

# REVISITING THE LIMITS OF PROFESSIONAL AUTONOMY: THE INTERSEX RIGHTS MOVEMENT'S PATH TO DE-MEDICALIZATION

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*Social movements that seek to change biomedical policy face the particularly challenging task of effectively contesting the scientific and normative basis used to justify medical professional practices in the present. Such is the case of the intersex rights movement, which fights to change the medical standard of genital-normalizing surgeries in infancy.<sup>1</sup> To change conventional medical policy, the movement is required not only to establish that such treatments are infringing on rights to bodily integrity and autonomy, but it also must invalidate the scientific ground on which the current treatment protocol is established. This Article analyzes and compares medical and legal activism, which are the two main approaches to achieving change in the intersex rights movement. This Article argues that medical activism leads to a substantial democratization of the policy-making process, and legal activism helps politicize the standard of care and stirs a public discussion over its legitimacy. While both medical and legal activism challenge existing medical standards, the costs of cooptation to the movement's ideology are not comparable. Activists who chose legal avenues remained loyal to their baseline agenda, whereas activists who chose to collaborate with the medical establishment made greater ideological compromises. I suggest that this is because unlike medical advocacy, legal activists make arguments based on justice and social values. Furthermore, this Article argues that the legal sphere serves a critical function to challenge professional norms because it supports political change in an allegedly apolitical arena.*

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<sup>1</sup> This Article uses, for the most part, the term "intersex" to indicate the condition of undetermined biological sex. However, because the nomenclature in this subject is contested and changing, this Article may use additional terms interchangeably according to the relevant professional and historical context, or in order to highlight controversies.

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## INTRODUCTION

“The problem with medicine is that it only listens to medicine—if you express an alternative viewpoint, you’re viewed as an activist . . . but there’s nothing to change practice like a lawsuit.”<sup>2</sup>

—Katrina Karkazis, medical anthropologist and advocate for intersex rights.

In 2013, the adoptive parents of M.C. filed two lawsuits in South Carolina against a hospital and the attending physicians who conducted a feminizing surgery on M.C.’s genitals when he was sixteen months old. M.C. was diagnosed as a “true hermaphrodite,” a condition describing the existence of both male and female reproductive structures, also known as Disorders of Sex Development (DSD) or Intersex.<sup>3</sup> M.C.’s feminizing surgery was conducted to assign him to the female sex and gender. The lawsuits argued that M.C.’s treatment was a medically unnecessary sex-assignment surgery that breached his statutory and constitutional rights. The lawsuits were filed with the support and representation of an advocacy organization from the intersex rights movement, which fights for the rights of people born with biological sex characteristics that do not fit neatly into male or female categories.<sup>4</sup> Since the 1990s, the movement has been struggling to change the conventional medical standard of care for intersex persons by asking to postpone irreversible interventions that are not medically necessary to a time when the patient can participate in the decision.<sup>5</sup> The movement’s agenda was that intersex conditions that are neither functionally disabling nor threatening to health are not pathological.<sup>6</sup>

The intersex rights movement, and other social movements that work to change biomedical policy, are required to pass socio-ethical and technical-professional boundaries. The intersex rights movement not only has to prove that its agenda is socially desirable, but it also must discredit the professional standards that authorize gender-normalizing practices to begin with. This Article will review the movement’s legal and non-legal efforts to collapse the

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<sup>2</sup> Azeen Ghorayshi, *Born In Between: Should Doctors Operate on Intersex Babies?*, BUZZFEED (Aug. 5, 2015), <https://www.buzzfeed.com/azeenghorayshi/born-in-between> [<https://perma.cc/VQ9Y-RRF2>].

<sup>3</sup> Ieuan A. Hughes, Christopher P. Houk, S. Faisal Ahmed & Peter A. Lee, *Consensus Statement on Management of Intersex Disorders*, 2 J. PEDIATRIC UROLOGY 488, 488 (2006) [hereinafter Hughes et al., *Consensus Statement on Management of Intersex Disorders*].

<sup>4</sup> The organization is now called InterACT (Advocates for Intersex Youth), and was formally called AIC (Advocates for Informed Choice), See INTERACTADVOCATES, <https://interactadvocates.org/about-us/mission-history/> [<https://perma.cc/2X4E-SX4M>].

<sup>5</sup> ISNA, <http://www.isna.org> [<https://perma.cc/76KY-XTS8>] (“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.”).

<sup>6</sup> ISNA, <https://www.isna.org/compare> [<https://perma.cc/UM5B-L9CX>].

normative and professional grounds on which these practices are established. By closely exploring the intersex movement's struggles, this Article will attempt to engage with a prominent dilemma that has long occupied legal scholars in the field of social change: Should activists use law to change medical practices, or should they pursue change through extralegal avenues such as direct engagement with medical professionals regarding their practices?

By examining the strategies used by the intersex rights movement, this Article offers a detailed case study that evaluates and compares the effectiveness of legal and non-legal activism to achieve the postponement of medical intervention on individuals born intersex. This Article evaluates the costs and benefits of legal and non-legal paths to social change by exploring the victories and defeats of each.

**Part I** of this Article introduces the medical profession's conventional definition and contemporary treatment of intersex persons and follows with a history of the emergence of the intersex rights movement, which inspired the de-medicalization project. This Part provides an analytic framework to distinguish between subgroups in the movement, which include the "identity activists," "treatment activists," and "assimilators," each of which has a different approach to de-medicalization. This Part ends with two claims about de-medicalization and the law, and it presents the main question that stands at the core of this Article: whether the law helps or disrupts the struggle of the intersex rights movement to release individuals from medical jurisdiction and correction.

**Part II** dives into the legal branch of activism, led mainly by identity activists, who use the law as a primary means of transforming the standard of care for intersex persons. This Part explores the various legal instruments that identity activists utilize to make their cases, particularly human rights advocacy and litigation around identification documents. The main thread that connects these techniques is the capacity to politicize the medical management of intersex persons while igniting values-based public discussion.

**Part III** is dedicated to the medical branch of activism, led mainly by treatment activists, who focus on direct engagement with medical institutions through a variety of forums that integrate patients and families with medical professionals. This engagement is meant to increase collaboration when it comes to designing clinical care and conducting research. These activities challenge the status quo of scientific production of knowledge and democratize biomedical policy-making.

**Part IV** provides an overview of the criticisms directed towards both legal and medical activism. This Part focuses mostly on the cooptation critique, used to describe the varying degrees of institutional and ideological

assimilation of activists with the systems they use to implement change.<sup>7</sup> In the legal context, cooptation refers to problems of movement fragmentation and engagement with identity politics. In the medical context, cooptation addresses a similar set of problems such as de-radicalization of the movement's agenda and legitimization of the current pathological approach to intersex care.

**Part V** explores a possible advantage of legal activism in the context of biomedical reform based on the experience of the intersex movement's struggle. It argues that despite the familiar cooptation critique, cooptation by the law did not destroy the movement's original de-medicalization efforts. This is because activists were not required to preserve a collaborative relationship with medical professionals when pursuing legal avenues and because legal language and arguments provide space to express a normative agenda.

Ultimately, this Article demonstrates that legal and medical activism are both useful techniques for advocacy that produce an aggregate challenge to the medical status quo, but criticizes different ways in which each strategy transforms the social movement and its agenda. While activists may have been coopted by both medical and legal professions, medical cooptation was more detrimental to the objective of de-medicalization for the intersex movement. For intersex activists, law is better equipped to obtain the objective of de-medicalization. Therefore, this Article further contends that legal domains provide a critical space for a collective social review of highly established professional standards in a deliberative manner.

## I. THE INTERSEX RIGHTS MOVEMENT'S STRUGGLE AGAINST MEDICALIZATION

Medicalization of intersex in the United States and Europe began in the early 19th century, and accelerated since the 1930s, leading to the creation of the modern medical approach to intersex. Contemporary intersex rights activists resist the current medical model of intersex and fight to end the shame and secrecy around being intersex.<sup>8</sup> This Section describes the history and development of the traditional medical view of intersex and the three main approaches by activists to change the current treatment of intersex. It ends with two speculative illustrations about the role of law in the execution of the activists' anti-medicalization agenda.

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<sup>7</sup> See discussion of cooptation in Orly Lobel, *The Paradox of Extralegal Activism: Critical Legal Consciousness and Transformative Politics*, 120 HARV. L. REV. 937, 948–56 (2007).

<sup>8</sup> Peter Conrad defines medicalization as “a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses or disorders.” See Peter Conrad, *Medicalization and Social Control*, 18 ANN. REV. SOC. 209, 209 (1992). De-medicalization is often defined as “the obverse of medicalization.” Drew Halfmann, *Recognizing Medicalization and Demedicalization: Discourses, Practices, and Identities*, 16 HEALTH 186, 187 (2011).

### A. *What is Intersex?*

“Intersex” is an umbrella term used to describe different conditions in which a person’s birth sex is not clearly established by any of the commonly used sex indicators, such as chromosomes (XY/XX), gonads (testes/ovaries), genitals (penis/clitoris), hormones (Androgens/Estrogens) or secondary sex characteristics like breasts and body hair.<sup>9</sup> Typically, five conditions are grouped under the intersex umbrella. The first condition is Congenital Adrenal Hyperplasia (CAH), in which the body produces high levels of the “male sex hormone” Androgen.<sup>10</sup> In the case of genetic females with CAH (those with XX chromosomes), they may develop masculinized genitals at birth or later. If not treated, CAH sometimes causes potentially dangerous problems with salt-metabolism.<sup>11</sup> The second condition is Androgen Insensitivity Syndrome (AIS), a condition in which genetic males (those with XY chromosomes) are born with insensitivity to androgen, leading to the development of some or all of the physical traits associated with females, including feminine-looking genitals.<sup>12</sup> Another common condition is Hyperandrogenism, which is characterized by an elevated concentration of Androgen.<sup>13</sup> After professional athletes Caster Semenya and Dutee Chand were associated with having Hyperandrogenism, the condition received large media attention.<sup>14</sup> In females, this Hyperandrogenism leads to clitoral enlargement, a reduction in breast size, and the development of a “male body habitus.”<sup>15</sup> The fourth condition is Turner Syndrome, which describes genetic females who are “missing” one X chromosome, leading to the abnormal development of gonads and secondary sex characteristics. The fifth condition is Klinefelter Syndrome, in which genetic males have an “extra” X chromosome (XXY), also leading to the development of abnormal gonads and breasts after puberty.<sup>16</sup> The United Nations Fact Sheet about intersex estimates that 0.05% to

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<sup>9</sup> JULIE A. GREENBERG, INTERSEXUALITY AND THE LAW: WHY SEX MATTERS 11–18 (2012).

<sup>10</sup> Chad Haldeman-Englert, *Congenital Adrenal Hyperplasia*, MEDLINEPLUS (Oct. 27, 2015), <https://www.nlm.nih.gov/medlineplus/ency/article/000411.htm> [<https://perma.cc/9PN7-GU69>].

<sup>11</sup> ANNE FAUSTO-STERLING, *SEX/GENDER: BIOLOGY IN A SOCIAL WORLD* 25 (2012).

<sup>12</sup> Chad Haldeman-Englert, *Androgen Insensitivity Syndrome*, MEDLINEPLUS (Sept. 11, 2014), <https://medlineplus.gov/ency/article/001180.htm> [<https://perma.cc/7ZLT-HMAQ>].

<sup>13</sup> CLINICAL FINDINGS IN HYPERANDROGENISM, *THE JOHNS HOPKINS MANUAL OF GYNECOLOGY AND OBSTETRICS* 536 (Johnson Clark et al. eds., 5th ed., 2015).

<sup>14</sup> Katrina Karkazis & Rebecca Jordan-Young, *The Trouble With Too Much T*, N.Y. TIMES (Apr. 10, 2014), <http://www.nytimes.com/2014/04/11/opinion/the-trouble-with-too-much-t.html>; Ruth Padawer, *The Humiliating Practice of Sex-Testing Female Athletes*, N.Y. TIMES MAGAZINE (June 28, 2016), <https://www.nytimes.com/2016/07/03/magazine/the-humiliating-practice-of-sex-testing-female-athletes.html>.

<sup>15</sup> Clark et al., *supra* note 13, at 538–39.

<sup>16</sup> FAUSTO-STERLING, *supra* note 11, at 25.

1.7% of people born are intersex,<sup>17</sup> though more radical estimations suggest that intersex accounts for 4% of all births.<sup>18</sup>

In modern western cultures, intersex babies are assigned to one sex or the other immediately following birth through different medical interventions. Historically, medical practitioners made independent decisions regarding sex assignment and treatment and often failed to tell parents the nature of normalization procedures.<sup>19</sup> Today, however, the parents usually choose the sex after receiving medical advice about the prospects of an optimal sex assignment.<sup>20</sup> Physicians have nevertheless admitted that there is uncertainty in choosing the supposedly “right” sex.<sup>21</sup> Doctors attempt to predict the future gender identity that is most likely to emerge according to genetic, chromosomal, and hormonal indicators, knowing that none of these factors can fully predict or offer definitive conclusions about someone’s sex or gender identity.<sup>22</sup> Some intersex persons comply with the sex chosen for them in infancy or childhood, though many eventually reject it.<sup>23</sup>

After a decision is made regarding gender assignment, the child often undergoes hormonal therapy and surgical interventions to create normal-looking genitalia and secondary sex characteristics that are coherent with the chosen gender of rearing.<sup>24</sup> Genitoplasty surgeries may include a clitoris reduction (Clitoroplasty), penile reconstruction, vaginal dilatation, and refashioning of the perineum, among other procedures.<sup>25</sup> In some instances, gonad

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<sup>17</sup> UNITED NATIONS OFFICE OF THE HIGH COMMISSIONER, INTERSEX FACT SHEET, [https://www.unfe.org/system/unfe-65-Intersex\\_Factsheet\\_ENGLISH.pdf](https://www.unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf) [https://perma.cc/HZ2Z-6PVY].

<sup>18</sup> For example, there is a dispute between Anne Fausto-Sterling claiming the rate is 1.7% and Leonard Sax arguing the rate is only 0.018%. See ANNE FAUSTO-STERLING, *SEXING THE BODY: GENDER POLITICS AND THE CONSTRUCTION OF SEXUALITY* 51 (2000); Leonard Sax, *How Common Is Intersex? A Response to Anne Fausto-Sterling*, 39 J. SEX RES. 174, 177 (2002). Extreme estimations can go far as 4%. See Kate Haas, *Who Will Make Room for the Intersexed?*, 30 AM. J.L. & MED. 41 (2004). But even according to conservative estimations, in the United States alone there are approximately 2.7 million intersex people. Julie A. Greenberg, *Defining Male and Female: Intersexuality and the Collision Between Law and Biology*, 41 ARIZ. L. REV. 265, 267 (1992).

<sup>19</sup> See Peter A. Lee et al., *Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care*, HORMONE RES. PAEDIATRIC 158, 170 (2016); Kenneth Kipnis & Milton Diamond, *Pediatric Ethics and the Surgical Assignment of Sex*, 9 J. CLINICAL ETHICS 398, 398 (1998).

<sup>20</sup> Lee et al., *supra* note 19, at 168.

<sup>21</sup> See Jakub Mieszcza, Christopher P. Houk & Peter A. Lee, *Assignment of the Sex of Rearing in the Neonate with a Disorder of Sex Development*, 21 CURRENT OPINION PEDIATRICS 541, 541 (2009).

<sup>22</sup> See Claudia Wiesemann, *Ethical Guidelines for the Clinical Management of Intersex*, 4 SEX DEV 300, 302 (2010).

<sup>23</sup> See INTERSEX SOCIETY OF NORTH AMERICA, CLINICAL GUIDELINES FOR THE MANAGEMENT OF DISORDERS OF SEX DIFFERENTIATION IN CHILDHOOD 25–26 (2006), <http://www.dsdguidelines.org/files/clinical.pdf> [https://perma.cc/F3FC-TFPC].

<sup>24</sup> See Catherine 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 LANCET 1252, 1252 (2003).

<sup>25</sup> See Ieuan A. Hughes et al., *Consequences of the ESPE/LWPES Guidelines for Diagnosis and Treatment of Disorders of Sex Development*, 21 BEST PRAC. RES. CLINICAL

removal surgery is also performed on XY children who are raised as girls or to avoid risk of future malignancy.<sup>26</sup> This treatment approach is primarily based on the supposition that creating normal-looking genitals in infancy combined with normative sex rearing is likely to generate a coherent gender identity, enhancing child-parent relationships and later social acceptance.<sup>27</sup>

Since the beginning of the 1990s, intersex people, ethicists, human rights activists, and even physicians heavily criticized the practice of sex assignment surgery in childhood. Such objectors argued that surgeries focused on sculpting external organs potentially removed orgasmic tissues and harmed reproductive abilities.<sup>28</sup> They also contended that current practices generally violated the patient's autonomy by assigning them to a sex through an irreversible procedure in infancy using the consent of their parents alone; they believed that the secrecy that traditionally accompanied medical normalization efforts caused shame, anger, and frustration among intersex adults and their families.<sup>29</sup> Critics have also often argued that the normalization project is driven by sexist views of gender and aspires to instill a heteronormative ideal.<sup>30</sup>

Critics and defenders of mainstream medical practices strongly disagree about both the success of normalization procedures' outcomes and satisfaction rates. The defenders of the medical approach assert that general satisfaction rates from early normalization surgeries are high.<sup>31</sup> They argue that

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ENDOCRINOLOGY & METABOLISM 351, 362–63 (2007) [hereinafter Hughes et al., *Consequences of the ESPE/LWPES*]; Hughes et al., *Consensus Statement on Management of Intersex Disorders*, *supra* note 3 at 491.

<sup>26</sup> See Hughes et al., *Consequences of the ESPE/LWPES*, *supra* note 25, at 363.

<sup>27</sup> See Anne Tamar-Mattis, *Exceptions to the Rule: Curing the Law's Failure to Protect Intersex Infants*, 21 BERKELEY J. GENDER L. & JUST. 59, 64 (2006); S.M. Creighton & L.M. Liao, *Changing Attitudes to Sex Assignment in Intersex*, 93 BRIT. J. UROLOGY INT'L 659, 661 (2004); Kristin Zeiler & Anette Wickstrom, *Why Do 'We' Perform Surgery on Newborn Intersexed Children? The Phenomenology of Parental Experience of Having a Child with Intersex Anatomies*, 10 FEMINIST THEORY 359, 359–60 (2009).

<sup>28</sup> See Tamar-Mattis, *supra* note 27, at 67–68; MARCUS DE MARIA ARANA, A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL 'NORMALIZATION' OF INTERSEX PEOPLE: A REPORT OF A PUBLIC HEARING BY THE HUMAN RIGHTS COMMISSION OF THE CITY & COUNTY OF SAN FRANCISCO 20–21 (2005).

<sup>29</sup> SHARON E. PREVES, FOR THE SAKE OF THE CHILDREN: DESTIGMATIZING INTERSEXUALITY: INTERSEX IN THE AGE OF ETHICS 51–58 (Alice Domurat Dreger ed., 1999). For testimonies of people with intersex anatomies see DE MARIA ARANA, *supra* note 28, at 36–45; Janik Bastien-Charlebois, *My Coming Out: The Lingering Intersex Taboo*, MONTREAL GAZETTE (Aug. 9, 2015), <http://montrealgazette.com/life/my-coming-out-the-lingering-intersex-taboo> [<https://perma.cc/ZE6Q-N49R>].

<sup>30</sup> *U.S. Harmful Surgery on Intersex Children*, HUMAN RIGHTS WATCH (July 25, 2017), <https://www.hrw.org/news/2017/07/25/us-harmful-surgery-intersex-children> [<https://perma.cc/8D8S-4DVB>].

