

RHETORICAL INTERACTIONS OF SOCIAL MOVEMENT ORGANIZATIONS
IN A MOVEMENT: A STUDY
OF THE INTERSEX RIGHTS ADVOCACY MOVEMENT

BY

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ABSTRACT

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Department of Communication Studies, May 2010

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While rhetorical scholars have long studied social movements, few studies investigate the rhetorical interactions of organizations working within a single movement. In this dissertation, I explore the rhetoric deployed by several social movement organizations and analyze the ways that discourse functions to produce and limit opportunities for the organizations to coalesce and work as a single, unified movement.

In this dissertation, I develop a theory of social movement organizations by analyzing the four leading intersex rights organizations in the United States, including the Intersex Society of North America, the Accord Alliance, the Advocates for Informed Choice, and the Organisation Intersex International. I explore how their constructions of organizational identity and their positions on naming, parental informed consent, and gender create opportunities for some to cooperate, while ensuring divergences among other groups. I conclude by discussing the implications these individual debates have on the success of the overall intersex advocacy movement.

DEDICATION

This work is dedicated to the thousands that have suffered mistreatment due to society's failure to understand intersexuality. Although it is not much, I hope I have illuminated several of the important battles being fought for just treatment and understanding. May we one day live in a world free of shame and stigma and full of compassion for all.

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CHAPTER 1: Introducing the Social Movement Organizations of the Intersex Rights Movement

There is remarkable variety in human physiology. Indeed, the amount of human variation is truly extraordinary. From size and features to abilities, interests, and intelligences, there are innumerable differences from one individual to the next. Despite all of this variation, we tend to assume with relative certainty that human beings develop “one of two common sets of a particular group of organs” (Dreger, 1998, p. 3). That is, despite our advanced understanding of genetic anomalies and our attempts to celebrate difference, we rely on a very basic, but problematic, assumption that all individuals are either male or female as a consequence of having the corresponding sexual anatomy. It is true that for a large majority of the world’s population this assumption is relatively safe. However, for a small percentage of the population, this assumption is not only untrue because their sexual anatomy is atypical, but also dangerous because they are forced to face extreme stigma and painful and unnecessary corrective procedures to make them more “normal.”

Take, for example, Cheryl Chase. When she was eighteen months old, doctors announced that Cheryl Chase was indeed a girl. Born with “both ovarian and testicular tissue, a phallus midway between an average penis and an average clitoris, and a vaginal opening behind her urethra” (Nussbaum, 1999, p. 42), Chase was labeled a “true hermaphrodite” at birth. Her physiology was considered to be somewhere between wholly male and wholly female. She underwent many invasive tests and procedures before doctors made their gender proclamation. Once decided, doctors quickly worked to

“correct” her condition. They removed her clitoris, arguing it was too large and therefore looked too much like a penis, surgically “normalized” her internal reproductive organs, and prescribed a series of feminizing hormones to be taken as she grew older. As she matured, she felt neither normal nor feminine. Instead she felt isolated and different.

Her story is similar to Alex A’s. Alex was given a female gender assignment at birth. Identifying the condition as “labial-scrotum fusion” (Kessler, 1998, p. 1), physicians decided Alex’s genitalia appeared more female than male. Before age two, however, Alex’s mother noticed that Alex’s phallus was beginning to enlarge. At puberty, Alex’s voice deepened and he began to irregularly menstruate from his phallus. Hoping to correct the condition and make him fully male, an endocrinologist suggested Alex should undergo genital surgery and begin a daily testosterone regimen. Alex declined the treatment indicating that his conservative mother disapproved and was thus “encouraging him to grow breasts” (Kessler, p. 1). By age twenty-four, his breasts did begin to develop. At that point, another endocrinologist suggested he take estrogen and undergo a reduction of the clitoris to make him fully a woman. Again, he turned down the treatment. He was confused by the lack of transparency and contradictory information from doctors. He felt like a male, but was labeled female and had no idea what his diagnosis actually was.

Unfortunately, his story, as well as Chase’s, is just one of literally thousands that share similar themes of isolation, stigma, and despair as a result of being diagnosed with variations of sexual development that are generally called intersexuality (Koyama, 2003). As more people like them have shared their stories, there has been a growth in advocacy

on their behalf. A dedicated core of a few brave individuals has begun championing the cause of improving the lives of intersex individuals. Devoted to ending the shame, secrecy, and dangerous medical treatment of intersex individuals, advocates have faced severe opposition to their message because it forces many people to reexamine a core idea of human sex identity: that humans are either male or female. Dedicated to procuring equal treatment and a dignified lifestyle for intersex individuals, intersex advocates engage in trenchant critiques of not only the medical establishment but also one another in hopes of proving their position correct. Since their founding, the organizations fighting for intersex rights have engaged in strident and divisive debates with one another. As a result, the discourses surrounding intersex advocacy offer a rich site for exploring the public ideological struggle between several competing perspectives. In this dissertation, I uncover and investigate many of the underlying tensions and debates that have arisen among the major advocacy organizations in the fight for intersex rights.

Despite a general rise in public awareness and the scholarly study of intersex issues, there has been a dearth of rhetorical scholarship that seeks to chronicle and discuss the dialectics at play in discussions over intersex rights. In this study, I begin to fill that gap. While rhetorical scholars are not prepared or equipped to discuss the biological manifestations or the appropriate treatment of intersex, rhetoricians do have valuable insight to add to the public debate surrounding intersex advocacy. Because one “will recognize immediately how issues of language, definition, and culture are central” (Breu and Gardner, 2009, p. 104) to fulfilling the goals of intersex advocacy, one can

easily anticipate the ways in which scholars of rhetoric and persuasion might help clarify and illuminate the debates. The advocacy groups rely on various forms of public sphere communication to prove their position correct. In the debates over intersex, advocates engage in a “struggle over meaning,” which provides us with an excellent site to examine how “rhetors . . . respond to one another in their attempts to understand the world and persuade others to action” (Stevens, 2006, p. 289). As rhetorical scholars, we are trained to do just this—to evaluate the relative merits of different arguments and assess the efficacy of differing forms of communication. In addition to having expertise from training, we also have an obligation to take a critical stance toward public argument. Young (1990) argues, that absent such a stance, “many questions about what occurs in society and why, who benefits and who is harmed, will not be asked, and social theory is liable to reaffirm and reify the given social reality” (p. 5). However, before analyzing the key debates among intersex advocates, I first offer some background on intersexuality, including a summary of the main intersex diagnoses. Second, I review the current state of literature surrounding intersex advocacy and justify the need for further exploration. Third, I argue for the expansion of social movement criticism to include a study of social movement organizations (SMOs). Such an expansion will lay the foundation for a rhetorical criticism of the key issues being discussed by SMOs within the intersex advocacy movement. In the chapters that follow I analyze each of the key issues in depth.

Background on Intersexuality

Even a cursory glance at the academic and medical literature surrounding intersex individuals reveals that there is not a single, agreed upon definition of intersexuality (Aliabadi, 2004). In general, intersexuality refers to “atypical congenital physical sexual development” (Gross, 1999, p.65), which often results in a child being born with ambiguous genitalia (Speroff et al., 1999). It implies a state in which an individual is neither entirely male nor female; they are “in between” (Sytsma, 2006, p. xvii). In a more technical sense, intersexuality is an umbrella term for a host of “congenital conditions in which the development of chromosomal, gonadal, or anatomical sex is atypical” (Lee, et al., 2006, p. 488). Although the causes of intersexuality are not entirely known, it is clear that the process of in-utero sex differentiation strays from typical development resulting in one of the many variations of intersexuality.

Importantly, the varied intersex conditions may be more common than many would expect. Although conservative estimates suggest that intersex variations exist in one in every 4,500 births (i.e., Vilain, 2006), others suggest that it is more likely, after accounting for underreporting and including all of the major intersex conditions, that it is closer to one in every 1,500 births (Blackless et al., 2000; ISNA, 2005c). Gurney’s (2007) research, currently the most recent on the topic, points to even higher frequency. She writes, “Some researchers now suggest a frequency of 1.7 intersexed births per 100, with surgical rehabilitation required in one in 2000 births” (p. 626). Diamond (2007), one of the leading experts on intersexuality, says that the best data suggest and consensus is increasingly growing that “more than one in every hundred newborns has an intersexed

condition” (p. 37). Of course, certain intersex variations have a higher incidence than others, and depending on the specific hormonal imbalance or genetic configuration, a variety of anomalous conditions may result. To better understand each of the different categories of intersex conditions, it is first useful to more fully develop the typical process of sexual differentiation and how the development of intersexed bodies might differ from that.

It is generally considered useful to view human sex as being contingent upon five separate aspects: genotypic sex (genes), gonadal sex (internal sex organs), hormonal sex (masculine or feminine hormones), phenotypic sex (external sex organs), and psychological sex (the sex one considers oneself) (Kemp, 2006). In the overwhelming majority of the population, each of these aligns to create a unified sexual identity. For example, most human females have 46 chromosomes with two X chromosomes (46,XX), produce and use estrogen and progesterone, have a fully functioning internal reproductive system with ovaries, fallopian tubes, and a uterus, as well as typical external genitalia, and understand themselves to be women. In the case of intersexed individuals, however, discordance among some of these occurs during gestation.

Until the seventh week of fetal development, male and female embryos appear identical with two amorphous gonads, undifferentiated urogenital ducts and indifferent genitals (Hospital for Sick Children, 2005; Wang, 2008). During the seventh week and beyond, however, sexual differentiation takes place. The gonads will develop into testes in the presence of a hormone called testes-determining factor (TDF), which is controlled by the SRY gene on the Y chromosome. In the absence of TDF and SRY, ovaries form.

In males, the testes subsequently produce two hormones: Mullerian Inhibitory Substance (MIS), which inhibits the growth of the female Mullerian ducts; and testosterone, which transforms the Wolffian ducts into spermatic ducts. In the absence of testosterone triggering their growth, the Wolffian ducts disappear. Without MIS to stop them, the Mullerian ducts turn into the uterus and uterine tubes. As the testes continue to develop they begin to emit androgens that transform the previously undifferentiated genitals into typical male external genitalia. Without such androgens the genitals become those of a typical girl (Cohen-Kettenis and Pfafflin, 2003; Grumbach and Conte, 1998; Wilson, George, and Griffin, 1981). It is during the specific stages in this developmental process that each of the various intersex conditions occurs. Such conditions can be divided into five heuristic categories: sex chromosomal anomalies, congenital development of ambiguous genitalia, congenital disjunction of internal and external sex anatomy, incomplete development of sex anatomy and disorders of gonadal development (Consortium on the Management of Intersex Disorders, 2006).

Sex Chromosomal Anomalies

Although most people usually have a total of 46 chromosomes consisting of two sex chromosomes (XX in females and XY in males) and 22 chromosomal pairs called *autosomes*, individuals with gonadal dysgenesis have sex chromosomal anomalies (either more or fewer chromosomal pairs) that result in abnormal development of their internal sex organs. Such variations include Klinefelter Syndrome, Turner Syndrome, and sex chromosome mosaicism. Klinefelter's is the most common cause of gonadal dysgenesis (Heffner and Schust, 2006). Those with Klinefelter's have one extra X-chromosome,

making them 47,XXY. They tend to be tall males with non-sperm producing testicles and delayed puberty (Cohen-Kettenis and Pfafflin, 2003; Heffner and Schust, 2006; Verp and Simpson, 1987). Estimates suggest that it may occur in one in every 500 to 1000 phenotypic males (Heffner and Schust, 2006).

Turner syndrome is the second most common cause of gonadal dysgenesis. Individuals with Turner syndrome are phenotypically female, but lack one X chromosome, making them 45,X (Naeraa and Nielsen, 1990; Vilain, 2006). People with Turners tend to be short in stature, have delayed menses, and often are infertile due to fibrous cysts on their ovaries. Kidney and heart defects are common (Ferguson-Smith, 1965; National Institute of Child Health and Human Development, 2007). It is estimated that one in every 2,500 live female births worldwide may be Turners (Ferguson-Smith, 1965; National Institute of Child Health and Human Development, 2007 National Institute of Health, 2008).

Individuals with mosaicism, or mixed gonadal dysgenesis, have chromosomal karyotypes that vary from one cell to the next as a result of atypical cell division early in embryonic development (Ropke et al., 2004; Shreenlwas, 1994). For example, one cell may be 45,X, while another may be 46,XX. The type of mosaicism will determine the extensiveness of variation and the outward appearance of the individual (Davidoff and Federman, 1973). Rates for frequency cannot be found.

Congenital Development of Ambiguous Genitalia

Congenital development of ambiguous genitalia occurs much less frequently than chromosomal anomalies, with an occurrence rate of one in every 13,000 births. It

includes, as the name suggests, a myriad of variations that manifest as atypical genitals. The most common of these are Congenital Adrenal Hyperplasia (CAH), Partial Androgen Insensitivity Syndrome (PAIS), micropenis, and clitoromegaly. The most serious of these is CAH, or female pseudo-hermaphroditism, which may result in death from the adrenal gland's overproduction of testosterone and other hormones in place of cortisone (White and Speiser, 2000). Individuals who are 46,XX with CAH are said to have ambiguous genitalia because they have enlarged clitorises that appear to some to resemble penises (Mayo Clinic Staff, 2007). As they age, their bodies masculinize; they tend to grow excess body hair, their hairline recedes and their voices deepen (Mayo Clinic Staff, 2007; Speiser and White, 2003). Individuals with CAH who are 46,XY will not have ambiguous genitalia because their testes already produce so much testosterone and their bodies cannot process it (Kliegman et al., 2007). However, they do tend to go through puberty extremely young and are often short in stature from the early excess of testosterone in their bodies (Alizai et al., 1999). At birth, 46,XY children with PAIS have can have entirely typical female genitalia, frank ambiguous genitalia or typical male-appearing genitalia; generally, outward appearance will determine whether the patient is raised male or female (Gottlieb, Beitel, and Trifiro, 2007). Because it is most common for PAIS to result in female-appearing genitalia, most PAIS patients are raised female (Wisniewski, et al., 2000). They have functioning testes, but because the body is insensitive to androgens male external genitalia do not develop normally (British Society for Paediatric Endocrinology and Diabetes, n.d.). Anti-Mullerian hormone is produced at

typical levels, however, so the Mullerian Ducts regress (Cohen-Kettenis and Pffafliin, 2003).

Two other versions of the development of ambiguous genitalia include micropenis and clitoromegaly. Individuals with these disorders are said to have genitals that fall outside the range of what is considered normal size. Although the cause is unknown, infant boys with micropenis have normally functioning sex organs but have a smaller penis than is considered normal (Dreger, 2005b; Lee et al., 1980). Similarly, infant girls with clitoromegaly have normally functioning reproductive anatomy, but have a clitoris that is considered larger than what is normal (Dreger, 2005a; Edmonds, 2003).

Congenital Disjunction of Internal and External Sex Anatomy

Individuals with congenital disjunction of internal and external sex anatomy have, as the name suggests, discordance between their internal gonads and external sex organs. Although overall this condition is very rare at approximately one in every 20,400 births (Bangsboll et al., 1992), the most common versions of these are Complete Androgen Insensitivity Syndrome (CAIS) and 5-Alpha-Reductase Deficiency (5A-RD). Children with CAIS are 46,XY karyotype, have undeveloped Wolffian Ducts and female-appearing external genitalia and, thus, are not generally diagnosed until later in life. Their outward appearance is entirely feminine, but their internal sex organs are male and generally need to be removed because their presence heightens the risk of cancer (Gottlieb, Beitel, and Trifiro, 2007). Individuals with 5A-RD have an enzyme deficiency that causes them to be born with ambiguous or female external genitalia (Dreger, 2007). As with CAIS, their internal gonads are fully functioning, but often need to be removed

due to the increased cancer risk from excessive production of androgen. During puberty, people with this condition tend to develop some secondary masculine sex characteristics, such as increased muscle mass, deepening of the voice, development of pubic hair, and a growth spurt. The penis also tends to grow larger (U.S. National Library of Medicine, 2008). Those with 5A-RD typically do not develop much facial or body hair. Most affected males are infertile (Medline Plus, 2008).

Incomplete Development of Sex Anatomy

Patients with incomplete development of sex anatomy, or Vaginal Agenesis (VA) and Gonadal Agenesis (GA), have congenital disorders of the female reproductive tract, which presents as underdeveloped or absent uteruses, vaginas, or Mullerian Ducts (Children's Hospital Boston, 2007). VA occurs in roughly one in every 5,000 infant girls (Center for Young Women's Health, 2006; Mayo Clinic, 2009). Few health risks are related to either VA or GA; however, about thirty percent of those with VA have some form of kidney abnormality (Mayo Clinic, 2009). Many people choose to undergo constructive surgery to create the appearance of typical-looking external female genitalia (Foley and Morley, 1992; Mayo Clinic, 2009).

Disorders of Gonadal Development

Those diagnosed with disorders of gonadal development, such as ovotestes, were historically referred to as true hermaphrodites. Their internal gonads have some combination of ovarian and testicular tissue. The variations are many and may include two ovotestes, one ovoteste and one ovary, or one ovary and one teste (ISNA, 2005f). Although not necessary for the condition to be present, the external genitals often also

display atypical variation. When no atypical appearance exists, the condition may not be discovered until later in life (Dewing, Bernard, and Vilain, 2002). Overall, disorders of gonadal development are extremely rare (Simpson, 1996).

Summary of Medical Treatment

Although specific treatment differs depending on the actual diagnosis, several common themes exist in discussions of traditional medical handling of intersex cases. Developed by psychologist John Money and his colleagues in the 1950s (e.g., Money, Hampson, & Hampson, 1955a, 1955b, 1956, 1957) and further solidified in his work with Anke Ehrhardt (1972), the predominant twentieth century treatment of intersexuals grew out of several assumptions regarding the development of gender identity. Money and his colleagues reported that one's gender identity is neutral at birth and is developed as a consequence of one's social environment; gender is a product of "nurture" and not "nature." Similarly, the healthy development of one's gender identity is dependent on the appearance of normal genitals (Diamond & Sigmundson, 1997). Specifically, upon the birth of a baby,

As soon as the shape of the external genitals is perceived, it sets in motion a chain of communication: It's a daughter! It's a son! This communication itself sets in motion a chain of sexually dimorphic responses, beginning with pink and blue, pronominal use, and name choice, that will be transmitted from person to person to encompass all persons the baby ever encounters. . . . Dimorphism of response on the basis of the shape of the sex organs is one of the most universal and

pervasive aspects of human social interaction. It is so ingrained and habitual in most people. . . . (Money and Ehrhardt, 1972, p. 12)

Money and his colleagues argued that society would continue to reinforce the initial gender assignment in correspondence with external genitalia. Their thinking has several consequences for the treatment of intersexual individuals. Because “gender identity arises primarily from psychosocial rearing (nurture), and not directly from biology (nature) . . . all children must have their gender identity fixed very early in life for a . . . ‘successful’ gender identity to form” and because “very early in life the child's anatomy must match the ‘standard’ anatomy for her or his gender,” (Dreger, 1998, p. 27), children with intersexual conditions manifesting in ambiguous genitalia were expected to undergo medical interventions to ‘normalize’ their bodies. The result of Money’s positions can be seen in medical texts outlining proper treatment. In *The Intersexual Disorders*, doctors Dewhurst and Gordon (1969) advised:

To visualize individuals who properly belong neither to one sex nor to the other is to imagine freaks . . . condemned to a solitary existence of neglect and frustration. Few of these unfortunate people meet with tolerance . . . from their fellows and fewer find even limited acceptance in a small section of society: all are constantly confronted with reminders of their unhappy situation. The tragedy of their lives is the greater since it may be remediable; with suitable management and treatment, especially if this is begun soon after birth, many of these people can be helped to live happy, well-adjusted lives, and some may even be fertile and be enabled to enjoy a normal family life. (p. vii)

The course of treatment suggested by Dewhurst and Gordon typically included invasive cosmetic genital surgeries on infants and administering rigorous hormone therapy regimens to adolescent youth.

Genital surgeries may involve a variety of procedures, including removing part or all of the penis and scrotum or clitoris and labia, reshaping a penis, or creating a vaginal opening. Typically, the first surgery is performed in the first month of a child's life with follow-up surgeries often performed on older children in order to better the appearance of the genitals or to make the medically constructed genitals functional (Haas, 2004).

Gender-appropriate hormones are then administered at puberty to complete the successful establishment of a stable gender identity. Medical practitioners argue that administering high doses of synthetic hormones is essential to effectively prevent the onset of gender dysphoria and ensure the intersexed individual safely and comfortably transitions to a well-adjusted heterosexual adult lifestyle (Haas, 2004). Intended to “normalize” intersexed individuals, the coupling of surgery with hormone therapy has maintained its position as preferred treatment regimen for over sixty years.

