoria be jettisoned; that those institutional bureaucracies which administer medical knowledge/power be radically reconstructed so that those who can provide informed consent can access gender-confirmation in the absence of pathology (and so that sex/gender designations cannot function as gatekeepers to care more

generally); and finally, that political theory and resistance focus on those institutional bureaucracies responsible for the government of gender—and subsequently, for the maldistribution of life chances for those with pathologies of cisgendered function—and their radical reconstruction.

Chapter One: From Politicized Intersex Activism and Feminist Critique to Disorders of Sex Development

I. Introduction

In 2006, the American and European pediatric endocrine associations published a special article in three medical journals titled “Consensus Statement on Management of Intersex Disorders” (“Consensus Statement” hereafter) proposing the first official revision in both the treatment model and the system of nomenclature for these conditions since the 1950s. The publication of this document—and its rapid adoption by clinicians engaged in intersex management in North America, Europe, and beyond—sent off a shockwave within the intimately entangled communities of both feminist academics engaged in intersex scholarship and intersex activists of such magnitude that both groups were left fractured in its aftermath, heatedly dividing themselves in terms of whether they were for or against this new standard of care.

Unofficially lumped under the umbrella category “intersex” since the mid-20th century, intersex conditions are those congenital (usually endocrine) conditions that may give rise to atypical development of bodily markers of sex such that an individual’s status as male or female is called into question.¹ Traditionally, intersex conditions have been identified with the birth of a child with ambiguous genitalia. However, many individuals with intersex conditions are neither born with nor develop ambiguous genitalia, and further, many others

¹ While the term intersex has been in use since the mid-twentieth century and adopted by activists and academics in the late 1980s/early 1990s as an alternative to the historically stigmatizing “hermaphrodite,” “intersex” was never formally adopted by the medical community (Reis, 2009). Those with variations of congenital sex anatomy continued to receive diagnoses such as “male pseudohermaphrodite” or “true hermaphrodite” (ostensibly) until the adoption of “disorder of sex development” in 2006. For historical summaries of the nomenclature see Feder and Karkazis, 2008 and Reis, 2009.

will not be diagnosed until adolescence or adulthood, if at all. At least 20 different etiologically distinct intersex conditions have been identified, each with its own unique presentation and associated health risks or sequelae. However, the frequency of individual intersex conditions and of intersex conditions generally remains subject to debate (Adam et al., 2012, p. 1339). 1-2 in every 1,000 infants born are treated with cosmetic surgery to normalize the appearance of their genitals; however, current best estimates hold that somewhere between 1.7%-2.3% of the general population have atypical chromosomal, gonadal and anatomic sex (Blackless et al., 2000). Yet beyond this, many predict that as technological advances increase, including our knowledge about the “molecular genetics of gonadal development and neurological sex differences,” the number of those who count as having bodies that are neither typically male nor female will greatly increase (Rosario, 2009, p. 278; Clune-Taylor, 2010). Generally speaking, the presence or development of atypical markers of sex that define intersex conditions are a side effect or symptom of the congenital condition that gives rise to it and are, generally speaking, not pathological in and of themselves (barring, for example, impairment to one’s ability to void and excrete for those with variations in genital development).

The Consensus Statement cites progress made in “diagnosis, surgical techniques, understanding psychosocial issues, and [in] recognizing and accepting the place of patient advocacy” as motivating the revision in treatment model and nomenclature it lays out (Lee et al., 2006, e488). Situating the change in nomenclature specifically as responding to “advances in identification of molecular genetic causes of abnormal sex with heightened awareness of ethical issues and patient advocacy concerns,” the Consensus Statement proposed that from then on, the intersex system of nomenclature, which utilized the diagnoses “male pseudohermaphrodite,” “female pseudohermaphrodite,” and “true hermaphrodite” grouped

under the umbrella category “intersex” be replaced by the new “Disorder of Sex Development” or DSD system of nomenclature. Under this new system, “Disorder of Sex Development” would come to replace intersex as the umbrella category for those “congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical” and individuals would now receive a DSD specific diagnosis referencing an individual’s total chromosome number, their specific “sex chromosome” makeup and, in some cases, gonadal makeup, such as 46 XY testicular DSD (see table 1) (Lee et al., 2006, e488-e489).²

Table 1. *Nomenclature Revision Proposed by the “Consensus Statement on Management of Intersex Disorders”*

Previous	Revised
Intersex	DSD
Male pseudohermaphrodite, undervirilization of an XY male, or undermasculinization of an XY male ³	46 XY DSD ⁴

² I have placed the term “sex chromosome” in quotation marks as a gesture towards the literature critiquing the continued identification of the X chromosome as the female chromosome given the existence of reliable scientific evidence since as early as 2001 of the necessary role the X chromosome plays in both male and female development. For an excellent review of the history of sex chromosome research and the association of the X chromosome with “femaleness” as an instance of how the gendering of objects for biological study can shape the production of biological knowledge, see Richardson, 2013.

³ The Consensus Statement is listing all synonyms that have been used within the literature for these bodily states. Chronologically, “male pseudohermaphrodite” is the first of these terms, having been introduced as a diagnosis in 1876 by Theodor Albrecht Klebs. Due to the stigma associated with the term “hermaphrodite,” practice unofficially shifted to the use of diagnoses in terms of “masculinization” or “undermasculinization” (For in-depth discussion of the history of this nomenclature, see Reis, 2009; Feder and Karkazis, 2008). While I acknowledge the plethora of heterosexist problems associated with the use of masculinized and undermasculinized—and indeed, the arguments presented in this dissertation aim specifically at laying bare the problems with attributing masculinity or femininity to any particular set of physical traits and the sexism underwriting such attributions—I personally find the invocation of a binary in terms of virility, with its connotation of sexual potency, to be more troubling than one which invokes masculinity or femininity. Further, I find the use of masculinization/undermasculinization to be far more

Female pseudohermaphrodite, overvirilization of an XX female, or masculinization of an XX female	46 XX DSD
True hermaphrodite	Ovotesticular DSD
XX male or XX sex reversal	46 XX testicular DSD
XY sex reversal	46 XY complete gonadal dysgenesis

Note. From Peter A. Lee et al., “Consensus Statement on Management of Intersex Disorders,” *Pediatrics* 118.2, 2006, e489, table 1.

As with the old system of nomenclature, the new system of diagnoses occurs in conjunction with condition-specific diagnoses such as congenital adrenal hyperplasia (CAH) or complete androgen insensitivity syndrome (CAIS), such that an individual will receive a final diagnosis such as 46 XY testicular DSD (CAIS) (Lee et al., 2006, tables 1 & 2). The Consensus Statement further outlines an optimal model of investigation and management of DSDs that emphasizes sex assignment *only* following expert evaluation in newborns; evaluation and long term management by an experienced multidisciplinary team (one ideally comprised of “pediatric subspecialists in endocrinology, surgery, and/or urology, psychology/psychiatry, gynecology, genetic, neonatology, and, if available, social work, nursing, and medical ethics”); open communication and shared decision making with both patients and their families; and that concerns of patients and families be addressed and respected in confidence (Lee et al., 2006, e490). Furthermore, biology or biological factors would gain a new centrality in determining optimal sex assignment in contrast to the more social constructionist recommendations of the Optimum Gender of Rearing (OGR) treatment model for intersex conditions that this model was intended to replace (Lee et al.,

representative of the anxieties underwriting contemporary intersex clinical management strategies insofar as they aim at precluding the existence of masculine girls and inadequately masculine boys. Thus, I limit myself to the use of the terms masculinized and undermasculinized in the rest of this dissertation.

⁴The Consensus Statement places a comma between the chromosome number and type (e.g. 46, XY DSD), however, this convention is inconsistently followed in the literature. I exclude it, however, wanted to flag that this does not cohere to the nomenclature as it was first introduced.

2006, e491). For example, while under the old model infants with XY chromosomes and phalluses that were either absent (aphallia) or smaller than average (microphallus) would have received a female sex assignment via vaginoplasty, gonadectomy, and hormone therapy, under the DSD model, these infants will receive a male assignment in accordance with their chromosomal makeup (For a table summarizing the etiology, frequency of, and treatment recommendations for the most common intersex conditions under both the OGR and DSD treatment models, see Appendix A).

The DSD treatment model proposed by the Consensus Statement has been taken up by the medical community in a swift and universal manner. By 2010 (a mere four years after the Consensus Statement's publication), British pediatrician, Consensus Statement co-author, and internationally renowned expert in intersex management Ieuan A. Hughes would proclaim the OGR treatment model's 50 year reign as *the* paradigm for treating intersex conditions ended.⁵ In a 2010 review of the literature in the field as well as a recent survey of practitioners at 60 European medical centers engaged in intersex management, Hughes found the adoption of the DSD nomenclature and implementation of the treatment protocol in both clinical practice and medical and/or scientific literature to have been so rapid and so near total that he characterized it as "a quiet revolution in medicine" (Hughes, 2010, p. 160).

Despite the apparently "revolutionary" uptake of the DSD treatment model by the medical community, the generally positive reception both the Consensus Statement and the DSD treatment model have received in this community have not been mirrored in others. Rather, the publication of the Consensus Statement, the process and politics out of which the document emerged, and clinical adoption of the DSD treatment model itself has sparked a particularly bitter and divisive controversy within two intimately entangled and often

⁵ By DSD treatment model, I refer both to the DSD system of nomenclature and the revised treatment model for intersex conditions laid out within the Consensus Statement.

overlapping communities: the intersex activist community and the feminist academy. It is true that the majority of the debate that has emerged within (and between) these two communities in the aftermath of the Consensus Statement's publication has focused on the pathologizing nature of the term "disorder of sex development." Nonetheless, it is reductive to characterize either that which has been achieved through the adoption of the Consensus Statement's nosological and clinical recommendations, or the resultant debate, as centrally an issue of nomenclature. Rather, these debates, as they have been hashed out and reflected on, in and through various online message boards, academic journals and edited volumes, organizational newsletters, and social media forums, have raised questions. These concern the relationship between political theory and political activism; the place and limits of feminist theory in practice; how (and why) we define pathology; health identity politics (and the place of allies within identity politics); speaking for others; authority (both medical and otherwise); as well the limits of intelligibility in terms of both sex and gender; and how certain lives are constituted as unliveable.

Both the visceral nature of the controversy sparked by the clinical adoption of the DSD treatment model and its primary localization within the intersex activist and feminist academic communities are a function of the history out of and against which the Consensus Statement emerged in 2006. Indeed, the Consensus Statement's publication is undeniably a watershed moment in the deeply, and at times ambivalently, entangled histories of both groups. Accordingly, the history of the Consensus Statement and the nosological reclassification and revised treatment model it introduces is not merely a story about scientific, clinical and or empirical "progress"—though it is at times that.⁶ It is at the same

⁶ I place the term 'progress' in quotations here for, as I will make clear in the course of this dissertation, not only has little changed between the two treatment models, but further, it is

time, like the histories of many models for naming, identifying and treating diseases, a story about politics, practices, identities, organizations, institutions, contingent events, and particular alliances.

In this first chapter, I provide a brief overview of the histories of medicine, of the feminist academy, and of the intersex activist movement that constitute the conditions of possibility for the emergence of the Consensus Statement in 2006 and the controversy that erupted in its aftermath. In the next section, subtitled “Intersex, (Optimum) Gender (of Rearing) and the Feminist Academy,” I offer a short history of the system of nomenclature and treatment model the Consensus Statement was developed to replace—the OGR treatment model for intersex conditions developed by Dr. John Money and his colleagues Joan and John Hampson at Johns Hopkins Medical Center during the 1950s. I will also begin to sketch the history of what is probably best termed Anglo-liberal feminist academic engagement with intersex, beginning with second wave feminist theoretical use of the medical management of intersex conditions and Money’s “hermaphroditic” research to challenge biological determinism, moving through third wave feminist troubling of the sex/gender binary (and through it, the nature/culture binary) and ending with feminist critiques of the science, ethics, and politics of pathologization and medical treatment of intersex bodies.

In section three, “From the Intersex Society of North America and ‘Hermaphrodites with Attitude’ to the Accord Alliance and ‘Disorders of Sex Development’,” I turn to the history of the largest and most influential organization of the intersex activist movement within the global north—Intersex Society of North America or ISNA—beginning with its foundation by Cheryl Chase/Bo Laurent in 1993 and ending with its dissolution and

unclear that what has changed should be regarded as “progressive” or that it is even clear what progress might mean with regards to this treatment model.

reformation as the Accord Alliance in 2008. Being a philosopher rather than a historian, I construct this overview using existing primary historical research, and highlight those events, individuals, and arguments that influenced the ISNA's formation and eventual emergence at the forefront of intersex activism; the complex relationship between the ISNA and the feminist academy that continued to grow throughout the 1990s and 2000s; and the ISNA's controversial trajectory in practical and political orientation, which lead them from "politicizing a pan-intersexual identity" and demanding the demedicalization of intersex conditions to endorsing the DSD treatment model and reforming as an apolitical lobby group. After surveying reaction to the DSD treatment model and the ISNA's role in its development among intersex activists and feminist academic in section four, I move on in section five to lay out the most philosophically rigorous arguments that have been offered in favour of the move to DSD. Thus, by the time I conclude this chapter, it will be clear both *why* former critics of the pathologization of intersex conditions came to endorse their repathologization as DSDs and *how* they argued for this apparent about face.

II. (Inter)Sex, (Optimal) Gender (of Rearing) and the Feminist Academy

The treatment model and system of nomenclature laid out by the European and American pediatric endocrine associations in the Consensus Statement was created as a replacement for the standards of care and diagnostic classification that had been in place since they were first published in the *Bulletin of the Johns Hopkins Hospital* ("the *Bulletin*" hereafter) between 1955 and 1957 (Germon, 2009, p. 24). These treatment standards—known as the OGR treatment model—were created by John Money and his colleagues Joan and John Hampson at Johns Hopkins Medical Center in Baltimore during the early 1950s and were based on Money's theory of gender acquisition that he had begun developing during his doctoral studies at Harvard between 1947 and 1952. By the time the Consensus

Statement was published in 2006, the ethics, politics, and science underlying the OGR treatment model had been the subject of almost 20 years of intense, often scathing critique.

The OGR treatment model, along with the tools it utilized to assess patient outcome, was based on the theory of gender acquisition John Money began to develop in his doctoral dissertation titled “Hermaphroditism: An Inquiry into the Nature of a Human Paradox”—though at the time, he had yet to use the word gender (Germon, 2009, p. 18; Money, 1952; Rubin, 2012, p. 894). After graduating with his Ph.D. in clinical psychology in 1952 from the Department of Social Relations at Harvard University, Money took up the position of co-director of the newly established Psycho-Hormonal Research Unit at Johns Hopkins Medical Center with psychiatrist Joan Hampson. On the basis of their work with intersex patients through this research unit housed in the department of endocrinology, Money and Hampson (along with her husband John Hampson), further expanded and refined Money’s theory of gender acquisition, introducing the concept of gender as human attribute distinct from sex in the process.

Money first introduced his theory of gender in a 1955 article that appeared as part of a series of articles by Money and/or his colleagues in *The Bulletin* between 1955 and 1957, laying out their treatment model for intersex conditions, its theoretical foundation, and tools for assessment. Money’s theory of gender as first articulated in this article, “Hermaphroditism, Gender and Precocity in Hyperadrenocorticism: Psychologic Findings,” encapsulated what we today would distinguish as gender identity, gender role or behavior, and sexual orientation (Money, 1995, p. 18; Rubin, 2009, p. 892). Money has often been reductively portrayed as strict social constructionist—and maligned for this view (Diamond, 1965; Zucker, 1996; for an in depth review of challenges to Money’s position as a social constructionist, see Karkazis, 2008, pp. 63-80). In fact, however, he was—at least initially—

an interactionist in a manner revolutionary for his day. In the first chapter of his 1995 book *Gendermaps: Social Constructionism, Feminism and Sexosophical History* titled “Lexical History and the Constructionist Ideology of Gender” Money writes

The first step was to abandon the unitary definition of sex as male or female, and to formulate a list of five prenatally determined variables of sex that hermaphroditic data had shown could be independent of one another, namely, chromosomal sex, gonadal sex, internal and external morphologic sex and hormonal sex (prenatal and pubertal), to which was added a sixth postnatal determinant, the sex of assignment and rearing. The seventh place at the end of this list was an unnamed blank that craved a name. After several burnings of the midnight oil I arrived at the term, gender role, conceptualized jointly as private in imagery and ideation, and public in manifestation and expression (Money, p. 21).

The development of gender role, for Money, was a “multistage process that relied on multiple attributes of biological sex and social variables but that could not be said to derive from these exclusively” (Karkazis, 2008, p. 53). However, for a large portion (95%) of the hermaphroditic patients studied by Money and the Hampsons at Johns Hopkins, gender identity corresponded to sex of rearing (Rubin, 2009, p. 888). This led Money and the Hampsons to identify sex of rearing as being of particular importance to gender role development—perhaps even more so than biological variables given the stability of gender role once learned (Karkazis, 2008, pp. 52-54).

Given the importance of sex of rearing to the Money and the Hampsons’ account of gender role development, their OGR treatment model for intersex patients recommended that infants born with intersex diagnoses receive a sex assignment by 18 months of age (ideally within the first few weeks of life) and that those infants whose intersex conditions

gave rise to ambiguous genitalia receive normalizing genital surgery (Karkazis, 2008, p. 55). Money and the Hampsons saw normalized genitalia as key to normal gender role development; genitals that did not match a child's assigned sex would impede the child's identification with their assigned sex and gender and, further, ambiguous genitalia might cause parents to "waver in their commitment to raising the child in the assigned gender" (Karkazis, 2008, pp. 57-58). Certainty—both the parents' and the child's—regarding the child's sex assignment played an integral role in Money and the Hampsons' account of normal gender role development and subsequently in the OGR treatment model. Thus, the model in practice fostered what intersex philosopher Morgan Holmes refers to as a "genital determinism" with regards to sex and gender, despite Money and the Hampsons' more complex, interactionist view in theory (Holmes, 2008, p. 69). Further, it meant that even though Money and the Hampsons often provided ambivalent (and at times contradictory) recommendations with regards to disclosure, in practice, patient and parental certainty regarding the patient's "true sex" was often secured by failures to disclose and at times, outright deception on behalf of both physicians and parents (Karkazis, 2008, p. 60).

The first sustained critiques of the OGR model emerged between 1985 and 2000 in the works of feminist academics such as biologist Anne Fausto-Sterling, sociologist Suzanne J. Kessler, and historian of science Alice D. Dreger.⁷ Academic feminists' first non-critical engagement with the issue of intersex bodies and their medical management came in 1972 with the publication of Anne Oakley's monograph *Sex, Gender and Society*. As David Rubin (2012), Germon (2009), and Hausman (1995) all note, the sex/gender distinction adopted

⁷ While Fausto-Sterling's (1985) critique of the OGR model in *Myths of gender: Biological theories and men and women* predates the publication of Suzanne J. Kessler's (1990) article "Medical construction of gender: Case management of intersexed infants" in the feminist journal *Signs* by five years, Kessler's article, which is described by Dreger and Herndon (2009) as "the first publication to provide a sustained feminist critique of the OGR model" is generally identified as the first of its kind (p. 203; Fausto-Sterling, 1985, pp. 133-41).

and employed here first by Oakley and later by many other second-wave feminists in the 1970s to challenge biological determinism, comes from Money by way of psychoanalyst Robert Stoller. Oakley draws on Money and the Hampsons' studies showing a high rate of correspondence between sex of rearing and gender identity to forward a social constructionist theory of gender (Oakley, 1972; Rubin, 2012, p. 888). Though Oakley's interpretation is something of a reductio of Money's actual theory of gender role and its development (though perhaps, not of his practice regarding it), it was nonetheless eminently helpful to her and feminists of her era. If sex was natural and gender cultural, then gender roles and inequalities were contingent and changeable. The bodies and genders of so-called hermaphrodites provided early feminist academics with tools to undermine the biological determinism underwriting women's oppression. Importantly, however, as Rubin (2012) points out, this logic kept intact both the naturalness of sex dimorphism and the abnormality inherent in intersex states (p. 888).

By the late 1980s and early 1990s, feminists would come to challenge the purported naturalness of sex that their predecessors had accepted, most notably Judith Butler in her groundbreaking 1990 book *Gender Trouble*. In it, Butler too considers the example of intersex, but this time to critique the sex/gender distinction and the assumption of sex as the raw bodily difference upon which the social meaning of gender is inscribed that it entailed. Butler engages Foucault to argue that prediscursive (or *natural*) binary sex is a fiction, that sex is as culturally constructed as binary gender and that the "production of sex as the prediscursive ought to be understood as the effect of the apparatus of cultural construction designated by *gender*" (p. 11). That is, gender must, she writes

designate the very apparatus of production whereby the sexes themselves are established. As a result, gender is not to culture what sex is to nature; gender is also

the discursive/cultural means by which “sexed nature” or “a natural sex” is produced and established as “prediscursive,” prior to culture, a politically neutral surface *on which* [emphasis in original] culture acts. (1999, p. 11).

By “casting the duality of sex in a prediscursive domain” the “internal stability and binary frame for sex is effectively secured” (p. 11). However, the need to “fix” the sex of those with intersex conditions as male or female by way of their “optimal gender of rearing” throws into relief both the fiction of binary sex and its production in the service (and as an effect of) gender. Thus, Butler concludes that sex is, by definition, “gender all along” (p. 8).

Furthermore, though Butler emphasizes the centrality of gender to identity, cultural intelligibility and personhood, she nonetheless troubles the notion of gender as “an abiding substance,” arguing there is no “gendered self” beyond that which is “produced by the regulation of attributes along culturally established lines of coherence” (pp. 32-33). Thus, gender, writes Butler,

is not a noun, but neither is it a set of free-floating attributes, for we have seen that the substantive effect of gender is performatively produced and compelled by the regulatory practices of gender coherence. Hence, within the inherited discourse of the metaphysics of substance, gender proves to be performative—that is, constituting the identity it is purported to be. In this sense, gender is always a doing, though not by a subject who might be said to preexist the deed (p. 33).

Thus, Butler rejects the notion of a gendered self for a definition of gender as “the repeated stylization of the body, a set of repeated acts within a highly rigid regulatory frame that congeal over time to produce the appearance of substance, of a natural sort of being” (p. 44).

Despite gender's failure to exist beyond its expression, the gender identity that "is performatively constituted by the very 'expressions' that are said to be its results," remains essential to cultural intelligibility and personhood (p. 33). The stabilizer of binary sex, gender is thus not only the condition of possibility for heterosexuality, but further, its production by Money in the 1950s is what establishes the particular configuration of the *heterosexual matrix* within which we currently operate—a tripartite system of sex-gender-sexuality. The heterosexual matrix functions as a grid through which those performatively constituted genders that "in some sense institute and maintain relations of coherence and continuity among sex, gender, sexual practice, and desire" are rendered "intelligible," while those that fail to institute and maintain these relations are not (p. 23). Butler writes,

the spectres of discontinuity and incoherence, themselves unthinkable only in relation to existing norms of continuity and coherence, are constantly prohibited and produced by the very laws that seek to establish causal or expressive lines of connection among biological sex, culturally constituted genders, and the "expression" or "effect" of both in the manifestation of sexual desire through practice (p. 23).

The production of intelligible or *normal* gender (and sex and sexuality) is thus simultaneously the production of *abnormal* gender (and sex and sexuality); that is, by fixing sex through gender, sex is constituted as the stable ground with regards to which gender can misalign. Thus, Money's fixing of sex via gender simultaneously produced *cis-aligned gender* or *cisgender* as normal and made trans* gender, or gender variance

pathological.⁸ Furthermore, the fact that identity is “assured through the stabilizing concepts of sex, gender and sexuality,” such that one doesn’t simply *have* a gender, but *is* a gender, means that those who fail to cohere with gender norms, argues Butler, call into question “the very notion of ‘the person’” (p. 23).

Following Butler’s germinal theoretical excavation of sex as “by definition . . . gender all along,” feminist academics like Suzanne J. Kessler (1990) Anne Fausto-Sterling (1993, 2000), and Sharon Preves (2002) began to critique in detail both the medical management of bodies that failed to accord with biomedical definitions of male and female and the production of scientific knowledge that underwrote that management. Their critiques of the OGR treatment model focused on the performance of medically unnecessary genital normalizing surgeries on infants and children who did not and/or could not consent—often at the expense of later sexual function. They called into question the presumed naturalness of physical sex dimorphism that constituted intersex conditions as pathologies requiring treatment, as well as the heterosexism underlying treatment recommendations and outcome analyses that valued “aggressiveness and sexual potency for boys and passiveness and reproductive/sexual-receptive potential for girls” and according to which homo or bisexuality and instability of gender identification constituted bad outcomes (Dreger & Herndon, 2009, p. 204). Furthermore, these critiques questioned the positioning of the medical treatment of intersex conditions as exceptional, legitimating practices that routinely violated bioethical principles of respect for autonomy, beneficence, non-maleficence, and justice. These early critiques by feminist academics like Fausto-Sterling and Kessler provided the theoretical foundation for the emergence of an international intersex activist movement at the forefront of which stood the Intersex Society of North America (ISNA).

⁸ I use trans* to refer both to those who identify as transsexual and those who identify as transgender.

III. From the Intersex Society of North America and “Hermaphrodites with Attitude” to the Accord Alliance and Disorders of Sex Development

In a 1993 letter to the editor of *The Sciences* responding to Fausto-Sterling's (1993) germinal article “The Five Sexes: Why Male and Female Are Not Enough,” self-identified “intersexual” Cheryl Chase announced the foundation of the Intersex Society of North America (Chase, 1993). Though not the first organization to form around the issue of intersex conditions (the Turner Syndrome Society formed in 1987 and the Androgen Insensitivity Syndrome Support Groups formed in 1988), the ISNA was, undeniably, the first intersex *activist* group, drawing its energy and rhetoric not only from feminist academic challenges to the OGR model (as well as their challenges to biological determinism, sexism, and medical authority more generally) and queer theory, but also from social movements for women's rights, civil rights, and gay liberation. In contrast to other groups' focus on peer support, the ISNA (and many of the groups that formed in its aftermath) took a page from the gay liberation movement reclaiming and politicizing the term intersex (and to a lesser extent, hermaphrodite), such that “by the late 1990s ‘intersex’ had become an identity and a social movement claimed by activists as a legitimate variation in human biology and anatomy, rather than a form of disease” (Holmes, 2011, p. 392). Intersex activists often engaged in a two-pronged strategy, attacking the OGR treatment model that had caused them psychological and physical harm on the one hand, and taking part in a larger social and political project on the other, one that argued for “acceptance, dignity and human treatment for those with gender-atypical bodies in an effort to challenge ideology, practices and consciousness” regarding gender, sex and sexuality (Karkazis, 2008, p. 8). Their position was based fundamentally on the notion that

although certain intersex-related conditions (such as salt-[wasting] associated with Congenital Adrenal Hyperplasia) can be life threatening and thus may require intervention, intersexuality itself is not pathological and thus does not require medical treatment (Spurgas, 2009, p. 99).

It was because intersex conditions generally, and ambiguous genitalia in particular, threatened the social norms about sex, gender, and sexuality that structure so much of daily existence, that they were pathologized, they argued, and this pathologization justified their treatment with unsuccessful, experimental surgeries and secrecy, causing immense physical and psychological harm. Preves (2005) writes that the ISNA was fairly successful in not only increasing public awareness of intersex conditions, but of also “personalizing intersex” by drawing attention to personal stories of individual harms done under the OGR treatment model, a process which provided “nonintersexed individuals a human connection and political context within which to understand these stories of medicalization, secrecy and shame” (p. 271). By 1995 individuals’ stories were being featured in the popular press, as well as in college textbooks and other educational forums, and by 1996, features on the intersex activist movement (and the ISNA in particular) ran in *The New York Times*, the *Utne Reader* and *Out* magazine (Preves, 2005, p. 271).

The ISNA’s successes in garnering media attention—particularly by way of direct action protests under the name “Hermaphrodites with Attitude”—forced physicians to respond to their claims about the physical and psychological harms done under the OGR treatment model. In collaboration with the group Transsexual Menace, the ISNA held the world’s first protest by intersex activists at the 1996 meeting of the American Academy of Pediatrics (AAP), after learning that the “U.S. Congress passed legislation prohibiting clitorrectomy that was drafted in a way that tried to avoid protecting intersexed children”

(Hegarty & Chase, 2000, p. 127). Their protest pressured the AAP into releasing its first ever position statement on the medical management of intersex conditions to the press, stating that “the Academy is deeply concerned about the emotional, cognitive and body image development of intersexuals and believes that successful early genital surgery minimizes these issues ” (as cited in Chase, 1998b, p. 202).⁹ As Preves notes, LGBT and mainstream media coverage of intersex conditions and harms done under the OGR treatment only increased following the publication of follow-up studies on David Reimer in 1997, putting even more pressure on physicians and health care professionals to clarify their position on intersex treatment (Preves, 2005, p. 277).

Born Bruce Reimer in 1965, David—an identical twin—lost his penis during a botched circumcision and subsequently was treated by OGR architect John Money. Money recommended that Bruce be surgically and socially reassigned as female, arguing that his lack of a penis would prevent normal male gender role development. This surgical and social reassignment was done at 22 months of age and, as Preves writes, “Money and colleagues used this surgical mishap and sex reassignment to test the impact of gender socialization by rearing a male child as female and using his genetic identical twin [Brian] as an empirical control” (Preves, 2005, p. 273). Known in medical literature as John/Joan, Money and his colleagues published multiple articles reporting that Bruce/John’s reassignment as Brenda/Joan had been an unqualified success, providing proof not only the claim that sex of rearing was the primary determinant of gender role and identity acquisition, but also for the OGR treatment model for intersex conditions based on this claim. In 1997, biologist Milton

⁹ The 1996 protest of the AAP is often described as the moment or event that “put the ISNA on the map,” however as Karkazis notes in *Fixing Sex*, Chase was interestingly not at the protest itself. Rather Chase “...worked very closely with the “transsexual” activist Riki Wilchins and members of Transsexual Menace to “get bodies” for the protest” (Karkazis, 2008, p. 317, n10; See also Valentine & Wilchins 1997 for a firsthand account of the protest).

Diamond and psychiatrist Keith Sigmundson's article "Sex Reassignment at Birth: Long-Term Review and Clinical Implications" revealed that, counter to Money and his colleagues' claims, John's reassignment as Joan never "took," and that Brenda had transitioned to male at the age of 14 (Diamond & Sigmundson, 1997). While David Reimer had never been diagnosed with an intersex condition, the publicity surrounding his case "opened the door for intersex rights activists to tell their stories and influence medical reform" (Preves, 2005, p. 274). Furthermore, David's story served to discredit both Money and the premise upon which the OGR treatment model was founded; that sex of rearing, bolstered by surgical assignment, was the key to development of a happy heteronormative child. As Chase writes, by the time Reimer's story broke in 1997, she and the ISNA were ready to capitalize on this publicity.

By 1997, we had a large community of adult intersexuals who would speak publicly; we have a few parents willing to speak about their experiences and could rebut doctors' assertions that "things are so much better now." We had sexologists, sociologist, psychotherapists, historians, and even one or two surgeons and ethicists on our side. We were in a good position to extract from the media the story we wanted: A story about us and how intersexuals are fighting for social change, a story avoiding painting intersexuals as "Other," as freak, as victim. Just as all of these pieces fell into place, a stroke of good luck came to us. Sex researcher Milton Diamond publicized the outcome of what has become known as the "John/Joan" story. . . . We took advantage of the press's attention to the John/Joan story, making them aware that intersex children are treated daily with the same medical arrogance, mutilating surgery and willful deception imposed on John (Chase, 1997, p. 25).

Multiple stories covering the controversy over Reimer's case, and subsequently the medical management of intersex conditions, appeared in 1997. Many featured interviews with physicians and pointed to "tensions within medicine about how best to frame and respond to intersexuality" (Preves, 2005, p. 277). The debate that emerged among physicians was, as Preves recounts, strikingly polarized, with a vocal minority of "physicians and others," like Diamond and Sigmundson, challenging the dominant paradigm of "normalization" on the one hand, and those who supported the OGR treatment model on the other (p. 277). Those who challenged the dominant paradigm of normalization, however, often framed it not as a question of whether or not to do surgery, but *when* to do it (pp. 277-278). Media coverage of the harms done to those with intersex conditions under the OGR treatment model, bolstered by the outing of John's failure to become Joan, put intense pressure on physicians to respond to their critics and in many cases, attenuate their support of the OGR model. Physicians began to claim that they were far less eager in their surgical recommendations and by 2000, those physicians engaged in the treatment of intersex conditions found their field to be in a state of "deep and divisive crisis" driven there by intersex activists' "chorus of demands" (Preves, 2005, p. 282; Karkazis, 2008, p. 3). That same year Ian Aaronson, a pediatric endocrinologist at the Medical University of South Carolina convened the North American Task Force on Intersex (NATFI) "in response to the increasing debate over medical sex assignment in order to reevaluate medical care for children with ambiguous sexual anatomy," a committee which included not only feminist social psychologist and author of *Lessons from the Intersexed* Suzanne J. Kessler, but also ISNA executive director Cheryl Chase (Preves, 2003, pp. 150-151).

Due in large part to their successes in raising public consciousness about intersex conditions and challenging the medical establishment, the ISNA grew a great deal during the

years following the publication of the John/Joan case, not only in size, but also—and most importantly—in terms of profile, legitimacy and thus, political clout. As the ISNA began to garner recognition as “a credible voice in the debate over” the treatment of intersex conditions, new opportunities for collaboration with physicians began to arise (Preves, 2005, p. 271). The organization had initially established itself as a radical queer activist group, more interested in the “complete demedicalization of the intersex body and on a reclamation of intersex via explicit and strategic solidarity among people of diverse embodiments, genders and sexualities” than in any (even strategic) collaboration with physicians. However, as its profile grew, members of the ISNA started being invited to speak at those very same meetings of medical associations they had once been relegated to protesting (for example, in addition to her membership on the committee of the above mentioned NATFI, Chase gave a keynote address at the May 2000 meeting of the Lawson Wilkins Pediatric Endocrine Society) (Preves, 2005, p. 271; Spurgas, 2009, pp. 99-100). As opportunities for the ISNA (and those associated with it) to effect change at the level of the treatment model began to arise, so too did concerns about the group’s ability to take advantage successfully of those opportunities in light of its history of politicized queer activism. Though the ISNA and other intersex activist groups were at least moderately effective at challenging the surgical “correction” protocol, their influence was inconsistent at best and highly dependent on whether particular physicians were willing to listen to their critiques and take them seriously, or dismissed them as being an “angry,” “militant” minority of “zealots” (Preves, 2005, pp. 277-278). In her 1998 *GLQ* article “Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism,” Chase acknowledged the difficulty the ISNA had in changing medical practice and the “deaf ear” medical specialists treating intersex had generally turned to the ISNA’s appeals. Furthermore, though the ISNA had enjoyed a “central role in

defining the intersex movement and its activities” due to its successes in publicizing the plight of intersex individuals and challenging the medical establishment, its politically queer nature had alienated it from other intersex groups from the start (particularly those peer support groups for or run by parents of children with intersex conditions who, Preves writes, often made in her discussions with them, “explicit efforts to sever associations between intersex and GLBT issues”) (Preves, 2005, p. 264). Preves notes that both the centrality of the ISNA to the intersex activist movement and the tension its undertaking a queer identity politics had created were evident in the responses, or rather identifications, interviewees gave during the course of her research in the late 1990s and in her experiences as an academic called upon to discuss intersex. She writes,

While I was conducting interviews with members of various intersex support groups in the later 1990s, several interviewees frequently identified themselves as non-ISNA members with a sentiment of, “You know I am not part of that radical lobbying group, right?” More recently, when I was asked to speak about my research at an intersex support group’s annual conference, I was given a list of issues to avoid, lest I present intersex as too political or too “queer” (read: “too ISNA”) and thus end up alienating potential recruits of the group or their family members (Preves, 2005, pp. 263-264).

Though the group’s engagement in queer identity politics had long caused divisive tension, once opportunities for collaboration with clinicians began to arise, the ISNA’s politics, practices and, in particular, the queer and non-normative intersex identity that it had articulated and around which it had organized, came to seem insurmountably problematic. Underwriting intersex identity as activists had articulated it was a critique of the heterosexual matrix (the presumed natural alignment of dimorphic sex with binary gender with

heterosexuality) that was too radical, and subsequently antithetical to collaboration with physicians and parents. Moreover, its constitution in opposition to dominant heteronormative configurations of sexed and gendered bodies meant that those identified as having intersex conditions were assumed to be queer in terms of their sex, gender or political identity. This connotation troubled physicians, individuals with intersex conditions who did not identify as queer, and, in particular, parents of affected children who were offended by the implication that their children did not and would not have a clear, unambiguous, heteronormative sex, gender, and sexual identity (Koyama, 2006). Furthermore, many within the movement had begun to raise concerns about the co-optation and appropriation of intersex as an identity by those within the trans* community and as a conceptual or theoretical tool by academic feminists. For example, DSD-proponent, activist founder of Intersex Initiative, and former ISNA intern Emi Koyama writes in her 2006 article, “From ‘Intersex’ to ‘DSD’: Toward a Queer Disability Politics of Gender”

The word ‘intersex’ began to attract individuals who are not necessarily intersex, but feel that they might be, because they are queer or trans. Many of these people felt that to be intersex meant a social and biological justification for being who they are, as in it’s okay that you’re queer or trans because they were literally ‘born that way’ [sic]. This obviously clashes with the majority of people born with intersex conditions, who despite their intersex bodies feel that they are perfectly ordinary heterosexual, non-trans men and women (2006, para. 23).

The ISNA’s solution to this problem amounted to two simultaneous shifts. The first was to reconceptualize intersex conditions—the issue around which the ISNA organized—in a way that physicians would respond to, that is, in terms of their language of pathology. The second was to jettison the queer-sociopolitical identity that had once been their focus—

intersex—by distancing themselves from or eliminating all discussion of identity, gender, or sexuality. Preves (2005) notes that soon after the extensive mainstream media coverage of the Reimer case in 1997, new ways of articulating the “problem” of the treatment of intersex conditions under the OGR model began to emerge, focusing specifically on issues of informed consent, human rights, and children’s rights. However, externally apparent signs of a shift or change in the organization’s practices and politics didn’t appear until 2001 when the ISNA changed the title of its newsletter from “Hermaphrodites with Attitude” to the “ISNA News” and the newsletter itself moved from featuring personal stories and humor to “professional and organizational concerns such as financial reports, profiles of board members, and the continued coverage of medical conferences and research” (Preves, 2005, p. 262). Preves describes this change in the ISNA’s newsletter as mirroring an “overarching frame realignment that has taken place within the movement, as activists and doctors have begun working alongside one another for change, rather than against each other as political adversaries.” (p. 262)

The political and practical transition undertaken by the ISNA has been characterized in many ways, from being identified as a sign of progress and/or professionalization, to “surprising” and “counterintuitive,” to a betrayal to those committed to the queer identity politics movement it had spawned (Dreger & Herndon, 2009; Preves, 2005; Spurgas, 2009, p. 100). Davidson (2009) describes the ISNA’s trajectory as moving from espousing a revolutionary approach of “opposing medical discourse on intersex and the logic through which it operates, for example by challenging the very language of ‘intersex’ conditions,” to taking up what he calls an “evolutionary approach” of attempting to “alter *how* intersex is medicalized . . . by working within the medical paradigm and through medical logic and language to bring about eventual changes for individuals with intersex ‘conditions’”

(Davidson, 2009, p. 64). Preves (2005), who did extensive field research at the organization's offices, describes the ISNA as leaving behind "an injustice frame characterized by personal medical trauma," and argues this "frame transformation was made even more complete" with the resignation of Cheryl Chase as the organization's executive director and the appointment of "nonintersexed medical sociologist" Monica Casper in January 2003 (p. 262). It was under Casper that the ISNA created a medical advisory board, and further

extend[ed] the intersex movement's concerns to other movements and communities such as those communities such as those focused on women's health, disability rights, children's rights, sexual rights and reproductive rights. ISNA created a strategic planning process in 2003 designed to reposition the organization vis-à-vis these communities, while strengthening its relationship to the medical profession and other health care providers (Preves, 2005, p. 284).

In a footnote to her 2008 book *Fixing Sex: Intersex, Medical Authority and Lived Experience*, bioethicist Katrina Karkazis writes that during the 2000 NATFI meetings she heard "the first push for changing the nomenclature . . . from Chase and Dreger" (p. 317, n 11; Preves, 2005, p. 279).¹⁰ However, the first time Chase and Dreger made their (and ostensibly, the ISNA's) desire and rationale for moving away from intersex to a pathology-based taxonomy clear in a public way was in 2005 in the article "Changing the Nomenclature/ Taxonomy for Intersex: A Scientific and Clinical Rationale" in the *Journal of Pediatric Endocrinology & Metabolism*. The publication of this article, which Spurgas describes as "the harbinger of a new highly medicalized model of intersex treatment, a model that would focus on genetic and endocrinal etiologies for specific intersex comportments and which

¹⁰ Though Karkazis identifies both Chase and Alice Dreger (then chair of the board for the ISNA) as having been present at the 2000 meetings of NATFI, Dreger is not officially listed as a member of the group (Karkazis, 2008, p. 317, n11).

purported to ‘label the condition rather than the person,’” signaled the ISNA’s first official endorsement of a not only a new highly medicalized treatment model for intersex conditions, but also a reconceptualization of intersex conditions as pathologies (Spurgas, 2009, p. 101; Dreger, Chase, Sousa, Gruppuso, & Frader, 2005, p. 733).

In the article, Dreger, Chase, and three clinicians/researchers associated with the ISNA’s medical advisory board argue for the clinical abandonment of the intersex system of nomenclature, which uses gonadal makeup to diagnose individuals as male, female, or as belonging to one of three “intersex” types: true hermaphrodite, male pseudo-hermaphrodite, or female pseudo-hermaphrodite. The authors argue that the current system of nomenclature is “illogical, outdated and harmful,” and review what they describe as its scientific, clinical, and rhetorical shortcomings before suggesting the use of “specific etiology-based diagnoses (such as AIS, 5 α -reductase deficiency, etc.) organized under the umbrella term “disorders of sexual differentiation” (Dreger, Chase, Sousa, Gruppuso, & Frader, 2005, pp. 729, 733). Having been developed “approximately 125 years ago, before the development of modern genetics and endocrinology, and well before the current diagnostic techniques and scientific knowledge of sexual anatomy,” including the “discovery and understanding of ‘sex chromosomes,’” the intersex system of nomenclature “problematically privileges gonadal makeup as the primary or sole variable in diagnoses” (pp. 730-731). Presumably to illustrate the illogic of the current system, the authors stress the failure of the current nomenclature to “carve the world at its joints,” as it were, prior to reviewing the nomenclature’s scientific, clinical and rhetorical drawbacks in detail (p. 730). This point, they write “is critical—the current taxonomy does *not* [emphasis in original] represent a division into what philosophers of science call ‘natural kinds’. Nature does *not*

[emphasis in original] tell us the existing system is the one and only way to view sexual anatomies” (p. 730).

This privileging of gonadal makeup, they argue, is problematic for two reasons. First, it is “scientifically questionable” insofar as “scientists and clinicians now recognize that the structure of gonads does not correlate simply with genotype, phenotype, physiology, diagnosis or gender identity” such that “continu[ing] to use rhetoric suggesting that gonadal anatomy is the most important marker or is a simple marker of sex type denies the full breadth of our current scientific knowledge” (Dreger, Chase, Sousa, Gruppuso, & Frader, 2005, pp. 730-731). Second, the current system of nomenclature has multiple “clinical shortcomings” insofar as it “provides little clinical help, often confusing and harming the patient, and sometimes also the physician” (p. 730). Under the current system, individuals can end up with diagnoses that can conflict with their sex or gender identity—for example, an individual with Androgen Insensitivity Syndrome (AIS) may receive the diagnosis of male pseudo-hermaphrodite as a result of having testes, yet identify as and appear to be an unremarkably feminine woman. In order to avoid the distress these conflicts between “supposed ‘sex’” and gender could cause for patients, physicians at times resorted to the “now widely criticized” practice of withholding true diagnoses from patients and to early childhood surgeries “to ‘resolve’ the conflict”—something “that patients (and then many clinicians) later regretted” (pp. 731-732).

The authors move on to provide a list of four rhetorical problems they see as plaguing the intersex system of nomenclature. First, the term hermaphrodite, on which the intersex nomenclature is based, still conjures for many people a mythical figure who is both male and female, in possession of two full sets of genitals and/or sex organs. This image not only “frightens and confuses many non-professionals, including patients and their families,”

it further may “attract the interest of a large number of people whose interest is based on a sexual fetish and people who suffer from delusions about their own medical histories”—so much so that “this unwanted attention can rise to a level that interferes with the work of support groups and clinicians” (Dreger, Chase, Sousa, Gruppupuso, & Frader, 2005, p. 732). Second, conflicts between diagnosis and self-identified or presented gender can lead to distress for patients, parents, and physicians. The authors stress that nomenclature can have serious implications for the patient, writing that

Most patients with intersex conditions are confronted with social and sexual issues at many developmental stages over the course of their lives; a patient’s understanding of her condition will be strongly affected by labels she encounters in her own medical record or in medical journals and texts (p. 732).

Third, they argue that the intersex system of nomenclature labels the person (i.e., male pseudohermaphrodite) rather than the condition (male pseudohermaphroditism). Finally, they argue that “the division into ‘pseudo’ and ‘true’ forms of hermaphroditism implies a hierarchy of authenticity, whereby one person has a fake form of intersex and another a real form” (p. 732).

In the concluding section of the article, titled “Towards a New Taxonomy,” the authors write that a new clinical approach to intersex “should aim to use methodologically sound evidence to facilitate the development of healthy and happy patients” and state that determining this new system of nomenclature “will depend on what patients and clinicians decide they need” (Dreger, Chase, Sousa, Gruppupuso, & Frader, 2005, p. 732). They do, however, provide a list of suggestions for any new taxonomic system, like that it “*should* enhance, but not complicate, the use of medical informatics in research and clinical practice”; that it “*should* make clear that diagnosis does not simply dictate therapy”; and that

it “*should* recognize that diagnosis and taxonomy inform, but do not determine, gender assignment and/or identity (thus, should avoid the words ‘male’ and ‘female’)” (p. 733). Finally, they conclude by suggesting the use of specific etiology-based diagnoses under the umbrella category “disorder of sexual differentiation,” arguing that “such an approach would have the salutary effects of improving patient and physician understanding and reducing the biases that are inherent in the use of the current language of ‘hermaphroditism’” (p. 733).

In October 2005, just few months after this article was published, Cheryl Chase and intersex activist Barbara Thomas of the German group AIS XY-Frauen attended the International Consensus Conference on Intersex hosted by the American Lawson Wilkins Pediatric Endocrine Society and European Society for Pediatric Endocrinology in Chicago, Ill (Lee et al., 2006, e497). At this meeting the working groups that later developed the Consensus Statement were formed. The activists’ involvement in the document’s production, however, has been described as limited at best and tokenistic at worst and this exclusion is evident in the document’s recommendations regarding both nomenclature and treatment (Karkazis, 2008, p. 3; Karkazis, personal communication, August 2010). Rather than Dreger and Chase’s initial suggestion of “disorders of sexual differentiation,” the Consensus Statement infamously reclassified intersex conditions as “disorders of sex development.”¹¹ The authors of the Consensus Statement do admittedly come “closer than any group of physicians before them in publicly advocating against sex assignment surgery at birth,” limiting their recommendations to the performance of genital normalizing surgery by experienced surgeons in “cases of severe virilization,” emphasizing functional outcomes over

¹¹ In a 2007 blog post on her website, Alice Dreger writes regarding the nomenclature that “Disorders of Sexual Differentiation” was rejected by those “clinicians helping with the handbooks” because “different disciplines mean different things when they say ‘differentiation’”. She continues, “I also heard about ‘disorders of sexual development.’ But ‘sexual’ seemed to mean ‘erotic,’ so we rolled that middle word back to ‘sex.’ (Dreger, 2007, para. 13)

aesthetic and even cautioning that though “it is generally felt that surgery that is performed for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents; the systematic evidence for this belief is lacking” (Spurgas, 2009, p. 103; Lee et al., 2006, e491). Surgery nonetheless remained central to the treatment model. Karkazis notes that the idea that early, non-medically necessary genital surgery was a necessary part of optimal care remained fairly entrenched within the medical community, writing that not only did many of the physicians she interviewed for the book see “early genital surgery as necessary, most surgical articles take for granted that surgery will be performed (and hence simply describe how to do it) [and] opinions at professional meetings appear to agree that surgery still makes for good care” (2008, p. 134).

In 2006, the ISNA electronically published *The Handbook for Parents* and *The Clinical Guidelines for the Management of Disorders of Sex Development in Childhood* (*The Clinical Guidelines* hereafter) both of which are attributed to the Consortium on the Management of Disorders of Sex Development (the ISNA’s medical advisory board) and use the DSD nomenclature almost exclusively. This was the last major initiative undertaken by the ISNA prior to its quiet dissolution in 2008, via an open letter posted to their website. In the letter, the group cites lingering public confusion over their goals such that they find themselves, as a group, “hamstrung” in their ability to achieve these goals. Ostensibly as a result of their queer political history they were taken by many to be advocating the extreme position that children should not be assigned a sex or gender, or raised as a third/intermediate gender in opposition to their true goal of achieving a moratorium on all medically unnecessary genital normalizing surgery. In its place the ISNA left the Accord Alliance, a medical lobby group dedicated to the promotion of “comprehensive and integrated approaches to care that enhance the health and well-being of people and families affected by [Disorders of Sex

Development] by fostering collaboration among all stakeholders,” which it identified as parents, patients, and physicians (Accord Alliance, 2008). Notably, there is no mention of the word intersex anywhere on the Accord Alliance’s website or its materials.

IV. Post-Intersex/DSD

News of both the official revision in treatment model for what were now known as disorders of sex development, as well as the ISNA’s involvement in the DSD treatment model’s development and adoption came as a surprise to the majority of intersex adults (and activists). As Karkazis writes, it wasn’t really until somewhere around the time that the DSD guidelines were published online that “intersex adults began having an intense discussion about the new nomenclature, especially concerning the term *disorders of sex development*” (2008, p. 317, n11). Karkazis’s characterization of the discussion that began outside of the medical community about the DSD treatment model as intense is something of an understatement; as Jennifer Germon bluntly puts it in her 2009 book *Gender: A Genealogy of an Idea*, “when it became apparent that the ISNA had driven the terminology change, all hell broke loose” (Germon, 2009, p. 173). A few of those closely associated with the ISNA were aware of the organization’s plans to transition into a medical lobby group fairly early on, leading some associated with the group to found their own organizations in the early 2000s in order to fill lacunae in the movement they saw created by the ISNA’s organizational evolution. The most notable of these groups, which now make up the three most prominent intersex activist organizations internationally, include politicized intersex activist group Intersex Initiative Portland (IPDX) founded by former ISNA intern and communications director Emi Koyama in 2000, the non-diagnosis-specific outreach, education and support focused Bodies Like Ours (BLO) founded in 2002, and politicized activist group Organisation Intersex

International (OII) founded in 2003 by Curtis Hinkle (which, at the time of writing, had affiliates in 20 countries on six continents speaking 10 languages including Mandarin and Arabic) (Preves, 2005, 264; OII, 2012). Officially these groups have split on their responses to the DSD treatment model: Koyama has argued (albeit somewhat resignedly) in favor of the DSD nomenclature (Koyama, 2006, 2008), while representatives of BLO and OII remain critical of the nomenclature and of collaboration with physicians to varying degrees, with OII holding the more critical position of the two.

The internet (and the various forms of electronic communication it has engendered) has played a large role in the development and mobilization of the intersex activist movement, acting as the primary site where activists recruit, network, and communicate and affected individuals and their families access information and support beyond the clinic. Undeniably, there were many—particularly physicians, parents, and individuals with intersex conditions who identify as gender normative (and heterosexual)—who were very pleased with the new treatment model and nomenclature. However, the majority of response online to both the Consensus Statement and the ISNA’s involvement in its production was overwhelmingly negative (even granting that one’s involvement in an intersex activist organization and/or on their online message board might bias them towards a negative response). For example, Peter Trinkl, chair of the board of directors of the organization Bodies Like Ours stated that of those who had expressed an opinion on the subject via the organization’s online “Intersex Community Forum,” “roughly 80-90% of the intersex people . . . are against the DSD nomenclature” (Trinkl, 2008, para. 1).

The ISNA did attempt to deal with these concerns: in response to the increasingly heated online debate over both the DSD nomenclature and the ISNA’s endorsement of it, the group posted an article on its website in May 2006, explaining both their endorsement of

the term and their adoption of it in their own communications beginning in 2005. The post, titled “Why is ISNA using ‘DSD’?,” lists many of the same problems associated with the term intersex mentioned in 2005’s “Changing the Nomenclature/Taxonomy for Intersex” such as the overabundance of meaning the term has come to accrue and its tendency to label the person rather than their condition. However, it takes pains to achieve something of a middle ground on the issue of nomenclature, positioning the organization’s use of the term as primarily pragmatic and acknowledging opposing viewpoints hosted on the ISNA’s own website. In the post, Chase writes that since the organization’s incorporation in 1999, the group has focused their efforts on achieving one of their longstanding “cherished goals”—reforming medical care for children with intersex conditions (ISNA, 2006c, para. 1).¹² The term Disorders of Sex Development or DSD was far better suited to achieving this goal than intersex as it was found to be “much less charged” than “intersex” when used in medical contexts, making the group’s “message of patient-centered care much more accessible to parents and doctors” alike (ISNA, 2006c, para. 2). The group’s aim in adopting and endorsing DSD is not “to make intersex an entirely medical issue,” but rather “to meet them [parents and doctors] where they are.” The article goes on to explicitly acknowledge that “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!” (ISNA, 2006c, para. 4). Further, the post even encourages readers to “have a look at the wonderful essay . . . by Sherri Groveman Morris” (founder of the Androgen Insensitivity Syndrome Support Group US and a former member of ISNA’s board of directors) to which it links and which the ISNA hosts. In “DSD

¹² This post is attributed, like many posts on the website, simply to the ISNA. However, in a 2007 blog post on her own website, Alice Dreger attributes the entry to Cheryl Chase (Dreger, 2007, para. 38).

but intersex too: Shifting paradigms without abandoning roots,” Morris cautions the ISNA against abandoning the term intersex as it “looks forward,” reminding them that

In supporting a change in terminology within the medical community, ISNA must remain mindful that many of its prime constituents are adults who define themselves using the term “intersex.” It would be a mistake to advocate that “intersex” be replaced with “DSD” within such community, in the same way that people with a variety of different conditions identify themselves using terms which may vary from the terms employed by their health care providers (Morris, 2006, para 4.).

Despite this public acknowledgement of Morris’s warning, the ISNA did, in the end, abandon intersex altogether. And as it became increasingly clear that the move towards DSD was, for the ISNA, simultaneously a move away from intersex, many of those who had initially supported the ISNA began to distance themselves from the organization, including some of the very individuals who helped develop *The Handbook for Parents* and *The Clinical Guidelines* (Karkazis, 2008, p. 317, n11). As Karkazis (2008) writes, “several individuals who had helped contribute to the handbooks argued the new term medicalized and pathologized intersex conditions and people” and of them, three had their objection to the term included within the acknowledgements section of both documents (p. 317, n11). Esther Leidolf explained her motive for having her objection to DSD noted for the record as such: “As an intersex activist, educator and president of the MRKH Organization, I know many people who are deeply hurt and troubled by being told they have a disorder and they do not want to be part of a disorder movement” (Leidolf, 2006, para. 3).

It is unsurprising after so many years of activist and academic critiques calling specifically for the demedicalization of intersex conditions that so much of the controversy that emerged in the aftermath of the treatment model’s adoption focused specifically on the

pathologizing nature of the nomenclature. Many affected individuals and their advocates within both the academy and the activist community were angered specifically by the adoption of the language of disorder, leading some to argue for alternative diagnoses that carry a “non-stigmatizing, non-correction demanding” tone, such as “variations of sex development” or “divergence of sex development” (Karkazis, 2008, p. 259; Reis, 2007, p. 541; Diamond & Beh, 2006). Critics argued that not only does DSD merely replace an “already generic label”—intersex—in a more pathologizing manner, but further, that this generic label is ultimately useless, given that the new nomenclature requires the use of specific diagnoses (such as Congenital Adrenal Hyperplasia or Androgen Insensitivity Syndrome) for disorders which already “are classified within current medical diagnostic categories and [for which] the appropriate treatment is already established” (Alaniz, 2006, para. 3; Torres, 2006, para. 5). For those sympathetic to the critiques of the medicalization of intersex conditions and the general gender non-conformity that characterized the intersex activist movement and the queer identity politics undertaken by the ISNA in its early years in particular, the nomenclature’s adoption represents twin insults. First, the nomenclature itself is experienced by some as pathologization of the self, an effacement or delegitimization of their intersex identity. And second, the endorsement of the DSD treatment model by some of those very same activists and academics previously critical of the pathologization of intersex conditions—and further, their involvement in the treatment model’s adoption—come “as a betrayal and an abandonment of what they regarded as the larger goal” (Karkazis, 2008, pp. 258-59). Online reaction to both the DSD nomenclature and the ISNA’s endorsement of it became so heated at times that many of the critiques soon became infamous for devolving into ad hominem arguments, taking the form of “vituperative screeds against the integrity and motives of the nomenclature’s authors, as if an appropriate

response to the bad feelings generated by *disorders of sex development* would be to make its authors feel bad too” (Morland, 2012, p. 30).

While activists associated with the ISNA undeniably bore the brunt of the ire generated by the adoption of the DSD treatment model, a notable portion of this disdain was reserved specifically for feminist academics without diagnosed intersex conditions who were both publicly endorsing DSD and who had previously argued for the depathologization of intersex conditions—especially if they were either formally or informally associated with the ISNA—like Alice Dreger, April Herndon, and Ellen K. Feder.¹³ As Spurgas writes, many of

those who favor *intersex* [emphasis in original] over DSD resent what they consider an apolitical (or reactionary) and assimilationist conspiracy among certain intersex activists (many of whom are not intersex themselves) with members of the medical establishment and a myopic focus on abolition of surgical treatment, without considering the necessity of abolishing other types of unnecessary medical treatment (Spurgas, 2009, p. 107).

