A QUIET REVOLUTION:
MEDICINE, INTERSEX ACTIVISM, AND THE POLITICS OF CONSENSUS

By

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To Laura,

swim coach extraordinaire

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CHAPTER 1

CONCEPTUALIZING INTERSEX IN MEDICINE AND SOCIAL MOVEMENTS

Intersex has been framed almost exclusively as a biomedical issue given that, until recently, the classification and treatment of intersex has been under the purview of biomedicine. Intersex traits may be associated with any of dozens of diagnoses, but generally refer to atypical sexual anatomy—chromosomal, gonadal, and genital characteristics considered non-standard for "male" and "female." The birth of a child with intersex traits has often been considered a medical and social emergency.[1] What intersex is and how—or whether—it should be treated has been a source of, at times, acrimonious debate among multiple actors, including clinicians, researchers, activists, intersex adults, and parents of intersex children. That is, "[w]hatever intersexuality may be physiologically (and it is many things), intersexuality as a category of person (requiring medical treatment) is not natural" (Karkazis 2008: 11; see also Holmes 2002). This dissertation will show, in part, that such contestations are struggles for legitimation; they challenge who has the authority to classify and treat particular bodies and more broadly, raise questions over the credibility afforded to embodied experiences.

Central to the debate over the medical management of intersex is a debate about defining the "normal" body. Developments in medical knowledge and technology have offered tools to

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[1] Most children born with atypical sexual anatomy do not require medical intervention for their physiological health. In rare cases, intersex is associated with life-threatening concerns (e.g., one form of congenital adrenal hyperplasia (CAH) is characterized by severe salt and hormonal imbalances) that warrant immediate medical intervention. Additionally, though also rare, immediate medical attention may be needed to allow for the elimination of urine or to close open abdomens with exposed organs (e.g., cloacal exstrophy).

understand intersexuality chromosomally, leading to more precise diagnostic categories and a greater ability to identify intersex conditions at birth. While some in the intersex community staunchly oppose medicalization, others are forming alliances with medical professionals in order to "gain a seat at the table" and change medical care. As a result of medical advancements and growing pressures from intersex activists, a group of experts convened to evaluate clinical protocols, and subsequently published the "Consensus Statement on Management of Intersex Disorders" (Lee et al. 2006). Along with outlining new clinical recommendations for care, the Statement also endorsed the new clinical nomenclature of "disorders of sex development" (DSD) (Lee et al. 2006).

My research uses the case of intersex to examine a set of controversial diagnoses that have changed as a result of both technological developments and the visibility of new social groups who challenge medical authority with collective, experiential knowledge. Medical clinicians suggest the DSD classification schema reduces confusion, increases precision and standardization, and emphasizes genetic etiology (Lee et al. 2006; Vilain et al. 2007). Others outside of the medical profession argue the reclassification is an attempt to reassert medical authority amidst increasing lay challenges (Davis 2015). Specifically, my dissertation responds to calls in the sociology of diagnosis (e.g., Jutel 2011) to investigate how and why particular conditions are framed as they are by examining the layers of negotiation, compromise, and interests that surround the scientific evidence of disease and illness. My dissertation examines how understandings of and responses to intersex have changed as a result of these new classifications, amidst a backdrop of evidence-based medicine, technological innovations (e.g., genetics), and vocal advocacy communities.

INTERSEX: BRIEF OVERVIEW AND PREVIOUS SCHOLARSHIP

There are few reliable estimates of the prevalence of intersex, in part, because there is debate about what individuals or diagnoses count as intersex. Medical professionals also do not fully understand the biological causes of intersex. Medical experts agree that sex is multi-faceted, but as my research will show, the attributes used to differentiate males from females have varied over time and remain controversial.[2] Moreover, there is no national census or tracking method for recording intersex births (Karkazis 2008). One oft-cited study (Blackless et al. 2000) that attempted to develop estimates of the frequency of intersex concluded that the frequency of all causes of non-dimorphic sexual development are approximately 1 in 100 or 1.7% of all live births. Elsewhere, Anne Fausto-Sterling (2000) estimated that between 1 in 1000 and 1 in 2000 live births may be subject to genital surgery.

Medical intervention was not routine for intersex before the twentieth century. Advancements in medical knowledge and practice (e.g., surgical techniques, chromosomal testing, the discovery of “sex” hormones) in the early-to-mid twentieth century expanded understandings of the biological markers of sex (Oudshoorn 1994; Dreger 1998b) and paved the way for interventionist models of treatment. In the 1950s, John Money and colleagues (Money et al. 1955b; Money and Ehrhardt 1972) introduced a systematic model for the medical management of intersex conditions. Money and his team at Johns Hopkins University emphasized swift clinical workups to determine a sex for these infants, and then recommended surgery to modify the infant’s body, especially the genitals, to conform to the assigned sex. Money’s protocol was rapidly and widely adopted, in part because it offered a systematic

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[2] Since the late 1970s, many scholars have distinguished between sex and gender, using the terms in a general way to refer to biological (*sex*) versus social dimensions (*gender*) (see also Jordan-Young 2010).

approach to previous imperfect and uncertain knowledge (Karkazis 2008). Money's protocol was virtually uncontested from within the medical profession for decades, and by the 1970s, the medical protocol for intersex diagnoses almost exclusively reflected Money's paradigm, forming "a consensus rarely encountered in science" (Kessler 1998: 136).

While Money's protocol retained widespread dominance throughout the latter half of the twentieth century, divergent ideas were also developing, both within and outside of science, about the medical management of intersexuality. By this time, the first generation of those treated according to Money's protocol had reached adulthood, and began seeking information about their condition, as well as about others who had similar experiences (Preves 2003; Karkazis 2008). Feminist scholars, parents of children with intersex diagnoses, and eventually clinicians, ethicists, and legal experts also began to critique intersex medical management. These critiques facilitated the development and formation of the intersex movement, beginning with the founding of the Intersex Society of North America (ISNA) in 1993.

Intersex activists have increasingly claimed knowledge and authority about the meaning and responses to intersex. Activist groups, such as ISNA, have been a partner and resource to medicine—although limited—for knowledge about intersex conditions. Clinicians initially approached the emergence of early activist groups as a collection of outsiders toward whom they felt deep suspicion (Karkazis 2008). Over time, some activist efforts began to include the formation of alliances with clinicians in order to challenge medicine. For some activist groups, the growing collaboration with clinicians slowly strengthened activists' credibility in the medical arena.

After a decade of efforts to challenge conventional medical approaches to intersex, from both medical professionals and lay activists, fifty international experts convened in Chicago to review medical guidelines for intersex diagnoses (Lee et al. 2006). At this Chicago meeting, and later summarized in the published Consensus Statement (Lee et al. 2006), the new classification schema, “disorders of sex development” (DSD) was endorsed. In addition, the Statement outlined a more cautious approach to early genital surgery, and recommended the use of multi-disciplinary teams, including the integration of psychosocial support (Lee et al. 2006). It is unclear, however, the extent to which the protocols have been adopted in clinical practice. The historical and contemporary controversies over intersex illustrate that understanding and classifying certain bodies are debated by actors both within and outside of medicine, and change with time, place, and technologies. My dissertation seeks to understand the shifting boundaries of medicine’s jurisdictions, especially since the emergence of the Consensus Statement, particularly as a result of diverse efforts to manage uncertain knowledge.

Previous Scholarship on Intersex

While the medical literature on intersex has largely focused on gender identity and surgical outcomes, some clinicians have begun to question the psychosocial ramifications of medical management of intersex. This research has challenged the effectiveness of surgery and questioned whether interventions promote well-being (e.g., Creighton et al. 2004; Liao and Boyle 2004; Roen 2004). Scholarship in the social sciences and humanities has also focused on the stigma and trauma associated with surgical normalization (Dreger 1999; Preves 2003; Karkazis 2008), drawing attention to ethical concerns and even calling for medical reform (Dreger 1998a; 1999; Parens 2006; Sytsma 2006). There is also a growing body of research utilizing legal and human rights perspectives to examine and critique intersex and medical management. Lawyer Julia Greenberg (2012) examined the emergence of intersex activism and explored the potential of several legal strategies, including disability law, sex discrimination, and human rights protections to support the goals of intersex activists.

Feminist scholars were among the first to critique the ways in which intersex medical management contributes to processes of regulating gender and to lend support to the growing intersex movement of the early 1990s. Suzanne Kessler (1998) and Anne Fausto-Sterling (2000), for example, began to examine how biomedical approaches to intersex draw upon and reinforce dominant ideologies of sexed embodiment. Kessler (1990, 1998) revealed how the medical management of intersex ultimately relies on normative understandings of gender. Based on interviews she conducted with physicians involved in intersex medical management, she demonstrated that physicians' decisions were influenced by cultural factors, including notions of proper genital size.

Fausto-Sterling (2000) also exposed the politics of sex and gender implicit in research on brain organization and gendered behavior, sex hormones research, and outcomes research on genital surgeries. Along with critiquing intersex medical management, her research illustrated how beliefs about gender affect definitions of sex as well as the kinds of knowledge scientists produce about sex in the first place. Historian Alice Dreger (1998b) examined medical treatment of hermaphroditism in France and Britain in the late nineteenth and early twentieth century. Using archival research, she traced negotiations and disagreements among medical professionals about which bodily parts would count as essentially masculine or feminine. Her historical analysis highlights the role of normative ideas about proper genital size and sexual partners in shaping medical treatment for hermaphroditism.

Scholarship in the social sciences has focused on the lived experience of intersex persons and experiences of parents of intersex children, drawing largely from qualitative interviews with these two groups. This research has highlighted problems inherent in medical practices and the negative consequences of medicalization, including stigma, shame, and other psychosocial concerns (Preves 2003; Holmes 2004). Sharon Preves (2003), a sociologist, examined the experiences of intersex adults and how they coped with their differences. She conducted life-history interviews with intersex adults to examine how they learned of their intersex status, their medical experiences, and how they negotiated issues of identity (Preves 2003). She argued that medical interventions often contribute to—rather than mitigate—stigma about their differences. Preves (2003) also highlighted the role of support groups in providing a forum to connect intersex persons, and helping to mobilize the intersex movement. She later conducted research on intersex media activism and examined how activists used mass media strategically, particularly through their framing processes, to make claims for cultural and medical reform (Preves 2005).

Anthropologist Katrina Karkazis (2008) examined contemporary intersex medical management by conducting interviews with intersex adults, parents of children with intersex traits, and clinicians. She examined the ideologies of sex, gender, and sexuality at the core of intersex medical management and that guide medical decisions over gender assignment and treatment. Her work extends that of Kessler (1998) by interviewing clinicians after the emergence of intersex activism. Moreover, like Preves (2003), Karkazis (2008) examined the ways in which the subjective experiences of intersex people challenge medical authority.

Building upon Karkazis's (2008) work, sociologist Georgiann Davis (2015) investigated how intersex became a DSD. Drawing from interviews with adults with intersex traits, parents of children with intersex traits, and medical experts, she argued that medical professionals replaced intersex with DSD in an effort to reclaim their authority over intersex in the face of ongoing challenges from intersex activists. She also examined tensions over terminology among intersex individuals, finding that those who adhered to a binary or essentialist understanding of gender were more accepting or more likely to endorse DSD nomenclature.

A group of researchers at the University of California at Los Angeles, led by sociologist Stefan Timmermans analyzed parent-clinician consultations to examine decision-making processes pertaining to surgery (Timmermans et al. 2018). Their findings illustrated that that while clinicians were sensitive to external critiques about surgeries and expressed caution, they also presented surgery as beneficial in their communications with parents. Clinicians strategically steered parents toward decisions clinicians perceived as most appropriate (Timmermans et al. 2018). In a subsequent article, Timmermans et al. (2019) similarly examined parent-clinician consultations to examine decisions around gender assignment, finding that parents and clinicians choose an “appropriate” gender based on the child’s potential for sexual intimacy, fertility, gender dysphoria, stigma, and cancer risk.

Much of this previous scholarship uses the case of intersex to explore the politics of sex and gender (e.g., Kessler 1998; Fausto-Sterling 2000; Karkazis 2008; Davis 2015), and often assumes a “top down” approach, focusing on medicalization and the consequences of medical control over intersex bodies. However, as ISNA once declared, “intersex is a problem of stigma and trauma, not gender” (ISNA 2008a). My research examines the processes and consequences of medicalization, and how the process occurs both from the top down and bottom up. Little research has explicitly examined the strategies and tactics of the intersex movement, and their role in medical reform. Specifically, I build on the work of Preves (2003, 2005), Karkazis (2008), and Davis (2015) to examine current debates around intersex, particularly the ways in which medical practice has (or has not changed) since the publication of the Consensus

Statement (Lee et al. 2006). I examine how and why the material and discursive practices of medicine have changed, and also investigate the ways in which medical professionals adopt and/or resist protocols in their clinical work. My research also investigates the trajectory of intersex activism, and examines the ways in which intersex people have actively engaged in efforts to reform medical practice.

A brief note on terminology. I acknowledge that terminology used to refer to intersex is a source of ongoing debate. Indeed, I explore some of this tension over nomenclature in this dissertation. I predominately use the language of intersex, intersex traits, and people with intersex traits throughout my research. The term "disorders of sex development" (DSD) is now common in the medical literature and among medical professionals. I use DSD when discussing the terminology changes and related debates, and in order to maintain clarity and consistency when referencing the medical literature or medical profession. "Hermaphrodite" was the common label used, particularly in medicine, prior to the shift to DSD. I use the labels of hermaphroditism specifically when it is relevant to the historical context.

THEORY AND LITERATURE

I situate this research in the literatures of a.) the sociology of diagnosis and medicalization; b.) knowledge and practice, particularly the symbolic interactionist framework of social worlds/arenas and c.) health social movements.

Diagnoses and Medicalization

Diagnoses are "social" for two reasons. First, diagnosing a condition is connected to political, economic, cultural, and/or social factors. Diagnoses are made on the basis of the technology and values available at a given time. As classification tools, diagnoses delineate and organize the continuum of human conditions, and validate what counts as disease. Classifications operate as social framing devices, and perform the work of "making it appear that science describes nature (and nature alone)" (Bowker and Star 1999: 46), yet the work of diagnosis is often invisible (Bowker and Star 1999). In other words, diagnoses are presented as natural factors, yet they hide a deeply grounded, socially negotiated genesis (Jutel 2011).

Second, multiple actors conduct diagnosis, and the actions of one group often spill over to affect the actions of others (Brown et al. 2011). Diagnoses are shaped by the complex interactions among lay individuals, professionals, institutions, and organizations (Brown 1995). Once a diagnosis is made, a treatment can be planned, a prognosis determined, and resources are allocated. Given the power of diagnosis to confirm status and allocate resources, the diagnosis is an important site of contest and compromise (Jutel 2011). By engaging with a social model of diagnosis, I do not presume that categories like intersex or DSD are not real or useful. Rather, I consider how and why particular conditions are framed as they are and examine how many forces and agents interact to shape diagnoses, binding the biological, the technological, the social, the political, and the lived (Jutel 2009, 2011).

Medicalization is frequently, although not invariably, enabled by diagnostic categories. According to sociologist Peter Conrad (1992), medicalization "consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using medical intervention to "treat" it" (211). Diagnostic labels affix a medical model to conditions, behaviors, or processes and thus, define, understand, and treat phenomena through medical practices (Zola 1972; Conrad 1975, 1992; Conrad and Schneider 1980).

Medicalization has been the subject of sociological inquiry for half a century, with research often focusing on how non-medical problems become medicalized, as well as the negative and positive consequences of medicalization (Zola 1972; Conrad 1992, 2007). Some work in this area built upon labeling theory and focused on the medicalization of deviant behaviors such as same-sex attraction (Conrad and Schneider 1992). Other work built upon feminist theory and the women's health movement, focusing on the medicalization of "normal" aspects of women's bodies and experiences such as childbirth and menopause (Riska 2003; Lock 2004; Conrad 2007). In these works, medicalization is often shown functioning as an agent of social control (Zola 1971; Illich 1976; Conrad and Schneider 1980; Conrad 1992; Williams and Calnan 1996) and as a "top down" process, or with physicians as the active agents in facilitating medicalization (Conrad 2007). Moreover, in the literature, medicalization is often synonymous with overmedicalization, or inappropriate medicalization (Conrad 1992, 2007).

Foucault (1973, 1977) contributed to a more complex understanding of medicalization, suggesting how the discursive and material practices of medicine are both sites of control and productive in constituting new categories, identities, and bodies (Rabinow 1999; Klawiter 2008). Research began to highlight additional factors driving the expansion of medicalization, such as professional dominance, patriarchy, the growing reliance on science, as well as the efforts of people experiencing illness to gain recognition and seek treatment for their conditions (Rabinow 1999; Barker 2002; Brown and Zavestoski 2004; Klawiter 2008). Work has also examined the role of people outside the medical professions in medicalization processes, shifting focus to how lay people actively participate in the process, at times resisting, while at other times, embracing medicalization (Barker 2002; Dumit 2006; Brown and Zavestoski 2004; Zavestoski et al. 2004; Conrad and Leiter 2008). Although medical beliefs and institutional interests often facilitate medicalization, processes are not always “top down,” and often involve collective organizing and strategic claims-making across multiple arenas. Lay individuals and groups, including individual patients and advocacy organizations, also negotiate medicalization processes, and may involve sympathetic medical professionals (Brown 1990, 1995; Conrad 1992).

Scholars have argued that medicalization is intensifying and changing. Clarke et al. (2003) conceptualize this shift as biomedicalization, in which medical authority is widening through increased technoscientific formulations, where risk is monitored, medical knowledges are produced, information is standardized, and identities are created along genetic lines. Central to biomedicalization processes are clinical innovations, such as new diagnostics, treatments, and practices. Whereas medicalization practices often emphasize exercising *control* over medical phenomena (e.g., diseases, bodily malfunctions), biomedicalization practices emphasize *transformations* of bodies and lives, particularly through technoscientific interventions (Clarke et al. 2003).

Critics have argued medicalization is individualizing and depoliticizing, locating the source of the problem in the individual rather than the social, encouraging medical interventions rather than collective solutions (Conrad 2007). Research on the medicalization of gender variance and more specifically, intersex, has echoed these critiques. Scholars argue that diagnoses such as inversion, homosexuality, and hermaphroditism represent attempts to control individuals who pose fundamental threats to both gender and sexual norms and the sex/gender system itself (Hausman 1995; Dreger 1998b; Fausto-Sterling 2000; Meyerowitz 2002; Preves 2003; Matta 2005; Reis 2009).

Despite a tendency to focus on negative consequences of medicalization, research has also suggested positive implications of medicalization (Broom and Woodward 1996; Conrad

2007), including the potential for greater social tolerance and a more humanitarian approach to atypical behaviors and bodies (Conrad and Schneider 1992; McGann and Conrad 2007). Similar to work in the sociology of diagnosis, research suggests that medicalization can have benefits such as legitimating patient's concerns and support for their problems (Broom and Woodward 1996; Nettleton 2006; Conrad 2007). Through diagnosis and medicalization processes, patients can form collective identities and facilitate the formation of support and advocacy networks (Barker 2002; Brown and Zavestoski 2004; Jutel 2009).

Davis (2015) has demonstrated how, in the face of intersex activism, the shift from "intersex" to "DSD" allowed physicians to reclaim authority over intersex. Building on this, my dissertation will show that diagnosis is a site of both intergroup *and* intragroup contestation. Some activists critique and reject DSD as pathologizing, while others endorse DSD pragmatically, viewing it as a route to work with medicine and reform treatment. Indeed, whereas medicalization studies document patient resistance to diagnosis and the expansion of medical jurisdiction, scholarship on contested illness illustrates how individuals work to achieve diagnosis and thereby increase medicalization (Conrad and Stults 2008). In this way, DSD is constructed in a "contradictory symbolic position" (Hutson 2011: xxxiii)—simultaneously normalizing and stigmatizing.

At the same time, both patients and clinical providers express ambivalence and anxiety about medico-scientific interventions (Kaufman 2005; Landzelius 2006). My own research seeks to better understand how patients and providers engage with medicalization processes so that policies and practices might be improved to better meet people's needs and preferences—as individuals and as members of patient groups (e.g., Loe 2004; Mamo 2007, 2010; Fishman 2010). Ethically charged situations when one person makes decisions for another, such as a parent deciding for a child, are particularly fraught, as with surgical modifications in the case of intersex (e.g., Parens 2006).

Knowledge and Practice

Scholars at the intersection of medical sociology and science studies have emphasized the relationship between medical knowledge and the social context in which it is embedded (Conrad and Barker 2010). Freidson (1970) showed how the medical profession has a set of assumptions of what illness is that reflects, in part, biological realities, but also the social world. In considering lay beliefs, one can understand how medical knowledge is constructed, both formally within the medical system as well as informally in the community. There are multiple interpretations of illness and professional and lay understandings of illness are often at odds. Scholars have also highlighted ways in which our notions of biological disease or biomedical evidence are negotiated and interpreted within a specific social context (Timmermans 2007; Joyce 2008). Certain groups have the power to define what is an illness and how it should be treated, whereas others are largely the subject of the medical gaze (Foucault 1973). My dissertation builds upon this body of work, which underscores the different knowledge systems that often clash in interpretations of health, disease, and illness.

Symbolic interactionism is a theoretical tradition that explicitly asserts the situational, perspectival nature of knowledge, and further contributes to the notion of knowledge as constructed through interactions (e.g., Mead 1934; Blumer 1969; Strauss 1993). According to Blumer (1969), society is constructed through human interaction. Individuals make meaning individually and collectively in social groupings of various kinds from professions to social movements. Anselm Strauss (1993) built on this work with emphasis on interaction and organizations. Strauss and others (Strauss 1978, 1991; Becker 1982) proposed social worlds/arenas theory where social worlds constitute the shared realities within which people act, interact, and make meanings of their situations.

The social worlds framework focuses on meaning-making among collectivities or groups of actors, and on collective action, or people “doing things together” (Becker 1986), and working with shared objects, technologies, or tools (Clarke and Fujimura 1992). Strauss (1978, 1982, 1993) and Becker (1982) defined social worlds as groups with shared commitments to certain activities, sharing resources of many kinds to achieve their goals, and building shared ideologies about their work (Clarke and Star 2008). The social worlds framework relies heavily upon Mead’s (1934) key concepts of perspective and commitment—that all actors, including collective actors as social worlds, have their own perspectives, sites of work, and commitments to action vis-à-vis the situation or arena. The social worlds framework thus seeks to examine all the human and non-human action and elements contained in the situation from the perspectives of each. It seeks to analyze the various work activities involved in creating and utilizing science, technologies, and medicine, elucidating multiple levels of group meaning-making and material involvements, commitments, and practices (Clarke and Star 2008).

Social worlds are “universes of discourse” that, over time, intersect with other worlds with which they share topical interests and commitments (Strauss 1978). Scholars can analyze these wholes/intersections as an arena, which is composed of multiple worlds organized around issues of mutual concern and commitment to action. Social worlds theory assumes multiple collective actors—social worlds—in negotiations in a broad and often contentious arena. Arenas are focused on matters about which all of the involved social worlds and actors are 1.) committed in action and 2.) produce discourses about arena concerns. Arenas, therefore, are sites of action *and* discourse (Clarke 2009). Social worlds (e.g., an occupation, a social group) generate a shared perspective that form the basis for collective action while individual and collective identities are constituted through commitments to and participation in social worlds and arenas (Strauss 1959). Within social worlds and the arenas in which worlds intersect, knowledge is constructed in an ongoing fashion vis-à-vis the everyday practices of a given social world. The social worlds framework became the conceptual infrastructure of situational analysis on which my study relies (Clarke 2005; further explained under DATA AND METHODS).

By attending to diagnostic or clinical work, the researcher can see how knowledge and practice are intimately connected. The practices involved in categorizing pathologies, establishing treatment protocols, and determining treatment are all linked to assumptions about health, illness, and appropriate care (Pickering 1992; Casper and Berg 1995). Biomedical and scientific work are collective and heterogeneous. Understanding the coordination and negotiation of practices in diagnostic work, which takes place across disciplines and domains (e.g., social worlds), is key to understanding knowledge production. The arena of intersex medical management demonstrates one such setting. This is a contested arena, at the intersection of multiple practitioners (e.g., urologists, endocrinologists, psychologists) with a range of skills, interests, and commitments (e.g., surgery, hormones, identity).

Health Social Movements

As previously discussed, (bio)medicalization processes are not always “top down.” As questions of health and illness have been recast as political matters, individuals—often organized into patient groups or broader social movements—have demanded a say in medico-scientific work, challenging assumptions that such matters are best left to the experts (Epstein 1996, 2008).

Many such groups are hybrid insofar as they blur divisions between “expert” and “lay” (Brown and Zavestoski 2004; Epstein 2004). Scholars have suggested that this increase in health and disease-based mobilizations reflect the prevalence of more skeptical attitudes towards doctors, scientists, and other experts, trends which also manifest in new conceptions of patients’ rights and renewed concerns with bioethical debates (Brown and Zavestoski 2004).

Health social movements (HSMs) have had a significant role in pressing for social change, and have profoundly influenced the health care system and public awareness of health and illness (Brown et al. 2010). HSMs are “collective challenges to medical policy and politics, belief systems, research, and practice that include an array of formal and informal organizations, supporters, networks of cooperation, and media” (Brown et al. 2010: 119). Different types of HSMs address different health issues, and also use different strategies and tactics to meet their goals, ranging from advocacy to radical activism (Brown et al. 2004).

Brown et al. (2004) offer a typology of HSMs that includes the subcategories of health access movements, constituency-based health movements, and embodied health movements (EHMs). Access movements are HSMs that seek equality of access to health care, focusing on reform in provision of services and improvement in their quality. Here, groups work within the existing system and biomedical model and use education rather than direct action. Access movements do not challenge the existing system. In contrast, constituency-based movements are strategically oriented to inequality and health inequities based on race, ethnicity, gender, class, and sexuality. These movements advocate in social, political, and cultural arenas for change. Many of these groups are activist-oriented, challenging current medical practices and pursuing greater radical reform. Constituency-based movements link institutionalized medicine to other forms of social inequality, such as gender and sexuality (Zavestoski et al. 2004). EHMs introduce the subjective experience of the biological body to social movement activism (Brown et al. 2004; Zavestoski et al. 2004). These categories are ideal types, and the goals and activities of social movements and advocacy organizations may span more than one, as in the case of intersex. Indeed, elements of all three types of HSMs are evident in the intersex movement. However, in my research I emphasize the intersex movement as an EHM.