<sup>31</sup> One piece of recent research reported higher satisfaction rates among patients that underwent surgical construction. See Ute Thyen et al., *Utilization of Health Care Services and Satisfaction with Care in Adults Affected by Disorders of Sex Development (DSD)*, 29 J. GEN. INTERNAL MED. S752, S755–56 (2014). Some research done from a psychological perspective reports general satisfaction, but sheds doubt on the ability of the gender binary approach to include the spectrum of identifications that intersex people experience in adulthood. See, e.g., Katinka Schweizer et al., *Gender Experience and Sat-*

“surgery is done because it is thought to result in better psychological outcomes for the child than leaving the genitalia unaltered,”<sup>32</sup> and because “it is generally felt that surgery that is performed for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents.”<sup>33</sup> However, such statements are controversial, even among medical professionals, and recent studies published in medical journals have urged the medical community to reexamine findings and approaches.<sup>34</sup>

### B. *The Rise of the Social Model of Intersex*

Critics who view medical normalization as harmful offer an alternative view of intersex. De-medicalization activists view intersex as biological or human variance instead of a pathology.<sup>35</sup> This view resembles a central tenet of the disability movement, namely, that disabled bodies are not inherently pathological, but that disability is in large part socially constructed.<sup>36</sup> Accordingly, disability studies distinguish between medical and social models of disability. While the medical model views disability as a tragedy and hence seeks to “fix” the problem, the social model shifts attention away from the individual towards the social, economic, and cultural constraints that disable the individual.<sup>37</sup> Similarly, activists who reject the pathological

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*isfaction with Gender Allocation in Adults with Diverse Intersex Conditions (Divergences of Sex Development, DSD)*, 5 PSYCHOL. & SEXUALITY 56, 73 (2014). For earlier research demonstrating good satisfaction rates see Wei Ling Lean et al., *Cosmetic and Anatomic Outcomes After Feminizing Surgery for Ambiguous Genitalia*, 40 J. PEDIATRIC SURGERY 1856, 1857–58 (2005); Garry Warne et al., *A Long-Term Outcome Study of Intersex Conditions* 18 J. PEDIATRIC ENDOCRINOLOGY & METABOLISM 555, 562 (2005).

<sup>32</sup> Catherine Minto & Froukje M. E. Slijper, *Clitoral Surgery Could Impair Sexual Function for People with Intersex Conditions*, EUREKALERT! (Apr. 10, 2003), [https://www.eurekalert.org/pub\\_releases/2003-04/l-csc040903.php](https://www.eurekalert.org/pub_releases/2003-04/l-csc040903.php) [<https://perma.cc/B882-AG4G>].

<sup>33</sup> See Lee et al., *supra* note 19, at 153.

<sup>34</sup> See, e.g., Douglas A. Canning, *Can We Correct Hypospadias with a Staged Operation? If Not, Are We Bold Enough to Report it?*, 194 J. UROLOGY 284, 284 (2015); Irina Stanasel et al., *Complications Following Staged Hypospadias Repair Using Transposed Preputial Skin Flaps*, 194 J. UROLOGY 512, 512 (2015); Birgit Köhler et al., *Satisfaction with Genital Surgery and Sexual Life of Adults with XY Disorders of Sex Development: Results from the German Clinical Evaluation Study*, 97 J. CLINICAL ENDOCRINOLOGY & METABOLISM 577, 577 (2012).

<sup>35</sup> The claim is that atypical reproductive systems are not inherently ill, but are rather an expression of the spectrum of natural anatomical and biological values. A similar diversity claim is made in the context of neurology. See Pier Jaarsma & Stellan Welin, *Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement*, 20 HEALTH CARE ANALYSIS 20, 20–30 (2012).

<sup>36</sup> Sagit Mor, *Between Charity, Welfare, and Warfare: A Disability Legal Studies Analysis of Privilege and Neglect in Israeli Disability Policy*, 18 YALE J.L. & HUMAN. 63, 69–71 (2006).

<sup>37</sup> *Id.*

view of intersex conditions seek to draw attention to the societal and cultural constructs that fuel pathological labeling of intersex persons.<sup>38</sup>

Although it seems almost impossible to think about intersex outside of the medical context, recent history demonstrates that intersexuality was once a familiar condition in public life, subject to regulation by other, non-medical systems. Before the nineteenth century, intersex people (known then as hermaphrodites) were not routinely subjected to intrusive medical correction procedures but were regulated instead by religious and legal codes.<sup>39</sup> Such codes attempted to solve particular difficulties concerning hermaphrodites, including marital and property rights.<sup>40</sup> However, with the development of modern medical sciences and sophisticated surgical techniques, the medical profession gradually gained jurisdiction over intersex people in the U.S and Europe,<sup>41</sup> turning intersex into an exclusively medical issue governed by clinical guidelines.<sup>42</sup> Medical normalization technologies, both hormonal and surgical, started becoming a formal treatment recommendation in the 1950s at Johns Hopkins Hospital.<sup>43</sup> There, collaboration between leading doctors, including the famous psychologist Dr. John Money, led to the publication of several articles containing treatment recommendations for hermaphrodites.<sup>44</sup> In 1965, Dr. Money argued that it was necessary to surgically correct external organs to fit genetically-assigned sex.<sup>45</sup> The protocols issued by the med-

<sup>38</sup> For a development of this idea with respect to the social model of disability, see Iain Morland, *Postmodern Intersex*, in *ETHICS AND INTERSEX* 319, 326 (David N. Weiss-tub ed., 2006) (analyzing the writings of Alice Dreger). Bioethicist Ellen K. Feder offers to locate “the problem” outside the body. Ellen K. Feder, *Tilting the Ethical Lens: Shame, Disgust, and the Body in Question*, 26 *HYPATIA* 632, 633–35 (2011).

<sup>39</sup> FAUSTO-STERLING, *supra* note 11, at 33.

<sup>40</sup> *Id.*

<sup>41</sup> See ALICE DOMURAT DREGER, *HERMAPHRODITES AND THE MEDICAL INVENTION OF SEX* 10–13 (1998); *What’s the History Behind the Intersex Rights Movement?*, ISNA, <http://www.isna.org/faq/history> [<https://perma.cc/DY4R-KULB>].

<sup>42</sup> KATRINA KARKAZIS, *FIXING SEX: INTERSEX, MEDICAL AUTHORITY, AND LIVED EXPERIENCE* 287 (2008).

<sup>43</sup> Minto et al., *supra* note 24, at 1252; *Hopkins Hospital: a history of sex reassignment*, THE JOHNS HOPKINS NEWS-LETTER (May 1, 2014), <http://www.jhunewsletter.com/2014/05/01/hopkins-hospital-a-history-of-sex-reassignment-76004/> [<https://perma.cc/MMBK-4TN2>].

<sup>44</sup> See John Money, Joan G. Hampson & John L. Hampson, *An Examination of Some Basic Sexual Concepts: The Evidence of Human Hermaphroditism*, 97 *BULL. JOHNS HOPKINS HOSP.* 301, 319 (1955); Joan G. Hampson, *Hermaphroditic Genital Appearance, Rearing, and Eroticism in Hyper Adrenocorticism*, 96 *BULL. JOHNS HOPKINS HOSP.* 301, 319 (1955); John Money, Joan G. Hampson & John L. Hampson, *Sexual Incongruities and Psychopathology: The Evidence of Human Hermaphroditism*, 98 *BULL. JOHNS HOPKINS HOSP.* 43, 55–56 (1955); John L. Hampson, Joan G. Hampson & John Money, *The Syndrome of Gonadal Agenesis (Ovarian Agenesis) and Male Chromosomal Pattern in Girls and Women: Psychologic Studies*, 97 *BULL. JOHNS HOPKINS HOSP.* 265, 273 (1955); John Money, Joan G. Hampson & John L. Hampson, *Hermaphroditism: Recommendations Concerning Assignment of Sex, Change of Sex, and Psychologic Management*, 97 *BULL. JOHNS HOPKINS HOSP.* 284, 299–300 (1955).

<sup>45</sup> John Money, *Psychologic Evaluation of the Child with Intersex Problems*, 36 *PEDIATRICS* 51, 55 (1965).

ical team at Hopkins had extensive influence on clinical practice that largely remains in place today.

Patient advocacy resistance gained momentum in the 1990s when Cheryl Chase founded the Intersex Society of North America (ISNA).<sup>46</sup> The organization was originally designed to provide day-to-day support for intersex people, but gradually began to advocate for systemic change in intersex management practices.<sup>47</sup> ISNA activists called for an end to the shame and secrecy that surrounded intersexuality and argued that we should postpone genital correction surgeries until intersex people were able to decide if and what type of surgery they wished to have.<sup>48</sup> ISNA challenged both the moral and scientific foundations of intersex medical management and defined normalization surgeries as violations of basic liberties and human rights.

Much of the fight around the pathologization of intersex conditions has centered on social meaning of intersex in general.<sup>49</sup> Since the establishment of the ISNA, an important step towards self-affirmation has been the creation of an intersex identity to be used in professional nomenclature debates as well as in everyday life. As noted above, until the mid-nineteenth century, physicians used the term “hermaphrodite” for a wide spectrum of conditions for which a person’s sex did not comport with common indicators.<sup>50</sup> The ISNA activists wanted to move away from the archaic label of “hermaphrodite” toward a less figurative and misleading name like “intersex.”<sup>51</sup> The formation of “intersex” as a new, self-affirming identity available to others successfully created an alternate discourse that empowered intersex individuals to generate knowledge and a community.

In a revealing book about the inner politics of the intersex rights movement, Georgiann Davis notes that during the identity-formation years, intersex individuals exchanged experiences and knowledge through a kind of

<sup>46</sup> See Cheryl Chase, *What is the Agenda of the Intersex Patient Advocacy Movement?*, 13 *ENDOCRINOLOGIST* 240, 240 (2003).

<sup>47</sup> Alice D. Dreger & April M. Herndon, *Progress and Politics in the Intersex Rights Movement: Feminist Theory in Action*, 15 *GLQ-J. LESBIAN GAY STUD.* 199, 204 (2009).

<sup>48</sup> ISNA, <http://www.isna.org> [<https://perma.cc/76KY-XTS8>] (“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.”).

<sup>49</sup> As was the case of other “new” social movements from the 1980s that worked under an “identity-oriented” paradigm. See Jean L. Cohen, *Strategy or Identity: New Theoretical Paradigms and Contemporary Social Movements*, 52 *SOC. RES.* 663, 663–65 (1985).

<sup>50</sup> ELIZABETH REIS, *BODIES IN DOUBT: AN AMERICAN HISTORY OF INTERSEX* 42–43 (2009).

<sup>51</sup> The term intersex was introduced in 1917 by the biologist Richard Goldschmidt to describe lack of coherence in sex anatomy features. *Id.* at 154; Alice D. Dreger et al., *Changing the Nomenclature/Taxonomy for Intersex: A Scientific and Clinical Rationale*, 18 *J. PEDIATRIC ENDOCRINOLOGY & METABOLISM* 729, 732 (2005); *Is a Person Who is Intersex a Hermaphrodite?*, ISNA, <http://www.isna.org/faq/hermaphrodite> [<https://perma.cc/QS9D-BJEW>].

“informational biocitizenship” that enhanced their scientific expertise.<sup>52</sup> Together they employed confrontational mobilization strategies, such as protests and public criticism that forced medical institutions to consider their positions and value the perspectives of intersex patients when devising clinical guidelines.<sup>53</sup> As a byproduct of the emergence of this new identity, patient-advocacy organizations, community members, and even medical practitioners to some extent, began to use the term “intersex.”<sup>54</sup> However, the term was not fully embraced by all. Some parents worried that it marked their children as a third gender and felt uncomfortable with the intermediacy that the name imposed on them. Others found it just as disparaging as “hermaphrodite” and put too bright a spotlight on the sexual aspects of the condition rather than on anatomical differences.<sup>55</sup> The greatest challenge, however, came from the medical profession itself.

2006 was a turning point for the movement when the medical profession began to seriously absorb the movement’s criticisms. That year, Cheryl Chase and Barbra Thomas were invited to participate in a conference organized by the Lawson Wilkins Pediatric Endocrine Society and the European Society for Pediatric Endocrinology in Chicago. This led to the creation of a contemporary treatment protocol known as the “Consensus Statement on Management of Intersex Disorders” (“2006 consensus”).<sup>56</sup>

In the 2006 consensus, the American Academy of Pediatrics (AAP) used the term “DSD” instead of “intersex,” transforming the movement once again. The AAP defined DSD as a disorder in sex development “in which development of chromosomal, gonadal, or anatomic sex is atypical,” in order to enhance patient-doctor communication about diagnosis and management options.<sup>57</sup> This new nomenclature created a division between those who were willing to accept DSD terminology and work with medical professionals, and those who preferred intersex. Those who adhered to the intersex terminology claimed that the term “DSD” pathologized intersex while violating the movement’s original core principle: namely, that intersex requires neither medical intervention nor a “cure.”<sup>58</sup> Although prominent figures in the movement endorsed DSD terminology for mostly pragmatic reasons, in particular a desire to facilitate dialogue between activists and medical pro-

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<sup>52</sup> GEORGIANN DAVIS, *CONTESTING INTERSEX: THE DUBIOUS DIAGNOSIS* 33–34 (2015).

<sup>53</sup> According to Davis the guidelines issued by the American Academy of Pediatrics (AAP) in year 2000 signified a slight change in attitude towards the consideration of fertility potential, and capacity for normal sexual function, and were proof that the activists were successful in gaining increasing credibility. *Id.* at 42.

<sup>54</sup> See REIS, *supra* note 50, at 155.

<sup>55</sup> *Id.*

<sup>56</sup> Hughes et al., *Consensus Statement on Management of Intersex Disorders*, *supra* note 3 at 488–89.

<sup>57</sup> *Id.*

<sup>58</sup> REIS, *supra* note 50, at 156; Sherri Groveman Morris, *DSD But Intersex Too: Shifting Paradigms Without Abandoning Roots*, ISNA (May 24, 2006), <http://www.isna.org/node/1067> [<https://perma.cc/LVH7-C6HQ>].

professionals, Davis notes that the use of DSD language was hotly contested and highly divisive.<sup>59</sup>

Today, different terms are strategically used by stakeholders when referring to intersex management. Though the use of archaic terms such as “hermaphroditism” is scarce in general, the use of DSD and intersex terminology is often simultaneous and determined by context.<sup>60</sup> Davis argues that the medical profession offered the term “DSD” as an attempt to reclaim their jurisdiction over intersex. Accordingly, the acceptance of DSD terminology by some organizations brought about a shift in activism itself from “collective confrontation” to “contested collaboration,”<sup>61</sup> suggesting that the movement is now divided between collaborators and confrontationists.

Ultimately, this divide led to the dissolution of the ISNA to better facilitate collaboration between activists and medical professionals. The 2006 consensus symbolized the cooptation of radical voices within the movement into the medical establishment. Chase mentioned in a phone call to one activist that the ISNA was closing and “opening a more conservative organization,” which would work with medical professionals and accept the DSD terminology over the term “intersex.” The activist, along with many others, was amazed and disappointed.<sup>62</sup> Some movement members resisted the collaboration and others even saw it as a betrayal and abandonment of the original goal of de-medicalization.<sup>63</sup> The collaborative approach remains controversial. Some intersex community members even claim that the movement is no longer working *with* the medical community, but working *for* it.<sup>64</sup>

Inner conflicts over nomenclature suggest that activists have partly rejected, partly accepted, and partly engaged with the medical model of intersex as DSD. Over the past two and a half decades, mainstream voices in the intersex movement in the U.S. have pushed for the modern standard of care to show greater tolerance for biological variation, while more radical voices have advocated for the wholesale de-medicalization of intersex conditions that do not pose a threat to health. As a result, subgroups within the movement have employed a variety of strategies both to reduce the scope of medical jurisdiction and to actively create self-affirming identities by making space for new social and cultural displays of intersexuality. It is precisely because of the ideological variety within the intersex movement that this Article can evaluate the successes and failures of medical and legal activism.

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<sup>59</sup> DAVIS, *supra* note 52, at 97–106.

<sup>60</sup> *Why is ISNA using “DSD?”*, ISNA (May 24, 2006, 9:02 AM), <http://www.isna.org/node/1066> [<https://perma.cc/4FUB-GF9Q>]; ADVOCATES FOR INFORMED CHOICE (AIC), STRATEGIC PLAN 2015, 15–16 (2015), <http://aiclegal.us1.list-manage1.com/track/click?u=f8291560ebb2dafc25097480f&id=0e53ab2e51&e=2a170b812a> [<https://perma.cc/Y795-KQN2>].

<sup>61</sup> DAVIS, *supra* note 52, at 46.

<sup>62</sup> *Id.* at 48.

<sup>63</sup> See KARKAZIS, *supra* note 42, at 259.

<sup>64</sup> DAVIS, *supra* note 52, at 50.

### C. *Movement in Conflict: Ideologies on De-medicalization*

In this Section, I present the three main approaches by the intersex movement to incite change as represented by movement members, whom I call: “identity activists,” “treatment activists,” and “assimilators.”<sup>65</sup> The goal of this typology is to outline the three main ideologies within the intersex movement and explore their relationship to the current medical profession’s pathological approach to intersex care.<sup>66</sup>

#### 1. *Identity Activists*

“I respect everyone’s right to identify as whatever they want, but personally, saying that intersex is what I am, feels much better than saying it’s something I have—like a disease.”<sup>67</sup>

– Hida Viloría, a prominent intersex activist and chairperson of the Organization Intersex International (“OII”).

Identity activists reject the pathological approach to intersex conditions and strive to create a separate political and social identity around intersexuality. They work to strengthen the creation of a self-affirming intersex identity by increasing intersex visibility in the social sphere and in popular media,<sup>68</sup> and even advocating for legal recognition of a “third sex” category.

OII is one organization that represents the identity activist approach. Founded in 2008, OII is an international network for intersex activists that placed itself in opposition to the perceived collaboration between the ISNA

<sup>65</sup> My proposed typology of internal principle conflicts might also be applicable to other health related movements like the deaf and autistic communities, whose pathology has been contested through identity and cultural narratives. See generally ANDREW SOLOMON, *FAR FROM THE TREE: A DOZEN KINDS OF LOVE* 50–51 (2013) [(describing anti-pathological narratives in the Deaf culture)]; Daniela Caruso, *Autism in the U.S.: Social Movement and Legal Change*, 36 AM. J.L. & MED. 483, 494–95 (2010) [(demonstrating a taxonomy of the Autism movement following lines of identity and disability)].

<sup>66</sup> In fact, even within this very particular issue, the division I offer is very basic and does not elaborate nuanced positions within the three subgroups. I recognize, for example, that amongst treatment activists one would find different levels of resistance ranging from slight modifications to current protocol on the moderate end to virtual de-medicalization on the extreme end.

<sup>67</sup> Hida Viloría, *What’s in a Name: Intersex and Identity*, ADVOCATE (May 14, 2014), <http://www.advocate.com/commentary/2014/05/14/op-ed-whats-name-intersex-and-identity> [https://perma.cc/XW6M-YMJW].

