

# OUT OF THE O.R. AND INTO THE STREETS: EXPLORING THE IMPACT OF INTERSEX MEDIA ACTIVISM<sup>† ‡ ‡‡</sup>

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## ABSTRACT

Babies are born intersexed, with ambiguous genitalia or other reproductive anatomical features, every day. Physical sexual ambiguity occurs frequently, affecting approximately one in 2000 births. Most infants born intersexed are surgically and hormonally altered to reflect the sexual anatomy associated with “standard” female or male sex assignment. This article explores the mobilization and methods of intersex individuals and their allies to destigmatize intersexuality and to alter the medical treatment they receive. I explore the intersex movement’s use of mass media as a strategic activist tool and the implications of this mobilization for cultural and medical reform, arguing that media attention to intersex medicalization has been instrumental in initiating clinical reform.

## INTRODUCTION

Every day babies are born with bodies that are deemed sexually ambiguous and with regularity they are surgically altered to reflect the sexual anatomy associated with “standard” female and male sex assignment. Recent estimates indicate that approximately one or two in every 2000 infants are born with anatomy that some people regard as sexually ambiguous; that is, they are born with

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ambiguous genitalia, sexual organs, or sex chromosomes.<sup>1</sup> To put these numbers in perspective, although its occurrence has only recently begun to be openly discussed, physical sexual ambiguity occurs about as often as the well-known conditions of cystic fibrosis and Down syndrome.<sup>2</sup> These statistics indicate that intersexuality is far more common than is publicly recognized.<sup>3</sup>

Due to the efforts of intersex activists, the frequency and medicalization of sexual ambiguity have recently become common topics of classroom and dinner table conversation. What it means to be intersexed is itself currently being redefined. Given the context of the social movements of the last 40 years it is not a surprise that many people recently began questioning the ethics and effectiveness of intersex medical sex assignment procedures.<sup>4</sup> Most of these critics agree that surgical sex assignment is not in the best interest of the intersexuals and that performing surgery without the patient's consent (meaning the child's consent, *not* the parents') is unethical. They argue that intersex ought to be demedicalized

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<sup>1</sup> M. Blackless et al., *How Sexually Dimorphic Are We?*, 12 AM. J. HUM. BIOLOGY 151 (2000).

<sup>2</sup> S.S. Desai, *Down Syndrome: A Review of the Literature*, 84 ORAL SURGERY, ORAL MEDICINE, ORAL PATHOLOGY, ORAL RADIOLOGY, & ENDODONTICS 279 (1997); A.D. DREGER, HERMAPHRODITES AND THE MEDICAL INVENTION OF SEX. (Harvard University Press 1998); H.E. Roberts et al., *Increased Frequency of Cystic Fibrosis Among Infants with Jejunoileal Atresia*, 78 AM. J. MED. GENETICS 446 (1998).

<sup>3</sup> Note that there are other intersex characteristics that go beyond genital ambiguity. In addition to the estimated one or two per 2000 children born with visible external genital ambiguity, nearly 2% of all children are born with chromosomal, gonadal, genital, or hormonal features that could be considered "intersexed"; that is, they are born with ambiguous genitalia, sexual organs, or sex chromosomes. Blackless et al., *supra* note 1.

<sup>4</sup> C. Chase, *Affronting Reason*, in LOOKING QUEER: BODY IMAGE AND GAY IDENTITY IN LESBIAN, BISEXUAL, GAY, AND TRANSGENDER COMMUNITIES 205 (D. Atkins ed., Harrington Park Press 1998) [hereinafter *Affronting Reason*]; C. Chase, *Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism*, 4 GLQ 189 (1998) [hereinafter *Mapping the Emergence*]; C. Chase, *Surgical Progress Is Not the Answer to Intersexuality*, 9 J. CLIN. ETHICS 385 (1998); C. Chase, *Rethinking Treatment for Ambiguous Genitalia*, 25 PEDIATRIC NURSING 451 (1999); C. Chase & M. Coventry eds., *Intersex Awakening*, 2 CHRYSALIS 1 (Fall-Winter 1997-1998); M. Diamond & K. Sigmundson, *Sex Reassignment at Birth: Long-Term Review and Clinical Implications*, 150 ARCH. PEDIATRIC & ADOLESCENT MED. 298 (Mar. 1997) [hereinafter *Sex Reassignment at Birth*]; M. Diamond & K. Sigmundson, *Management of Intersexuality: Guidelines for Dealing with Persons with Ambiguous Genitalia*, 151 ARCH. PEDIATRIC ADOLESCENT MED. 1046 (Oct. 1997); A.D. Dreger, *'Ambiguous Sex'—or Ambivalent Medicine? Ethical Issues in the Treatment of Intersexuality*, 28 HASTINGS CENTER REP. 24 (1998) [hereinafter *Ambiguous Sex*]; DREGER, *supra* note 2; A.D. Dreger, *A History of Intersexuality: From the Age of Gonads to the Age of Consent*, 9 J. CLIN. ETHICS 345 (1998); A. Fausto-Sterling, *The Five Sexes: Why Male and Female Are Not Enough*, 33 THE SCIENCES 20 (1993) [hereinafter *The Five Sexes*]; A. FAUSTO-STERLING, SEXING THE BODY: GENDER POLITICS AND THE CONSTRUCTION OF SEXUALITY (Basic Books 2000); K.I. Glassberg, Editorial, *Gender Assignment and the Pediatric Urologist*, 161 J. UROLOGY 1308 (Apr. 1999); S.A. Groveman, *The Hanukkah Bush: Ethical Implications in the Clinical Management of Intersex*, 9 J. CLIN. ETHICS 356 (1998); S.J. Kessler, *The Medical Construction of Gender: Case Management of Intersexed Infants*, 16 SIGNS 3 (1990); S.J. Kessler, *Meanings of Genital Variability*, 2 CHRYSALIS 33 (Fall-Winter 1997-1998); S.J. KESSLER, LESSONS FROM THE INTERSEXED (Rutgers University Press 1998); K. Kipnis & M. Diamond, *Pediatric Ethics and the Surgical Assignment of Sex*, 9 J. CLIN. ETHICS 398 (1998) [hereinafter *Pediatric Ethics*]; S.E. PREVES, INTERSEX AND IDENTITY: THE CONTESTED SELF (Rutgers University Press 2003); J.M. Schober, *Feminizing Genitoplasty for Intersex*, in PEDIATRIC SURGERY AND UROLOGY: LONG-TERM OUTCOMES 549 (M. D. Stringer et al. eds., W. B. Saunders 1998); B.E. Wilson & W.G. Reiner, *Management of Intersex: A Shifting Paradigm*, 9 J. CLIN. ETHICS 360 (1998).

because it is not in itself pathological. The critics claim, rather, that the pathology lies in the social system and its strict adherence to gender and sexual binarism.

This article explores how the very definition of what it means to be intersexed has transitioned from what was once considered an obscure and shameful medial condition to a recently politicized category of identity within the past 15 years. I outline the recent mobilization of North American intersexuals and their attempts to destigmatize physical sexual variation and to transform medical practice. I also consider the intersex movement's use of mass media as a tool to reframe medical and lay conceptions of hermaphroditism, and the explosion of medial coverage about intersex in recent years. Using frame analysis to understand the ways in which meanings about intersex are constructed, I examine the impact of the intersex rights movement on medial education and practice, scholarly research, and popular culture. This research is significant, as sociologists have yet to address the political and social psychological processes by which the intersex movement has established itself. Even though intersex activists have undergone a process of coming out and community empowerment that is similar to other stigmatized groups,<sup>5</sup> there is still much to be learned from the particular ways that these individuals and groups have begun to effect a broad cultural transformation of intersex treatment and identity.

### I. IDENTITY POLITICS

One strategy for coping with stigmatization is for marginalized individuals to embrace their difference and find ways to exploit it. Sometimes people do this by associating with groups that emphasize positive aspects of difference to develop pride in their marginal identities. According to Jones et al. "drawing attention to the mark [of stigma] may occasionally take the form of idealization ('Black is beautiful,' 'Gay is the way'), but more often than not, it serves as a rallying cry for self-protection and political action."<sup>6</sup> Examples of groups that highlight their differences in this way include Queer Nation, an activist group for gays and lesbians; CRIPS, an activist group for people with disabilities; Little People of America, an activist group for people of short stature; and the Intersex Society of North America's early activist branch, Hermaphrodites with Attitude. Other, less politically active groups still highlight their difference in the group's name, but serve a primary purpose of social support rather than political activism. Examples of these well-known groups include Alcoholics Anonymous, Weight Watchers, Gamblers Anonymous, and the less-known intersex Androgen Insensitivity Syndrome Support Groups.<sup>7</sup>

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<sup>5</sup> PREVES, *supra* note 4.

<sup>6</sup> E.E. JONES ET AL., *SOCIAL STIGMA: THE PSYCHOLOGY OF MARKED RELATIONSHIPS* 201 (W.H. Freeman 1984).

<sup>7</sup> Individuals with androgen insensitivity syndrome (AIS) have a male-typical 46, XY karyotype, but lack a key androgen (male hormone) receptor that incapacitates the ability, fetally and onward, to respond to the androgens produced in normal amounts. This results in a feminization of the external

Identity politics movements acknowledge the agency individuals and collectives have in constructing not only their identities but also in responding to and negotiating social expectations of who others think they ought to be. In the words of Alberto Melucci, “Social actors enter a conflict to affirm the identity that their opponent has denied them, to reappropriate something that belongs to them because they are able to recognize it as their own.”<sup>8</sup> This trend of identity reconstruction is evident among intersex individuals who have been mobilizing across North America over the past 15 years. Rather than passively accepting a socially stigmatized identity, intersexuals have demonstrated both the capacity to transform their own self-conceptions and the means to redefine how others see them as well.

The intersex movement is clearly indebted to the accomplishments of earlier activists, such as those in gay, lesbian, bisexual, and transgender (GLBT) movements, as well as the achievements of the civil rights, women’s health, and disability rights movements. The increasing visibility of GLBT-identified people, for example, has provided an expanded level of social tolerance for those with nonbinary genders and a plurality of sexualities, ultimately paving the way for intersex movement to take shape. On the whole, each of these newer movements is indebted to the ground gained by 1960s civil rights activists. In fact, the historic retaliation by GLBT bar patrons to the June 1969 police raid of New York City’s Stonewall Inn came just a few years after the U.S. Congress passed the Civil Rights Act (1964) and the Voting Rights Act (1965).<sup>9</sup>

In the 1970s and 1980s, gay, lesbian, and bisexual activists extended civil rights discourse to such a significant extent that “sexual orientation” became part of the expanding human rights cultural landscape. In the 1990s, building on GLB gains, transsexual and transgender activist pushed the rights discourse even further by calling for the inclusion of “differently gendered” persons and lives.<sup>10</sup> Rather than attempting to adapt and conform to normative expectations of gender and sexual expression, transactivists seek to normalize transgenderism. As is the case with other identity-based movements, by increasing their visibility transgender activist participate in “social movements which seek to alter the self-conceptions and societal conceptions of their participants.”<sup>11</sup> Another movement that is important to contemporary intersex activist is the women’s health movement, which helped to elucidate the sociopolitical construction of health and illness and

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genitalia and abdominal testicles. Most people with AIS are raised female; many go without ever knowing the reason they don’t menstruate or can’t get pregnant.

<sup>8</sup> A. Melucci, *The Process of Collective Identity*, in SOCIAL MOVEMENTS AND CULTURE 41, 48 (H. Johnston & B. Klandermans eds., University of Minnesota Press 1995).

<sup>9</sup> B.D. ADAM, *THE RISE OF A GAY AND LESBIAN MOVEMENT* (Twayne Publishers 1987).

<sup>10</sup> The term “transsexual” refers to a person who seeks or desires medical intervention to make their gender identity and physiological sex congruent, whereas the term “transgender” refers to someone whose gender identity and physiological sex are incongruent, but does not pursue or desire a physiological “sex change.”

<sup>11</sup> R.R. Anspach, *From Stigma to Identity Politics: Political Activism Among the Physically Disabled and Former Mental Patients*, 13A SOC. SCIENCE & MED. 765 (1979).

pave the way for subsequent patient advocacy including the articulation of intersex rights. The intersex movement has also benefited from the visibility and achievements of the disability rights movement, which forced the larger culture to recognize and accommodate the rights and needs of persons with disabilities through the implementation of policies such as the Americans with Disabilities Act.

In addition to the political gains outlined above, the hegemonic social order has been challenged by the increasingly frequent and positive representation of formerly disempowered, marginal groups in the mass media.<sup>12</sup> Such groups have turned to the oftentimes exhibitionist venues of television talk shows to publicize their personal issues.<sup>13</sup> In Josh Gamson's words, "In a society that has made television such an important arbiter of worth, and where power circulates in part through the televisual certification of political subjects, profiting from those of us starved for voice and affirmation is a cinch."<sup>14</sup> Indeed, "freaks" have used popular culture to "talk back" to the society that has so labeled them.

Popular medial coverage of the gay and lesbian movement took off once the activist groups became more political in their actions, for example following the Stonewall Riots and the Gay Activist Alliance implementation of the "zap"—a confrontational, nonviolent political tactic meant to draw attention to homophobia and increase gay civil rights through widely publicized events.<sup>15</sup> For example, during a 1969 mayoral campaign stop at Temple Torah in Queens, NY sponsored by the League of Women voters, mayoral candidate Mario Angelo Procaccino was selected as a zap target. Upon his entrance to the temple, gay activists shouted out, "It's 1776, Mr. Procaccino! The homosexual revolution has begun!" They quickly followed up their "welcome" call by asking a stunned Procaccino what he would do for New York gays and lesbians if here [sic] were to be elected mayor.<sup>16</sup> The nonviolent, highly visible technique of the "zap" has been widely adopted by other movements and has been effective in both building morale among movement members and raising awareness about the grievances and objectives of movement members. Such political action is evident among intersex activists as well.

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<sup>12</sup> S. CAPSUTO, *ALTERNATE CHANNELS: THE UNCENSORED STORY OF GAY AND LESBIAN IMAGES ON RADIO AND TELEVISION, 1930S TO THE PRESENT* (Ballantine Books 2000); J. GAMSON, *FREAKS TALK BACK: TABLOID TALK SHOWS AND SEXUAL NONCONFORMITY* (University of Chicago Press 1998) [hereinafter *FREAKS TALK BACK*]; L. GROSS, *UP FROM INVISIBILITY: LESBIANS, GAY MEN, AND THE MEDIA IN AMERICA* (Columbia University Press 2001).