There are three components of EHMs. First, the illness experience is the source of movement identity and "represents the intersection of social constructions of illness and the personal illness experience of a biological process" (Zavestoski et al. 2004: 256). The collective identity is politicized through the understanding of the stigmatized self as a structural problem not as a personal problem. Second, EHMs challenge not only medical authority but scientific knowledge and the practices involved in its production. For EHMs, the embodied illness legitimates the claims of activists, and are based on the underlying assumption that experiential knowledge constitutes justifiable medical knowledge. That is, the challenges of EHMs are distinct not because they are based in the physical body, but because legitimation is based on people's own experience of their bodies (Archibald and Crabtree 2010). The third element is that EHMs involve a degree of collaboration that blurs distinctions between movement insiders and outsiders. That is, actors seek to subvert scientific authority structures while simultaneously allying with them.

Attention to patient groups and HSMs is crucial for understanding the consequences of biomedical transformations, such as those that facilitated and resulted from the Consensus Statement and DSD nomenclature change (Lee et al. 2006), particularly the agency and the resistances that have arisen in response to them (Epstein 2008). Intersex individuals initially mobilized in the 1990s around shared experiences of trauma and pain as a result of medical practices. Additional variation-specific groups began to form with the aim of offering support and medical information for patients and their families. Whereas early advocacy efforts emphasized demedicalization and embodied difference, as activism increased over time, some intersex activists began to form alliances with clinicians as part of their collective efforts. These tensions between activists' orientations to medicine and aligning with medical professionals are particularly evident in activists' reactions to the DSD nomenclature.

In chapter three, I examine activists' diverse positions regarding DSD. Here, in brief, it is worth noting that supporters argue that DSD emphasizes the etiological bases of conditions and also reduces confusion, especially for parents, that has accompanied the term "intersex" (Dreger et al. 2005; Dreger and Herndon 2007). On the other hand, opponents argue the shift to "disordered" language reinforces notions that intersex is pathological (Reis 2007; Karkazis 2008). Multiple actors and organizations promote differing degrees of alignment with a biomedical model. My dissertation builds upon previous scholarship on patient groups and HSMs by examining a case in which collective efforts are divided by the extent to which activists and advocacy groups are oriented to medicalization, or engage with medical discourse and practice (Epstein 2008).

In this dissertation, I use the tools of social worlds/arenas theory via situational analysis, and draw on the literatures of medicalization, particularly its intersection with the sociology of diagnosis, and health social movements to examine the following research questions:

1. How has medico-scientific discourse and practice on intersex changed over time?
    a. What role has intersex activism played in changes to medical understandings and treatment for intersex?

    b. What are the primary concerns and challenges of medical professionals in delivering care?
    c. How do medical professionals understand and implement recommended protocols into their practice?
2. What is the role of medico-scientific discourse in the efforts of intersex activists and advocacy organizations?
    a. How do intersex activists and advocacy organization engage with medico-scientific discourse and research in their claims-making and in their challenges to medical practice?
    b. What strategies and tactics do intersex activists and advocacy organizations utilize in their efforts to challenge medicine?

DATA AND METHODS

This dissertation engages the tools of situational analysis (Clarke 2005) to analyze diverse sources of data that includes qualitative interviews, textual analysis, and participant observation. Within situational analysis, social worlds/arenas theory expands to include everything within in a given situation as consequential elements (Clarke 2005). That is, it is not just the social worlds and their human and non-human elements that situate and shape knowledge and practices, but histories, discourses, institutions, etc. In situational analysis, the conditions of the situation are the situation—there is no such thing as "context" (Clarke and Star 2008). The analysis of the situation specifies the conditional elements of the situation, whereby what structures and conditions any situation is an empirical question (Clarke and Star 2008). The situation per se becomes the unit of analysis, and understanding its elements and their relations is the primary goal. The situation of inquiry is empirically constructed through three kinds of mapping exercises. I used the analytic techniques of situational mapping (Clarke 2005; explained further under Analytic Strategies) to understand the situation of concern, particularly intersex medical management.

Data Sources

Interviews. I conducted 20 interviews with medical providers involved in diagnosing, treating, and clinically managing individuals with intersex traits. I also conducted 21 interviews with individuals engaged in intersex activism and involved in various advocacy organizations. I began recruitment efforts for my interviews by drawing on my existing social networks in order to locate medical professionals and advocates. I also located additional physicians and advocates by looking at medical publications and organizational websites to identify key players in medical and advocacy social worlds, respectively. I then used snowball strategies, and asked interviewees for referrals to other medical professionals and advocates. Snowballing is often the best way to locate individuals with certain attributes or characteristics necessary for research (Berg 2009).

I sought to interview people from the different specialties that are typically involved in intersex care. These specialists also represent the key disciplines that compromise the multidisciplinary team in current clinical recommendations to delivery care for individuals born with intersex traits (Lee et al. 2006; Lee et al. 2016). I also aimed to recruit professionals with differing levels of experience. I conducted semi-structured interviews with 20 medical and clinical providers. These participants were specialists in urology (n=9), endocrinology (n=6), psychology (n=4), and psychiatry (n=1). Sixty percent (n=12) of medical interviewees were men, while forty percent were women (n=8). Participants' years in practice ranged from 4-44 years, with a median of 26 years.

Interviews with clinical providers lasted from 30 to 90 minutes. Compared to other areas of medicine, the medical providers involved in clinical work for intersex are a relatively small, but widespread community, and therefore geographic distance and costs often prohibited in-person interviews. Therefore, I completed most interviews by telephone. I interviewed three physicians in person. Topics covered during my interviews included perceived changes in care, the impact of the Consensus Statement, clinical decision-making particularly for gender assignment and surgery, communicating with patients and families, and the perceived impact of intersex activism.

Activism is also an important site of engagement with and contestations over medical management, with different interests and efforts taken up by various activist and advocacy organizations. Knowing that the intersex movement includes diverse organization ranging from patient support groups to activist-oriented organizations, I sought to interview individuals involved in multiple organizations. To explore this side of the story, I conducted formal interviews with 21 activists and completed informal discussions with two individuals (one in-person; one online). Most interviewees were a person with an intersex trait (n=19). Two activists were family members of a person with intersex traits, and two allies from the lesbian, gay, bisexual, and transgender (LGBT) community. Participants' involvement in advocacy work ranged from 2 to 38 years, with a median of 13 years. Interviewees were associated with 7 groups or organizations that represented both variation-specific groups (e.g., Turner Syndrome Foundation) and activist-oriented organizations (e.g., ISNA). Almost all interviewees were involved in more than one organization.

Interviews with activists ranged in length from approximately 35 minutes to two hours and fifteen minutes. Similar to that of medicine, advocates are a small, but diffuse community, similarly making in-person interviews prohibitively difficult. Therefore, most interviews were completed by telephone (n=19) and video conferencing (n=2). Interviews covered topics pertaining to their involvement and work with different organizations, including the extent to which they engaged with medical professionals or other institutional actors, perceived medical changes as a result of activism, and the impact of the Consensus Statement.

Participant observation. In June 2013, I began my fieldwork by attending the 4th International Disorder of Sex Development (i-DSD) Symposium in Glasgow, Scotland. The i-DSD Symposium is a multidisciplinary conference held every two years. It is attended by international experts as well as patient representatives. An explicit aim of the Symposium was to facilitate collaborations among these groups. The scientific program in 2013 included invited talks and research presentations, and covered a range of topics, including drug therapies, surgical interventions, treatment outcomes, and patient and family communication. I participated in and took fieldnotes at numerous information sessions, research presentations, training workshops, and other events.

The cornerstone of the Symposium is the i-DSD Registry. The registry provides a platform to connect clinical and research centers around the world in an effort to collect standardized information on various diagnoses associated with intersex traits. To learn more about it, I participated in a pre-symposium training workshop offered for those interested in conducting clinical research and in using the registry. Regrettably I was not able to attend a support group session that brought together affected patients and family members with members of the medical community. Despite contacting the Session Chair to express my interest in attending, they refused my request, and I was not able to attend this session, which was primarily by invitation only.

Later on, I also attended three "gender team" meetings at a large, academic pediatric hospital. I was invited to attend after meeting the pediatric endocrinologist that coordinates and leads these meetings. During these meetings, unusual or "difficult" cases were discussed, and various specialists presented diagnostic and treatment information regarding their involvement in the case. These meetings were attended by medical professionals and medical students.

Each of these sites for participant observation provided important data to supplement my research, and offered particular insight into professional and lay dynamics, interprofessional dynamics, and also highlighted current areas of debate. These observations also helped me to identify key challenges encountered by professionals in clinical practice and research.

Textual materials. To collect data on current areas of controversy, collective efforts of activist and groups, and key claims, I also collected and read articles, press releases, and other information created by popular media, support groups, and advocacy organizations. I also collected published accounts on medical treatment and research on intersex in both scientific and popular media, medical education texts, and other written documents. These data not only were important for my analysis, but they also helped me to identify key players in the worlds of intersex medicine and advocacy—that is, the people I interviewed.

Analytic Strategies

Interview recordings were transcribed, and all textual materials were uploaded into the qualitative data analysis software program, *Atlas.ti*. To analyze these data, I followed Strauss and Corbin's (1998) grounded theory methodologies. Grounded theory, very briefly, is an "empirical approach to the study of social life through qualitative analysis" (Clarke 2005: xxxi). This emphasizes the on-going coding of data and memo-writing in order to conceptualize a particular project that is grounded in data. I initially coded data segment by segment (open coding), giving temporary labels (codes) to particular phenomena. I also used “sensitizing concepts” based on the review of relevant literatures to guide my open coding. Then, I began to determine the extent to which generated codes appeared across multiple data sources, and elaborated their properties. Codes that were related and extended across sources were then “densified” (Clarke 2005: xxxi) in categories that were ultimately integrated.

Unlike the “basic social process” that undergirds traditional grounded theory, the conceptual infrastructure of situational analysis centers on Strauss’s “social worlds/arenas/negotiations” framework (Clarke 2005). Clarke (2005) argues for situational analyses in which a particular situation of interest is analyzed through examination of all the salient elements and their relations in that situation. Situational maps lay out the major human, non-human, discursive, and other elements in the research situation of inquiry and facilitate analysis of relations among them. A second type of map, social worlds/arenas maps, offers meso-level interpretations of the situation by laying out the collective actors and the arena(s) of commitment and discourse within which they are engaged in negotiations. Lastly, positional maps lay out the major positions taken and not taken in the data vis-à-vis axes of concern and controversy around issues in the situation of inquiry. These maps center on elucidating the key elements, discourses, structures, and conditions of possibility that characterize the situation of inquiry (Clarke 2009). I used mapping strategies throughout the coding and memo-writing process, to work through initial ideas and areas of exploration. The very doing of maps provoked my thinking and analysis, and helped me work through data more systematically.

OVERVIEW OF CHAPTERS

In chapter two, I provide a historical situational analysis of the medical management of intersex. Drawing from primary and secondary data, and using mapping techniques of situational analysis, I examine diverse collaborations between and among medical professionals, activists, and others, highlighting the ways in which intersex has been understood and responded to over time. I empirically examine negotiations over processes of classification and standardization, and elucidate key elements of the situation, particularly the technologies, concepts, and conditions most consequential for contemporary practices and clinical recommendations, particularly those outlined in the landmark 2006 Consensus Statement (Lee et al. 2006).

In chapter three, I draw largely on interviews with intersex activists to examine different styles of activism within the intersex movement. I analyze the multiple strategies and tactics of activists, including their diverse positions on DSD nomenclature. Some activists, many of whom endorse DSD, focus on direct engagement with medicine and want to collaborate with medical professionals to improve clinical care and research. Others, including those that reject DSD and generally oppose working within the medical model, are looking to legal strategies, particularly human rights advocacy and litigation, to politicize intersex medical management.

In chapter four, I examine the impact of the Consensus Statement recommendations on clinical practices by drawing on my interviews with clinical providers that care for intersex people and their families. In particular, I analyze how providers engage in multidisciplinary team-based care and patient-centered care. Additionally, I examine clinicians' perceptions of their interactions with intersex patients and families, as well as the challenges they face in their daily work.

In chapter five, I conclude this dissertation by reviewing key findings from my research and discuss their contributions to the literature. I also review implications for policy.

CHAPTER 2

CHRONICLING INTERSEX MEDICAL MANAGEMENT: A SITUATIONAL ANALYSIS

In this chapter, I provide a historical situational analysis of the medical management of intersex. I examine the medical understandings and responses to atypical sex over time, including the technologies, concepts, and conditions most pertinent in shaping contemporary practices, classifications, and standards of care. Current recommendations for the clinical management of intersex are outlined in the "Consensus Statement on the Management of Intersex Disorders" (Lee et al. 2006). Endorsed by professional pediatric endocrine associations in both the U.S. and Europe, this landmark publication proposed the new nomenclature of "disorders of sex development" (DSD) and laid out a revised approach to intersex medical management for the first time since the 1950s.

When the Statement was published in 2006, the ethics, politics, and science underlying intersex medical management had been subject to almost 20 years of strong critique from actors within and outside of medicine. The Statement and its recommendations have since provoked a range of reactions from different actors and communities, and debates and controversies persist. While the new standards were swiftly embraced by clinicians in medical discourse and practice, in general, outside the worlds of medicine, they are particularly contentious. Among the worlds of intersex activism, the DSD nomenclature is especially divisive.

In this chapter, drawing from primary and secondary data, I examine negotiations and diverse collaborations between and among medical professionals, activists, and others, and trace the ideas and practices mobilized in intersex classifications. I demonstrate how different actors and communities of practice have variously engaged in collaborative endeavors to classify, define, and standardize intersex health care. Using the tools of situational mapping (Clarke 2005), I empirically examine negotiations over processes of classification and standardization, and show how, at times, concerns about defining and treating intersex are negotiated through "cooperation without consensus" (Star 1993).

In what follows, I first provide a brief overview of situational analysis and mapping techniques. Next, I trace the parallel histories of intersex medicalization and the rise of scientific medicine in the nineteenth and early twentieth centuries, and examine the influential work of John Money and his colleagues at Johns Hopkins University, whose work defined the standard of care for intersex management for the latter half of the twentieth century. My analysis then turns to elements both within and outside the worlds of medical science that are particularly consequential for current clinical management, as represented by the Consensus Statement. I also explore subsequent—and ongoing—controversies in the current clinical arena.

I situate this work in the histories of biomedicine and intersex activism, which constitute the "conditions of possibility" (Foucault 1973) from which the DSD model emerged. The conditions, processes, and politics of the DSD model are consequential elements for these multiple social worlds, and debates between and among these worlds have played out in various outlets, including academic journals and organizational materials. Further, the process and practices of defining and treating intersex reveals multiple contingencies, conflicts, and differing objectives. In their analysis of Pap smear classifications, Adele Clarke and Monica Casper (1996) highlight how organizing different entities (e.g., people, diseases) into classificatory groups "reveal something of the social, cultural, symbolic, and political contexts within which classifications occur" (601). In my analysis I highlight ways in which clinicians have developed new standards and classifications in an effort to stabilize uncertainties that have characterized intersex and its management over time. In doing so, however, they have also produced new uncertainties. That is, uncertainty is both the cause and consequence of standardization efforts. Thus, the DSD model is one effort at "sorting things out" (Bowker and Star 1999) in the historical trajectory of intersex medical management.

MAPPING THE SITUATION

Understanding medico-scientific work and knowledge production requires understanding everything in the situation: organizations and groups, physicians, researchers, and other actors, theories and models, technologies, and so on (Clarke and Fujimura 1992). These situational elements are not simply contextual, but conditional. I illuminate these situational elements, by mapping out the key elements in the situation of intersex medical management over time.

In outlining situational analysis, Clarke (2005) presents three cartographic strategies for doing situational analyses: situational maps, social worlds/arenas maps, and positional maps. Each of these maps offer points of access into one's data. Situational maps require the analyst to lay out all of the "analytically pertinent human and non-human, material and symbolic/discursive elements of a particular situation *as framed by those in it and by the analyst*" (Clarke 2005: 87). The process of mapping the various elements over time and in multiple ways was of great benefit for me and provided useful insight into my data. In this chapter, I offer an ordered situational map (Figure 1) as a final analytic product in charting the relevant and important elements of the "situation" of intersex management over time.

Figure 1. Ordered situational map of intersex medical management.

Individual Human Actors
Cheryl Chase
John Money
Medical professionals
Intersex advocates
Academic scholars/allies

Collective Actors/Elements
Activist organizations
Intersex Society of North America
Organization Intersex International
InterACT
Support groups
Human rights bodies
United Nations
Human Rights Watch
Multidisciplinary teams
Social movements
LGBT activism
Patient rights
Women's health/Feminism
Media
Feminist academy

Non-human Actants/Elements
Treatment Protocols
Optimal Gender Policy (OGP)
Consensus Statements
Surgical interventions/techniques
Diagnostic tools
Classifications
Internet
Advocacy organizational websites/materials
Research networks/registries
International Disorders of Sex Development registry
Disorders of Sex Development-Translational Research Network
Disorders of Sex Development (DSD) clinics
Gender role theory
Brain organization theory

Discourses
Patient-centered care
DSD discourses
Surgery discourses
Activist discourses
Human rights
Bioethics
Medical discourses
Evidence-based medicine
Nature vs. nurture
Historical discourses
Rise of scientific medicine
Hermaphroditism
OGP

Implicated Actors/Actants
Parents
Intersex child

Political/Economic Elements
Evidence-based medicine

Temporal Elements
Rise of intersex advocacy
Age of Gonads
Early intervention

Major Debates
DSD
Surgery

Sociocultural Elements
Sex
Gender

Embodied Elements
Genitals
Hormones
Chromosomes
Gonads
Other sex characteristics

The categories listed reflect what ended up being most salient and central to my analysis as I made sense of my data. As analytic tools, the use of situational maps is important for helping to uncover relations between elements. Therefore, I use this situational map to chronicle intersex medical management, highlighting key elements and the relationships between them. Other elements from the map and their relationships are evident and further explored in Chapters Three and Four as well.

SITUATING (INTER)SEX

From "True Sex" To "Best Sex"

In the early modern period, medicine did not exercise hegemony over defining and controlling hermaphroditism. Rather, the sixteenth, seventeenth, and eighteenth centuries were characterized by a coexistence of alternative and heterogeneous conceptions of the body. As Hippocratic medicine, which was based on a humoral theory of the body's fluids and temperature, gradually shifted to "scientific medicine" throughout Europe and the United States during the nineteenth and early twentieth centuries, medical conceptualizations of the human body underwent major shifts. Physicians and scientists developed a clear sense of the statistical aspects of natural variation and with the tools of medical measurement, could set standards of human physiology, evaluate deviations, and classify individuals (Porter 1986; Foucault 1989; Starr 1982; Poovey 1995). With such knowledge, medical professionals steadily acquired greater authority over the disposition of atypical bodies, defining certain bodies as abnormal and in need of correction (Daston 1992; see also Canguilhem (1991). Hermaphrodites, like many others whose unusual bodies were previously viewed as unnatural and freakish, were now explainable in terms of variations of normal and abnormal development and classified in relation to the natural order of things (Daston and Park 1995; Dreger 1998b; Fausto-Sterling 2000).

During the nineteenth century, most newborns were not seen by a doctor given the prevalence of traditional, women-centered home births, which were overseen by women giving birth and their female assistants (Martin 1987; Leavitt 1986). If questions about sex determination arose at birth, they were usually handled within the family, except for the rare case in which the child's health was compromised and necessitated medical intervention (Schwartz Cowan 1992; Preves 2002). Moreover, if a hermaphrodite sought medical opinion, it was usually to relieve discomfort or pain, receive a diagnosis, or for sex determination or revision; in some instances, the patient sought to marry, divorce, acquire inheritance, or avoid military deployment (Dreger 1998; Reis 2009). However, there was little agreement among doctors about which traits conclusively determined sex, provoking professional debate over the nature of sex and its proper diagnosis (Dreger 1998b; Reis 2009). Doctors often focused on visual markers, particularly on the penis and clitoris, though sometimes the vagina, uterus, and menstruation were offered as proof of womanhood. If biological indicators proved inconclusive, medical practitioners often turned to social cues such as an individual's mannerisms, clothing, tastes, as well as sexual desires (Dreger 1998b; Reis 2009).

As scientific medicine became institutionalized, with the concomitant and interrelated changes including the rising status and professionalization of doctors, the reform of medical education, and the building and expansion of hospitals, medical practice moved from the bedside to the hospital (Starr 1982). New technologies of seeing—including the microscope, anatomical dissection, and most importantly, what Foucault (1989) termed the "clinical gaze"—began to transform the doctor/patient relationship, expanding physicians' interpretive power to the body's interior in clinical examinations and reducing reliance on the patient's experiences and reported symptoms (Foucault 1973; Starr 1982; Armstrong 1995; Lachmund 1998). As hospitals became loci of knowledge production and treatment-oriented medicine, doctors began to see an increasing number of patients whose sex came under question, often because of their external genitalia. With the rise of gynecology and increasing access to medical care, more and more people were subject to genital examination (Dreger 1998b). Moreover, medical interest in hermaphroditism increased markedly during the nineteenth century and reported cases proliferated (Dreger 1998b).

The Age of Gonads

While medical science asserted jurisdiction over the body and the medical profession constituted its professional authority (Waddington 1990), doctors in the U.S. and Europe were investigating, documenting, and defining sex, searching for the incontrovertible marker of "true sex." In the late nineteenth century, a consensus emerged that the reliable marker of true sex was found in the gonads, that is, the ovary or testicle (Dreger 1998b). Scientists and medical practitioners began to rally around a gonadal model of sex, looking for conclusive evidence of ovaries or testes (e.g., Blacker and Lawrence 1896). This notion was first codified by Theodor Albrecht Klebs in 1876—initiating what historian Alice Dreger (1998b) called the "Age of Gonads." Klebs, a German pathologist, developed a system that classified hermaphroditism based on gonadal status. Klebs labeled individuals with both an ovary and a testicle as "true hermaphrodites," those with testicles as "male pseudohermaphrodites," and those with ovaries as "female pseudohermaphrodites." These categories were used until 2006, when they were replaced by the current DSD classifications.

Most doctors remained convinced that the presence of either ovaries or testes would provide the answer to sexual uncertainty (Reis 2009). Doctors' widespread adoption of the gonadal definition was driven, in part, by pragmatism. This was critical at a time of ideological, social, and political shifts in public culture, and heightening concerns around gender, bodies, and morality (Laqueur 1990; Dreger 1998b; Reis 2009). The first women's movement and suffragists were expanding political activism and agitating for equal rights (Dicker 2008). Moreover, the newly named "homosexual" was becoming more visible in society (Dreger 1998b). Anxiety about gender and sexual boundaries led many physician and scientists to insight on tighter definitions of acceptable malehood and femalehood, meaning a strict division between males and females (Dreger 1998b). They rallied behind the gonadal model because it meant that nearly all bodies could be limited to one and only one sex.

Doctors' claims that true sex should be determined solely by the anatomical nature of the gonads were also motivated by trends in scientific pathology, particularly a histological (tissue-based) approach to understanding disease and growing international interest in laboratory-based medical research (Bynum 1994; Bonner 1995; Dreger 1998b). However, given the high risk of exploratory surgery and lack of non-surgical imaging techniques until the twentieth century, gonadal sex determination proved difficult for doctors who could only assess an individual's gonadal tissue by superficial palpation in living patients or autopsy after death (Dreger 1998b; Fausto-Sterling 2000; Mak 2012). Doctors could positively identify the structure of the gonad by microscopic analysis by the end of the nineteenth century, though more often for deceased than for living individuals.

Around the turn of the century, with improvements in anesthesia and medical hygiene, doctors could use laparotomy (exploratory surgery of the abdominal cavity) and biopsy to assess the internal gonadal tissue of living patients (Dreger 1998b; Mak 2012; Mak 2015). Yet as doctors performed more of these procedures, they increasingly faced the limits of the gonadal classificatory system. Clinicians were now confronted not only by living "true" hermaphrodites, but also by the fact that some gonads contained both ovarian and testicular tissue (ovotestes;

Blacker and Lawrence 1896). Moreover, sometimes a person's external genitalia contradicted a biopsy. For example, they confirmed that some women had testes but phenotypically were completely feminine.

Understandings of sexual difference continued to evolve in the early twentieth century. By this time, sexual development was a particularly controversial topic in the biological sciences. One scientific hotspot was the theory of "bisexual" human organs—referring to a perceived bi-potentiality of development wherein all embryos could develop into either a male or female organism—and the question of how, when, and why this bisexual embryo develops into a male or female human fetus became increasingly important (Laqueur 1990; Kenan 1998). There was an ongoing rift between physiologists who suggested the sexual characteristics were determined by environmental and physiological conditions during fetal development in utero, and geneticists who argued that nuclear elements—later known as the sex chromosomes—irrevocably fixed sex at conception (Oudshoorn 1994). Medical and scientific developments, particularly in the worlds of endocrinology and genetics, revealed multiple conflicting and contradictory markers of sex. Between 1880 and 1910, a series of discoveries suggested that chromosomes carried hereditary information and that sex determination was tied to a so-called sex chromosome, ushering in the notion of a chromosomal basis for sex. The emergent science of endocrinology was also drawing interest for its potential to provide "unambiguous medical explanations for sexual ambiguity" (Karkazis 2008: 41) and the possibility of using endocrine therapies to correct an individual's sexual ambiguity (Karkazis 2008).

By 1910, endocrinologists had discovered that ovaries and testes not only produced reproductive cells but were also glands that secrete chemicals. These secretions, scientists believed, were sex-specific hormones that functioned as chemical messengers of masculinity and femininity (Oudshoorn 1994), shaping the physical body as well as the human psyche and behavior (Hausman 1995). The first to suggest a hormonal basis for hermaphroditism was zoologist, Frank Lillie. Lillie's (1916, 1917) research on freemartin cows demonstrated that the fetal environment (i.e., hormonal milieu) could influence the development of atypical reproductive anatomy, resulting in a mixture of sex characteristics. In the 1910s and early 1920s, Sex hormone research was considered the "missing link between genetic and physiological models of sex determination" (Oudshoorn 1994:21), challenging previous understandings that sex was determined solely through chromosomes and initiating a shift away from understanding the gonads as the sole locus of sex. Assigning a true sex became more complicated as medical and scientific advances identified not only reproductive structures and the physiological and developmental importance of the gonads, but also molecular components such as hormones and chromosomes—and undermined reliance on a single or straightforward gonadal marker of true sex.