Karkazis too notes the characterization of the controversy in terms of assimilation, writing, the debate, which one person has referred to as a rift between assimilationists and non-assimilationists, appears to be an inevitable result of ISNA becoming more mainstream and has proven incredibly heated because it is deeply, achingly personal, centering on who gets to define, determine and label the truth and authenticity of one’s life (Karkazis, 2008, pp. 259-260).

¹³ While Herndon’s sole endorsement of the term came in Dreger and Herndon (2009), Dreger and Feder argued for its use in multiple publications (See Dreger, Chase, Sousa, Gruppuso, & Frader, 2005; Dreger, 2007; Feder, 2009a; Feder, 2009b; Feder & Karkazis, 2008).

This was not the first time feminist academics without diagnosed intersex conditions have been criticized for either their theoretical and pedagogical treatment of intersex issues or for their involvement in intersex activism. Emi Koyama of IPDX has developed multiple tools specifically for those without diagnosed intersex conditions teaching and/or writing about intersex, all of which are available on the group's website. In 2002's "From Social Construction to Social Justice: Transforming How We Teach about Intersexuality," Koyama and co-author Lisa Weasel provide specific "guidelines for teaching intersex issues" after their survey of 24 scholars found that "intersex existence is understood and presented largely as a scholarly object to be studied in order to deconstruct the notion of binary sexes (and thus sexism and homophobia) rather than as a subject that has real-world implications for real people" (Koyama & Weasel, 2002, p. 170). Some of their recommendations for those teaching about intersex issues include "giv[ing] authority to intersex people" through the inclusion of first-person narratives on course syllabi and "mak[ing] an effort to avoid presenting intersex voices as in need of legitimizing or interpretation by nonintersex 'specialists'"; not "exploit[ing] intersex existence for gender-sex deconstruction only"; "assum[ing] that intersex people are everywhere including in your classroom"; "recogniz[ing] that the intersex movement may have priorities and strategies beyond those of the gay and lesbian or transgender movement" and considering other movements the intersex movements have implications for (and vice versa) such as

the (dis) ability movement (normalization of bodies marked as different); psychiatric survivor movement; medical ethics (informed consent), health activism, and feminist antiviolence movements (child sexual abuse, domestic violence, female genital cutting, etc.); reproductive rights; children's and youth rights; and so on (Koyama & Weasel, 2002, pp. 175-176).

Even Cheryl Chase herself echoed this criticism of the instrumentalization of intersex individuals and intersex issues by feminist academics in order to prove a theoretical point in a fascinating interview between her and psychiatrist and the first chair of the ISNA's Medical Advisory board Vernon Rosario conducted in 2003 and published in a 2006 issue of the *Journal of Gay and Lesbian Psychotherapy*. In the published interview Chase responds to Rosario's question, "Returning to feminist appropriations of intersex, Suzanne Kessler in *Lessons From The Intersexed* proposes that intersex will help break down the gender divide. How do you feel about that?" with the following:

Among the humanities scholars who have taken an interest in intersex, Kessler is one of the early ones to actually be willing to listen to us and be helpful. She has been helpful in many ways, and we are grateful for that. However, I find the idea that intersex is a tool we can use or a bit of evidence we can use to create a society that has no sexes or genders to be ludicrous (Rosario, 2006, p. 98).

Some critics singled out feminist theory and the small group of those feminist academics without diagnosed intersex conditions both formally and informally associated with the ISNA as having in some way had undue influence over its political and tactical trajectory (Spurgas, 2009, p. 107). Ultimately, any attempt to determine just how much influence any one particular feminist theory or one particular academic had on the intersex rights movement generally or the ISNA in particular can be nothing more than conjecture, and this is a methodological obstacle that anyone engaging with these events and their outcomes must manage. Such conjecture is also, in my mind, a distraction from serious consideration of the important concerns these critiques raise. However, it is understandable that some individuals began to wonder about the relationship between the feminist academy/academics and the ISNA's political and practical transformation and its ultimate

endorsement of the DSD nomenclature. The nine-year period between the ISNA's successful capitalization upon the John/Joan case in 1997 and the publication of the Consensus Statement in 2006 saw both the ISNA's transformation as an organization and a substantial increase in both feminist academic theoretical and practical engagement with intersex issues and activism. Not only was there a proliferation of feminist academic publications on the ethics, politics, history of, and science behind the medical management of intersex conditions¹⁴ during this period, individuals with diagnosed intersex conditions and/or who identified as intersex activists starting coming into increased contact with and even joining the academy. For example, Associate Professor of Sociology at Wilfrid Laurier University Morgan Holmes completed her PhD at Concordia University in 2000 and cites both Anne Fausto-Sterling and Suzanne Kessler as providing her with inspiration and support in the Acknowledgements to her 2008 book *Intersex: A Perilous Difference* (Holmes, 2008, p. 9). After publishing "Feminism and Intersexuality" in the journal *Feminist Theory* in 2001, Iain Morland went on to complete his PhD in English Literature and Media Arts at the University of London and has held lectureships at both Cardiff University and the University of the West of England. Later articles of Morland's have appeared in *Textual Practice* (2001) and *Feminism and Psychology* (2008), and Morland would come to guest edit the 2009 special

¹⁴ In 1998, social psychologist Suzanne J. Kessler published her monograph *Lessons from the Intersexed*, the second chapter of which "The Medical Construction of Intersex" first appeared in a 1990 issue of *Signs* and is cited by many (most notably Dreger & Herndon, 2009) as foundational to both the intersex rights movement and the vaguely bounded field occasionally referred to as intersex studies. That same year, feminist historian and philosopher of science Alice D. Dreger published her monograph *Hermaphrodites and the Medical Invention of Sex* surveying the history of the medical management of "human hermaphrodites" in France and Britain between 1880 and 1915 and guest edited a special issue of the *Journal of Clinical Ethics* devoted to the topic of intersexuality. In 1999, articles from this special issue along with additional articles by academics, activists and physicians appeared in a volume edited by Dreger titled *Intersex and the Age of Ethics*. Additional noteworthy publications of this period of time include 2000's *Sexing the Body: Gender Politics and the Construction of Sexuality* by Anne Fausto-Sterling and 2003's *Intersex and Identity: The Contested Self* by sociologist Sharon E. Preves.

issue of *GLQ* devoted to academic ruminations on (as well as criticisms and defenses of) the adoption of DSD appropriately titled “Intersex and After.”¹⁵ And many intersex activists began publishing in and appearing at (primarily feminist) academic journals and conferences and their work was increasingly taken up by at least some feminist academics.¹⁶ Furthermore, and perhaps most importantly, at the same time that intersex individuals and activists began to get more involved in academic culture, feminist academics began to get more involved in the intersex activism on the streets—or at the very least, on the non-profit boards. There was an influx of feminist academics into the ranks of the ISNA, most notably Alice Dreger whose formal association with the ISNA began in 1996 and who spent six of the nine years she was with the ISNA serving as Chair and President of the board of directors (1998-2003 and 2004-2005) before taking up the paid, part-time position of director of medical education in 2005 (Dreger & Herndon, 2009, p. 200).¹⁷ In addition to Dreger, feminist scholar April M. Herndon served as the ISNA’s director of programming from June 2005 to May 2006, feminist philosopher Ellen K. Feder is identified on the ISNA’s website as having been an active member of the organization since 1999, and it was under feminist sociologist Monica Casper’s leadership as executive director of the ISNA in 2003-2004 that

¹⁵ This is, of course, by no means an exhaustive list, particularly given that there are likely many individuals within the academy who neither take up intersex issues in their work, publically identify as having intersex issues and/or are unaware of their having an intersex condition having never been diagnosed.

¹⁶ At the 2000 meeting of the Central Division of the American Philosophical Association, Chase appeared on a panel on Issues in Intersexuality presented by the Society of Lesbian and Gay Philosophy titled “Philosophy as a Tool for Real-World Activism” (APA, 2000, p. 65). For examples of articles written by intersex activists or individuals with intersex conditions that either appeared in academic journals or were at the very least taken up by feminist academics, see Chase, 1993, 1997, 1998a, 1998b, 1999; Davis, 2011; Davis & Murphy 2013; Holmes, 2005, 2008a, 2008b, 2009, 2011; Morland, 2009, 2011, 2012.

¹⁷ During the interim 2003-2004 period, Dreger served as chair of the ISNA’s fundraising committee (Dreger & Herndon, 2009).

the group created the Medical Advisory Board, which many see as marking the end of an era in the history of the organization (Dreger & Herndon, 2009, p. 200; Preves, 2004-2005).

It is likely a result of this history that many of those activists and feminist activists who have found themselves in the “admittedly uncomfortable” position of strategically endorsing the DSD treatment model after years critiquing the pathologization of intersex conditions have provided some of the most philosophically rigorous versions of the arguments in its favour. Generally speaking, four types of arguments have been offered in the DSD treatment model’s favour.

V. The Arguments for DSD

The first of these—which is also least commonly given—defends the adoption of the DSD nomenclature and treatment model on specifically biological and/or medical grounds. Within the Consensus Statement itself we can find two such arguments: that “a modern lexicon is needed to integrate progress in molecular genetic aspects of sex development” and that “because outcome data in individuals with DSD are limited, it is essential to use precision when applying definitions and diagnostic labels” (Lee et al., 2006, e488). In addition to this, we can add, with some caution, Dreger et al.’s 2006 arguments for the “disorders of sex differentiation” as a nomenclature that integrated progress in the science of sex differentiation (and specifically, did not privilege gonads given they do “not correlate simply with genotype, phenotype, physiology, diagnosis or gender identity”), that did not confuse physicians and patients (thus complicating treatment) and that enhanced rather than complicated the use of “medical informatics in research and clinical practice” (Dreger et al., 2006, pp. 731, 733).

The second and third types of argument favor these changes on specifically sociopolitical

grounds, with the former focused specifically on the sociopolitical problems of intersex and the latter on the sociopolitical good (or at least, neutrality) of DSD. Academic and/or activist proponents of the DSD nomenclature and treatment model often give a combination of both types of arguments when articulating their position. Each of these corresponds to one part of the discursive shift that others (Germon, 2009; Spurgas, 2009) have argued occurred with the adoption of DSD and with whom I agree: the jettisoning of intersex as a legitimate queer sociopolitical identity, and the constitution of a new, specifically biomedical reconstitution of intersex conditions as disorders of sex development.

Arguments focused on the problems associated with intersex point out that not only does the question of who “counts” as intersex remain contentious, but further, they deny the existence of an intersex community similar to the “lesbian community” and subsequently deny the existence of an intersex identity (beyond that of the intersex activist) that is not the sexualized result of medical power. The term forces a normalizing, politicized, and presumably queer identity upon individuals with these conditions to which many not only do not relate, but further, find offensive (Dreger & Herndon, 2009).¹⁸ They argue that many understandably mistake intersexuality as analogous with homosexuality, such that they assume there is an intersexual identity and thus that the “intersexual” exists in the same way the “homosexual” does. As a result, they argue: 1) that those who object to the adoption of DSD as offensive are trying to prevent a pejorative meaning from attaching to something which does not really exist and 2) that “the pathologization putatively effected by the new nomenclature would constrain unduly the range of possibilities of affected individuals to

¹⁸ While parental concern regarding the politicized nature of the term intersex and of assigning such a term to a child is understandable, it is not clear to me either that a) physicians were ever assigning children that diagnosis at birth (especially given the large amount of literature on physicians withholding diagnoses) or that b) intersex is somehow a more inherently political a label than male or female.

understand themselves” (Feder, 2009, p. 226). Furthermore, these arguments point to concerns about the co-optation of intersex by trans* individuals¹⁹ and instrumentalizing feminist academics, as well as the unwanted attention “intersex” draws from fetishists as a result of its implied sexual nature, individuals who are known contemptuously within the community as “wannafucks.”²⁰

The third type of argument deals specifically with the presumed benefits of the DSD nomenclature and treatment model, and these arguments can be further sub-divided into those which are explicitly sociopolitical and those which are couched in terms of pragmatism or practicality (and which I would argue are nonetheless still sociopolitical insofar as they aim at social and political interventions). Beyond the DSD nomenclature meeting parents and physicians “where they live,” and thus better facilitating collaboration between activists and medical authorities, the other main pragmatic argument has to do with the ability of the DSD nomenclature to improve access to care for those with intersex conditions unable to get it. Ellen K. Feder (2009) makes this argument most explicitly, stating that as a result of years of politicized intersex activism and a mistaken (though understandable) assumption of intersexuality as analogous with homosexuality, medicine has come to ignore or marginalize some of the concrete medical concerns faced by those with intersex conditions “in favor of a

¹⁹ For example, in addition to the quote introduced on page 46 of this dissertation by Koyama (2006, para. 23) regarding trans* individuals turning to intersex identity in order to find “a social and biological justification for being who they are,” Dreger et al. (2005) make a rather oblique reference to the terms intersex and hermaphrodite attracting “a large number of people whose interest is based on a sexual fetish and people who suffer from delusions about their own medical histories”(p. 732).

²⁰ It is not clear to me that increased medicalization of a bodily state or condition necessarily removes those with those bodies or conditions out of the realm of the pornographic; the increasing medicalization and pathologization of obesity has done little to temper the desires of “chubby chasers.” Moreover, the abundance of non-condition or body specific medicine-related fetishes to a more general sexualization of the clinic that I would argue is often seen in and should be expected of other sites of knowledge/power such as the school and the prison.

disproportionate, or even what appears in some cases to be a kind of hysterical, concern with gender and genitalia” (p. 229). Through the remedicalization of intersex conditions as disorders of sex development, we can reorient medical attention to the matters of health and “human flourishing” which are its proper purview, such that individuals with intersex conditions may be able to receive the competent, respectful care they need. The explicitly sociopolitical arguments offered in the DSD nomenclature’s favor stress the benefits of the language’s ability to render intersex conditions “disorders like any other,” that is, manageable discrete problems of the body which in no way influence sex, gender or sexuality. Unlike the socio-politically challenging term ‘intersex’—with its implications that one is neither male nor female—‘DSD’, it is argued, takes pressure off both parents and physicians to “shore up” an infant’s sex through genital normalizing surgery. Furthermore, this will not only allow individuals to avoid the imposition of a sexualized, queer identity to which they do not relate, but further, “makes the phenomenon seem more manageable by being less potentially all-encompassing of their identities” (Dreger & Herndon, 2009, p. 212). Beyond the nomenclature, DSD proponents emphasize the new treatment model as espousing “patient centered care” (ISNA, 2000; Consortium on the Management of Disorders of Sex Development, 2006a). According to the ISNA, patient-centered care is care that grants the individual with an intersex condition the authority and autonomy to direct their own health care. In terms of the clinical environment, ISNA’s “Clinical Guidelines” identifies “patient-centered care” as ideally cashing out as lifelong medical management that espouses a

multidisciplinary team approach to caring for individuals with variations in congenital sex anatomy—with teams ideally consisting of members from the following disciplines: child psychology/psychiatry, genetic counseling, gynecology, nursing,

pediatric endocrinology, pediatric urology, social work and ‘others as needed’

(Consortium on the Management of Disorders of Sex Development, 2006a, p. 10).

The fourth and final type of argument offered in favour of the DSD treatment model, is one upon which the prior two forms of sociopolitical argument rest. It states that we need to “remedicalize” these conditions so as to separate them specifically from sociopolitical issues. For example, Feder (2009) contends that by rendering intersex conditions “disorders like any other,” we may in turn make clear the distinction between “the cultural issues of identity in which medicine has intervened and narrower matters of health,” such that medicine may reorient itself towards its proper subject of “human flourishing” (p. 239). Thus, DSD proponents claimed that the language would make physicians and parents feel less compelled to choose surgery and “fix” the problem of the intersex body by rendering intersex conditions less sociopolitically challenging through their identification as manageable disorders of the body. These four types of arguments are the ground upon which some of the most vocal critics of the pathologization of intersex conditions supported their repathologization as disorders of sex development.

VI. Conclusion

In addition to reviewing the histories of medicine, feminist scholarship, and intersex activism out of and against which the DSD treatment model emerged, I have, thus far, also sketched out both the *why* and the *how* behind the move from intersex to DSD. That is, I have thus far both 1) outlined the motivations that drove those who once criticized the pathologization of intersex conditions to endorse a treatment model reclassifying them as disorders of sex development and 2) detailed the four arguments via which this apparent reversal in position was achieved. I say apparent here because I do not think that the way any

of these people actually think about intersex conditions has fundamentally changed. That is, I don't think that Chase, Dreger, Feder, Karkazis, Herndon, or any other activist or academic who endorsed DSD did so because they had actually come to believe that having an intersex body is in fact pathological *in itself*.²¹ Supporting the identification of conditions with the potential to cause the atypical development of sex characteristics as disorders of sex development was merely a strategy, not a sign of their newfound belief that atypicality was indeed equivalent to pathology; ambiguous genitalia are not the “concrete medical needs” they are trying to shift medical attention towards.

The hope was to achieve a shift in rhetoric that would dispel the specter of queerness haunting those bodies of those deemed *inter-sex*, so that both physicians and parents would focus their anxieties, attention and interventions on that which was *really* or rather *naturally* pathological (such as the oft-cited potentially fatal salt-wasting associated with some forms of CAH), as opposed to that which was *socially constructed* as pathological (such as failing to cohere with norms of sex and gender).²² The goal here—if not a moratorium, then at least a reduction in the performance of genital normalizing surgeries—was, uniquely, one shared by the vast majority of activists and academics whether they were for or against DSD. And if that goal had been achieved, perhaps the ends (fewer surgeries) would have justified the means (a more pathologizing diagnostic label that at least some intersex people experience as an imposition and/or a betrayal). Unfortunately, DSD failed as a strategy; not only are the surgical recommendations in the Consensus Statement nowhere near the moratorium that the majority of activists and academics wanted, it is now painfully clear that there has been

²¹ Karkazis did initially endorse DSD (Feder & Karkazis, 2008) but has since backed off from this position.

²² Though the term “real” is often invoked as the oppositional binary term to “socially constructed,” this is a mistake for many socially constructed things are very obviously *real* and obtain in the world such as race, the cosmetics industry, or professional associations.

no decrease in the frequency with which medically unnecessary genital normalizing surgeries are performed (Feder, 2014, p. 88, pp. 133-152). In her 2014 book *Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine*, Feder writes that although the paternalism that characterized the clinical management of those with intersex conditions under the OGR treatment model is increasingly a thing of the past, “no significant change in the number of surgeries performed has occurred” (Feder, 2014, p. 140). Drawing on interviews with physicians engaged in intersex management, Feder found that where counseling parents regarding the performance of genital surgeries is concerned, physicians often see themselves as ethically required to engage in the type of non-directive counseling that characterizes the realm of prenatal genetic counseling. Clinicians see themselves as ethically required to present the potential benefits and harms of genital normalizing surgery (as well as the absence of evidence for both) in a way that achieves a type of “net neutrality” wherein the physician withholds their own value judgments and leaves the final decision to the parents on the basis of facts alone. Thus, even those physicians who are personally skeptical about genital-normalizing surgeries withhold that judgment and their concerns from parents or proxy decision-makers, for it is “not their place to promote ethical reflection in the parents of the children with atypical sex anatomies they treat,” particularly in the context of “nonurgent medical decisions” (Feder, 2014, p. 136). Subsequently, genital normalizing surgeries are now constituted in a way such that they are performed with the same regularity as before, but are now almost exclusively justified by parental desire and choice (Feder, 2014, pp. 133-141).²³ Thus, despite the Consensus Statement’s official caution against unnecessary

²³ It is worth noting that in light of the overwhelming lack of clinical evidence regarding the various surgical techniques used with intersex infants, there is really little physicians can tell parents regarding the potential benefits or harms associated with them. Cohering with this logic, then, ethical counseling would necessarily focus on the absence of evidence for

surgeries (particularly in cases of less severe masculinization), the frequency with which they are performed remains undiminished.

Unsurprisingly, critiques of the DSD nomenclature and of the practice of surgical normalization continue to be raised. Beyond its potentially stigmatizing and delegitimizing effects for those who identify as intersex, many have countered that the pathological language of disorder not only *demand*ed fixing, but further, made it even more difficult to talk about intersex conditions with children who have them in a way that doesn't make them feel "inherently dysfunctional and bogus" (Baechler, 2006, para. 3). Further still, many have pointed to the lack of consensus surrounding the "Consensus Statement"—including some of those involved in the process. For example, Alice Dreger writes,

[A]s I'm finishing up the handbooks, there's a "consensus" meeting of pediatric endocrinologists coming about in Chicago. I put "consensus" in quotes because this was an invitation-only meeting of mostly M.D.'s; no parents were invited, only two adults with intersex were invited, and most of the medical specialties who care for people with intersex were either not represented or very underrepresented.

Nevertheless, this was an important meeting, and we knew that it was a chance to move the system forward, towards more patient-centered care (Dreger, 2007, para. 20).

Whatever little international input there was regarding either the terminology or the treatment model came solely from medical professionals, leading critics to accuse both the treatment model itself and the process out of which this internationally applied standard of care was generated of an ethnocentricity that is evident in the nomenclature's failure to translate in other languages (Spurgas, 2009, p. 111). Critics have pointed out that "disorders

regarding both potential harms and benefits, and thus, the experimental nature of these procedures.

of sex development” has “unfortunate overtones of ‘disturbed’ in German” (“Störungen der Geschlechtsentwicklung”) and that the ambiguity between *sex* development and *sexual* development in Romance languages such as French (“désordres du développement sexuel” or “anomalies du développement sexuel”) and Spanish (“trastorno de desarrollo sexual”) “leads the layman to think that you are talking about sexual orientation, pedophilia, fetishism, masturbation, etc.” (Thomas, 2006, p. 3). As Spurgas (2009) writes,

Regardless of being ‘pro-intersex’ or ‘pro-DSD’, most intersex individuals, activists and allies around the world agree that the DSD initiative was almost exclusively a U.S.-based enterprise and that there will inevitably be widespread international consequences for this North American medical and taxonomic imperialism (as there has been in other situations of Western medical colonialism) (p. 111).

In addition to the pathologizing, ethnocentric nature of the nomenclature, others, like self-identified intersexed sociologist Georgiann Davis (2011) argue that the shift to DSD has accomplished a reassertion of medical authority over intersex conditions—authority that was successfully challenged by intersex activists, “with legitimacy gained from feminist scholarship,” in the 1990s (p. 158). Davis argues that through the identification of intersex conditions as discrete disorders of the body “like any other” properly and best managed by expert teams, physicians are able to reassert their authority over intersex conditions (and the bodies and individuals that have them), while at the same time minimizing their exposure to liability (p. 175). Moreover, Davis is but one of many who have raised concerns over the nomenclature’s “perceived complicity with

capitalism, in a system in which medicalization is made profitable” (Davis, 2011, p. 167; Spurgas, 2009, p. 106).²⁴

Beyond this, intersex scholar Morgan Holmes (2008b, 2009) and critical-disability scholar Robert McRuer (2009) have argued that DSD not only fails to bring intersex into closer contact with disability studies and activism (as some have argued, particularly Koyama, 2006), but furthermore, Holmes (2008) has argued that the pathologization of intersex bodies through DSD serves to reinforce the pursuit of prenatal technologies for the eugenic purposes of identifying intersex fetuses for selective termination. Eugenic practices aim at modifying the population by preventing or ending certain lives through practices like contraception, sterilization, abortion, and euthanasia, as well as improving or bringing about other lives through practices like environmental reforms or pre-implantation screening and selection of embryos (Levine and Bashford, 2010, pp. 3-4). Critical disability scholars and bioethicists have critiqued that which Levine and Bashford (2010) refer to as the “evaluative logic” at the core of such practices, identifying “some human life [as] of more value—to the state, the nation, the race, future generations—than other human life” (pp. 3-4). Thus, such practices are applied differentially in order to eliminate particular lives or populations and to promote and proliferate others. Though few of those who strategically endorsed DSD have acknowledged or attempted to address these eugenic concerns, the concerns are justified if recent publications like Adam et al.’s 2012 article “Ambiguous Genitalia: What Prenatal Genetic Testing is Practical?” or the 2013 *American Journal of Bioethics* target article and a suite of replies debating the ethics of

²⁴ As Davis (2011) points out, “[t]he surgical modification of intersex genitalia is an incredibly lucrative practice for urologists because the surgeries are imperfect and often require revisions and modifications, or more directly, reoccurring visits to a costly operating room” (p. 167).

prenatal genetic testing to prevent the birth of infants with intersex conditions are any indication.²⁵

Finally, in a surprise move, the United Nations Special Rapporteur on Torture and other Cruel, Inhumane or Degrading Treatment or Punishment, Juan E. Méndez, released a statement in February 2013 condemning the performance of genital normalizing surgeries on intersex infants unable to consent, as well as their involuntary sterilization, and calling upon all States to repeal any laws allowing such “intrusive and irreversible treatments” (Méndez, 2013, p. 23). Méndez’s critique is the only one I’ve managed to find any acknowledgement of or response to by health care professionals, official or otherwise, since the adoption of the DSD treatment model. In November 2013, AIC posted a letter by a group of endocrinologists responding to the Special Rapporteur’s report. It is signed by S. Faisal Ahmed, the Samson Gemmell Chair of Child Health at the University of Glasgow, on behalf of a group 14 international endocrinologists (including Faisal), who collectively represent members of the European, American, Latin-American, Japanese, and African pediatric endocrine societies.

The letter begins by thanking the Special Rapporteur for drawing attention to the issue of the treatment of atypical genitalia (“in [patients for] whom a condition classified as a ‘disorder of sex development’ is suspected”), which they note is associated with “stigma and shame,” with the hope that “discussions and greater awareness generated by this report may eventually lead to improved care, long-term outcomes and wellbeing for

²⁵ Thankfully, our limited knowledge of the molecular genetics underlying many intersex conditions also limits our ability to prenatally screen for fetuses with such conditions, for the moment. Adam et al. lament that although our knowledge of the multitude of genetic mutations responsible for DSDs is increasing, “our postnatal genetic testing is still low yield,” concluding “until we are able to fully understand the genetic causes of the clinical diagnoses made after birth, our ability to molecularly diagnose these conditions prenatally will remain elusive” (Adams et al., 2012, p. 1341).

affected children and families” (Ahmed et al., 2013, para. 1). They agree that historically, “a great deal of emphasis has been placed on surgical interventions that have been aimed at ‘normalizing’ the appearance of the child’s genitalia” and acknowledge that “some individuals who have undergone such procedures have felt that they have been harmed as a result” (para. 2). Nonetheless, they argue that “over the last few years, medical practice has begun to change considerably, with a greater emphasis being placed on consideration of functional and psychosocial outcomes rather than simply cosmetic appearance,” while admitting there is also a great deal of variation in clinical practice internationally. They stress the need for both the standardization of practice and increased knowledge production about these practices, writing,

there is a need for greater cooperation and collaboration amongst clinical specialists who deal with such conditions through local, national and international networks to increase knowledge regarding long-term outcomes and optimal care for affected individuals, now and in the future (Ahmed et al., 2013, para. 2).

The authors go on to stress the need for access to competent medical care, arguing that every affected child and their family “require access to highly-skilled specialists who can cater for and are receptive to [their] diverse needs,” before concluding with the acknowledgement that “any clinical intervention, medical or surgical, irrespective of the underlying condition, needs to be considered very carefully in all young children who cannot give informed consent,” which they identify as the principle at “the heart of all clinical practice in children” (Ahmed et al., 2013, paras. 3-4).

This letter and its logic are, I argue, exemplary of the general position among clinical practitioners in the Post-Intersex/DSD era. Intersex conditions and ambiguous genitalia in particular are obviously pathological and need to be fixed, but medical practice historically

focused on aesthetic over “functional” and/or “psychosocial” outcomes and was not evidence-based (with the implication being that ethical medicine is equivalent to evidence-based medicine). Thus, the goal in the Post-Intersex/DSD era is not *fewer* surgeries, but *better* surgeries along with their international standardization. The two main specters that haunt the practical and rhetorical management of intersex—a general paucity of evidence and inability to acquire informed consent—are present here as well, in an emphasis on knowledge production and an acknowledgement of informed consent (or lack thereof) as at “the heart” of all pediatric care, with no real discussion of how we might address concerns regarding informed consent specifically when dealing with actual intersex kids. Thus, current surgical practice is positioned as superior to past surgical practice on the grounds of the latter’s improper focus, paucity of evidence, and violation of autonomy. However, the only real difference here seems to be that of surgical *focus*: current surgical practice suffers the same paucity of evidence and engages in the same violations of autonomy. In fact, physicians have never been quite as explicit about the extent of what they *don’t know* about DSDs or DSD management as they are now, and yet the frequency with which infants are subjected to surgical “treatment” continues unabated. For example, a 2012 meeting of the multi-disciplinary Working Party on DSD in Annecy, France focused specifically on “needed information” rather than attempting to “define the present status of management of each of the various DSD diagnoses” with the hope that “by recognizing that which was *not known* [emphasis in original], protocols will be developed for improving both early management and transition to adult life” (Schober et al., 2012, p. 617). As Diamond and Garland write, the Working Party concluded that the studies they reviewed in order to “assess the validity of surgery for children with [DSDs]” suffered from “methodological weaknesses,” the fact that evidence-based recommendations regarding timing and surgical approach cannot be made,

“that critical long-term studies are ‘scarce’ and unlikely to emerge, and, most significantly, that ‘no studies’ support the belief that gender variant children require early genital surgery for societally favored gender development” (Diamond & Garland, 2014, pp. 2-3; Creighton et al., 2012; Schober et al., 2012).

Thus the epistemic and ethical context of DSD seems to be exactly the same as that of OGR; if anything, the twin specters conjured by a lack of clinical evidence and the violations to autonomy these practices constitute loom larger than ever before. And yet, there is no indication that medical practice has changed in the least. Furthermore, following the adoption of the DSD nomenclature and treatment model, it seems unclear to many of those interested and invested in bringing about bigger changes to the treatment model what to do next. This lack of clarity was only compounded by the fractious controversy the Consensus Statement and the ISNA’s involvement in its production has ignited within the intersex activist and feminist academic communities. The political power of intersex activist community once embodied in the ISNA is now scattered among multiple different activist groups like the Accord Alliance, Organisation Intersex International, Bodies Like Ours, Intersex Initiative Portland, and Advocates for Informed Choice, which range along the political spectrum and undertake a variety of different forms of activism from hosting online message boards to legal initiatives.²⁶ Further, the prolonged timelines associated with

²⁶ Notably, Advocates for Informed Choice, a non-profit organization which undertakes legal strategies “to advocate for the legal and human rights of children born with intersex traits,” is currently pursuing a lawsuit in the state of South Carolina that could set a new precedent regarding intersex management in that jurisdiction (Advocates for Informed Choice, n.d., para. 1). In 2013, the group, in collaboration with the Southern Poverty Law Center and the firms of Janet, Jenner & Suggs and Steptoe & Johnson, filed two lawsuits on behalf of an intersexed child known as M.C. who received feminizing surgical normalization (including gonadectomy) at the age of 16 months while under state care and who now identifies as male (Tamar-Mattis, 2013). The state-level lawsuit (*M.C. vs. Medical University of South Carolina*) brought claims against the hospitals “based on lack of informed consent and

academic publishing delayed the response of many feminist academics for whom both the Consensus Statement and their colleagues' endorsement of it came as a surprise. This uncertainty has taken on an increasingly tragic dimension as it has become clear that the strategy of meeting physicians at the level of the biomedical has failed. As Feder (2014) writes, "for several years, it did not appear that change beyond that modestly outlined in the 2006 Consensus Statement was possible" (p. 207). I would argue that for many of those interested and invested in resisting the DSD treatment model and the practices of normalization outlined within it (myself included), it is still not clear what change is possible, or, more importantly, how best to achieve it. Indeed, the fracturing of the activist and feminist academic communities this strategic failure has brought about seems to have left both groups ill-equipped to address this outcome and faced with the same lesson they had themselves been trying to teach physicians through their critical intersex scholarship and activism: good intentions do not necessarily lead to good outcomes.

In an attempt to move both our discussion and practice around intersex forward, I turn in chapter two to those four arguments outlined above in favor of the DSD treatment model, undertaking a detailed review of them in order to examine what went wrong with DSD. That is, I want to cash out why it is that DSD failed as a strategy to achieve the goals of reorienting medical attention towards natural rather than socially constructed pathologies, and thus bring about reduction in the frequency with which medically unnecessary genital normalizing surgeries are performed on infants and children unable to consent.

against the Department of Social Services based on gross negligence," while federal-level companion lawsuit (*M.C. vs. Aaronson*) charged that the defendants—including NATFI convener Aaronson—violated M.C.'s constitutional rights (Pagonis, 2015, para. 8). In January 2015, the United States Court of Appeals for the Fourth Circuit overturned a district court's ruling in the case of *M.C. vs. Aaronson*, preventing the federal case from proceeding to trial (Pagonis, 2015). As of September 2015, the group is continuing its pursuit of the state-level case, which the state court has already ruled may proceed to trial (Pagonis, 2015).

Chapter Two: Diagnosing the Failure of DSD: Medical Power/Knowledge and the Fictitious Unity of Sex, Gender, and Sexuality

I. Introduction

In this chapter, I lay out my diagnosis of what went wrong with DSD—that is, why it failed to achieve the specific goal of a reduction in the performance of medically unnecessary genital normalizing surgeries on intersex infants. I begin with an analysis of the arguments offered in favour of DSD, which I argue are at the heart of DSD's failure. I conclude that these arguments entailed a theoretical commitment to 1) an objectivist theory of pathology and the nature/culture distinction it entails; 2) the binaries of impairment/disability and sex/gender which follow from the logic of nature/culture; and 3) an understanding of power which Michel Foucault refers to as sovereign or juridico-discursive. This shifted the terrain for thinking and talking about intersex conditions in the post-Intersex/DSD era in ways that have contributed to the uncertainty that still plagues many of those hoping to move beyond DSD.

II. Troubling DSD

In this section, I critically assess the three remaining types of arguments offered in favor of the DSD nomenclature—beginning with the specifically biomedical arguments in its favor—toward the end of providing an argument for DSD's failure as a strategy. It is worth noting that few activists and feminist academics or clinicians provide these types of arguments in favor of the DSD nomenclature or its accompanying treatment model. And this makes sense—as the Working Party on DSD concluded at their 2012 meeting in Annecy, France, there is no clinical evidence to ground the surgical management of intersex

conditions and until there is, “decisions about techniques and timing of genital surgery will continue to be debated by a multidisciplinary team on a case-by-case basis with individual surgeons relying on their own professional expertise and opinions to recommend what they judge best for their patients” (Creighton et al., 2012, p. 608).²⁷ The primary (and really the only) biomedical arguments in favour of DSD come from the Consensus Statement itself, to which we can cautiously add Dreger, Chase, Sousa, Gruppuso, & Frader’s (2005) arguments in favour of “disorders of sex differentiation.”

In addition to “recognizing and accepting the place of patient advocacy” as well as heightened awareness of ethical issues and patient advocacy concern,” the Consensus Statement provides two specifically biological or biomedical arguments for the reclassification of intersex conditions as disorders of sex development and the revision in treatment model it outlines. First, that “a modern lexicon is needed to integrate progress in molecular genetic aspects of sex development” noting that the ideal nomenclature is one that is both “sufficiently flexible to incorporate new information yet robust enough to maintain a consistent framework” and “is descriptive, reflect[ing] genetic etiology when available and accommodate[ing] the spectrum of phenotypic variation” (p. 490). Second, that “it is essential to use precision when applying definitions and diagnostic labels” given the limited outcome data on those with DSD. Additionally, Dreger, Chase, Sousa, Gruppuso, & Frader (2005) identify the intersex system of nomenclature as “scientifically questionable” due to its failure to represent or capture natural kinds or, in their words, to “carve the world at its joints” (p. 730). Further, they appeal for a nomenclature that does not have any implications regarding future sex or gender identity, given that they may be at odds with the particular

²⁷ The move to non-directive counselling, however, seems to imply that patients—and particularly, parents/surrogate decision makers—do not in fact have access to their surgeon’s professional expertise or opinions during the decision-making process.

markers of sex (for example, a woman with CAIS may identify and present as a woman, yet nonetheless have testicles and normal androgen production). They also join the Consensus Statement authors calling for a nomenclature that would better facilitate knowledge production about those with intersex conditions.

There is, unfortunately, little explanation within the Consensus Statement as to how DSD might be a less confusing or more precise diagnostic label than intersex, or how it is somehow closer to “carving the world at its joints,” given that its categories capture a variety of more or less well-known and more or less related conditions, each with their own unique etiology, sequelae, health risks, and treatment mode. For example, as illustrated in Table 2 below, 46 XY DSD alone captures individuals with CAIS, PAIS, cloacal exstrophy, hypospadias, and micropenis, as well as any former “true hermaphrodites” with 46 XY chromosomes.

Table 2

Intersex Conditions Sorted by DSD Classification

46 XY DSD	46 XX DSD	Sex Chromosome DSD
CAH; Cloacal Exstrophy; 17 β -Hydroxysteroid Dehydrogenase-3 Deficiency; 5 α reductase deficiency; PAIS; CAIS; Hypospadias; Micropenis; Complete or Partial Gonadal Dysgenesis; Ovotesticular DSD; Penile Agenesis or Aphallia	CAH; Cloacal Exstrophy; 17 β -Hydroxysteroid Dehydrogenase-3 Deficiency; De La Chappelle or XX Male Syndrome (46 XX Testicular DSD or 46 XX Ovotesticular DSD); Labial Adhesions	Klinefelter Syndrome and variants (47 XXY, 48 XXXY etc.); Turner Syndrome and variants (45 X); 45 X/46 XY Mixed Gonadal Dysgenesis; 46XX/46XY Chimerism

Note. From Peter A. Lee et al., “Consensus Statement on Management of Intersex Disorders,” *Pediatrics* 118.2, 2006, e489, table 2.

Indeed, given the wide array of diagnoses that fall within each category, not only is it not clear how the DSD nomenclature integrates progress made in our understanding of the molecular genetics of sex differentiation, but it’s also not clear that such integration is even

possible. Furthermore, given our lack of knowledge about the molecular genetic mutations responsible for the majority of DSDs, it's unclear how we could even hope to incorporate it into a system of nomenclature or treatment model at this time. As Hiort et al. (2012) write, "exact aetiology and pathogenesis remain unclear in the majority" of intersex conditions (p. 625):

For some disorders like complete androgen insensitivity, a molecular diagnosis can be obtained in almost 90% of the cases, while in others like complete gonadal dysgenesis it may be below 20%. For some clinical entities like Mayer-Rokitansky-Küster-Hauser syndrome (MRKHS) (a syndrome with aplasia of the uterus and renal abnormalities) molecular pathways and genetic causes are completely elusive at this point (Hiort, Wunsch, Cools, Looijenga, & Cuckow, 2012, p. 625).

Given this, it is unsurprising that in the majority of cases, diagnosis achieved via a combination of biochemistry and karyotype is rarely confirmed by genetic analysis (only ~20% of those with intersex conditions receive a specific genetic diagnosis) (Lee et al., 2006, e491). Thus, it is unclear how a system of nomenclature that represented this kind of information would be helpful, let alone possible.

Despite the apparent failure of the nomenclature with regards to precision or accuracy it is worth noting that the shift to DSD nomenclature has nonetheless been very successful in terms of spurring knowledge production about individuals with DSDs. Both feminist/activist critics and clinicians have identified and bemoaned lack of outcomes studies (particularly long term) and thus the paucity of clinical evidence supporting the treatment model for those with intersex conditions. Indeed, I would argue that for many on both sides, the accumulation of more data about those with intersex conditions has been positioned as the "magic bullet" which would silence social, political, and ethical concerns

about the treatment model. Within contemporary clinical practice, ethical medicine is often seen as equivalent to evidence-based medicine, insofar as the evidence indicates the best, and thus the most ethical course of action. As Borry, Schotsmans, and Dierickx (2006) put it, “the provision of empirical medical data about particular interventions seems to improve and even *conclude* [emphasis added] the process of ethical decision making” (p. 307). The production of data itself thus comes to take on a moral value such that there exists a moral imperative to produce it, particularly in those cases where there is an inadequate evidence base. In this sense, what Borry et al. refer to as the “empirical value and the normative value” of that evidence and its production “often cannot be clearly distinguished” (p. 309). The authors, however, caution against this equation of ethical medicine with evidence-based medicine, pointing out that while evidence might be a necessary condition for ethical medical decision-making, it is an insufficient one:

Obviously, an ethical decision will benefit from research information about the diagnosis, prognosis or treatment of a given condition provided by guidelines, systematic reviews, or randomized controlled trials. This will lend the necessary justification for the ethical decision which must be made. However, this does not mean that it is sufficient justification for a particular choice. The best choice from an empirical point of view is not necessarily the best from an ethical point of view (p. 309).

In fact, the “normative views of the doctors and patients might flatly contradict the empirical reality” in that either or both parties might see the best course of action from an empirical perspective to be the worst course of action from an ethical one (p. 309).²⁸

²⁸ Indeed, this situation often arises in the context of end-of-life care.

Two years after the publication of the Consensus Statement, the EuroDSD project, which describes itself as “a collaboration of doctors and scientists from all over Europe” formed, with initial funding provided by the European Society for Paediatric Endocrinology (ESPE) (Hiort et al., 2012, p. 625). This group began the web-based EuroDSD clinical research database, which has been known as the International DSD (I-DSD) database since 2011 and which has been expanded beyond Europe to now include “clinical centres from Africa, Asia, South America and the USA for entry of patients—many of whom are now using the I-DSD platform for their own DSD patient data management following the high standards defined in the EuroDSD project”(Hiort et al. p. 625). As Hiort et al. (2005), outline in their article, patients of any age treated at a center with “an approved clinician can be included into the I-DSD registry” (pp. 624, 625). It is the clinician’s responsibility to obtain informed consent either from the patient or their legal guardian, “according to national regulations,” however, once this is done, the approved clinician can enter a variety of detailed information regarding the patient, all of which is stored in a “non-identifiable” manner using automatically generated identifiers (p. 625). As the authors write, in its current form, the database compiles “information about birth weight, karyotype, initial sex assignment and the underlying diagnosis, as well as the level of certainty of this diagnosis. Additionally, associated malformations can be entered in a standardised manner” (p. 625).

In the second module, clinicians can input relevant family history (including consanguinity), “initial presentation and the genital phenotype . . . based on the Prader” scale (allowing for the calculation of “an external masculinization score”) and updates on phenotypic description in order “to offer insights into long-term changes and outcome” (p. 625). In the third diagnostic module, clinicians can input genetic and chromosomal data and any other relevant studies. Finally, in the fourth module,

the entry site can state if further information can be shared, for example data on puberty and growth, or if there is consent to access case notes. This module also contains information about biomaterials that are available for defined research purposes, such as DNA-samples, cell culture, tissue, or plasma and urine samples (p. 626).

According to a 2014 article based on data used from the I-DSD Registry in the *Journal of Clinical Endocrinology and Metabolism*, 1050 cases had been submitted to the database by physicians from 20 centers in 14 countries, 62% of which (or 649/1050) “had a sufficient level of consent to allow sharing of suitable information” (Cox et al., 2014, e349). While a pool of 649 potential subjects for research may not seem like a lot, this represents an exponential increase in the field of intersex research when one considers, for example, that the summary table in the Consensus Statement titled “Risk of Germ Cell Malignancy According to Diagnosis” is based on over 1,400 studies of a total of 83 patients. Thus, as an incitement to produce knowledge about those with intersex conditions, the move to DSD has been overwhelmingly successful.

Yet at the same time, clinicians acknowledge the problems inherent to producing knowledge about those with DSDs *on the basis of the DSD nomenclature itself* due to its representational failure. In a review article that came out of the 2012 meeting of the Working Party on DSD, Schober et al. (2012) comment that an international database that sounds much like the I-DSD registry is necessary “for best consideration of the status of patients across a number of essential health domains,” one that comprehensively details “anatomy, surgical modifications and a variety of health outcome measures for staged growth and development, as well as social detailing of gender and partnering outcomes” (p. 621). Nonetheless, they lament,

The difficulties in this ambitious scheme are self-evident. DSD is not a diagnosis. It comprises a spectrum of abnormalities where there is a discordance of the standard criteria that define gender. Although some of these very rare conditions have factors in common, there is great danger in extrapolating findings from one to another (Schober et al. 2012, p. 621).

Thus, it seems that even though the DSD nomenclature has been wildly successful in terms of its incitement to produce knowledge, it's not clear that how effective or useful that knowledge will be owing to the nomenclature's failures in terms of precision, accuracy and representation.

Second are those arguments for the sociopolitical good, or at the very least, the sociopolitical neutrality of DSD. Recall, these arguments generally hold that we must repathologize intersex conditions through the adoption of the DSD nomenclature and the biomedical understanding of intersex conditions it entails, in order to reorient focus towards its proper objects of health and human flourishing and away from sociopolitical issues of gender and identity. Given that some intersex individuals have experienced DSD as a negative imposition, DSD has, at the very least, failed to be socio-politically neutral. Furthermore, given that it has failed to bring about a reduction in the performance of genital normalizing surgeries, it seems to have also failed to bring about the kind of refocusing proponents had hoped for—away from *socially constructed* pathologies like ambiguous genitalia and towards *natural* pathologies like salt-wasting. Thus it has failed to achieve its promised sociopolitical good as well.

This brings me to the fourth and final type of argument offered by those who endorsed the DSD nomenclature—that we must separate sociopolitical or *cultural* issues of gender and identity from properly *natural* issues of health and human flourishing, replicating

the nature/culture binary logic set up in the third type of argument in its distinction between socially constructed or cultural pathologies vs. natural ones. This argument—particularly the version of it forwarded by Feder (2009a)—is the most philosophically rigorous one offered in favor of DSD, in large part due to the emphasis Feder places on normalization’s dual nature as both capacity-building and docility inducing. Indeed, there are some intersex individuals for whom medical normalization of their physical states is capacity-building in the same way that normalization of the diabetic’s blood sugar is capacity-building—most obviously those with salt-wasting CAH. There are problems with this argument, however, specifically as regards its use of the terms health and human flourishing.

Feder does not explicitly state what she means by health in the context of her argument that we must separate cultural issues of gender and identity from those of health and human flourishing, possibly because health is a notoriously difficult thing to define and is generally only constituted in relation to disease or pathology. According to the dominant biomedical model of disease—Christopher Boorse’s objectivist Biostatistical Theory of Disease or BST—health is defined simply as “the absence of disease” (Boorse, 1997, p. 8). This definition might strike one as unsatisfying given the moral, political, economic, and material weight that health has in our society. Indeed, one might think that a society with the technology to perform face transplants would be able to produce a minimally acceptable definition of health. However, I argue that we shouldn’t be surprised at our inability to generate a positive account of health given that the pathological is, as Canguilhem (2007) tells us, prior to the normal—that is, the normal only comes to be defined once the pathological appears (pp. 125-144). As Gutting (1989) writes, “the concept of health is only formed as a contrast to an experience of disease or of the threat of disease” (p. 49). Health is a “that” which is constituted contextually, in terms of a “not this” (i.e., one is healthy with

regards to blood sugar metabolism if one does not have diabetes) and further can be defined in degrees relative to disease (i.e. being healthy for a diabetic). Thus it is perhaps unsurprising that Feder fails to stipulate what she means by health.

Feder does, however, tell us what she means by human flourishing. In a footnote accompanying her first use of the term, Feder (2014) identifies it as “most closely associated in Western philosophy with Aristotle’s treatment of *eudaimonia*, frequently translated as “happiness,” writing: “ I have found the concept helpful in this context precisely because the philosophical provenance of the term connotes for contemporary thinkers a concept of flourishing that is historically specific, emerging from a particular cultural context” (p. 247, n59). It is not clear, however, that medicine is indeed in the business of promoting happiness or takes happiness as one of its proper goals or objects.²⁹ Furthermore, it is also not clear that the DSD nomenclature or treatment model itself actually promotes human flourishing defined in terms of happiness, or that such a definition of human flourishing places it on the side of the *natural*. One could turn (although Feder does not do so explicitly) to the work of Neo-Aristotelian philosopher Martha C. Nussbaum and her Capabilities Approach, in an attempt to cash out this point. Nussbaum has been described as having “pioneered a modern version of how the *eudaimonia* approach in practical philosophy can be employed, both in ethics and politics” and identifies the Capabilities Approach as an attempt to “give shape and content to the abstract of dignity,” using the Aristotelian notion of *eudaimonia* as a ground upon which she can constitute a robust account of the good (as opposed to thinner accounts

²⁹ One might object that psychiatry takes one of its goals as the promotion of happiness in its management of mental illnesses such as depression or anxiety. However, I would argue that psychiatry is not in the business of promoting happiness, but rather, of reducing the symptoms of psychiatric illness in order to restore normal social function and alleviate distress (indeed, as I discuss in Chapter 4, psychiatric disorders are defined in terms of the distress and impairment to social function their symptoms cause). Not being depressed, rather than happiness, is the goal in the treatment of clinical depression. Just as with other pathologies, mental health is defined in terms of the absence of pathology.

provided within the social contract tradition)(Brinkmann, 2001, p. 93). Nussbaum identifies ten central human capabilities as the “central requirements of a life with dignity”—Life; Bodily Health; Bodily Integrity; Senses, Imagination and Thought; Emotions; Practical Reason; Affiliation; Other Species; Play and Control over One’s Environment—that she argues are “mutually supportive and all of central relevance to social justice” such that no one capability can come at the expense of others (Nussbaum, 2006, pp. 75-77).

In relation to Nussbaum’s account, it seems Feder defines human flourishing fairly thinly, equating it with what Nussbaum refers to as Bodily Health, defined as “being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter” (Nussbaum, 2006, p. 76). However, given that infants continue to be subject to unnecessary genital normalizing surgeries as well as sterilizing gonadectomies under the DSD treatment model, it is unclear that the DSD model actually manages to promote this capability. Furthermore, it seems to diminish other capabilities such as that of Bodily Integrity, which for Nussbaum includes “having opportunities for sexual satisfaction and for choice in matters of reproduction” (p. 76). Finally, even if we were to grant that the DSD treatment model did in some way promote human flourishing as encapsulated by Nussbaum’s Capabilities Approach, it is not clear that these capabilities are in some way either *medical* or *natural*. While Bodily Health may fall under the purview of medicine, I am not sure that many of the others do. Furthermore, many of these, like Play and Control over One’s Environment, Affiliation, and even Bodily Integrity are socially, culturally, and historically constituted, generated through our relations with others (for example, arguments for women’s reproductive freedom occur in a particular social and political context).

Feder’s attempt to separate matters of health and human flourishing from cultural concerns is clearly under-theorized, and even this small scratch on the philosophical surface

reveals the two spheres to be far more intimately entangled than her arguments presume. Her failure to define health is likely a function of its negative definition within philosophy of medicine in terms of the absence of pathology. It is instructive, then, to read both this argument and the failure of DSD as a strategy through biomedical accounts of pathology and the binary logic of nature/culture underwriting them. In the following section of this chapter, I argue that those who strategically endorsed DSD through the adoption of a biomedical model of intersex conditions were forced to make a number of problematic theoretical commitments—specifically, to an objectivist theory of pathology and the nature/culture distinction it entails; to the binaries of impairment/disability and sex/gender that follow from this nature/culture logic; and finally, to an understanding of power which Michel Foucault refers to as sovereign or juridico-discursive. These theoretical commitments, which I further argue have framed the majority of analyses of DSD since its adoption, ultimately misrepresent both the way in which modern medical/knowledge power *works* in terms of identifying individuals as objects of medical study and intervention through their pathologization, *and* the unique place that the management of intersex conditions holds in the historical development of modern medicine.

III. Diagnosing DSD's Failure (or Nature/Culture, Sex/Gender, and Impairment/Disability)

At the heart of DSD's failure sits the binary logic of nature/culture that those who strategically endorsed it were forced to commit to when they adopted a biomedical model of intersex conditions as DSDs. This is because underwriting that biomedical model is an Objectivist or so-called "Naturalist" model of disease in general, and of the pathology of intersex conditions in particular, which conceive of pathology as "an objective, transhistorical and transcultural entity of which modern bio-medicine has acquired

knowledge and understanding and which it can accurately represent” (Tremain, 2001, p. 617).³⁰ Objectivism regarding impairment entails an implicit commitment to the binary nature/culture distinction where pathology is defined with regards to the natural physiological functioning (or malfunctioning) of the organism, while disability is confined to the cultural, in terms of the temporally and culturally specific ways in which we value and treat those who exhibit various forms of function. The classic example of this distinction, which defines the social model of disability, is that while not having the use of one’s legs is indeed an impairment, it is the presumption that everyone can walk and the concomitant devaluation of bodies that cannot which is disabling.³¹

It is this objectivism regarding pathology, and the binary logic of nature/culture it entails, that underwrites, authorizes, and legitimates the fourth type of argument DSD proponents have made: that we separate properly biomedical or natural issues of health and “human flourishing” from sociopolitical or cultural issues like gender and identity (either implicitly in the case of Dreger & Herndon, 2009 or explicitly in the case of Feder, 2009a). For example, while Feder grants “that the medical cannot be neatly disentangled from the social” she argues that many

can nevertheless agree that there are distinctions between *the cultural issues of identity in which medicine has intervened and narrower matters of health* [emphasis added], be they urgent in the case of a newborn with salt-losing CAH, or longer term, as is the case with different kinds of hormone replacement or special vulnerabilities to other

³⁰ Though both terms strike me as problematic, I will limit myself to the term Objectivist as I believe Naturalist is even more of a misnomer in this context and is invoked merely for its rhetorical weight.

³¹ The Social Model of disability was developed as a challenge to the individual or medical model of disability, which failed to distinguished between disability and impairment, taking both as “the unfortunate consequences of a personal attribute or characteristic”(Tremain, 2001, p. 630).

conditions of the lifespan. Proponents for ‘demedicalization’ of intersex conditions have focused principally on social issues and have not considered seriously the fact that attention to the important needs of affected individuals to receive health care attentive to their conditions *is something that requires the application of a “pathologizing” term, be it disease, disorder, or injury—the only categories that authorize medical intervention* [emphasis added] (Feder, 2009a, pp. 238-239).

Commitment to the kind of binary logic characteristic of objectivist accounts of disease and the social model of disability and at work here in Feder’s distinction between “natural” issues of health and “cultural issues of identity” is problematic for number of intimately related reasons, particularly where intersex conditions and their management are concerned.

First, commitment to the nature/culture binary paves the way for a number of other binaries that follow from it, most obviously impairment/disability, but also sex/gender as well, with impairment and sex taken as *natural* objects and disability and gender as *socially constructed* objects. Evidence of the emergence of both of these binaries can be found in the organizational discourse of the ISNA and in the arguments of those former critics who came to strategically endorse DSD. Commitment to the binary logic of impairment/disability is perhaps most obvious under DSD, and is evinced by the disappearance of critiques of the pathologization of intersex conditions from a scholarship and activism that was founded on such critiques, and the eventual emergence of positive arguments for the “repathologization” of these states in order to meet the unspecified medical needs of those who suffer them. The clearest version of this is likely Feder’s (2009) argument that we should focus on and address the concrete medical needs of those with intersex conditions rather than cultural concerns of gender and identity. On this argument, what is disabling are those interventions aimed at fixing culturally constituted pathologies or concerns regarding gender and identity rather

than natural impairments like salt-wasting, the normalization of which is positioned as enabling. It is this final clause—that the normalization of natural impairments is enabling—that distinguishes the unique way in which the impairment/disability binary is invoked by the ISNA and others who have strategically endorsed DSD. This binary was first invoked by the group in the course of its professionalization in the early 2000s, during which it reformulated the problem of intersex in terms of the first clause of the argument above—disabling stigma and trauma resulting from interventions which aimed at solving socially constructed, and thus, unnatural pathologies.

Many have noted that the professionalization of the ISNA during the early 2000s involved not only an attempt to distance itself from LGBT organizations and to depoliticize the issue of intersex, but also a reconceptualization of sex and gender within the organization's discourse and an explicit distancing from the issue of gender in particular (Preves, 2005; Germon, 2009). Germon writes that in its early years while it was still functioning as a politicized queer activist organization, the ISNA conceptualized intersex bodies as having a unique ontological status, quoting its 1996 online FAQ identifying the intersexed as being “a biological uniqueness of their own form” rather than being “both sexes in one” (Germon, 2009, p. 160). She writes,

The intersexed were positioned as one of at least three types of humans within a discrete model of difference, a model comparable with that used to classify blood groups, for example, where there is no obvious sense of ordering, even though each type falls along a single axis. This was a serial rather than a supplemental concept (Germon, 2009, p. 160).

Accompanying this conception of the intersexed as ontologically unique was a critique of gender that was, in many ways, even more central to ISNA's discourse in the early

1990s (Turner, 1999). In her 1998 article “Affronting Reason,” ISNA founder Cheryl Chase points specifically to gender and to the discordance between her gender behavior and desires—her femininity—and her bodily sex as constitutive of her intersex identity, writing:

Who am I? I now assert both my femininity and my intersexuality, my “not female”-ness. This is not a paradox; the fact that my gender has been problematized is the source of my intersexual identity. Most people have not struggled with their gender, are at a loss to answer the question, “How do you know you are a woman (a man)?” (Chase, 1998a, p. 211).