<sup>13</sup> *FREAKS TALK BACK*, *supra* note 12.

<sup>14</sup> *Id.* at 224.

<sup>15</sup> GROSS, *supra* note 12.

<sup>16</sup> K. TOBIN & R. WICKER, *GAY CRUSADERS (HOMOSEXUALITY: LESBIANS AND GAY MEN IN SOCIETY, HISTORY AND LITERATURE)* (Arno Press 1975).

## II. USING FRAME ANALYSIS TO UNDERSTAND THE INTERSEX MOVEMENT

Social movements, such as the intersex rights movement, rely on members' mobilization, collective identification, and common grievances.<sup>17</sup> In order for collective action to be effective and meaningful to those engaged in it, groups must develop a common way of understanding their circumstances as well as their objectives for change. David Snow and Robert Benford discuss the useful concept of "collective action frames" to elucidate the social psychological process by which movement participants align their beliefs to make collective action possible and meaningful.<sup>18</sup> Take, for example, discussions at retreats of the Intersex Society of North America in the mid to late 1990s where attendees outlined their grievances with medical treatment and objectives for social change. William Gamson further elaborated on the concept, arguing that collective action frames are emergent, action-oriented "*injustice* frames" that are "necessarily adversarial" and must identify specific antagonists.<sup>19</sup> Certainly, for such a conceptual framework to lead to political action, a group must also develop its belief in the efficacy of collective action.

In the case of intersex, activists' grievances revolve around the cultural treatment of sexual ambiguity as a shameful medical emergency. The movement's primary adversaries are the medical doctors who perform genital "normalizing" surgeries and other procedures that mask physically benign intersex variation.<sup>20</sup> This target was easy to identify (and vilify) as the primary "injustice" identified by activists stems from medical treatment, information, and advice that is experienced as harmful, alienating, and shaming. Not all medical doctors have been identified as equal targets, as some serve as more visible proponents and spokespersons of intersex medical sex assignment than others. Indeed, as the intersex movement has gained ground, some doctors who were once advocates of surgical sex assignment have become allies of movement activists seeking medical reform. I explore key medical figures related to this movement in further detail below.

In an attempt to bridge structural and social psychological factors affecting social movement participation, Snow, Rochford, Worden and Benford<sup>21</sup> extended Goffman's<sup>22</sup> frame analytic theory in their development of frame alignment processes. Their contribution has had a lasting impact on social movement theory,

<sup>17</sup> B. KLANDERMANS, *THE SOCIAL PSYCHOLOGY OF PROTEST* (Blackwell Publishers 1997).

<sup>18</sup> D.A. SNOW & R.D. BENFORD, *Master Frames and Cycles of Protest*, in *FRONTIERS IN SOCIAL MOVEMENT THEORY* 133 (A.D. MORRIS & C.M. MUELLER eds., Yale University Press 1992).

<sup>19</sup> W.A. GAMSON, *The Social Psychology of Collective Action*, in *FRONTIERS IN SOCIAL MOVEMENT THEORY* 53, 68 (A.D. MORRIS & C.M. MUELLER eds., Yale University Press 1992) (emphasis in original).

<sup>20</sup> While my focus here is North American, and in particular on intersex in the United States, intersexuality is medicalized in much of the Western world. For a discussion of nonmedical, cross-cultural, and historical responses to intersex, see PREVES, *supra* note 4.

<sup>21</sup> D.A. SNOW et al., *Frame Alignment Processes, Micromobilization, and Movement Participation*, 51 *AMER. SOC. REV.* 464 (1986).

<sup>22</sup> E. GOFFMAN, *FRAME ANALYSIS: AN ESSAY ON THE ORGANIZATION OF EXPERIENCE* (Harper & Row 1974).

as discussion of alignment processes is frequently employed to elucidate the ways in which movement participants interpret and construct meaning, recruit new participants who may not yet belong to the movement, and garner attention from various sources to further their cause. I incorporate Snow et al.'s theory of frame alignment processes, highlighting the concepts of frame bridging, frame amplification, frame extension, and frame transformation, in my analysis of intersex activism. Allow me to briefly introduce these concepts here.

Snow et al. define frame alignment as the connection between an individual and a social movement organization's ways of viewing the world (e.g. their values and beliefs, goals, and ideologies).<sup>23</sup> They take the terms "frame" and "framework" from Goffman's definition of a frame as a "schemata of interpretation" that gives individuals the ability to attribute meaning to situations as they unfold. In Goffman's words, a frame allows individuals "to locate, perceive, identify, and label,"<sup>24</sup> thus providing people with a social psychological structure within which to understand everyday events. For intersex activists, articulating the meaning of the word "intersex" itself has been a process of establishing such a frame. Early on in the intersex movement, for example, participants found it necessary to specify who qualified for membership in "intersex only" space, such as in private intersex-only Internet chat rooms.

Frame bridging is "the linkage of two or more ideologically congruent but structurally unconnected frames regarding a particular issue or problem."<sup>25</sup> Such bridging can occur between two seemingly unrelated social movement organizations or between individuals who are connected in their outlook and experiences, but not networked with one another. These connections are made by making the issues visible and by educational outreach through various mediums, including websites, mailings, and media coverage. Intersex activists employ frame bridging at both the organizational level (by affiliating with other groups who have similar grievances, such as their GLBT-allies) and the individual level (by diffusing their grievances and objectives through relaying their personal stories in scholarly and popular media).

Frame amplification is "the clarification and invigoration of an interpretive frame that bears on a particular issue, problem or set of events."<sup>26</sup> Such amplification can include vilification and stereotyping of the movement's target, as in the intersex movement's early claim that all doctors abuse power.

Frame extension is the process whereby movement leaders connect their cause to "values and beliefs that may not be especially salient or readily apparent to potential constituents and supporters."<sup>27</sup> Such is the case in the intersex movement as activists have connected their goals to demedicalize intersex to broader concerns

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<sup>23</sup> Snow et al., *supra* note 21.

<sup>24</sup> GOFFMAN, *supra* note 22, at 21.

<sup>25</sup> Snow et al., *supra* note 21, at 467.

<sup>26</sup> *Id.* at 469.

<sup>27</sup> *Id.* at 472.

of human and children's rights, informed consent, and medical ethics. Gamson argues that frames are in competition with one another and that in order for one frame (or paradigm) to replace another, one frame must do a better job of getting its "interpretations to stick" than the other.<sup>28</sup>

Frame transformation occurs when "new values may have to be planted and nurtured, old meanings or understandings jettisoned, and erroneous beliefs or 'misframings' reframed<sup>29</sup> in order to garner support and secure participants."<sup>30</sup> That is, there are times in a movement's work when it needs to reconceptualize its identity and objectives. Such a transition is easily identifiable in the intersex movement, as activists have gone from railing against power within medicine to using it as a means to an end. More specifically, intersex activists have gone from picketing medical conferences to developing allied relationships with medical professionals to help them attain their goals of medical reform.

### III. THE SEXUAL POLITICS OF MEDICAL SEX ASSIGNMENT

There are numerous ways to respond to ambiguous genitalia, including not responding at all. Because sex, gender, and sexuality operate as inflexible and central organizing principles of daily existence, such indifference is rare to nonexistent. Instead, interference with sex and gender norms are cast as a major disturbance to social order, and people go to remarkable lengths to eradicate threats to the norm, even though they occur with great regularity.

While being born with indeterminate sexual organs indeed problematizes a binary understanding of sex and gender, there seems to be general consensus (even among the doctors performing the "normalizing" operations) that most children with ambiguous sexual anatomy do not require medical intervention for their physiological health.<sup>31</sup> Nevertheless, the majority of sexually ambiguous infants are medically assigned a definitive sex, often undergoing repeated genital surgeries and ongoing hormone treatments, to "correct" their variation from the norm.

For well over 50 years in the United States, doctors have framed intersex as a social emergency in need of immediate medical attention to mitigate the stigma that may be associated with being perceived as sexually "deviant." That is, medical treatments to surgically or hormonally alter intersexed children to appear genitally "normal" serve to erase or downplay what doctors perceive to be sexual abnormalities. Because of its association with "deviant" sexuality, medical doctors have also constructed intersex as a shameful condition, one many physicians claim

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<sup>28</sup> *The Social Psychology of Collective Action*, *supra* note 19, at 70.

<sup>29</sup> GOFFMAN, *supra* note 22, at 308.

<sup>30</sup> Snow et al., *supra* note 21, at 473.

<sup>31</sup> Intersex conditions rarely cause physiological problems. Such problems are most common in cases where eliminating bodily waste, such as urine and feces, is difficult because of internal physiological complications or, in rare cases of salt-wasting congenital adrenal hyperplasia, which is a condition where children have hyperactive adrenal glands and hormone therapy is required to regulate the body's endocrine system. *Management of Intersexuality*, *supra* note 4; *Ambiguous Sex*, *supra* note 4; LESSONS FROM THE INTERSEXED, *supra* note 4; Wilson & Reiner, *supra* note 4.

(despite a lack of documentation) that will result in feelings of suicidal despair. Doctors' and parents' expectations of heteronormativity clearly foster the medical "normalizing" approach. That is, newborns are completely oblivious to the rigid social conventions to which their families and caregivers adhere. Threats to the duality of sex and gender undermine inflexibly gendered occupational, education, and family structures, as well as the institution of heterosexuality itself. After all, if one's sex is in doubt, how would they identify their sexual orientation, given that heterosexuality, homosexuality, and even bisexuality are all based on a sexual binary? The medical construction of intersex as a shameful social emergency has recently begun to shift with the continued attempts at reframing intersex in a more positive and less pathological light brought about by intersex activists.

Medical discussions about intersex sex assignment revolve around infants' genitals, chromosomes, hormones, and gonads, with special emphasis given to the potential for the appearance of genital, gender, and heterosexual normalcy in adulthood. Although modern medical technology allows for the acquisition of chromosomal sex, contemporary sexing decisions ultimately revolve around the size and capacity of an infant's penis/clitoris, making such decisions not only heterosexist, but phallogocentric as well. As a result, the overwhelming majority of intersex children are sexed as female. In other words, if a child has a phallus deemed socially adequate as a penis, the child is given a male sex assignment. Conversely, if a child's phallus is deemed socially inadequate to be a penis, the child will be assigned as female, despite gonadal or chromosomal factors. Thus, a child's physical makeup may be male, but unless the medical team deems the infant's phallus to be of adequate size, capable of "proper" urination while standing, and likely to pass as [hetero]sexually "normal," the child will be surgically and hormonally constructed as female.<sup>32</sup> As some intersex specialists have been known to say, "You can make a hole [vagina] but you can't build a pole [penis]."<sup>33</sup>

Perpetuating treatments that seem to be both noneffective and disempowering raises ethical questions. Gecas notes that having a sense of autonomous control over one's own existence is crucial to the development of a positive and empowered self-concept.<sup>34</sup> As he writes, "It is the quality of the individual-environment interaction, primarily with regard to the opportunities it provides for engaging in efficacious action—that continues to be the major condition for self-efficacy throughout a person's life."<sup>35</sup> Why would there be reluctance to discontinue a course of treatment when there is reason to believe it is noneffective and even potentially harmful? Such resistance to clinical reform is evident in

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<sup>32</sup> P.K. Donohoe et al., *Clinical Management of Intersex Abnormalities*, 28 CURRENT PROBLEMS IN SURGERY 513 (1991); LESSONS FROM THE INTERSEXED, *supra* note 4.

<sup>33</sup> M. Hendricks, *Is It a Boy or a Girl?* JOHNS HOPKINS MAG. 10, 15 (Nov. 1993).

<sup>34</sup> V. Gecas, *The Social Psychology of Self-Efficacy*, 15 ANN. REV. SOC. 291 (1989); V. Gecas, *The Self-Concept as a Basis for a Theory of Motivation*, in THE SELF-SOCIETY DYNAMIC 171-185 (J.A. Howard & P.L. Callero eds., Cambridge University Press 1991).

<sup>35</sup> *The Social Psychology of Self-Efficacy*, *supra* note 34, at 300.

historical uses of non-esteem-building treatment, especially in the case of various aversion or “reparative” therapies for GLBT individuals whose families hope for their “heterosexual conversions” or “shifts.” According to Freire, people in positions of power, such as medical authorities, may disregard critiques and mobilization efforts of those they serve because supporting such action would only undermine their efforts to perpetuate and uphold the status quo.<sup>36</sup> As Kuhn and Freire demonstrate, paradigmatic shifts are hard won, especially when attempted by a disempowered or marginal population.<sup>37</sup> In order to effect social change, connections must be established between constituencies that formerly did not see eye to eye and were not allied with one another. Intersex activists have attempted such frame bridging in their outreach to various groups with which they may not intuitively be aligned, such as disability activists and scholars, transactivists, lawyers, and GLBT-identified medical personnel.

#### IV. THE INTERSEX SOCIAL MOVEMENT

In the early to mid-1990s a heated debate about the medical management of intersex developed between intersex activists, scholars, and clinicians all seemingly dedicated to the same goal: destigmatizing people who are born with sexual ambiguity. Primary points of contention between these groups are whether or not most interventions are medically necessary, or whether these procedures are primarily cosmetic and potentially psychologically and physiologically harmful. This debate is quite polarized. Many involved say there isn't sufficient evidence to warrant continued medical intervention. Others dismiss the critiques of intersex activists as representative of only an unhappy vocal minority.

A cornerstone of this debate is the popular attention many intersex groups and individuals have garnered by expressing their dissatisfaction with intersex medical intervention in such a way as to identify a unified injustice frame<sup>38</sup>

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<sup>36</sup> P. FREIRE, *PEDAGOGY OF THE OPPRESSED* (Continuum 1970).

<sup>37</sup> *Id.*; T.S. KUHN, *THE STRUCTURE OF SCIENTIFIC REVOLUTIONS* (University of Chicago Press 1962).