Labeled by some as the “concealment-centered paradigm of intersex treatment” (Dreger, 1998) and by others as the “cut now, maybe ask about quality of life later” approach, (ISNA, 2005g, para. 2), this model has faced severe criticism from a variety of sources. Although the critiques are many, there are several recurring themes. First, critics worry that the procedures are performed to appease and comfort parents and doctors; they are not performed out of necessity for the child’s safety. Preves (2003) elucidated, “these elaborate, expensive, risky procedures are performed to maintain social

order for the institutions and adults that surround that child” (p. 12). Second, they argue that the current system is one based on lying. Doctors lie to, or at least conceal important information from, parents, who in turn lie to their intersexed children about the nature of their condition. Although often having good intentions, doctors may limit the information given to parents in order to protect the parents from feeling at fault for their child’s condition. For example, Van Wyk, a doctor who used to follow traditional protocol, would conceal information from parents because he worried “they could not accept the truth” (Nussbaum, 1999). As a result, parents have inadequate information to share with their child and tend to cover up information in hopes of protecting the child and ensuring consistent gender identity development (Tamar-Mattis, 2006). Third, they argue that the system, as it currently exists, is sexist because it treats girls differently than boys. Specifically, doctors’ primary concern in relation to girls is to maintain fertility, while their primary concern for boys is ensuring the size and function of the penis for sexual pleasure (Dreger, 1998). Finally, they worry that the standards for genital anatomy, which determine if surgery is essential, are arbitrary and illogical (ISNA, 2005k). In fact, the status quo of treatment allows doctors to “make decisions about gender on the basis of shared cultural values that are unstated, or perhaps even unconscious” (Kessler, 1990, p. 25).

Worried about the dangerous effects of this model of treatment, members of the Intersex Society of North America (ISNA) and its supporters started a crusade in 1993 aimed at ending what they saw as the medical mismanagement of intersexed individuals. Although they were frustrated for over a decade due to lack of knowledge on the subject,

doctors' stubbornness, and a host of other constraints, they continued to push hard for alternative treatment regimes and more sympathetic perspectives. In October 2005, their call was partially heeded when fifty international experts, including pediatricians, endocrinologists, reproductive specialists, and two intersex adults convened in Chicago to formulate a document guiding proper intersex management derived from an evidence-based literature review (GGH, 2006). The conference resulted in a consensus statement suggesting significant changes to intersex management. The report stops short of outlawing early genital surgery, but does suggest that appropriate management should include the following:

- (1) Gender assignment must be avoided before expert evaluation in newborns; (2) evaluation and long-term management must be performed at a center with an experienced multidisciplinary team; (3) all individuals should receive a gender assignment; (4) open communication with patients and families is essential, and participation in decision-making is encouraged; and (5) patient and family concerns should be respected and addressed in strict confidence. (p. e490)

Some intersex advocates have hailed the new recommendations as an enormous success. As Weil (2006) argues, "Where the consensus departs from tradition is that it also instructs doctors to discourage families from rushing into surgery" (p. 2). Further, the report states that "no good scientific studies prove infant cosmetic genital surgery improves quality of life" (Weil, p. 2). It also satisfies many because the report asks for open communication between patients, parents and the multidisciplinary medical team, including endocrinologists, geneticists, urologists, gynecologists, sexual-medicine

specialists, and mental-health professionals. Chase (2002) wrote, “Families and patients need complete and honest medical information, presented in a comprehensible way” (p. 3) and the report takes a step toward accomplishing this. Finally, while the report does not end all the problems and complications surrounding intersexuality, it does promise confidential management of the intersexed child’s records and treatment. This is a huge departure from past treatment, which often allowed public viewing of intersexuals’ bodies as a “learning tool” for young doctors (Colapinto, 2006). Overall, the report was perceived and touted as a major victory for the ISNA and went a long way in fulfilling the group’s objectives.

It would be impossible to overstate the importance of early criticisms of routine medical practices. The determination and hard work of the ISNA, academics, activists, other intersex advocacy organizations, and several sympathetic doctors were essential to changes in treatment, both in theory and in practice. Although it is true that more change needs to happen, Levine (2007) argued that over the last decade we have witnessed a “sea-change” in “assumptions about how to manage children with ambiguous genitalia” (p. 113). In particular, there is a general move toward a moratorium on cosmetic sex assignment surgery, and doctors are typically using more honesty and candor in their discussions with parents and patients. However, “Just as wars are too important to be left solely to generals, the future sexual life of children is too important to be left solely to physicians and parents. . . . Yes, we have come far in the understanding and management of intersex conditions. There is still a ways to go” (Diamond, 2007, p. 38). As such, countless individuals and groups are still fighting for further medical reform, changes in

societal conceptions of gender, end to stigma, legal rights for intersex individuals, and a myriad of other issues. The groups at the forefront of this struggle in the United States have been the Intersex Society of North America, the Accord Alliance, the Organisation Intersex International and Advocates for Informed Choice.

Intersex Society of North America

As the first prominent, longest running, and best-known intersex advocacy and policy organization (Dreger and Herndon, 2009), the Intersex Society of North America (ISNA) has been hailed as central to the struggle for intersex rights. The group was started in 1993 by an individual who publicly went by the name Cheryl Chase, but was known by friends and family as Bo Laurent.¹ The group was intended to fight for those harmed by their experiences with the health care system and was “devoted to systemic change to end shame, secrecy, and unwanted genital surgeries for people born with an anatomy that someone decided is not standard for male or female” (ISNA, 2005a). Worried about the stigma faced by intersex individuals, Chase sought to find other intersex individuals and allies willing to publicly take a stand against the traditional treatment of intersexuality in the medical establishment and society at large. Although it took them over a decade of hard fought battles, the group found success in 2005 when the consortium of medical practitioners signed new recommendations, which, as stated earlier, urged changes in the medical treatment of intersexuals. Excited that a consensus now existed on the appropriate treatment of intersex individuals but uncertain where to

¹ Named Bonnie Sullivan by her parents, she legally changed her name to Bo Laurent in 1995. Preferring the pseudonym Cheryl Chase for her public, activist life, she decided in 2008 to use Laurent in all aspects of her life. There are many different and conflicting reports on why she chose and pseudonym and what her motives were for returning to Laurent in 2008.

go next, the ISNA closed in March of 2008. They did, however, choose to leave their website as an archive of historical documents and useful information for parents, advocates, and researchers to use.

Due to its tremendous success and outspoken leader, the Intersex Society of North America is referenced in most discussions and literatures surrounding intersex, from mainstream popular sources like the *Oprah Winfrey Show* (“Growing Up Intersex,” 2007), the New York Times (e.g., NYT Health Guide, 2009; Weil, 2006), and the San Francisco Chronicle (e.g., Torassa, 2002) to a host of scholarly disciplines, including gay, lesbian, and queer studies (e.g., Dreger & Herndon, 2009; Hackford-Peer, 2005; Rosario, 2004; Rosario, 2009), human sexuality studies (e.g., Melby, 2002, Rye, 2000; Serano, 2008), education and pedagogy (e.g., Breu & Gardner, 2009) philosophy (e.g., Morland, 2008; Valentine & Wilchins, 1997), law (e.g., George, 2006; Tiefer, 2000) and sociology (e.g., Turner, 1999). Despite the breadth of scholarship referencing the ISNA, very little, if any, goes further than detailing when it was founded and labeling it as the leading intersex advocacy group. Because of how recently the ISNA dissolved, only a few have publicly recognized its closure and transition to the Accord Alliance (e.g., Breu & Gardner; Rosario, 2009).

Accord Alliance

Upon its closure many of the Intersex Society of North America board members, including Bo Laurent, traveled across the United States from San Francisco to Boston and opened the Accord Alliance in March 2008. Although sharing similar board members, the Accord Alliance set itself apart from ISNA with newly defined goals and a distinct

mission statement. Focusing almost exclusively on the medical aspects of intersexuality, the Accord Alliance's "mission is to promote comprehensive and integrated approaches to care that enhance the health and well-being of people and families affected by DSD by fostering collaboration among all stakeholders" (Accord Alliance, 2008a). Preferring the term *disorder of sex development* or *DSD* to the term *intersex*, members of the Accord Alliance are in the midst of a two-year plan to create a public research database full of information about intersex conditions and to lobby for the implementation of Consortium guidelines for the medical treatment of intersex conditions. Specifically, their plan includes creating and disseminating new model of care guidelines, assembling teaching curricula for college classrooms, expanding their website, hosting a symposium about quality DSD research, and crafting a video to increase awareness about DSDs (Accord Alliance, 2008b). If these programs are successful, they believe the following will be true:

People and families affected by DSD will consider themselves well informed about DSD; they will have the skills and support they require to promote a positive health-related quality of life and overall well-being; and they will express satisfaction with their participation in treatment decisions and their overall healthcare experience.

Accord Alliance will have forged solid partnerships with medical and allied healthcare professional institutions and with community-based (consumer) organizations that share our objectives.

A model of care to guide the interdisciplinary team approach and family-centered decision making will be developed by working collaboratively with stakeholders and will be widely [sic] shared in the form of a "manual" or "tool-kit".

Best practices and solutions for barriers to the successful implementation of the model of care will be identified, evaluated, and broadly disseminated.

Over time, interdisciplinary teams will be in place across the country, and recognized as fully operational, effective [sic], and successful. (Accord Alliance, 2008b)

Because they are only halfway through their first phase of work, it is not yet possible to tell whether they have met their objectives. Similarly, because Accord Alliance is such a young organization, little scholarship in journals or newspapers has been produced detailing their existence, mission, or successes. However, the Accord Alliance is already referenced and attacked by another advocacy group, namely the Organisation Intersex International, which takes issue with many of Accord's positions.

Organisation Intersex International

Like the ISNA, the Organisation Intersex International (OII) is "devoted to systemic change to end the fear, shame, secrecy and stigma experienced by children and adults through the practice of non-consensual normalisation treatments for people born with atypical anatomy, and the arbitrary assignment of a particular gender without an informed consultation with the individual concerned" (OII, n.d.-a). Notably, unlike Accord, OII does not identify intersexuality as being primarily a medical issue. Instead it sees intersex as being an issue of gender and human rights recognition. With chapters in

over 14 countries, the OII is the largest intersex support group in the world (Diamond and Beh, 2008). OII campaigns to “exchange . . . ideas and different perspectives about intersex from various groups and geographical regions” (OII, n.d.-a, para. Q4) and attempts to secure equal treatment and human rights for intersex individuals. Skeptical of binary gender categories, the pathologization of biology and the medical construction of identity, the OII and its founder, Curtis Hinkle, push for the view that individuals should be able to choose their own identity. Because Hinkle is so outspoken and prolific, it is common for other groups to refer to the OII either by the group’s name or by Hinkle’s name. The group has yet to receive much, if any, attention by English scholarly sources. This is surprising considering that the website has such a large library of articles that clearly establishes the organization’s position on the nature of the problem and even overtly differentiates itself from other advocacy groups.

Advocates for Informed Choice

Founded in 2006 by Anne Tamar-Mattis, a longtime community organizer for lesbian, gay, bisexual, transgender, queer and intersex rights, Advocates for Informed Choice (AIC) is the first organization in the United States to focus on attaining legal rights for intersex individuals. Originally named the Institute for Intersex Children, the AIC defines its mission as one that uses “legal strategies to advocate for the civil rights of children born with variations of reproductive or sexual anatomy” (Advocates for Informed Choice, n.d.-b, para. 1). In particular, they focus on teaching parents, individuals with intersex variations, and interested members of the public the legal issues surrounding medical privacy, informed consent, medical records retrieval, school

accommodation and bullying, and children in foster care. Although all of the AIC's public statements are published under the organization's name, their positions arise from the input of many board members, including anatomy and gender expert, Milton Diamond; professors of law, Hazel Glenn Beh, Nancy Ehrenreich, Julie Greenberg and Wenona Whitfield; directors of several nonprofit intersex rights groups, David Cameron, Jim Lake, Jody Marksamer, and Peter Trinkl; and several anonymous individuals or families of individuals with intersex conditions. On their regularly updated homepage they attempt to offer new information and resources about the problems faced by intersex individuals and the AIC's role in overcoming these problems, as well as a discussion board for individuals seeking to find out more information or share their personal stories.

Organizational Justification

As the four leading American intersex advocacy groups, the Intersex Society, Accord Alliance, Organisation Intersex International, and Advocates for Informed Choice have the ability to help shape public and medical discourse about intersexuality. Their prominence and ability to foster change is only one reason why they are apt for study, however. Because of the prominence and importance of the Intersex Society of North America (ISNA) no study of intersex would be complete without its inclusion. In fact, even after its closure, the ISNA is still being actively cited and referenced. As such, it is the natural starting point when discussing the debate over intersex advocacy. Because the Accord Alliance carries on the legacy of the ISNA, but has selected a new objective and missions, it creates an interesting case that overlaps with yet stands in contradiction to the ISNA. With these two organizations selected, it begs the question of why to include the

Organisation Intersex International and Advocates for Informed Choice among all other groups.

There are important similarities that make Accord Alliance, Organisation Intersex International (OII) and Advocates for Informed Choice (AIC) apt and equal units of study. They are nationally focused (as opposed to regional or local support groups), maintain active websites (proving ongoing advocacy), advocate in English (making it accessible to me), and choose to engage intersexuality as a whole (rather than breaking it down into individual disorders, like the Turner Syndrome Society). Further, they reference one another on their homepages; this seems to indicate that they are in dialogue or dispute with one another, which make them excellent candidates for a study on the ongoing debates with intersex advocacy. Of course, despite their structural or organizational similarities, they have very real differences in terms of content, position, mission statement and focus. Each undertake advocacy from a unique perspective—medicine, culture, and law, for Accord, OII, and AIC, respectively. The juxtaposition of these perspectives provides interesting sites for exploration. An analysis of their public rhetoric helps illuminate these issues and offers insight into how these organizations with similar objectives compete and build coalitions to further their cause. Before wading into each of the key issues in contemporary intersex advocacy it is useful to develop a theoretical framework for analysis.

Social Movement Organizations

Although rhetorical scholars have developed a host of theories regarding social movements as unified entities, surprisingly few studies have been published analyzing the

rhetorical interaction of social movement organizations (SMOs). If social movements were entirely unified fronts with one single leader or organization dominating we could ignore the interplay of social movement organizations. However, social movements are hardly ever unified; instead social movement organizations compete with one another for symbolic leadership, occasionally form ad hoc coalitions, and sometimes engage in all-out war with one another (Zald and McCarthy, 1980). In order to explore the relationships of social movement organizations, it is first useful to define social movements and establish a working understanding of the meaning of social movement organizations.

Taking a sociological perspective, Herbert Simons (1970) defined a movement as “an uninstitutionalized collectivity that mobilizes for action to implement a program for the reconstitution of social norms and values” (p. 3). DeLuca (1999) argues that Simons’ approach has maintained a preeminent position in the study of social movements. This is evidenced by “Simons’ pride of place in three important publications, the social movement issue in 1980 of the *Central States Speech Journal*, Arnold and Bowers (1984) weighty *Handbook of Rhetorical and Communication Theory*, and the special issue on social movement criticism in 1991 of *Communication Studies*” (DeLuca, p. 27). Despite maintaining preeminence, it is certainly not universally accepted as the sole perspective on social movements.

Leland Griffin (1969), building on and revising his earlier perspective on movements (1952), offered a dramatic definition. Attempting to synthesize the works of Kenneth Burke, he wrote that “man moves through the moments of his movements:

moves, all told, from Order, Guilt, and the Negative, through Victimage and Mortification, to Catharsis and Redemption. He moves, and is moved, through speech—through the rhetorical power of the word, the persuasive power of language (for rhetoric is the essentially human mode of surviving)” (Griffin, 1969, p. 457-458). Movements thus function rhetorically to achieve transformation through language. Further, movements, according to Griffin, are always met with counter-movements, “a reactive corps of defendant rhetors that give salience to the errant symbols of the existing order” (p. 463-464). Thus, movements are inherently dialectical, forcing competition between those attempt to push for change and those hoping to maintain the status quo.

Building on Griffin, Cathcart (1972) argued that the central attribute of a movement is the existence of a “dialectical tension growing out of moral conflict” (p. 87). It is this “dialectical enjoinder in the moral arena” that sets social movements apart from other dramatistic acts (p. 87). Cathcart (1978) further clarified that movements can be identified by their confrontational form. Specifically, “movements are a kind of ritual conflict whose most distinguishing form is confrontation” (p. 224). Wilkinson offered a complementary perspective, arguing that movements are “Languaging strategies by which a significantly vocal part of an established society, experiencing together a dialectical tension growing out of moral (ethical) conflict, agitate to induce cooperation in others, either directly or indirectly, thereby affecting the status quo” (p. 91). At the heart of social movements is the confrontational use of symbols to encourage some sort of societal transformation through dialectical enjoinder.

Such definitions offer important insight into how movements as a whole use rhetoric to challenge existing social institutions. However, social movement theory, as currently conceptualized may be too limited in several ways. First, definitions of social movements and existing social movement criticism seem to assume that social movements are monolithic entities, but they are not; they consist of shifting constituencies from varying backgrounds that push for a wide variety of ideological positions (Gamson, 1975; McCarthy and Zald, 1977; Staggenborg, 1986; and Tilly, 1978). The definitions fail to adequately account for the competing forces at work within an individual social movement. In other words, existing definitions provide us with the ability to analyze the ways in which suffragettes fought against existing social norms and legal structures to gain voting rights. They even allow us to analyze the rise of counter-movements attempting to quash the suffrage movement. The definitions are too limited, however, to allow for an evaluation of the ways in which the multiple and varied groups within the suffrage movement formed coalitions, competed for resources, fought over symbol use, and argued over strategies and tactics.

Overall, social movement criticism operates on a macro level. It focuses on the meta-dialectic between those who challenge the existing social order and those who defend it. I believe this perspective can be supplemented by a more micro-level analysis. Because a social movement is a collective of people and groups pushing for change, it should be assumed that the rhetoric exchanged among those individuals and organizations is an important factor in overall movement success or failure. An

exploration of the relationships between the groups provides important insight into how a larger movement works.

Second, a majority of movement criticism has focused on historical methods or, at least, on movements that can be understood in a historical context. In other words, the movements that are typically studied are complete and can be analyzed as self-contained units with discreet stages of pre-inception, inception, rhetorical crisis and consummation. Such historical distance gives the researcher the perspective necessary to be able to identify distinct parts of a movement and to isolate from afar the different strategies used by key players. However, when a movement is still evolving it is much more difficult to succinctly label stages and to understand precisely where a movement is going. Because there is tremendous value to studying on-going movements, it is important to find a method that allows for contemporary study of on-going phenomena.

Social movement organization (SMOs) theory can help overcome the shortcomings of social movement criticism by encouraging scholars to evaluate the micro-level rhetoric of competing organizations within a social movement and by allowing researchers to engage in the study of contemporaneous movement. In the end, I believe that a more fully developed understanding of SMOs enriches social movement criticism overall by offering a more complete analysis of what is occurring within the movement.

Zald and McCarthy (1970) defined a social movement organization (SMOs) as “a complex, or formal, organization which identifies its goals with the preference of a social movement or countermovement and attempts to implement these goals” (p. 2).

Staggenborg (1986) simplified this, asserting that SMOs are “the key actors in modern social movements” (p. 375). Stewart et al. (2001) offer a complementary perspective asserting that they are simply elements of a broader social movement. They are the more or less formalized groups that engage in actions to advance a movement’s goal.

The existing studies of social movement organizations arose out of the resource mobilization theory. Developed by sociologists, resource mobilization theory asks the question, “How can . . . people organize, pool resources, and organize them effectively?” (Fireman and Gamson, 1979, p. 9). Assuming organizations will act rationally, it focuses on the ability of members of a social movement to acquire resources and mobilize people towards certain ends (Kendall, 2006). In its original iteration, “resources” meant money, time, media access, and material goods such as equipment and property (e.g., McCarthy and Zald, 1977). In contrast to this economic-material focus, later versions of the theory suggested that resources also include political-ideological aspects, such as motivation, ideology, legitimacy and political environment (e.g., McAdam, 1982; McAdam, McCarthy and Zald, 1988). Studies of resource mobilization theory suggest that movements require economic and political resources to be successful. Thus, coalition building among SMOs and securing resources from external parties will help movements achieve their goals.

Despite such findings many SMOs are unwilling or unable to assemble workable coalitions (Staggenborg, 1986). This seems counter-intuitive: why would groups choose not to pool their resources and work together if it increases their chances of success? I argue that resource mobilization theory cannot answer this question because it assumes

that SMOs tend to prefer short-term, tangible gains. Such a view, however, ignores the interrelated factors of rhetoric and ideology. Although resources are relevant to movement success, it is important to recognize the key areas of activities for SMOs include framing movement agendas, cultivating collective identities, and mobilizing collective actions (Gamson and Wolfsfeld, 1993; Smith, 2001; Watkins, 2001). Thus, it is necessary to adopt a rhetorical lens and analyze the way public discourse functions to do such things. Further, whereas resource mobilization theory offers an *external* proscription of the key factors for movement success, focusing on the rhetorical choices made by the groups themselves provides more complete insight for what the SMOs themselves value and how they define their success. Focus on the groups' own rhetoric offers a more contextually specific analysis and recognizes that all movements are rooted in particular socio-historical contexts that dictate the terms of their struggle and success.