<sup>68</sup> See Inter-Act’s involvement in the MTV show *Faking It*, which features an intersex character. Kimberly Zieselman, *AIC Plays a Role this Season in MTV’s New Hit Show, Faking It!*, INTERACT (Sept. 12, 2014), <http://aiclegal.org/aic-plays-a-role-this-season-in-mtvs-new-hit-show-faking-it/> [https://perma.cc/B8KG-VAN6]; James Michael Nichols, ‘*What It’s Like to Be Intersex*’ Explains And Clarifies Intersex Identity [Video], HUFFINGTON POST (Mar. 31, 2015), [http://www.huffingtonpost.com/2015/03/31/intersex-identity\\_n\\_6977528.html](http://www.huffingtonpost.com/2015/03/31/intersex-identity_n_6977528.html) [https://perma.cc/Z7J6-LZZH]. For another example, see HERMAPHRODITES SPEAK! a film that presents healthy and satisfied intersex adults who hadn’t gone through corrective surgery, INTERSEX SOC’Y OF N. AM., HERMAPHRODITES SPEAK! (1996).

and medical institutions. OII limited its acceptance of biomedical language and sought to give a voice to “people who do not fit the medicalized categories of disorder promoted by some other intersex groups [. . .] OII resists all efforts to make intersex invisible, including genital mutilation, medicalization and normalization without consent.”<sup>69</sup> According to anthropologist and bioethicist Katrina Karkazis, “more than any group, OII views itself in opposition to ISNA.”<sup>70</sup> OII argued “that the ISNA has been too accommodating about the medicalization of intersexuality.”<sup>71</sup> OII’s activism is committed to anti-medicalization, which inspired the organization since its inception. It does not focus on the body, but rather on the social acceptance of different bodies in the hope that this will result in fewer medical interventions.<sup>72</sup> The OII does not argue that intersex is necessarily accompanied by a non-binary gender identity, but refers to the intersex community as one that unsettles hegemonic ideals of sex, gender, and sexuality expressions.<sup>73</sup>

Lesbian Gay Bisexual and Transgender (LGBT) groups increasingly include the intersex community in their politics.<sup>74</sup> Some activists who aspire to affirm an intersex identity are already associated with LGBT advocacy organizations, such as the International Intersex Forum of the International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA),<sup>75</sup> which assembles intersex leaders from different countries and organizations annually. A repeated aim in its forum statements is “[t]o put an end to mutilating and ‘normalising’ practices such as genital surgeries, psychological and other medical treatments.”<sup>76</sup>

The idea of intersex as a separate identity has roots in gender studies beginning with the publication of Suzanne Kessler’s study, “The Medical Construction of Gender,” which was the first to expose the sexist views that pervade the medical treatment of intersex children.<sup>77</sup> Kessler’s research was followed by a growing body of critical intersex scholarship and attention from academics, activists, ethicists, the media, and even physicians.<sup>78</sup> Importantly, Kessler’s research provided a “scholarly legitimacy” that helped

<sup>69</sup> See DAVIS, *supra* note 52, at 37.

<sup>70</sup> KARKAZIS, *supra* note 42, at 261.

<sup>71</sup> *Id.*

<sup>72</sup> DAVIS, *supra* note 52, at 52.

<sup>73</sup> For OII-AUS’s position, see Anna Leach, *Third Gender? No Thanks, Says Australian Intersex Organization*, GAY STAR NEWS (July 12, 2012), <http://www.gaystarnews.com/article/third-gender-no-thanks-says-australian-intersex-organization120712/> [<https://perma.cc/GCU8-N6KA>].

<sup>74</sup> For a discussion on the inclusion of the letter I in the LGBT acronyms, see Emi Koyama, *Adding the “I”: Does Intersex Belong in the LGBT Movement?*, INTERSEX INITIATIVE, <http://www.intersexinitiative.org/articles/lgbti.html> [<https://perma.cc/3WAW-GDMY>].

<sup>75</sup> ILGA, <http://ilga.org/> [<https://perma.cc/LST2-ELW8>].

<sup>76</sup> Alessia Valenza, *First Ever International Intersex Forum*, ILGA (May 22, 2013), <http://ilga.org/first-ever-international-intersex-forum/> [<https://perma.cc/AB6Q-2PB7>].

<sup>77</sup> Suzanne J. Kessler, *The Medical Construction of Gender: Case Management of Intersexed Infants*, 16 SIGNS: J. WOMEN IN CULTURE & SOC’Y 3, 19 (1990).

<sup>78</sup> See Dreger & Herndon, *supra* note 47, at 204.

kick-start intersex activism.<sup>79</sup> Additional writing from gender and sexuality studies suggested the emergence of a “third sex” identity in intersex activism, arguing that some intersex activists have identified a new intersection between sex and gender, a kind of third sex that has cohered into a separate identity category.<sup>80</sup>

Drawing on the idea of intersex as a separate identification, “sex markers” contained in official documentation, such as birth certificates, passports and other identification documents is one frontier of public debate where identity activists have achieved success.<sup>81</sup> For instance, LAMBDA Legal filed a lawsuit on behalf of Dana, an intersex activist and the associate director of OII-USA, who identifies as neither male nor female, to have a passport issued marked “X” instead of “F” or “M” in the sex field.<sup>82</sup>

The main aim of identity activists is seemingly to fight non-consensual normalization and correction by revolutionizing the social and cultural meaning of intersex from pathology to identity in both popular and bureaucratic arenas. The rejection of the pathological approach and its terminology has its price. As Davis noted, “to reject DSD language is to challenge the medical profession’s biopower over one’s body.”<sup>83</sup> Indeed, identity activists have challenged cultural and bureaucratic systems of sex classification as a way to produce visibility and to reclaim their subjectivity in the world.

## 2. *Treatment Activists*

“I am endorsing the shift from ‘Intersex’ to DSD not as a simple gesture of either defeat or confidence, but as a way to affect gradual reforms of the medical model that pathologize intersexuality.”

- Emi Koyama, activist and founder of Intersex Initiative.<sup>84</sup>

“Treatment” activists is a term I borrowed from the AIDS Treatment Action Group (AIDS-TAG), a decedent of the AIDS Coalition to Unleash Power (AIDS ACT-UP) movement, and is used to describe activism that focuses on *treatment* through clinical research procedures.<sup>85</sup> This term use-

<sup>79</sup> DAVIS, *supra* note 52, at 56.

<sup>80</sup> Stephanie S. Turner, *Intersex Identities: Locating New Intersections of Sex and Gender*, 13 GENDER & SOC. 457, 458 (1999).

<sup>81</sup> For example, in a recent case from Kenya, the court was asked to designate a separate sex category for intersex people. See *Baby ‘A’ v. Attorney General* (2014) K.L.R. ¶ 1 (Kenya), [hereinafter *Baby A*], <http://kenyalaw.org/caselaw/cases/view/104234/> [<https://perma.cc/HE2M-HBF2>]; GREENBERG, *supra* note 9, at 65–72.

<sup>82</sup> See Complaint for Declaratory Injunctive and Other Relief at 1–2, *Zzyym v. Kerry*, 220 F. Supp. 3d 1106 (2016) (No. 1:15-cv-02362), 2015 WL 6449495 [hereinafter *Dana Alix ZZYYM Complaint*].

<sup>83</sup> DAVIS, *supra* note 52, at 109.

<sup>84</sup> Emi Koyama, *From “Intersex” to “DSD”: Toward a Queer Disability Politics of Gender*, INTERSEX INITIATIVE (Feb. 2006), <http://www.intersexinitiative.org/articles/intersextodsd.html> [<https://perma.cc/86S7-LYXT>].

<sup>85</sup> Raan Medley, *ACT UP and TAG: A Brief History of Treatment ACTAGanism*, ACT UP, <http://www.actupny.org/treatment/Medley.html> [<https://perma.cc/6ATF-P3CA>].

fully describes a strong and dominant strand of intersex advocacy in the United States that does not reject normalization technologies altogether, but rather seeks to improve the quality of services offered while consolidating the importance of informed consent and choice among intersex individuals.

The fight of intersex treatment activists to achieve credibility among the medical profession has greatly followed that of AIDS treatment activists. The sociologist Steven Epstein has described how AIDS activists gradually gained a seat at the decision-making table and directly negotiate with governmental and scientific elites, including the FDA and the National Institute of Allergy and Infectious Disease of the National Institute of Health (NIH).<sup>86</sup> Similarly, intersex treatment activists engage in a direct dialogue with medical professionals and associations to try and convince them that their practices are biased, often harmful, and should be improved and liberalized.<sup>87</sup> One prominent area of direct engagement is the field of clinical practice guidelines, for which patient advocates are invited to participate in policy design. Hybrid organizations and partnerships composed of patients, their families, and medical professionals routinely produce joint statements regarding the objectives of clinical care and research.<sup>88</sup>

Treatment activism is contradictory in the sense that it expresses faith in the medical profession while also opposing some of its practices. Collaboration with medical institutions is a necessity for successful treatment activism and is often regarded as a prominent characteristic of embodied health movements (EHM). Phil Brown and others have argued that “EHM activists do not typically have the luxury of ignoring the science. While they may appeal to people’s sense of justice or shared values, they nevertheless remain dependent to a large extent upon scientific understanding and continued innovation if they hope to receive effective treatment and eventually recover.”<sup>89</sup> Accordingly, treatment activists who are reluctant to accept “DSD” terminology have offered an alternative interpretation of the first “D” in DSD, calling it “Differentiation” or “Divergence” instead of “Dis-

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<sup>86</sup> See generally STEVEN EPSTEIN, *IMPURE SCIENCE: AIDS, ACTIVISM, AND THE POLITICS OF KNOWLEDGE* (1996); Steven Epstein, *The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials*, 20 SCI. TECH. & HUMAN VALUES 408, 417–19 (1995) (both sources describe how through self-education, AIDS activists built inner-movement expertise that granted them credibility and influence within public-health agencies).

<sup>87</sup> Dreger & Herndon, *supra* note 47, at 203–08.

<sup>88</sup> Examples of such hybrid organizations: AIS-DSD SUPPORT GROUP, <http://aisdso.org/who-we-are/presidents-message/> [<https://perma.cc/PYA3-KE79>]; LIVING WITH CAH, [http://www.livingwithcah.com/support\\_group.html](http://www.livingwithcah.com/support_group.html) [<https://perma.cc/9FTQ-9QZT>]; HEA, <http://heainfo.org/index.php/who-we-are/our-mission/> [<https://perma.cc/GX74-7RTV>]; CARES FOUNDATION, <http://www.caresfoundation.org/what-we-do/> [<https://perma.cc/8CJR-752V>]; DSDFAMILIES, <http://www.dsdfamilies.org/dsdfamilies/index.php> [<https://perma.cc/EZC2-WR3N>].

<sup>89</sup> Phil Brown et al., *Embodied Health Movements: New Approaches to Social Movements in Health*, 26 SOC. HEALTH & ILLNESS 50, 56 (2004).

order,” in an attempt to avoid pathologization, but also be more clear than “intersex.”<sup>90</sup>

Treatment activists are the pragmatic segment of the intersex rights movement. They work to achieve incremental changes within medical practice instead of campaigning for a wholesale conceptual change in attitudes. Treatment activists may differ in their support regarding initiatives of other intersex groups. For example, the debate about medical terminology, the formation of an intersex identity or a third sex, and the association with LGBT politics, all are fundamental issues that treatment activists might not have a unified stance on.

### 3. *Assimilators*

“[Intersex is] bad because it describes a possible third sex or worse . . . a limbo state between them, and I don’t think humans are in limbo.” –Karen, 54-year-old woman with intersex trait.<sup>91</sup>

“Intersex rubs me the wrong way . . . I’m comfortable. . . with disorder of sex development . . . I think it explains . . . something that happened versus something that you chose.”– Vanessa, 43-year-old woman with intersex trait.<sup>92</sup>

“I like DSD . . . because if you say DSD, [sex is] kind of camouflaged. When you say intersex, it has the word sex right in it and it’s like, ‘What?’ It’s kind of a red flag for people.” – Hanna, 42-year-old woman with intersex trait.<sup>93</sup>

Assimilators hope to blend in or at least to avoid being “outed.” This is not a classic “closet” argument that adopts a reluctance to “come out” because of its potentially high price, but a more deliberate stance that views bodily normalization as a positive outcome. This group is not actually part of the intersex rights movement and it has no interest in joining the resistance project. However, the voices of assimilators are often brought to the table by physicians who offer accounts of patients and their parents. Physicians report that “[t]he patients who are happy don’t want to be spoken to; the parents don’t want it . . . my kid is well adjusted. Everything is fine.”<sup>94</sup> Accordingly, vocal activists are occasionally accused of being unrepresentative and ignorant of the interests of the satisfied “quiet majority” in favor of the “troubled and angry minority.”<sup>95</sup>

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<sup>90</sup> REIS, *supra* note 50, at 159.

<sup>91</sup> DAVIS, *supra* note 52, at 102.

<sup>92</sup> *Id.*

<sup>93</sup> DAVIS, *supra* note 52, at 102.

<sup>94</sup> KARKAZIS, *supra* note 42, at 266.

<sup>95</sup> *Id.* at 261.

The assertion that most intersex patients are satisfied with the treatment they received is neither empirically validated nor refuted.<sup>96</sup> It is plausible that some people are happy with the treatment they received at earlier ages and are not interested in problematizing the medical approach. Many might also be unaware of their condition or disinterested in knowing more. However, the emergence of the intersex movement created an opportunity for reticent intersex persons to be more vocal. The following description of the assimilators group draws from the recorded statements made by intersex patients, their physicians, and their families.

Assimilators fully embrace DSD, both for its clarity and for its pro-medical agenda. According to Davis, many intersex individuals who support the DSD terminology are not involved in activism and have no interest in constructing intersex as a social identity.<sup>97</sup> Assimilators probably prefer the first “D” to indicate a “disorder” instead of “differentiation” and are generally inclined to accept the biomedical model of intersex for its beneficial implications for them. Davis argues that those who choose to use the DSD terminology enjoy better relationships with physicians and other benefits vested in the medical support system. She writes about Jane, a 54-year-old woman who does not understand why activists reject the DSD terminology when it has the power to produce a productive dialogue: “I can be on the outside of the room arguing about terminology and if I embrace [DSD] and the door opens . . . .”<sup>98</sup>

Based on statements made by intersex people who prefer to conform to the traditional male-female dichotomy and stick to the term DSD, it is likely that they would endorse some or all normalization technologies and their routine implementation for improving techniques and outcomes in future patients. They would likely object to activism that undermines the ethical and legal foundations of the procedure that may deter practicing physicians or hinder insurance coverage. Assimilators would highlight the costs of postponing gender-normalizing surgeries, such as supposed bullying in locker rooms or other concerns from having abnormal-looking genitals while growing up.

The assimilators’ view is often communicated through parents to intersex children. Parents sometimes prefer “DSD” over “intersex”, on the belief that it would serve their children’s best interest.<sup>99</sup> A survey conducted in 2010 showed general satisfaction among parents and healthcare professionals from such terminology shifts, which they found less stigmatizing and

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<sup>96</sup> See *supra* notes 31–33 and accompanying text.

<sup>97</sup> DAVIS, *supra* note 52, at 107.

<sup>98</sup> *Id.* at 103.

<sup>99</sup> One explanation for parents’ choice in the assimilation approach is that their choice is de-facto constrained by the way information is conveyed to them by doctors. See J. Hester, *Intersex(es) and Informed Consent: How Physicians’ Rhetoric Constrains Choice*, 25 THEORETICAL MED. BIOETHICS 21, 29–39 (2004).

more helpful in conveying information.<sup>100</sup> From interviews conducted with parents, Davis found that most parents preferred “DSD” language over “intersex”, mostly because they were concerned that “intersex” created an association with the LGBT movement.<sup>101</sup> A group of European support groups for DSD conditions, which has parents in leadership, recently issued a statement along with prominent DSD research and clinical centers, in which they question the authority of the LGBT movement to speak on their behalf:

We understand that some adults reject the medicalisation of variant sex development and the word disorder. By the same token, some of us would argue that the majority of medical professionals, and many patients and parents, consider the term intersex inappropriate and feel that it increases a sense of stigma around individuals living with these conditions, rather than addressing them.<sup>102</sup>

#### *D. Paths to De-Medicalization: Legal and Medical Activism*

In her book “Intersexuality and the Law,” Julie Greenberg suggests that the law has the potential to become the next means of operation: “Thus far, the intersex movement has focused most of its efforts on extralegal strategies. Legal challenge can provide an additional effective tool to improve the treatment of infants and adults with an intersex condition.”<sup>103</sup> After the intersex movement divided in 2006, law became more relevant to intersex reform. Though some members of the ISNA collaborated with the medical profession and were hopeful about their capacity to mobilize change from within, other activists maintained a stronger opposition. These activists gradually started using the law to politicize and problematize medical standards of care through human rights advocacy, medical malpractice litigation, and government identification policies.

The general approach to intersex has shifted because of activists who resisted assimilation. Their arguments have been acknowledged by powerful institutions like the United Nations and European Parliaments.<sup>104</sup> Some professional medical societies have begun admitting past mistakes and accepting claims about the harms caused by the over-medicalization and treatment of intersex patients.<sup>105</sup> Even medical encyclopedias are revising

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<sup>100</sup> See J.H. Davies et al., *Evaluation of Terminology Used to Describe Disorders of Sex Development*, 7 J. PEDIATRIC UROLOGY 412, 413–14 (2011).

<sup>101</sup> DAVIS, *supra* note 52, at 137–42.

<sup>102</sup> Martine Cools et al., *Response to the Council of Europe Human Rights Commissioner’s Issue Paper on Human Rights and Intersex People*, 70 EUROPEAN UROLOGY 407, 408 (2016).

<sup>103</sup> GREENBERG, *supra* note 9, at 128.

<sup>104</sup> See discussion *infra* Section II.A.

<sup>105</sup> See discussion *infra* Section III.B.

their intersex entries to suggest the growing recognition that professional consensus on the topic is changing.<sup>106</sup>

After the 2006 consensus in which vocal advocates of the movement embraced a collaborative approach with the medical profession, the law certainly became a crucial tool for those in the intersex rights movement that maintained a critical stance towards the pathological view. But what has been the specific role of law in these shifts? Did it serve as a successful mobilizer for the anti-medicalization agenda, or to the contrary, did it inhibit the progressive movement that was led by activists who collaborated with the medical establishment? Activists differ in their opinions regarding whether legal activism or extralegal activism is the best route to promote change.

The first view idolizes the work of treatment activists who directly engage with medical professionals to inspire progressivism. This claim follows the legacy of AIDS-TAG that successfully revolutionized access to drug experiments through its involvement and collaboration with medical agencies to *democratize* the issues facing people with AIDS. This process made standard procedures more open to criticism by incorporating patient perspectives, and by bringing change to the process of knowledge production.

The second claim comports with the ideology of identity activists who were disappointed with the alignment or cooptation of intersex activists by the medical establishment. This disappointment led to legal activism, which revived the de-medicalization project through various legal strategies and frameworks. According to this narrative, law is used to de-stabilize the medical standard in a way that treatment activists failed to. Law is not a catalyst for movement conservatism, as is often suggested in legal mobilization literature,<sup>107</sup> but it is rather a path to its re-radicalization.

These two claims take up a major debate in social movement literature: whether social movements should pursue legal avenues or should engage in direct negotiation in extralegal arenas.<sup>108</sup> The intersex context provides a richly detailed case study to compare each path. This Article will discuss these distinguished paths to de-medicalization, highlighting the multifaceted nature of legal mobilization and its inconclusive and unintended consequences. Ultimately, this Article argues that for the intersex rights movement, legal activism was more effective than extralegal mobilization to promote a radical agenda of de-medicalization. The following Sections analyze the costs and benefits of each approach while maintaining a critical view of their implications for movement members.

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<sup>106</sup> The National Institute of Health's medical encyclopedia describes "intersex" as a full medical condition yet admits the transition in attitudes taking place at the present. *Intersex*, MEDLINEPLUS (July 10, 2013), <http://www.nlm.nih.gov/medlineplus/ency/artic/001669.htm> [<https://perma.cc/5Z9B-GU7W>].