<sup>38</sup> M. Beck, *Hermaphrodites with Attitude Take To the Streets*, 2 *CHRYSALIS* 45 (Fall-Winter 1997-1998); *Affronting Reason*, *supra* note 4; *Mapping the Emergence*, *supra* note 4; *Surgical Progress*, *supra* note 4; *Rethinking Treatment*, *supra* note 4; .M. Coventry, *Finding the Words*, 2 *CHRYSALIS*, 27 (Fall-Winter 1997-1998); Derick, *In Progress*, 2 *Chrysalis* 51 (1997-1998); Groveman, *supra* note 4; M.M. Holmes, *Medical Politics and Cultural Imperatives: Intersexual Identities Beyond Pathology and Erasure* (1994) (unpublished Master's Thesis, York University) (on file with author); M.M. Holmes, *Queer Cut Bodies: Intersexuality and Homophobia in Medical Practice*, Paper Presented at the Fifth Annual National Lesbian, Gay and Bisexual Graduate Student Queer Frontiers Conference (Mar. 23-26, 1995), University of Southern California, *available at* <http://www.usc.edu/isd/archives/queerfrontiers/queer/papers/holmes.long.html>; M.M. Holmes, *Is Growing Up in Silence Better Than Growing Up Different?*, 2 *CHRYSALIS* 7 (Fall-Winter 1997-1998); R. Kaldera, *Agdistis' Children: Living Bi-Gendered in a Single-Gendered World*, in *LOOKING QUEER: BODY IMAGE AND GAY IDENTITY IN LESBIAN, BISEXUAL, GAY, AND TRANSGENDER COMMUNITIES* 227 (D. Atkins ed., Harrington Park Press 1998); B.D. Kemp et al., *Sex, Lies and Androgen Insensitivity Syndrome*, 154 *CAN. MED. ASSOC. J.* 1829 (1996); J. McClintock, *Growing Up in the Surgical Maelstrom*, 2 *CHRYSALIS* 53 (Fall-Winter 1997-1998); A. Moreno, *In Amerika They Call Us Hermaphrodites*, in *INTERSEX IN THE AGE OF ETHICS* 137 (A. D. Dreger ed., University Publishing Group 1999); A. Moreno & J. Goodwin, *Am I a Woman or a Man?*, *MADemoiselle*, Mar. 1998, at 178;

These activists articulate their grievances as follows: (1) the majority of medical interventions, from a strictly physiological point of view, are not necessary for survival; (2) as a result of medical intervention, both sexual and psychological satisfaction and functioning are often impaired; and (3) for intersex individuals the lack of open discussion of their intersex status results in feelings of shame and isolation. This critique is evident in intersexuals' personal stories, many of which have been featured in popular and scholarly publications. For example, in intersex activist Howard Devore's experience: "My childhood was filled with pain, surgery, skin grafts, and isolation. I remember that when school vacation came, the other kids went somewhere fun. I went to the hospital."<sup>39</sup> And in the words of intersex activist Angela Moreno, "I am horrified by what has been done to me and by the conspiracy of silence and lies. I am filled with grief and rage, but also relief finally to believe that maybe I am not the only one."<sup>40</sup>

Despite the medical aim to surgically erase or downplay sexual ambiguity, many intersexuals are finding each other through their own activism and are attempting to reframe their difference as a source of pride. In fact, in recent years intersexuals have been implementing their own networks of support and avenues for social change at a rapid pace.

As is true with other contemporary social movements, the intersex movement has used electronic media and communications, including the Internet and electronic mail, as a primary means of participant recruitment and networking.<sup>41</sup> The use of the Internet as a primary means of contact, education, and support has afforded the development of a geographically diverse advocacy movement. According to intersex activist and scholar Cheryl Chase,

The growth of the Internet has been a great boon for us. We have been able to leverage our computer skills into high visibility, making it very easy for intersexuals, parents, journalism, and professionals to find us. This visibility amplifies the impact each time major media covers us . . . . It is not an overstatement to say that without the Internet, it would have taken decades to get where we are now.<sup>42</sup>

Internet technology, with its relative accessibility, has given former patients and family members an opportunity to discuss intersex beyond the clinic, in their own homes and virtual communities. For successful mobilization of disparate individuals, such communication networks are essential. Many individuals and

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S. Nicholson, *Take charge! A Guide to Home Catheterization*, 2 CHRYSLIS 39 (Fall-Winter 1997-1998); K. Triea, *As a Former Intersexed Patient, Letter to the Editor*, TIME, Apr. 14, 1997, at 19; K. Triea, *Power, Orgasm and the Psychohormonal Research Unit*, 2 CHRYSLIS 23 (Fall-Winter 1997-1998); H. Walcutt, *Time For a Change*, 2 CHRYSLIS 25 (Fall-Winter 1997-1998).

<sup>39</sup> H. Devore, *Growing Up in the Surgical Maelstrom*, in INTERSEX IN THE AGE OF ETHICS 78, 80 (A.D. Dreger ed., University Publishing Group 1999).

<sup>40</sup> Moreno, *supra* note 38, at 139.

<sup>41</sup> Snow et al., *supra* note 21; S.S. Turner, *Intersex Identities: Locating New Intersections of Sex and Gender*, 13 GENDER & SOC'Y 457 (1999).

<sup>42</sup> C. Chase, *Making Media: An Intersex Perspective*, IMAGES, 22, 23 (Fall 1997) [hereinafter *Making Media*].

families have developed their own web sites that are linked to a larger support group's site, in order to tell their stories and connect with other people and families who are also connected to intersex. Given the silence and secrecy surrounding intersex, the Internet has been especially important for people to seek out others in a relatively anonymous forum.

#### V. EMERGENCE OF A KEY ADVOCACY GROUP: THE INTERSEX SOCIETY OF NORTH AMERICA

For the purposes of this article, I focus on one organization in particular, the Intersex Society of North America (ISNA), because it is the most active and visible group with regard to intersex advocacy and media action; indeed, it has become the movement's most well known representative. In addition to exploring the activism of the Intersex Society, I focus on the work of one key figure within the organization: ISNA's founding director, Cheryl Chase. As evidence of their significance, consider that ISNA and Chase had acquired so much media attention by 1998 that Chase was voted one of the one 100 "most interesting and influential gay men and lesbians in America" in *Out Magazine's* top 100 people of the year.<sup>43</sup>

In addition to ISNA, a significant number of intersex support and advocacy groups formed throughout North America between 1987 and 2003. I summarize these organizations in Table 1.

Beyond the groups I outline in Table 1, there are many others around the world developing at a rapid pace, especially with the use of Internet and electronic technology including websites, listservs, and chat groups.

I have been following the intersex movement and debates about medical sex assignment since they first emerged in the early 1990s. In the late 1990s, I spent two years interviewing adult intersexuals about their experiences with medical assignment and their overall quality of life. In April 2003, for the purpose of collecting data for this article, I spent several days at the Intersex Society's office in Seattle combing through their archives. The objective of this trip was to gain a better understanding of ISNA's history, activism, and media coverage. What follows is a brief account of the organization and an analysis of their political action.

Cheryl Chase founded the Intersex Society of North America in 1993 by publishing a letter to the editor in the July/August issue of the New York Academy of Sciences' journal, *The Sciences*.<sup>44</sup> Chase wrote this letter in response to biologist Anne Fausto-Sterling's article "The Five Sexes," which appeared in the March/April issue of the journal that same year.<sup>45</sup> In her letter, Chase critiqued intersex medical sex assignment as "immensely destructive" raising concerns about

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<sup>43</sup> *The Out*, OUT MAG., Dec.-Jan. 1998, at 100.

<sup>44</sup> C. Chase, *Intersexual Rights, Letter to the Editor*, 34 THE SCIENCES 3 (July-Aug. 1993).

<sup>45</sup> *The Five Sexes*, *supra* note 4.

TABLE 1. An Overview of Intersex Support and Advocacy Organizations in North America<sup>46</sup>

Organization	Year Formed	Mission	Population Served	Medium of Service
Turner's Syndrome Society <sup>47</sup>	1987	Medical information clearing-house and support	People with Turner's Syndrome	Website: <a href="http://www.turner-syndrome-us.org">www.turner-syndrome-us.org</a> & newsletter
Androgen Insensitivity Syndrome Support Groups K.S. & Associates	1988	Support and education	People with AIS and their family members	Website: <a href="http://www.aissg.org">www.aissg.org</a> newsletter, and annual conferences
	1989	Support and education	Families affected by Klinefelter's Syndrome <sup>48</sup>	Website: <a href="http://www.genetic.org/ks">www.genetic.org/ks</a>
Intersex Society of North America	1993	Medical reform and cultural change to destigmatize intersex	People who are intersexed, their family members, scholars, doctors, news media	Website: <a href="http://www.isna.org">www.isna.org</a> newsletter, demonstrations, films, lectures, outreach
Ambiguous Genitalia Support Network <sup>49 50</sup>	1995	Support for parents of intersex children	Parents of intersex children	Pen-pal relationships
Hermaphrodite Education and Listening Post	1996	Peer support and education	Intersex people and their family members	Website: <a href="http://www.jax-inter.net/~help/">www.jax-inter.net/~help/</a>
Intersex Support Group International	1998	Christian-based intersex support	Intersex people, parents of intersex children, medical personnel & scholars	Website: <a href="http://www.isgi.org">www.isgi.org</a>
Intersex Initiative Portland	2000	End medical abuse of intersex children	Intersex people and their family members	Website: <a href="http://www.ipdx.org">www.ipdx.org</a> & speakers' bureau
Bodies Like Ours	2002	Non-condition specific education, outreach & peer support		Website: <a href="http://www.bodieslikeours.org">www.bodieslikeours.org</a>

<sup>46</sup> Cheryl Chase's article, *Mapping the Emergence*, *supra* note 4, was an invaluable source in constructing this historical overview of intersex organizations.

<sup>47</sup> Turner's Syndrome is a common form of chromosomal variation where the typical karyotype is 45,XO, meaning that one of the "X" sex chromosomes is missing.

<sup>48</sup> Klinefelter's Syndrome is a type of chromosomal variation in which a "male" child has a karyotype with more than one X chromosome, such as 47, XXY (or 48, XXYY, 48, XXXY, or 49, XXXXY).

<sup>49</sup> Individuals with androgen insensitivity syndrome (AIS) have a male-typical 46, XY karyotype, but lack a key androgen (male hormone) receptor that incapacitates the ability, fetally and onward, to respond to the androgens produced in normal amounts. This results in a feminization of the external genitalia and abdominal testicles. Most people with AIS are raised female; many go without ever knowing the reason they don't menstruate or can't get pregnant.

<sup>50</sup> The first AIS support group was founded the UK. At the time of this writing, the group has chapters in 17 countries, nine of which were formed since 2000. In addition to groups in the United Kingdom, the United States, and Canada, there are active AIS support groups in India, Poland, New Zealand, Sweden, Greece, Italy, the Netherlands, Norway, France, Spain, Switzerland, South Africa, Germany, and Australia, and a widely distributed newsletter called ALIAS. Personal communication; ALIAS, The Biannual Newsletter of the Androgen Insensitivity Syndrome Support Group, *available at* <http://lwww.medhelp.org/ww/ais> (last visited Feb. 15, 2004).

the ethics and effectiveness of phallocentric surgical procedures that impair sexual and psychological function. In doing so, Chase paired this intersex injustice frame with ISNA's very inception. In the last line of her letter, Chase announced the formation of a support group for intersexuals called the Intersex Society of North America. At the time she wrote the letter, the Intersex Society didn't yet exist. In actuality, the organization was formed by Chase's publication of this letter to the editor. In the signature line, Chase listed a mailing address for ISNA and she soon began receiving mail from other intersexuals throughout the world.

In the winter of 1994-1995, less than 18 months after Chase published her letter to the editor, the Intersex Society published the first issue of its newsletter, *Hermaphrodites with Attitude*, with the claim of being, "The world's only newsletter by and for intersexuals."<sup>51</sup> By the time they published the newsletter's first issue, ISNA had established a mailing list that included recipients in 14 of the United States and five countries.<sup>52</sup> The newsletter's title aptly reflects the political content of the publication, as well as the organization's intent to reconceptualize the word "hermaphrodite," transforming it from a term of shame to one of empowerment. For years intersexuals had learned from their doctors and families that intersex was something to be ashamed of—a dirty secret to hide. Through the newsletter's title, they encountered a competing frame that presented intersex as a source of pride. Chase wrote of her monumental decision to reconstruct the term "hermaphrodite" in the newsletter's opening column:

Why "Hermaphrodites with Attitudes,"<sup>53</sup> you may ask. 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. In fact, by their own admission, plastic surgery on intersexual infants' genitals is a form of psychosurgery. I believe that 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.<sup>54</sup>

ISNA's reappropriation of the term "hermaphrodite" as a positive form of self-identification is reminiscent of similar tactics used by gay, lesbian, and AIDS organizations in previous years and the widespread destigmatization of homosexuality.<sup>55</sup> For example, in 1990, ACT UP (The AIDS Coalition to Unleash Power) began using the word "queer" to identify its members, after decades of gays and lesbians roundly denouncing the term. Following their lead, in 1990 a new

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<sup>51</sup> Intersex Society of North America, HERMAPHRODITES WITH ATTITUDE 6 (Winter 1994-1995), at [www.isnaorg/newsletter](http://www.isnaorg/newsletter) (last visited Feb. 15, 2004).

<sup>52</sup> *Id.* at 1.

<sup>53</sup> The first issue of the ISNA newsletter was called HERMAPHRODITES WITH ATTITUDES. All subsequent publications of the newsletter used the title HERMAPHRODITES WITH ATTITUDE.

<sup>54</sup> *Id.* at 1.

<sup>55</sup> GROSS, *supra* note 12.

political action organization named their group Queer Nation and introduced the slogan “We’re here, we’re queer, get used to it.”<sup>56</sup> The 1990s and 2000s have been a time of widespread cultural reframing of queer identity as positive, and the term “queer” has been adopted by scholars (for example, with the development of queer theory) and popular culture at large (for example, with the new Bravo cable show *Queer Eye for the Straight Guy*). Similarly, ISNA has extended its reappropriation of the term “hermaphrodite” and the phrase “hermaphrodites with attitude” beyond its newsletter title through an intentional process of frame amplification. Take for example ISNA’s T-shirts, which have the slogan “I’m an Hermaphrodite with Attitude”; financial donor status: give a certain amount of money and ISNA once dubbed you “A hermaphrodite with major attitude”; and activism: when ISNA members have called their political action group “Hermaphrodites with Attitude.”

One of Chase’s primary objectives in establishing ISNA was to document intersex people’s experiences to further amplify the injustice frame she established in her letter to the editor in *The Sciences*.<sup>57</sup> Fittingly, the early issues of the *Hermaphrodites with Attitude* newsletter consisted primarily of personal stories, essays, and poetry. These personal contributions provided formerly isolated individuals with the means to develop political consciousness and frame resonance about their personal experiences by connecting them to the experiences of others like themselves.<sup>58</sup> The newsletter quickly extended beyond its role of providing support to formerly isolated intersexuals by becoming a source of activism and frame bridging in its own right when Chase and others began distributing the newsletter to journalists, scholars, civil rights organizers, medical doctors and others who could draw attention to ISNA’s grievances and their mission to effect clinical change.

