



## ARTICLE

**Medicalization and the New Civil Rights**

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**Abstract.** In the last several decades, individuals have advanced civil rights claims that rely on the language of medicine. This Article is the first to define and defend these “medical civil rights” as a unified phenomenon.

Individuals have increasingly used the language of medicine to seek rights and benefits, often for conditions that would not have been cognizable even a few years ago. For example, litigants have claimed that discrimination against transgender individuals constitutes illegal disability discrimination. Others have argued that their fatigue constitutes chronic fatigue syndrome (which was, until recently, a novel and contested diagnosis) to obtain Social Security disability benefits. Homelessness has similarly been framed as a medical problem complete with a diagnosis code. Recently, progressive states have used Medicaid funds to help address homelessness. While some scholarship focuses piecemeal on specific areas—such as obesity or transgender rights—I use qualitative and quantitative evidence to show that these claims, which rely on their medical pedigree for their power, are part of a larger phenomenon, which I term “medical civil rights.”

After defining the phenomenon and its scope, the core of the Article departs sharply from existing legal scholarship by defending medical civil rights-seeking. The piecemeal legal scholarship that explicitly addresses the question of medicalization uniformly critiques the use of medical civil rights. However, this siloed perspective has obscured the broad benefits these rights can provide. The legal protections that accompany medical status are more robust than those received by other vulnerable groups, such as the poor, the unemployed, or even racial minorities. Further, compared to other disadvantaged groups such as the unemployed or the poor, society holds the medically disadvantaged relatively blameless

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for any disadvantage. Finally, medical language creates a sense of objectivity and legitimacy for those invoking it. These underappreciated benefits may far outweigh the disadvantages of medical civil rights-seeking. As it is invoked to liberate rather than oppress, medicine itself might become a site of jurisgenesis through which those invoking it conceive of themselves as rights-holding individuals.

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## Introduction

There was a time when race was the civil rights master frame.<sup>1</sup> In order to convince courts, legislators, and the public that they were worthy of rights, disadvantaged groups—women, gays, people with disabilities (PWD), and individuals born to unmarried parents—have all compared themselves to African Americans to assert discrete and insular status,<sup>2</sup> with its accompanying judicial solicitude and legislative protection. But those days appear to have passed. Beset by “pluralism anxiety,” as new groups seek rights, courts have ceased to expand the legal haven that the Constitution provides and have contracted the reach of race-based antidiscrimination protections themselves.<sup>3</sup> With the promise of racial justice tempered, if not broken,<sup>4</sup> those seeking rights have looked elsewhere to frame their claims and, in so doing, themselves.

In the meantime, an interesting phenomenon has emerged. Many individuals and groups have turned to medical frames as a vehicle for civil rights claims both inside and outside courts.<sup>5</sup> Although gay activists have, for

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1. For a description of the term “master frame,” see Robert D. Benford, *Master Frame*, in 2 THE WILEY-BLACKWELL ENCYCLOPEDIA OF SOCIAL AND POLITICAL MOVEMENTS, 723, 723-24 (David A. Snow et al. eds., 2013).
  2. See SHARON BARNARTT & RICHARD SCOTCH, DISABILITY PROTESTS: CONTENTIOUS POLITICS 1970-1999, at 32 (2001); *Mathews v. Lucas*, 427 U.S. 495, 504 (1976) (noting that plaintiffs raised a race analogy). See generally SERENA MAYERI, REASONING FROM RACE: FEMINISM, LAW, AND THE CIVIL RIGHTS REVOLUTION (2011) (describing analogies to race in the women’s rights movement); Ellen C. Wertlieb, *Minority Group Status of the Disabled*, 38 HUM. REL. 1047 (1985) (describing analogies to race in the disability rights movement); Craig J. Konnoth, Note, *Created in Its Image: The Race Analogy, Gay Identity, and Gay Litigation in the 1950s-1970s*, 119 YALE L.J. 316 (2009) (describing analogies to race in the gay rights movement).
  3. See Kenji Yoshino, *The New Equal Protection*, 124 HARV. L. REV. 747, 748 (2011).
  4. Some scholars consider the possibility that “civil rights law” is “dead.” See, e.g., John Valery White, *Foreword: Is Civil Rights Law Dead?*, 63 LA. L. REV. 609, 630-37 (2003); see also Angela P. Harris & Aysha Pamukcu, *The Civil Rights of Health: A New Approach to Challenging Structural Inequality*, 67 UCLA L. REV. (forthcoming 2020) (noting that “[s]ince White published his article, the barriers to civil rights litigation have only grown higher”). To be clear, I am not suggesting that medical civil rights have supplanted racial justice claims, merely that they are increasingly being used as a similar framing device. I also do not mean to suggest that courts are the only forum for rights seeking or that the civil rights movement has not made concrete gains that remain vitally important.
  5. Some may argue that “civil rights” only encompass negative rights. As I note below, I join others in taking a more capacious view, a defense of which is beyond the scope of this Article. See, e.g., Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 4-8 (2004) (incorporating both positive rights (such as welfare) and negative rights (such as antidiscrimination law) seamlessly within a disability rights model). Such positive benefits are essential to vindicating civil rights.

half a century, disavowed a medicalized label,<sup>6</sup> some commenters have recently suggested reversing that position.<sup>7</sup> Others argue that, instead of framing pregnancy discrimination as a form of sex discrimination, the Americans with Disabilities Act (ADA) is a potential vehicle for even greater protections.<sup>8</sup> Commenters have long argued that a medical frame provides transgender individuals with access to insurance and protections against discrimination.<sup>9</sup> Heeding these calls, a federal court recently held that an individual with gender dysphoria was disabled under the ADA and was therefore protected from discrimination (even though the federal ADA explicitly excludes gender identity disorders).<sup>10</sup> Media outlets also emphasize the medical harms of various policies over other kinds of harm. Thus, the *New York Times*, the *Los Angeles Times*, the *Washington Post*, and ABC News (to name just a few) focused primarily on the *medical* harms of the Trump Administration's policy towards undocumented minors, including those caused by separating them from their parents at the border.<sup>11</sup> Recent school-related litigation has highlighted how poverty, racism, and discrimination on the basis of sexuality (among other factors) create trauma with "neurobiological" effects, to which the law must pay heed.<sup>12</sup> And finally, veterans of racial justice advocacy Angela Harris and Aysha Pamukcu, have advocated for "promot[ing] 'the civil rights of health,'" which emphasizes "physical consequences of subordination" in order "to leverage

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6. See, e.g., Konnoth, *supra* note 2, at 346-48.

7. Alok K. Nadig, Note, *Ably Queer: The ADA as a Tool in LGBT Antidiscrimination Law*, 91 N.Y.U. L. REV. 1316, 1317 (2016).

8. Mary Crossley, *The Disability Kaleidoscope*, 74 NOTRE DAME L. REV. 621, 675-76 (1999).

9. Alvin Lee, Note, *Trans Models in Prison: The Medicalization of Gender Identity and the Eighth Amendment Right to Sex Reassignment Therapy*, 31 HARV. J.L. & GENDER 447, 456-57 (2008); Zach Strassburger, Note, *Disability Law and the Disability Rights Movement for Transpeople*, 24 YALE J.L. & FEMINISM 337, 341-45 (2012).

10. *Blatt v. Cabela's Retail, Inc.*, No. 5:14-cv-04822, 2017 WL 2178123, at \*2, \*4 (E.D. Pa. May 18, 2017) (reading the ADA to not exclude coverage of gender dysphoria).

11. See, e.g., Benedict Carey, *Reuniting and Detaining Migrant Families Pose New Mental Health Risks*, N.Y. TIMES (June 22, 2018), <https://perma.cc/KTY7-BSUY>; Melissa Healy, *Q&A: The Long-Lasting Health Effects of Separating Children from Their Parents at the U.S. Border*, L.A. TIMES (June 20, 2018, 3:00 AM), <https://perma.cc/G4TJ-Y72C>; Serena Marshall et al., *Doctor Compares Conditions for Unaccompanied Children at Immigrant Holding Centers to "Torture Facilities"*, ABC NEWS (June 23, 2019, 12:51 PM), <https://perma.cc/5U95-7QGA>; William Wan, *What Separation from Parents Does to Children: "The Effect Is Catastrophic"*, WASH. POST (June 18, 2018, 3:15 PM PDT), <https://perma.cc/X7EK-ZSGA>.

12. See, e.g., *P.P. v. Compton Unified Sch. Dist.*, 135 F. Supp. 3d 1098, 1104-05 (C.D. Cal. 2015); see also *Stephen C. v. Bureau of Indian Educ.*, No. 3:17-cv-08004, 2018 WL 1871457, at \*3-4 (D. Ariz. Mar. 29, 2018).

new types of evidence to demonstrate civil rights harms and violations.”<sup>13</sup> Other groups have followed suit in linking medical arguments to civil rights claims.<sup>14</sup>

The medical-framing phenomenon has not escaped notice. Legal scholars describe medicalization in specific contexts and tend to focus on specific shortcomings. While recognizing the benefits medicine can sometimes provide, Khiara Bridges and Dorothy Roberts emphasize how medical entities and institutions have surveilled and exerted control over poor pregnant women.<sup>15</sup> Russell Robinson and David Frost argue that medical institutions continue to pathologize homosexuality to this day.<sup>16</sup> Dean Spade describes how trans individuals have to navigate gatekeeping by medical professionals in order to get gender-affirming care.<sup>17</sup> And disability scholars have long explained how medical institutions have controlled and coerced people with

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13. Harris & Pamukcu, *supra* note 4. But see Pamela S. Karlan & George Rutherglen, *Disabilities, Discrimination, and Reasonable Accommodation*, 46 DUKE L.J. 1, 2 (1996) (questioning whether “women or African-Americans [should] claim they are victims of discrimination on the basis of disability—because they are regarded as being physically or mentally impaired in the performance of major life activities—rather than on the basis of sex or race”).
  14. See Odelia R. Bay, *Malingering or Maligned: A Comparative Study of Multiple Chemical Sensitivity Case Law*, 36 COMP. LAB. L. & POL’Y J. 381, 383 (2015); Daniela Caruso, *Autism in the U.S.: Social Movement and Legal Change*, 36 AM. J.L. & MED. 483, 493 (2010). See generally Blake R. Bertagna, Comment, *The Internet—Disability or Distraction? An Analysis of Whether “Internet Addiction” Can Qualify as a Disability Under the Americans with Disabilities Act*, 25 HOFSTRA LAB. & EMP. L.J. 419 (2008); Kathleen V. Wade, Note, *Challenging the Exclusion of Gambling Disorder as a Disability Under the Americans with Disabilities Act*, 64 DUKE L.J. 947 (2015).
  15. See KHIARA M. BRIDGES, *THE POVERTY OF PRIVACY RIGHTS* 109, 111–13 (2017); see also *infra* text accompanying notes 196–99 (discussing Bridges’s position in greater detail). For other work describing how medical discourse can oppress minorities, see generally DOROTHY ROBERTS, *KILLING THE BLACK BODY: RACE, REPRODUCTION, AND THE MEANING OF LIBERTY* (1997) (discussing how reproductive health has long been a site for the oppression of black women); HARRIET A. WASHINGTON, *MEDICAL APARTHEID: THE DARK HISTORY OF MEDICAL EXPERIMENTATION ON BLACK AMERICANS FROM COLONIAL TIMES TO THE PRESENT* (2006) (discussing the unethical treatment of African Americans in medical research); cf. Dorothy Roberts, *The Social Immorality of Health in the Gene Age: Race, Disability, and Inequality*, in *AGAINST HEALTH: HOW HEALTH BECAME THE NEW MORALITY* [hereinafter *AGAINST HEALTH*] 61, 62 (Jonathan M. Metzl & Anna Kirkland eds., 2010) (questioning the “false dichotomy between health and justice that hides the social factors that determine health not only for individuals, but for the entire nation” and noting that “[a] more just society would be a healthier one”). But see Roberts, *supra*, at 68 (recognizing, albeit with reservations, the power of “biological citizenship” to “empower patients”).
  16. See Russell K. Robinson & David M. Frost, *The Afterlife of Homophobia*, 60 ARIZ. L. REV. 213, 234–36, 253 (2018).
  17. See Dean Spade, Commentary, *Resisting Medicine, Re/modeling Gender*, 18 BERKELEY WOMEN’S L.J. 15, 23, 28–29 (2003).

disabilities.<sup>18</sup> Each of these scholars argues—to various degrees—for an end to medicalization in specific contexts.

This Article takes a different tack. It is the first in the legal literature to step back and consider the contours of what I call “medical civil rights” claims as a unified phenomenon across numerous contexts.<sup>19</sup> It explains the considerable advantages that come with medical civil rights-seeking and concludes that medical civil rights-seeking is often justified from a pragmatic point of view. While medical rights can coerce those who invoke them, such burdens differ neither in kind nor degree from those of legal rights in general—civil rights doctrine often coerces and forces assimilation. Further, medical discourse is itself changing and becoming more accommodating of rights claims. Thus, medical civil rights, both today and in the future, are a promising source of rights claims.<sup>20</sup>

While this Article is situated primarily within the law and medical humanities tradition, it is also indebted to many other literatures: disability studies, welfare policy, civil rights law, health policy, queer theory, and social movement theory, among others. It cannot do full justice to any of them. There are many nuances, counterarguments, and caveats that I consciously—or unconsciously—elide. At the same time, this Article follows calls by scholars in other fields to cross-pollinate literatures in order to share lessons across disciplinary boundaries.<sup>21</sup>

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18. See, e.g., Chai R. Feldblum, *Definition of Disability Under Federal Anti-Discrimination Law: What Happened? Why? And What Can We Do About It?*, 21 BERKELEY J. EMP. & LAB. L. 91, 96 (2000) (discussing how government programs sought to change persons with disabilities by curing them or by excluding them from society).

19. Alondra Nelson uses the term to describe the health activism of the Black Panther movement. ALONDRA NELSON, *BODY AND SOUL: THE BLACK PANTHER PARTY AND THE FIGHT AGAINST MEDICAL DISCRIMINATION* 5-7 (2011). My focus is different and described below in greater detail.

20. None of this seeks to deny or trivialize the fact that medical conditions can be the source of stress and burden, both physical and mental. Indeed, if anything, I show how seriously we take medical harm. Legal rights, after all, are often enacted to address society's harms: For instance, the existence of laws targeted at protecting African Americans (at least originally) reinforces the fact that African Americans have been historically disadvantaged. By contrast, the law often treats other kinds of vulnerability—those flowing from poverty, lack of education or credentials, unemployment, or even lack of pedigree or familial status—less seriously than medical vulnerability, as discussed in Part IV.A.3 below.

21. For example, disability studies scholar Diane Price Herndl laments the lack of conversation across medical humanities and disability scholarship. As a result, “medical humanists most often take the physician’s medicalized point of view of bodies and disabilities” while disability scholars can ignore the materiality of the body. Diane Price Herndl, *Disease Versus Disability: The Medical Humanities and Disability Studies*, 120 PMLA 593, 594-95, 597 (2005); see also Tom Shakespeare & Nicholas Watson, *Defending the Social Model*, 12 DISABILITY & SOC’Y 293, 297 (1997) (“Medical sociology is another discipline that appears to have problems accepting or working within the social

*footnote continued on next page*

Medical civil rights flow from medical status. As Part I explains, an individual holds a medical status by virtue of falling into some medically identifiable group. This includes being diagnosed as having some disease, illness, or condition. The opinions of the medical establishment hold great weight in determining whether someone holds a medical status—most of us defer to professional diagnoses. However, social activists, religious groups, and lawmakers may also seek to change the definition of medical status, especially for particular audiences. For instance, certain groups still argue that homosexuality is an illness. Similarly, the law sets out its own definitions of medical status that do not fully track those of the medical establishment.

Various groups leverage these definitions—many of them contested—to claim legal rights, which I refer to as “medical civil rights.” These rights are claims that can be made against the state and others. I define them broadly to include both negative rights (such as freedom from discrimination), as well as positive rights (such as cash benefits).<sup>22</sup> I term these rights *civil* rights because the vast majority of this advocacy self-avowedly seeks to address disadvantage or government overreach.<sup>23</sup> Medical civil rights are therefore civil rights claims for which invoking a medical status plays a legitimating role.

Part II describes these rights in greater detail. It shows how medical civil rights advocates frame a particular condition as a medical status in order to formally trigger legal rights in court or before administrative agencies. Like all legal concepts, medico-legal claims are open-textured.<sup>24</sup> Some claims fit easily within the core of widely shared understandings as to what constitutes a medical harm. Some are far from the core. And others are in gray, contested areas. Included in this last category are gender identity disorder, chronic fatigue, attention deficit disorders, and sensitivity to chemicals. Advocates

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model . . . .”); Joseph A. Stramondo, *Why Bioethics Needs a Disability Moral Psychology*, HASTINGS CTR. REP., May/June 2016, at 22, 22, 29 (noting the conflict between disability and bioethics); Carol Thomas, *Medical Sociology and Disability Theory*, in NEW DIRECTIONS IN THE SOCIOLOGY OF CHRONIC AND DISABLING CONDITIONS: ASSAULTS ON THE LEIFEWORLD [hereinafter NEW DIRECTIONS IN THE SOCIOLOGY OF CHRONIC AND DISABLING CONDITIONS] 37, 44-45 (Graham Scambler & Sasha Scambler eds., 2010) (outlining critiques of medical sociologists by disability studies scholars, and of disability studies scholars by medical sociologists).

22. See *infra* note 276 (recognizing the controversy around contrasting negative and positive rights).

23. I therefore elide the distinction some draw between civil rights and civil liberties. Christopher W. Schmidt, *The Civil Rights-Civil Liberties Divide*, 12 STAN. J. C.R. & C.L. 1, 3 (2016) (“[C]ivil rights involves the unequal treatment of different groups. . . . [C]ivil libertarianism is premised on skepticism toward government interference in the private sphere. Autonomy rather than equality is the guiding principle of civil liberties.”).

24. I borrow the term and concept from H.L.A. HART, THE CONCEPT OF LAW 123, 127-36 (Peter Cane et al. eds., 2d ed. 1994).



explain—quite candidly—that they seek medical framing to trigger rights claims, from employment and public accommodations protections to tax and social security benefits.<sup>25</sup>

But advocates frame certain harms as medical even when such a framing does not yield formal legal rights. For instance, the opioid crisis is framed as a medical problem though such framing does not trigger specific legal provisions. Similarly, commenters have argued that homelessness and poverty should be seen as medical problems. Finally, activists who do not even seek to claim medical rights *per se* (for example, those who seek to make sex or sexuality discrimination claims) attempt to imbue those categories with a medical component.

Part III briefly reviews the critiques of the medicalization I describe above. Critics argue that medical status is harmful in two ways. First, it can limit individual rights. Medical status can impose rigid forms of social control and stigma on those upon whom it is foisted, and force their assimilation into medical discourse. A second, less prominent line of criticism stresses institutional concerns. Undemocratic medical institutions, it claims, should not determine who receives medical status and who does not. Indeed, medical institutions might lose the authority to pronounce on medical issues themselves if they seek to alleviate broader social ills. In turn, other powerful institutions, such as pharmaceutical companies, might co-opt medical framing simply to turn a profit.

Given these critiques, why use medicine to frame disadvantage? Part IV argues that three primary factors animate medical civil rights-seeking. First, as a formal matter, those who are able to persuade courts that they hold legally recognized medical statuses can obtain legal rights. These rights are more robust than those accompanying other disadvantage, such as poverty or even racial discrimination. Second, even when advocates do not seek formal legal rights, their medical status claims generate greater sympathy. As survey data and medical policy show, society is less likely to blame medical disadvantage on an individual's shortcomings (in contrast to other kinds of disadvantage such as poverty or unemployment). Rather, we are more likely to attribute medical disadvantage to bad luck or social discrimination and, therefore, are more likely to offer assistance. Finally, medical claims bring a veneer of expertise that advocates *and* decisionmakers might use to determine which outcome is better or to bolster the legitimacy of the claims they wish to back.

Part V measures these benefits I outline against the charges that critics level at medical civil rights. My core defense is merely that while often accurate, the criticisms of medical civil rights fail to acknowledge the benefits that I describe and that these benefits might outweigh the costs. The costs of

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25. See *infra* text accompanying notes 123, 155, 223.

medical civil rights are the same as those all kinds of legal claims exact; numerous civil rights scholars have cautioned that rights claims coerce, force assimilation, and extort as a condition of being invoked. But the benefits medical civil rights offer often far exceed those that accompany traditional civil rights claims. Thus, we see why individuals are willing to pay the price of claiming medical civil rights.

To be sure, writing on a blank slate, medical civil rights may not be the best vehicle for addressing human vulnerability. In an ideal world, our views on poverty, homelessness, and unemployment would evolve. Programs that provide housing, basic income, and employment for low-income and older individuals would be on par with Medicaid and Medicare or at least enjoy the same cachet as universal healthcare, endorsed by prominent leaders of at least one major party.<sup>26</sup> Individuals then would not have to assimilate within the language of medicine; they would not have to expend vast resources to claim basic rights.

But in our world, courts as well as legislatures are bound by constraints (some of their own making). Thus, individuals are left to seek medical civil rights—not because they present ideal solutions but because they are the best of a set of flawed options for many of those who suffer harm. Advocates must balance the harms these rights impose against their benefits in specific instances. In many instances, medical framing might be used in tandem with other approaches in order to achieve desirable outcomes.<sup>27</sup> My concern, however, is that scholarship—and sometimes activism—overemphasizes the harms and ignores the benefits of medical civil rights.

Beyond this core defense, however, I also advance a more aspirational—and speculative—response. Medical claims are malleable, contingent, and (as Part I argues) fundamentally social phenomena. We, as a society, discursively structure the moral and material implications of medical status. Medical status has historically stigmatized and coerced—but entrenched, ongoing efforts inside medical institutions seek to engage patients in shaping medical discourse in order to enhance their autonomy. New consumer medical technologies, such as genetic tests and wearable devices, engage individuals with medical discourse, even if they do not themselves seek medical status. These dynamics enhance the autonomy of individuals who invoke medical status to alleviate disadvantage and decrease the stigma they experience. This engagement with

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26. See Bob Bryan, *Bernie Sanders' Unconventional Healthcare Plan Is Getting Backing from a Lot of Big-Name Democrats*, BUS. INSIDER (Sept. 12, 2017, 10:09 AM), <https://perma.cc/Z2B6-7RST>.

27. See Frank S. Bloch, *Medical Proof, Social Policy, and Social Security's Medically Centered Definition of Disability*, 92 CORNELL L. REV. 189, 230 (2007) (pointing to how other forms of proof, such as “vocational” information, are used in addition to medical knowledge in Social Security disability determinations).

multiple stakeholders also increases the legitimacy of medical status designations and defends against being co-opted. The future of these changes, however, is yet to be determined.

Medical status, despite its flaws, is therefore a site of civil rights, a space for self-empowering jurisgenesis.<sup>28</sup> Medical discourse can act as a rallying point for future rights-seeking across numerous areas. But while important on their own terms, these medical rights are also a starting point for understanding the relationship between medicine and law. This analysis shows that medicine can become a site of jurisgenitive potential, in which individuals and groups situate themselves as holding legal rights, but through discourse characterized primarily in medical rather than legal terms. This raises questions that are best explored in future work: As courts (purportedly) defer to medical experts and institutions to reify rights, what is the relationship between law and medicine? Is law infusing itself into medicine, or medicine into law? How does one conceptualize of the hybrid role of law-medicine? This Article is but a first step in elucidating these questions.

## **I. Medical Status**

Medical civil rights flow from medical status. Medical status is a designation that places someone into a particular, identifiable group determined by medical criteria. The most straightforward example of such a designation is a diagnosis of a certain disease or illness, but others abound.<sup>29</sup> This Part makes three claims. First, medical status is socially constructed and, therefore, often contested. Second, medical status designations can produce material and symbolic effects that are both positive and negative. Third, legal ramifications often number among these effects: The law draws on medical status to construct its own categories to award or deny rights and, in so doing, participates in the dialogue and contestation as to what constitutes medical status. The key question in medical rights claims is whether the medical status

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28. A helpful explanation of the term is provided by John Valery White, Note, *Reactions to Oppression: Jurisgenesis in the Jurispathic State*, 100 YALE L.J. 2727, 2730 (1991).

29. Here I agree with scholars from several disciplines who argue that the concept of diagnosis and related concepts, like impairment, are deeply socially constructed. For prominent treatments, see TOM SHAKESPEARE, *DISABILITY RIGHTS AND WRONGS* 34-37 (2006); Phil Brown, *Naming and Framing: The Social Construction of Diagnosis and Illness*, 35 J. HEALTH & SOC. BEHAV. (EXTRA ISSUE) 34, 40-45 (1995). In particular, Phil Brown explains how lay individuals, social movements, professional factors, organizations, and institutions all play a role in constructing diseases from illness experiences, organized knowledge, and other social discourse. Brown, *supra*, at 43-45; *see also id.* at 38 (“Diagnosis represents the time and location where medical professionals and other parties determine the existence and legitimacy of a condition.”). I ally myself most closely with the view that social problems, such as medical harm, are contextually constructed. *Id.* at 35.

designation is accepted by the relevant audience. In formal rights claims, this audience is the courts. With less formal, public-facing claims, the audience consists of legislatures and maybe even the general public.

Medical status is constructed in certain contexts for certain purposes, using existing, historically developed social understandings. Most audiences will share an understanding that some claims (such as cancer diagnoses) are clearly medical statuses, while others are not. But many claims are in a gray area because they share characteristics with identities that are considered both medical and nonmedical. For example, some question whether obesity should be recognized as a medical condition and argue that even if medical institutions recognize it as such, the law should not.<sup>30</sup>

In defining what medical status is, one might start by looking to medical establishment definitions. Even within the establishment, different definitions abound. Take, for example, the Manual of Style of the American Medical Association (AMA), the largest and oldest existing organization of medical professionals.<sup>31</sup> The AMA's blog for the Manual offers a helpful breakdown of some of the terms at issue. The narrowest kind of medical status is "disease," which "refer[s] to conditions affecting a physical system ([e.g.,] cardiovascular disease) or a part of the body ([e.g.,] diseases of the foot)."<sup>32</sup> By contrast, "disorder" is "less restrictive" and is defined "simply as 'an abnormal physical or mental condition.'"<sup>33</sup> In other words, both disease and disorder imply a deviation from "normal" functioning, but "disease" requires structural change while "disorder" does not. Finally, "condition" is "perhaps the least specific" of the terms, "often denoting states of health considered normal or healthy but nevertheless posing implications for the provision of health care ([e.g.,] pregnancy)."<sup>34</sup> Nonetheless, many authorities use "condition" to indicate the presence of pathology.<sup>35</sup>

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30. See *infra* notes 125-27 and accompanying text.

31. See Judith Graham, "Like a Slap in the Face": Doctors No Longer Feel the Nation's Largest Doctors Group Represents Their Interests, BUS. INSIDER (Dec. 22, 2016, 10:00 PM), <https://perma.cc/BNU5-PJ6A>. However, the AMA has had its detractors who feel it is not representative. See *id.*

32. Phil Sefton, *Condition, Disease, Disorder*, AMA STYLE INSIDER, <https://perma.cc/YT9A-TZPY> (archived May 9, 2020). I take the AMA guide as authoritative, but others suggest alternative definitions. See generally John Cooper, Commentary, *Disorders Are Different from Diseases*, 3 WORLD PSYCHIATRY 24, 24 (2004) (differentiating psychiatric disorders from diagnosable diseases).