In assessing SMOs there are several key concerns. First, what are the goals of an organization? The specific goals of an organization can vary dramatically from another organization within the same overall social movement (Packwood Freeman, 2009). From cooperative to confrontational and reformist to revolutionary, there exist several spectra along which a group can identify itself and its goals (Jasper, 1997; McAdam, et al., 1996). Second, how does a group understand and construct the nature of the problem they are trying to solve? SMOs exist to transform some element of society. The way they construct the thing they are trying to change is extremely important. They face pressure to use socially acceptable language to appear credible and reasonable (Cox, 2006); if they are too moderate they risk being assimilated, yet if they are too extreme, they risk being

trivialized (Gitlin, 2003). Third, how do they define success? This question results in several corresponding queries: Whom do they intend to reach, or who is in their target audience? What structures or ideologies need to change before they have fulfilled their organizational mission? And what actions need to be undertaken to achieve those changes? Asking such questions helps, first, to figure out what organizations believe to be important, and, second, to understand and compare the different visions SMOs have for societal change.

An analysis of the SMOs associated with intersex advocacy can provide insight into the specific case of the intersex movement. The groups engaged in intersex rights advocacy provide an excellent site for exploring the public rhetoric of several social movement organizations operating under the auspices of a single social movement. A review of their public discourses, including websites, publications and press releases, finds several recurring topics.

First, each of the groups seeks to develop its own unique organizational identity. The groups identify distinct organizational missions and strategic objectives. Chapter two attempts to answer the questions, how do the organizations define themselves and what are the goals implications of these self-definitions on the overall movement? This is done by looking at the rhetorical framing of organizational mission and strategic purpose as discussed on each of the group's websites. The Intersex Society of North America sought an end to shame and stigma by raising awareness among parents, doctors, and the general public and hoped to prevent unnecessary surgeries by calling for medical reforms. The Accord Alliance is almost exclusively focused on the medical field, hoping

to help implement comprehensive and integrated health care reforms. The Advocates for Informed Choice is pushing for legal reform in the long term and offering legal services in the short term and Organisation Intersex International has a much broader agenda of campaigning for human rights and exchanging ideas across various groups and geographical regions. This has important implications for how and to what extent that organization will compete or cooperate with other organizations in the movement.

Second, each of the groups defines the nature of intersexuality very differently. They have different answers to the questions: What is intersexuality? What does it mean to be intersexual? How should we label, define, and identify this phenomenon? The third chapter of this study therefore answers the question, how do the different groups understand and construct the nature of the problem they are trying to solve? The power to name and define intersexuality is a primary concern; all four groups devote a significant portion of their websites to the issue of naming. While the Intersex Society of North America and the Organisation Intersex International strongly defend the nomenclature of *intersex*, Accord Alliance regards *Disorders of Sex Development* to be preferable, while still Advocates for Informed Choice opts for *Differences of Sex Development* and self-selection of terms. Importantly, these are not just minor semantic differences; there are important implications for how the groups interact with one another. The third chapter of this study assesses the rhetorical implications of each name and identifies what is at stake for the intersex rights movement in the organizational battle over naming.

Third, the role of parental decision-making on behalf of intersex youth is taken on by all four leading intersex advocacy groups. Positioned both as an agent of needed

reform and an impediment to important change, parents factor into whether each of the groups can successfully meet their objectives. As a result, chapter four addresses the question, how does each of the groups define its success, in relation to the role of parental decision-making? Unified in their belief that parents are currently uninformed about intersex variations and thus make bad decisions on their child's behalf, each of the groups suggests a change in the way parents make decisions. However, the changes they suggest differ greatly from one another. Chapter four assesses how the groups understand the role of parents in relationship to their organizational mission.

Fourth, the relationship of gender to intersexuality is also discussed by all four groups. Each group offers its own interpretation for how doctors, parents, and society at large should conceptualize gender in relationship to intersex infants. While some of the groups focus on short-term pragmatic reforms, others focus on large ideological transformations. Chapter five continues to address the question, how does each group define its success? However, in this case, the question is in relation to gender identity. Because intersexuality plays with our social constructions of what it means to be a man or a woman, it has interesting implications for how we understand, theorize, and live a gendered existence. While the Intersex Society of North America and Accord Alliance normatively support the two-sex binary system, Advocates for Informed Choice argues that we ought to abide by it because no alternative exists. Conversely, Organisation Intersex International offers a strong critique of the binary gender system and is pushing for the development of a more expansive understanding of gender.

The final chapter connects the findings of the previous chapters to a larger theory of social movement organizations. It attempts to build upon existing theories of social movements by building a case for how our understandings of social movements as a whole can be enhanced by a more micro-level view of the organizations comprising movements. It suggests that an individual analysis of social movement organizations can help answer questions about the reasons for why some groups meet their objectives, while others fall short. It finally suggests directions for future research and offers ideas for what can still be learned from future study.

Conclusion

Each chapter addresses a key issue related to social movement organizations, evaluating the merits of each position and arguing for what is at stake in each of the issues. I draw from the four groups' websites, secondary sources that explain the groups' positions, the testimony of intersex individuals, views of medical personnel, and academic theorists to accomplish my ultimate goal of assessing the current state of intersex advocacy and offering ideas about how SMOs function in the context of a larger social movement. As such, this study contributes to the future of intersex advocacy in hopes of ensuring a life free of shame and stigma for those currently suffering.

There is unfortunately a dearth of rhetorical scholarship on intersexuality and even fewer number of studies regarding intersex advocacy groups. Although medical protocols have changed, it is clear that many believe some sort of reform is necessary, whether those reforms happen in the medical field, among parents, or in society at large. This study attempts to clarify the positions taken by the leading intersex advocacy groups

in hopes of uncovering how they understand their role in the overall movement. In doing so it helps generate an understanding of the ways social movement organizations operate to shape a larger social movement.

CHAPTER 2:

The Importance of Organizational Identity for SMOs

Social movements arise out a perceived need to push for social or institutional change. To form a social movement, individuals must share a common sense of what ought to be changed, how best to create that change and what the ideal outcome will be. These common visions emerge in the form of ideological discourses, which “are interest- and experience-based idealizations offering alternative courses of action; they provide solutions to circumstances that are perceived as having created . . . moral, cognitive, and emotional troubling experiences” (Platt and Williams, 2002, p.334). Using ideological discourses, participants in a movement create a collective identity. However, it is often the case in a social movement that there are differences among members about which ideologies and discourses should be shared and valued. Such dissent is certainly present in the intersex rights movement. The organizations fighting to reform treatment of intersex individuals are ideologically distinct. Their ideological perspectives provide the foundation from which they rhetorically develop their organizational identity. Each of the organizations establishes a clear organizational identity through their mission statements and public documents. In doing so, they codify a public organizational identity that constrains their actions in meaningful ways, putting limits on types of activism allowed, shaping the type of individuals likely to join their fight, and influencing with which groups they can ally. After examining the mission statements and purposes of the four leading intersex organizations it is possible to understand why the construction of organizational identity is so important for a movement.

The Intersex Society of North America

Aiming to “make the world a safer place for families dealing with intersex conditions,” (ISNA, 2005a, para. 3), the Intersex Society of North America (ISNA) was devoted to systemic change to end shame, secrecy, and unwanted genital surgeries for people born with an anatomy that someone decided is not standard for male or female. We have learned from listening to individuals and families dealing with intersex that:

- Intersexuality is primarily a problem of stigma and trauma, not gender.
- Parents’ distress must not be treated by surgery on the child.
- Professional mental health care is essential.
- Honest, complete disclosure is good medicine.
- All children should be assigned as boy or girl, without early surgery. (ISNA, 2005a, para. 1-2)

A link on their homepage for “Our Agenda” brings readers to a page asking, “What does ISNA recommend for children with intersex?” The page outlines the characteristics of a patient-centered model of treatment, which includes a call for open and truthful communication, access to psychologists and counselors rather than surgeons and endocrinologists, development of peer support networks between individuals with similar intersex variations, resorting to medical interventions only if medically necessary, and cosmetic surgeries to be postponed until an individual is old enough to decide for him or herself. On “What does ISNA do?” they write (2005h), “Because our resources are limited, we prioritize organizing efforts that would achieve systemic changes rather than

simply providing service directly to intersex people and their family members. To that end, we focus our resources strategically on educating medical professionals as well as general society about issues faced by people with intersex conditions” (para. 1).

Largely as a result of their targeted efforts, there was acknowledgement from doctors that change in treatment was necessary. However, there is still little evidence that this acknowledgement has produced change in practice. The ISNA Homepage (2008) states,

In the current environment, there is a strong need for an organization to assume the role of a convenor of stakeholders across the health care system and DSD communities. . . . Unfortunately, ISNA is considerably hamstrung in being able to fulfill this role. . . . there is concern among many healthcare professionals, parents, and mainstream healthcare system funders that ISNA’s views are biased. . . . We believe the most fruitful way to move beyond the current dynamic is to support a new organization with a mission to promote integrated, comprehensive approaches to care that enhance the overall health and well-being of persons with DSDs and their families. (para. 7-10)

Believing they had completed what their organizational mission set out to accomplish, the ISNA felt constrained and unable to proceed. As such they closed their doors in March of 2008.

Accord Alliance

The Accord Alliance’s mission is narrowly focused on medical reform. They state (2008a), “Accord Alliance's mission is to promote comprehensive and integrated

approaches to care that enhance the health and well-being of people and families affected by DSD by fostering collaboration among all stakeholders (para. 1). Disappointed that the 2006 consensus on medical care has yet to be fully implemented, Accord seeks to ensure that “stakeholders across the health care system and DSD communities” are aware of and implementing the new protocol. They argue there is “a strong need” to promote this new standard of care and see themselves as the right group to do so (Accord Alliance, 2008a, para. 3). They are “filling this role by becoming the ‘go-to’ organization for resources and information for health care professionals and the community. At the local level, we are fostering this approach by providing consultation and support to interdisciplinary teams striving to deliver the new standard of care to persons with DSD” (Accord Alliance, 2008a, para. 3). In order to fulfill their mission, the Accord Alliance crafted and has begun implementing a two-year strategic plan.

The plan contains two foci. First, it seeks to develop a comprehensive online library of resources “to support the understanding and improvements in care and well-being of persons with DSD and their families” (Accord Alliance, 2008a, para. 4). Second, it calls for Accord to partner with multidisciplinary health care teams in an effort to ensure full implementation of the new standard of care. The board and members of the Accord Alliance (2008a) will consider themselves successful if, at the end of two years:

- People and families affected by DSD will consider themselves well informed about DSD; they will have the skills and support they require to promote a positive health-related quality of life and overall well-being; and they will express

satisfaction with their participation in treatment decisions and their overall healthcare experience.

- Accord Alliance will have forged solid partnerships with medical and allied healthcare professional institutions and with community-based (consumer) organizations that share our objectives.
- A model of care to guide the interdisciplinary team approach and family-centered decision making will be developed by working collaboratively with stakeholders and will be widely [sic] shared in the form of a "manual" or "tool-kit."
- Best practices and solutions for barriers to the successful implementation of the model of care will be identified, evaluated, and broadly disseminated.
- Over time, interdisciplinary teams will be in place across the country, and recognized as fully operational, effective [sic], and successful. (para. 5)

The Accord Alliance has undertaken several programs to help them meet these goals. These programs include piloting a training program for health care workers, co-hosting a symposium on DSD research in 2009, expanding information on their website, creating an instructional video for the general public and developing curriculum for teaching about DSDs in the classroom (Accord Alliance, 2008b).

Organisation Intersex International

With chapters in fourteen different countries, Organisation Intersex International (OII) is the largest intersex advocacy organization in the world. It is “devoted to systemic change to end the fear, shame, secrecy and stigma by children and adults through the practice of non-consensual normalisation treatments for people born with

atypical anatomy, and the arbitrary assignment of a particular gender without an informed consultation with the individual concerned” (OII, n.d.-a). OII “resists all efforts to make intersex invisible, including genital mutilation, medicalisation and normalisation without consent and offers another face to intersex lives and experience by highlighting the richness and diversity of intersex identities and cultures” (OII, n.d.-a, Q1). Its mission includes campaigning in favor of human rights for intersex individuals, encouraging exchange of ideas about intersex across diverse geographical regions, providing information about the actual life experiences of people with intersex variations to medical personnel, psychologists, sociologists and feminists, and assisting families and friends of intersexed individuals to better understand intersex and how to offer support.

Started in Quebec, OII was originally a French-speaking organization. The founders, Curtis Hinkle and Andre Fiset, found that there was “absolutely nothing in French on the internet about intersexuality” (OII, n.d.-c). As such they started compiling information in French and posting it online. Many others from other French speaking areas joined in. Not wishing to dictate what information needed to be shared and unwilling to speak for all intersex individuals, Hinkle and Fiset decided each section of OII “would be independent and work within their own countries on a grassroots level” (OII n.d.-c, para. 3). As a result, OII is a decentralized organization with no rigid hierarchical structure. Hinkle touts that “Each member is the face of OII. OII wants no personality cult to develop with a ‘leader’” (OII, n.d.-c, para. 8). Because of this, they fight for an individual’s right to “define oneself” (OII, n.d.-a, Q1).

To fulfill its mission and meet its objectives, OII focuses primarily on consciousness-raising and educational efforts. They write, “The raising of consciousness of society, the medical profession, and intersex people themselves to the full range of intersex issues is paramount for all intersex people to achieve equality, dignity, respect, the most appropriate health-care, and acceptance within society. Human rights organisations and intersex human rights advocates offer the best prospect of informing and influencing people in society, politicians and the medical community” (OII FAQ, Q7). Their events include commemorating November 8 as Intersex Solidarity Day, encouraging readers and members to sign petitions to change the treatment of intersex, updating their webpage with information relevant to contemporary intersex issues, and offering online support groups in English, French and Spanish and supplies information about intersex in seven languages.

Advocates for Informed Choice

Aimed at “promoting the civil rights of children born with variations of sex anatomy,” (AIC, 2010, p. 1), Advocates for Informed Choice (AIC) is:

the first organization in the country using innovative legal strategies to advocate for the civil rights of children born with variations of reproductive or sexual anatomy. Our mission is to engage parents, doctors, attorneys and intersex activists in strategy discussions; stimulate legal dialogue about the fundamental rights of children born with intersex conditions or DSDs; and employ traditional and non-traditional legal tools to ensure justice for children born with intersex conditions or DSDs. These activities are grounded in a sense of respect and

compassion for the children, parents, doctors and intersex adults involved. (AIC, n.d.-b)

To fulfill this mission, the AIC works with doctors to provide training on “the difficult legal and ethical questions” surrounding intersex treatment, focusing on giving parents answers to questions about their children’s rights to health care, privacy and school accommodations, among others, and with “affected teens” to help teens advocate on their own behalf (AIC, 2010, p. 2). Specifically, members of the AIC and its director, Anne Tamar Mattis, have spoken at medical forums, consulted legislators on state policies, advocated on behalf of numerous individuals with intersex variations in legal disputes and published many articles and pamphlets attempting to increase awareness and education about the legal rights of individuals with intersexuality.

The Founding of Social Movement Organizations

Using ideological discourses, participants in a movement create a collective identity through a process called identicization. Eder, et al., (2002) argue that identicization “is the chain of events through which *objective* conditions of economic or political grievances become the basis of political claims justified by reference to a collective identity” (emphasis mine, p. 17). Identification, thus, offers an explanation for why and under what circumstances social movements might form. However, although their theorizing offers a useful starting point, I wish to expand the concept of identicization beyond an evaluation of *objective conditions* to *symbolic constructions* of social conditions or the ways in which groups perceive the conditions of their

surroundings. For the intersex rights movement changes in material and symbolic circumstances are essential for their objectives to be met.

Citing problems that require change, individuals will begin to form loosely joined collectives. The collectives are based around shared understandings of the problem and similar ideas on how to overcome the problem. Importantly, there are always competing discourses about the nature of the problem and the appropriate solution. Such disagreements occur not only between the dominant institutions and those pushing for change, but also between different sects of people pushing for change. Platt and Williams (2002) and Schegloff (1991) argue that because all ideologies are local, arising out of the different ways in which circumstances are interpreted and communicated, not all groups or people will share an exact image of what constitutes an improved society. Interpretations vary because of the differences in conceptions of the circumstances that must be confronted and the calculus of obstacles to overcome and opportunities possible (McAdam, McCarthy and Zald, 1996). Differences in interpretation tend to mean that many collectives will form as a part of a larger social movement.

Over time these collectives can become more rigid as the groups' identities become more salient. When this happens, it is not uncommon for groups to formalize into organizations pushing for change. How one understands the problem, however, will determine how the organization defines itself and later dictate who joins the organization. At its inception then, it is important for an organization to clearly define who it is and why it exists. It needs a statement of organization identity.

Theory of Organizational Identity

Since its development by Albert and Whetten (1985), there have been a myriad of conceptual and empirical works attempting to better understand the concept of organizational identity (Cornelissen et al., 2007). Whetten (2006) defines organizational identity as the central and enduring attributes of an organization that distinguish it from other organizations. Known as the CED perspective, the theory of organizational identity forwarded by Whetten and developed by many others investigates the central, enduring, and distinctive characteristics of an organization. Organizational identities are thus “engaging and influential conceptualizations of the organization, which are shared by members and/or upheld by its leaders, and often emphasized in formal corporate statements (mission, vision, etc.) and expressions (logos, buildings, symbols, etc.)” (Lerpold et al., 2007, p. 2).

Legitimate identity claims satisfy three criteria (Albert and Whetten, 1985; Whetten, 2006). First, they must be central to the organization’s success and survival; members and leaders must believe the identity feature captures the essence of their organization. In so doing, it gives *raison d’etre* to the organization. Second, identity claims must prove the distinctiveness of the organization. In so doing the identity claim distinguishes the organization from others with which it might be compared and satisfies the members’ needs for self-distinction and self-esteem. Finally, identity claims must display continuity. Identity features should be enduring; they must prove that they can withstand the test of time. In so doing they offer stability to members and prove the organization has a strong commitment to fulfilling its central purpose.

Although organizational identities can also be constructed and perpetuated through members' collective beliefs about the organization and managers' aspirations for what the organization could become (van Riel, 1995), the most public and tangible way an organization creates and disseminates its identity is through the use of identity claims (Lerpold et al., 2007). Identity claims can be found in formal statements about what the organization is, such as mission statements or claims of values and purpose. Through such formal claims, leaders and spokespersons attempt to influence how audiences interpret their organization (Whetten and Mackey, 2002) and hope to provide members with a consistent narrative about the organization (Czarniawska, 1997).

For new organizations, clear organization identity statements are necessary to answer questions regarding who or what the organization is and why people should prefer a given organization to others (Lounsbury and Glynn, 2001). In other words, early statements of organizational identity set the boundaries for the organization, creating markers that set it in relation to some and in competition with others.

For older, more developed organizations, organizational identity is important because identity is likely to influence strategic decisions. Shared identity creates the basis for action (Smircich, 1983). Decision-makers' perception of the identity of their organization tends to affect the way corporate issues are interpreted, attended to, and addressed (Dutton and Dukerich, 1991). Because organizational identity is rooted in core values, acting in line with identity expectations is crucial for the maintenance of the organization. In other words, organizations are built on core values about which the organization's leaders feel passionate. The core values lay the foundation for

organizational identity and thus guide the leaders to make certain choices and follow certain paths (Childre and Cryer, 1999).

Identity related issues also affect every day behavior, with their influence reaching far beyond the boundaries of strategic decisions (Lerpold et al., 2007). Organizational identity provides justification for organizational practices, routines, and policies, and provides the context within which members assign meaning to behavior. Organizational identity thus helps members make sense of their everyday behavior (Fiol, 1991). It is common for organizational members to define themselves in line with the core values of their organization (Ashforth and Mael, 1989). Appealing organizational identity traits positively influence the way members feel about their organization and may stimulate identification and cooperative behavior (Dutton, Dukerich, and Harquail, 1994).

Because organizational identity is so central to individuals' understandings of themselves and their organization, it can be a powerful force preventing change. When changes are suggested that challenge beliefs about an organization's identity, they are likely to be met with strong resistance from members (Reger et al., 1994). This is especially true if the suggested changes violate core values because they negatively influence the psychological wellbeing and commitment people feel to the organization. Whetten (2006) argues that, when challenged, "identity claims are likely to be represented as categorical imperatives—what the organization must do to avoid acting out of character" (p. 221). Of course, challenges to identity can come from a multitude of sources, including from those within the organization who are unhappy with the direction

the organization has taken and from those outside of the organization who disagree with the organization's purpose.

Social Movement Organization Identity

When applied to social movement organizations (SMOs) the salience of organizational identity increases. The role of organizational identity creation in SMOs cannot be understated. The public identity statements made by SMOs are crucially important for several reasons. Organizational identity determines what types of strategies are appropriate for an organization to take, who is likely to join an organization, which organizations are possible allies, which are likely enemies, and also under what conditions the organization will no longer cease to function. Each of these can be seen in the case of the four leading intersex advocacy groups.

Those founding and leading social movement organizations are responding to a perceived societal exigency. In the case of intersex advocacy, the four leading intersex groups are broadly responding to societal and medical mistreatment of persons with intersex variations. Interestingly, however, each of the organizations has a very distinct mission statement and purpose. This is because social movement organizations will craft their mission statements and purposes to match their perception of the nature of the problem. Whereas the Accord Alliance understands the problem as inadequate implementation of new standards of care, the Organisation Intersex International sees the problem as being the result of binary gender conceptions and the forced, non-consensual normalization treatments people are forced to endure to conform. Further, the Advocates for Informed Choice (AIC) interpret the biggest shortcoming of the current system to be

the lack of legal protections for individuals with intersex variations. Because of their unique understandings of the nature of the problem, each organization chooses to adopt a different mission statement.