*Hermaphrodites with Attitude* was published on a fairly regular basis from 1994 to 1999. (After the first year of quarterly issues, the newsletter moved to an annual publication schedule.) In addition to its newsletter, ISNA has provided other resources over the years to intersexuals and the public at large such as the former bimonthly support groups, which started in January 1995, a popular Internet website that went online in January 1996, and the once-held annual retreats that began in September 1996.

More recently, ISNA retooled itself to put forth a more professional image. This frame transformation is apparent in the organization’s new newsletter format, *ISNA News*, introduced in February 2001. In addition to the newsletter’s change in title, *ISNA News* moved away from the personal stories and humor that were commonplace in *Hermaphrodites with Attitude* to amplify its reporting of

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<sup>56</sup> CAPSUTO, *supra* note 12.

<sup>57</sup> *Intersexual Rights*, *supra* note 44.

<sup>58</sup> D.A. Snow & R.D. Benford, *Ideology, Frame Resonance, and Participant Mobilization*, 1 INT’L SOC. MOVEMENT RES. 197 (1988); V. Taylor & N. Whittier, *Collective Identity in Social Movement Communities: Lesbian Feminist Mobilization*, in FRONTIERS IN SOCIAL MOVEMENT THEORY 104 (A.D. Morris & C.M. Mueller eds., Yale University Press 1992).

professional and organizational concerns such as financial reports, profiles of board members, and the continued coverage of medical conferences and research. The Intersex Society's shift in newsletter format mirrors the overarching frame realignment that has taken place within the movement, as activists and doctors have begun working alongside one another for change, rather than against each other as political adversaries. This frame transformation from ISNA being associated with an injustice frame characterized by personal medical trauma was made even more complete when Cheryl Chase stepped down as the executive director and a nonintersexed medical sociologist, Monica Casper, took the helm in January 2003. Under Casper's leadership, ISNA extended its frame to utilize Casper's networks in disability studies, and children's and women's rights arenas. After a year of service, Casper decided to step down as ISNA's executive director, effective January 2004. In a surprising turn of events, Cheryl Chase stepped back in at the beginning of 2004 to serve as ISNA's executive director once again. It is unclear at the time of this writing as to whether or not Chase's reprised role as ISNA's executive director will be to merely bridge a gap between the service of others, or if she is back as the director for the long term.

ISNA's mission is to destigmatize intersexuality and stop unnecessary surgery on intersexed children. They articulate their mission further on their website's home page as follows:

The Intersex Society of North America (ISNA) is devoted to systemic change to end shame, secrecy, and unwanted genital surgeries for people born with an anatomy that someone decided is not standard for male or female. We urge physicians to use a model of care that is patient centered rather than concealment-centered.<sup>59</sup>

The ISNA has grown tremendously since its formation in 1993. It now has a mailing list of 3,500 people and more than 1000 donors.

## VI. FRAMING IDENTITY: TENSIONS WITHIN THE INTERSEX MOVEMENT

As is true with other social movements, there is a diversity of groups within the intersex movement and not all agree on the goals or methods of making change. In fact, there has been considerable tension between intersex activists about the objectives and tactics of the movement, including how best to frame intersex to be most attractive to potential movement recruits and supporters. As the number of intersex groups, voices, and opinions proliferated, struggles over the methods and very purpose 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. Such tensions are a predictable element of frame alignment processes, indeed because individuals and groups bring competing ideologies to their interactions with one another. As William Gamson says, "On most political

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<sup>59</sup> Intersex Society of North America, *What is ISNA?*, at <http://www.isna.org/> (last visited Feb. 15, 2004).

issues, there are competing interpretations, ways of framing information and facts in alternative ways. Indeed, one can view social movement actors as engaged in a symbolic contest over which meaning will prevail.<sup>60</sup>

Clearly, all of the intersex groups work toward destigmatizing intersex; however, some do this through peer support while others work toward achieving systemic social change and changes in medical education and practice. In fact, what began as a peer support movement in the late 1980s has more recently developed into an advocacy movement focused on medical, political, and cultural transformation. As the reader can see from Table 1, most intersex organizations are support-focused and several provide condition-specific support (e.g. the Turner's Syndrome society).<sup>61</sup> Indeed, of the nine groups listed in the table, only two stand apart as advocacy, rather than support, organizations: ISNA and Intersex Initiative Portland. It was ISNA's shift away from peer support and toward political action that caused the first divide among intersex groups. This is where the story of intersex activism (and media activism in particular) becomes a story about ISNA, rather than the larger intersex movement.

The second, longer lasting split occurred as ISNA continued to associate intersex with gay, lesbian, bisexual, and transgender issues. Given that fear of sexual difference seems to drive medical sex assignment, this conflict should come as no surprise. Some of the support groups have intentionally aligned themselves with GLBT allies. Other groups, especially those run by parents of intersex children, have expressed their reticence to associate intersex with GLBT persons and concerns. In fact, in speaking with parents of intersex children, I have encountered parents' explicit efforts to sever associations between intersex and GLBT issues. Despite this clear divide among interested parties, the Intersex Society of North America has made deliberate appeals to queer activists, press outlets, and medical organizations, framing intersex as an issue of gender and sexuality from its inception in 1993. ISNA's decision to do so has no doubt increased its linkages to GLBT persons and groups, but at the same time alienated itself from the potential support of others who disagree with the organization's framing of intersex in this way.

In its infancy, ISNA's mission was divided between providing peer support to its members and its objective of medical reform. While other intersex groups chose to address the mission of providing support, ISNA ultimately decided to pursue advocacy and social change. Their political action, which I detail below, alienated them from other activists and groups that were far less political. In fact, while I was conducting interviews with members of various intersex support groups in the late 1990s, several interviewees frequently identified themselves as non-ISNA members with a sentiment of, "You know I'm not part of that radical lobbying group, right?" More recently, when I was asked to speak about my

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<sup>60</sup> *The Social Psychology of Collective Action*, *supra* note 19, at 67.

<sup>61</sup> Turner's Syndrome is a common form of chromosomal variation where the typical karyotype is 45,XO, meaning that one of the "X" sex chromosomes is missing.

research at an intersex support group's annual conference, I was given a list of issues to avoid, lest I present intersex as too political or too "queer" (read: "too ISNA") and end up alienating potential recruits of the group or their family members. Thus, even when activists disagree with ISNA's position, the organization maintains its central role in defining the intersex movement and its activities.

Consider the intersex groups that have formed more recently, such as Intersex Initiative Portland and Bodies Like Ours, both of which emerged in direct response to services their leaders perceived to be lacking in the work of the Intersex Society of North America. Intersex Initiative's founding director, Emi Koyama, used to be an intern and staff member at ISNA. Because of her experience working for ISNA, she saw a need to develop another intersex political action group that had the willingness to confront medical doctors the way ISNA once did, before its recent collaborative, and more palatable, approach to medicine. Her decision to form Intersex Initiative is an example of a movement participant's negative response to ISNA's "professional" frame transformation and extension through its allegiance building within medical communities. That is, Koyama was disappointed that ISNA no longer voiced its critique in the acerbic tones it once employed. Furthermore, Koyama's choice to return to the movement's earlier, more radical, frame is an example of frame amplification (or perhaps even frame resurrection). Here Koyama conveys the need to implement a radical intersex political organization and rearticulates the movement's earlier injustice frame:

I think of Intersex Initiative as similar to what ISNA used to be. With one foot inside the medical community, ISNA can no longer afford to take certain positions that they used to. For example, our mission statement says that we are working to end the medical abuse of intersex children, but ISNA cannot afford to use the word "abuse" to describe what happens to intersex children today—"misguided treatment" perhaps, but calling it "abuse" would instantly result in ISNA losing its ability to work with medical "experts." This is understandable, but is sometimes difficult for many people who feel that what was done to them was nothing less than "abuse." As it should be obvious, any doctor who is now on ISNA's side used to belong to the other side until three years ago. There are a lot of intersex people who are murderously angry at them, but now they see these same doctors being friendly and having dinner with ISNA, which most people understand, but still feels like a betrayal. I reactivated Intersex Initiative instead of continuing to work within ISNA because I felt that there needed to be other groups that work on the goals we share through different tactics.<sup>62</sup>

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<sup>62</sup> Personal communication from Emi Koyama, Director, Intersex Initiative Portland, to Sharon E. Preves, Assistant Professor of Sociology, Hamline University (on file with author) (quote used with permission).

Similarly, Bodies Like Ours was developed in response to what the founding directors saw as lacking in the larger intersex movement, and in the Intersex Society in particular. As ISNA moved toward advocacy and away from providing peer support, other groups emerged to provide support to people affected by specific diagnoses or “conditions” (e.g. the Androgen Insensitivity Support Groups). Some activists dedicated to providing support saw the need for bridge building to network people with disparate intersex diagnoses. In co-founder Betsy Driver’s words,

Eventually, we came to realize that the intersex movement needed more than just ISNA as they were focused on the policy and advocacy side. After speaking with Cheryl [Chase] about it, and tossing around ideas to expand the movement, it became clear that there was a need for a non-condition specific peer support organization.<sup>63</sup>

Although it is focused on support, Bodies Like Ours integrates political action into its work, such as their September 26, 2003 protest of “intersex genital mutilation” in front of the Connecticut Children’s Medical Center in Hartford, after the organization’s leaders learned about an upcoming intersex surgery to be performed in a teaching theater. They summarize this event on their website: “The hospital went from ignoring us early in the week to inviting us in for a future date to share the adult survivor perspective. Dr. Rink [the doctor from Indiana University who was to perform the procedure] cancelled his appearance due to the publicity surrounding our plans. Finally, we made the front page of the Hartford Courant that morning with a well-written article about intersexuality.”<sup>64</sup>

Despite their differences, ISNA, Intersex Initiative, and Bodies Like Ours frequently work closely with one another and have formed an allegiance to further destigmatize intersex by cosponsoring the first-ever international “Intersex Awareness Day” in 2004.<sup>65</sup>

## VII. LEARNING TO USE MEDIA AS A FORM OF ACTIVISM

The Intersex Society’s early use of media as an activist tool solidified the association of intersex with GLBT issues. Using media as a tool to meet its goals, ISNA adopted the methods and networks of veteran transgender activists.<sup>66</sup> In Chase’s words,

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<sup>63</sup> Personal communication from Betsy Driver, Executive Director, Bodies Like Ours, to Sharon E. Preves, Assistant Professor of Sociology, Hamline University (on file with author) (quote used with permission).

<sup>64</sup> D. Altamari, *Born Neither Girl Nor Boy, They Speak Out*, HARTFORD COURANT, Sept. 26, 2003, at A1; Bodies Like Ours, *Hartford Action Wrap-Up*, at <http://www.bodieslikeours.org/hartford03.html> (last visited Feb. 15, 2004).

<sup>65</sup> Intersex Awareness Day: The Day of Intersex Activism Together, at <http://www.intersex-awareness-day.org> (last visited Feb. 15, 2004).

<sup>66</sup> *Mapping the Emergence*, *supra* note 4.

I began searching for community and consequently moved to San Francisco in the fall of 1992, based entirely on my vague notion that people living in the ‘queer mecca’ would have the most conceptually sophisticated, socially tolerant, and politically astute analysis of sexed and gendered embodiment. I found what I was looking for in part because my arrival in the Bay Area corresponded with the rather sudden emergence of an energetic transgender political movement . . . . In the fall of 1993, Transgender Nation pioneer Anne Ogborn invited me to participate in a weekend retreat called the New Woman Conference, where postoperative transsexual women shared their stories, their griefs and joys, and enjoyed the freedom to swim or sunbathe in the nude with others who had surgically changed genitals. I saw that participants returned home in a state of euphoria, and I determined to bring that same sort of healing experience to intersex people.<sup>67</sup>

Chase’s vision of support was realized when ISNA held its first intersex retreat, with ten attendees, in the fall of 1996.

Chase was intentional in her use of media to record intersex grievances from the very beginning. This included videotaping ISNA’s first retreat, which was later edited and broadly circulated as the medical and university teaching video “Hermaphrodites Speak!” She also publicized intersexuals’ mobilization from the outset. In her own words,

ISNA’s most immediate goal has been to create a community of intersex people who could provide peer support to deal with shame, stigma, grief, and rage as well as with practical issues such as how to obtain old medical records or locate a sympathetic psychotherapist or endocrinologist. To that end, I cooperated with journalists whom I judged capable of reporting widely and responsibly on our efforts, listed ISNA with self-help and referral clearinghouses, and established a presence on the Internet (<http://www.isna.org>). ISNA now connects hundreds of intersexuals across North America, Europe, Australia, and New Zealand. It has also begun sponsoring an annual intersex retreat, the first of which took place in 1996 and which moved participants every bit as profoundly as the New Woman Conference had moved me in 1993.<sup>68</sup>

Speaking to the way ISNA learned to use the media to gain legitimacy and establish connections with other groups who had similar ideologies, Chase writes,

We generated credibility by association. The Gay and Lesbian Medical Association carried some of our releases in their newsletter and invited us to present a panel at their annual meeting in 1996. The Association of Gay and Lesbian Psychiatrists helped us to set up a case presentation and open house at the APA’s annual meeting in spring 1997. Perhaps even more significant than the education of a few dozen physicians that was

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<sup>67</sup> *Id.* at 196-197.