33. Sefton, *supra* note 32 (quoting *Disorder*, MERRIAM-WEBSTER'S COLLEGIATE DICTIONARY (11th ed. 2003)).

34. *Id.*

35. See *id.*

Disagreement as to whether something is medical or not stems from the context-determinative nature of such designations. The definitions of disease and disorder, for example, turn heavily on what constitutes “normal” functioning. Normalcy is often socially determined, depending on time and place.<sup>36</sup> A classic example is homosexuality’s transformation from pathology to nonpathology as it became considered more “normal.”<sup>37</sup> Similarly, as the blog for the AMA Manual of Style recognizes, social context is important: “Because *disorder*, like *condition*, is relatively value-neutral when compared with *disease*, it is often used in place of the latter term when a less stigmatizing or less alarming term is desirable,” such as when first communicating the information to a patient or loved ones.<sup>38</sup>

Thus, the AMA’s definitions with respect to some of these concepts are hardly dispositive.<sup>39</sup> Medical authorities within the same field might disagree on whether a particular affliction is a medical condition.<sup>40</sup> (Homosexuality is one example, but I offer others below.<sup>41</sup>) There might also be disagreement on *who* constitutes a medical authority—for instance, many reject practitioners of alternative medicine.<sup>42</sup> Moreover, the views of medical authorities, while weighty, do not hold a monopoly. Social groups seek to disturb accepted definitions based on their own views, and “[d]iagnostic categories are often

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36. For a preliminary treatment of this point, see generally Lars Noah, *Pigeonholing Illness: Medical Diagnosis as a Legal Construct*, 50 HASTINGS L.J. 241 (1999) (exploring how legal actors determine what constitutes a medical condition in contexts ranging from tort litigation and criminal law to private insurance and disability litigation). See also Bradley A. Areheart, *Disability Trouble*, 29 YALE L. & POL’Y REV. 347, 363 (2011) (“[T]he acts of creating and applying diagnoses, ubiquitous in describing biological symptoms, are ‘always contingent upon social factors.’” (quoting with unmarked modifications ROBERT A. ARONOWITZ, MAKING SENSE OF ILLNESS: SCIENCE, SOCIETY, AND DISEASE 171 (1998))); Michelle A. Travis, *Impairment as Protected Status: A New Universality for Disability Rights*, 46 GA. L. REV. 937, 973-74 (2012) (explaining how the medical “translation of a trait or condition into an ‘impairment’ can be affected by medical fads, technological innovation, financial interests, and other social phenomena” (quoting Areheart, *supra*, at 364)).

37. See Jack Drescher, *Out of DSM: Depathologizing Homosexuality*, 5 BEHAV. SCI. 565, 571-72 (2015).

38. Sefton, *supra* note 32.

39. For a helpful discussion of some of the difficulties in defining disease, see generally Larissa K.F. Temple et al., Essay, *Defining Disease in the Genomics Era*, 293 SCIENCE 807 (2001).

40. The disagreement might proceed on many levels. Questions might arise as to whether the symptoms the patient claims are genuine, whether they are measurable, and whether they proceed from an etiology that is sufficiently cogent to be considered a specific condition.

41. See *infra* note 90 and accompanying text.

42. For example, in many cases, courts have held that chiropractors and osteopaths cannot make determinations for public medical aid programs. See generally David F. Stever, Annotation, *Limitation on Right of Chiropractors and Osteopathic Physicians to Participate in Public Medical Welfare Programs*, 8 A.L.R. 4th 1056 (1981).

fought out as turf battles between medicalizers and their opponents.”<sup>43</sup> Consider the subset of Americans who *still* consider homosexuality a disease,<sup>44</sup> or Christian Scientists who generally deny the existence of medical illness at all.<sup>45</sup> Political actors might also seek to affect the definition of disease—the Bush Administration, for example, pushed back against the diagnosis of PTSD, seeking “to demedicalize the aftereffects of combat.”<sup>46</sup> Such medical approaches, it feared, would undermine warmaking from both a financial and public relations perspective.<sup>47</sup> Further, with the growth of the internet, online self-help communities, discussion boards, and websites, patients themselves are playing a greater role in illness definition than ever before: In many contexts, “the lay public is increasingly involved as patients (or potential patients) in collectively defining their ‘illnesses.’”<sup>48</sup> These forms of advocacy often succeed in producing change in legal and medical definitions of particular statuses— consider the depathologizing of homosexuality thanks, in part, to the work of gay rights activists who collaborated with medical professionals.<sup>49</sup> Many of these movements engage in advocacy to avoid the burdens of medicalization or to seek some of its benefits as the next Parts describe.

The determination of whether or not someone should be designated as having a medical status within a particular situation is often just the first step. In many contexts, medical status produces effects that depend on the kind of status involved. These consequences may be material. Thus, whether

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43. Brown, *supra* note 29, at 39.

44. See *10 Things You Should Know About Focus on the Family*, HUM. RTS. CAMPAIGN, <https://perma.cc/V9VN-UX74> (archived May 9, 2020).

45. See PARK RIDGE CTR., THE CHRISTIAN SCIENCE TRADITION: RELIGIOUS BELIEFS AND HEALTHCARE DECISIONS 2 (Deborah Abbott ed., 2002) (“Christian Scientists believe that all illness and suffering are ultimately illusory.”). One Christian Scientist claimed that “a patient who came to him with a lump under his arm was experiencing ‘a manifestation of fear, not a lump.’” Paul Vitello, *Christian Science Church Seeks Truce with Modern Medicine*, N.Y. TIMES (Mar. 23, 2010), <https://perma.cc/9WAS-AAEV> (quoting Christian Science practitioner John Q. Adams).

46. M. GREGG BLOCHE, THE HIPPOCRATIC MYTH: WHY DOCTORS ARE UNDER PRESSURE TO RATION CARE, PRACTICE POLITICS, AND COMPROMISE THEIR PROMISE TO HEAL 69 (2011).

47. *Id.* at 74 (noting that postcombat medical diagnoses of troops “issue a declaration about the state’s responsibility since the state sent them to war, exposing them to battle stress and its biological consequences”).

48. Kristin Barker, *Self-Help Literature and the Making of an Illness Identity: The Case of Fibromyalgia Syndrome (FMS)*, 49 SOC. PROBS. 279, 280 (2002).

49. Jack Drescher provides a recent account of this history. See Drescher, *supra* note 37, at 570-71. For a broader description of the homosexuality and homosexuality-related categories that have historically pervaded the Diagnostic and Statistical Manual of Mental Disorders (DSM), see generally RONALD BAYER, HOMOSEXUALITY AND AMERICAN PSYCHIATRY: THE POLITICS OF DIAGNOSIS (1981).

one obtains dialysis or a wheelchair depends on the specific status assigned, in other words, whether one has kidney failure or mobility issues.

Medical status can also produce symbolic meaning by altering an individual's identity, as perceived by herself or by others. Some critics felt that the diagnosis of soldiers with PTSD was stigmatizing, marking them as victims instead of heroes.<sup>50</sup> On the other hand, many individuals find diagnosis validating. For example, in one study, "the majority of parents" whose children received a diagnosis of Autism Spectrum Disorder reported feeling "relief . . . and empowerment."<sup>51</sup> For some, the diagnosis reassured their own perception: "Okay, I'm not crazy. There really is something going on here."<sup>52</sup> Others were comforted that their "parenting style" was not to blame for their child's behavior.<sup>53</sup> Still others were relieved to have a concept around which to frame their understanding and future learning—a "parachute" or "anchor."<sup>54</sup> Other studies report similar findings with respect to other diagnoses.<sup>55</sup>

Indeed, medical status may sometimes act as a threshold for membership in a broader political and social community—such as people living with AIDS or breast cancer survivors. Some disability advocates maintain that people with disabilities (PWD) must have impairments that "significantly affect daily life" and must "[with some consistency] present [themselves] to the

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50. BLOCHE, *supra* note 46, at 68.

51. Janice Mulligan et al., *Transparency, Hope, and Empowerment: A Model for Partnering with Parents of a Child with Autism Spectrum Disorder at Diagnosis and Beyond*, 10 SOC. WORK MENTAL HEALTH 311, 319 (2012).

52. *Id.*

53. *Id.*

54. *Id.* at 320.

55. See, e.g., Pia H. Bülow, *Tracing Contours of Contestation in Narratives About Chronic Fatigue Syndrome*, in *CONTESTING ILLNESS: PROCESSES AND PRACTICES* [hereinafter *CONTESTING ILLNESS*] 123, 129 (Pamela Moss & Katherine Teghtsoonian eds., 2008) (discussing how a Chronic Fatigue Syndrome diagnosis gave some patients "joy," a sense of being "exculpate[ed]," and "peace"); Annemarie Jutel, *Sociology of Diagnosis: A Preliminary Review*, 31 SOC. HEALTH & ILLNESS 278, 289-90 (2009) (noting how "the absence of diagnosis impugns the medical legitimacy of the individual's complaint" and the "difficulties of living with the uncertainty of non-diagnosis"); Drew Leder, *The Experience of Pain and Its Clinical Implications*, in *THE ETHICS OF DIAGNOSIS* 95, 95 (José Luis Peset & Diego Gracia eds., 1992) ("When the words 'peptic ulcer disease' . . . are pronounced, the ambiguous complaints of the patient—gnawing pain, hunger . . . —are reorganized into a medically defined world. Events take on a new spatial contour: they now center around and radiate from the duodenum."); Sarah Nettleton, *"I Just Want Permission to Be Ill": Towards a Sociology of Medically Unexplained Symptoms*, 62 SOC. SCI. & MED. 1167, 1170 (2006) ("[T]he lack of clinical confirmation made them question themselves. All the participants reported how, at some point, they had asked themselves questions such as: 'Am I imagining it?' 'Am I just being lazy?' 'Is it something I have manifested?'").

world at large as . . . disabled person[s].<sup>56</sup> This definition, while capacious, will include some but exclude others.<sup>57</sup> Many understand the concept of impairment through medically developed etiologies and frameworks.<sup>58</sup> The

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56. SIMI LINTON, CLAIMING DISABILITY: KNOWLEDGE AND IDENTITY 13 (1998) (first alteration in original) (quoting Carol J. Gill, *Questioning Continuum*, in THE RAGGED EDGE: THE DISABILITY EXPERIENCE FROM THE PAGES OF THE FIRST FIFTEEN YEARS OF *THE DISABILITY RAG* 42, 46 (Barrett Shaw ed., 1994)). To be clear, I do not read Linton here as suggesting that only individuals with visible disabilities qualify as disabled; rather, she is arguing that only those with some degree of openness in *identifying* as disabled count as such.

57. Individuals with impairments such as cancer, HIV, mental illness, neurological conditions, and diabetes, to name a few will be in—but those without impairments that “significantly” or “consisten[tly]” affect daily life would be out. *See id.* at 12-13.

58. To be sure, many groups in the disability rights movement would claim that the disability identity they promote is social rather than medical. *See* Feldblum, *supra* note 18, at 96. As scholars explain, the medical model sees disability as inherent to the person who suffers from impairment. *See id.* Accordingly, to address the disability, the medical model requires PWD to “cure” or rehabilitate themselves by eliminating the biological trait to conform to social norms. Crossley, *supra* note 8, at 650. The social model pushes back, arguing that, to a greater or lesser degree, the trait is constructed as disabling—the disability lies in social prejudice, in architectural barriers (stairs), or practices (for example, the use of visual cues rather than braille). *See* Feldblum, *supra* note 18, at 100. The solution is therefore to transform society by prohibiting discrimination, changing structures (ramps), and the like. *Id.* Some might argue that all disability is socially contingent—an individual with a traumatic brain injury would not be disabled in a society where all individuals had, say, low cognitive function. Others might argue that some conditions are more socially contingent than others. Traumatic brain injury, some might argue, is inherently “medically” disabling, whereas being deaf is not because social practices could accommodate deaf individuals. Thus, this distinction between “medical” and “social” is far from settled.

I have a limited stake in the debate, however. By invoking medical status, I simply invoke discourse that is understood to be—by some, or many—medical, without making any particular claims about biological situatedness. *See* Thomas, *supra* note 21, at 47 (seeking to bring “impairment” back into disability analysis). Medical discourse remains a part of the social model of disability. For example, even as the social model eschews identities and solutions that the medical establishment identifies, it still draws on the concept of impairment. *See* SHAKESPEARE, *supra* note 29, at 35. Such impairment is generally conceptualized as a biological trait. *Id.* Current language often requires looking to (and even reimagining) medical discourse, in order to understand, make legible, and articulate this trait that society burdens. *Id.* The concept of impairment remains “visib[le] and salien[t]” because of social expectations and arrangements, such as socially constructed medical discourse. *Id.*

Yet, even as medical discourse is invoked, those invoking it change the focus of power and definition from medical institutions to the community itself. *See* JENNY MORRIS, PRIDE AGAINST PREJUDICE: A PERSONAL POLITICS OF DISABILITY 71 (1991) (“[W]e must also demand that it is we who define the negative things about the experience—and not the medical profession . . .”). Further, denying the relevance of the body altogether can be problematic. For example, pain exerts burden independent of social phenomena. *See* Sara Goering, *Rethinking Disability: The Social Model of Disability and Chronic Disease*, 8 CURRENT REVIEWS MUSCULOSKELETAL MED. 134, 135 (2015). Further, the medical-social distinction presumes some kind of separation between the body and social construction, which is highly untenable and indeed, to my mind, a major failing in the

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identities thus produced are often fluid and change over time.<sup>59</sup>

Yet in other circumstances, medical status may have only a limited or no effect on individual sense of identity or community. Consider risk designations made by medical authorities. These designations may be defined with less discreteness and clarity than official diagnoses,<sup>60</sup> but might also trigger access to drugs. For example, flu vaccines are recommended for individuals in high-risk groups, which includes young, old, and pregnant people.<sup>61</sup> Similarly, Pre-Exposure Prophylaxis (PrEP), a once-a-day pill that individuals can take to effectively prevent contracting HIV, is recommended by the Centers for Disease Control and Prevention (CDC) for individuals that meet certain risk criteria.<sup>62</sup> It is unlikely that such designations alter their subjects' self-perception or sense of identity. Indeed, some individuals might resist medical redefinition. Duke law professor Jerome Culp, Jr., for example, recounted how at first, he resisted efforts by a student to welcome him into the "community of diabetics" because he "still saw himself as someone who had discovered [he] had

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literature itself. See Bill Hughes & Kevin Paterson, *The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment*, 12 DISABILITY & SOC'Y 325, 325-26, 329-30 (1997) ("The social model of disability proposes an untenable separation between body and culture . . ."); see also Herndl, *supra* note 21, at 594 ("This isn't to deny the materiality of disease and disability but to foreground the ways that our interpretations of that materiality matter and to highlight the way that the body is central but not an object that is itself defining." (emphasis added)). For a fuller critique of the social model, and a discussion of a more interactionist model which I myself am drawn to, see SHAKESPEARE, *supra* note 29, at 31-33, 35-43, 55-62. For responses to some of these critiques, see MICHAEL OLIVER, UNDERSTANDING DISABILITY: FROM THEORY TO PRACTICE 48-50 (2d ed. 2009).

59. See, e.g., Jerome McCristal Culp, Jr., *Seventh Aspect of Self-Hatred: Race, Latcrit, and Fighting the Status Quo*, 55 FLA. L. REV. 425, 430 (2003) (describing Culp as a diabetic but noting that "[i]t was not an identity that existed at every moment").

60. Though diagnoses themselves might be based on statistical probability or correlation with certain etiologies.

61. See *People at High Risk for Developing Flu Complications*, CENTERS FOR DISEASE CONTROL & PREVENTION, <https://perma.cc/7RBR-QRXL> (last reviewed Aug. 27, 2018); see also Robert Roos, *CDC Says Flu Shots Should Go to High-Risk Groups First*, CTR. FOR INFECTIOUS DISEASE RES. & POL'Y (Dec. 11, 2003), <https://perma.cc/9488-29D6>.

62. CTRS. FOR DISEASE CONTROL & PREVENTION, PREEXPOSURE PROPHYLAXIS FOR THE PREVENTION OF HIV INFECTION IN THE UNITED STATES—2017 UPDATE: A CLINICAL PRACTICE GUIDELINE 11, 36 (2018). For example, PrEP is recommended for men who have sex with men who in the past six months have had anal sex without condoms. *Id.* at 36. While studies on the topic are scarce, anecdotal evidence suggests that gay individuals claim to meet the threshold merely to satisfy the requirements for inclusion in the indicated group. Telephone Interview with Spencer Schaff, Assoc., ICF Int'l, Inc. (Sept. 17, 2017) (on file with author). This conforms with the recommendation by prominent commenters from the gay community that all gay men with multiple partners should take the pill. See Mark Joseph Stern, *There Is a Daily Pill That Prevents HIV. Gay Men Should Take It*, SLATE (Jan. 6, 2014, 12:00 PM), <https://perma.cc/2S23-9LA5>.

diabetes.”<sup>63</sup> Ultimately, given the wide variation across medical conditions in terms of transience, the extent of intervention (for example, eyeglasses versus dialysis), and the affected individuals, medical status’s import for identity can change—as may its legal ramifications.<sup>64</sup>

The law defines medical status as it does many other categories.<sup>65</sup> Those statuses, as I describe below, produce legal rights. A few examples that illustrate (albeit not comprehensively) how the law conscribes legally relevant medical statuses are:

- *Social Security disability benefits*, at base, require the claimant to have a “severe impairment,” that is, an impairment “which significantly limits . . . physical or mental ability to do basic work activities” or other “gainful activity.”<sup>66</sup>
- The *Americans with Disabilities Act (ADA)* defines disability in relevant part as “a physical or mental impairment that substantially limits one or more major life activities,” as well as a record of having, or “being regarded as having,” a disability.<sup>67</sup>

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63. Culp, *supra* note 59, at 428-29.

64. I thank Rachel Moran for this point.

65. For instance, as Ian Haney López notes, law helps define the social category of race. IAN HANEY LÓPEZ, *WHITE BY LAW: THE LEGAL CONSTRUCTION OF RACE* 82-86 (10th anniversary ed. 2006). Similarly, Khiara Bridges notes how law distinguishes between race as a scientific category and race as a legal category, though it implicitly relies on the former. Khiara M. Bridges, *The Dangerous Law of Biological Race*, 82 FORDHAM L. REV. 21, 23-24 (2013).

66. 20 C.F.R. §§ 404.1520(b)-(c), 416.920(b)-(c) (2019). Evaluations of disability for Social Security benefits rely on a five-step framework. *Id.* §§ 404.1520(a), 416.920(a). To pass step one, the claimant cannot currently be engaged in “substantial gainful activity.” *Id.* §§ 404.1520(a)(4)(i), 416.920(a)(4)(i). Step two examines whether the claimant has a “severe . . . impairment,” that is, an impairment “which significantly limits . . . physical or mental ability to do basic work activities.” *Id.* §§ 404.1520(a)(4)(ii), (c), 416.920(a)(4)(ii), (c). At this step, the agency “will not consider your age, education, and work experience.” *Bowen v. Yuckert*, 482 U.S. 137, 140-41, 145 (1987) (quoting 20 C.F.R. §§ 404.1520(c), 416.920(c)). If the claimant makes it past this step, the third step requires the Secretary to consider “the medical severity of [the] impairment(s).” 20 C.F.R. §§ 404.1520(a)(4)(iii), 416.920(a)(4)(iii) (2019). For this, the claimant must present objective medical evidence (such as symptoms, signs, and laboratory findings) of an impairment either found on a published list or that is “equal to a listed impairment[.]” *See id.* §§ 404.1520(d), 416.920(d), 416.929(a)-(b). If the claimant clears that hurdle, she is found to be disabled. If not, the fourth step considers whether the plaintiff can, assuming that she has work experience, do her previous job in view of her medical limitations; if she cannot, she proceeds to the fifth step and is eligible for benefits only if, in view of her health, age, education, and experience, she cannot engage in other work in the national economy. *Id.* §§ 404.1520(a)(iv)-(v), (f), (g), 416.920(f), (g).

67. 42 U.S.C. § 12102(1)-(3) (2018). The Rehabilitation Act has a similar definition. 29 U.S.C. § 705(20) (2018) (defining an “individual with a disability” as an individual who “has a physical or mental impairment which for such individual constitutes or results in a substantial impediment to employment”).

- The *Individuals with Disabilities in Education Act (IDEA)* provides for certain educational assistance for a “child with a disability,” defined as a child who has “intellectual disabilities, hearing impairments . . . , speech or language impairments, visual impairments . . . , serious emotional disturbance . . . , orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities,” or, for children aged three through nine, “experienc[es] [certain] developmental delays.”<sup>68</sup>
- The *Internal Revenue Code* allows some deductions for medical care, defined as money spent towards “the diagnosis, cure, mitigation, treatment, or prevention of disease, or for the purpose of affecting any structure or function of the body.”<sup>69</sup> Courts may evaluate whether the individual was designated as having a medical status that warranted treatment.<sup>70</sup>
- The *Family Medical Leave Act (FMLA)* provides leave benefits if an employee or qualified family member has a “serious health condition,” that is, “an illness, injury, impairment, or physical or mental condition that involves . . . inpatient care . . . [or] continuing treatment by a health care provider.”<sup>71</sup>
- Medical benefits under *Medicare* are premised on them being “reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member.”<sup>72</sup>
- *Medicaid* benefits vary according to state definition, but do rely on concepts such as illness and disability.<sup>73</sup>
- The *Fair Housing Act (FHA)* prohibits discrimination in the sale or rental of housing on the basis of a person’s “handicap” which, like the ADA’s definition of disability, is defined as “a physical or mental impairment which substantially limits . . . such person’s major life activities” or as a “record of having . . . [or] being regarded as having such an impairment.”<sup>74</sup>

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68. 20 U.S.C. § 1401(3)(A)-(B) (2018).

69. 26 U.S.C. § 213(a), (d)(1)(A) (2018).

70. See, e.g., *O'Donnabhain v. Comm'r*, 134 T.C. 34, 59 (2010) (considering whether gender identity disorder qualified as a disease), *acq.* 2011-47 I.R.B. 789.

71. 29 U.S.C. §§ 2611(11), 2612(a)(1)(D).

72. 42 U.S.C. § 1395y(a)(1)(A).

73. See, e.g., *Cowan v. Myers*, 232 Cal. Rptr. 299, 301 (Ct. App. 1986) (examining Medi-Cal provisions restricting benefits to those “medically necessary to prevent significant illness, to alleviate severe pain, to protect life, or to prevent significant disability”).

74. 42 U.S.C. § 3602(h).

- The *Help America Vote Act (HAVA)* requires that voting in federal elections be made accessible to individuals with disabilities, but does not define disability.<sup>75</sup>
- The *Developmental Disabilities Assistance and Bill of Rights Act* provides various protections for individuals with a “developmental disability,” defined in part as “a severe, chronic disability of an individual that . . . is attributable to a mental or physical impairment or combination [thereof],” “manifested before . . . age 22,” “likely to continue indefinitely,” and “results in substantial functional limitations in . . . [certain] major life activit[ies].”<sup>76</sup>

To be sure, as the (extremely simplified) definitions above suggest, law’s definition of medical status is in constant dialogue with the medical establishment’s, often relying on and deputizing to the medical establishment part of the task of designating a person as having a particular qualifying medical status. It is also in conversation with, and influenced by, other social forces. Thus, as Deirdre Smith shows, courts conceptualize impairments under the ADA primarily through the language of medicine<sup>77</sup>—even though activists intended the opposite (as I discuss later in this Article<sup>78</sup>). Sam Bagenstos explains how courts have superimposed further requirements upon the ADA, in part influenced by disability activists who seek to restrict ADA protections to a delimited minority.<sup>79</sup> Other statutes are more or less restrictive in their definition of medical status.<sup>80</sup>

Medical status is therefore an elastic concept that changes from statute to statute and context to context. Thus, it makes little sense to speak about medical status claims in the abstract. Rather, medical status claims are deployed for particular purposes in particular situations. The question is whether the relevant audience recognizes that particular status.<sup>81</sup> In many cases, claims fall

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75. 52 U.S.C. § 21081 (2018).

76. 42 U.S.C. § 15002(8)(A).

77. See Deirdre M. Smith, *Who Says You’re Disabled? The Role of Medical Evidence in the ADA Definition of Disability*, 82 TUL. L. REV. 1, 4-5 (2007) (discussing “judges’ reliance on medical evidence”).

78. See *infra* Part IV.C.

79. See SAMUEL R. BAGENSTOS, *LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT* 41-45 (2009).

80. For example, the Supreme Court rejected a challenge to the emphasis on medical criteria in the Social Security context. *Bowen v. Yuckert*, 482 U.S. 137, 150 n.8 (1987) (discussing evidence that the Secretary of Health and Human Services must “determine[] ‘first, on a strictly medical basis and without regard to vocational factors, whether the individual’s impairments, considered in combination, are medically severe’” (quoting S. REP. NO. 98-466, at 22 (1984))).

81. By deconstructing the concept of medical status, I do not seek to dissolve it. The contextually varying meanings that medical status comprehends are no different from  
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within the core of these definitions as understood by the relevant audience. But many other claims are contested. If medical professionals or insurance companies do not recognize a particular diagnosis, such as Multiple Chemical Sensitivity Disorder, they may refuse to provide treatment for it. If a particular community of deaf individuals refuses to recognize someone who is hard of hearing, the person will be excluded.<sup>82</sup>

The context with which I am concerned is the claiming of legal rights and benefits: If the particular government entity or legal program refuses to recognize a particular status as medical—either because it does not fall within a specific, legally defined medical status, or for other reasons—then the individual will not experience the legal rights and benefits that flow from that status. It is to those claims I now turn.

## II. Medical Rights Advocacy

Medical civil rights approaches can be separated (albeit not cleanly) into two categories. The first category consists of claims in which advocates seek formal legal rights. In those cases, litigants attempt to fit their claims within formal, legally defined medical statuses, such as the ones I list above. The second category consists of claims in which no formal rights are sought, but where advocacy will help change legal and public opinion.

### A. Formal Advocacy

Medical civil rights claims are important in part because their sheer number has increased dramatically, thereby increasing their social and legal prominence.<sup>83</sup> ADA or Rehabilitation Act charges filed with the Equal Employment Opportunity Commission (EEOC) have increased in number

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the variety of meanings other identities encompass. The Supreme Court has defined race as involving ancestry under the one drop rule, as involving scientific classifications between the Caucasian race and others, as comprising cultural distinctions (to exclude South Asians who qualify as Caucasian), and as essentially constituting nationality. *See* HANEY LÓPEZ, *supra* note 65, at 82-84 (discussing racial construction); Bridges, *supra* note 65, at 28-36 (same). Context determined the content of a very real category.

82. *See, e.g.*, Carol Padden & Tom Humphries, *Deaf People: A Different Center*, in *THE DISABILITY STUDIES READER* 393, 399 (Lennard J. Davis ed., 3d ed. 2010).

83. While not looking at legal claims specifically, over the past few decades medical sociologists have observed an increase in the number of various diagnoses. *See, e.g.*, Lennard J. Davis, *Obsession: Against Mental Health*, in *AGAINST HEALTH*, *supra* note 15, at 121, 121 (noting that “[i]n 1973, a researcher could write that OCD was ‘unquestionably, one of the rarest forms of mental disorders,’” but that it now is “a quite common, routinely diagnosed, and treatable disorder” (quoting with unmarked modifications PAUL L. ADAMS, *OBSESSIVE CHILDREN: A SOCIOPSYCHIATRIC STUDY* 17 (1973))).

from approximately 18,000 in 1997 to almost 24,000 in 2019—surpassing sex and race discrimination as the most numerous set of group-based EEOC charges.<sup>84</sup> Similarly, with a few blips, the number of Social Security disability beneficiaries has increased steadily over the last few decades.<sup>85</sup> FMLA leave-taking has increased from 17.1% in 2000 to 21.0% in 2012.<sup>86</sup> The number of Medicare and Medicaid claims and recipients has also grown significantly since the programs' inceptions.<sup>87</sup>

Now, many legal rights claims flow from medical statuses that fall within the core of what all relevant audiences agree are medical conditions<sup>88</sup>—and one might reasonably infer that where there is agreement, there is less litigation. Litigation therefore suggests that in some cases, claimants have sought to increasingly advance so-called “contested illnesses”: novel, borderline claims where medical status is not self-evident and which, as one sociologist puts it, are “illnesses you have to fight to get.”<sup>89</sup> While controversy rages over what illnesses are contested, at least at some point in time the list has “[t]ypically included . . . Chronic Fatigue Syndrome [(CFS)], Multiple Chemical Sensitivity Syndrome [(MCS)], Fibromyalgia, hypo-glycemia . . . Post Traumatic Stress Disorder (PTSD), [and] ADHD [Attention Deficit Hyperactivity Disorder],”

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84. *Charge Statistics (Charges Filed with EEOC): FY 1997 Through FY 2019*, U.S. EQUAL EMP. OPPORTUNITY COMMISSION, <https://perma.cc/5U2X-LRX4> (archived May 9, 2020); see also *Disability Discrimination*, U.S. EQUAL EMP. OPPORTUNITY COMMISSION, <https://perma.cc/4U54-YU95> (archived May 9, 2020). The rise in disability-related charges filed with the EEOC can be largely attributed to the increase in formal rights that became available after 2008 amendments to the ADA, discussed in greater detail in note 263 below.