Ambiguous Sex, Ambiguous Medicine

While in theory, the "Age of Gonads" extended well into the first half of the twentieth century, the "application of the gonadal dictum in practice was at best uneven" (Dreger 1998b: 158), functioning more as a practical guide than the "gold standard" or medical doctrine. Although medical evaluation aimed to simplify the diagnosis and treatment of hermaphroditism, assigning a true sex became more complex, as clinicians made determinations based on their own interpretation of a plethora of somatic data (Preves 2003; Mak 2005; Karkazis 2008). During this time—a period Redick (2004) more aptly named the "Era of Idiosyncrasy"— there was no unifying theory, principles, or method for sex determination and treatment was highly contested.

With the advent of scientific medicine, surgery had grown both in prestige and accomplishments, bringing about new possibilities for medical intervention. Improved surgical techniques contributed to a more interventionist approach to intersex variations. In the case of intersex, surgery was increasingly used to remove organs incongruous with what was deemed the patient's true (i.e., gonadal) or social sex and to correct perceived genital anomalies. Moreover, doctors had not yet established pediatric surgery as a separate discipline: general surgeons or anatomical specialists—in this case urologists—performed most procedures. One of the first to offer such procedures was the "Father of Urology," Hugh Hampton Young. In 1916, Young opened the Brady Urological Institute at Johns Hopkins Medical School where he later pioneered pediatric genital reconstructive procedures, including clitoral and vaginal plastic surgery. However, medical intervention was not routine, and often occurred only in adolescence or adulthood at the request of the individual (e.g., Young 1937).

In the face of numerous conflicting and contradictory signifiers of sex, doctors began to express uncertainty about assigning sex to intersex individuals (Hausman 1995) and the best course of action. Dr. James McCahey (1938: 927-928) wrote, "Present day management of hermaphroditism is based on this [gonadal] explanation, but the therapy is unsatisfactory because uncertainty as to the proper procedure in any given case." From the mid-1930s, psychology became an increasingly important element in the diagnosis of true sex (Redick 2004). Writing in the *American Journal of Surgery*, Dr. Leo Bleyer (1948) agreed that reliance on the gonads was an "arbitrary standard," (449) contending "[t]he approach from a personalistic psychologic standpoint and the consideration of the total psychophysic pattern seems to be a better way for the practical purpose of a happy adjustment of the patient" (449). Most physicians agreed that surgical decisions in adolescent and adult patients should rest on psychological and emotional factors rather than on a strict adherence to the presence of ovaries or testes (e.g., Rubovits and Saphir 1938; Finesinger et al. 1942; Smith and Stockwell 1940; Ingersoll and Finesinger 1947). Doctors began to take time to assess patients' psychological makeup before deciding whether to perform surgeries that would alter their gender presentation.

In sum, the medical certainty postured in the late nineteenth century by doctors affirming the gonadal model as a marker of true sex, gave way to a period in which there were no straightforward agreed-upon norms. By the middle of the twentieth century, new scientific technologies and developments including the availability of chromosomal testing, hormone assays, and imaging techniques (such as ultrasound) provided additional data that both informed and further complicated sex determination and assignment. As I discussed earlier, medicine had also achieved professional dominance, and matters such as childbirth were now firmly under clinical purview. These factors combined paved the way for what became the dominant medical paradigm for intersex management throughout the latter half of the twentieth century.

OPTIMAL GENDER AND THE TRADITIONAL TREATMENT PARADIGM

Johns Hopkins University was one of few U.S. institutions known for clinically managing hermaphroditism, owing, in part, to Young's pioneering work in surgery. His innovations made the Brady Urological Institute a magnet for cases of indeterminate sex, garnering referrals for "interesting" or "unusual" cases from physicians across the country (Kenan 1998). Another esteemed physician, Lawson Wilkins, the founder of pediatric endocrinology, established the first pediatric endocrine clinic at the Harriet Lane Home in Baltimore, a children's clinic associated with Hopkins. Moreover, the mid-century was a particularly exciting time at Hopkins as Wilkins had developed treatments to suppress virilization in congenital adrenal hyperplasia (CAH) by administering the newly synthesized hormone cortisone (Wilkins et al. 1951; see also Money and Ehrhardt 1972). The geneticist Murray Barr had also discovered that a test for chromatins in skin samples could conclusively determine chromosomal sex (Moore et al. 1953). These technological innovations made it increasingly easy to diagnose intersex and intervene at an earlier age.

For the latter half of the twentieth century, clinical management for intersex was dominated and defined by the work of John Money, a psychologist, and his colleagues at Johns Hopkins University. Money came to work at Hopkins in 1951 under the aegis of Wilkins, who was assembling the first cross-specialty team to study and treat intersex infants (Redick 2004). The team included gynecologic surgeon Howard Jones, urologist William Scott, and two psychiatry fellows, John Hampson and Joan Hampson. Money sought to bring unity and coherence to the "anarchy of idiosyncrasy" (Money 1952: 194) that prevailed in the preceding decades as emerging evidence increasingly undermined adherence to a gonadal model (Redick 2004).

In a series of articles published in the 1950s (Hampson 1955; Hampson et al. 1955; Money 1955, 1956; Money et al. 1955a; Money et al. 1955b; Money et al. 1956; Money et al. 1957), Money and his colleagues introduced principles and protocols for intersex management based on a theory of gender acquisition first developed during Money's doctoral studies. Their innovative research highlighted the role of rearing and socialization in shaping what they called a person's "gender role," defined as "all those things that a person says or does to disclose himself or herself as having the status of a boy or man, girl or woman, respectively" (Money et al.

1955b: 285; further elaborated in Money and Ehrhardt 1972). For Money, the development of gender role, encapsulating what we would today distinguish as gender identity, gender behavior, and sexual orientation (Money 1995; Rubin 2012),[3] was a multistage process, that relied on multiple attributes and variables of biological sex and but did not derive from these exclusively (Karkazis 2008).

According to their work, gender development resulted from a process of consistent upbringing and the child's identification with his or her normatively sexed body (Money and Ehrhardt 1972). Money et al. (1957: 333) argued:

> [T]he sex of assignment and rearing is consistently and conspicuously a more reliable prognosticator of a hermaphrodite's gender role and orientation than is the chromosomal sex, the gonadal sex, the hormonal sex, the accessory internal reproductive morphology, or the ambiguous morphology of the external genitalia.

The notion that gender was a product of rearing also meant that it was somewhat flexible and malleable during the first two years of a child's life (Money et al. 1955a). They recommended that for an optimal outcome, the decision concerning sex assignment and rearing be made before that time, and that the child was raised without any ambiguity about their gender (e.g., Money et al. 1955a; Money et al. 1955b; Money 1956; Money and Ehrhardt 1972). From this theory, they developed what was later known as "optimal gender policy" (OGP) for the psychosocial and medical management of intersex conditions (Money et al. 1955a, 1955b; Meyer-Bahlburg 1998), which guided clinical practices for the next several decades. In contrast to earlier work on hermaphroditism that was dominated by sciences such as embryology, endocrinology, and

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[3] The term gender identity emerged several years later and is credited to the psychoanalyst Robert Stoller (1964). Eventually Money would use the term gender-identity/role (G-I/R) to refer to what today we would distinguish as gender identity, gender behavior, and sexual orientation (see Money and Ehrhardt 1972; Money 1994, 1995).

urology, the OGP provided a method for gender assignment and set standards for treatment that incorporated biological and psychological variables, linking the fields of psychology, endocrinology, and surgery.

Under the OGP, surgical innovations and technical capabilities were particularly important, as limits to surgical techniques often directed decisions on whether to assign a child male or female (Money et al. 1957). Mid-century surgeons were able to cosmetically construct a convincing-looking vagina and reduce the size of the clitoris, however, surgeons had limited ability to construct a penis that was convincing in appearance or function.[4] As a result, most children born with atypical genitals were assigned and reared as female under the OGP (Dreger 1998a),[5] and usually underwent normalizing genital surgeries that involved clitoral reduction and/or vaginoplasty (Creighton and Minto 2001).

Early intervention to construct genitals that most closely corresponded to those appropriate for boys or girls was thought to be imperative to ensure parents' commitment to raising their child as the assigned gender and to avert any purported risks to the child's psychological health (Money 1955b; Money 1965; Money and Ehrhardt 1972). Once a gender was assigned by medicine, genital surgery was "delayed as little as possible after birth" because genital appearance "dictates not only the expectancies of other people, but also contributes to the development of the child's own body image" (Money 1965: 11; see also Hampson 1955). In addition to genital surgery, treatment also included hormone therapy to direct the body to

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[4] The "adequacy" of the phallus was based on two functional assessments: the ability to pee standing up and the capacity for penetrative intercourse (Dreger 1998a; Fausto-Sterling 2000).

[5] Based on the surgical opinion that it "easier to dig a hole than build a pole" (Hendricks 1993: 15), most intersex babies were assigned female—approximately in the ratio of 9:1 (Newman et al. 1992).

develop secondary sex characteristics anticipated at puberty for the assigned sex (e.g., breasts for female assignment). “Erasing” ambiguity was thought to ensure parents’ acceptance of their child’s assigned gender and prevent the child or others from questioning their gender (Beh and Diamond 2000).

The presumed need for certainty or lack of ambiguity on the part of parents, the community, and the child about the child’s gender motivated both the urgency of treatment and the “conspiracy of silence” (Dreger 1998a). The conspiracy of silence ensured that the diagnosis and purposes of treatment were concealed from families and their children to “spare” them the psychological and emotional trauma thought to be caused by such knowledge (Tamar-Mattis et al. 2014). Doctors often withheld or misrepresented information—what Chase (2003:240) referred to as “spin control”—in order to secure patient and parental certainty regarding the patient’s sex of rearing. Practices of non-disclosure included different strategies such as the use of euphemistic language, misleading diagnostic explanations, and outright deception. Common reasoning among clinicians treating intersexuality was the belief that talking truthfully with intersex individuals and their families would undo all the “positive” effects of the technological efforts aimed at covering up ambiguity. The urgency of treatment[6] and use of an ethics of non-disclosure[7] are documented in medical literature well into the 1990s.

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[6] This rhetoric of emergency is evident in medical publications: “[I]t is now well-accepted that ambiguity of the genitalia is a medical emergency” (Lobe et al. 1987: 651); “The child with ambiguous genitalia is a neonatal surgical emergency” (Canty 1977: 279). Even a published statement by the American Academy of Pediatrics (2000) stated, “[t]he birth of a child with ambiguous genitalia constitute a social emergency” (138).

[7] In the late twentieth century, medical professionals advocated that it was ethically responsible to withhold information or tell partial truths in order to spare patients the reality of their diagnosis. In a 1988 commentary, Brendan Minogue and Robert Tarszewski argued that a physician could justifiably withhold information from a 16-year-old patient with androgen insensitivity syndrome (AIS) and/or her parents if he believed that the patient and/or family was

Money's paradigm emerged as the "epistemic foundation for the new pediatric standard of practice" (Kipnis and Diamond 1999: 177), forming among clinicians "a consensus rarely encountered in science" (Kessler 1998: 136). The OGP, particularly its framework for early surgical intervention, was incorporated in medical literature and medical school curricula, "appended to the clinical teaching repertoire as spoken truths of clinical practice" (Reiner 1996: 661), and embedded in health care practice in hospitals throughout the U.S. The growth of hospitals and medical training programs in the early twentieth century and the key role played by Hopkins in reforming and standardizing American medicine, in general, and more specifically, in pioneering techniques for the diagnosis and treatment of intersex conditions, contributed to the hegemonic status of Money's paradigm. Subsequently, the number of clinics able to treat affected infants grew, with interventions more routinely performed in infancy (Karkazis 2008). By the 1970s, medical protocol almost exclusively reflected Money's paradigm.

Although Money published extensively in medical journals for almost 20 years, it was with the publication of his landmark book with Anke Ehrhardt, *Man and Woman, Boy and Girl* (Money and Ehrhardt 1972), that his work garnered extensive professional and popular interest. The linchpin of Money's theory was the now-infamous case of John/Joan, later known as David Reimer. The case involved a boy born with typical sex features who lost his penis during a botched circumcision procedure. Unsure how this would impact his development, his parents contacted John Money and followed his recommendations to reassign and rear David as a girl.

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likely incapable of handling the fact that she had testes and an XY chromosomal complement (Minogue and Taraszewski 1988). Anita Natarajan, at the time a second-year medical student the University of British Columbia, placed second and won $750 in the Logie Medical Ethics Essay Contest in which she also argued that "physicians who treat AIS patients are justified in not disclosing the information that the patient is genetically male" (Natarajan 1996: 569). Moreover, because physicians were selectively withholding information about patients' bodies, they "are not actually lying; they are only deceiving" (Natarajan 1996: 570).

Money initially proclaimed the case a success, and eventually concluded "gender dimorphic patterns of rearing have an extraordinary influence on shaping a child's psychosexual differentiation and the ultimate outcome of a female or male gender identity" (Money and Ehrhardt 1972: 144-145). The apparent success of the John/Joan case was touted in Money's research and popular media (e.g., Money and Ehrhardt 1972; "The Sexes" 1973; Money 1975).

Feminists, scholars, and professionals in fields such as psychology, psychiatry, sociology, and gender studies also embraced Money's theory and research to challenge conventional explanations for gender differences (e.g., Rubin 1975; Kessler and McKenna 1978; Vance 1991), such as those emerging from the controversial field of sociobiology that framed them as natural or biologically determined (e.g., Wilson 1975; Barash 1977). *TIME* ("The Sexes" 1973) described Money's book as

> [S]trong support for a major contention of women's liberationists: that conventional patterns of masculine and feminine behavior can be altered. It also casts doubt on the theory that major sexual differences, psychological as well as anatomical, are immutably set by the genes at conception.

In general, nurture was given prominence over nature in popular discourse of human sexual and gendered behavior. This belief, in the scientific, professional, and public worlds, held from the 1970s for more than two decades.

CONTESTED MEDICINE: POLITICAL, SCIENTIFIC, AND PROFESIONAL CHALLENGES

By the 1990s, the first generation of those treated according to the OGP were reaching adulthood and they began to examine what had happened to them and seek information about their condition (Karkazis 2008). Some of them were profoundly unhappy. In 1993, Cheryl

Chase[8] founded the Intersex Society of North America (ISNA) with the goal of providing peer support and to challenge medical protocols. Activists used confrontational mobilization strategies—what Davis (2015) characterizes as collective confrontation—to pressure doctors to listen to the voices of those affected by their practices (e.g., Chase 1998, 1999). Their objections and criticisms were often delivered publicly via experiential narratives, and garnered attention from medical and public worlds (Karkazis 2008). For example, ISNA published members' stories in their newsletter *Hermaphrodites with Attitude*, corresponded with clinicians through letters to the editor in medical journals, and protested outside of hospitals and medical conferences. Activists argued that treatment resulted in both physical and psychological harms (e.g., Chase 1999), including the loss of reproductive capacity, pain, scarring, urinary incontinence, diminished erotic response, and emotional trauma (ISNA 2008c). In publicly voicing their negative experiences, activists demonstrated that the outcomes that normalizing interventions purported to alleviate or protect against, such as shame and stigma, were instead often consequences of those treatments (Kessler 1998; Preves 2003).

The arena of intersex activism now includes diverse actors and multiple collectivities and organizations that provide peer support, pursue overt, direct action, and promote seeing intersex through a human rights frame and a broader appreciation for diverse embodiments (Karkazis 2008). The development and expansion of the internet during the 1990s facilitated the connection of intersex adults and as a result, the formation of support groups and advocacy organizations has proliferated. For example, the CARES Foundation began advocating for patients and families affected by CAH in 2001, and in 2003, Organization Intersex International (OII) was formed; and has since expanded to include chapters around the world. New ways of articulating the

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[8] The activist who was previously known as Cheryl Chase is now Bo Laurent.

"problem" of the treatment of intersex conditions under the OGP also began to emerge, focusing specifically on issues of informed consent and human rights (Preves 2005). Intersex activists employed a two-pronged strategy that, on one hand, argued for "acceptance, dignity and humane treatment for those with [sexually] atypical bodies in an effort to challenge ideology, practices and consciousness" (Karkazis, 2008: 8), and on the other hand, called into question the timing and necessity of genital surgeries as well as the right of medical professionals to make treatment decisions that were based on limited scientific information and without fully informing intersex patients or their families.

Health-related Activism and Patient Rights

While Money's treatment paradigm dominated the latter half of the twentieth century, broad social changes were also in motion that paved the way for a reexamination about intersex clinical management. Since the 1970s, various social movements, such as the women's health movement, patient health movement, and lesbian, gay, bisexual, and transgender (LGBT) advocacy were increasingly focused on health and patients' rights, and a notion about patient-centered care was gaining importance in general medical practice (Laine and Davidoff 1996). These diverse movements were concerned with rights in health care, such as the right to informed consent and the right to participation in treatment decisions. The demands of these activists also went beyond more traditional demands for more medical care and challenged medical expertise and the distribution of power (Starr 1982). The intersex movement has benefited from and built upon the organizations, strategies, and rhetoric of these earlier social movements, and their challenges to medical authority more generally. Intersex activists have generated new, alternative knowledges grounded in their own medical experiences, and developed critiques of medical practice that question medical conventions, call for increased patient autonomy, condemn medical paternalism, and challenge the legitimacy of medico-scientific knowledge.

The growth of health movements in over the past several decades can be viewed as a response to the expansion of medical authority over the twentieth century. The worlds of health-related movements have brought medical decision making and practice into public discourse, as activists sought to reduce physicians' discretion and enhance patients' autonomy through collaboration between clinicians and patients. For example, the demedicalization of homosexuality highlighted the waning authority traditionally held by clinicians and the medical establishment (Starr 1982; Rothman 1991). The efforts by gay activists, along with critics in psychiatry, successfully pressured the American Psychiatric Association to remove homosexuality from the official list of psychiatric disorders in the *Diagnostics and Statistical Manual of Mental Disorders (DSM)* (Bayer 1981). Moreover, patient rights advocates, questioned the prerogatives of the doctors' role and implicitly claimed that the interests of doctors and patients often diverged (Starr 1982). In the 1970s, feminists questioned medical orthodoxies, called for increased patient autonomy and critiqued medical paternalism (Kline 2010). They also countered medical accounts by providing alternative knowledge based on their own experiences.

Health-related activism and patient-centered discourse constitute the conditions by which the intersex movement emerged. Since the 1970s, the patients' perspective has been an important part of the rationalization of medical practice, and coincided with a general trend in this period attending to patient subjectivity (Armstrong 1983). Whereas prior to this time, the physician was expected to make decisions for the patient, patients' subjective preferences were increasingly incorporated in clinical decision making (Schwartz et al. 1987; Berg 1997). Since the late twentieth century, there is a general expectation that patients (or their surrogates) will participate with clinicians in decisions about medical treatment. Patients now have greater autonomy in health care decisions due, in part, to health activism. This shift towards patient centered care reflects a shift to make health care more responsive to patients' needs and preferences.

Nature, Revisited: The John/Joan Case

Although few people critiqued Money's ideas publicly early on (Karkazis 2008), as early as 1965, however, Milton Diamond challenged Money's theory, arguing that hormonal influences, prenatally and during critical periods after birth, determined psychosexual development. However, his critiques of Money's theory would not garner much attention until the late 1990s, when he published a follow-up on the John/Joan case with Keith Sigmundson, the psychiatrist on the case (Diamond and Sigmundson 1997). Their findings challenged the credibility and "success" of the John/Joan case and, ultimately, Money himself. In their 1997 article, Diamond and Sigmundson (1997) revealed that David had felt different and unhappy since childhood and by the age of 14, was living as a boy. For Diamond and Sigmundson (1997), this finding was demonstrative of the failure of Money's gender socialization hypothesis, "Normal humans are not psychosexually neutral at birth but are, in keeping with their mammalian heritage, predisposed and biased to interact with environmental, familial and social forces in either a male or female mode" (303).

Soon after publication, popular media were abuzz with stories on the case and claims that biological determinism had prevailed (Preves 2005). The general public was alerted to the updated findings by a front-page report in the *New York Times*:

> A classic case of a gruesome surgical accident and its consequences that was long used as evidence of the pliability of sexual [sic] identity turns out, in follow-up, to suggest the opposite: that a sense of being male or female is innate, immune to the interventions of doctors, therapists and parents (Angier 1997b).

Reimer's story was also disseminated in an article in *Rolling Stone* (Colapinto 1997) followed by a *New York Times* bestselling book-length expose (Colapinto 2000), and a documentary ("The Boy who was Turned Into a Girl" 2000).[9] The updated story of David Reimer reignited long-standing nature-versus-nurture disputes and catapulted intersex issues into popular consciousness. Activists also took advantage of the publicity generated by the case to bring visibility to intersex individuals' stories and features sympathetic to activist concerns, which were increasingly showcased in popular media and news outlets (e.g., Angier 1997a, 1997b; Colapinto 1997; Cowley 1997; "Gender Limbo" 1997; Gross 1997; "Intersexuals" 1997; ISNA 1998; Davis 2000).

The John/Joan case became so influential, in part, because it raised issues that dovetailed with broader, social debates of the late twentieth century, especially those over the origins of gender differences. The 1990s saw a reassertion of "nature" through the rise of evolutionary psychology (Buss 1989; Tooby and Cosmides 1989) and increasing efforts to apply the science of brain structure and hormones to traits, abilities, behaviors, and attitudes and beliefs (Hines 1993; Collaer and Hines 1995; Davatzikos and Resnick 1998).[10]

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[9] Tragically, in 2004, David Reimer took his own life (Colapinto 2004).

[10] See Jordan-Young (2010) for a thorough examination and critique of this body of research.

DSD AND THE POLITICS OF CONSENSUS

The John/Joan follow-up and the ensuing controversy stimulated a re-examination of long-standing intersex management practices and further increased intersex visibility in the public arena. In 2005, a group of 50 international experts from multiple medical specialties and two intersex advocates— Chase, as Executive Director of ISNA, and Barbara Thomas, a member of XY-Frauen, a German support group—convened in Chicago to evaluate clinical management practices, review available outcomes research, and propose an agenda for future research. Jointly sponsored by the Lawson Wilkins Pediatric Endocrine Society (now known as the Pediatric Endocrine Society) and the European Society for Paediatric Endocrinology, this was the first meeting in which medical professionals and advocates worked together to reconsider medical care and the first time in over 50 years that physicians so thoroughly reviewed intersex treatment practices. Conference attendees were organized into six working groups, each assigned a different topic (AIS Support Group 2018), and tasked to devise new clinical recommendations, which were subsequently published in the "Consensus Statement on the Management of Intersex Disorders" (Lee et al. 2006). This meeting and the published statement it developed was a professional response to the proliferating uncertainties related to clinical management of intersex in the face of increasing intersex activism.

In developing guidelines, a group of experts typically evaluates scientific literature and then offers recommendations aimed at the practicing clinician. However, in the case of intersex, evidentiary base is highly variable and generally limited, and there is not available evidence to evaluate all clinical decisions covered in a guideline. The consensus meeting is one way to fill in the blanks and to interpret conflicting statements in the literature. Experts convene to discuss the contentious issues and to work toward a practically feasible recommendation (Timmermans and

Berg 2003). However, critics have pointed to the lack of transparency in consensus statement decision-making, with suspicions that "the resulting guidelines are often as much the result of group dynamics during the meeting as of the scientific literature" (Timmermans and Berg 2003:4). Some critics suggest that such reports may be based more on "compromise" than on actual consensus (Rennie 1981; May 1985; Oliver 1985).

Intersex Medical Management Post-Consensus

The 2006 Consensus Statement proposed new nomenclature and outlined an updated model for diagnosis, treatment, and clinical care. Citing progress in "diagnosis, surgical techniques, understanding psychosocial issues, and recognizing and accepting the place of patient advocacy" (Lee et al. 2006: e488), the recommendations for an optimal approach included clinical evaluation and management of DSDs with emphasis on sex assignment *only* following expert evaluation in newborns; evaluation and long-term management by an experienced multidisciplinary team (MDT) of specialists; open communication and shared decision making with patients and their families; and a commitment to respecting and addressing patient and family concerns in confidence (Lee et al. 2006).

The Statement also proposed the term "Disorder of Sex Development" (DSD) to replace the umbrella category "intersex," which covered the longstanding classifications of "male pseudohermaphroditism," "female pseudohermaphroditism," and "true hermaphroditism." Conference participants framed DSD as a response to "advances in identification of molecular genetic causes of abnormal sex with heightened awareness of ethical issues and patient advocacy concerns" (Lee et al. 2006: e488), and defined DSD as "congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical" (Lee et al. 2006: e488). The DSD classification categories are structured around the karyotype (chromosomal features in the nucleus of the cell, including number, size, and shape): 'Sex chromosome DSD, 46 XY DSD and 46 XX DSD. Within these categories, individual diagnoses are further classified based on hormonal, gonadal, chromosomal or other bodily variations or differences (Griffiths 2018).

The 2006 Statement and a global update published 10 years later (Lee et al. 2016) highlight the promise of biomedically-grounded classifications, and the DSD system has also led to the development of international research networks. I observed a user training for the International Disorder of Sex Development registry (i-DSD) while attending an international DSD conference in Glasgow, Scotland. i-DSD is an international biomedical registry developed for intersex variations. Modeled on the rare disease approach, this research network enacts intersex variations as rare genetic diseases, with the assumption that bodily difference is best understood through more, better, and future-oriented genetic and molecular knowledge production (Griffiths 2018).

The increasing centrality of biology or biological factors are also evident in particular changes in male assignment for certain patients with 46 XY chromosomes. For example, under the OGP, infants with XY chromosomes and a phallus that was absent (aphallia) or smaller than average (microphallus) were assigned female and subsequently underwent vaginoplasty, gonadectomy, and hormone therapy. The DSD treatment model, however, now recommends male assignment for these infants in accordance with their chromosomal makeup. Data from a 2011 survey of American pediatric urologists found that 79% of respondents recommended male assignments for 46 XY cloacal exstrophy,[11] and almost all (97%) reported "brain imprinting" by

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[11] Cloacal exstrophy is a condition in which abdominal organs protrude through the abdominal wall. Infants can be born with their intestines and bladder exposed (Meyer-Bahlburg 2005).

prenatal androgens as an important factor in their decision (Arboleda et al. 2011). According to the 2016 global update to the Consensus Statement (Lee et al. 2016: 169; *emphasis mine*),

> The previously widespread routine assignment of 46, XY newborns with markedly hypomasculinized genitalia as females has given way to more *detailed considerations of biological factors*…Physicians are now more likely to suggest male assignment of 46, XY newborns who presumably had *normal-male prenatal androgen levels with nonhormonal genital malformations*, such a cloacal exstrophy of the bladder.