<sup>68</sup> *Id.* at 197.

accomplished at each of these events was the fact that media took us more seriously because we had gained a medical audience.<sup>69</sup>

While intersex is not entirely parallel to GLBT concerns, the issues connected to sexual minority status are in common. That is, intersexuals, regardless of sexual orientation or identity, nonetheless fall into socially constructed categories of “otherness” based on perceived sexual difference. Indeed ISNA aligned itself with other sexually marginalized groups from its inception, establishing long-lasting connections with other groups and their causes. Chase speaks to developing these specific alliances:

One key to our success has been a process of self-education facilitated by the generosity of activists in Transsexual Menace, GLAAD [Gay and Lesbian Alliance Against Defamation], and NGLTF [National Gay and Lesbian Task Force], especially Rikki Ann Wilchins and Robert Bray. Many individuals in these organizations generously gave time and knowledge, teaching us how to write press releases, assemble press kits, pitch stories and develop relationships with journalists.<sup>70</sup>

It was the sexuality and gender “queer” communities both inside and outside medicine that could relate most easily to intersexuals’ grievances of stigma, shame, and alienation. Speaking to the effectiveness of this frame bridging, Chase writes,

More mainstream gay and lesbian political organizations such the National Gay and Lesbian Task Force have also been willing to include intersex concerns as part of their political agendas. 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.<sup>71</sup>

Bridging the frames between GLBT and intersex groups provided much needed support to members of each community given the similarity of the groups’ goals and grievances. At the same time, aligning intersex issues with other sexual minorities’ compromised intersex activists’ ability to establish credibility with the non-GLBT medical mainstream, who view heterosexual normalcy as one of the primary objectives of intersex medical sex assignment.

### VIII. INTERSEX AND TRANSGENDER/TRANSSEX TENSIONS

While the intersex movement has clearly benefited from its coalition with transactivists, there have been considerable tensions between intersex and trans

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<sup>69</sup> *Making Media*, *supra* note 42, at 24-25.

<sup>70</sup> *Making Media*, *supra* note 42, at 24.

<sup>71</sup> *Mapping the Emergence*, *supra* note 4, at 200-201.

communities over the years. These conflicts are similar to those experienced by gay and lesbian communities when bisexuality became a more visible identity in the 1980s and 1990s.

The term transgender is used by some as an umbrella category meant to be inclusive of all persons whose bodies and identities aren't adequately represented by the gender binary (e.g. transgenders, transsexuals, and intersexuals). The conflation of intersex and transgender/transsex issues and identities has led to the alienation of some intersex individuals from intersex support resources and has also created the perceived need to demarcate criteria for membership in each group, thus amplifying the very definition of what it means to be intersexed. For example, one of the people I interviewed was denied membership in an intersex support group because she was perceived to be transsexual, rather than intersexed.

Her experience clearly illustrates that identity-based political movements, such as the intersex movement, are problematic in their simplification of social categories as unified and generalized phenomena. That is, establishing criteria for identifying oneself as intersexed leads to the privileging or essentializing of certain features of intersex experiences (e.g. medical trauma), which is exclusionary in the end. Critics of such generalizations claim that there is no such thing as the gay or straight or intersexed identity. Speaking to the constraints of this essentialism, Steven Seidman writes, "Positing a gay identity, no matter how it strains to be inclusive of difference, produces exclusions [and] represses difference."<sup>72</sup> In a similar vein, Ki Namaste asks several questions that are pertinent to the discussion of identity-based social movements. As Namaste has noted,

How do categories such as "gay," "lesbian," and "queer" emerge? From what do they differentiate themselves, and what kinds of identities do they exclude? How are these borders demarcated, and how can they be contested? What are the relations between the naming of sexuality and political organization it adopts, between identity and community? Why is a focus on the discursive production of social identities useful? How do we make sense of the dialectical movement between inside and outside, heterosexuality and homosexuality?<sup>73</sup>

Moving away from traditional definitions of identity, Seidman offers a poststructural approach to identity, saying that poststructuralism

dissolves any notion of a substantial unity in identity constructions leaving only rhetorics of identities, performances, and the free play of difference and possibility. Whereas identity politics offers a strong politics on a weak, exclusionary basis, poststructuralism offers a thin politics as it

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<sup>72</sup> S. Seidman, *Identity and Politics in a 'Postmodern' Gay Culture: Some Historical and Conceptual Notes*, in FEAR OF A QUEER PLANET: QUEER POLITICS AND SOCIAL THEORY 105, 135 (M. Warner ed., University of Minnesota Press 1995).

<sup>73</sup> K. Namaste, *The Politics of Inside/Out: Queer Theory, Poststructuralism, and a Sociological Approach to Sexuality*, in QUEER THEORY/SOCIOLOGY 194, 198-199 (S. Seidman ed., Blackwell 1996).

problematizes the very notion of a collective in whose name a movement acts.<sup>74</sup>

According to Seidman, Davis, and others, identity politics movements create a new kind of nationalism, in that identity-based social movements serve to erect artificial boundaries and borders, and thus increase the potential for in-group/out-group assimilation and separatism. According to Davis, “the deaf have created their own ‘nationalism’ as a resistance to audist culture.”<sup>75</sup> In their efforts to develop consensus of meaning and identity, intersexuals may be participating in a similar exclusion of nonintersexuals from their activities.

In a powerful article that explores the identity issues that face intersex and trans communities, intersex and transgender author Raven Kaldera illustrates the frequency with which transsexual and transgender individuals lay claim to intersex identities. This is perhaps an illustration of one group trying to participate in frame bridging, if not extension, while the other group denies the overture. In Kaldera’s words,

I’m finding myself doing frantic damage control between two groups who should be allies. The newest issue is whether or not transgendered people should be “allowed” to call themselves intersexuals, to claim that both groups are, for all practical purposes, the same, and should be combined into one big gender-transgressive group.<sup>76</sup>

The desire to claim an intersexed identity has been particularly attractive to some transsexual and transgender individuals who seem to covet the naturally occurring sexual ambiguity experienced by intersexuals. In fact, when seeking out sex reassignment surgery some transsexuals claim naturally occurring anatomical sex changes at puberty and intersex as the underlying cause of their gender ambiguity. After all, it is easier to point to one’s anatomy rather than one’s psyche as the cause of gender dysphoria. Beyond the claim of being intersexed, transsexuals’ actual belief in being born intersexed is commonly reported by transsexuals to sex reassignment clinicians.<sup>77</sup> About some transsexuals’ desire to adopt both an intersexed identity and injustice frame by extending their own, Kaldera says:

Claiming the medically defined identity of intersex when you have none of the problems involved has been compared to claiming a nonexistent disability to get better parking spaces, or claiming a minority identity that you don’t have in order to get a better job in an area with affirmative action laws. We are all minorities, and we don’t need to prey on each other. If

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<sup>74</sup> Siedman, *supra* note 72, at 135.

<sup>75</sup> L.J. Davis, ENFORCING NORMALCY: DISABILITY, DEAFNESS, AND THE BODY 78-79 (Verso 1995).

<sup>76</sup> R. Kaldera, *Dangerous Intersections: Intersex and Transgender Differences*, at <http://www.amboyz.org/intersection/dangerousIntersections.html> (last visited Feb. 15, 2004).

<sup>77</sup> S.E. Preves, & A.E. Eyler, *Belief in Having Been Born Intersexed as a Psychological Defense Among ‘Transphobic’ Transsexuals: Report of Three Cases*, Harry Benjamin International Gender Dysphoria Association Symposium, London, England, August 17-21, 1999, available at <http://www.symposion.com/ijt/greenpresidential/green42.htm>.

those transgendered people who feel that they: (a) have an identity somewhere between male and female; and (b) that it is biologically based would like to create a previously unused term to describe themselves, I'll add it to my vocabulary. But please don't steal another minority group's term, or declare that "we are all one" without actually consulting any of them.<sup>78</sup>

Despite visible tensions between these groups, there are ways in which intersex is clearly related to transgender/transsexuality, as some intersexuals are also transsexual. That is, some intersex individuals go through sex reassignment in adulthood when they realize that the medical sex assignment in infancy was inappropriate. Such is the case for 24% of the people I interviewed.<sup>79</sup> In addition, people who are intersexed are indeed a sexual minority, treated differently and subjected to medical "normalization" procedures because their bodies are framed as sexually deviant; these issues of normalization and pathologization link intersex to GLBT communities and concerns.

These linkages have been codified in recent years among university and other groups who have included intersex issues as part of their campus sexual minority groups' concerns. Such frame extension is indeed welcoming and supportive to intersex members of various communities, but there are also problems with tacking on the "I" to the already unwieldy GLBT acronym. Indeed the question of whether or not to include the "I" in GLBT is complicated. First, intersex people can be straight, bi, gay, lesbian, and/or transsexual or transgender. Also, "intersex" is often not an identity for most people the way that it may be for members of GLBT communities; because of the stigma, secrecy, and the unwanted treatment surrounding intersex, people with these conditions do not necessarily rally around the term as one of pride and community. Moreover, given the secrecy with which their conditions are treated, many intersexuals don't self-identify as such because they don't even know their own diagnoses.

#### IX. CHRONOLOGY OF INTERSEX MEDIA ACTIVISM

ISNA began putting a human face to the mythology of hermaphroditism for the first time when Chase wrote that letter to the editor of *The Sciences* in reply to Fausto-Sterling's *Five Sexes* article.<sup>80</sup> To quote Chase's letter directly, "As an intersexual I found Anne Fausto-Sterling's article 'The Five Sexes' of intense personal interest. Her willingness to question medical dogma on intersexuality is unique and refreshing. I understand that she has not had the chance to meet with any 'corrected' intersexuals; I think I can provide some perspective on the experience."<sup>81</sup> Indeed, much of the media coverage on intersex features

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<sup>78</sup> *Dangerous Intersections*, *supra* note 76.

<sup>79</sup> PREVES, *supra* note 4.

<sup>80</sup> *Intersexual Rights*, *supra* note 44.

<sup>81</sup> *Id.* at 3.

individuals' personal stories about medical sex assignment, gender identity, and overall quality of life.

Personalizing intersex through individuals' stories provides nonintersexed individuals a human connection and political context within which to understand these stories of medicalization, secrecy, and shame. As early as 1995, intersexuals' personal stories were being featured not only in the popular press, but in college textbooks and other educational forums as well.<sup>82</sup>

Beyond personalizing intersex, Chase and other activists seek to extend the frame of intersex issues by connecting the personal experiences of intersex individuals to political issues and events. In a follow-up to her *Sciences* letter to the editor, Chase wrote a brief informational article about intersex for the *NOCIRC Newsletter*,<sup>83</sup> a publication of the National Organization of Circumcision Information Resource Centers. NOCIRC has worked to extend the critique and ban against female genital mutilation (FGM) to include male circumcision, or what the group calls male genital mutilation (MGM). Chase's reaching out to an anti-circumcision group in 1993 was perhaps foreshadowing of the intersex movement's later attempts to extend arguments against female genital mutilation to encompass intersex bodies and genital surgeries. In a 1995 newsletter, in anticipation of the success of former U.S. House Representative Patricia Schroeder's (D. Colorado) anti-FGM bill, ISNA again spoke out against intersex genital mutilation (IGM).<sup>84</sup>

By February of 1996, the intersex movement (and ISNA in particular) had garnered the attention of the *New York Times* and was featured in an article entitled "Intersexual Healing: An Anomaly Finds a Group."<sup>85</sup> In September of 1996, press coverage of the movement broadened to include a feature article in the *Utne Reader*<sup>86</sup> and a cover story in *Out* magazine,<sup>87</sup> promising an exclusive on "the intersexual revolution." This coverage portrayed the grievances of intersex activists as a concern of human rights and medical ethics, giving activists an opportunity to connect intersex issues to broader concerns of civil rights.

Early on in the movement, before intersex activists had established a credible voice in the debate about their medical treatment, some groups used political tactics to gain visibility. In September 1996, at precisely the same time the popular press coverage of intersex took off, Schroeder's federal anti-FGM bill became law. This law bans any genital cutting in the United States on girls under the age of 18 years old. Prosecution includes a prison sentence of up to five years for parents who arrange for the procedure as well as the people who actually perform the cutting. As with any law, there are exceptions to this ban. In this case, no violation of the

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<sup>82</sup> See e.g., J.W. KALAT, *BIOLOGICAL PSYCHOLOGY* 404 (Brooks/Cole Publishing 1995).

<sup>83</sup> C. Chase, *Males, Females . . . and Us*, 7 *NOCIRC NEWSLETTER* 2 (1993).

<sup>84</sup> C. Chase & M. Holmes, *Genital Mutilation Has Never Stopped in the U.S.*, 5 *BODY IMAGE TASK FORCE* 9 (Winter-Spring 1995).

<sup>85</sup> N. Angier, *Intersexual Healing: An Anomaly Finds a Group*, *N.Y. TIMES*, Feb. 4, 1996, at E14 [hereinafter *Intersexual Healing*].

<sup>86</sup> M. Bauerlein, *The Unkindest Cut*, *UTNE READER*, Sept.-Oct. 1996, at 16.

<sup>87</sup> A.C. d'Adesky, *The Third Sex*, *OUT*, Sept. 1996, at 104.

law is made if genital cutting is deemed “. . . necessary to the health of the person on whom it is performed, and is performed by a person licensed in the place of its performance as a medical practitioner . . . .”<sup>88</sup> Thus, the law bans cutting on girls’ genitalia except in cases where “health” demands its necessity, allowing for intersex “emergencies” to be exempt.

Press coverage of this new law included a front-page article in the *New York Times* on October 12, 1996.<sup>89</sup> Chase and other members of ISNA were outraged by the law’s complicit endorsement of intersex genital surgeries. Putting their media mentoring and frame bridging into action, they began to stage protests to draw attention to not only this law’s loophole, but to “intersex genital mutilation” as well.<sup>90</sup> By picketing at medical conferences, the Intersex Society’s critique gained the attention of the larger public. Speaking to this strategy of staging events to garner press time, Chase says, “It’s a lot easier to get media to cover events than issues.”<sup>91</sup>

The Intersex Society’s first major media event was a “zap” of the October 26, 1996 American Academy of Pediatrics’ meeting in Boston. Members of the Intersex Society of North America and Transsexual Menace joined together for this event—calling themselves “Hermaphrodites with Attitude” (HWA)—after the intersex activists were denied floor time to address the doctors in attendance.<sup>92</sup> The intersex members of HWA were affiliated with the Intersex Society of North America and adopted the name for their activist group from ISNA’s newsletter *Hermaphrodites with Attitude*. Intersex Society representatives used the name HWA frequently during the 1990s when activists engaged in protests at medical conferences and in other venues. Chase referred to this event as, “the first recorded instance of intersex public protest in modern history.”<sup>93</sup>

Before HWA picketed the AAP, no one had ever bothered to ask for the Academy’s position statement on the treatment of infants with ambiguous genitals. During the protest, and attendant media focus, the AAP felt pressured to provide such a position statement. In Chase’s words,

In response to the Hermaphrodites with Attitude protests at the American Academy of Pediatrics meeting, that organization felt compelled to issue the following statement to the press: ‘The Academy is deeply concerned about the emotional, cognitive, and body image development of

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<sup>88</sup> Federal Prohibition of Female Genital Mutilation Act, H.R. 941 & S. 1030, 104th Congress (1995).