85. L. SCOTT MULLER ET AL., OFFICE OF RESEARCH, EVALUATION, & STATISTICS, SOC. SEC. ADMIN., SSA PUB. NO. 13-11831, TRENDS IN THE SOCIAL SECURITY AND SUPPLEMENTAL SECURITY INCOME DISABILITY PROGRAMS 15-16 (2006), <https://perma.cc/BVT6-NU3J>.

86. JACOB ALEX KLERMAN ET AL., ABT ASSOCS., FAMILY AND MEDICAL LEAVE IN 2012: TECHNICAL REPORT 62 (rev. ed. 2014), <https://perma.cc/2SXV-QFBM>. While some leave was taken for nonmedical situations such as adoption, the vast majority of FMLA leave appears to have been taken for medical issues of the employee or her family. See *id.*

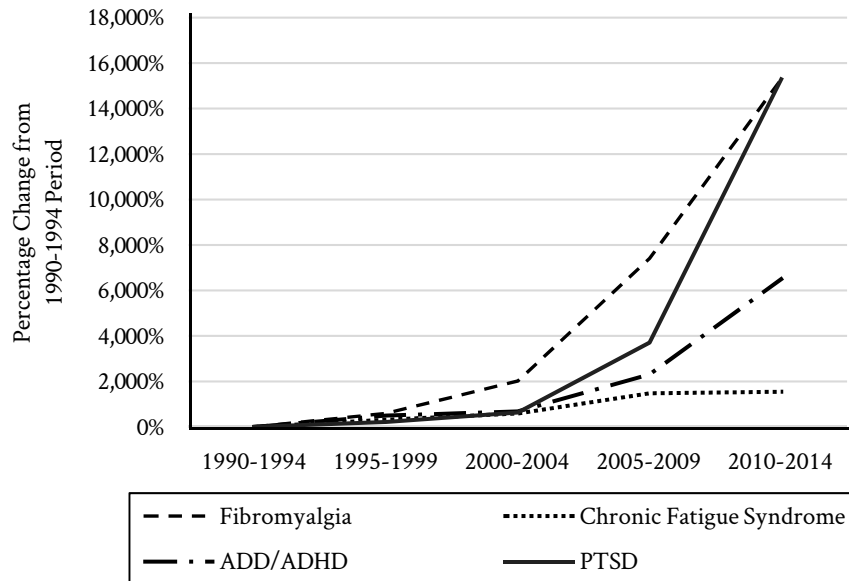
87. See Ctrs. for Medicare & Medicaid Servs., 2007 Data Compendium 27, 32 (2007), <https://perma.cc/W855-HACM>.

88. For example, an individual with advanced Parkinson's disease or a veteran who is a wheelchair user is likely to have welfare or accommodations claims approved without too much ado. See Carl May, *Rethorizing the Clinical Encounter: Normalization Processes and the Corporate Ecologies of Care*, in NEW DIRECTIONS IN THE SOCIOLOGY OF CHRONIC AND DISABLING CONDITIONS, *supra* note 21, at 129, 138 (“[F]or many people doing sickness work, contests over the legitimacy of sickness identities or over the warrantability of symptom expressions are matters for the margins.”).

89. Joseph Dumit, *Illnesses You Have to Fight to Get: Facts as Forces in Uncertain, Emergent Illnesses*, 62 SOC. SCI. & MED. 577, 577-78 (2006).

among others.<sup>90</sup> Nonetheless, as I show below, and in more detail in the Data Appendix, benefits litigation over these claims seems to have exploded. Individuals appear more likely than ever to translate harms they experience into the language of medical diagnosis to seek rights.<sup>91</sup> The contested illness claims below represent the total across five categories: Social Security disability benefits, and claims under the ADA, the FMLA, the Employee Retirement and Income Security Act (ERISA), and the IDEA. The Data Appendix provides a breakdown.<sup>92</sup>

**Figure**  
Growth in Contested Illness Claims over Time



90. Peter Conrad & Cheryl Stults, *Contestation and Medicalization*, in *CONTESTING ILLNESS*, *supra* note 55, at 323, 331; *see also* Katherine Lippel, *Workers' Compensation and Controversial Illness*, in *CONTESTING ILLNESS*, *supra* note 55, at 47, 52-59 (providing an overview of how such claims have played out in Canadian workers' compensation cases); Catherine Trundle et al., *Fighting to Be Heard: Contested Diagnoses*, in *SOCIAL ISSUES IN DIAGNOSIS: AN INTRODUCTION FOR STUDENTS AND CLINICIANS* 165, 166-67 (Annemarie Goldstein Jutel & Kevin Dew eds., 2014) (listing CFS, MCS, fibromyalgia, and ADHD as contested illnesses).

91. I offer caveats in the Methodological Appendix below.

92. I omit other contested like Gulf War Syndrome and Sick Building Syndrome in the Figure above as the numbers involved are either too small or too tied to a specific event. Similarly, MCS is excluded from the graph (but not the Data Appendix) due to small, nonrepresentative numbers.

The contested illness claims in the preceding Figure grew both as medical institutions became more willing to recognize these diagnoses and as the legal benefits offered expanded, with the passage of statutes like the ADA and the FMLA that made the claims possible. Further, even as this Article goes to press, conversations have begun over newer disorders: For instance, commentators have recently raised the question of whether videogaming disorder qualifies for disability benefits.<sup>93</sup>

Contestation arises for three reasons: (1) Medical opinion is settled and recognized by the law, but the law narrows the definition of medical status relative to medicine; (2) medical opinion as to whether a harm qualifies as a medical status might be unsettled, and the law reflects this confusion; or (3) medical opinion is settled, but the law's definition of medical status disregards it.

First, as the previous Part suggests, the way medical and legal authorities define medical status can differ. Some laws define medical status more narrowly than medicine. In those circumstances (which constitute the vast majority of cases), courts will recognize medical opinion, but layer on additional legal requirements in order to determine whether a legally cognizable medical status exists.

For example, for the purposes of the ADA, demonstrating a medically recognized impairment is not enough: Medical status is awarded only if one's impairment also "substantially limits one or more major life activities."<sup>94</sup> As the Fourth Circuit explained in a recent but frequently cited decision, while "[t]he ADA provides a nonexhaustive list of major life activities, including 'speaking,' 'concentrating,' 'thinking,' 'communicating,' and 'working,'" the statute leaves room for discretion.<sup>95</sup> Judges and administrative agencies can further define what a major life activity is, while medical evidence helps determine whether the plaintiff is substantially limited in performing that activity.<sup>96</sup> Thus, the Fourth Circuit held that a reasonable jury could conclude that a plaintiff with social anxiety disorder was substantially limited in the major life activity of "interact[ing] with others."<sup>97</sup> However, other important activities do not count—most courts have held that "driving is not, in itself, a

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93. See, e.g., Christopher Coble, *Can I Get Disability for Gaming Disorder?*, FINDLAW (June 28, 2018, 12:55 PM), <https://perma.cc/P4EH-QYWJ>.

94. 42 U.S.C. § 12102(1)(A) (2018).

95. *Jacobs v. N.C. Admin. Office of the Courts*, 780 F.3d 562, 572-74 (4th Cir. 2015) (citing 42 U.S.C. § 12102(2)(A)).

96. See *id.*

97. *Id.* at 574. The court therefore reversed the district court's order, which had granted summary judgment on the ground, inter alia, that the plaintiff was not "disabled as a matter of law." *Id.* at 568, 582.



major life activity.”<sup>98</sup> Thus, even while recognizing medical authority, the law might superimpose additional requirements.

Second, the medical establishment itself may be divided about a condition; in other words, doctors may disagree whether the claimant has a recognizable medical status. Take, for example, MCS, in which “exposure to a small amount of chemicals” (such as from perfume or computer equipment) triggers physiological reactions, including difficulty breathing, rashes, headaches, depression, and fatigue.<sup>99</sup> The response of one court was typical in the early days of this disorder. The court referenced “[r]eviews of the MCS literature by several established medical organizations” and noted that they had “generally found that little scientific evidence exists to substantiate the existence of MCS or establish a cause and effect relationship between MCS and chemicals.”<sup>100</sup> The court relied heavily on similar approaches by other courts in reaching its conclusion.<sup>101</sup> Another court similarly observed that the diagnosis was “controversial,” and cited to a report noting “considerable doubt in the scientific medical community regarding the legitimacy of MCS as a valid nosologic/diagnostic entity.”<sup>102</sup> The “questionable scientific validity of MCS” therefore “undermine[d]” the plaintiff’s expert testimony.<sup>103</sup>

More recently, in *P.P. v. Compton Unified School District*, civil rights advocates argued that the difficult living conditions some students experienced inflicted trauma, which sufficiently qualified as an impairment entitling these students to certain legal remedies.<sup>104</sup> Litigators sought to address some of the harms caused by poverty, race, and sexuality discrimination, inter alia, through a disability framework.<sup>105</sup> As they explained, students had been subject to various traumatic

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98. See, e.g., *Winsley v. Cook County*, 563 F.3d 598, 603 (7th Cir. 2009); see also *id.* (noting agreement with three other circuits).

99. Bay, *supra* note 14, at 384-85.

100. *Frank v. New York*, 972 F. Supp. 130, 135 (N.D.N.Y. 1997) (quoting E.E. Sikorski et al., Roundtable Summary, *The Question of Multiple Chemical Sensitivity*, 24 FUNDAMENTAL & APPLIED TOXICOLOGY 22, 23 (1995)). The article quoted in *Frank* reviewed literature by the American College of Physicians, the American Academy of Allergy and Immunology, the California Medical Association, and the American Medical Association. *Id.* For examples of how other courts have considered contemporary medical knowledge regarding MCS, see *Summers v. Mo. Pac. R.R. Sys.*, 897 F. Supp. 533, 535-37 (E.D. Okla. 1995), *aff’d*, 132 F.3d 589 (10th Cir. 1997); and *Bradley v. Brown*, 852 F. Supp. 690, 697 (N.D. Ind.), *aff’d*, 42 F.3d 434 (7th Cir. 1994).

101. See *id.* at 136.

102. *Cavallo v. Star Enter.*, 892 F. Supp. 756, 768 (E.D. Va. 1995) (quoting Expert Report of Dr. Philip Witorsch at 16-17, *Cavallo*, 892 F. Supp. 756 (No. 1:94-cv-01499)), *aff’d in part, rev’d in part*, 100 F.3d 1150 (4th Cir. 1996); see also *Treadwell v. Dow-United Techs.*, 970 F. Supp. 974, 982 (M.D. Ala. 1997) (relying on prior cases to raise similar concerns).

103. *Cavallo*, 892 F. Supp. at 768.

104. 135 F. Supp. 3d 1098, 1104-05 (C.D. Cal. 2015).

105. *Id.*

experiences, including separation from family after being placed in the foster system, homelessness, “multiple incidents of racism,” being told being gay was “wrong,” and the deaths of close family members.<sup>106</sup> These experiences caused “neurobiological effects” that “impair[ed] the ability to perform activities essential to education—including, but not limited to, learning, thinking, reading, and concentrating.”<sup>107</sup> They therefore sought remedies under the ADA and the Rehabilitation Act, which included training for school personnel to create a “healthy, supportive environment.”<sup>108</sup>

Nonetheless, even sympathetic authors critique some of the science behind the plaintiffs’ alleged impairments.<sup>109</sup> The school sought to dismiss the complaint, on the grounds, *inter alia*, that “[e]nvironmental, cultural, or economic disadvantages such as poverty, lack of education, or a prison record are not impairments.”<sup>110</sup> The court, however, agreed with plaintiffs that while these harms were not in themselves impairments, they could trigger medical harms that constituted impairment.<sup>111</sup> After *P.P.*, other litigation has followed in its footsteps.<sup>112</sup>

Even when there is medical consensus, litigants might pretend (sometimes disingenuously) that there is not. Thus, in a 2010 tax controversy, a transgender individual successfully argued that she should receive a tax deduction for her

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106. *Id.* (quoting Class Action Complaint at 10, *P.P.*, 135 F. Supp. 3d 1098 (No. 2:15-cv-03726), 2015 WL 2393294, ECF No. 1).

107. *Id.* at 1105; *see also* Class Action Complaint, *supra* note 106, at 24-25, 29-35 (discussing the effects of racism and other forms of discrimination, the death of loved ones, placement in the foster care system, and homelessness).

108. Class Action Complaint, *supra* note 106, at 72-73.

109. *See, e.g.*, Nancy E. Dowd, Annual Wells Conference Lecture, *Straight Out of Compton: Developmental Equality and a Critique of the Compton School Litigation*, 45 CAP. U. L. REV. 199, 235-36 (2017) (suggesting that the science is limited in its reach and offering solutions).

110. *P.P.*, 135 F. Supp. 3d at 1108-09 (alteration in original) (quoting Memorandum of Points & Authorities in Support of Defendants’ Motion to Dismiss Plaintiffs’ Class Action Complaint Pursuant to Fed. R. Civ. P. 12(b)(6) at 8-9, *P.P.*, 135 F. Supp. 3d 1098 (No. 2:15-cv-03726), 2015 WL 7687767, ECF No. 41).

111. *See id.* at 1109-11.

112. *See* Stephen C. v. Bureau of Indian Educ., No. 3:17-cv-08004, 2018 WL 1871457, at \*4 (D. Ariz. Mar. 29, 2018). In *Stephen C.*, the court weighed the plaintiffs’ claims that students experienced trauma due to

involvement in the juvenile justice and child welfare systems; family disruption, including separation from caregivers due to boarding school placements; historical trauma, including parent experience with boarding schools; physical and sexual violence, including exposure to restraints in the school setting; alcohol and substance abuse in the community; denial of access to education; and poverty,

*id.* (quoting Second Amended Complaint for Declaratory & Injunctive Relief at 39, *Stephen C.*, No. 3:17-cv-08004 (D. Ariz. July 14, 2017), ECF No. 60), leading to “palpable, physiological harm to a young person’s developing brain,” which “manifest[s] in the classroom.” *Id.* (quoting Second Amended Complaint, *supra*, at 40).

gender-confirming treatment as Gender Identity Disorder (GID) was “a ‘disease’ for purposes of section 213 [of the tax code] because it is well recognized . . . as a legitimate mental disorder.”<sup>113</sup> The IRS (unsuccessfully) argued that GID was merely “a ‘social construction’—a ‘social phenomenon’ that has been ‘medicalized’” rather than “a significant psychiatric disorder.”<sup>114</sup> State courts have similarly validated gender-identity-related diagnoses.<sup>115</sup>

Finally, the law might simply deviate from settled medical opinion. For example, the recognition of GID as a legally cognizable medical status has been challenged for yet another reason in ADA cases—the ADA excludes from its coverage “gender identity disorders not resulting from physical impairments.”<sup>116</sup>

Even in such situations, courts are loath to disregard medical opinion. In 2017, a district court held in *Blatt v. Cabela’s Retail, Inc.* that the ADA did not exclude all protections against discrimination based on transgender status.<sup>117</sup> Like the IRS, the defendant argued that being transgender did not constitute a medical status as defined by the ADA.<sup>118</sup> The court noted that the ADA excluded GID, that is, a

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113. *O’Donnabhain v. Comm’r*, 134 T.C. 34, 59 (2010), *acq.* 2011-47 I.R.B. 789.

114. *Id.* In addition to this case, another notable set of examples is where employers in workers compensation cases—here in the Canadian context—raised controversy over “musculo-skeletal disorders . . . associated with repetitive work.” See Lippel, *supra* note 90, at 51-52. With respect to some additional conditions, employers challenged benefit claims in ways that resulted in gendered outcomes—in other words, women were more likely to lose. See *id.*

115. *Lie v. Sky Publ’g Corp.*, No. 013117J, 2002 WL 31492397, at \*6 (Mass. Super. Ct. Oct. 7, 2002) (relying on documentation of diagnosis and treatment); *Doe v. Electro-Craft Corp.*, No. 87-E-132, 1988 WL 1091932, at \*4 (N.H. Super. Ct. Apr. 8, 1988) (“The only reasonable reading of DSM III is that transsexualism is a mental handicap as that term is used by knowledgeable medical experts.”); *Evans v. Hamburger Hamlet*, No. 93-E-177, 1996 WL 941676, at \*8 (Chi. Comm’n Human Relations May 8, 1996) (“Gender dysphoria is listed in the DSM III as a psychological disorder. The DSM III describes symptoms which demonstrate whether a person fits the diagnosis of gender dysphoria.”).

116. 42 U.S.C. § 12211(b)(1) (2018); see also Kevin Barry & Jennifer Levi, Essay, *Blatt v. Cabela’s Retail, Inc. and a New Path for Transgender Rights*, 127 YALE L.J.F. 373, 376 (2017) (noting that the ADA contains morality-driven exclusions); *infra* text accompanying notes 357-59 (explaining how the ADA excludes certain conditions for moralistic reasons). Other examples exist where courts have disregarded medical evidence and concluded that certain conditions are not disabilities under the ADA even without specific statutory authorization. Compare *Runnebaum v. NationsBank of Md., N.A.*, 123 F.3d 156, 167-69 (4th Cir. 1997) (en banc) (relying on no medical evidence in determining that asymptomatic HIV was not an impairment), *overruled by* *Bragdon v. Abbott*, 524 U.S. 624, 633-35, 637 (1998) (relying heavily on medical evidence), with *Runnebaum*, 123 F.3d at 180-81 (Michael, J., dissenting) (also relying on extensive medical evidence, but concluding that asymptomatic HIV was an impairment).

117. No. 5:14-cv-04822, 2017 WL 2178123, at \*4-5 (E.D. Pa. May 18, 2017).

118. *Id.* at \*2.

misalignment between gender assigned at birth and experienced gender.<sup>119</sup> However, many transgender individuals experience *distress* or *dysphoria* separate from, and as a result of, such misalignment. The court held that the canon of constitutional avoidance required it to read the ADA as not excluding *gender dysphoria* (characterized by “clinically significant stress” and other disabling impairments),<sup>120</sup> to avoid the question whether the exclusion violated the equal protection rights of trans individuals.<sup>121</sup> Notably, the Trump Administration has endorsed the *Blatt* position in filings in other courts, acknowledging that the ADA covers certain kinds of gender dysphoria.<sup>122</sup> Thus, some trans advocates push for disability rights claims,<sup>123</sup> though, admittedly, some of these claims have failed.<sup>124</sup>

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119. *See id.*

120. *Id.* at \*2, \*4. Indeed, the DSM’s diagnosis has changed from GID to gender dysphoria. *See* Jack Drescher et al., *Minding the Body: Situating Gender Identity Diagnoses in the ICD-11*, 24 INT’L REV. PSYCHIATRY 568, 571 (2012). This helped normalize transgender individuals who experience GID. Gregg Bloche, Opinion, *Transgender Law Shouldn’t Be Written by Psychiatrists*, WASH. POST (June 15, 2016, 6:00 AM PDT), <https://perma.cc/NZ7W-HNC7> (“With one stroke, psychiatry thereby normalized transgender identity while preserving health insurance coverage for gender-reassignment treatment as therapy for ‘dysphoria.’”).

121. *Blatt*, 2017 WL 2178123, at \*2-6.

122. Statement of Interest of the United States of America at 2-3, *Doe v. Arrisi*, No. 3:16-cv-08640 (D.N.J. July 17, 2017), ECF No. 49 (“[B]ecause Plaintiff has alleged that her GD resulted from a ‘physical impairment,’ by definition she has alleged that she falls within the statutory protections of the ADA.” (citing 42 U.S.C. § 12211(b)(1))). Other states have also followed this trend. *See* Kevin M. Barry & Jennifer L. Levi, *The Future of Disability Rights Protections for Transgender People*, 35 *TOURO L. REV.* 25, 63 (2019) (pointing to litigation in which the state defendant (Connecticut) appeared to concede at oral argument that the ADA did not exclude gender dysphoria). In another prominent case, a court extended ADA coverage to trans individuals, acknowledging that gender dysphoria may indeed arise from “physical causes,” and that gender dysphoria and GID are distinct diagnoses. *Doe v. Mass. Dep’t of Corr.*, No. 1:17-cv-12255, 2018 WL 2994403, at \*6 (D. Mass. June 14, 2018).

123. *See* Barry & Levi, *supra* note 116, at 376 (arguing that trans plaintiffs “should” invoke disability protections); Strassburger, *supra* note 9, at 338-39 (advocating a disability frame for trans rights); *see also* Complaint in Intervention of Plaintiff/Intervenor Ms. Britney Austin at 1-4, *EEOC v. Deluxe Fin. Servs., Inc.*, No. 0:15-cv-02646 (D. Minn. Oct. 22, 2015), 2015 WL 13283300, ECF No. 26 (intervening in an EEOC case to add an ADA claim, when the EEOC had originally only advanced a Title VII and retaliation claim). Two of the attorneys representing the intervenor were Jillian Weiss and Ezra Young (who later both went on to work at the Transgender Legal Defense and Education Fund); the other two attorneys were activists from Gender Justice. *Id.* at 40-41; *Education*, TRANSGENDER LEGAL DEF. & EDUC. FUND, <https://perma.cc/9V9M-QSCV> (archived May 9, 2020).

124. *See* *Sommers v. Iowa Civil Rights Comm’n*, 337 N.W.2d 470, 476-77 (Iowa 1983) (“No claim is made that a transsexual has an abnormal or unhealthy body. The commission could reasonably conclude that under its rule *Sommers* had no physical impairment.”); *see also* *Dobre v. Nat’l R.R. Passenger Corp. (Amtrak)*, 850 F. Supp. 284, 289 (E.D. Pa. 1993) (“[Dobre] did not allege in the complaint that she suffers from any organic

*footnote continued on next page*

It bears noting that these approaches to making formal medical rights claims are not distinct. For example, in cases that refuse to recognize obesity as a disability, courts adopt different tactics.<sup>125</sup> In one early, frequently cited decision, a court based its concerns on the lack of medical authority or consensus—the second of the three approaches I outline above. As the court noted, the record lacked “any testimony . . . that *all* morbidly obese persons are handicapped. . . . [T]he most that [one] medical witness . . . would say is that in morbidly obese persons, disability is ‘more likely’ to occur.”<sup>126</sup> However, in a more recent case, the Eighth Circuit followed the third of the three approaches: It ignored medical evidence and relied on EEOC guidance in holding that obesity does not constitute a “physiological disorder.”<sup>127</sup>

Finally, the elastic nature of medical status definition means that the same medical status might trigger only some of these statutes. Some statutes only provide benefits if a certain set of conditions are met, or when the medical status invoked is considered serious or particularly burdensome, for example.<sup>128</sup> Judges also do much of the work in constructing and reconstructing how law interacts with various definitions, sometimes resulting in inconsistent claims across jurisdictions, and even within particular cases.<sup>129</sup>

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disorder of the body. Thus, she is not physically impaired.”); *Holt v. Nw. Pa. Training P’ship Consortium, Inc.*, 694 A.2d 1134, 1139 (Pa. Commw. Ct. 1997) (analogizing to *Dobre*). The trend, however, is toward recognition of protections.

125. Notably, many cases *do* recognize obesity as a disability. *See, e.g.*, *Chism v. Berryhill*, No. 6:16-cv-01106, 2017 WL 6060161, at \*9-10 (D. Or. Dec. 7, 2017) (“The medical record establishes that plaintiff’s obesity is a medically determinable impairment because plaintiff consistently presented with a BMI over 30.0. . . . [T]he Social Security Regulations provide that [o]besity in combination with another impairment may or may not increase the severity or functional limitations of the other impairment. We will evaluate each case based on the information in the case record.” (third alteration in original) (quoting SSR 02-1p, 2002 WL 34686281, at \*6 (Sept. 12, 2002), *rescinded by* SSR 19-2p, 2019 WL 2374244 (May 20, 2019))); *State Div. of Human Rights v. Xerox Corp.*, 480 N.E.2d 695, 698 (N.Y. 1985) (“[T]he Commissioner could find that the complainant’s obese condition itself, which was clinically diagnosed and found to render her medically unsuitable by the respondent’s own physician, constituted an impairment and therefore a disability within the contemplation of the statute.”).

126. *Phila. Elec. Co. v. Commonwealth*, 448 A.2d 701, 706 (Pa. Commw. Ct. 1982).

127. *Morriss v. BNSF Ry. Co.*, 817 F.3d 1104, 1108 (8th Cir. 2016).

128. Some courts, indeed, have held that if your condition qualifies you for Social Security, it means that you cannot qualify for protections under the ADA. *See* Matthew Diller, *Dissonant Disability Policies: The Tensions Between the Americans with Disabilities Act and Federal Disability Benefit Programs*, 76 TEX. L. REV. 1003, 1007-08 (1998).

129. I thank Michael Stein for this point.

B. Nonformal Advocacy

In various contexts, advocates make medical status claims even though no statutory benefits formally flow from such advocacy. This occurs for two reasons. First, because the statute simply does not cover the problem at hand. Second, because the claimants do not seek medical benefits, but rather believe that the legitimacy of their cause is boosted through medical evidence, concepts, or analogies.

First, statutes may not cover the particular “medical” issue being identified. Take opioid addiction. From 1999 to 2015, over 183,000 people died from opioid overdoses in the United States.<sup>130</sup> By 2008, these deaths exceeded those involving heroin and cocaine *combined*.<sup>131</sup> The crisis has received sustained coverage from the *New York Times*<sup>132</sup> and the *Washington Post*,<sup>133</sup> among other outlets. While some individuals, including medical providers, see opioid users as unscrupulous addicts bamboozling gullible doctors for prescriptions,<sup>134</sup> the government’s response, in some instances at least, has been to frame this addiction as a medical “disorder.”<sup>135</sup> Thus, a Congressman noted in a 2010

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130. Tatum Anderson, *Curbing Prescription Opioid Dependency*, 95 BULL. WORLD HEALTH ORG. 318, 318 (2017).

131. See Leonard J. Paulozzi et al., *Vital Signs: Overdoses of Prescription Opioid Pain Relievers—United States, 1999–2008*, 60 MORBIDITY & MORTALITY WKLY. REP. 1487, 1489 tbl.1 (2011).

132. A collection of articles is available at *Opioid Epidemic*, N.Y. TIMES, <https://perma.cc/3983-6T8Z> (archived May 9, 2020).

133. The *Washington Post*’s coverage included videos of a symposium. See *Addiction in America: A Nation Responds*, WASH. POST LIVE, <https://perma.cc/XCG6-ABYF> (archived May 9, 2020).

134. See Jerome Groopman, *What’s Missing from the National Discussion About the Opioid Epidemic*, NEW YORKER (Nov. 7, 2017), <https://perma.cc/5Z88-7PTB>. There are also some limited trends toward criminalization. Rebecca Haffajee, *Fight the Urge to Criminalize Opioid Addiction Behaviors*, HEALTH AFF. BLOG (Mar. 9, 2016), <https://perma.cc/QQ9Y-E432>.

135. See Elizabeth Newcomer, “HOPE FOR EVERY ADDICTED AMERICAN”—An Opioid Epidemic in the Age of Ethopolitics: Implications for U.S. Drug Policy and Governing Problematic Subjects 50 (2015) (unpublished M.A. thesis, The City University of New York), <https://perma.cc/C9VN-WT4P> (documenting this framing in the 2008 Mental Health Parity and Addiction Equity Act and the Affordable Care Act). The same is true of other legislation. In July 2016, President Obama signed into law the Comprehensive Addiction and Recovery Act, which took steps to address opioid addiction and authorized grants for opioid research and treatment. Comprehensive Addiction and Recovery Act of 2016, Pub. L. No. 114-198, sec. 108(a), sec. 201, § 3021, sec. 301, § 514b, 130 Stat. 695, 705, 711-12, 717-18 (codified at 34 U.S.C. § 10701 (2018); 42 U.S.C. §§ 284q-1, 290bb-10 (2018)). Passed in December 2016, the 21st Century Cures Act similarly included \$1 billion in state funds to fight the opioid epidemic. 21st Century Cures Act, Pub. L. No. 114-255, § 1003(a)-(b), 130 Stat. 1033, 1044-45 (2016) (codified at 42 U.S.C. § 290ee-3 note (2017)); see also *HHS Provides States Second Installment of Grant Awards to Combat Opioid Crisis*, U.S. DEP’T HEALTH & HUM. SERVICES (Apr. 18, 2018), <https://perma.cc/MC5Q-54WR>.