Those with nonhormonal etiologies, such as cloacal exstrophy, are presumed to have had typical androgen exposure or responsiveness during fetal life, and now receive male rather than female assignment on the basis of their presumably masculinized brains. This change parallels a broader shift towards biologically-based explanations, especially the emphasis on brain organization and hormonal imprinting embraced by Diamond and publicized with the fall-out from the John/Joan case.

Due in part to the constraints of a limited evidence base, consensus reports are typically fairly indeterminate, non-compulsory guidelines (Timmermans and Berg 2003). The 2006 Consensus Statement is rather general and the global update published a decade later (Lee et al. 2016) confirms much of the same. Moreover, the extent to which the Consensus Statements have impacted clinical practice is less clear, and seemingly more than variable. My own interviews with physicians suggest that some of the changes outlined in the Consensus Statement were "realized in word but not deed" (Feder 2015: 134; see also Feder 2014). (In chapter four, I examine how some of the specific recommendations such as multidisciplinary team care and engaging with families plays out in practice). All of the physicians I interviewed viewed the Statement, generally speaking, in favorable terms. Almost all of the clinicians I interviewed also viewed the growth of multidisciplinary teams as a positive change in caring for both the physical and psychosocial aspects of intersex patients and their families. One pediatric endocrinologist, Dr. 7, noted that the Statement was beneficial to her relationship with parents, who were reassured of doctors’ competence and general awareness of the state of practice pertaining to intersex variations.

As I will discuss further in Chapter Four, many of the physicians I interviewed also agreed that a child with intersex traits was not the emergency requiring rapid response of prior decades. It was also clear from my interviews with physicians that their role in engaging with families and advising them on clinical options has changed. In contrast to the early surgery physicians urgently advocated, physicians often reported, especially the pediatric urologists I spoke with, that they are performing these same surgeries on request of the parents. While this appears to comply with the bioethical promotion of parent autonomy (Feder 2015), it also provides doctors the benefit of protection. For example, Dr. 11, a pediatric urologist, explained the benefit of including parents and a multidisciplinary team in decisions as potential protection from malpractice.

Perceptions were somewhat more variable among activists I interviewed, and I explore this more fully in chapter three. Some saw the Statement initially as a potentially good first step in gaining some of the clinical reforms they had been advocating for. Others activists I spoke with lamented the lack of truly assessing the needs of the community and including them in the decision-making process. Some advocates counter that the organizers and participants of the consensus meeting consulted few intersex people before endorsing the new DSD nomenclature and only two individuals with intersex traits participated in the conference and were pre-assigned to specific workgroups (AIS Support Group 2018). However, the 2006 Consensus Statement did result in several changes to the standard of care that were advocated by activists and patient advocates and represent a more patient centered approach to care. These updates include acknowledging that intersex variations are not a social emergency, are not shameful, and the provision of complete, and honest information and encouraging participation in decision-making.

Sociologist Georgiann Davis (2015) argued that the shift to DSD nomenclature was a move to reassert medical authority in the face of continuing challenges by intersex activists. My own research supports this claim, but takes this further and contends that consensus development was a strategy to maintain both professional *and* political credibility. In the face of challenges both within and outside of medicine, the recourse to guidelines was necessary to legitimate the professionals' claim to exclusive expertise over intersex, further grounding classifications in a biologically-based model. Moreover, the reassertion of scientific expertise and medical authority seems borne out by the increased funding for biomedical research on intersex (Sandberg et al. 2015) and development of research networks and registries, such as the i-DSD international registry I previously discussed.

The development of consensus statements and associated efforts for outcomes research represent contemporary efforts toward standardization, particularly a movement towards evidence-based medicine (EBM). EBM is "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett et al. 1996: 71). EBM commonly refers to the use of clinical practice guidelines to disseminate proven diagnostic and therapeutic knowledge. In response to more emancipated patients, increasing attention to variations in medical practices, an information overload, and an overall critical scrutiny of the role of experts and professionals in society, the medical profession had to act in order to maintain its position as exclusive keepers of medical knowledge (Timmermans and Berg 2003).

Similarly, the Disorders of Sex Development-Translational Research Network (DSD-TRN), a large, NIH-funded collaborative encompassing seven DSD clinics across the U.S., was formed in 2009. Standardization forms the foundation of these international and national research collaboratives. DSD care providers standardized terminologies and communication routes, which are necessary in order for medical data to be comparable across international sites. Whereas in the early twentieth century, standardization was associated with the "ideological luster" (Timmermans and Berg 2003: 12) of scientific and technological progress that accompanied the growth of hospitals and developments in laboratory sciences and diagnostic technologies (Stevens 1989), a century later the reemergence of standardization via EBM is about delineating what sequence of activities constitutes a professional response to a given situation (Timmermans and Berg 2003).

"A Quiet Revolution?"

Despite the Consensus Statement projecting an ideal of certainty and of good medical practice and addressing some of the concerns raised by activists and other actors, several points of controversy persist. The DSD nomenclature is particularly controversial, and has divided advocates and clinicians. Published responses to the Statement illustrate a range of reactions (e.g., Diamond and Beh 2006; Hughes 2008; Feder 2009) with some hailing it a success, some responding with partial acceptance, and others resisting it outright. Medical discourse suggests a rapid and near universal adoption of DSD nomenclature, leading one of the co-authors of the Consensus Statement to characterize its rapid ascent as "a quiet revolution in medicine" (Hughes 2010: 160).

However, there is continuing debate between medical specialists as to whether DSD refers primarily to genetic or anatomical variation (e.g., Griffiths 2018). Some clinicians support the inclusion of syndromes in which genital appearance is typical and are not typically associated with questions about gender identity, arguing that this expansion does away with the notion that atypical genitalia are the *sine qua non* of DSD (Vilain and Sandberg 2009). Other medical professionals have suggested that Turner and Klinefelter's syndromes be excluded from DSD (Aaronson and Aaronson 2010; Sandberg 2012) and that the features that anchor DSD should necessarily be gonads, genitals, and the assignment of gender as close to the moment of birth as possible. Moreover, there are no shared medical criteria uniting the different and distinct conditions referred to by the term DSD. In contrast, Schober et al. (2012: 621) states:

> DSD is not a diagnosis. It comprises a spectrum of abnormalities where there is a discordance of the standard criteria that define gender. Although some of these very rare conditions have factors in common, there is great danger in extrapolating findings from one to another. Physicians will generally concentrate on aspects that they can easily influence by treatment such as hormonal control and anatomical alteration of the external genitalia. Patients, on the other hand, may be more concerned with criteria that are much more difficult to quantify and are often ignored in the medical literature.

There is an array of views on DSD terminology among other academics and within support, advocacy, and activist networks, ranging from pragmatic acceptance in order to engage with doctors (e.g., Dreger and Herndon 2007) to outright rejection of DSD language as inherently pathologizing (e.g., OII 2007; Reis 2007; Holmes 2011; Davis 2015). Cheryl Chase advocated for the DSD nomenclature from the start, arguing that the new terminology was necessary to shift the focus from who the patient *is* to what they *have*. Such a move is justified for destigmatizing atypical sex by shifting focus from gender identity to medical illness (Chase 2006; Feder and Karkazis 2008). As Bowker and Star (1999) explain, classifications always involve social and ethical choices. “Each standard and category valorize some point of view and silences another. This is not inherently a bad thing—indeed it is inescapable. But it is an ethical choice, and as such it is dangerous—not bad, but dangerous” (Bowker and Star 1999: 5-6).

Although the Statement describes the goals of medical intervention in patient-centered terms, some areas of medical practice have not changed substantively, as I will show in chapter four. The timing and necessity of genital surgery is a site of particularly heated debate. While the Statement acknowledged the harms of early clitoral surgeries, and called for moderation, only some teams have since reported a reduction of these procedures (Pasterski et al. 2010) and some national statistics reflect no clear reductions over time (Creighton et al. 2014; see also Wilffenbuttel and Crouch 2014; Mouriquand et al. 2016), and in fact, such interventions may have increased since 2006 (Creighton et al. 2014; Greenfield 2014).[12] Within the clinical literature many papers continue to indicate a preference for early surgery, ideally between two and 24 months (Crawford et al. 2009; Vidal et al. 2010; Palmer et al. 2012; Massanyi et al. 2013; Yankovic et al. 2013). Some advocacy and support groups also argue that despite the shift in rhetoric, medical practice has not significantly changed since the 2006 publication, and also claim that genital normalizing surgery remains the standard response to intersex variations (e.g., OII 2013).

These diverse and partial effects of the Consensus Statement explain the diverse goals and strategies adopted by advocates and different organizations since its publication (see also Hegarty et al. 2020). Some activists and groups describe current medical practices, particularly those performed in infancy, threaten human rights, especially children’s rights to bodily

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[12] For example, based on data from the National Health Service, Sarah Creighton and her colleagues (2014) note an increase in clitoral operations performed on those under 14 years old in the United Kingdom since 2006.

autonomy and self-determination (Carpenter 2016; UN Office of the High Commissioner for Human Rights 2019). Along with international human rights bodies, groups such as OII, who have remained critical of the Statement since its publication, have increasingly contributed to efforts challenging the legitimacy and ethics of medical practices. Activists have recently worked with the World Health Organization, the United Nations, Human Rights Watch, the National Institutes of Health, and Amnesty International to draw attention to their goal of stopping medically unnecessary early genital surgeries, and even defining such procedures as a category of human rights abuse (UN Human Rights Council 2013; Elders et al. 2017; HRW 2017). Other activists are focused on getting intersex representatives "at the table" in order to change guidelines and to democratize clinical and research efforts (e.g., Davis 2015; Sudai 2018) (In chapter three, I examine controversy over DSD and these diverse efforts in the activism arena.).

CONCLUSION

In this chapter, I chronicled intersex medical management, examining the medical understandings and responses to atypical sex over time. Using the tools of situational mapping, I highlighted the technologies, concepts, and conditions most consequential for contemporary practices, classifications, and standards of care, particularly those laid out as current recommendations in the 2006 Consensus Statement (Lee et al. 2006).

The history of intersex medicalization parallels that of the rise of scientific medicine. In doing so, the consequential elements, including technologies, medical disciplines and its representative actors, and professional and institutional dynamics contributed to the consolidation of Money's treatment paradigm, whose protocols held sway for nearly fifty years. The updated standard of care, as the DSD model, emerged out of conditions within and outside of biomedicine, particularly that of intersex activism. Moreover, current medical management links multiple discourses and interests in various ways. Larger social processes such as classification and standardization are crucial, so too are the discourses of patient-centered care and patient's rights. Also important is the historical situatedness of intersex medical management, particularly the various politics, scientific advancements, theories, and technologies that came before and contributed to its content over time.

While critiques about the medical science and politics of intersex medical management are not new, they have intensified since the publication of the Statement. The DSD model is one effort at "sorting things out" (Bowker and Star 1999) in the historical trajectory of intersex medical management, as clinicians have attempted to stabilize uncertainties that have characterized intersex medical management throughout history. However, such efforts at standardization have led to new sources of uncertainty. Current debates related to DSD and current treatment practices demonstrates the multiple interests and actors involved and further implies there is no consensus about what intersex is and how—or even if—it should be treated. In the next two chapters, I look more closely at some of these sites of tension, within intersex activism and through the work of medical professionals.

CHAPTER 3

THE TRAJECTORY OF INTERSEX ACTIVISM: TENSIONS AND TACTICS

Since the 1990s, medical understandings and treatment for intersex have been contested terrain. In the U.S., following the founding of the Intersex Society of North America (ISNA) in 1993, there have been organized protests against medical organizations and treatment practices and critiques have proliferated within activist, academic, and medical communities. As the number of involved actors and intersex groups proliferated, struggles over objectives and tactics of the movement ensued. “The very definition of what it means to be intersexed is politicized, contested, and fraught with conflict, as is the objective of such mobilization” (Preves 2005: 262). The intersex movement includes overlapping membership and strategies, from public-facing actions such as protest and media awareness campaigns to groups that provide peer support and social connection while demanding better health care (Crocetti et al. 2020). While some activists advocate complete demedicalization, others seek medical reforms and advocate for expanded research.

These pressures from both within and outside of medicine are reflected in changes in the standards of care and diagnostic nomenclature over the last two decades. While debates over intersex medical management are not new, activism has intensified since the 2006 publication of the Consensus Statement (Lee et al. 2006), which was subsequently affirmed and updated a decade later (Lee et al. 2016). Some activists have gone from picketing medical conferences to engaging with medicine as a means to an end and even collaborate with medical professionals in their efforts to reform clinical practices. Moreover, national commissions and international human rights bodies are increasingly acknowledging concerns about intersex medical treatment

(HRW 2017; Cabera 2018; Bauer et al. 2020), with attention focused on “normalizing” procedures performed on children without their consent (Astraea Lesbian Foundation for Justice 2016; Carpenter 2016). Intersex activists and organizations are increasingly advocating for rights to self-determination, bodily autonomy and physical integrity, promoting a more expansive understanding of bodily diversity, and challenging stigma, discrimination, and the pathologization of intersex bodies.

Social movement scholars have studied the strategic choices of activists and movement organizations and found that social movement strategy and tactical innovation are shaped by external and internal factors (Taylor and Van Dyke 2004; Meyer and Staggenborg 2008). Social movement strategy includes interrelated decisions about tactics, claims, targets, and alliances, and activists often debate strategic decisions (Meyer and Staggenborg 2012). External influences such as political opportunity structure (McAdam 1999; Hilson 2002; De Fazio 2012) and cultural contexts (Engel 2001; Giugni et al. 2005) shape activists’ strategic choices, and activists adapt their strategies through an iterative trial-and-error process (Koopmans 2005). Movement characteristics such as organizational structures, interests, and resources affect strategic choices (Gamson 1990; Minkoff 1999; Ganz 2000; McCammon 2003; Meyer and Staggenborg 2008). For example, McCammon (2003) found that organizational diversity, decentralization, and conflict facilitated some state woman suffrage movements to engage in new forms of collective action. A group’s history and ideology also shape its tactical repertoire, influenced by the institutional logics the movement encounters (Taylor and Rupp 1993; Swidler 1995; Crossley 2002; Haines 2006; Smithey 2009).

In this chapter, I will explore the role of framing in influencing social movement strategy, insofar as my analysis of the intersex movement suggests that activists’ strategic orientations are shaped by the way they understand and frame DSD. Research on strategic choices of social movements has largely focused on the structural conditions of social movement organizations, emphasizing resource mobilization perspectives and "opportunity structure" perspectives, which emphasize the relationship between actors and the political environment (see also Vanhala 2009). This work has not adequately accounted for the role of framing in shaping strategy, despite its relevance for understanding social movement activity. Activists must choose what issue to pursue as well as how to describe or frame what they are doing (McCammon 2012; Meyer and Staggenborg 2012). That is, the strategies pursued by activists and organizations, their efforts to mobilize resources, and their temporal viability are influenced by their interpretive work (Snow et al. 1986).

Framing is an important focus in the social movement literature. Activists and groups assign meaning to, frame, and interpret events and conditions in order to mobilize potential adherents, acquire support, and demobilize antagonists (Snow and Benford 1988). In constructing meanings, frames reflect the "interpretive discussions and debates that social movement actors engage in among each other and in the framing contests that occur between movement actors and other parties within the movement field of action" (Snow and Benford 2005: 207). Functionally, frames identify problems, and prescribe and motivate courses of action in ways that align the interests and values of activists and social movement organizations with those of potentially sympathetic audiences (Snow et al. 1986; Frickel 2004). In the case of intersex, the movement is comprised of diverse groups, who do not all share the same goals or strategies, and activists debate how best to frame intersex.

In this chapter, I draw largely on interviews with 20 U.S.-based activists, as well as additional primary and secondary data, including intersex organizational materials, to analyze differing perspectives on intersex medical management within the contemporary intersex activism arena. I examine different styles of activism within the movement and explore the multiple strategies and tactics of activists, with particular attention to how they relate to activists' understandings and framing of "disorder of sex development" (DSD) terminology. Many activists who employ DSD frames focus on direct engagement with medicine in various ways that integrate patients, families, and medical professionals in order to increase collaboration in designing clinical care and guiding research directions. Activists who oppose DSD generally oppose working within the medical model and are less willing to work with medical professionals. Many of these more oppositional activists are exploring legal strategies, particularly human rights advocacy and litigation, to challenge and politicize the standard of care for intersex persons. My research, then, shows an important link between how activists frame a core discursive element and how they formulate their strategic approach.

HEALTH SOCIAL MOVEMENTS AND STYLES OF ACTIVISM

Different types of health social movements (HSMs) address different health issues, and also use different strategies and tactics to meet their goals, ranging from advocacy to radical activism (Brown et al. 2004). Brown et al. (2004) offer a typology of HSMs that includes the subcategories of health access movements, constituency-based health movements, and embodied health movements (EHMs). Access movements are HSMs that seek equality of access to health care, focusing on reform in provision of services and improvement in their quality, and groups work within the existing system and biomedical model and use education rather than direct action. Constituency-based movements are strategically oriented to inequality and health inequities based on race, ethnicity, gender, class, and sexuality and challenge the existing system by advocating in social, political, and cultural arenas for change. Many of these groups are activist-oriented, challenging current medical practices and pursuing greater radical reform. Lastly, embodied health movements (EHMs) introduces the biological body to social movement activism (Brown et al. 2004; Zavestoski et al. 2004). These categories are ideal types, and the goals and activities of social movements and advocacy organizations may span more than one. Indeed, as this chapter will demonstrate, characteristics of all three types of HSMs are found in arena of intersex activism. In particular, however, I conceptualize the intersex movement as an EHM.

There are three components of EHMs. First, bodily experiences are a central source of movement identity and "represents the intersection of social constructions of illness and the personal illness experience of a biological process" (Zavestoski et al. 2004: 256). The collective identity is politicized through the understanding of the stigmatized self as a structural problem not as a personal problem. In the case of intersex, individual biology often varies significantly, and therefore the collective action of intersex activists is not underpinned by a particular disease process, but rather a broad "illness experience" (Kleinman 1988): an awareness of the "shared familial, social, and medical treatment experiences" (Karkazis 2008: 246). Intersex activists draw on their embodied experiences in their efforts for social and medical change. In addition, activists also employ embodiment by proxy (Newman and Carpenter 2018) drawing on physical experiences that they imagine for others' bodies, particularly children, in their work targeting parents and medical professionals.

Second, EHMs challenge not only medical authority but also scientific knowledge and the practices involved in its production. For EHMs, the embodied illness legitimates the claims of activists, and are based on the underlying assumption that experiential knowledge constitutes justifiable medical knowledge. The third element is that EHMs involve a degree of collaboration that blurs distinctions between movement insiders and outsiders. That is, actors seek to subvert scientific authority structures while simultaneously allying with them. Thus, even as they challenge medical authority and knowledge, EHM activists often collaborate with the individuals and institutions they challenge. EHMs, then, can be conceptualized as a type of boundary movement, in which the divide between lay and expert knowledge is blurred, and as a result, some activists develop particular scientific credibility enabling them to get a seat at the table (Epstein 1996; see also Newman and Carpenter 2018).

Brown et al. (2004) also suggests a strategy-agenda continuum for considering the boundaries of insider and outsider that are often blurred in EHMs. At one end are actors and organizations that are advocacy-oriented, who work within the medical model and sometimes promote the inclusion of lay knowledge. At the other end of the continuum are the actors and organizations that are more activist-oriented, who challenge the medical model through direct action and seek democratic participation. Intersex activists have overlapping membership in various organizations that span this continuum. In what follows, I examine the trajectory of the intersex movement, analyzing activists' framing of DSD and the influence of DSD framing on movement strategy. I first trace early intersex activism, focusing on the movement's emergence in the early 1990s until the introduction of the 2006 Consensus Statement and shift to DSD terminology. I then explore activists' framing of DSD and the role of that framing in shaping the diverse strategies and tactics that activists and organizations pursue.

THE GROWTH OF INTERSEX ACTIVISM

The intersex movement began like other social justice movements of the twentieth century, working to remove the shame and stigma associated with group membership and to provide support for individuals with shared experiences, grievances, and concerns (Greenberg 2012). The intersex movement built upon the strategies, tactics, and accomplishments of earlier social movements, such as gay, lesbian, bisexual, and transgender (LGBT) activism, feminism and the women's health movement, and the disability rights movement (Karkazis 2008). Like many health social movements, the formation of support groups and advocacy organizations brought affected individuals and their supporters together, raised awareness, and ultimately facilitated mobilization around intersex issues.

Intersex activism was initially rooted in conscious opposition to the dominant biomedical model of intersex; activists focused on questioning the necessity of medical treatment for gender-atypical bodies (Karkazis 2008). Activist critiques of medicalization primarily focused on ending early, medically unnecessary surgeries, based on the notion that intersex itself is not pathological and does not require medical treatment. It was because intersex conditions generally, and ambiguous genitalia in particular, threatened normative ideas of sex, gender, and sexuality that they were pathologized, activists claimed, and this pathologization allowed medical professionals to justify their treatment with surgical intervention and secrecy, causing immense physical and psychological harm (Spurgas 2009).

The growth of intersex activism in the early 1990s made visible the testimonies of intersex adults who documented the consequences they experienced from their medical treatment including shame, pain, loss reproductive capacity, and diminished sexual response (e.g., Preves 1999; Chase 2003). Additionally, genital surgeries often led to psychological trauma—the very problems the procedures were purported to prevent (Preves 2003; Tamar-Mattis 2006; Spurgas 2009). Activists also contended that the protocols, which were based on incomplete information and concealment, exacerbated their sense of shame by reinforcing cultural norms of sexual abnormality (Chase 2003; Preves 2003).

In the U.S., early intersex activism was spearheaded by the Intersex Society of North America (ISNA). ISNA was founded in 1993 by Cheryl Chase, with a dual mission of providing peer support and seeking medical reform. The internet was integral during the early years of ISNA, which focused on community building activities, and facilitated connections and communication between intersex people. ISNA challenged both the science and ethics of intersex medical management, and defined surgical "normalization" as violations of human rights.

Rather than aligning strategically with medicine, Chase and other early intersex activists focused on demedicalization of the intersex body and on reclamation of intersex solidarity among people of diverse embodiments, gender, and sexualities. Part of this early activism attempted to re-appropriate, reclaim, and politicize the terms "hermaphrodite" and "intersex." Some activists reclaimed hermaphrodite as a means of empowerment, while intersex was embraced as a positive marker of difference, rather than as a medicalized term denoting pathology, and has become a political identity. Accounting for the wresting of meaning and control from its medical or clinical articulation, Chase (1998a: 195) writes of the decision to adopt "intersex" as the term under which the movement would organize:

> I did possess the rudimentary knowledge that the gay rights movement had the momentum only when it could effectively deny that homosexuality was sick or inferior and assert to the contrary that "gay is good." As impossible as it then seemed, I pledged similarly to affirm that "intersex is good," that the body I was born with was not diseased, only different.

While in medical discourse, “intersexuality” was an umbrella term capturing a diverse group of loosely-connected diagnoses, intersex activists adopted the label to emphasize similarities in their experiences.

The title of ISNA’s newsletter, *Hermaphrodites with Attitude*, also aptly reflected the intent of activists to reclaim and recharacterize the term “hermaphrodite.” In the first newsletter, Chase (ISNA 1994: 6) explained:

> The word hermaphrodite is one which has been, for many of us, associated with deep pain and stigma. Physicians whose careers are dedicated to erasing intersexuality (by performing invasive medical procedures on nonconsenting infants) characterize the birth of an intersexual infant as a “social emergency,” and a traumatic emotional shock for the parents…I believe it is time for us to counter physicians’ assertion that life as a hermaphrodite would be worthless, by embracing the word and asserting our identity as hermaphrodites.

The early issues of the newsletters were filled with personal narratives, stories, poetry and artwork. For individuals who were previously isolated—who often had never interacted with another intersex person—these individual contributions were the means through which members could politicize their experiences. These individuals often shared a common experience: they were born with atypical sex anatomy, often surgically “corrected” as young children, subjected to continued medicalization and stigma both within and outside of the medical clinic, and eventually they developed an “oppositional consciousness” (Mansbridge and Morris 2001) that allowed them to understand their plight as unjust (see also Preves 2003; Karkazis 2008).

The growth of intersex activism in the 1990s not only led to a critique of medical protocols by giving voice to harms they had caused, it also allowed for intersex to become an identity with which some people began to identify in some situations (Preves 2003; Karkazis 2008). Through personal intersex narratives, activists documented the primary “injustice”

(Gamson 1992) identified by activists as the harms and shame they experience as a result of their medical treatment (Dreger 1999; Preves 2003). This parallels the efforts of other "new" social movements (Cohen 1985; Melucci 1996) in which actors and collectivities construct identities and challenge social expectations of diverse bodies and embodiments. The creation of an intersex identity is an important step towards self-affirmation, and provided an alternative discourse that empowered intersex individuals, facilitated community-building, and generated knowledge.

Activist critiques via experiential knowledge was featured in popular and scholarly publications (e.g., Chase 1998, 1999; Devore 1999; Groveman 1999; Moreno 1999). ISNA members and fellow activists wrote letters to magazines and medical journals to publicly critique and challenge reports on intersex by medical experts. Activists also engaged in direct, confrontational tactics. Additionally, Davis (2015) shows how in the early years of the intersex movement, intersex individuals exchanged experiences and knowledge that enhanced their scientific expertise. Collectively, they employed direct, confrontational tactics, such as protests and public criticism so that medical professionals would consider their positions and perspectives when devising clinical care.

In 1996, ISNA picketed a symposium of plastic surgeons in New York, and held a demonstration before the annual meeting of the American Academy of Pediatrics (AAP) in Boston (Germon 2006). Medical professionals largely disregarded the claims of activists, even writing them off as "zealots" (Angier 1996) or a "vocal minority" (Karkazis 2008). Activist 1 described to me clinicians' initial response to activists:

> Clinicians really wrote [ISNA] off. That's when they realized that they would have to be more confrontational. You know, that was at a time when people with AIDS had to get together and be confrontational. Women with breast cancer were ignored. So, they got together and did a march on Washington and raised awareness about the lack of funding and screening and treatments. So, all of this was going on at the same time. I think advocacy is important because there has been tremendous resistance to this idea that the patient feedback about some of these negative things is really true. You know there's a belief out there—there has been a belief—among lots of clinicians that there's a silent majority of people who are really happy, but they're not saying anything because they're happy.