However, as Germon writes, “by late 2002, a decentering of gender from ISNA’s official discourse was evident. Intersex was no longer to be considered outside a strictly binary frame; rather it had fully been co-opted into it,” such that by 2003 the ISNA’s mission statement had been revised to specify that “intersexuality is primarily a problem of stigma and trauma, *not gender*” [emphasis added] (Germon, 2009, p. 160). Germon notes that “nowhere was this disavowal of gender as an intersex issue more obvious than in the organization’s informational material for parents and the recommendations on how best to raise an intersex child” (p. 160). Germon focuses her analysis on 2006’s *Handbook for Parents*, which she identifies as providing a “contemporary window into both clinicians’ and mainstream advocacy groups’ understandings of gender, and . . . the most current example of the intersection medical and (some) activist understandings of intersex” (p. 161). Germon concludes that by the end of the ISNA’s political transformation, the ISNA had settled on a sex/gender distinction which she notes is slightly different from “its more usual conceptualization where sex signifies the biological and gender the sociocultural,” though she notes “that the more common usage underpins many of the ideas promoted by ISNA” (p. 162). Specifically, she argues that the ISNA settles on a far more useful conception of sex

as bipolar, with male and female constituting privileged endpoints along a continuum with “no clear or obvious points of demarcation,” and gender as an exclusive binary of boys/men and girls/women (p. 162). Thus, writes Germon, “the sex/gender distinction serves as the ground upon which to make such parallel constructions,” reducing (inter)sex, once again, “to the level of the body and *only* [emphasis in original] the body” (p. 162). As Alyson Spurgas (2009) writes, once we enter the era of DSD, “the intersex individual is . . . to be understood fundamentally as a *patient* [emphasis in original] and more specifically as a patient of normative binary gender identity who happens to *have* [emphasis in original] a treatable (yet never fully curable) disorder” (p. 103).

The nature/culture distinction and the binary logics of impairment/disability and sex/gender not only structured the approach taken by those who strategically endorsed the DSD treatment model, but further, I argue, have persisted in the aftermath of its adoption. Adherence to these binary logics is undeniably politically useful, as they not only render oppression on the basis of the cultural term contingent—i.e. if gender and disability are culturally constituted, then gendered oppression and ableism could be otherwise—but they also underwrite “born that way” arguments. Despite this acknowledgement, I follow Germon (who joins Eve Kosofsky Sedgwick), in her position that committing to the nature/culture binary, as well as the binaries of impairment/disability and sex/gender constitute “expensive leaps,” particularly where intersex conditions are concerned (Germon, 2009, p. 6; Sedgwick, 1985). As politically useful as the binaries of nature/culture, sex/gender and impairment/disability may seem to be, adherence to them limits us in multiple ways.

First, leaving impairment and sex on the side of the natural precludes acknowledgement of the specific, particular ways in which biomedicine has historically

constituted impairment and “sexed the body,” as well as any analyses of how the DSD treatment model might be continuing such projects. Within an approach that posits both sex and pathology as pre-discursive ground and gender and disability as culturally specific configurations, one cannot interrogate the constitution of sex or of impairment.

Furthermore, even nature, the pre-discursive ground of the initial binary, is off limits. As Tremain (2001) writes, within such a framework, one cannot “interrogate what counts as ‘nature’ within a given cultural and historical context, in accordance with what interests, whose interests and for what purposes” (p. 625). Indeed, as Butler reminds us, casting the body as pre-discursive is itself a discourse. This serves to reauthorize medical power over and epistemological interest in both impairment and sex in general as natural objects, and over those with intersex conditions, as individuals with impairments of sex.

This, I argue, is the reason for the complete absence of any biomedical or scientific arguments in favour of the DSD treatment model by those who strategically endorsed it. By rendering “the impaired body the exclusive jurisdiction of medical interpretation,” the science underwriting the treatment model and classification system fell out of the purview of social critics; they no longer had authority to speak on the science (Tremain, 2001, p. 621). Furthermore, there has been no critical analysis of the science underwriting the DSD treatment model since its adoption. This lacuna is all the more striking when considered against the fact that the science of sex differentiation (and its history) has long been of particular interest to many feminist scholars, such as Anne Fausto-Sterling (1985, 1993, 2000), Alice Dreger (1998), Elizabeth Lloyd (2005), and Sarah Richardson (2013) among others, as an exemplary case of the influence of sociopolitical investments on scientific research and subsequently, medical practice.

Finally, I argue that the nature/culture distinction has also contributed to the sense of uncertainty that has mounted since the adoption of the DSD treatment model, as well as the theoretical and practical limitations of those initiatives and analyses that have been offered in its aftermath. As Tremain writes,

Both “natural sex” and “natural impairment” have circulated in discursive and concrete practices as nonhistorical (biological) matter of the body, which is molded by time and class, is culturally shaped, or *on which* [emphasis in original] culture is imprinted. The matter of sex and of impairment itself has remained a prediscursive, that is, politically neutral given. When we acknowledge that matter is an *effect* [emphasis in original] of certain historical conditions and contingent relations of social power, however, we can begin to identify and resist the ways in which these factors have material-ized it (2001, p. 623).

Because of gender’s position as both natural *and* socioculturally mediated, this serves to obscure the specific ways in which biomedicine produces gender, as well as to reinforce medicine’s epistemic authority over it. As Germon (2009) writes, “by being emphatic that intersex is not about gender, ISNA ceded to medicine the authority to produce gender. The organization was unable ultimately to challenge the fact that [Intersex Case Management] is done for genders, in the interests of an appropriate gender” (pp. 164-165). Thus we are unable to acknowledge the specific history of the production of gender by John Money in the service of grounding the treatment of intersex conditions, or consider the ways in which the DSD treatment model continues the project of reconstituting binary gender as the stabilizer of bipolar sex.³²

³² This may, however, simply be the continuation of an already established trend, at least among feminist theorists. Germon (2009) argues that while “gender’s origins” in John

Germon identifies five consequences of this occlusion of Money's work, including the ahistoricization of gender; the uncritical acceptance within feminism of the binary logics of sex/gender, male/female, man/woman and straight/gay (to which I added impairment/disability); and the maintenance of "an epistemological investment in sexual difference—to the order of two" (p. 4). To this, Germon adds that failing to acknowledge the origins of gender in the history of intersex management not only "contributes, however unwittingly, to the ongoing status of hermaphrodites as abject: as the impossible Other," it also "allowed earlier poststructuralist analyses to remain firmly fixed on the discursive rather than the material production of sex, since it sustains the idea that gender is at heart a category of signification constituted through discourse" (p. 4).

This, I argue, is why we see a turn towards cultural or discursive analysis in the aftermath of DSD such as Karkazis (2008) and more recently, in Feder (2014). In the latter, for example, Feder employs Pierre Bourdieu's concept of the *habitus*—the "realm of the taken for granted, establishing that which is not questioned . . . a kind of implicit normative order" (p. 46)—as a framework through which we can read parents' choices in order to explain the apparent intransigence of the practice of surgically normalizing ambiguous, if otherwise healthy genitals. She argues that because ambiguous genitalia conflict with assumptions about sex difference and normality, which are such a deep part of our "cultural unconscious," we can understand the *habitus* as acting *through* those parents who choose normalizing surgery rather than being enacted *by* them (p. 46). Further, Feder convincingly argues that these cultural assumptions concerning the normality of dimorphic sex situate and reframe the ethical questions regarding intersex management for both physicians and bioethicists, such that focus is on the best way surgically to normalize atypical genitals, rather

Money's work are "vaguely acknowledged in some feminist accounts, its intimate relation to the intersexed and intersex case management practices is not" (p. 3).

than on the ethicality of such interventions in the first place (see esp. pp. 110-132). She does not, however, consider the biomedical models of sex and gender invoked under DSD, or the scientific evidence underwriting them, in her examination of the constitution of this “implicit normative order” regarding sex and gender within our “cultural unconscious.”

Beyond obfuscating the genealogy of gender (and of disability), commitment to the binary logic of sex/gender and impairment/disability serves to restrict both the causes of and avenues for resistance to ableism and gender oppression to the level of the cultural, often in the form of rights-based appeals such anti-discrimination initiatives and hate crime laws. Interestingly, because both ableism and gender oppression/sexism are considered to be discrimination or rights-based issues, the effect in terms of resistance is the same for both disability and gender, despite the former’s status as fully socially constructed (and thus seemingly fully demedicalized) and latter’s status as both natural and sociocultural. For the ISNA, this was reflected in their turn away from activities like protesting and reclaiming a politicized intersex identity and towards framing the issue of intersex management in terms of rights (with an emphasis on children’s rights) and bioethical principles such as autonomy. Rights-based arguments appealing to fair treatment are often accompanied by a repudiation of essential difference or, as Germon (2009) puts it, a consolidation “around a politics of sameness” (p. 166). In the organizational discourse of the ISNA, this cashed out as an emphasis on intersex individuals’ status as “ordinary men and women” with regards to gender and a reframing of the physical differences of those with intersex difference in terms of inconsequential variations such as skin and hair colour (Koyama, 2006, para. 22; Germon, 2009, p. 166).

In *Normal Life: Administrative Violence, Critical Trans Politics and the Limits of the Law*, trans* legal scholar Dean Spade (2011) argues that rights-based initiatives problematically

appeal to what Michel Foucault calls a juridico-deductive or sovereign model of power, which he opposes to biopower. As a result, standard rights-based law reform strategies like anti-discrimination and hate crime initiatives “fundamentally misunderstand the nature of power and control and the role of law in both” and subsequently fail to improve the lives of those they seek to help (p. 101). As a result, Spade cautions trans* activists against focusing on rights-based initiatives, arguing that they risk “recapitulating the limits of leftist, lesbian, gay, feminist, and anti-racist politics that have centered on legal recognition and equality claims (p. 19). He does grant that law reform strategies can and do have an important role to play in social justice movements; however, he argues the effects such initiatives can achieve are limited such that they should be “employed as a small part of a broader trans* struggle that articulates demands that far exceed legal reform” (p. 101).³³ Spade uses racism as an example to argue that rights-based initiatives and the effects they can achieve are limited specifically by the account of power they employ and their subsequent conceptualization of harm of racism through “the perpetrator/victim dyad, imagining that the fundamental scene is that of a perpetrator who irrationally hates people on the basis of their race and denies service to or beats and kills the victim based on that hatred” (p. 84). The perpetrator/victim dyad corresponds to a sovereign conception of power as deductive or subtractive, and serves both to individualize racism, rendering its structural and systemic forms invisible, and to obscure its historical context (pp. 84-85). As a result, not only are these initiatives “ineffective at eradicating racism” but they “contribute to obscuring the actual operations of racism,” making resistance to it all the more difficult (p. 84).

³³ Specifically, Spade acknowledges that anti-discrimination laws provide a basis for legal claims and may “send a preventative message to potential discriminators” and that hate law crimes are similarly meant to act as a deterrent (though points out that they have not actually been shown to have a deterrent effect) (See Spade, 2011, pp. 80-82).

Because the “systems of meaning and control that maldistribute life chances, such as racism, ableism, transphobia, xenophobia, and sexism, among others, operate in ways more complicated and diverse than the perpetrator/victim model allows,” Spade recommends the centering of analyses that adopt a Foucauldian understanding of power as productive rather than deductive (pp. 102, 101). If trans* activists hope actually to “address the violence and marginalization that shortens trans lives” writes Spade, then it is necessary to adopt a theory of power which actually represents “how those conditions are produced and examine[s] what kinds of resistance will actually alter them” (p. 101). Similarly, I argue that the adoption of a Foucauldian understanding of power and a decentering of rights-based initiatives is necessary to improve meaningfully the lives of those with intersex conditions with regards to not only the performance of medically unnecessary genital normalizing surgeries, but also the shame and stigmatization experienced by many with these conditions. It will allow us to examine both how the conditions which render intersex lives unlivable (or less livable) are produced, and those methods of resistance that will actually have an impact on them. Furthermore, employing a Foucauldian analysis is important because of the central role that sex and the intersexed play in the historical consolidation of biopower as a power over life and death. Indeed, the naturalization and materialization of dimorphic sex in the context of the clinic through the deployment of sexuality is what allows the twin poles of biopower—disciplinary normalization of individuals and regulatory biopolitics of populations—to coalesce, giving rise to biopower in its current form. As a result, both the challenge to dimorphic sex posed by intersex bodies and their clinical management play an important role in the development of biopower, as well as the way in which it functions, both historically and today. Thus, if I am indeed correct that the nature/culture distinction stands at the heart of DSD’s failure as a strategy and has in fact made moving beyond DSD more difficult, then

it seems that those with intersex conditions would be best served by Foucauldian analyses (which begin from a rejection of this binary) and strategies informed by them, as well as clarity regarding the history of sex and intersex with regards to biopower. Given this, it is to this history of biopower and the medical management of intersex conditions that I turn in the following sections of this chapter. By resituating sex, intersex, and gender, in terms of this larger history of biopower, this genealogy of intersex will set the stage for the analyses of and arguments about the DSD treatment model offered in the final three chapters of this dissertation.

IV. The Constitution of Impairment and the Deployment of Sexuality

Michel Foucault is arguably best known for his account of the supersession of sovereign power over the course of the seventeenth to early nineteenth centuries by a “uniquely modern” form of power over “life itself” that he calls biopower. Foucault identifies biopower as “an indispensable element in the development of capitalism,” for it made possible the “the controlled insertion of bodies into the machinery of production and the adjustment of the phenomena of population to economic processes” (1990a, p. 140). In contrast to the deductive, repressive nature of sovereign power, biopower is the power to “foster life or disallow it to the point of death,” rather than the power to “take life or let live” (pp. 140, 138). He writes:

Power would no longer be dealing simply with legal subjects over whom the ultimate dominion was death, but with living beings, and the mastery it would be able to exercise over them would have to be applied at the level of life itself: it was the taking charge of life, more than the threat of death, that gave power its access even to the body (pp. 142-143).

This power works, according to Foucault, by way of twin poles or registers, each with their respective targets: 1) *an anatomo-politics of the human body* or *disciplinary power*, aimed at the human body's maximization and efficiency and 2) a regulatory *bio-politics of the population* aimed at the management of the species body or biopolitics (p. 139).³⁴ Foucault argues that multiple conditions had to obtain for the emergence of these two forms of power, most notably the emergence of the concept of *bios* or life itself in the work of French naturalist and zoologist Georges Cuvier (1769-1832). In *The Order of Things* (1994) Foucault argues that Cuvier “discovers” *bios* or life in his understanding of *organic structure* or the structure of an organ in terms of the *function* the organ performs (pp. 263-279). As Gutting (1989) writes, this is how “we arrive at the modern definition of a living thing as a functional system:”

In drawing up a list of species, what is of importance is no longer identities and differences in plants' and animals' properties but only functional similarities in their organs. Thus, organs (e.g. gills and lungs) that have no elements at all in common may nonetheless be grouped together on the basis of their similar functions.

Likewise, organisms themselves will be classified on the basis of their similarities as functional systems (Gutting, 1989, p. 190).

The emergence of this function-bound definition of life is what constitutes the break between natural history and biology as a science of life itself for Foucault. Further, this new concept of life is of central importance to Foucault's understanding of biopower, for it is, as philosopher Mary Beth Mader (2011) writes, “the discursive condition for the constitution of a theoretical homogeneity Foucault terms a ‘biological continuum’ which is itself the condition for the emergence of a form of state power that establishes the legitimacy of itself

³⁴ Though Foucault and others often use biopower and biopolitics synonymously (and thus refer to the second pole of biopower as biopower), I will refrain from this convention for the sake of clarity.

in relation to life and death on the basis of a new biological conception of race” (p. 98). In her 2011 article “Modern Living and Vital Race: Foucault and the Sciences of Life” Mader connects Foucault’s work on life and the biological continuum in *The Order of Things* to his controversial arguments in *Society Must Be Defended* on racism against the abnormal. She writes,

after the advent of the biological continuum, if the modern state wishes to kill any of its population with alleged legitimacy, it must resort to a justification and comprehension of this action in relation to that biological continuum. That is, the modern state must understand its relation to the life and death of its citizens and its population against the background of the scientifically founded homogeneity of the human race or species that is the biological continuum (Mader, 2011, pp. 98-99).

Thus Foucault’s (2003) controversial assertion that racism, and specifically a biological racism against the abnormal, are necessary under biopower, for “in a normalizing society, race or racism is the precondition that makes killing acceptable” (p. 256). Racism is the only mechanism through which “the function of death “ can be exercised under biopower, in order to introduce interruptions into the biological continuum of life which constitutes all members of the human race in terms of a “vital sameness” (Foucault, 2003, p. 254):

What is racism? It is primarily a way of introducing a break into the domain of life that is under power’s control: the break between what must live and what must die. The appearance within the biological continuum of the human race of races, the distinction among races, the hierarchy of races, the fact that certain races are described as good and that others, in contrast, are described as inferior: all this is a way of fragmenting the field of the biological that power controls. It is a way of

separating out the groups that exist within a population. It is, in short, a way of establishing a biological-type caesura within a population that appears to be a biological domain (Foucault, 2003, pp. 255-256).

Biological race is the way in which those lives within the biological continuum that should be fostered are differentiated from those lives that should be disallowed until the point of death under biopower—that is, it determines *which lives should be made live or let die*. However, before biopower could function in this way, its twin registers of disciplinary normalization and regulatory biopolitics had to emerge and then coalesce through the deployment of sexuality via the production of a *scientia sexualis*, or science of sex.

In *Discipline and Punish* (1995), Foucault tracks the emergence of the first of these “registers”—disciplinary power—which he identifies with the individuating and normalizing practices of institutions such as the school, the workshop, the prison, and the psychiatric hospital. Disciplinary power is centered on “the body as a machine: its disciplining, the optimization of its capabilities, the extortion of its forces, the parallel increase of its usefulness and its docility, its integration into systems of efficient and economic controls” (Foucault, 1995, p. 139). Disciplines are those methods “which made possible the meticulous control of the operations of the body, which assured the constant subjection of its forces and imposed upon them a relation of docility-utility,” marking the birth of “an art of the human body” (p. 137). Through the measurement and continual management of the operations of the body in relation to norms with increasing specificity, disciplinary power attains “an infinitesimal power over the active body” (pp. 139, 137). The result is the production of subjectivities through the means of hierarchical observation, normalizing judgment, and “their combination in a procedure that is specific to [disciplinary power]”—

the examination—with the aim of increasing “the forces of the body (in economic terms of utility)” while at the same time “[diminishing] these same forces (in political terms of obedience)” (pp. 170, 138).

In the eighteenth century, the disciplines surpassed that which Foucault calls “the ‘technological’ threshold” or the point at which “the formation of knowledge and the increase of power regularly reinforce each other in circular process” (1995, p. 224). He identifies the hospital as first site where this threshold is reached, writing that the disciplines did not merely reorder the hospital (or, later, the school, or the workshop), but transformed them into

apparatuses such that any mechanism of objectification could be used in them as an instrument of subjection, and any growth of power could give rise in them to possible branches of knowledge; it was this link, proper to the technological systems, that made possible within the disciplinary element the formation of clinical medicine, psychiatry, child psychology, educational psychology, the rationalization of labour. It is a double process, then: an epistemological ‘thaw’ through a refinement of power relations; a multiplication of the effects of power through the formation and accumulation of new forms of knowledge (Foucault, 1995, p. 224).

Through objectifying clinical discourses (as well as non-discursive institutional practices) “the body” emerged in the eighteenth century as both an effect and object of medical knowledge/power, open to surveillance, documentation, and intervention. The birth of the clinic in the nineteenth century, notes Tremain, only furthered the conception and treatment of the body as a thing, as “spatial, temporal and social compartmentalization” worked in concert with that which Foucault called “dividing practices” to refer to modes of manipulation that combine a scientific discourse with practices of segregation and social

exclusion in order to categorize, classify, distribute, and manipulate subjects who are initially drawn from a rather undifferentiated mass of people” (Tremain, 2001, p. 619). These dividing practices lead to the *subjectivation* of the individual in two senses: 1) the *objectification* of the individual as they come to constitute an object of study and target for intervention (as a homosexual or a criminal for example), and 2) their *subjectification* as the individual comes to understand themselves in terms of the identity posited by the scientific discourse, and perhaps even embrace it.³⁵ As Tremain writes,

This new clinical discourse about “the body” created and caused to emerge new objects of knowledge and information and introduced new, inescapable rituals into daily life, all of which became indispensable to the self-understandings, perceptions, and epistemologies of the participants in the new discourse (2001, p. 619).

It was during the second half of this same century that the second pole of biopower, regulatory power or biopolitics, began to establish itself. Unlike disciplinary power, which addressed “man as body,” biopolitics rather attended to “to living man, to man-as-living-being; ultimately, if you like, to man as species . . . [to men] as they form . . . a global mass that is affected by overall processes characteristic of birth, death, production, illness and so on” (Foucault, 2003, pp. 242-243). In his 1975-1976 lecture series, *Society Must Be Defended*, Foucault argues that biopolitics established itself during the last half of the eighteenth century and in the first years of the nineteenth century in three domains. First, it takes up “a set of processes such as the ratio of births to deaths, the rate of reproduction, the fertility of a population, and so on” which Foucault characterizes as “‘biopolitics’ first objects of knowledge and targets it seeks to control” (2003, p. 243). The second area or field which

³⁵ Foucault eventually introduced the term *subjectivation* to refer to these twin processes. Prior to this, however, he used the term “*assujettissement*” to refer to one’s subjection by and subjugation to power.

biopolitics takes up towards the end of the eighteenth century is that of endemics, or “the form, nature, extension, duration and intensity of the illnesses prevalent in a population” (p. 243). Unlike epidemics, which resulted in large numbers of sudden quick deaths, endemics were

permanent factors which . . . sapped the population’s strength, shortened the working week, wasted energy, and cost money, both because they led to a fall in production and because treating them was expensive. In a word, illness as phenomena affecting a population. Death was no longer something that suddenly swooped down on life—as in an epidemic. Death was now something permanent, something that slips into life, perpetually gnaws at it, diminishes it, weakens it (p. 244).

According to Foucault, it is the taking up of these phenomena—the biological processes of a population and the illnesses endemic to it—that results “in the development of a medicine whose main function will now be public hygiene, with institutions to coordinate medical care, centralize information, and normalize knowledge” and ultimately to medicalize the population (2003, p. 244). This focus on endemics, that is “permanent factors . . . which sapped the population’s strength” opened to biopolitics a new field of phenomena which Foucault describes as “universal, and some of which are accidental but which can never be fully eradicated, even if they are accidental,” but which nonetheless have the ability to “incapacitate individuals, put them out of circuit or neutralize them” such as “accidents, infirmities and various anomalies” (p. 244).

Gutting emphasizes the importance of epidemic medicine and its concern with the spread of disease through the population, to the birth of the clinic at the end of the eighteenth and beginning of the nineteenth centuries and to the emergence of modern

clinical medicine. Because epidemic medicine concerned itself with the spread of disease through the population, it required, writes Gutting (1989) “the analysis of temporal series with a view to determination of causality” unlike the then-dominant Classical “medicine of species,” that conceptualized diseases as having essences with no temporal qualities (p. 115). The goal of the Classical physician was to recognize a disease in its essential nature despite the various influences that serve to mask and *denature* it, including the patient and their characteristics. Thus, the “paradoxical position” that “if one wishes to know the illness from which he is suffering, one must subtract the individual, with his particular qualities” (Foucault, 2008b, p. 15). As a result, writes Foucault:

A medicine of epidemics is opposed at every point to a medicine of classes, just as the collective perception of a phenomenon that is widespread but unique and repeatable may be opposed to the individual identity of an essence as constantly revealed in a multiplicity of phenomena (2008b, p. 29).

Subsequently, epidemic medicine required the “definition of a political status for medicine and the constitution, at state level, of a medical consciousness whose constant task would be to provide information, supervision and constraint” (Foucault, 2008b, p. 29), leading to a social restructuring of medicine, beginning with the foundation of the Société Royale de Médecine as the central medical authority in France in 1778 and the corresponding emergence of what Foucault calls a “new medical consciousness” (2008b, especially pp. 24-36). This new medical consciousness was uniquely collective, reconstructing medical knowledge as a body under constant revision. As Foucault writes,

The locus in which knowledge is formed is no longer the pathological garden where God distributed the species, but a generalized medical consciousness, diffused in space and time, open and mobile, linked to each individual existence, as well as to the

collective life of the nation, ever alert to the endless domain in which illness betrays, in its various aspects, its great solid form (2008b, p. 36).

Foucault identifies this new medical consciousness with the emergence of two “complementary myths”: first, of a “nationalized medical profession” who would attend to the body in the way that clergy attended to the soul, and second, of “a total disappearance of disease in an untroubled, dispassionate society returned to its original state of health,” such that doctors would become unnecessary (2008b, pp. 36-37). These myths play “an important role” according to Foucault, insofar as they link “medicine with the destinies of states,” such that “the first task of the doctor is therefore political,” and thus reveal it to have a positive status or significance (pp. 38-39). He writes,

instead of remaining what it was, the ‘dry, sorry analysis of millions of infirmities,’ the dubious negation of the negative, it was given the splendid task of establishing in men’s lives the positive role of health, virtue and happiness. . . . Medicine must no longer be confined to a body of techniques for curing ills and of the knowledge that they require; it will also embrace a knowledge of *healthy man*, that is, a study of *non-sick man* and a definition of the *model man* [emphases in original]. In the ordering of human existence it assumes a normative posture, which authorizes it not only to distribute advice as to healthy life, but also to dictate standards for physical and moral relations of the individual and of the society in which he lives (pp. 39-40).

Armed with this positive project and a new understanding of medical knowledge, nineteenth century medicine reformulated its understanding of health in terms of *normality*. Or rather, whereas 18th century medicine concerned itself with restoring the sick individual to health, 19th century medicine “was regulated more in accordance with normality than with health; it formed its concepts and prescribed its interventions in relation to a standard of

functioning and organic structure and in physiological knowledge” (Foucault, 2008b, p. 40). Thus, it was through medicine that man came to be divided, taken up, and attended to in term of “the medical bipolarity of the normal and the pathological” (p. 41). Foucault emphasizes the importance of the “healthy/morbid opposition” entailed in the medical distinction of the normal and the pathological to both “the prestige of the sciences of life in the nineteenth century,” as well as to the development of “the science of man,” devoted to the study of “man, his behavior, his individual and social realizations” (p. 41). This legacy gives the science of man its unique character according to Foucault, insofar as it “cannot be detached from the negative aspects in which it first appeared, but which is also linked with the positive role that it implicitly occupies as norm” (p. 41).

If disciplinary power, then, is the micro-physics of biopower, regulatory power or bio-politics is its macro-physics administering to the management of the population. Further, while regulatory power is necessarily bound up with disciplinary power and vice versa (for bodies make up populations and populations are collections of individual bodies), Foucault remarks that the development of these twin registers remained fairly separate through the eighteenth century. However, they would come to be joined in the nineteenth century, not at the level of “a speculative discourse, but in form of concrete arrangements” of which the deployment of sexuality would be “one of the most important” (Foucault, 1990a p. 140). In *Society Must be Defended*, Foucault elaborates on the “privileged position” sexuality occupies in the history of biopower, writing that sexuality was a “field of vital strategic importance” to its constitution due to its existence at “the point where the body and the population meet” (2003, pp. 251-252). Central to this elaboration and deployment of sexuality was the materialization and naturalization of dimorphic sex, “the most speculative, most ideal and most internal element in a deployment of sexuality organized by power in its grip on bodies

and their materiality, their forces, energies, sensations and pleasures” (Foucault, 1990a, p. 155). Sex, writes Foucault (1990a),

was at the pivot of the two axes along which developed the entire political technology of life. On the one hand it was tied to the disciplines of the body: the harnessing, intensification, and distribution of forces, the adjustment and economy of energies. On the other hand, it was applied to the regulation of populations, through all the far-reaching effects of its activity. It fitted in both categories at once, giving rise to infinitesimal surveillances, permanent controls, extremely meticulous orderings of space, indeterminate medical and psychological examinations, to an entire micro-power concerned with the body. But it gave rise as well to comprehensive measures, statistical assessments, and interventions aimed at the entire social body or at groups taken as a whole. Sex was a means of access both to the life of the body and the life of the species (pp. 145-146).

The deployment of sexuality, then, is what establishes the notion of sex, as something more than “bodies, organs, somatic localizations, functions, anatomo-physiological systems, sensation, and pleasures” and with its own intrinsic properties and laws (2003, p. 153). However, it is the numerous functions that sex performs that, according to Foucault, make it “indispensable.” It is sex that,

Made it possible to group together, in an artificial unity, anatomical elements, biological functions, conducts, sensations, and pleasures, and it enabled one to make use of this fictitious unity a causal principle, an omnipresent meaning, a secret to be discovered everywhere: sex was thus able to function as a unique signifier and as a universal signified (1990a, p. 154).

As the ground for a connection between “a knowledge of human sexuality and the biological science of reproduction,” the “artificial unity” of sex allowed the study of sexuality as a field of knowledge to gain “through proximity a guarantee of quasi-scientificity” and further, allowed “some of the contents of biology and physiology [to] . . . serve as a principle of normality for human sexuality” (1990a, 154-155). Further, sex brings about, according to Foucault “a fundamental reversal” in “the representation of the relationships of power to sexuality,”

causing the latter to appear, not in its essential and positive relation to power, but as being rooted in a specific and irreducible urgency which power tries as best it can to dominate; thus the idea of “sex” makes it possible to evade what gives “power” its power: it enables one to conceive of power solely as law and taboo. Sex—that agency which appears to dominate us and that secret which seems to underlie all that we are, that point which enthralls us through the power it manifests and the meaning it conceals, and which we ask to reveal what we are and to free us from what defines us—is doubtless an ideal point made necessary by the deployment of sexuality and its operation (1990a, p. 155).

The deployment of sexuality as well as the discursive and material production of the “fictitious unity” of sex were achieved through the production of a *scientia sexualis* or a science of sex. Biomedical knowledge of the sexed body revealed its truth and it was by way of and with reference to this knowledge that discipline and regulation functioned. However, the production of sex is simultaneously the production of abnormal sex; indeed, the creation of the “truth” of the sex renders all that fails to accord with this truth as not simply false, but unintelligible, excess. As Foucault writes,

It is through sex—in fact, an imaginary point determined by the deployment of sexuality—that each individual has to pass in order to have access to his own intelligibility (seeing that it is both the hidden aspect and the generative principle of meaning), to the whole of his body (since it is a real and threatened part of it, while symbolically constituting the whole, to his identity (since it joins the force of a drive to the singularity of a history) (1990a, pp. 155-156).

Furthermore, the creation of sex is the way in which “the deployment of sexuality established one of its most essential internal operating principles: the desire for sex”—that is, the incitement to produce knowledge about sex “to have it, to have access to it, to discover it, to liberate it, to articulate it in discourse, to formulate it in truth” (p. 156). He continues,

It is this desirability of sex that attaches each one of us to the injunction to know it, to reveal its law and its power; it is this desirability that makes us think we are affirming the rights of our sex against all power, when in fact we are fastened to the deployment of sexuality that has lifted up from deep within us a sort of mirage in which we think we see ourselves reflected—the dark shimmer of sex (1990a, pp. 156-157).

Intersex bodies, in their failure to accord with standard biomedical definitions of male or female, have threatened the naturalness of dimorphic sex underwriting the deployment of sexuality since the first constitution of a science of sex. Historically, biomedical response to this threat has been the incorporation of these bodies within the “truth” of dimorphic sex, either through the medical discovery of the individual’s true sex, or by rearticulating biomedical definitions of male and female such that an individual’s true sex may be identified, followed by individual correction/normalization

justified by way of this “truth.” As Tremain writes, “an array of scientific, medical and social discourses must be continuously generated to refresh [sex’s] purportedly definitive criteria”—particularly in the face of intersex bodies and the challenge they pose to “the regulatory force of knowledge/power about the category of sex” (2001, p. 628). Dreger (1998) documents historical shifts in biomedical definitions of sex (and subsequently, in biomedical practices regarding abnormal sex) spurred by those bodies for which established definitions could not account. Dreger argues that these discursive shifts generally entail a reclassification of “abnormally” sexed bodies so as to create a more inclusive definition of determinate binary sex, such that more people could become intelligible as “truly” male or female. For example, in 1876, German physician Theodor Albrecht Klebs initiated a shift in biomedical truth-discourses of sex, ushering in what Dreger calls the “Age of Gonads” with the publication of his classification system for hermaphroditism in the *Handbuch der Pathologische Anatomie* (Dreger, 1998, p. 145). Through his classification of individuals with both an ovary *and* a testicle as “true hermaphrodites,” those with testicles as “male pseudo-hermaphrodites” and those with ovaries as “female pseudo-hermaphrodites,” Klebs sedimented the truth of sex in gonadal makeup (Dreger, 1998, p. 145). It did not matter how masculine or feminine one appeared or behaved, what one’s genitals looked like, or even where their gonads were located—if they had two ovaries they were a woman and two testicles they were a man. Furthermore, the limitations of surgical techniques at the end of the nineteenth century (in particular, the limited availability and reliability of anesthetic) meant that gonadal makeup and thus, true sex, could only be diagnosed post-mortem. The true hermaphrodite—the individual with both an ovary and a testicle—could exist only in death. Of the gonadal definition of sex Dreger writes,

It accomplished the desired preservation of clear distinction between males and females in theory and practice in the face of creeping sexual doubt. The practical result of the adoption of the gonadal definition was that most bodies, no matter how ambiguous looking or acting, were entitled only to a single sex, and “true” living hermaphrodites were—by definition—impossible (1998, p. 153).

This approach aligns with Foucault’s characterization in *Discipline and Punish* of the way in which disciplinary power “traces the limit that will define difference in relation to all other differences, the external frontier of the abnormal” so as to create a class which, like the shameful class of the École Militaire in his example, exists “only to disappear” (Foucault, 1995, pp. 183, 182). The authoritative medical deployment of sexuality required a clear and, importantly, natural distinction between males and females; all bodies must be rendered (or renderable) as “naturally” male or female in order to maintain sex in its fictitious unity.

However, as advances in surgical and microscopy techniques and the development and availability of anesthetic allowed for living biopsies, clinicians found themselves faced not only with living “true hermaphrodites” but further, with the fact that some gonads were neither fully ovaries nor fully testes, but rather ovotestes, a combination of both.

Furthermore, as technological advancements in biomedicine in the early part of the twentieth century allowed for the increasingly specific elaboration of the bodies of the intersexed, the fictitiousness of sex—of its unity—was drawn into relief. As Germon writes,

Together, the emergence of embryology as a branch of medicine; the discovery and isolation of estrogen, testosterone, and other hormones through the field of endocrinology; and the consolidation of genetics as a field of biology produced evidence that the various physiological markers of sex could no longer be assumed to

be unilateral. Nor could a person's somatic sex be relied upon as an absolute (2009, P. 33).

Germon notes the existence of a hesitancy within the medical literature regarding sex assignment for intersex patients during the 1920s-1940s, though the refinement of surgical techniques during WWII meant that by the mid-1940s, clinicians were more capable of normalizing intersex bodies, and more uncertain about how to justify it than ever before (p. 34). The solution to this uncertainty was provided in the mid-1950s by Dr. John Money and his colleagues in the Psycho-Hormonal Research Unit at John Hopkins University with the introduction of gender into the field of biomedical knowledge/power constituted by the deployment of sexuality as a "a new conceptual realm of sex" (Germon, 2009, p. 23). Money's search for a "single over arching term that would enable him to discuss the masculinity and femininity of the intersexed" led him to introduce gender into his "framework for understanding the phenomenon of human hermaphroditism," which was itself, writes Germon, "first and foremost a rationale for clinical practices designed to habilitate the intersexed into girlhood and boyhood, womanhood and manhood" (pp. 24, 23). With the introduction of Money's OGR treatment model, clinicians were no longer "compelled to discover a person's *true* sex; now their job involved determining a *best* sex for each of their patients" (p. 24). Gender, writes Germon, operated both "symbolically *and* [emphasis in original] pragmatically" (p. 34) and its introduction into this field of knowledge/power had "specific consequences—epistemological and material—for those in whose name gender was initially put to work" (p. 24):

At a pragmatic level, gender provided a solution to the uncertainty of any absolute somatic sex. Gender served to stabilize what advances in medical technology had rendered more and more unstable during the first half of the twentieth century. It

was no longer so important that the somatic signifiers of sex failed to align; what increasingly mattered were the psychosocial and cultural signifiers of masculinity and femininity. Where once clinicians sought to discover a true sex hidden within an ambiguous body, now it was a matter of determining a best sex for any given individual—that is, whichever sex seemed most appropriate in light of the person’s genital appearance, psychological makeup and familial environment. The promise was that a best sex would give a person the best kind of life. In this way, gender provided a solution to an unintended consequence of technological advancement and, at the same time, to the sociocultural problem of “excessive” sexual difference” (p. 35).

In the next section, I examine the historical production of gender by Money through the OGR treatment model for intersex conditions. Gender allowed the fictitious unity of sex to remain intact in the face of the intersex body by allowing us to read binary sex on to it in terms of best or optimum gender. As I will show, Money’s account of gender development includes multiple natural and sociocultural variables from sex chromosomes and prenatal hormone exposure to sex of rearing; however, optimum gender under OGR is defined specifically in terms of cisgender. In this sense, the production of gender by Money is simultaneously the production of cisgender as normal and trans* or variant gender as pathological, and thus OGR aims at securing cisgendered futures for intersex children, or the production of cisgendered lives.

V. John Money and the Production of Dimorphic of Sex via Binary, Univocal Gender

Born in New Zealand in 1921, John Money received two double Master of Arts degrees in psychology/philosophy and education at the Victoria University of Wellington in 1944 and following a period at the University of Otago as a Junior Lecturer, emigrated to the United States in 1947 (Germon, 2009, p. 25; Ehrhardt, 2007, p. 223). After a year spent as a clinical psychologist in Pittsburgh, Pennsylvania, Money entered the Ph.D. program in clinical psychology through the Department of Social Relations at Harvard University and completed his dissertation titled “Hermaphroditism: An Inquiry into the Nature of a Human Paradox” in 1952 (Money, 1952; Ehrhardt, 2007; Rubin, 2012, p. 894). It was during the course of this doctoral research that Money began to both formulate the theories that would come to underlie the OGR treatment model for intersex conditions and make the professional relationships that would later help to secure his position as “the leading authority on hermaphroditism during the second half of the twentieth century” (Germon, 2009, p. 24).

Money’s doctoral dissertation involved a comparative review of 248 case studies of intersex patients written in English between 1895 and 1951, as well as 10 additional detailed case studies written by Money himself on the basis of patient interviews, psychological tests, and clinical files (Germon, 2009, p. 26). Money (1952) begins his study of hermaphrodites, whom he identifies as “a living paradox, providing invaluable materials for the comparative study of body morphology and physiology, rearing and psychosexual orientation” (p. 1) by sorting the cases into the following 8 categories, expanding the schema introduced by Theodor Albrecht Klebs in 1876 on the basis of gonadal makeup:

1. Female pseudohermaphrodites with the adrenogenital syndrome characterized by precocious virile development
2. Female pseudohermaphrodites with ovogenesis and without post-natal virilization

3. True hermaphrodites with ovarian and testicular structures
4. Male pseudohermaphrodites with Mullerian organs differentiated and developed
5. Male pseudohermaphrodites with atrophic, undescended testes, but simulant females in their morphology
6. Pseudohermaphroditic males with hypospadias and breasts, resembling Klinefelter's syndrome
7. Pseudohermaphroditic males with penoscrotal or perineal hypospadias
8. Miscellaneous cases, unclassifiable owing to insufficient data (Money, 1952, pp. 2-3).

Money approached his so-categorized case reports with two primary research questions. The first, writes Money, concerned “the manner in which these people adapt themselves to the sex of their rearing, especially when their bodily form and physiology contradict it” (p. 3). Tied to this first question, notes Germon were a “set of secondary questions about the relative influences of physiological functioning and socialization (vis-à-vis nature versus nurture) and how enduring the impact of each of these was” (2009, p. 28).

The second research question focused on the mental health status of

[t]hese people who so often appear ludicrously dressed in the clothes of the wrong sex. Do they, with such manifest sexual problems to contend with, break down under the strain as psychiatric theory may lead one to believe; or do they make an adequate adjustment to the demands of life? (Money, 1952, p. 3)

Money was undeniably pessimistic regarding the mental health of those with intersex conditions when he began his research. For example, his scale for analysis had only three points, in descending order of psychosocial success: 1) Adequate, 2) Disheartened and/or guardedly reticent, and 3) Manifesting symptoms of psychopathology—psychoneurosis, organic and nonorganic psychosis (Money, 1952, p. 4). However, as many others have noted, including Germon, the results of Money's research failed to support his initial pessimism. As Money writes,

The findings are somewhat disconcerting, for one would not have been surprised had the paradox of hermaphroditism been a fertile source of psychosis and neurosis. The evidence, however, shows that the incidence of so-called functional psychoses in the most ambisexual of hermaphrodites—those who could not help but be aware that they were sexually equivocal—was extraordinarily low. The incidence of neurotic psychopathology of the classic types, sufficiently severe and incapacitating to be unmistakable, was also conspicuously low. . . . Apparently, therefore, sexual conflicts and problems are not in themselves sufficient to induce psychosis or neuroses (p. 6).

Furthermore, Money's research undermined theories that posited what he referred to at the time as "nonlibidinal orientation and demeanor," referring to one's social role in terms of behavior, and their "libidinal orientation" in terms of sexuality, as instinctually or biologically driven. Instead, Money found that while "presence or lack of libido is clearly a function of the presence [of] sex hormones, regardless of their biochemical structure or their source of origin," the evidence nonetheless

weighs heavily . . . against the conception that individual erotic preferences—the direction and goal toward which libido is exercised—bear a direct or precise relationship to unlearned determinants. It does not appear feasible to ascribe these aspects of libido to a basis which is commonly described as constitutional or instinctive, organic or innate, unless it be specifically in terms of the localization of erotic sensation in the genitalia. The evidence weighs even more heavily against the conception that the more general aspects of sexual outlook and sexual behavior—in contrast to the specifically erotic aspects—bear a direct or precise relationship to unlearned determinants. In brief, it appears that psychosexual orientation bears a

very strong relationship to teaching and the lessons of experience and should be conceived as a psychological phenomenon (1952, p. 5).

During the course of his doctoral studies, John Money came to develop relationships with many physicians involved in the treatment of hermaphrodite patients—most notably Lawson Wilkins, the individual widely regarded as the founder of the field of pediatric endocrinology and for whom the American pediatric endocrine society is named (Germon, 2009, p. 31). Money’s association with Wilkins was central to not only Money’s later professional success, but also to the stronghold Money’s theory of gender acquisition and his OGR treatment model had for decades over the domain of clinical practices that make up intersex clinical care. After meeting at a pediatric seminar in Boston, Money visited the endocrinology clinic at John Hopkins Medical of which Wilkins was both Chair and founder (Germon, 2009; Feder, 2014). Wilkins, whose research focused on the role of hormones in fetal development, granted Money access as a doctoral student to not only his own unpublished case studies, but also his patients, some of whom Money interviewed as part of his doctoral research. Germon notes that it was due to Money’s relationship with Wilkins that Money was offered a position at John Hopkins in 1951, prior to his completion of his doctoral studies (Germon, 2009, p. 31; Money, 1986, p. 8; Money, 1993, pp. 94-95). Money took up the position of co-director of the newly established Psycho-Hormonal Research Unit along with psychiatrist Joan Hampson upon completion of his doctoral studies in 1952, further testifying to Wilkins’ confidence in Money (Germon, 2009, p. 31).

In 1955, after presenting their ideas at pediatric conferences in the United States and Europe, Money and Hampson (along with, eventually, her husband John Hampson) published a series of consecutive articles in *The Bulletin of the John Hopkins Hospital* that further elaborated and “crystallized the ideas Money had articulated in his doctoral dissertation”

(Germon, 2009, pp. 24, 31). In these articles, Money laid out his theory of gender role and hermaphroditic development, guidelines for clinical treatment and tools for measuring the success or failure of that treatment; it was, “effectively . . . a complete package that included a theory that served as a rationale for a set of clinical practices and a means of measuring not the efficacy of those practices but rather people’s capacity to *be* [emphasis in original] the gender to which they were assigned” (Germon, 2009, p. 18).

Money’s theory of gender encapsulated what we today would distinguish as gender identity (an individual’s sense of self), gender role or behaviour (public manifestations of one’s gender identity, as well as sexual orientation, and was first introduced in his 1955 article in the *Bulletin of the Johns Hopkins Hospital* titled “Hermaphroditism, Gender and Precocity in Hyperadrenocorticism: Psychologic Findings” (Money, 1955). In a 1995 book chapter titled “Lexical History and the Constructionist Ideology of Gender,” Money writes that it was in this 1955 paper that,

the word *gender* made its first appearance in English as a human attribute, but it was not simply a synonym for *sex* [emphases in original]. With specific reference to the genital birth defect of hermaphroditism, it signified the overall degree of masculinity and/or femininity that is privately experienced and publicly manifested in infancy, childhood, and adulthood, and that usually though not invariably correlates with the anatomy of the organs of procreation (Money 1995, pp. 18-19).

Rubin (2012) argues that Money’s further study of intersex patients at John Hopkins, along with advances in technology, led him “to the hypothesis that biological sex is itself radically unstable, composed of heterogeneous elements that do not add up to a conceptual entity” (p. 895). Rubin supports his claim by citing the passage from Money’s 1995 book chapter quoted above in which Money describes abandoning “the unitary definition of sex as male or

female” and introducing gender-role as a name for that “unnamed blank that craved a name” at the end of his list of the variables of sex (Money, p. 21).

Tremain writes that despite “concluding that sexed identity had no instinctual or innate basis” as is clear from the long list of variables Money identifies as determining sex, he nonetheless identified intersex bodies as abnormal and in need of fixing (2001, p. 628).³⁶ Money held that hermaphroditic bodies were the result of improper differentiation of the sex anatomy: “the [intersex] baby is, in other words, sexually unfinished” (Money & Ehrhardt, 1972, p. 5). Rubin notes that two presuppositions ground this claim that are “fundamental to the logic of normalization Foucault discusses as emerging in the late eighteenth century in *Abnormal*,” during the time when hermaphroditism comes to be understood as a “defective structure” rather than a “breach of nature” (2012, pp. 893-894). First, sex anatomy has a “proper mode of differentiation that, second, constitutes a complete or finished form of sexual dimorphism” (p. 893). Rubin writes, “in accordance with this view, Money and [co-author of the 1972 textbook *Man and Woman, Boy and Girl* Anke E.] Erhardt’s understanding of intersex was not only pathologizing but also structured by a spatial and temporal logic of human development whose telos is wholeness” (p. 893). Rubin argues that the concept of gender role allowed Money to “cover over and displace the biological instability of the body he discovered through his research on intersex,” and furthermore, provided a method by which clinicians might achieve that wholeness (p. 887). Drawing on Hausman (1995) and Germon (2009), Rubin argues that *gender role* served as both

³⁶ Feder (2014) draws on work by historians Sandra Eder and Alison Redick to argue that the contradiction inherent in Money’s treatment model—that is, his insistence that intersex bodies required surgical normalization despite his findings that those without surgery did pretty well psychologically—is the result of his attempt to reconcile the differing conceptual, generational, and disciplinary approaches to intersex of his two mentors at John Hopkins, Wilkins, and urologist Hugh Hampton Young (2014, see Chapter One in particular).

a diagnostic category and treatment protocol for patients whose anatomical configurations were regarded as unintelligible within the dominant frame of dimorphic sex. For people with intersex characteristics, whose bodies Money read as improperly sexed, *gender role* [emphasis in original] became a way for Money to predict and . . . to literally fashion the sex they were “supposed” to have all along (p. 892).

Money, writes Rubin, “dismantled the unitary conception of sex and, in so doing, produced ‘an unnamed blank’ at the site of the body” that he filled with gender in order to “contain the threat” this dismantling posed (p. 895). By using gender role “to name and thereby semantically fill (or cover over) the void left by sex’s lack of conceptual and referential unity,” he maintained the fictitious unity of sex and kept the agency of sex intact (p. 895). As Germon (2009) writes,

In a clinical context gender proved to be a powerful stabilizing factor at a time when technology was increasingly undermining the long-held medicoscientific assumption that the bodily signifiers of sex aligned unilaterally. And then it became a stabilizing factor in a broader social context. Gender served to substantiate the idea that one’s identity and behaviors were natural and inevitable products of one of two natural and inevitable types of bodies: male and female. In this way, gender can be read as the most recent historical apparatus to contain the body within a political economy of dimorphic sexual difference (p. 62).

Money’s method of naturalizing dimorphic sex by introducing gender into the field of power/knowledge constituted by the deployment of sexuality ended the Age of Gonads where one’s “true” sex was defined in terms of their gonadal makeup and, via the OGR treatment model, ushered in what Dreger calls the “Age of Conversion,” where one’s sexed

body is medically normalized in accordance with predicted gender role (Dreger, 1998).³⁷ In this way, Money didn't simply propose gender as preceding sex long before Butler, as Rubin states, but rather constituted the specific configuration of the heterosexual matrix she identifies and undermines, with sex—the purportedly stable ground for gender and heterosexual desire—emerging as the phantasmic effect of a specific domain of medical knowledge/power (Rubin, 2012, p. 896). Furthermore, it is through the functioning of this form of power, along its twin axes of discipline and regulation, and the constitution of the heterosexual matrix via a *scientia sexualis* or a science of sex, gender and sexuality, that Western subjects have come to be fashioned such that sex remains central to our intelligibility *as* subjects—we do not have a sex, but rather *are* male or female. With Money, this truth of sex comes to be read through *binary, univocal, oppositional gender* such that gender becomes the essential pivot upon which our intelligibility as subjects rests. Sex is gender all along and the goal of intersex management is thus to fix sex with regards to gender in order to secure a cisgendered future for the intersex infant—one that, as Butler says, is “produced by the regulation of attributes along culturally established lines of coherence” in terms of not only identity, but presentation (part of which is having a “normally” cis-sexed body), behavior or role, and desire as well (1990, pp. 32-33). As a result, intersex conditions and their management in the clinic are necessarily an issue of gender, identity, and pathology insofar as the “health” of the intersex patient is measured in terms of gender and identity.

³⁷ This would eventually come to be limited to gender identity, however, as I argue in chapter three, there remains some slippage within the DSD treatment model between gender identity, gender behaviour and gender presentation. This slippage seems coherent with contemporary common sense use of the term in the West, particularly where gender identity and presentation are concerned. Indeed, I would argue that while feminism has done much to loosen the tie between gender identity and many socially constructed behaviours or interests (e.g. women can be pilots/doctors/scientists/engineers too), we continue to take gender presentation as a sign of gender identity (i.e., those who present as women identify as women).

Intersex management is about the securing of cisgendered lives through their surgical and hormonal production. As a result, I argue that any approach to intersex premised upon the separation of these issues—gender, identity and pathology—was (and is), always already, doomed to failure.

VI. Conclusion

In this chapter, I argued that the nature/culture distinction underwriting the DSD treatment model as a *strategy* is at the heart of its failure. Our concept of pathology and our concern with it are themselves thoroughly sociopolitical, the products of a specific history of a particular form of power Foucault calls biopower. Furthermore, the materialization and naturalization of dimorphic sex through the deployment of sexuality is, according to Foucault, one of the most important of those “concrete arrangements” through which the twin poles of biopower—disciplinary normalization and regulatory biopolitics—came together in the nineteenth century. The fact that an individual’s ability to sort into the category of male and female remains necessary to their social, legal, and political intelligibility, is, I argue, a reflection of the essential role sex played in the historical development of biopower. Intersex conditions, insofar as they call into question the “naturalness” of this binary sorting and integrity of the heterosexual matrix, cannot fairly be rendered “disorders like any other”; our sociopolitical investment in (and the sociopolitical effects of) our definitions of “normal” and “disordered” sex development exceeds our sociopolitical investment in our definitions of disordered insulin production/regulation³⁸ or disordered thyroid function.

³⁸ However, in light of our increasing anxiety regarding the racialized and classed “obesity epidemic,” the connections made between obesity and failed citizenship as exemplified through the identification of obesity with terrorism as exemplified by Surgeon General

Money's introduction of gender is merely the next stage in this deployment of sexuality, through which a binary and natural form of sex is maintained in what Foucault calls its "fictitious unity." Gender is thus a technology of power, an object of study, and normalizing intervention measured not merely in terms of identity, but also in terms of desires and in terms of repeated stylized and behavioral manifestations in Butler's citational, performative sense (1990, 1993, 2004). Thus, Feder (2009a) is wrong when she argues that those who seek to save intersexual identity are misguided insofar as the intersexual does not exist in a manner analogous to the homosexual. The intersexual is just as real as the homosexual in terms of existing a figure or object for study and intervention within the same field of medical knowledge/power first constituted by the deployment of sexuality. Moreover, the appearance of the homosexual and the production of sex are what make the appearance of the intersexual through the production of gender possible. In this sense, not only do they both exist, but are in a way kin, born out of the same set of networks of knowledge/power and the same assumptions about the normality of cisgendered life (which importantly included sexuality, given Money's initial conflation of sexuality and gender). Furthermore, the introduction of gender is what allows the transsexual to appear within this field of medical/knowledge power, and thus the transsexual stands within this field in a similar sort of relation. Of course, this is not to say that trans* people, like homosexuals and the intersexed did not exist prior to the nineteenth century. Rather, it is to say that the introduction of gender is what allows the transsexual to be apprehended as an object of study and target of intervention for medicine specifically as a subject who is discordant in terms of sex and gender. Gender stabilizes sex such that it becomes the ground across which those who transition do so, producing the cis-alignment of sex and gender as normal and the

Richard Carmona's identification of obesity as "the terror within" and the conflation often made between obesity and Type 2 Diabetes, one could imagine a future "Diabetic Politics."

trans-alignment of sex and gender as abnormal or pathological. In this way, the history of medical study of and intervention upon the homosexual, intersexual, and transsexual under biopower has always aimed at the production of cisgendered lives. The deployment of sexuality is thus the production of cisgendered lives as those which should be made live, and non-cisgendered or gender variant lives as those which should be let die.

Through the arguments and histories presented in this chapter, I have argued that activists and academics hoping to move beyond what has been achieved with the DSD treatment model in ways that actually impact the lives of those with intersex conditions must begin our analyses from a Foucauldian understanding of power that rejects the nature/culture binary, as well as the binaries of impairment/disability and sex/gender that follow from it; one that takes into account this unique position sex (and now gender) holds within both the history of biopower's development and its contemporary operations; one that takes gender as the most recent technology of dimorphic sex, produced and maintained via what Oksala (2011) identifies as the three axes of Foucault's work, "regimes of truth (knowledge), relations of power (governmentality), and subjectivation (forms of relations to oneself)" (p. 210); one that takes its aim as the examination of what Foucault calls the *government* or the "conduct of conduct" with regards to gender (Oksala, 2011, p. 210; Foucault, 2007a, p. 108). During his 1977-1978 lecture series at the Collège de France, Foucault identifies biopower with a particular type of power which he calls "governmentality," and which he identifies with the

ensemble formed by institutions, procedures, analyses and reflections, calculations, and tactics that allow the exercise of this very specific, albeit very complex, power that has the population as its target, political economy as its major form of knowledge, and apparatuses of security as its essential technical instrument . . . [and

with the development of] a series of specific governmental apparatuses [and] of a series of knowledges (savoirs)(2007a, p. 108).

With regards to gender, then, I argue we must examine the DSD treatment model in terms of the wider government of gender, in terms of the apparatuses and series of knowledges it justifies and reinforces, the regimes of truth, the relations of power and forms of subjectivation it reifies. In the remainder of this dissertation I begin to undertake this work.

In the next chapter, I turn to the DSD treatment model itself, reviewing the nosological shift it brought about and its clinical recommendations, as well as the science underwriting both. As I argued in this chapter, one of the effects of the DSD treatment model's adoption and the arguments offered by those who strategically endorsed it has been a lack of critical engagement with the science. Given that we know that the frequency with which genital normalizing surgeries are performed has not changed under DSD, the goal of this chapter is to make clear what, if anything, *has* changed under DSD. Or, to put it another way, are we, under DSD, still aiming at the production of cisgendered lives and if so, how? As Borry et al. (2006) argue, clinical evidence is not a sufficient condition for ethical medical decision-making, but it is a necessary one. Given this, any discussion of the ethicality of the DSD treatment model will require clarity regarding both the clinical evidence to which it appeals and the nature of the pathology it treats.

Chapter Three: The Disordering of Sex Development and the (Re)Production of Cisgendered Lives

I. Introduction

The introduction of gender and the OGR treatment model for managing intersex conditions in the 1950s are both the conditions of possibility for the emergence of specifically cisgendered as opposed to trans* gendered (or gender variant) lives, and what established them as *normal*. As a result, the aim of intersex management under OGR was securing a cisgendered future for the intersex patient, and thus, the production of cisgendered lives. In this chapter, I examine the DSD treatment model in light of and against the history of biopower laid out in chapter two vis-à-vis the deployment of sexuality and of gender, looking first at the shift in nomenclature and then at its clinical recommendations in order to determine what—if anything—has changed from intersex to DSD. Specifically, through my analysis of the new treatment model's nosology and revised practical recommendations, I seek to answer the questions of whether or not this DSD also aims at the medical production of cisgendered lives, and if so, how?

A central component of activist and academic critiques of OGR focused on the science underwriting the treatment model. Critics charged that not only was there inadequate clinical evidence to justify its use, but further, whatever clinical research and/or biological theories it did appeal to were both politically and epistemically suspect. As I established in chapter two, a side effect of the move to DSD has been a lack of critical engagement with the clinical and scientific research it appeals to. The biomedical model of intersex conditions as DSDs, as well as the nature/culture binary logic it entails, reauthorized medical authority over intersex conditions as pathologies. As result, the DSD treatment model, in terms of the scientific research and biological theories that ground it, seem to have fallen out of the

activist and critical, non-medical, theorist's purview, leading to a lacuna in literature post-Intersex/DSD. This chapter, in addition to the one that follows, aims at filling this gap. Further, it serves as an update to the genealogy of intersex management reviewed in the previous chapter, detailing the nature of the pathology of intersex conditions under DSD as constituted through nomenclature and normalizing clinical practices.

I begin my analysis of the DSD treatment model with the nomenclature, which has been one of its most controversial aspects since its introduction in 2006. As I established in chapter two, the DSD nomenclature fails to achieve the goals of being more precise or accurate than the intersex nomenclature it supplanted, and of incorporating or reflecting progress made in the molecular genetics of sex differentiation. Nevertheless, it has excelled in terms of inciting knowledge production about those with intersex conditions—even though the production of knowledge within medical science is generally positioned as hinging on the identification of accurate, precise, and hence *meaningful* diagnostic categories. DSD, like intersex before it, seems to be nothing more than an umbrella term, capturing a large group of etiologically distinct conditions, each with their own unique set of symptoms, risks, etc. In the following section, I examine a fascinating debate over the merits of the DSD nomenclature that took place in the October 2010 issue of the *Journal of Pediatric Urology* between two internationally recognized experts in intersex management and clinical research—American pediatrician Ian A. Aaronson and British pediatrician (and Consensus Statement co-author) Ieuen Hughes. Via this analysis, I will draw a number of conclusions, the most important of which are that: 1) despite the historical critique of the pathologization of intersex conditions, there remains no clear account of their pathology under DSD, despite their reclassification specifically as disorders and 2) at the level of nosology, DSD remains aimed at the production of cisgendered lives.