House hearing: “We shouldn’t . . . be talking about criminal justice . . . . This has nothing to do with crack addicts in California driving buses or prisoners in prison,” but instead has more in common with efforts to combat Alzheimer’s and Parkinson’s—“[o]ur fight is neuroscience.”<sup>136</sup> His witness, a government official, agreed and promoted legal methadone programs first created to “treat the . . . opiate problems of returning veterans.”<sup>137</sup>

Now, as a formal matter, there are few benefits opioid addicts can claim. The ADA has excluded drug addiction from its coverage since its inception in 1990<sup>138</sup> and Social Security began to exclude addicts with the passage of welfare reform in 1996.<sup>139</sup> But some advocates believe that medical framing has garnered relative benefits. Compare the response to crack addiction and opioid addiction. Crack users were “skinny, dirty,”<sup>140</sup> and “deprav[ed].”<sup>141</sup> Most commenters agree that the medical framing helps soften the image of opioid users. They get “compassionate care,” while “criminal justice” approaches are critiqued.<sup>142</sup>

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136. *Treating Addiction as a Disease—The Promise of Medication-Assisted Recovery: Hearing Before the Subcomm. on Domestic Policy of the H. Comm. on Oversight & Gov’t Reform*, 111th Cong. 38, 40 (2010) (statement of Rep. Patrick J. Kennedy).

137. *Id.* at 42 (statement of A. Thomas McLellan, Deputy Director, Office of National Drug Control Policy) (emphasis added).

138. See Americans with Disabilities Act of 1990, Pub. L. No. 101-336, § 511(b)(3), 104 Stat. 327, 376 (codified as amended at 42 U.S.C. § 12211(b)(3) (2018)).

139. See Contract with America Advancement Act of 1996, Pub. L. No. 104-121, § 105, 110 Stat. 847, 852 (codified as amended at 42 U.S.C. § 423(d)(2)(C)). This was preceded by earlier retrenchment. See Social Security Independence and Program Improvements Act of 1994, Pub. L. No. 103-296, § 201(a)(1)(A), (a)(3)(A), (b)(1)(A), (b)(3)(A), 108 Stat. 1464, 1490, 1496-97, 1499-1500, 1503 (codified as amended at 42 U.S.C. §§ 405(j)(1)(B), 1382(e)(3)(A)(v)(I)-(II), 1383(a)(2)(A)(ii)(II)) (capping the length of time during which individuals who qualified on the basis of addiction could receive Social Security disability benefits and requiring someone to act as gatekeeper for their benefits); see also Dru Stevenson, *Should Addicts Get Welfare? Addiction & SSI/SSDI*, 68 BROOK. L. REV. 185, 186-87 (2002) (describing the debate over these reforms).

140. Tom Morganthau et al., *Crack and Crime*, NEWSWEEK, June 16, 1986, at 16, 17 (quoting a social worker).

141. 132 CONG. REC. 29,611 (1986) (statement of Rep. Lungren).

142. See *Combating the Opioid Abuse Epidemic—Professional and Academic Perspectives: Hearing Before the Subcomm. on Oversight & Investigations of the H. Comm. on Energy & Commerce*, 114th Cong. 68, 91 (2015) (statement of Patrice A. Harris, Secretary, Board of Trustees of the American Medical Association); *id.* at 91 (statement of Adam Bisaga, Research Scientist, New York State Psychiatric Institute). This account deserves moderation. As Leo Beletsky explains, despite the rhetoric, criminal approaches pervade our approach to opioid legislation; he advocates for a clearer shift to an evidence-based public health approach. Leo Beletsky, *America’s Favorite Antidote: Drug-Induced Homicide in the Age of the Overdose Crisis*, 2019 UTAH L. REV. 833, 863-69; see also Leo Beletsky et al., *Expanding Coercive Treatment Is the Wrong Solution for the Opioid Crisis (Updated)*, HEALTH AFF.: BLOG (Feb. 11, 2016), <https://perma.cc/CUJ2-9LFH> (criticizing the “blurring [of] the line between health care and incarceration” and advocating for “bolstering treatment

*footnote continued on next page*

While many statutes exclude opioid and other drug addictions deliberately, other rights-giving statutes simply do not cover certain conditions. In such situations, medical discourse is used to bolster social advocacy.<sup>143</sup> Consider so-called “social determinants of health,” which have blossomed as a field of study since the early 2000s. As this scholarship explains, health disparities are not simply a function of access to medical services.<sup>144</sup> They are as much, if not more, a product of one’s social environment—including one’s housing, employment, financial, family, social, and educational circumstances.<sup>145</sup> Thus as Dayna Matthew points out, a lack of “walkable proximity to green and recreational spaces, healthy food outlets, or even high-quality medical care” is linked to “obesity, depression, and even alcohol abuse.”<sup>146</sup> Matthew therefore argues for “medicalization” out of “altruism”—medicalizing social determinants in a way that will yield rights.<sup>147</sup> The logic is simple. If, say, cancer has an impact on your quality of life and, ultimately, your mortality (and we therefore seek to cure it), why not do the same for homelessness, which might have just as much of an effect?

The call has not gone unheeded. The last two editions of the International Classification of Diseases (ICD-9 & ICD-10), issued by the World Health Organization, listed lack of housing, low income, and the like as actual diagnoses.<sup>148</sup> Furthermore, several states have sought and received permission

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capacity, health care provider training, criminal justice reform, and scaling-up prevention education and naloxone access”).

143. An example is marijuana legalization. See Beau Kilmer & Robert J. MacCoun, *How Medical Marijuana Smoothed the Transition to Marijuana Legalization in the United States*, 13 ANN. REV. L. & SOC. SCI. 181, 184-85, 192 (2017) (describing how support for medical marijuana was linked, in part, to individuals living with cancer and AIDS).

144. Jeff Niederdeppe et al., *Message Design Strategies to Raise Public Awareness of Social Determinants of Health and Population Health Disparities*, 86 MILBANK Q. 481, 482-83 (2008).

145. See Sandro Galea et al., *Estimated Deaths Attributable to Social Factors in the United States*, 101 AM. J. PUB. HEALTH 1456, 1456, 1462 (2011). See generally ROBERT WOOD JOHNSON FOUND., A NEW WAY TO TALK ABOUT THE SOCIAL DETERMINANTS OF HEALTH (2010), <https://perma.cc/2GMW-Z58V> (providing an overview of social determinants of health while discussing messaging methods regarding them); Wendy K. Mariner & George J. Annas, *A Culture of Health and Human Rights*, 35 HEALTH AFF. 1999, 2000-02 (2016) (explaining the importance of human rights to health).

146. Dayna Bowen Matthew, *Health and Housing: Altruistic Medicalization of America’s Affordability Crisis*, 81 LAW & CONTEMP. PROBS. 161, 167 (2018); see also Mary Crossley, *Bundling Justice: Medicaid’s Support for Housing*, 46 J.L. MED. & ETHICS 595, 595 (2018) (discussing housing as a medical necessity).

147. Matthew, *supra* note 146, at 162, 170.

148. See Craig Konnoth, *Data Collection, EHRs, and Poverty Determinations*, 46 J.L. MED. & ETHICS 622, 623 (2018) (explaining how the income determinant is listed within the Z-code diagnostic category of the ICD-10). See generally Karen M. Kostick, *From V Codes to Z Codes: Transitioning to ICD-10 (Updated)*, AHIMA (Nov. 2011), <https://perma.cc/J4A4-D6FS> (describing V- (now Z-) codes).



from the federal government to use Medicaid waivers to address housing problems.<sup>149</sup> While the federal government refused to allow Medicaid to pay for rent, it has permitted payment for lead testing, security deposits for leases, utilities, household furnishings, and moving expenses, as well as employment assistance.<sup>150</sup>

But most of the statutes listed in Part I do not cover these conditions, as their language usually requires changes to bodily structure or a physical or mental impairment in order for a condition to count as a medical status.<sup>151</sup> In some instances, it is nevertheless possible to address social harms. For example, in *P.P.*, discussed above, the court stressed the harms that racism, poverty, and homelessness cause.<sup>152</sup> But advocates were careful to address the physiological *trauma* caused by these conditions.<sup>153</sup> This means that the litigation only “focuse[d] on resilience without reaching systemic discrimination” extending “beyond the educational system” that caused the harm in the first place.<sup>154</sup> Nonetheless, as advocates explain, the purpose of medicalizing status—like

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149. This permission was obtained under various waiver programs. See Vikki Wachino, Ctr. for Medicaid & CHIP Servs., U.S. Dep’t of Health & Human Servs., CMCS Informational Bulletin: Coverage of Housing-Related Activities and Services for Individuals with Disabilities 1-2, 4-7 (2015), <https://perma.cc/5C4G-27DZ>. See generally U.S. Dep’t of Hous. & Urban Dev., Developing a Medicaid Supportive Housing Services Benefit: Considerations and Decision Points (n.d.), <https://perma.cc/4FZW-Q8H4> (highlighting approaches for developing Medicaid benefits for housing services). Some of these waivers cover home and community-care services that apply only to specific populations, including people with disabilities, those experiencing chronic homelessness, and older adults needing long-term services and support. See *id.* at 4-7. However, certain newer programs exist through Section 1115 waivers, which offer more flexibility. See generally Medicaid & CHIP Payment & Access Comm’n, Medicaid’s Role in Housing (2018) (describing how Medicaid funding can support housing services).

150. See AMERIGROUP WASH., INC., SUPPLEMENTAL PROVIDER MANUAL: FOUNDATIONAL COMMUNITY SUPPORTS PROGRAM 6-7 (2019), <https://perma.cc/PD2K-KQ7P>; Henry J. Kaiser Family Found., Michigan’s Medicaid Section 1115 Waiver to Address Effects of Lead Exposure in Flint 5 (2016), <https://perma.cc/FJR5-2AEX> (discussing “financial, housing and transportation assistance and lead assessment and abatement resources” covered under Michigan’s waiver for Flint); Julia Paradise & Donna Cohen Ross, Henry J. Kaiser Family Found., Linking Medicaid and Supportive Housing: Opportunities and On-the-Ground Examples 14 (2017), <https://perma.cc/HV29-LSA5>; Michael Ollove, *States Freed to Use Medicaid Money for Housing*, PEW CHARITABLE TR.: STATELINE (Nov. 20, 2015), <https://perma.cc/96XN-FAWD>.

151. See sources cited *supra* notes 66-76; see also Smith, *supra* note 77, at 19-30. As both Smith and Crossley explain, there is both doctrinal and scholarly controversy as to what constitutes an impairment. Crossley, *supra* note 8, at 670-90; Smith, *supra* note 77, at 7-12. However, as used, impairment appears to refer to some kind of physical trait, which interacts with the environment to produce a disabling condition.

152. See *P.P. v. Compton Unified Sch. Dist.*, 135 F. Supp. 3d 1098, 1104 (C.D. Cal. 2015).

153. See *id.* at 1104.

154. Dowd, *supra* note 109, at 235.

homelessness and poverty—is to make a normative case for legal and policy changes, rather than relying on existing formal categories.<sup>155</sup>

Finally, activists borrow from medical frameworks to reinforce other kinds of legal claims. Medical challenges to bans on the sale of sexual devices, such as vibrators, have been more successful than those made purely on sexual autonomy grounds.<sup>156</sup> Cases in which advocates press the claim that sexual devices are *medically* necessary fare better than cases in which advocates “depart from a medicalized framework.”<sup>157</sup> Similarly, as Paul Freund famously noted, *Roe v. Wade* situated the liberty interest of the woman in a “medical point of view—making distinctions that turn on trimesters and on the development of the fetus and its viability.”<sup>158</sup>

Litigants also seek medical reinforcement in the equality context in both constitutional and nonconstitutional litigation, even with respect to categories that are not themselves medical in nature. Consider *Schroer v. Billington*, a landmark 2008 case in which a court held that the Library of Congress discriminated based on sex when it refused to hire a woman while she was transitioning.<sup>159</sup> At the motion to dismiss stage, the court emphasized how “components of biological sexuality—chromosomal, gonadal, hormonal, and neurological—interact with each other.”<sup>160</sup> Anti-transgender discrimination constituted discrimination based on sex because it involved hostility to the nonalignment of these putatively sex-determining biological characteristics.<sup>161</sup> In other cases, courts rely on medical understandings of sexual nonconformity

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155. See Taylor N. Mullaney, Comment, *Litigating Trauma as Disability in American Schools*, 13 NW. J.L. & SOC. POL’Y 452, 465–66 (2018) (“[T]he benefit of bringing a lawsuit like [*P.P.*] is not only the hope of winning. . . . Litigation can be part of a greater movement that involves policy changes at the school level, at the legislative level, in public awareness campaigns, and more.”).

156. See Susan Reid, *Sex, Drugs, and American Jurisprudence: The Medicalization of Pleasure*, 37 VT. L. REV. 47, 85–89 (2012).

157. *Id.* at 85, 89; see also *State v. Hughes*, 792 P.2d 1023, 1032 (Kan. 1990) (“We hold the dissemination and promotion of such devices for purposes of medical and psychological therapy to be a constitutionally protected activity.”); *State v. Brennan*, 772 So. 2d 64, 75 (La. 2000) (“The Alabama and Kansas cases . . . clearly show that it is common for trained experts in the field of human sexual behavior to use sexual aids in the treatment of their male and female patients’ sexual problems.”).

158. Paul A. Freund, *Storms over the Supreme Court*, 69 A.B.A. J. 1474, 1480 (1983). The scholarship on abortion (and reproductive rights more generally) and its relationship with medicine is far too vast to engage with here. I can only touch on highlights, while saving a more sustained treatment for later work.

159. 577 F. Supp. 2d 293, 308 (D.D.C. 2008). For a prominent casebook relying on the case as a teaching aid, see WILLIAM N. ESKRIDGE, JR. & NAN D. HUNTER, *SEXUALITY, GENDER, AND THE LAW* 55–56 (3d ed. 2011).

160. *Schroer v. Billington*, 424 F. Supp. 2d 203, 212–13 (D.D.C. 2006).

161. See *id.* at 213 n.5.

to find evidence of sex discrimination.<sup>162</sup> Thus, Jessica Clarke finds that “transgender individuals are more likely to win their cases” compared to many women who seek to protest gender stereotyping (such as makeup requirements), “because courts regard gender identity as immutable—a medical condition that an individual cannot change.”<sup>163</sup> Similarly, in the gay rights movement, while early activists rejected conceptualizing homosexuality as a medical status,<sup>164</sup> new advocacy relied on a raft of medical studies in the 1990s that claimed that homosexuality was biologically determined.<sup>165</sup> In *Windsor v. United States* and *Hollingsworth v. Perry*, battling medical professional amici argued over the extent to which sexuality had a biological component.<sup>166</sup>

To be clear, these professionals are not claiming that being gay, or male, or female are themselves medical statuses. But they seek to use medical vernacular

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162. *Glenn v. Brumby*, 663 F.3d 1312, 1314 (11th Cir. 2011) (noting early in its statement of facts that the plaintiff was “diagnosed with GID, a diagnosis listed in the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders” and that the plaintiff was “under the supervision of health care providers”); see also *Enriquez v. W. Jersey Health Sys.*, 777 A.2d 365, 372 (N.J. Super. Ct. App. Div. 2001) (“A person who is discriminated against because he changes his gender from male to female is being discriminated against because he or she is a member of a very small minority whose condition remains incomprehensible to most individuals.” (emphasis added)).
163. Jessica A. Clarke, *Frontiers of Sex Discrimination Law*, 115 MICH. L. REV. 809, 813 (2017) (reviewing KIMBERLY A. YURACKO, *GENDER NONCONFORMITY AND THE LAW* (2016)); see also YURACKO, *supra*, at 95 (describing an example of how medical frames have assisted in advancing trans rights); Abigail W. Lloyd, *Defining the Human: Are Transgendered People Strangers to the Law?*, 20 BERKELEY J. GENDER L. & JUST. 150, 179 (2005) (offering another example).
164. Manuela Soares, *The Purloined Ladder: Its Place in Lesbian History*, in *GAY AND LESBIAN LITERATURE SINCE WORLD WAR II: HISTORY AND MEMORY* 27, 38-39 (Sonya L. Jones ed. 1998). See generally Konnoth, *supra* note 2 (documenting the transition away from medicalization).
165. See, e.g., J. Michael Bailey & Richard C. Pillard, *A Genetic Study of Male Sexual Orientation*, 48 ARCHIVES GEN. PSYCHIATRY 1089, 1094-95 (1991) (concluding from a study of sets of male twins that there may be a genetic component to sexuality); Dean H. Hamer et al., *A Linkage Between DNA Markers on the X Chromosome and Male Sexual Orientation*, 261 SCIENCE 321, 325-26 (1993) (identifying a statistically significant correlation between certain genetic markers on the X chromosome and sexuality); Simon LeVay, Report, *A Difference in Hypothalamic Structure Between Heterosexual and Homosexual Men*, 253 SCIENCE 1034, 1036 (1991).
166. Compare, e.g., Brief of Amicus Curiae GLMA: Health Professionals Advancing LGBT Equality (Gay & Lesbian Medical Ass’n) Concerning the Immutability of Sexual Orientations in Support of Affirmance on the Merits at 12-27, *United States v. Windsor*, 570 U.S. 744 (2013) (No. 12-307), 2013 WL 860299 (claiming that homosexuality is primarily biological rather than behavioral), with, e.g., Amicus Curiae Brief of Dr. Paul McHugh in Support of *Hollingsworth & Bipartisan Legal Advocacy Group Addressing the Merits & Supporting Reversal* at 15-20, *Hollingsworth v. Perry*, 570 U.S. 693 (2013) (Nos. 12-144 & 12-307), 2013 WL 315228 (taking the opposite position).

to define sex and sexuality.<sup>167</sup> As trans advocate Jennifer Levi writes, medical evidence gives “courts . . . a more specific and concrete understanding of how painful it is to require the plaintiff to conform to the particular expectation of gender at issue in the case.”<sup>168</sup> Similarly, although many criticize the biological argument,<sup>169</sup> others argue that gay rights would be bolstered “[i]f homosexuality were viewed legally as a biological phenomenon, rather than a fuzzier matter of ‘choice.’”<sup>170</sup> Thus, *Obergefell v. Hodges* suggested that marriage equality is important because the “immutable nature” of sexuality meant that “same-sex marriage is [the] only real path to . . . profound commitment” for gay individuals: They have no other choice.<sup>171</sup> And for this characterization, the Court relied on the expertise of medical professionals—in particular, the brief of the American Psychiatric Association filed in the case.<sup>172</sup> Further, medical professionals

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167. See Lance Walhert, *The Painful Reunion: The Remedicalization of Homosexuality and the Rise of the Queer*, 9 J. BIOETHICAL INQUIRY 261, 266 (2012) (noting how homosexuality was remedicalized as “gay etiology studies were renewed by the end of the 1980s and in full force by the end of the 1990s”). I, of course, do not mean to claim that all forms of biology—including botany and zoology—fall under the study of medicine. However, biological study of the structure and functioning of the human body, with little exception, overlaps completely with the study of medicine. See Craig Konnoth, *Medical Stereotypes* (May 8, 2020) (unpublished manuscript) (on file with author) (discussing the relationship between biology and other sciences to medicine).

168. Jennifer L. Levi, *Clothes Don’t Make the Man (or Woman), but Gender Identity Might*, 15 COLUM. J. GENDER & L. 90, 101 (2006).

169. For prominent examples, see Garland E. Allen, *The Double-Edged Sword of Genetic Determinism: Social and Political Agendas in Genetic Studies of Homosexuality, 1940-1994*, in SCIENCE AND HOMOSEXUALITIES 242, 243 (Vernon A. Rosario ed., 1997); Janet E. Halley, *Sexual Orientation and the Politics of Biology: A Critique of the Argument from Immutability*, 46 STAN. L. REV. 503, 505-06 (1994) (highlighting criticisms of gay etiology studies and the immutability arguments based on them); Edward Stein, *Immutability and Innateness Arguments About Lesbian, Gay, and Bisexual Rights*, 89 CHI.-KENT L. REV. 597, 597-601 (2014) (reviewing and critiquing biological arguments).

170. Natalie Angier, *The Biology of What It Means to Be Gay*, N.Y. TIMES (Sept. 1, 1991), <https://perma.cc/E7DB-RBMU>.

171. 135 S. Ct. 2584, 2594, 2596 (2015). This phrase produced a raft of scholarship and commentary. See, e.g., Lisa M. Diamond & Clifford J. Rosky, Review, *Scrutinizing Immutability: Research on Sexual Orientation and U.S. Legal Advocacy for Sexual Minorities*, 53 J. SEX RES. 363, 363 (2016); Matthew W. Green, Jr., *Same-Sex Sex and Immutable Traits: Why Obergefell v. Hodges Clears a Path to Protecting Gay and Lesbian Employees from Workplace Discrimination Under Title VII*, 20 J. GENDER RACE & JUST. 1, 16-17 (2017); Ian Millhiser, *Here Is the Single Most Important Word in Today’s Historic Marriage Equality Opinion*, THINKPROGRESS (June 26, 2015, 4:02 PM), <https://perma.cc/5J28-S9XN>.

172. “[P]sychiatrists and others recognized that sexual orientation is both a normal expression of human sexuality and immutable.” *Obergefell*, 135 S. Ct. at 2596 (citing Brief of the American Psychological Ass’n et al. as Amici Curiae in Support of Petitioners at 7-17, *Obergefell*, 135 S. Ct. 2584 (Nos. 14-556 et al.), 2015 WL 1004713). I believe that this view reflects what Jessica Clarke refers to as the old view of immutability that is “linked to notions of childhood innocence, eliciting empathy for those who were blameless in their misfortunes.” Jessica A. Clarke, *Against Immutability*,  
*footnote continued on next page*

themselves can call for legal rights. For example, the American Psychiatric Association has, in a fact sheet discussing its most recent iteration of the DSM, suggested that “social and legal transition to the desired gender” is a part of the appropriate treatment regimen for gender dysphoria.<sup>173</sup>

Similarly, scholars have suggested that medical discourse is a powerful frame for advancing racial justice. Dayna Matthew, for example, notes that “[r]acial segregation has been shown to be a risk factor for poor health outcomes.”<sup>174</sup> Angela Harris and Aysha Pamukcu similarly argue in a forthcoming article that the “pathways through which social determinants of health shape health disparities” share “a single origin: subordination.”<sup>175</sup> They develop this insight to use medical frames to elucidate the harms of racism.<sup>176</sup> They are careful to point out that they do not seek to replicate old chestnuts about biological differences between races; relying on public health literature, they explain that instead of “racialized expressions of biology”—the narrative that races are intrinsically biologically different from each other—they seek to describe the “biological expressions of race relations.”<sup>177</sup> Race is “socially constructed” to be sure—but social constructs are imprinted on society, which in turn, through social determinants, leave their mark on “physical health.”<sup>178</sup> Therefore, race is “less a risk factor itself than a marker of risk for racism-related [health] exposures.”<sup>179</sup>

In adopting this strategy into legal scholarship, Harris and Pamukcu are, in many ways, harking back to a strategy adopted by elements of the civil rights movement. As Alondra Nelson’s excellent work on the Black Panthers shows, “the provision and politicization of medicine was a significantly developed feature of the Party’s broader mission. By . . . 1972, [its] health activism was full-fledged.”<sup>180</sup> Health rights were seen as a vehicle “to provide resources to poor

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125 YALE L.J. 2, 16-17 (2015). In this I disagree with Clarke, who characterizes *Obergefell* as reflecting a “new” form of immutability, *id.* at 4-5.

173. Bloche, *supra* note 120 (quoting Am. Psychiatric Ass’n, Gender Dysphoria 1-2 (2013), <https://perma.cc/9R8G-YGNS>); *see also* Ranna Parekh, *What Is Gender Dysphoria?*, AM. PSYCHIATRIC ASS’N (Feb. 2016), <https://perma.cc/CA46-4L99>.

174. Matthew, *supra* note 146, at 191.

175. Harris & Pamukcu, *supra* note 4.

176. *Id.* at 12-17, 21.

177. *Id.* at 25 (quoting Nancy Krieger, *Does Racism Harm Health? Did Child Abuse Exist Before 1962? On Explicit Questions, Critical Science, and Current Controversies: An Ecosocial Perspective*, 93 AM. J. PUB. HEALTH 194, 195 (2003)).

178. *See id.* at 24-25.

179. *Id.* (quoting Chandra L. Ford & Collins O. Airhihenbuwa, Commentary, *Critical Race Theory, Race Equity, and Public Health: Toward Antiracism Praxis*, 100 AM. J. PUB. HEALTH (SUPP. 1) S30, S33 (2010)).

180. NELSON, *supra* note 19, at 4.

blacks who formally held civil rights” but “lacked social and economic citizenship.”<sup>181</sup>

The pivot to using medicine, both formally and informally, to frame civil rights claims is inherently and strategically important. Nelson remarks on the “power[]” and “elastic[ity]” of health as a “political lexicon that could signify many ideals simultaneously.”<sup>182</sup> Similarly, as Harris and Pamukcu explain, medical frames offer strategic benefits in the modern world. As traditional civil rights approaches are undermined, “the civil rights of health framework offers the opportunity to leverage new types of evidence to demonstrate civil rights harms and violations, and new means for expanding the scope of anti-discrimination law.”<sup>183</sup> Moreover, “pursuing the civil rights of health makes visible the physical consequences of subordination, and the necessity of law and policy change so that no one is denied the opportunity to thrive.”<sup>184</sup>

### III. Critiques of Medical Civil Rights

While my description of medical civil rights as a unified phenomenon is original, other legal scholars have discussed medical rights claims. These discussions focus on the medicalization of rights in particular contexts—social determinants, trans advocacy, obesity claims, and the like. Advocates of medicalization usually simply explain how medical civil rights would help advance a particular cause, without much discussion about the controversy over medicalization.<sup>185</sup> Thus, in the legal scholarship, the medicalization question is addressed at length only by its critics, whose work ultimately comes out against the explosion in medical civil rights claims.<sup>186</sup>

Objections can be separated into two categories. First, the individual rights objections claim that medical status imposes negative forms of social control on individuals, stigmatizes them, and forces them to shoehorn nonmedical claims into medical ones, with problematic consequences. Second, the institutional position objections argue that the medical civil rights approach lacks legitimacy, saps medical institutions of *their* legitimacy, and invites co-optation by other institutions.

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181. *Id.* at 10.

182. *Id.* at 5.

183. Harris & Pamukcu, *supra* note 4, at 6.

184. *Id.*

185. See, e.g., Matthew, *supra* note 146, at 161-62 (providing only a brief discussion of medicalization before explaining how housing problems should be medicalized).

186. Even outside legal scholarship, medical sociologists acknowledge that “most studies of medicalization express concerns about overmedicalization.” Conrad & Stults, *supra* note 90, at 332 (emphasis omitted).

A. Individual Rights

Individual rights harms come in three varieties. Critics argue that medical status claims can (1) coerce individuals, (2) impose stigma, and (3) warp nonmedical harms into medical ones. These arguments are often advanced together.<sup>187</sup> Different groups of individuals might be subject to these harms to different degrees.<sup>188</sup>

From the 1960s onward, many scholars argued that medical statuses were imposed onto individuals as a tool of social control, discipline, and coercion. Thus, as Michel Foucault observed toward the end of his life, “[p]athology has become a general form of social regulation.”<sup>189</sup> Similarly, in 1972 Irving Zola wrote a widely cited essay, *Medicine as an Institution of Social Control*, where he argued that medicine is “nudging aside, if not incorporating . . . religion and law”; this occurs through “‘medicalizing’ much of daily living, by making medicine . . . relevant to an ever increasing part of human existence.”<sup>190</sup> In 1980, Joseph Schneider and Peter Conrad’s book, *Deviance and Medicalization: From*

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187. Scholars such as Bill Sage and Jennifer Laurin expound on criticisms that medicalization can, as applied to some groups, at least, “sap[] . . . agency” from those who are brought within their reach. William M. Sage & Jennifer E. Laurin, *If You Would Not Criminalize Poverty, Do Not Medicalize It*, 46 J.L. MED. & ETHICS 573, 577-78 (2018). Individuals can be “subject[] . . . to misguided paternalism or worse.” *Id.* at 578. Relatedly, Gregg Bloche describes how some criticize new forms of medication as rewarding individuals who forget to take their medication; he uses the example of replacing cheaper inhaled medication with long-lasting, but very expensive, injections that do not need to be taken regularly. BLOCHE, *supra* note 46, at 89-90. Such an approach might also be construed as rewarding individuals who lack agency or efficacy. These arguments are somewhat paternalistic, in that they embody judgment about the irresponsible or “bad” behavior of others. They can be (and have been) extended to undermine state assistance in other contexts besides medicine. See, e.g., Sara Sternberg Greene, *The Bootstrap Trap*, 67 DUKE L.J. 233, 236 (2017) (discussing these arguments in the context of 1990s-era welfare reform).