Correspondingly, each of the organizations chooses a different strategy for overcoming the problem. This occurs because certain symbolic responses set the limits within which certain strategies can be formulated. This is clearly reflected in their organizational purpose statements. Central to AIC's identity is its use of legal strategies. Because the problem is one of legal inadequacy, only legal solutions will suffice. Thus, they are a legal organization. Similarly, the Accord Alliance's (2008a) mission is "to promote comprehensive and integrated approaches to care that enhance the health and well-being of people and families affected by DSD by fostering collaboration among all stakeholders" (para. 1). Their plan for action is thus targeted at creating alliances with different health care providers and implementing a successful model of care across the United States. Because OII views the problem as a larger societal problem and not a medical one, their main initiatives focus on educational efforts and raising awareness. The specific steps taken by each of the organizations are clearly shaped by their organizational mission.

There is much more at stake, however, than just which strategies are adopted by an organization. Although this is critically important for giving an organization a guide or direction by which to proceed, the organizational identity crafted by an organization is also important because it determines who will join or support the organization. The specific language of the mission statement "may mobilize different segments of activists

to participate in different organizations . . .” (Platt and Williams, 2002, p. 338). As a consequence, organizations prominently feature their mission statement on public documents and on their webpages. It is often one of the first things that interested readers will see when first encountering an organization. This is certainly true for the different intersex advocacy organizations. All four of the groups display either their entire mission statement or the key phrases of their mission statement in the center of the group’s homepage. All of them also prominently feature a link or tab that leads readers to a page that more comprehensively develops their organizational mission. This seems to indicate that the groups are aware of the importance of mission statements and core organizational identity when it comes to attracting new members.

Once new members have decided to join the organization, a clear mission statement is important for the long-term endurance of the organization. Kebede, Shriver, and Knotterus (2000) argue, “A movement’s endurance depends on its ability to develop and sustain a strong sense of collective identity” (p. 313). However, once collective identity begins to weaken either due to organizational change or because the organization met its purpose, the organization may cease to exist. The Intersex Society of North America illustrates this idea. From its founding in 1993, the ISNA was dedicated to making “the world a safer place for families of dealing with intersex conditions” (ISNA, 2005a). In particular, this meant ensuring complete disclosure of medical information to parents and individuals with intersex variations, decreased reliance on surgery, and the encouragement of more well rounded treatment for intersexed individuals. After many hard fought battles, Cheryl Chase, the founder of the ISNA, was invited to take part in the

2005 consortium of intersex management. The meeting resulted in codification of many of the ISNA's beliefs. It encouraged open communication between parents, doctors, and patients; it urged delaying surgery until the best gender assignment could be determined; and it pushed for more inclusion of intersexed voices in improving treatment (Lee et al., 2005). Although this change was exciting for members of the ISNA, it hailed an organizational identity crisis. They were left wondering what their organization ought to do now that its mission had been fulfilled. In the end, they decided to close. Their final letter to members and researchers states,

Largely as a result of ISNA's efforts, there is now widespread acknowledgment among health professionals that the time has come to change how we think about and care for persons with DSDs. . . . This is ISNA's dilemma: we finally have consensus on improvements to care for which we have advocated for so long, but we lack a consistent way to implement, monitor, and evaluate them. . . . there is a strong need for an organization to assume the role of a convenor of stakeholders across the health care system and DSD communities. It's the primary gap between today's status quo and the wide-spread implementation of the new standard of care we envision. Unfortunately, ISNA is considerably hamstrung in being able to fulfill this role. (ISNA, 2008)

This clearly was not an easy decision. It took nearly two years from the announcement of the new consensus for the ISNA to publicly announce its closing. One could likely safely guess that the decision to close was so difficult because organizational identity was tied

to individual members' sense of identity. They fought under the title of ISNA for so long; it would be very difficult to make the decision to leave.

Organizational identity is also important because it may explain why one social movement organization may choose to cooperate with some organizations while alienating or vilifying others. The construction of identity is about establishing sameness and difference, or finding “what you have in common with some people and what differentiates you from others” (Weeks, 1990, p. 89). It is about creating an *us* and separating *us* from *them*. The rhetoric of organizational identity, thus, has severe implications for whether the SMOs will build coalitions with or vilify one another. For example, the Organisation Intersex International would have allied with the ISNA if it had stuck to its initial mission statement, but is horrified by the medical focus of the Accord Alliance. Angela Erde (2010) of OII-Australia writes,

Now, Accord Alliance is everything it set out to be – an organization of doctors wielding the needle and the knife against the bodies of intersex children, in collaboration with their academic apologists cum cheerleaders. This trojan horse against intersex people was set in motion when Bo Laurent, Alice Domurat Dreger and their medical allies began throwing actual intersex people out of ISNA – a society of intersex people seeking radical reforms in medical practices against intersex people – and then transformed it into the Accord Alliance – a privately-funded private medical organization pursuing its own right-wing agenda. Two extreme opposites, in fact. (para. 4-5)

It is clear that the way an organization frames its purpose and identity has real implications for the ability of groups to form coalitions and work together. The language an organization uses to identify itself is simultaneously creating the opportunity to work with some while limiting or even totally precluding the possibility of working with others.

Conclusions

Although all four of the organizations are fighting for intersex rights, the leading intersex advocacy groups have constructed very different organizational identities. Through their use of carefully crafted mission statements and public documents on their websites, each of them clearly outlines the core values and frames their existential purposes. The Intersex Society of North America sought to improve the lives of intersex individuals by pushing for systemic change through education of doctors, parents and society at large. The Accord Alliance seeks a narrower goal of implementing better health care protocol through work with interdisciplinary medical teams. The Advocates for Informed Choice intends to offer legal services to intersex parents and children who currently are unprotected by the law and the Organisation Intersex International seeks large scale societal reform in hopes of achieving human rights and better conceptions of gender.

The mission statements developed by each of the four leading intersex advocacy groups have important implications. They illustrate the organization's understanding of the nature of intersexuality. They offer insight into the means that the organization will take to remedy the problems it sees surrounding intersex. They contribute to recruiting

and maintaining members, set the limits on the life of the organization, and even influence the ability of groups to work with one another. Of course, organizational identity is not the only factor that contributes to organizational longevity or success. There are clearly other issues that matter as well. However, the framing of organizational identity through a mission statement plays a crucial role in setting the trajectory an organization will follow and guide that organization through its lifespan.

CHAPTER 3: Intersex, Disorder, or Difference:

The Debate over Naming in Intersex Advocacy

In October 2005 a groundbreaking conference on intersex issues took place in Chicago, Illinois. The participants—50 international intersex experts from various medical fields including endocrinology, urology, gynecology, psychiatry, and psychology, and two intersex adults—came to agreement over significant and revolutionary changes in treatment, including limiting surgery and increasing honest communication between patients and doctors. The resulting consensus statement also admitted that past treatment of intersex infants had been dangerous and counter-productive and acknowledged that genital surgery does not do what it is intended to do (Hughes et al., 2006); it did not “improve attachment between child and parents, ease parental distress about atypical genitals, ensure gender identity development in accordance with the assigned gender, or eliminate the intersex condition” (Reis, 2007, p. 538).

In addition to changes in treatment protocol, the participants also agreed that a new nomenclature was essential. Instead of using the language of *intersex* people were to begin using *Disorders of Sex Development*. Although the changes in medical procedures have been highly praised as an important first step, the suggested change in nomenclature has received mixed reactions from those outside of the conference. While the decision produced rancor in some, it drew praise from others. Each of the four leading advocacy groups represents a different view on proper nomenclature. Because of their divergent positions, each deserves attention. Before evaluating the relative merits and

disadvantages of their respective positions, it is first important to lay out what is at stake in this particular debate over the power to name.

What's at Stake?

The power of language has long been studied and discussed. Its ability to modify, create, and disrupt has been recounted countless times. It is no mystery that the names we give to people have tremendous creative power. This formative potential is inherent in language. Burke (1974) argues, "The magical decree is implicit in all language; for the mere act of naming a specific object . . . decrees that it is not to be singled out as such and such rather than as something other. . . . What we need is *correct* magic . . . whose decrees about the naming of real situations is the closest possible approximation to the situation named" (p. 3-4). Cameron (1999) adds, "Names are a culture's way of fixing what will actually count as reality in a universe of overwhelming, chaotic sensations, all pregnant with a multitude of possible meanings" (p. 10). Thus, once a name has been chosen it brings into being a particular, singular subject. This is the ontological quality of language.

Language also plays an important epistemological function in society. In a general sense, "Language mediates reality to the individual. It makes it possible for one to find one's bearings in the world as a person" (Luckmann, 1975, p. 50-51). In particular, names shape one's orientation toward the world. A name is an "identifying tag that follows its referent wherever she goes" (Margolin, 2002, para.3). It is not something easily changed or reformed. Instead, once a name is selected the individual receiving the name will find it difficult to detach herself from the implications of that

label. This is because, as Vacarescu (2004) argues, “There is an intimate relationship between language and knowledge, between the act of naming and that of knowledge production, a relationship in which the former influences, structures and constructs the latter” (p. 3). Thus a name is not simply an empty label; rather it plays an integral part in shaping the “details of everyday life” (Vittoria, 1999, p. 370) and in constructing one’s reality. This is possible because of language’s ability to select certain aspects of reality while deflecting others (Burke, 1966).

The axiological implications of language cannot be divorced from a discussion of naming either. The act of naming and accepting a name conveys “powerful imagery” and “can be a political exercise” (Martin, 1991, p. 83). The ethical implications of choosing a name are an important concern and the “belief that some labels are more stigmatising than others may lead to a search for an alternative label that is regarded by the person as less stigmatizing” (Gillman et al., 2000, p. 395). The potential for some names to empower and for others to harm is especially evident when particularized in a medical setting.

The language of illness, disease, diagnoses and medicine can be particularly powerful for individual understandings of self. Karkazis and Feder (2008) argue, “The ways we identify medical conditions—together with their permutations in labels, identities, or diagnoses attributed to (and sometimes embraced by) individuals thereafter— are freighted with meaning that is tied to a sense of self” (p. 2016). Gergen et al. (1996) add, “Diagnoses, official and unofficial, often concretise identities that limit people; they create black boxes with few, obscure exits, and they form obstacles to more

viable and liberating self definitions” (p. 5). Gillman et al. (2000) take this a step further and argue that diagnoses can be a form of social control that possibly “‘bring forth’ pathology, create problem saturated identities, and construct careers as patients and cases” (p. 403). Of course, the individual alone does not complete the process of diagnosis; a medical expert is an integral player in this process. As such their role should be explored further.

Medicine and its attendant “discursive practices, such as diagnosis, have been central to the construction of the subjectivity and the objectification of people . . .” (Gillman et al., 2000, p. 391). This is because the choice of terminology and the way it is presented to the patient “may have a profound effect on the patient” (Wood, 1991, p. 534). Unfortunately, medical practitioners often are untrained in the use of “illness language to negotiate the relief of the sufferer” (Good, 1977, p. 27). This is especially problematic because, as Mendez et al. (1988) suggest society empowers certain groups of people to make definitions . . . of health or sickness, and ‘in consequence, the right to be heard and be obeyed in those domains’ (p. 145). Thus, if doctors are applying certain diagnoses to some patients they are not applying neutral labels for a condition; instead, they are “actively involved in the very production of the phenomena they represent” (Lackmund, 1998, p. 780). Further, research in medical setting suggests that social meanings attached to illness and disease have a powerful effect on standards of care and treatment options (Mishler et al., 1981; Cottrell and Schulz, 1993). The names applied by doctors themselves function to shape their understandings of their patients.

The implications of naming stretch beyond the medical realm; “the voice of medicine” implicates the “voice of the life-world” (Mishler, 1984). In other words, diagnosis “is often enough the legal basis for provision of health services, welfare benefits, unemployment certification, worker's compensation claims, and legal testimony” (Brown, 1995, p. 39). Additionally, the choice of language “influences . . . how parents view their affected children, how intersex people understand themselves, and how others not directly involved in medical settings—such as gender and legal scholars, historians, and media commentators—conceive of and theorize about gender, sex, and the body” (Reis, 2007, p. 536). It should be clear that the choice of naming, especially in relationship to a medical condition, has severe implications for how people perceive themselves and are treated by others; it sets limits on the possibilities open to that individual. With this general theory in mind, it is now possible to lay out arguments for what counts as appropriate nomenclature in the debate surrounding intersex advocacy. Once complete, a more specific discussion of the chosen discourses can ensue.

Intersex Society of North America

As should be clear from the organization’s name, the Intersex Society of North America (ISNA) originally chose *intersex*, which they argue could be used as a “general term . . . for a variety of conditions in which a person is born with a reproductive or sexual anatomy that doesn’t seem to fit the typical definitions of female or male” (ISNA, 2005j, para. 1). The ISNA argued that intersex simply reflects the fact that there is nearly infinite variation in human biology, even in regards to reproductive and sexual anatomy. Labeling this a *pragmatic approach*, they hesitated to set limits on who counts as intersex

and instead worked on behalf of “anyone born with what someone believes to be non-standard sexual anatomy” (ISNA, 2005j, para. 8). The fact that they saw value in such an all-encompassing term can further be seen when they questioned, “Which variations of sexual anatomy count as intersex? In practice, different people have different answers to that question. That’s not surprising, because intersex isn’t a discreet or natural category” (ISNA, para. 3). It is clear that their initial intent was to be extremely inclusive.

Of course, this is not to imply that members of the Intersex Society totally delimited their understanding of what it means to be intersex. Instead, they contrasted intersex with *hermaphrodite*, *ambiguous genitalia*, and being transgender and transsexual. For them, the latter terms had several problems. First, they argued that hermaphrodite was inappropriate because it is a “mythological term . . . that implies a person who is both fully male and fully female. This is a physiologic impossibility” (ISNA, 2006b, para. 1). They also claimed that the term may be stigmatizing and fails “to reflect modern scientific understandings of intersex conditions, confuse clinicians, harm patients, and panic parents” (ISNA, 2006b, para. 2). The phrase ambiguous genitalia was similarly problematic because not all intersex individuals have ambiguous genitals and would thus be excluded and because the phrase was stigmatizing and may cause shame since “no one thinks his or her own genitals are ‘ambiguous.’ They’re just their genitals” (ISNA, 2005d, para. 2). Finally, they differentiated intersexuality from transsexuality and transgenderism because they viewed intersexuality as a physical anomaly, whereas, according to ISNA, being trans- is a psychological condition in which one feels that their

physical anatomy does not match their “internal experience of gender identity” (Herndon, 2006a, para. 2).

Interestingly, their support for the public invocation of intersex changed in 2006 after the Chicago Conference and the publication of the Consensus Statement. As such, they ISNA began to publicly support the language of *disorders of sex development* (DSD). Of course, their justification for this language switch is in line with the Accord Alliance’s as it was members of the ISNA that founded the Accord Alliance after the closing of the ISNA in the spring of 2008.

Accord Alliance

Opting for the label *disorders of sex development* (DSD), the Accord Alliance chooses to define the issue as a medical one. Basing their definition on the 2006 Consensus Statement on Intersex Disorders that resulted from the 2005 conference in Chicago, the Accord Alliance writes, Disorders of Sex Development (DSD) “is defined by the 2006 ‘Consensus Statement on Intersex Disorders’ as ‘congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical’” (Accord, 2008c). The Consensus Statement (2006) offers its criteria for determining what terminology should be selected:

A modern lexicon is needed to integrate progress in molecular genetic aspects of sex development. Because outcome data in individuals with DSD are limited, it is essential to use precision when applying definitions and diagnostic labels.^{3, 4} It is also appropriate to use terminology that is sensitive to the concerns of patients.

The ideal nomenclature should be sufficiently flexible to incorporate new

information yet robust enough to maintain a consistent framework. Terms should be descriptive and reflect genetic etiology when available and accommodate the spectrum of phenotypic variation. Clinicians and scientists must value the nomenclature's use, and it must be understandable to patients and their families.

(Lee et al., pp. e488-e489)

The Consensus goes on to argue that Disorders of Sex Development meets these criteria. In essence, the label Disorders of Sex Development is best because it is precise, limiting and, most importantly, supported by a group of well-respected medical doctors.

Interestingly, the Alliance goes a step further and argues against intersex as a public label. In their "Glossary of Terms," they write,

The definitions of such older terms such as "hermaphrodite" and "intersex" were considered problematic because of a lack of consensus on definitions and because they labeled persons (rather than conditions). Further, they implicitly labeled patients with a gender, and one that was frequently inappropriate because incongruent with the patient's assigned or experienced gender. (Accord Alliance, 2008c)

In their opinion, people should use caution with the label intersex because it has a tendency to construct an identity rather than label a disorder a person has or an issue with which they must deal. Importantly, they do not eschew the term entirely. Indeed, they recognize that intersex may be a useful strategic label. In their definition of intersex, they write, "The term is often used by adults with DSD to talk about their bodies and their experiences. Using the general term 'intersex' has allowed many adults with different

kinds of DSD to come together and work for progress in the way families with DSD are treated” (Accord Alliance, 2008d). It seems then they recognize that some people will continue to use the term, but noticeably those people are not intersex individuals, rather they are people with DSD.

Organisation Intersex International

As was the case with the Intersex Society of North America (ISNA), the Organisation Intersex International (OII) supports *intersex*. Their initial definition sounds very similar to that of the ISNA. They state, “An intersexed person is an individual whose internal and/or external sexual morphology has characteristics not specific to just one of the official sexes, but rather a combination of what is considered ‘normal’ for ‘female’ or ‘male’ (OII, n.d.-b, Q1). After this beginning definition, however, OII takes a more radical position than the one taken by the ISNA. They do not seek a precise definition and argue that intersex is preferable both because it accurately captures the idea that intersex is an identity and not a condition (Hinkle, 2006) and because “it includes all the different variations . . .” (OII, n.d.-b, Q1) that are inherent in human biology. Thus, while the ISNA subscribed to the two-sex system, arguing that those called intersex do not fit into one of the two, OII argues that there are more than two sexes. “There is a third, a fourth, even a fifth sex, etc. within a continuum from very female to very male” (OII, n.d.-b, Q3). As such, they seek an end not only to the two-sex system but also a moratorium on those with different intersex conditions being forced into one of the two.

In addition to being clear about what intersex is, OII is also clear about what intersex is not. The organization's fundamental principles lay out what is excluded when they invoke intersex:

- Intersex is not a medical condition: intersex refers to those individuals born of intermediate sex between what is considered standard for male or female in our societies.
- Contrary to what is often asserted, the various degrees of intersex are not innately an illness or deformity. They are simply variations of the human body similar to the length of the nose, the colour of eyes, etc. . . .
- We stress the whole person from infancy through adulthood and choose not to focus on an individual's genitalia. We are people, not genitals. . .
- The basic problems faced by the intersexed are socio-cultural in nature and not medical and are a result of the dogmatic fundamentalism inherent in the current binary construct of sex and gender. Some intersexed individuals are subjected to genital mutilation in childhood as a result of this totalitarian, sexist oppression. For this reason, we denounce all forms of sexism prevalent in our societies, which is principally directed against women, the intersexed, and other communities which challenge sex and gender norms. (OII, n.d.-b, para. 2)

In essence, they define intersex as being an issue of biological variation that can only be solved by social revision of conceptions of identity, specifically through deconstruction of the gender binary and through alliances with other communities fighting sexism; it cannot be solved by medical intervention.

Advocates for Informed Choice

Unlike the Organisation Intersex International's directly confrontational style, the Advocates for Informed Choice (AIC) opt for a middle ground approach. Dedicated to "promoting the civil rights of children born with variations of sex anatomy" (AIC, n.d.-b, para. 1), the AIC uses both DSD and intersex to "reflect our commitment to listening with compassion and respect to all of these different groups as we work to promote the rights of affected children" (AIC, n.d.-a). AIC seems so concerned about inclusion that they use the phrase *DSDs or intersex*, rather than one or the other, throughout their webpage. It is interesting to note, however, that for the AIC the acronym DSD is said to mean *differences of sex development*, rather than disorders of sex development as suggested by Accord. Citing the fact that there is no real consensus on terms, they argue their decision to use both stems out of the following values and beliefs of board members:

- The language we use is important, and has consequences.
- Identity is a very personal matter; no one can tell another how to identify him- or herself.
- We are advocates for children, many of whom are not able to voice an opinion about how they identify or what terminology is most respectful.
- There is a wide diversity of opinion about what is best for children born with DSDs or intersex conditions, and these differences extend even to such basic matters as what language is best to describe affected children.

- In order to have a complete picture, we need to listen to all the many stakeholders with unique perspectives on what life is like for these special children: their families, adults with similar conditions, medical caregivers, mental health specialists, and the children themselves.
- We will be most effective as advocates for children if we are able to bridge the gaps that currently exist between and among the various groups who care about their futures. (Advocates for Informed Choice, n.d.-a, Q6)

It is interesting to note that the AIC was originally called the Institute for Intersex Children and the Law when it opened in 2006. However, after observing the controversy surrounding the release of the Consensus Statement, AIC board members worried that their original name would exclude children and families who needed legal help in fighting for the rights of patients. They changed their name in 2008.