II. How Should We Classify Intersex Disorders?

The Consensus Statement presents the DSD system of nomenclature as a replacement for the intersex system and its problematic diagnoses of “male pseudo-hermaphrodite,” “female pseudo-hermaphrodite,” and “true hermaphrodite” (Lee et al., 2006, e489). It would be a mistake, however, to read the move from intersex to DSD as a mere reclassification, or even the re-division of the same set of diagnoses on new terms. Despite the fact that the Consensus Statement and its recommendations “rapidly achieved widespread acceptance,” the document actually failed to “specify precisely which conditions should be considered” DSDs (Aaronson & Aaronson, 2010a, p. 444). Further, the comprehensive list of DSDs published in 2008 by Consensus Statement co-author Ieuen Hughes included conditions that had not previously been considered intersex under OGR, such as undescended testis and labial adhesions (pp. 121-122; Aaronson & Aaronson, 2010a, p. 444).³⁹ The inclusion of these new conditions indicates that nosologically, the move to DSD—at least as it is officially laid out—is not a mere reclassification, but the constitution of a new expanded category.

This nosological expansion of “who counts” from intersex to DSD is cited by Ian Aaronson (writing with Alistair Aaronson, 2010a) in “How Should we Classify Intersex Disorders?” as a reason why the medical community would be better served by redefining DSD as “discordant sexual development,” rather than disorder of sex development, and that the term should be “strictly limited to those conditions traditionally regarded as intersex” (p. 443). Further, the Aaronsons argue in this article, initiating the exchange between themselves and Hughes, that these conditions (and individuals with them) should be sorted according to gonadal histology or makeup rather than according to karyotype, which they state is “but a

³⁹ Hughes is also a member of the *Journal for Pediatric Urology*'s editorial board.

crude reflection of the genetic makeup, is diagnostically non-specific, and is not in itself relevant to subsequent clinical developments” (p. 443). In place of the current karyotype-driven nomenclature, they offer the following system of categorization based on gonadal status:

Ovarian DSD, in which the gonads are composed of normal ovarian stroma embedded in which are numerous follicles, thus having the potential for normal hormonal function and ovulation.

Ovotesticular DSD, in which the gonads comprise both ovarian and testicular tissue distributed either separately in two distinct gonads, or within a single gonad with either a bipolar arrangement or as a diffuse admixture of ovarian and testicular elements. The ovarian element must contain at least one well-defined follicle. The testicular component comprises architecturally ordered tubules, although the intervening stroma may be more abundant than normal.

Testicular DSD, in which the semeniferous tubules are normal in configuration and cell type, although Leydig cells may be prominent.

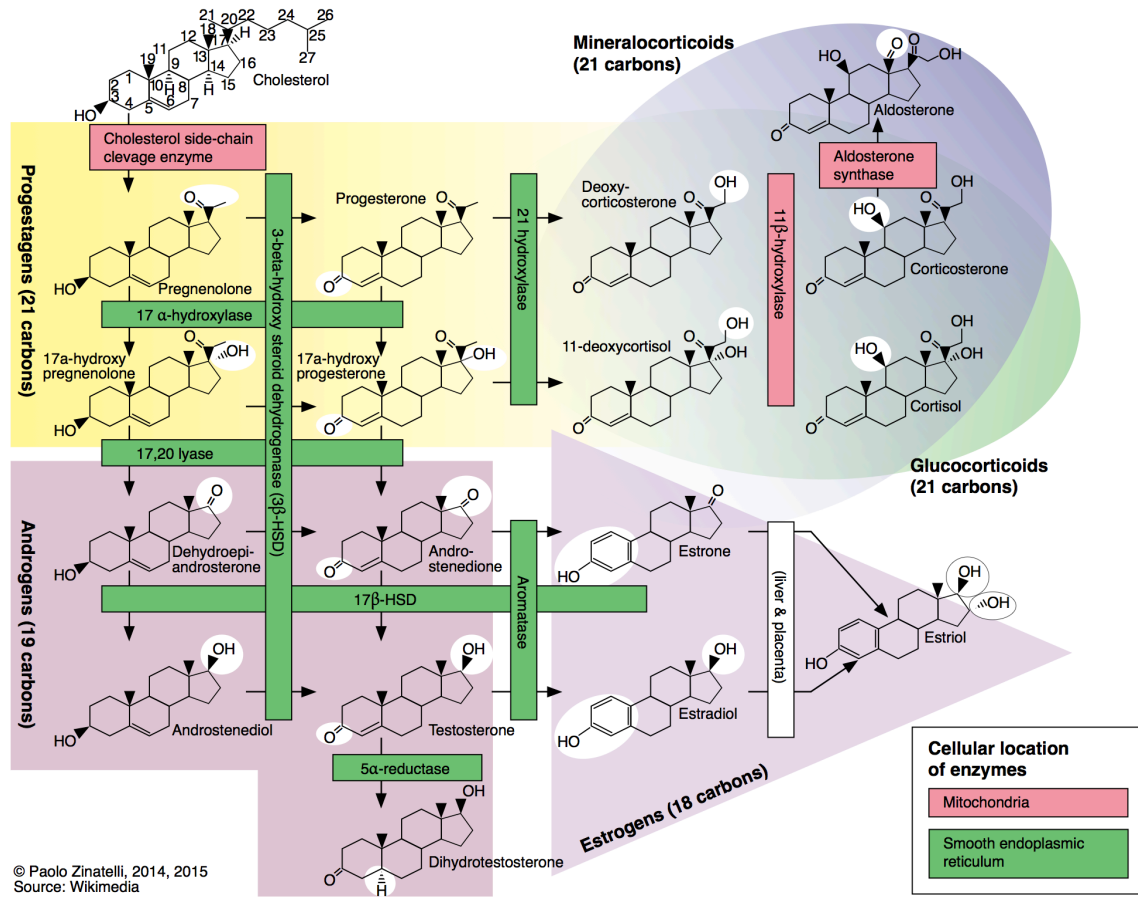
Dysgenetic DSD, in which the tubules are disordered and often sparse, in distinct contrast to testicular DSD, with an abundance of stromal tissue; because of the strong propensity for such gonads to undergo malignant degeneration, we believe this group requires classification as a distinct entity (p. 444).

The Aaronsons provide a number of arguments justifying their call for the nosological and clinical re-privileging of gonadal status over karyotype, and for narrowing the number of conditions captured by DSD to those previously known as intersex, including the kind of concerns I raised in chapter two regarding its nomenclature’s failure to represent natural kinds. In the course of making these arguments, however, the Aaronsons also unwittingly

forward their own unique account of the pathology of intersex conditions. This account, which I will call the Etiological-Mechanistic Account, locates the primary pathology of both intersex conditions and DSDs in disordered function with regards to the endocrine cascade or multi-step set of processes known as steroidogenesis, wherein cholesterol is converted by enzymes into biologically active hormones such as cortisol, androgens and estrogens (see figure 2 on the following page).⁴⁰ According to this account, disordered function with regards to steroidogenesis is defined either in terms of failing to produce typical or “normal” amounts of the products of this pathway (i.e. hormones) *or* failing to be sensitive to them (such as in the case of those with androgen insensitivity syndromes). For the Aaronsons, it is the disruption in this hormone-producing pathway that gives intersex conditions the unique ability to potentially “cause life-threatening metabolic disturbances, inappropriate physical changes at puberty or confusion with gender identity” (2010a, p. 443) as sequelae, which is what defines them as a kind. And as endocrine organs in which steroidogenesis takes place, gonads and their histological makeup are a better indicator of disruption (or potential disruption) in steroidogenesis than karyotype.

⁴⁰ I am not sure the Aaronsons would approve of my characterization of their account—particularly of my inclusion of Mechanistic—however, I do so in order to signify the level at which I am defining “etiology,” for the Aaronsons and Hughes use the term to refer to different things. The Aaronsons identify etiology at the level of the endocrine cascade, writing, “ideally, the classification of medical conditions should bring together those with shared fundamental characteristics, where possible based on their etiology. Among the wide range of aberrations affecting the appearance of the genitalia, those that are caused by a well-defined error in the pathway of sexual differentiation during the first trimester clearly belong together” (2010a, p. 444). Hughes, however, identifies etiology at the level of the gene, as evident through his urging that we use the DSD classification system in as a way by which “to establish aetiology in so many examples of DSD” (which is often generally established at the level of the endocrine pathway)(2010b, p. 448).

Figure 2. *The Steroidogenesis Pathway*



Note. From Paolo Zinatelli, 2014

Aaronson and Aaronson begin their article calling for the adoption of their gonadal histology-based system of classification by acknowledging the “unease” felt by many regarding the similarly gonad-based intersex diagnoses “true hermaphrodite,” “male pseudo-hermaphrodite” and “female pseudo-hermaphrodite” created by Klebs in 1876. However, they lament the privileging of karyotype status over gonadal histology they see as having been engendered by this discomfort with gonad talk, in combination with limitations in our molecular genetic knowledge:

Although it is conceptually attractive from the scientific perspective to base the classification of intersex disorders on the specific underlying genetic error, our current knowledge in this regard is insufficiently complete to allow this to be done in a comprehensive fashion. Recognizing these limitations, the Consensus Group favored using the karyotype as the overarching basis for classification (2010a, p. 444).

Not only is the Aaronsons' characterization of our knowledge of the genetic errors underlying intersex conditions as "insufficiently complete" generous, while it may be conceptually attractive to integrate molecular genetic knowledge into our system of classification, it is not clear that it would be very useful. As Adam et al. (2012) note, only about 20% of patients ever receive a molecular genetic diagnosis (p. 1341). Furthermore, in their 2012 article "Disorders of Sex Development: Challenges for the Future," Sarafoglou and Ahmed (2012) write:

The perpetual challenge in the diagnosis and management of patients with disorders of sex development (DSD), to paraphrase the adage, is that as our circle of knowledge in the genetic mechanisms of DSD expands, so does the circumference of darkness surrounding it (p. 2292).

They go on to say that while "new technologies (comparative genomic hybridization, sequencing by hybridization, and next generation sequencing) are rapidly generating massive amounts of information on the pathogenesis of DSD," all of this information comes with the "caveat . . . that identifying a pathogenic mutation may not predict the clinical picture because phenotype can be highly variable, even within the same family" (p. 2292).

Beyond specific genetic mutation, basing a system of classification on karyotype is problematic for a number of reasons according to the Aaronsons. Karyotype, they argue, is "of limited diagnostic value because of the considerable overlap in the patterns found among

various underlying intersex conditions,” noting that, for example, “a patient with a 46 XX karyotype may have any of the conditions historically listed under the heading female pseudohermaphroditism, but might also have true hermaphroditism” (Aaronson & Aaronson, 2010a, p. 444). By comparison, they identify “the histological integrity of the gonads and their consequent function” as “universally recognized . . . as fundamental to normal sexual differentiation and the subsequent physiological and anatomical changes which will occur in postnatal life” (p. 444):

Thus, those with histologically normal ovaries have at least the potential to be sexually active and fertile women, once any underlying hormonal imbalance has been corrected and suitable surgery carried out. Those with histologically normal testes can be expected, in the absence of severe androgen insensitivity, to show some virilization at puberty with enlargement of the penis, whereas those harboring both testicular and ovarian tissue are likely to develop a conflicted phenotype at puberty as a result of a surge in both testosterone and estrogen production. Of particular long-term importance is the risk of the gonads undergoing malignant degeneration, this potential being particularly high when attempted differentiation has resulted in dysgenetic gonadal tissue (p. 444).

Evidence of the Aaronsons’ unique Etiological-Mechanistic Account of the pathology of intersex conditions can be seen in their emphasis on the importance of gonadal histology in terms of function over that of karyotype, specifically with regards to its “fundamental” role in “normal sexual differentiation” (both pre and post-natally) and on the development of a “conflicted phenotype”—ostensibly to prevent it. They identify karyotype as of limited diagnostic value specifically because it results in failure to distinguish patients in terms of gonadal status (i.e. true vs. pseudo-hermaphroditism) and thus, gonadal

functionality in terms of hormone production. The Aaronsons do also identify gonad function (and the importance of it) in terms of fertility and malignancy risk. Fertility or malignancy risk are ultimately secondary or sequelae for the Aaronsons to the primary issue of hormone production and securing “normal sexual differentiation” across the lifespan for the DSD patient in terms of the development of a non-“conflicted phenotype” or a cisgendered life. The clearest evidence of this can be seen in the conditions that the Aaronsons seek to exclude from their reformulated category of DSD and the arguments they provide for their exclusion.

Noting that the Consensus Statement and its recommendations have “rapidly achieved widespread acceptance” despite the fact that the document failed to “specify precisely which conditions should be considered under this heading” (Aaronson & Aaronson, 2010a, p. 444) they argue that the comprehensive list of disorders later published by Hughes (2008), problematically included “in order to be comprehensive, various conditions (e.g. simple hypospadias, undescended testis, and micropenis on the one hand, and cloacal anomaly variants, vaginal agenesis, and labial adhesions on the other)” (Aaronson & Aaronson, 2010a, p. 444). Not only do none of these, according to the Aaronsons, “carry the potential long-term complications of the conditions traditionally grouped under the heading of intersex” (p. 444), but further, the inclusion of these conditions contradicts common practice and understanding of intersex conditions as distinguishable (and properly distinguished) from

other genital malformations by a clearly defined aberration in the endocrine cascade responsible for normal development of the fetal internal and external genitalia, and so have the potential to cause life-threatening metabolic disturbances, inappropriate

physical changes at puberty or confusion with gender identity. In some cases, the gonads also have the propensity to undergo malignant change (p. 443).

Infants with hypospadias and undescended testes clearly fall outside of this category, and while micropenis can often be confused with or taken as an intersex condition, such infants, they write, “apart from the small size of their penis, very rarely have any of the problems common to intersex infants.” Simple labial adhesion, they argue, is also not an intersex condition and should be “regarded as a trivial, acquired lesion which, once separated, is of no consequence.” Further, of those more complicated conditions often requiring surgical construction of genitalia such as cloacal anomalies and vaginal agenesis, the authors write, “all represent complex but local developmental errors, without any identifiable underlying endocrine disorder typical of the intersex patient” (p. 446).

Merely having atypical genitals deemed to require surgical normalization is thus, importantly, inadequate for inclusion under DSD for the Aaronsons because these patients rarely have “any of the problems common to intersex infants.” Here, they identify these problems with the potential for gonadal malignancy (acknowledged to only be a risk “in some cases”), “the potential to cause life-threatening metabolic disturbances” (which is only necessarily true for cases of SW-CAH) and “inappropriate physical changes at puberty or confusion with gender identity” (p. 443). These latter problems, and the atypical hormone production posited as engendering them, are what constitute the core pathology of intersex conditions and thus distinguish them as a kind for the Aaronsons. Both the girl with CAH-masculinized genitals and the girl with labial adhesions may receive normalizing genital surgeries, but the latter’s genital atypicality is trivial and “of no consequence” once separated because they are not a sign of the kind of underlying disruption in steroidogenesis which could lead to “inappropriate physical changes at puberty or confusion with gender identity”

(p. 443). That is, once the genitals of the girl with labial adhesions are surgically fixed, she no longer needs to be surveilled and managed with regards to her development as cisgendered.

Additional evidence that the Aaronsons identify the primary pathology of intersex conditions/DSDs in the disruption of the steroidogenesis pathway can be found in their controversial recommendation to exclude aneuploidy—(anomalous chromosome number) related conditions like Klinefelter’s syndrome or Turner’s syndrome, as well as those with de la Chappelle or XX male syndrome, from the category of DSD (and retroactively, intersex). Indeed, this is what grounds their claim that although those with Klinefelter syndrome and those with Turner syndrome may share things in common with those with intersex conditions (such as concerns about fertility or some phenotypic features), both conditions “should be regarded as . . . strictly chromosomal aberration [s]” (p. 446). This is because disruption of the steroidogenesis pathway does not necessarily result in atypical development of internal and external genitalia—though it may. Conversely, not every instance of atypical internal or external genital development is the result of an initial disruption of this specific endocrine cascade (though steroidogenesis disruption that results as a sequela may contribute to it). These latter cases do not “count” as intersex conditions (or DSDs) for the Aaronsons and that is why they argue for the exclusion of Klinefelter’s, Turner’s, and de la Chappelle or XX male syndrome. Though they can result in symptoms associated with intersex conditions and even sequelae characteristic of them (that is, disruptions in steroidogenesis), these are the result of chromosomal abnormalities (aneuploidy in the case of Klinefelter’s and Turner’s, and the presence of an SRY gene on an X chromosome as a result of unequal crossing over during meiosis for an individual with de la Chappelle’s). An individual with Klinefelter’s syndrome (XXY), for example, may experience atypical development of the testes or primary hypogonadism, interrupting testicular steroidogenesis

and thus resulting in atypically low testosterone production and associated fertility issues. However, this disruption in steroidogenesis and hypergonadism is a sequela of the primary or core pathology for the Aaronsons: the presence of an additional X chromosome.

The Aaronsons stress that implementation of their nosological system would not require gonadal biopsy in “the large majority of cases” as gonadal status can often be determined via deduction from biochemical and genetic studies (including, but not limited to karyotype), and in those cases where gonadal status cannot be confidently deduced are situations in which a gonadal biopsy would be indicated anyway (p. 446). They conclude with what they identify as “perhaps the most compelling reason to base the classification of DSD on gonadal histology” (p. 446)—the training of physicians—writing,

Understanding what has gone wrong in a patient with DSD starts with an appreciation of the *fundamental role the gonad plays in normal sexual differentiation* [emphasis added]. It is then a relatively small step to appreciate that an error somewhere along this pathway may lead to *undermasculinization*, or that androgen exposure of the female fetus can lead to *virilization* [emphasis added]. (p. 446).

As this final quote makes clear, for the Aaronsons, the central issue is clearly the role of the endocrine system here in terms of “normal sexual differentiation” which is read as cisgendered insofar as error is cashed out in terms of both physical (“inappropriate physical changes at puberty”) and psychological (“confusion with gender identity”) undermasculinization as a result of atypical hormone exposure. For Hughes, on the other hand, DSD is a much broader category that captures more conditions because, unlike for the Aaronsons, etiology is not what defines DSDs as a kind. In his rebuttal article, Hughes (2010b) argues for retaining the DSD system of nomenclature as formulated in the Consensus Statement and in doing so, forwards his own account of the pathology of intersex

conditions, which I will refer to as the Atypical Sex/Non-Etiological Account. According to Hughes, the primary pathology of DSDs is defined in terms of the atypical development of a primary or secondary sex characteristic such that it is deemed to require medical normalization, regardless of the mechanism (genetic or otherwise) by which it is brought about.

In his response to the Aaronsons (titled “How should we classify intersex disorders?”), Hughes defends the existing nomenclature while acknowledging the existence of debate over whether it represents the best way to classify intersex conditions, even among the authors of the Consensus Statement at the time of its writing. Hughes provides many arguments for the DSD nomenclature’s retention, many of which are practical, pedagogical, or related to knowledge production. For example, Hughes counters the Aaronsons’ claim that karyotype is not a good starting point for a system of classification as it is “unreliable as a diagnosis,” by arguing that karyotype is but a starting point that “merely steers the investigator towards one of three subgroups”: 46 XY DSDs, 46 XX DSDs, and aneuploidy-related DSDs such as 47 XXY, 45X0/46XY etc. (Hughes, 2010b, p. 447). He continues by arguing that the Aaronsons’ recommendation of using gonad histology as a starting point for classification is both unnecessary and impractical. While he acknowledges the importance of gonadal histology “in the context of DSD and their investigation,” he argues that “the reality is that all newborns with atypical external genitalia will have a karyotype performed” (p. 448), that gonadal histology will only ever be confirmed via biopsy in those cases where it cannot be deduced from karyotype and biochemical studies (thus, where we would have done them anyways), and further, that gonadal histology is often not particularly helpful:

One would hope that the dysgenetic DSD could be defined with equal clarity but unless there is obvious evidence of a ‘streak’ gonad on histology, too often the

clinician is provided with a report that documents changes in a testis akin to that found in an undescended testis. That is hardly a diagnosis that sheds light on the mechanism of a defect that could have arise along a pathway of sex determination through to sex differentiation (pp. 447-448).

After noting that students who have taken part in a popular course titled “Mechanisms of Disease” at the Part II Medical Sciences Tripos in Cambridge, “in which lectures on DSD have figured in recent years” have found the course “universally satisfactory,” Hughes writes that “the DSD nomenclature and the classification system which it spawned have been cemented in major programmes of research underway in Europe (EuroDSD), in standard textbooks of endocrinology and in recent monographs on DSD” (p. 448), citing two books of which he is co-editor, and concluding that:

With such a head of steam having emerged as a consequence of the Chicago Consensus and the remarkably rapid and widespread adoption of its principles into clinical practice, the proposals proffered [by the Aaronsons] are not sufficiently robust to make the case for changing what has now become the *status quo* [emphasis in original] (2010b, p. 448).

Evidence of Hughes’ unique account of the pathology of intersex conditions—the Atypical Sex/Non-Etiological Account—can be seen in the sole argument he gives defending the expansion of DSD to include conditions previously excluded from intersex, such as labial adhesions and undescended testes. Of these, he writes:

Many are not what previously would be considered as intersex, but DSD are not defined in that vein. This is a distinction that the authors have failed to grasp when arguing that the conditions such as simple hypospadias, cryptorchidism, cloacal anomalies and labial adhesions are not examples of intersex. Of course they are not,

but they *are* [emphasis in original] disorders of sex development; even the common labial adhesion which can completely occlude the vaginal opening is not a ‘trivial’ matter for the mother who is concerned that her daughter does not have a normal vagina (p. 447).

The emphasis here for Hughes is notably on both the presence of atypical sex characteristics (i.e. genitalia) *and* on the social response that atypicality elicits (specifically, maternal concern). Etiology is irrelevant for Hughes; what matters is that the individual has an atypically sexed body and that it is experienced as such. Importantly, in the context of intersex infants and children, this experience is not that of the child, but rather of their proxy decision-makers, such as “the mother who is concerned that her daughter does not have a normal vagina,” and physicians who deems their bodies worthy of normalization. Hughes’ DSD category is thus constituted at least in part through assumptions regarding self-evidently normal and abnormal genitals, as well as the type of parental (and perhaps physician) distress “abnormal” genitals are presumed to elicit, even in the absence of health risks and questions regarding sex assignment or gender identity development.⁴¹

This exchange between Hughes and the Aaronsons is important, I argue, for multiple reasons, not the least of which is its setting. *The Journal of Pediatric Urology* is the official journal of the majority of pediatric urology associations internationally and of the

⁴¹ One might argue that Hughes does identify the abnormality of labial adhesions in this quote as vaginal occlusion. However, as Hughes himself states, labial adhesions *can* result in problematic vaginal occlusion, but they do not always. Furthermore, I would be surprised if Hughes (or any other clinician) would limit their recommendation regarding surgically “correcting” labial adhesions in infants and children unable to consent to only those occasions where vaginal occlusion does occur. Parental distress regarding one’s daughter’s normal vagina is the constant in this scenario, which marks labial adhesion as a non-trivial matter, not vaginal occlusion. Further, while questions existed in the past regarding optimal sex assignment in patients with 46 XY cloacal exstrophy variant, the traditional practice of assigning these patients female (in large part due to the ease of vaginoplasty compared to phalloplasty and their lack of available tissue) is now considered a mistake given that these patients generally exhibit normal hormone production and receptivity.

International Society for Hypospadias and Disorders of Sex Development (ISHDSD) since 2013 (Frank, Mouriquand, Caldamone, & Malone, 2013).⁴² That the journal for those specialists engaged primarily (and to a great extent, solely) in the surgical normalization of the genitals of infants and children with DSDs has become *the* official journal of an international professional society for clinicians engaged in DSD management is, I argue, a sign that in this post-Consensus Statement era, the management of intersex conditions is still considered to be both a pediatric specialty and one primarily organized around surgical intervention.⁴³

Beyond this, however, the first substantive conclusion I draw from this debate is that in spite of all the historical discussion of whether or not intersex conditions and intersex bodies were pathological, there remains no contemporary articulation of, nor consensus on, the nature of their pathology. The mere existence of the debate itself attests to the lack of consensus that exists among clinicians regarding intersex conditions (or DSDs) in this post-Consensus Statement era and the pressing need for more analysis of the nature of the pathology of DSDs and their treatment. Indeed, how else should we read a debate between some of the most influential experts in the field of intersex management regarding the traditionally uncontroversial status of conditions like Klinefelter's and Turner's as intersex?

In the previous chapter, I argued that feminist academics were unable to speak about the

⁴² As of June 21, 2014 the *Journal of Pediatric Urology* was the official journal of the Asia Pacific Association for Pediatric Urologists, the British Association of Paediatric Urologists, the European Society for Paediatric Urology, Nucleo de Urologia Pediátrica da Escola Paulista de Medicina, Section Française d'Urologie Pédiatrique, Sociedad Iberoamericana de Urología Pediátrica, and the Society for Fetal Urology ("Society Information," <http://www.jpuirol.com/societyinfo>).

⁴³ The management of intersex conditions has long been considered a pediatric specialty such that adults are often unable to find non-pediatric care providers with adequate knowledge of these conditions (Feder, 2012, personal communication). Though some hoped the move to DSD would dispel the notion that intersex conditions are diagnosed and "fixed" in childhood, there is no evidence such a shift in thinking has occurred (Feder, 2014; Karzakis, 2008).

science underwriting the DSD treatment model because their theoretical and rhetorical strategy of embracing a biomedical model of intersex conditions and a nature/culture distinction excluded them from that field of analysis. In short, by demanding we recognize intersex conditions as disorders, they were left unable to question or theorize both the *nature* of such disorder and the constitution of *nature* that rendered them pathological.

For their part, clinicians seem to take the pathological nature of intersex conditions in general and ambiguous genitalia in the absence of health risks in particular as so self-evident that justifying this pathological nature (or even acknowledging the existence of any debate regarding it) is completely unnecessary. However, this means that not only can two of the most widely recognized experts in intersex care disagree about the nature of the pathology of intersex conditions, they can do so *without even realizing this is what they are disagreeing about*. Indeed, though Hughes and the Aaronsons frame their exchange as one primarily about best practices regarding classification, it is best understood as a debate about the nature of the pathology of intersex conditions. They each put forth competing accounts of the core or primary pathology of intersex conditions (and/or disorders of sex development), and of what might be properly understood as sequelae or secondary pathologies (in the way that nephropathy, neuropathy, and retinopathy leading to blindness are common sequelae of the primary pathology diabetes). As a result of these essential and conflicting assumptions, these eminent medical experts are left simply speaking past each other and failing to engage the other's arguments.

Second, I argue that even though the Aaronsons' Etiological-Mechanistic Account and Hughes' Atypical Sex/Non-Etiological Account capture a different set of conditions, both accounts aim at the production of cisgendered lives insofar as they both constitute the DSDs as *pathological* via reference to cisgendered lives as *normal*. Both Hughes and the Aaronsons

assume Money's understanding of sex as variable and bipolar, of gender as binary and oppositional (in terms of identity, physical presentation, and behaviour), and of the unambiguous cis-alignment of sex and gender as normal. The reason why the Aaronsons and Hughes capture different sets is because their respective accounts emphasize different aspects or poles of this alignment between sex and gender—sex in the case of Hughes and gender in the Aaronsons.

In its generality, Hughes' account is more in line with the Consensus Statement's simple and vague definition of DSDs as “congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical” than that of the Aaronsons'. Through his Atypical Sex/Non-Etiological Account, Hughes echoes Money's later “genital determinism” by emphasizing the importance of “normal” genitals for binary gender identity development. For Hughes, one cannot be a “normal” girl (or develop as one) if they don't have a typically female sexed body. If the Aaronsons are right, however, that physicians practically use DSD as a synonym for intersex, then it seems that their account is more reflective of actual medical practice. Moreover, insofar as it limits itself to those conditions traditionally identified as intersex, it more seems to more closely resemble the spirit or goal of OGR than Hughes' account. However, I argue that it is the Aaronsons' emphasis on the gender side of the constellation between sex and gender through their focus on hormones that bring them more in line with the OGR treatment model and with Money's thinking than Hughes. The Aaronsons' define the pathology of DSDs in terms of hormone disruption (either in terms of production or sensitivity)—identifying this as the fundamental element in “normal sexual differentiation” or the development of a cis-aligned sex and gender. This echoes not only Money's thinking on gender development, but also the dominant popular and scientific account of gender development that has succeeded it: brain organization

theory. In her 2010 book *Brainstorm: The Flaws in the Science of Sex Differences*, Rebecca Jordan-Young writes that according to brain organization theory,

prenatal hormone exposures cause sexual differentiation of the brain—that is, early hormones create permanent masculine or feminine patterns of desire, personality, temperament, and cognition. Further, hormones later in life could ‘activate’ behavioral predispositions, but the predispositions themselves result from the initial ‘organizing’ effects of hormones very early in development, before birth (p. xi).

While one might think that such a biologically determinist sounding account would be at odds with Money’s thinking, given his frequent representation as a social constructionist with regards to gender, Jordan-Young writes that this misrepresentation is ironic given that “Money was actually the *first* [emphasis in original] to apply . . . brain organization theory to data from humans and was easily the most prolific researcher in the field” (p. 30). Though Money’s early work—particularly those articles from 1955 to 1957 in which he laid out the OGR treatment model—emphasized the social aspects of gender development, Jordan-Young points to Money’s eventual embrace of brain organization theory, citing a 1965 article in which Money suggests that “women with CAH may have masculine sexuality because of the brain-organizing effects of prenatal androgens” (p. 31). Not only did Money maintain the position that “hormone effects were real, but subtle and limited” for the rest of his career, but further, as Jordan-Young argues, “[h]is influence on brain organization theory research in humans cannot be overestimated. Over the duration of his career, he was the author or co-author of literally scores of reports suggesting that early hormone exposures created masculine and feminine sexual predispositions in humans” (p. 30).

Money’s turn towards brain organization theory as a theory of normal and abnormal gender development makes sense given his constitution of gender as not only prior to sex,

but that which *fixes* sex. By constructing the pathology of DSDs in terms of hormones, the Aaronsons are thus following Money in not only positioning gender as prior to sex, but into brain organization theory, a field of research which Money helped define. Unsurprisingly, research on intersex conditions is “a cornerstone of studies relatd to brain organization”; indeed, disciplinary normalization is a system of not merely power, but knowledge (Jordan-Young, 2010, p. 5). Jordan-Young stresses the central importance of intersexuality for those studying brain organization theory in both humans and animals, “because genital development is a marker of prenatal hormone exposure—the same exposures that may affect the developing brain (albeit possibly during a different time frame)” (pp. 28-29). Thus, ambiguous genitalia indicate atypical prenatal hormone exposure, providing researchers with those “abnormal” cases from which we can glean knowledge and insight into the normal. As Jordan-Young writes, “an enormous proportion of brain organization research has been conducted on intersex subjects, because many scientists believe intersex people offer an opportunity to study the effects of hormones that ‘disagree’ with gender socialization” (p. 17). Thus, intersex conditions are intimately entangled with the emergence of brain organization theory not only as a field of knowledge, but as a *discipline*—that is, as a field of knowledge/power. Intersex conditions have played (and continue to play) a central organizing role in brain organization research, while the empirical claims generated within this field are used to justify and direct the forms of normalization visited upon intersex patients. In light of this intimate entanglement, I turn in the following section to briefly review the history of research into brain organization theory.

III. Intersex, Hormones, and Brain Organization Theory

Rebecca Jordan-Young (2010) identifies the origins of brain organization theory with a 1959 article by William Young and his colleagues at the University of Kansas tying the effects of prenatal administration of hormones on the sexual differentiation of the genitals in guinea pigs to their mating behavior (p. 21). She writes that this initial article “rests on a very simple idea: the brain is a sort of accessory reproductive organ”:

Males and females don’t just need different genitals in order to have sex, or different gonads that make the eggs and sperm necessary for conception. Males and females also need different brains so they are predisposed to complementary sexual desires and behaviors that lead to reproduction. This theory suggests that the same mechanism is responsible for both kinds of development – that is, for sexual differentiation of “both sets” of reproductive organs: the genitals and the brain (p. 21).

Since its first formulation in this 1959 article, brain organization theory “quickly moved past its humble beginning...to become the ‘grand theory’ for sexual differentiation of behavior in mammals, and then even more generally extending to vertebrates,” such that by the 1970s, any investigations into masculinity and femininity that didn’t invoke it were considered marginal or illegitimate (pp. 21, 36). Importantly, Jordan-Young notes that the sexually differentiating effect attributed to hormones are not restricted to “those behaviors that are directly involved in reproduction or courting. Instead, brain organization theory is used to explain a very wide range of differences related to gender and sexuality—in humans these

include everything from spatial relations, verbal ability, or math aptitude, to a tendency to display nurturing behaviors, to sexual orientation” (pp. 21-22).

This was not the first experiment or theory regarding hormone effects on behavior; however, earlier work focused on behavior in terms of sexuality rather than gender, in accordance with Foucault’s account of the deployment of sexuality through a *scientia sexualis* preceding Money’s introduction of gender into this field of medical knowledge/power between 1955 and 1957. The study of hormones, and thus, the establishment of endocrinology as a discipline, emerged at the beginning of the twentieth century, and, as Jordan-Young writes, “from the beginning, endocrinologists cast an eye toward understand how sex differences develop in both bodies and psychology” (p. 22). Early endocrinologists thought of hormones as “the chemical messengers of masculinity and femininity,” which were posited as “responsible for the development of sex differences throughout the body, as well as for the distinctions in how the sexes think, feel and act” (Oudshoorn, 1994, p. 17; Jordan-Young, 2010, p. 22). Nelly Oudshoorn (1994) identifies three key assumptions about hormones that underwrote early hormone research. First, hormones were sex-specific “in origin and in function” such that they not only “appear[ed] and relat[ed] to proper functioning in only one sex,” but were understood to generally “cause malfunction in the other” (Oudshoorn, 1994, p. 22; Jordan-Young, 2010, p. 23). Second, hormone function was posited as limited to “or at least most important for, functions that were directly related to sex and reproduction” (Jordan-Young, 2010, p. 23; see Oushoorn, 1994, pp. 22-24). Finally, hormones were considered to be “antagonistic,” in the sense that “the hormones of one sex would counteract the hormones of the others” (Jordan-Young, 2010, p. 23). Jordan-Young writes that “each of these assumptions was assaulted by data as early as 1921,” yet they nonetheless persisted (likely due to the sexist oppression they could be used to justify),

eventually giving rise to studies of the effects of hormones on sexual behavior in humans and then, with Money, in terms of gender. Though brain organization theory is now a theory about both gender and sexuality, as Jordan-Young writes, the story of hormones masculinizing or feminizing brains is “[s]till, at its heart...a story about the development of sexuality” (p. 22).

Early research studying the effects of hormone exposure on human behavior focused on homosexuality, and was based on the then-dominant theory of homosexuality as “inversion,” “meaning that the mind or soul of homosexual men was feminine and that of lesbians was masculine” (p. 25). The first studies of this kind, by Viennese psychologist Eugen Steinach beginning in approximately 1912, were ultimately failures: the seven homosexual men who had one of their testicles replaced with one from a heterosexual man failed to become heterosexual in response to treatment (Jordan-Young, 2010, p. 25; Fausto-Sterling, 2000, p. 158). However, Jordan-Young notes that despite accumulating evidence undermining the idea that gay men had a more “feminine” hormone profile (and lesbians a more masculine one), the idea “continued to be quite popular with scientists” (p. 25). Indeed, by the end of the 1950s, “much of the data regarding hormone effects on *behavior* [original emphasis] seemed disjointed and even contradictory” (p. 25). In response to the conflicting research, Young and his colleagues determined that “the key to predicting the effects of certain hormones was understanding the timing of exposures” (p. 27). They argued that gonadal hormones acted on both the brain and the genitals in the same way, “influenc[ing] the direction of differentiation” towards either male or female during the prenatal period and “stimulat[ing] function” postnatally (Young, Goy, and Phoenix, 1965, p. 184). Jordan-Young writes that “this new framework significantly shifted the direction of future experiments,” positing that hormones permanently organized brains (and genitals) in

the prenatal period, making this an irreversible step. Subsequently adult hormone exposure could not be expected to bring about “sex reversals” in terms of sexual behavior – explaining away all prior contradictory results – though it might, as a stimulant, affect that behavior in terms of timing and frequency (p. 27).

Brain organization theory as formulated by Young and his colleagues on the basis of their guinea pig studies in 1959 had clear relevancy for humans; however, as Jordan-Young writes, there were two substantial obstacles to proving it. The first was the lack of experimental data in humans and the fact that there was “no possibility of generating such data,” given that such experiments “would involve risky and unethical manipulation of human fetuses” (p. 28). The second problem was Money and his research on those with intersex conditions which indicated that rearing was the “the only variable that reliably predicted whether the intersex person would feel male or female,” and thus seemed to contradict their theory. Jordan-Young writes that Money’s team and Young’s team “were already corresponding before the definitive [1959] paper on brain organization theory came out, and the mutual implications of the two research programs were already clear,” insofar as Money’s research could indicate that brain organization theory was limited in its applicability to nonhuman animals (p. 28). Money was, however, eventually won over, such that by “a decade later, [he] had subtly modified his position, walking a fine line between his earlier strong claims for the primacy of sex assignment and the possibility of a psychological predisposition stemming from prenatal hormone exposures” (p. 29).

The central role Money played in the establishment of brain organization theory as a field is evident in the simple fact that “for the first six years of brain organization research in humans, all of the published work was conducted by...Money and various junior colleagues” at Johns Hopkins (Jordan-Young, 2010, p. 33). In these early studies, Money and his

colleagues reported that “girls and women exposed to high levels of androgen exhibited sexual traits and behavior that was more masculine than was expected. Conversely, they found that unusually low exposure to androgen among boys and men resulted in behavior that was more feminine than expected” (p. 33). In line with Money’s re-articulation of the field of medical power/knowledge initially constituted through the deployment of sexuality via the introduction of gender, he and his fellow researchers expanded or rearticulated the way in which they studied the behavioral effects of hormones in their patients, moving beyond sexuality to include other sex-typed behaviors such as “subjects’ interest in careers versus interest in ‘marriage and motherhood,’ preferred patterns of games and playmates in the children, manner of dress, extent of expressed satisfaction in their sex, specific cognitive skills like verbal or math ability and spatial relations, and occupational patterns among adults” (p. 33). Jordan-Young points out that the specific ways in which the intersexed difference from controls or expectations “varied from study to study...and often the differences that showed up in one report didn’t show up in another” (p. 33). Nonetheless, she writes, “each report suggested enough differences between hormone-exposed and unexposed groups that the idea of brain organization in humans began to look very convincing” (p. 33).

Money and his colleagues described their intersex patients as “analogues” simulating hormone exposure experiments on brain organization in animals (p. 33). However, Jordan-Young points out that not only were they “studying the same *syndromes* from which Money and the Hampsons had earlier concluded that ‘psychosexuality’ (that is, gender and sexuality) is entirely based on socialization,” but were often studying “the *same actual patients*,” and reaching a far more biologically determinist conclusion about the organizing effects of hormones (p. 33). Jordan-Young argues that two things had changed: first, “brain

organization theory introduced a theoretical mechanism whereby hormones might influence the brain directly in a process distinct from genital differentiation” (p. 33). And second, by the late 1960s, those with intersex conditions were being diagnosed and treated much earlier in life than they had before, such that “most of these patients were presumed to have relatively sex-typical exposures after birth” (p. 34). This made it possible to separate out atypical fetal and post-natal hormones in humans in a way that had previously only been possible experimentally in animals. This introduced a symmetry between the human and the animal studies in terms of the ability to differentiate the “organizing” and the “activating” effects of hormones, and by the 70s, Money and his colleagues had grown much less tentative regarding brain organization theory and were beginning to “assert that there was a growing evidence of a real, though limited, organizing effect from prenatal hormone exposure” (p. 34).

Nonetheless, Jordan-Young notes that Money and his colleagues were still “convinced that the ‘big picture’ of development in what they called ‘gender dimorphic behavior’ was best seen by focusing not on prenatal hormones but on postnatal rearing experiences” (p. 34). Researchers working on brain organization theory disagree about the relative importance of the social vs. the natural in terms of hormone exposure (p. 8). Money and his colleagues, however, represent those brain organization researchers who most emphasized the social, with Jordan-Young writing that in the research that’s followed Money, his “preference for seeing postnatal social experiences as the major player gender and sexuality gave way” to ones which emphasize the biological (p. 36). Normative statements about the role of men and women or “appropriate” masculinity and femininity “were replaced with more neutral statements about what women and girls versus boys and men do and think and say they want” (p. 36). This descriptive approach, argues Jordan-

Young, “significantly deemphasized the role of norms, social structures and modeling in developing gendered traits. Instead, disembodied as ‘naked facts’ or sexual differences, they began to look more and more like simple reflections of male and female nature” (p. 36). “Among scientists conducting brain organization research, Money, Ehrhardt, and their respective collaborators have indeed devoted more ink than others to emphasizing the social aspects of development” (p. 7)

Brain organization theory is thus an extension or elaboration of *scientia sexualis* as Foucault describes it, with contemporary researchers (and popular culture) emphasizing the role of the biological or natural over that of the social in the development of gender and sexuality. Further, though most brain organization researchers think of themselves as “interactionists,” Jordan-Young argues brain organization theory is a “biosocial” rather than “interactionist model” “because it does not attempt to account for how physical and social variables *work in tandem* [original emphasis]” (p. 8). That is, it presumes an additive, linear model of social and natural (hormonal) inputs leading to later behavioral outputs, without considering the way in which these inputs might interact or how that interaction might affect development. A properly interactionist model, she writes, would “suggest that the *character* [original emphasis] (not just the amount) of biological influence is affected by specific aspects of the environment, and vice versa” (p. 8). Research studies on brain organization theory – which are performed primarily on intersex and trans* individuals – are underwritten by a two part hypothesis, which defines the theory in its contemporary form. Part one is the assumption that “that male-typical sexual orientation or gender identity will correlate with other male-typical physical or psychological traits (and vice versa for female-typical sexual orientation and gender identity),” while part two is the assumption that those traits correlate

because “both are influenced by hormones during the critical period of development” (p. 38).

If I am correct that the Aaronsons’ Etiological-Mechanistic Account of the pathology of intersex conditions is appealing to brain organization theory by constructing pathology in terms of atypical hormone production or sensitivity, then their account is more properly considered the heir to Money’s than that of Hughes. In doing so, the Aaronsons cohere to the specific constellation of the heterosexual matrix as Money created it, prioritizing gender as that both constitutes and fixes sex. Though the Aaronsons’ agree with Hughes that those atypical genitals in the form of labial adhesions or hypospadias resulting from “complex but local developmental errors” should have their genitals surgically normalized, it is the “endocrine disorder typical of the intersex patient” – that is, a disorder in the pathway of hormone production – that defines those with DSDs. In this way, both nosological systems aim at the production of cisgendered lives, insofar as they define pathology by situating cisgendered life as normal; the Aaronsons simply emphasize gender while Hughes emphasizes typically sexed genitals.

While it might be true that DSD aims at the production of gendered lives at the level of nosology, it does not mean that this is necessarily true at the level of practices. Categorization (particularly in terms of pathology) and practices are intimately linked for Foucault; objectifying discourse and non-discursive institutional practices are together what produce the intersex body as an effect and object of medical knowledge/power. However, there can be fissures or misalignment between our systems of categorization and the practices they both justify and enable. Thus, in the next section, I turn to examine the clinical recommendations outlined in the Consensus Statement in order to cash out how the DSD treatment model *practically* constitutes the core pathology of DSD. I focus in particular on

the ways in which practices have changed from intersex to DSD. Given that the overall frequency with which genital normalizing surgeries are performed hasn't changed under DSD, changes to the specific ways in which these surgeries are performed will be far more illustrative in terms of establishing any changes that may have occurred from intersex to DSD in terms of both the treatment model's goals or aims and the account of sex and gender it posits.⁴⁴

IV. OGR vs DSD: The Clinical Recommendations

Contemporary medical management of intersex conditions under DSD deviates from their management under OGR as it was first laid out by Money in three ways: 1) with regards to gender assignment recommendations for those with micropenis, for 46 XY patients with cloacal exstrophy and for severely masculinized 46 XX infants with CAH; 2) with regards to the prenatal treatment of intersex infants with dexamethasone (often called “fetal dex”) and; 3) with regards to the treatment of intersex teens with puberty blockers such as the gonadotropin releasing hormone (GnRH) analogue leuprolide (known commercially as Lupron). Through an examination of these three shifts in intersex management between OGR and DSD, I will conclude that at the level of clinical practice, the DSD treatment model still aims at the production of cisgendered lives, with gender defined within a frame established by brain organization theory. Further, I conclude that the use of puberty blockers in intersex adolescents aims at *simulating the appearance* of a cisgendered life where one cannot

⁴⁴ The table titled “Common Intersex Conditions and their Etiology, Frequency, Symptomology, Psychosexual Outcome Data and Differential Treatment Under OGR and DSD” available in Appendix A, however, outlines detailed information regarding the most common intersex conditions, from their underlying etiology and frequencies, to information on psychosexual differentiation where available and the clinical recommendations for treating them under both the OGR and DSD treatment model.

actually be secured or produced. In these contexts, medical efforts aim at the production of a life that *passes as such*, by preventing or eliminating visibly trans* futures.

A. Shifting Ideas on Sex Assignment

Whereas the OGR treatment model recommended female sex assignment for both 46XY patients with micropenis or cloacal exstrophy (both the result of “local developmental errors” rather than a disruption in steroidogenesis), and severely masculinized 46 XX infants with CAH, consensus has shifted in the post-Intersex/DSD era to assigning these patients male, primarily as a result of the popular and scientific dominance of brain organization theory. The rationale for assigning the 46 XY patients female under OGR had to do with the limitations of phalloplasty techniques—it is often simply too difficult to build a penis capable of, as Creighton et al. say (2012), “voiding in a standing position and achieving straight erections and proper ejaculation that will permit suitable sexual intercourse” (p. 607). Furthermore, the XX chromosomes of 46 XX CAH patients, coupled with the relative ease of vaginoplasty, meant that clinicians saw themselves as *restoring* these latter patients’ bodies rather than changing them in some way; surgery and hormone therapy for these patients restored them to being the girls that they both should have been, and really were, all along. However, the Consensus Statement recommends male assignment for infants with micropenis (or a penis that is smaller than 2.5 standard deviations below the mean), “taking into account equal satisfaction with assigned gender in those raised male or female but no need for surgery and the potential for fertility in patients reared male” (Lee et al., 2006, p. 491; Hatipoğlu, N. & Kurtoglu, 2013, p. 217).

Although avoiding surgery and preserving fertility seem in themselves to be excellent reasons for assigning infants with micropenis a male sex (especially if the limited outcome

data available on satisfaction with assigned sex is ambivalent), Karkazis (2008) locates the motivation behind this change in recommendation to brain organization theory:

It would be an oversimplification to assume that clinicians' more expansive understandings of masculine sexuality alone are responsible for the recent reevaluation of female gender assignment for infants with a micropenis. More important is the recent scientific and popular resurgence of biologically based theories of gender difference that, generally speaking, emphasize the importance of chromosomes, genes, and hormones in making us men and women (p. 105).

I concur with Karkazis's assessment, and argue that the real appeal here is to a notion of binary, oppositional gender grounded in brain organization theory, and to the production of a cisgendered future. Those with micropenis have enough of the markers of male sex—such as XY chromosomes, but most important, typical testosterone production—such that their body is taken to act as an adequate indicator of future gender and sexuality (despite equivocating superficial evidence). Further evidence that brain organization theory is at work in clinicians' rationales regarding sex assignment can be seen in shifting positions on 46 XY cloacal exstrophy patients. The Consensus Statement itself equivocates on the issue of treating these patients, simply noting that those “reared female show variability in gender identity outcome, but >65% seem to live as female” (Lee et al., 2006, e491). However, Arboleda, Sandberg, and Vilain (2014) point to a 2004 report of “self-initiated gender-change in a cohort of patients with 46 XY cloacal exstrophy” as initiating a shift in pediatric urologists' recommendations regarding sex assignment. They cite a survey of American pediatric urologists published in 2011 in which 79% of respondents recommended male assignments for 46 XY cloacal exstrophy, “with 97% identifying ‘brain imprinting’ by prenatal androgens as an important factor in their decision” (p. 611). Furthermore, though

the Consensus Statement itself reproduces the OGR treatment model's recommendation that "markedly masculinized 46 XX CAH infants be assigned female" there is a good deal of evidence to suggest that clinical practice is moving away from this position. In a 2010 *Journal of Endocrinology and Metabolism* article titled "Approach to Assigning Gender in 46 XX Congenital Adrenal Hyperplasia with Male External Genitalia: Replacing Dogmatism with Pragmatism," Consensus Statement co-authors Christopher Houk and Peter Lee argue specifically for male assignment for these patients. In it, Houk and Lee specifically identify "the primary goal" in treating those with DSDs as "*gender identity [being] consistent with gender assignment*" [emphasis added] (p. 4508) and argue that given this, clinicians should seriously consider male assignment for the 46 XX patient with male external genitalia despite the Consensus Statement's contrary recommendations (which they identify as "implicitly tentative because of the low level of scientific support that underpins them, most being in the weakest category" [p. 4508]). Though they acknowledge that outcome evidence for their proposal "is incomplete," they argue there are nonetheless "several lines of evidence which support it" (p. 4503). In addition to citing studies showing that there appears "to be a high risk of gender dysphoria" in markedly masculinized patients assigned female, "regardless of karyotype" they also note "additional, albeit indirect support" from a study revealing gender transition (if not dysphoria) to be relatively rare among the few (33) markedly masculinized XX individuals assigned male that have been studied (pp. 4503-4504). Finally, they identify the avoidance of genital surgery and "the irrevocable loss of sensitive genital tissue" as an additional benefit of male assignment in these cases, pointing out that it will "offer more options for the adult DSD patient who would logically have a better outcome with surgical reassignment from male to female than vice versa" (p. 4504).

Houk and Lee invoke brain organization theory both implicitly and explicitly in their arguments for assigning severely masculinized 46 XX patients male, despite acknowledging that “the understanding of the effect of *in utero* androgens on human central nervous system (CNS) development remains inadequate to provide clear guidelines for gender assignment” (p. 4506). Their reference to a high risk of gender dysphoria for markedly masculinized patients assigned female “regardless of karyotype,” for example, is a thinly veiled appeal to brain organization theory and its assumption that the developmental effects of hormones on the genitals is mirrored in the brain. Thus masculinized (or “virilized”) the genitalia, the more masculinized the brain. More explicitly however, Houk and Lee identify “androgen-induced masculinization of the fetal brain” as appearing to be “important in the DSD patient exposed to male typical levels of testosterone during fetal life, including masculinized 46, XX DSD patients in whom such exposure produced male genitalia” (p. 4506). Furthermore, they cite “high levels of fetal androgen exposure” as a key justification for the move to male assignment for 46 XY cloacal exstrophy patients within the Consensus Statement, and argue that “similar consideration be given to the 46, XX CAH child with functional male genitalia whose existence implies a high degree of masculinization of the brain” (p. 4506). Thus, in all three of these cases—micropenis, 46 XY cloacal exstrophy patients, and 46 XX CAH patients—changes in treatment are not motivated exclusively or even primarily by a desire to avoid surgery and its attendant complications or to preserve fertility, but to produce stably cisgendered subjects, and secure a future free of gender ambiguity, dysphoria, and/or transition.

The final two ways in which contemporary intersex management differs from management under the OGR model as laid out by Money are the prophylactic prenatal treatment of 46 XX intersex infants with dex and the treatment of intersex adolescents with

puberty-blockers like Lupron. Interestingly, neither practice is officially endorsed, nor explicitly mentioned by the Consensus Statement, likely because both treatments are off-label, having never been approved by the FDA for use in this context (though the prenatal use of dex is discussed in articles cited by the Consensus Statement, most notably Warne, Grocer, and Zajac's (2005) "Hormonal Therapies for Individuals with Intersex Conditions: Protocol for Use" which positions it as the prenatal phase of the intersex patient's life-long hormone management). Nonetheless, evidence of the use of both treatments to manage those with intersex conditions can be found within the literature.

B. Fetal Dex

The more well known and controversial of these two practices is the treatment of women identified as at risk of having a child with CAH (either through genetic screening or having already had a child with classic CAH) prenatally with dex in order to prevent the masculinization of 46 XX CAH fetuses. Prenatal administration of dex for this specific reason was first introduced in France in 1978 and in the USA in 1986 by endocrinologist Maria New (Meyer-Bahlburg et al., 2012, 103). Dreger, Feder, and Advocates for Informed Choice director Anne Tamar-Mattis write in their 2012 article "Prenatal Dexamethasone for Congenital Adrenal Hyperplasia: An Ethics Canary in the Modern Medical Mine," that it is now seen by many specialists in the area as constituting the standard of care when treating women who might give birth to a child with CAH (p. 278). A glucocorticoid steroid 25 times more potent than cortisol, fetal dex *will not cure CAH*. Rather, the goal is specifically to prevent overproduction of androgens in only those CAH-affected fetuses with XX chromosomes, and thus, the masculinization of both their genitals and their brains. While the atypically low cortisol production associated with CAH results in the production of

atypically high levels of androgens in all affected fetuses, it is not considered a problem for those with XY chromosomes as such exposure does not carry the risk of genital or gender ambiguity as it does for those with XX chromosomes. However, because the masculinization process this treatment seeks to avoid occurs prior to clinicians' ability to test whether the fetus is affected—that is, before we can test whether the fetus has both XX chromosomes and CAH—fetal dex must be administered to a pregnant woman as soon as she learns she is pregnant (ideally 5-6 weeks gestation) (Warne, Grover, & Zajac, 2005, p. 23). Therapy is thus discontinued if the fetus is found to have XY chromosomes or if it is found to have XX chromosomes but tests negative for CAH, which accounts for 7/8 of all cases.⁴⁵

Administration of fetal dex to prevent masculinization of 46XX CAH infants has been lauded as “an excellent example of pharmacological therapy during pregnancy” and a “paradigm of prenatal diagnosis and treatment” (Rosner et al., 2006, p. 803; Nimkarn & New, 2010, p. 5).

Despite this, multiple concerns have been raised regarding the ethicality of fetal dex in recent years. Because the administration of fetal dex to avoid masculinization in 46 XX fetuses with CAH is an off-label use of the steroid, it has never been clinically trialed and thus, despite being lauded as paradigmatic and promoted as safe (particularly to those pregnant woman who receive it), we have no real idea of the effects of the prenatal administration of dexamethasone—which exposes the developing fetuses to 60-100 times the normal level of glucocorticoids—on either the fetus or the mother (p. 281). Fetal dex can nonetheless be administered for this use due to its categorization as a category C drug, meaning: “Animal reproduction studies have shown an adverse effect on the fetus and there

⁴⁵ An autosomal recessive condition, only 1/4 of fetuses will be positive for CAH and only 1/2 of those will be XX fetuses, leaving the total likelihood of having an XX, CAH positive fetus at 1/8.

are no adequate and well-controlled studies in humans, but potential benefits may warrant use of the drug in pregnant women despite potential risks”(FDA Pregnancy Categories, 2011). Animal studies as well as retroactive studies of human children treated with fetal dex prenatally for this purpose, however, have raised many concerns over the use of fetal dex. For example, in the past five years, studies have reported correlations between prenatal exposure to fetal dex and increased risk for heart disease and diabetes (Kelly et al., 2012), as well as cognitive delays in both animals and humans (Hirvikoski et al., 2012; Meyer-Bahlburg et al., 2012; Dreger, Feder, & Tamar-Mattis, 2012, p. 281). In fact, so many problems have been identified with fetal dex that American endocrinologists Walter L. Miller and Selma Feldman Witchel published a “clinical opinion” piece in the May 2013 issue of the *American Journal of Obstetrics & Gynecology* urging obstetricians to abstain from treating their pregnant patients at risk of having a child with CAH with fetal dex, and prevent their being treated with it by endocrinologists. They argue that the risks of this intervention outweigh the benefits of “ameliorating genital virilization” for about 80-85% of affected fetuses—by citing evidence from both human and animal studies showing that “first-trimester dexamethasone decreases birthweight; affects renal, pancreatic beta cell, and brain development; increases anxiety; and predisposes to adult hypertension and hyperglycemia,” in addition to retroactive human studies showing that “first-trimester dexamethasone is associated with oro-facial clefts, decreased birthweight, poorer verbal working memory, and poorer self- perception of scholastic and social competence” (Miller & Witchel, 2013, p. 355). Furthermore, Swedish researchers performing the only controlled and prospective study of fetal dex to have ever occurred announced in 2012 that they stopped recruiting new patients into the study beginning in 2010 after “severe adverse events” were noted in the treatment group on follow-up such as developmental delay, hydrocephalus, and severe mood fluctuations

(Hirvikoski et al., 2012, p. 1882). In their article in the *The Journal of Clinical Endocrinology & Metabolism*, the Swedish team conclude that the use of fetal dex is unethical not only in daily medical practice, but even in the context of clinical trials, given our inadequate understanding of its risks *and* that 7/8s of those fetuses exposed “do not benefit from the treatment *per se*” (p. 1882). They write:

We find it unacceptable that, globally, fetuses at risk for CAH are still treated prenatally with DEX without follow-up. If further treatment is initiated in other centers, we wish to stress that the minimal requirement should be to . . . perform prenatal DEX treatment of children at risk for CAH only within clinical trials including long-term follow-up of all treated individuals, as well as to give thorough information to the parents about the potential risks and uncertainties, in addition to the benefits of this treatment (Hirvikoski et al., 2012, p. 1882).