<sup>107</sup> Lobel, *supra* note 7, at 941–42.

<sup>108</sup> *Id.* at 942–56; QUEER MOBILIZATIONS: LGBT ACTIVISTS CONFRONT THE LAW 4–12 (Scott Barclay et al. eds., 2009).

## II. LEGAL ACTIVISM: POLITICIZING THE STANDARD OF CARE

Activists pursuing a strong de-medicalization agenda use legal instruments and language to politicize the medical standard of care and make it into a controversial object of discussion. Identity activists use the law in creative ways to destabilize its widely agreed-upon objective and sound characterization.

Bringing the debate about intersex medical management into courts, parliaments and human rights organizations allowed activists to frame the issue in ways that introduced the social context around medical practices and triggered a public discussion about the broader objectives that underlie them. Relocation to the legal domain pushed medical professionals outside of their comfort zone and weakened their ability to assert expertise against social challenges. As Sheila Jasanoff notes, the courtroom strikes “new balances between lay and expert understandings of risk, benefit, safety, and harm.”<sup>109</sup> In addition to contesting the merits of a given scientific method, legal avenues allowed activists to criticize the social and cultural contexts that justify the practices in the first place.

In some respects, politicizing the standard of care is an attempt to combat the effects of “scientization,”<sup>110</sup> a term describing the phenomenon of framing public policy debates in scientific terms that conceal core political and moral disagreements. Politicizing the standard of care reverses the scientization effect by reformulating the debate in non-scientific language to allow for discussion on conflicting values rather than conflicting numbers.<sup>111</sup> Jasanoff points to the courts’ potential to fulfill an important democratic function of challenging expert authority: “[I]tigation . . . is an especially potent resource for making transparent the values, biases, and social assumptions that are embedded in many expert claims about physical and natural phenomena.”<sup>112</sup> Accordingly, activists use the law to expose the political

<sup>109</sup> SHEILA JASANOFF, *SCIENCE AT THE BAR: LAW, SCIENCE, AND TECHNOLOGY IN AMERICA* 22 (1955).

<sup>110</sup> Brown and others argued that the superiority given to scientific knowledge claims contributes to “the scientization of decision-making” in the public political sphere, and improperly frame ethical or political questions in scientific terms, leaving little room for non-experts to participate in the discussion over important policy debates. Phil Brown & Stephen Zavestoski, *Social Movements in Health: An Introduction*, 26 *SOC. HEALTH & ILLNESS* 679, 681 (2004).

<sup>111</sup> In the public debate about vaccinations for example, some argue that a portrayal of the controversy as a disagreement on scientific facts on the risks and harms from vaccinations obscures the real controversy as to whether the state should have the power to force parents to bear that risk, minor as it may be. See Maggie Koerth-Baker, *Values and Vaccines*, AEON (Feb. 16, 2016), <https://aeon.co/essays/anti-vaccination-might-be-rational-but-is-it-reasonable> [<https://perma.cc/X8LT-FD8E>]; see also Maya J. Goldenberg, *Public Misunderstanding of Science?: Reframing the Problem of Vaccine Hesitancy*, 24 *PERSPECTIVES ON SCIENCE* 552 (2016) (arguing that the anti-vaccination movement is not driven by a lack of knowledge but rather from distrust in scientific institutions).

<sup>112</sup> JASANOFF, *supra* note 109, at 20.

disagreements about the conventional standard of care, which typically go unchallenged due to general trust in medicine.

In the U.S., activists and academics use rights-based arguments that correspond to existing legal frameworks to politicize intersex-normalizing treatments. For example, Julie Greenberg offers to challenge medical practices by crafting legal arguments using the body of legal human rights.<sup>113</sup> Indeed, the first route of politicization focuses on the apparatus of international human rights and analogizes normalization surgeries to female genital mutilation (FGM) or even torture. The second route of politicization litigates human rights violations proclaimed in U.S. law that are endangered by normalization surgery in infancy, such as the rights to bodily autonomy, privacy, self-determination, informed consent, reproductive liberty, and physical integrity. The third route of politicization litigates identity documentation issues raised by intersex persons. The following Sections elaborate the specifics of each route of politicization and demonstrate how they vary in their deference to medical and social arguments.

#### A. *Human Rights Advocacy*

In the U.S., intersex-normalizing treatment was first considered a human rights violation in 2005 after the San Francisco Human Rights Commission conducted an investigation due to the requests of “people with intersex anatomies.”<sup>114</sup> The report included the perspectives of intersex people, their parents, medical staff, and academics, despite the reluctance and refusal of some medical providers to submit testimonies or to participate in the public hearing.<sup>115</sup> In response to the San Francisco commission’s inquiry, some medical providers and associations repeatedly resorted to the scientific bases that legitimized their practices. For example, the AAP responded by submitting two professional articles published in the “Pediatrics” journal in 2000 and 1994 illustrating their position,<sup>116</sup> as did the American Association of Clinical Endocrinologists (AACE).<sup>117</sup> Other medical professionals and associations were receptive toward improving medical practices. The Ameri-

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<sup>113</sup> GREENBERG, *supra* note 9, at 109–10.

<sup>114</sup> MARCUS DE MARIA ARANA, A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL ‘NORMALIZATION’ OF INTERSEX PEOPLE: A REPORT OF A PUBLIC HEARING BY THE HUMAN RIGHTS COMMISSION OF THE CITY & COUNTY OF SAN FRANCISCO 4 (2005), [http://www.isna.org/files/SFHRC\\_Intersex\\_Report.pdf](http://www.isna.org/files/SFHRC_Intersex_Report.pdf) [https://perma.cc/R44K-HQYZ].

<sup>115</sup> *Id.* at 5.

<sup>116</sup> See Celia Kaye et al., *Evaluation of the Newborn with Developmental Anomalies of the External Genitalia*, 106 PEDIATRICS 138–42 (2000); Evan Kass et al., *Timing of Elective Surgery on the Genitalia of Male Children with Particular Reference to the Risks, Benefits, and Psychological Effects of Surgery and Anesthesia*, 97 PEDIATRICS 590–94 (1996).

<sup>117</sup> The AACE referred to the same materials published by the AAP, but commented that the association “does not have any standards of care and preferred procedural recommendations regarding the treatment of children born with ambiguous genitals.” DE MARIA ARANA, *supra* note 28, at 56.

can Urological Association (AUA) for instance argued that intersex treatment is very complex while admitting that an increasing number of physicians believe that “delaying reconstructive surgery until the individual is able to participate in the decision-making process” is advised.<sup>118</sup> Individual physicians who were interviewed engaged willingly with questions about social causes for these surgeries and whether this “social emergency” really justified an irreversible surgery with questionable benefits.<sup>119</sup> The majority of them expressed openness to the criticism and supported a change of practices.<sup>120</sup> The report findings clearly state that normalizing surgeries in intersex infants are a violation of their human rights to privacy, bodily integrity, informed consent, dignity, and autonomy.<sup>121</sup> The medical reaction to these assertions was often angry, dismissive, and distressing, though some in the profession were also accommodating and cooperative.<sup>122</sup>

Activists primarily frame intersex surgeries as a form of human rights violations by analogy to FGM.<sup>123</sup> American activists tried to harness the vast support for anti-FGM politics in western countries to support the criminalization of intersex surgeries in infancy in the U.S.<sup>124</sup> These efforts, however, failed when the bill drafted to prevent FGM practices ended up including an exemption for “medically necessary” surgeries, which de-facto included normalizing surgeries for intersex.<sup>125</sup> According to Alice Dreger, a prominent bioethicist and intersex activist, the analogy to FGM failed because of the strong view held at that time in the U.S. that intersex conditions were legitimate medical problems of non-conforming sex expression, and hence gender normalizing surgeries were not a cultural practice that violated basic human rights like FGM did.<sup>126</sup> The lack of political support also came from the anti-FGM feminists themselves who viewed intersex-normalizing surgeries as fundamentally different.<sup>127</sup>

<sup>118</sup> DE MARIA ARANA, *supra* note 28, at 57.

<sup>119</sup> *Id.* at 57–61.

<sup>120</sup> *Id.*

<sup>121</sup> *Id.* at 17.

<sup>122</sup> See, e.g., Hughes et al., *Consequences of the ESPE/LWPES*, *supra* note 25, at 364 (“The medical profession is listening to criticism and is striving to make changes. This can be successfully achieved only by teamwork which includes patients and their advocates as equal partners.”).

<sup>123</sup> This framework is sometimes stretched to include FGM, intersex normalization surgeries, and circumcision. See GENITAL CUTTING: PROTECTING CHILDREN FROM MEDICAL, CULTURAL, AND RELIGIOUS INFRINGEMENTS: PROCEEDINGS OF THE 11TH INTERNATIONAL SYMPOSIUM ON CIRCUMCISION, GENITAL INTEGRITY, AND HUMAN RIGHTS (George C. Denniston et al. eds., 2013).

<sup>124</sup> Sharon E. Preves, *Out of the O.R. and into the Streets: Exploring the Impact of the Intersex Media Activism*, 12 *Cardozo J.L. & Gender* 247, 271–72 (2005).

<sup>125</sup> *Id.*

<sup>126</sup> Alice Dreger, “*Ambiguous Sex*”—or *Ambivalent Medicine?*: *Ethical Issues in the Treatment of Intersexuality*, 28 *HASTINGS CTR. REP.* 24, 34 (1998).

<sup>127</sup> Nancy Ehrenreich & Mark Barr, *Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of Cultural Practices*, 40 *HARV. C.R.-C.L. L. REV.* 71, 104 (2005).

The conceptualization of genital-normalizing treatments as violations of human rights gained momentum in recent years after International Human Rights (IHR) organizations, such as the United Nations and the European Council showed interest in intersex management.<sup>128</sup> An early breakthrough was the inclusion of genital-normalization treatments for intersex conditions in the “Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment” from 2013, which called for States to stop non-consensual sex-normalizing surgeries on intersex infants,<sup>129</sup> with later reports repeating similar statements.<sup>130</sup>

Aside from raising issues about the current standard of care for intersex persons, IHR organizations have helped intersex activists to create an intersex identity and culture like the LGBT movement identity politics agenda. For example, intersex awareness was included in the United Nations’ “Free and Equal” campaign for “lesbian, gay, bisexual, and transgender equality” in a special “Intersex fact sheet” created to educate the public about intersexuality. The fact sheet called to “[p]rohibit medically unnecessary surgery and procedures on the sex characteristics of intersex children, protect their physical integrity and respect their autonomy.”<sup>131</sup> The United Nations also conducted a meeting with experts on ending human rights violations against intersex persons in 2015.<sup>132</sup> United Nations High Commissioner for Human Rights, Zeid Ra’ad Al Hussein, attributed the growing attention to the violation of intersex human rights to advocacy organizations and noted how some

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<sup>128</sup> See SWISS NATIONAL ADVISORY COMMISSION ON BIOMEDICAL ETHICS NEK-CNE, ON THE MANAGEMENT OF DIFFERENCES OF SEX DEVELOPMENT: ETHICAL ISSUES RELATING TO “INTERSEXUALITY” 18 (2012), [http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK\\_Intersexualitaet\\_En.pdf](http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf) [https://perma.cc/4367-A6YK]; EUR. CONSULT. ASS. DEB. 31st Sess. ¶ 2 (Oct. 1, 2013), <http://www.assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=20174&lang=en> [https://perma.cc/L3PX-MVG6]; AUSTRALIAN SENATE COMMUNITY AFFAIRS COMMITTEE, VOLUNTARY OR COERCED STERILISATION OF INTERSEX PEOPLE IN AUSTRALIA XIII-IV (2013), [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Involuntary\\_Sterilisation/Sec\\_Report/index](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index) [https://perma.cc/BQG6-7MDS]; WORLD HEALTH ORGANIZATION, ELIMINATING FORCED, COERCIVE AND OTHERWISE INVOLUNTARY STERILIZATION: AN INTERAGENCY STATEMENT 1 (2014), [http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1) [https://perma.cc/4BMU-3ZBY]; COUNCIL OF EUR. COMM’R OF HUMAN RIGHTS, HUMAN RIGHTS AND INTERSEX PEOPLE 7, 9 (2015), [https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDC\\_TMContent?documentId=09000016806da5d4](https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDC_TMContent?documentId=09000016806da5d4) [https://perma.cc/J344-2GBU] (recognizing a right NOT to undergo sex assignment treatments).

<sup>129</sup> Juan E. Méndez (Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment), *Report on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, U.N. Doc. A/HRC/22/53, at 23 (Feb. 1, 2013).

<sup>130</sup> See U.N. High Commissioner for Human Rights, *Discrimination and Violence Against Individuals Based on Their Sexual Orientation and Gender Identity*, U.N. Doc. A/HRC/29/23, at 5–6 (May 4, 2015), [http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session29/Documents/A\\_HRC\\_29\\_23\\_en.doc](http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session29/Documents/A_HRC_29_23_en.doc) [https://perma.cc/U554-6XSB].

<sup>131</sup> INTERSEX FACT SHEET, *supra* note 17, at 2.

<sup>132</sup> Office of the High Comm’r, *A Step Forward for Intersex Visibility and Human Rights*, UNITED NATIONS (Sept. 25, 2015), <http://www.ohchr.org/EN/NewsEvents/Pages/Astepforwardforintersexvisibility.aspx> [https://perma.cc/SHX2-4KMV].

States had already reformed their laws to protect the rights of intersex people.<sup>133</sup>

Intersex visibility continues to grow and is garnering more institutional attention. In 2015, Malta became the first state to pass legislation that directly prohibits unconsented normalizing surgery on intersex infants on the grounds that infants have a right to bodily autonomy and integrity under the “Gender Identity, Gender Expression, and Sex Characteristics Act.”<sup>134</sup> According to Hida Vilorio, the chairperson of OII, this legislation was a product of collaboration between intersex leaders and strong allies in the government, which signified a revolutionary step forward in the commitment of governments to protect the rights of intersex people.<sup>135</sup> Since then, Chile’s ministry of health issued a circular calling physicians to stop performing “unnecessary ‘normalization’ treatments of intersex children, including irreversible genital surgeries, until they are old enough to decide about their bodies,” and until clinical guidelines and legislation that affirm intersex human rights can be composed.<sup>136</sup>

Medical professionals’ reactions to the human rights framework are often dismissive and defensive, emphasizing the basic sentiment that physicians neither have a role in social revolutions nor are they politically invested in this debate in any way.<sup>137</sup> However the Human Rights framework is receiving greater traction in the U.S. in recent years,<sup>138</sup> along with increasing voices from within the medical profession that are beginning to accept fundamental stances of the Human Rights framework.<sup>139</sup>

<sup>133</sup> Zeid Ra’ad Al Hussein, Opening Remarks at the Expert Meeting on Ending Human Rights Violations Against Intersex Persons (Sept. 16, 2015), <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16431#sthash.CAxQKIYu.dpuf> [<https://perma.cc/2NPF-LEDT>].

<sup>134</sup> See The Gender Identity Act, (Malta, 2015), <http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=12312&l=1> [<https://perma.cc/9XH2-PYTB>]; *We Celebrate Maltese Protections for Intersex People*, OII AUSTRALIA (Apr. 2, 2015), <https://oii.org.au/28592/we-celebrate-maltese-protections-for-intersex-people/> [<https://perma.cc/YHY9-DDQ2>].

<sup>135</sup> Mark Hay, *What Will Malta’s New Intersex Law Mean for the Rest of the World?*, VICE (Apr. 7, 2015), <http://www.vice.com/read/maltas-new-intersex-legislation-is-the-most-progressive-in-the-world-192> [<https://perma.cc/P7GP-XQ25>].

<sup>136</sup> *Chilean Ministry of Health Issues Instructions Stopping “Normalising” Interventions on Intersex Children*, OII AUSTRALIA (Jan. 11, 2016), <https://oii.org.au/30250/chilean-ministry-stops-normalising/> [<https://perma.cc/R6HR-47HQ>].

<sup>137</sup> A leading physician commented on the inclusion of intersex surgeries in the special report on torture by the United Nations, stating that “[t]his completely antagonizes the medical community. This is not progress, in my opinion . . . . It’s a tactic that’s likely to work, and it’s a tactic that will prevent us from actually understanding what’s going on.” Azeen Ghorayshi, *Intersex Surgeries Are a Human Rights Violation*, *Says U.N. Group*, BUZZFEED NEWS (Sept. 19, 2015) <http://www.buzzfeed.com/azeenghorayshi/intersex-surgeries-human-rights-violation> [<https://perma.cc/TD6V-3KQ5>].

<sup>138</sup> HUMAN RIGHTS WATCH, “I WANT TO BE LIKE NATURE MADE ME” (2017), <https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us> [<https://perma.cc/QSS8-RHE2>].

<sup>139</sup> M. JOYCELYN ELDERS, DAVID SATCHER, & RICHARD CARMONA, *RE-THINKING GENITAL SURGERIES ON INTERSEX INFANTS* (2017), <http://www.palmcenter.org/wp-con>

### B. *Constitutional and Patient Rights Litigation*

Some advocacy organizations have decided to take cases to court as a way to make the claim that non-consensual normalizing surgery on infants is a violation of their constitutional and statutory rights.<sup>140</sup> Despite being an indirect path to change, activists have found that the law has the capacity to penetrate and regulate the core of the medical profession. As Dreger has remarked: “[p]hysicians constantly say to me that lawsuits and laws are not the way to change medical practice . . . [a]nd I say, I agree with you, but if you will not change your practices—then that’s what it’ll take.”<sup>141</sup> When interviewed about the M.C. lawsuit, Dreger observed:

I do think it would be a lot better if this system changed because hearts and minds were changed among doctors and parents. But after 20 years of working in this area, I don’t know what it’s going to take to achieve that—and I am starting to think we can’t wait anymore for the legal prohibitions to be enacted. How many children are losing healthy genital tissue while we wait for the pediatric establishment to “evolve”?<sup>142</sup>

Legal interventions in the medical standard of care can potentially destabilize the delicate balance between medical autonomy and legal regulation.<sup>143</sup> For this reason, the medical profession tends to strongly resist legal interventions in the way it exercises medical discretion.<sup>144</sup> Although not impossible, it is unlikely that patients would convince a court to apply a standard of care that diverts from the mainstream professional norm.<sup>145</sup>

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tent/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf [https://perma.cc/35VS-ZLZB].

<sup>140</sup> Complaint at 4, *Crawford v. Med. Univ. of S.C.*, 2013 WL 2143761 (S.C.com.Pl. May 14, 2013) (No. 2013CP4002877), [hereinafter *State Complaint*]; Complaint at 15–18, *Crawford v. Aaronson*, 2013 WL 1961775 (D.S.C. May 14, 2013) (No. 2:13cv01303) [hereinafter *Federal Complaint*].

<sup>141</sup> Ghorayshi, *supra* note 137.

<sup>142</sup> Alice Dreger, *Malta Bans Surgery on Intersex Children*, THE STRANGER (Apr. 3, 2015), <http://www.thestranger.com/blogs/slog/2015/04/03/22001053/malta-bans-surgery-on-intersex-children> [https://perma.cc/FQ9S-TV29].

<sup>143</sup> Maxwell J. Mehlman, *Professional Power and the Standard of Care in Medicine*, 44 ARIZ. ST. L.J. 1165, 1226 (2012).

<sup>144</sup> D. Clay Kelly & Gina Manguno-Mire, *Commentary: Helling v. Carey, Caveat Medicus*, 36 J. AM. ACAD. PSYCHIATRY LAW 306, 306 (2008).