<sup>89</sup> C.W. Dugger, *New Law Bans Genital Cutting in United States: Violators Could Face Five Years in Prison*, N.Y. TIMES, Oct. 12, 1996, at 1A.

<sup>90</sup> *Making Media*, *supra* note 42; *Mapping the Emergence*, *supra* note 4; K. Harvey, *A Mother’s Dilemma*, ST. PAUL PIONEER PRESS, Mar. 4, 1999, at IF.

<sup>91</sup> *Making Media*, *supra* note 42, at 24.

<sup>92</sup> Beck, *supra* note 38.

<sup>93</sup> *Mapping the Emergence*, *supra* note 4, at 201.

intersexuals, and believes that successful early genital surgery minimizes these issues.<sup>94</sup>

As Chase had hoped, the story, replete with photos, of HWA's protest made the news. In November of 1996, for example, the *Boston Phoenix*<sup>95</sup> reported on intersex activists' picketing of the annual meeting of the American Academy of Pediatrics and their demands for a position statement on infant genital surgery from the Academy. As Chase indicated, the *Boston Phoenix* also reported that until that day, nobody had ever requested the AAP's position statement on genital surgery for infants with ambiguous genitalia. This position statement, evoked by intersex activism, is an example of the medical establishment's early attempts to publicly frame and articulate their stance on intersex issues.

#### X. INTERSEX MAKES THE HEADLINES: THE IMPACT OF THE DAVID REIMER CASE

ISNA's early efforts to raise public awareness about the plight of intersexuals were catapulted forward by the mass media's fascination with one person's medical tragedy that came to light in the spring of 1997. Oddly, the most well known and widely cited case in the intersex medical literature involves *nonintersexed* identical twin boys, Bruce and Brian Reimer, born in Canada in 1965. The twins were not circumcised at birth, but at the age of eight months they both developed phimosis—a painful tightening of the foreskin. The twins were scheduled for circumcision to relieve their pain. Bruce Reimer (known formerly as “John” in the medical literature) was scheduled for circumcision first. Tragically, he lost his penis due to accidental burning during the routine electrocautery procedure.<sup>96</sup>

Although Bruce was not sexually ambiguous and had been raised as a male for nearly a year, psychologist John Money, the harbinger of medical sex assignment, and his colleagues recommended that he be reassigned as female because he lacked a penis and therefore could not develop a normal male gender identity. Bruce was 22 months old before his parents consented to his surgical and social reassignment as “Brenda” (previously known as “Joan” in the medical literature), turning an unfortunate surgical accident into an “experiment of nature” for researchers and others interested in gender identity acquisition.<sup>97</sup> Money and colleagues used this surgical mishap and sex reassignment to test the impact of gender socialization by rearing a male child as female and using his genetic identical twin as an empirical control.

For more than 30 years, Money reported Brenda's gender reassignment as an undeniable success and used the case as unquestionable evidence of the value and

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<sup>94</sup> *Id.* at 202.

<sup>95</sup> E. Barry, *United States of Ambiguity*, BOSTON PHOENIX, Nov. 22, 1999, at 6.

<sup>96</sup> J. COLAPINTO, AS NATURE MADE HIM: THE BOY WHO WAS RAISED AS A GIRL (Harper-Collins 2000).

<sup>97</sup> J. Colapinto, *The True Story of John/Joan*, ROLLING STONE, Dec. 11, 1997, at 62; *Sex Reassignment at Birth*, *supra* note 4.

success of surgical sex assignment for intersexed children.<sup>98</sup> Money's findings were widely cited by sociologists, feminists, psychologists, and in the mass media as proof that biology is not destiny, and that gender is socially malleable, at least in early childhood. Money's findings were promoted widely in classrooms and textbooks as incontrovertible evidence that environmental factors outweigh biological ones in gender identity development.

In March of 1997, biologist Milton Diamond and psychiatrist Keith Sigmundson revealed in *The Archives of Pediatric and Adolescent Medicine* that Brenda was never satisfied with a female gender identity and that she began the process of male sex reassignment at age 14 when s/he learned the history of the surgical accident and gender reassignment from his/her father.<sup>99</sup> When Brenda Reimer started living as a boy again at age 14, he took the name David. David spoke with Diamond and Sigmundson after learning that Money was still reporting "Brenda's success." David and his family chose to keep their identities under wraps despite a flurry of media attention in 1997.

The overlap of intersex mobilization, the call for clinical reform, and the follow-up reports on the cornerstone David Reimer case are not accidental. Although a shy and reticent person, David felt compelled to speak out so that what happened to him would not happen to other children. Reimer came forward after learning that thousands of other children were being subjected to the same alienating treatments he received, and that they were being treated in this way largely based on the reported success of his sex reassignment in early childhood. That Reimer went public with his account of traumatic clinical neglect has, in turn, opened the door for intersex rights activists to tell their stories and influence medical reform. In addition to Reimer's personal tragedy, it was the public downfall and scientific discrediting of John Money, the modern day father of intersex medicalization, which made Reimer's story so broadly appealing in both medical and scholarly arenas. Chase and ISNA were well prepared to take advantage of this opportunity and to use the media coverage to frame intersex the way they wanted to. In Chase's words:

By 1997, we had a large community of adult intersexuals who would speak publicly; we had a few parents willing to speak about their experiences and could rebut doctors' assertions that "things are so much better now." We had sexologists, sociologists, psychotherapists, historians, and even one or two surgeons and ethicists on our side. We were in a good position to extract from the media the story we wanted: A story about us and how intersexuals are fighting for social change, a story avoiding painting intersexuals as "Other," as freak, as victim. Just as all of these pieces fell

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<sup>98</sup> J. Money, *Ablatio Penis: Normal Male Infant Sex-Reassignment as a Girl*, 4 ARCHIVES OF SEXUAL BEHAVIOR 65 (1975); J. MONEY & A. EHRHARDT, MAN AND WOMAN BOY AND GIRL: THE DIFFERENTIATION AND DIMORPHISM OF GENDER IDENTITY FROM CONCEPTION TO MATURITY (Johns Hopkins University Press 1972).

<sup>99</sup> *Sex Reassignment at Birth*, *supra* note 4.

into place, a stroke of good luck came to us. Sex research Milton Diamond publicized the outcome of what has become known as the “John/Joan” story . . . . We took advantage of the press’s attention to the John/Joan story, making them aware that intersex children are treated daily with the same medical arrogance, mutilating surgery and willful deception imposed on John.<sup>100</sup>

The major media were abuzz with reports of biological determinism within days of Diamond and Sigmundson’s publication.<sup>101</sup> The media also became interested in other cases of infant sex reassignment and turned to newly emergent intersex activists and parents for their stories. Print media reports in the spring of 1997 included front-page coverage in the *New York Times*<sup>102</sup> and cover stories in *Newsweek*,<sup>103</sup> *Rolling Stone*,<sup>104</sup> *Time*,<sup>105</sup> *On the Issues*,<sup>106</sup> *Out*,<sup>107</sup> and *Mademoiselle*<sup>108</sup> magazines. In addition, television media featured the David Reimer story on *NBC Dateline*,<sup>109</sup> *Inside Edition*,<sup>110</sup> and *Prime Time Live*,<sup>111</sup> with interviews of David Reimer himself, leaders of intersex support groups, as well as biologists Fausto-Sterling and Diamond. Another coup came for ISNA and the movement in December of 1997 when Chase, pediatric urologist Antoine Khoury, and social worker Barbara Nielson (both of the Hospital for Sick Children in Toronto) were interviewed by Terry Gross on National Public Radio’s program “Fresh Air.” Similar media coverage followed Colapinto’s publication of *As Nature Made Him: The Boy Who Was Raised as a Girl*.<sup>112</sup>

On the heels of the Reimer follow-up, ISNA traveled to Washington, DC in May of 1997 to lobby policymakers directly to extend the anti-FGM bill to be inclusive of intersex bodies. New to Capitol Hill, Chase and other members of ISNA once again turned to their GLBT activist mentors for help.

In the spring of 1997, ISNA joined a lobby day in DC sponsored by GenderPAC. We were absolute novices, but GenderPAC held our hands, helped us create literature appropriate for legislative aides, and notified the press. Professional lobbyists from HRC [Human Rights Campaign] and

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<sup>100</sup> *Making Media*, *supra* note 42, at 25.

<sup>101</sup> *Sex Reassignment at Birth*, *supra* note 4.

<sup>102</sup> *Intersexual Healing*, *supra* note 85; N. Angier, *New Debate Over Surgery on Genitals*, N.Y. TIMES, May 13, 1997, at B7; N. Angier, *Sexual Identity Not Pliable After All, Report Says*, N.Y. TIMES, Mar. 14, 1997, at A1 [hereinafter *Sexual Identity Not Pliable*].

<sup>103</sup> G. Cowley, *Gender Limbo*, NEWSWEEK, May 19, 1997, at 67.

<sup>104</sup> *The True Story of John/Joan*, *supra* note 97.

<sup>105</sup> *As a Former Intersexed Patient*, *supra* note 38.

<sup>106</sup> M. Coventry, *The Tyranny of the Esthetic: Surgery’s Most Intimate Violation*, 7 ON THE ISSUES 16 (Summer 1998); M. Hassibi, *Designing Sex: Playing God, Have Doctors Gone Too Far?*, ON THE ISSUES 13 (Summer 1998).

<sup>107</sup> d’Adesky, *supra* note 87.

<sup>108</sup> Moreno & Goodwin, *supra* note 38.

<sup>109</sup> *NBC Dateline: Gender Limbo* (NBC television broadcast, June 17, 1997).

<sup>110</sup> *Inside Edition: Caught in the Middle* (NBC television broadcast, Sept. 11, 1997).

<sup>111</sup> *Prime Time Live: Boy or Girl?* (ABC television broadcast, Sept. 3, 1997).

<sup>112</sup> *AS NATURE MADE HIM*, *supra* note 96.

NGLTF [National Gay and Lesbian Task Force] coached us and accompanied us on our visits.<sup>113</sup>

Aware of the potential power their lobbying held for generating media coverage, Chase went on to say, “Women from four states converging on DC to explain to elected officials that clitorrectomy happens here, it was done to us, and we want it stopped—and are willing to be photographed—that’s news.”<sup>114</sup> And she was right. The *New York Times* once again featured ISNA, this time with photographs of the group’s lobbying efforts on Capitol Hill.<sup>115</sup>

Inspired by their work on Capitol Hill, ISNA and HWA went on to protest two Human Rights Campaign (HRC) fundraising events for lesbians with cancer in the fall of 1997. Given ISNA’s ties with the lesbian and gay community, its members likely chose HRC’s fundraisers as a protest site with difficulty. In lieu of these connections, they forged ahead with the protests in Washington, DC and Minneapolis because former Surgeon General Jocelyn Elders, a pediatric endocrinologist and outspoken proponent of intersex surgery, was the featured speaker. ISNA’s work to educate the public about Elders’ position began years before these demonstrations, when they published the following information about “Jocelyn Elders’ medical career” in the “Did You Know?” section of the spring 1995 issue of the *Hermaphrodites with Attitude* newsletter.

Before her ill-fated stint as Surgeon General, Jocelyn Elders’ specialty was pediatric endocrinology. Dr. Elders taught these “rare” surgical procedures at the University of Arkansas. “I always taught my students, ‘I can make a good female, but it’s very hard to make a male.’” She was ultimately dumped as Surgeon General for having the gall to speak openly about healthy masturbation. We wonder if any of the hermaphrodites made into “good females” by Dr. Elders or her students are able to masturbate today.<sup>116</sup>

In February 2000, Canadian journalist John Colapinto published his book *As Nature Made Him: The Boy Who Was Raised as a Girl*. Upon publication of the book, the Reimer family, at David’s lead, made several talk show and news program appearances revealing their stories and identities to the world. More recent press coverage has included numerous documentaries, the publication of the Pulitzer-Prize winning book *Middlesex*,<sup>117</sup> and a cover story in the Canadian magazine *Maclean’s*.<sup>118</sup> Despite the impact of their stories on intersex treatment and raising social awareness about these issues, both David Reimer and his twin brother Brian tragically died of suicide in 2004 and 2002, respectively.

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<sup>113</sup> *Making Media*, *supra* note 42, at 24.

<sup>114</sup> *Id.* at 24.

<sup>115</sup> *New Debate Over Surgery on Genitals*, *supra* note 102.

<sup>116</sup> Intersex Society of North America, HERMAPHRODITES WITH ATTITUDE 12 (Spring 1995), at [www.ISNA.org/newsletter](http://www.ISNA.org/newsletter) (last visited Feb. 15, 2004).

<sup>117</sup> J. EUGENIDES, *MIDDLESEX: A NOVEL* (Farrar, Straus, & Giroux 2002).

<sup>118</sup> S.D. Driedger, *Gender Paradoxes: People With Intersex Conditions Want the Shame and Stigma to End*, *MACLEAN’S*, May 26, 2003.

## XI. MEDICAL RESPONSE TO INTERSEX MEDIA ACTIVISM

At the same time that the GLBT and mainstream media were covering intersex, physicians and other health care providers began making use of various media outlets to clarify their positions about intersex treatment, especially following the follow-up studies about David Reimer that discredited not only John Money, but the premise of intersex medical sex assignment as well. As early as 1995, in response to a letter from Cheryl Chase, an article appeared in a Bay Area newspaper<sup>119</sup> announcing support available from ISNA. That same year, the GLB task force of the American Medical Student Association wrote about ISNA and intersex activism as “challenging medical education.” In November of 1995 the leading national organization for sexologists, the Society for the Scientific Study of Sexuality (SSSS), devoted a plenary symposium to exploring “Genitals, Identity, and Gender,” and featured intersex scholars Milton Diamond, Suzanne Kessler, and Heino Meyer-Bahlburg. Also in 1995, queer medicine began to take notice of shifts in intersex perception and treatment. The *GLMA* (Gay and Lesbian Medical Association) *Reporter* published an article about the formation of ISNA, framing the group’s work in terms of “health advocacy.”<sup>120</sup> The 1996 GLMA annual meeting, held in Montreal, featured two presentations on intersex, one by a physician, Dr. Bruce Filmer, “Revisiting Intersexuality,” and one by Chase and Filmer, “Hermaphroditism: Challenging Current Practice,”<sup>121</sup> showing early signs of intersex frame transformation within medicine.