One of the acknowledged goals of prophylactic, prenatal administration of fetal dex is preventing the development of (and avoiding the surgery to treat) a urogenital sinus in CAH-affected XX fetuses, wherein the urethra and vagina are joined, increasing the risk of repeat infections. However, Dreger, Feder, and Tamar-Mattis (2012) argue that this is but a secondary goal, pointing to articles by New—one of the primary proponents of fetal dex—to argue that the primary aim of the treatment is to ensure that “CAH-affected female fetuses . . . develop in a more female-typical fashion than they otherwise might,” so as to avoid both ambiguous genitalia (and thusly secure a typically female sexed body) *and* so-called “behavioral masculinization” in the form of tomboyishness and lesbianism or bisexuality (p. 280). Dreger, Feder, and Tamar-Mattis identify brain organization theory as playing a key role in the rationale behind the use of fetal dex, writing:

Androgens contribute to sex differentiation, including in the brain and genitals;

relatively low prenatal levels ordinarily result in a more female-typical development; relatively high levels usually result in male-typical development. In certain forms of CAH—including 21-hydroxylase deficiency (21-OHD CAH), i.e., the type of CAH most at issue here—the prenatal production of high levels of androgens may result in a genetic female (46, XX) fetus developing along a more masculine pathway neurologically and genitally. Prenatal dexamethasone is meant to engineer the CAH-affected female fetus's hormonal system to be typically female (pp. 280-281).

The authors underscore the central importance of securing what I call a Cisgendered future in clinicians' rationales, quoting a 2010 article co-authored by Nimkarn and New stating that,

Without prenatal therapy, masculinization of external genitalia in females is potentially devastating. It carries the risk of wrong sex assignment at birth, difficult reconstructive surgery, and subsequent long-term effects on quality of life. Gender-related behaviors, namely childhood play, peer association, career and leisure time preferences in adolescence and adulthood, maternalism [interest in being a mother], aggression, and sexual orientation become masculinized in 46, XX girls and women with 21HOD deficiency. . . . Genital sensitivity impairment and difficulties in sexual function in women who underwent genitoplasty early in life have likewise been reported. We anticipate that prenatal dexamethasone therapy will reduce the well-documented behavioral masculinization and difficulties related to reconstructive surgeries (Nimkarn & New, 2010, p. 9).

Dreger, Feder, and Tamar-Mattis note both that Nimkarn and New seem particularly concerned with XX CAH women failing to be heterosexual wives and mothers, having

raised the issue in multiple publications and at multiple events,⁴⁶ and the irony of Nimkarn and New's positioning of one elective, experimental prenatal intervention (fetal dex) as necessary in order to avoid another elective, experimental intervention (feminizing genitoplasty). Importantly, the goal and ultimate achievement of each of these elective, experimental interventions is a future that is cisgendered. Whether we use fetal dex or, we use feminizing genital surgery and hormones—either way, we're trying to produce girls who are girls, in both body (sex) and mind (gender).

C. Puberty Suppression

The final clinical practice to be introduced into the toolbox of intersex management strategies in the past few years is the treatment of intersex adolescents with puberty-blockers such as Lupron. Another off-label use, there isn't as much evidence in the clinical literature for the use of puberty-blockers in intersex adolescents as there is for the use of fetal dex in sex assignment. I have, however, found some very interesting bits of evidence for the use of Lupron in intersex adolescents in two sources—the ISNA's 2006 publications: the *Handbook for Parents* and *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood*. The practice is mentioned twice in the *Handbook for Parents* (2006b), first in the section titled “Puberty,” where the authors suggest that parents talk to a pediatric endocrinologist “in the event puberty is beginning before your child is sure of what she or he wants, [as] special

⁴⁶ For example, Dreger, Feder, and Tamar-Mattis report that at a 2001 meeting of parents of CAH affected children organized by the CARES Foundation, New showed a photo of an XX infant with CAH and ambiguous genitalia and stated “The challenge here is . . . to see what could be done to restore this baby to the normal female appearance which would be compatible with her parents presenting her as a girl, with her eventually becoming somebody's wife, and having normal sexual development, and becoming a mother. And she has all the machinery for motherhood, and therefore nothing should stop that, if we can repair her surgically and help her psychologically to continue to grow and develop as a girl” (New quoted in Dreger, Feder, & Tamar-Mattis, 2012, p. 282).

hormone treatments may be used to hold off puberty a little longer” (p. 31). The second mention comes in an answer in the section titled “Questions About Medical Care and Surgeries,” detailing the pros and cons of gonadectomy. In it, the authors write:

If a child is entering puberty and has a kind of gonad that is making her or his puberty go the “wrong way,” you should give the child the option of having the gonads out. (For example, a girl with 5-AR Deficiency and testes might start turning more masculine when she starts puberty, something she may not want. Her parents should talk with her and her doctor about her options, *including medicines to delay puberty* [emphasis added] if she’s unsure of her gender identity, or surgery to remove her testes.) (p. 62)

The references to the use of Lupron in the *Clinical Guidelines* (2006a) are very similar to those in the *Handbook for Parents*. The first mention also deals with the issue of puberty going “the wrong way,” this time in the context of those 46 XY PAIS patients assigned female whose gonads were not removed in childhood, whom the authors caution will experience “some pubertal virilization” as a result of their testes (p. 5). The authors suggest that in these cases “leuprolide (marketed as Lupron) may be used to delay puberty so that patient’s decision-making about orchidectomy [testicle removal] is not rushed” (pp. 5-6). Further in a section titled “Gender Assignment,” the authors again suggest the use of Lupron; however, this time the practice is importantly positioned as a way of dealing specifically with *gender ambiguity* rather than the development of the “wrong” secondary sex characteristics or facilitating patient decision-making:

On rare occasions, a child with a DSD may approach puberty without having clearly expressed a gender identity. Consider, for example, a child with histologically normal testes, 46,XY, and partial virilization who is being raised as a girl but who is

approaching puberty without a clearly expressed gender identity. In such cases, leuprolide (marketed as Lupron) may be used to delay puberty while psychologists and psychiatrists help the child explore feelings and options (2006a, pp. 25-26).

Because of these four very specific references to the practice of treating intersex adolescents with puberty-blockers in these two documents, I argue that those who specialize in intersex care are likely fairly familiar with it, even if it is not explicitly endorsed in the Consensus Statement and rarely if ever mentioned in the clinical literature in the context of intersex care. Many clinicians working in intersex management are listed as contributors in both of these documents, with the *Clinical Guidelines* in particular listing Creighton in addition to physicians Joel Frader, Philip Gruppuso, William Reiner, Justine Schober, and Aron Sousa, among others (pp. iii-v).

The use of puberty-blockers in adolescents has received quite a bit of attention recently, specifically in the context of medically managing trans* adolescents. The latest version of the international standard of care for the medical management of trans* individuals, the World Professional Association for Transgender Health (WPATH) *Standards of Care for the Health of Transsexual, Transgender and Gender-Nonconforming People*, is the first to include puberty-blockers as part of the standard suite of therapies available for the treatment of trans* adolescents (though they acknowledge that not all clinics offer this treatment and that its high cost “is prohibitive for some patients”) (WPATH, 2012, pp. 18-20). In the seventh version of the WPATH’s *Standards of Care* published in 2012, one of the listed roles for “mental health professionals working with children and adolescents with gender dysphoria” is “refer[ring] adolescents for additional physical interventions (such as puberty-suppressing hormones) to alleviate gender dysphoria” (p. 14). Further, the use of puberty-blockers is the first type of physical intervention for adolescents listed within that section, as

well as the sole fully reversible intervention, as opposed to partially reversible interventions (such as hormone therapy to masculinize or feminize the body) and irreversible interventions (such as surgical procedures).⁴⁷ WPATH recommends a “staged process” in order to “keep options open through the first two stages,” stating that movement “from one stage to another should not occur until there has been adequate time for adolescents and their parents to assimilate fully the effects of earlier interventions” (p. 18). Thus, under the latest version of the WPATH’s standards of care, puberty suppression using GnRH analogues has become the official first step in treating trans* adolescents.

WPATH identifies two goals as justifying the use of puberty-blockers, which adolescents may be eligible to receive as soon as puberty begins (pp. 18-19). The first of these is that it “gives adolescents more time to explore their gender nonconformity and other developmental issues,” and the second is that “their use may facilitate transition by preventing the development of sex characteristics that are difficult or impossible to reverse if adolescents continue on to pursue sex reassignment” (p. 19). The *Standards of Care* further emphasizes the importance of puberty-blockers in their statement on the risks of withholding medical treatment from adolescents, in which they caution:

Refusing timely medical interventions for adolescents might prolong gender dysphoria and contribute to an appearance that could provoke abuse and stigmatization. As the level of gender-related abuse is strongly associated with the degree of psychiatric distress during adolescence, withholding puberty suppression and subsequent feminizing or masculinizing hormone therapy is not a neutral option for adolescents (p. 21).

⁴⁷ If puberty blockers are followed by hormone therapy, the ability to reproduce is eliminated (Sadjadi, 2013, p. 2).

However, it nonetheless acknowledges concerns that have been raised regarding the paucity of evidence to support this off-label use of GnRH analogues, the possible negative side effects this treatment may have on both bone development and height, as well as possible complications its use might have for patients with penises who later seek feminizing genital surgeries:

Adolescents with male genitalia who start GnRH analogues early in puberty should be informed that this could result in insufficient penile tissue for penile inversion vaginoplasty techniques (alternative techniques, such as the use of a skin graft or colon tissue, are available) (p. 19).

Subsequently, WPATH recommends that any adolescent on puberty-blockers be closely monitored, preferably by an endocrinologist, “so that any necessary interventions can occur (e.g., to establish an adequate gender appropriate height, to improve iatrogenic low bone mineral density)” and remarking that for these patients,

Neither puberty suppression nor allowing puberty to occur is a neutral act. On the one hand, functioning in later life can be compromised by the development of irreversible secondary sex characteristics during puberty and by years spent experiencing intense gender dysphoria. On the other hand, there are concerns about negative physical side effects of GnRH analogue use (e.g., on bone development and height). Although the very first results of this approach (as assessed for adolescents followed over 10 years) are promising, the long-term effects can only be determined when the earliest- treated patients reach the appropriate age (p. 20).

Thus, while I conclude that the general goal of intersex management is the production of cisgendered lives, I argue where those efforts fail, intersex management aims at the production of lives that *pass as cisgendered* through the use of puberty blockers like

Lupron. Mallon (2004), defines passing as occurring “whenever a member of some category is perceived (and allows herself to be perceived) as a member of another, mutually exclusive category” (p. 646). The use of puberty blockers with intersex adolescents facilitates their “acquiring the physical appearance of the opposite sex/gender in adolescence and adulthood” in the same way that it does for their trans* counterparts, and the subsequent elimination of any futures as visibly or “readably” trans* (Sadjadi, 2013 p. 2). The *Clinical Guidelines*’ (ISNA, 2006a) invocation of puberty blockers in the context of both incoherence between hormone production and gender (i.e. the “wrong hormones”) and gender ambiguity speaks to this point. Whether we feel uncertain about an individual’s sex at birth (in the case of intersex) or not (in the case of trans* persons), the assumption is that they will (and indeed must) come to inhabit a single, oppositional, and univocal gender with which their body can surgically and hormonally be positioned into cisgendered alignment. The DSD treatment model thus replicates the OGR model both practically and at the level of nosology. Like OGR before it, DSD aims at the production of cisgendered lives via appeal to an additive, linear model of brain organization theory and a notion of hormonally constituted masculine and feminine brains. Moreover, where cisgendered lives cannot be secured, medical efforts aim at the production of lives that pass as such, through the elimination of visibly trans* futures.

All of this, however, assumes—both practically and nosologically—that cisgendered lives are indeed normal such that gender variant or trans* lives are pathological. Hughes and the Aaronsons, for example, simply assume the pathology of intersex conditions and thus, never attempt to justify their identification as such; they simply proceed to lay out and argue the different ways they see that pathology cashing out. Further, at the level of clinical practices, securing a cisgendered future is constituted as so important that medical efforts

work towards making it *appear* even when it fails to obtain. In this sense, those questions initially posed under OGR regarding what makes the sex-atypical yet otherwise healthy bodies of intersex infants and children pathological such that we justify the performance of non-consensual, cosmetic genital normalizing surgeries upon them remain for DSD.

I find it fascinating that not only do we continue to lack an account of the pathology of intersex conditions post-Intersex/DSD, but that clinical experts in this era can both disagree about what constitutes the core pathology of DSDs *and* fail to realize they appeal to differing accounts of it. Intersex conditions' status as pathologies was the central critique around which both activist and academic engagement with OGR was organized. Yet, in my review of the biomedical literature on intersex conditions—and more specifically, in my review of the literature cited by the Consensus Statement itself—I have only ever found one explicit argument by a clinician-researcher that both acknowledges the existence of any controversy regarding the identification of intersex conditions as pathological *and* explicitly attempts to defend it. It occurs in a footnote accompanying the first sentence of Kenneth Zucker's 1999 article "Intersexuality and Gender Identity Differentiation." In the main text Zucker writes: "People born with physical intersex conditions (often better known as hermaphroditism) remind us that the ordinary or 'normal' process of physical sex differentiation is by no means automatic," while elaborating in the footnote:

The word normal is intentionally surrounded by quotation marks to alert the reader to one of the current controversies in the literature on physical intersex conditions, namely whether they should be considered "abnormal" or simply variants of typical or normal physical sex differentiation in ordinary biological males and females. I believe that physical intersex conditions are "abnormal," or, to use Money's

descriptor, “sex errors of the body.” I reach this conclusion by following King’s definition of normal: “that which functions in accordance with its design” (Zucker, 1999, p. 50).

Zucker’s invocation of the Yale graduate student’s nine-page, 1945 treatise “The Meaning of Normal,” puts him in good company—most notably that of the aforementioned author of the BST, Christopher Boorse. In his first publication on BST, 1975’s “On the Distinction between Disease and Illness,” Boorse begins his exploration of the theoretical notion of disease by invoking C. Daly King’s “admirable explanation of clinical normality” from 1945, in which he argues that the “the normal” is that which should “objectively and properly . . . be defined as that which functions in accordance with its design” (Boorse, 1975, pp. 56-57; King, 1945, pp. 493-494). Reflecting on this in 1997’s “A Rebuttal on Health,” Boorse would redefine “clinical normality” to “medical normality,” writing “[m]edical normality, as King said, is functioning according to design. But the species design is, in fact, simply those functions statistically typical in species members. Given a focus on functions, medical normality and statistical (nonsub) normality are the same thing” (Boorse, 1997, pp. 17-18). This 1997 piece is also where Boorse forwards his most current definition of the BST in terms of the following four steps, including the figure reproduced below.

1. The *reference class* [emphasis in original] is a natural class of organisms of uniform functional design; specifically, an age group of a sex of a species.
2. A *normal function* [emphasis in original] of a part or process within members of the reference class is a statistically typical contribution by it to their individual survival and reproduction.
3. A *disease* [emphasis in original] is a type of internal state which is either an impairment of normal functional ability, i.e. a reduction of one or more

functional abilities below typical efficiency, or a limitation on functional ability caused by environmental agents.

4. *Health* [emphasis in original] is the absence of disease (pp. 7-8).

Figure 3. *Boorse's Illustration of the Normal and the Pathological*

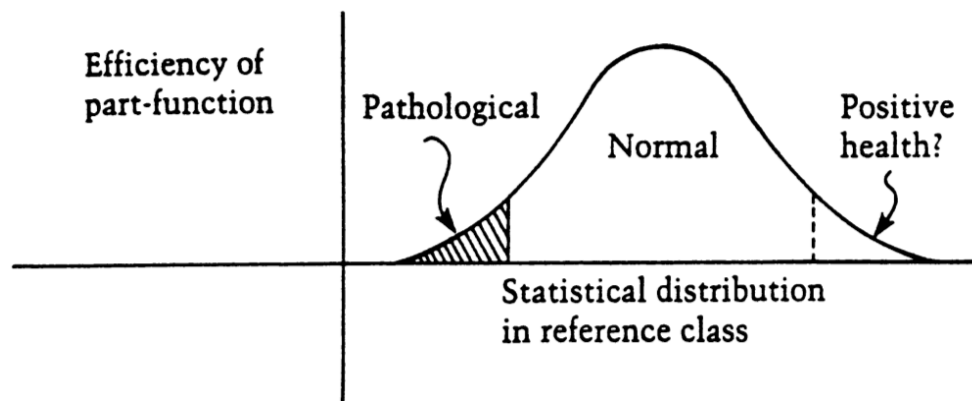


Fig. 1. Normal vs pathological.

Note. From Boorse, 1997, p. 8.

It is unclear exactly which function Zucker believes is interrupted as a result of the atypical bodily development of those with intersex conditions; he seems to take this as self-evident. However, combining the Consensus Statement's definition of disorders of sex development with Zucker's assertion, I argue we can understand the claim that bodies with atypical chromosomal, gonadal, or anatomic sex development are those unable to function in accord with their design as invoking a concept of what I will refer to as "The Normal Functions of Physical Sex" to refer to the concerted function normally played by physiological sex characteristics such as sex chromosomes, gonads, internal and external sex morphology, and hormones. This concept can be cashed out in three ways or senses, referring to three different kinds of function—none of which I personally endorse: 1)

Reproductive Function referring to one's physical capacity to reproduce; 2) Hetero-Coital Function referring to one's capacity to engage in penile-vaginal intercourse; and 3) Cisgendered Function referring to the capacity one's physical sex is assumed to have with regards to one's predicted future gender identity, presentation, and behavior.

We often conflate these three “normal functions of physical sex,” in the same way we tend to conflate the three constituents of the heterosexual matrix—sex, gender, and sexuality. In fact, this tendency to conflate the latter terms is bemoaned by pretty much everyone involved in intersex scholarship and activism from clinical researchers, to activists (e.g. the positioning of intersex as an issue of disordered sex development and *not* gender), to academics. This tendency to conflate sex, gender, and sexuality in addition to the three normal functions of physical sex I have outlined is, I argue, a consequence or artifact of the historical relationship between these terms/entities in terms of their constitution under biopower, as well as the way in which this relationship has concretized in the field of medical knowledge/power first produced through the deployment of sexuality—currently in the form of brain organization theory. We assume that the normally sexed body is so because of sex-typical hormone production/sensation, which will result in a cisgendered future that is characterized by both engagement in hetero-coital intercourse and the desire to reproduce.

Because of our tendency to conflate not only sex, gender, and sexuality, in addition to the three normal functions of physical sex I outlined above, I turn in the following section to examine each of these functions in relation to the DSD treatment model's recommendations. This exploration might seem unnecessary given that in the previous sections I concluded that the DSD treatment model aims at the production of cisgendered lives at the level of both clinical practice and of nomenclature, rendering the pathology of intersex conditions one constituted in terms of cisgendered function. I undertake it,

however, for two main reasons. First, because the surgical achievement of the goals of care that is stipulated by each of these normal functions of physical sex can be at odds with each other—for example, we often remove the gonads of intersex infants in order to secure cisgendered function at the sacrifice of reproductive function—examining the clinical recommendations with regards to these functions will be a matter of seeing which senses are practically prioritized over others and serve to solidify my conclusions that the role of intersex management is to ensure that cisgendered lives are made live. Second, given that we are now almost three decades beyond the first critiques of the pathologization of intersex conditions and still lack a clear account of their status or nature as pathologies, I seek to fill this gap in the literature by explicitly forwarding such an account.

V. The Normal Functions of Physical Sex: Reproductive, Hetero-Coital, and Cisgendered

A. Reproductive Function

The first way that function is understood in relation to sex refers to one's capacity (or incapacity) to reproduce. One's ability to reproduce can be hindered by multiple different variables, most obviously by the capacity of one's gonads to produce gametes and one's capacity to bring one's gametes together with another's to create an embryo (presumably without the use of reproductive technologies).⁴⁸ The thinking here is that intersex conditions

⁴⁸ The introduction and ubiquitous use of reproductive technologies from medications that facilitate ovulation to in vitro fertilization or IVF has led to a radical reconceptualization of reproduction in both the medical and popular spheres in a way that is evident in the specific way in which I define Reproductive Function. Reproductive technologies have not only divorced reproduction from heterocoital intercourse (and the desire for it), they has also redefined Reproductive Function and subsequently, infertility as impairment in reproductive function such that I suspect few who have utilized such technologies would think of themselves as infertile. Exploring the relationship between reproductive technologies and the constitution of fertility and infertility—both discursively and non-discursively—could easily be its own paper, if not dissertation, and is ultimately beyond the scope of this text. For my

leave those who have them unable to reproduce either due to sterility or the inability to engage in reproductive intercourse and thus, intersex conditions are obviously pathological. Grounding the pathology of intersex conditions in terms of reproduction or impairment to reproductive function coheres, at least in part, with evolutionary accounts of pathology according to which any genetic variation which necessarily results in sterility is indeed a genetic defect, for it results in what evolutionary biologists refer to as a 100% reduction of Darwinian Fitness or “the probability of surviving to breed times the number of offspring produced” (Roughgarden, 2009, p. 281).

There is some evidence within the Consensus Statement that Reproductive Function (or the capacity for it) is one of the targets of treatment. On the topic of fertility the Consensus Statement’s authors recommend that “surgical management in DSD should also consider options that will facilitate the chances of fertility,” noting that patients with “bilateral ovotestes are potentially fertile from functional ovarian tissues” and suggesting the “technically difficult” surgical separation of ovarian and testicular tissue “be undertaken, if possible, in early life” (Lee et al., 2006, e492). However, the treatment model’s specific recommendations regarding the surgical management of hypospadias contradicts the notion that Reproductive Function is physicians’ primary concern. Regarding moderate to severe hypospadias patients, who generally have normal testes, but whose urethra opens anywhere along the shaft the base of the penis, the Consensus Statement writes that “standard techniques for surgical repair such as chordee correction, urethral reconstruction, and the judicious use of testosterone supplementation apply” (Lee et al., 2006, e492). It goes on to caution, however, that

purposes here, however, it is enough to be clear that fertility is not an all-or-nothing thing, particularly in a context where reproductive technologies are available. Nonetheless, the DSD treatment model and its recommendations not only treat it as such, but further, fail to take into the account the existence of reproductive technologies.

The magnitude and complexity of phalloplasty in adulthood should be taken into account during the initial counseling period if successful gender assignment depends on this procedure. At times, this may affect the balance of gender assignment.

Patients must not be given unrealistic expectations about penile reconstruction, including the use of tissue engineering” (Lee et al., 2006, e492).

Phalloplasty has always been a more difficult procedure than feminizing genital surgeries like vaginoplasty or labioplasty, dependent as it is on the physiological structures available, which can vary greatly (even amongst those with the same underlying condition). Indeed, in many ways, phalloplasty is something of a misnomer, for as Kessler wrote in 2002’s *Lessons from the Intersexed*:

Although there are phalloplasty techniques designed to increase the size of the penis and to improve penises that are irregular (for example: bent, buried in an abnormally developed prepuce, or with the glans not proportional to the shaft), the most common surgeries are not for small or misshapen penises, but for those penises whose urethral opening is not in the typical location—the center of the glans tip (p. 49).

Thus, phalloplasty in the context of intersex surgical management is generally synonymous with hypospadias repair. And the willingness of the Consensus Statement authors to sacrifice the potential fertility of those with hypospadias, the most common DSD with a global frequency of 1/1725 in its moderate and severe forms, belies a prioritization of Reproductive Function or the identification of its disruption as constituting the core pathology of intersex conditions. Generally speaking, surgical sex assignment in all infants and children with intersex conditions entails either the performance of feminizing genital surgeries (clitoroplasty or clitoral recession, vaginoplasty, and labioplasty as needed) or masculinizing

genital surgery (phalloplasty) *as well as* gonadectomy in order to prevent the development of both the development of a discordant phenotype and gonadal malignancies. Those with severe hypospadias assigned female would necessarily be sterilized, as their testicles would not only prevent the construction of “normal looking” female genitalia, but would produce testosterone resulting in the development of masculine characteristics.

While avoidance of gonadal malignancy is often cited as motivating gonadectomy, very little data exists regarding the actual risks of malignancy, and thus the primary reason for these procedures is avoiding the development of a phenotype that might conflict with sex of assignment given that. For example, the Consensus Statement includes a table titled “Risk of Germ Cell Malignancy According to Diagnosis” compiling information from over 1,400 studies of a *total* of 83 patients (Lee et al., 2006, e493). While a high risk is clear in certain cases, this is the exception rather than the rule (for example, patients with intra-abdominal gonads which display gonadal dysgenesis *and* have the portion of the Y chromosome that contains TSPY (testis-specific protein Y encoded) gene appear to have a 15-35% risk of gonadal malignancy, though this determination is itself based on >350 studies of the same 12 patients). For the majority of cases, we have very little evidence upon which to recommend gonadectomy over, say, a “wait and see” approach using regular screenings which would have the additional benefit of avoiding potential risks associated with synthetic rather than endogenous hormone exposure (ISNA, 2006a, 2006b; WPATH, 2012). It is, for example, unclear why we should consider the determination that Ovotesticular DSD carries a 3% risk of germ cell malignancy from 426 studies of 3 patients or that those with PAIS and nonscrotal gonads face a 50% risk of germ cell malignancy based on 24 studies of 2 patients as valid determinations of the true risk these patients face or base treatment recommendations on them (See Table 4, Consensus Statement, e493).

Furthermore, in a 2005 practical guide cited by the Consensus Statement, “Hormonal Therapies for Individuals with Intersex Conditions: Protocol for Use,” Warne, Grover, and Zajac identify the primary goals of hormonal therapy (which they note “forms part of the treatment of every intersex condition”) as 1) replacing hormones necessary for survival for those with salt-wasting CAH and 2) suppressing the *unwanted hormone excess* [emphasis added] by exerting negative feedback” (p. 19). The “unwanted hormone excess” Warne and his colleagues are referring to here are those hormones which, as the Aaronsons would put it, might lead to a “discordant” phenotype, or a physical gender presentation that conflicts with sex of assignment. Thus, while Reproductive Function may be one of the targets of intersex management practices, it is clearly not *the* target.

B. Hetero-Coital Function

The Consensus Statement’s recommendation regarding the surgical management of hypospadias does, however, provide evidence for the second sense of the Normal Function of Physical Sex. I argue we might understand Zucker as invoking in his argument for the pathology of intersex—Hetero-Coital Function. I define Hetero-Coital Function as referring solely to the physical capacity to engage in penile-vaginal intercourse independent of reproduction and independent of heterosexual desire, though it is worth noting that the physical ability to engage in heterosexual sex and the desire to have it are often conflated. Allowing for “vaginal-penile intercourse” is indeed one of the three aims of genital normalizing surgeries identified by gynecologist Sarah Creighton and her colleagues in their 2012 *Journal of Pediatric Urology* review article “Timing and Nature of Reconstructive Surgery for Disorders of Sex Development—Introduction,” along with “improv[ing] the cosmetic

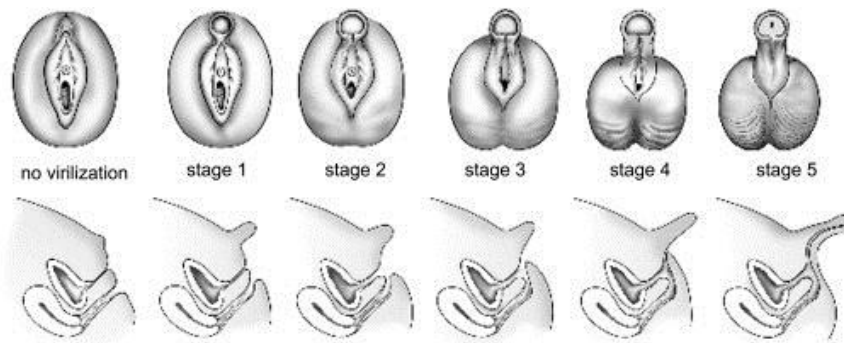
appearance of the genitals” and “achiev[ing] an unobstructed, sex-typical manner for urination (i.e. standing for males)” (Creighton et al., p. 603).

It is well established within the literature that both heteronormative definitions of “normal sexual activity,” and a clinician’s surgical capacity to fashion genitals capable of engaging in it, played a large role in physician recommendations regarding sex assignment under the OGR treatment model. As Suzanne Kessler detailed in her foundational text *Lessons from the Intersexed*, Money felt the ability to engage in normal sexual activity was necessary for one’s normal psychosexual or gender role development, which for him encompassed what we today would differentiate as gender behavior, gender identity, and sexuality. His definition of normal sexual activity, however, was thoroughly heteronormative, equating the ability for it with having a normal-appearing vagina capable of penetration by an average size penis for a woman and with having a normal-appearing, average size penis capable of penetrating a vagina to orgasm for a man; a woman’s capacity for orgasm was not considered (Kessler, 1998, pp. 24-27). The technological limitations of phalloplasty compared to vaginoplasty (“it’s easier to dig a hole than build a pole”), as well as the dependence of the former surgery’s success on the physiological structures available, meant that Money’s phallocentrism cashed out as the general rule that physicians were never to “assign a baby to be reared, and to surgical and hormonal therapy, as a boy, unless the phallic structure, hypospadiac or otherwise, is neonatally of at least the same caliber as that of same-aged males with small-average penises” (Money, 1975, p. 610; qtd. in Kessler, 1998, p. 25). The primary determination of sex assignment was the capacity to make a “normal phallus”—if one could not be made, patients were to be assigned female. It is thus completely unsurprising that Kessler found that although all of the physicians she interviewed identified the “prospects of constructing good genitals” as their primary

consideration when making sex assignments, they also cited the specialty of the attending physician as of central importance to these decisions, given that a physician's specialty in many ways determines their capacity to construct "good genitals" (p. 27).

The "Surgical Management" section of the Consensus Statement recommends that surgery "only be considered in cases of severe masculinization" that is, Prader stages III-V (see Fig. 4), and "be performed in conjunction, when appropriate, with repair of the common urogenital sinus" – a more moderate position than the OGR treatment model which recommended surgery whenever the treating physician deemed it appropriate (Lee et al., 491).

Figure 4. *The Prader Scale from Source: Medscape Reference*



Note. From: <http://emedicine.medscape.com/article/924291-overview>

However, we already know that there has been no decrease in the frequency with which these surgeries are performed, despite the Consensus Statement's apparent leniency. Furthermore, evidence that surgical management aims in part at restoring a thoroughly heteronormative conception of sexual function, or Hetero-Coital Function remains.

Despite the Consensus Statement's comparative tolerance with regards to less severe genital ambiguity, it nonetheless recommends surgery in more severe cases. In these cases, the authors stipulate that the emphasis in surgical management should be on "functional

outcome rather than a strictly cosmetic appearance” while at the same time acknowledging the practice as being motivated by aesthetic concerns, specifically stating that “it is generally felt that surgery that is performed for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents; the systematic evidence for this belief is lacking” (Lee et al., 2006, e491). In fact, serious tensions are clear throughout the section on surgical management, as the authors clearly acknowledge the risks associated with genital normalizing surgeries, particularly with regards to function, while at the same time stressing the importance of “functional” rather than aesthetic outcomes. Both the subsection on feminizing surgeries and the subsection on masculinizing surgeries detail the technical limitations of, and possible complications associated with these procedures, as well as the lack of outcomes studies available for a variety of those most commonly performed techniques, yet nonetheless position them as necessary. For example, in the section regarding feminizing genital surgery techniques, the Consensus Statement cautions that “orgasmic function and erectile sensation may be disturbed by clitoral surgery” and thus recommends that surgical procedures be “anatomically based to preserve erectile function and the innervation of the clitoris,” with emphasis again placed on “on functional outcome rather than a strictly cosmetic appearance” (Lee et al., 2006, e491). It goes on to endorse vaginoplasty in infancy on the basis of guidelines created by the American Academy of Pediatrics in 1996, while at the same time acknowledging “that surgical reconstruction in infancy will need to be refined at the time of puberty” and that “no one technique has been universally successful; self-dilation, skin substitution, and bowel vaginoplasty each have specific advantages and disadvantages” (e492).

Interestingly, beyond the above-mentioned caution that clinicians consider “the magnitude and complexity of phalloplasty” required if “successful gender assignment

depends on this procedure,” the Consensus Statement says fairly little regarding masculinizing genital surgeries. In their 2012 review of surgical management options for DSDs, however, Creighton et al. invoke Hetero-Coital Function in their identification of the goals of “proximal hypospadias repair” (which we might read as synonymous for phalloplasty) as allowing for 1) the ability to urinate in a standing position, 2) “achieving straight erections and proper ejaculation” which are seen as the conditions that will “permit,” 3) “suitable sexual intercourse” (Creighton et al., 2012, p. 607). They nonetheless conclude that despite the fact “most surgeons still agree that hypospadias surgery should be done early (especially for proximal cases), the quality of the evidence for such an approach is limited and will likely be challenged until there is additional strict scientific data in support of it” (p. 608).

Compared to the authors of the Consensus Statement, Creighton and her colleagues present a far more agnostic view regarding the efficacy of genital normalizing surgeries. They begin their review by explicitly acknowledging that as a result of “evidence that many adult patients who have undergone reconstructive surgery are dissatisfied with the outcome because of reduced sexual satisfaction and function” heated debate exists regarding “the age at which surgery is best conducted, which type of procedure offers the best outcome and whether surgery should be performed in all” despite the fact that “such procedures have been performed for decades” (p. 603).

Importantly, though Creighton and colleagues mention reduced sexual satisfaction, I argue that the priority here is genitals that look “normal” and are capable of penetration or of being penetrated as opposed to those capable of what we might think of as sexual satisfaction in terms of sensation and the ability to orgasm—echoing my definition of Hetero-Coital Function. It is no coincidence that Creighton and her colleagues initially

identify the physical capacity for vaginal-penile intercourse, cosmetic appearance, and, for men, being able to urinate standing up as the goals of genital normalizing surgery and that genital sensation or orgasm are not listed at all. Interlocutors on both sides of the debate regarding surgery have noted that parents of affected children are both concerned about their child's ability for future sexual ability and satisfaction, and wary of or uncomfortable with discussion about these aspects of their child's treatment (Feder, 2014; Karkazis, 2008; Karkazis, Tamar-Mattis, & Kon, 2010). Thus, despite all this emphasis on functional outcome, genital sensation and the ability to orgasm are rarely explicitly discussed. However, I argue that it would be a mistake to attribute the persistent silence on these issues in both the clinical literature and in the doctor's office to taboo alone—though that surely is part of it. Rather, I argue that its persistence in the face of both parental concerns about the genital sensation and future sexual satisfaction of intersex infants and the mounting evidence mentioned by Creighton et al. that normalizing surgeries compromise both is primarily the result of the fact that ensuring an infant has genitals capable of Hetero-Coital Function and ensuring an infant has genitals capable of sensation and orgasm are necessarily contradictory in this context. Genital normalizing surgeries carry the same kind of risks associated with any kind of surgical procedure—most importantly for the purposes of this discussion, nerve damage and the development of scar tissue, both of which compromise genital sensation and the ability to orgasm.

On the rare occasions that these issues are raised or positioned as a factor in the medical decision-making process, it is done in as heteronormative a fashion as ever before. The inability to create genitals capable of orgasm is only ever positioned as a factor in gender assignment in relation to phalloplasty procedures, though notably the emphasis here is not on the individual's personal sexual satisfaction, but their ability to replicate what is

positioned as typical or normal male sexual behavior in terms of visible cues or aesthetic function. Evidence of this can be seen in Creighton et al.'s (2012) inclusion of "achieving straight erections and proper ejaculation that will permit suitable sexual intercourse" (p. 607) in their stated goals for phalloplasty; it is not enough to simply be capable of erection, ejaculation and sexual intercourse—it must be a straight erection capable of proper ejaculation in the context of suitable intercourse. However, nowhere is the subservience of genital capacity for sensation and orgasm to the ability to penetrate (or be penetrated) via aesthetically typical genitals clearer than in the context of feminizing surgeries and in particular, surgeries to reduce clitoromegaly or enlarged though otherwise healthy clitorises.

For its part, the Consensus Statement recommends the performance of both vaginoplasties and clitoral reductions or clitoroplasties (again, in those cases of severe masculinization) despite acknowledging the risks/problems associated with both in terms of loss of sensation and potential scarring. Regarding vaginoplasty the authors write that techniques "carry the potential for scarring at the introitus necessitating repeated modification before sexual function can be reliable" (Lee et al., 2006, e493). However, on the topic of clitoroplasty they are even more explicit, identifying them to be solely cosmetic procedures done for the sake of relieving parental distress and promoting attachment (while, again, acknowledging a lack of evidence that these surgeries accomplish these goals), and explicitly stating that "outcomes from clitoroplasty identify problems related to decreased sexual sensitivity, loss of clitoral tissue, and cosmetic issues" (e493). Despite this, they continue to recommend the performance of these procedures, simply cautioning that "because orgasmic function and erectile sensation may be disturbed by clitoral surgery, the surgical procedure should be anatomically based to preserve erectile function and the innervation of the clitoris" (e491). This caution seems to imply that we know which

“anatomically-based” surgical procedures will preserve erectile function and the innervation of the clitoris and thus it is simply a matter of choosing those techniques over those that prioritize cosmetic outcome. Creighton et al. (2012), however, make clear the lack of consensus or clarity on the best or most effective surgeries, emphasizing the complete lack of scientific evidence for *any* of the surgical techniques commonly used in clitoroplasty or vaginoplasty in terms of their efficacy and ideal timing (p. 605). As a result, they conclude that it is ultimately impossible to recommend *any* of these surgical techniques, either on their own, or over any others (p. 605). Despite this, they too continue to recommend their performance, while at the same time reinscribing a heteronormative conception of normal Hetero-Coital Function for women through their identification of the goal of clitoroplasty (which they acknowledge to be “essentially a cosmetic procedure”), as “reduc[ing] the size of the clitoris whilst maintaining a *feminine appearance*,” [emphasis added] and their simultaneous acknowledgement that “surgery carries the risk of disruption of the nerve supply of the clitoris” (p. 603). Regarding clitoroplasty specifically, they write,

Most descriptions of clitoral reduction techniques usually report small series of patients with limited follow-up; there are no comparative studies of the short or long-term advantages of specific techniques. There is much debate but little data on all aspects of clitoral surgery including the appropriate size and site for incisions on skin and crura, whether or not to anchor the clitoris to the bony pelvis, how much corporal tissue to remove as well as the requirement for reduction of the glans clitoris and what techniques best achieve this (p. 603).

Similarly, Creighton et al. invoke heteronormative ideas of Hetero-Coital Function in their identification of creating “a vagina suitable for menstruation and sexual intercourse” as among the goals of vaginoplasty (in addition to maintaining urinary continence) (p. 605).

They prioritize Hetero-Coital Function over Reproductive Function in their recommendation that sterilizing gonadectomies continue to be performed. Further, they identify the goals of gonadectomy as first the “preserv[ation] of gonadal function (sex hormone production in accord with sex of rearing and fertility)” and second, “[the] avoid[ance of] gonadal malignancy” (p. 608).

Creighton et al’s inclusion of fertility in their identification of “the preservation of gonadal function” is interesting here, for gonadectomy, as it is generally performed, necessarily leads to a loss of fertility.⁴⁹ However, their identification of gonadal function with “hormone production in accord with sex of rearing” (or gender assigned) is, I argue, very illustrative and gestures specifically to ensuring the development of a coherent phenotype (or in the Aaronsons’ words, preventing the development of a “conflicted phenotype”). Maintenance of a “coherent” phenotype—that is, a body that develops in concordance with sex of assignment—is considered necessary for both Hetero-Coital Function and for the third and final sense of The Normal Function of Physical Sex commonly deployed, that of Cisgendered Function.⁵⁰ Indeed, bodies that are unambiguously and typically male or female

⁴⁹ There are certain surgical techniques which attempt to remove so called discordant gonadal tissue only, i.e. resecting testicular tissue while leaving ovarian tissue. This is recommended by both the Consensus Statement (p. e492) and Creighton et al. (p. 608). Unfortunately, however, I am unable to get a clear sense from the literature regarding how often this type of discrete surgical procedure is performed vs. complete gonad removal. Thus, while I am willing to grant that this occasionally does occur, it does seem to be quite rare and thus my use of the term “as it is generally performed.” That being said, even in the context of those kinds of practices, it’s not clear to me that the primary goal of resection is the preservation of fertility over and above the development of a coherent phenotype given that the presence of cells producing the hormones of the “wrong sex” would have a more of an effect on the latter (phenotype development) than on the former (fertility) given how many women with high levels of testosterone (such as women with CAH) are nonetheless fertile.

⁵⁰ Insofar as a “coherent phenotype” is taken as a sign for Normal Reproductive Function, it is also generally considered necessary for that as well. This accounts for the disorientation caused by and the spectacle made of those who exhibit signs of reproductive function which conflict with their gendered phenotype (e.g. pregnant butches).

are bodies that are capable of both engaging in heteronormative penile-vaginal intercourse, *and* serving as the immutable, stable ground for predictions regarding the notoriously fluid and culturally mediated entities of gender and sexuality. However, I argue that Creighton et al.'s identification of gonadectomies with “the preservation of gonadal function” can only be made sense of if one defines gonadal function in terms of cisgendered hormone production and thus, in terms of Cisgendered Function.

C. Cisgendered Function

Bodily sex is assumed to predict future gender identity, gender presentation (hence the emphasis on maintaining a coherent phenotype), and gender role or behavior. Our inability to determine clearly or categorize the body of an individual with an intersex condition—or even the mere fact their body calls the naturalness and stability of dimorphic sex into question—leaves sex unable to perform its function as the primary, most stable, grounding term in our constellation of sex, gender, and sexuality. This is why unlike those strategic endorsers of DSD who identify the problems of DSD management (which they seek to solve) as unnecessary genital surgeries, bureaucratic obstacles to accessing competent care, and an obsession with gender and genitals, Warne and his colleagues identify the problem of intersex conditions in terms of them being “difficult to treat,” specifically because “they may intrinsically perturb complex aspects of the person’s gender identity, gender-role behavior, sexual orientation, sexual functioning and psychologic adjustment” (Warne et al., 2005, p. 19). Thus it seems that like the OGR model before it, the DSD treatment model aims at the securing of cisgendered futures and thus, ultimately, the production of cisgendered lives.

There are reasons outside of the practices carried out under the DSD treatment model to believe that Zucker (1999) is invoking Cisgendered Function in his remark about intersex bodies failing to function in accord with their design, and that this remains the ultimate aim of intersex management. Aside from Zucker's article itself being specifically on the topic of Gender Identity Differentiation in those with intersex conditions, gender identity development in general (particularly in children) is Zucker's recognized area of expertise. More importantly, however, sex assignment remains both *the* central feature of intersex clinical management *and* is commonly identified as the primary concern of both clinicians engaged in it and parents of intersexed children, who want to know whether to raise their child as a boy or a girl. Indeed, the issue of sex assignment and gender identity differentiation dominates the biomedical literature on intersex conditions and their management. In a 2012 article in the *Journal of Pediatric Urology*, Liao and colleagues write that "professional concerns regarding sex assignment" are "reflected in the relatively high proportion of psychological studies devoted specifically to psychosexual differentiation outcomes, as opposed to other clinical concerns, such as patient experience and emotional well-being" (Liao et al., 2012, p. 598). For example, they note that a recent review of 98 original studies on patients with congenital adrenal hyperplasia from 1955 to 2009, found that 68% investigated aspects of psychosexual differentiation (Liao et al., 2012). The goal of these studies of psychosexual differentiation, and of sex assignment, is always securing a cisgendered future through the prevention of trans* or gender variant futures.

I thus conclude that the DSD treatment model aims, like the OGR model before it, at the production of cisgendered lives. Clinicians are still attempting to determine the intersex infant's "optimal gender of rearing"—currently via an appeal to brain organization theory—and thus continue along the path constructed by Money of fixing sex by way of

gender such that sex remains gender all along. Furthermore, puberty blockers are a new technology in this field of medical knowledge/power whereby those lives that are not in fact cisgendered can be made to pass as such. Thus it seems that not only has nothing changed from intersex to DSD, but the few differences we do see between the OGR and DSD treatment model result from the scientific and popular dominance of notions of “brain gender,” leaving us with a more biologically determinist model than its predecessor.

VI. Conclusion

When an infant is born, the announcement that “it’s a boy” or “it’s a girl” is simultaneously an assessment of physical sex (where externally visible genitalia is taken as a indicator of other markers of physical sex such as chromosome status and internal genital structures, etc.) and a prediction about their gendered future in terms of identity, behavior, and non-sexual desires (though to be sure, sexual desire is often also assumed to be a dimension of gender). Further, it is also an indicator of which social and political norms govern engagement with this individual—that is, whether or not we should treat them like a boy or a girl. “Treating one like a boy or a girl” is itself a multi-dimensional, multi-variable, reciprocal engagement, encompassing not only norms about how others should treat them, but further, how we expect them to treat themselves and others. For example, knowing whether or not an individual is a boy or a girl entails knowing what norms govern their behavior, thoughts, desires, as well as the behavior, thoughts, and desires of others towards them.

When markers of sex fail to perform this function, we are unable to predict future gender (which is always appropriately presumed to be in a coherent cis-alignment with physical sex) or have a sense of the norms with regards to either gendered or sexed

interaction with them. This, I argue, is the reason why cosmetically normalizing genital surgery is justified via two specific claims, neither of which is supported by clinical evidence: 1) that “normal” looking genitals are necessary to one’s “normal” psychosexual development as unambiguously cisgendered and 2) that an infant must have “normal” genitals and thus appear to have a typically-sexed body for parents to bond with it and raise it in an unambiguously cisgendered way, and for others to treat it like a boy or a girl, both of which are posited as essential to a child’s “normal” psychosexual development as unambiguously cisgendered.

Importantly, while continuing to position bipolar sex on the side of the natural, this account positions gender as necessarily both *natural* and *socially mediated*. Indeed, having a brain that has been organized by hormones in a typically male or female fashion is not enough for normal cisgendered development—others *must* also treat you like a boy or a girl in order for you both to know that you are one, and for you properly to become one. This is a sign of the fact that gender is a technology of biopower, introduced into the field of medical/knowledge power in order to strategically shift or displace the naturalized binary of sex in the face of sexed bodies which revealed it as fiction.

It is ironic that gender, the most mediated, impure, and unstable element of our constellation of sex-gender-sexuality, is the term that has become saddled with the heavy work of stabilizing the truth of sex. Sexuality seems far more capable of this kind of heavy lifting than something as notoriously fluid and culturally mediated as gender. Though these arguments are fallacious, sexuality’s closer proximity to reproduction allows for the invocation of evolutionary arguments regarding Darwinian Fitness more easily than gender or sex does. Indeed, the argument about homosexuality runs: how can a trait that leads one not to want to copulate with specifically those individuals with whom they can exchange

gametes *not* be maladaptive?⁵¹ However, the declassification of homosexuality as a mental disorder by the American Psychiatric Association in 1973 and by the American Psychological Association in 1975 means that sexuality is unable to provide this clinical ground for either sex or gender, though it is worth noting that under the OGR treatment model, homosexual activity or desire in those with intersex conditions was taken as an indicator of incorrect sex assignment (Zucker et al., 2013).⁵² This, I argue, is in part an artifact of Money's initial definition of gender role in such a way so as to collapse into it what we would call both gender identity and sexual orientation.

With sexuality unable to do this work and in the absence of a true unambiguous single marker of sex or the insertion of a new term into the field of medical power-knowledge that takes up and governs bodies as sexed, gendered, or sexual, I argue that clinicians really have no other recourse than to continue Money's legacy of turning to binary gender as the ground for the naturalization and materialization of dimorphic sex in the face of its bipolar reality. This project is essential to justifying the continued medical management of not only intersex bodies, but the general government of all bodies with regards to norms of sex and gender. It should thus, I argue, be no surprise that despite decades of critique, and in spite of equivocating, shoddy outcome studies with few participants and a poor understanding of the development of gender in all its dimensions, the DSD treatment model continues the tradition set out by the OGR treatment model of using experimental, cosmetic procedures to assign sex surgically on the basis of predictions about gender development (and in particular, a clinician's capacity to bring the development of a specific gender about).

⁵¹ This argument, of course, is fallacious. For more on problems with evolutionary arguments for the pathology of homosexuality see Roughgarden, 2004.

⁵² Furthermore, there was a period when many transpersons were unable to access sex reassignment services if their transition might make them homosexual (Zucker et al., 2013).

A side effect of Money's introduction of gender to "fix" the sex of the intersex is, I have argued, the appearance of the transsexual in the field of medical knowledge/power first constituted by the deployment of sexuality. The introduction of gender gave us a way to read the pathology of the trans* individual in terms of cisgendered function—for their bodies also fail to develop a cis-aligned gender, despite being typically sexed. This gave rise to the narrative of being born in "the wrong body," with gender constituting the truth of sex. A side effect of the current biomedical understanding of gender in terms of brain organization theory, and thus as both natural or biological and culturally mediated, is a kind of collapse of the distinction between sex and gender, and the resurgence of a kind of biological determinism in the form of brain sex/gender. Evidence of this can be seen in the shift in the literature to replace "sex assignment" with "gender assignment" (or at least use the two synonymously), as can be seen in prominent psychiatrist Heino Meyer-Bahlburg's introduction to a 2005 special issue of the *Archives of Sexual Behaviour*, devoted to the topic of gender identity development in those with intersex conditions, in which he writes, "the question of how *gender assignment* [emphasis added] at birth should be decided in cases of intersexuality and related conditions, so as to minimize the later development of gender dysphoria and gender change, is one of the highly controversial issues in the ongoing debate on clinical management policies in this area" (Meyer-Bahlburg, 2005a, p. 371).⁵³ Furthermore, in a section titled "What to Tell Your Friends and Family In General," the *Handbook for Parents* provides parents with the following scripted answer for friends and family who question the sex of their child, which justifies it specifically in terms of gender development:

⁵³ The Consensus Statement also uses the language of gender assignment.

Sometimes babies are born with a body type that is not either the average male or female. This is a variation that happens about one in every 1500 births. *In our daughter Sue's case, we figured out with our doctors that Sue should be raised as a girl since most children with Sue's condition tend to follow along with that gender* [emphasis added] (ISNA, 2006b, p. 40).

Even more explicit evidence of this collapse between sex and gender via the use of brain organization theory can be found in Meyer-Bahlburg's 2011 book chapter "Transsexualism ('Gender Identity Disorder')—A CNS-Limited Form of Intersexuality?" and in a 2012 commentary by Zucker titled "Born This Way: Comment on Factitious Intersex Conditions." Meyer-Bahlburg concedes there isn't enough evidence to make the claim that transsexuality is a central nervous system limited form of intersex, though the question itself attests to the potential collapse between sex and gender occurring at the level of the brain. Zucker, however, was far more willing to hedge his bets on this point in his commentary on Cadet and Feldman's 2012 article in which the two authors argue that trans* patients are more likely to claim to have an intersex condition due to the internet, and that these false claims should be identified as a factitious disorder or Munchausen syndrome (Cadet & Feldman, 2012). In his commentary, Zucker elaborates on Cadet and Feldman's (2012) claim and agrees that an increasing number of trans* patients do present to psychiatrists claiming to have an intersex condition, but justifies this by invoking determinist theories of brain gender to argue that "Lady Gaga may well be on to something" and hazarding that by 2020, we should have enough evidence to prove that they too were "born that way" (Zucker, 2012, p. 98).

Importantly, all of this—the DSD treatment model, the pathologization of intersex and trans* persons with regards to cisgendered function, and both the reliance on and pursuit of research like brain organization theory in order to make sense of and thus treat these individuals—presumes the pathology of non-cisgendered life. That is, it assumes the failure of the sexed body and the gendered self to develop in cis-alignment is in itself necessarily pathological and thus worthy of both study and “fixing.” In the following chapter, I reconstruct and then critique the most compelling philosophical answers to the question that clinicians tacitly believe has a self-evident response: Is being gender variant or non-cisgendered a pathology?

Chapter Four: Securing Cisgendered Lives: A Critical Analysis of the Pathologization of Gender Variance

I. Introduction

Having established that the DSD treatment model aims—like the OGR model before it—at securing cisgendered futures for intersex infants and thus, at the production of cisgendered lives, I turn in this chapter to examine critically the pathologization of non-cisgendered or gender variant lives. The presence of pathology is not, in itself, a necessary condition of medical intervention. There are pathological states that we do not normalize (like asymptomatic bacterial vaginosis), while there are bodily states we think it ethical to medically surveil and normalize even though we think them to be non-pathological (like pregnancy). Ethical medical practice or decision-making is constituted through a multitude of variables, necessarily including (but not limited to): clinical evidence regarding the diagnosis, prognosis, and treatment options; clinical ignorance regarding the diagnosis, prognosis, and treatment options; the values and desires of the patient; as well as whether or not the patient provided informed consent (which is itself conditional on their ability to do so). Borry, Schotsmans, and Dierickx (2006) note the tendency within clinical medicine to equate evidence-based practice with ethical practice, as though empirical data is sufficient for determining ethicality, thus completely conflating its implications. While empirical evidence regarding both the nature of a pathology, and the clinical interventions used to treat it, cannot “*conclude* [emphasis added] the process of ethical decision-making,” it is necessary for that process (Borry et al., 2006, p. 307). Further, this information seems to be particularly important to ethical medical decision-making where those unable to provide informed consent (such as children) are concerned. Indeed, it is in the context of such cases that we come across those rare situations when such information can and does conclude the process

of ethical decision-making—most obviously, when one’s life or viability are at risk. For example, in the case of a 5 year-old Jehovah Witness child requiring a live-saving blood transfusion, the pathology and prognosis without treatment is enough to justify its administration, despite the grave metaphysical implications receiving it has for members of that faith (the inability to join one’s family in the afterlife). Furthermore, most ethicists agree that in such cases, health care professionals are morally obligated to intervene not only without the patient and their proxy decision-makers’ consent, but even in the face of their explicit refusal, undertaking legal strategies to do so if necessary. In this way, both the biomedical account of the pathology of intersex conditions that I offered in the last chapter—rendered, traditionally, in terms of function—and the critical analysis of it I offer in this one, contribute a vital piece to the ethical puzzle in scholarship on intersex management, especially with regards to infants and children.

Beyond those with intersex conditions, the critical analysis of the pathologization of gender variance I offer in this chapter also has important implications for ethical medical decision-making regarding the treatment of gender dysphoria—as a pathology of cisgendered function—particularly in children unable to provide informed consent. In particular, it will have implications for the controversial use of so-called “conversion” or “reparative” therapies that aim at the production of cisgendered life for children diagnosed with gender dysphoria (or what was previously called gender identity disorder). These therapies, which Drescher (2010) calls “Gender Identity Conversion Efforts (GICE)” aim at lessening both gender dysphoria *and* gender variance in trans* kids in terms of their “cross-gender behaviors and identification” and include “promotion of same-sex peer relations; encouragement of gender-typical and ‘neutral’ activities; limit-setting of cross-gender behavior; and dialogues on gender” between both the physician and the child, and the

parents and the child (Drescher, 2010, p. 451; Zucker, 2008, p. 360). Much like the surgical and hormonal management of intersex children, the aim of GICE is securing a cisgendered future for the child with Gender Dysphoria (GD), by preventing its “persistence” into adolescence and adulthood, and thus, their eventual transition (Byne et al., 2012, p. 763).⁵⁴

II. Pediatric Management of Intersex Conditions and Gender Dysphoria: Medical Efforts to Secure Cisgendered Lives

The treatment of queer and trans* kids has received a good deal of very high profile attention in the past year. In April 2015, President Barack Obama quietly announced his condemnation of “conversion” therapies aimed at “repairing” LGBTQ individuals in response to the suicide of 17-year old transgender teen Leelah Alcorn, whose parents had withdrawn her from school and forced her to attend “conversion therapy” (Jarrett, 2015). The official statement, written by one of Obama’s senior advisors and posted to the White House’s website alongside a petition to enact “Leelah’s Law” banning “all LGBTQ+ conversion therapy,” states explicitly states that the Obama Administration “supports efforts

⁵⁴ There is no evidence that GICE is used to treat adolescents or adults with GID or Gender Dysphoria under DSM-V, and its use (or the appropriateness of its use) in these populations is not debated in the literature as it is with regards to children. I argue there are two reasons for this: 1) There is a good deal of clinical evidence to support the notion that the majority of those whose gender dysphoria and variance persist into adolescence or who are diagnosed in adulthood do end up transitioning, and thus, given that this is the trajectory the majority of these individuals are already developing along (as opposed to the minority in the case of children), there’s no point in attempting to reverse that trajectory—such efforts will generally fail (Byne et al., 2012, p.736). 2) Even though it is never framed this way in the literature, I argue that the use of GICE in the context of adolescents or adults with GID or Gender Dysphoria would likely constitute a violation of autonomy. As I will discuss later in this chapter, Gender Dysphoria is one of the few diagnoses within the DSM in which an individual’s failure to cohere to social norms and their resultant social exclusion and stigmatization are acknowledged to play a major role in its etiology or development. Furthermore, the way in which we lessen their symptoms (and the way in which individuals want to have their symptoms lessen) is by confirming their gender variance via surgical and hormonal intervention. To use GICE in this context would be to try to make competent adults and mature minors both *desire* a cisgendered life and ultimately to take on a different interpretation of themselves in terms of gender. I think that this would look like coercion in the context of the clinic.

to ban the use of conversion therapy for minors,” which it describes as having been proven by scientific evidence to be “neither medically nor ethically appropriate and can cause substantial harm” (para. 4). Rather than turning to conversion therapies, which they define in terms of both GICE and Sexual Orientation Change Efforts (SOCE), the statement stresses the importance of familial support to the well-being of the LGBTQ+ child, writing that “this Administration believes that young people should be valued for who they are, no matter what they look like, where they’re from, the gender with which they identify, or who they love” before providing a list of resources under the categories of Bullying, Family Acceptance and LGBTQ+ Youth Homelessness (para. 13). Furthermore, an NDP member of the Ontario Parliament, Cheri DiNovo, tabled a bill in March 2015 that would bar Ontario health care professional from treating LGBT children and teens with so-called conversion therapies (Pyne, 2015, 14). DiNovo’s tabling of the bill came just months after a petition appeared online calling for Zucker’s termination from his position as head of the Gender Identity Clinic at Toronto’s Centre for Addiction and Mental Health (Roche, 2014). In response to the bill’s tabling and following years of complaints about Zucker and the clinic’s use of GICE with trans* kids, CAMH announced on March 19, 2015 that the clinic would undergo a 6-month external review “in response to community concerns” (Pyne, 2015, 14). It is still unclear at the time of writing whether GICE will remain the standard of care for trans* kids at CAMH. However, the clinic’s founder and Zucker’s colleague Susan Bradley has issued an open letter calling upon DiNovo to withdraw her bill, arguing that the legislation would “infringe upon a patient and their parent’s rights to seek appropriate treatment for their children” (as qtd. in Pyne, 2015, 14). In comments issued to *The Toronto Star* newspaper, CAMH medical director Kwame McKenzie described the situation by stating, “Therapists are caught in the middle, between parents who may want their girl to be

a girl, and boy to be a boy . . . and at the moment, you have some professionals who say ‘OK, we should support the parents,’ and some people in various groups in the community who say ‘no, you should support the child here’” (as qtd. in Rushoway, 2015, n.p.).⁵⁵

The controversy over the use of GICE in trans* kids has left many psychiatrists on the defensive about the practice. GICE is but one of three different approaches to treating trans* kids in found in the clinical literature, with the second approach being one that “makes no direct effort to lessen gender dysphoria or gender atypical behaviors” given that GID does not persist beyond childhood for the majority (~80%) of those diagnosed, and the third being one that “may entail affirmation of the child’s cross-gender identification by mental health professionals and family members)” (Bynes et al., 2012, p. 763).⁵⁶ Critics, however, have charged that the use of GICE is unjustifiable, analogizing it with the unjustifiable submission of individuals to SOCE under the now illegitimate diagnosis of Homosexuality (Drescher, 2010; Zucker & Spitzer, 2005). Furthermore, some have argued that GICE is merely SOCE by another name, a relabeling done in order to ensure that psychiatrists could still treat queer kids with SOCE after the removal of Homosexuality from the *Diagnostic and Statistical Manual* (DSM) (Pickstone-Taylor, 2003). This is why psychiatrists like Zucker and Spitzer (2005) have taken such pains to separate clearly GICE from SOCE in recent years, the latter of which they identify with the terms “conversion” or “reparative” therapy. In their article “Was the Gender Identity Disorder of Childhood Diagnosis Introduced into DSM-III as a Backdoor Maneuver to Replace Homosexuality? A Historical Note,” Zucker and Spitzer argue that GICE is not simply SOCE or a “backdoor” way to

⁵⁵ This bill passed unanimously on June 4, 2015 (Ferguson, 2015, n.p.)