<sup>145</sup> For such exceptions see, for example, *Helling v. Carey*, 519 P.2d 981, 983 (1974) (disapproved in *Barton v. Owen*, 139 Cal. Rptr. 494 (Cal. App. 1977)). In Washington state, in a case in which an ophthalmologist did not perform an eye pressure test to detect glaucoma because the patient was under the age of forty, the state Supreme Court ruled that he was negligent despite it being a professional “universal practice.” *Id.*; see also *Burton v. Brooklyn Doctors Hosp.*, 452 N.Y.S.2d 875, 879–80 (1982) (imposing liability on hospital and medical staff who exposed a premature baby to enhanced oxygen supply, even though it was an established “conventional medical wisdom” at the time, but started revealing itself as dangerous); *Lundahl v. Rockford Mem’l Hosp. Ass’n*, 235 N.E.2d 671, 674 (Ill. App. Ct. 1968) (“[T]he fact that the treatment given [to patient] was ‘usual’ or ‘customary’ would not, of itself, preclude the possibility of either negligence or want of

Despite these challenges, Pamela and Mark Crawford, the adoptive parents of M.C., filed two lawsuits against the hospital and physicians that treated M.C. The first was filed in federal district court in South Carolina for the violation of M.C.'s constitutional rights. The second was filed in South Carolina state court for medical malpractice. Pamela Crawford, who is a psychiatrist herself, said that "[i]f there were any other way of getting this across to the medical community than a lawsuit, then I'd be 100% for it, but I haven't been able to see a way to make those kind of changes, and so I've had to put aside my own squeamishness about that."<sup>146</sup> With the support of advocacy organizations such as Advocates for Informed Choice (AIC),<sup>147</sup> and the Southern Poverty Law Center, these lawsuits directly challenge the standard of care for intersex infants.

M.C.'s federal constitutional claim argued that the feminizing surgeries were medically unnecessary and they violated constitutional rights to substantive and procedural due process, including rights to bodily integrity, procreation, liberty, privacy, and the right to a pre-deprivation hearing before subjection to irreversible, sterilizing, and risky surgery.<sup>148</sup> In its motion to dismiss, defendants' lawyers questioned AIC's legal executive director's motives for pursuing the lawsuit, bringing the issue of politicizing the standard of care to the fore: "Ms. Tamar-Mattis's agenda to eradicate the medical option of sex assignment surgery for young intersex patients is best pursued through public debate and legislative action rather than legal action against these defendants who acted within an acceptable medical standard of care and the legal requirements for informed consent."<sup>149</sup> In this way, the defendants sought to draw the court's attention to the underlying social and normative agenda being pursued by the plaintiffs and asked the court to occupy a supposedly non-political position by upholding the status quo. In 2014, the Court of Appeals for the Fourth Circuit granted defendants' motion for qualified immunity,<sup>150</sup> and dismissed the case on the basis that there was no fair warning to the hospital or the doctors that the surgery violated M.C.'s constitutional rights at the time the procedure was conducted. The court noted that

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skill. It is entirely possible . . . that what is the usual or customary procedure might itself be negligence."); *Toth v. Cmty. Hosp. at Glen Cove*, 239 N.E.2d 368, 373 (1968) ("If a physician fails to employ his expertise or best judgment, and that omission causes injury, he should not automatically be freed from liability [in a malpractice action] because in fact he adhered to acceptable practice.").

<sup>146</sup> Ghorayshi, *supra* note 137.

<sup>147</sup> The organization has transformed to focus on youth leadership building and is now called Inter-Act. See Letter from Kimberly Zieselmann, Exec. Dir., Inter-Act, to Members (Jan. 6, 2016), <http://us1.campaign-archive2.com/?u=f8291560ebb2dafc25097480f&id=bc68c4b818&e=2a170b812a> [https://perma.cc/X2NW-STVY].

<sup>148</sup> See *Federal Complaint*, *supra* note 140, at ¶ 82.

<sup>149</sup> Motion to Dismiss, Rule 12(b)(6) Qualified Immunity and Memorandum in Support at 9, *M.C. ex rel. Crawford v. Aaronson*, 2013 WL 3091537 (D.S.C. June 7, 2013) (No. 2:13-cv-01303-DCN).

<sup>150</sup> *M.C. ex rel. Crawford v. Amrhein*, 598 F. App'x. 143, 147 (4th Cir. 2015).

“[o]fficials are not liable for bad guesses in gray areas; they are liable for transgressing bright lines.”<sup>151</sup>

The malpractice claim was filed against M.C.’s attending physicians, the Medical University of South Carolina (MUSC), and the Greenville Hospital System for failure to gain informed consent. According to the complaint, the defendants urged social services officials to consent to the surgery on behalf of M.C. without disclosing the material risks of the procedure, such as sterilization, the loss of sexual function, its irreversibility, and that it could be postponed until M.C. formed a gender identity.<sup>152</sup> According to the plaintiffs, failure to disclose deviated from the standard of care amounting to malpractice.<sup>153</sup> MUSC counterclaimed that “[t]he surgery that was performed for M.C. is a commonplace treatment for Plaintiffs [sic] particular intersex condition.”<sup>154</sup> And that “[t]hough Plaintiffs’ intent is to change the standard of care, they cannot prove that a ‘reasonable person’ would not have chosen medical treatment that was, in fact, perfectly within the standard of care.”<sup>155</sup> Last July however, the lawsuit ended with a settlement giving M.C. almost half a million dollars.<sup>156</sup>

In both suits, the plaintiffs used rights and other legal symbols to problematize the professional standard of care and question its motivation and effectiveness in light of stated social, ethical, and legal norms. Whether plaintiffs claimed that the standard of care was unconstitutional or negligent, the defendants’ response was that customary claims by medical professionals on the standard of care should be relied on. The Court of Appeals for the Fourth Circuit effectively accepted this argument by adhering to the doctrinal “bright line transgression.”<sup>157</sup> For the state case, the recent settlement agreement is likely to initiate a re-examination of current protocols among intersex care providers; however even the process of litigation itself created a new reality in which physicians are forced to rethink their recommendations so that patients can reimagine their futures.<sup>158</sup>

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<sup>151</sup> *Id.* at 148 (relying on *Maciariello v. Sumner*, 973 F.2d 295, 298 (4th Cir. 1992)).

<sup>152</sup> See *State Complaint*, *supra* note 140.

<sup>153</sup> See *id.* at ¶ 47.

<sup>154</sup> Med. Univ. of S.C.’s Amended Mem. in Support of Motion for Summary Judgment at 17, *M.C. ex rel. Crawford v. Med. Univ. of S.C.*, 2015 WL 12159168 (S.C.L. Dec. 15, 2015) (No. 2013CP4002877).

<sup>155</sup> *Id.*

<sup>156</sup> Azeen Ghorayshi, *A Landmark Lawsuit About An Intersex Baby’s Genital Surgery Just Settled For \$440,000*, BUZZFEED NEWS (Jul. 27, 2017), [https://www.buzzfeed.com/azeenghorayshi/intersex-surgery-lawsuit-settles?utm\\_term=.pqErDv9xdj#.pyMODGwrMv](https://www.buzzfeed.com/azeenghorayshi/intersex-surgery-lawsuit-settles?utm_term=.pqErDv9xdj#.pyMODGwrMv) [<https://perma.cc/7V35-FRAW>].

<sup>157</sup> In South Carolina, the state in which the M.C. cases are litigated, a plaintiff asking to establish a medical malpractice claim must prove “the recognized and generally accepted standards and procedures which would be exercised by competent physicians . . . under similar circumstances.” See *Smith v. United States*, 119 F.Supp.2d 561, 562 (D.S.C. 2000).

<sup>158</sup> A 2016 report on global disorders of sex dedicates a section to reviewing developments made on the international and national legal-ethical turf regarding intersex medical management and concludes that “[p]hysicians working with these families should be

### C. Sex-Marker Litigation

Activists use sex-marker litigation to gain formal recognition to intersex identity.<sup>159</sup> In these cases, individual plaintiffs and interest groups challenge the sex-binary classification system in official identification documents, such as passports, birth certificates, and drivers' licenses.<sup>160</sup> The basis for these challenges against state bureaucracy is that the system lacks accurate registration options for people with either sexual traits or gender identities that do not comport as male or female. Unlike activists who directly attack the medical standard of care, this approach elegantly leaves physicians out of the formal dispute. By gaining formal recognition from administrative authorities about the existence of a third/unspecified sex/gender, activists hope that this will flow to other social and professional institutions like medicine.

The debate about sex-markers on official documentation is happening globally with different kinds of contestations between activists and government bodies. Australia was quick to recognize gender and sex nonconformity, issuing the first "X passport" to an intersex citizen in 2003.<sup>161</sup> In 2011, requirements to obtain an X passport were softened and in 2013 this policy was solidified in federal guidelines.<sup>162</sup> Current Australian passport policy states: "We can issue a passport to sex and gender diverse applicants as M (Male), F (Female) or X (Indeterminate/Intersex/Unspecified)."<sup>163</sup> Although surgery is not a prerequisite for a passport to be issued in the preferred sex, applicants still need to submit medical certification that the person is "of

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aware that the trend in recent years has been for legal and human rights bodies to increasingly emphasize preserving patient autonomy." Lee et al., *supra* note 19, at 177.

<sup>159</sup> Reuters, *'We Exist': Navy Veteran Dana Zzyym Sues State Department for Denying 'Intersex' Passport*, RAW STORY (Oct. 27, 2015), <http://www.rawstory.com/2015/10/we-exist-navy-veteran-dana-zzyym-sues-state-department-for-denying-intersex-passport> [<https://perma.cc/GP6J-KQ3R>].

<sup>160</sup> See, e.g., Mary Emily O'Hara, *Oregon Becomes First State to Add Third Gender to Driver's Licenses*, NBC NEWS (June 15, 2017), <https://www.nbcnews.com/feature/nbc-out/oregon-becomes-first-state-add-third-gender-driver-s-licenses-n772891> [<https://perma.cc/8PZM-MG96>]; Mary Emily O'Hara, *Nation's First Known Intersex Birth Certificate Issued in NYC*, NBC NEWS (Dec. 29, 2016), <https://www.nbcnews.com/feature/nbc-out/nation-s-first-known-intersex-birth-certificate-issued-nyc-n701186> [<https://perma.cc/Y9BH-8U59>]; Susan Scutti, *NYC Issues Nation's First "Intersex" Birth Certificate*, CNN (Jan. 2, 2017), <http://www.cnn.com/2016/12/30/health/intersex-birth-certificate/index.html> [<https://perma.cc/33F5-ZUEZ>].

<sup>161</sup> *Ten Years of 'X' Passports, and No Protection From Discrimination*, OII AUSTRALIA (Jan. 12, 2013), <https://oii.org.au/21597/ten-years-of-x-passports-and-no-protection-from-discrimination> [<https://perma.cc/VVF6-8J6W>].

<sup>162</sup> AUSTL. GOV'T, AUSTRALIAN GOVERNMENT GUIDELINES ON THE RECOGNITION OF SEX AND GENDER ¶ 19-21 (2013), <https://www.ag.gov.au/Publications/Documents/AustralianGovernmentGuidelinesontheRecognitionofSexandGender/AustralianGovernmentGuidelinesontheRecognitionofSexandGender.pdf> [<https://perma.cc/P9VN-82LV>].

<sup>163</sup> AUSTRALIAN GOV'T, DEP'T OF FOREIGN AFFAIRS AND TRADE, *Sex and Gender Diverse Passport Applicants*, AUSTRALIAN PASSPORT OFFICE, <https://www.passports.gov.au/passportsexplained/theapplicationprocess/eligibilityoverview/Pages/changeofsexdoborpop.aspx#quest1> [<https://perma.cc/NT9U-FDL3>].

indeterminate sex or are intersex.”<sup>164</sup> Other countries, including India,<sup>165</sup> Nepal,<sup>166</sup> and Malta<sup>167</sup> have followed in Australia’s footsteps by granting official recognition of a “third gender/sex” category. In many of these cases, LGBT identity politics are involved in the broader initiative to reform policy.

In the United States, LAMBDA Legal filed a sex discrimination suit against the Secretary of State and the Director of the Colorado Passport Agency for the United States Department of State on behalf of Dana Alix Zzyym for violating of the Administrative Procedure Act and depriving Dana of due process and equal protection. Dana was an intersex activist who applied for a passport “with a gender marker that respect[ed] Dana’s identity.”<sup>168</sup> According to the complaint, Dana listed “Intersex” instead of “M” or “F” in the application sex-field, and clarified, “I’m not male or female.”<sup>169</sup> Accordingly, Dana asked the State Department to issue a passport that “accurately reflected Dana’s gender by the use of a third gender marker,”<sup>170</sup> such as “X.”<sup>171</sup> The State Department denied Dana’s request. Dana’s suit challenges the denial on the basis of “Dana’s fundamental rights and liberty interests, including the freedom to travel and right to define and express one’s own identity.”<sup>172</sup> As with global trends, Dana’s case is also intertwined with the greater LGBT identity politics movement and purports to represent the entire class of people whose gender identity does not comport with male or female designations. “This is something I believe every other intersex and non-binary person has a right to do,” said Dana,<sup>173</sup>

<sup>164</sup> *Id.*

<sup>165</sup> Jennifer Rellis, “Please Write ‘E’ in this Box” *Toward Self-Identification and Recognition of a Third Gender: Approaches in the United States and India*, 14 MICH. J. GENDER & L. 223, 233 (2008).

<sup>166</sup> Kyle Knight, *Nepal’s Third Gender and the Recognition of Gender Identity*, HUFFPOST (Apr. 24, 2012), [http://www.huffingtonpost.com/kyle-knight/nepal-third-gender\\_b\\_1447982.html](http://www.huffingtonpost.com/kyle-knight/nepal-third-gender_b_1447982.html) [<https://perma.cc/PNU2-L5HS>]; see generally Michael Bochenek & Kyle Knight, *Establishing a Third Gender Category in Nepal: Process and Prognosis*, 26 EMORY INT’L L. REV. 11 (2012) (analyzing path of legal implementation of Nepali third gender); Maria Federica Moscati & Hari Phuyal, “The Third Gender Case” *Decision of the Supreme Court of Nepal on the Rights of Lesbian, Gay, Bisexual, Transsexual and Intersex People*, 4 J. COMP. L. 291 (2009) (analyzing landmark LGBTI case decided by Supreme Court of Nepal).

<sup>167</sup> Miriam Dalli, *Male, Female or X: The New Gender Options on Identification Documents*, MALTA TODAY (Feb. 3, 2015), [http://www.maltatoday.com.mt/news/national/49185/male\\_female\\_or\\_x\\_the\\_new\\_gender\\_options\\_on\\_identification\\_documents#.WJHtqlMrKM9](http://www.maltatoday.com.mt/news/national/49185/male_female_or_x_the_new_gender_options_on_identification_documents#.WJHtqlMrKM9) [<https://perma.cc/8YA4-ATJV>].

<sup>168</sup> Dana Alix ZZYYM Complaint, *supra* note 82, at ¶ 1.

<sup>169</sup> *Id.* at ¶ 35.

<sup>170</sup> *Id.* at ¶ 37.

<sup>171</sup> *Id.* at ¶ 35 (“Dana requested “X” as the marker in the sex field of the passport because such designation conforms to the International Civil Aviation Organization (ICAO) standards for machine-readable travel documents.”).

<sup>172</sup> *Id.* at ¶ 2.

<sup>173</sup> Leticia Miranda, *Intersex Activist Denied A Passport Sues The U.S. Government*, BUZZFEED NEWS (Oct. 26, 2015), <http://www.buzzfeed.com/leticiamiranda/intersex-activist-denied-a-passport-sues-the-us-government#.xbb8wj3Dm> [<https://perma.cc/QAN6-L52X>].

When I was a child, I had no say in what was done to me in order to make me ‘fit’ in some acceptable category . . . I continue to suffer the consequences of those decisions today. But, as an adult, I can take a stand. I am not male, I am not female, I am intersex, and I shouldn’t have to choose a gender marker for my official U.S. identity document that isn’t me.<sup>174</sup>

While sex-marker litigation may seem to be about mere symbolic self-identification preferences, it actually embeds meaningful distributive consequences.<sup>175</sup> For example, in 2014, a mother petitioned Kenya’s High Court for her five-year-old child, whose sex was unclear at birth, to be issued a birth certificate reflecting a sex that was neither male nor female.<sup>176</sup> The mother argued that:

a birth certificate is of great importance in all spheres of life and development of a child because it is the ticket to admission in school, issuance of a passport, a national identity card, employment, etc. and without that document and or legal recognition, a child cannot realize or enjoy the rights, protection and guarantees.<sup>177</sup>

The right to “legal recognition” as it was framed in the Kenyan case is actually a pathway to other benefits in the legal and administrative system. Ultimately, the court was not convinced that a third category for intersex infants was needed and even if it was, the court did not have jurisdiction to mandate such change. However, the court agreed that intersex medical management should correspond to basic human rights and ordered the respondents to initiate a process of formulating guidelines that would align intersex medical management with legal norms and the children’s best interests.<sup>178</sup> The judge further urged parliament to consider legislation that would consider the positions of various interested stakeholders in line with the principle of “public participation.”<sup>179</sup>

In the U.S. context, the right to “define and express one’s own identity” translates into the freedom to “make intimate decisions concerning marriage, procreation, and family life, all without undue government interference.”<sup>180</sup> It is also tied to the freedom to travel internationally and to access

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<sup>174</sup> Michael K. Lavers, *Intersex Person Sues State Department over Passport Denial*, WASHINGTON BLADE (Oct. 26, 2015), <http://www.washingtonblade.com/2015/10/26/inter-sex-person-sues-state-department-over-passport-denial/#sthash.7625ihua.dpuf> [https://perma.cc/45KN-HMDS].

<sup>175</sup> NANCY FRASER, *JUSTICE INTERRUPTUS: CRITICAL REFLECTIONS ON THE “POST-SOCIALIST” CONDITION* 11–33 (1997).

<sup>176</sup> Baby A, *supra* note 81, at ¶ 3.

<sup>177</sup> *Id.*

<sup>178</sup> *See id.* at ¶ 62–72.

<sup>179</sup> *See id.* at ¶ 67.

<sup>180</sup> Dana Alix ZZYYM Complaint, *supra* note 82, at ¶ 71.

legal protection from discrimination.<sup>181</sup> The desired redistribution of resources following legal recognition of intersex identity is not limited to accessing administrative and legal benefits, but actually underpins a change in power distribution between parties in the traditional doctor-patient relationship. Despite the outcome, the Kenya case triggered a process of judicial scrutiny of the humaneness and lawfulness of intersex-normalization treatments.

Legal recognition of intersex as a distinct administrative category has the potential to legitimize the social model of intersexuality. From a distributive perspective, the mere discussion of intersex as a distinct category in the administrative system has the potential to undermine medical assumptions and practices that surround intersex individuals, and encourage their re-examination by official organizations and intersex individuals. Legal recognition of intersex may also solidify the notion that intersexuality cannot be erased by medical measures. It might also be interpreted as a normative stance against normalizing treatments, meaning not only that intersexuality cannot, but also perhaps, should not be erased.

### III. MEDICAL ACTIVISM: DEMOCRATIZING THE STANDARD OF CARE

Critics of legal activism often urge social movements to neglect litigation or legal reforms in favor of political mobilization.<sup>182</sup> This approach argues that social movements should focus on “softer” regulations and rules in order to change or challenge institutions controlled by standards contained in professional codes.<sup>183</sup> According to this approach, treatment activists are actually engaged in a supposedly more radical and fundamental struggle that avoids the pitfalls of legal cooptation. This section focuses on the achievements of treatment activists and argues that their actions have democratized biomedical policy-making.