Assessing the Debate

The fact that the advocacy groups offer a robust defense of their nomenclature lends credit to the idea that winning the battle over language is a primary concern for contemporary advocates. While their justifications offer part of the story, a deeper analysis of each of the possible terms is essential to resolving the debate over language and naming.

Considering the historical context in which the Intersex Society of North America (ISNA) was created, their use of intersex makes sense. As one of the, if not the, original advocacy group fighting for patient rights, an expansive definition was necessary. Indeed, attempts to limit by particular variation or by physical manifestation may have

been overly fragmentary and unlikely to gain broad support, especially considering how secretive most individuals and families were and, in many instances, still are in regards to their positions. History seems to bear out its effectiveness, as Reis (2007) argues that, for many, intersex took on a “political valence” (p. 537). It was a rallying point for many individuals who previously lacked a public voice. Before closing its doors in 2008, however, the ISNA argued that intersex had lost its efficacy and become a term with more complications and drawbacks than benefits. Were they right?

In some sense, perhaps. First, the term intersex seems to lack a precise interpretation and holds very different, and often negative, meanings for different groups. Empirical evidence suggests the term is applied by clinicians to mean only ambiguous genitalia and thus is too narrowly applied to service all interested parties (Simmonds, 2007). Additionally, the media and general public have historically conflated intersex with problems with sexual identity, demonstrating further lack of precision and misunderstanding of the language. Parents also worry that having a child labeled as intersexed is “frightening, off-putting, and freakish” (Reis, 2007, p. 537) because it implies that their child is neither boy nor girl, but rather something else entirely.

Second, there are fears that intersex, even when precise understanding exists, may not be in the best interest of those individuals it is trying to help. The term intersex worries some advocates because it functions as an all-encompassing identity label. Karkazis and Feder (2008) found that some individuals frown upon the term because they *are not* intersexed; rather they are someone *with* an intersex condition. In other words, they see intersex as referring to something “one essentially was” (Karkazis and Feder, p.

2016) and find this to be a limiting and dangerous simplification of their life. An unintended consequence of this is that the medical needs of those with intersex conditions can be obscured (Feder, 2009). The reasoning is that if intersex is an identity then the role of medicine is minimized and this may be a problem for those who need or desire medical intervention.

It appears to be the case that the nomenclature of Disorders of Sex Development (DSD) can remedy some of the shortcomings of intersex. It removes any connotation of constructing an all-encompassing identity. It is clear that DSD is a condition with which one must deal rather than a truth about one's whole existence (Reis, 2007). DSD also has the potential to appease parents because the ambiguity surrounding their child's existence can be remedied through medical intervention. Further, it may even help to remedy some of the public's misconceptions because people are less likely to sensationalize health conditions than they are issues of sexual identity (Vilain et al., 2007).

Disorders of Sex Development (DSD) has other important advantages as well. First, clinicians and medical practitioners use it and understand it (Simmonds, 2007). If one accepts that intersex is primarily a medical condition this advantage becomes more important. Second, conceding the normalizing potential inherent in the label DSD, Feder (2009) argues that this is not necessarily dangerous: DSD can normalize in a positive sense by directing attention to appropriate and ethical treatment of various conditions. Considering the long history of medical mismanagement of intersex conditions the importance of ethical treatment should not be downplayed.

It seems at first glance then that the Intersex Society and later the Accord Alliance are correct; the era of intersex is, or at least should be, over. However, if one were to eschew the language of intersex one would be ignoring that many intersex people have benefited from its use. Reis (2007) argues that because intersex complicates understandings of natural sex categories and the relationship between sex and gender it has helped many whose anatomies do not fit easily into these socially constructed categories. Cameron (2006) adds that some have felt more comfortable identifying as intersexed because they are not solely female or male. For them, intersex is an accurate and accommodating concept. Further, while there may be confusion about the term in society at large it is clear that for many the term intersex has been usefully appropriated for political purposes. It is difficult to argue that intersex cannot be successfully deployed publicly, as all successes to this point have been achieved while using the language of intersex. Additionally, it is unclear that public dissensus about the meaning of intersex is a reason to stop using it. Instead better education efforts and public awareness campaigns may be helpful, especially since it is likely that misinformation and lack of understanding will be a preeminent concern regardless of which label is selected. If, for example, Disorder of Sex Development were to become to dominant nomenclature, it is unlikely that the public would suddenly understand the condition and its related issues.

Disorder of Sex Development (DSD) has other drawbacks as well. The primary concern is that the language of disorder is pathologizing; it marks the body as impaired and in need of fixing (Holmes, 2002). This “contradicts one of intersex activism’s central

tenets: that unusual sex anatomy does not inevitably require surgical or hormonal correction” (Reis, 2007, p. 538) and is dangerous because it functions to legitimate invasive medical interventions. Second, some worry DSD is not recognized internationally or even by several domestic advocacy groups, which limits the potential to build coalitions and alliances (Simmonds, 2007). Further, some argue it is essentialist at its core because it perpetuates reliance on the binary two-sex system by assuming that there are naturally only two groups—men and women—and those outside of this are disordered. Unfortunately, reliance on gender essentialism necessarily erases the experiences and even bodies of those who do not easily fit into either category. Moving toward a nomenclature of Disorder results in a definitional foreclosure that precludes viewing gender as varied.

Further, although speaking the language of doctors might mean more recognition of different conditions by the medical establishment and even some changes in care standards, there are latent consequences to this move. Ceding control of the issue doctors grants them a level of authority to decide the fate of a large population of people. This seems counterproductive when one thinks about the manipulation and deceit inherent in the traditional concealment model of treatment. Habermas (1984) affirms this concern by arguing, “Instrumental categories of professional ideology come to dominate all forms of human experience” (p. 19). Further, Reis (2007) queries, “By adopting the term disorders of sex development, and granting doctors the power to do the naming, do we, in fact, give disproportionate control to the medical establishment? I think we do” (p. 541). As the move to Disorders is relatively recent, it is yet to be seen whether she is correct.

With the history of medical mismanagement and manipulation in mind, it is wise to keep these concerns in mind.

Overall, it seems that the later edicts of the Intersex Society and the Accord Alliance are accurate in pointing out that intersex has its limits. Sloppy application of the language as well as fears that it might be an ill fit for those who do not identify as intersex are well-founded and supported in history. However, history also supports the original position of the ISNA and the continuing position of the Organisation Intersex International. There has been empirical success from using the language of intersex both in terms of changing public consciousness and in terms of accurately describing some people's existence. Further, intersex helps avoid the dangerous essentialism and pathologization implicit in the move to the language of disorders. The question that remains now is, does *Differences of Sex Development* as used by the Advocates for Informed Choice avoid the types of problems seen with the other discourses?

The moderate approach selected by the Advocates for Informed Choice (AIC) seems apt in theory. Encouraging individuals to select and apply the vernacular appropriate to their situation and circumstances does overcome the problem of individuals feeling that one of the other terms do not fit for them. It also seems to remedy public clarity issues because the terms serve to mutually reinforce one another to create clearer meanings. Further, AIC's refusal to use the language of disorder clearly avoids the problems of pathology associated with disorder. Unfortunately, their choice to use of the language of difference is not devoid of negative connotation. Lunsford (2005) argues that difference is simply a euphemism for disabled. Similarly, different still

implies a standard of normal from which one varies or deviates; one is man or a woman or different and that difference is still based on anatomical build. In other words, it still has some essentialist undertones. Thus, while the move toward inclusivity by the AIC's adoption of dual-terminology is to be applauded, their choice of *difference* should be regarded with a critical eye.

Conclusion

Naming matters immensely. All of the advocacy groups argue explicitly that the selected rhetoric matters to them and their cause. Similarly, evidence suggests that the language of the debate shapes how the individuals being talked about think of themselves and how other people interact with them whether in a health setting or in larger society. Resolution of the debate is not easy. There is no one winner and one loser. Instead, their utility is almost entirely dependent on context and objective. There is a strong argument to be made for the potentially debilitating effect of viewing physiological variations as disorders. There is a similarly strong case to be made that speaking the language of the experts may mean they are more likely to respond to demands and suggestions for changes in treatment. As such, strategic use of the medicalized language of disorder should be encouraged in health settings. It appears, however, that applied more broadly, the language of disorder may produce disastrous results, including increased reliance on medical solutions, internalization of shame, and the reentrenchment of the two-sex binary system. The adoption of a multi-word model may remedy many of the problems associated with each of the discourses.

Although the debate over which term should reign preeminent will likely remain unsettled, it is clear that each organization's choice of terminology has several important consequences. First, selection of a term reflects an organization's choice to cater to a certain, target audience. As the first organization of its kind, ISNA chose an expansive umbrella term in hopes of garnering a large audience. Further, because the Accord Alliance is interested in conversing with doctors and thus chose a limited, medical term. OII is primarily concerned with speaking to an international audience concerned about constraints of the two-gender system and thus chose the term most line with those followers. Finally, the Advocates for Informed choice selected a term that could easily include any clientele.

Second, selection of terminology reflects the actions taken and outcomes desired by each of the organizations. Each of their interpretations of the situation directs what they perceive to be the best form of advocacy. For example, whereas Accord Alliance uses the medical frame to pursue medical reform, OII uses the gender frame to push for societal reconceptualizations of what it means to be a man or a woman.

Third, selection of a term reflects shapes the ontology of the individuals at the heart of the debate. It is evident that choice of terminology will either represent an individual as being intersexed or as having an intersexed condition. This has important repercussions for self-understanding, interpersonal relations, and treatment.

Finally, selection of terminology greatly limits the ability for these organizations to coalesce into a single movement. They define the essential characteristics of the situation in fundamentally different ways. Reading their vociferous defenses, one

wonders if they are even a part of a single movement. Interestingly, however, this may not ultimately be too much of a setback for intersex advocacy. Just as the Advocates for Informed Choice prove that flexibility in naming and use of dual-terminology may broaden one's appeal, a larger social movement that rests on multi-faceted and diverse understandings of the nature of the problem contains enormous potential for change. Simply because the intersex advocacy movement conceptualizes intersex in a variety of ways it can appeal to a diverse audience, push for a myriad of varied reforms and hopefully increase the chances of end the shame and stigma surrounding intersex conditions.

CHAPTER 4:

The Battle over Parental Decision-Making Paradigm

Paul, the father of a child with an intersex variation, stated in an interview with Gough, et al. (2008), “We were just . . . confused obviously, what don’t, why don’t they know what he is?”(p. 499). Another parent, Naomi, recalled, “I just felt numb you know and, I didn’t, I couldn’t register with, with her anyway, ‘cos I didn’t even know what she was!” (p. 499). Such feelings are not uncommon. A study completed by Slijper et al. (2000) finds that the majority of the parents surveyed expressed shock, grief, anger and shame upon hearing their child’s intersex diagnosis. Another study by Le Marechal (2001), summarized by Carmichael and Alderson (2004), finds parents typically report devastation and confusion when they learn their child is intersexed. Gough, et al. conclude that intersex children can engender tremendous shock, uncertainty, and discomfort in parents. Karkazis (2008) adds that for the parents of children with intersex diagnoses, all of the usual anxieties of childcare are compounded by the intersex variation.

Although there is currently a limited amount of research detailing parental reactions to having children with differing intersex variations (Gough, et al., 2008), the research that does exist seems to indicate that the reactions and feelings of the parents very likely contribute to the outcome of the child. Howe (1998) finds that parents tend to communicate a sense of shame to their children as their child ages. Carmichael and Alderson (2004) report that how parents adapt to their child’s variation strongly influences how the child understands and adapts to his or her own body and variation.

Liao and Boyle (2004) find similarly that parents first need to come to terms with and accept their child as intersexed in order to help their child accept their condition. It is clear that whether a parent opts for surgery or not, acceptance of their child and his or her specific circumstances is important for the child's long-term health.

Parents' fears are often magnified by medical professionals, who characterize the birth of a child with atypical genitalia as "a true medical and social emergency," (i.e., al Jurayyan, et al., 1995; Coran and Polley, 1991; Hutcheson and Snyder, 2009). This emergency is used as justification for early genital surgeries that seek to normalize the genitalia through reconstructive procedures (Beh and Diamond, 2005). Doctors argue that early surgeries spare the child the pain and embarrassment of discovering that his or her genitals are atypical and that surgery can seal the child's gender identity (Karkazis, 2008). Dr. A. Barry Belman reasons that postponing surgery will have an adverse effect on a child's emotional wellbeing because the child will feel different from his or her peers (qtd. in Aliabadi, 2005). It is also argued that surgery can encourage parental acceptance of their child because the surgery normalizes the external appearance of the infant, making it easier for the parents to bond with their child (Hermer, 2007). This is because, as Wilson and Reiner (1998) note, parents will likely grieve the loss of their "expected 'perfect' child" and it is therefore better to push surgery early to help the parents.

Many intersex individuals and intersex advocacy organizations have dedicated themselves to disproving such claims and arguments made in favor of surgery. The four leading intersex advocacy groups in the United States are united in their belief that

surgery must end. Taken together, their positions develop a multilayered case against early, non-essential surgery. However, they strongly disagree over the best way to lead to a ban on surgeries. More specifically, the four groups disagree on the role parents should play in bringing an end to surgery. Whereas the Intersex Society of North America, the Accord Alliance, and Organisation Intersex International push for increasing information to parents to better ensure informed consent and decrease the chances that parents will approve surgery for their children, the Advocates for Informed Choice worries that, even with more information, parents will approve surgery for their children. They thus support a court-imposed moratorium on early, non-essential surgeries. To better investigate this issue, I, first, develop their arguments against early surgical intervention; second, I discuss in more detail the positions taken by each organization about parental consent; and, third, I discuss the implications of the different positions.

No Surgery without Sufficient Informed Consent

The case against early surgery is strongly developed by all four intersex advocacy groups and is supported by a host of intersex allies. The websites of all four groups contain information detailing the problems and risks associated with early surgery. Specifically, the ISNA believes that “competent patients” should be able to choose the surgeries they want after they have been fully informed of the risks and benefits; however, they are against “elective surgeries done on people (usually children) without their informed consent. Such surgeries subject patients to unnecessary harm and risk” (Dreger, 2005c, para. 3-4). The Accord Alliance espouses a similar position. Their

position is stated in the *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood* (Consortium on the Management of Intersex Disorders, 2006) featured prominently on their webpage. It states that doctors should “Delay elective surgical and hormonal treatments until the patient can actively participate in decision-making about how his or her own body will look, feel, and function” (p. 3). The Organisation Intersex International also prioritizes the choice of the child. In their Official Positions, they write, “We campaign against all non-consensual normalisation treatments of infants that are not medically necessary and favour the right of all intersexed children to determine their own sex identity once they are capable of communicating it to us” (n.d., para. 2). The Advocates for Informed Choice, led by Anne Tamar-Mattis, also push for the right of the child to make a decision on his or her own behalf once she has reached a sufficient level of maturity.

The child’s rights are not the only reason that AIC urges delayed surgery. The AIC, along with the three other organizations, fears that parents often are not given enough information to make an informed decision on their child’s behalf. They write, “There are important questions about whether current medical practices meet legal standards for informed consent. Some parents of children born with DSDs or intersex conditions have reported feeling pressured to make quick decisions, often without complete information about the risks of surgery and the uncertainty of outcomes” (AIC, n.d.-a, para. 7).

Many scholars and intersex allies bolster the case made by all four of the organizations. They argue that early, non-essential surgeries pose many risks to the child.

First, surgery can have dangerous physical results, including extreme physical pain (Benson, 2005). Commonly, individuals require repeat surgical procedures (Ehrenreich and Barr, 2005; Fausto-Sterling, 2000). Beginning before the sixth month of life and repeating through puberty and beyond, the surgeries can result in infection, genital pain, scarring, urinary problems, and infertility (Ehrenreich and Barr; Fausto-Sterling). They can “create long-term health problems, inhibit sexual response and sexual functioning” (Lloyd, 2005, p. 161). Some procedures, like vaginoplasty, can cause physical and psychological distress because they require parents to dilate their daughter’s vagina several times daily (Kessler, 1998).

They also argue that, in addition to physical pain, surgeries can result in psychological trauma. Lloyd (2005) finds that many adult individuals with intersex variations express anger and shame from being denied a choice about their body. Ehrenreich and Barr (2005) point to a host of testimonials by intersex individuals that show they feel shame and humiliation from repeated surgeries and follow-up medical observations. Further, many mourn their loss of sexual capacity and fertility (Minto, 2003).

Allies also suggest that the initial justification for surgery is based on a misinterpretation of studies. Surgery was viewed as the preeminent method of treatment because of the acceptance of John Money’s reports about the success of David Reimer’s surgery. Money reported that David Reimer, born as a typical boy, was successfully raised as a girl after a botched circumcision forced the surgical construction of female genitals. Reimer’s parents were instructed to dress him as a girl, give him toys

appropriate for girls, and treat him as if he were a girl. Money reported that Reimer accepted this new gender assignment and thus surgeries could ensure proper psychosexual development. It was later found that Reimer had never accepted his new gender assignment and lived his adult life as a male. Before this was discovered, however, Money's theory of successful gender development through surgical intervention was nearly universally adopted (Benson, 2005; Diamond and Sigmundson, 1997; Reiner, 1997).

The discrediting of Money's theory helps support the idea that surgery is not necessary for healthy gender identity development. In fact, there is growing evidence that one's genitalia are of little consequence to gender identity (Beh and Diamond, 2005; Karkazis, 2008). Further, although some fear that surgery is essential to help the child avoid bullying or stigma from others, "the reality is that genitalia are generally covered in modern society and studies of intersexuals throughout the ages demonstrate that they are not at all psychologically damaged by the experience" (Benson, 2005, p. 64; see also Fausto-Sterling, 2000). Moreover, "surgery to assign or solidify a particular sex denies the intersex individual the opportunity to develop his or her own sense of who they are and the gender with which they most closely identify" (Lloyd, 2005, p. 180).

Delaying surgery until a child is ready to choose for him or herself naturally leads to the question of at what age one is capable of understanding with relative certainty what her or his gender identity is. The Advocates for Informed Choice argue that this question is only important once it is firmly established that children should be given the right to decide in the first place. In other words, it is a question of sequencing priorities. They

must first establish the position that children should decide for themselves before hashing out the specifics of at what age a child is ready to decide. Tamar-Mattis (2006) writes, “This is an important question to answer once it is established that the child’s participation is necessary” (p. 74, fn. 109). The Accord Alliance tries to answer the question more directly, but argue that the decision is difficult and specific to each case. They write, “There is a lack of agreement on the recommended age for various treatments and this inevitably influences the ability of affected children to participate in decision-making. A formal assessment of the child’s cognitive status by a child psychologist or psychiatrist can assist in determining the extent to which the child is capable of participating in the decision-making process” (Consortium on the Management of Disorders of Sex Development, 2006a, p. 29). Accord and the Intersex Society of North America also implicitly begin to answer this question in their *Handbook for Parents* (2006b), when they suggest that, in her toddler years, a child “may start to understand that she is considered a girl, like her sister, and not like her brother” and that “children have a sense of being boys or girls by about two years of age” (p. 17). It will not be until the latter part of middle childhood years, ages nine to eleven, according to Accord and the ISNA, that a child may begin to ask about surgery.

Regardless of their positions on the age of consent for surgical intervention and gender assignment, all four organizations agree that there ought to be a moratorium on early, non-essential surgeries. Together they make a strong case for banning surgery. However, despite their agreement about the problems inherent in early surgery, the four organizations reach different conclusions about what ought to be done. Three of the

organizations, ISNA, Accord, and OII, argue that parents should be given more information and time to decide, thus decreasing the likelihood that parents opt for surgery. The AIC agrees that parents should learn more about the surgery and other treatments, but still worry that parents may make rash decisions that are not in the best long-term interests of their child. It is helpful to lay out each of their positions on the role of parental decision-making before discussing the merits of each of the positions.

Organizational Positions

Intersex Society of North America and the Accord Alliance

The Intersex Society of North America touts itself as “the premiere resource” (ISNA, 2004, para. 1) for people seeking information about different intersex conditions. As such, they focus extensively on helping parents navigate through the medical establishment by offering a handbook helping parents understand and adjust to their children’s needs (Consortium on the Management of Intersex Disorders, 2006). Written by a group of medical doctors, psychiatrists, psychologists, bioethics specialists, individuals with DSDs, and parents of individuals with DSDs, the *Handbook for Parents* (Consortium on the Management of Intersex Disorders, 2006) is intended to be a very practical guide for parents who very recently were told their child has an intersex condition. The book consists of seven chapters, written in plain language, that cover topics such as defining disorders of sex development (DSD), offering key questions to ask doctors, and suggesting how best to talk to friends, family and one’s child about DSDs. The handbook also seeks to assure parents that they are not alone by offering a series of narratives and personal anecdotes from parents of children with DSDs and from

adults who themselves were born with DSDs. The book does not include a large amount of medical information or terminology; instead it attempts to offer parents “emotional support and ideas about how to cope with your feelings and your day-to-day life;” it is intended to allow parents to “travel on the journey of life” with their child (Consortium on the Management of Intersex Disorders, p. 2). It attempts to comfort through introductory material and may serve as a jumping off point for parents with little or no prior knowledge about intersexuality.