By 1997, health care professionals began to take a more active role in media discussions. An article in the *Chicago Tribune*<sup>122</sup> featured several key players in the field of gender identity and psychiatry, including Ken Zucker, Melvin Grumbach, and Simon LeVay. The *New York Times* carried a piece in March 1997<sup>123</sup> featuring Diamond and Sigmundson’s critique of Money and the John/Joan case. Following publication of this article, the medical debate about intersex really took off, signifying tensions within medicine about how best to frame and respond to intersexuality. On one side were physicians and others challenging the dominant paradigm of “normalization,” and on the other were supporters and proponents of that paradigm. This debate is quite polarized; very rarely does somebody fall somewhere in between. In fact, there was an overwhelming dismissal of intersex critiques early on in their activism. Many clinicians disregarded intersex activists as “radical zealots” who represent perhaps only 3% of the entire surgically altered intersex population. In fact, UCSF Associate Professor of Urology and Pediatrics Laurence Baskin once said, “I honestly feel sorry for those people who feel

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<sup>119</sup> S. Horowitz, *The Middle Sex*, S.F. WEEKLY, Feb. 1, 1995, at 11.

<sup>120</sup> Gay and Lesbian Medical Association, *Hermaphrodites Form Health Advocacy Group*, GLMA REPORTER, Summer 1995, at 14.

<sup>121</sup> Gay and Lesbian Medical Association, *Official Program: 14th Annual GLMA Symposium*, August 22-24, 1996, Montreal.

<sup>122</sup> D. Riose, *Gender More Ambiguous Than Anatomy*, CHI. TRIB., Feb. 23, 1997, Section 13, at 1.

<sup>123</sup> *Sexual Identity Not Pliable*, *supra* note 102.

mutilated by their surgeries. They need counseling to get over their loss. Their surgeries were performed years ago, and the nerve supply wasn't understood. For [every] three [unhappy intersexuals], my guess is there are 97 who are happy. But they're not going to be out talking [about it]."<sup>124</sup>

Throughout 1997, the media featured a number of stories on the "controversy" over intersex management. The *Vancouver Sun*<sup>125</sup> profiled Dr. George Szasz, who labeled Cheryl Chase and Hermaphrodites with Attitude as "very, very militant." The *New York Times*<sup>126</sup> discussed the "New Debate Over Surgery on Genitals," and interviewed Dr. Anthony Caldamone, head of pediatric urology at Hasbro Children's Hospital in Providence, RI, as well as Dr. Antoine Khoury of Toronto's Hospital for Sick Children. (Khoury has become one of the leading spokesmen in favor of surgery for intersex). That article also cited Dr. Justine Schober, who became one of the first physicians to publicly support the perspective of the Intersex Society of North America and other intersex advocacy groups. In June of that year, *Newsweek*<sup>127</sup> carried an article about intersex treatment, which sparked a letter to the editor from Khoury,<sup>128</sup> who took this opportunity to amplify the frame of the benevolent clinician, insisting that intersex doctors do care for their patients and do not randomly "hack off babies' genitals." This letter seemed to indicate that many physicians were being put on the defensive by the tenor and thrust of the debate over treatment. A lead article in *Clinical Psychiatry News*<sup>129</sup> framed the intersex medical debate as immediate versus delayed surgery, and cited Dr. William Reiner, who would later become an advocate of nonintervention, as saying that "to not do something would be a disaster." What is striking here is that to "not doing anything" isn't even presented as a possibility. In these early debates, there was a clear assumption of the necessity of medical intervention; the debate as framed here is about *when, and not if*, to intervene. However, this too has shifted as physicians have more recently begun to advocate not doing anything at all. In October 1997, a letter to the editor of *OB. GYN. NEWS*<sup>130</sup> brings the question of research to the table, namely suggesting that physicians "spare the knife, study the child." The author, Dr. Jack Drescher, calls for evidence beyond simply anecdotal reports from patients. This appeal for "more research" continues to be a major theme of the intersex debate.

Human rights and legal considerations (e.g. informed consent) entered into the ongoing debate in the late 1990s, following the highly publicized Reimer

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<sup>124</sup> A. Yronwode, *Intersex Individuals Dispute Wisdom of Surgery on Infants*, 43 SYNAPSE 3, 4 (University of California) (Mar. 11, 1999).

<sup>125</sup> I. Mulgrew, *Controversy Over Intersex Treatment*, VANCOUVER SUN, Apr. 7, 1997, at A1.

<sup>126</sup> *New Debate Over Surgery on Genitals*, *supra* note 102.

<sup>127</sup> Cowley, *supra* note 103.

<sup>128</sup> A. Khoury, *Responsible Decision Making, Letter to the Editor*, NEWSWEEK, June 23, 1997, at 19.

<sup>129</sup> K. Maurer, *Immediate Versus Delayed Surgery: Genital Ambiguity Brings New Debate*, 25 CLIN. PSYCHIATRY NEWS 1 (1997).

<sup>130</sup> J. Drescher, *Spare the Knife, Study the Child, Letter to the Editor*, OB. GYN. NEWS, Oct. 1, 1997, at 14.

follow-up studies, as new discourse began to be used to frame intersex activism, grievances, and treatment. Framing intersex demedicalization as a broad concern of human rights occurred about the time the High Court of Columbia established the necessity of “persistent, informed consent” for intersex surgery,<sup>131</sup> recognizing only the child’s interests and not those of parents or physicians. Intersex activists began appearing at legal conferences, and the intersex movement took a decidedly legalistic turn in some of its activities, extending their framing of intersex to be inclusive of broader issues, such as the U.S. anti-FGM legislation. This period also marks a consolidation of various international activities into a more cohesive set of issues; that is, intersex activism began to appear less fragmented and more connected geographically in scope. Above and beyond questions of GLBT allies, the discourse of “rights” opened the doors not just to sexual and human rights, but also to the language of civil rights. Several articles appeared in 1998 and 1999, featuring both activists and health care providers, in which rights discourse is dominant.

In the fall of 1997 ethics entered into the medical profession’s discourse about intersex, quite likely promoted by highly visible reporting about David Reimer’s experiences of medical mistreatment. Several publications, such as the *Medical Humanities Report*<sup>132</sup> and *Pediatric News*,<sup>133</sup> as well as a major conference on ethics and humanities,<sup>134</sup> began reporting on the ethical aspects of intersex treatment. That is, these approaches began to reframe the intersex “problem” in terms of ethics, raising questions about informed consent, the costs of “normalization,” and the lack of evidence for surgical approaches. Here we also begin to see the emergence of what might be called a children’s rights approach to intersex activism, calling into question the rights of physicians to operate and parents to consent in the absence of true informed consent given by the child.

## XII. EVIDENCE OF CLINICAL REFORM

The implementation of radical, invasive, and life-changing medical sex assignment procedures for children born with bodies deemed intersexed was standard practice until very recently. However, the intersex patient advocacy and medical reform movement that began to reframe and demedicalize intersex in the 1990s has gained tremendous legitimacy and ground in a very short period of time. What’s more, the patients’ rights movement has upset this formerly unquestioned

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<sup>131</sup> Constitutional Court of Colombia, SU-337199, May 12, 1999; Constitutional Court of Colombia, T-551/99, Aug. 2, 1999.

<sup>132</sup> A.D. Dreger, *Ethical Problems in Intersex Treatment*, 1 MED. HUMANITIES REP. 4 (Fall 1997).

<sup>133</sup> K. Maurer, *Delaying Surgery May Help Intersex Children*, 31 PEDIATRIC NEWS 29 (1997).

<sup>134</sup> *Visions for Ethics & Humanities in a Changing Healthcare Environment* (abstracts from the joint meeting of the American Association of Bioethics, the Society for Bioethics Consultation, and the Society for Health and Human Values (Nov. 5-9, 1997)).

approach in medical education and practice and placed it into its current state of flux, crisis, reform, and frame transformation.<sup>135</sup>

As a direct result of intersexuals' vocal critiques, clinicians have started to reform their practices—and their frames of intersex and intersex treatment—and many are now claiming to be far less eager advocates of surgical intervention on intersexed infants and children.<sup>136</sup> Those who have made these changes are often physicians who have had personal interaction with adult intersexuals who are critical of medicalization. The critiques that are deemed most credible are adults' complaints of sexual dysfunction, due to medically induced nerve damage, and complaints of incorrect gender role assignment.<sup>137</sup> This shift was notable in pediatric urologist Yuri Reinberg's 1999 grand rounds presentation at the University of Minnesota's Medical School. During his presentation and discussion thereafter, several noted advocates of intersex surgery spoke of their newfound reluctance to perform genital operations on infants and children due to adult intersexuals' critiques of sexual dysfunction and inappropriate sex assignment.

In addition to this emerging frame transformation within medicine, there is also an apparent shift in the way ISNA frames itself and in the way others perceive the organization. The ISNA that was once barred from attending and speaking at medical conferences is now seen as a credible advocacy organization. This shift is no doubt related to the way ISNA has transformed its approach from its once hostile anti-medical stance to working alongside clinicians to effect change. For example, pediatric endocrinologist and ISNA Medical Advisory Board member David Brown said recently during an educational presentation on intersex, "ISNA was a pariah five years ago. Now it's an honor to be on their board." As a result of intersex activism "surgical techniques are being modified."<sup>138</sup>

Certainly, many clinicians have begun to listen to the concerns, experiences, and needs of intersexuals. Most importantly, some in the medical profession have begun to recognize that the "success" of sex assignment surgery should not rest on the outcome measure of gender identity alone. That is, whether or not the individual later transitions to the "other" gender should not be the only criterion for determining whether surgery is the correct approach or not. Intersex activists have pushed to broaden definitions of clinical success to include quality of life measures and measures of sexual function, family dynamics, and psychological well-being. The National Institutes of Health even issued a program announcement in 2001 for funding dedicated to new and continued research on intersex, and in May 2002 convened a committee dedicated to overseeing research on the topic. This call for

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<sup>135</sup> K.J. Zucker, *Intersexuality and Gender Identity Differentiation*, 15 J. PEDIATRIC ADOLESCENCE & GYNECOLOGY 3 (2002).

<sup>136</sup> E. Nussbaum, *The Sex That Dare Not Speak Its Name*, 9 LINGUA FRANCA 42 (1999); Wilson & Reiner, *supra* note 4.

<sup>137</sup> *Pediatric Ethics*, *supra* note 4; J.M. Schober, *A Surgeon's Response to the Intersex Controversy*, 9 J. CLIN. ETHICS 393 (1998); Wilson & Reiner, *supra* note 4.

<sup>138</sup> D. Brown, Presentation on Intersex to the Catholic Pastoral Committee on Sexual Minorities, Minneapolis, MN (Nov. 17, 2003).

more evidence and research has been echoed by many health care providers and scientists, and has resulted in some of the first follow-up studies since the inception of the “normalization” paradigm. Indeed, this call for more research indicates a shift in the intersex injustice frame and objectives of the movement, from activists’ previous call to be heard to their new stance of needing more data to support their plea for surgical nonintervention. Some of the findings from this new research are just now beginning to be reported.

In 2003, British medical doctors, Catherine Minto, Liao, Woodhouse, Ransley and Creighton<sup>139</sup> published the results of a study examining adult women’s quality of life, sexual function, and psychological health following childhood clitoral surgery. They sampled intersex women from both clinical populations and intersex support groups. Their data showed overwhelmingly that the vast majority of these women (78%) were significantly negatively impacted by genital surgery with specific regard to sexual function, and that a full 39% were unable to achieve orgasm altogether.<sup>140</sup> To quote their findings directly,

Our results indicate that individuals who have had clitoral surgery are more likely than those who have not to report a complete failure to achieve orgasm and higher rates of non-sensuality—in particular, a lack of enjoyment in being caressed and in caressing their partner’s body. To claim that clitoral surgery has no long-term effect on sexual function is wrong.<sup>141</sup>

Additional studies focusing on gender identity development and the long-term outcome of male, rather than female, sex assignment for boys with micropenis are also in the works. Some have reported findings similar to Minto et al. In summary, the studies reveal that the less surgery, the less trauma.<sup>142</sup> These reports signify the significant shift in medicine to “spare the knife and study the child.”<sup>143</sup>

Even though the American Academy of Pediatrics and others may still be strong adherents of the “intersex is a social and medical emergency” paradigm, their willingness to be informed by former patient critiques is undoubtedly a dramatic shift. Instead of being relegated to “zapping” and picketing medical conventions, intersex activists are now being featured as invited keynote speakers at prominent medical conventions. Chase, for example, spoke at the May 2000 meeting of the Lawson Wilkins Pediatric Endocrine Society, giving “the grand

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<sup>139</sup> C.L. Minto et al., *The Effect of Clitoral Surgery on Sexual Outcome in Individuals Who Have Intersex Conditions with Ambiguous Genitalia: A Cross-Sectional Study*, 361 THE LANCET 9365 (Apr. 12, 2003).

<sup>140</sup> *Id.* at 1252.

<sup>141</sup> *Id.* at 1254.

<sup>142</sup> C.J. Migeon et al., *46, XY Intersex Individuals: Phenotypic and Etiologic Classification, Knowledge of Condition, and Satisfaction with Knowledge in Adulthood*, 110 PEDIATRICS e32 (2002); C.J. Migeon et al., *Ambiguous Genitalia with Perineoscrotal Hypospadias in 46, XY Individuals: Long-Term Medical, Surgical, and Psychosexual Outcome*, 110 PEDIATRICS e31 (2002); A.B. Wisniewski et al., *Congenital Micropenis: Long-Term Medical, Surgical and Psychosexual Follow-Up of Individuals Raised Male or Female*, 56 HORMONE RES. 3 (2001); Zucker, *supra* note 135.

<sup>143</sup> Drescher, *supra* note 130.

finale to a four-hour symposium on the treatment of [sexual] ambiguity in newborns.”<sup>144</sup> More recently, in May 2002, Chase addressed the First World Congress on the “Hormonal and Genetic Basis for Sexual Differentiation Disorder,” informing them of the agenda of the intersex patient advocacy movement. Clearly, the intersex patients’ rights and medical reform movement has garnered significant attention and has begun to effect change. As further evidence, consider the 1998 publication of the *Journal of Clinical Ethics* special issue on intersex, which brought together essays written by intersex activists, scholars, and physicians in one volume. This special issue was published in book form as *Intersex in the Age of Ethics* in 1999,<sup>145</sup> and featured photographs of the authors on the cover. Notably, this was the first time that photographs of intersex doctors and intersex individuals appeared alongside one another without drawing attention to intersexed genitalia. In fact, by looking at the photos alone, there is no way to discern between doctor and patient; intersexed and not.