After the well-publicized follow-up on David Reimer (Diamond and Sigmundson 1997), intersex activists gained visibility, capitalizing on the media coverage to draw attention to medically unnecessary surgeries on intersex infants (e.g. Angier 1997a, 1997b; Colapinto 1997; "Gender Limbo" 1997). Activists also connected their experiential knowledge to other political concerns. For example, in the mid-1990s, ISNA spoke out against what they called "intersex genital mutilation" (IGM) and lobbied to extend arguments for an anti-female genital mutilation bill to encompass intersex bodies and genital surgeries. In addition, arguments about human rights and legal considerations such as informed consent entered the debate in the late 1990s (Preves 2005).

Moreover, during the 1990s, the LGBT movement was also gaining increasing population and political ecognition, and many intersex activists joined or at least allied with LGBT and queer organizations. ISNA generated a "patchwork of alliances" (Chase 2006: 308) with organizations they believed shared common concerns and goals such as the Gay and Lesbian Alliance Against Defamation, the National Gay and Lesbian Task Force, and the Gay and Lesbian Medical Association (Preves 2005; Karkazis 2008; Spurgas 2009; Greenberg 2012).

Describing these alliances, Chase (1998: 200-201) said:

> Transgender and lesbian/gay groups have been supportive of intersex political activism largely because they see similarities in the medicalization of these various identities as a form of social control and (especially for transsexuals) empathize with our struggle to assert agency within a medical discourse that works to efface the ability to exercise informed consent about what happens to one's own body. Gay/lesbian caucuses and special interest groups within professional medical associations have been especially receptive to ISNA's agenda.

Intersex people are subjected to "normalizing" medical interventions because their bodies are perceived as sexually deviant; these issues of normalization and pathologization link intersex and LGBT concerns and communities (Preves 2005). However, some groups, particularly those that run by parents of intersex children, were concerned with associating intersex with LGBT persons and concerns. Moreover, LGBT alliances also compromised intersex activists' ability to establish credibility with mainstream medicine (Preves 2005).

Slowly, medical professionals and doctors became more receptive to activists' claims. In 2000, Ian Aaronson, a pediatric urologist, founded the North American Task Force on Intersex (NAFTI) with Chase as one of its members. The group was a loose network of medical specialists from various fields and selected activists, however, participants did not necessarily agree on the best practice in intersex treatment (Preves 2003).[13] That same year, Chase was invited to speak at the annual meeting of the Lawson Wilkins Pediatric Society. In 2003, Chase presented to the First World Congress on the Hormonal and Genetic Basis for Sexual Differentiation and Disorder. These activities marked the growing efforts of ISNA and some activists to collaborate with medical professionals and engage with medical discourse. Moreover,

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[13] For additional details regarding the internal debates that ultimately led to the group folding, see Karkazis (2008).

in an effort to put forth a more professional image, ISNA began to retool itself and focus resources strategically on educating medical professionals as well as larger society about issues faced by people with intersex traits (e.g., ISNA 2005; see also Preves 2005; Karkazis 2008).

The number of organizations advocating for intersex individuals and to change medical practice proliferated. Some organizations were variation-specific, such as the Androgen Insensitivity Syndrome/Disorder of Sex Development Support Group (AISDSD-SG; now called InterConnect), and focus more on education and peer support and are more advocacy-oriented. Other organizations are more activist-oriented, and pursue social change and medical reform through direct action. While organizations vary based on membership, goals, and tactics, the connective thread is a shared belief that conventional intersex medical management has led to irreversible physical and emotional harms and violate basic human rights (Spurgas 2009). Activist 20 stated:

> I'm all in favor of surgery, if it's medical necessary or if it's a consenting young adult. [An] adult who wants to do this, absolutely. Fine, fine, fine. But, man, cosmetic surgery on young children? That's wrong for the parents, wrong for the babies, and wrong for the doctors to sell that service.

Activists challenged the medical necessity of early genital surgery, often arguing they are performed by doctors for social reasons, rather than the health of the child. Moreover, the goals shared by all activists is to enhance physical and emotional well-being and to end shame and stigma. Activist 11 explained:

> Physicians behaved as if their actions didn't have consequences. Like, I'm going to cut this kid's penis off, and she'll function as a girl fine, completely fine sexually. Even if they, like, cut her genitals off. I mean, there just is an emotional disconnect. You know, like—what they're doing is they're failing to see these children as future sexual beings. They're failing, right? Because what they're treating is not the kid. They're not treating the child. The child doesn't have a problem with its genitals. The parents have a problem with the genitals, and the doctor has a problem with the genitals. So, I mean, it's just flat, plain, kneejerk prejudice.

Intersex organizations generally shared ISNA's overall goal of changing the medical standard of care and supported the shift from a "concealment-centered" model to what ISNA (2008b) called a "patient-centered" approach. However, ISNA's increasing distance from identity-based politics to ever-closer relationships with medical professionals estranged some activists and allies. In 2003, for example, concerned about the direction of intersex advocacy, Curtis Hinkle founded the Organization Intersex International (OII) with the mission of "attain[ing] human rights for intersex infants, children, and adults, particularly the right to bodily integrity and self-determination (OII 2012). These tensions—conceptualized by sociologist Georgiann Davis (2015) as the shift from "collective confrontation" to "contested collaboration"— culminated with the shift to a new DSD terminology endorsed in the 2006 Consensus Statement.

EMBODIED TENSIONS: DSD TERMINOLOGY

Throughout the twentieth century, medical professionals occasionally used the term intersex for what they more often referred to as hermaphroditism or pseudo-hermaphroditism. Activists initially embraced intersex because it was less confusing and stigmatizing than labels based on the root hermaphrodite, although as I discussed above, they used those terms strategically as a form of empowerment. In light of definitional challenges encountered with physicians along with rejection of the intersex label by some parents, some activists and allies began to work toward developing a new umbrella terminology.

The idea of a new umbrella nomenclature began circulating among a group of patient advocates, intersex organizations, and clinicians in 2005 (Dreger et al. 2005), and was formally endorsed in the clinical arena with the publication of the 2006 Consensus Statement (Lee et al. 2006). The new terminology was proposed as the harbinger of a new medical model of intersex treatment, focused on genetic and endocrinological etiologies, and would "label the condition rather than the person" (Dreger et al. 2005: 733) and facilitate evidence-based research. Also, around this time, a consortium comprised of ISNA members, clinicians, parents, and intersex adults were developing a set of clinical guidelines and a handbook for parents, which were ultimately published using DSD terminology (Consortium on the Management of Disorders of Sex Development 2006a, 2006b).

Alice Dreger, an academic and long-time intersex ally who promoted the change in nomenclature and was involved with the consortium, explained the rationale for the new terminology. In a retrospective essay, she described how activists felt stuck and that they needed a new way of talking with doctors, and it had to be a term doctors would accept (Dreger 2018). Supporters of DSD within ISNA stressed that the term "is much less charged than 'intersex,' and that it makes our message of patient-centered care much more accessible to parents and doctors. Our aim is to meet them where we are" (ISNA 2008d). ISNA explained on their website that with ISNA's focus on medical reform, DSD was "created with parents and doctors in mind," (ISNA 2008d) and thus, a logical step in their politics of cooperation and compromise (Germon 2006). In 2008, ISNA closed its doors and transferred its assets to a new organization, Accord Alliance, which focused on "lead[ing] national efforts to improve DSD-related health care and outcomes" (ISNA 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" (Accord Alliance n.d.)

The shift to DSD nomenclature, including its early endorsement by some activists, has been particularly contentious issue among activists I interviewed. Several activists I spoke with reflected on the immediate impact DSD had on activism at the time it was introduced. For example, Activist 3 compared the initial introduction of DSD to a weapon of mass destruction:

> [I]t was a nuclear bomb within the community, within the activist community. The recriminations became so heated so fast…people went really extremely on the attacks over this issue…you know the movement had been starting to pick up steam. And a lot of people who maybe were hovering around the verge of becoming more public activists and advocates really faded back because the public scene of intersex got so violent. Well, not literally violent, but verbally violent...you pretty much had to pick sides. You pretty much had to like, you had to say intersex and you had to say DSD and that announced all your loyalties. And you know, you're on one side or the other…But a lot of people who were, I think, taking their first tentative steps out of the closet in the world of intersex activism just checked out during the years from maybe 2006 until probably 2010. And the only people left were the people who wanted to fight really hard about language.

Activist 12 also reflected on the divisiveness engendered with the publication of the Consensus Statement and its endorsement of DSD language:

> I feel like that really was one probably one of the most hurtful, most divisive measures, and really struck a significant blow to the activism that was taking place. Just the terminology alone, "disorders of sex development." Continuing to pathologize a group that has been already and historically pathologized. I think what is so hurtful and divisive about it is that it was a bunch of doctors and a few intersex people in a room who agree to this terminology. I think as a result, it created a huge schism in the community that I feel like we're still trying to heal from.

Some activists described DSD as a highly divisive issue that fractured the movement and at times, continues to inhibit some activists and organizations from working together.

Some activists I spoke with expressed strong opposition to DSD on the grounds it reifies intersex bodies as in need of fixing. This position is also shared by some organizations, such as OII (2007). According to OII, DSD is pathologizing and "[r]educ[es] intersex to a genetic defect" (OII 2007). Activists argue the use of "disordered" language was stigmatizing and pathologizing, and countered much of what the intersex movement had advocated over the years (Morris 2006; Reis 2009): that intersex requires neither medical intervention nor a "cure." Activist 25 stated:

> All intersex people are now labelled as medically disordered. This obviously justifies continuing medicalization and conflicts with the argument that sex variance is natural and should be accepted…I would never apply the term DSD to myself, and see it as counterproductive. I see intersex people having adopted the term as proof of the power of medicalization—the very thing I am working to combat.

Similarly, Activist 6 strongly opposed DSD language in light of his embodied experiences, particularly negative treatment experiences, which he was actively working against.

> I cannot agree with intersex people being referred to as disordered. We're not. We have healthy, normal, intersex genitalia. I want my intersex genitalia back. I'm very angry that I had more than a dozen surgeries before I was 12 years old. That's ridiculous.

While those that opposed DSD critique the terminology for its pathologizing connotation, only two activists I interviewed suggested that it actively inhibited their work with other intersex activists. For example, Activist 23 adamantly refused to work with activists' organizations that engaged with a medical model.

> There are a lot of people who I think, in general, their message is fantastic and I'd love to work with the organization…support what they're doing. But if they're using a medicalized model, I just can't do it. It's one of those things in general we're working towards the same thing, but the words that we're using in this case are really, really important. And if we're advocating for ourselves as disorders that might not get us all the rights that we're supposed to have. That's not progress. I'm not willing to align myself with that model. To me, going halfway or [a] quarter way or three-quarters way is still not actually getting the protection and the rights that you want.

While it was clear the terminology was still a subject of debate, my interviews suggested that positions were increasingly more nuanced and varied among activists and organizations, many of whom actively sought or at least engaged with medicalized terminology as part of their broader collective aims. Given the diversity of the intersex community, which includes individuals with disparate diagnoses, the move to embrace medicalization and DSD terminology was posited as the most utilitarian move available (Spurgas 2009). Many activists I interviewed who took up DSD nomenclature, frame it as part of the logic and evolution of the movement. Activist 4 said:

> I think everybody that is an activist or an advocate wants—would love to have a united front…strength in numbers And there's part of me that thinks that society is more ready for DSD than they are to embrace intersex…I really see DSD as an interim until we really bring everybody up to speed that you can't change sex or sexuality or gender by modifying genitals…I am like a Jew in the desert with Moses and I'm walking around for forty years and I am not going to see the Promised Land. I just don't think I'm going to be alive for it. But I've been walking and I've been doing what I can do. And I do believe that we do get to the Promised Land. But I don't think society is ready yet. So, we're just going to keep walking.

Activist 16 identified politically as intersex, but supported DSD as a step towards the movement's goals, while acknowledging it as controversial.

> I am a big proponent for the use of the term “disorders of sex development,” even though my political identification is intersex. But, I say to people, “Babies aren’t republications or democrats and they’re not intersex either, because that’s a political identification that you came to in the fullness of time. Babies have something that is unexpected in their bodies or their chromosomes or their ability to biosynthesize hormones and that’s a disorder of sex development.” And, you can call it whatever you want…but when I am talking to parents, which I do on almost a daily basis, brand new parents, or I’m talking to clinicians, I say “disorders of sex development” because that’s what it is and doctors don’t speak in euphemisms. They don’t speak in baby talk. I have sleep apnea, Erin. It’s not a difference of sleep patterns. It’s a sleep disorder. And I’ve probably got about five or six other disorders too [*laughs*]. So, why would something where a girl has XY chromosomes and internal testes that can’t process or recognize testosterone, why should that be any different than diabetes or sleep apnea or any other thing? It is what it is. Now, I understand that our pioneers and the people that feel really angry—and they have every right to be angry—something like “disorder” pisses them off royally because it pathologizes and medicalizes who we are. But it is what it is. Like I said, you can call it whatever you want to call it…as long as they don’t perform unnecessary and unwanted medical interventions and they don’t lie to people and they don’t let people just grow up to be who they are. You can call me whatever you want to.

In line with Activist 16’s view, DSD refers to the underlying physiology causing atypical anatomy, whereas intersex labels the person, not the condition. Accord Alliance, for example, lists on their website in their “Glossary of Terms” (Accord Alliance 2013):

> 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.

Similarly, some activists saw DSD terminology as a way to avoid potentially pejorative and confusing terms such as “intersex” and “hermaphrodite,” especially when interacting with clinicians and parents. Activist 15 said:

> I do think the term “intersex”—I mean, first of all, it has the word “sex” in it. So, that’s kind of a catalyst. For some people, that’s like, “Oh that’s “inter.” It kind of implies you’re between sexes, which people don’t necessarily feel or want to feel. I think for a lot of the rank-and-file general society parents hearing the term are fine when their kids are diagnosed [with a DSD] or someone reading it in an article. I think you hear “intersex,” and I think a lot of people get confused with transgender and automatically hook sexual orientation into it.

Activist 1 explained how DSD was in line with the logic of clinical medicine:

> The terminology, changing the terminology, was a big thing. At that time, I would say families really did not like the word “intersex” …I thought that “disorders of sex development” was good. I felt that way, in part, because, you know, the education of clinicians…There is an orderly process of typical sex development. When it’s different, when something different happens, you have a DSD. I thought that was much better than, you know, having students who were like, “Intersex? Oh, my god. What is this?” You know, they can’t even listen because it’s presented in kind of a disturbing way.

Activist 21, who supported DSD from its first introduction in 2005, described why she supported the change, and similarly touches on its potential utility in the medical arena:

> [DSD is] a label that doctors could use that did not imply any identity and did not imply a gender…I wanted doctors to use a label that doesn’t apply to the person but rather the condition…And I wanted to have a label that fit pretty comfortably within the framework of how physicians think of other kinds of developmental conditions…It needed to be a label that would be easy for them to adopt. And I think “disorders of sex development” fits all of those ways and it works for a lot of people, and it has largely replaced hermaphrodite in the literature, and I think it’s doing some really good work.

For many activists I interviewed, then, engaging with DSD was, in part, strategic and based on pragmatism. In this sense, “the ends justified the means,” and activists often reflected on how it allowed them to work more collaboratively with doctors and even parents.

Activist 3 described how when working with Advocates for Informed Choice (AIC; now InterACT), they are purposefully flexible with the language they use, based on who they are targeting:

> I had been through a lot of the language wars in the LGBT community. I lived through adding the "B." I lived through adding the "T." I lived through all the different words you were supposed to use for "transsexual." And I felt like it gave me a little perspective on it. And that's why AIC has never tried to stake out any position in what I would call the language wars…We use whatever language we think will work best with any given audience. We're not the ones who should decide what language should be used, and there is no agreement in the community right now, so we will use, you know, we'll use both terms [intersex and DSD].

Some intersex activists and organizations use both intersex and DSD nomenclature based on context (ISNA 2008d; InterAct 2016). Similarly, Activist 16 described having to "flex your style" based on the intended audience. She reflected:

> [Y]ou have to flex your style and therefore, somewhat, your language, to suit the situation that you're in, without being disingenuous. So, I try to be somewhat consistent, but if I'm participating in an online forum, which has a vocal anti-medical group as part of it, I tone it down quite a bit, because I know I'm just going to get flames relentlessly…Although, sometimes it feels like, if we're all going off in different directions and spending way too much time and energy arguing about nomenclature and terminology, it does seem awfully wasteful sometimes. But, I am not going to change any of those minds. I know that for a fact. So, I try to flex my style.

She went on:

> [P]eople have questioned my integrity over my methodology for achieving change. Because I use "disorders of sex development," I don't go into the children's hospital every Wednesday with a saber or a flamethrower, I'm invited to all sorts of meetings. I'm invited to all sorts of things and the door's wide—[doctors] phone me and say, "Can you help this new family—they're so upset." If I went in there calling them all a bunch of heartless bastards, blah, blah, blah, that would never happen in a million years…Some people that can't stand "disorders of sex development" or don't want to medicalize and pathologize any of this…it's like I am a collaborator. My goal is to stop bad things from happening to kids.

Several also suggested, while acknowledging the pathologizing potential of medicalized terminology, that speaking a common language with medicine contributed to a more positive relationship and more moderate perception of activists by the clinicians they were targeting. Activist 5 said:

> The medical profession has a hundred percent accepted, endorsed, and used DSD, and I think organizations that refuse to work with that term are like cutting off their noses to spite themselves. You can't get all hooked up on a term when you have a goal in mind and you want to change the world. You're going to be seen as an angry person that somebody doesn't want to work with. You think the hospital's going to want to work with an intersex person that says "I hate DSD and this stinks"? —no.

Similarly, activists also reflected on the confrontational tactics of early intersex activism and ISNA, and the lack of attention they received by clinicians to their claims. Activist 15 explained:

> "DSD," which is very much, I think, an accepted—it's a medical term. It's a way to work with the medical community…It was very much a compromise by some and obviously many others in the community…A compromise to me, is language that worked with the medical community. We are going to have to work with them moving forward. Holding signs and screaming and protesting is not going anywhere. We're going to have to accept the term "disorder of sex development." It's a physical difference—there are physical differences with many disorders.

She went on to reflect:

> I've grown more understanding of people's dislike of the term because it is pathologizing. Once you get more comfortable with yourself and you understand who you are and what your condition is about it's like, you know what? It's just a part of me. It's not necessarily "disorder" just implies you're wrong—there's something that needs to be fixed. I totally understand the activist community that argues against the term "disorder" because it's just perpetuating the medicalization and the pathologizing of intersex conditions…So, I do get that. It's a really tough argument...but the other side is, we're trying to work with, you know…the medical establishment, if you will. [They were] more accepting of the term, "disorder." It fit into their world. So, let's work with them.

Some activists also acknowledged the potential positive effects of medicalization via diagnosis, but described a more ambivalent position to DSD terminology. For example, Activist 20 said:

> DSD is the preferred nomenclature in the medical arena…And you'll find people in the national support groups that like DSD, and you'll find people that hate DSD and some prefer intersex. I don't care which one you label me, whichever pays bills better for the health insurance. You know, is it getting my estrogen a little cheaper? I don't care what you call me…it pays the bills.

In my interviews, several activists also acknowledged the use of alternative terminologies that have been proposed, including "variations of sex development" (Diamond and Beh 2006), "variations of reproductive development" (Simmonds 2006), "divergence of sex development" (Reis 2007), and "differences of sex development" (Topp 2012). Activist 1 explained:

> I was in favor of [DSD], and lot of the parents were too. But a lot felt like they did not like the word "disorder." They found it pathologizing. So, there were people with lots of different opinions. What has happened is that within the medical community, DSD is the standard terminology, but out in the community of affected people, in the advocacy community, people use different terms.

These terms could be considered a more "middle-ground" approach to medicalized language, but that attempted to be less pathologizing.

STRATEGIES FOR CHANGE

Intra-movement conflicts over nomenclature suggest that activists have engaged, accepted, and rejected the medical model in various degrees. These different views or frames of DSD are a factor shaping variations in strategy. Activists have employed various strategies both to reduce the scope of medical jurisdiction and to "mak[e] space for new social and cultural displays" (Sudai 2018: 13) of intersex. Intersex activists and organizations utilize various strategies that build community, raise awareness, advocate for medical reform and research, and advance the human rights of intersex people. Many activists recounted to me experiences of stigma, shame, and isolation. In response, they are using various tactics to reach and empower intersex people and their families, providing information, and creating spaces for community-building where they can share their experiences.

Education and Visibility

One common aspect of activists' work is less about changing official medical policy, but instead directed at the health of their constituents. This, of course, includes education and information about medical care, and activists also note support as a major priority. Several activists highlighted the importance of support particularly for a marginalized and traumatized community. "I think that support is really an important activist tool because as people heal they become more capable engaging in activism" (Activist 21). Similarly, Activist 20 described the benefits of mutual support:

> [T]he power of these [support] groups come from their ability to put out that welcome mat and say, “Hey, come on in to a room where everybody knows exactly how you feel. And everybody has walked along the path that you’re on.” So many of us were told when were diagnosed as younger people, that we would never meet another person with the same odd genetic syndrome that we have, and to walk into a room with 50 or 100 other people who have the exact same syndrome or a similar syndrome, or parents of a child with the syndrome, you know it’s very life-affirming that you’re not as screwed up as you might have thought and it’s wonderful to be able to get the kind of support that you get from peers, rather than a medical establishment that isn’t always the most welcoming and friendly. To be honest, not even the most educated.

Many activists I spoke with emphasized the importance of coming out and sharing their stories publicly in order to facilitate broader awareness of their concerns and the efforts of the broader movement. Activist 3 explained:

> I actually think the most important thing is about more individual people speaking out. There are many, many, more intersex people out there than have spoken publicly and I think individual stories are what most move policy anywhere…I mean, I draw my lessons from the LGBT movement…When the pole shifted so that more people than not knew that they knew a gay person, public opinion shifted about gay rights…Coming out was the thing that changed things for the LGBT community…Intersex is much less common, but everybody does know an intersex person. And I think when more people come out, that’s going to have an enormous impact on what it means because I think being part of what allows the mistreatment of intersex people, not just in the medical world, but everywhere, is this sense of unreality. It’s hard for people to imagine an intersex person as a person. When you put a face on it…when it’s a person you can imagine, then you can respond to them as a person.

“Coming out” or publicly sharing their stories is a vital tactic that activists use to counter the problem of invisibility (Astraea Lesbian Justice Foundation 2016; Saguy 2020). Activists described proactively engaging the media, participating in public events to provide information about intersex issues, and sharing their experiences. Activists reported providing written testimonies online, partaking in documentary films, and giving lectures in both public forums such as libraries and local events. Reflecting on her participation in talk shows and a documentary, Activist 5 said:

> [T]he more we get out there, the more people say, “Oh, I’ve heard of that.” So, this is one way we can try to reach people all around the world…I don’t think that the treatment of intersex people will change until intersex is a household word.

As part of raising awareness, both in the social arena and popular media, activists are also engaging new media to foster more positive perceptions of intersex, promote diverse embodiments, and raise awareness about intersex human rights. For example, AIC founded the Interface Project in 2012, which “communicates the lived experiences of intersex people by recording the voices, transcribing the words, and publishing the stories of people born with a variation of sex anatomy” (Interface Project 2019). The Project’s website hosts testimonies from intersex people in order to capture the diversity of experiences and to empower intersex individuals.

In addition to public awareness, some activist efforts at raising awareness are geared to particular audiences, such as parents and intersex youth. Reflecting on the education of parents, Activist 1 said:

> I think part of what changes medical practice is that parents are more educated and saying, “You know what? You’re recommending this, but I joined this group of parents, and you know, they’re doing these things to raise their children, and they don’t want to do this surgery. Educating parents helps educate clinicians as well.

Activist 6 also described the importance of raising awareness among parents, particularly through media efforts and sharing experiential knowledge:

> I've worked hard to continue to get media attention for this issue because really, the people who are going to make the difference here are young parents. If young parents have heard something like me or me on television, radio, or they read something somewhere in a women's magazine or newspaper, that said the advocator was born with different looking genitals, maybe you shouldn't do surgery right away, that's all I want them to think.

Similarly, Activist 11 also describe the usefulness of raising awareness among parents:

> [I]t's important for these parents who have just had these kids or who haven't yet had kids to realize that this is, you know, that you might have a kid like this…more often than not you're going to be offered the option to normalize your kid in some way, and share some examples, share some stories, share some brief stories of people—their perspective, the story that people can tell you.

The U.S. affiliate of OII (now known as Intersex Campaign for Equality) created a brochure for parents that provides "information in a balanced, education, non-alarming, non-stigmatizing manner" as well as educational and medical resources to ease parents' concerns about their intersex children (OII 2013).

AIC has also focused efforts on intersex youth, for example, through their InterAct Youth Program. Founded in 2014 with "the goal of building advocacy skills and support for the next generation of young intersex leaders," (InterACT n.d.) the youth-led InterAct Youth Program has created educational materials for intersex youth and parents from the youth perspective in order to raise awareness and to facilitate pride in their embodied differences. Describing the youth program, Activist 3 explained:

> [T]he idea of that program [InterACT Youth] is to give young people in the intersex community just a platform to share their voices…part of the idea of that project was we now hear—after two decades of activism in which very little has changed in the medical world—what we're now hearing from doctors is "Well, our surgical techniques are better now. So, all those thirty, forty, fifty year old people who are complaining about the surgery that was done to them, that's not the surgery we're doing any more."…[S]o, part of the idea of InterACT was to turn to young people who have very recently experienced what's been termed the more modern medical treatment and hear what they have to say about how they've been treated and about their bodies.

Activists I interview also target their efforts at medical professionals. Some acknowledge the importance of working within the medical model as part of the movement's efforts. Activist 4 described the benefit of focusing advocacy efforts on working with doctors:

> I think there are a lot of participants and stakeholders in this arena that understand that the care that is being given and is currently given is not ideal for the patient. And I think advocacy—you're just allowed in more rooms. You're allowed to have these discussions with people that are making decisions. And that's really where we need to be.

Similarly, Activist 13 said:

> I don't know whether this is education or whether this is just better alliances…but I don't forever want to be in opposition to medicine, "medicine" with a capital "M." You know, wow, it just always come off that way and despite my intentions…but that doesn't make it right, you know. There is some form of liaison between intersex people and medicine that I think needs to happen.