One way to explain intersex medical activism is to understand it as intended to enhance the role of collective patient groups in the making of biomedical policy. Scholars Nikolas Rose and Carlos Novas observed the democratizing effect of social movements in the field of biomedical policy, and introduced the concepts of “bio-citizenship” and “bio-societies” to de-

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<sup>181</sup> See Hay, *supra* note 135. When explaining the necessity of a specific sex marker for intersex people, Vilorio gives the example of Curtis Hinkle, an intersex activist who filed a harassment complaint to the Equal Employment Opportunity Commission and was denied because intersex was not covered under the act’s protection from sex discrimination. See Hida Vilorio, *X Marks Evolution: The Benefits of the “Indeterminate Sex” Passport Designator*, HASTINGS CTR. BLOG (Dec. 7, 2011), <http://www.thehastingscenter.org/x-marks-evolution-the-benefits-of-the-indeterminate-sex-passport-designator/#ixzz43eqzbnZ1> [<https://perma.cc/TJ28-5EQM>].

<sup>182</sup> See QUEER MOBILIZATIONS, *supra* note 108, at 5.

<sup>183</sup> This approach is based on an idea central to legal pluralism that multiple bodies of norms order behavior, including self-regulation and non-formal laws. See Lobel, *supra* note 7, at 966–70.

scribe the form of activism patient advocacy groups engage in based on a shared biological identity.<sup>184</sup> Bio-citizenship synthesizes a biological notion of personal identity and the collective consciousness and ideology of civil rights to explain the motivation of citizens to redress a “democratic deficit,” referring to their lack of control over scientific and medical norms that affect them.<sup>185</sup> The glue that sticks bio-citizens in collective action together is not just a shared political agenda, but also a shared biological experience such as a disease, injury, genetic status, etc.<sup>186</sup> These concepts stress the capacity of collective lay organizing to enhance citizen participation in biomedical policy-making and to democratize scientific authority.<sup>187</sup>

The following sections describe the benefits of intersex medical activism, which democratizes the standard of care by giving activists a seat at the decision-making table. This section reviews the changes made to the official standard of care in intersex management through the consideration of patients’ voices and elaborates on the deeper epistemological challenges these actions impose on the scientific standard and research methods.

### A. *Becoming Insiders*

Frustration among some activists about the seemingly fruitless attempts to influence medical institutions led to the movement’s development of a scientific “insider” position. The same phenomenon occurred in AIDS activism, which has a long legacy of members becoming insiders. Some AIDS activists gained enough credibility within the scientific community to become full-fledged members of biomedical regulatory boards within the government by “playing their cards well” in collective organizing and through self-education in the vocabulary and culture of the scientific community.<sup>188</sup> Using their acquired credibility, AIDS activists were able to help resolve scientific controversies and change the rules of scientific knowledge production, such as evidentiary norms and the eligibility of participants in clinical

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<sup>184</sup> Nikolas Rose & Carlos Novas, *Biological Citizenship*, in *GLOBAL ASSEMBLAGES: TECHNOLOGY, POLITICS, AND ETHICS AS ANTHROPOLOGICAL PROBLEMS* 439, 448–51 (Aihwa Ong & Stephen J. Collier eds., 2005). Steven Epstein had also offered a similar concept: “biopolitical citizenship.” STEVEN EPSTEIN, *INCLUSION: THE POLITICS OF DIFFERENCE IN MEDICAL RESEARCH* 20–21 (2007).

<sup>185</sup> See generally SHEILA JASANOFF, *THE FIFTH BRANCH: SCIENCE ADVISERS AS POLICYMAKERS* (1990) (discussing the inherent tension between expertise and democracy).

<sup>186</sup> Jessica Mulligan, *Biological Citizenship*, *OXFORD BIBLIOGRAPHIES* (Feb. 28 2017), [http://www.oxfordbibliographies.com/view/document/obo-9780199766567/obo-9780199766567-0164.xml# \[https://perma.cc/8JRH-KMMZ\]](http://www.oxfordbibliographies.com/view/document/obo-9780199766567/obo-9780199766567-0164.xml# [https://perma.cc/8JRH-KMMZ]).

<sup>187</sup> The need to democratize scientific and medical knowledge is an established idea in research. See, e.g., BEATRIX HOFFMAN ET AL., *PATIENTS AS POLICY ACTORS* 1–5 (2011). This is also present in the context of patient social movements. See Brown & Zavestoski, *supra* note 110, at 682.

<sup>188</sup> See EPSTEIN, *IMPURE SCIENCE*, *supra* note 86, at 333, 335–36; Epstein, *The Construction of Lay Expertise*, *supra* note 86, at 410.

trials.<sup>189</sup> The invasion of and collaboration with scientific institutions had a transformative effect on the production of scientific knowledge.

Intersex activists have endured a long and sometimes painful process of finding a similar seat at the table. The movement's early years included attempts to engage with the medical profession by questioning the scientific merits of existing evidence and theories and by providing alternative credible data that should be taken into consideration. ISNA looked to the work of Milton Diamond, who refuted one of the most fundamental justifications for contemporary medical approaches: Dr. John Money's experiment on David Reimer in 1997 (also known as the John/Joan case).<sup>190</sup> By 2004, the attitudes of medical professionals changed slightly when they partially acknowledged a lack of evidentiary support for traditional medical intersex treatments.<sup>191</sup> In response, the ISNA produced alternative guidelines for intersex management in partnership with allied physicians.<sup>192</sup>

Despite the oppositional de-medicalization agenda pursued by ISNA activists at the time, Cheryl Chase and Barbara Thomas were invited to participate in a national professional conference that led to the issuance of the 2006 consensus.<sup>193</sup> Although Chase's and Thomas's views were not fully accepted, the consensus statement expressed the importance of a cautionary approach to surgical interventions for the first time. Their views put an emphasis on functionality over cosmetics,<sup>194</sup> called for open communication between, and decision-making with, patients and their families,<sup>195</sup> and included statements about preserving reproductive capabilities when possible.<sup>196</sup> The participation of activists left a clear mark on the new guidelines; "there has been progress in diagnosis, surgical techniques, understanding psychosocial issues, and recognizing and accepting the place of patient advocacy."<sup>197</sup> These successes marked an important change in the perception of activists, who had moved from the "picket lines to having a seat at the table in medical conferences."<sup>198</sup>

<sup>189</sup> See EPSTEIN, *IMPURE SCIENCE*, *supra* note 86, at 333; Epstein, *The Construction of Lay Expertise*, *supra* note 86, at 410.

<sup>190</sup> Milton Diamond & H. Keith Sigmundson, *Sex Reassignment at Birth: Long-Term Review and Clinical Implications*, 151 *ARCHIVES PEDIATRICS & ADOLESCENT MED.* 298, 298–99 (1997), <http://www.hawaii.edu/PCSS/biblio/articles/1961to1999/1997-sex-reassignment.html> [<https://perma.cc/M29X-XQLM>].

<sup>191</sup> See Dreger & Herndon, *supra* note 47, at 205.

<sup>192</sup> ISNA, *HANDBOOK FOR PARENTS* (2006), <http://www.accordalliance.org/dsdguidelines/htdocs/parents/index.html> [<https://perma.cc/AZ47-L43E>].

<sup>193</sup> Hughes et al., *Consensus Statement on Management of Intersex Disorders*, *supra* note 3.

<sup>194</sup> *Id.* at 491.

<sup>195</sup> *Id.* at 490.

<sup>196</sup> *Id.* at 491.

<sup>197</sup> *Id.* at 488.

<sup>198</sup> A similar description can be found on ISNA's website. See *What's the History Behind the Intersex Rights Movement?*, *supra* note 41 ("ISNA members have gone from picket lines to having a seat at the table in medical conferences.").

After the 2006 consensus statement was issued, the ISNA realized that its highest priority was to monitor and promote its implementation. Unable to fulfill these goals, the ISNA decided to shutter its operation. An explanatory letter to friends and supporters published on the ISNA's website explained that, "[a]lthough it has been very successful in recent years in creating collaborative relationships . . . there is concern among many health-care professionals, parents, and mainstream healthcare system funders that ISNA's views are biased or that an association with ISNA will be frowned upon by colleagues and peers."<sup>199</sup> Accordingly, a new organization was formed for the purpose of fulfilling the movement's new direction,<sup>200</sup> symbolically called the "Accord Alliance," which was meant to accommodate work in accordance with, instead of in opposition to, medical professionals in the promotion of change.<sup>201</sup>

### B. *Participation in the Composition of Clinical Practice Guidelines*

The influx of intersex activists into the arena of scientific knowledge production is perhaps best reflected in the composition of clinical practice guidelines (CPGs) for the management of intersex conditions. The Institute of Medicine defines CPGs as "systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances."<sup>202</sup> Their primary function is to unify and regulate the internal standard of care.<sup>203</sup> Whereas malpractice litigation attempts to challenge the standard of care from the outside, involvement of activists in CPG composition attempts to challenge the standard of care from the inside by going to the source of professional authority.

A recent update to the 2006 consensus statement that further revised the standard of intersex care ("2016 update") demonstrates the enormous credibility that this moderate strand of the movement has managed to achieve thus far.<sup>204</sup> The revision was motivated by recognizing changes in "knowledge and viewpoints" and by the demands of advocacy groups to become more active participants in the design of clinical practice and research that concerns them.<sup>205</sup> Medical activists respond to "community members

<sup>199</sup> *Dear ISNA Friends and Supporters*, ISNA, <http://www.isna.org> [<https://perma.cc/V3ZR-D238>].

<sup>200</sup> *See id.*

<sup>201</sup> DAVIS, *supra* note 52, at 38.

<sup>202</sup> CLINICAL PRACTICE GUIDELINES: DIRECTIONS FOR A NEW PROGRAM 8 (Marilyn J. Field & Kathleen N. Lohr eds., 1990).

<sup>203</sup> *See* Michelle M. Mello, *Of Swords and Shields: The Role of Clinical Practice Guidelines in Medical Malpractice Litigation*, 149 U. PA. L. REV. 645, 647 (2001).

<sup>204</sup> "The goal of this update regarding the diagnosis and care of persons with disorders of sex development (DSDs) is to address changes in the clinical approach since the 2005 Consensus Conference, since knowledge and viewpoints change. An effort was made to include representatives from a broad perspective including support and advocacy groups." Lee et al., *supra* note 19, at 158.

<sup>205</sup> *Id.*

[who] now call for evidence-based interventions, the consistent inclusion of evidence and of controversies in informed consent processes and the creative identification of alternative strategies, including psychosocial support and PS [peer support] as primary interventions,”<sup>206</sup> instead of “the monolithic approach to treatment.”<sup>207</sup> The 2016 update seems to adhere to this approach. It praises the ongoing collaboration between national peer support groups (“PSGs”) and providers caring for intersex patients since the 2006 consensus, which reflects “growing prioritization of patient perspectives focusing on health and well-being outcomes.”<sup>208</sup>

The 2016 update views the incorporation of PSG representatives and affected persons in clinical practice as an essential part of quality of care because of their ability to “enhance the teams’ psychosocial services”<sup>209</sup> and to ensure routinized consideration of patient perspectives.<sup>210</sup> The update suggests that PSG volunteers can become a source of emotional support and education for patients and families. The update specifically states that “routine incorporation of PS into clinical care at the earliest possible time can ease what can be a bewildering experience for parents.”<sup>211</sup> The update also refers its readers to a comprehensive list<sup>212</sup> of American and international PSGs and advocacy resources on DSDs and intersexuality.

The revised standards also express a strong belief in collaboration with patients as a way to mitigate scientific uncertainties and social controversies, including those created by legal and ethical communities. For example, the 2016 update includes reference to instances in which uncertainty and the lack of strong empirical basis in intersex treatment are openly admitted, such as the inability to predict gender identity<sup>213</sup> or to safeguard sexual functioning in the future.<sup>214</sup> It even admits previous biases and mistakes in the medical profession’s treatment protocols.<sup>215</sup> As a result of scarce data and strong disagreements over optimal treatment practices, including the timing and type of procedures performed, the update states that a collaborative approach is the key to overcoming setbacks in care alongside the concurrent effort to produce evidence that supports a patient-centered, evidence-based treatment plan in the future.<sup>216</sup>

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<sup>206</sup> *Id.* at 160.

<sup>207</sup> *Id.*

<sup>208</sup> *Id.*

<sup>209</sup> *Id.*

<sup>210</sup> *Id.*

<sup>211</sup> *Id.*

<sup>212</sup> *Id.* at 161.

<sup>213</sup> *Id.* at 168.

<sup>214</sup> *Id.* at 169.

<sup>215</sup> *Id.* at 170 (“Historically, health professionals – primarily physicians – did not openly and fully communicate with patients and families about their DSDs, in part because of the belief that there would be difficulties accepting a full disclosure.”).

<sup>216</sup> *Id.* at 176.

### C. *Bringing Epistemic Change*

Among all the strategies employed by activists, the march into the heart of scientific knowledge production poses the deepest epistemic challenge to scientific methodology. The 2016 update demonstrates an aspiration not only to provide better care, but also to produce better knowledge to guide practice through the incorporation of patient advocates in the design of research goals and priorities in a way that protects and serves the interests of patients.<sup>217</sup> The inclusion of activist and patient perspectives at different stages in the scientific enterprise supports the democratization of the medical science process, which seeks to emphasize the benefits of participatory knowledge over the tyranny of expertise.<sup>218</sup>

Scholars suggest that social movements in the field of health “serve as a critical counter-authority” that “democratize[s] science” and “enhance[s] public engagement in knowledge production.”<sup>219</sup> David Hess argues that the decline of medical professional dominance in the late twentieth century, the rise of health social movements, and the growth of counter-expertise evidence have led to an epistemic change in the status of patients, from a submissive lay consumer to an active and learned community of knowledge producers.<sup>220</sup> As Hess notes, the medical profession has responded in a variety of ways to the knowledge claims by health advocacy movements, from outright rejections, which have emphasized the purity of scientific medical knowledge, to meaningful engagement, which has resulted in the development of a middle ground between lay and expert knowledge in which the public participates.<sup>221</sup> Through direct engagement, activists have made their way to the table by becoming legitimate contributors to scientific research and knowledge-making. Their views have been integrated and institutionalized into the research process, converting the patient advocacy movement into an insider participant in research policy-making.<sup>222</sup>

A way to challenge scientific knowledge from within is by creating an epistemic conflict. An epistemic conflict can be created, for example, when

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<sup>217</sup> For example, the AIS-DSD (Androgen Insensitivity Syndrome) support group composed a policy that facilitates participation in research if a medical advisor from the support group serves as a consultant. *Id.* at 160.

<sup>218</sup> See generally Kelly Moore, *Powered by the People: Scientific Authority in Participatory Science*, in *THE NEW POLITICAL SOCIOLOGY OF SCIENCE: INSTITUTIONS, NETWORKS, AND POWER* 299 (Scott Frickel and Kelly Moore eds., 2006) (comparing the characteristics and benefits of participatory science that is initiated by activists, professionals, or amateurs).

<sup>219</sup> Rachel Morello-Frosch et al., *Embodied Health Movements Responses to a “Scientitized” World*, in *THE NEW POLITICAL SOCIOLOGY OF SCIENCE*, *supra* note 218, at 244, 266–67.

<sup>220</sup> David Hess, *Medical Modernisation, Scientific Research Fields and the Epistemic Politics of Health Social Movements*, in *SOCIAL MOVEMENTS IN HEALTH* 695, 695 (Phil Brown & Stephen Zavestoski eds., 2005).

<sup>221</sup> *Id.* at 702–03.

<sup>222</sup> *Id.* at 705.

vague phrases—such as “best interest” or “medically necessary”—receive dramatically different interpretations from patients and doctors. The San Francisco Human Rights report highlighted the problem of scientific knowledge production that fails to capture the concerns and needs of intersex patients. The report discussed the inherent risk in producing *additional* scientific data that fails to correspond with the lived experiences of intersex people:

The definition of a “successful outcome” differs greatly between medical providers and patients. Questions in follow-up studies tend to focus on heterosexual sexual behavior as being the standard for success, as opposed to fertility or pleasure. It is more common to ask a patient if she or he is married than to ask if that patient has a pleasing sexual life, is able to procreate, or has the ability to achieve orgasm.<sup>223</sup>

The 2016 update also goes further, requiring not only an incorporation of patient perspectives into policy-making and clinics, but also a transformative change in attitudes towards the core scientific method of collecting patients’ testimonies in the future, with suggestions for reforming the design of research and the type of empirical methods used. For example, the 2016 update suggests the value in mixed methods of research and the need to enrich the data collected through research:

Stakeholders’ openness to use a mix of methods might resolve historical differences on issues as basic as the value of quantitative versus qualitative evidence. For example, a narrative analysis may reveal themes such as emotional openness or resilience that could lead to studies of effective psychosocial interventions . . . the open-endedness of qualitative approaches offers a greater scope for participants to define their own challenges and articulate emotions.<sup>224</sup>

The 2016 update suggests that collaboration with PSGs is a valuable source of empirical data and a “reservoir[ ] of qualitative lived experience of patients and families.”<sup>225</sup> The update also supports a collaborative model called “community-based participatory research,” which aims to develop a stakeholder forum comprised of patient advocates, clinicians, and researchers to produce research that better aligns with the needs and priorities of patients.<sup>226</sup>

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<sup>223</sup> DE MARIA ARANA, *supra* note 28, at 19.

<sup>224</sup> Lee et al., *supra* note 19, at 164–67.

<sup>225</sup> *Id.* at 160.

<sup>226</sup> *Id.* at 164.

## IV. CRITIQUES OF LEGAL AND MEDICAL ACTIVISM

After examining claimed victories of medical and legal activism, this part illustrates the critiques of each. Comparing the critiques reveals that although law and biomedicine are distinct arenas of social change with their own particular logics and constraints, criticisms directed towards them are similar in nature. The collaboration of activists with medical or legal institutions and professionals generates compromises that implicate inter-movement politics and relations. The presented critiques punch holes in the claimed victory stories and ultimately complicate any simple attempt to defend one path over the other as enhancing the life quality of intersex people.

A. *A Critique on Legal Activism: Legal Cooptation*

One of the most pronounced critiques of social movements pursuing change through legal reform is legal cooptation: “a process by which the focus on legal reform narrows the causes, de-radicalizes the agenda, legitimizes ongoing injustices, and diverts energies away from more effective and transformative alternatives.”<sup>227</sup> This critique applies directly to intersex legal activism: focusing on a narrow group’s interests, which leads to counter-productive and potentially harmful unintended consequences, and the abandonment of a transformative agenda to destabilize the male-female binary in favor of constructing a fixated notion of intersexuality.

1. *The Narrow Focus on Legal Recognition and its Unintended Consequences*

Finding a position that bridges the range of personal and collective biographies and the interests of non-vocal members and serves the broadest common ground is a classic dilemma for social movement lawyers. Legal activism problematically requires a “united front, which flattens internal debates, fragments and marginalizes segments of the broader vision and obscures the complexity of interests, needs and stakes that exist within the social field.”<sup>228</sup> Accordingly, the focus on legal recognition, for example, highlights the conflicting interests of movement members. The fight for legal recognition of intersex people in different legal settings, like official documentation, is implicitly criticized for taking focus away from the de-

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<sup>227</sup> Lobel, *supra* note 7, at 939.