The *Handbook for Parents* is relatively quiet on the role of surgery in intersex treatment. In Chapter 3, while giving advice to parents on what to ask their child’s doctor, the handbook states,

If the doctors are offering genital surgeries designed to change the way your child’s genitals look, ask: Why do you think my child may need to have his or her genitals changed? What evidence do you have this will help my child in the long run? Sometimes surgeons will suggest surgeries not because it will make your child physically healthy, but because they’re worried about the way your child looks to others. (p. 49)

The book also encourages parents to ask for evidence that surgeries have been empirically successful and indicates that gathering more information is in the parents’ best interest. It stops well short of calling for an all out ban of surgery. Instead, it encourages parents to be informed and make the best decision possible.

To stay informed, parents are urged to read the *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood* in addition to the *Handbook*

for Parents. The Clinical Guidelines were published by the Consortium on the Management of Disorders of Sex Development, which is accessible through several links adjacent to the original handbook link, as well as on several pages throughout the handbook. The Clinical Guidelines, which are the result of the 2005 Chicago meeting of a host of doctors and intersex specialists, seek to implement new, treatment guidelines for doctors to follow.

Because the Intersex Society of North America is the antecedent to the Accord Alliance it is not surprising that the Accord Alliance opted to adopt the ISNA's *Handbook for Parents*. Featured prominently on Accord's homepage the Handbook for Parents is highly praised by Accord. The ISNA and Accord are thus unified in their vision on how best to talk with parents about DSDs. They use rudimentary language to help calm parents, explain the background of DSDs, offer helpful hints on how to talk to doctors and friends, and implicitly encourage parents to avoid non-essential surgery.

Organisation Intersex International

The Organisation Intersex International also published a handbook for parents. The OII website indicates the handbook was written by parents, but does not identify the specific authors. The OII handbook (2008) is much shorter than the ISNA one. Although it also covers seven chapters, it is only ten pages. It is intended to help parents "better understand how to deal with what is most likely an unknown world for them – intersex" (p. 10). Less of a "how to" guide than the ISNA edition, the OII handbook focuses more on the emotions parents might be feeling upon hearing their child has a sex variation. The chapters walk parents through feeling of shock, acceptance, and

unconditional love and encourage parents to be open with their children about the condition. Unlike the ISNA Handbook, which speaks to parents, using the second person pronoun “you,” most of the OII handbook speaks about parents, using the third person pronoun “they.”

The *Handbook for Parents* developed by OII takes a slightly stronger position than the ISNA does on surgery. It argues, “Surgery is not automatically the solution. Doctors must be honest with parents. It will be the parents who have to decide. So, first of all, it is the duty of the medical community to inform the parents of the consequences of surgery – all of them” (p. 8). The chapter goes on to say, “OII campaigns against all nonconsensual normalization treatments of infants that are not medically necessary and favours the right of all intersexed children to determine their own sex identity once they are capable of communicating it to us” (p. 8). Like the ISNA, OII emphasizes that parents should be fully informed by the medical community. OII just goes a step further by explicitly suggesting that it may be wise for parents to avoid surgery or other permanent means for sex assignment until children are prepared to make the decision on their own.²

Advocates for Informed Choice

The Advocates for Informed Choice (AIC) takes a very different approach to dealing with parents than any of the other organizations. AIC agrees with the Intersex Society of North America and the Organisation Intersex International that parents tend to

² The Handbook does not discuss at what age a child is ready to make his or her own determination of gender or the procedure that should be used to ensure proper assignment.

be uninformed or at least under-informed about intersex issues and treatment. As a result, the AIC has begun to question the process of parents making medical decisions on behalf of their children, even in the cases in which doctors give parents sufficient information. They state, “The ethical and clinical uncertainty that exists in this area raises important questions about whether the current model of decision-making is legally valid,” (AIC, n.d.-a, Q5) and they seek to help clarify such legal issues.

Advocates for Informed Choice founder, Anne Tamar-Mattis (2006) argues that in the status quo there is a dangerous presumption that parents should be the preferred decision makers. She thus proposes to solve this supposition by calling for the state courts to rule that there should be a categorical exception that bans early, non-essential surgeries on non-consenting intersex infants.

Tamar-Mattis (2006) offers a robust criticism of the current parental decision-making model. First, parents are given absolute legal authority because of the constitutional right to family privacy and because of the legal presumption that parents are best situated to make medical decisions for their children. However, in the case of intersex, most parents are not very informed about intersex and may not know what is best for their children. As a result, they tend to defer to the medical establishment. Specifically, doctors make recommendations for what they determine to be best care and parents make the decisions based on these recommendations. Most often doctors’ suggestions “form the base for the validity of the parents’ decisions” (Tamar-Mattis, p. 78). This alone may not be too troubling if the doctors always make the best decisions. However, history suggests that medical standards for care of individuals with intersex

conditions may be far from appropriate. For AIC this is especially problematic because doctors cannot legally be held accountable when following medical standards of care. In other words, if it is widely accepted that normalizing genital surgery is appropriate for those with atypical genitalia then the doctor legally should be encouraged to perform the surgery.

Further, Tamar-Mattis (2006) argues that the model violates the child's right to privacy and may otherwise compromise the child's fundamental rights. Because parents typically lack sufficient information to make informed decisions about their child's gender and because most decisions are heavily influenced by the incorrect assumption that external biological factors are important to the formation of one's gender identity, AIC believes parental consent should not be the preferable legal model (Tamar-Mattis). Instead, state courts should intervene and impose a categorical exception that outlaws early, non-essential surgeries for individuals with atypical genitals. The AIC believes this will overcome the problems of the parent-centered decision-making model.

Basing their legal reasoning in previous court decisions protecting vulnerable children, Tamar-Mattis (2006) argues that legal precedent regarding children who are organ donors and children whose parents want to have them sterilized can be applied to intersex cases. "Where there are strong indications that parental instincts and medical judgment are not sufficient to protect the interest of the child, we can look to the existing categorical exceptions for a model of decision-making that ensures independent consideration of the child's interest" (p. 98). According to Advocates for Informed Choice, this should be preferred because 1) there is no demonstrated medical benefit from

genital normalization surgery, 2) there is the potential for parental conflict of interest, and 3) genital-normalizing surgery can infringe on the fundamental rights of the child. If enacted, the categorical exception model can provide “a protective and proven structure for making difficult medical decisions affecting the rights of children when their parents face a conflict of interest” (Tamar-Mattis, p. 109).

Skeptical of the possibility of mobilizing enough people to pass a legislative moratorium in the short-term, Tamar-Mattis and Advocates for Informed Choice support court intervention because it does not require large-scale organizing. Instead, it would just require one doctor who questioned the appropriateness of surgery to bring a civil case insisting on declaratory judgment by the court. Tamar-Mattis (2006) writes, “Doctors, recognizing the legal risk of performing these operations with only parental authorization and fearing later lawsuits from dissatisfied patients, insisted on declaratory judgments before operating” (p. 107-108). This was the same path that was taken for categorical exceptions for sterilization and organ donation by mentally disabled individuals. In lieu of doctors stepping forward, the court could also be encouraged to enact a statewide categorical exception by a state agency fighting on behalf of an abandoned intersex child. AIC argues that just one case could set a precedent for universal categorical exception, preventing parents from approving non-essential genital surgery.

In the instance that a case was brought before a court, an attorney would be appointed as guardian ad litem to represent the child’s interests and fight against surgery. He or she would be responsible for “arguing vigorously against the proposed surgery in order to assure a meaningful adversarial process” (Tamar-Mattis, 2006, p. 104). The

court would then be charged with deciding the best interest of the child by weighing the short- and long-term physical risks and benefits, the short- and long-term psychological risks and benefits, the maximization of the child's future options, the quality of evidence offered, and the child's input. Tamar-Mattis and the AIC are confident that the categorical exception model "offers the best chance to make good decisions for them in the absence of either proof that genital-normalizing surgery is beneficial or the political will to ban it outright" (p. 104).

Assessing the Debate

The position taken by the Advocates for Informed Choice (AIC) is developed by many legal scholars who draw the same analogies between parental decision-making for children with mental disabilities and for children with intersex variations. Their position against parental consent can be easily laid out using a problem-solution format. The problem, in general, is that more information given to parents does not guarantee an end to, or even a decrease in the number of, non-consensual surgeries. They argue that this is true for four reasons. First, as mentioned by the Advocates for Informed Choice, there does not exist sufficient information to fulfill the standard of informed consent for parents. Beh and Diamond (2005) argue that there is still a lack of adequate long-term follow-up studies as well as clinical experience both about those who had early surgery and those who did not. The AIC argues that even when there is full transparency between doctors and parents and even when parents read the handbooks developed by the other intersex advocacy organizations, parents will still be forced to make decisions based on incomplete information about "surgical outcomes and the psychosocial

adjustment of intersex individuals who have not had surgery” (Beh and Diamond, para. 1). The information offered by doctors and handbooks may make parents better informed, but does not make them sufficiently informed to justify the risks of surgery because the information necessary to justify surgery does not yet exist.

Second, the Advocates for Informed Choice and their supporters argue that more information is inadequate to help parents decide because that information may come from physicians, who may inadvertently frame discussions with parents in a manner that encourages surgery. The information doctors provide is not neutral. Instead, “a physician's own biases regarding the proper treatment may inform the way she discusses options with the parents of intersex children. For example, a doctor might tell parents that they may decide to postpone genital surgery until post-puberty or until the patient can make the decision him/herself, but that “in the doctor's professional opinion, there is a high risk of psychological problems relating to gender identity or homosexuality” (Lloyd, 2005, p. 171). Further, parents tend to trust doctors (Aliabadi, 2005) and doctors have thus far proven unlikely to discontinue early use of surgery. Lloyd argues that although “the education efforts of adult intersex activists have not gone entirely unheeded by the medical community,” the efforts have “not spurred an end to the performance of surgeries on intersex infants” (p. 195).

The Advocates for Informed Choice also worry that even if parents looked beyond doctors’ information to the other organizations’ handbooks when making decisions about surgery, parents may still not be persuaded to choose to delay surgery. This is because none of the handbooks actually demand any end to surgery. They not

only fail to place a moratorium on surgery, but also, and more troubling to AIC, the Handbook of the ISNA and Accord actually encourages parents to read the DSD Guidelines for treatment that is established for physicians. For AIC this is a problem because the DSD Clinical Guidelines frames intersex as a medical disorder that is “treated by a mixture of surgical techniques” (Zeiler and Wickstrom, 2009, p. 367). Parents are thus indirectly encouraged to consider surgical fixes for their child.

Finally, the Advocates for Informed Choice are concerned about the parental decision-making paradigm because they believe information is unlikely to help parents overcome their anxiety about violating social gender norms. Ford (2001) argues that there is strong evidence that parents are not competent to give consent to surgery because stress about their child’s difference may cause parents to make impulsive decisions. Even with information it is difficult to imagine parents overcoming their fear that their child is neither a boy nor a girl. For many parents, the fear that their child is not “normal” will result in a decision in favor of surgery in an “effort to help the child be accepted in society” (Zeiler and Wickstrom, p. 367).

Because they believe many parents are likely to opt for surgery for their children even with more information provided, the Advocates for Informed Choice support a state-court mandated categorical exception that outlaws early genital surgeries. Their position is supported by several legal scholars who argue, first, that categorical exceptions have empirically been effective for analogous cases (e.g. Beh and Diamond, 2005; Dufault, 1991; Rosato, 2000) and, second, that a court appointed guardian ad litem is in the best interest of the intersex infant (e.g. Benson, 2005; Ford, 2001; Haas, 2004;

and Muckle, 2006). According to the AIC, a civil suit ruling that a categorical exception exists is the fastest way to abolition of genital surgeries.

A move toward a court-imposed moratorium is not without its problems, according to the Intersex Society of North America, the Accord Alliance, the Organisation Intersex International and their supporters. They present a myriad of arguments against rescission of the parental decision-making paradigm. First, a court moratorium, even at the state level would be too broad (Aliabadi, 2005; Hermer, 2007). The moratorium would not account for individual circumstances and could not be applied to particular situations. Such a blanket policy would not meet the needs of all families or individuals with intersex variations.

They further argue that a moratorium should be discouraged because it takes too long to help the child. Blizzard (2002) contends that a moratorium “ignores the potential for psychosocial harm to intersex children when years pass before decision-making is finalized” (p. 619). If the court forced families to wait until the child is old enough to decide for him or herself, there are potentially traumatic side effects for the child who is forced to live without a permanent gender assignment. Hermer (2007) worries that the forcing a family to delay surgery may result in stigma for the child and Aliabadi (2005) fears that child will be psychologically damaged.

Supporters of the Accord Alliance and the Organisation Intersex International also argue that a court ruling that bans surgery on intersex infants may have far-reaching and damaging legal implications. Hermer (2007) queries, “If cosmetic intersex surgeries . . . should be banned, what happens to parental ability to consent to other ‘extraordinary’

cosmetic surgeries, such as those on . . . cleft lips” (p. 269). They note that, although it is hard to determine whether a ruling on intersex surgeries would set such precedent, it may be important to consider the ramifications if it did.

Another concern forwarded by those supporting parental discretion is that a moratorium on surgeries could also diminish, if not eliminate, “the burgeoning scientific investigation of the best treatment practices for different intersex conditions” (Hermer, 2007, p. 255). Martin (2002) suggests that important improvements are already being implemented in treatment protocols and advances are being made in the empirical study of the effectiveness of intersex treatment. Moreover, she argues that most problems that are identified about surgery have already been rectified. Specifically, “current techniques that were not possible 30-35 years ago now can maintain nerves and sensitivity of the organs, and some experimental evidence shows sensitivity may be preserved” (p. 159). The improvement in technique and advancement of medical knowledge are important for the long-term health of intersexed individuals. For them, a moratorium may not be worth the risk if it damages the overall improvement of care.

Finally, the organizations in favor of parental choice believe that offering more information to parents is more likely to lead to an end of surgeries than trying to solve through the courts. Courts have long held that parental rights are “sacred,” especially in the context of making medical decisions on their children’s behalf (“See, e.g., *Parham v. J.R.* 442 U.S. 584 (1979). See also Bryan Shartle, Comment, Proposed Legislation for Safely Regulating the Increasing Number of Living Organ and Tissue Donations by Minors, 61 *La. L. Rev.* 433 (2001) (stating the need for legislation in organ donations by

minors)” (Aliabadi, 2005, n106). Supporters of parental decision-making point out that the law assumes parents can and do act to protect their children’s welfare and it broadly allows parental discretion in treatment decisions. Thus, those opposed to the court based solutions believe judges are likely to find in favor of parents opting for surgery.

In lieu of court intervention, the ISNA, Accord Alliance, OII and their allies, support parental choice. They argue that with increased information parents will be able to successfully determine what is best for their child. They suggest there are three main arguments in favor of parental choice. First, they argue that because parents love their children, they will make the decision that is best for the child and their family (Aliabadi, 2005). Second, they point out that parents have the greatest knowledge of their child, of the cultural and religious environment in which the child will be raised, and of the nature of the specific intersex variation their child has. Their particular and situated knowledge makes them better suited than a universal, blanket moratorium to decide what is best for the child (Aliabadi). Finally, they contend that parents have to live with their decisions. Unlike the court, which will make a detached decision and not have to deal with the consequences, parents will have to weigh all options and will choose what is best for their child. ISNA, Accord, and OII hope that parents ultimately decide that the best option is to delay surgery.

Implications/Conclusions

For all parents the birth of a new child brings a certain level of anxiety. For parents of intersexed infants that anxiety may be heightened by the need to make some very difficult decisions. Most importantly, they must decide whether or not to approve

genital surgery on their child. The leading intersex advocacy groups agree with each other that surgery can have dangerous effects on a child's psychological and physical wellbeing. They also agree that parents are often given insufficient information from doctors and, as a result, are typically unprepared to make an informed decision about whether or not surgery is the best option. This is where their agreement ends, however. Worried about legally protecting the rights of intersexed youths, the Advocates for Informed Choice push for a court imposed categorical exception that would result in a statewide ban of non-essential genital surgery on intersex infants. This approach, they argue, is the only certain way to ensure the end of surgeries. However, the other organizations fear that there are limitations to selecting this strategy. The Organisation Intersex International, the Accord Alliance and Intersex Society of North America hope educational efforts will suffice in encouraging parents to elect alternatives to surgery. These efforts have currently been unsuccessful, as parents are still regularly opting for surgeries.

Unlike many of the other disputes that are occurring between the advocacy organizations, the battle over whether or not to accept the parental decision-making paradigm is most difficult to imagine easy resolution. The strategies proposed to bring an end to surgery are antithetical to one another. Whereas three of the organizations support parental choice, one is opposed to it. Importantly, however, the debate that is occurring is really at the strategic level. It is not about core value or ideal end point.

If there is opportunity for convergence on this issue, it seems that it would occur around the fact that they all are working diligently to end non-essential surgery. Laureau

(2003) offers a possible synthesis: “Ideally, the legal community should support heightened informed consent standards while explicitly noting that the ultimate goal is a moratorium” (p. 150). In other words, all organizations could redouble educational efforts for parents, while working toward a larger goal of a moratorium. Even if a moratorium fails to come to fruition all groups may reach their goals of minimizing surgeries.

CHAPTER 5: Sex and Gender Dimorphism:

Pragmatism versus Idealism

With the advancement of new technology, such as ultrasound and amniocentesis, parents are given information on the sex of their child while the fetus is still in utero. That information, whether given pre- or post-natally, generates a variety of feelings and triggers a series of actions taken on behalf of the child. The child is given a name, clothes of appropriate style and color are picked out, and the family is primed to expect certain behaviors as a result of the announcement (Thorne, 1993). It is through gender socialization that children learn how to exist in gendered power structures (Lorber, 1994), that children learn ritualized, stylized gender performances (Butler, 1990), and that children learn to do gender in a way to avoid sanctions for incorrect performances (West and Zimmerman, 1987). Sex and gender assignment is typically the first of a large series of developments that fall under the rubric of gender socialization (Zucker, 2002).

The declaration of “It’s a boy!” or “It’s a girl!” has long-term implications as well. The announcement of one’s sex will have monumental effects on one’s entire life because gender is “omnirelevant” in contemporary Western culture (Garfinkle, 1967). Although feminists have raised substantial challenges to and questions about gender relations, the importance of clear gender roles remains evident (Martin, 2005). They “enter into and are constituent of elements in every aspect of human experience” (Flax, 1987, p. 624). As such, individuals that challenge our understandings of gender are often stigmatized and pushed to conform. We can see this in the case of intersexual individuals.

The birth of an intersex newborn is treated as a “medical emergency” (i.e. al Jurayyan, et al., 1995; Coran and Polley, 1991; Hutcheson and Snyder, 2009, Pagon, 1987) because his or her body fails to easily conform to dimorphic cultural notions of male or female (Hird, 2000). Chase (1998) estimates that one in every 100 births shows some morphological anomaly, which is observable enough in one in every 1000 births to initiate questions about a child’s sex. Thus, although not every intersex newborn will have observable atypical features, there are many that will. Those that do not have observable differences at birth still challenge the notion that there are two and only two naturally occurring sexes.

Advocates fighting on behalf of intersex individuals unanimously recognize that intersex bodies complicate the notion of the dual-sex system. However, they vociferously disagree over what to do about this complication. Whereas the Intersex Society of North America and the Accord Alliance recognize some limitations of the dimorphic sex system, but encourage intersex individuals to conform to one of the two, the Organisation Intersex International hopes to broaden concepts of gender beyond the existing binary to a larger spectrum, with all individuals, whether intersexual or not, falling in different places along the spectrum. The Advocates for Informed Choice (AIC) criticizes continued reliance on binary understandings of sex because it increases the likelihood of non-essential surgeries to force bodies to fit into one of the two sexes, but they do not explicitly state whether they support the deconstruction of the dimorphic model. The AIC is thus troubled by the implications of gender dualisms, but discusses issues related to the effects of gender dimorphism, like surgery, rather than the dualism

itself. The positions taken by the organizations set up an interesting debate that can be characterized as pragmatism versus idealism.³ In order to explore the ramifications of their positions on gender theory and on the organizations' ability to coordinate with one another, I first explain the contemporary relationship between gender theory and intersexuality. Second, I lay out the positions on gender taken by each of the groups. Third, I discuss the implications of the positions for the larger intersex social movement.