188. Lance Liebman, *The Definition of Disability in Social Security and Supplemental Security Income: Drawing the Bounds of Social Welfare Estates*, 89 HARV. L. REV. 833, 865-66 (1976) (suggesting that Aid to Families with Dependent Children recipients have lower status than SSI recipients); 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, 109 (2006) (illustrating powerfully how disability policy can demarcate status in the Israeli context). The discussion that follows also explains how historically underprivileged groups are more susceptible to these harms. For a full treatment, see Konnoth, *supra* note 167.

189. Michel Foucault, *The Crisis of Medicine or the Crisis of Antimedicine?*, FOUCAULT STUD., Dec. 2004, at 5, 15 (translation of Michel Foucault, *La Crisis de la Medicina o la Crisis de la Antimedicina*, 10 EDUCACIÓN MÉDICA Y SALUD 152 (1976)).

190. Irving Kenneth Zola, Essay, *Medicine as an Institution of Social Control*, 20 SOC. REV. 487, 487 (1972).

*Badness to Sickness*, made the case that medicine was a tool of social control.<sup>191</sup> These scholars were not alone.<sup>192</sup>

Modern day legal scholars who explicitly grapple with medicalization at length tend to follow in these footsteps. Trans scholar and activist Dean Spade, for example, declares that his “goal for trans law and policy remains demedicalization.”<sup>193</sup> He recounts how doctors require transgender individuals to unambiguously conform to gendered stereotypes before diagnosing them with gender dysphoria so that they might receive gender-affirming treatment.<sup>194</sup> Such approaches “coerce people into expressing gender identity through a narrowly defined binary.”<sup>195</sup>

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191. PETER CONRAD & JOSEPH W. SCHNEIDER, *DEVIANCE AND MEDICALIZATION: FROM BADNESS TO SICKNESS* 44-57 (1980); *see also* PETER CONRAD, *THE MEDICALIZATION OF SOCIETY: ON THE TRANSFORMATION OF HUMAN CONDITIONS INTO TREATABLE DISORDERS* 151-52 (2007).

192. *See, e.g.*, Brown, *supra* note 29, at 41. As Steven Epstein recounts, activists have opposed the consideration of deafness, intersex conditions, and even mental health as medical issues for related reasons. *See* Steven Epstein, *Patient Groups and Health Movements*, in *THE HANDBOOK OF SCIENCE AND TECHNOLOGY STUDIES* 499, 510 (Edward J. Hackett et al. eds., 3d ed. 2007). The criminal law, in particular, has used mental health as a tool to extend its control. *See* Allegra M. McLeod, *Decarceration Courts: Possibilities and Perils of a Shifting Criminal Law*, 100 GEO. L.J. 1587, 1614-16 (2012) (discussing the “net widening” effect of a therapeutic approach to jurisprudence). And when groups are medicalized, they are often subject to paternalistic forms of control. *See* Roy G. Spece, Jr. et. al., *(Implicit) Consent to Intimacy*, 50 IND. L. REV. 907, 919 (2017) (“Medicalization of a resident’s sexuality supports the nursing home’s perception that persons with dementia need protection from their own impaired memory and judgment.”). For an excellent summary of these criticisms, *see* Robert A. Nye, *The Evolution of the Concept of Medicalization in the Late Twentieth Century*, 39 J. HIST. BEHAV. SCI. 115, 117-19 (2003).

193. Spade, *supra* note 17, at 29. Spade has other critiques: for example, noting that the poorest individuals cannot get access to medical resources. *Id.* at 18; *see also* M. Robin DiMatteo et al., *Physician-Patient Communication in the Care of Vulnerable Populations: The Patient’s Voice in Interpersonal Policy*, in *PATIENTS AS POLICY ACTORS* 43, 43 (Beatrix Hoffman et al. eds., 2011) (offering additional reasons why “patients of higher education and income are often heard”). However, Spade’s critique is properly cast at a higher level of generality—it is hard for the poor and vulnerable to get access to formal legal rights as a general matter. His quarrel is not with medicalization, but with larger social and institutional structures. *See also* Lee, *supra* note 9, at 467 (making an analogous point regarding medicalization in the prison context). Others make similar critiques to Spade. *See, e.g.*, YURACKO, *supra* note 163, at 105 (“Those who do not experience transsexualism in the prescribed ways will either be (newly) pathologized or discredited.”); Franklin H. Romeo, Note, *Beyond a Medical Model: Advocating for a New Conception of Gender Identity in the Law*, 36 COLUM. HUM. RTS. L. REV. 713, 731 (2005) (“[T]he medical model of gender holds transgender people to hyper-normative standards . . .—thereby reifying the idea that ‘real’ men and women look and act a certain way.”).

194. Spade, *supra* note 17, at 28-29.

195. *Id.* at 29.



Women's and reproductive rights scholars level similar criticisms. Khiara Bridges, who studies the experiences of poor, pregnant women of color on Medicaid and welfare, argues that medicine can be used to justify a system of regulation when it comes to those populations.<sup>196</sup> To be sure, Bridges recognizes that medicine as such can provide benefits, and “thankfully acknowledge[s] the radical nature” of a New York Medicaid program oriented toward pregnant women.<sup>197</sup> At the same time, she “criticiz[es]” its operation in the specific context in which she focuses.<sup>198</sup> She notes that “pregnancy is not a legal event,” and yet it justifies “precise controls and comprehensive regulations” by the state because it is assigned medical status.<sup>199</sup> Others document how law relies on medical designations to subject women,<sup>200</sup> racial minorities,<sup>201</sup> and children (both in the juvenile justice system<sup>202</sup> and in schools<sup>203</sup>) to its control, using tools ranging from forced medication,<sup>204</sup> to shackling of pregnant women,<sup>205</sup>

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196. KHIARA M. BRIDGES, *REPRODUCING RACE: AN ETHNOGRAPHY OF PREGNANCY AS A SITE OF RACIALIZATION* 16 (2011).

197. *Id.* at 12; see also Khiara M. Bridges, *Wily Patients, Welfare Queens, and the Reiteration of Race in the U.S.*, 17 TEX. J. WOMEN & L. 1, 9 (2007) (noting that many women desire the services provided by the program).

198. BRIDGES, *supra* note 196, at 12.

199. See Khiara M. Bridges, *Pregnancy, Medicaid, State Regulation, and the Production of Unruly Bodies*, 3 NW. J.L. & SOC. POL'Y 62, 66 (2008) (quoting 1 MICHEL FOUCAULT, *THE HISTORY OF SEXUALITY* 137 (Robert Hurley trans., Vintage Books 1980) (1976)).

200. See, e.g., Katherine M. Aizpuru, *Gardasil, Gendered Discourse, and Public Health*, 16 GEO. J. GENDER & L. 347, 369-70 (2015) (“This attitude reflects the way women’s bodies are treated in general: throughout their lives, women are socialized to have their reproductive and sexual organs medically examined, even when they are not ill.”).

201. See, e.g., Danielle Thompson, Note, *Midwives and Pregnant Women of Color: Why We Need to Understand Intersectional Changes in Midwifery to Reclaim Home Birth*, 6 COLUM. J. RACE & L. 27, 40 (2016). See generally Troy Duster, *Lessons from History: Why Race and Ethnicity Have Played a Major Role in Biomedical Research*, 34 J.L. MED. & ETHICS 487 (2006) (offering numerous examples of how race is deployed in medical and diagnostic categorization, from the slavery era to modern day genetic studies).

202. See, e.g., Angela Olivia Burton, “*They Use It Like Candy*”: *How the Prescription of Psychotropic Drugs to State-Involved Children Violates International Law*, 35 BROOK. J. INT’L L. 453, 496 (2010).

203. LaToya Baldwin Clark offers a powerful example of how medicine can be used to oppress minority children who are diagnosed with behavioral conditions in schools, even as white parents more skillfully navigate the system and use medicine (namely, autism diagnoses) to extract *benefits* for their children. LaToya Baldwin Clark, *Beyond Bias: Cultural Capital in Anti-Discrimination Law*, 53 HARV. C.R.-C.L. L. REV. 381, 395-404 (2018).

204. See, e.g., Aizpuru, *supra* note 200, at 360-61 (discussing forced HPV vaccination for women but not for men).

205. See generally Geraldine Doetzer, Note, *Hard Labor: The Legal Implications of Shackling Female Inmates During Pregnancy and Childbirth*, 14 WM. & MARY J. WOMEN & L. 363 (2008).

and detention.<sup>206</sup> Bill Sage and Jennifer Laurin similarly argue that medicalizing poverty by subjecting it to the scrutiny of the medical profession is part of a broader “paternalistic project [that] replaced empathy and charity with supervision and ‘tough love,’ seldom consulting the poor about their most pressing needs and desires,” thus “disciplining the poor.”<sup>207</sup>

At an even higher level of generality, numerous scholars explain how health discourses can control individuals by becoming elevated into a moral imperative.<sup>208</sup> Media portrayals, corporate advertising, and other interactions exhort individuals to remain productive members of society, and to engage in activities and buy products to remain healthy enough to do so. These can range from health tracking devices and gym memberships, to pills and other medication. Employers similarly institute so-called wellness programs to surveil employee health behavior: Employees who obtain gym memberships or who do not smoke receive health insurance discounts.<sup>209</sup> The moral obligation of health that these practices inculcate can discipline individuals into being model actors.<sup>210</sup>

Related to these critiques of control are critiques of stigma. It is worth noting that medical civil rights laws were often passed with the *intention* of decreasing stigma. The purpose of many laws was to signal that those with medical status were owed benefits, not out of charity or pity, but as a matter of right—they sought to provide dignity. Thus, Matthew Diller documents how Social Security legislation was meant precisely to eradicate the stigma of charity: “Recipients could draw benefits without the stigma of being on ‘welfare.’”<sup>211</sup> “Indeed,” Diller notes, “the cryptic name of the program [(i.e., Social Security)] was chosen to discourage the benefits from being called

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206. See, e.g., Dorothy E. Roberts, *Punishing Drug Addicts Who Have Babies: Women of Color, Equality, and the Right of Privacy*, 104 HARV. L. REV. 1419, 1431-34, 1462 (1991) (discussing how racist behavior in medical contexts leads to disproportionately high reporting of substance abuse by minority pregnant women, leading in turn to their incarceration at disproportionately high rates).

207. See Sage & Laurin, *supra* note 187, at 575-76.

208. The scholars who offer this critique, especially outside the legal context, are too numerous to list. For a good review, see Steven Epstein & Laura Mamo, *The Proliferation of Sexual Health: Diverse Social Problems and the Legitimation of Sexuality*, 188 SOC. SCI. & MED. 176, 177-78 (2017).

209. See *infra* text accompanying notes 315-16.

210. See Vincanne Adams, *Against Global Health? Arbitrating Science, Non-Science, and Nonsense Through Health*, in *AGAINST HEALTH*, *supra* note 15, at 40, 41; Kathleen LeBesco, *Fat Panic and the New Morality*, in *AGAINST HEALTH*, *supra* note 15, at 72, 72; see also NIKOLAS ROSE, *THE POLITICS OF LIFE ITSELF: BIOMEDICINE, POWER, AND SUBJECTIVITY IN THE TWENTY-FIRST CENTURY* 23, 27 (2007).

211. Matthew Diller, *Entitlement and Exclusion: The Role of Disability in the Social Welfare System*, 44 UCLA L. REV. 361, 439 (1996).

‘welfare.’”<sup>212</sup> Michael Ashley Stein provides a similar account of the ADA, which was “intended to correct past injustice rather than act[] as a charitable handout.”<sup>213</sup>

However, despite these intentions, rather than dignifying individuals, these rights can impose various kinds of stigma. These stigmatic narratives can fall into several categories. First, those with medical conditions might be blamed for their status. Bridges’s work demonstrates such a reaction: “[T]he decision [of a mother] to reproduce while poor is an irrational, irresponsible one,” thus justifying government control.<sup>214</sup> Similarly, Russell Robinson and David Frost document how public health bodies promote HIV prevention medication for male same-sex encounters at higher rates than for heterosexual encounters.<sup>215</sup> “Medicalizing sex between men” is premised on the belief that gay men “are less sexually responsible, more sex-focused, and indiscriminate in selecting sex partners, as compared to straight people; because of their sexuality, gay and bisexual men are inherent vectors of disease.”<sup>216</sup>

Another kind of stigma might result from marking a group as less capable than others. Whether or not they are morally culpable, this inferiority can be used to justify control: A group might be seen as crippled, unable to take care of themselves, and a burden on society. Thus, as Alex Geisinger and Michael Ashley Stein write, the existence of the ADA’s remedies that require workplace accommodations might confirm society’s belief that PWD “are relatively unproductive and costly.”<sup>217</sup> Medical status, particularly the pity or charity that accompanies it, might be seen as stigmatizing in and of itself by marking individuals as requiring assistance.<sup>218</sup>

Third and finally, medical status might stigmatize an individual simply by marking her as an outsider. Thus, Dean Spade notes that some find it stigmatizing to apply medical status to trans individuals because it marks them

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212. *Id.* at 439, 465.

213. Michael Ashley Stein, *Under the Empirical Radar: An Initial Expressive Law Analysis of the ADA*, 90 VA. L. REV. 1151, 1184 (2004) (reviewing DAVID M. ENGEL & FRANK W. MUNGER, *RIGHTS OF INCLUSION: LAW AND IDENTITY IN THE LIFE STORIES OF AMERICANS WITH DISABILITIES* (2003)).

214. *See* BRIDGES, *supra* note 15, at 109-11.

215. *See* Robinson & Frost, *supra* note 16, at 235, 255, 258.

216. *See id.* at 235, 253 (capitalization altered).

217. Alex C. Geisinger & Michael Ashley Stein, *Expressive Law and the Americans with Disabilities Act*, 114 MICH. L. REV. 1061, 1077-78 (2016) (reviewing RICHARD H. MCADAMS, *THE EXPRESSIVE POWERS OF LAW: THEORIES AND LIMITS* (2015)).

218. *See* Paula E. Berg, *Ill/Legal: Interrogating the Meaning and Function of the Category of Disability in Antidiscrimination Law*, 18 YALE L. & POL’Y REV. 1, 42 (1999) (noting that disabled “plaintiffs are asserting their fundamental equality with the able-bodied” but are forced to establish “entitlement to benefits through the evocation of sympathy and pity”).

as abnormal, and therefore, as outsiders.<sup>219</sup> Peter Conrad similarly explains how medical professionals and pharmaceutical companies marked bald or short individuals as outsiders or as “disorder[ed]” persons who must address their defects.<sup>220</sup> Simply not belonging to a group—being an outsider—can stigmatize.<sup>221</sup>

The final individual-rights-focused criticism argues that medical rights claims require assimilation to shoehorn other vulnerabilities into medical harm. This critique, indeed, is redolent of the first critique—claiming medical status exerts a disciplining function by requiring individuals to assume certain identities to advance their claims. It might involve outright malingering: overstating or pretending to have a condition simply to get benefits. Thus, when disability claims plummet as unemployment falls, some may argue that individuals who were unemployed were pretending to have disabilities in order to get benefits.<sup>222</sup> It might also involve self-transformation in ways that law and medicine require. Thus, in one chilling example, the *Boston Globe* reported how some parents administer psychotropic drugs to their children in order to get benefits: “To get the check,” one mother “concluded with regret, ‘you’ve got to medicate the child.’”<sup>223</sup> It also bears mentioning that either pretended or actual assimilation can be difficult, requiring access to medical resources beyond the reach of many.<sup>224</sup> Conversely, the transformation might be symbolic rather than material. Medicalizing categories such as race, gender, or sexuality can essentialize them into biological traits, which might promote claims regarding inherent inferiority, among other harms.<sup>225</sup> Medical status can therefore harm individuals.

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219. See Spade, *supra* note 17, at 25.

220. CONRAD, *supra* note 191, at 38-39, 95.

221. Many of these stigmatic signals can travel together. Thus, one commenter observes that the *P.P.* litigation’s

use of a disability framework is troubling as the basis for claims. It has the potential to feed into persistent racial and ethnic stereotypes of incapability, lack of intellectual capacity, and dangerousness. . . . Or it may tend toward identifying causes or laying blame on the individual or their family, rather than on structural harm.

Dowd, *supra* note 109, at 235.

222. Nelson D. Schwartz, *Disability Applications Plunge as the Economy Strengthens*, N.Y. TIMES (June 19, 2018), <https://perma.cc/KN6G-EGRS>.

223. Patricia Wen, *A Legacy of Unintended Side Effects*, BOS. GLOBE (Dec. 12, 2010), <https://perma.cc/Y9XA-T59L>.

224. See *id.*

225. See Bridges, *supra* note 65, at 29 (discussing race).

B. Institutional Harms

Fewer scholars offer institutional objections to medicalization. However, one can imagine three varieties of objections: (1) medicine lacks the legitimacy to be a source of legal rights; (2) medicine will *lose* its legitimacy if it engages with unpopular causes, such as poverty issues; and (3) medicine could be co-opted by nefarious causes.<sup>226</sup>

The first objection is that law, and law alone, has the legitimacy to create civil rights, and that deputization to medicine is problematic. Protected classes have historically been designated by governmental institutions. Title VII, for example, offers protections based on specific criteria.<sup>227</sup> Many of these criteria, such as race, are culturally and historically constructed; yet the ultimate gatekeeping authority rests with courts and the legislature. These institutions determine whether discrimination based on speaking Spanish, braided hairstyles, or pregnancy constitutes discrimination based on national origin, race, or sex.<sup>228</sup> Similarly, constitutional doctrine offers a set of criteria—political powerlessness, historical discrimination, or immutability, to name a

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226. Bill Sage and Jennifer Laurin present a different objection, namely, that medical institutions are simply ineffective. As they explain, “[s]everal decades of health services research have revealed an enormously wasteful and underperforming healthcare system rife with unexplained variation, major safety lapses, and poorly defined quality.” Sage & Laurin, *supra* note 187, at 574. However, that objection is less relevant to my conception of medicalization, which locates part of the medicalization phenomenon outside medical institutions and the “healthcare system.” The latter plays a big role in the formation of medical discourse, as I note in Part I, but it does not have a monopoly. Furthermore, Sage and Laurin note how “medical offices and clinics with highly directive professionals offering a limited set of billable interventions are too remote from the sources of underlying risk—blighted neighborhoods, gun violence, poor diet.” *Id.* at 577. But as I explain, the new vision of medicalization seeks to address these harms, without necessarily implicating medical professionals. See Tiago Correia, *Revisiting Medicalization: A Critique of the Assumptions of What Counts as Medical Knowledge*, FRONTIERS SOC. 3, 6 (Sept. 2017), <https://perma.cc/WC4E-W6MD> (noting that a view of medicalization that is “profession-based” is “culturally biased” and that “a profession-based approach to medicalization results in the acceptance and reproduction of medical boundaries and definitions directly from biomedical knowledge”). See generally *infra* Part V.B.2 (discussing how medicine engages noninstitutional actors).

227. 42 U.S.C. § 2000e-2(a) (2018) (forbidding employment discrimination based on “race, color, religion, sex, or national origin”).

228. The answer to these questions in many cases is no, according to courts. See, e.g., *Gen. Elec. Co. v. Gilbert*, 429 U.S. 125, 145-46 (1976) (holding that a disability plan that excluded pregnancy did not violate Title VII); *Garcia v. Gloor*, 618 F.2d 264, 270, 272 (5th Cir. 1980) (holding that a workplace “speak-English-only” rule did not discriminate on a national origin basis); *Rogers v. Am. Airlines, Inc.*, 527 F. Supp. 229, 233 (S.D.N.Y. 1981) (holding that a policy forbidding braided hair did not violate Title VII).

few—for designating groups that enjoy higher judicial solicitude.<sup>229</sup> But these criteria were judicially crafted, and ultimately judges determine which groups satisfy them.

In the context of medical civil rights, legal institutions delegate far more discretion compared to traditional civil rights. The legislature sets up the framework for medical civil rights,<sup>230</sup> and courts referee competing medical evidence.<sup>231</sup> However, much of the heavy lifting relies on medical institutions and professionals. It is usually their threshold determination of medical status that is key to any claim. They decide not just whether a particular individual has a particular medical condition, but whether a particular condition should be termed medical in the first place. While judges and administrators might make the ultimate decision in particular cases, their decisions rely on the weight of *medical* authorities.<sup>232</sup>

The concern, however, is that medical institutions, unlike legal ones, have no democratic legitimacy. Legislators, judges, and administrators carry out their decisionmaking (in theory at least) openly, subject to myriad statutory and constitutional requirements. More importantly, they are *tasked* by the Constitution with developing and administering a system of legal rights. The decisionmaking within medical institutions lacks this imprimatur. The decision to depathologize homosexuality,<sup>233</sup> the changes to diagnoses pertaining to gender identity,<sup>234</sup> and the development of ADHD as a diagnosis, particularly in adults<sup>235</sup>—to name just a few—were the result of the work of relatively small and invisible cadres of activists, expert groups, and professional associations. Some might fairly argue that delegating legal decisionmaking to medical institutions is problematic.

A second objection is that medicine will lose its legitimacy. That is to say that apart from lacking the legitimacy to provide input on civil rights matters,

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229. See *City of Cleburne v. Cleburne Living Ctr., Inc.*, 473 U.S. 432, 442-45 (1985) (laying out characteristics); *United States v. Carolene Prods. Co.*, 304 U.S. 144, 152 n.4 (1938); David Schraub, *Unsuspecting*, 96 B.U. L. REV. 361, 367-96 (2016).

230. Indeed, with the ADA, legislators specifically noted that they could not list all possible medical conditions, in part, because of the changing nature of medical knowledge. See Kevin M. Barry, *Disabilityqueer: Federal Disability Rights Protection for Transgender People*, 16 YALE HUM. RTS. & DEV. L.J. 1, 12 (2013).

231. See, e.g., *Schroer v. Billington*, 577 F. Supp. 2d 293, 306 (D.D.C. 2008) (“[C]ourts render opinions about scientific controversies with some regularity . . .”).

232. See *supra* notes 117-27 and accompanying text (explaining how the EEOC and courts rely heavily on medical diagnoses to determine whether a condition qualifies for the ADA).

233. See Drescher, *supra* note 37, at 571.

234. See Drescher et al., *supra* note 120, at 571 (explaining how gender identity disorder was replaced primarily with gender dysphoria).

235. See CONRAD, *supra* note 191, at 48-69.

using medicine to bolster less popular causes (such as poverty reduction) might reduce the power of medical institutions to shape even medical discourse.<sup>236</sup> Individuals' beliefs in medicine are embedded in "cognitive processes that . . . can be adapted to serve specific functions in a context or setting."<sup>237</sup> Thus, their belief in social determinants of health depends on their demographic characteristics and political sympathies.<sup>238</sup> Therefore, associations between medicine and poverty reduction might reduce society's appetite to address medical problems: As researchers explain, "if policymakers and the media emphasize a connection between low socioeconomic status and illness, they will draw attention to a particular social group: those living in poverty."<sup>239</sup> And because society is prejudiced against the poor, they may soon also become prejudiced against the unwell. Using funding earmarked for medicine for causes seen as only tenuously linked to health may generate opposition to medical funding itself.<sup>240</sup>

Scholars at a National Academies of Science Workshop raised these very concerns. "Politicians bring science and scientists into the policy arena in an effort to say 'the science is on my side.'"<sup>241</sup> However, if "the public's historical trust in scientists" is leveraged "to move political agendas forward," the public, "which generally has an unfavorable view of politicians, can extend its negative feelings toward science."<sup>242</sup> This might well mean that using medicine to frame poverty and homelessness will discredit medical frames themselves.

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236. Cf. RICHARD K. SCOTCH, FROM GOOD WILL TO CIVIL RIGHTS: TRANSFORMING FEDERAL DISABILITY POLICY 87-88 (1984) (discussing how officials feared that extending protections to conditions like alcoholism would weaken protections for already-established ones).

237. See Helen Lundell et al., *Public Views About Health Causation, Attributions of Responsibility, and Inequality*, 18 J. HEALTH COMM. 1116, 1118 (2013).

238. See Rosemary Davidson et al., *The Wealthy Get Healthy, the Poor Get Poorly? Lay Perceptions of Health Inequalities*, 62 SOC. SCI. & MED. 2171, 2175 (2006).

239. Sarah E. Gollust et al., *The Polarizing Effect of News Media Messages About the Social Determinants of Health*, 99 AM. J. PUB. HEALTH 2160, 2160 (2009); see also James A. Morone, *Enemies of the People: The Moral Dimension to Public Health*, 22 J. HEALTH POL. POL'Y & L. 993, 993-94 (1997) (discussing how groups are otherized based on their perceived threat to public health). See generally Helena Hansen et al., *Pathologizing Poverty: New Forms of Diagnosis, Disability, and Structural Stigma Under Welfare Reform*, 103 SOC. SCI. & MED. 76 (2014) (discussing how poverty—and in turn, healthcare for the poor—becomes stigmatized).

240. Relatedly, some may see medicine as being dishonest, as trying to "smuggle[]" in rights. See Bloche, *supra* note 120 ("Protection for transgender people shouldn't be smuggled in quietly in medical disguise. Doing so isn't just dishonest; it invites backlash—against transgendered Americans, against psychiatry and against public officials who refuse to own up to their pursuit of legal change.").

241. NAT'L ACADS. OF SCI., TRUST AND CONFIDENCE AT THE INTERFACES OF THE LIFE SCIENCES AND SOCIETY: DOES THE PUBLIC TRUST SCIENCE?—A WORKSHOP SUMMARY 21 (2015).

242. *Id.*

We might, as a nation, stop placing emphasis on solving problems related to medical care (however we conceive of the term).

Third, critics might point out that medicine can be—and indeed has been—co-opted by other movements. In the abortion context, for example, anti-choice groups have harnessed pseudoscience to defend scientifically indefensible restrictions, such as unnecessary requirements that abortion providers have admitting privileges at nearby hospitals, in order to deter abortion.<sup>243</sup> In 2016, the Supreme Court struck down some such limitations.<sup>244</sup> As my own work has described, religious conservatives have co-opted scientific approaches to promote harmful efforts to change sexual orientation.<sup>245</sup> Pharmaceutical companies play a role in medicalizing conditions for profits and emphasize investment in those conditions that have a higher profit margin.<sup>246</sup> Furthermore, companies might urge drug access ostensibly for “bioethical” reasons, but in reality to maximize financial gain.<sup>247</sup> The criminal justice system medicalizes certain individuals thus justifying deprivations of liberty for longer periods than would constitutionally be allowed, often by placing them in medical diversion programs that do not come with the due process protections of standard imprisonment.<sup>248</sup> What should we make of these uses of medical status that many would argue, harm, rather than enhance, liberty?

#### IV. Strengths of Medical Civil Rights

The damning criticisms of medical civil rights pervade the literature. Far more elusive are the justifications, which this Part lays out. First, those who qualify for medical legal rights as a formal matter are awarded a formidable array of protections. As I show, these protections are robust, even superior, when compared to the protections other disadvantaged groups might receive. Second, even without formal protections, being able to claim medical status often triggers a normative cachet—it tells the world and society that

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243. See Linda Greenhouse & Reva B. Siegel, *Casey and the Clinic Closings: When “Protecting Health” Obstructs Choice*, 125 YALE L.J. 1428, 1454-60 (2016).

244. *Whole Woman’s Health v. Hellerstedt*, 136 S. Ct. 2292, 2310-11, 2318 (2016).

245. See generally Craig J. Konnoth, *Reclaiming Biopolitics: Religion and Psychiatry in the Sexual Orientation Change Therapy Cases and the Establishment Clause Defense*, in *LAW, RELIGION, AND HEALTH IN THE UNITED STATES* 276 (Holly Fernandez Lynch et al. eds., 2017) (discussing how religious conservatives drew from psychiatric techniques in order to engage in biblical counseling).

246. See CONRAD, *supra* note 191, at 32, 38-39 (discussing how pharmaceutical companies, among others, promote medicalization of certain conditions); Adams, *supra* note 210, at 53.