⁵⁶ Byne et al. (2012) report that although “the rate of persistence [of gender dysphoria] into adulthood was initially reported to be exceedingly low . . . more recent studies suggest that it may be 20% or higher” with one study of 77 children (59 boys and 18 girls) finding a persistence rate of 27% (p. 769).

treat homosexuality following its 1973 removal from DSM-II by, in part, pointing out that psychiatrists were still able to pathologize and treat homosexuality with SOCE in those cases where an individual was distressed and experienced social impairment as a result of their same-sex desires under other diagnoses in the DSM, like Sexual Orientation Disturbance (SOD) in DSM-II (1973) and Ego-Dystonic Homosexuality (EDH) in DSM-III (1973) (p. 35). Though Drescher (2010) argues that with the removal of EDH from DSM-III-R in 1987, “the APA implicitly accepted a normal variant view of homosexuality in a way that had not been possible 14 years earlier,” it was actually still possible for those who were adequately distressed and/or impaired with regards to social function as a result of their same-sex attraction to be pathologized and treated with SOCE until the publication of DSM-V in 2013 (p. 435).⁵⁷ Thus, the treatment of trans* kids with GICE is not the same as the treatment of homosexuals with SOCE because it’s doesn’t need to be—psychiatrists still had ways available to them to treat individuals with SOCE who wanted it.

The conflation between GICE and SOCE is, I argue, not coincidental, but rather an artifact of the historical relationship between sex-gender-sexuality with regards to biopower. In the same way that contemporary articulations of brain organization theory in terms of hormone-mediated brain gender grows out of and distinguishes itself from the initial *scientia sexualis* or hormone-mediated sexuality, GICE grows out of and distinguishes itself from SOCE. GICE can only appear as GICE once gender is introduced into the field of medical knowledge/power first constituted through the deployment of sexuality. Prior to this strategic displacement of the binary to gender, all efforts to produce what we now think of as “normal” cisgendered lives were SOCE, targeting those whose pathology was read in

⁵⁷ For example, in DSM-IV-TR (2000), the diagnosis Sexual Disorder Not Otherwise Specified is reserved for “a sexual disturbance that does not meet the criteria for any specific Sexual Disorder and is neither a Sexual Dysfunction nor a Paraphilia,” an example of which is “persistent and marked distress about sexual orientation”(p. 582).

terms of inversion.

Beyond this historical connection, however, there are additional factors that might explain the tendency to conflate GICE with SOCE. Clinicians, for example, are unable to distinguish between the ~20% of kids diagnosed with gender dysphoria whose dysphoria will actually persist until they transition from the ~80% of those whose gender dysphoria will “desist”—the majority of whom will be gay—and this plays a major role in the way clinicians think about and approach this issue.⁵⁸ Indeed, as mentioned above, the inability to differentiate those trans* kids who will actually transition from those who are merely likely to be queer is the primary motivation behind the second, “wait and see” approach to care, and has further led some to argue for the removal of gender identity disorder or gender dysphoria as a diagnosis in children altogether (Bynes et al., 2012, p. 763). However, for those clinicians who see transitioning and thus living a trans* or non-cis life as a necessarily bad outcome to be avoided, treating all children diagnosed with GID with GICE is worth it if it will lower the rate of persistence in those ~20% of children—particularly given that the treatment is assumed to be neutral or have no effects on the other ~80%. The exposure of this latter group to GICE, then, is worth it in service of the production of a greater number of cisgendered lives overall. It is worth noting, however, that “no long-term follow-up data have demonstrated that any modality of treatment has a statistically significant effect on later gender identity” and thus, there is no outcome evidence to recommend any of the three

⁵⁸ Zucker and Spitzer (2005) also identify this as a reason for the conflation of GICE and SOCE, noting that although there is some evidence “that a minority of GID children develop a heterosexual sexual orientation, without co-occurring GID,” the data to date suggests that of the “range of developmental outcomes for children with GID . . . a homosexual orientation without co-occurring GID is the most common” (p. 33). Further, they acknowledge that homosexuality is a target for some parents who seek out GICE for their children as well as some clinicians who use it, writing, “of course, this is not to say that some clinicians offer treatment for children with GID, in part, to prevent homosexuality or that some parents request treatment, in part, for the same reason. There is clear evidence that this is sometimes the case” (p. 36).

approaches (Bynes et al., 2012, p. 763).

The controversy over GICE and what constitutes appropriate treatment for children with GID-C is rumored to have been one of the primary reasons behind the many delays in the publication of DSM-V (2013). Interestingly, the American Psychiatric Association (APA) has been unable to come to a consensus on the appropriate or best approach to use when treating children with GID, in part due to their inability to come to a consensus as to whether or not being gender variant is a pathology. As part of the development of DSM-V, the APA convened the Task Force on Treatment of Gender Identity Disorder, which was charged with performing a “critical review of the literature on the treatment of GID at different ages, to assess the quality of evidence pertaining to treatment, and to prepare a report that included an opinion as to whether or not sufficient credible literature exists for development of treatment recommendations by the APA” (Bynes et al., 2012, p. 759).

Because the APA has never issued official Practice Guidelines for the treatment of GID outlining the goals of treatment, and thus, the boundaries of ethical care—despite the recommendation it do so by this very Task Force—its report is the closest we get in terms of an official statement from the APA regarding the management of GID. In it, the Task Force explicitly acknowledges the lack of Consensus among psychiatrists regarding the treatment of GID in children specifically, writing,

The overarching goal of psychotherapeutic treatment for childhood GID is to optimize the psychological adjustment and well-being of the child. What is viewed as essential for promoting the well-being of the child, however, differs among clinicians, as does the selection and prioritization of goals of treatment. In particular, opinions differ regarding the questions of whether or not minimization of gender atypical behaviors and prevention of adult transsexualism are acceptable goals of

therapy (Bynes et al., 2012, p. 763).

Furthermore, the Task Force takes an explicitly agnostic position regarding what constitutes the core pathology of GID—that is, whether it is the distress and impairment in social function caused by the perceived discordance of one’s sexed body and gendered self that makes GID pathological, or whether it is the discordance itself—as well as what constitutes appropriate, and thus ethical, care for trans* kids. They write,

The Task Force could not reach a consensus regarding the question of whether or not persistent cross-gender identification sufficient to motivate an individual to seek sex reassignment, *per se*, is a form of psychopathology in the absence of clinically significant distress or impairment due to a self-perceived discrepancy between anatomical signifiers of sex and gender identity. . . . Similarly, a consensus could not be reached regarding the legitimacy of particular goals of therapy with children diagnosed with GID (e.g., prevention of transgenderism or homosexuality) even when consistent with the religious beliefs or sociocultural values of the parents or primary caregivers (p. 761).

Thus, ethical medical management of both intersex *and* trans* children hinges, at least in part, on the question of whether or not be gender variant and subsequently living a non-cisgendered life is in fact a pathology, *per se*. Thus, in the remainder of this chapter, I take up the task of critically analyzing the pathologization of gender variance or impairment with regards to cisgendered function, beginning with the dominant biomedical definition of pathology—Boorse’s BST.

III. A Critical Analysis of Pathology

Recall from Chapter Three Boorse’s definition of pathology as “a type of internal state which is either an impairment of normal functional ability, i.e. a reduction of one or

more functional abilities below typical efficiency, or a limitation on functional ability caused by environmental agents,” where the normal function of a part or a process is defined as “a statistically typical contribution by it to [one’s] survival and reproduction” (1997, pp.7-8).

This definition of pathology, as well as the notion of function it invokes, has been critiqued by philosophers of biology, disability scholars, and bioethicists on multiple fronts. First, it is worth noting Wouters’s argument in his 2003 article “Four Notions of Biological Function” that there are “at least four different ways in which the term ‘function’ is used in connection with the study of living organisms” (p. 633) such that the particular sense of function being invoked in discussion of it often requires clarification. The four senses of function Wouters elaborates are as follows: 1) function “as (mere) activity,” referring to what an “part, organ, or substance by itself does or is capable of doing”; 2) function “as biological role,” referring to “the way in which an item or activity contributes to a complex activity or capacity of an organism”; 3) function “as biological advantage,” referring to “the advantages to an organism of a certain item or behavior being present or having a certain character”; and 4) function “as selected effect,” referring to “the effects for which a certain trait was selected in the past which explain its current presence in the population” (p. 635). I shall not attempt to determine exactly which sense of function Boorse is invoking in the BST, at least in part because I don’t believe he actually invokes a single sense of the term, but rather slips between the four different usages of function that Wouters identifies. For example, even in his single sentence definition of normal function Boorse invokes function in both the second and third senses of the term, by indexing the *normality* of function in terms of its biological role—or contribution to a larger system—to its advantages for the organism in terms of survival and reproduction. Most importantly, however, determining the exact sense of function that Boorse invokes here is unnecessary for my purposes given the multiple

problems that Ron Amundson has raised with Boorse's definition of pathology, specifically in terms of his definition of normal function.

In his 2000 article "Against Normal Function," Amundson unintentionally echoes Foucault in arguing that the concept of biological normality underwriting Boorse's biostatistical theory of disease is much like the traditional concept of race insofar as they are both "invoked to explain certain socially significant differences, such as unemployment and segregation," yet have no biological basis and are thus a "biological error": "the partitioning of human variation into the normal versus the abnormal has no firmer biological footing than the partitioning into races. Diversity of function is a fact of biology" (p. 34). Amundson flags that "as with other quasi-statistical uses of the concept of normality," on Boorse's account "abnormality is usually read as subnormality. Better-than average function is not usually labeled as abnormal even though it is statistically atypical" (p. 35). He goes on to argue that Boorse's account problematically presumes that "natural species have a certain statistical characteristic: the variations of function among their members is sufficiently narrow to justify a dichotomy between normality and abnormality based on the distribution alone" (p. 35). This "statistical claim about functional diversity within species," which Amundson refers to as Boorse's "functional determinism," is what allows Boorse (and his followers) to use terms like "typical contribution to . . ." and "species typical function" as synonymous with normal function (p. 35). It is also the basis of Amundson's challenge to Boorse, for, as he argues, "the facts of functional variation do not support functional determinism" (p. 35).

Amundson begins by pointing out that although Boorse acknowledges the existence of some "normal variation" with regards to function, often by pointing to eye colour and blood type as examples, Boorse provides "no account of how normal variation is

differentiated from abnormal variation” (2000, p. 35). Amundson argues that for Boorse, normal variation must mean something like *functionally equivalent variation* in terms of *mode* or “the manner in which a functional outcome or performance is achieved,” and *level of performance*, or “the quantitative degree of the functional performance” (p. 36). Thus, green eyes and brown eyes are normal variants because both see just as well (level of performance) and in the same way (mode). Thus, for the functional determinist, normal functions are those that “take place in a uniform mode at a relatively uniform performance level by a statistically distinctive portion of the members of a species” (p. 36). As a result, there is no room on Boorse’s account for “functionally distinct but still normal variation” (p. 36). Amundson, however, argues that not only does functionally distinct yet normal variation obtain in the world, pointing to examples from physiology and anatomy as evidence of this point, but further argues such variation should be expected to obtain in the world on the basis of evolutionary theory and developmental biology.

Amundson notes a considerable amount of tension between the functional determinism underwriting BST and the large amount of heritable variation within a natural species both presumed by evolutionary theory and evident within organisms (2000, pp. 36-38). According to Darwinian evolutionary theory, variation among members of a species can arise as a result of 1) genetic variation and natural selection *or* 2) developmental plasticity in response to the environment. Amundson points out, however, that the common division of these two sources of variation in terms of nature (the random emergence and selection of certain genotypes over others) and nurture (trait variation as a result of non-genomic influences) is something of a misnomer, writing that “developmental plasticity itself evolves by natural selection, and genomes only determine phenotypic traits within the context of developmental plasticity” (p. 36). Thus, once again, the nature/culture binary breaks down,

this time at the level of the genome and developmental trajectories. However, even if we grant the nature/nurture binary here (as Amundson does for the purpose of his argument), the “Darwinian view of rich ranges of heritable variation still seems to be at odds with functional determinism” and “the notion of a determinate species design” (p. 36).

Boorse has issued three arguments or justifications for the functional determinism posited by the BST. First, Boorse argues that BST is based on typology or types/kinds that are evident in contemporary physiology and as such, represents a determinism with regards to species design that is actually seen in nature (Amundson, 2000, p. 37; Boorse, 1997, p. 32). Second, he argues that “evolution typically drives traits to fixation in a species, and the traits thereafter are kept from varying by normalizing selection” (which, presumably, explains why we see the kind of physiological evidence appealed to in argument one) (Amundson, 2000, p. 37; Boorse, 1997, p. 32). Finally, Boorse argues that BST is not essentialist insofar as it does not involve a claim about the causal powers of the essential traits (Amundson, 2000, p. 37; Boorse, 1997, p. 38). The most convincing response here comes from David Hull, who holds that appeals to “‘normality’ have little if any foundation in biology” and that “no set of traits can be constructed so as to characterize all and only members of a natural species, that species are rife with variation, and that this is an unavoidable outcome of Darwinian biology” (Hull, 1986, p. 4; Amundson, 2000, p. 37). Amundson nonetheless acknowledges that the question of whether or not the variation posited by evolutionary theory actually obtains in the world is ultimately an empirical one, writing “evolution is a process that gave rise to tapeworms and elephants. It could surely give rise to species members as functionally alike as paper clips, and to species members as functionally diverse as . . . well, as human beings” (p. 38). Further, regarding Boorse’s second argument about normalizing selection “fixing” traits in a species and thus giving rise

to the typology he claims we see in contemporary physiology, Amundson amusedly notes that normalizing selection would be “a very aptly named phenomenon” if it indeed truly accomplishes what Boorse claims it does (p. 37). Amundson responds simply by stating, “I am willing to consider it an open empirical question whether evolution results in the kind of functional uniformity that would license normality definitions. Frankly I doubt it, but theoretical considerations do not suffice to answer the question” (p. 37). Finally, with regards to Boorse’s third response regarding the non-essentialism of BST, Amundson writes,

I agree that the concept of normality invokes no essentialist causal powers, in that the functional type does not explain biological form. I am concerned, however, that once the concept is introduced and reified, it is *itself* [original emphasis] used in causal explanations of social phenomena. It is used to explain and rationalize the social disadvantages of people labeled abnormal (p. 37).

If theory is not enough to ground either the BST proponent’s claims regarding the functional uniformity (and thus, the statistical uniformity) of species *or* to refute them, Boorse’s first claim—that typology or normality with regards to species design *obtains in the world* and is thus rooted in contemporary physiology, not in evolutionary theory—becomes the bedrock upon which the theory stands. Further, the question of whether this is indeed true becomes a particularly pressing one when considered in light of not only the objectifying and subjectifying effects of pathologization, but also the social, political, and economic disadvantages that accrue to those labeled abnormal through the reification of the concepts of biological normality and functional uniformity, as Amundson points out. The burden of proof is thus on those towing the BST line that species, and in this case humans, exhibit the level of functional uniformity and thus statistical uniformity required to equate

normal function with species-typical function. Unfortunately for Boorse and his followers, Amundson points to multiple examples which give us good reason to believe that not only might contemporary physiology be nowhere near as typological as the functional determinist holds, but further, that whatever typology contemporary physiology does posit “might well be wrong” (2000, p. 37). Quite apart from the lack of empirical support for functional uniformity, Amundson reviews two features of the biological development of organisms — developmental plasticity and functional integration — in order to argue that the functional determinism posited by the BST is simply unnecessary, whether it actually obtains in the world or not.

Functional determinism, notes Amundson, is understood as following from the *goal-directedness* of life processes, which Boorse understands as cashing out in the form of *species-design* (Amundson, 2000, p. 38; Boorse, 1997, p. 9). Amundson agrees that life is goal-directed, but argues that functional determinism “does not follow from life’s goal-directedness,” contrasting William Paley’s pre-evolutionary concept of teleology with that of Kant’s in order to illustrate the difference between his understanding of goal-directedness with that of Boorse. He identifies Boorse’s position with that of Paley, according to which “body parts of an organism are specifically designed to adapt the organism to its environment, and each member of a species is functionally identical” (Amundson, 2000, p. 38). Kant’s concept of biological directedness, on the other hand, focused “on the processes of embryological, ontogenetic development,” which were understood as “directed towards the development of a functioning adult,” and that took these processes to be “remarkably plastic and resilient to perturbation” (p. 38). As Amundson writes, “[t]he goal-directedness seen in developmental plasticity renders the concept of *species design* [emphasis in original] highly suspect. Development yields adults that *function*, but not adults that *function identically*

[emphases in original]. Functional diversity is a product of developmental plasticity” (pp. 38-39).

Amundson further points out that during the processes of ontogeny that “bring about the functional integration of the organism,” the body parts and systems of every organism adjust to each other as they develop, whether or not the organism “is destined to be statistically typical or atypical of its species” (2000, p. 39). Amundson points to the development of the eye to illustrate this point:

The lens of the eye is not determined to develop in the location it does by its position on some genetic blueprint. Rather, the already-formed optic vesicle induces the ectoderm that overlays it to differentiate into the lens (after an earlier and more complex series of tissue interactions). If some trauma happened to relocate an optic vesicle to an unusual position on the head, lens induction would still proceed and result in a functioning eye (p. 39).

Altogether, this leaves Amundson to conclude that although the “facts of developmental biology do not conclusively refute functional determinism,” they nonetheless seem to render it unnecessary. He writes,

A non-typical but viable phenotype is not *broken* by its failure to comply with some imagined blueprint for its species. It will function anyhow, in spite of its atypicality. It will owe its function to the same developmental processes of integration and adaptation responsible for the function of typical organisms of its species (p. 39).

Amundson reviews five different examples of functional variation in different humans and other animals in order to prove the point that not only is tremendous functional diversity possible, but that “the kind of functional diversity that follows from developmental plasticity is also an ordinary part of everyday life” (p. 39). The examples vary as to the kind

of counterfactual they pose to BST. For example, Amundson's example of Slipjer's goat highlights the capacity for an organism to accomplish a function (such as walking) via an atypical mode as a result of developmental plasticity and functional integration (p. 39). The goat was highly atypical relative to the statistical norm for her species in terms of both skeletal and muscular anatomy, having an S-shaped spine, no forelegs, as well as "an atypically broad neck, many atypically shaped bones and atypically positioned muscles" (p. 39). Nonetheless, the goat learned to walk bipedally on its hind legs, such that "by the species design criterion of goal-directedness, Slipjer's goat was a notable failure," however, "by the developmental criterion it was a roaring success" (p. 40). Biological "types," writes Amundson,

are unified not by the functional identity of their eventual phenotypes, or the common blueprint from which they were built. Rather they are unified by their shared developmental processes. These processes generate phenotypes that are functionally diverse, both between and within species (p. 40).

Additional examples, such as humans' ability to adapt to the surgical reversal of nerve attachments to muscles better than primates, highlight other aspects or expressions of functional diversity—in this case, the greater capacities some species have for developmental plasticity compared to others (p. 41). One of Amundson's examples, however, is particularly useful for the purposes of my discussion here, given the way it underscores our species' extreme capacities for neuroplasticity and neurointegration, as well as functional variation. The case, first reported by Roger Lewin in his 1980 article "Is Your Brain Really Necessary?" is that of a "functionally normal" University student in the UK with an IQ of 126 and "virtually no brain" (Amundson, 2000, p. 40; Lewin, 1980). The student had a severe form of hydrocephaly, in which an excess of cerebrospinal fluid can lead to the "enlargement of the

cranium and/or reduction in the volume of brain tissue” (Amundson, 2000, p. 40).

Amundson notes that in its most severe form, “ventricle expansion fills 95% of the cranium” leaving only 5% for brain tissue, and while many with this severe form of hydrocephaly experience profound mental and physical disabilities, about half have IQs above 100 (Amundson, 2000, p. 40; Lewin, 1980, p. 1232). Furthermore, there are those like the student Lewin discusses with hydrocephaly who are “subclinical,” meaning they exhibit normal cognitive and physical function and tend to have average or only slightly above average craniums compared to those without hydrocephaly. As Amundson writes, the student was only tested “because his professor was familiar with a colleague’s ongoing study of subclinical hydrocephaly, and the student had a large head” (p. 40). Though the student turned out to be “functionally indistinguishable from his colleagues,” he was determined to have “*no more than 10%* [emphasis added] of the average person’s brain tissue” (p. 40).

Amundson points out that “accounts of similar phenomena are common in medical literature” (p. 40), using the case as an example of an organism’s achieving statistically average levels of performance via a statistically atypical mode of function, by way of their capacity for neuroplasticity and neurointegration. This, along with his other examples of functional variation, lead Amundson to conclude that “the goal-directed processes of biological development are not finely tuned towards the production of functionally identical species members. Their inherent flexibility can be expected to generate a rich diversity of functional modes” (p. 43).

Amundson thus critiques the BST in terms of the unnecessary functional determinism it posits. Not only does the capacity for developmental plasticity and functional integration equip us with the ability to achieve equivalent or at times even superior levels of performance via a variety of functional modes, but further, not all functions are equal in

terms of their importance to the organism's viability. For example, digestion, which can be accomplished via a variety of modes (such as orally, via a nasogastric tube, or via a gastric tube for humans), is a necessary function for human viability, whereas other functions Amundson mentions, such as walking, are not. Furthermore, as Amundson points out, humans are "distinctive among species in their extensive use of tools and in the degree to which they modify their environment" (p. 45). "Tool use and environmental design" is statistically typical among humans in the sense that all humans engage in it, while such engagement "changes the modes and levels of human function available" (as the car changes locomotion) (p. 45). Amundson argues that "from a broad biological perspective these changes can be seen as an extension of the principle of functional integration," opening up even greater modes of functional variation beyond those constituted through the body alone (p. 45). This leads Amundson to the following conclusion, in which one can hear echoes of Tremain:

The present unequal distribution of opportunities among people with varying biological traits can only appear to be fixed by nature if we ignore the fact that *all* [emphasis in original] human beings use tools and live in built environments, and that the design of tools and environments is an outcome of human choices. Given the appropriate technology and environment, blind people can read and paralyzed people can be mobile. The disadvantage that attaches to blindness and paralysis derives not from the atypicality of one's biology, but from the absence of appropriate tools and environments (p. 47).

Further, given that our focus in pathologization is on the mode of function rather than the level achieved—for example, in the way that we continue to identify the person in a wheelchair as impaired even if they can do the 100m dash faster than a person without

one—Amundson argues that pathologization is often about privileging a particular mode of function over others. This is why, he argues, we sometimes force individuals to *pass* as able-bodied even when they are not and often at the expense of the level of function, as in the case of therapeutic efforts which aim at making autistic children *appear* normal by decreasing the amount of self-stimulation or “stimming” they engage in, even if it results in a lower level of function (p. 50).

Equipped with Amundson’s critical insights into the dominant biomedical account of pathology, I now turn to examine critically the pathologization of intersex conditions in terms of the three normal functions of physical sex that I laid out in the previous chapter. For each one, I show that attempting to ground the pathology of intersex conditions in terms of that function fails to take into account the wide range of functional diversity both seen and expected in nature as a result of developmental plasticity and functional integration. Furthermore, it also constitutes the arbitrary privileging of a particular, fashionable mode of function over others, often at the expense of functional performance level.

IV. The Pathology of DSDs

As mentioned in chapter three, one’s capacity for reproductive function can be hindered in multiple different ways, most obviously with regards to their gonadal ability to produce gametes or their physical ability to bring their gametes into contact with another’s gametes to produce an embryo. Sterility, or the inability to reproduce, is a pathology from an evolutionary standpoint because, even though it does not comprise an organism’s viability, it does compromise their ability to pass on their genes, and thus results in a 100% loss of Darwinian Fitness, a technical term referring to “product of fertility and probability of survival” (Roughgarden, 2009, p. 106). Arguments for the pathologization of intersex conditions on the basis of sterility, however, will ultimately apply to a very small proportion

of that population, for while it is true that some intersex conditions result in the complete loss of fertility (rather than merely decreased fertility), most notably CAIS, this is only the case for the minority of conditions. In fact, the majority of the sterility experienced by intersex patients is iatrogenic or medically-induced—the result of gonadectomies performed as part of the surgical and hormonal normalization process. Furthermore, it is worth noting that if it is true that advances in molecular genetic knowledge of sex development and of intersex conditions will result in an increase in the number of people who count as having one (and who remain subclinical), it is likely the case that only a minority of those with intersex conditions will have the fertility issues this argument presumes.

Evolutionary definitions of pathology or defect, however, are made at the level of the population or species, not at the level of the individual. As biologist Joan Roughgarden (2009) writes in *Evolution's Rainbow: Diversity, Gender and Sexuality in Nature and People*, in order for a genetic inherited trait to be a genetic defect, it must meet two specific criteria: 1) “the trait must be extremely rare” as a result of being continuously opposed by natural selection and 2) the trait must be deleterious or non-advantageous under every condition (not merely the current conditions) (p. 281). The frequency of a trait in a population, known as its mutation-selection equilibrium, is, as Roughgarden writes, “set by a balance between two rates: the rate of formation by mutation and the rate of elimination by natural selection” (p. 281). Thus those traits that are lethal (and similarly result in a 100% loss of Darwinian Fitness) occur only as frequently as the mutation rate itself (1/1,000,000), because they are necessarily always selected against (Roughgarden, 2009, pp. 281-282). For non-lethal traits, the frequency of the trait in the population increases as the effect of the trait on Darwinian Fitness decreases—for example, a trait that results in a 10% loss in Darwinian Fitness will have a frequency of 1/100,000 while one resulting in a 5% loss in Darwinian Fitness will

have a frequency of 1/50,000, etc. (p. 282). Roughgarden herself takes this latter frequency, 1/50,000 as “threshold rarity at which a trait can be considered a defect,” writing,

Even if a trait isn’t particularly harmful, and a 5 percent loss of fitness wouldn’t be all that easy to detect, this degree of disadvantage, if sustained through all generations everywhere, would eventually lead to the trait becoming as rare as 1 in 50,000 (p. 282).

Roughgarden argues that “regardless of medical opinion,” if a trait is more frequent in the population than this, it cannot be a genetic defect:

If the trait is, say, ten times more common than the cutoff value (1 in 50,000) and has been traditionally considered a “disease,” then either the trait’s overall disadvantage has been overestimated to begin with, or else the trait has some possibly unknown advantages in addition to the known disadvantages (pp. 282-283).

We can see a breakdown between evolutionary scale definitions of pathology at the level of the population and medical definitions of pathology with regards to the individual in the case of sterility, for not only do many individuals find being sterile to be personally advantageous, but further, many use medical interventions to render themselves both temporarily and permanently unable to reproduce. Indeed, there are those for whom finding out they are sterile comes as a relief rather than as the discovery of a pathology or defect. Furthermore, as Roughgarden points out, the majority of intersex conditions are too frequent and/or inadequately disadvantageous to meet the criteria for genetic defect.

In a section titled “Is Intersexuality a Genetic Defect?” Roughgarden writes that only three intersex conditions could be genetic defects according to evolutionary criteria: CAIS, the Salt-Wasting form of CAH (SW-CAH), and hermaphroditism (defined as the possession of ovarian and testicular tissue, regardless of phenotype) (2009, pp. 288-293).

Hermaphroditism and Cloacal Exstrophy are the only intersex conditions that are rare enough to arguably meet the frequency threshold for defect, with frequencies of 1/85,000 and 1/250,000 respectively (CAIS has a general frequency of 1/13,000 and Classic CAH frequency of 1/13,000, two-thirds of whom will have the salt-wasting phenotype) (Roughgarden, 2004, p. 290).⁵⁹ Roughgarden identifies CAIS and SW-CAH as pathological because in the case of the former, though “not necessarily painful,” it is nonetheless, “deleterious to fertility,” while in the case of the latter, SW-CAH is lethal without treatment (this is also true of those with Cloacal Exstrophy) (pp. 290-291). Regarding those with hermaphroditism, however, she is more agnostic:

Medical consensus unquestioningly stigmatizes hermaphroditism as a genetic defect because of cancer risks and lower fertility. . . . Still, one must recall that in some mammals ovotestes are the norm. . . . Hermaphroditic people should not be pathologized as violating some law of nature. They possess a trait that’s rare in our species but common in others (p. 293).

Roughgarden thus concludes that “the most common forms of intersexuality” including hypospadias, non-salt-wasting versions of CAH, PAIS, and aneuploidies, are not defects, but rather “differ only cosmetically from nonintersexes” (p. 293). This echoes Amundson’s claim regarding the role of pathologization as privileging particular modes of function—which he calls “fashionable”—over other, unfashionable modes. That is, Roughgarden argues that for the majority of cases, the pathologization of intersex conditions is not the function of a natural, biologically-based distinction between the normal and the pathological, but rather of a cosmetic distinction made between two modes of gendered function: via typically-sexed bodies and via atypically-sexed bodies. Further, evidence for the

⁵⁹ For a summary of the frequencies of the most common intersex conditions, see Appendix A.

privileging of a particular mode over level of functional performance, as well as a failure to take into account functional integration, can be seen in the practice of sterilizing gonadectomies. Advances in reproductive technology have firmly separated reproduction from conjugal ability such that it is a mistake to conflate the ability to combine one's gametes with another's with the ability to physically engage in reproductive intercourse. Assigning an XY infant with severe hypospadias female due to the limitations in phalloplasty and removing their otherwise normal gonads as part of their surgical and hormonal feminization sacrifices whatever level of reproductive function might have been available to them through the use of reproductive technologies simply because it could not be achieved via a particular mode (that is, penetrative intercourse). Thus we foreclose from intersex infants whatever level of reproductive function that reproductive technologies might have made possible due to our surgical inability to construct bodies that can reproduce in the right *way*, that is, bodies capable of reproducing via hetero-coital function.

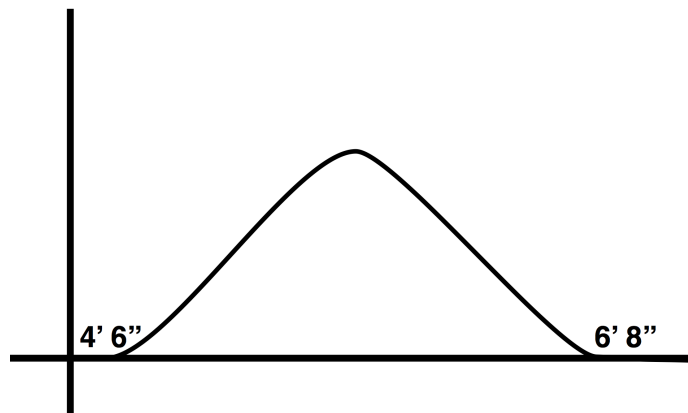
Once you separate hetero-coital function from reproductive function, attempting to ground the pathologization of intersex conditions on the basis of the former becomes even more suspect than trying to ground it on the basis of the latter. Pathologizing and subsequently surgically and hormonally normalizing an infant based on their inability to physically engage in penile-vaginal intercourse not only problematically assumes that infant's future preferences will be to engage in penile-vaginal intercourse, but that they will so value the capacity to engage in it, that they would assume the risks associated with surgery in order to obtain it (such as loss of genital sensation and compromised ability to orgasm). Indeed, given the costs associated with surgical normalization, its performance for the sake of hetero-coital function seems to epitomize the sacrificing of level of function performance for mode of functional performance (unless you take sexual functional performance to entail

mere penetration in itself). Moreover, it also assumes that it is ethical to surgically intervene upon those unable to consent in order to secure their capacity to engage in hetero-coital function, a position that cannot be defended, even if individuals themselves view their inability to do so as a pathology they would like fixed. One could—for example—imagine a case where a comatose adult patient without ID was admitted to a hospital and subsequently found to have ambiguous genitalia. Even if that individual longed for genital normalizing surgery in their pre-comatose state, we would nonetheless consider it unethical for physicians to perform this kind of medically unnecessary surgery on them in this situation without their consent. It is not clear to me that surgery to secure the future Hetero-Coital Function of an intersex infant without their consent is any different than this scenario, or any less unethical.

This brings me, finally, to cisgendered function, the primary way through which the pathology of intersex conditions is constituted. As I argued in Chapter Three, it is in the service of producing a cisgendered life that intersex infants are surgically and hormonally masculinized or feminized on the basis of two assumptions: 1) that a body which is “sex-typical” in both appearance as well as hormonally is necessary to one’s psychosexual development as unambiguously cisgendered, and 2) a necessary component of one’s development as such is being treated in an unambiguously gendered way by others—that is, as a boy or a girl—which requires sex-typical genitals. Thus the development of gender is posited as both natural and social, the product of the sexed body (likely via hormones) and of social interaction. As I (and many others) have noted, there is no empirical evidence to support either of these two assumptions. Furthermore, empirical investigation into either of these two claims itself presumes that cisgendered life is itself normal rather than pathological, a biopolitical good to be studied in order to be (re)produced.

Additionally, even if we do grant that a cisgendered life is in fact “normal,” intersex management practices seem unjustifiably to entail the privileging of a particular mode of function over others, often over the level of functional performance. Imagine we were to revise our definitions of the normal male or female sexed body in terms of what is *normal* to expect with regards to the model of bipolar sex that we have been working with since Money, rather than what is *statistically normal* or *typical*. On such an account, *statistically atypical* bodies are *normal* insofar as we expect them to exist/appear—their statistical atypicality does not render them *abnormal*. Consider, for example, a normal distribution curve (identical to the one Boorse uses when formulating his definition of the normal and the pathological) representing the heights of members of a population, ranging from 4 feet 6 inches, to 6 feet 8 inches (see Figure 5).

Figure 5. *Normal Distribution of Heights in Hypothetical Population A*



Note. From Paolo Zinatelli (2015).

While it would be statistically atypical to be 4 feet 7 inches tall in this population, it would nonetheless be *normal* insofar as we would expect some (if few) members of the population to be that height. Mere statistical atypicality of a cosmetic feature, such as height, is not enough to confer abnormality or pathology. Similarly, our bipolar model of sex assumes a

bimodal distribution of sex characteristics upon which it is expected for certain sexed bodies to be *statistically atypical*. Thus, while ambiguously sexed bodies may not be statistically normal, they are nonetheless a necessary component of statistically valid distributions and thus it is normal to expect their appearance. Were we to identify such statistically atypical bodies as normal with regards to the bimodal distribution of male or female physical sex (wherever we draw the boundary between them), those who developed in a cisgendered fashion would still be performing cisgendered function, simply via an atypical or unfashionable mode. The fact that we commence with medically unnecessary normalization rather than take on more representative definitions of the sexed body privileges a particular mode of function over level of performance (assuming one takes the ability to orgasm to be a part of cisgendered life).⁶⁰

Those engaged in intersex management not only assume all this, but also fail to recognize their problematic or questionable assumptions. This, I argue, is why despite years of intersex activism and feminist critique, Zucker (1999) is the only clinician explicitly to knowledge or attempt to address the question of intersex conditions' pathologization and that only very superficially. Cisgendered life is, to all medical experts, obviously normal, and having a sex-typical body (and particularly genitals) is necessary to its development. Thus, those without sex-typical bodies are obviously pathological—their bodies fail to function in accordance with their cisgendered design. As a result, there is no consideration of the

⁶⁰ While medical and popular opinion has shifted such that women's ability to orgasm has come to take on increasing importance with regards to what we think of as "normal womanhood" or "normal female sexuality," this is not consistently the case (Tuana, 2004). has not always been the case. Indeed, medical practices performed under the OGR treatment model have often been used as evidence of the sexist and heteronormative subordination of women's capacity for arousal and orgasm to concerns about an aesthetically appropriate vulva or a vagina of adequate depth for penetration (Kessler, 1998). Further, the continued use medically unnecessary clitoral reduction surgeries indicates that this subordination of women's sexuality to men's sexuality persists under DSD.

identification of cisgendered life as normal and of gender variant life as pathological in the clinical literature on intersex for me to critically examine. Fortunately, however, trans* critiques of pathologization have been so forceful that psychiatrists have been very explicit about their justifications for retaining Gender Identity Disorder as a diagnosis, even in the absence of consensus regarding its status as a pathology *per se*. Indeed, not only does the retention of Gender Identity Disorder in DSM-V as Gender Dysphoria remain one of the more controversial aspects of the generally controversial “Bible” of psychiatric disorders, but further, the nosological shift itself speaks to the differential success that the intersex and trans* activist communities have had in terms of getting clinicians to respond to their concerns about pathologization. Thus, I now turn to examine the pathologization of gender variance by the APA through Gender Identity Disorder and in particular, the justifications given for its continued pathologization under DSM-V through the diagnosis of Gender Dysphoria.

V. Gender Variance and Mental Disorders

Gender Identity Disorder (GID) was first introduced in DSM-III (1980), with the subtypes of “Transsexualism,” “GID of Childhood,” and “Atypical GID” within the group of Psychosexual Disorders. Prior to the 1980s, individuals who exhibited gender variance were pathologized or “treated” via other diagnoses in the DSM—generally those in the Sexual Deviations supracategory such as Homosexuality or Transvestism (Meyer-Bahlburg, 2010, p. 462). As Meyer-Bahlburg writes (2010), sex reassignment first became “a salient issue” in North America following the surgical and hormonal transition of George/Christine Jorgenson in 1952, and by the mid-1960s, the first transsexual clinic was opened at Johns Hopkins Hospital (though it would close in 1979 as a result of “ideological backlash”) (p. 462).

Between 1980 and 2013, GID has undergone multiple redefinitions within the DSM. In DSM-III-R (1987), GID was separated from the Psychosexual Disorders and placed under Disorders Usually First Evident in Infancy, Childhood, or Adolescence with the new subcategories of “Transsexualism,” “GID of Childhood,” “GID of Adolescence and Adulthood, Nontranssexual Type” (GIDAANT) and “GID Not Otherwise Specified” (GID-NOS) (Meyer-Bahlburg, 2010; Drescher, 2012; APA, 1987). In DSM-IV (1994) and DSM-IV-TR (2000), the supraordinate category Sexual and Gender Identity Disorders was introduced, including the sub-categories of “GID in Children” (GID-C) and “GID in adolescents and adults” and “GID-NOS.”⁶¹ Meyer-Bahlburg (2010) writes that despite its many reformulations, the “core construct of GID” has been the same across all versions, and is

a combination of identification with the other gender and a sense of inappropriateness, if not rejection, of one’s assignment to the natal gender, with the key specifiers of age (in terms of some age-specific criteria), gender (including some gender-specific criteria for childhood), and sexual orientation (for adolescents and adults) (p. 462).

Notably, the second specifier here—gender—coheres with my definition of cisgendered function, in its reference to gender role or behavior as well as sex-specific, non-sexual desires or preferences, such as “a strong preference for the toys, games, or activities stereotypically used or engaged in by the other gender”(Meyer-Bahlburg, 2010, pp. 462-463; APA, 2013, p. 452). Psychiatrist and member of the Work Group tasked with revising the section on Gender Identity Disorder for DSM-V, Jack Drescher writes that the introduction of

⁶¹ Other diagnoses within the Sexual and Gender Identity Disorders category include Orgasmic Disorders, Sexual Arousal Disorders, Paraphilias and Sexual Desire Disorders (APA, 2000).

transsexualism in DSM-III was “based on the research and clinical contributions” of four individuals: Money (1921-2006), psychiatrist Robert Stoller (1924-1991), physician Harry Benjamin (1924-1991), and psychiatrist Richard Green (1936-) (Drescher, 2010, pp. 437-439). The history of the formal pathologization of gender variance and its management via networks of knowledge/power in the West is a direct result of the thinking and practice of these four physicians and close friends.

Unsurprisingly, transsexuality’s introduction into the DSM begins with Money’s work on intersex patients, his subsequent production of gender, and his belief that “a person’s gender identity was fixed by three years of age,” such that he considered changing the gender identity of anyone older “difficult, if not impossible” (Drescher, 2010, p. 438). As Drescher writes,

Pessimism about changing an adult’s gender identity left only one therapeutic alternative to improve the affected individual’s well-being: sex reassignment. In the mid-1960s, in the wake of Money’s theoretical work and his clinical and research findings, Johns Hopkins opened the first university-affiliated, multidisciplinary gender clinic offering sex reassignment to transsexuals seeking treatment. More than 40 academic centers in the U.S. would later open gender clinics as well (p. 438).

Stoller, whom Drescher characterizes as having been “a preeminent member of both the American psychiatric and psychoanalytic establishments of his time” (Drescher, 2010, p. 438), was also working on and theorizing about gender, and like Money, on the basis of trans* and intersex patients. Stoller, Drescher notes, was the first to tease gender identity out of Money’s concept of gender-role, giving rise to their current mode of existence as two separate, though intimately related entities. Stoller was not an essentialist about gender, but rather believed that some cases of adult transsexualism were caused by “childhood family

dynamics,” (Drescher, 2010, p. 439). The physician to whom he sent many of his patients for surgical and hormonal treatment, however, was an essentialist about gender. Harry Benjamin was an early adopter of brain organization theory, and held that MTF transsexuals were likely the result of “a biological disorder” wherein the brain “was probably ‘feminized’ in utero” (Drescher, 2010, p. 438). Subsequently, Benjamin had “little regard for his era’s psychiatrists and psychologists” and “believed psychotherapeutic attempts to change gender identity were ‘futile’” (Drescher, 2010, p. 438). His work with transsexuals was, in fact, “an outgrowth of his interests in the developing fields of endocrinology, gerontology, and sexology in the 1920s and 1930s. Benjamin was among the first physicians to experiment with hormonal and surgical treatments for aging—he eventually pioneered the treatment of gender dysphoric individuals using sex hormones” (Drescher, 2010, p. 438).

A German-born physician who received his medical degree in Berlin in 1912, Benjamin was described by a colleague as having “diagnosed, treated, and befriended at least a thousand of the ten thousand Americans known to be transsexual” by the time he turned 60 (Person, 2008, p. 260). In the process, writes Person, Benjamin established himself as “not only . . . the discoverer but also as the patron saint of transsexuals” (Person, 2008, p. 260). As Drescher points out, Benjamin accomplished this work “in a private practice setting without either university or academic support” (2010, p. 438). The group formed in 1979 to develop the first Standards of Care (SOC) for treating trans* individuals was named the Harry Benjamin International Gender Dysphoria Association (HBIG- DA) in recognition of Benjamin’s “early advocacy for the medical treatment of transsexualism,” though in 2009, this organization renamed itself the World Professional Association for Transgender Health (WPATH) (Drescher, 2010, p. 438). In 2011, WPATH published the 7th Version of its SOC for the Health of Transsexual, Transgender, and Gender-Nonconforming People (a full two

years prior to the publication of DSM-V) which, given the APA's failure to issue formal Practice Guidelines for treating these patients, remains the international SOC.⁶²

A medical student at Johns Hopkins, Richard Green studied “cross-gender behavior in children under the supervision of his mentor John Money,” before moving on to do his psychiatric training at UCLA under Stoller, as well as to develop a “close relationship” with Benjamin (Drescher, 2010, p. 439). Green co-edited or co-authored multiple foundational texts in on trans* patients including *Transsexualism and Sex Reassignment* (Green & Money, 1969), which Drescher refers to as a “groundbreaking, multidisciplinary treatment textbook,” as well as the book *The “Sissy Boy Syndrome” and the Development of Homosexuality* (Green, 1987) in which he found that 75% of the 66 gender atypical boys he studied grew up to be gay men (Drescher, 2010, p. 439).

Drescher writes that in addition to being “among the most prominent of psychiatrists who supported the APA decision to remove homosexuality from the DSM-II,” Stoller and Green were also on the subcommittee that recommended introducing transsexualism into DSM-III. Two reasons are generally given for the introduction of transsexualism or GID in both adults and children in DSM-III: 1) By 1980, there was enough clinical literature about and clinical experience of those with gender identity disorder to “support its uniqueness as a clinical entity,” and 2) Unlike previous versions which had relied quite heavily on “expert consensus,” DSM-III “placed much greater emphasis on the establishment of explicit diagnostic criteria . . . which would increase the likelihood of

⁶² The American Medical Association formally endorsed the WPATH's SOC with Resolution 122 in July 2008 (AMA, 2008), as has the Endocrine Society (Hembree et al., 2009). The APA has yet to do so. Importantly, the 7th version of WPATH's SOC (2011) explicitly condemns the use of GICE, stating that “[t]reatment aimed at trying to change a person's gender identity and lived gender expression to become more congruent with sex assigned at birth” is “no longer considered ethical” (p. 32). However, because the APA has never formally endorsed the WPATH SOC, psychiatrists need not abide by this treatment model with regards to the administration (or non-administration) of GICE.

establishing a putative disorder's reliability and validity" (Zucker & Spitzer, 2005, p. 36). In fact, it was with DSM-III that the APA first adopted its current account of and system of classification for mental disorders, based on German psychiatrist Emil Kraepelin's system of classifying mental illnesses in the manner of syndromes—that is, in terms of common patterns of symptoms over time (Murphy, 2006, pp. 30-31). Under this neo-Kraepelinian system, mental disorders are clusters of signs and symptoms that regularly co-occur, but are not defined or classified in terms of the physical processes on which they undoubtedly rely, such that psychiatric pathologies are not bound to any particular etiology or causality, with the threshold or boundaries for mental disorder drawn in terms of distress and impairment of social function (Murphy, 2006, p. 211). Indeed, in DSM-V, mental disorder is defined as

a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress or disability in social, occupational, or other important activities. An expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder. Socially deviant behavior (e.g., political, religious, or sexual) and conflicts that are primarily between the individual and society are not mental disorders unless the deviance or conflict results from a dysfunction in the individual, as described above (APA, 2013a, p. 20).

Thus, we get the current format of the DSM that lays out the diagnostic criteria for a mental disorder in terms of regularly co-occurring symptoms and clinically significant distress or impairment in social function. There are two very interesting and important features of this account of mental disorder first adopted by the APA in DSM-III: 1) it emerged out of

debates over the removal of homosexuality from DSM-II and 2) it remains agnostic with regards to causality, defining mental disorder solely in terms of distress and social impairment as a result of “clinically significant disturbance in an individual’s cognition, emotion regulation, or behavior” (excluding those clinically significant disturbances which are culturally approved or merely socially deviant).

In his detailed review of the diagnostic histories of Homosexuality and Gender Identity Disorders, Drescher writes that debates over Homosexuality’s place in the DSM forced those working on the issue for the APA to reformulate their definition of mental disorder and stresses that the removal of the diagnosis from DSM-II was merely a concession that homosexuality did not fit the criteria for a mental disorder per se according to this new definition, rather than the organization’s acceptance of it as a normal human variant. Homosexuality was included in the first edition of the DSM (1952) where it was classified as a “sociopathic personality disturbance,” though it would re-classified as a “sexual deviation” in DSM-II (1968) (Drescher, 2010, p. 434). Drescher argues that etiological theories of homosexuality can be generally divided into three types; 1) Theories of Normal Variation that posit homosexuality to be (as one might imagine) a normal and likely natural variation in human sexual behavior; 2) Theories of Pathology that “hold that some internal defect or external pathogenic agent causes homosexuality and that such effects can occur pre- or post-natally (intrauterine hormonal exposure, excessive mothering, inadequate or hostile fathering, sexual abuse)”; and 3) Theories of Immaturity that hold homosexuality to be a normal step in the development of adult heterosexuality and see the homosexual as “arrested” in that stage of development (pp. 431-432).

By the mid-1950s, Theories of Pathology dominated the psychiatric community and the issue was more about being clear about the type of pathology homosexuality was—i.e.

was it a sociopathy or an anxiety disorder or a sexual deviance—and thus how to best “cure” it. Drescher argues that because American psychiatry was so heavily influenced by “psychoanalytic ego psychology,” psychiatrists largely ignored the growing body of sex research by individuals like Kinsey and Hooker that indicated that not only was homosexuality more common than psychiatry maintained, but further, that homosexuals failed to suffer any more psychological disturbances than heterosexuals (Drescher, 2010, pp. 433-434). However, Drescher writes that “by 1970 the scientific research arguing for a non-pathological view of homosexuality was dramatically brought to the attention of the APA” most notably by gay activists who disrupted both the 1970 and 1971 annual meetings of the APA. Gay activism alone did not lead to the removal of Homosexuality from the DSM, however. Many factors both inside and outside the APA played a role, including a growing anti-psychiatry movement, a “generational changing of the guard within APA comprised of younger leaders urging the organization to greater social consciousness” (p. 434) and presentations by gay activists and a disguised gay psychiatrist at the 1972 annual meeting.

A subcommittee of the APA’s Nomenclature Committee tasked with reviewing Homosexuality was forced to review the larger account of mental disorder and redefine it. The subcommittee, writes its Chair, psychiatrist Robert Spitzer

reviewed the characteristics of the various mental disorders and concluded that, with the exception of homosexuality and perhaps some of the other “sexual deviations,” they all regularly caused subjective distress or were associated with generalized impairment in social effectiveness of functioning (p. 211).

With this novel definition of mental disorder in terms of impairment and distress in hand, the Nomenclature Committee concluded that homosexuality was not a mental disorder *per se* and in December 1973, the APA’s Board of Trustees (BOT) voted to remove

homosexuality from the DSM (Drescher, 2010, p. 434). Drescher notes, however, that this did not settle the issue. Rather, as a result of a petition by “psychiatrists from the psychoanalytic community” who objected to the BOT’s decision, a referendum of the APA’s membership was held on the matter. Nonetheless, the BOT’s decision was upheld by a 58% majority of the voting members, and Homosexuality was removed from the DSM (p. 434).

Following its removal from the DSM, the APA issued a formal statement endorsing civil rights protections for gay people (APA, 1973). Nonetheless, as Spitzer writes, this was not an endorsement of a normal variant position, as can be seen in this statement from the APA’s 1973 position paper announcing the diagnosis’ removal:

If homosexuality per se does not meet the criteria for a psychiatric disorder, what is it? Descriptively, it is one form of sexual behaviour. Our profession need not agree on its origin, significance, and value for human happiness when we acknowledge that by itself it does not meet the requirements for a psychiatric disorder. Similarly, by no longer listing it as a psychiatric disorder we are not saying that it “normal” or as valuable as heterosexuality. . . . What will be the effect of carrying out such a proposal? No doubt, homosexual activist groups will claim that psychiatry has at last recognized that homosexuality is as “normal” as heterosexuality. They will be wrong. In removing homosexuality per se from the nomenclature we are only recognizing that by itself homosexuality does not meet the criteria for being considered a psychiatric disorder. We will in no way be aligning ourselves with any particular viewpoint regarding the etiology or desirability of homosexual behavior (APA, 1973, pp. 2-3).

The definition of distress and social impairment created to deal with homosexuality was then enshrined in DSM-III at the same time that transsexuality

entered it. Further, this is why the pathologization and management of individuals with SOCE since the DSM-III has hinged whether or not an individual's same-sex desire caused them distress and social impairment (i.e. in terms of *ego-dystonic* homosexuality or sexual orientation *disturbance*). Interestingly, while the APA points out here that they need not agree on homosexuality's origin in order to determine that it *is not* a pathology, they actually need not agree about this to determine it *is* a pathology either.

Importantly, though the account of mental disorder established with DSM-III assumes that the individual's symptoms in some way reflect "a dysfunction in the psychological, biological, or developmental processes underlying mental functioning" (APA, 2013a, p. 20) it is ultimately an *atheoretical* account remaining agnostic with regards to etiology, as evidenced by a personal communication between Zucker and Cynthia Kraus quoted in the latter's 2015 article "Classifying Intersex in DSM-5: Critical Reflections on Gender Dysphoria" in which Zucker writes "DSM is largely agnostic regarding etiology: a rose is a rose, regardless of what causes a plant to be a rose" (Zucker, personal communication, August 30, 2014; as cited in Kraus, 2015, p. 4). This is why the task force specifies that they are unable to come to a Consensus on the GID's status as a pathology *in the absence of clinically significant distress and impairment*. I argue, however, that there is no reason for the APA to come to a Consensus on this issue, for it simply doesn't matter; there is simply no way to ground the identification of a state as a psychopathology beyond clinically significant distress and social impairment because that's all this account consists in. Thus, it doesn't matter if trans* kids have brains that have been atypically masculinized or feminized in utero or if their mothers didn't hug them enough or breastfed them for too long; under the DSM you can't justify the pathologization of a trans* individual on the basis of the organization of their brain in the same way you can't justify diagnosing an individual with

clinical depression in the absence of clinically significant symptoms of it, even if they exhibit patterns of neuronal activity correlated with clinical depression in studies.

The reclassification of GID as Gender Dysphoria (GD) in DSM-V is, at least partially, an attempt to emphasize the centrality of distress and social impairment to the definition of mental disorder and thus narrow the diagnosis to only those who experience dysphoria as a result of their gender variance rather than merely a variant gender identity. Despite this shift in DSM-V and its general agnosticism regarding causality, etiology is nonetheless the reason behind the APA's inability to come to a consensus regarding the GID's status as a pathology in the absence of distress and social impairment, and subsequently regarding appropriate medical management in children with GID. If it's pathological, then the use of GICE in trans* kids seems not only biopolitically appropriate, but ethical as well, and subsequently we might even be morally obligated to intervene in such a manner. If not, then the use of such efforts might be coercive, and would likely fall into DSM-V's definition of merely "socially deviant behavior," signaling a conflict between the individual and society rather than a "true" mental disorder. Furthermore, despite its assertions to the contrary, mere distress and social impairment isn't enough for something to qualify as a mental disorder for the APA. Indeed, as Drescher notes, the removal of both SOD and EDH from DSM-III and DSM-III-R respectively were occasioned by arguments that merely being distressed by one's same-sex desires didn't seem to be adequate justification for pathologizing and treating those desires. SOD, for example, was introduced for the purpose "purpose of legitimizing the practice of sexual conversion therapies (and presumably justified insurance reimbursement for those interventions as well), even if homosexuality per se was no longer considered an illness" (Drescher, 2010, p. 435). However, it "also allowed for the unlikely possibility that a person unhappy about a

heterosexual orientation could seek treatment to become gay”(p. 435). Its successor, EDH, raised concerns that “all kind of identity disturbances could be considered psychiatric disorders,” such as those who were distressed by their height (Ego-Dystonic-Height) (p. 435). These debates about SOD and EDH and the inadequacy of the distress criteria in particular are, I argue, actually debates about etiology and specifically whether or not homosexuality is a normal human variant, like variations in height or race, or a pathological one, such that it is biopolitically appropriate and ethical to fix those who seek out normalization with regards to it, even if it is not biopolitically appropriate or ethical to force it upon them. Thus, even though the APA defines mental disorder solely in terms of distress and social impairment with regards to a disturbance in one’s “cognition, emotion regulation, or behavior,” etiology in terms of the normal and the pathological development does matter in some unclear way, and is often lurking in the background of these discussions.

I argue that the APA’s continued failure to issue official Practice Guidelines for the treatment of GID/GD 35 years after introducing the diagnosis and thus formalizing the pathologization of gender variance in the West, is a direct result of their failure to come to consensus on the status of gender variance, *per se*, as a pathology.⁶³ The lack of official Practice Guidelines for treating GID by the very organization that produced it as a diagnostic entity has tragic consequences for those captured by it. Both Drescher and the Task Force (Byne et al., 2012) point out that it is used by multiple insurance companies in the United States to justify their failure to cover hormonal and surgical interventions for the purposes of gender reassignment. As Drescher (2010) writes,

While it is often asserted that the DSM (and ICD) diagnoses provide the only pathways to insurance reimbursement for trans individuals seeking medical

⁶³ The World Health Organization followed the APA’s lead and included transsexualism and GID of childhood in the 1992 version of ICD-10 (WHO, 1992; Drescher, 2010, p. 439).

assistance, APA has issued no treatment guidelines for either GIDC or adult GID. This omission is in stark contrast to an increasing proliferation of APA practice guidelines for other DSM diagnoses. In addition, the absence of a formal APA opinion about treatment of a diagnosis of its own creation has contributed to an ongoing, troubling problem: many health care insurers and other third party payers claim that SRS is an “experimental treatment,” an “elective treatment,” or “not medically necessary” and therefore not reimbursable or covered under most insurance plans and treatment is not always accessible to wards of governmental agencies, such as foster care and prison systems. In other words, the presence of the GID diagnosis in the DSM is not serving its intended purpose of creating greater access to care—one of the major arguments for diagnostic retention (p. 449).