Gender and Intersexuality

On August 22, 1965, Janet and Ron Reimer welcomed into the world identical twin boys, who they named Bruce and Brian. At six months of age, the boys were diagnosed with phimosis after their parents witnessed the boys experiencing problems with urination. At eight months of age, the boys underwent circumcision to correct the problem. However, during the procedure, which included electronic cauterization of the foreskin, the equipment malfunctioned. Bruce's penis was burned beyond surgical repair. The Reimers brought Bruce to the office of Dr. John Money of Johns Hopkins University in Baltimore, Maryland. Money, a psychologist, had a growing reputation for his new gender identity theory based on his work with intersex patients. After several interviews and examinations, Money concluded that a functional vagina could be surgically created and that a successful surgery would help Bruce achieve functional sexual maturation as a

³ I recognize the large philosophical debate regarding these terms. Although they can be understood as large, all-encompassing epistemological paradigms, I use them here as heuristics meant to offer insight into the two positions taken by the intersex advocacy organizations. Specifically, pragmatism is deployed to mirror Rorty's (1993) use of it in relations to the contemporary feminist movement, which he described as "reformist," which goals that are "fairly concrete and not difficult to envisage being achieved" (p. 97). This sort of "piecemeal reform" (p. 97) is the opposite of idealism which involves envisioning a "revolutionary political scenario or a post revolutionary utopia" (p. 97).

girl, rather than a boy. At age 22 months, Bruce underwent surgery to remove his testes and to begin the process of constructing a vagina. He was reassigned and raised to be a girl and renamed Brenda. Money and his team offered psychological support, counseling, and treatment for the entire Reimer family. For years, Money published reports about the successful gender reassignment of one half of a set of identical twins, which he called the John/Joan case to protect the family's privacy (Colapinto, 2001).

The Reimer case was touted by Money and supported by many as an ideal case to test Money's theory of gender identity development because the Reimer boys were identical twins which meant they not only shared identical genetic make-up, but also the same family and environmental surroundings. It was also ideal because Bruce was the first known case of a reassignment that happened on a child born as a male who had no atypical postnatal sex characteristics. As such, when Money reported that Bruce, now Brenda, was acting like a typical girl who loved dresses, hated being dirty, and eschewed the boyish ways of her twin brother (Money and Ehrhardt, 1972), it was thought that his theory of gender identity was correct. He believed that children were psycho-sexually gender neutral at birth and that one's gender identity would develop in accordance with his or her external genitalia as well as one's surrounding cultural environment (Money and Ehrhardt, 1972). The theory suggested that a child born with a vagina and raised as a girl will grow up with a female gender identity and a boy born with a penis and raised as a boy will have a male gender identity, regardless of genes. It assumed that genitals strongly correlate with gender identity, where physicians consider the success of future gender presentations based on the appearance of infants' sexual anatomy (Donohoe et al.,

1991; Horowitz and Glassberg, 1992; Kessler, 1998; Voorhess, 1982). Money (1972) concluded, “To use a Pygmalion allegory, one may begin with the same clay and fashion a god or a goddess” (p. 152). Money’s theory laid the groundwork for the idea that gender identity is socially constructed.

Money’s work with the John/Joan case helped solidify his growing influence in the medical community and codified contemporary medical treatment of intersexual individuals. Because one’s understanding of his or her own gender corresponds to the visual appearance of his or her genitals and socialization, Money argued for surgical intervention as soon after birth as possible for the child’s psycho-social well-being (Hird and Germon, 2001). Genitals considered to be atypical thus need to be made to be more typical in appearance for the child’s healthy gender development and surgery merely provides the “right genitals to go along with socialisation” (Kessler, 1990, p. 17). Implicit in his theory is the idea that sex and gender are both dimorphic. In other words, one is male or female, boy or girl, and thus ought to have the genitals that symbolize typical male or female sex organs.

For Money, the John/Joan case was “the most publicly celebrated triumph of a 40-year career that . . . earned him the accolade ‘one of the greatest sex researchers of the century’” (Colapinto, 1997, p. 56). However, for the actual Brenda/Bruce Reimer, the case was a failed experiment. Milton Diamond, a biologist from the University of Hawaii, and Keith Sigmundson, a psychiatrist from Victoria, British Columbia, reported in the *Archives of Adolescent and Pediatric Medicine* in 1997, that Bruce/Brenda had struggled against his reassignment as a girl from the start. They reported that at the age

of seven, Joan⁴ began to rebel against consultations and treatments. By the age of nine, Joan knew she did not feel like a girl. At fourteen, Joan refused to live as a girl and opted, against the wishes of her parents and doctors, to begin living as a boy and administer testosterone. At fourteen, Joan/Brenda took the name David. As an adult, David married a woman, adopted her kids, and had a penis reconstructed. At age 38, feeling he had no way to cope with flashbacks to his earlier troubled life, David committed suicide (Diamond and Beh, 2006).

Diamond and Sigmundson's findings not only raised questions about why it took so long to find out the truth about David Reimer's life and why Money's reports did not expose the same observations, but also challenged the by now widely accepted idea that gender is dimorphic and socially constructed. Despite Diamond and Sigmundson's reports, Money's model is still preeminent. "Money's management philosophy is almost exclusively adopted, and the vast majority of published literature has been written or co-written by Money. Very few physicians seem prepared to contradict Money, or provide alternative management theses" (Hird, 2000, p. 360). Even the new guidelines that resulted from the 2005 Chicago consortium that called for changes in treatment protocol are influenced by Money's theory. Lee et al. (2006), reporting the resulting guidelines, write, "Factors that influence gender assignment include diagnosis, genital appearance, surgical options, need for lifelong replacement therapy, potential for fertility, views of the family, and, sometimes, circumstances relating to cultural practices" (p. e491). The choice of gender assignment is thus dependent on factors that would have also been

⁴ Diamond and Sigmundson chose to continue to use the same pseudonym as the one chosen by Money.

recommended by Money, including how the genitals currently look, what surgical options are available to change the genitals, and how the family and cultural environment will affect gender socialization of the intersex child.

The adoption of Money's theory has thus had important and far-reaching effects on how doctors and parents interpret the gender of the bodies of intersex newborns. Each of the organizations takes a position on the relationship between current conceptions of gender and intersexuality. Their positions have significant consequences for the larger intersex rights movement.

Intersex Society of North America

Criticizing the work of Dr. Money, the Intersex Society of North America (ISNA) (2005e) argued that gender identity is much more complicated than what was suggested by Money and “unfortunately legions of doctors thought Money was right and did ‘normalizing’ surgeries in an attempt to make intersex go away” (para. 1). The surgeries resulting from acceptance of Money's theories tend to be performed due to the belief that surgery will help a child better conform in a gendered world that assumes one must be either male or female. The ISNA wanted to be clear, however, that their criticism of surgeries was not a criticism of the dimorphic gender system. The ISNA webpage stated, “Intersex people don't tell us that the very concept of gender is oppressive to them. Instead, it's the childhood surgeries performed on them and the accompanying lies and shame that are problematic” (Herndon, 2006b para. 4).

Troubled by the use of early surgeries as the means by which gender is assigned, the Intersex Society of North America offered a new set of procedures that ought to be

followed. Specifically, they endorsed what they labeled as a patient-centered model, in which, “Following diagnostic work-up, newborns with intersex should be given a gender assignment as boy or girl, depending on which of those genders the child is more likely to feel as she or he grows up” (ISNA, 2005i, para. 5). They acknowledge that figuring out what gender someone will feel they are can be difficult but that certain diagnoses tend to produce specific gender outcomes. For example, most newborns with complete androgen insensitivity syndrome grow up to feel female, and many children with cloacal exstrophy and 46,XY will grow up to feel male (ISNA, 2005b). Laying out the ethical guidelines shaping ISNA’s position, Dr. William Reiner (2000), on the medical advisory board of the ISNA, in a lecture at the University of Michigan, says,

Gender will be assigned at or near birth—legally and socially. We cannot know if our assignment will be correct, at the time of the child’s birth. Therefore, we must choose what appears to be the likeliest gender identity. If the children later tell us we are wrong, we shall then adjust accordingly. We must be flexible and patient, and teach the parents flexibility and patience. (para. 1)

They argue that assigning a child to be one of the two existing genders is supported empirically. Specifically, “many intersex people are perfectly comfortable adopting either a male or female gender identity and are not seeking a genderless society or to label themselves as a member of a third gender class” (Herndon, 2006b, para. 3).

Many academic feminists and even other intersex advocacy organizations have suggested the idea of deconstructing gender or expanding gender categories. Many specifically push for the creation of a third gender to be added to the two existing genders

(e.g., Fausto-Sterling, 1993; Garber, 1992; Gilley, 2010; Herdt, 1996; and Looy and Bouma, 2005). The Intersex Society of North America strongly opposed this proposal, however (ISNA, 2006a). They identified two problems associated with the notion of a third gender. First, it would be impossible to create a bright line for deciding who would be included. They write, “how would we decide who would count in the ‘third gender’? How would we decide where to cut off the category of male and begin the category of intersex, or, on the other side of the spectrum, where to cut off the category of intersex to begin the category of female?” (ISNA, 2006a). For them, because intersexual is not a discreet category, it would be difficult, if not impossible, to decide the limits of a new gender category. More importantly, according to them, ISNA is trying to make the world safer for intersex children and “we don’t think labeling them with a gender category that in essence doesn’t exist would help them” (ISNA). Emphasizing how obvious this should be to readers, they flippantly add, “Duh, huh?” (para. 3).

By encouraging parents and doctors to assign one of two existing genders without surgery and by eschewing expansion of existing gender categories, the Intersex Society of North America can be characterized as adopting a pragmatic perspective. Although they “would like to see people become less freaked-out by people who don’t fit sex and gender cultural norms,” (ISNA, 2006a, para. 1), they do not believe it is in the best interest of intersex children to push for the deconstruction of gendered thought.

Accord Alliance

Continuing the work of the Intersex Society of North America, the Accord Alliance adopts a position very similar to that of the ISNA. Overseeing the

implementation of the Consensus Statement on the treatment of intersex brokered between the ISNA and medical professionals, the Accord Alliance supports early assignment of either a male or female gender role without normalizing genital surgery. They encourage all parents of intersex children and clinicians who deal with intersex issues to read the *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood* (Consortium on the Management of Intersex Disorders, 2006) and the Consensus Statement on Management of Intersex Disorders (2006). Both suggest maintenance of the two-gender system through the early assignment of gender and the recognition that the child may reject the initial assignment as they age. In fact, studies seem to suggest that children with intersex conditions are more likely than the general population to feel that their initial gender assignment was incorrect (Consortium on the Management of Intersex Disorders). Because gender atypical behavior or even gender identity disorder can develop as the child ages, the Accord Alliance encourages parents and doctors to be flexible in allowing the child to experiment with their identity and to seek psychosocial counseling to help develop a more cohesive and stable gender identity.

The Accord Alliance does not deal directly with the issue of a third gender or expansion of the gender categories. Their omission of this discussion can be seen as evidence that they not only do not support it, but also that they do not consider it a viable alternative. The Consensus Statement, Clinical Guidelines, and the Programs and Missions sections on their webpage very clearly establish the policies and issues they normatively support and they choose to omit discussions of a third gender.

Just as with the Intersex Society of North America, the Accord Alliance's position can be characterized as pragmatic. The Accord Alliance offers suggestions on how best to determine which of the two genders is optimal for the child and encourages doctors to follow those guidelines to the best of their ability, while simultaneously recognizing that the two existing gender categories may not fit the child permanently.

Advocates for Informed Choice

The Advocates for Informed Choice offer the least information about their position on gender out of the four leading groups. Such silence does not mean gender is an unimportant concern for them; it just indicates that they view the issue of gender slightly differently than the others. For them, gender is important to their fight for intersex rights because it is societal notions of gender that encourage the continuation of genital normalizing surgery (Tamar-Mattis, 2006).

After a lengthy exposition and then criticism of Dr. Money's position, Anne Tamar-Mattis (2006) argues that surgical interventions to create so-called normal genitalia are a "magic wand" approach that rely on "the simplified vision that surgery is a one-time, painless, cost-free event in which the child goes to sleep as intersex and awakens transformed into a 'real' boy or girl. The problem, however, is that neither surgery nor gender is quite so simple." (p. 67-68). Parents, society and even those "who are open to discussions of . . . critiques of the gender binary" (p. 84) have trouble accepting alternatives to the two-gender model when faced with an intersex child. Because the gender dualism is so entrenched, the Advocates for Informed Choice aim to attack a byproduct of the system, rather than the system itself. They choose to focus on

the problems of gender normalizing surgery, which they argue limits the child's ability to choose for herself later in life which gender she feels she is.

Organisation Intersex International

The Organisation Intersex International's (OII) position on the relation of gender with intersex is more idealistic than that of the previous three. They support a more flexible, subjectivist understanding of gender and the abolition of a two-gender system (OII, n.d.-d). They criticize the status quo's notion of a two-gender system because it fails to adequately include all of the diverse gendered forms inherent in humanity. "Our societies have accepted a binary construct between male and female which does not reflect Nature and the enormous variety of possible sexes which overlap one another in various gradations on a spectrum with male at one end and female at the other" (OII, n.d.-b). One of their main organizational objectives is "to work in favour of human rights for the intersexed by helping people to understand that there are not just two pre-existing sexes. There is an infinite combination of possibilities on the spectrum of sex and gender" (OII, n.d.-d). Seeing gender as operating on a spectrum they propose allowing individual to choose for themselves where they fall along this spectrum; individuals should decide for themselves "which gender they wanted, if they wanted one" (OII, n.d.-d). They argue that their membership reflects this ideology. They include many people with intersexed variations who have rejected their assignment as either male or female. The leadership of OII feels strongly that all intersex people, "regardless of their gender identification, should be included, not just those with firm male or female identities and who have not rejected their male or female gender assignment" (OII, n.d.-a).

Importantly, however, the Organisation Intersex International is against the creation of a third gender that only includes intersex individuals because it “only reinforces the binary structure of sex, with a ‘defect’ squeezed in between which would be the third sex” (OII, n.d.-a).

Because they support self-selection of gender, OII is opposed to early or immediate assignment of gender. They instead encourage informing parents of their child’s physical difference in such a way “that they will be able to make informed decisions about the real health needs of their child (and not all this focus on which gender identity is best for the child which is what we are doing now)” (Hinkle, n.d., para. 2). Once parents understand the specifics of the particular intersex variation, the parents should work with doctors to assign a “TEMPORARY” gender assignment (Hinkle, para. 3, emphasis in original). The doctors should subsequently stress to parents that they are assigning a gender and not a sex and the child should be allowed to transform and adapt their gender as they see fit. Importantly, OII stresses that they only reluctantly support this provisional gender assignment and hope that eventually society will evolve to no longer be bi-gender reliant.

Assessing the Debate

Scholarly literature discussing the relationship between intersexuality and gender has proliferated in the last decade. Because intersexuality presents a unique case from which to explore gender, feminists, gender theorists and many others have begun to explore the possibilities for moving away from reliance on sexual dimorphism and to investigate the relative merits of new theories of gender. To better understand what is

happening in the contemporary intersex movement, it is useful to layout some of those key arguments and tie them back to the debate occurring among the different intersex advocacy groups.

The Organisation Intersex International is the most outspoken of the organizations in their criticism of gender dualisms. Their position mirrors closely those taken by many feminists and gender theorists, who argue that current dichotomous conceptions of male and female are problematic. They point to several shortcomings with what they refer to as an essentialized view of sex. First, they argue that binary notions of sex do not sufficiently account for the differences that occur in human morphology and psychology. The very presence of intersexuals, transgender people, transsexuals, bisexuals, and gay and lesbian men and women challenge the polarized categories of sex, gender and sexuality because they prove that “the actual combination of genes and genitalia . . . hormonal input; and procreative capacity may or may not be congruous with each other and with the components of gender and sexuality, and the components may also not line up neatly on only one side of the binary divide” (Lorber, 1996, p. 146-147). Intersex bodies, in particular, shake the foundations of the dimorphic sex schema. Acting as paradox that cannot be accounted for in the current system, they prove that not all bodies are born fitting the normative concepts of what we generally consider to be either male or female. This should lead us to question how something so ‘natural’ as ‘sex’ can be or needs to be artificially created after birth (Hird and Germon, 2001; Kessler, 1990) and lead us to the conclusion that material, corporeal accounts of what it means to be a man

or a woman are problematic and that “nature does not itself provide sufficient material from which ‘sex’ can be read” (Hird, 2000, p. 351).

It is also clear that nature does not provide the materials from which gender can be read. Even those bodies that may be easily categorized using traditional notions of male and female cannot be easily categorized into the two existing gender categories. Although it is widely assumed that those born with female anatomy are woman and those born with male anatomy are men, there are a myriad of groups who dispel this myth (Lorber, 1996). Binary gender accounts based on assumptions about anatomy fail to account for transsexual, transgender and queer-identifying individuals, as well as a host of others (Monro, 2002). The assumption that gender has a one-to-one correspondence with sex is troublesome in relation to the current treatment of intersex individuals because it is assumed that gender can be detected as a byproduct of sex designation and parents are encouraged to raise their child as a single gender from birth. Although the current guidelines do afford some room for possible gender reassignment later in life, continued societal insistence on unitary and corresponding genders means an intersex individual will face tremendous challenges in attempting to claim a new gender identity.

Finally, sex does not provide sufficient materials from which sexuality can be read. Organisation Intersex International and its supporters argue polarized conceptions of sex result in polarized conceptions of sexuality. Jackson (2006) points out that binary conceptions of sex and gender result in heteronormative conceptions of sexuality. In other words, heterosexuality is assumed to be the norm, whereby female born women and

male born men are heterosexual. Lesbians, gays, and bisexuals do not fit easily into this dichotomous system.

A second shortcoming of the dimorphic sex schema identified by those in agreement with Organisation Intersex International's position is that it is dangerous. Those falling outside of what is considered to be normal are met with both discursive and structural violence. Non-conforming bodies face the task of "building identities in a social environment that invalidates their reality and may even punish them for violating traditional gender roles" (Burdge, 2007, p. 246). Social stigma, harassment, societal and familial rejection, and physical and sexual assault regularly result (Brooks, 2000; Burgess, 1999; Donovan, 2001). Because the traditional gender dichotomy is so central to cultural formation those seen as existing outside of the norm are vulnerable to discrimination and oppression (Bern, 1993).

For intersex individuals there are also attendant medical dangers associated with reliance on a dimorphic sex schema. Belief that there are only two legitimate sexes results in dangerous medical treatments used to force intersex bodies to conform to one of the two sexes. Kessler (1998) suggests that genitals that vary from "a narrowly defined standard could have any number of different meanings" (p. 8), including that the "genitals signal the wrong gender category" and we "must operate to make them conform," "your genitals are inferior (less functional, ugly). We pity you and suggest you have corrective/cosmetic surgery," or "your genitals signify something about your parents. They must have misbehaved or be genitally unsuitable. They are embarrassed by you and your genitals" (p. 9). Because it is believed that "normal-looking" (read:

those perceived to be typical of an infant boy or girl) genitals are critical for an infant's psychosocial development, doctors have empirically performed cosmetic genital-normalizing surgery on intersexed infants (Crouch, 1998). With consequences ranging from repeated painful surgeries and loss of sexual sensation to shame regarding botched surgeries and feelings of inadequacy (Ford, 2001) it is clear that the medical treatment resulting from doctors' reliance on dimorphic ideations of sex is quite dangerous.

The arguments against the dimorphic sex schema should be clear. The position of the Organisation Intersex International is supported by feminists and gender theorists who argue that the dimorphic sex schema is insufficient because it doesn't account for the "shades of difference" (Hird, 2000, p. 248) that occur in nature and is dangerous because it exerts social and physical control over bodies. Intersexual, transgender, bisexual, gay and lesbian individuals call into question the aptness of our contemporary understandings of sex because they "challenge the ontological assumption that sex/gender fall into binary categories" (Monro, 2007, para. 1.1). Although the Organisation Intersex International is the only one of the groups that explicitly criticizes the sex dimorphism, none of the others would likely disagree with these arguments. What they take issue with, however, is whether the problems of the current situation warrant deconstruction of the current system or whether we should do work with the current system.

If the deconstruction of binary views of gender meant the creation of a new category just for intersex, all four organizations would likely unite with one another against the new system. One such system is offered by Anne Fausto-Sterling (1993), a renowned feminist author and intersex scholar. Her approach is characterized by its

additive nature. She suggests that a better gender schema would include not only males and females, but also herms (those who possess one testis and one ovary), merms (those who have testes and some aspects of female genitalia but no ovaries), and fermes (those who have ovaries and some aspect of male genitalia but no testes). Theoretically her approach creates a space for intersexuals because it recognizes men, women, and then three different categories of intersexuality. However, as the Intersex Society of North America and the Organisation Intersex International attest, this simple expansion of the binary view may not be in the best interest of intersexual individuals. Because it does not question the legitimacy of unitary conceptions of male and female, those will always be the norm, while the subsequent categories will be devalued. Further, expanding genders may still exclude some intersex people and those whose bodies do not form to the newly established categories (Monro, 2007). Even if great consideration is given to selecting the optimal new categories to account for the most people, there will be individuals that do not fit and will be made to conform.