247. Carl Elliott, *Pharmaceutical Propaganda*, in *AGAINST HEALTH*, *supra* note 15, at 93, 101-02 (describing how a pharmaceutical company argued that denying patients a drug because of expense was “unethical” as part of a public relations campaign).

248. See McLeod, *supra* note 192, at 1615-16.



a particular disadvantage is not your fault. Medical status, unlike other statuses such as unemployment, is less likely to be attributed to individual responsibility and is therefore better protected in the law. Third, medical status claims come with a certain sense of expertise, which lends them legitimacy that others might lack.

I hasten to add that I do not believe that any of these benefits are intrinsic to my conception of medical status. Indeed, given the constructed aspect of medical status I emphasize in Part I, I would claim that many aspects of medical status are contingent and subject to change. That said, because of the practical benefits that currently come with medical status, I believe that advocates should seriously evaluate whether these benefits are available in the particular contexts in which they are operating.

#### A. Formal Benefits

Assessing the robustness of formal legal rights that pertain to medical status is best done by comparing it to the legal rights that flow from other categories, such as race, sex, sexuality, poverty, or geographic disadvantage. As this Subpart explains, medical rights are superior in terms of both context and content. Where race or sex discrimination might generate elevated protections, medical civil rights also provide affirmative accommodations. Where poverty might generate government payments, medical civil rights also produce protections in a wide array of contexts including antidiscrimination. Thus, from a formal perspective, medical status claims are highly desirable.

##### 1. Scope

Despite lacking the constitutional pedigree of many other rights categories, such as race, medical rights reach all (or close to all) of the contexts of the former. Taking public contexts first, the Fourteenth Amendment triggers elevated judicial scrutiny of *any* state action taken based on certain protected categories such as race, sex, illegitimacy, and national origin.<sup>249</sup> In those cases, the government must demonstrate that the classification is at least “substantially related to a sufficiently important governmental interest.”<sup>250</sup> In cases involving other categories, such as age, the government must show only that the classification has a rational relationship to a legitimate interest.<sup>251</sup>

The ADA’s reach roughly includes all contexts in which the Fourteenth Amendment applies, namely those involving state action. Title II prohibits a

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249. *See City of Cleburne v. Cleburne Living Ctr., Inc.*, 473 U.S. 432, 439-41 (1985) (listing protected categories).

250. *Id.* at 441.

251. *See id.* at 439-42.

qualified disabled individual from being “denied the benefits of the services, programs, or activities of a public entity, or be[ing] subjected to discrimination by any such entity.”<sup>252</sup> As with protected classes under the Fourteenth Amendment, states can escape the requirement only if they satisfy a standard that exceeds what would be rational basis scrutiny in a constitutional context. The burden shifts to the state actor to show that it should be exempted.<sup>253</sup> Section 504 of the Rehabilitation Act of 1973 similarly states that an individual cannot “solely by reason of her or his disability, be . . . subjected to discrimination under any program or activity receiving Federal financial assistance.”<sup>254</sup>

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252. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, § 202, 104 Stat. 327, 337 (codified at 42 U.S.C. § 12132 (2018)).

253. The entity may claim that the individual is not qualified, that is, not “an individual . . . who, with or without reasonable modifications . . . meets the essential eligibility requirements for” services or programs by the particular government activity. 42 U.S.C. § 12131(2). The implementing regulations exempt a public entity if “the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.” 28 C.F.R. § 35.130(b)(7)(i) (2019). But this exception is limited. As commentary on the regulations explains, a qualified individual is one who meets “essential eligibility requirements”: “The ‘essential eligibility requirements’ for participation in many activities of public entities may be minimal.” *The American with Disabilities Act: Title II Technical Assistance Manual*, AMERICANS WITH DISABILITIES ACT, <https://perma.cc/F9ZJ-6F2B> (archived May 9, 2020). In other cases, an entity might argue that a covered individual is excluded for safety reasons, or because that individual poses a direct threat. *See* 28 C.F.R. §§ 35.130(h), 35.139; *see also id.* § 35.104 (defining direct threat); Stephen F. Befort, *Direct Threat and Business Necessity: Understanding and Untangling Two ADA Defenses*, 39 BERKELEY J. EMP. & LAB. L. 377, 385 (2018) (noting that, according to judicial decisions, “a de minimis or slightly increased risk to health or safety is insufficient to establish the direct threat defense” and that the evidence must instead “establish ‘a high probability of substantial harm’” (footnotes omitted) (quoting *EEOC v. Hibbing Taconite Co.*, 720 F. Supp. 2d 1073, 1082 (D. Minn. 2010))).

254. Pub. L. No. 93-112, § 504, 87 Stat. 355, 394 (codified as amended at 29 U.S.C. § 794(a) (2018)). Some might argue that, in some ways, the ADA’s protections fall slightly short of the Fourteenth Amendment’s by failing to reach all state entities. The law forbids exclusions or denials from “services, programs, or activities,” and additionally forbids “discrimination by any [public] entity.” 42 U.S.C. § 12132. Some courts have focused only on the first clause, and closely interrogated whether a particular act of discrimination occurred in the context of a “service,” “program,” or “activity.” For example, the Fourth Circuit rejected the argument that government action carried out through an arrest fell within the ambit of these terms. *See Rosen v. Montgomery County*, 121 F.3d 154, 157-58 (4th Cir. 1997). However, the Supreme Court unanimously gave a broad interpretation to the clause, holding (in an opinion authored by Justice Scalia) that participation in prison programs, services, and activities fell under Title II. *See Pa. Dep’t of Corr. v. Yeskey*, 524 U.S. 206, 210 (1998). Notably, the Court relied on constitutional state action cases in reaching its conclusion that the program at issue fell under the ADA. *Id.* (citing cases where the Court applied constitutional provisions applicable only to state action). Since then, courts seem somewhat inclined to adopt this broader interpretation. Kelley B. Harrington, Note, *Policing Reasonable Accommodations for Individuals with Disabilities*, 50 U.C. DAVIS L. REV. 1361, 1370-72 (2017). And before *Yeskey*, the Second and Eleventh Circuits had already held that the

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Legal protections also extend beyond state action to private contexts. Title VII of the Civil Rights Act of 1964 prohibits employment discrimination based on race, sex, religion, and national origin.<sup>255</sup> Title I of the ADA similarly protects certain individuals who claim medical status from employment discrimination.<sup>256</sup> To be sure, the regulations implementing Title I allow employers to offer a justification for excluding a PWD.<sup>257</sup> But similarly, Title VII allows an employer to claim a “bona fide occupational qualification” to justify discrimination based on sex, religion, or national origin (but not race).<sup>258</sup> Finally, while both statutes allow for disparate impact discrimination, proof under Title VII can be harder than under the ADA.<sup>259</sup>

Title III of the ADA is also one of the few examples in which *federal* law prohibits discrimination in public accommodations.<sup>260</sup> The only other

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second clause of the provision, which generally forbids “discrimination by any such entity,” 42 U.S.C. § 12132, “is a catch-all phrase that prohibits all discrimination by a public entity, regardless of the context,” *Bledsoe v. Palm Beach Cty. Soil & Water Conservation Dist.*, 133 F.3d 816, 821-22 (11th Cir. 1998) (quoting *Innovative Health Sys., Inc. v. City of White Plains*, 117 F.3d 37, 44-45 (2d Cir. 1997)).

255. 42 U.S.C. § 2000e-2(a) makes it unlawful for an employer “to fail or refuse to hire or to discharge any individual, or otherwise to discriminate against any individual with respect to his compensation, terms, conditions, or privileges of employment, because of such individual’s race, color, religion, sex, or national origin.”
256. *Id.* § 12112(a) (“No covered entity shall discriminate . . . on the basis of disability in [employment].”).
257. See 29 C.F.R. § 1630.2(m) (2019) (noting that to be a “qualified” employee, an individual with a disability must show that she “satisfies the requisite skill, experience, education and other job-related requirements . . . and, with or without reasonable accommodation, can perform the essential functions of such position”).
258. That is, “where religion, sex, or national origin is a bona fide occupational qualification reasonably necessary to the normal operation of that particular business or enterprise.” 42 U.S.C. § 2000e-2(e).
259. Title VII plaintiffs “must not only amass statistical evidence of . . . disparities, but also establish a ‘robust’ connection between the disparity and a specific policy or practice.” Kimani Paul-Emile, *Blackness as Disability?*, 106 GEO. L.J. 293, 317 (2018) (quoting *Tex. Dep’t of Hous. & Cmty. Affairs v. Inclusive Cmty. Project, Inc.*, 135 S. Ct. 2507, 2523 (2015)). On the other hand, since an ADA plaintiff need not prove intent, they need not amass any additional statistical evidence to show disparate impact. *Id.* at 325.
260. See 42 U.S.C. § 12182(a) (“No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation.”).

categories so protected are race, color, religion, and national origin.<sup>261</sup> Notably, sex is not included.<sup>262</sup>

There are limitations. The remedy structure under portions of the ADA undermines enforcement and incentives for litigation.<sup>263</sup> But those limits should not be overstated. While some commenters suggest that Title I plaintiffs fare worse on appeal than plaintiffs who have brought actions under other civil rights statutes,<sup>264</sup> the data are more complicated: Other data show higher pretrial and trial verdict Title I win rates compared to Title VII cases.<sup>265</sup> Recent data suggest that the ADA amendments Congress passed in 2008 to ease the burden on plaintiffs were effective in some ways.<sup>266</sup> ADA settlement amounts are also comparable to (and on some accounts, exceed) those received by individuals facing discrimination in other categories, especially race discrimination.<sup>267</sup> Studies also show that the vast majority of employers take steps to accommodate disabled employees.<sup>268</sup> Further, Michael Waterstone's

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261. See *id.* § 2000a(a) (“All persons shall be entitled to the full and equal enjoyment of the goods, services, facilities, privileges, advantages, and accommodations of any place of public accommodation, as defined in this section, without discrimination or segregation on the ground of race, color, religion, or national origin.”).

262. See David S. Cohen, *The Stubborn Persistence of Sex Segregation*, COLUM. J. GENDER & L., Jan. 2011, at 51, 115. However, all states provide public accommodations protections based on sex. *State Public Accommodation Laws*, NAT’L CONF. ST. LEGISLATURES (Apr. 8, 2019), <https://perma.cc/65FY-WNWU>.

263. Courts have historically been hostile to employment-based disability claims, for example, offering a constricted interpretation of disability that was overturned in part legislatively. See ADA Amendments Act of 2008 (ADAAA), Pub. L. No. 110-325, § 2, 122 Stat. 3553, 3553-54 (codified at 42 U.S.C. § 12101 note). Title I damages against states are prohibited under the Eleventh Amendment’s sovereign immunity doctrine. See *Bd. of Trs. of the Univ. of Ala. v. Garrett*, 531 U.S. 356, 360 (2001). Title III has been interpreted to only require modifications that are readily achievable (as opposed to those that impose an undue burden), 28 C.F.R. §§ 36.104, 36.304(a) (2019), and does not allow private parties to seek damages, see, e.g., *Molski v. M.J. Cable, Inc.*, 481 F.3d 724, 730 (9th Cir. 2007). It does not permit a government agency to investigate or initiate lawsuits or seek out violations. *BARNARTT & SCOTCH*, *supra* note 2, at 172. Thus, because there are no compensatory damages, there is less interest from lawyers in Title III cases. See *id.*

264. See, e.g., Ruth Colker, *Winning and Losing Under the Americans with Disabilities Act*, 62 OHIO ST. L.J. 239, 242 (2001). Colker carefully nuances her argument through an exhaustive survey of the data. See *id.* at 252-54.

265. Kevin M. Clermont & Stewart J. Schwab, *How Employment Discrimination Plaintiffs Fare in Federal Court*, 1 J. EMPIRICAL LEGAL STUD. 429, 445 tbl.2 (2004).

266. The ADAAA included various changes, most prominently, clarifying the definition of disability. sec. 4(a), § 3, 122 Stat. at 3555-56 (codified at 42 U.S.C. 12102). Despite some reservations, the rate of defendant wins on summary judgment has declined overall since the ADAAA’s passage. See Stephen F. Befort, *An Empirical Examination of Case Outcomes Under the ADA Amendments Act*, 70 WASH. & LEE L. REV. 2027, 2070-71 (2013).

267. Sharona Hoffman, *Settling the Matter: Does Title I of the ADA Work?*, 59 ALA. L. REV. 305, 316-17 (2008).

268. See *id.* at 319-26.

study of ADA Title II and Title III plaintiffs reveals a more optimistic story, placing them on par with other civil rights litigants (with Title II plaintiffs perhaps faring a little bit better).<sup>269</sup>

Finally, it bears noting that for some groups, ADA protections have sometimes proved more versatile than protections arising from other statutes. For transgender individuals in particular, attempts to use sex discrimination protections can be limited—for instance, sex discrimination claims generally do not apply to prisons.<sup>270</sup> Most prominently, the Trump Administration is in the process of rewriting the rules implementing the antidiscrimination protections of the Affordable Care Act (ACA). The rules, as written by the Obama Administration, concluded that the ACA’s sex-based antidiscrimination provisions also prohibited anti-transgender discrimination.<sup>271</sup> However, after a district court expressed skepticism of this interpretation,<sup>272</sup> the Trump Administration began the process of rewriting the rules to exclude transgender individuals.<sup>273</sup> On the other hand, the Administration has endorsed disability-related protections for trans individuals, and at least one plaintiff has argued that since the ACA prohibits disability discrimination, anti-transgender discrimination should be prohibited.<sup>274</sup>

## 2. Content

The previous Subpart focused on how medical status can lead to negative rights against discrimination in public and private contexts (primarily under

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269. Michael Waterstone, *The Untold Story of the Rest of the Americans with Disabilities Act*, 58 VAND. L. REV. 1807, 1836 chart 4 (2005).

270. Barry & Levi, *supra* note 116, at 393.

271. See Nondiscrimination in Health Programs and Activities, 81 Fed. Reg. 31,375, 31,467, 31,471-72 (May 18, 2016) (codified at 45 C.F.R. §§ 92.4, 92.206-92.207 (2019)).

272. See *Franciscan All., Inc. v. Burwell*, 227 F. Supp. 3d 660, 689 (N.D. Tex. 2016).

273. Nondiscrimination in Health and Health Education Programs or Activities, 84 Fed. Reg. 27,846, 27,871 (June 14, 2019). It bears noting that the Supreme Court is currently considering whether gender identity discrimination counts as sex discrimination for the purpose of Title VII. *R.G. & G.R. Harris Funeral Homes, Inc. v. EEOC*, 139 S. Ct. 1599 (2019), *argued*, No. 18-107 (U.S. Oct. 8, 2019). As full disclosure, I filed an amicus brief in this case as counsel of record. Brief of Law & History Professors as Amici Curiae in Support of Respondent Aimee Stephens, *R.G. & G.R. Harris Funeral Homes, Inc. v. EEOC*, No. 18-107 (U.S. July 3, 2019), 2019 WL 3027048. If it holds in the affirmative, such a decision will (in my opinion) render the sex discrimination argument more robust than the one based on the ADA. Nonetheless, affirmative accommodations and medical benefits may still not be forthcoming, as is discussed further in the next Subpart.

274. See Complaint ¶¶ 100-102, *Doe v. United States*, No. 3:16-cv-00640 (S.D. Ill. June 14, 2016); *supra* text accompanying notes 117-22.

the ADA<sup>275</sup>). However, positive rights also routinely flow from medical status claims.<sup>276</sup> Since traditional civil rights protections for race, sex, and the like do not include positive rights, I do not discuss positive rights when comparing those categories to medical status in the previous Subpart.

Statutes such as the ADA do not just prohibit discrimination. They also mandate accommodations. These include making “existing facilities used by employees readily accessible to and usable by individuals with disabilities” and offering “job restructuring, part-time or modified work schedules, reassignment to a vacant position . . . and other similar accommodations,” unless these accommodations impose an undue hardship.<sup>277</sup> Public accommodations must

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275. But perhaps not exclusively. Some could construe the ability to withhold taxes as a negative right as well. *See supra* text accompanying note 113. “[P]ermanently and totally disabled” individuals also obtain tax breaks. 26 U.S.C. § 22 (2018).

276. I am sympathetic to the claim that the distinction between positive and negative rights is difficult to draw. *See, e.g.*, STEPHEN HOLMES & CASS R. SUNSTEIN, *THE COST OF RIGHTS: WHY LIBERTY DEPENDS ON TAXES* 51-52 (1999). For example, requiring an employer to install a ramp can be recast as prohibitive—he cannot exclude an individual by choosing to put in place only a staircase. But the distinction is a pervasive one in law and conforms to the intuition of many jurists and theorists. *See* *Wideman v. Shallowford Cmty. Hosp., Inc.*, 826 F.2d 1030, 1033 (11th Cir. 1987) (“The Constitution is ‘a charter of negative rather than positive liberties.’” (quoting *Jackson v. City of Joliet*, 715 F.2d 1200, 1203 (7th Cir. 1983))); HOLMES & SUNSTEIN, *supra*, at 36; David P. Currie, *Positive and Negative Constitutional Rights*, 53 U. CHI. L. REV. 864, 872-80 (1986) (providing a review of Supreme Court decisions on this issue).

The criticism is particularly relevant in the disability context given the overlap between the concepts of antidiscrimination and accommodations. *See* BAGENSTOS, *supra* note 79, at 56-58; Christine Jolls, *Commentary, Antidiscrimination and Accommodation*, 115 HARV. L. REV. 642, 686-87 (2001); Michael Ashley Stein, *Same Struggle, Different Difference: ADA Accommodations as Antidiscrimination*, 153 U. PA. L. REV. 579, 583 (2004) (“[T]he [ADA] is consistent with other antidiscrimination regulations in remedying historical inequities.”). In my view, while conceptual distinctions exist between positive and negative rights, they may have the same effect—both of them can create costs, and both are necessary for achieving equality. *See* Bradley A. Areheart, *Accommodating Pregnancy*, 67 ALA. L. REV. 1125, 1143 (2016) (observing this in the context of the Pregnancy Discrimination Act); Michael Ashley Stein & Penelope J.S. Stein, *Beyond Disability Civil Rights*, 58 HASTINGS L.J. 1203, 1209 (2007) (“[T]he full inclusion of a socially marginalized group requires invoking both negative and positive rights.”); *see also* Samuel R. Bagenstos, *Disability, Universalism, Social Rights, and Citizenship*, 39 CARDOZO L. REV. 413, 431-32 (2017) (recognizing the contested line between positive and negative rights, but explaining their continued relevance for equality).

277. 42 U.S.C. §§ 12111(9), 12112(b)(5)(A) (2018). I do not mean to overstate the benefits here. Apart from the undue hardship exception, Title I’s “regarded as” prong—which prohibits discrimination against individuals *regarded as* PWD—requires no accommodations. *Id.* §§ 12102(1)(C), 12201(h). Title II’s implementing regulations similarly exempt a public entity’s discrimination on the basis of disability if “the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.” 28 C.F.R. § 35.130(b)(7)(i) (2019); *see also id.* §§ 35.150(a)(3), 35.164; *The American with Disabilities Act: Title II Technical Assistance Manual*, *supra* note 253, at II-3.6100. I cannot here provide an analysis of what

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make “readily achievable” architectural changes, among other modifications, in order to enable access.<sup>278</sup>

Similarly, the FMLA requires most employers to provide twelve weeks of leave during a twelve-month period for a medical condition, though the leave may be unpaid.<sup>279</sup> Furthermore, Social Security provides financial and medical benefits, among others.<sup>280</sup> Medicaid and Medicare are, of course, designed to assist those who are unwell. But, as described above, Medicaid benefits might include housing and work assistance in some states.<sup>281</sup> These rights stand in sharp contrast to race-based affirmative action programs that are not just nonobligatory, but actively frowned upon and limited to certain contexts.<sup>282</sup>

In addition to these positive rights, medical status claims do not require individuals to prove invidious intent and do not allow reverse discrimination claims.<sup>283</sup> Thus, for example, even though she sees them as implicating social

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constitutional standard of scrutiny would be analogous to Title I “undue hardship” or Title II “fundamental alteration” objections, but the language suggests some kind of heightened scrutiny in order for a defendant to escape its obligation to provide reasonable accommodations. Finally, some scholars argue that the accommodations mandate has been severely tamed and describe how disability rights advocates have turned to welfare programs for structural protections. Bagenstos, *supra* note 5, at 6-7.

278. 42 U.S.C. § 12182(b)(2)(A)(iv)-(v).

279. 29 U.S.C. § 2612(a), (c) (2018). The employee can seek—or the employer can require—application of any paid time off that the employer generally provides to some of those twelve weeks. *Id.* § 2612(d)(2).

280. Social Security Disability Insurance (SSDI) is the older program passed in 1956. *See* Diller, *supra* note 128, at 1005. SSDI payments are made when an individual, who is eligible because of her work history, becomes disabled. *See id.* at 1005 n.8. Supplemental Security Income (SSI), created in 1972, *id.* at 1005, provides income that does not depend on work history, but rather on “limited income and resources,” U.S. SOC. SEC. ADMIN., PUB. NO. 64-030, 2019 RED BOOK: A SUMMARY GUIDE TO EMPLOYMENT SUPPORTS FOR PERSONS WITH DISABILITIES UNDER THE SOCIAL SECURITY DISABILITY INSURANCE (SSDI) AND SUPPLEMENTAL SECURITY INCOME (SSI) PROGRAMS 8, 10, 54 (2019), <https://perma.cc/J26N-NC8F>. SSDI beneficiaries become eligible for Medicare, and most SSI beneficiaries for Medicaid. *Medicare Information*, U.S. SOC. SECURITY ADMIN., <https://perma.cc/SB75-9H43> (archived May 24, 2020); *Supplemental Security Income (SSI) Disability & Medicaid Coverage*, HEALTHCARE.GOV, <https://perma.cc/BZC3-E4P3> (archived May 9, 2020). Additionally, in some states an SSI application automatically constitutes an application for food stamps for individuals who live alone. *See* Brad Trenkamp & Michael Wiseman, *The Food Stamp Program and Supplemental Security Income*, 67 SOC. SECURITY BULL., no. 4, 2007, at 71, 74, 76; *Understanding Supplemental Security Income SSI and Other Government Programs—2020 Edition*, U.S. SOC. SECURITY ADMIN., <https://perma.cc/4Z3P-XPG8> (archived May 9, 2020).

281. *See supra* notes 149-50 and accompanying text.

282. Only a “compelling interest . . . justifies consideration of race,” even if the program seeks to ensure that historically disadvantaged groups are represented. *See Fisher v. Univ. of Tex.*, 136 S. Ct. 2198, 2210 (2016).

283. Jon Hyman, *Do You Know? The ADA and Reverse Discrimination*, LEXISNEXIS: LEGAL NEWSROOM (Mar. 1, 2012), <https://perma.cc/ZZ59-Q9JR>; *see also supra* note 259.

rather than medical discourses, health and race expert Kimani Paul-Emile concludes that “the antidiscrimination laws that govern disability are significantly more equality enhancing than those governing race.”<sup>284</sup>

### 3. Comparing nonprotected categories

When compared to nonprotected categories, such as poverty, homelessness, or unemployment, the power of medicine is even starker. For instance, individuals with those nonprotected vulnerabilities often enjoy positive rights in the form of government benefits but rarely enjoy antidiscrimination protections. Thus, although Social Security’s temporary unemployment benefits predated disability benefits by twenty-one years,<sup>285</sup> evidence suggests that unemployed individuals experience job discrimination.<sup>286</sup> However, only two states plus the District of Columbia have enacted antidiscrimination protections.<sup>287</sup>

Further, the positive rights that are seen to arise from medical status are more robust than those arising from poverty more generally. Compare Medicaid with Social Security disability benefits, for example. Like earlier state efforts to provide health care to those in poverty, Medicaid was “a stigmatized welfare program,” with its recipients treated worse than those on Medicare.<sup>288</sup> Medicaid’s status remains precarious: States have recently added additional obstacles such as work requirements.<sup>289</sup> Unlike Medicaid, Social Security

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284. Paul-Emile, *supra* note 259, at 328, 331-33. She says this even as she acknowledges that “discrimination against persons with disabilities is not entitled to increased constitutional scrutiny under equal protection doctrine.” *Id.* at 332; *see also* Karlan & Rutherglen, *supra* note 13, at 2-3 (suggesting that ADA protections are robust because of the “accommodations” they provide, observing that “how the law defines discrimination makes a big difference in the kinds of remedies it provides,” and noting that the ADA, “the newest comprehensive federal antidiscrimination statute, offers a fundamentally different approach to—and a fundamentally different remedy for—invidious discrimination than prior legal regimes”).

285. Social Security Act of 1935, ch. 271, §§ 301-303, 49 Stat. 620, 626-27 (codified as amended at 42 U.S.C. §§ 501-503 (2018)); *see also* Social Security Act Amendments of 1956, ch. 880, § 103, 70 Stat. 807, 815-24 (codified as amended in scattered sections of 26 and 42 U.S.C.).

286. *Discrimination Against the Unemployed*, NAT’L CONF. ST. LEGISLATURES, <https://perma.cc/95SU-Y683> (archived May 9, 2020).

287. *Id.*

288. *See* Beatrix Hoffman, “Don’t Scream Alone”: The Health Care Activism of Poor Americans in the 1970s, in *PATIENTS AS POLICY ACTORS*, *supra* note 193, at 132, 134. Though, as will be discussed below, it is notable that ill health is one of the few harms that legislators are willing to somewhat alleviate for the poor.

289. *See* Phil Galewitz, *Despite U.S. Court’s Ruling, Medicaid Work Requirements Advance in Other States*, WASH. POST (July 9, 2018, 1:38 PM PDT), <https://perma.cc/2368-76TH>; Phil Galewitz, *Verma Attacks Critics of Medicaid Work Requirement, Pushes for Tighter Eligibility*, KAISER HEALTH NEWS (Nov. 12, 2019), <https://perma.cc/9CPR-G4R9>.



benefits are triggered by medical status rather than poverty.<sup>290</sup> As Matthew Diller recounts, this medical framing bolstered the case for Social Security. He notes that Social Security programs, comparatively at least, do not involve “the kind of close involvement with [recipients’] lives and individual circumstances that had been characteristic of” welfare-based predecessors of Medicaid.<sup>291</sup>

More generally, it is notable that problems that are framed through medical discourse generally remain insulated from political tides. Even in the 1990s, “when overall confidence in the federal government remain[ed] rather limited,” scholars still found a “growth in public support for federal action in health care.”<sup>292</sup> Medical benefit programs—even ones somewhat tainted by their association with poverty, like Medicaid—can remain relatively unscathed. The benefits rollback of 1996 largely left disability benefits untouched,<sup>293</sup> and the de facto repeal of the ACA mandate in 2017 left Medicaid expansion and ACA subsidies intact.<sup>294</sup> More recently, legislation to extend Child Health Insurance Program Funding by six years passed in the Republican-controlled Senate and was signed into law by President Trump.<sup>295</sup> Recent work similarly observes that “[m]ental health and chronic pain claims have now become virtually the only avenues available for access to relatively stable benefits.”<sup>296</sup> Medical civil rights are weathering today’s storms better than their counterparts.

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290. *See supra* note 66.

291. Diller, *supra* note 211, at 439 (quoting STAFF OF S. COMM. ON FIN., 95TH CONG., THE SUPPLEMENTAL SECURITY INCOME PROGRAM 13 (Comm. Print 1977)). Lance Liebman similarly observes that “we feel that medical disability provides a more compelling occasion for income protection than changes in individual capacity to work, when both events have the effect of ending the opportunity to earn[.]” *See* Liebman, *supra* note 188, at 843.

292. Mark Schlesinger & Tae-ku Lee, *Is Health Care Different? Popular Support of Federal Health and Social Policies*, 18 J. HEALTH POL. POL’Y & L. 551, 617 (1993).

293. *See* Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Pub. L. No. 104-193, 110 Stat. 2105 (codified in scattered sections of the U.S. Code). As discussed above, there were some rollbacks for certain groups of individuals that were far more limited than those otherwise contemplated. *See supra* note 139 and accompanying text; *infra* notes 327-32 and accompanying text.

294. *See* Jayne O’Donnell & Herb Jackson, *Obamacare Is Hardly Repealed, but Some May Have More and Costlier Insurance Choices*, USA TODAY (updated Dec. 21, 2017, 5:40 PM ET), <https://perma.cc/DH3Y-FVJZ>.