<sup>228</sup> *Id.* at 951. Scholars observed that the tendency to focus on identity-based equality arguments in legal reform fragments the movement to particular small-scale collectivities who fight for their own slice of the cake, instead of aligning with other groups in a broad-based social movement directed towards transformative political change. See MICHAEL W. McCANN, TAKING REFORM SERIOUSLY: PERSPECTIVES ON PUBLIC INTEREST LIBERALISM 200 (1986); Janet E. Halley, *Like-Race Arguments*, in WHAT’S LEFT OF THEORY?: NEW WORK ON THE POLITICS OF LITERARY THEORY 40, 48–64 (Judith Butler et al. eds., 2000).

medicalization efforts and imposing unwanted identification on children and adult assimilators.

*a. Tensions with Treatment Activists: Shifting Energies from the Improvement of Care Objective*

The struggle for an administrative third category creates tension between activists who see intersex mainly as a sex/gender non-conforming identity on the LGBT spectrum, and activists who are more focused on improving the standard of care. Treatment activists and some assimilators object to the association of intersex with a particular administrative category because it does not focus on improving the standard of care. For example, the Australian branch of OII (OII-AUS) supports the creation of a third category for *all* people who do not identify as male/female (M/F), but rejects advocacy that associates intersexuality specifically with a third sex/gender, choosing instead to fight normalization as a first priority.<sup>229</sup> It is also unclear how such developments play out in reality. For example, in 2013, a legislative change in Germany allowed parents to leave the sex box on birth certificates empty.<sup>230</sup> The press reported that the new legislation removed pressure on parents to rush into a sex-assignment decision when an intersex baby was born and presented the legislation as a major achievement for intersex advocacy.<sup>231</sup> But some intersex organizations warned against the unexpected consequences of this development.<sup>232</sup> The language of the new policy failed to clarify whether this permission recognized a third category or just created a temporarily empty one. The policy did not clarify whether it was a choice given to parents to opt-in or whether it was simply a default option. When would one have to decide and what proof would one have to present in order to enter traditional categories? One activist commented that this might even increase pressure on parents to choose surgery as “[p]arents will be under more pressure than ever to avoid being forcibly outed by the state.”<sup>233</sup> More-

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<sup>229</sup> See *Ten Years of ‘X’ Passports, and No Protection From Discrimination*, *supra* note 161; *On Norrie v. NSW Registrar of Births, Deaths and Marriages*, OII AUSTRALIA (June 22, 2013), <https://oii.org.au/22681/norrie-v-nsw-registrar-of-births-deaths-and-marriages/> [<https://perma.cc/T5KV-GYF3>]; *Third Sex, Redux*, OII AUSTRALIA (June 14, 2013), <https://oii.org.au/22663/third-sex-redux/> [<https://perma.cc/598B-5GLC>].

<sup>230</sup> Die Rechtsfähigkeit des Menschen beginnt mit der Vollendung der Geburt [Beginn der Rechtsfähigkeit] [Legal Capacity Act], Nov. 1, 2013, BGBl I at § 3.6.

<sup>231</sup> See, e.g., Jacinta Nandi, *Germany Got It Right by Offering a Third Gender Option on Birth Certificates*, THE GUARDIAN (Nov. 10, 2013), <https://www.theguardian.com/commentisfree/2013/nov/10/germany-third-gender-birth-certificate> [<https://perma.cc/8632-65QC>]; *Germany Allows ‘Indeterminate’ Gender at Birth*, BBC NEWS: EUROPE (Nov. 1, 2013), [www.bbc.com/news/world-europe-24767225](http://www.bbc.com/news/world-europe-24767225) [<https://perma.cc/7A6P-V5VL>]; *Germany Allows ‘Third Sex’ Option at Birth*, DEUTSCHE WELLE: TOP STORIES (Nov. 1, 2013), [www.dw.de/germany-allows-third-sex-option-at-birth/a-17198361](http://www.dw.de/germany-allows-third-sex-option-at-birth/a-17198361) [<https://perma.cc/3GNJ-MNAG>].

<sup>232</sup> Hida Voloria, *Why Intersex Germans Aren’t Crazy About Germany’s New Third Gender Law*, TRANSVANILLA, <http://transvanilla.hu/news/why-intersex-germans-aren-t-crazy-about-germany-s-new-third-gender-law> [<https://perma.cc/792R-6CK8>].

<sup>233</sup> Nandi, *supra* note 231.

over, the German law was recently reported to have generated no change in the amount of gender-normalizing surgeries conducted each year and only some changes in clinical terminology.<sup>234</sup>

*b. Tensions with Assimilators: May Impose Unwanted Outing*

Another ideological and practical tension is created between activists who see intersex as a sex/gender non-conforming identity and activists who identify as males and females. On a practical level, current efforts to create a third category for intersex babies outside of the United States have already been criticized for their potential to impose unwanted “outing.” The promotion of policies that provide a third gender option on official documentation needs to be highly sensitive to language, timing, and the institutional dynamic that authorizes it. The association between intersex biology and a non-conforming gender identity and sexuality is known to be troubling for parents,<sup>235</sup> but may also be worrying for adults. The international OII Intersex Network’s position is that:

The creation of a specific category for intersex risks even more marginalization of a group which is poorly understood. We base our legal arguments on the right of every person to determine her/his own identity in the binary system in the hope that eventually there would be no attempt to impose legal sex categories on anyone.<sup>236</sup>

The clash between recognition and assimilation was raised in the context of passports. Dreger has criticized the Australian policy of providing X passports, arguing that it is designated and available to only intersex people, whereas the vast majority of intersex people are actually not interested in identifying as different at all. Moreover, Dreger argues that this type of policy leaves doctors with the authority to certify people’s intersex status, reaffirming their traditional role as arbiters of social identity.<sup>237</sup> This is supported by recent data presented by OII-AUS suggesting that 75% of people born with atypical sex characteristics define themselves as male/female and that 19% choose other options.<sup>238</sup> In response to Dreger, Hida Vioria replied that activists are starting to advocate for a voluntary opt-in mechanism only for

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<sup>234</sup> *Miraculous Thinking*, OII AUSTRALIA (Dec. 22, 2016), <https://oii.org.au/31093/miraculous-thinking/> [<https://perma.cc/6LAF-EDGC>].

<sup>235</sup> For example, parents to newborns with unclear sex characteristics object to such identity politics that associate their children with non-normative sexuality. *See, e.g.*, Cools et al., *supra* note 102, at 408.

<sup>236</sup> *On a Third Sex*, OII AUSTRALIA (Jan. 16, 2012), <https://oiiinternational.com/2614/on-third-sex/> [<https://perma.cc/4EVV-7LKP>].

<sup>237</sup> *See* Alice Dreger, *Australia’s Passport to Gender Confusion*, THE HASTINGS CTR. (Sept. 28, 2011), <http://www.thehastingscenter.org/australias-passport-to-gender-confusion/> [<https://perma.cc/F68B-6GBJ>].

<sup>238</sup> *See Miraculous Thinking*, *supra* note 234.

those who desire it, even if they are the minority.<sup>239</sup> Essentially, policies made to distinguish intersex people as a separate administrative class need to be sensitive to the interests of intersex people who identify as males and females. Activists need to make sure that the creation of another classification option is empowering to those who want it and not imposed on those who are not interested in it.

## 2. *Fixing Intersexuality*

For intersex activists, legal framing helped to combat medical models of intersexuality and create new contexts in which community perspectives could be transformed into a valuable source of knowledge. However, the reframing of the medical-social clash in legal language also required activists to accommodate their presentation to the law's frameworks.<sup>240</sup> For example, in order to pursue a malpractice lawsuit, plaintiffs needed to establish a doctor-patient relationship and bring lawsuits under the causes of action available. In IHR advocacy and sex-marker litigation, for example, activists presented themselves as members of a discriminated sexual minority.<sup>241</sup> In many ways, the legal framework not only dictates the rules of the debate, but also governs the way parties present and define themselves in public life.

Accordingly, legal framing and argumentation can sometimes have disciplining effects over the way intersex people tell their stories and manage their lives. The pursuit of a non-binary gender marker in passports, for example, pushed identity activists to make "like-race arguments" that emphasize the inborn and fixed intersex traits in order to strengthen their case.<sup>242</sup> For example, in Dana Alix ZZYM's suit, the "statements of facts" section declared that "Dana, who was born intersex, is neither male nor female."<sup>243</sup> After explaining the complexity of sex determination in childhood and Dana's medical history, it is said that "[n]one of the surgeries Dana under-

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<sup>239</sup> See Vilorio, *supra* note 181.

<sup>240</sup> ELLEN ANN ANDERSEN, *OUT OF THE CLOSET AND INTO THE COURTS* 12 (2009).

<sup>241</sup> See, e.g., UNITED NATIONS, *THE UNITED NATIONS SPEAKS OUT: TACKLING DISCRIMINATION ON GROUNDS OF SEXUAL ORIENTATION AND GENDER IDENTITY* (2011), [http://www.ohchr.org/Documents/Issues/Discrimination/LGBT\\_discrimination.pdf](http://www.ohchr.org/Documents/Issues/Discrimination/LGBT_discrimination.pdf) [<https://perma.cc/H3MW-WUZD>] (collecting statements made by officials in prominent International Human Rights institutions on the commitment to ending violence, abuse and discrimination on grounds of gender identity and sexual orientation).

<sup>242</sup> Janet E. Halley, *Like-Race Arguments*, *supra* note 228, at 40–41. A similar argument was made by Aziza Ahmed who observed how during the AIDS/HIV epidemic, both the gay and women's movements used narratives of risk embedded in their biological-social identities in order to win support from IHR organizations. While recognizing the benefits of identity mobilization, Ahmed criticizes the stabilization of identity through biological narratives, arguing that such legal frameworks conservatize the movement and exclude affected individuals who do not fit the bio-social categories. See Aziza Ahmed, "Rugged Vaginas" and "Vulnerable Rectums": *The Sexual Identity, Epidemiology, and Law of the Global HIV Epidemic*, 26 *COLUM. J. Gender & L.* 1, 51 (2013).

<sup>243</sup> Dana Alix ZZYM Complaint, *supra* note 82, at Part I.

went altered, or even fully disguised, Dana's intersex nature."<sup>244</sup> This background is presumed relevant for Dana's request to get recognized as having non-binary gender identification.<sup>245</sup> Besides the problematic implication that an intersex condition somehow ratifies the possibility of a non-conforming gender, the underlying troubling logic of this framework is that intersexuality is an unchangeable nature that cannot be altered, whereas that is not a universal experience.<sup>246</sup> Intersex advocates should be aware that their advocacy has the capacity to shape consciousness and ultimately create disciplining scripts for group members to follow when making legal claims or in simply living their lives.<sup>247</sup> Therefore, capitalizing on the notion that intersexuality is fixed and cannot be changed, in order to win a legal case, requires an ethical reflection over whether or not such manifestations of intersexuality indeed best serve the liberty interests of movement members.<sup>248</sup>

### 3. *Neglected a Subversive Agenda*

As stated earlier, the translation of the intersex fight to legal language can also be constraining. As legal scholar Orly Lobel notes, "law offers a limited and generalizing account of what ought to be considered a 'problem' and what can be envisioned as a 'solution.'" <sup>249</sup> Accordingly, legal strategies that aim to "solve" the problems of intersex people by solidifying a special status for them arguably forgo a transformative opportunity to deconstruct the M/F biological classification system altogether.

In practice, the legal creation of a third category naturalizes existing binaries. Dreger, for example, opposes the artificial gathering of intersex variations into a separate coherent category:

The truth is that there aren't three sex categories in nature – male, female, and intersex. In nature, sex blends in complicated ways from one sex trait to another. So the idea that there is a natural third category also legitimizes the other two categories as if *they*

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<sup>244</sup> *Id.* at ¶ 15.

<sup>245</sup> Dana argues that the U.S. passport policy discriminates against the class of people "whose sex is neither male nor female." *Id.* at ¶ 86.

<sup>246</sup> The worry about firmly associating a non-specified gender identity (or any gender identity for that matter) with intersex conditions pursues lines similar to those in the essentialism/constructivism debate in the pro-gay movement, when pro-gay constructivists resisted reports on new scientific revelations that homosexuality is hard-wired in human biology or that they are a part of "a minority distinguished by a stable, natural identity." Janet E. Halley, *Sexual Orientation and the Politics of Biology: A Critique of the Argument from Immutability*, 46 STAN. L. REV. 503, 505 (1994).

<sup>247</sup> Janet E. Halley, *Like-Race Arguments*, *supra* note 228, at 42–43.

<sup>248</sup> *Id.* at 52–53; see also Katherine M. Franke, *Becoming a Citizen: Reconstruction Era Regulation of African American Marriages*, 11 YALE J.L. & HUMAN. 251, 251–54 (1999) (discussing the paradox of recognition and regulation).

<sup>249</sup> Lobel, *supra* note 7, at 950–51.

are natural, when in fact nature doesn't draw these lines. We draw these lines on nature.<sup>250</sup>

This critique ultimately argues that activists should not negotiate with the government over what intersexuality is or how to define and classify it. Instead, they should resist institutional discrimination of intersex people that stems from the ideology of a biological sex-binary or heteronormativity.

### B. *A Critique on Medical Activism: Medical Cooptation*

Medical activism has been generally criticized for being too collaborative rather than confrontational. Despite the transformative changes made to the medical protocols (CPGs) since 2006, it has been argued that progressive statements are only made on the declarative level and are not implemented effectively. Moreover, it is argued that collaboration with the medical institution legitimates a notion of pathology that conservatizes the movement and generates an internal professionalization process that divides “good” from “bad” activists.

#### 1. *Inefficient Participation*

Over the past few years, international governmental and professional bodies, including those in the United States, have recognized the value of public participation in the composition of CPGs and have proposed regulatory initiatives meant to facilitate routine patient participation. In 2007, for instance, the Guidelines International Network (GIN) launched a working group to develop strategies to involve the public and patients in CPGs developments.<sup>251</sup> Additional efforts to develop public involvement programs in CPG have appeared in Britain,<sup>252</sup> Spain,<sup>253</sup> Canada,<sup>254</sup> and elsewhere.<sup>255</sup> The inclusion of stakeholder and patient perspectives in the United States has

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<sup>250</sup> Dreger, *Australia's Passport to Gender Confusion*, *supra* note 237.

<sup>251</sup> See generally ANTOINE BOIVIN ET AL., G-I-N PUBLIC TOOLKIT: PATIENT AND PUBLIC INVOLVEMENT IN GUIDELINES 6 (2012), <http://www.g-i-n.net/document-store/working-groups-documents/g-i-n-public/toolkit/toolkit-2015> [<https://perma.cc/FMB4-2L6A>].

<sup>252</sup> See Antoine Boivin et al., *Why Consider Patients' Preferences?: A Discourse Analysis of Clinical Practice Guideline Developers*, 47 *MEDICAL CARE* 908, 909 (2009).

<sup>253</sup> See generally P. Díaz del Campo et al., *A Strategy for Patient Involvement in Clinical Practice Guidelines: Methodological Approaches*, 20 *BRIT. MED. J. QUALITY & SAFETY* 779, 780 (2011).

<sup>254</sup> See Frances Légaré et al., *A Knowledge Synthesis of Patient and Public Involvement in Clinical Practice Guidelines: Study Protocol*, *IMPLEMENTATION SCI.* (June 4, 2009) <https://implementationscience.biomedcentral.com/articles/10.1186/1748-5908-4-30> [<https://perma.cc/K33D-A4KV>]. See generally John Church et al., *Citizen Participation in Health Decision-Making: Past Experience and Future Prospects*, 23 *J. PUBLIC HEALTH POL'Y* 12, 12–13 (2002).

<sup>255</sup> See Antoine Boivin et al., *Patient and Public Involvement in Clinical Guidelines: International Experiences and Future Perspectives*, 19 *BRIT. MED. J. QUALITY & SAFETY* 22 (2010).

been strongly promoted by the Patient-Centered Outcome Research Institute (PCORI) of the Affordable Care Act (ACA),<sup>256</sup> which attempts to facilitate better communication between caregivers and patients<sup>257</sup> and promotes the engagement of patients and other stakeholders in research design.<sup>258</sup>

However, the mere inclusion of patients in the formulation of clinical practice guidelines or the growing representation of patients in decision-making bodies does not mean that patient viewpoints have been taken into substantive consideration.<sup>259</sup> In fact, the limited studies conducted on the topic suggest these involvements are not necessarily productive at all.<sup>260</sup> Researchers have studied programs that involve the public to different degrees (e.g., notification, consultation, etc.)<sup>261</sup> and have articulated the challenges and difficulties currently facing the field.<sup>262</sup> A repeated difficulty has been the lack of support and training for public representatives to meaningfully engage in such discussions.<sup>263</sup> In addition, there is no clear data on the actual impact of public involvement on the quality of health care or even a consensus over what constitutes effective involvement.<sup>264</sup> Another challenge is whether patients' representatives are expected to bring in their own experience of illness or to speak on behalf of a presumed constituency.<sup>265</sup>

This data raises questions regarding the effectiveness of the contribution made by intersex activists in the hybrid forums of policy-making. How are patient representatives selected to participate in policy-making, e.g., based on their competency or agenda? Are their perspectives given fair consideration? How is effectiveness measured? Does a good participatory pro-

<sup>256</sup> See Patient Protection and Affordable Care Act, 42 U.S.C. §§ 18001–18121 (2012); see also PCORI, COMPILATION OF PATIENT PROTECTION AND AFFORDABLE CARE ACT: EXTRACTED SECTIONS CONCERNING PATIENT-CENTERED OUTCOMES RESEARCH AND THE AUTHORIZATION OF THE PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE (PCORI) (2010), [http://www.pcori.org/sites/default/files/PCORI\\_Authorizing\\_Legislation.pdf](http://www.pcori.org/sites/default/files/PCORI_Authorizing_Legislation.pdf) [<https://perma.cc/VK4V-7XQA>].

<sup>257</sup> See *Patient-Centered Outcomes Research*, PCORI, <http://www.pcori.org/research-results/patient-centered-outcomes-research> [<https://perma.cc/3UXX-CVWC>].

<sup>258</sup> See *What We Do*, PCORI, <http://www.pcori.org/about-us> [<https://perma.cc/9WHH-7ZXJ>] (last updated Mar. 29, 2017).

<sup>259</sup> See, e.g., Jo Brett et al., *Mapping the Impact of Patient and Public Involvement on Health and Social Care Research: A Systematic Review*, 17 HEALTH EXPECTATIONS 637, 646 (2014) (describing the difficulties of measuring the impact of patient and public involvement in research through a systematic literature review); Díaz del Campo, *supra* note 253, at 783 (describing a lack of consensus over whether or not patient participation in CPG design has advantages).

<sup>260</sup> Hester M. van de Bovenkamp & Margo J. Trappenburg, *Reconsidering Patient Participation in Guideline Development*, 17 HEALTH CARE ANALYSIS 198, 211 (2009) (commenting that although the general consensus seems to be that patients should be involved in guideline development, the added value of their participation has yet to be established).

<sup>261</sup> See Gene Rowe & Lynn J. Frewer, *A Typology of Public Engagement Mechanisms*, 30 SCI. TECH. & HUM. VALUES 251, 265 (2005).

<sup>262</sup> See Brett et al., *supra* note 259, at 642; Díaz del Campo, *supra* note 253, at 782.

<sup>263</sup> Díaz del Campo, *supra* note 253, at 783.

<sup>264</sup> See Légaré et al., *supra* note 254, at 3–4.