Activists and organizations, particularly among those that were willing to engage with DSD and the medical model, at least strategically, are targeting medical professionals in their educational efforts. Activist 21 reflected on the importance of advocating "inside" medicine and working with medical professionals:

> A social change movement needs to have people using different strategies, but some of those strategies need to be [an] educator insider [who] gets to be invited to meetings like the NIH consensus meeting…[Y]ou need to be able to play on the inside, as well as on the outside…I think there needs to be more people that are able to do that, to learn then—to be able to speak in a way physicians can understand them as peers.

Activist 3 also emphasized the importance of working with and educating doctors:

> It's important because they're the ones who are making medical decisions and they're the ones that are presenting information to parents at a time when they're very vulnerable and where they don't know what other information is available. So, when decisions about treatment of intersex children are being made. The information is often only what the doctor chooses to present. So, it's very, very important for us to reach doctors and affect how they talk to parents about these decisions. And also, to impact how they think about the decisions themselves.

She also went on to describe her efforts to target medical professionals:

> [W]e do a fair bit of aggressive medical education. I present at medical conferences. There're a few hospitals where I'll either do training with their DSD treatment team, or I'll be sort of a backup—actually go consult on individual cases. And I publish with or without—whether or not I have doctors as co-authors—I publish pretty widely in the medical press. So, in all those ways, we're communicating with the medical world.

Several activists noted the importance of targeting younger doctors or medical students in an effort to reach the newer generation of providers who may be more receptive to delaying surgery and open to a model other than Money's protocols, which dominated the latter half of the twentieth century. Activist 6 described his willingness to speak to medical professionals:

> I just presented at this conference last September with an international group of pediatric urologists. Some of the younger ones are also interested in being educated and learning something new. I want to work with physicians as much as I can, as long as they are not shunning me and basically rejecting what I have to say out of hand because what it means is they're going to do less of the surgery that they want to do.

He then went on to further elaborate:

> I think it's a great idea for us to be meeting with and working with people who are in the field right now, physicians that have been trained in the old model who are open to considering something different. I'm going to be participating in two conferences this year where I'll be doing exactly that, sitting with teams of physicians who are interested in being educated and getting a different idea of how they might pursue treatment with intersex patients. So, I want to do that work. I want to believe there are some people out there, some physicians, who are conscious about the fact that it isn't just their job to do more surgery, it's their job to treat patients well.

Some activists and groups are also advocating for research that engages the intersex community meaningfully in the study process. Activist 1 said:

> We want to interact with people and participate in studies where the research goals are our goals, where the research is actually going to be of some value clinically…I think it's important to continue advocacy in the sense of education. I think that it's matured a lot, and it's become more of a process of education and give-and-take.

Several activists I spoke with described participating in formal trainings, guest lecturing at educational settings such as universities, and engaging with various medical professionals one-on-one to discuss intersex concerns. For example, the AISDSD-SG developed a medical education program that coincides with their annual member retreat (InterConnect 2021; see also Davis 2015). Activist 15 explained the impact of this medical education program:

> More and more doctors are getting to hear—and at those one-day conferences they're getting to hear from parents, panels of youth, adults, and other doctors. They're getting more educated and they're getting more up-to-date on—not medical practice, but medical procedures—but on the more emotional/social part of this, you know, how it affects the families and how it affects kids.

In this forum, intersex people and their parents share their experiences directly with medical professionals, share their concerns and advocate for their medical and research needs. Activist 1 also described the importance of this program:

> I think it’s just really important for a clinician to see who we are and what our families are like and what our adults are like to realize that we’re not a group of people who need to have something fixed in order to be happy and healthy. Please listen to us about what our real issues are, and help us with those, but don’t be thinking that we have something horrible about us, and this includes people with unusual-looking genitals. People can deal with that just fine.

Legal and Human Rights Advocacy

Intersex activists are increasingly looking to the law to challenge and politicize the medical standard of care. Some activists and intersex organizations are educating policy makers and advocating for laws and policies that recognize and protect the human rights of intersex people. Informed by groups such as OII who remained critical after the 2006 Consensus Statement, global human rights bodies are increasingly researching ongoing medical practices and further challenge their ongoing legitimacy (Hegarty et al. 2020). Many of these activists directly oppose DSD and the medical model and their primary aim is to achieve a moratorium on non-consensual, medically unnecessary surgeries and treatment.

International human rights forums, such as the UN Human Rights Committee provide disadvantaged groups with new opportunities for claims-making, enabling boomerang patterns by which repressed local actors go to international forums to gain leverage against their government (Keck and Sikkink 1999). These international forums exert varying levels of pressures on local authorities to address human rights problems, ranging from naming-and-shaming to legally binding decisions. While international human rights mechanisms create soft law that may not be directly enforced in practice, transnational advocacy efforts have demonstrated that this strategy can create a “boomerang” effect” (e.g., Kollman and Waites 2009) that, in turn, impacts national law and practice and can lead to hard laws in individual nations (Bauer et al. 2020). Thus, the appeal to international human rights mechanisms may have a dual impact of raising public awareness about rights claims, while simultaneously promotion legislative change

Activists have used rights-based arguments corresponding to existing legal frameworks to politicize normalizing treatments performed on intersex individuals. For example, some challenge medical practices by crafting legal arguments using the body of legal human rights (Greenberg 2012; Sudai 2018). Activists engage in human rights advocacy, particularly through international networks, and utilize the review processes of the UN, using shadow reports and partnering with other non-governmental organizations to highlight the concerns of intersex people and to pressure national governments. By engaging national and international human rights bodies, intersex activists and groups are bringing additional visibility to their concerns (e.g., HRW 2017). Intersex awareness, for example, was included in the UN *Free and Equal* campaign in a special “Intersex Fact Sheet,” developed to educate the public on intersex (InterAct 2015). These efforts have resulted in recommendations to uphold the rights of bodily integrity, autonomy, and self-determination, to require informed consent, and in some cases, criminalize non-consenting treatments.

Along with the apparatus of international human rights, additional routes of politicization include litigating human rights violations proclaimed in U.S. law that are jeopardized by early normalizing interventions (Sudai 2018), such as the rights to bodily autonomy, self-determination, informed consent, and physical integrity. Some activists I spoke with referenced the use of litigation to challenge medical practices, as Activist 15 explained:

> [I]f you can get a court to make a decision, you know, that calls attention to the fact that says there was adequate informed consent perhaps or negligence in a malpractice case or in a constitutional case. So, you can talk about children having rights to bodily integrity and the right to procreate and those kinds of things that were taken away from them unconstitutionally. You have those kinds of decisions. Those decisions are made public and that sends a message to society and to the medical professionals. When you're talking about malpractice, too, there's money and there's a lawsuit. So, that sends a message. It's kind of like they need a slap on the wrist for them to pay attention and include support groups and provide real informed consent to families who are making decisions for their children.

In addition, activists have begun exploring litigation as a strategy to advance their goals. Based on my interviews, legal strategies were emphasized by activists opposed to DSD and those particularly frustrated with the lack of change or response from the medical community. Activist 6 said:

> I think medical practice changes when malpractice makes it necessary for them to change what they do. That's legal. Frankly, if I can get state statues to say you can't do this anymore, then I don't care what the American Academy of Pediatrics says. I used to think I had to work with them. I'm never going to get anywhere with the American Academy of Pediatrics.

He went on:

> I don't think this is going to change until physicians are at risk for malpractice…That's the only thing that's going to change medical practice…These people are about normalization. They don't understand that there is a tremendous amount of variability within what is normal.

Similarly, Activist 26 succinctly said that "nothing makes a doctor listen like an attorney." She went on: "[I]f you're looking at it from sort of a systems perspective, like, having the sort of the tooth of the law and the threat of litigation is what does make people sit up and listen, and what will drive change in practice."

Particularly significant was a malpractice lawsuit filed by Pamela and John Mark Crawford, in collaboration with AIC and the Southern Poverty Law Center, in South Carolina in 2013 in both federal and state courts on behalf of their adopted eight-year-old son, M.C. M.C. was born with an intersex trait and prior to his adoption was in the foster care system. During that time, he underwent medically unnecessary surgery which ultimately affected his sexual function (e.g., InterAct 2017). At the time I was interviewing activists, this case was still making its way through the various court systems, and many activists emphasized its potential as a step forward in the movement's goals. Activist 15 explained:

> Nothing was changing and so the carrot wasn't really working; the stick was kind of necessary. I think it's going to take a lawsuit or two or three to send a message and hopefully this M.C. litigation that is now pending is going to be a huge start to that.

Activist 13 was also hopeful about the M.C. legal case, particularly in that legal strategies could offer the innovative means to pressure medical professionals to change their practices:

> I can't march into medicine and change them. What we're doing right now is not being effective enough. It's not happening quickly enough. As we've been on the phone now, almost for two hours, probably at least one child has been operated on unnecessarily. I mean, how fucked up is that? That's a bad, bad thing. So, if this is the way it is right now, and we're not communicating effectively enough, then we have to look for game-changing things…and the M.C. thing...I think, is one of them because it takes the jeopardy away from the child, and puts it on the surgeon. That's pretty game-changing. But something game-changing needs to happen in the conversation between us and medicine, in the discourse between us and medicine.

In addition, even long-time ally, Alice Dreger (2015), who led many direct efforts to work with medical professional to change their practices, reflected on the M.C. case:

> I do think it would be a lot better if this system changed because hearts and minds were changed among doctors and parents. But after 20 years of working in this area, I don't know what it's going to take to achieve that—and I'm starting to think we can't wait anymore for the legal prohibitions to be enacted. How many children are losing healthy genital tissue while we wait for the pediatric establishment to "evolve"?

A Diverse Repertoire

DSD, at least initially, created an "intrasex" debate (Greenberg 2005) within the movement between those willing to accept DSD terminology and work with medical professionals, and those that claimed DSD was pathologizing and preferred "intersex." However, my interviews with activists suggest that the heat behind this contested collaboration (Davis 2015) has simmered down and led to a more diversified repertoire of strategies and tactics. Activist 16 said:

> I also feel that there's many, many ways to skin a cat and in the fullness of time, when we all wake up in this world and decide that kids can be whoever they want to be with the body they were born with, we will appreciate that many different people took different strategies and different voices and different ways of tackling this, and together, we made a difference.

Some activists valued the diversity of strategies, particularly because medicine was a difficult institution to change particularly the approach to early genital surgeries. Activist 21 said:

> I think successful change will have to use a lot of strategies at the same time, and it's good…But I think that this practice [medically unnecessary surgery] has proven to be sufficiently resistant to change over time...[S]omething with a little bit more friction in it—and a little bit more power to course is also needed. So, I'm really in favor of the kind of work that AIC is doing, and people who are bringing a human rights focus on it.

Many activists reflected on the utility of direct and indirect challenges, both confrontational and cooperative. Activist 3 said:

> [A]s [the intersex movement] matures as a movement, there will be recognition that a mature civil rights movement uses multiple tactics, multiple strategies, doesn't agree on everything, and focuses joint action on points of agreement. You know, focuses on where the real enemy is and fighting the real enemy. And yes, having lively internal discussions about points of differences…no civil rights movement is led by one organization. And no civil rights movement has one monolithic view of how things should be or one set of tactics…Yes, we should have confrontational tactics. And we should have groups that work from the inside and that are not confrontational.

Activist 11 described the benefit of multiple tactics:

> I think that all movements need all of those things. I mean, there are people—there's a little group in Switzerland [Zwischengeschlecht] who constantly does street protests and protests in front of hospitals, and they have these inflammatory signs and they're very in your face, and it's great. We need that. We need that. We need that. We need AIC working indoors and working with lawyers and physicians…You know, we need all of that. And that's also pretty typical of a movement. It's not only going to be one method, and it's important to have [them] out there, you know, going outside and joining them, ranting and raving, causing havoc. I mean, it's important…You know, the idea that there are multiple ways to start a conversation is valid and true, and I'm glad they're doing that work.

Similarly, Activist 16 said:

> Some people have a light saber or flame thrower and some people are quote on quote collaborators like me, and I use the accepted medical terminology. Another prong has to be legal litigation because sometimes the only way institutional and systemic change is going to happen is when you hit people in the pocketbook, hit institutions in the pocketbook.

Intersex activism includes diverse actors and organization with multiple goals and strategies. While DSD terminology remains a point of contention, the divisiveness has ultimately led to an expended repertoire of strategies and tactics. Activists increasingly acknowledge the utility of using multiple strategies in order to effect change in medical practice.

Activists and groups that engage DSD tend to be more willing to work within the medical model and collaborate with medical professionals. For example, the AISDSD-SG coordinates a medical education program that coincides with their annual member retreat (InterConnect 2021). Activists educate doctors on their concerns and collaboratively establish research priorities. Activists and groups that oppose DSD, such as OII, tend not to engage with the medical model or work with medical professionals. OII focuses on human rights, and activists are increasingly engaging with international advocacy networks and human rights bodies, such as the International Intersex Forum and the UN, to achieve social and medical change. Lastly, some activists described tailoring the extent to which they engaged DSD based on their audience, employing a more flexible or pragmatic approach in order to pursue strategies that will best achieve their goals.

CONCLUSION

Intersex activism takes a variety of forms, from public and direct actions such as protest and media awareness, to the efforts of peer support groups to facilitate research or treatment reform by promoting the role of “patient expert.” By making visible their embodied experience, some intersex actors and organizations have sought to promote greater tolerance for diverse bodies and recast intersex as more positive than pathologizing. Early intersex activism was largely grounded in conscious opposition to medicalization or the extension of medical frames of understanding. Over time, some actors and organizations have sought medical reform and now advocate for improved quality of care and expanded research.

While DSD initially divided the movement, and remains an area of debate, my research demonstrates that activists frame DSD in diverse ways. Activists' views of DSD range from pragmatic acceptance to outright rejection. The ways in which activists and groups frame DSD shapes the strategies they pursue. Activists and groups that engage DSD prioritize medical reform and seek to improve clinical interactions and quality of care. Other activists oppose DSD and are increasingly frustrated with the slow pace of medical change. They are exploring legal and human rights advocacy in an effort to create additional pressure on medical professionals. Some organizations employ terminology flexibly, based on their intended audience. Intersex activists and organizations are variously engaging with medicalization from the "bottom up," and even strategically endorsing DSD to work more closely with medical professionals and some parents.

CHAPTER 4

COORDINATING CARE POST-CONSENSUS: MULTIDISCIPLINARY TEAMS AND ENGAGING FAMILIES

For the latter half of the twentieth century, clinicians relied on protocols based on work by John Money and colleagues, which emphasized the role of rearing in gender identity development (e.g., Money et al. 1955b; Money and Ehrhardt 1972). Their research, first published in the 1950s, hypothesized that concordance between genital appearance and assigned gender was necessary for psychological adaptation and a stable gender identity (e.g., Money et al. 1955b). Clinicians posited that it was in the child’s and family’s best interest to perform surgery early and withhold information about their condition. Intersex activists and their allies criticized the extensive medicalization, which they argued caused irreversible harm and violated human rights (Chase 1999; Davis 2015; Carpenter 2016). These challenges, along with revelations of questionable research and clinical conduct (Colapinto 2000) cast considerable doubt on the legitimacy of the long-dominant protocols. ISNA activists adopted patient-centered care as a strategy to reform clinical practices and outcomes by formulating care guidelines The Intersex Society of North American (ISNA), in collaboration with sympathetic clinicians, began to promote a patient-centered approach as an alternative to the paternalism of Money’s protocols, with emphasis on open communication, informed consent, avoidance of unnecessary interventions, and psychosocial considerations (Consortium on the Management of Disorders of Sex Development 2006a, 2006b; ISNA 2008b; Hegarty et al. 2020). Moreover, they attended to the importance of minimizing stigma and shame by promoting openness and interpersonal connection, and addressing patient and family psychosocial concerns and distress (ISNA 2008b).

These pressures eventually culminated in a 2005 meeting of international experts and two patient advocates. During this meeting, participants reviewed available research and developed clinical recommendations later published as the “Consensus Statement on the Management of Intersex Disorders” (Lee et al. 2006). Included in these recommendations for “optimal clinical management” (Lee et al. 2006: e490) was the provision of care by a multidisciplinary team (MDT) of specialists, open communication with patients and families and their participation in decision-making, and attention to psychosocial concerns with acknowledgement of the importance of psychological and peer support. Moreover, the commitment to patient-centered care has since been confirmed with the Global Update to the Consensus Statement in 2016 (Lee et al. 2016).

However, the extent to which these guidelines “work” in practice and how the recommendations, particularly for MDTs and open communication, play out, are not clear. Clinical guidelines, as part of the evidence-based medicine movement, aim to rationalize decision making and clinical practice. However, “[m]any reform attempts are…weakened by discretion and autonomy inherent to professional medical power” (Timmermans et al. 2018: 522). In other words, clinicians still exert professional autonomy over the decision of whether and how to implement such standards (Timmermans and Berg 2003). Based on interview data with 20 clinical providers, I examine the impact of the Consensus Statement recommendations on clinical practices, particularly how health care providers engage in multidisciplinary team-based care and patient-centered care. I explore their perceptions of interactions with intersex patients and their families and the challenges they face in practice.

PATIENT-CENTEREDNESS

The role of patients in medical care and decision making has transformed over the course of the last century. The shift away from paternalistic- or clinician-centered decision making that dominated the early twentieth century and the subsequent discourse of patient autonomy was facilitated, in part, by the emergence and increasing authority of bioethics and patients' rights which emphasize the importance of patient autonomy (Rothman 1991).[14] This emphasis on patient autonomy places new pressures on health professionals who now have the responsibility to ensure that clinical information and potential courses of action are conveyed to patients in accessible language (Morgan 2008).

Central components of clinical decision-making are the doctor-patient relationship and the organizational structure of care (Eisenberg 1979; Clark et al. 1991). Two sets of reforms to the organization and delivery of health services—the creation of multidisciplinary teams and the involvement of patient and families—have sought to improve patient-centeredness of health care provision. The Institute of Medicine (2001) defines patient-centered care as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring the patient values guide all clinical decisions" (40). Moreover patient-centered care focuses on the individual experience of illness and care, in order to promote patient involvement and the

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[14] The move towards patient involvement in decision-making has also impacted the rights of children. According to the United Nations "Convention on the Rights of the Child" (UN Office of the High Commissioner for Human Rights 1989) children and young people have the right to express opinions freely, and these opinions should be given weight, according to their age and maturity, in decisions that directly affect them. In chapter three, I highlighted the growing salience of human rights advocacy and discourse in intersex activism. The efforts of some intersex activists and organizations, particularly those that remained critical of the Consensus Statement after 2006, focus on engaging international human rights bodies in challenging the ongoing legitimacy of medical practices, particularly medically unnecessary infant genital surgeries.

individualization of care (Stewart et al. 2000; Epstein et al. 2005; Robinson et al. 2008). The formation of MDTs and patient and family engagement are both seen as a means of improving collaboration, knowledge sharing, and accountability in health care and ensuring that services are built around patients' needs and wishes (Martin and Finn 2011). Within the current health care arena, multidisciplinary teams are an essential tool for delivering more patient-centered, coordinated, and effective health care (Poole and Real 2003; Mitchell et al. 2012).

In this chapter, I assess some of the impact of the Statement and the ways its components are engaged by clinicians in practice. I first explore providers perceptions of key changes since the Consensus Statement, particularly in light of Money's long-dominant and controversial care protocols. I then explore providers' experiences providing team-based care, as well as clinicians roles on the team, and specific challenges they face in practice. Then, I explore their perceptions of family engagement, including patient-centered strategies they employee along with barriers they face when working with parents of children born with intersex traits.

SITUATING INTERSEX CARE

The providers I interviewed expressed sensitivity to issues that intersex advocates have raised over the past three decades. Dr. 16, a pediatric urologist, explained:

> The lay press discrediting Money—John Money—and patients speaking out about how they had felt mismanaged…I think it made all of us [physicians] uneasy. Here we were feeling as though we were doing great work and helping kids and families, and out of the blue we were under attack. We were being told that we were doing the wrong thing and maybe we were hurting people. That just caught my specialty completely by surprise and set us back on our heels…I think all of us felt very uneasy and on uncertain footing as to what we were doing…I think that the literature from the lay press and lay groups has just given us pause to wonder what the right approach for the family is.

While providers, particularly the surgeons I interviewed, reaffirmed the good intentions that guided previous practices, they also acknowledged the clinical ignorance—even clinical arrogance—about protocols that were virtually unquestioned until patient advocacy and media coverage of David Reimer. Dr. 20, a pediatric urologist reflected:

> Many times decisions were made based on incomplete information…false experience and information—mainly the teaching that if you provide the right environment it really doesn't matter whether you choose male or female, and if you provide the right genitalia from the external standpoint, then the individual will do fine…I, as any other surgeon, have a certain level of confidence when they go into the operating room, that they're doing the right thing…I'd always sort of had the philosophy [that] I'll never do something unless I'm comfortable doing it on my own child, and now all of a sudden patients that would fall into lap…do I have any idea that we're doing the right thing here? The answer was clearly no. I'm certainly not the only one that felt that way, and there was a feeling that there was a tremendous need to better understand, and really sit back and say, "We really don't know what the heck we're doing," and why don't we study this the right way and why don't we be willing to admit that we don't know what we're doing and be open with families and take the philosophy that this doesn't have to be a decision that's rushed into? And it can be a decision with the input with several specialists, including endocrinologists and geneticists, and you know, most importantly, psychologists and psychiatrists. And like I said, that was not the way I was trained. I was trained completely opposite. I was trained—you know, you're the surgeon. Be sure of your decision and you do what you need to do and clearly that was not the right approach…So, it was a challenge to me personally that am I doing the right thing?

Under Money's protocols, other specialists were involved in evaluation, however, decisions about gender assignment were guided by the urologist's judgement regarding the potential for surgical "reconstruction" (Wilson and Reiner 1999). Under the current approach to care, the input of multiple specialists is critical in order to foster a therapeutic alliance with the family. The clinicians working largely in isolation—a lone ranger, a cowboy—is no longer considered best practice, and is even seen as potentially putting patients and their practice at risk

(Grumbach and Bodenheimer 2004; Gawande 2011). What was known as the "optimal gender policy" (OGP; Meyer-Bahlburg 1998), they acknowledged, may now reflect paternalism largely discouraged in modern health care delivery and constitute ethically dubious practice (Siminoff and Sandberg 2015).

Given the still marked uncertainty about whether treatment benefits patients, the OGP no longer explicitly guides physicians' clinical recommendations. Dr. 16, a pediatric urologist, said:

> John Money's theories that influenced all of us so heavily—they're certainly not the gospel. Whether there is something to them, I think, remains to be seen. Most of us feel that you cannot simply rely on those theories to guide treatment.

Doctors I interviewed acknowledged that decisions are particularly complex, and given the heterogeneous factors they must weigh, these services are suited for a team approach. As Dr. 7, a pediatric endocrinologist, told me:

> In the "olden days" we just looked at [the baby] and said "Okay, this [child] is going to have to be a female. I mean, it really wasn't that simple, but it was simpler then. Now it's, "Okay, what is the chromosomal sex? What do we know about exposure to androgens in the brain? What kind of anguish will this child go through if the child is raised female but is really male? What do the parents think about it? What do they want to do? Where are they from and what do they believe?

Some doctors affirmed the value of MDTs while also distancing themselves from the paternalism inherent in Money's protocols. Dr. 7, went on:

> I am very comforted in knowing that we now have things like gender teams, where it's not just one person making the decision. You really have to have the family buy in and participate. And, to me that's much more comforting than going to a family and saying "We have decided." I remember that feeling always made me uncomfortable. So, it's much better to have a team approach and have the family be a part of that. It's much better care.

Providers acknowledged differences in care following the 2006 Consensus Statement, suggesting a trend towards a more patient- or family-centered approach to care. Two changes in intersex care especially indicative of a patient-centered approach are the provision of care by a multidisciplinary team and a shift away from the concealment centered model characteristic of the OGP. Diagnosis and treatment by an MDT with open communication and the involvement of family are now recommended practices in intersex medical management (Lee et al. 2006; Lee et al. 2016).

The providers I spoke to reflected on the clinical complexity as well as the clinical uncertainty involved in managing conditions associated with intersex traits. Doctors weighed complex decisions with little or poor evidence bases. "What we have to base our recommendations on is just such poor information, and so it's hard to make good decisions without good evidence" (Dr. 9, pediatric endocrinology). All of the clinicians I spoke with pointed to the lack of available data guiding this area of medicine. They described having to weigh heterogeneous factors in decisions about gender assignment and treatment. They supplemented published evidence, which varies by diagnosis, with their own clinical experience and training. "We sort of all fly by quote-unquote clinical experience and what we've learned from our patients" (Dr. 12, clinical psychologist).

Other clinicians also wrestled with balancing concerns for the child and for the family. Dr. 17, a pediatric endocrinologist, said:

> How do you balance the best interest of the child, but many times you can't make the decisions always in the beginning versus the impact of the parents…What to do in the surgical end, and…our people are better off having surgery earlier in life means it would happen in a time when they wouldn't be able to decide?

They also increasingly accounted for parents' preferences. It was clear from the interviews I conducted with providers on MDTs that they were working to provide the best care possible. Moreover, many emphasized that MDTs provide better care. Dr. 17, a pediatric endocrinologist, said:

> From my previous experience from not being in one [a MDT] to now, to me it's evident that the care of the children is better And I can say whatever care I was delivering is better now that I'm part of a team in many, many ways…it's about as obvious as if a brick fell on my head and it hurt. I didn't need a statistical test to tell me what was going on.

Recognizing the need to base clinical practice upon discussion and debate, including the best clinical and scientific evidence along with patient and family circumstances, current recommendations place the surgeon within a MDT model of care with an explicit mandate to communicate openly with families and encourage their participation in decisions (Lee et al. 2006; Creighton et al. 2014). The MDT creates an environment in which medical professionals, along with the family, draw on a collective expertise and formulate a plan of action.

MULTIDSCIPLINARY PROVISION OF CARE

The Team Players

Endocrinologists. Pediatric endocrinologists are medical doctors who complete training in pediatrics along with three or more years of fellowship training in pediatric endocrinology. They diagnose, treat, and manage conditions in children and young adults related to hormones and the glands that produce them, including those involving growth, puberty, and development of secondary sex characteristics, and adrenal and pituitary function. Pediatric endocrinologists also advise, administer, and monitor hormone replacement therapies for adolescents. Because atypical genitalia are most commonly associated with congenital adrenal hyperplasia (CAH),[15] which can signal a potential emergency, they place a central role in initial assessments. Clinicians I interviewed often pointed to the pediatric endocrinologist as the first point of contact after a baby is referred to a clinic and as taking the lead in directing and ordering diagnostic evaluations.