295. Tricia Brooks, *CHIP Funding Has Been Extended, What’s Next for Children’s Health Coverage?*, HEALTH AFF.: BLOG (Jan. 30, 2018), <https://perma.cc/KZE3-PQTA>.

296. Helena Hansen et al., *Pathologizing Poverty: New Forms of Diagnosis, Disability, and Structural Stigma Under Welfare Reform*, 103 SOC. SCI. & MED. 76, 77 (2014); *see also* Henry J. Whittle et al., “The Land of the Sick and the Land of the Healthy”: Disability, Bureaucracy, and Stigma Among People Living with Poverty and Chronic Illness in the United States, 190 SOC. SCI. & MED. 181, 182 (2017) (“[F]ederal disability benefits [are] the last form of substantial government cash assistance available to many indigent US adults . . .”).

B. Normative Cachet

Even when no formal rights are available, persuading an audience that a burden constitutes a medical status brings a certain normative cachet. Admittedly, given the varying attitudes to different kinds of medical status among different groups, we treat different kinds of medical harm differently. Illnesses—such as HIV or alcoholism—are sometimes blamed on their victims, as even medicalization cannot overcome anti-sex and anti-drinking sentiment.<sup>297</sup> But as a general matter, medicalizing a status shifts moral blame for the disadvantage to bad luck or social discrimination, and treats the victim as deserving of aid.<sup>298</sup> This Subpart looks to limited survey evidence and actual policy enactments to make this point.

1. Normative framework

My primary claim is a descriptive one about the normative intuition individuals hold about health and responsibility. But to make it comprehensible, I must briefly outline the underlying normative framework.

Health policy and bioethics scholarship have wrestled at some length over the normative question whether individuals should be blamed for their own medical disadvantage on the grounds of morality and efficiency.<sup>299</sup> This question is different from whether individuals *cause* the harm they face—a two-year-old might knock over a vase, but we are unlikely to hold her morally culpable for the act. Moral responsibility is therefore not the same as causal responsibility.<sup>300</sup>

The applicable moral framework is primarily luck egalitarianism. On this account, individuals may be penalized for harmful choices for which they are morally responsible; otherwise, they deserve help. As Allison Hoffman pithily explains, if a person has reason to know that something is medically harmful,

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297. See, e.g., *Powell v. Texas*, 392 U.S. 514, 535 (1968) (plurality opinion) (refusing to hold that alcoholics completely lack control over their behavior which would thus render them not responsible for their behavior); Jack L. Powell et al., *Adding Insult to Injury: Blaming Persons with HIV Disease*, 2 AIDS & BEHAV. 307, 314-15 (1998).

298. Depending on what is blamed for a particular moral status—bad luck, societal discrimination, or individual choices—the legal response is different. For further discussion, see Craig Konnoth, *The Normative Bases of Medical Civil Rights*, in *DISABILITY, HEALTH, LAW, AND BIOETHICS* 200, 201 (I. Glenn Cohen et al. eds., 2020).

299. See E. Feiring, *Lifestyle, Responsibility and Justice*, 34 J. MED. ETHICS 33, 34-36 (2008). See generally SHLOMI SEGALL, *HEALTH, LUCK, AND JUSTICE* (2010) (discussing luck egalitarianism accounts of justice in health care).

300. See Phoebe Friesen, Extended Essay, *Personal Responsibility Within Health Policy: Unethical and Ineffective*, 44 J. MED. ETHICS 53, 54 (2018) (“Moral responsibility can be thought of as a subset of causal responsibility . . . but not all cases of causal responsibility involve moral responsibility . . .”).

can control the triggers that lead to the harm, and opts to pull those triggers, they are morally responsible for the bad choice leading to harm or illness, and society lacks the obligation to pay for care.<sup>301</sup>

This approach presents complications in practice. Even medical authorities often know little about the causes of medical harm, it is often unclear whether a known cause is under an individual's control, and whether she knowingly assumed the risk.<sup>302</sup> For example, research shows that the health of middle-aged women is affected by the expectations they believe society has about them.<sup>303</sup> But how strong is the causal link? Should they be expected to know about this relationship? And to what degree do they have control over the social expectations that surround them? In a given situation under luck egalitarianism, then, it is unclear whether an individual is morally at fault for medical affliction.

I do not seek to enter the *normative* debate.<sup>304</sup> But as a *descriptive* matter, law and society treat most medical disadvantage as arising from bad luck or societal discrimination rather than from bad individual choices.<sup>305</sup> Therefore, medical disadvantage triggers greater social assistance.

## 2. Surveys

The best evidence that society sees medical affliction as the result of misfortune or social discrimination would be surveys that show how individuals rank-order moral responsibility among various illness-causing factors. But such clear evidence is lacking.

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301. See Allison K. Hoffman, *Three Models of Health Insurance: The Conceptual Pluralism of the Patient Protection and Affordable Care Act*, 159 U. PA. L. REV. 1873, 1925-29 (2011).

302. *Id.* at 1929.

303. See Sharon Bond, *Health Behaviors of Midlife Women Formed More by Social Expectations than Personal Responsibility*, 55 J. MIDWIFERY & WOMEN'S HEALTH 596, 597 (2010) (reviewing Kathleen Smith-DiJulio et al., *The Shaping of Midlife Women's Views of Health and Health Behaviors*, 20 QUALITATIVE HEALTH RES. 966 (2010)).

304. For ongoing normative discussion and an alternative framework, see generally JESSICA L. ROBERTS & ELIZABETH WEEKS, *HEALTHISM: HEALTH-STATUS DISCRIMINATION AND THE LAW* (2018) (offering a discussion for when and how health-related discrimination is appropriate). Normative debates in the obesity context that examine whether obese individuals should be held responsible for any health concerns that arise (and if so, when) are particularly interesting. See, e.g., M. Gregg Bloche, *Essay, Obesity and the Struggle Within Ourselves*, 93 GEO. L.J. 1335, 1337-38 (2005); Lindsay F. Wiley, *Shame, Blame, and the Emerging Law of Obesity Control*, 47 U.C. DAVIS L. REV. 121, 126-30 (2013) (discussing the personal responsibility approach and its problems).

305. Different groups might have different opinions about responsibility. Cf. Davidson et al., *supra* note 238, at 2174-76 (discussing how different demographic groups have different views on social determinants). I assume that what ends up embedded in the law represents some broader social attitude.

Existing studies show that respondents assign moral responsibility for illness *both* to individuals and to fate.<sup>306</sup> In allocating resources, severity of illness is a more important factor than personal responsibility.<sup>307</sup> And today, a majority of Americans believe that the government is responsible for providing healthcare.<sup>308</sup> This would be unlikely if they saw personal responsibility as the key factor involved in illness. Further, even political conservatives (who tend to assign a greater role for individual responsibility) “tend[] to articulate a boundary for individual responsibility at genetic factors, environmental contaminants, and school environments, over which it [is] acknowledged that the individual ha[s] little direct control.”<sup>309</sup>

That said, the evidence is not conclusive. Individuals might seek to provide universal health coverage simply out of charity, even if they hold sick individuals morally responsible. Further, as researchers note, survey instruments present inherent problems: Individual attributions of responsibility change not just based on the illness, but on how questions are framed, whether they pertain to groups or individuals, whether they refer to specific incidents or trends over time, and the like.<sup>310</sup> Given these shortcomings, one must be careful before drawing conclusions about the normative valence of medical status from this data.

Nonetheless, there are two other relevant pieces of evidence. First, even if it is hard to assess the normative valence individuals assign to medical status on its *own* terms, the limited research that places it in a *comparative* perspective is enlightening. Individuals are held less responsible for medical harm than other kinds of disadvantage: As one review of the empirical literature noted, “people tend to think of diseases as conditions for which individuals do not bear primary responsibility, afflictions of which the sufferer is at least to some extent a victim.”<sup>311</sup> This attitude was definitional—when people believed that a

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306. See, e.g., Bethany Keeley et al., *Functions of Health Fatalism: Fatalistic Talk as Face Saving, Uncertainty Management, Stress Relief and Sense Making*, 31 SOC. HEALTH & ILLNESS 734, 742-43 (2009).

307. See Richard Edlin et al., *Public Preferences for Responsibility Versus Public Preferences for Reducing Inequalities*, 21 HEALTH ECON. 1416, 1423 (2012). Other evidence suggests that stigma and bias influence perceptions of responsibility. See Peter A. Ubel, *Transplantation in Alcoholics: Separating Prognosis and Responsibility from Social Biases*, 3 LIVER TRANSPLANTATION & SURGERY 343, 345-46 (1997) (discussing how biases interact with perceptions of responsibility as well as prognosis).

308. See Pew Research Ctr., September 2018 Political Survey: Final Topline (2018), <https://perma.cc/76QG-SFDR>.

309. Lundell et al., *supra* note 237, at 1122-23.

310. *Id.* at 1118.

311. Kari A.O. Tikkinen et al., *What Is a Disease? Perspectives of the Public, Health Professionals and Legislators*, BMJ OPEN 5 (Dec. 2012), <https://perma.cc/7SFG-QTRF>. Studies show that “perceived preventability” and, thus, responsibility “may depend on *who specifically* is considering *what particular illness*.” Todd Lucas et al., *Individuals and Illnesses as Sources of Perceived Preventability*, 14 PSYCHOL. HEALTH & MED. 322, 323 (2009).

condition, such as addiction, was caused by “moral failing, bad habit or retribution for bad behaviour (all related perspectives),” they were less likely to consider it a disease.<sup>312</sup>

Second, medical harm is more often than not used as an excuse to skip work and school. For instance, CareerBuilder’s 2017 survey of work absenteeism found that in the year preceding the survey, between 35% and 40% of workers had called in sick when they were not.<sup>313</sup> While employees and students might choose to use sickness simply because it is seen as a more serious or contagious harm, it is also reasonable to conclude from such data that employees see illness as a harm for which they will not be seen as responsible.<sup>314</sup> Thus, what evidence exists suggests that as a general matter, individuals may be held less responsible for medical harm.

### 3. Health policy and bad luck

Unlike surveys, in which one can simply ask individuals where they assign moral responsibility for medical disadvantage, it is harder to assess whether a particular policy does so. Consider employer wellness programs. The ACA allows employers to give health insurance discounts to individuals who, for example, join and attend a gym—effectively charging individuals who do *not* join a gym more for health insurance.<sup>315</sup> Hoffman suggests that these programs treat individuals as morally culpable for failing to take care of their own health.<sup>316</sup> But this is debatable. Another way to look at these programs is as attempts to change the social conditions in which people live, in order to produce healthy behaviors.

Take the example of an individual who lives in a food desert—an area without many available food options. We are likely to agree that social conditions are heavily responsible for causing any unhealthy eating behaviors

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312. Tikkinen et al., *supra* note 311, at 5.

313. Press Release, CareerBuilder, Increased Number of Workers Calling In Sick When They Aren’t, Finds CareerBuilder’s Annual Survey (Nov. 16, 2017), <https://perma.cc/B7MB-ZQ67>.

314. In the school context, researchers seem to focus more squarely on the actual rather than the claimed causes for absenteeism. *See, e.g.*, Brian A. Jacob & Kelly Lovett, *Chronic Absenteeism: An Old Problem in Search of New Answers*, BROOKINGS (July 27, 2017), <https://perma.cc/H2FG-TPVW> (noting that school absenteeism varies by age). Nonetheless, the law treats illness as a good reason to miss school. *See, e.g.*, CAL. EDUC. CODE § 48205(a) (West 2019) (listing different kinds of health-related excuses).

315. *See* 42 U.S.C. § 300gg-4(b), (j)(1)(A) (2018).

316. *See* Hoffman, *supra* note 301, at 1880, 1922-23.

on her part.<sup>317</sup> Similarly, if society treats people who go to the gym as favorably as those who do not, then (one might argue) it is *society* that fails to create the conditions that encourage people to go to the gym. Thus, just as building grocery stores in food deserts would encourage individuals to eat healthily, one might see the ACA wellness discounts for gym attendance as transforming social practices.<sup>318</sup> Because individual behavior is so enmeshed with and influenced by the social environment in which the behavior occurs, discerning whether a particular policy seeks to assign blame or to alter these social conditions is fraught with challenges.<sup>319</sup>

To be clear, my claim here is not that Hoffman is incorrect—indeed, I agree with her assessment of wellness programs—but rather, that assigning blame is fundamentally an expressive, socially contingent act. Determining whether a particular policy assigns blame requires us to draw on social norms to interpret it.

These norms include looking at statements by legislators: If a presidential candidate who emphasizes “personal responsibility” as a healthcare solution incorporates wellness programs into that platform,<sup>320</sup> some might conclude that such programs are meant to advance personal responsibility.<sup>321</sup> Other social practices besides contemporaneous statements are similarly expressive: Imprisoning alcoholics would send a strong blame-assigning message given the connotations of imprisonment.

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317. See James F. Sallis & Karen Glanz, *Physical Activity and Food Environments: Solutions to the Obesity Epidemic*, 87 MILBANK Q. 123, 124 (2009) (noting that the explanation for the obesity epidemic “must lie in broader environmental, policy, and societal changes”).

318. Either qualifies as a form of choice architecture under the rubric offered in RICHARD H. THALER & CASS R. SUNSTEIN, *NUDGE: IMPROVING DECISIONS ABOUT HEALTH, WEALTH, AND HAPPINESS* 3–6 (2008).

319. In general, it is sometimes hard to discern from the face of many policies whether they seek to assign blame—and if so, to whom—without contemporaneous statements. For example, the ACA requires insurance entities sold on exchanges to offer certain so-called “essential health benefits” (EHBs). 42 U.S.C. § 18022. On one hand, this might reflect a social constructivist model—an individual’s ill health is affected by the deficiencies in socially available insurance policies. The EHB obligation might be seen as assigning moral responsibility to insurance companies for their inferior policies, and demanding change. On the other hand, the policy might also be seen as an attempt to improve health for everyone, without taking any position on who is morally to blame. Making EHBs available to everyone might satisfy what some believe is a human right, or efficient utilization of resources. One might provide those benefits even if an individual behaves irresponsibly.

320. See, e.g., John McCain, *McCain’s Approach to Health-Care Reform*, CBS NEWS (May 1, 2008, 11:08 AM), <https://perma.cc/M3D8-M4D2>.

321. Cf. MICHAEL MOORE, *PLACING BLAME: A GENERAL THEORY OF THE CRIMINAL LAW* 84 (1997) (noting that punishment is, in part, “symbolic blaming”). To the extent the wellness programs in the ACA can be seen as an indirect way to punish individuals for bad choices, they point to the belief that individuals are morally responsible for those choices.

Scholars appear to claim that policies that place the risk of medical disadvantage on the individual rather than the health system are such expressive, social practices. They express a desire to hold the individual morally responsible, to blame her for her medical disadvantage. For example, in explaining how the ACA assigns moral responsibility to the insured, Hoffman points to how the law effectively allows insurance rate variation based on smoking and wellness program participation.<sup>322</sup> Similarly, Medicaid responsibility programs have increased in the last few years. On pain of having benefits drastically cut, Indiana beneficiaries must contribute to a “Personal Wellness and Responsibility Account.”<sup>323</sup> West Virginia beneficiaries must sign a personal responsibility agreement that, *inter alia*, requires them to keep appointments and take prescribed medication in order to qualify for enhanced benefits.<sup>324</sup> And politicians like Paul Ryan, Mike Pence, and even Barack Obama, have touted the importance of personal responsibility to avoid medical harm.<sup>325</sup>

If shifting risk to the medically disadvantaged expresses blame—which I believe is a fair assumption—then shifting risk *away* from them expresses

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322. Hoffman, *supra* note 301, at 1880; *see also* 42 U.S.C. §§ 300gg(a)(1)(A)(iv), 300gg-4(j)(1)(A). The ACA also allows premium variation based on age and geography. 42 U.S.C. § 300gg(a)(1)(A)(ii)-(iii), (a)(2). Hoffman suggests (with caveats) that the ACA could be read to blame individuals for choices they make as to where to live, “although perhaps choice is less evident in this instance.” Hoffman, *supra* note 301, at 1934. I think it is far more likely that the geography-based premium variations are a pragmatic recognition that, as with age, costs vary based on geography and are an attempt to be fair to insurers. Finally, Hoffman also points out that the ACA cuts insurance-purchase subsidies for those who smoke. *Id.* at 1937. However, evidence suggests that smoking is an outlier—people attach far more responsibility to cancer caused by smoking cancer than other kinds of cancer for example. *See* Lucas et al., *supra* note 311, at 323. Using smoking policy to draw conclusions about health responsibility in general is precarious.

323. Dhruv Khullar, *You’re Sick. Whose Fault Is That?*, N.Y. TIMES: UPSHOT (Jan. 10, 2018), <https://perma.cc/9C2N-HEXK>. If Indiana residents “fail to pay, they may have benefits cut or lose coverage entirely for six months.” *Id.* Additionally, “[t]hey must also make co-payments for certain services, and pay a fee if they use the emergency department unnecessarily.” *Id.*

324. *Id.*

325. Allison K. Hoffman, *The Unhealthy Return to Individual Responsibility in Health Policy*, BILL OF HEALTH (Jan. 16, 2017), <https://perma.cc/LMA2-EFWM> (“[A] large percentage of heart disease, stroke, and type 2 diabetes, as well as many cancers, could be prevented if Americans would stop smoking, start eating better, and start exercising.” (quoting a summary of Paul Ryan’s proposed health care plan)); Khullar, *supra* note 323 (“Vice President Mike Pence has argued for ‘bringing freedom and individual responsibility back to American health care.’”); *id.* (“Barack Obama said, ‘We’ve got to have the American people doing something about their own care.’”).

exoneration. And it is notable how much the law insulates individuals from health risk.<sup>326</sup>

First, compare how the law treats health risk relative to other kinds of risk. As I discuss above, problems framed as medical are relatively insulated from political tides. The key hallmarks of the major welfare rollbacks of 1996 created block grants and raised qualification requirements for cash assistance, thus reducing those rolls in the following decades.<sup>327</sup> It eliminated most welfare benefits for noncitizens<sup>328</sup> and drastically increased qualifications for the food stamps program.<sup>329</sup> Relative to this, protection for medical harms remained intact, primarily involving slight changes to the definition of child disability and the exclusion of certain conditions.<sup>330</sup> An earlier bill, by contrast, foregrounded cuts to disability insurance, seeking cuts as high as 25% to SSI income for children.<sup>331</sup> This bill did not become law—in part because of a presidential veto.<sup>332</sup>

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326. Relative to other developed countries, however, the United States probably does place a greater emphasis on responsibility. See Harald Thomas Schmidt, *Just Health Responsibility: A Comparative Analysis Focussing on the Role of Individual Behaviour in Relation to Cancer and Weight-Control Policy in German and US Health Care Systems* 52-53 (Mar. 2012) (unpublished Ph.D. dissertation, London School of Economics), <https://perma.cc/97S9-WH42>.

327. Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Pub. L. No. 104-193, sec. 103(a)(1), §§ 403-404, 407-408, 110 Stat. 2105, 2115-28, 2129-42 (codified as amended at 42 U.S.C. §§ 603-604, 607-608); IFE FLOYD, CTR. ON BUDGET & POLICY PRIORITIES, CASH ASSISTANCE SHOULD REACH MILLIONS MORE FAMILIES 1 (2020), <https://perma.cc/6EWB-XF3M> (“In 2018, for every 100 families in poverty, only 22 received direct financial assistance from [Temporary Assistance for Needy Families]—down from 68 families in 1996. This ‘TANF-to-poverty ratio’ (TPR) is the lowest in the program’s history.” (citation omitted)); Lisa Schaefer, *The 1996 Personal Responsibility and Work Opportunity Reconciliation Act in the US*, CTR. FOR PUB. IMPACT (Oct. 30, 2017), <https://perma.cc/C45X-ATCS> (noting tightening of eligibility criteria).

328. Personal Responsibility and Work Opportunity Reconciliation Act § 401, 110 Stat. at 2261-62 (codified as amended at 8 U.S.C. § 1611 (2018)).

329. See *id.* §§ 814-15, 820-821, 823, 110 Stat. at 2315-17, 2321-22 (codified as amended at 7 U.S.C. § 2015 (2018)).

330. *Id.* § 211, 110 Stat. at 2188-90 (codified as amended at 42 U.S.C. § 1382c(a)(3)); see also Sage & Laurin, *supra* note 187, at 576 (“This medical model for aiding the poor through federal entitlements coincided with a backlash against welfare dependency and cash assistance. Competing narratives of medical innocents, on one hand, and ‘predators’ and ‘welfare queens,’ on the other, achieved rough equipoise in the welfare reforms of the mid-1990s. Federal cash welfare was drastically curtailed . . . . Medicaid, by contrast, emerged intact . . .”).

331. *The Personal Responsibility and Work Opportunity Reconciliation Act of 1996*, OFF. ASSISTANT SECRETARY FOR PLAN. & EVALUATION (Sept. 1, 1996), <https://perma.cc/3SHD-EMRD> (discussing previous failed legislation).

332. *Id.* I am not alone in making the observation that disability programs are more protected, though other commenters have been more critical of this phenomenon. See, e.g., Diller, *supra* note 211, at 365 (“[T]he emphasis of our social welfare system on  
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Further, even on its own terms, health policy does more to insulate individuals from risk than expose them to risk. Thus, the ACA “pushed the needle toward [social] solidarity” by insulating more individuals from risk than before.<sup>333</sup> It strengthened blanket prohibitions on insurance companies varying rates based on medical status.<sup>334</sup> Provisions related to smoking and wellness programs, which Hoffman and others point to, are limited exceptions and even there the ACA limits risk shifting by restricting the extent of rate or discount variation plans can offer.<sup>335</sup>

The degree to which laws like the ACA insulate individuals from medical risk becomes all the more apparent by comparing them to proposals that *do* shift responsibility to individuals. Former Republican Senate Majority Leader (and doctor) Bill Frist, for example, recommended a “consumer-driven” system, that “gives people a greater stake in, and more responsibility for, their own health care.”<sup>336</sup> In this way, Frist and others argue that consumers are morally responsible for their own healthcare.

Such plans include, for example, catastrophic plans coupled with tax-advantaged medical savings accounts.<sup>337</sup> By contrast, the ACA imposes limits on out-of-pocket expenses.<sup>338</sup> Even while touting the importance of personal responsibility,<sup>339</sup> President Obama pointed only to the margins. The “self-responsibility” he identifies in the ACA resides primarily in a subset of provisions that encourage people to “stop smoking, lose weight, get exercise, [and] get regular checkups,”<sup>340</sup> which are few in number when read against the

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disability distracts attention from other causes of chronic unemployment that are not explicitly recognized as a basis for benefit receipt, such as lack of job skills, lack of education, and long-term labor market conditions.”).

333. Abbe R. Gluck & Nicole Huberfeld, *What Is Federalism in Healthcare For?*, 70 STAN. L. REV. 1689, 1698 (2018).

334. 42 U.S.C. § 300gg(a)(1).

335. *Id.* §§ 300gg(a)(1)(A)(iv), 300gg-4(b)(2)(B), (j).

336. William H. Frist, Shattuck Lecture, *Health Care in the 21st Century*, 352 NEW ENG. J. MED. 267, 268-69 (2005).

337. REGINA E. HERZLINGER, MARKET-DRIVEN HEALTH CARE: WHO WINS, WHO LOSES IN THE TRANSFORMATION OF AMERICA’S LARGEST SERVICE INDUSTRY 253, 256-57 (1997).

338. *See* 42 U.S.C. § 18022(c).

339. Nancy Snyderman, *Obama on Health Care Policy: “No Free Lunch,”* NBC NEWS (July 16, 2009, 9:04 AM ET), <https://perma.cc/JW5W-W4V2>.

340. *Id.* One might also argue that the ACA’s penalty for failing to buy insurance at the outset, the so-called individual mandate, places blame on the individual. But on my reading, and more importantly, the Supreme Court’s, that is precisely what the mandate does not do. The mandate raises revenue and incentivizes individuals to buy insurance, but it is not a “penalty.” *Nat’l Fed’n of Indep. Bus. v. Sebelius*, 567 U.S. 519, 566 (2012). Therefore, it should be read as an attempt to alter the social conditions that surround individuals and influence their behavior, rather than as an attempt to assign blame. *Id.* at 567 (noting that the mandate seeks to influence individual behavior).

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vast changes to healthcare provision the Act seeks to put in place. Indeed, in *limiting* the medical risk individuals must bear, legislative history places greater blame on forces other than the individual—such as bad luck. Congressman Steny Hoyer, for example, applauded early efforts toward the ACA because individuals “will [n]ever again suffer financial disaster because they had the bad luck to get sick.”<sup>341</sup>

This luck-blaming attitude is of a piece with past insurance programs. Medicare proponents explained that the elderly “through no fault of their own . . . had lower earning capacity and higher medical expenses than any other adult age group.”<sup>342</sup> A few decades before that, those who sought to extend Social Security benefits to certain people with disabilities explained their rationale: “[O]ne day [a worker] suffers a severe heart attack or is instantaneously mashed up in the mines” and he is “incapacitated through no fault of [his] own.”<sup>343</sup> Indeed, because “it is impossible to anticipate such a calamity,” disability is a “hardship even greater than the loss of earnings from forced retirement because of age.”<sup>344</sup>

While health policy mostly blames bad luck rather than the individual, there are exceptions.<sup>345</sup> The ACA’s smoking and wellness provisions are one

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Some states have argued that the repeal of the penalties associated with the mandate in 2017, *see supra* note 294 and accompanying text, has rendered the rest of the ACA unconstitutional. The case is pending before the Supreme Court. *Texas v. United States*, 945 F.3d 355 (5th Cir. 2019), *reh’g en banc denied*, 949 F.3d 182, *cert. granted*, 140 S. Ct. 1262 (2020).

341. Press Release, Rep. Steny Hoyer, Hoyer Gives Remarks on the 43rd Anniversary of Medicare (July 2, 2009), <https://perma.cc/7HGB-A4LQ>.

342. THEODORE R. MARMOR, *THE POLITICS OF MEDICARE* 11 (2d ed. 2000).

343. 96 CONG. REC. 12,775 (1950) (statement of Rep. Perkins); *see also id.* at 11,936 (statement of Rep. Biemiller) (stating that “people who have worked . . . but who through no fault of their own are now destitute” play “a tragic role in our society”); *id.* at 12,141 (statement of Rep. Lynch) (noting that disability strikes “without advance warning” and thus presents a stronger case for benefits than retirement).

344. *Id.* at 11,836 (statement of Rep. McCormack).

345. A special note on mental illness is called for. This term includes “psychological disorders, such as mood, anxiety, thought, and personality disorders (e.g., depression, obsessive-compulsive disorder, schizophrenia, borderline personality disorder), and excludes those impairments commonly understood as more physical or organic than psychiatric, including learning disabilities.” Elizabeth F. Emens, *The Sympathetic Discriminator: Mental Illness, Hedonic Costs, and the ADA*, 94 GEO. L.J. 399, 403–04 (2006). Mental illness is often highly stigmatized as a social matter (though in most cases, the law treats it on par with physical illnesses). Part of the issue is that mental illness is often not *seen* as a medical problem. As law professor and psychiatrist Gregg Bloche notes, “[b]efore 1980, psychiatrists lacked generally accepted standards for the diagnosis of mental illnesses . . . . The result was skepticism about what psychiatry had to offer—and reluctance by health insurers to pay for it.” BLOCHE, *supra* note 46, at 67; *see also* Michael E. Waterstone & Michael Ashley Stein, *Disabling Prejudice*, 102 NW. U. L. REV. 1351, 1364 (2008) (noting that some argue that mental illnesses are not “legitimate

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example. While many legislators blame bad luck for most medical disadvantage, some (such as Frist) tend to place greater focus on individual choices.<sup>346</sup> In those cases, compromise requires exceptions in the statute that place risk for certain kinds of medical disadvantage on individuals. For example, opponents of Social Security disability benefits placed the onus of recovery on the individual and noted that the “availability of cash benefits actually undermines the will to recovery.”<sup>347</sup> Thus, much like the ACA, Social Security lets individuals bear the risk for certain conditions for which they are seen as more morally responsible, such as alcoholism or drug addiction.<sup>348</sup> Further, “[i]n order to receive benefits, [a] claimant must follow treatment prescribed by his [or her] medical sources(s).”<sup>349</sup> But these are *exceptions* to the general rule that insulates those with medical status from risk and treats medical disadvantage as the result of bad luck. Health law and policy, in general, has over time increasingly reflected an approach that insulates individuals from, and therefore communicates a reluctance to blame individuals for, bad health.