<sup>265</sup> See van de Bovenkamp & Trappenburg, *supra* note 260, at 209–12.

cess necessarily produce a good consensus, or is the effectiveness of the policy measured in terms of actual change of practices? The latter question seems to be most relevant for the intersex cause. Progressive transformations made to the 2016 update do not necessarily reflect popular medical consensus. Although the 2016 update demonstrated a dramatically growing influence of patient perspectives over medical protocols, there is no evidence that the new protocol actually changed practices or that the aspiration to integrate patient perspectives is shared by the relevant experts. In fact, a group of experts issued an alternative summary of the data and practices for DSD management in accordance with the 2016 update that reaffirmed the authority of experts in intersex management and has few mentions of the importance of integrating patient perspectives in the guidelines or in the provision of future care.<sup>266</sup> Advocates for the movement criticized the alternative summary of practices for running “afoul of bedrock principles of informed consent and open[ing] up their practice to legal liability”<sup>267</sup> and ignoring the recognized violations of human rights in the current standard of care.<sup>268</sup> These developments draw attention to the possible gap between accomplishments made on the declarative level of medical protocols and their lack of implementation in practice.

## *2. Legitimizing Pathology: Neglecting the De-medicalization Project*

Medical activism brings to the surface a profound tension rising from resistance through collaboration. Despite the transformative potential embedded in the strategy of collaborating with medical professionals, it is also purported to strengthen medical authority over intersex conditions and discourages resistance to it. Accordingly, treatment activists have been criticized for affirming medical authority and for neglecting the initial de-medicalization project.

Treatment activists who cooperate with medical professionals have negotiated and conceptualized their goals within the corpus of medical regulations in a way that has inevitably accepted some degree of pathology associated with intersex conditions. The reincarnation of the ISNA as the more conservative organization, Accord Alliance, offered a new model for advocacy, one diffused by the medical profession in its acceptance of the medical vocabulary of DSDs, instead of intersex, and the integration of med-

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<sup>266</sup> See Pierre D.E. Mouriquand et al., *Surgery in Disorders of Sex Development (DSD) with a Gender Issue: If (Why), When, and How?*, 12 J. PEDIATRIC UROLOGY 139, 146 (2016).

<sup>267</sup> Alesdair Ittelson & Anne Tamar-Mattis, *Letter to the Editor: Avoiding Liability in the Treatment of Intersex Patients*, 12 J. PEDIATRIC UROLOGY 439, 439 (2016).

<sup>268</sup> See Ellen K. Feder & Alice Dreger, *Still Ignoring Human Rights in Intersex Care*, 12 J. PEDIATRIC UROLOGY 436, 436 (2016).

ical professionals into its leadership.<sup>269</sup> This new model of advocacy asserted the importance of partnering with different stakeholders “to promote comprehensive integrated approaches to care that enhance the health and well-being of people and families affected by DSD by fostering collaboration among all stakeholders.”<sup>270</sup> Its goals and mission are now more moderate: instead of ISNA’s goal to end non-consensual surgeries on intersex infants, Accord Alliance aims to “improve care.”<sup>271</sup>

Katrina Karkazis has explored the tension between social activism and collaboration around CPG design, and argued that those who aspire to reform intersex CPGs by adhering to Evidence Based Medicine (EBM) are unable to ensure that evidence-based protocols will be safe from the flaws of the old bad science.<sup>272</sup> As she notes, though many believe that EBM is universal and objective, this is hardly ever the case because knowledge is always socially situated and subject to the cultural forces of the mechanisms that produce it.<sup>273</sup> Karkazis also argues that EBM works to enforce, rather than limit, the physician’s authority by attempting “to provide a technological fix, solution, or justification for what might otherwise be resolved in the social realm.”<sup>274</sup>

According to this view, activism aiming to improve CPGs comes at the cost of re-medicalizing the discourse about intersexuality. Karkazis believes that in the intersex context, activists who seek to promote change through consensus statements and outcome studies actually “reinforce, restore, realign, and stabilize clinical authority over this issue,” because “who can argue with treatments based on ‘evidence’?”<sup>275</sup> Moreover, according to Hida Vilorio, the alignment of intersex activists with the medical institution is the reason why the American struggle for de-medicalization is lagging behind that of Europe:

In Europe, the intersex movement bonded with the LGBT community. In the US, the first organization [the Intersex Society of North America], did not want to work in alliance with the LGBT community, where LGBT leaders were told that they should not add the *I* to *LGBT*. In my opinion, that has slowed us down . . . .<sup>276</sup>

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<sup>269</sup> See *Our People*, ACCORD ALL., <http://www.accordalliance.org/about-accord-alliance/our-people/> [https://perma.cc/X87Q-ZWY2].

<sup>270</sup> *Our Mission*, ACCORD ALL., <http://www.accordalliance.org/about-accord-alliance/our-mission/> [https://perma.cc/56DR-3RKY].

<sup>271</sup> *Our Programs*, ACCORD ALL., <http://www.accordalliance.org/about-accord-alliance/our-programs/> [https://perma.cc/6A67-YVUB].

<sup>272</sup> KARKAZIS, *supra* note 42, at 283.

<sup>273</sup> *Id.*

<sup>274</sup> *Id.* Mhelman shares Karkazis’s skepticism towards the potential of EBM to “purify” clinical practice guidelines from old pathologies. See Mhelman, *supra* note 143, at 1219.

<sup>275</sup> KARKAZIS, *supra* note 42, at 284.

<sup>276</sup> Hay, *supra* note 35.

The fear of legitimating intersex conditions as pathological through collaboration with the medical institution was recently demonstrated when a group of nine bioethicists resigned from their involvement in a longitudinal study about the psychological and medical well-being of children with DSDs.<sup>277</sup> This group included Dreger, who announced,

I am fed up with being asked to be a sort of absolving priest of the medical establishment in intersex care . . . [w]orking from within was a major goal of our early intersex work—to get in the halls of medicine and change it from within. But the truth is that medicine has not really let in our most basic criticism, our most basic insight, and it looks as if it will not do so anytime soon.<sup>278</sup>

The resignation of Dreger and the other bioethicists from the study is indicative that the radical goal of ending non-consensual surgeries is still boiling underneath the collaborative approach that attempts to simply ‘modify’ or ‘improve’ care.<sup>279</sup>

Collaboration with medical professionals poses theoretical and practical difficulties. When activists help medical professionals produce better knowledge, they also solidify and legitimize medical authority over them. For that reason, some activists are inherently suspicious of collaborations with medical professionals, and even treatment activists may withdraw participation from research in extreme cases.

### 3. *Professionalization and Expertise: From Dissolution to Construction*

The collaboration of treatment activists with medical professionals to produce better guidelines for the management of intersexuality entails a mutual strengthening and consolidating of expertise. The shared goal of producing better knowledge and policy has paradoxically shifted the focus of activists away from dismantling professional expertise to affirming its necessity. Different policy documents and reports produced by collaborative forums commonly observe the importance of specialized medicine and the establishment of multidisciplinary expert centers.<sup>280</sup> The shared realization

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<sup>277</sup> See Sara Reardon, *The Spectrum of Sex Development: Eric Vilain and the Intersex Controversy*, 533 NATURE 160, 162 (2016), <http://www.nature.com/news/the-spectrum-of-sex-development-eric-vilain-and-the-intersex-controversy-1.19873> [https://perma.cc/49XE-NKKS].

<sup>278</sup> Alice Dreger, *Rejecting the Tranquilizing Drug of Gradualism in Intersex Care*, BLOG (Nov. 21, 2015), [http://alicedreger.com/DSD\\_human\\_rights](http://alicedreger.com/DSD_human_rights) [https://perma.cc/V5XL-JZLP].

<sup>279</sup> For a very early expression of this tension, see an interview with Cheryl Chase, who addresses this fundamental ideological conflict. Elizabeth Weil, *What If It's (Sort of) a Boy and (Sort of) a Girl?*, N.Y. TIMES MAGAZINE (Sept. 24, 2006), <https://www.nytimes.com/2006/09/24/magazine/24intersexkids.html> [https://perma.cc/EQ47-VCZN].

<sup>280</sup> See Ahmed et al., *UK Guidance on the Initial Evaluation of an Infant or an Adolescent with a Suspected Disorder of Sex Development*, 75 CLINICAL ENDOCRINOLOGY 12,

that intersex conditions and management are only partially understood and based on insufficient evidence has also led to a shared call to further fund and support the establishment of specialized treatment and research centers.<sup>281</sup> These calls are evidence of consolidation among expertise in the field, which effectively creates opportunities for new networks of traditional experts to flourish.<sup>282</sup>

The collaboration and mutual embrace of activists and medical professionals has led to a form of in-movement specialization. Epstein notes that the cooptation of treatment activists in the AIDS movement divided AIDS activists into lay-experts and lay-lay groups in a way that reproduced external lay-expert hierarchy of perspectives.<sup>283</sup> In the intersex context, the fundamentally different approaches of activists to the idea of collaboration with the medical institution has produced a distinction between supposedly “good” and “bad” activists through nuanced terminological distinctions. In some ways, one’s value as patient representative is determined according to one’s agenda. As a prominent intersex expert replied after being asked about his work with patient advocates: “I call the ones who work with us advocates; those against us activists.”<sup>284</sup> This statement should concern treatment activists who help experts deepen their authority over intersex conditions, as it signals the view that disagreement with medical experts leads to de-legitimation of patient advocates.

#### V. AN ADVANTAGE OF LEGAL ACTIVISM?

Cooptation critiques are not peculiar to legal activism and are characteristic of extralegal activism as well. As demonstrated, the problem of compromising lies in advocacy itself and not in the law per se.<sup>285</sup> Extralegal avenues are also neither democratic enough nor radical enough, and they legitimize the systems they engage with. But with the intersex movement,

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13, 24 (2011); Cools et al., *supra* note 102, at 408; Lee et al., *supra* note 19, at 170; Hughes et al., *Consensus Statement on Management of Intersex Disorders*, *supra* note 3, at 490; Mouriquand et al., *supra* note 266, at 146; *see also* SWISS NATIONAL ADVISORY COMMISSION ON BIOMEDICAL ETHICS NEK-CNE, *supra* note 128, at 9.

<sup>281</sup> Hughes et al., *Consensus Statement on Management of Intersex Disorders*, *supra* note 3, at 490; Lee et al., *supra* note 19, at 176; Karkazis, *supra* note 42, at 281 (making the argument that the lack of knowledge problem usually leads to support in the creation of standardized CPGs).

<sup>282</sup> *See* Hughes et al., *Consequences of the ESPE/LWPES*, *supra* note 25, at 362.

<sup>283</sup> *See* Epstein, *The Construction of Lay Expertise*, *supra* note 86, at 429.

<sup>284</sup> *See* Reardon, *supra* note 277.

<sup>285</sup> *See* Lobel, *supra* note 7, at 977 (“It is not the particularities of lawyers as a professional group that create dependency. Rather, it is the dynamics between skilled, networked, and resourced components and those who need them that may submerge goals and create reliance. It is not the particularities of the structural limitations of the judiciary that threaten to limit the progressive vision of social movements. Rather, it is the essential difficulties of implementing theory into practice. Life is simply messier than abstract ideals.”).

this feature goes even one step further as the extralegal avenue—medical activism, took a high toll on the ability to pronounce a radical ideology.

Despite common wisdom that legal activism is conservatizing, the intersex case demonstrates the contrary. The strand of the intersex movement that has collaborated with the legal profession seems less conservatized than the strand that has cooperated with the medical profession. Legal activists continue to lead the original project of de-pathologizing intersex conditions that are not threatening to health, while extralegal activists invested in the sphere of professional codes satisfy with pragmatic incremental progress that has, in the opinion of some, forsaken the master plan and paradoxically extended the medical jurisdiction over intersexuality.<sup>286</sup> While activists who collaborated with medical professionals upheld a strong association between intersexuality and pathology, activists pursuing legal avenues better retained the anti-pathological component of their agenda.

One possible explanation for why the law maintained a radical agenda better concerns a fundamental difference between the institutional logic of law and science. Law assumes to promote justice and social order and operates according to normative artifacts, such as rights and liberties. Science, on the other hand, envisions itself to do the exact opposite by establishing facts, revealing the natural order, and representing the world as it *is* and not as it *ought to be*.<sup>287</sup> Accordingly, instead of fighting medical norms solely on the basis of scientific evidence, legal instruments give activists a path to argue against the *normativity* of a particular treatment.<sup>288</sup> In contrast to medical-scientific terminology that assumes to provide only hard-and-dry facts about the “laws of nature” and leaves social values outside its scope of jurisdiction, the legal system is responsible for implementing the “laws of men” and is therefore inherently informed by social values, leaving much room to discuss what *ought* to be rather than describing and arguing about what *is*.

At the beginning of the movement, when anti-medicalization goals were the standard agenda, activists invested many resources in exposing the methodological failures that had corrupted scientific research. They adopted medical terminology for the purpose of engaging with medical professionals, collaborated with allies within the medical community to generate alterna-

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<sup>286</sup> See *supra* Part III.D.

<sup>287</sup> See TAL GOLAN, LAWS OF MEN AND LAWS OF NATURE: THE HISTORY OF SCIENTIFIC EXPERT TESTIMONY IN ENGLAND AND AMERICA 2 (2004); JASANOFF, *supra* note 109, at 7.

<sup>288</sup> See Michael Orsini, *Reframing Medical Injury? Viewing People with Hemophilia as Victims of Cultural Injustice*, 16 SOC. & LEGAL STUD. 241, 252 (2007). On collective reframing of the disability movement from the medical to the social model, see Nicholas Pedriana, *From Protective to Equal Treatment: Legal Framing Processes and Transformation of the Women’s Movement in the 1960s*, 111 AM. J. SOC. 1718, 1720-23 (2006); Nicholas Pedriana, *Help Wanted NOW: Legal Resources, the Women’s Movement, and the Battle Over Sex-Segregated Job Advertisements*, 51 SOC. PROBS. 182, 185 (2004); Lisa Vanhala, *Disability Rights Activists in the Supreme Court of Canada: Legal Mobilization Theory and Accommodating Social Movements*, 42 CAN. J. POL. SCI. 981, 987 (2009).

tive treatment protocols, and tried to expose existing biases within the current treatment framework. The main goal was to delegitimize the theoretical and empirical foundations on which contemporary treatment protocols were based.

But activists operating through contemporary legal avenues have an additional edge of fighting on the normative turf as well. When activists use law, they politicize medical norms and expose contested social values that fuel and construct their legitimacy. In that sense, legal activists, relying on various medical definitions, studies, and opinions, can argue that non-consensual genital normalization surgeries are not just medically unnecessary; they can also argue that they *should not* be considered medically necessary.

Such arguments can be made in the legal turf by placing medical professional norms under critical observations and evaluating their coherence with social values protected by law in previous cases. Through a critical legal approach, scholars scrutinized several parameters of the current treatment protocol in order to destabilize assumptions embedded within it. For example, they demonstrated that the concerns that surrounded the birth of an intersex child were actually psychosocial and not medical and therefore the “medical emergency” exception—sometimes used to override formal requirements of informed consent—should not apply as there is no danger to life.<sup>289</sup> By conducting classical legal research that looks to similar case laws to draw normative and legal insights the scholars scrutinized the legal assumption that parents are the best decision makers for their children and suggested that intersex surgeries fit the definition of “experimental” treatment in a way that can undermine their ethical and legal legitimacy.<sup>290</sup> By revealing the motivations that animated medical practices and their normative-social character, norms were examined not just with respect to their scientific validity, but also with respect to their alliance with values protected in the body of rights and liberties codified in law, precedents, and legal doctrine.

While both law and science engage in the construction of facts and the production of descriptive knowledge about the world, law provides the space to make normative arguments regarding how the world ought to be as part of its prerogative. Accordingly, while intersex activists try to undermine scientifically established practices through legal and medical activism, legal activism allows another type of argument which undermines practices on a normative level as well.

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<sup>289</sup> Kishka-Kamari Ford, *First, Do No Harm - The Fiction of Legal Parental Consent to Genital-Normalizing Surgery of Intersexed Infants*, 19 YALE L. & POL'Y REV. 469, 477 (2001); Karen Gurney, *Sex and the Surgeon's Knife: The Family Court's Dilemma . . . Informed Consent and the Specter of Iatrogenic Harm to Children with Intersex Characteristics*, 33 AM. J.L. & MED. 625, 631–32 (2007).

<sup>290</sup> Kishka-Kamari Ford, *supra* note 289, at 477–80.

## CONCLUSION

This Article began with presenting a dilemma regarding the role of law in the struggle for de-medicalization of intersexuality. What path better serves the intersex anti-medicalization agenda: legal or medical activism?

Medical activism has proven effective at giving intersex patients more representation in biomedical policy-making bodies. Indeed, the creation of hybrid forums between medical professionals and intersex activists has generated a call for systematic incorporation of patient voices and perspectives into medical policy-making. It has also posed an epistemic challenge to the scientific arena by recognizing patients' particular expertise and experimental knowledge. As the intersex movement demonstrates, the inclusion of activists' perspectives and voices within the process of biomedical policy-making managed to gradually generate more progressive guidelines and develop incremental changes in professional consensus regarding the appropriate standard of care for intersex people. On the other hand, the intersex case also demonstrates that a collaborationist approach with the medical profession encompasses ideological compromises, at least on the declarative level, that may defeat the original goal. The acceptance of intersexuality as pathological and a subject of normalization is one example of this.

In contrast to medical activism, legal activism did not have the same de-radicalizing effects for the intersex movement. Although legal framing also constrains the movement's agenda, and is notorious for generating distrust and antagonism between physicians and advocates, it nevertheless allowed activists to maintain their de-pathologizing agenda. Intersex activists have used different legal mechanisms to politicize and problematize the standard of care in a way that has ignited public discussion and triggered a rethinking about the way intersexuality is conceptualized, both among the lay public and within the medical profession. Unlike medical activism, legal activism is confrontational, directly opposing the medical agenda, and has no commitments to any form of pathology. Legal activists employ a variety of legal rights, claims, and settings to situate their dispute in a way that serves their agenda.

This Article ultimately suggests that we can think of the legal arena as serving an important critical function in relation to medical and scientific institutions and norms. The flexibility of the legal language and receptivity of law to normative claims about the injustices embedded in professional norms provide legal activists with more leverage to occupy a radical, non-conforming position. Bringing professional norms produced by experts to a legal tribunal enhances the public's understanding of the normative decisions and power struggles embedded within these norms.

In both medical and legal activism, progressive change was achieved at the price of some form of cooptation with the systems that activists tried to change. Although the costs of collaborating with professional elites are difficult to evaluate and can be extremely problematic for individuals and

ideologies, activists should not rule out the idea of collaboration as a whole. In fact, the intersex case demonstrates that the fusion of activists and professional elites, whether legal or medical, is not only an inevitable by-product of social reform, but also one with positive consequences, such as orienting the work of elites towards the needs of their consumers through constant disagreement and revising positions and reshaping of boundaries between elites and the social movement.<sup>291</sup>

Notwithstanding the possible case for legal action, this Article follows the advice to be “critical” regarding legal reform.<sup>292</sup> There is a lack of data regarding the actual improvements or progress toward the de-medicalization objective resulting from alleged legal victories. Additionally, the preference for legal activism in the fight for de-medicalization should be re-evaluated according to the desired social reform. If the goal is medicalization or change of practices, the medical path may be proven more effective. However, the lesson learned from the intersex movement suggests that a social vision aimed at shuttering pathological definitions and avoiding normalizing technologies may find hope in law.

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<sup>291</sup> Other scholars have also suggested a general theoretic support for the idea of dismantling boundaries between laypersons and professionals and the creation of “hybrid forums” as a matter of principle. See Michel Callon et al., *In Search of a Common World*, in *ACTING IN AN UNCERTAIN WORLD: AN ESSAY ON TECHNICAL DEMOCRACY* 107, 109–11 (Graham Burchell trans., 2009).

<sup>292</sup> Lobel, *supra* note 7, at 987.