Both Drescher (2010) and the Task Force (2012) recommended the APA issue Practice Guidelines in order to remedy these problems, despite the latter’s acknowledgement that GID will likely not meet the criteria set out by the APA’s Steering Committee on Practice Guidelines (SCPG) which develops such documents. These criteria include information about the 1) prevalence of the disorder and 2) quality of the relevant database (Byne et al., 2012, p. 760). Indeed, they explicitly acknowledge that good quality evidence on GID will likely never be possible, writing,

The randomized double blind control trial is the study design that affords the highest quality evidence regarding the comparative efficacy of various treatment modalities; however, no such trials have been conducted to address any aspect of the treatment of GID. Given the very nature of GID, such trials, or even unblinded trials with random assignment to treatment groups, are not likely to be forthcoming due to a lack of feasibility and/or ethical concerns (p. 760).

Nonetheless, the Task Force recommends the APA develop Practice Guidelines on the basis of the database available and expert consensus, arguing that it would, among other things, ease obstacles to care faced by trans* individuals, as well as allow the APA to “frame its position on what constitutes realistic and ethical treatment goals as well as what constitutes ethical and humane approaches to treatment” (p. 768). Despite this, the APA has still not issued official Practice Guidelines for the treatment of GD. It did, however, issue an official “Fact Sheet” via its website accompanying the publication of DSM-V, announcing its reclassification as Gender Dysphoria. In addition, the APA acknowledged the subjectifying effects of psychiatric diagnoses and affirmed, for the first time publically, its commitment to ensuring that trans* patients have access to gender confirming interventions, while also asserting gender variance in itself to be non-pathological (though falling short of endorsing a normal human variant view). As the Fact Sheet states:

DSM not only determines how mental disorders are defined and diagnosed, it also impacts how people see themselves and how we see each other. While diagnostic terms facilitate clinical care and access to insurance coverage that supports mental health, these terms can also have a stigmatizing effect. DSM-5 aims to avoid stigma and ensure clinical care for individuals who see and feel themselves to be a different gender than their assigned gender. . . . *It is important to note that gender nonconformity is not in itself a mental disorder* [emphasis added]. The critical element of gender dysphoria is the presence of clinically significant distress associated with the condition (APA, 2013b paras. 2-3).

In addition to detailing some of the ways in which GD as a diagnosis differs from GID under DSM-IV, the Fact Sheet goes on to state these changes are the product of a compromise between the need for diagnostic categories that better represent and the need to

ensure access to medical care, with the conclusion that “ultimately, the changes regarding gender dysphoria in DSM-5 respect the individuals identified by offering a diagnostic name that is more appropriate to the symptoms and behaviors they experience without jeopardizing their access to effective treatment options” (para. 11).

In the following and final substantive section of this chapter, I briefly review the specific differences between GID in DSM-IV-TR and GD in the DSM-V, and examine a set of explicit arguments justifying the continued pathologization of trans* lives. The APA’s assertion in the quote above—that gender variance in the absence of dysphoria is *not* a mental disorder—means it exists in this grey area between the normal and the pathological, not yet a normal human variant, but not a pathology either. Its inability fully to enter the realm of the normal or of the pathological is the result of the APA’s inability to come to a consensus on its status. But dysphoria itself clearly isn’t enough; indeed, if gender variance is a normal feature of human diversity, then whatever distress gender variant individuals experience as a result of it is a socially constituted conflict between the individual and society. Thus, unique arguments must be given to justify the continued pathologization of GD that paradoxically do not rely on any standard of account of pathology and can account for its unique features. Specifically, GD (and GID before it) are one of the few mental disorders to appear within the DSM that are treated with therapies which aim at the level of the somatic body rather than at the level of the mind, and which reduce an individual’s distress and social impairment through the confirmation rather than the reduction or elimination of their symptoms.⁶⁴ Unlike with other mental disorders such as Obsessive

⁶⁴ Another such condition is Body Integrity Identity Disorder (BIID) referring to the desire for healthy limb amputation in order to bring one’s physical body into alignment with how one feels it both “really is” and should be (i.e. without the limb). Interestingly, BIID appears in the DSM-V under the differential diagnoses sections for both Body Dysmorphic Disorder and Gender Dysphoria (i.e. treating clinicians should rule out BIID when diagnosing these

Compulsive Disorder or Separation Anxiety Disorder, the aim of treatment for GID is not to reduce distress and social impairment by reducing the characteristic symptoms associated with the condition (here, gender variance). Rather, distress and social impairment are reduced through the somatic *confirmation* of one's symptoms, fixing their body in order to bring it into an apparent cis-alignment with their mind. With this in mind, I seek to make explicit how the production of passably cisgendered life through the diagnosis of Gender Dysphoria is justified under DSM-V, in the absence of appeals to pathology.

VI. From Gender Identity Disorder to Gender Dysphoria

Drescher (2010) identifies five issues raised by trans* activists that dominated debate over GID in the lead up to DSM-V: 1) that GID as a diagnosis only served to stigmatize and harm an already stigmatized and highly vulnerable population; 2) that removal of GID would prevent access to care; 3) that retention of GID would allow for the reintroduction of homosexuality; 4) that the use of GICE to secure cisgendered futures for trans* kids was “unscientific, unethical and misguided” and 5) individual members of the Working Group—specifically Zucker and his mentor Ray Blanchard—were transphobic and should be removed (p. 428). After dismissing the third and fifth concerns as unfounded, Drescher acknowledges that many of those issues raised in relation to GID mirror those raised by earlier critics in relation to Homosexuality. He writes,

As in the case of homosexuality, arguments for removal of the “trans diagnoses” include societal intolerance of difference, the human cost of diagnostic stigmatization, using the language of psychopathology to describe what some consider to be normal behaviors and feelings and, finally, inappropriately focusing

patients) (APA, 2013 pp. 246, 458). However, it is not itself a DSM-V diagnosis (as each mention makes explicit) (pp. 246, 458).

psychiatric attention on individual diversity rather than opposing social forces that oppress sexual and gender nonconformity (p. 429).

Drescher goes on, however, to point out key ways in which the question of removing GID differs from the question of removing homosexuality from the DSM, the most important of which is access to medical care. Indeed, these are the grounds upon which he justifies the continued pathologization of GID in the DSM, though he urges a refinement of categories in ways that did actually show up in DSM-V (such as narrowing them to exclude those gender variant individuals who are not “anatomically dysphoric or distressed”) (p. 454). Fascinatingly, Drescher makes a purely consequentialist argument for the continued pathologization of GID on the basis of access to care that in no way references pathology or etiology. Simply put, he argues that physicians must “take to heart the dictum ‘first do no harm’” and on that basis he concludes that

at this moment in time, I believe the less harmful choice would be retaining and modifying the adolescent and adult GID diagnostic criteria to make them more narrowly inclusive of individuals who are distressed about the dissonance between their anatomical and psychological gender (p. 454).

Drescher acknowledges the serious, stigmatizing effects of GID, but argues that the pathologization of GID has not posed a major obstacle to the rapid “acceleration of legal trans protections in the last decade” (p. 454). He acknowledges this may be due to rapidly changing social mores, which themselves might come to one day make both gender variance and transition itself seem like normal human variants, writing,

it is entirely possible that the lagging social acceptance of gender variance will catch up with the more advanced social normalization of homosexuality. For example, gay marriage, once unimaginable, is now the law of the land in many places. It is not

unthinkable that, in the future, gender variant people transitioning from one sex to another might be treated by medical specialists who, like obstetricians, use medical and surgical interventions to facilitate what society considers to be a normal life event (p. 453).

However, because this future does not obtain today, Drescher argues for the inclusion of a restricted version of GID in DSM-V, while at the same time acknowledging that retention might slow down progress towards that future:

While retaining the diagnoses, even with modification, can undoubtedly contribute to perpetuating stigma (in a manner similar to being diagnosed with major depression or bipolar disorder can be stigmatizing), such an outcome would constitute a lesser harm to anatomically dysphoric members of the trans community than the denial of access to medical and surgical care likely to ensue following removal from the DSM (p. 454).

Thus, Drescher argues for the restriction of GID to those who subjectively determine they require access to care, *specifically* for the purpose of providing access to care. And this is basically what was enshrined in DSM-V through the reformulation of GID as GD, plus a few other fascinating additions.

In their 2013 “Memo Outlining Evidence for Change for Gender Identity Disorder” (MOEC), the GID subworkgroup (Zucker et al.) recommended eleven substantive changes to GID in DSM-V, which I will group into four sets.⁶⁵ All of these changes were more or less adopted in DSM-V (with the exception of one which I will flag) and thus, these are the

⁶⁵ MOECs or Memos Outlining Evidence for Change, are documents which outline and justify all of the revisions the work groups for the various sections of the DSM recommend for their respective section to the APA’s Board of Trustees (Zucker et al., 2013). The Board of Trustees decides which revisions to accept and which to reject and thus, have the final say regarding the official content of the DSM.

four primary ways in which GD under DSM-V differs from GID under DSM-IV-TR (See Appendix B summarizing GID and GID-NOS under DSM-IV-TR and GD under DSM-V).

The first set of changes has to do with the wording of the introductory descriptor to the A criteria and to the status of the A1 criterion for GD in children. Whereas under GID the introductory descriptor to the A criteria read: “A strong and persistent cross-gender identification (not merely a desire for any perceived cultural advantages of being the other sex). In children, the disturbance is manifested by four (or more) of the following” (APA, 2000, p. 581), under GD, the introductory descriptor to the A criteria reads “A marked incongruence between one’s experienced/expressed gender and assigned gender, of at least 6 months’ duration, as manifested by at least six of the following (one of which must be Criterion A1) (APA, 2013a, p. 452). The wording of the A criterion has been changed to stipulate a minimal threshold in duration in order to distinguish between “very transient and persistent GID,” and to include the term “incongruence” as this “better reflects the core of the problem, namely, an incongruence between, on the one hand, the identity that one experiences and/or expresses and, on the other hand, how one is expected to live based on one’s assigned gender (usually at birth)” (Zucker et al., 2013, p. 903). Further, the GID subworkgroup identify incongruence as preferable to “cross-gender identification” because it does not imply “a strictly binary gender identity concept” that is “no longer in line with the spectrum of gender identity variations that one sees clinically” (p. 903). “Sex” is also replaced with “gender” in DSM-V “in order to make the criteria applicable to individuals with a DSD” as well as provide an “exit clause” for those who have successfully transitioned, so that they can “lose’ the diagnosis” (p. 903). Finally, the proviso that one’s cross-gender identification not be a sign of or “merely a desire for any perceived cultural advantages of being the other sex” was removed in line with the DSM’s general agnosticism regarding

etiology. As the MOEC writes,

there is no reason to ‘impute’ one causal explanation (in this case, a cultural advantage hypothesis) for GD without mentioning any others. Deleting this phrase would be consistent with a purely phenomenological approach that eschews any reference to putative underlying causal mechanism with regards to the diagnostic criteria (p. 903).

Making the A1 criterion necessary for GD-C under DSM-V was done in order to avoid the possibility of false positives, or children being inappropriately diagnosed with GID-C on the basis of social (and particularly parental concerns) about “pervasive cross-gender behavior (gender nonconformity or gender variance)” in the absence of a expressed desire to be the other gender (p. 904). Under DSM-IV-TR, children only required 4 (or more) of the 5 listed diagnostic criteria and thus could be diagnosed with GID-C on the basis of their behavior and preferences alone, in the absence of a professed desire to transition. Interestingly, allowing for this possibility was an explicit choice made by the DSM-IV subcommittee on GID in order to allow for the possibility that there

might be a small number of children who showed all the signs of a GID (including the criteria from Point B), yet did not express the desire to be of the other gender, perhaps because of reasons of social desirability, a harsh social environment, etc. It was therefore argued at the time that the desire to be of the other gender need not be a necessary symptom indicator (p. 904).

Importantly, however, the language is changed to merely state “strong desire,” rather than “repeatedly stated strong desire” or “expressed strong desire,” for example, in order to provide themselves an “out” and “capture some children who, in a coercive environment, may not verbalize the desire to be of the other gender” (p. 905).

The second set of changes have to do with the B criteria for the condition. Under GID, the B criteria read as follows:

Persistent discomfort with his or her sex or sense of inappropriateness in the gender role of that sex. In children, the disturbance is manifested by any of the following: in boys, assertion that his penis or testes are disgusting or will disappear or assertion that it would be better not to have a penis, or aversion toward rough-and-tumble play and rejection of male stereotypical toys, games, and activities; in girls, rejection of urinating in a sitting position, assertion that she has or will grow a penis, or assertion that she does not want to grow breasts or menstruate, or marked aversion toward normative feminine clothing. In adolescents and adults, the disturbance is manifested by symptoms such as preoccupation with getting rid of primary and secondary sex characteristics (e.g., request for hormones, surgery, or other procedures to physically alter sexual characteristics to simulate the other sex) or belief that he or she was born the wrong sex (APA, 2000, p. 581).

However, under GD, the B criteria reads: “The condition is associated with clinically significant distress or impairment in social, school, or other important areas of functioning” (APA, 2013a, p. 452). Thus, under GD, we see the merging of the A criterion (cross-gender identification) and B (persistent discomfort) criterion from DSM-IV-TR and the rewording of the point B criterion to “emphasize distress, impairment and increased risk of suffering or disability” (Zucker et al., 2013, pp. 903, 906). The GID subworkgroup recommended merging the A and B criteria on the basis that existing studies failed to support this distinction (p. 904). However, it is worth noting that this merger makes sense under DSM-V even without supporting studies, given that merely gender variant individuals (or those who express cross-gender identification) without persistent dysphoria or discomfort is not the

population that the APA is attempting to capture with this diagnosis. In its MOEC, the GID subworkgroup motivate rewording the point B criterion based on consensus among them “that some adolescents who are planning gender change and are undergoing puberty-blocking hormonal therapy are not distressed when a clear path towards gender change is mapped out for them, but may become strongly distressed if parents or others try to strongly block this path” (p. 906). Interestingly, this is the only one of the subworkgroup’s recommendations that the APA did not adopt in full. In DSM-V, the B criterion for GD in adolescents and adults in DSM-V merely stipulates that the “condition is associated with clinically significant distress or impairment in social, occupational, or other important areas of functioning” rather than that “the condition is associated with clinically significant distress or impairment in social, occupational, or other important areas of functioning, or with a significantly increased risk of suffering, such as distress or disability,” as the subworkgroup suggested (APA, 2013a, p. 453; Zucker et al., 2013, p. 906).

The third set of changes deal with the wording of the diagnostic criteria for GD in both children and adults and adolescents, to make both more detailed, as well as more clearly polythetic with a minimal threshold for the latter diagnosis. As the subworkgroup note, “in DSM-IV, the GID criteria for adolescents and adults were somewhat sketchy and, for some, even lacked a reference to intensity or frequency (e.g., “a stated desire to be the other sex”)” (Zucker et al., 2013, p. 905). Furthermore, they once again appeal to a spectrum rather than binary notion of gender and specifically acknowledge that individuals can accordingly vary with regards to the medical interventions they pursue, writing,

The current formulation makes it more explicit that a conceptualization of GD acknowledging the wide variation of conditions will make it less likely that only one type of treatment is connected to the diagnosis. Taking the above regarding the

avoidance of male–female dichotomies into account, in the new formulation, the focus is on the discrepancy between experienced/expressed gender (which can be either *male, female, in-between or otherwise*) [emphasis added] and assigned gender (in most societies male or female) rather than cross-gender identification and same-gender aversion (p. 905).

The final and most obvious set of changes deal with the categorization of GID, the diagnoses themselves and their specifiers. GD was removed from the supracategory Sexual and Gender Identity Disorders (which also housed the Paraphilias and Sexual Dysfunctions) and given its own chapter under its new diagnostic name, Gender Dysphoria. In their “Memo Outlining Evidence for Change for Gender Identity Disorder” (MOEC) the GID subworkgroup recommended this re-categorization given that the association of GID with Paraphilias is “somewhat stigmatizing” and that generally speaking the theoretical overlap among GID, Sexual Dysfunctions, and Paraphilias “is far from complete,” though they do note “there can be a co-occurrence of one paraphilia, Transvestic Fetishism, with GID in adolescents and adults” (Zucker et al., 2013, p. 903). They motivate the move in diagnosis from Gender Identity Disorder to Gender Dysphoria as accomplishing two goals: 1) highlighting “a conceptual change in the formulation of the diagnosis” in terms of “distress (dysphoria) and not identity per se” and 2) satisfying “critics concerned about the stigmatizing use of the ‘disorder’ term in the name of the diagnosis” (p. 902). The diagnostic categories for GID in adults and adolescents as well as GID in children underwent a simple shift in nomenclature (i.e., GID-C to GD-C). However, where we had Gender Identity Not Otherwise Specified under DSM-IV-TR (reserved in part for those with DSD who were excluded from the other two categories), under DSM-V, we have Other Specified Gender Dysphoria (OSGD) for those who exhibit symptoms “characteristic of gender dysphoria

that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning” but do not meet the full criteria for gender dysphoria for a reason the clinician specifies (e.g. their symptoms last less than the required 6 months), and Unspecified Gender Dysphoria (UGD) for OSGD patients who fail to meet the requirement for GD for unspecified reasons (APA, 2013, p. 459). With regards to Specifiers, we see the removal of the sexuality specifier in DSM-V and the introduction of two new specifiers: “with a DSD” and “if posttransition.” All three of these changes are noteworthy.

The GID subworkgroup motivate the removal of the long controversial sexuality specifier on their conclusion that “sexual attraction (sexual orientation) per se plays only a minor role in contemporary treatment protocols” given that gender-confirming interventions are no longer restricted to those who will be heterosexual posttransition (pp. 906-907). They write,

this is very different from what happened clinically in the early years of gender-reassignment surgery decisions that were managed by psychiatrists in specialized gender identity clinics who would only provide treatment to individuals attracted to their own natal sex and would not endorse the medical creation of post-operative “homosexuals” (p. 907).

They nonetheless suggest that physicians continue to take note of trans* patients’ sexuality given that “sexual attraction (sexual orientation) is of interest to researchers in the field”—just that it not be used as a specifier to subgroup the population (p. 907).

The MOEC recommends the inclusion of the DSD specifier (which they note was not an exclusionary criteria for GID until DSM-IV) in light of the fact that “considerable additional evidence has accumulated that some individuals with a DSD

experience GD and may wish to change their assigned gender”(Zucker et al., 2013, p. 907). Fascinatingly, the GID subworkgroup very cautiously and ambiguously suggests that GD in those with DSDs may be causally different from GD in those without, vaguely noting that,

From a phenomenologic perspective, DSD individuals with GD have both similarities and differences to individuals with GD with no known DSD.

Developmental trajectories also have similarities and differences. The presence of a DSD is suggestive of a specific causal mechanism that may not be present in individuals without a diagnosable DSD (p. 907).

However, given the DSM’s general agnosticism regarding causality, differing causal mechanisms and developmental trajectories don’t really matter in terms of diagnosis and treatment, and thus the re-inclusion of those with DSDs into the population of those diagnosable with GD make sense—as Zucker says, “a rose is a rose, regardless of what causes a plant to be a rose” (Zucker, personal communication, August 30, 2014; as cited in Kraus, 2015, p. 4).

Finally, the subworkgroup recommends the inclusion of a posttransition specifier not in order to recognize or distinguish those who have transitioned as an explicitly unique subgroup or population, but specifically in order to ensure access to care. As they write, many individuals no longer meet the criteria for GD after transition, given that transition generally resolves one’s dysphoria and social impairment, and, further, following gender-confirming interventions, their behaviors and preferences that were previously symptoms can no longer be read as such. Nonetheless, these individuals often still require access to medical care in terms of “chronic hormone treatment, further gender-confirming surgery, or intermittent psychotherapy/counseling to facilitate the adaptation to life in the desired

gender and the social consequences of the transition” (Zucker et al., 2013, p. 907). The posttransition specifier is modeled on the concept of “in partial or full remission.” The MOEC authors note this is not quite the same in this case, in light of the need for continued access to care even though the dysphoria and social impairment lessen in these patients (as they do in other patients we might deem to be in remission on such a basis, such as mood disorder patients). They do however note that remission in the standard sense of the term may be applicable to that majority of GD-C patients whose condition fails to persist.

Under DSM-V, then, pathological gender variance is understood in terms of incongruence between the gender one expresses and/or experiences and “how one is expected to live based on one’s assigned gender (usually at birth),” in combination with resultant dysphoria or distress and social impairment (Zucker et al., 2013, p. 903).

Importantly here, gender, along with sex, is understood as existing along a spectrum, such that individuals may vary in terms of the medical interventions they choose (from no interventions to hormones alone, to hormones in combination with some or all surgical interventions available). The reason for or cause of gender variance itself is irrelevant; all that matters is that it causes dysphoria, the reduction of which is the primary target of treatment. GID as GD maintains its distinctive status within the pantheon of mental disorders insofar as the reduction of dysphoria is achieved via the confirmation rather than the lessening of symptoms through interventions at the level of the somatic body instead of the mind.

Further, it is one of the few mental disorders (and likely, pathologies in general) in which the patient is granted primary authority with regards to determining the necessary treatment plan. By this, I mean that while health care professionals play a role in the medical decision-making process (e.g. providing both empirically derived information and clinical expertise with regards to various treatment options), it is the patient who stipulates what type or level

of interventions are required to confirm their gender as they experience and understand it.

All of this brings me to me to four conclusions regarding pathological gender variance or pathologies with regards to cisgendered function, and sex, gender and sexuality as the elements out of which those pathologies are constituted. First, intersex conditions and GD are both, primarily, *bureaucratically constituted pathologies*, with the sole function of licensing or preventing the medical normalization of particular bodies in particular ways, as well as the production of those knowledges that both enable and justify such forms of normalization. Kathy Ferguson (1984) argues that bureaucracy “needs to be understood both as a structure and as a process” (p. 6). It is both, she argues, “a fairly stable arrangement of roles and assignment of tasks” that are often experienced as “static and fixed authority structures,” *and* “a temporal ordering of human action that evolves out of certain historical conditions toward certain political ends” (p. 6). The traits Ferguson lists as characteristic of bureaucratic organizations eerily echo Foucault’s characterization of disciplinary institutions such as the school and the clinic:

a complex rational division of labor, with fixed duties and jurisdictions; stable, rule-governed authority channels and universally applied performance guidelines; a horizontal division of graded authority, entailing supervision from above; a complex system of written record-keeping based on scientific procedures that standardize communications and increase control; objective recruitment based on impersonal standards of expertise; predictable, standardized management procedures following general rules; and a tendency toward the way of life the organization requires (Ferguson, 1984, p. 7).

Bureaucracies, like other disciplinary institutions, discipline both those they take up or target (i.e. criminals and patients), and those who work within them (i.e. prison guards

and health care professionals) to ensure they do that disciplinary work effectively and efficiently.

As administrative structures, bureaucracies seem, as Ferguson emphasizes, static and politically neutral in ways that obscure their biopolitical functions and their complex, contingent histories. Moreover, Spade (2011) argues that administrative institutions and their bureaucratic demands/obstacles are primary vectors via which life chances are maldistributed among populations (p. 110). Intersex conditions and GD are, I conclude, primarily bureaucratic entities, categories via which life chances are maldistributed that certain (i.e. cisgendered or cis-passing) lives are made live while others (trans*, or at least visibly trans*) lives are let die. In the case of intersex infants and trans* children, the pathology is used to justify the use of efforts to secure cisgendered futures, in accordance with the initial purpose or goal of gender and its production by Money in the context of intersex management; gender was meant to stabilize the heterosexual matrix in a cisgendered fashion and the pathologization of gender variance allows this project to continue where trans* and intersex kids are concerned. In the context of intersex and trans* management beyond childhood, however, pathologization with regards to cisgendered function justifies the production of lives that pass as cisgendered, even if they truly aren't such—an end towards which the use of puberty-blockers and fetal dex are directed.⁶⁶ Given Money's initial pessimism regarding the success of GICE beyond childhood, the *appearance* of cisgendered life is the best outcome available to those whose gender variance persists beyond childhood.

⁶⁶ The ability of those capable of providing informed consent to choose the level and types of gender confirmation they desire means that achievement of this end is often frustrated within the clinic.

Additional evidence of the bureaucratic nature of pathologies of cisgendered function can be seen in the fact that gender incongruence is importantly not enough to receive a diagnosis of GD and thus gain access to gender-confirming interventions for those with GD; it must exist in combination with distress and social impairment as a result of that incongruence. The winnowing of the diagnosis to only those with dysphoria or distress and social impairment means that GD functions, ultimately, as a way of identifying only those who both want and consider themselves to need access to gender confirming interventions. Further, the APA's purported agnosticism regarding etiology means whatever biological factors might influence gender development are irrelevant, and thus whether or not gender variance is a pathology in itself does not matter—the only thing that does is the desire and belief that one needs access to these forms of normalization. The diagnosis is thus nothing more than a mechanism via which one might overcome bureaucratic obstacles to particular forms of gendered normalization and is thus primarily bureaucratic in nature.

The bureaucratic nature of pathologies of cisgendered functions guarantees that they are, at least in part, socially constituted entities. One could argue, however, that while they might function primarily at the level of administrative bureaucracies in the service of particular biopolitical ends, they nonetheless represent or capture certain important biological facts about the world. This brings me to my second conclusion: not only are both pathologies of cisgendered function, and the three elements of the heterosexual matrix that produce cisgendered life as we know it are in no way biological, they are all, necessarily, *socially constituted entities*. The pathologies function within socially constituted, bureaucratic networks of knowledge/power in order to license submission to or withhold access from various forms of gender-confirming

normalization. Further, given that from the perspective of the bureaucratic, disciplinary institutions that govern abnormal gender development, biological facts do not matter, it is not clear that biological facts can matter where “normal” cisgendered lives are concerned either. Evidence of this can be seen in Meyer-Bahlburg’s (2010) rumination regarding what a biological explanation of gender incongruence would and would not mean for biomedical definitions of normal and abnormal life in terms of the alignment between sex-gender-sexuality and for medical practice:

Let us assume that in the future one or several of the human biological findings above will be shown to be replicable in G[ender] I[identity] V[ariant] samples by independent, reliable laboratories. Would the gender-atypical behavior (including sexual orientation) in such cases then be considered “pathologic”? And what about those who become gender-dysphoric and initiate gender change? Would public opinion and government officials not likely refer to a “correction of wrong gender assignment,” in parallel to the analogous cases with somatic intersexuality? Again, on the other hand, if patient-initiated gender change in such GIV cases is a “correction,” a question arises about the psychiatric status of those cases who develop a lasting identification with the assigned gender. The examples above show that there is no clear scientific solution based on etiology alone to the psychiatric categorization of behavior and identity outcomes of pathological medical conditions (p. 466).

Even if we discover a distinctively male vs. female brain or gay vs. straight brain, it would make no difference at the level of those bureaucratic networks of medical knowledge/power which practically discipline and normalize gender, and maldistribute life chances with regards to it. Indeed, this is why—as pathologies—intersex

conditions/DSDs and GD are unable to represent biological or natural kinds; sex, gender and sexuality are not biological kinds, but the socially constituted elements of cisgendered life as a norm, historically produced in the context of medicine as technologies via which biopower might enforce that norm. If biology plays any role where sex, gender, and sexuality are concerned, it is rhetorical in nature. In the context of intersex conditions and GD, particular biological traits (e.g. the presence or absence of a uterus or XY chromosomes) or biological kinds (e.g. male or female brains) are invoked as pre-discursive, biological evidence used to justify particular normalizing interventions, as well as the programs of clinical research that make such interventions possible and further legitimate their use. For example, consider the argument that 46 XX CAH infants with severely masculinized genitalia *should* be assigned male because of their likely similarly masculinized brains or that MTF individuals *should* receive gender-confirming interventions as their gender dysphoria and social impairment likely indicate they have a feminized brain.⁶⁷ However, the positing of gender here as pre-discursive is itself a discourse (Butler, 1990, p. 11). Furthermore, as Meyer-Bahlburg's quote above makes clear, the biopolitical goal is the production of lives in which gender develops in cis-alignment with sex—or, as he puts it, “assigned gender”—leading to questions about the “psychiatric status” of those with biologically trans* brains who nonetheless live “normal” cisgendered lives. There can be “no clear scientific solution based on etiology alone to the psychiatric categorization of behavior

⁶⁷ Jordan-Young notes that biologically determinist accounts of gender and sexuality in terms of brain organization theory are increasingly invoked in the context of political arguments for equal rights (e.g. “gay men, lesbians, and transgender people of both sexes have brains that are ‘wired’ differently from most people”) (p. 5). Further, acceptance of these accounts is increasingly positioned as “an important component of combating anti-gay prejudice” such that “critics of the idea are increasingly cast as not only antiscience, but antidiversity” (p. 5)

and identity outcomes of pathological medical conditions” because neither sex, gender, sexuality, nor cisgendered life is biological kind such that biological facts can render them incoherent. A lot of women have cervixes, but so do some men. Further, many individuals with ambiguously sexed bodies live cisgendered lives featuring heterocopulative, reproductive intercourse, while others do not. Sex, gender and sexuality, as well as pathologies with regards to them, are thus nothing more (or, nothing less) than socially constituted entities.

Finally, while all of this assumes that people *should* receive the gender-confirming interventions they desire and believe that they need, there is an ethically important distinction between the way in which the medical management of intersex conditions and GD practically cashes out in terms of those patients able to provide informed consent (i.e. adolescents and adults) and those who cannot (i.e. children). Whereas those who are able to provide informed consent are granted authority with regards to their gender such that it is their gender dysphoria which initiates the process of gender-confirming normalization, *intersex and trans* children treated with medical efforts to secure cisgendered futures are denied this authority*. Furthermore, while some trans* kids may be granted this authority if they happen to see a psychiatrist who is personally against the use of GICE, the steady frequency with which intersex normalization occurs means that intersex children are rarely (if ever) afforded the authority to stipulate what (if any) somatic changes are necessary to bring their bodies into alignment with their gender such that it is confirmed, let alone develop that gender in the first place.⁶⁸ That

⁶⁸ I do not mean to imply that those granted the authority over their gender such that it is their gender dysphoria that initiates the normalizing process also have the authority to choose the forms of gender-confirming normalization they access. Indeed, there are multiple bureaucratic barriers to accessing care, such that many are unable to access gender-confirming interventions specifically because they seek them for the reason of gender

is, it is not their distress and social impairment which constitutes the need for their gender to be confirmed. Rather, this authority is left in the hands of health care professionals and proxy decision-makers who decide what interventions are necessary to make the child a “normal” boy or girl. In this sense, medical efforts to produce cisgendered lives for intersex and trans* children might be better described as treating these conditions *by proxy*, by which I mean the distress and social impairment such efforts aim to relieve is not the child’s, but rather, that of parents and treating health care professionals. Indeed, it is not clear to me that an infant has or can have a gender, let alone a dysphoric one, or a conception of their body as sexed, with regards to which incongruence is indexed. The distress experienced as a result of an intersexed infant’s incongruent sex-gender can only be that of those who actually register that incongruence. Further, rather than attempting to stave off the future social impairment an ambiguously sexed body is assumed to necessarily bring, such efforts actually aim at relieving others’ social impairment with regards to relating to the child as a gendered subject. We just don’t know how to engage with that infant as a human subject in the absence of gender—that is, whether to treat them like a boy or a girl, or what to expect

confirmation. For example, insurance companies will cover gender-confirming interventions like mastectomies, or breast reductions, as long as they are being done for reasons of “medical necessity” (e.g. to treat cancer or alleviate back pain) and *not* to confirm gender (Butler, 2004, 85-87; Namaste, 2005; Spade 2011) – this is the reason why I argue for the radical reconstruction of these institutions. This impotence experienced by many trans* and intersex people in the face of the bureaucratic administration of medical knowledge/power might make my use of the term “authority” appear hyperbolic. I use it because while it may be true that many trans* individuals able to provide informed consent have little authority over the way in which their transition occurs or how long it takes, they are nonetheless granted authority with regards to their gender insofar as they are the ones who get to assert whether their gender exists in misalignment with their sexed body. The fact that it is their distress and social impairment regarding the relationship between their sexed body and gendered self that constitutes that relationship as pathological and in need of “fixing” via gender-confirming normalization is ethically important.

from them as such. While it might turn out in the case of a trans* kid that we were wrong about whether they were *really* a boy or girl, and thus misapplied gendered social norms, the intersex infant leaves us unable to appeal to norms, correctly or not, from the start.

VII. Conclusion

The three elements of the heterosexual matrix—sex, gender, and sexuality—as well as those pathologies of cisgendered function constituted with regards to them are thus socially constituted and primarily bureaucratic entities. Within the networks of disciplinary institutions that administrate medical knowledge/power, they function to license the submission of certain populations to various forms gender-confirming normalization, while preventing other populations from accessing them. In this way, these seemingly neutral bureaucratic institutions function biopolitically to ensure that cisgendered lives are made live under biopower while trans* (or at least, visibly trans*) lives are let die. In the case of intersex* and trans* children treated with GICE, these pathologies justify the use of medical interventions to secure a cisgendered future on individuals unable to consent. Thus, such patients are denied the authority over their gender granted to adolescents and adults with such conditions. Indeed, this authority is why even though treatment models were (and remain) constructed with the assumption that treatment aims at *full transition* in order to produce a life that can pass as cisgendered, this is not (and cannot) be required. Treatment strategies that are thus considered unethical in the context of patients able to consent are somehow simultaneously constituted as ethical in the context of the more vulnerable populations of patients unable to consent. I argue this discrepancy is an artifact of two main factors: 1) the bureaucratic, socially constituted nature of both cisgendered life and the

elements of the heterosexual matrix that constitute it as normal within the context of biopower, and 2) that in the context of children, the dysphoria and social impairment interventions aim at relieving is that experienced by health care professionals and guardians by proxy. Furthermore, unlike trans* children, whose gender variance only emerges in relation to the sexed body (or gender assigned at birth), intersex children draw into the relief the fiction of naturally dimorphic, pre-discursive sex that gender was introduced specifically to secure, visibly failing to provide a stable ground upon which gender expectations can be built.

In the final chapter of this dissertation, I turn to consider the implications these conclusions have for not only the ethical medical management of these conditions, but also for ethically producing knowledge and theorizing about them, as well as the individuals who have them. Further, I consider what these conclusions mean with regards to effectively resisting the oppression that individuals with pathologies of cisgendered function face.

Chapter Five: Ethics, Medical Knowledge/Power and Politics After DSD

I. Introduction

In this chapter, I examine the implications of my conclusions from Chapter Four for ethics, medical knowledge/power, and politics post-Intersex/DSD. Specifically, I provide Foucauldian justifications for the following series of prescriptive claims: that a moratorium be placed on the performance of medical efforts to secure cisgendered futures for those unable to provide informed consent; that those able to provide informed consent and who desire access to gender-confirming interventions receive it in a timely and affordable manner; that both the DSD nomenclature and the gender dysphoria be jettisoned as diagnoses; that those institutional bureaucracies which administer medical knowledge/power be radically reconstructed so that those who can provide informed consent can access gender-confirmation in the absence of pathology (and so that sex/gender designations cannot function as gatekeepers to care more generally); and finally that political theory and resistance focus on those institutional bureaucracies responsible for the government of gender—and subsequently, for the maldistribution of life chances for those with pathologies of cisgendered function—and their radical reconstruction.

Some might argue that issuing these kinds of concrete prescriptions for medical practice, as well as theoretical and activist politics from within a Foucauldian theoretical framework, is at tension with the use of the framework itself. Indeed, the liberatory potential (or lack thereof) of Foucault's project is one of the most controversial and debated aspects of his works—particularly among academic feminists. There is no outside of power for Foucault, no pre-discursive, natural, or authentic self to which one can return—positing such is itself a discourse, a production or deployment of modern biopower. To issue new norms and call them liberatory is not to liberate oneself or others from power, but simply to

re-deploy it in new ways and on new terms. An outcome of this redeployment may involve the “liberation” of some populations insofar as new ways of living—new norms—become available. It seems then that our only escape from current forms of subjectivation is into new forms of subjectivation. Further, given the productive nature of biopower in terms of subjectivation or “assujettissement,” it is unclear whether freedom, and thus resistance, is even available to the Foucauldian subject. If the subject is constituted by power through the interplay of discursive and non-discursive elements like institutional and somatic practices, then the subject seems to be determined by power with regards to their desires, their choices, and their incapacity for resistance. If there is no freedom for Foucault, no outside of power, then any prescriptions I make seem to be nothing more than arguments for the constitution of new norms through the productive redeployment of power. In the same way that positioning sex as pre-discursive is a discourse, so too is my positioning of this redeployment of power as ethical a discourse. This is the quandary of Foucauldian genealogy, in particular, as a theoretical framework: it is immensely useful for understanding the discursive and practical subjectification and subjugation of specific populations (such as women) under biopower—and thus, revealing their contingency—yet it seems to provide us with no escape.

Interlocutors vary in their interpretations of Foucault with regards to the constitutive determination of the subject, and thus, in their pessimism with regards to the possibilities for freedom and resistance under biopower.⁶⁹ I follow Oksala (2005) in her position that dimensions of freedom are available in at least three different domains within Foucault’s work, corresponding with the three different phases within his oeuvre. Within his

⁶⁹ For an in depth review of the various readings of Foucault in terms of the determination of the subject by biopower and thus their capacity for freedom under it, see Oksala, 2005, pp. 118-121; Butler, 1997, pp. 92-94; Dreyfus & Rabinow, 1982, pp. 111; Gutting, 1989, pp. 1-3.

archeological works—*The Archeology of Knowledge* (1969) and *The Order of Things: An Archaeology of the Human Sciences* (1970)—Foucault identifies freedom not in the subject nor in her characteristics, but in the generative possibilities of language, which necessarily produces an excess of meaning. In *The Archeology of Knowledge*, Foucault explicitly states the discursive “positivities” he is examining are

not so much limitations imposed on the initiative of subjects as the field in which that initiative is articulated. . . . I have not denied—far from it—the possibility of changing discourse: I have deprived the sovereignty of the subject of the exclusive and instantaneous right to it (1969, p. 197).

Thus, while it may not be the kind of open-ended ideal posited within sovereign account of power, freedom is nonetheless available to the subject at the level of language—even for those subjects taken up and produced by scientific discourses, which, as regimes of truth, epitomized the formalized discursive conditioning of thought for Foucault such that he “questioned the possibility of saying something completely new” in this context (Oksala, 2005, p. 87). This is because, language—even scientific language—always “outruns the subject, who can never completely master it” (Oksala, 2005, p. 10).

Similarly, freedom can be found within Foucault’s genealogical work at the level of the lived body, because like language, experience also outruns the subject. Foucault claims that “where there is power there is resistance” in *The History of Sexuality, Volume One* because while meaning, normality, and intelligibility are all constituted by power, experience is not wholly determined by it, but can exceed those norms (1990, p. 96). Indeed, we can have experiences that transgress the boundary of the normal into the abnormal (such as depression or homosexual desire), as well as those that transgress the limits of intelligibility. This, argues Oksala, is why Foucault identifies “bodies and pleasures” as “the rallying point

for counterattack against the deployment of sexuality,” rather than “sex desire” (Foucault, 1990a, p. 157):

The experiential body is a locus of resistance in the sense that it forms the spiral of limits and transgressions. Power/knowledge inscribes the limits of normal experiences, but it exactly the existence of these limits that makes their transgression possible. The experiential body is constituted by power/knowledge network, but the limits of its experiences can never be firmly set because they cannot ever be fully determined and articulated. The experiential body can multiply, distort and overflow the meanings, definitions and classifications that are attached to experiences, and in this sense it is capable of discursively undefined and unintelligible pleasures, for example. . . . In Foucault’s genealogy, as in his archeology, there is thus a dimension of freedom in the sense of a constitutive outside to the discursive order, even though there is no outside for the apparatus of cultural network of practices as a whole. If language can never be totally mastered and brought within the discursive order, neither can experience ever be wholly defined. It always remains contestable and resistant to articulation (Oksala, 2005, p. 132).

Foucault’s historical understanding of ethics, as well as his prescriptive sense of ethics in terms of “an attitude or way of life,” means both that a dimension of freedom is available to the subject in the domain of ethics, and that the prescriptive claims I make here can be justified as ethical without the constitution or privileging of new moral rules or subjectivities (Oksala, 2005, p. 160). In this sense, what Foucault supplies us with is a shell or framework for ethicality rather than a specific set of rules regarding how individuals should be or should act. Indeed, it is in opposition to a moral code (or set of moral rules) and moral behavior (or behavior in relation to the code), that Foucault defines ethics in terms of the

relationship of oneself to the self, the process by which one forms oneself as an “ethical subject (Foucault, 1990b, p. 28). Ethics thus entailed modes of acting on the self via practices of the self that Foucault identified with the ancient principle of “*epimeleia heautou*” or “care of the self” (Foucault, 1991, pp. 359-360). Further, freedom can be exercised in this domain for Foucault via critically and self-reflexively engaging in practices of the self in ways that stretch the limits of subjectivity and intelligibility – this is the form his normativity with regards to ethics takes (counter to the claim Foucault’s work is “not normative”) (Taylor, 2009, 46).⁷⁰ Foucault’s identification of ethicality with the critical and self-reflective stretching of norms is the reason why there can be no concrete prescriptions in terms of moral rules or behavior from within his account of ethics – as Dianna Taylor writes, “with Foucault, we do not get certainty” (Taylor, 2009, 59). This is also the source of Foucault’s controversial claims regarding ethics as an “arts” or “aesthetics” of existence, which he describes in *The Use of Pleasure* as “those intentional and voluntary actions by which men not only set themselves rules of conduct but also seek to transform themselves, to change themselves in their singular being, and to make life into a oeuvre that carries certain aesthetic values and meets certain stylistic criteria” (Foucault, 1990b, pp. 10-11). Oksala (2005) argues that Foucault’s invocation of art or aesthetics in the context of ethics is due to art’s capacity to transgress constitutive norms and veer beyond intelligibility (pp. 161-166). Ethics is the space in which Foucault locates resistance to the “individualizing, yet totalizing” normalization of biopower through

shaping one’s self and one’s lifestyle creatively: by exploring possibilities for new forms of subjectivity, new fields of experiences, pleasures, relationships, modes of living and thinking. It consists of creative activity as well as critical interrogation of

⁷⁰ The argument that Foucault’s work is not normative or that normative claims are impossible within his account is a common one. See Taylor 2009.

our present and contemporary field of possible experience. The quest for freedom in Foucault's late thought . . . becomes a question of developing forms of subjectivity that are capable of functioning as resistance to the normalizing power. Ethics is a practice that stretches the limits of the subject (Oksala, 2005, p. 168).

Thus, not only are dimensions of freedom possible for the Foucauldian subject at the levels of language, the body, and relations of oneself to the self, they seem necessarily to be available in some sense within the first two of these domains given the necessarily generative and excessive nature of both language and lived experience. Further, if critical self-reflection and creative engagement with practices of the self in order to explore/contest and further the limits of subjective intelligibility is the form that freedom takes at the level of ethics, then there is no reason to posit new moral rules or values beyond that of freedom itself. Ethical medical practice, political theory, and activism, then, is that which enables or cultivates freedom, in the form of the critical, self-reflective engagement with practices of the self, and the proliferation of meaning at the level of language and of the body. This will require a radical reconstruction of the bureaucratic structures via which gender is governed and life chances are maldistributed among those who fail to meet norms of cisgendered function. Indeed, in *Normal Life*, Spade (2011) argues that as we move away from a sovereign conception of power to a more Foucauldian one, our focus shifts to the level of the bureaucratic administration of power—the government of gender—and “become[s] interested in the legal systems that distribute security and vulnerability at the population level and sort the population into those whose lives are cultivated and those who are abandoned, imprisoned, or extinguished” (137). Thus, after exploring the prescriptive claims which issue from Foucault's understanding of freedom in the following section, I turn in section III to consider avenues for resistance in the aftermath of DSD, focusing on those often obfuscated

forms of “administrative violence” via which life chances are maldistributed such that cisgendered lives are made live, while gender variant ones are let die.

II. Ethical Medicine and Politics Under Biopower

A. Ethics

Ethical medical practice—or administration of medical knowledge/power according to Foucault’s understanding of ethics in terms of the relation of oneself to the self—will be medical practice that facilitates freedom in terms of care of the self. For those unable to provide informed consent, this account justifies a moratorium on gender-confirming normalization given that such practices seem to restrict the possible ways in which one can relate to oneself (specifically, in gender variant ways). Indeed, one’s inability to provide informed consent is in function of one’s inability to engage critically in such decisions or practices, such that possibilities for taking up such practices in ways Foucault would describe as ethical are foreclosed. For those who can provide informed consent, on the other hand, and desire gender-confirmation, this account justifies the claim that they should not only have access to it—both somatically and administratively—but that this access should be timely and affordable given the harms we know to accrue to when access is withheld.⁷¹

Gender-confirming technologies can indeed function as practices of the self for individuals

⁷¹ For example, the GID subworkgroup explicitly acknowledged that the distress and dysphoria that trans* individuals experience correlates with access to care. Their only recommendation not adopted by the APA’s Board of Trustees—that the B criterion for the diagnosis be reworded to identify the conditions as associated with a “significantly increased risk of suffering, such as distress or disability”—is based on their consensus that many adolescent patients are not distressed as long as “a clear path towards gender change is mapped out for them, but may become strongly distressed if parents or others try to strongly block this path” (Zucker et al., 2013, p. 906). The distress and social impairment trans* individuals experience is relieved through somatic gender confirmation; this is the treatment for it as a pathology.

that open up new possibilities for not only modes of relating to the self, but modes of relating to others as well. As Butler (2004) writes in “Undiagnosing Gender,” it would be ideal if insurance companies were swayed by claims that gender-confirmation

will allow someone to realize certain human possibilities that will help this life to flourish, or . . . will allow someone to emerge from fear and shame and paralysis into a situation of enhanced self-esteem and the ability to form close ties with others, or that this transition will help to alleviate a sound of enormous suffering, or give reality to a fundamental human desire to assume a bodily form that expresses a fundamental sense of selfhood (p. 92).

One might question granting access to technologies of gender-confirmation to those who desire it—even if they are able to provide informed consent—however, given that these technologies emerge out of and are used within the context of biopower, and more specifically, that of white supremacist heteropatriarchy. Indeed, one might argue—as many feminists and non-feminists have—that both the normalizing technologies used to confirm gender such as hormone administration or breast augmentation, and the desire for their use are merely the products of problematic biopolitical norms. Forms of gender-confirming normalization are thus technologies of domination via which clinicians strengthen oppressive heteronorms through their literal inscription upon the body. On this argument, those who engage with these practices not only reify white supremacist and heteropatriarchal norms, but they are also dupes, fully determined by the subjectivizing deployment of cisgendered life as normal.⁷²

⁷² Raymond (1994) is the most obvious exemplar of this position. However, Heyes (2007) argues that Hausman (1995) also succumbs to this picture, reductively defining the transsexual “tautologically, as the individual who accedes to the terms of the discourse that generated a particular subject position” (Heyes, 2007, p. 50). As a result, “both Raymond and Hausman’s analyses conspire to preclude the agential resistance on the part of transsexuals”

Even if such practices can function as practices of domination, they can also function as practices of the self, as the means by which individuals critically and creatively explore the limits of subjectivity, of pleasure, and of relationality. Indeed, there can be overlap between technologies or practices of the self and those of domination—in “Technologies of the Self” (Rabinow, 1997), Foucault explicitly identifies the “encounter between technologies of domination and [technologies] of the self” as “governmentality” (p. 225). However, technologies of the self, which he defines in this text as the ways in which “individuals effect by their own means, or with the help of others, a certain number of operations on their own bodies and souls, thoughts, conduct, and a way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection or immortality,” are not identical to, or mere reproductions or extensions of technologies of domination (p. 225). Rather, what characterizes them as ethical is the mode via which they are engaged; that is, one can engage gender-confirming technologies ethically as technologies of the self if one does so creatively, investigatively, and critically. While this does mean that ethicality requires certain kinds of cognitive engagement, this does not imply that ethical engagement with the world is only cognitive or intellectual in nature – indeed, ethicality often seems to require certain forms of affective and somatic engagements – or that one need be particularly educated or “intellectual” in order to creatively, investigatively, and critically engage gender-confirming practices of the self. This critical ethical attitude is often prompted by one’s coming face-to-face with their own sex-gender (and the fictitiousness of its unity) such that this ethical style is less likely to be generated when an individual’s self-understanding fits neatly within systems of domination. Indeed, those conditions that seem more likely to engender this kind of ethical relation of the self to the

(p. 50). For more on this point, see Prosser (1998), Hale (1998), Whittle (2006), Riddell (2006).

self are the same ones that deny trans* individuals the privileges accorded to cisgendered ones, which make it easier to pursue one's education – particularly to the high levels one needs in order to be considered “intellectual”.

While it is indeed the case that some individuals may engage these gender-confirming technologies in oppressive ways, there is no reason to presuppose this is the case in every, or even the majority of cases. To argue that trans* individuals somehow merely re-instantiate or re-inscribe gender norms through transition (including in those cases where one transitions such that they pass) is to hold that trans* persons are somehow uniquely reducible to their discursive and practical subjectivation as trans*. It is to uniquely deny trans* individuals the capacity for critical self-reflection and, on that basis, deny them vital access to gender-confirmation. We acknowledge that a cisgendered woman who chooses breast augmentation can nonetheless be critical of the heteronorms against and through which that choice is made. It is unclear why we should deny trans* persons that same capacity. Indeed, one could argue the wealth of experiences forced upon trans* persons with regards to navigating and transgressing gender norms are more likely to yield critical insights with regards to those norms.⁷³

In fact, I see the foreclosure of these kinds of problematic arguments that undermine trans* access to gender-confirmation by denying the possibility for trans* resistance and

⁷³ I recognize that the issue of cisgendered women's use of medical practices that are gender-confirming for trans* individuals – such as breast augmentation – is complex. For example, there those who hold that cisgendered women do not and cannot autonomously choose breast augmentation, even if they may seem to be critical of this choice. Further, one might argue that my account paradoxically implies that medical forms of gender-confirming normalization (such as breast augmentation) should be restricted to those who engage such practices ethically (i.e. critically), such that the only people who should be able to access them are those who take them up reluctantly or guiltily. My point here is simply that we cannot restrict trans* individuals' access to these practices based on the assumption that they are somehow uniquely duped by heteropatriarchy given that we do not restrict cisgendered individuals' access in the same way.

freedom under biopower, to be one of the positive features of Foucault's understanding of ethics and of the possibilities for the subject in the domains of language and the body. The irreducibility of language and experience to the discursive and non-discursive elements constitutive of sexed, gendered, and sexual subjects applies to all individuals constituted as such. Indeed, everyone fails with regards to norms of sex, and gender, and sexuality—these are the transgressions in which freedom and resistance may be found. As I suggested above, given the greater experience a transwoman has with biopolitical binds produced by the heterosexual matrix than as a cisgendered woman, she is likely epistemically privileged with regards to critical insights into that system. Further, through transition, a transwoman will come to occupy a significantly different epistemic position than a cisgendered woman with regards to heteropatriarchy—even if her transition renders her “unreadable” as trans. While transmisogyny and misogyny may emerge out of the same discourses and non-discursive elements responsible for the government of populations as sexed, gendered, and sexual, these are unique phenomena with differing political and material effects. If anything, my account has greater ethical implications for those of us who are cisgendered—particularly those who live most comfortable within the norms of the heterosexual matrix. Ethical relation for Foucault is a relation of the self to the self, calling into question whether our focus should be on the relation of others to themselves from the start. If anyone should bear the burden of having to prove somehow that the technologies of the self they engage in are not technologies of domination, but rather ethical practices of the self, it should be those living within the norm and enjoying its relative privileges, and not those suffering most under the weight of heteropatriarchal biopower.

B. Language

Foucault's understanding of freedom at the level of language justifies the jettisoning of both the DSD system of nomenclature and the use of GD as a diagnosis within clinical medicine. For Foucault, freedom is found in the generative excess of language – its “formless, mute, unsignifying space” – which is more or less open to reinterpretation or the accumulation of novel, diverse, and potentially contradictory meanings depending on its mode (Foucault, 1994, p. 383). Scientific discourses, and the language deployed within them, however, are – as regimes of truth – particularly intransigent to reformulation or change– so much so that in the course of his discussion of Mendel in *The Archaeology of Knowledge*, Foucault questioned the possibility of saying anything new in the context of scientific discourse given their formalized and regulative nature (2007b, pp. 224-225). As I have shown, their authoritativeness reifies problematic norms regarding sex, gender, and sexuality, and strengthens both their discursive and non-discursive instantiation (for example, through medical management practices) and problematic, homogenizing normative narratives about those with pathologies of cisgendered function. Both require—as Butler (2004) writes of GD—“that a life takes on a more or less definite shape over time,” and that “gender is a relatively permanent phenomenon” (p. 81). Furthermore, as I illustrated in previous chapters, while biomedical accounts of gender assume that it is in some way socially mediated (though according to a non-interactionist, biosocial model in terms of brain organization theory), it denies that one's dysphoria or desire for gender confirmation may in some way also be socially mediated. As Butler makes clear, one

would be ill-advised to say that you believe that the norms that govern what is a recognizable and livable life are changeable, and that within your lifetime,

new cultural efforts were made to broaden those norms, so that people like yourself might well live within supportive communities as a transsexual, and that it was precisely this shift in public norms, and the presence of a supportive community, that allowed you to feel that transitioning had become possible and desirable (2004, p. 81).

Retaining pathology—even strategically—strengthens norms about the subject with a DSD or GD in terms of their life history, psychology, embodiment, and capacities for critical self-reflection, autonomy, and resistance—including those arguments which position trans* individuals as dupes of biopower mentioned above. This elides the possibility of understanding “the demands of some transsexuals for [sex reassignment surgery] as historical products with their own social logic, which in certain moments dovetails with the demands of non-transsexuals” in the way that Butler highlights in the quote above (Heyes, 2007, p. 47). These norms contribute to the subjectivation of those with GD and DSD in both senses of the term—subjectification and objectification—as well as all subjectivation of all sexed and gendered subjects, insofar as they set the terms of our intelligibility. Those with DSD and GD bear the brunt of this deployment of power as those lives that are let die through the maldistribution of life chances. Further, these discourses can open up others—such as family members of those with DSDs—to forms of subjectivization that are only beginning to be explored in the literature (Feder, 2014). The most obvious example of this comes from Davis’s (2011) work in which she argues that the re-articulation of intersex conditions as DSDs reasserted medical authority over intersex bodies and their management, on the basis of qualitative interview with intersex persons, their families, and clinical experts in the field. She details the following anecdote provided by Dr. C., a physician who treats intersex conditions, revealing the ways in which the diagnosis discursively facilitates the

subjectification and objectification of the parents of a child with an intersex condition, exposing them to forms of psychiatric normalization with regards to norms of sex and gender:

Dr. C.: The father said, “[Doctor], can I ask you a question?” I said, “Absolutely, this is your forum. I’m at your disposal. You’re hiring me.” He said. “Why should we do anything?” And I acted physically surprised, I’m sure I did. And I said, “Well, I’m concerned that if you raise this child in a male gender role without a straight penis, he’s not going to see himself as most other males and he’s not going to certainly be able to function as most other males.” And the father said, “Well, in our family we like to celebrate our differences and not try to all be the same and feel the social pressure to do everything like everyone else does.” . . . I said, I do have to say one thing, and I think it’s of key importance that you both see a psychiatrist. (Davis, 176)

In this quote, we see the problematic norms about sex and gender discursively reified through DSD function to justify submitting the parent of a child with a DSD to psychiatric normalization. The parent’s assertion of a normal variant view of their child’s intersexed body comes to mark them as “abnormal” and in need of treatment. In this way, the problematic norms strengthened by the pathologization of gender-variant lives constitutes a form of epistemic injustice—the brunt of which is, once again, borne by those with intersex conditions and GD. In her 2007 book *Epistemic Injustice: Power and the Ethics of Knowing*, Miranda Fricker identifies the structural biasing of our collective hermeneutical resources as hermeneutical injustice, insofar as it can lead to “having some significant area of one’s social experience obscured from collective understanding” (p. 154). She argues that our understanding of our social experiences is a “sphere of epistemic activity” wherein relations of identity and power can engender a particular kind of epistemic injustice, such that some

social groups are rendered unable to dissent from distorted interpretations of their social experiences (p. viii). In order to illustrate this point, Fricker points to women's experiences of sexual harassment prior to the consolidation of the concept of sexual harassment as an example of how "extant hermeneutical resources can have a lacuna where the name of a distinctive social experience should be" (pp. 150-151). This lacuna results from a group's hermeneutical marginalization; their sociopolitical inequality leads to their unequal hermeneutical participation such that they lack the resources to render intelligible experiences that it may be in their best interest to communicate or understand. Because our "interpretative efforts are naturally geared to interests," lacunae in our collective hermeneutical resources are most likely to obscure those experiences of which, as Fricker writes, "the powerful have no interest in achieving a proper interpretation, perhaps indeed where they have a positive interest in sustaining the extant misinterpretation," rendering these resources structurally prejudiced (p. 163, 152).

Fricker argues that the primary harm of hermeneutical injustice issues can be understood in two ways, depending on what the hermeneutical lacuna renders unintelligible. The first type of harm she identifies is "*situated hermeneutical inequality*" referring to "the concrete situation in which the subject is rendered unable to make communicatively intelligible something which it is particularly in his or her best interests to be able to render intelligible" (p. 162). This is the case of the victim of sexual harassment being unable to communicate intelligibly her workplace experiences as sexual harassment to herself and others, unable to dissent from those dominant interpretive frameworks which position the behaviour she has experienced as merely "flirting." The second type of primary harm Fricker details but does not label, is what I call *constitutive hermeneutical inequality*, referring to the effect

these lacunae in our hermeneutical resources can have on one's understanding of their social identity (see esp. pp. 162-169).