Urologists. Pediatric urologists are surgeons who complete training in both general surgery and general urology, followed by additional subspecialty training in pediatric urology. They diagnose, treat, and manage conditions related to the urinary tract and genitals, and provide surgical services. Urologists I spoke with described performing detailed examinations of the child, focusing on the presence and location of the gonads and the size and appearance of the external genitalia. They also determine other investigations necessary to help establish a diagnosis such as imaging, vaginoscopy, and laparoscopy.[16] As Dr. 1, a pediatric urologist, explained to me:

> We do an ultrasound of the pelvis and what we call a genitogram…and you'll see what's hooked to what and get an idea of what parts are there. Then, to us, the endocrinologists are really running the show…They're bleeding the babies dry, doing all the hormone tests, you know, trying to figure out what exactly is the issue and then we go from there.

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[15] CAH is a family of conditions caused by enzyme deficiencies in the adrenal cortex (Hughes 1990) most commonly 21-hydroxlyase deficiency. The majority of babies born with 21-hydroxilase deficiency—about 75%--have a "salt-losing" form in which the adrenal glands do not produce sufficient amounts of aldosterone, which regulates salt balance. Without this hormone, the child loses too much salt and water in their urine and becomes dehydrated. Symptoms develop shortly after birth and without treatment, dehydration causes an "adrenal crisis," or shock, and can lead to serious heart problems. As of 2007, newborn screening programs in all 50 states and the District of Columbia include testing for CAH (STAR-G 2012).

[16] Vaginoscopy is a diagnostic procedure to examine the vaginal canal using a cystoscope, a thin cable with a small video camera on the end. Laparoscopy is an operation to view the organs of the abdomen or pelvis through small incisions using a laprascope.

Other urologists I interviewed similarly pointed to the pediatric urologists, who they saw as leading the diagnostic efforts, while they assessed feasibility of surgery. Two urologists I interviewed, Dr. 1 and Dr. 2, referred to the role of the pediatric urologist as the "technician." Ultimately, the urologist performs surgery that may restore function or modify the appearance of external genitalia and that removes gonads perceived to be at risk of malignancy.

Psychologists and psychiatrists. The mental health provider on a team is typically a psychologist or psychiatrist. Psychologists were either masters-level or Ph.D.-level with specialty training in subdisciplines such as health psychology, child psychology, behavioral psychology, and clinical psychology. Psychiatrists complete training in medicine, general psychiatry, or neurology, followed by additional specialized training in child and adolescent psychiatry. Based on my interviews, the psychologist or psychiatrist was often in the role of helping to coordinate the team and organize case conferences. They were also responsible for explaining the team approach to the family, educating parents and the child (over time) about their diagnosis and child development, and ensuring continuity in case management. Dr. 6, a psychologist, described his role:

> [My role is] to coordinate people, to make sure they [the team] all get there and then we have a meeting to discuss the case and just kind of make sure it's all running smoothly. I talk to the family about who's coming in to see their baby…I explain the team concept to them and why we have a team.

Clinicians I interviewed often highlighted the important liaison role held by the psychologist or psychiatrist, in which they serve as the point person for team-family communications. As intersex traits are usually unexpected for parents, the psychologist or psychiatrists are often focused initially on managing parents' emotions and facilitating their understanding of the situation. They provide psychological support and intervention to address the mental health needs of the child and to facilitate the child-parent relationship. They may also connect the family to resources and support services.

Modes of Team-based Care

The clinicians I interviewed worked on teams that differed by institutional commitment and resources. Of the 20 physicians I interviewed, nine providers worked at medical centers affiliated with a large academic institution that held a clinic devoted to intersex medicine. Each month or so, they met and saw intersex patients and their families. The care was coordinated, in that patients and families could see multiple specialists in one day, and these doctors had particular space available for meetings. Additionally, in line with the broader trend towards evidence-based medicine, these teams tended to devote considerable attention and resources to conducting research and producing outcomes data, which some doctors I spoke with described as necessary in order for their clinic to continue receiving institutional support.

The other 11 providers I interviewed participated in less structured or "informal" MDTs. These specialists, who were also affiliated with both academic medical centers and smaller, regional hospital networks, typically were consulted based on who was the specialist scheduled on-call at a particular time. These team often mobilized only for "complicated" cases, or more specifically, those cases in which gender assignment was uncertain.

While team composition may vary from one center to another, clinicians I interviewed confirmed that MDTs typically include a pediatric endocrinologist, a pediatric urologist and/or surgeon, and a trained mental health provider (e.g., psychologist, psychiatrist, and/or social worker) who can provide psychosocial care and social support resources. Based on my interviews, providers who worked on teams with a devoted DSD clinic typically had access to psychologist or behavioral health provider and incorporated them upon first meeting with the family. Endocrinologists and urologists on "informal" teams, described less interaction with psychological specialists, at least initially, and often would not consult them unless there was concern about parental distress or in regards to the child's development over time. Some teams, particularly those with a DSD clinic, extended membership to genetics and genetic counseling, nursing, gynecology, neonatology, and/or ethics.

Constructing Teamwork

Despite these differences, clinicians I interviewed made similar references to the team aims and activities, often describing the value of teamwork, highlighting the quality of teamwork in which they were engaged, or lamenting about the challenges of teamwork or institutional barriers. Providers I spoke with often highlighted the benefits of MDTs, particularly the communication and collaboration among different specialists. For example, Dr. 20, a pediatric urologist, reflected:

> Surgeons see their world, endocrinologists see their world, psychologists see their world, and by working together, you see how much what you do overlaps what they do. Whereas previously I didn't know the world of endocrinologists and psychologists and the implications it has to the family.

Like Dr. 20, underlying some respondents comments was how teamwork helped them in their clinical work, usually in the context of exchanging knowledge and coordinating care. This is particularly important in cases such as intersex, which are characterized by high clinical uncertainty and for which multiple clinical options exist (Politi et al. 2013). More specifically many clinicians I interviewed felt that MDTs contributed to the achievement of a more informed, cohesive—and therefore, better—care plan. Describing the utility of MDTs, Dr. 17, a pediatric endocrinologist, said:

> I think two things are helpful [about MDTs]. The most important is probably the interchange that goes around our meetings with regard to the best approach to individual patients, many of whom have complex issues and not completely straightforward solutions to their issues. And I think the second is that because the team actually meets together and exchanges information, we come up with the plan and approach for the family that is unified, I guess. And I think that helps them a lot.

Dr. 5, a clinical psychologist, also emphasized the unifying feature of MDTs:

> That's our biggest, kind of, promise that we make to parents, is that they're not going to get differing information from different providers. We're all going to sit down together, and we do a family meeting with them, obviously once we come to a decision or even if it's taking longer, we'd do two family meetings. But that's what we promise them is that we will be united and on the same page.

"Good" decisions, according to providers I interviewed, are those made together. Dr. 11, a pediatric urologist, explained the importance of including others in decisions not only in light of uncertain knowledge, but also as a sort of malpractice protection.

> All of these people with different backgrounds come together to come to a consensus that they deliver to the family that then leads to a super consensus or whatever of "What can be done." It also has high potential for being litigious in terms of doing it. So, what I have seen is that it's great that there's all of this talk about the gender assignment team. I think the more formal a gender assignment team, the better it is. The reason being is there's been a number of cases in this country where a decision has been made to proceed in a certain way. Then the family or the individual has been angry at what's been chosen. The person that takes the heat, and almost completely the heat, is the surgeon.

He went on:

> So, what we do is we made sure that we have endocrinologists that we trust, that we have a frank discussion with the family if we don't know for sure, then we get an extensive verbal written consent from the family. Their understanding that we do not know for sure and we are going on the best knowledge that we have at this point in time. Here's how we proceed and that we do not have to if they don't want to. This is—it's a hot topic that we are extremely cautious. We want to join as many people in the decision as possible and do just the opposite of what surgeons usually do, which is act like they know everything. Even when we feel very strongly that there's only one way to do this, we do that because we feel—from a lot of ways I'm sure, to be honest, just personal malpractice protection that it's like this.

Especially for controversial aspects of care such as surgery, a team approach may be beneficial not only for clinical purposes, but also for legal reasons. By including individuals from different backgrounds, an array of perspectives is available to MDTs that is arguably more likely to provide a comprehensive assessment of a patient's needs and helps to determine an appropriate course of action.

Coordinating Teamwork

Providers with whom I spoke identified the development of MDTs as a key change in the clinical approach. The providers I interviewed saw MDT-based care as enabling them to practice more "competent" care. "These kids are very complicated and no one specialty really has all the answers, has a complete handle on things. We very much learn from one another" (Dr. 16, pediatric urologist). By determining their recommendations on a case-by-case basis, clinicians I interviewed acknowledged the medical uncertainty they face, and share the responsibility for determining a recommended plan of action.

In most cases, according to my interviews, families are referred to a team of providers for consultation by a midwife, pediatrician, or obstetrician who recognizes or suspects intersex traits after the child is born. Some providers also described cases in which a child was evaluated or treated initially at an outside facility before their family was referred to the center with a MDT or clinic in order to receive specialized services or a second opinion.[17] First actions are primarily medical: ruling out any potential metabolic crisis, gathering details on the child's internal and external characteristics, and determining a diagnosis. Dr. 16, a pediatric urologist, explains the initial testing, which was similar across the clinicians I interviewed:

> Typically, the first thing that is done is to send blood work. So, that would include electrolytes—serum electrolytes—given the concern about CAH…typically, there's a battery of endocrine tests that will go out. Then we would do it all, ultrasound looking for the presence of the female reproductive structures, uterus, fallopian tubes and so forth, or absence of those. We would do a karyotype. That would typically get us started.

Doctors order a variety of laboratory and imaging tests, which include karyotyping and chromosomal analysis; evaluation of electrolytes, hormones, and steroids; imaging, including ultrasound and a genitogram, a form of x-ray examination that uses a dye to reveal the structure of internal genitals in an attempt to establish a diagnosis.

Before meeting with the family, clinicians described first meeting as a team to evaluate the test results, determine a diagnosis, and create unified recommendations for gender assignment and care. According to Dr. 21, a pediatric endocrinologist:

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[17] Most children with intersex traits are identified by the appearance of atypical external genitalia—what doctors refer to as "ambiguous genitalia"—shortly after birth. Others (approximately 10-20%) are identified in childhood or as young adults, such as after referral for absent, delayed, or incomplete puberty or amenorrhea, the absence of menstruation (Parisi et al. 2007; Romao et al. 2011; Creighton et al. 2014).

> We'd be talking as a group…our thoughts and our ideas and our plans through the group to make sure that we're not missing anything, and that everyone feels like we're making a good decision. So, I feel like we're pretty careful about that and I don't think any of us would be, you know, like some rogue person out there doing their own thing. So, we all want to be on the same page…speaking the same message. And, so we talk about [patients] and, you know, as the test results come back, what's the appropriate thing.

Providers told me that the team meeting was particularly important because it was held "backstage," without the presence of the patient or family, which enabled team members to "get on the same page" and define a plan for families. Clinicians described discussion-based meetings in which they integrated the patient's clinical findings with published research to determine their clinical recommendations. Dr. 20, a pediatric urologist, said:

> We have a "power conference" before we see the patient. The basic goal overall is to rate the results and what these things have shown—the various testing and what the next steps are. You know, the last thing you ever want to do is walk in there and have some distorted information communicated to the family…We find that the conference we have ahead of time is extremely important before we go see the family and set foot in there.

While convening about a case, clinicians I interviewed described reviewing the results, and emphasized how each team member offers their approach to care based on their own working knowledge. As one subspecialty cannot define the parameters for best care for the family and child, doctors determine a "common vision for success" (Sandberg and Mazur 2014: 97) by evaluating the test results with the knowledge of all specialists involved. Medical authority is diffused among the team members and then cohered into a unified consensus. Dr. 19, a psychiatrist, explained:

> We listen to each other. Each one of us presents a clinical picture based on what we see. You know, it may be the geneticist will say, "Well gee, I don't think genetically there's much for me to say here." Fine, then we go on. Then we hammer out a point, we argue points, and then we come up with ideas…We hammer out an approach…We present recommendations that each of us have or the biases that each of have.

These case conferences were particularly useful for the clinicians I interviewed, acting as what Gardner (2014) refers to as a "binding strategy" that coordinates activities and structures multidisciplinary decision-making. In addition, as a binding strategy, case conferences also helped to manage uncertainty and facilitate team synergy.

Team Challenges

Providers also highlighted the difficulty of establishing and working within MDTs. Dr. 6, a clinical psychologist, reflected on the lack of "equal footing" among team members.

> They say they have teams, but how well they [do] they function together…I think that's the real challenge. That's a real challenge of getting people together. Will they really work together and so everybody's on an equal par? There used to be…you know, this kind of "surgeon is king," you know? And that's hasn't changed a bit…Everybody has to be sort of on equal footing and I think that's a challenge. And having people understand their roles…So they can communicate and talk with one another.

In addition, some providers described a lack of institutional resources, such as adequately trained psychosocial professionals, cross-disciplinary relationships, and funding needed to implement integrated and comprehensive team-based care. Providers, particularly those practicing at medical centers holding a regular DSD clinic, frequently described challenges pertaining to costs and physician time. Dr. 20, a pediatric urologist, who helped spearhead the development of the DSD team and clinic at his institution, explained:

> You know, the problem, is it cost effective? Oh, heck no. You know, surgeons, if they were to have every single clinic like this, they'd be poor and unfortunately in today's world is one in which a lot of things are based upon costs and time. So, we—the group that takes care of these children—very honestly, without the proper support that we've been able to gather, would not be able to see them and maintain any sort of fiscal responsibility. So, that is the challenge that we have going down the line is how do we maintain support from the institutions to conduct something that is not really very honestly worthwhile to the practitioner seeing them? Also, understanding that a lot of the things that the families need, but [will] not necessarily be appropriately reimbursed by either their state insurance or their private insurance.

Dr. 20 alludes to the fact that not all services, such as psychological counseling, are adequately reimbursed by insurance. Moreover, what might be beneficial and/or efficient for a patient or family traveling in order to receive specialized care, may be, at the same time, inefficient for the physician's time. This is echoed by Dr. 5, a clinical psychologist:

> I think that we all kind of struggle with the new clinic and time and billing, and all of those things, unfortunately, play a role…I mean, our hospitals don't like multi-disciplinary clinics…I should say that. Our physicians like multi-disciplinary clinics. Our patients love the clinics because we're dealing with low-income. You know, getting here is hard and getting to see everybody at the same time is great. From a billing standpoint, we are actually a for-profit hospital. So, that's something that we run into. I mean, our urologist could generally see, you know, 20 kids in an afternoon, and now they're seeing four. I mean, it hasn't been enough for any of our physicians to say, "Well, I'm not doing it," but there's kind of always that pressure.

Some providers I interviewed also mentioned challenges in coordinating clinician schedules. In their multidisciplinary clinic, Dr. 17, a pediatric endocrinologist, described how his team overcame this challenge by scheduling their regular team meetings at 7:00am on Monday mornings, and requiring attendance at all clinic meetings. Finding a convenient time for consults or case conferences was difficult given the different responsibilities that each specialist may have.

The high degree of diagnostic uncertainty was also particularly challenging for providers that I interviewed. Dr. 20, a pediatric urologist, said:

> What's challenging for me is when we have no idea what we're dealing with. So, they're [the parents] just walking in and you feel like you look stupid to the family saying, "Well, this is what your child has and we really don't know what is means.

Establishing a diagnosis is important for determining an approach to care and available treatment options. Conditions associated with intersex traits are no different, but have the additional complexity that a decision for gender assignment is often contingent on this information. However, it is not always possible to determine a diagnosis. For children born with intersex traits and who have XY karyotype, only about 50% receive a diagnosis (Lee et al. 2006; Hughes 2015; Ahmed et al. 2016).[18] Such cases were often the most challenging for clinicians I spoke with, as they had little evidence on which to base their recommendations.

Dr. 17, a pediatric endocrinologist, said: The trouble is we don't usually have a diagnosis, so it's hard to assess what's the real risk of malignancy, what's the real chance of fertility, those are very difficult things to sort out. There's no good measure of gender identity in a baby. You just don't have it." For providers I interviewed, determining a diagnosis offered doctors a codified body of knowledge from which to work—however small—and for families it offered a label or explanation for an inherently disorderly experience. "Families really do want a diagnosis, and they don't like to be in limbo…they typically, I think, feel a sense of relief,

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[18] A diagnosis doesn't ensure certainty regarding a child's future gender identity. The rates of dissatisfaction with assigned gender and gender change varies dramatically by syndrome (Meyer-Bahlburg 2005; de Vries et al. 2007).

because they have an explanation" (Dr. 9, pediatric endocrinologist). Providers reported challenges to facilitating parental involvement, particularly in such cases with a high degree of medical uncertainty. Dr. 18, a pediatric endocrinologist said:

> In a lot of these patients, particularly the ones with 46 XY karyotypes, we don't ultimately get a diagnosis. I think with those families it's difficult because it's hard to counsel them about what to expect in the future in terms of fertility, gender identity, and all these things because we don't know what they have. I think those are the most challenging cases because I feel bad that I can't even really tell those families what to expect in the future and what to prepare themselves for.

Providers I spoke with also lamented the lack of quality of research evidence on which to guide their clinical recommendations. Many expressed concerns that this uncertainty threatened their therapeutic alliance with parents and they worried that it potentially diminished parents' trust in the team. Dr. 20, a pediatric urologist, said:

> It's hard for you to build a relationship with a family—whether they're going to have trust in you when your doctor is walking in saying, "Well, we don't know. This is what we think is going to happen. It's based upon this data, but I've got to be truthful. We don't know." So, we want to present it in that way and we want to allow [parents] to be involved in the decision-making process.

ENGAGING WITH FAMILIES

Building a Relationship, Managing Distress

The MDT plays an important role in building the relationship among the team members and family. The birth of a child with atypical sex anatomy is difficult for parents because they often known little about intersex, are unaware that sex can be undeterminable, and are distressed upon learning that their newborn's sex is not immediately clear (Karkazis 2008). During the neonatal period, the child often does not require immediate medical care, however, teams are focused on “getting the parents comfortable with the ambiguity for the initial period” (Dr. 3, pediatric urologist). Given a high degree of clinical uncertainty, many doctors I interviewed emphasized the importance for parents to participate in decisions. “We feel very strongly that it’s essential to engage parents in the decision making because, you know, you never know what the child’s ultimate decision regarding their gender identity will be” (Dr. 16, pediatric urologist). He elaborated further:

> It’s very humbling because you realize that you’re making your best decision—your best recommendations—but at the end of the day, there’s always an element of uncertainty as to what the child’s own gender identity is going to be. I think for that reason, it’s especially crucial to get the parents involved and for them to realize that this is not a decision we can be 100% certain about.

Initial interactions with the family are of particular importance for team doctors, according to my interviews, because parental distress can inhibit parents’ receptivity to medical advice as well as their participation in decision-making. Dr. 10, a clinical psychologist, explained (*emphasis mine*), “If I don’t have a relationship with them, one where they see me as trustworthy and somebody who is interested in their welfare, the welfare of their family, their child, nothing else, really, is heard in a *productive* way.”

For both physicians and families, intersex is associated with limited information and high stress (Karkazis 2008; Siminoff and Sandberg 2015). In my interviews, providers described working to establish a relationship with the family and to convey information in ways that aim to ease parental distress and foster trust in doctors and the team approach. Providers I interviewed frequently described the desperation and distress expressed by many parents after learning about their child’s atypical sex anatomy, and many clinicians found it challenging to manage parental distress. Dr. 18, a pediatric endocrinologist said:

> A lot of these families have been told prenatally that they're having a boy or a girl, and that's what they're expecting. Then, when the child is born and that's called into question, they're extremely distraught, as expected. I think when we talk to them in that initial period they're just in a state of shock. It's hard oftentimes for them to absorb much information.

Several doctors I interviewed recognized the distress and uncertainty that parents face after receiving a new diagnosis, and noted the potential benefits for families in having access to a MDT. The multiple specialists were viewed as additional sources of both information and support who could begin to address the family's various concerns and questions with team members. Dr. 10, a clinical psychologist said, "I see it as our team's responsibility to assess the family's understanding of their child's birth, what it means, and how they're doing with it." With parents' capacity and desire for information potentially impaired, medical provides sought to reassure parents and facilitate the doctor-patient relationship, which is integral to parents' engagement in decision-making.

Some clinicians I interviewed highlighted the importance of MDTs for involving both parents and other specialists from the start in order to provide information, build relationships, and set expectations. Dr. 18, a pediatric endocrinologist explained:

> Well, I think particularly for patients that are newly diagnosed, so like an infant with ambiguous genitalia, I think those families are very distressed. You know, they've just been told, it may be their primary care physicians or somebody in the NICU [neonatal intensive care unit], that somebody's concerned about ambiguous genitalia. And maybe there is a gender assignment, maybe there isn't. There's just a whole lot of issues and concerns. So, for those families particularly, I think it's very beneficial to come in and they meet with, at least, the urologist, an endocrinologist, and a mental health professional all in the same day. I think that helps them a lot because a lot of their questions get answered.

Dr. 7, another pediatric endocrinologist, explained that the role of the MDT was important in terms of providing both information and support.

> What we do is, we [the team] meet initially—and discuss, you know, learn about the baby biologically and what was the clinical course and what's happened. All of the available information is discussed, and then we talk about how to synthetize that and present it to the family. Then we either go to the bedside, a smaller core of us…or we invite them to a sit-down conference and let them hear the diagnosis and the available information. We give them a lot of support in terms of not making decisions right away and taking it all in and thinking about it.

Parents' ability to understand and make proxy decisions for their child may be diminished by fear, anxiety, and denial that can accompany this set of complicated and unfamiliar diagnoses (Wisniewski and Sandberg 2015). Intersex care entails complex decisions over time and can involve numerous medical professionals. Moreover, with multiple providers from different specialties involved in developing clinical recommendations, it can be difficult for distressed parents to clearly navigate information (Siminoff and Sandberg 2015).

Although it was clear from clinicians I spoke with that they typically shared the goal of open communication with parents, some clinicians did acknowledge the tension in providing enough information so that parents could make appropriate decisions, while also recognizing that in their role they have the ability to influence that decision. Dr. 17, a pediatric endocrinologist, describes some of these tensions:

> One [challenge] is making sure you've conveyed enough information to bring them along, to support them in a way that you're giving them support, information, and backup without giving undue influence to their decision. So, it's a little tricky, I think. When I first started out in medicine…I just lay out all the information and the people just decide. That's going to be easiest. But, these are difficult things, and they have their one child that they're faced with, and they've never had a DSD before…I've had three years of experience and seen hundreds. So, they want more than just a book…They want somebody to say, "Doctor, I came to you for your opinion about what to do. You can tell me all this stuff, but what do you think is best?" It's disingenuous not to at least deal with that a little bit. They don't have the same background.

He went on:

> So, if I'm really stuck in the middle, I say, 'I'm stuck in the middle.' Sometimes, I'll say, well, I've been here before many times, and people…They choose different ways. But, my experience in this situation that people chose this way seem to be happier. So, be supportive in a way that you should be really. I think that's the challenge. How much of your own view in a difficult case do you put in? And some people would say zero, but I don't think that.

Providers maintained an advisory role, in which they educate and inform the parents. However, doctors determine when and how this information is given based on their perceptions of whether parents can understand and handle the information. There is a notable tension among doctors who, on the one hand, want to help parents adjust to the situation, and on the other hand, want to avoid overloading them with information. Parents involvement, particularly in the early period, is contingent on the team's perceived receptivity of the family to the clinical information.

Some clinicians also noted that some parents prefer to have less involvement in decisions or prefer to look to doctors for their expertise and input, which could be uncomfortable for providers when the clinical evidence did not offer certain guidance on a recommended course of action. In such cases, their experience may be brought to bear. Notably, several psychologists I interviewed noted the risk of surgeons, in particular, having the ability to frame or influence decisions, such as those about whether to pursue early surgery, in the direction they see as appropriate. Dr. 10, a clinical psychologist said:

> If a surgeon comes into to the nursery and the child is born with ambiguous genitalia, examines the child then goes to the parents and sort of says what he saw and points out in what ways the genitalia are atypical all he or she has to do is say that they've seen this before and they can correct this. It's a done deal. Anything that follows is, this is going to sound a little bit crazy to many families; not to all families, because if you can fix it why wouldn't you?

Providers also acknowledged that parents' ability to participate varied often. Clinicians described in their interviews with me an acknowledgement of families' different educational backgrounds, perceived competencies, as well as cultural differences that may influence the extent of their participatory role as well as the decisions they may make. "When the family is uneducated and they don't have the capacity to participate in the decision-making process, I actually feel bad…and a lot of families are that way…you really wonder how much they're getting" (Dr. 20, pediatric urologist). Dr. 16, a pediatric urologist, said:

> We deal with parents of many cultures. There is a wide spectrum of reaction. Some parents are not so well educated and very upset about the whole thing, have a hard time handling it, may not be that verbal about it. Others are better educated, they've been on the web, they have a variety of concerns and so forth and may do better. We deal with cultures where there is great value placed on raising a child as male—if all things are equal.

Psychosocial Support

Many providers also reported to me that they offered potential support to help assimilate information in order to help engage parents. This involved engaging with psychosocial support staff, support groups, and sometimes connecting local families. In addition to providing psychological support by way of the behavioral health provider on the team, some providers I spoke with also put families in touch with each other to communicate and share information. This was emphasized by Dr. 4, a behavioral psychologist:

> Based on what I've observed in the families who I work with, I would say if a clinic can offer only one thing…They should make groups of families where they can get together and meet with each other and talk with each other because its inexpensive. It's easy to do. Then the families gain tremendously from it.

Many specialists acknowledged the value of support groups, and even maintained relationships with local or regional groups for their patient and family referrals. Teams offered families information on support groups, as one source of helping parents to cope with the situation. Dr. 16, a pediatric urologist, said:

> I think [support groups] serve a very important function. When you're trying to counsel families and help them understand that their child is not the only one out there with this disorder and that there are other kids that have grown up and done pretty well and so forth, these support groups are of great value.

Dr. 21, a pediatric endocrinologist, also found support groups beneficial, particularly as a source of information:

> I think [support groups] are a really good place for the families to go initially because generally the information is accurate and appropriate, and it gives them a little bit of community, which can be helpful. It's often they're not going to know anybody else who has the same issue.