Also consider the January 2000 formation of the North American Task Force on Intersex (NATFI), which is a clear example of frame bridging that has networked previously unconnected groups to address issues of intersex clinical treatment. The task force was convened by pediatric urologist Ian Aaronson of the Medical University of South Carolina in response to the increasing debate over medical sex assignment in order to reevaluate medical care for children with ambiguous sexual anatomy. A first of its kind, the committee is comprised of specialists from various medical fields, as well as ethicists and members of intersex advocacy organizations, including former patients and critics of medical sex assignment themselves. The committee represents the first decision-making body to bring patients and doctors together to discuss the topic of medical treatment of sexual variation.

The mission of the task force is to improve the standards and experience of medical treatment for people who are subjected to sex “normalizing” procedures. In addition to establishing new medical guidelines, the group has set out to address the previously ignored legal and ethical issues of informed consent and quality of life for intersex patients following medical sex assignment. In the words of founder Ian Aaronson,

We are committed to learn from past mistakes in order to offer the best advice and treatment to our patients in the future. Long-term outcome data is very sparse and selective, and this puts surgeons on tenuous ethical grounds. I was very gratified at the positive response from members of the professional community and the patient advocate groups to the notion of forming a Task Force.<sup>146</sup>

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<sup>144</sup> *The Five Sexes*, *supra* note 4, at 18.

<sup>145</sup> A.D. DREGER, ED., *INTERSEX IN THE AGE OF ETHICS* (University Publishing Group 1999).

<sup>146</sup> News Release, ISNA, North American Task Force on Intersex Formed, Seeks Broad Interdisciplinary Consensus on Treatment (Feb. 23, 2000).

Psychologist John Money, the now infamous psychologist who popularized the medical paradigm in question, is notably absent from the 30-person executive committee; however, strong proponents of the current medical model, including the pediatric endocrinologist Claude Migeon and the pediatric urologists John Gearhart and Antoine Khoury, may make up for his absence. In an apparent balancing act, some of the committee's members are among the most vocal critics of intersex medical management, including the Intersex Society of North America's founder Cheryl Chase and the social psychologist Suzanne Kessler. Perhaps one of the biggest indicators of change is that the primary professional medical associations that have even recently touted the merits of conventional sex assignment have signed on as supporters of the group. NATFI is endorsed by the American Academy of Pediatrics, the American Urological Association, the American Academy of Child and Adolescent Psychiatry, the American College of Medical Genetics, the Lawson Wilkins Pediatric Endocrine Society, the Society for Pediatric Urology, the Society for Fetal Urology, and the Society of Genitourinary Reconstructive Surgeons.

The American Academy of Pediatrics (AAP) is among the list of task force endorsers. Their support of this path-breaking patient-doctor dialogue comes just four years after Chase and other members of *Hermaphrodites with Attitude* picketed the AAP's annual conference when they were refused the opportunity to present patients' perspectives to conference goers.<sup>147</sup> But despite their willingness to back the efforts of the task force, the American Academy of Pediatrics published an article in July of 2000 that reaffirmed and amplified the organization's framing of intersex as a medical emergency and their commitment to prompt medical intervention. I take the following from this article, on which NATFI head Ian Aaronson is listed as a consultant:

The birth of a child with ambiguous genitalia constitutes a social emergency. Abnormal appearance can be corrected and the child raised as a boy or a girl as appropriate. Parents should be encouraged not to name the child or register the birth, if possible, until the sex of rearing is established. Infants raised as girls will usually require clitoral reduction which, with current techniques, will result not only in a normal-looking vulva but preservation of a functional clitoris. [These children's] diagnosis and prompt treatment require urgent medical attention.<sup>148</sup>

What we see, then, is not only an escalating level of interest in intersex issues within medicine and beyond, but also an entrenchment of the controversy surrounding treatment. While mainstream media coverage focused on issues of gender and sexual identity, and helped to place intersex issues on the map, medical responses to intersex activism focused more specifically on treatment issues and physicians' role in relation to intersex conditions. What this coverage reflects is

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<sup>147</sup> *The Five Sexes*, *supra* note 4.

<sup>148</sup> American Academy of Pediatrics, Committee on Genetics, *Evaluation of the Newborn with Developmental Anomalies of the External Genitalia*, 106 PEDIATRICS 138 (2000).

both the enduring belief among many physicians that intersex is pathological—indeed an emergency—as well as the opposing belief that intersex is simply a benign bodily variation that might warrant some intervention, but not necessarily surgery. What is striking here is that this debate has played out not only at medical conferences, but also in a more public fashion. That is, intersex in the public eye has come to represent not just a bodily condition having to do with sex and gender, but also a condition that is associated with medical controversy. Thus, while intersex is not considered exclusively pathological anymore, it is still lodged firmly within the realm of science and medicine. What people know about intersex continues to be filtered and framed through a biomedical lens.

### XIII. IMPLICATIONS OF INTERSEX IDENTITY POLITICS

The possibility of developing new clinical guidelines or alternatives to the current medical treatment of intersex is expanding rapidly as a result of intersex activism and new research in this area. With this possibility on the horizon and more and more doctors coming on board to help, the intersex movement has transformed not only the way intersex is seen, but the way it has chosen to represent itself as well. That is, the activist organization that once “zapped” medical conferences is now working on building bridges and on making changes from within the medical arena. Consider ISNA’s formation of a Medical Advisory Board in 2003, which currently has 25 members representing general practice, pediatric urology, pediatric endocrinology, nursing, social work, psychiatry, psychology, and bioethics. In 2003, ISNA also established their umbrella project, the Medical Education and Reform Initiative (MERI), which represents a number of ISNA’s new programs, such as the Medical Advisory Board. Some of the additional projects included in the MERI initiative are the distribution of ISNA’S documentary: *First Do No Harm: Total Patient Care for Intersex*, the development of medical guidelines, replete with clinicians’ and parents’ handbooks, and ISNA’s plan to revise textbook representations of intersex.

ISNA’s move toward policy and advocacy, and away from direct peer support, was begun under Chase and intensified under Casper’s brief leadership. During her time at ISNA, Casper helped to extend the intersex movement’s concerns to other movements and communities such as those focused on women’s health, disability rights, children’s rights, sexual rights, and reproductive rights. ISNA began a strategic planning process in 2003 designed to reposition the organization vis-à-vis these communities, while strengthening its relationship to the medical profession and other health care providers. It will be interesting to see if ISNA continues to connect intersex to these broader issues and expand in these new directions with Chase now back at the helm. It is clear that ISNA will be building on its commitment to “build a foundation for a world free of shame secrecy, and unwanted genital surgeries” in its recent announcement that “In 2004 ISNA’s

energies are focused on reforming U.S. medical education with regard to intersex” with a plan to “sweep the nation’s medical schools this year.”<sup>149</sup>

The future success of intersex activism may be linked not only to growing social tolerance of sex and gender variability and the continued development of electronic communications, but also to the ability to connect the fight against genital surgery on intersex children to two related movements: the human rights-based movement against female genital excision, and the international emergence of children’s rights. Intersex activists have participated in the former effort for several years already, attempting to expand the language banning female genital mutilation (FGM) in the 1996 U.S. federal bill to include a ban on intersex genital mutilation (IGM).<sup>150</sup> At the time of this writing, their efforts to pass this legislation have not yet been successful.

As the intersex movement looks to ahead to the future, activists have many crucial decisions to make about how best to frame intersex to further its accomplishments. Currently, efforts are underway to extend the framing of the intersex movement in some different and exciting directions that may result in increased recruitment and participation of individuals and groups who have similar ideologies and objectives. These new directions include connecting intersex issues to broader concerns of children’s rights, legal and research ethics such as informed consent, and disability rights. In terms of children’s rights, the crucial issues center on informed consent and protecting children from harmful practices. However, infants themselves will be unable to act as constituents of the movement; adults will continue to have to speak and act on behalf of children, raising some interesting and potentially troubling issues, including informed consent. In terms of informed consent, the crucial issues center on individuals’ rights to self-determination—something intersex activists believe is taken away from children whose genitals are surgically altered without their explicit consent. The intersex movement may also benefit from defining itself in terms of disability rights, articulating the ways in which intersexed bodies are defined as pathological and/or deviant. This may be tricky, however, as the movement has worked hard to destigmatize intersex, and redefining intersex as a “disability” or “defect,” no matter how strategically, could potentially further stigmatize intersex conditions.

Regardless of which direction intersex activists move politically, media activism is likely to continue to be an indispensable tool. Whole new audiences might be found by emphasizing any of the above directions. At the same time, however, activists need to balance new approaches with ongoing concerns and commitments. It would be unfortunate if a shift in direction led to a decrease in support for intersex issues among, for example, either GLBT communities or physicians advocating non-surgical approaches. Also, as the movement has professionalized, including developing more formal relationships with the medical

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<sup>149</sup> Intersex Society of North America, *What’s Happening at ISNA in 2004?*, at <http://www.isna.org/> (last visited Feb. 14, 2004).

<sup>150</sup> *Making Media*, *supra* note 42; *Mapping the Emergence*, *supra* note 4; Harvey, *supra* note 90.

and legal professions, activists need to be careful to not slip into the more “radical” stance taken in the early days of the movement. With increased legitimacy comes increased responsibility to speak in more “established” ways, as Intersex Initiative founder Emi Koyama reminds us in her decision to develop an activist organization untethered to such political concerns.

### CONCLUSIONS

In sum, the intersex social movement and its adversaries have engaged in meaningful framing processes that have helped to further the advancement of the movement’s objectives and the medical establishment’s clarification of its changing perspectives on intersex treatment. Studying the intersex movement’s use of the framing processes outlined by Snow and Benford,<sup>151</sup> Gamson,<sup>152</sup> and Snow et al.<sup>153</sup> has helped to clarify the political and social psychological means through which the movement has established itself and achieved some of its objectives regarding medical and broader social reform.

Intersex activism is illustrative of framing processes in a number of ways. First, it offers a compelling case study of a burgeoning social movement’s strategic use of media activism, both to shape public consciousness about an issue and also to transform fundamental social practices and relations. Second, it also shows how media coverage of a particular issue or constituency may both inflame and mitigate controversy, depending on context. That intersex is a controversial topic has been good for activists in the sense that such controversy has helped to change medical practices, but it has also made the quest for social acceptance and destigmatization that much more challenging. This is especially evident in the movement’s tensions about whether or not to link intersex with the discourse and objectives of other “sexual minorities.” Third, media intersex activism suggests that capitalizing on concerns that extend beyond an organization’s immediate grievance to address, for example, issues of human rights and medical ethics might pave the way for articulating additional concerns of broader social interest. Intersex media activism has served to amplify and connect intersex injustice frames with these broader social issues.

Before intersex mobilization and political and media activism, most North Americans didn’t know the meaning of the word *hermaphrodite*, let alone *intersex*. Within recent years, the topic of sexual ambiguity has been featured in national magazines, popular and educational television shows, and local news media. With the breadth of activists’ important and effective efforts to demedicalize and destigmatize intersex, scholars have placed the topic of sexual ambiguity under the rubric of queer theory and gender studies. As a result, a new field of intersex studies, replete with its own canon, is currently in formation. Moreover, some

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<sup>151</sup> *Ideology, Frame Resonance, and Participant Mobilization*, *supra* note 58.

<sup>152</sup> *The Social Psychology of Collective Action*, *supra* note 19.

<sup>153</sup> Snow et al., *supra* note 21.

university and community groups have extended the customary GLBT classification (now GLBTI) to demonstrate their inclusion of intersex issues among queer rights and politics.

The intersex movement has shaped and been reshaped by the strategic use of media activism. During the first decade of the movement's growth, key players, such as the Intersex Society of North America and Cheryl Chase, used the media to position intersex as an important concern, and to generate public support for the movement's goals, building a bridge between those concerned with intersex and those concerned with broader themes of human and children's rights. The major accomplishment of this period was to put intersex issues on the map, making intersex injustice frames familiar to previously "unconcerned" others, and to work toward increasing public understanding and acceptance of intersex. However, because some of these strategies were learned from gender warriors and transactivists, and because intersex is culturally linked to gender and sexuality, the issue of intersex has been conflated with issues of sexuality and gender. On the one hand, this has enabled intersex activists to gain allies in GLBT communities, including the provision of crucial movement funding and mentorship. On the other hand, this attention to sex and gender has precluded others from resonating with the intersex movement's grievances and goals.

The medical profession has also been very present in media discourse about intersex. Initially weighing in on what intersex is, medical professionals subsequently began to use the media to challenge one another about appropriate means and methods of responding to intersex. In this public exchange, medical doctors have both amplified the traditional medical perspective of intersex as a "social and medical emergency" as well as articulated an emerging trend in medical education and practice towards nonsurgical intervention. The past decade has seen a quite lively debate about how intersex should be treated, with many physicians adhering to a "traditional" surgical approach, and others advocating the newer model of delayed or even no surgery. What is clear is that general media coverage of intersex helped to broaden the movement organized around intersex advocacy, which in turn helped to place the medical debate at the forefront of key intersex issues. Intersex media activism has been instrumental in destabilizing heretofore widely accepted medical practices. While intersex activists have not reached their ultimate goal of preventing surgery on all intersexed infants (in the absence of life-threatening conditions), they have been successful in putting the medical profession on the defensive, and in sparking what has become a heated and increasingly consequential controversy.

Future research on intersex will likely continue to follow the current trend within medicine to gather longitudinal data, with a sometimes unfortunately limiting and stereotypical focus on gender and sexual identity (e.g. researchers' incessant curiosity about whether an intersex child gravitates towards playing with dolls or trucks). Fortunately, there are promising new studies that have begun to address the dearth of quality of life data. In addition to this new direction within

the field, there is a need for further research on the intersex movement's use of media as an activist tool. Such exploration could expand the focus of frame analysis beyond popular media discourse to include content analysis of intersex electronic and print media archives, such as intersex Internet websites and support group materials. Another crucial focus of study in this area is the process through which sexual ambiguity has become pathologized in medical education, practice, and parent consultation. Such research could explore the attitudes and practices of physicians and parents who are involved in the primary care of children with regard to medical treatment, counseling, and decision making for children who are born intersexed. Ultimately, this combined program of new research on intersex could further clarify the processes through which categories of normalcy, deviance, health, and pathology are socially and politically constructed.

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