What is interesting about Fricker's view is that it points to the way in which our collective hermeneutical resources are constitutive of our understandings of not only our social experiences/ interactions, but of our social identities themselves. Hermeneutical marginalization renders both dominant and authoritative certain constructions of identity that can have constitutive effects on the subject's lived experiences. Fricker highlights the constitutive effects of discourse on both the individual's social identity, and on how they experience that which is identified as the cause of their identity. Fricker, however, is writing within an analytic tradition of social epistemology. Thus, while our ways of relating to the self are socially constituted for Fricker, they are more repressive than constrictive on her account, or deductive rather than productive. Further, Fricker focuses solely on discourse, in the same way Foucault does in his archaeology. However, incorporating Fricker's insights with Foucault's more expansive account of the constitution of subjects—especially with regards to regimes of truth like scientific and medical discourse—we can appreciate some of ways in which such discourses constrict the horizon of intelligible experiences, and of ways of relating oneself to the self, such that those taken up by them are epistemically harmed.

Consider, for example, dominant discourses regarding fatness, which have medical dimensions, but are less firmly rooted within the realm of medico-scientific discourse than DSD and GD.⁷⁴ These discourses bias our hermeneutical resources such that a fat woman

⁷⁴ Indeed, though obesity is a diagnosis—and from which we are apparently suffering an epidemic—I would argue that fat has not quite completed the trajectory from sin to sickness in the way things like homosexuality or mental illness have historically (though, of course, to greater and lesser degrees). Indeed, I would argue that the existence of television shows like *The Biggest Loser* are evidence that fatness is not quite yet primarily a pathology; if fatness were a first and foremost a disease (obesity), weight-loss focused game shows would seem unsavory in the way a weight-gain focused game show for anorexics does.

may come to count socially as lazy and weak-willed even if she is not and further, she may come to experience herself that way—her purportedly undisciplined appetite coming to exist for her as shameful or grotesque.⁷⁵ Furthermore, these discourses about fat have serious effects for the embodiment of fat and non-fat women alike. Not only do many women experience their bodies as shameful, necessarily undesirable, and uncomfortable, but further, studies have shown that these discourses can skew a woman's proprioception of their body, such that they believe they are bigger than they actually are and take up more space than they actually do (Young, 1980; Grogan 2007). Moreover, insofar as these discourses posit the truth about both the fat woman's body (as revolting), and of her experience of her body (as revolting), they allow us to claim that those who experience their bodies otherwise are in bad faith, a constitutive hermeneutical injustice or harm. This is what allows us to gaslight the fat activist when she claims to love her body and experiences it as beautiful and capable with the argument that while she might say that, we all know that—underneath it all—she'd really rather be thin. This is the power of our dominant discourses about fat, which in virtue of their failure to congregate primarily in the realm of the medico-scientific, should theoretically be more open to the proliferation of meaning than GD and DSD as pathologies.

The jettisoning of GD and DSD as pathologies will merely serve to further unmoor sex, gender, and sexuality from the realm of medico-scientific regimes of truth. While I do not want to underestimate the effect this discursive shift could have, it is clearly insufficient for bringing about the kind of changes many desire at level of medical practices and the way in which they take up those with intersex conditions and those with GD. Most importantly, in the absence of GD, it seems unclear how we justify affordable or timely access to care.

⁷⁵ My focus specifically on women here is not meant to imply that norms about fat do not also effect the subjectivization of those who are not women. I focus on them exclusively here, however, because norms about fat are inextricable from heterosexist norms of desire such that women currently suffer more with regards to them than non-women.

If it is the case, however, that the attribution of pathology is basic to flourishing as an embodied subject, then this is because our current configuration of disciplinary institutions responsible for the administration of medical knowledge/power renders it as such. Once we analyze the quandary of autonomy posed by pathology for those with GD and DSDs in terms of the larger biopolitical management of gendered populations, our attention turns to the administrative structures that make the maldistribution of life chances possible through these kinds of double binds. This is why I argue in the following section that the radical restructuring of institutions responsible for the maldistribution of life chances should be a target for theoretical resistance post-Intersex/DSD. Rather than attempting to navigate strategically the dominant discourses and non-discursive elements that together enact the government of gender, let us disrupt these discourses and non-discursive elements directly, and shift the terrain of their demands. Foucault's understanding of freedom at the level of the body only further justifies access to gender confirmation for those capable of providing informed consent and the jettisoning of the DSD nomenclature and GD as pathologies.

C. The Body

If freedom and possibilities for resistance are located for the Foucauldian subject within the experiential body under biopower, what does this mean for those with intersex conditions and with GD as pathologies of cisgendered function? It further justifies a moratorium on the use of medical efforts to produce cis-gendered lives for those unable to provide informed consent, and access to gender-confirming normalization for those who cannot. Like language, experience outruns the subject, but even this excess—its capacity for transgression in terms of normal/abnormal or intelligible/unintelligible—is constituted in relation to discursively and non-discursively constituted norms. Freedom, then, can be found

in the proliferation of the possibilities for meaning, both discursively and experientially. Such possibilities are constricted through the use of normalizing efforts on both intersex and trans* children via sexual normalizing surgeries, fetal dex, and treatments like GICE, insofar as they attempt to close off particular (re-)interpretations or meanings. Furthermore, this account of resistance generated via bodily experience implies that those surgeries performed on intersexed infants that compromise their genital sensation (and thus certain forms of sexual experiences), also compromise their access to certain avenues of resistance, and in a potentially significant manner. Sexual experience, of course, exceeds the specific experiences of genital pleasures or orgasm, and non-genital pleasures might take on a plethora of new meanings in the absence of the capacity for genital pleasure that would themselves transgress norms of sexual experiences in terms of both normality and intelligibility, and thus, count as forms of resistance. Additionally, the failure to experience is itself a kind of bodily experience that necessarily problematizes these norms. However, insofar as such surgeries do result in the incapacity for certain forms or modes of sexual experience, it would also limit avenues for bodily resistance constituted in relation to them, particularly in those cases where individuals are left anorgasmic. Thus, medical efforts to secure cisgendered futures constrict the horizon of possibilities for bodily discursive and experiential meaning. Where intersex infants treated with sensation-impairing surgical normalization are concerned, these efforts further seem permanently to foreclose one's capacities for certain types of sexual experiences and thus, certain experiential avenues for resistance.

This account of bodily-generated resistance via experience can also justify ensuring timely and affordable access to gender-confirmation for those who desire it. For many trans* individuals, gender-confirmation enables the positive re-articulation of the meaning and their experiences of their bodies. Further, it enables the proliferation of meanings insofar as for

many individuals it enables the expansion of one's social world—indeed, social impairment is one of the terms upon which GD is defined. Meaning and experience are cultivated relationally. Insofar as gender-confirmation expands the horizon for relational possibilities, it can also expand the horizon of possibilities with regards to the generation of discursive meaning.

My justification here seems to place those forms of normalization accessed by trans* persons to confirm their gender on a continuum with other forms of gender-confirmation accessed by cigendered persons such as breast augmentation, breast reduction, penile enhancement—or any one of a plethora of gendered “cosmetic” interventions—rendering us, apparently, unable to distinguish between them in terms of “medical necessity.” I counter that such distinctions are still possible, through appeal to the very deployments of power that produce such technologies as gender-confirming. Individuals who more closely approximate norms of sex, gender and sexuality have more privilege within the system of heteropatriarchy than those who don't. For example, beautiful women make more money than homely women, while fat employees are less likely to be promoted than thin ones (Hamermesh, 2013; Puhl & Brownell, 2012). However, those living along the limits of these norms bear the brunt of our systems of oppression far more harshly than those still intelligible within the realm of the “normal.” It may be the same system of heteropatriarchal norms that constrict the horizon of possibilities for meaning that compel both a cigendered woman and a MTF transwoman to increase the size of her breasts, believing that her future autonomy (be it materially, psychologically, etc.) depends on this intervention. The cigendered woman's failure to obtain breast augmentation would not constitute her as pathological with regards to cigendered function, however, in the sense that it would not mark her life as one to be let die under biopower; it would not expose her to disproportionately high risks of poverty or

physical or sexual violence or murder; it would not open her up to the bureaucratic maldistribution of life chances suffered by trans* individuals and exacerbated by their lack of access to gender confirmation. In this way, it is still possible to ground the medical necessity of such interventions for trans* persons. For better or worse, the current configuration of biopower under which (and through which) we live, gender is central to subjectivity such that gender is a necessary component to personhood. There are, of course, those who “live the line,” who disproportionately shoulder the burdens of heteropatriarchy while at the same time resisting those norms through their lived existence, contributing to the proliferation of meaning about sex, gender, and sexuality that expands the horizon of possibilities for all subjects. However, we cannot demand trans* individuals to disproportionately shoulder those burdens of abnormal—and unintelligible—living by withholding access to gender-confirmation in exchange for an exclusive focus on dismantling those oppressive norms and structures that make it (and the desire for it) possible.

If we accept that freedom is available to the Foucauldian subject in the context of biopower, what does this imply for politics in terms of effectively resisting the oppression of those with pathologies of cisgendered function? If freedom is found in language and in the body through the proliferation of meaning and experience, spiraling between transgression and the limit in a way that “no simple infraction can exhaust,” we must find our targets in those discursive and non-discursive elements like institutions and practices that stifle that proliferation of meaning, that dance between the normal and the abnormal, the intelligible and the unintelligible. If freedom in the domain of ethics is found in the critical and creative engagement with practices of the self to shape one’s self and one’s life, and to explore new “forms of subjectivity, fields of experiences, pleasures, relationships, modes of living and thinking,” then we must target those elements that constrict these kind of practices and

modes of living (Oksala, 2005, p. 168). The first and most obvious target that appears upon this reframing in terms of political goals are those entangled networks of public and private bureaucratic institutions responsible for the administration of medical knowledge/power including (but not limited to) hospitals, insurance providers, pharmaceutical companies, and clinical research institutions. These networks, as well as the discourses they generate and upon which they justify their actions, are primary contributors to the maldistribution of life chances for those with intersex conditions and GD. Indeed, the maldistribution of life chances for those with intersex conditions via health care administration seems to be one of the targets of those who strategically endorsed DSD and subsequent repathologization in order to surmount obstacles to competent care (Dreger & Herndon, 2009; Feder, 2014). Though these authors fail to make the nature of these obstacles explicit, anecdotally I have been told they are referencing two things: 1) limitations placed on accessing care (particularly specialist care) by private insurance companies in the United States and 2) adult patients' inability to find non-pediatric specialists trained in managing their unique condition due to the stereotype that intersex conditions are problems "fixed" in childhood. The hope was that the disorder language would make insurance companies more permissive in terms of accessing care and would make non-pediatric specialists take treating (and learning to treat) these patients more seriously.

I have not been able to find any evidence on whether DSD has been successful in terms of decreasing insurance company restrictions on accessing care, though the emergence of the *Journal of Pediatric Urology* as the primary site of clinical literature on intersex management indicates the stereotype of DSDs being uniquely pediatric issues remains. More importantly, however, this attempt by DSD endorsers strategically to navigate the bureaucratic administration of knowledge/power underscores two of my claims: that

obstacles to care are generated by governmental networks such that the networks themselves should serve as our theoretical and activist targets; and that such initiatives must be local and contextual in light of the way these bureaucracies function. The political work undertaken and the forms of restructuring required to achieve goals like ensuring access to gender-confirmation for those who can consent will necessarily differ between an American and Canadian context given their differing forms of health care systems (i.e. for-profit vs. public). This calls into question the appropriateness of adopting treatment models, as well as activist or theoretical strategies, created specifically to function within (or around) the American administration of health care beyond its borders. The United States is one of the only developed nations with a for-profit health care system, in which insurance coverage is tied to employment and there is a capitalist incentive to deny care, which makes the bureaucratic challenges it generates quite distinctive.

The administrative systems that produce and implement oppression and maldistribute life choices have their own unique histories and function in their own complex ways. Because of this, theory and activism to resist these forms of what Spade (2011) calls administrative violence will need to be particular and local in ways that acknowledge their histories, as well as their function within biopower to render certain lives unliveable. In the following section, I consider some concrete forms of administrative violence experienced by not only trans* but also intersex persons that contribute to the maldistribution of life chances for them as individuals without cisgendered lives.

III. Administrative Violence and the Government of Gender

Not only do many of the various agencies and institutions that issue identity documents require surgical transition in order to change one's gender identification, but, further, inconsistent policies among these various agencies mean there are often

discrepancies between the various forms of ID one might hold (i.e. birth certificates, driver's licenses, social security cards, etc). Identity documents that misidentify an individual's gender or discrepancies between identifying documents serve as a significant barrier to employment and can identify or "out" an individual as trans*, making them vulnerable to discrimination. Furthermore, Spade (2011) points out that those with identity documents that do not match their appearance or conflict in some way face heightened vulnerability with police and other public officials, when traveling, or even when attempting to do basic things like enter age-barred venues or buy age-barred products, or confirm identity for purposes of cashing a cheque or using a credit card or a public benefits card (p. 146). As a result, "conflicting identity information can make it difficult to obtain certain identity documents that are vitally necessary for day-to-day survival" (p. 146).

Further, Spade identifies gender mis-classification or inconsistent gender classification is a significant problem for trans* individuals accessing many services, institutions and public spaces like drug treatment programs, homeless and domestic violence shelters, foster care group homes and hospitals, and bathrooms because they are often structured around sex-segregation. Spade notes that trans* individuals "face significant vulnerability to violence in those spaces, especially in institutions that cannot be avoided because of their mandatory nature" (p. 147).

In the previous chapter I pointed out that the APA's failure to issue Practice Guidelines for the treatment of GD renders their primary argument for the retention of the diagnosis in DSM-V—maintaining access to care—moot. Spade identifies the way in which gender classification functions to administratively restrict access to care, insofar as most State Medicaid policies and health insurance programs actually deny individuals access to "gender-confirming" services if they are being sought specifically to confirm gender. That is,

as Spade writes, “medicaid provides all of the gender-confirming procedures and medications [e.g. breast reduction or augmentation, hormone therapy, vaginoplasty] that trans people request to nontrans people and only denies them to those seeking them based on a transgender diagnostic profile” or specifically to treat GID (p. 149).⁷⁶ The same is true in the two Canadian provinces that refuse to cover gender-confirming interventions for those with GD—New Brunswick and Prince Edward Island—yet will cover them for other patients (including those with DSDs). As Spade notes, “the impact of this denial can have significant mental and physical health consequences for trans* individuals (p. 149).

These administrative harms enacted upon trans* individuals similarly threaten the lives of those with intersex conditions as persons who fail to conform to bureaucratic demands regarding gender categorization. This is one of the reasons why legal scholar Julie Greenberg argues, in her 2012 book *Intersexuality and the Law: Why Sex Matters*, that there will be an increase in the number of legal cases involving intersex individuals. She writes that given that many lawmakers do not understand the difference between being trans* and being intersex, rules and policies created for trans* people will likely apply to both (p. 107). Furthermore, Greenberg cites anecdotal evidence from an interview with AIC director Anne Tamar-Mattis who states that that problems are already arising for intersex individuals “with identity documents (including birth certificates and passports) and insurance coverage” (p. 108):

We are seeing more cases where intersex people trying to change their identity

documents are being caught in a net that was developed to stop transsexuals from

⁷⁶A possible consequence of the inclusion of DSD as a method of subcategorizing those with Gender Dysphoria (GD) in DSM-V is that individuals with DSDs who seek gender-confirming treatments through a GID diagnosis may find themselves subject to the same denial of care experienced by trans* individuals. If they do not, the divide between those GD patients with a DSD and those without will be equivalent to those GD patients the state considers to have a legitimate claim to medical care and those it does not.

amending their documents. In the past, many intersex people who needed to change identity documents were able to do so under the “clerical error” provisions of state regulations governing birth certificates. Typically, a doctor’s letter stating that a mistake was made would be required, but many clerks would accept these physician statements at face value and amend the sex indicator on the birth certificate. Now that many states have adopted written procedures for addressing transsexuals’ birth certificate amendment requests, bureaucrats automatically turn to those rules no matter how inappropriate or inapplicable they may be (Tamar-Mattis, as cited in Greenberg, 2012, p. 109).

Furthermore, the surgical requirements bureaucratically imposed upon trans* individuals may similarly be applied to the intersex, and are themselves, I argue, an artifact of the assumption reified within the DSD treatment model that in order to be a man or a woman, one must have the unambiguous body of a man or a woman (recall Amundson’s privileging of a particular mode of function). Spade (2011), however, notes that the vast majority of trans* people do not undergo surgery, both because it is prohibitively expensive and because they do not want it or need it, citing a 2009 study which found that 80% of transgender women and 98% of transgendered men have not undergone genital surgery (p. 145). This, he writes identifies “the common misperception that surgery is the hallmark of trans experience” as particularly harmful to those “populations disproportionately lacking access to medical care, including low-income people, people of color, immigrants, and youth” (p. 145). I would further add that the assumption of a necessary coherence between bodily sex and gender is also particularly harmful socially insofar as it reinforces a particular narrative regarding who is and can be a “normal man or woman” and who isn’t or cannot.

The administrative violence enacted upon intersex and trans* persons via sex categorization renders it a useful and important target of activist theory and resistance. However, rather than argue for the introduction of additional methods or types of sex categorization like Germany's inclusion of a blank space option, I suggest we challenge the importance of sex categorization in these kinds of administrative contexts. The ubiquity with which we are forced to identify ourselves in terms of sex and/or gender naturalizes the demand for us. However, these systems of bureaucratic sorting have histories. If the elimination of sex/gender categories on government documents seems too unthinkable, I think it is worth questioning, at the very least, the state's interest in determining sex or gender. Why is it that people are not able to self-identify with regards to sex or gender as they see fit? Why does the state need to determine an individual's sex? As Greenberg (2012) points out, despite intersex individuals appearing in the historical records from all eras, "legal institutions did not begin to wrestle seriously with this issue until the 1970s" when sex reassignment surgery became more widely available (p. 48). Furthermore, Greenberg points out that given that majority of sex-based laws have been deemed unconstitutional in North America and Europe, a person's legal sex, is ironically "less important now than it has been at any other time in history," despite the fact that we call upon the state to determine an individual's legal sex more than ever before (p. 48). In fact, Greenberg argues there are only "two significant areas" where governmental distinctions based on sex remain in the United States: military rights and obligations (p. 48).⁷⁷

The argument that the state paternalistically needs to determine a trans* or intersex person's legal sex in order to identify which gendered spaces they can enter (e.g. prisons)

⁷⁷ This included marriage until the Supreme Court's ruling on June 26, 2015 in the case of *Obergefell v. Hodges* that marriage is a fundamental right guaranteed to all citizens, rendering same-sex marriage legal nationally (*Obergefell v. Hodges*, 2015).

assumes these individuals do not have the authority to determine, nor the capacity to know, their own gender—assumptions that we grant to cisgendered persons. It assumes they may be wrong in their self-identification, and that gendered sorting of this kind is necessary more generally. Challenging state interest in categorizing the population with regards to sex/gender is a necessary part of resisting the oppression of those with pathologies of cisgendered function. Even if a moratorium were placed on medically unnecessary interventions for those intersex patients unable to consent, the forms of administrative obstacles that work to make trans* and intersex lives unlivable would still exist. That is, those policies and rules which govern trans* lives and expose them to vulnerability would continue to capture those with intersex conditions. As Greenberg writes, even with a moratorium on surgery,

Those with atypical genitalia may be subject to challenges regarding their legal sex and thus may experience discriminatory practices similar to those experienced by trans individuals regarding the ability to marry in their self-identified gender, their ability to change their I.D., access to housing and facilities such as prisons in accordance with their self-defined identity and protection from discrimination on the basis of their status as intersex (p. 108).

This isn't to say that we should not ever categorize or sort individuals in terms of sex and gender: indeed, there are circumstances in which state or medical sorting of the population in this way is not only appropriate, but vitally important. For example, in order to be effective, state initiatives aimed at the reduction of domestic violence within the population need to take into account gender differences in that phenomenon. Furthermore, contemporary medicine is filled with examples of the kind of disparities in both medical care and knowledge production that can arise when sex/gender is not considered. A primary

example of this is the differential symptoms of heart attack exhibited by patients with typically-female versus typically-male bodies and the effects that failure to account for or study these differences have had for the latter patients in terms of higher rates of misdiagnosis and compromised access to care. Rather, my goal is to challenge state and medical interest in sex/gender categorization in itself, as a default, and argue that such sorting must be justified in terms of its capacity to facilitate freedom. In some cases, this justification may be more clear than it is in others, and may already have a powerful feminist history: sorting populations by gender when studying and generating initiatives to reduce domestic violence is justifiable insofar it is a gendered phenomena.⁷⁸ Not including gender as an axis of analysis would misrepresent that which it is in our interests to most accurately capture insofar as effective initiatives aimed at the reduction of domestic violence facilitate freedom.

Acknowledging particular social, political, economic, or even biological phenomena to be in some way sexed or gendered—such that sorting populations via sex or gender can facilitate freedom—does not require one that lapse into a new (or perhaps old) form of determinism with regards to sexed or gendered kinds. One might charge that the existence of

⁷⁸ I realize there's a lot of further discussion to be had here on the mechanisms of justification for this kind of sorting—potentially many pages worth. To say that this kind of sorting, or the justifications for this kind of sorting, may be clear in certain cases than in others is not to imply that this sorting is in any way self-evident or easy. There are many conditions of possibility for this kind of sorting; for example, the notion that violence against women is a distinct phenomena or category is the result of many years of political struggle. Further, to use an earlier example, the study of sexual harassment in the workplace—also a gendered phenomena—requires the emergence of an understanding of sexual harassment as distinct from “flirting,” as well as the establishment of it as a political problem to be addressed. Beyond this, there are many ways in which we can draw the boundaries of a population and reasons (political, or otherwise) for which we might want to configure or re-configure those boundaries. For example, when attempting to address violence against women, we may want to study the violence suffered by transgendered women separately from that suffered by transwomen in order to better capture and combat uniquely devastating effects of trans-misogyny. For discussion of the political sorting of populations that is beyond the scope of this text, see Spade, 2011 and Heyes, 2000.

sexed differences with regards to those symptoms of heart attack experienced by typically-female versus typically-male persons in particular, attests to the biological existence of *something* uniquely male or female; doesn't my granting this lead me into the trap of positing some kind pre-discursive, or otherwise exterior to power, sex? I grant that sexual (and gender) differences exist—and that these differences can indeed be vitally important for emancipatory projects and practices of freedom. However, I deny the existence of sex and gender beyond sex and gendered effects. That is, I deny the existence of sex—and subsequently, of gender, as that onto which Money strategically displaced the binary of sex—in terms of its agency, its causality, its unity. That women disproportionately suffer domestic violence is not a product or function of their “womanness,” but rather of the heteropatriarchal conditions of biopower within and against which they are constituted as women. Further, that typically female-bodied individuals exhibit different heart attack symptoms than typically male-bodied ones does not speak to the existence of a pre-discursive, biological male or female kind, let alone one from which gender and sexuality causally issue. Those with typically female bodies can exhibit “female-typical” symptoms of heart attack more or less typically; this would not make their symptoms pathological, merely atypical. Further, the level of phenotypic variation and functional integration exhibited by complex organisms like humans renders it unscientific in the most conventional sense of that term to assume the unlikely level of uniformity that the assumption of biological male or female kinds require, at least in the absence of overwhelming, reliable evidence. Moreover, those with typically-female bodies can inhabit a variety of genders and sexualities, more or less stably. Allowing that the sorting of populations in terms of things like sex and gender can facilitate freedom does not demand the positing of some pre-discursive, biological, or natural sex or gender.

IV. Conclusion

In this final chapter I argued for the imposition of a permanent moratorium on medical efforts to normalize the gender of those unable to provide informed consent—efforts that by default aim within our current biopolitical context at the production of cisgendered lives and the elimination of visibly transgendered lives. From within a Foucauldian framework, I provided additional arguments justifying my two main prescriptive claims. Freedom is not a right nor a characteristic of the subject for Foucault, but is rather found in the proliferation of discursive meaning; the lived experiences of the body irreducible to the discursive and non-discursive constitution of the subject; and the ethical, critical, engagement in relations of oneself to the self, enabled by practices of the self. This understanding of freedom reorients the focus of our political efforts to those concrete ways in which life chances are maldistributed to render the lives of those with pathologies of cisgendered function unliveable. Rather than deploying new medico-scientific discourses in the hopes of restructuring institutional practices in ways that facilitate freedom, I argue that we should focus our attention and effects on the local concrete ways in which those with pathologies of cisgendered function are let die under biopower. If we want to change the biopolitical management of this population, our approach must engage with this management directly and explicitly as such, in the full grip of its history.

Conclusion

In this dissertation I argued that where intersex conditions are concerned, it is both theoretically and practically impossible to separate cultural issues of gender and identity from medical issues of pathology—even if it might seem politically useful or desirable—in at least three different senses. First, in the context of intersex management, health—as the absence of pathology—is defined *specifically* in terms of gender and identity, such that these things cannot be unentangled. The tripartite constellation of sex, gender, and sexuality is the line along which both the intersexed patient and the trans* patient follow the homosexual in their constitution as abnormal. As pathologies of cisgendered function, intersex conditions may indeed be issues of “stigma and trauma,” but they are also, along with GD, necessarily about gender—even if the majority of individuals with them identify as “perfectly ordinary heterosexual, non-trans men and women” (Koyama, 2006, para. 22). Because of this necessary tie to the heterosexual matrix and its transgression, intersex conditions and GD are always already queer, such that reformulating the former in terms of disorder cannot dispel the specter of queerness that has come to haunt it.

Second, pathology in itself is a kind of queerness with regards to biopower, such that bringing intersex bodies more concretely into the realm of the pathological is not to displace them simultaneously from queerness. In *Crip Theory: Cultural Signs of Queerness and Disability*, Robert McRuer (2006) underlines the inextricable entanglement of queerness—specifically in terms of homosexuality—and disability. Both are generated through the deployment of biopower (specifically in the context of the clinic), such that the disabled subject and the homosexual subject (and the intersexed and the trans* subject) share conditions of possibility for their constitution as such. Indeed, pathology is one of, if not *the*, primary way in which “biological-type caesura[s]” are introduced into the biological continuum

constituted by life under biopower for Foucault. It is the way in which biological races are constituted such that a differentiation can be made between those lives which should be made live and those which should be let die when every human is alive in the context of a power over “life itself” (Foucault, 2003, pp. 255-256). This claim underlies McRuer’s (2006) that “the system of compulsory able-bodiedness, which in a sense produces disability, is thoroughly interwoven with the system of compulsory heterosexuality that produces queerness” (p. 2). Intersex and trans* lives are queered through their pathologization with regards to sex and gender; however, pathology is in itself a queerness under biopower. Hence, McRuer’s comment in his Afterword to Morgan Holmes’s 2009 edited collection *Critical Intersex* that the “pitting of queer theory and activism *as against* [emphasis in original] disability theory and activism [in the move to DSD] is paradoxical indeed” (pp. 247-248).

Finally, it is impossible to separate issues of gender and identity from those of health and pathology if the goal is to somehow divide the natural from the social or the cultural. Medicine, as well as its objects of surveillance and intervention, are necessarily, always already natural and cultural—permanently intermingled instantiations of nature-culture. Certain pathologies are merely more obvious in their cultural constitution than others. For these reasons, I argued that any theory and activism grounded on the separation of these issues—like the strategic endorsement of the DSD nomenclature—both is and was, always already, doomed to failure. It not only assumes the problematic binary logic of nature/culture, but is committed to a woefully inadequate account of power as sovereign, which both misrepresents the productive ways in which biopower functions, and obscures the historical constitution of its objects (including the subject). A good deal of the work this dissertation accomplishes is a kind of theoretical ground-clearing—an in-depth elaboration and exploration of particular histories and arguments—specifically, those that turn on

pathology and/or brain organization theory, in order to make clear what will *not* work regarding intersex conditions and GD. Further, the prescriptive claims that I've defended in this dissertation are likely to be accepted by many (at least, many in the field of intersex studies). My goal is to make this acceptance more sincere by revealing the terrain out of and upon which medical efforts to secure cisgendered futures for intersex and trans* children unable to provide informed consent are practiced, such that this acceptance actually impacts practice. Indeed, one of the quandaries of intersex management in particular is the persistence of these practices despite multiple decades of critical theory and activism which, unlike the clinical practices themselves, draw upon evidence regarding the potential harms associated with these interventions in order to justify their call for a moratorium. As a cisgendered philosopher with formal training in the medical sciences, I draw together a variety of literatures in order to unearth what lies between those claims we seem to agree on and our actions, and reveal it in its problematicity. Famously, Foucault claimed that “[p]eople know what they do; they frequently know why they do what they do; but what they don't know is what what they do does” (Dreyfus & Rabinow, 1982, p. 187). I would argue that where the management of intersex and trans* children is concerned, while it may be clear what they do, it is actually not clear to many engaged in the administration of these “treatments”—from clinicians to proxy decision-makers—either why they do what they do, or what what they do does. In corralling the various ways in which invested parties talk and think about intersex and trans* management practices, I not only reveal the fissures, disconnects, and misrepresentations between them, I also reveal the origin of these incoherencies to be the fictitious unity of sex itself, and the historical deployment of sexuality as a field of normalizing medical knowledge/power. Thus, I seek to lay bare both what these practices do, and why they are done in order to facilitate the constitution of a

context in which we might more easily translate those claims we seem to accept—that medical efforts to secure cisgendered futures for those unable to provide informed consent need to stop and that those who desire gender-confirming normalization should get it – into practice. In doing so, I hope to have positioned myself as a queer ally to intersex and trans* people, by providing an analysis that might help to make the context in which they receive or are denied medical care more humane.

McRuer (2009) draws upon Jacques Derrida’s late dialogue on “Unforeseeable Freedom,” to think about “spaces of intersexual futurity”(p. 235). McRuer summarizes Derrida’s contemplation on the “future-to-come,” in which one comes who “does not yet have a recognizable figure” and thus cannot be defined via historically and potentially exclusionary terms of likeness and difference (Derrida & Roudinesco, 2004, p. 52; as cited in McRuer, 2009, p. 245). The “always-anticipated figure” of the “future-to-come” necessarily “exceeds any determinism” for Derrida, for with determinism “there is no future” (pp. 52-53; as cited in McRuer, 2009, p. 245). Thus, writes McRuer “[t]he unforeseeable freedom that will arrive in a future-to-come, in other words, depends upon a relinquishment of determinism, which in turn allows us to risk welcoming the unexpected” (p. 245).

Determinism, of course, can never fully be relinquished; there is no outside of power, no outside of those discursive and non-discursive elements through which power is deployed and the subject is constituted. Nonetheless, there is a *beyond* power—one constituted by the irreducibility of life to power, by its necessary excess. This might not be a space *of* freedom, but a space *for* it, that can be cultivated and creatively explored. In this sense, I argue that one might read the kind of freedom I have articulated in terms of taking the risk of “welcoming the unexpected,” of cultivating an openness to and opportunities for that which exceeds, if not any determinism, than simple determinism. Dancing the unending

spiral between limit and transgression, normal and the abnormal, intelligible and unintelligible is a risk—and one with potentially deadly consequences, as many trans* persons of colour are intimately aware. The goal, then, is to hew out space for the taking of such risks “for exploring possibilities for new forms of subjectivity, new fields of experiences, pleasures, relationships, modes of living and thinking” (Oksala, 2005, p. 168). This, I argue, must begin by understanding and targetting those biopolitical discourses, regimes of truth, institutions, and practices which not only foreclose the capacity to take such risks, but render them so terribly grave.

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Appendix A

Common Intersex Conditions and their Etiology, Frequency, Symptomatology, Psychosexual Outcome Data and Differential Treatment Under OGR and DSD

Intersex Condition (w/DSD Diagnosis)	Frequency	Etiology	Symptoms	Psychosexual Differentiation	Treatment Recommendation
Hypospadias (46 XY DSD)	Roughgarden (2004) reports the frequency of hypospadias to be 450/1000 for all forms and 1/1725 for moderate and severe forms. However, the frequency of hypospadias is increasing at a significant rate. A 2003 review article notes that comparable increases in mild and severe forms of hypospadias have been noted in the both the United States and Europe and places the frequency at 1/125 live births (Manson and Carr, 2003)	One of the most common congenital mutations, hypospadias also has one of the more complex etiologies. As Manson and Carr (2003) write: “[h]ypospadias is believed to have a multifactorial etiology in which allelic variants in genes controlling androgen action and metabolism predispose individuals to develop this condition. When genetic susceptibility is combined with exposure to antiandrogenic agents, a threshold is surpassed, resulting in the manifestation of this birth defect” (p. 825).	Mild: Urethral opening on glans penis Moderate: Urethral opening on penis shaft Severe: Urethral opening below penis, on body wall No information available regarding risk of gonadal malignancy	The Consensus Statement simply states the following: “Long-term data regarding sexual function and quality of life among those [with hypospadias] assigned female as well as male show great variability” (Lee et al., 2006, e496). I have been unable to find a study that looks at gender identity and psychosexual differentiation solely in those 46 XY DSD patients with hypospadias (they generally include other 46 XY DSD patients such as those with PAIS, or partial gonadal dysgenesis, etc).	OGR: Male assignment and surgical revision were generally recommended, however, physicians often recommended female assignment due to the limitations of phalloplasty. DSD: “In the case of a DSD associated with hypospadias standard techniques for surgical, repair such as chordee correction, urethral reconstruction, and the judicious use of testosterone supplementation apply. The magnitude and complexity of phalloplasty in adulthood should be taken into account during the initial counseling period if successful gender assignment depends on this procedure. At times, this may affect the balance of gender assignment.” (Lee et al., 2006, p. e492).

<p>Congenital Adrenal Hyperplasia (CAH) (46 XY DSD; 46 XX DSD)</p>	<p>Non-Classic/Late-Onset: 1/66</p> <ul style="list-style-type: none"> • 1/27 for Ashkenazi Jews • 1/52 for Hispanics • 1/62 for Yugoslavs • 1/333 for Italians • 1/100,000 for a mixed Caucasian population <p>Classic: 1/17,000</p> <ul style="list-style-type: none"> • 1/300 for Yupik Native Alaskans • 1/800 for other Native Alaskans • 1/3,000 on La Reunion Island • 1/5,000 in Switzerland • 1/7,000 in Brazil • 1/8,000 in the Arab population 	<p>90%- 95% of all cases of CAH are caused by 21-hydroxylase deficiency. The various forms are the result of variations in an individual's specific level of enzyme function and other factors such as variations in androgen metabolism and sensitivity. Decrease or complete loss of enzyme activity results in a decrease in cortisol production which triggers the overproduction of adrenocorticotrophic hormone (ACTH) by the anterior pituitary gland – a hormone which stimulates cortisol production by the adrenal glands – leading to the overstimulation of adrenal steroid synthesis (and the <i>hyperplasia</i> or overgrowth of those adrenal cells involved in steroidogenesis). Progesterone substrates 21-hydroxylase would normally convert to deoxycorticosterone to 11-deoxycortisol begin to</p>	<p>Non-Classic/Late-Onset: Onset post year 5, symptoms include: early puberty, thick hair in a masculine body pattern, possible male pattern baldness, menstrual irregularity.</p> <p>Classic (Simple Virilizing): Varying levels of virilization in XX females; No external symptoms in males</p> <p>Classic (Salt-Wasting): Same phenotypic symptoms as those with SV-CAH, plus fatally impaired salt metabolism.</p> <p>No information available regarding risk of gonadal malignancy).</p> <p>It is worth noting that 46 XY CAH individuals referred to “clinically unrecognizable” because the increase in androgen</p>	<p>94.8% of those 46 XX individuals raised female identified and lived as female while 5.2% experienced gender dysphoria and 2% transitioned to male. Of those 46 XX individuals raised male, 12% experienced gender dysphoria while 88% did not (Dessens et al., 389).</p> <p>It is worth noting that all of the concern and data regarding psychosexual differentiation in patients with CAH focuses on those 46 XX patients, with the assumption being that increased testosterone could only make a boy more of a boy and the concern is identifying and preventing gender transition.</p>	<p>OGR: Sex assignment is not an issue with 46 XY patients. Female assignment for 46 XX patients due to the impossibility of creating a functional penis and gonadectomy to avoid the development of a “discordant phenotype” and to avoid gonadal malignancy.</p> <p>DSD: The Consensus Statement states that “evidence supports the current recommendation to raise markedly virilized 46,XX infants with CAH as female” (plus gonadectomy) however in 2010, Consensus Statement co-authors Lee and Houk recommended male assignment for severely virilized 46 XX CAH patients (with gonadectomy).</p>
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	of Israel <ul style="list-style-type: none"> • 1/9,000 in Austria • 1/40,000 in the United States 	accumulate and are converted to androgens by active enzymes in the environment, leading to an increase in androgen production and the virilization of XX individuals over the lifespan (Miller and Auchus, 2011)	production does not result in genital ambiguity in these patients.		
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Androgen Insensitivity Syndrome (AIS) (46 XY DSD)	Complete AIS (CAIS): 1 in 13,000 (R) <ul style="list-style-type: none"> • CAIS in births originally classified as male: 1/20,000 • CAIS in births originally classified as female: 1/8,000 Partial AIS (PAIS): 1 in 130,000	AIS in both complete and partial forms are the result of mutations in the genes which code the Androgen Receptor (AR) protein, located on the X chromosome at Xq11-12. Severity of androgen resistance correlates with severity of mutation. As of 2008 there were approximately 750 known AR mutations associated with conditions such as CAIS and PAIS (Oakes et al. 2008)	CAIS: typical female external appearance; 2% risk of germ cell malignancy PAIS: varying levels of virilization; PAIS (Non-scrotal gonads): 50% risk of germ cell malignancy PAIS (Scrotal gonads): Unknown	CAIS: The first case of female to male gender transition in a patient with CAIS was reported by T'Sjoen et al. in 2011. PAIS: Of those with PAIS, 9% transitioned from female to male and 1% reported gender dysphoria without transition (Mazur, 2005, p. 414)	OGR: Female assignment for those with CAIS and PAIS and gonadectomy to avoid the development of a “discordant phenotype” and to avoid gonadal malignancy. DSD: Female assignment in those with CAIS. Regarding those with PAIS, the Consensus statement fails to give clear directive sex assignment, simply noting that “among patients with partial androgen insensitivity syndrome (PAIS), androgen bio- synthetic defects, and incomplete gonadal dysgenesis, there is dissatisfaction with the sex of rearing in ~25% of individuals whether raised male or female” (e491). Though the table on page e493 of the Consensus Statement outlining “Risk of Germ Cell Malignancy According to
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					Diagnosis” recommends “Biopsy and ???” for the gonads of CAIS patients, gonadectomy for those PAIS patients with non-scrotal gonads and “biopsy and irradiation for those PAIS patients with scrotal gonads, the Statement formally recommends that “the testes in patients with CAIS and those with PAIS, raised female, should be removed to prevent malignancy in adulthood” a page earlier (Lee et al., 2006).
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Turner Syndrome (45, X0) (Sex Chromosome DSD)	Turner Syndrome: 1 in 2,700 <ul style="list-style-type: none"> 1/600 in Moscow 1/9,500 in Edinburgh 	Turner syndrome is the result of a nondisjunction event during meiosis that results in the loss of part or all of an X chromosome. Some individuals may have part or all of the Y chromosome present in some or all of their cells as a result of crossing over events.	Turner Syndrome: undeveloped ovaries, short stature, lack of secondary sex characteristics; 1-12% risk of germ cell malignancy depending on genotype. ⁴ Turner Syndrome: (-Y)= 1%; (+Y=12%).	No Information Available	OGR: Patients typically have female-typical genitals at birth such that sex assignment at birth is typically not an issue. Female assignment is assumed in these cases. DSD: Female Assignment still presumed. Gonadectomy recommended for those +Y, no action with regards to gonads recommended for those (-Y) (Lee et al).
Klinefelter Syndrome (47, XXY) (Sex Chromosome	Klinefelter Syndrome: Reports vary between 1 in 500 (Visootsak and	Klinefelter syndrome is the result of a nondisjunction event during meiosis that results in the presence of	Klinefelter Syndrome: possibly impaired fertility; development of feminine secondary sex characteristics at puberty.	No Information Available	OGR: Patients typically have male presenting (if sometimes atypical) genitals at birth such that sex assignment at birth is typically not an issue. Male assignment is assumed in

DSD)	<p>Graham, 2006) and 1 in 1,000</p> <ul style="list-style-type: none"> • 1/500 in Germany • 1/7,400 in Winnipeg 	<p>an additional X chromosome in some of all of the cells of XY individuals.</p> <p>The extra X chromosome in 47, XXY results sporadically from either meiotic nondisjunction where a chromosome fails to separate during the first or second division of gametogenesis or from mitotic nondisjunction in the developing zygote (Visootsak and Graham, 2006).</p>	<p>“In infancy, males with 47,XXY may have chromosomal evaluations done for hypospadias, small phallus or cryptorchidism, developmental delay. The school-aged child may present with language delay, learning disabilities, or behavioral problems. The older child or adolescent may be discovered during an endocrine evaluation for delayed or incomplete pubertal development with eunuchoid body habitus, gynecomastia, and small testes. Adults are often evaluated for infertility or breast malignancy” (Visootsak and Graham, 2006, 1)</p> <p>Though many are infertile, there are reports of individuals reproducing without medical assistance and a study 42 individuals with Klinefelter’s found</p>	<p>these cases.</p> <p>DSD: Male Assignment still presumed. Gonadectomy recommended for those (+Y), no action with regards to gonads recommended for those (-Y) (Lee et al., 2006).</p> <p>Vistook and Graham (2006): “Androgen replacement therapy should begin at puberty, around age 12 years, in increasing dosage sufficient to maintain age appropriate serum concentrations of testosterone, estradiol, follicle stimulating hormone (FSH), and luteinizing hormone (LH)” (pp. 4-5)</p>
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			<p>that 29 or 69% of those studied had sperm adequate for use in IVF using testicular sperm extraction and intracytoplasmic sperm injection (Visootsak and Graham, 2006).</p> <p>No information available regarding risk of gonadal malignancy</p>		
<p>Non-XX or non-XY Sex Chromosome DSDs (excluding Turner and Klinefelter Syndromes)</p>	<p>Non-XX or non-XY (excluding Turner and Klinefelter Syndromes): 0.639 per 1,000</p> <ul style="list-style-type: none"> • XYY: 1/1,100 • XXX: 1/2,000 • XYYY: 1/6,500 <p>45, X/46 XY (Mixed Gonadal Dysgenesis, Ovotesticular DSD):</p>	<p>Like Klinefelter and Turner Syndromes, these sex chromosome aneuploidies are the result of nondisjunction events during meiosis.</p>	<p>Non-XX or non-XY: The majority of these patients are phenotypically male or female are thus go undiagnosed, however, there can be variability in phenotype (Roughgarden, 2004, p. 292). The effects on physical and cognitive development increase with the number of extra Xs, and each extra X is associated with an intelligence quotient (IQ) decrease of approximately 15–16 points, with language most affected, particularly expressive language skills (Visootsak and Graham, 2006)</p>	<p>No Info Available.</p>	<p>OGR: No clear standards regarding sex assignment in these cases given the high variation in external appearance. Assignment is left to the expertise of the treating clinician.</p> <p>DSD: The Consensus Statement also fails to make clear recommendations regarding these patients. It states that for those making the decision regarding sex of rearing in patients with gonadal dysgenesis, factors to consider include: “prenatal androgen exposure, testicular function at and after puberty, phallic development, and gonadal location” (Lee et al., e491).</p>

	<p>Frequency Unknown 46, XX/46, XY (Chimeric, Ovotesticular DSD): Frequency Unknown</p>		<p>Risk of gonadal malignancy depends on gonadal histology (i.e. whether one has ovotestes or not) and the location of the gonads (i.e. whether they are intraabdominal or not). Those with gonadal dysgenesis, a Y chromosome and intraabdominal gonads face the highest risk of malignancy at 15%-35% (Lee et al., 2006).</p>		
<p>De La Chapelle or XX Male Syndrome (46, XX Testicular DSD or 46 XX Ovotesticular DSD)</p>	<p>XX males: 1 in 20,000 to 1 in 25,000 (Roughgarden, 2004; Alves et al., 2010)</p>	<p>De la Chappelle or XX male syndrome refers to individuals who have an X chromosome (or some other chromosome) that has acquired material from the Y chromosome. 90% are those whose translocated Y material contains the SRY or “sex determining region on the Y” gene (<i>SRY</i>-positive), generally as a result of translocation during paternal meiosis, while</p>	<p>SRY –positive XX males: Typically these individuals have male-typical external genitalia and are sterile, however, they may occasionally present with undescended testes and hypospadias (Visootsak and Graham, 2006; Alves et al., 2010).</p> <p>SRY-Negative XX males can range the spectrum of virilization</p>	<p>No Info Available.</p>	<p>OGR: Those with male-typical genitalia are “subclinical” and are generally only diagnosed in adulthood as a result of investigations into infertility. Thus, sex assignment is not an issue. Sex assignment in those SRY-negative patients is left to the expertise of the treating clinician.</p> <p>DSD: Similarly under DSD, sex assignment for those SRY-negative patients is left to the expertise of the treating clinician. The Consensus Statement does state that “Those making the decision on sex of rearing</p>

		10% do not (SRY-negative) (Visoosak and Graham, 2006; Alves et al., 2010, p. 686).	<p>present with normal male to ambiguous genitalia and, testicles or ovotestes (ovarian and testicular tissue) (Alves et al., 2010).</p> <p>Risk of gonadal malignancy depends on gonadal histology (i.e. whether one has ovotestes or not) and the location of the gonads (i.e. whether they are intraabdominal or not). Malignancy risk for those with ovotesticles is 3% (p. e493).</p>		for those with ovotesticular DSD should consider the potential for fertility on the basis of gonadal differentiation and genital development and assuming that the genitalia are, or can be made, consistent with the chosen sex”(p. e491).
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Micropenis	1.5/10,000 (Hatipoglu and Kurtoglu, 2013)	Micropenis is assumed to result from atypical testosterone production and/or sensitivity beginning after the 12 th week of gestation (Hatipoglu and Kurtoglu, 2013)	No information available regarding risk of gonadal malignancy	There are no reports of gender transition in patients with micropenis, regardless of whether they were assigned male or female (though 2% reported gender dysphoria). (Mazur, 2005, 414)	<p>OGR: Female Assignment</p> <p>DSD: Male Assignment: “Available data support male rearing in all patients with micropenis, taking into account equal satisfaction with assigned gender in those raised male or female but no need for surgery and the potential for fertility in patients reared male” (Lee et al., 2006).</p>
True	1 in 85,000 ²	The developmental	True Hermaphroditism is defined	Psychosexual	OGR: No explicit recommendations

Hermaphroditism (Ovotesticular DSD)		pathways leading to true hermaphroditism are largely unknown. One, however, is the fusion two embryos into one (chimerism) shortly after conception (Roughgarden, 2004, p. 292)	by the presence of both ovarian and testicular tissue in any combination (ie, one ovary and one testicle, one testicle and one ovotestes etc.). These patients exhibit high phenotypic variation, from having a male or female-typical appearance at birth, to exhibiting genital ambiguity. 3% risk of gonadal malignancy (Lee et al., 2006)	differentiation data specifically for this group is unavailable; likely due to the rarity of the condition.	with sex assignment in these patients left to the expertise of the treating clinician. DSD: Sex assignment remains left to the expertise of the treating physician, though the Consensus Statement cautions that : “Those making the decision on sex of rearing for those with ovotesticular DSD should consider the potential for fertility on the basis of gonadal differentiation and genital development and assuming that the genitalia are, or can be made, consistent with the chosen sex” (p. e491).
5 α reductase deficiency	Uncertain; up to 130 in 1000 in the Dominican Republic	5 α reductase is responsible for the interconversion of testosterone and dihydrotestosterone. XY patients with this deficiency generally present as typical females at birth.	Phenotypic presentation among those with XY chromosomes and 5 α RD2 deficiency can vary, however, the majority present as typically female at birth and begin to virilize at puberty in response to endogenous testosterone production using other isozymes of the enzyme within the extraglandular tissues (Andersson, Russel and Wilson, 1996). Malignancy risk is unclear, though reported by the Consensus Statement to be 0% (Lee et al,	56%- 63% of patients transition from female to male (Cohen-Kettenis, 2005, p. 400)	OGR: Female Assignment DSD: The Consensus Statement fails to made clear recommendations regarding sex assignment in these cases. Rather it states “Approximately 60% of 5- α -reductase (5 α RD2)-deficient patients assigned female in infancy and virilizing at puberty (and all assigned male) live as males” (p e491). They caution that for these patients who are diagnosed in infancy, “the combination of a male gender identity in the majority and the potential for fertility (documented in 5 α RD2...deficiencies) should be

			2006).		discussed when providing evidence for gender assignment” (p. e491).
17β-Hydroxysteroid Dehydrogenase-3 Deficiency	Frequency Unknown (Andersson et al.)	17β-Hydroxysteroid Dehydrogenase-3 is responsible for the interconversion of testosterone and androstenedione. XY patients with this deficiency generally present as typical females at birth.	Phenotypic presentation among those with XY chromosomes and 17β-Hydroxysteroid Dehydrogenase-3 deficiency can vary, however, the majority present as typically female at birth and begin to virilize at puberty in response to endogenous testosterone production using other isozymes of the enzyme within extraglandular tissues (Andersson, Russel and Wilson, 1996, p. 122). Malignancy risk is unclear, however Lee et al. report it at 28% based on 7 studies of 2 patients (p. e493).	39%-64% of patients transition from female to male (Cohen-Kettenis, 2005, p. 400)	OGR: Female Assignment DSB: The Consensus Statement fails to made clear recommendations regarding sex assignment in these cases. However, as with those with 5αRD2- deficiency, it cautions that for these patients who are diagnosed in infancy, “the combination of a male gender identity in the majority and the potential for fertility...should be discussed when providing evidence for gender assignment,” while noting that the potential for fertility in these patients remains unknown (p. e491). Further, it recommends “watchful waiting” with regards to these patients gonads (p. e491).
Cloacal Exstrophy	1 in 250,000		“Cloacal exstrophy of the bladder is a severe variant of the bladder exstrophy-epispadias-cloacal exstrophy complex involving an abdominal wall defect and associated with omphalocele, bladder exstrophy, short-gut syndrome, separated pubic bones, and variable additional severe malformations such as spina bifida and clubfoot. The penis is	A 2005 literature review by Meyer-Bahlburg found that of 51 patients assigned female, 33 (64.7%) were living as female, 7 (13.7%) as females with possible gender dysphoria and 11(21.6%)as males (only 8 of the 51	OGR: Female assignment due to the impossibility of creating a functional penis (Meyer Bahlburg, 2005b, p. 424). DSB: The Consensus Statement issues no firm recommendations regarding treating those with cloacal exstrophy, simply remarking that “individuals with cloacal exstrophy reared female show variability in gender identity outcome, but >65% seem to live as female” (p.

			<p>often aplastic and bifid, and sometimes entirely absent” (Meyer-Bahlburg, 2005b, p. 424).</p> <p>No information available regarding risk of gonadal malignancy</p>	<p>subjects were adults). Of the 15 patients assigned male, all (100%) were living as males (p. 425).</p>	<p>e491). Both Arboleda, Sandberg and Vilain (2014), and Houk and Lee (2008), however, indicate that the majority of clinicians (~80%) now recommend male assignment for XY patients with cloacal exstrophy.</p>
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Note. Compiled from Andersson, Russel and Wilson, 1996; Alves et al., 2010; Arboleda, Sandberg and Vilain, 2014; Cohen-Kettenis, 2005; Hatipoğlu and Kurtoglu, 2013; Houk and Lee, 2008; Lee et al., 2006; Manson and Carr, 2003; Mazur, 2005; Meyer-Bahlburg, 2005b; Miller and Auchus, 2011; Oakes et al., 2008; Roughgarden, 2004; T’Sjoen et al., 2011; Visootsak and Graham, 2006.

Appendix B

Gender Identity Disorder in DSM-IV-TR and Gender Dysphoria in DSM-V

DSM-IV-TR	DSM-V
<p>Gender Identity Disorder in Children (302.6) and Gender Identity Disorder in Adolescents or Adults (302.85)</p> <p>A. A strong and persistent cross-gender identification (not merely a desire for any perceived cultural advantages of being the other sex). In children, the disturbance is manifested by four (or more) of the following:</p> <ol style="list-style-type: none"> 1. Repeatedly stated desire to be, or insistence that he or she is, the other sex 2. In boys, preference for cross-dressing or simulating female attire; in girls, insistence on wearing only stereotypical masculine clothing 3. Strong and persistent preferences for cross-sex roles in make-believe play or persistent fantasies of being the other sex 4. Intense desire to participate in the stereotypical games and pastimes of the other sex 5. Strong preference for playmates of the other sex <p>In adolescents and adults, the disturbance is manifested by symptoms such as a stated desire to be the other sex, frequent passing as the other sex, desire to live or be treated as the other sex, or the conviction that he or she has the typical feelings and reactions of the other sex.</p> <p>B. Persistent discomfort with his or her sex or sense of inappropriateness in the gender role of that sex. In children, the disturbance is manifested by any of the following: in boys, assertion that his penis or testes are disgusting or will disappear or assertion that it would be better not to have a penis, or aversion toward rough-and-tumble play and rejection of male stereotypical toys, games, and activities; in girls, rejection of urinating in a sitting position, assertion that she has or will grow a penis, or assertion that she does not want to grow breasts or menstruate, or marked aversion toward normative feminine clothing. In adolescents and adults, the disturbance is manifested by symptoms such as preoccupation with getting rid of primary and secondary sex characteristics (e.g., request for hormones, surgery, or other procedures to physically alter</p>	<p>Gender Dysphoria in Children 302.6 (F64.2)</p> <p>A. A marked incongruence between one's experienced/expressed gender and assigned gender, of at least 6 months' duration, as manifested by at least six of the following (one of which must be Criterion A1):</p> <ol style="list-style-type: none"> 1. A strong desire to be of the other gender or an insistence that one is the other gender (or some alternative gender different from one's assigned gender). 2. In boys (assigned gender), a strong preference for cross-dressing or simulating female attire; or in girls (assigned gender), a strong preference for wearing only typical masculine clothing and a strong resistance to the wearing of typical feminine clothing. 3. A strong preference for cross-gender roles in make-believe play or fantasy play. 4. A strong preference for the toys, games, or activities stereotypically used or engaged in by the other gender. 5. A strong preference for playmates of the other gender. 6. In boys (assigned gender), a strong rejection of typically masculine toys, games, and activities and a strong avoidance of rough-and-tumble play; or in girls (assigned gender), a strong rejection of typically feminine toys, games, and activities. 7. A strong dislike of one's sexual anatomy. 8. A strong desire for the primary and/or secondary sex characteristics that match one's experienced gender. <p>B. The condition is associated with clinically significant distress or impairment in social, school, or other important areas of functioning.</p> <p>Specify if: With a disorder of sex development</p> <p>Gender Dysphoria in Adolescents and Adults 302.85 (F64.1)</p> <p>A. A marked incongruence between one's experienced/expressed gender and assigned gender, of at least 6 months' duration, as manifested by at least two of the following:</p> <ol style="list-style-type: none"> 1. A marked incongruence between one's experienced/expressed gender and primary and/or

<p>sexual characteristics to simulate the other sex) or belief that he or she was born the wrong sex.</p> <p>C. The disturbance is not concurrent with a physical intersex condition.</p> <p>D. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.</p> <p>Specify if (for sexually mature individuals): Sexually Attracted to Males Sexually Attracted to Females Sexually Attracted to Both Sexually Attracted to Neither</p> <p>302.6 Gender Identity Disorder Not Otherwise Specified: This category is included for coding disorders in gender identity that are not classifiable as a specific Gender Identity Disorder. Examples include:</p> <ol style="list-style-type: none"> 1. Intersex conditions (e.g., partial androgen insensitivity syndrome or congenital adrenal hyperplasia) and accompanying gender dysphoria 2. Transient, stress-related, cross-dressing behavior 3. Persistent preoccupation with castration or penectomy without a desire to acquire the sex characteristics of the other sex 	<p>secondary sex characteristics (or in young adolescents, the anticipated secondary sex characteristics).</p> <ol style="list-style-type: none"> 2. A strong desire to be rid of one's primary and/or secondary sex characteristics because of a marked incongruence with one's experienced/expressed gender (or in young adolescents, a desire to prevent the development of the anticipated secondary sex characteristics). 3. A strong desire for the primary and/or secondary sex characteristics of the other gender. 4. A strong desire to be of the other gender (or some alternative gender different from one's assigned gender). 5. A strong desire to be treated as the other gender (or some alternative gender different from one's assigned gender). 6. A strong conviction that one has the typical feelings and reactions of the other gender (or some alternative gender different from one's assigned gender). <p>B. The condition is associated with clinically significant distress or impairment in social, occupational, or other important areas of functioning.</p> <p>Specify if: With a disorder of sex development</p> <p>Specify if: Posttransition: The individual has transitioned to full-time living in the desired gender (with or without legalization of gender change) and has undergone (or is preparing to have) at least one cross-sex medical procedure or treatment regimen—namely, regular cross-sex hormone treatment or gender reassignment surgery confirming the desired gender (e.g., penectomy, vaginoplasty in a natal male; mastectomy or phalloplasty in a natal female).</p> <p>Other Specified Gender Dysphoria 302.6 (F64.8) This category applies to presentations in which symptoms characteristic of gender dysphoria that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for gender dysphoria. The other specified gender dysphoria category is used in situations in which the clinician chooses to communicate the specific reason that the presentation does not meet the criteria for gender</p>
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	<p>dysphoria. This is done by recording “other specified gender dysphoria” followed by the specific reason (e.g., “brief gender dysphoria”). An example of a presentation that can be specified using the “other specified” designation is the following: The current disturbance meets symptom criteria for gender dysphoria, but the duration is less than 6 months.</p> <p>Unspecified Gender Dysphoria 302.6 (F64.9) This category applies to presentations in which symptoms characteristic of gender dysphoria that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for gender dysphoria. The unspecified gender dysphoria category is used in situations in which the clinician chooses <i>not</i> to specify the reason that the criteria are not met for gender dysphoria, and includes presentations in which there is insufficient information to make a more specific diagnosis.</p>
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Note. Compiled from APA 2000, APA 2013a