The majority of providers I interviewed saw value in support groups, although some expressed uncertainty about the quality of information they provide, and that their value may depend on the needs of the family. Dr. 9, a pediatric endocrinologist, said, "I think one has to assess the strength of the individual family and their coping strategies, and figure it out on a case by case basis." A few clinicians I interviewed also expressed skepticism about the type and quality of information that may be provided to individuals and families. Perhaps in defense of her profession, which has come under strong criticism from advocacy groups after past treatments, Dr. 7, a pediatric endocrinologist, explained:

> The problem is that there is not very many support groups around, and some of them are very extreme. I don't know how to handle that…What I'm concerned about is, I want parents to feel comfortable and not be swayed into extremism…Either overly lulled into complacency or overly stimulated into extremism. I want them to have support no matter who they are.

The provision of psychosocial support was not always straightforward, as not all providers agreed on their potential value, and parents may have varying levels of acceptance of mental health support. Some clinicians I spoke with noted that some families may be less receptive or accepting of mental health support. Dr. 10, a clinical psychologist, described "the disadvantage of being a psychologist," which for some families may carry stigma. He elaborated:

> Here I am with the role of trying to help the family integrate what's happened, to normalize it, to help them see that others have gone forward, and that with the support they already have in their lives and with the support of our team, they have all that's necessary to move forward. It's sometimes difficult, in my experience, for families to look at the psychological or mental health professional as being the one to do that.

Similarly, pediatric urologist, Dr. 20, reported that families have "different levels of acceptance of mental health providers. A lot of families for various reasons, whether it be cultural or whatever, they're like "Are you kidding me? I'm not going to see a psychologist" …every family is different."

Overall, while the suggested provision of psychosocial support was understood by most providers as not necessarily appropriate for all parents, they did see value in support based on the evolving needs of the family. In general, supporting the family, whether through members of the MDT or external resources affirmed the importance of parents' coping and understanding of the situation.

Communicating and Sharing Information

Providers I interviewed often recognized the complexities and uncertainties related to what and how to communicate with families. They tailored how they presented recommendations to families in order to maintain the family's confidence in their care. Some providers struggled with wanting to share responsibility with families without giving the appearance of any incompetence that could threaten their therapeutic alliance. “There’s not a clear roadmap. We have discussions, but I think discussions can vary often…it’s very tricky. The last thing you want to do is undermine a family’s confidence in anyone caring for their child” (Dr. 10, behavioral psychologist).

Widely interpreted as an ideal of health communications, patient-centered care usually involves providing patients with information, engaging them in decision-making, attending to a range of biopsychosocial manifestations of illness and disease, and building a therapeutic alliance (Mead and Bower 2000). The hallmark of medical professionalism is the use of esoteric technical knowledge and information control as a means of preserving medical authority (Waitzkin 1991; Timmermans et al. 2018). Patient-centered communication aims to level the playing field by educating patients with sensitivity about their situation, even though patients’ explanatory models are often inconsistent (Kleinman 1988). Clinicians I interviewed believed that the use of particular communication strategies facilitated the doctor-patient relationship by assisting in managing parental concerns and uncertainty. These strategies helped to build confidence and trust in the team’s competence.

Clinicians I interviewed described several strategies they employed to educate families with sensitivity about their situation. In using these multiple communication strategies, they attempted to manage parental concerns and share information, reflecting elements of patient-centeredness as well as remaining in control. Providers described trying to help ease parents’ understanding and acceptance of the situation by presenting them with information in a compassionate and non-alarming way. During initial consultations and evaluations, clinicians I spoke with emphasized the importance of using gender-neutral language and modeled such communication while interacting with parents as well as other team members. Dr. 21, a pediatric endocrinologist, described:

> I try to be really careful with…the language that I use, and I really try to instruct the team about being careful about the language they use, particularly in terms of gender…I think you have to be very careful about how we refer to the patient or the baby…trying not to use pronouns and use, you know, really gender-neutral terms so that we can then try to figure things out.

The use of gender-neutral language avoids "planting the seed" (Dr. 1, pediatric urologist) about a particular gender assignment while the team conducts a battery of tests and exams. Clinicians also described using extra-medical information to learn about the patient and family, and to facilitate the doctor-family relationship. "You just have to take [families] one at a time. Just find out what their background is and decide what the family can deal with, how to present it to the family. I think ultimately we have the same goal" (Dr. 1, pediatric urologist).

Providers I spoke with often tailored their information and terminology to the perceived needs of the parents, often based upon perceived ability to understand or parents' current emotional status. Dr. 7, a pediatric endocrinologist, described tailoring her communications to ensure parental understanding:

> We get to know them better. We get to know their culture, their problems, their concerns, their level of education. Because of lot of what we tell them depends on their level or ability to understand. But we try to focus it and put it in terms that even anybody could understand. I mean, you'd be surprised, just anybody can understand things if you put them in the right terminology. And so, at that point, we might ask them how they're feeling, what kind of ideas do they have about what they want for their child, because they're the best advocates for their child.

Moreover, doctors convey information in ways that ensure their own role as "expert." In order to normalize information that is unfamiliar to many parents, clinicians I interviewed also described educating parents on typical fetal development, often using diagrams to illustrate the process of human development. Dr. 6, a clinical psychologist, explained how he educated parents soon after meeting with them:

> I see it this way; parents have waited nine months…They're waiting for a boy or a girl. So, when they hear that it can't be determined, they're totally like…they're in Finland. They're in the Land of the Midnight Sun. Everything is kind of topsy-turvy. So, I get in as soon as I can and then I start explaining to them about how, using diagrams about the external and internal sexual reproductive system, how that works, so it's not freakish…So, it's not so hard to then, if you show them diagrams, of why you couldn't determine if this should be announced as a boy or as a girl.

Educating parents on fetal development also normalizes information about the baby's body that parents may find distressing. Dr. 21, a pediatric endocrinologist, said, "I try to talk about what's going on…and the genitalia form like the heart forms, sometimes things don't form as they're supported so…there can be malformations." To normalize, or make less "freakish," and attempt to ease parental distress, clinicians described drawing attention to additional developmental characteristics, or what Dr. 7, a pediatric endocrinologist, referred to as "normal baby things:"

> What I have found most helpful, and most everybody follows this plan, is we just tell them step by step, because if you just keep them in the dark, if you're in the dark and then they're in the dark, it gives them a very uncomfortable feeling about "Well, what is going on and does the doctor really know what they're doing?" So, if you just take them through in a lay sense, explain it to them in their non-medical terms, you know, this is where we start from…And here's where we're going to first. You know, we're going to start with these chromosomes. We're going to look at the blueprints that God gave your child, or that are available, and put it in language that they feel comfortable with. Then, we'll get that back in three days. In the meantime, "Don't worry, let's look at all the other healthy aspects of the child." …Brain good, heart good, everything. And then we focus on normal baby things. Is the baby feeding well? You know, all this. And then we try to bring them up to date on what we know. I've gotten really good at drawing a lot of pictures, because some people are visual learners and some people are auditory learners, and I think a combination of both is good.

Some providers described ways of reassuring parents that their feelings are normal and acceptable, to emphasize that the child's condition is only one aspect of the child, and to emphasize positive aspects of the newborn child. The tactic of focusing on "normal baby things," averts parents' attention to other aspects of the child not associated with their genitals or sexually atypical traits. This helps reassure parents during an uncertain time, especially while waiting for test results.

Because clinicians I spoke with favored waiting until initial testing and information from evaluations was back and reviewed by the team—preferably backstage first, as previously noted—they often described controlling the access and flow of information. Dr. 5, a clinical psychologist, said:

> I explain, you know, what questions we have. I assure [families] that before they leave the hospital, we will have a recommendation for them about what sex we feel the baby was intended to be I actually act—in those cases—as the liaison between the family and the medical team…I'll say, "Okay, endocrine ordered these labs." Obviously, we'll get a karyotype too. You know, "These labs aren't back yet, or this is what we're looking for" without kind of leading them one direction or another.

Clinicians described giving information about the tests and what they were evaluating. Another clinical psychologist, Dr. 6, further described:

> We tell them, "We're not going to give you any test data until we get it all together." Because what we want to try to do, while that is anxiety provoking at some level, it keeps them from going on this roller coaster. You get one piece of information, "Oh, it's a boy." You get another piece of information that contradicts that, you know?

This was done to both minimize parental distress and also build trust in the team towards developing a unified approach. Moreover, as these quotes demonstrate, the psychologist, in their role as the liaison, often worked to limit this information while simultaneously trying to manage parental distress.

While waiting until a fuller picture was available after testing results were returned was most common, there was some variation regarding the optimal timing of information provision. Some providers reported early discussion of potential diagnoses and "bringing families along" as pieces of medical information came together. Like Dr. 17, a pediatric endocrinologist, some providers preferred to provide information in a more piecemeal fashion. He explained, "Generally, we try nowadays to be upfront and as pieces [of test results] come back, we tell them, and we tell them what we're thinking, and keep them on track…We try to bring them right along with us in terms of our thought processes." He went on, "If you spend time with the explanations, the circumstance, and give the reason for it, it's actually better for everybody." While some clinicians I interviewed described offering complex information to parents involving chromosomes, hormones, genitals, and gonads, others gave minimum information. Dr. 3, a pediatric urologist, said:

> I try to leave it as generic as possible. I don't put all the diagnoses on the table. I don't name of a lot of things, and speak in very broad terms…I try to put it in—how do I say this—very ambiguous terms, very general descriptive terms. If you give them a wave of specific possible diagnoses, they'll go on the Internet, see all the wrong things, and get attached to a specific diagnosis.

Many providers I spoke with acknowledged the complexity and sheer amount of information that parents are often faced with, and valued the MDT for the opportunity to convey information in varying ways multiple times. Pediatric urologist, Dr. 20, said:

> You only have a certain amount of time where the family understands what you're saying. I can go ahead and talk to them for half an hour and they may not hear anything more than the first give minutes, especially if I tell them something that is not what they want to hear. Even though there's things that I think I might have emphasized, they'll come back and it's clear they didn't hear what I was saying. So, the opportunity to repeat certain things and whether it comes from one specialist or another, and then at the end of the visit to put it all together and say, "Okay, this is what we're really thinking. This is what we need to do and these are the reasons why."

Through the team, and to help reiterate information and attend to parents' concerns, providers attempted to provide information that was slow, comprehensive, and typically repeated—"[I]t's educating parents over time and repeatedly" (Dr. 6, clinical psychologist)—as initial attempts at providing information may not be absorbed or remembered by parents who are coming to terms with the situation. The provision of information, across multiple interactions and multiple specialists, using both verbal and visual translations, helped to ensure that parents' emotions were addressed prior to making any decisions and also allowed providers to translate and tailor the information they provided to parents.This relational form of support—helping to translate, support, and reassure parents in the process—was recognized by providers as key to helping parents assimilate information and engage them in decisions. As in other contexts (Farnworth et al. 2008; Rapley 2008; Watson et al. 2008; Murtagh et al. 2012), parental involvement was a process and not an event.

CONCLUSION

The care for children born with intersex traits and their families presents particular challenges for providers. Patient centeredness is increasingly recognized as a prerequisite for quality health care (Zill et al. 2015), and the clinicians I interviewed described engaging in numerous efforts to provide patient-centered care, particularly through the coordination of MDTs and engagement with families. Current guidelines recommend MDTs and psychosocial and peer support as best practices (Lee et al. 2006; Lee et al. 2016). As with all treatment guidelines, however, there is no enforcement, and therefore no way to know the extent to which they are actually implemented. Further, in the case of intersex, the evidence upon which current recommendations are based is incomplete, and clinicians will adapt and supplement their practices based on their own views and experiences. Standardization, while appealing, is a contested solution to manage uncertain knowledge (Timmermans and Angell 2001).

Based on my research, it was clear that providers are more sensitive to the critiques raised by activists and have acknowledged changes in care since the published Consensus Statement. Most clinicians in my study distanced themselves from the paternalistic protocols associated with John Money in the 1950s, which emphasized early “normalizing” interventions. Compared to previous practices, most health care providers attempted to achieve patient-centeredness through their interprofessional practices as well as their doctor-parent communications. However, practices were not always straightforward and clinicians did encounter challenges both as part of MDTs and in working with parents, particularly in an area of uncertain medicine. Team-based coordination may be subject to institutional factors and limited resources, as well as the practices of individual physicians, their perceived roles, and interprofessional dynamics. The MDT provides an additional element of clinical support—and perhaps protection—for an uncertain area of medicine.

Based on my interviews, clinicians were attendant to *parent*-centered care and focused on sharing information and promoting their engagement in decisions. Patient centeredness depends then on *how* clinicians convey information to parents, and this chapter contributes to research demonstrating that communications during clinical encounters matters greatly (e.g., Timmermans et al. 2018). While doctors aim to engage families in their care, they faced additional challenges in working with different families, who may have different values and preferences. Clinicians I interviewed described several strategies through which they engaged families and attempted to convey information and promote their participation.

CHAPTER 5

CONCLUSIONS AND IMPLICATIONS

Intersex has been predominately framed as a medical issue, and until recently, clinical management of intersex has been firmly under the purview of biomedicine. However, over the last few decades, multiple actors, including clinicians, researchers, activists, intersex adults, and parents of intersex children, have engaged in debates over what intersex is and how—or whether—it should be medically treated at all. Although physiologically, intersex traits may manifest in diverse ways, intersex as a personal condition requiring intervention is not "natural" but a social construction (Holmes 2002; Karkazis 2008). In this dissertation, I demonstrated how these contestations about intersex are debates over who has the authority to classify and treat particular bodies and more broadly, the ways in which such debates raise questions about credibility afforded to embodied experiences.

With technological developments and advances in medical knowledge, intersex is increasingly examined and understood at a molecular level, which has led to more precise diagnostic categories and identification of more cases of intersex at birth. While some intersex actors and activists are directly opposed to medicalization, others seek collaboration with medical professionals, and are gaining a seat at the proverbial table with the aim of changing medical care. As a consequence of these medical innovations and increasing pressures from intersex activists and organizations, a group of international experts convened in Chicago in 2005 to evaluate clinical protocols and available medical evidence. Participants at this meeting developed new clinical recommendations, which were subsequently published in 2006 (Lee et al.

2006). In addition to new standards of care, the Statement also endorsed the new clinical terminology of “disorders of sex development” (DSD).

In this dissertation, I analyzed intersex medical management and DSD as a controversial diagnostic classification, which resulted of both technological developments and mobilization of new social groups who publicly challenged medical authority and treatment practices based on their own—often negative and traumatic—experiences. According to medical discourse, the DSD classification emphasizes genetic etiology, increases standardization and precision, and reduces confusion (Lee et al. 2006; Vilain et al. 2007). Outside medicine, however, lay challengers argue that DSD was an effort to reassert medical authority in light of the growing collective efforts of activists (Davis 2015). My research heeded calls in the sociology of diagnosis (e.g., Jutel 2011), to investigate how and why particular conditions are framed as they are. That is, I examined the social framing of intersex traits, and analyzed the layers of negotiation, compromise, and interests that shape notions of diagnosis, disease, and illness. Amidst a backdrop of evidence-based medicine, technological advances (e.g., genetics), and health social movements, my research demonstrates how understandings of and responses to intersex have changed since the Consensus Statement and as a result of DSD.

To conclude this dissertation, I review key findings from my research, and discuss their implications in light of their contributions to existing literature. Based on my research, as well as my own personal and professional interests, I also consider, briefly, some policy implications towards a larger goal of improving the well-being of intersex individuals and their families.

SITUATING KEY FINDINGS

In chapter two, I provided a historical analysis of the medical management of intersex. Using the innovative tools of situational analysis, particularly analytic mapping techniques, I traced this complicated and diverse history, highlighting the ways in which intersex has been understood and responded to over time. Understandings and responses to intersex bodies have changed a great deal since the nineteenth century as a result of factors both within and outside of medicine. In tracing this trajectory, I elucidated key elements of the situation, particularly the technologies, concepts, and conditions most consequential for contemporary practices, classifications, and clinical recommendations, particularly those outlined in the landmark 2006 Consensus Statement (Lee et al. 2006).

My analysis demonstrated the parallel rise of intersex medicalization and rise of scientific medicine. Ultimately, the consolidation of John Money's paradigm for treating intersex conditions was a consequence of multiple elements, including technologies, medical disciplines and its key actors, as well as professional and institutional dynamics. Over time, subsequent conditions within and outside of biomedicine, particularly intersex activism, contributed to changes in care, as represented by the Consensus Statement and the DSD model it endorsed.

Diverse actors and communities of practice have variously engaged in collaborative efforts to classify, (re)define, and standardize intersex health care. The trajectory of intersex medical management demonstrates the ways in which clinicians have attempted to stabilize uncertainties that have plagued this area of medicine. In turn, however, rather than resolving uncertainties, efforts at standardization and its related process of classification, have contributed to new sources of uncertainty. Moreover, as the contemporary terrain of DSD and current treatment practices have expanded, so too have the various interests and actors involved. While the elements of the debates have changed, what intersex is and how—or even if—it should be medically treated remains unresolved.

These findings contribute to the sociology of diagnosis and the (bio)medicalization literatures. In particular, this work demonstrates how diagnoses are "social." That is, diagnoses are made on the basis of available technology and current values, and are deeply connected to political, cultural, and/or social factors. The work of classifying atypically sexed bodies and making sex determinations are social framing devices. In this case, such classifications and determinations perform the work of making it appear that medicine defines the natural (or the natural body), yet hide the fact they are socially negotiated processes (Bowker and Star 1999; Jutel 2011). My research further extends a social diagnosis framework in showing the actors and elements that both *contribute to and resist* pathological framing of a condition.

Similarly, my analysis also provides evidence of the multiple actors involved in diagnosis, and the ways in which the actions of various groups affect the work of others (Brown et al. 2011). Further, although the definitions and tools afforded by scientific medicine enabled intersex medicalization, the transformation in the late twentieth century to the DSD model are indicative of biomedicalization (Clarke et al. 2003). This is demonstrated in the shifts to evidence-based medicine, patient rights and health social movements, and increasing emphasis on technoscientific practices, such as genetic diagnoses.

In chapter three, I examined key tensions and tactics of the intersex movement. Early intersex activism was aimed at antimedicalization, that is, in opposition to the medical model. However, as I illustrated, over time, the movement has evolved and is now comprised of actors and organizations with differing orientations to medicalization. That is, some actors and groups dvocate for medical reform—arguably, *different* medicalization—while others continue to focus efforts that are targeted at demedicalization.

Moreover, DSD remains a particular point of “intrasex” debates (Greenberg 2005), and my analysis demonstrated activists’ various positions pertaining to the updated terminology. Specifically, I illustrated how activists have partially accepted or rejected DSD and its implications for the strategies they employ in their collective efforts. Many intersex activists and organizations have strategically endorsed DSD in order to facilitate collaborative relationships with medical professionals and some parents.

Although intersex activism is characterized by overlapping organizational memberships and strategies, intersex activists are employing embodiment in their efforts to achieve both medical and social change. By making their experiences publicly visible, some activists have sought to promote a more positive definition and less pathologizing view of intersex and to facilitate greater tolerance for diverse embodiments. Others focus their efforts to improve the quality of care and clinical interactions. Further still, given the slow pace of medical change, activists have expanded their tactical repertoire and are exploring legal and human rights advocacy to pressure for medical change.

My analysis of activist debates over DSD suggest a form of embodied health movement (EHM) not typically addressed in the health social movement (HSM) literature (see also Burke 2011). Existing research on illness contestation are largely based on the conceptualization of contested illnesses as illnesses “that are either unexplained by current medical knowledge or have purported environmental explanations that are often disputed” (Brown et al. 2004: 52). This includes work on the HSMs of the environmental breast cancer movement and collective efforts around illnesses such as chronic fatigue syndrome, fibromyalgia, and multiple chemical sensitivity (Barker 2002; Brown et al. 2004; Murphy 2006; Klawiter 2008). These HSMs on contested illnesses focus on gaining recognition from medical professionals and scientific institutions in order to legitimate individuals' experiences of illness and to gain access to treatment, research funding, and other resources.

Debates over DSD, however, are contests over medical reform or demedicalization. Some actors accept and/or engage with DSD in order to collaborate with medicine or even access resources for their own care. Moreover, the relationship between medicine and the intersex movement is complicated in that DSD further suggests intra-movement debates over how to pursue the movement's broader goals of demedicalization. Thus, there is a tension between resistance to and reliance on medical discourse and practice (Burke 2011).

Scholarship on EHMs and contested illness emphasizes the positive potential of medicalization, in that efforts are focused on engaging or achieving medicalization in order to improve patient experiences or gain resources. However, research has illustrated the negative effects of medicalization, with critiques emphasizing the consequences of stigma and social control. In particular, these critiques are demonstrated in research on the medicalization of gender variance and intersex. Scholars have argued that diagnoses such as inversion, homosexuality, and hermaphroditism represent attempts to control individuals whose bodies or behaviors threaten gender and sexual norms as well as the sex/gender system itself (Hausman 1995; Dreger 1998b; Fausto-Sterling 2000; Meyerowitz 2002; Preves 2003; Matta 2005; Reis 2009). As my research shows, intersex activism and DSD is a case of activism in which actors seek diagnosis for its positive potential, for example, to communicate and collaborate with medical professionals, while at the same time also challenging DSD and intersex medicalization more broadly to avoid the negative effects of pathologization.

In chapter four, I examined some of the ways in which the new standards of care play out in practice, according to medical professionals who provide multidisciplinary team-based care. My analysis illustrated that multidisciplinary teams are one means through which medical professionals are engaging with patient-centered care in an effort to improve care and engage patients and families.

I found that professionals were sensitive to and reflected on the ways in which activism has impacted care as well as the ways in which their own practices have changed, particularly since the Consensus Statement. Most clinicians distanced themselves from the paternalism that so strongly characterized Money's traditional treatment paradigm. In line with broader trends in professional medicine towards patient-centered care and shared decision making (e.g., Charles et al. 1997, 1999; Mead and Bower 2000), I found that medical professionals engaged in interprofessional practices and communication strategies towards achieving these clinical aims.

In this chapter, I also demonstrated that medical professionals encountered challenges both in their work negotiating and coordinating teamwork as well as in their interactions with parents. Institutional factors and resources, and the practices of individual team members, their perceived professional roles, and team dynamics influence team coordination. Moreover, clinicians also navigated several challenges in engaging parents and sustaining the therapeutic alliance.

The multidisciplinary structure of the team, as recommended by the Consensus Statement (Lee et al. 2006), reflects a common belief that multidisciplinary teams can offer better health care for patients and families. According to medical professionals, their team-based practices have been influenced not only by activist challenges, but also by a broader trend in healthcare that promotes patient-centered care and patient participation in decision-making. This trend too, is not only encapsulated in the Consensus Statement, but also reflected in the ways in the medical professionals attempted to manage parental distress and to formally engage parents in communication and build a relationship.

Research suggests that since the Consensus Statement publication, there has not been a notable reduction in the number of genital surgeries on children with intersex conditions (Pasterski et al. 2010). In fact, work suggests the number of procedures may have actually increased (Creighton et al. 2014; Greenfield 2014). In light of this, my research lends evidence to the idea that patient-centeredness shapes “the conversation and not the outcome” (Timmermans et al. 2018: 532). Physicians, and now more so the team, maintain the role of expert in the clinical arena, but through patient centeredness, what has changed is *how* clinicians engage patients and families and the process of how decisions are made.

LIMITATIONS

This dissertation focused on intersex medical management in the U.S. context. All of the clinicians I interviewed were practicing in the U.S., and all activists and advocacy organizations were based in the U.S. Given differences in national health care systems, these findings may not be generalizable outside of the U.S. Future research should consider different national health care contexts to examine the ways in which practices may be comparable. Similarly, international activists and organizations can also be important data sources to examine, particularly given human rights advocacy and international legal developments.

My interviews with clinicians are evidence of what providers say they do in practice, and may not reflect their actual practices. Future research should consider observational methods to study the day-to-day practices of multidisciplinary teamwork processes. Similarly, as my work emphasized clinicians’ experiences and descriptions of their interactions with patients and families, additional work can also look to triangulate this with data from parents to further understand the ways in which they perceive interactions with their physicians and shared decision-making.

POLICY IMPLICATIONS

I am personally and professionally invested in improving the well-being of individuals with intersex traits, including ending harmful medical practices and ending stigma and shame associated with intersex. Like other intersex researchers (e.g., Davis 2015), my own research has led me to consider contributions for policy and social movement efforts. I discuss two such implications here.

First and foremost, medically unnecessary interventions, particularly surgeries, should not be pursued unless with the expressed consent of the intersex individual (and not parent by proxy, unless the situation is life-threatening). In 2020, two top pediatric academic hospitals in the U.S. publicly acknowledged the painful history of intersex medicalization and stated that, unless medically necessary, procedures such as clitoroplasty and vaginoplasty would not be performed until patients can participate meaningfully in the decision (Ann and Robert H. Lurie Children’s Hospital of Chicago 2020; Luthra 2020). Although the 2006 Consensus Statement and subsequent global update have expressed a more cautious approach to surgeries, research suggests that the practices continue, and may have increased (Pasterksi et al. 2010; Creighton et al. 2014; Greenfield 2014). Though not explicitly explored in analyses presented in this dissertation, my own interviews with clinicians also suggest that surgical practices continue. There are no national statistics or databases tracking intersex surgeries, but scholars have extensively documented the harms caused by these procedures, and the narratives of activists express similar sentiments (e.g., Dreger 1999; Chase 2003; Preves 2003; Karkazis 2008; Feder 2015).

Second, medical professionals should strive to engage in more productive collaboration with activists, intersex individuals, and their families. By this I mean truly sitting down "at the table" and listening to their concerns, their experiences, and their requests. I have no doubt that medical professionals want to help patients and families and do believe they are providing the most appropriate form of care. However, my research demonstrates that medical professionals continue to harbor skepticism pertaining to the value of lay, experiential knowledge. For example, medical professionals expressed concerns related to the value and involvement of social support groups. Further, my interviews with activists show that they make particular compromises in order to engage with medicine, but on medicine's terms. Medical professionals should take seriously the concerns of activists, patients, and families, with the shared goal of improving overall well-being for intersex patients and families. This includes collaborating not only through clinical interactions and decision-making, but also developing research directions and conducting studies, developing guidelines, and overall contributing to a broader conversation about how society understands and treats non-normative bodies.

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