If the deconstruction of binary views of gender meant the creation of an entirely new system of gender, one that abolished all current categories, the groups would no longer be in agreement. The Organisation Intersex International (OII) strongly favors such a reconceptualization of gender. Their position is explained and supported by many feminist scholars. For example, Tauchert (2001) writes, “The retreat from the binary that has dominated cultural forms in the modern period is an ethical project. It is not possible to ignore the binary, but it is possible to engender models for sexual embodiment that

reconstitute normativity” (p. 190). Further, such essentialism precludes the enunciation of, perhaps, more apt and fluid understandings of gender. Butler (1990) argues:

Gender is a complexity whose totality is permanently deferred, never fully what it is at any given juncture in time. An open coalition, then, will affirm identities that are alternately instituted and relinquished according to the purposes at hand; it will be an open assemblage that permits of multiple convergences and divergences without obedience to a normative telos of definitional closure. (p. 16)

Because of their belief in gender’s openness, the OII is pushing for viewing gender as a spectrum. Rothblatt (1995) argues that OII’s allows self-identification of a multitude of contingent identities and it calls for the proactive embrace of identities and categories. Pluralist models, such as the one suggested by OII, allow individuals to strategically position themselves along a spectrum or on a series of axes. Some argue that this can ultimately result in destabilizing binaristic thinking about gender (Cranny-Francis et al., 2003).

Although the United States and most Western cultures are far from such an expanded conception of gender, there are many examples of different societies that support the possibility of OII’s position coming to fruition. Empirically some societies afford room for non-binary notions of gender. For example, the Dominican Republic honors the guevedoce. Born with an intersex variation called 5-alpha reductase deficiency syndrome, most guevedoce are raised as girls until puberty when their voices lower, their muscles develop, and their clitorises elongate to resemble penises. After

puberty, the guevedoce are allowed to transition into male roles, with little or no societal constraint (Elliot, 1998). Herdt (1996) hypothesizes that the relative ease in gender switching is not due to a laissez-faire attitude about sexual identity, but rather due to the Dominican society's widely held acceptance of a third sex. Because 5-alpha reductase deficiency syndrome is relatively common they have a "triadic sexual code" (Herdt, p. 428). Children are not born into a society that is male and female, but instead, "male, female and guevedoce" (Elliot, p. 36). Several Native American communities also honor a three-gender system. The Navaho have the nadleeh, who are accorded high status and prestige. A family into which intersexed child, or nadle, is born is seen as very fortunate (Hill, 1935). With the expansion of understandings of sex beyond simply male and female, intersex individuals in these societies are able to avoid many of the problems faced by those in contemporary Western culture.

Although such societies have existed, many people question the possibility of Western societies adopting new understandings of sex. The Intersex Society of North America (ISNA) and the Accord Alliance are among the skeptics. Although they identify problems with the surgery and treatment that result from the dimorphic sex schema, they are more optimistic about banning surgeries than they are about societal reconceptualization of gender. Elliot (1998) supports their position, pointing out that such reform may not be possible in the short term:

It would be a mistake to overlook the consequences of damaging and stigmatizing cultural pressures an intersexed child may face. We might think the Navajo in the 1930s were more enlightened than we are today, but we can't simply decide to see

the world that way. We have the culture that we have, and we live in the present, not the past. Cultures change, of course, and it is more likely that ours will change if fewer surgeries are done and intersexuality is acknowledged openly. But few parents will willingly risk what they believe to be the well-being of their child in order to protest a cultural norm. (p. 39)

Emphasizing practical considerations over idealized outcomes, Elliot identifies the crux of the debate occurring about gender and intersexuality. Although the dimorphic sex scheme certainly poses problems for intersexuals, the question becomes, how do we best fix the problem? The ISNA and Accord argue that pushing for larger societal reform is not the answer. Instead, resources and efforts should be directed to what they consider to be more practical concerns. The Organisation International is so troubled by the dual gender system that they worry that maintenance of the system will mean continued stigmatization and unnecessary surgeries for intersexuals. The stasis point of this debate is thus pragmatic versus ideal.

Conclusion

With the widespread acceptance of Dr. Money's theory of gender socialization, the treatment of intersexuals came the reliance on surgery to ensure proper genital normalization. All four of the leading intersex advocacy groups staunchly oppose the use of surgery for such ends. Instead they support assignment of gender absent physical manipulation of the body, whenever possible. Despite this agreement the debate over gender continues.

Although the academic debate over the assets and drawbacks of the dual sex system makes the rift between the organizations seem insurmountable, the possibilities for organizational cooperation and movement agreement over what to do with gender are great. There are arguably very strong possibilities for organizational cooperation if viewed in terms of short-term versus long-term goals. All of the groups recognize there are limitations to maintenance of the two-gender system. In fact, the very existence of intersexed bodies calls into question the appropriateness of maintaining sex dimorphism. The disagreement for the groups seemingly rests on how to respond to the shortcomings of the gender dualism. However, when viewed in terms of temporality, the disagreement disappears.

All of the organizations understand the necessity of assigning a gender to a newborn. All of them agree that genital surgery is an unacceptable means by which to codify gender assignment and all of them assert that gender assignment should be considered temporary and subject to change as the child ages. Thus, in the short term, gender can be assigned heuristically as a means to help the child in a sexually dimorphic society. In the long term, however, there appears to be no reason from the organizations' perspectives not to allow the Organisation Intersex International to pursue the deconstruction of gendered categories. Even if Accord Alliance and Advocates for Informed Change do not choose to integrate gender criticism into their platforms, they offer no reason why breaking down gendered thinking would be disadvantageous for their overall objectives. In fact, moving away from gender dimorphism may help them reach their goals of ending non-essential surgery and preventing the stigmatization of

intersex individuals because it forces societal reconsideration of what it means to be a man, a woman or something else entirely.

CHAPTER 6: Conclusions

The history of medical mistreatment of intersexuals has long been documented. Emi Koyama of the Intersex Initiative (n.d.) summarizes the issue, “this ‘treatment’ . . . sets in motion a lifelong pattern of secrecy, isolation, shame, and confusion. Adult intersex people's stories often resemble that of those who survived childhood sexual abuse: trust violation, lack of honest communication, punishment for asking questions or telling the truth, etc. In some cases, intersex people's experiences are exactly like those of child sexual abuse survivors” (para. 3).

Speaking autobiographically, Morgan Holmes (2008) writes,

Contemporary intersexuals have little hope that the medical establishment that labels us will see our bodies as graceful expressions of difference. Instead, contemporary intersexed people are first rendered as freakish crises, as medical emergencies, and as the unraveling of meaning—all only to be repackaged in surgically corrected form as a testament to the wonders of medicine, the propriety of sexual dimorphism, and the correctness of what Judith Butler calls “the heterosexual matrix.” (p. 13)

The narratives of intersexual individuals and their parents tell a tale of confusion, isolation, stigma, and physical as well as psychological pain. The organizations of the intersex rights movement have emerged to bring an end to this trauma. Since the inception of the movement in 1993 with the founding of the Intersex Society of North America, the movement has grown both in size and in diversity.

The number of members has increased as awareness about intersexuality has risen and as intersex individuals and their family felt more comfortable sharing their stories and expressing their voices. As the movement grew, more organizations emerged, giving more options to the intersexed and their non-intersexual allies. The Intersex Society of North America was joined, in 2003, by the Organisation Intersex International and, in 2006, by the Advocates for Informed Choice, and was replaced by the Accord Alliance in 2008. Although the organizations are united under a single banner of seeking justice for individuals with intersex variations, they all have their own particular agendas, interests, and ideas for how best to proceed. As is true with all social movements, the intersex rights movement houses a diverse array of groups that dispute the proper objectives, methods, and tactics (Preves, 2005) to achieve their objectives. In fact, there is tremendous tension that exists among the advocacy groups. The public statements and websites of the organizations highlight not only the areas of convergence, but also the critical points of divergence. The preceding chapters investigate the debates and disagreements in great detail. They show that some of the divergence points create seemingly insurmountable antagonisms that prevent coalition building, while others make the case that despite seeming inconsistencies the groups are and should be able to work with one another to achieve their common objectives. In this final chapter, I summarize the key debates among the social movement organizations of the contemporary intersex rights movement, offer some conclusions about the findings of the study, identify some limitations of the study, and suggest the directions future research might take.

Summary of Chapters

Chapter two evaluates organizational identity creation through the publication of organizational mission statements and identifies the implications of mission statements on groups' organizing potential. Although all of the groups are committed to change, they disagree over the correct path to follow to achieve that change. Their differences are made visible in their organizational mission statements. As a public summary of the organization's purpose, the mission statement is instrumental in the organization's public image creation. As the first intersex rights organization, the Intersex Society of North America (ISNA) had a relatively broad mission focused on making the world safer for intersex individuals by helping to bring systemic change to end shame, stigma and unwanted genital surgeries. Facing as though they had accomplished their mission⁵, the ISNA closed in 2008 to make way for the Accord Alliance. The Accord Alliance explicitly narrowed their mission to focus solely on medical reform. For the Accord Alliance, the purpose of intersex activism ought to be improvement of healthcare for intersex individuals through the creation of interdisciplinary medical teams and a suspension of non-essential early surgery. The Organisation Intersex International frames itself as engaged in pushing for societal reforms. They hope to end medicalization, normalization, and genital surgeries without informed consent. They are opposed to groups like the Accord Alliance, which they believe lead to the dangerous medicalization of intersexuality. The Advocates for Informed Choice describe

⁵ It is debatable whether the Intersex Society of North America actually met its objectives. The public statement upon their closing suggests they were relatively satisfied with the results of the Consortium, but there seems to be some tension between the result of their Consortium in 2005 and the espoused goals of the ISNA in their organizational mission statement.

themselves as focused on legal reforms, hoping to procure rights for intersexual individuals. They make a point of repeating that they are the first and only group focusing on providing protections for intersexual individuals through legal mandates.

The ways social movement organizations, such as these, choose to identify themselves has important implications for their ability to ally with others, to attract and retain members, and to justify the existence of the organization. Short and to the point, an organizational mission statement is one of the first things available to interested parties. It will shape the likelihood of adherence to an organization and offers readers insight into how to categorize that organization, both descriptively and heuristically. Once an individual joins an organization, the mission statement functions to guide members on which activities can appropriately be undertaken by an organization. It also sets the boundary conditions of an organization, allowing members and leaders to know when their organizational purpose has been fulfilled. Moreover, the mission statement captures the ideological beliefs of the organization, making it seem like an appropriate ally to some, but an enemy to others. Although the mission statement is not the only factor in determining membership or coalition-building opportunities, it certainly plays an important role in shaping these functions.

Another key factor determining membership and coalition-building opportunities is the terminology selected by an organization. How a group labels the key issues of their organization plays an important role in predicting who the target audience of an organization is, who fits within an organization, what actions an organization will take, and what the chances are of working in tandem with another organization. As a result,

organizations ought to be quite reflexive in determining how best to frame and discuss the issues relevant to their organization.

For the intersex rights movement, the battle over naming is fierce. In chapter three, I explore the ongoing debate over the nomenclature of intersexuality. Although the Intersex Society of North America and the Organisation Intersex International both select the term intersexuality, they do so for different reasons. The Intersex Society uses intersex because they view this term to be the most pragmatic for starting a movement. Arguing it is an umbrella term, the Intersex Society of North America prefers intersex because many people with a diverse assortment of intersex variations can easily identify with the expansive term. The Organisation Intersex International, however, chooses intersex because it recognizes all the different sexual variations inherent in human morphology. As such, the OII's use of intersex is an implicit criticism of the dimorphic sex schema. The Accord Alliance, interestingly, agrees with OII and ISNA's assessment that intersex is an expansive, umbrella term, but believes such an expansion hurts those that the organizations are actually trying to help. As a response, the Accord Alliance selects the term Disorders of Sex Development (DSD). Leaders of the Accord Alliance believe that using DSD is preferable because it uses the language preferred by physicians dealing with patients with different sexual variations. The Advocates for Informed Choice opt for what they see as a middle ground approach. They simultaneously use the terms intersex and Differences of Sex Development, arguing that the combination of the terms best ensures that all individuals feel comfortable approaching their organization for help. They further argue that the term Differences best avoids the problems of

normalization and medicalization inherent in the term Disorder. Each of the groups' websites offers a robust defense of why they choose that terminology and why they eschew alternate terminology. It is clear that they believe this issue is important and winning this debate will have a real effect on their ability to achieve their mission.

Although debates over naming occur in every movement, the battle over parental rights and parental consent is unique to the intersex rights movement. Because intersex variations typically present themselves while children are minors, parents are currently legally obligated to make decisions on their children's behalf. Historically, parents have agreed to early genital surgery on their children, seeing it as a way to normalize children's bodies. All four of the leading intersex advocacy groups are troubled by the presumption for surgery, however. They cite data proving that surgeries tend to decrease sensation, increase pain, and produce shame. Their uneasiness regarding surgery is one of, if not the only issue with which all of the organizations agree. Their agreement ends, however, once the question of how to go about ending surgery is raised.

While the Intersex Society of North America, the Accord Alliance, and the Organisation Intersex International remain united in their belief that offering parents more information about surgery will lead to the eventual end of non-essential surgery, the Advocates for Informed Choice (AIC) are less optimistic. It is not that the AIC is against parents having more information; in fact, it supports parents educating themselves as much as possible about their child's condition. However, the AIC is doubtful that giving parents more information will overcome all of the other factors that drive parents to accept surgery, such as doctors' recommendations and cultural beliefs that a child must

have typical-appearing genitals. Although the AIC wants to respect parents, they push for the courts to intervene to prevent non-essential genital surgeries. The recommendation made by the AIC limits the opportunities for cooperation with the Accord Alliance because it would alienate one of the groups that Accord sees as its key constituents. The Accord Alliance names parents as a key component of their health care initiative and so taking power from parents to make the decision would be impossible for Accord to accept.

The final major issue currently debated between the four leading intersex advocacy groups is gender. Because of the preeminent role gender plays in shaping identity and producing appropriate social interactions, the question of how and when gender should be assigned to an intersex newborn is raised by all of the groups. While they all agree that surgery is not the means by which gender should be assigned, they disagree over whether they should advocate for the end of a dimorphic sex schema. Troubled by the shame and trauma caused by forcing intersex individuals into one of two sexes, the Organisation Intersex International is alone in its fight to end sexual dimorphism. While the others agree that there are limitations to the current Western gender configuration they disagree that intersex children should be used to push for change. They believe it is impractical and perhaps even unethical to ask parents of intersex children to raise their child as gender rebels.

Taken together, the chapters present a comprehensive analysis of the current debates occurring among the organizations leading the intersex rights advocacy movement. They begin to develop an explanation of how these disputes affect the

potential of organizations to attract and maintain members, to build partnerships with other organizations, and to achieve the ends they set out to accomplish. However, more studies in the future will be needed to more fully investigate both the intersex rights movements and the theory of social movement organizations.

Future Research and Challenges

Specifically, more studies need to be completed in the future to investigate the direction each of the organizations take and to analyze the ways in which this debate evolves. There should also be more studies done that test the relationship of social movement organizations and the relationship to the broader movement. The case of intersex advocacy organizations is an interesting one, but the theory of social movement organizations needs to be tested in different contexts as well. Doing so will help introduce a much more robust theory of movement studies as a whole.

If one does decide to take up such studies in the future, they should be aware of some of the challenges I faced in completing this study. One of the key challenges is that the movement is still ongoing. Most studies of social movements take place after the movement has ended. As such, the different stages are easy to measure and the subject does not change. This is not the case for the intersex rights movement. The movement is still very much alive and active. The organizations are at different points in meeting their objectives and the debates are occurring contemporaneously to my research. The updates can be exciting for me as a researcher, but it does make the task more difficult. It means that parts of the text are occasionally changing and that it is difficult to make empirical observations about the successes or failure of the organization. Being engaged in

research that is currently so fresh is to be encouraged because it has relevance to ongoing battles really happening in the world. However, if one chooses to take up a similar study with a living, changing text, they should be aware that the research becomes much more difficult.

The challenges of studying an ongoing phenomenon are magnified when the texts being studied are primarily on the Internet. Social movement organizations that exist primarily in cyber-space present a problem for researchers because their websites change. As with any active groups, new information is regularly published, homepages are routinely redesigned, and old information is taken down. These changes can present a problem for researchers because the “text” or subject of the study is constantly in flux. For the four leading intersex advocacy organizations, the changes were noticeable, but, fortunately for me, did not contradict earlier positions or force reevaluation of any of the organizations. Rather the changes were either aesthetic, as in the case with Advocates for Informed Choice, who moved to a different domain name and updated the visual appeal of their webpage, or supplemental, like in the case of Organisation Intersex International, Advocates for Informed Choice, and Accord Alliance, when they simply added new information about events and positions. Because websites tend to change rapidly and without warning, it would be wise for researchers to establish an archive system that stores key documents and pages on a regular basis. This would ensure continued access to important positions and also allow the researcher to analyze whether substantive changes are happening over time. These changes could not be followed if records have not been kept.

A further limitation of this study is that it only analyzes the public statements and documents of the organizations. Although this textual medium is appropriate for the nature of this study, different and important insights could be gained from interviewing leaders and members of the organizations. Doing so would provide a different perspective on their views of the necessity of coalition-building, could better explain their public positions and may offer insight into how they understand their organization's role in the larger movement.

Conclusion

Public debate among emerging social movement organizations may be important for young movements as they try to determine their long-term direction. The disputes may allow organizational members to clearly identify the key issues of their struggle and figure out what is best for the overall body of organizations fighting for a single cause. Indeed, there is tremendous value to public debate and deliberation. Hollihan, Riley, and Freadhoff (1986) and Schuetz (1986) observe that argumentation can be a valuable tool for achieving agreement and building consensus. Bernstein (1988) adds that through argument and public discourse people can confront one another as equal participants, forming a consensual judgment of the issue at hand. Goodnight (1999) argues that public argument is a way for participants "to share in the construction of the future" (p. 251).

Other historical movements prove that dissensus within a single movement may be productive for the overall movement. Although debates between organizations do take time, effort, and attention, they still force the organizations to publicly defend a well-reasoned position, which may, in time, produce a more agreeable outcome. Even if it

does not, the differences between organizations ensure complexity and depth to the movement. Many major movements in the United States have had different factions that push each other forward. The Civil Rights movement famously had the non-violent reformism of Dr. Martin Luther King, Jr. and violent, revolutionary perspective of Malcolm X. The second wave of the woman's rights movement similarly had liberal and radical feminism. The existence of such diverse perspectives ensures all those interested can find a group with which to identify.

The consensus building potential of public argument may even be heightened when the arguments occur online. Bowen (1996) asserts that the Internet provides numerous avenues for political expression and many ways for individuals to become politically active. Grossman (1995) adds that the Internet provides individuals with easier access to information, thereby spurring enthusiastic reformatory discourse among citizens and groups that are widely dispersed. Rash (1997) further points out that the Internet provides relatively unknown organizations the ability to gain attention and increase awareness in a relatively short timeframe.

However, despite the theoretical possibility that debate may create consensus and that the Internet will help clarify issues for movement adherents and interested readers, this does not seem to be the case for the intersex rights movement. Several years into their ideological battles, it does not appear that these organizations are willing to compromise. Because of the major debates over organizational identity, naming, parents, and gender, the groups are working relatively independently. Their ability to coalesce into a larger movement is hampered by their vociferous defense of their positions.

Although the organizations may find themselves in agreement with one another on a single issue, they are likely to disagree with each other on a different issue. I would argue that disagreements over policy issues are more easily overcome than disagreements over identity issues. In other words, organizational identity, naming, and perhaps even gender, are likely more salient issues that will dictate group divergence because they are much more value laden than the issue of how best to fix poor parental decision-making. Once groups define themselves in opposition to another or once they frame the phenomena they are working to change in contradiction to others, their ability to work as allies is hindered. Because these issues are at the very core of who they are they will play a much-greater role in determining whether a movement will unify than issues related to strategic action or policy implementation.

Although smaller disputes may be ever present in all movements, leaders and organizers need to recognize that they share core values with one another. In the intersex rights movement, it is clear that they all share the desire to end non-essential genital surgeries and to ensure that individuals with intersex variations are treated with dignity. It is unclear at this time whether the organizations wish to put differences aside; however, there is a strong case to be made that working with one another will produce their desired results more quickly because, in working with one another, they increase the amount of material resources available and provide the opportunity for like-minded individuals to build coalitions. Together, the organizations have a better chance of achieving the major goals of the overall movement. Thus, it is time for the organizations to stop engaging in endless discursive battles with one another and to start devising complementary strategies

for bringing their core values to fruition. Instead of vilifying one another and demonizing each other's positions, it is important to recognize that each of the organizations ultimately desire similar ends.

Consequently, the debates should be reframed away from dissent and disagreement toward recognition of the compatibility of the differing ideologies. Organizational identity should not be understood as one organization distinguishing itself apart and superior to all others; rather it should be about recognizing that some organizations are better suited to handling a different issue related to intersexuality. The issue of naming should not be about controlling the language of the debate, but should instead be thought of as necessary adaptation to different audiences. The dispute over parental consent for surgery should not be viewed as a battle over competing strategies, but should be seen as two complementary tools to lead to the same desired outcome. Finally, the issue of gender should not be about whether or not it is possible to end sexual dimorphism, but instead should be seen as the possibility for short and long term solutions to be implemented to ensure intersex individuals are no longer hurt by it.

Such a re-envisioning of the key issues of the intersex advocacy movement would go a long way toward helping the organizations achieve their goals of making the world more just for intersex individuals and their families. The necessary changes likely will not come about over night. However, it is hopeful that the world will eventually be a place free of stigma, shame, and trauma for intersex individuals. The Accord Alliance, the Organisation Intersex International, and the Advocates for Informed Choice have to

potential to fundamentally change the world. The question now is whether they will actually unite to do so.

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