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disabilities (for example, viewing a person with severe depression as ‘blue’ rather than as experiencing a psychiatric impairment”). See generally THOMAS S. SZASZ, *THE MYTH OF MENTAL ILLNESS: FOUNDATIONS OF A THEORY OF PERSONAL CONDUCT* (rev. ed. 1974). This discredited view of mental illness has slowly changed, with the profession seeking to adopt more exact categories backed by medical studies. BLOCHE, *supra* note 46, at 67-68.

What is notable, though, is that those who seek to discredit mental illness do not do so by claiming that mental illness—qua illness—does not deserve protection. Rather, in some cases, they simply seek to deny that mental illness is an illness at all—it “miscasts personal challenge as pathological process.” BLOCHE, *supra* note 46, at 68. The fact that discrediting mental illness requires detractors to claim that it is not an illness in the first place is suggestive of the power of the illness label. And in order to legitimate mental illness, many advocates seek to situate it in a physical etiology—to double down on the illness label—which, empirical work shows, imbues mental illness with legitimacy. See Jack K. Martin et al., *Of Fear and Loathing: The Role of “Disturbing Behavior,” Labels, and Causal Attributions in Shaping Personal Attitudes Toward Persons with Mental Illness*, 41 J. HEALTH & SOC. BEHAV. 208, 210 (2000) (“[M]ental health advocacy groups joined forces with providers in the medical sector to argue for the ‘medicalization’ of mental health.”); see also ROSE, *supra* note 210, at 194, 199-203, 207-08 (providing an overview of this phenomenon); *supra* notes 122-24 and accompanying text (seeking to situate gender dysphoria within a physical etiology).

346. See *supra* text accompanying notes 336-37.

347. 95 CONG. REC. 13,970 (1949) (statement of Rep. Jenkins).

348. See Contract with America Advancement Act of 1996, Pub. L. No. 104-121, § 105(a)(1), 110 Stat. 847, 852 (codified as amended at 42 U.S.C. § 423(d)(2)(C) (2018)).

349. RICHARD C. RUSKELL, *SOCIAL SECURITY DISABILITY CLAIMS HANDBOOK* § 2:45 (West 2019).

#### 4. Health policy and social circumstances

Apart from bad luck, medical policy also appears to communicate that the blame for medical disadvantage belongs to third parties, social attitudes and barriers, and discrimination. Section 1557 of the ACA, for example, prohibits discrimination based on race, disability, and sex, among other conditions, in healthcare settings.<sup>350</sup> This approach has its apogee in the ADA, which is explicitly designed to ameliorate the burdens society imposes on certain kinds of medical status.

On the account of the disability activists whose work helped pass the ADA, many of the burdens of disability come from how society *responds* to a physical trait rather than from the trait itself.<sup>351</sup> Environmental characteristics such as the choice to have steps rather than ramps render a person in a wheelchair disabled. Institutional and community practices and procedures, like the choice to communicate through sound or writing rather than signing or braille, disadvantage those who have hearing, speech, or sight deficits.<sup>352</sup> Further, social attitudes and prejudice result in intentional discrimination that additionally harms PWD.

Thus, the ADA is explicitly “targeted at social responses to and perceptions of disability.”<sup>353</sup> Its statutory findings focus on the “outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs or other opportunities”<sup>354</sup>—that is, the social practices that marginalize PWD. And in its original form, it noted that these harms were all “beyond the control of such individuals and resulting from stereotypic assumptions.”<sup>355</sup> In targeting discrimination that PWD face, the FHA, HAVA, IDEA, and other disability protections adopt a similar approach.<sup>356</sup>

Just as with the insurance programs above, within each of these programs is the understanding that *some* aspects of bad health should be blamed on

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350. 42 U.S.C. § 18116; *see also* 20 U.S.C. § 1681 (2018); 29 U.S.C. § 794 (2018); 42 U.S.C. §§ 2000d, 6101. The law also prohibits insurers from discriminating based on a range of conditions. *See* 42 U.S.C. §§ 300gg, 300gg-1 to -3, 1811.

351. *See, e.g.*, Feldblum, *supra* note 18, at 100.

352. For full accounts, *see* note 58.

353. Diller, *supra* note 128, at 1022; *see also id.* at 1029 (“In general, the ADA and the disability benefit programs ask society to think about disability in different and inconsistent ways.”).

354. 42 U.S.C. § 12101(a)(5).

355. 42 U.S.C. § 12101(a)(7) (1991).

356. *See supra* notes 66-76 and accompanying text.

individuals. For example, the ADA negotiation process resulted in the carveout of certain exceptions: “transvestism, transsexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, or other sexual behavior disorders,” “compulsive gambling, kleptomania, . . . pyromania,” and “psychoactive substance use disorders resulting from current illegal use of drugs.”<sup>357</sup> Republican opponents of the bill contrasted “people in wheelchairs or who have some kind of a physical disability . . . who are trying to overcome it,”—that is, those whose conditions are not their fault—with “homosexuality and bisexuality”<sup>358</sup> and the like, which “lack[] any physiological basis” and constitute “behavior . . . which individuals are engaging in of their own volition . . . . [These] people must bear some responsibility for the consequences of their own actions.”<sup>359</sup> But these exclusions were explicit compromises and exceptions: While conservative Senators sought to characterize all mental conditions as involving individual fault, the exception they achieved was quite narrow.<sup>360</sup>

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357. 42 U.S.C. § 12211(b) (2018). As Ruth Colker rightly observes, Congress made certain “trade-off[s]” when passing the ADA, opting not to protect sexual minorities while protecting “other minority groups, specifically individuals with HIV.” Ruth Colker, *Homophobia, AIDS Hysteria, and the Americans with Disabilities Act*, 8 J. GENDER RACE & JUST. 33, 34 (2004).

358. 135 CONG. REC. S10,753-54 (daily ed. Sept. 7, 1989) (statement of Sen. Armstrong). For an excellent treatment of the legislative history of these exclusions, see Barry, *supra* note 230, at 13, 16.

359. 135 CONG. REC. 19,896 (1989) (statement of Sen. Rudman).

360. See *supra* note 358. As Kevin Barry notes, in response to Senator Helms’s “opposition to the inclusion of various mental impairments,” Senator Harkin explained:

There is a wellspring of fears and unfounded prejudices about people with disabilities, unfounded fears, whether people have mental disorders, whether they are manic-depressives or schizophrenia or paranoia, or unfounded fears and prejudices based upon physical disabilities. The point of the [ADA] is to start breaking down those barriers of fear and prejudice and unfounded fears, to get past that point so that people begin to look at people based on their abilities, not first looking at their disability.

Barry, *supra* note 230, at 16 (alteration in original) (quoting 135 CONG. REC. S10,768 (daily ed. Sept. 7, 1989) (statement of Sen. Harkin)).

The legislative response to *Sutton v. United Air Lines, Inc.* reflects a similar dynamic, where the Court sought to expand the responsibility it assigned to PWD and Congress then passed legislation reducing the responsibility. See 527 U.S. 471 (1999), *superseded by statute*, ADA Amendments Act of 2008 (ADAAA), Pub. L. No. 110-325, 1222 Stat. 3553 (codified in scattered sections of 29 and 42 U.S.C.). In *Sutton*, the Supreme Court sought to limit ADA protections toward individuals who could correct their disabilities. 527 U.S. at 488-89. This went against agency and lower court approaches. See, e.g., *Bartlett v. N.Y. State Bd. of Law Exam’rs*, 156 F.3d 321, 329 (2d Cir. 1998) (holding that steps taken by plaintiffs to compensate for learning impairment do not remove them from ADA protection), *vacated*, 527 U.S. 1031 (1999); 29 C.F.R. pt. 1630, app. § 1630.2(j) (1998) (instructing that the “substantially limited” determination be made “without regard to mitigating measures, such as medicines, or assistive or prosthetic devices”).

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Medical civil rights (as the previous Subpart suggests) provide robust legal rights. The general thrust of American healthcare policy, accordingly, is best explained as arising from the tendency to blame medical disadvantage on bad luck and social factors (in that order).

#### 5. Advocacy examples

Finally, evidence of our solicitude toward medical status is evident in policy advocacy. To be sure, those seeking formal rights simply rely on the already-enacted laws I describe above. But those seeking more informal benefits also seek the normative cachet in which individual blame is avoided.

Take the opioid crisis. With the crack epidemic, as I observe above, society blamed crack users.<sup>361</sup> But by medicalizing prescription opioid users, advocates shift the blame to bad luck or social circumstances: The blame lies not on the users themselves, but rather on actors such as greedy pharmaceutical companies who marketed the drugs aggressively, or credulous, careless “drug-pushing doctors.”<sup>362</sup> Commentators who demanded harsh criminalization during the crack epidemic recommended solicitude when it came to opioids.<sup>363</sup>

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Scholars have offered many reasons for the Court’s decision in *Sutton*—see, for example, Feldblum, *supra* note 18, at 153-54. Compare Wendy E. Parmet, *Plain Meaning and Mitigating Measures: Judicial Interpretations of the Meaning of Disability*, 21 BERKELEY J. EMP. & LAB. L. 53, 72 (2000) (arguing, inter alia, that narrowing textualist interpretations were the cause), with Jill C. Anderson, *Just Semantics: The Lost Readings of the Americans with Disabilities Act*, 117 YALE L.J. 992, 1022-24 (2008) (arguing implicitly that textualism does not explain the outcomes). One additional factor for the Court’s somewhat opaque reasoning, however, that scholars appear not to have considered is the possibility that the Court felt that the ADA only applied to individuals who could not help themselves. As some amici explained: “Congress designed the ADA to help those individuals who could not help themselves, not to give special privileges to individuals who could control the effects of an impairment but chose not to.” Brief Amici Curiae of the Equal Employment Advisory Council et al. in Support of Respondents at 21, *Sutton*, 527 U.S. 471 (Nos. 97-1943 & 97-1992), 1999 WL 161056. But, notably, Congress disavowed this approach, functionally overruling *Sutton* in the ADAAA.

361. See *supra* text accompanying notes 140-41.

362. Carmen Balber, *CURES Database Will Be Vital in Preventing Opioid Deaths but Faces Powerful Special Interest Opposition*, CONSUMER WATCHDOG (May 1, 2018, 4:20 PM), <https://perma.cc/3HLC-WVXT>; see also Laxmaiah Manchikanti et al., Health Policy Review, *Opioid Epidemic in the United States*, 15 PAIN PHYSICIAN (OPIOID SPECIAL ISSUE) ES9 to -10, ES28 & fig.14 (2012) (providing a breakdown by specialty of opioid prescription sources).

363. See, e.g., Ed Stetzer, Perspective, “Lock Them Up:” My Double Standard in Responding to the Crack Crisis vs. the Opioid Epidemic, WASH. POST (Oct. 26, 2017, 4:58 PM PDT), <https://perma.cc/43ZN-SJHV>. The reasons for the difference, commentators believe, involve race and class. See, e.g., Taylor N. Santoro & Jonathan D. Santoro, *Racial Bias in the US Opioid Epidemic: A Review of the History of Systemic Bias and Implications for Care*, CUREUS 4 (Dec. 2018), <https://perma.cc/U3AS-L7LM>; Kevin McKenzie, *Largely White*  
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Rendering opioid addiction a medical rather than criminal status therefore meant that social conditions had to transform. Pharmaceutical companies began to make opioid formulations tamper resistant, in order to make it more difficult for users to crush and snort or inject them,<sup>364</sup> and the FDA rolled out guidance recommending Risk Evaluation and Mitigation Strategies (REMS), among other steps.<sup>365</sup> In June 2018, the House of Representatives passed sweeping legislation pushing for structural solutions, including treatment for addiction through Medicare and Medicaid, the use of alternatives to opioids, and public health surveillance.<sup>366</sup>

Similarly, the purpose of medicalizing social determinants such as poverty or homelessness is to shift blame away from the individual, and thereby increase support for addressing these problems. For example, one quantitative study showed that respondents thought that those factors seen as “most important” to health, namely “access to health care, and health insurance,” should be “high priority” areas for government intervention and assistance.<sup>367</sup> On the other hand, “social and economic factors” were not seen “as strong determinants of health.”<sup>368</sup> Thus, “it is also not surprising that respondents believe such strategies should not be a high government priority as a means to improve health.”<sup>369</sup> The authors of the study conclude that if more individuals see the importance of social determinants, there may be more support for interventions in those areas.<sup>370</sup>

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*Opioid Epidemic Highlights Black Frustration with Drug War*, COM. APPEAL (updated Mar. 27, 2017, 12:28 PM CT), <https://perma.cc/5L76-UZK8>. My primary concern, however, is to note that successful medical framing of the opioid epidemic obviates responsibility for addiction.

364. Marco Pappagallo & Marta Sokolowska, *The Implications of Tamper-Resistant Formulations for Opioid Rotation*, POSTGRADUATE MED., Sept. 2012, at 101, 103-05.

365. Scott Gottlieb & Janet Woodcock, Opinion, *Marshaling FDA Benefit-Risk Expertise to Address the Current Opioid Abuse Epidemic*, 318 JAMA 421, 422 n.6 (2017); see also CTR. FOR DRUG EVALUATION & RESEARCH, U.S. FOOD & DRUG ADMIN., ABUSE-DETERRENT OPIOIDS—EVALUATION AND LABELING: GUIDANCE FOR INDUSTRY 1 (2015). For more on REMS, see 21 U.S.C. § 355-1 (2018).

366. See generally Substance Use-Disorder Prevention That Promotes Opioid Recovery and Treatment for Patients and Communities Act, H.R. 6, 115th Cong., 2d Sess. (2018) (proposing the adoption of the steps listed above).

367. Stephanie A. Robert et al., *Public Views on Determinants of Health, Interventions to Improve Health, and Priorities for Government*, 107 WISC. MED. J. 124, 128 (2008).

368. *Id.* at 130.

369. *Id.* at 129.

370. *Id.* (“[I]f more people believed a range of social and economic factors strongly affect health, there may also be some increased policy support for a governmental role in social and economic policy to improve health.”); see also Helen C. Lundell et al., *Exploring Interpretation of Complexity and Typicality in Narratives and Statistical Images About the Social Determinants of Health*, 28 HEALTH COMM. 486, 496-97 (2013) (discussing strategies to educate individuals about social determinants of health).

A later study by some of the same authors found that “respondents who said that a range of social and economic approaches would be very effective at improving health” were also

more likely than were their counterparts to consistently endorse reducing pollution, reducing poverty, improving access to early childhood development programs . . . , reducing violence in communities, reducing unemployment, increasing the number of people who finish high school, improving social supports and social networks, and improving quality of housing.<sup>371</sup>

In other words, those who see these determinants as related to medical status also appear to endorse policies that would alter social conditions, instead of assigning fault to the individual.

Finally, trans advocates use medical frames to reinforce the claim that, unlike individuals who may choose not to conform to certain requirements (such as obligations to wear makeup), transgender individuals have less of a choice.<sup>372</sup> Thus, in criticizing North Carolina’s House Bill 2, which precluded localities from passing LGBT protective measures and denied restroom choice to transgender individuals, Attorney General Loretta Lynch cautioned against “turn[ing] on our neighbors . . . for something they cannot control.”<sup>373</sup> Similarly, as another advocate notes of one of the earliest appellate court decisions to hold that anti-transgender discrimination counted as sex discrimination: “[M]edical authority seemed to influence the court in seeing [the plaintiff’s] behavior as pursuant to trustworthy medical advice, and therefore less her fault or choice.”<sup>374</sup> Even in nonlegal contexts, activists advise parents who advocate for their gender-nonconforming children in schools that, while they should avoid language that suggests “deep pathology or mental illness,” they should “separate[] it from voluntary behavior.”<sup>375</sup> The work of advocates, then, reflects the vast sweep of health policy—that those who can frame their

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371. Stephanie A. Robert & Bridget C. Booske, *US Opinions on Health Determinants and Social Policy as Health Policy*, 101 AM. J. PUB. HEALTH 1655, 1661 (2011). Similarly, in the case of obesity, scholars find that those who saw obesity as a disability were associated with “support for antidiscrimination protections, support for increased funding for treatment, and opposition to charging an overweight individual more for health insurance.” Colleen L. Barry et al., *Obesity Metaphors: How Beliefs About the Causes of Obesity Affect Support for Public Policy*, 87 MILBANK Q. 7, 39 (2009). However, seeing obesity as linked to individual fault was negatively associated with these protections. *Id.* at 35 tbl.5.

372. Clarke, *supra* note 163, at 812.

373. Loretta E. Lynch, U.S. Attorney Gen., Remarks at Press Conference Announcing Complaint Against the State of North Carolina to Stop Discrimination Against Transgender Individuals (May 9, 2016), <https://perma.cc/3RHY-KYFU>.

374. Lloyd, *supra* note 163, at 179 (discussing *Smith v. City of Salem*, 378 F.3d 566 (6th Cir. 2004)).

375. See Hanna Rosin, *A Boy’s Life*, ATLANTIC (Nov. 2008), <https://perma.cc/4TZC-QWUY>.



conditions as medical are usually treated as not holding moral responsibility for any related burdens they experience.

C. Medical Legitimacy

Finally, the perceived objectivity that medicine brings to the law, especially as opposed to contemporary constitutional analysis, renders it attractive to those who invoke it to seek rights. Contrast the following passages from two prominent Supreme Court opinions:

[I]f the large and amorphous class of the mentally retarded were deemed quasi-suspect for the reasons given by the Court of Appeals, it would be difficult to find a *principled* way to distinguish a variety of other groups who have perhaps immutable disabilities setting them off from others, who cannot themselves mandate the desired legislative responses, and who can claim some degree of prejudice from at least part of the public at large. One need mention in this respect only the aging, the disabled, the mentally ill, and the infirm. We are reluctant to set out on that course, and we decline to do so.

— *City of Cleburne v. Cleburne Living Center, Inc.* (1985)<sup>376</sup>

[A] medical assessment of the worker's physical or mental condition is . . . a more sharply focused and easily documented decision than the typical determination of welfare entitlement. In the latter case, a wide variety of information may be deemed relevant . . . By contrast, the decision whether to discontinue disability benefits will turn, in most cases, upon "routine, standard, and unbiased medical reports by physician specialists . . ."

— *Mathews v. Eldridge* (1976)<sup>377</sup>

These two decisions, nine years apart, represent distinctive ways of thinking about classifications, legal protections, and who grants them. *Cleburne*, involved a *constitutional* question as to whether mental disability qualified as a suspect classification thus triggering strict scrutiny. In denying suspect classification, the Court expressed reservations about judges being able to distinguish in a principled way among all other groups who "might also claim heightened constitutional protections."<sup>378</sup> But these concerns appear absent in *Mathews*.<sup>379</sup> There, the distinctions would be "routine, standard, and

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376. 473 U.S. 432, 445-46 (1985) (emphasis added).

377. 424 U.S. 319, 343-44 (1976) (citation omitted) (quoting *Richardson v. Perales*, 402 U.S. 389, 404 (1971)).

378. *Cleburne*, 473 U.S. at 445-46.

379. While *Mathews* was the Social Security Administrator, and the case would therefore ordinarily be referred to as *Eldridge*, *Stanford Law Review* convention and the practice of the Supreme Court is to refer to the case as *Mathews*. See Brett V. Beaubien, Comment, *A footnote continued on next page*

unbiased.”<sup>380</sup> In deputizing the problem of classification to the medical establishment, the Court was untroubled by the lack of principled distinctions.

The anxiety of *Cleburne* when it came to constitutional distinctions, and the self-assurance of *Mathews* when it came to medical ones, reflect broader divisions in constitutional versus medical rights jurisprudence. According to commenters, judicial development of constitutional civil rights is at its nadir. The problem goes beyond just the political composition of the Supreme Court. As Kenji Yoshino has convincingly argued, courts, along with the rest of the nation, face “pluralism anxiety,” which has “transformed our civil rights jurisprudence.”<sup>381</sup> As groups claiming vulnerability proliferate, even a sympathetic Supreme Court would be hard-pressed to determine which groups get greater constitutional solicitude and which do not. Bertrall Ross traces these anxieties further back, arguing that the Court’s circumscribing of equal protection doctrine through the 1970s evinced “worrie[s] about the judiciary’s appropriate role in reviewing democratic actions.”<sup>382</sup> It is no understatement to claim—as yet another scholar, Deborah Hellman, has—that “[e]qual protection jurisprudence is a mess. Its moral foundation is uncertain, [and] its doctrinal structures are eroding . . . .”<sup>383</sup>

But there is reason to believe that the rot goes deeper than merely constitutional *rights* jurisprudence. In an open letter to Justice Breyer explaining his decision not to issue an updated edition of his foundational constitutional treatise, Laurence Tribe suggested that “conflict over basic constitutional premises is . . . at a fever pitch.”<sup>384</sup> The disagreement is not merely over doctrine but reaches “issues as fundamental as whose truths are to count and, sadly, whose truths must be denied”; indeed, there are “intractable divisions between wholly different ways of assessing truth and experiencing reality.”<sup>385</sup>

An important article by Dan Kahan lends empirical heft to these concerns. As Kahan’s empirical work has shown, individual cognition of basic facts about the world is heavily influenced by cultural biases; as he puts it (in the context of acts regarding global warming), “[w]hat people ‘believe’ . . . doesn’t reflect

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*Matter of Balance: Mathews v. Eldridge Provides the Procedural Fairness Rhode Island’s Judiciary Desperately Needs*, 21 ROGER WILLIAMS U. L. REV. 355, 356 n.6 (2016).

380. *Mathews*, 424 U.S. at 344 (quoting *Richardson*, 402 U.S. at 404).

381. Yoshino, *supra* note 3, at 747, 755.

382. See Bertrall L. Ross II, *Administering Suspect Classes*, 66 DUKE L.J. 1807, 1824–28 (2017).

383. Deborah Hellman, *Two Concepts of Discrimination*, 102 VA. L. REV. 895, 896 (2016).

384. Letter from Laurence H. Tribe, Carl M. Loeb Univ. Professor, Harvard Law Sch., to Stephen G. Breyer, Assoc. Justice, Supreme Court of the United States (Apr. 29, 2005), reprinted in 8 GREEN BAG 2D 291, 292 (2005).

385. *Id.* at 295, 302.

what they know; it *expresses* who they *are*.”<sup>386</sup> Facts that undermine self-identity in this way are simply not internalized. Such cultural cognitive biases have produced a “neutrality crisis” for the Supreme Court.<sup>387</sup> Judicial reasoning can “trigger[] self-reinforcing waves of self-deception and distrust.”<sup>388</sup>

Faced with scant agreement about facts—much less principle—judicial attempts to fashion protective constitutional remedies would, according to these accounts, deal a blow to judicial legitimacy. Deploying broadly textured, judicially crafted constitutional protections for specific groups is likely to be met with skepticism by the general public, not to mention judicial colleagues, lower courts, and lawyers.

Yoshino suggests that a solution to this problem lies in Justice Kennedy’s emphasis on dignity.<sup>389</sup> As in Justice Kennedy’s gay rights jurisprudence, dignity could be used to protect other disadvantaged minorities.<sup>390</sup> However, others point to the Justice’s vague conception of the term.<sup>391</sup> For Justice Kennedy, gays and lesbians have dignity.<sup>392</sup> But at the same time, anti-gay, religious bakers appear to have the right to have their faith remain free from “disparage[ment],” or “undue disrespect”<sup>393</sup>—concepts designed to preserve *their* dignity. Constitutional doctrine similarly seeks to preserve the dignity of states seeking sovereign immunity.<sup>394</sup> Thus, eking out concrete doctrine from so vague a concept would only exacerbate the Court’s legitimacy crisis—even if its importance survives Justice Kennedy’s departure from the Court.<sup>395</sup> What, then, is there to do?

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386. Dan Kahan, *What You “Believe” About Climate Change Doesn’t Reflect What You Know; It Expresses “Who You Are”*, CULTURAL COGNITION PROJECT (Apr. 23, 2014, 11:11 AM), <https://perma.cc/KRA2-7NRS>.

387. Dan M. Kahan, Foreword, *Neutral Principles, Motivated Cognition, and Some Problems for Constitutional Law*, 125 HARV. L. REV. 1, 27-28 (2011).

388. *Id.* at 57.

389. Yoshino, *supra* note 3, at 779, 792-95.

390. *See id.* at 776-87.

391. *See, e.g.*, Darren Lenard Hutchinson, *Undignified: The Supreme Court, Racial Justice, and Dignity Claims*, 69 FLA. L. REV. 1, 31-32 (2017); R.A. Lenhardt, *Race, Dignity, and the Right to Marry*, 84 FORDHAM L. REV. 53, 54-55 (2015).

392. *See* Yoshino, *supra* note 3, at 779 & n.222.

393. *See* Masterpiece Cakeshop, Ltd. v. Colo. Civil Rights Comm’n, 138 S. Ct. 1719, 1729, 1732 (2018).

394. *See* Hutchinson, *supra* note 391, at 36-38; Craig Konnoth, *Preemption Through Privatization*, 134 HARV. L. REV. (forthcoming 2021).

395. *Cf.* Adam M. Samaha, *Endorsement Retires: From Religious Symbols to Anti-Sorting*, 2005 SUP. CT. REV. 135, 137 (predicting the waning relevance of Justice O’Connor’s “endorsement” theory of the Establishment Clause after her retirement from the bench).

This brings us to *Mathews v. Eldridge*. *Mathews* suggests that medical science helps create at least an illusion of legitimacy.<sup>396</sup> To be clear, I am not suggesting that medical science *is* objective (indeed, I claim otherwise in Part I above), nor even that it is effective at allaying controversy. As the work of sociologist Robin Stryker and others has shown, “under some conditions scientific-technical rationality *increases* politicization.”<sup>397</sup> But the intention, Stryker recognizes, in invoking such rationality in political and judicial contexts is to create a veneer of (in most cases, I assume, sincerely believed) scientific objectivity.<sup>398</sup> In being able to invoke perceived, “objective” scientific sources, medical civil rights might allay—for courts at least—the pluralism and relativism concerns that plague their constitutional rights analysis.

Public opinion research suggests that medical frameworks are valuable sources of legitimacy. To be sure, a series of surveys shows that confidence in medicine, like confidence in other institutions, has dipped in the last few decades.<sup>399</sup> But it remains much higher than confidence in Congress or business institutions—only the military appears to score higher than medicine.<sup>400</sup> Further, confidence in certain *kinds* of medical entities is higher than others—thus, even over controversial issues such as the measles, mumps, and rubella (MMR) vaccine, confidence in medical scientists (as opposed to pharmaceutical companies) far outstrips confidence in other institutions more generally.<sup>401</sup>

Scientific evidence, as one advocate puts it, offers “intersubjective validity” that can help buttress the legitimacy of legal claims.<sup>402</sup> Just as law relies on a common set of shared premises and practices of reasoning that social actors

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396. See 424 U.S. 319, 343-44 (1976).

397. Robin Stryker, *Rules, Resources, and Legitimacy Processes: Some Implications for Social Conflict, Order, and Change*, 99 AM. J. SOC. 847, 851 (1994).

398. *Id.* at 849-52.

399. Cary Funk & Brian Kennedy, *Public Confidence in Scientists Has Remained Stable for Decades*, PEW RES. CTR.: FACT TANK (Mar. 22, 2019), <https://perma.cc/YL3T-CAVA>; see also NAT'L ACADS. OF SCIS., *supra* note 241, at 17 (offering reasons for the dip in confidence in medicine, such as conflicting headlines regarding health research in the media); NAT'L SCI. BD., NAT'L SCI. FOUND., 2018 SCIENCE & ENGINEERING INDICATORS 52-53, 58 (2018), <https://perma.cc/RKB5-FBFQ> (overviewing several studies regarding confidence in science and attitudes toward spending).

400. NAT'L SCI. BD., *supra* note 399, at 62-63; Funk & Kennedy, *supra* note 399.

401. While trust in medicine generally is at 36%, see Funk & Kennedy, *supra* note 399, further breakdown is revealing. Trust in pharmaceutical companies on the MMR vaccine, for example, is at 13%, compared to that in medical scientists, which is 55%. Cary Funk, *Mixed Messages About Public Trust in Science*, PEW RES. CTR. (Dec. 8, 2017), <https://perma.cc/6DBN-LDG2>.

402. Richard B. Katskee, *Science, Intersubjective Validity, and Judicial Legitimacy*, 73 BROOK. L. REV. 857, 858 (2008).

largely recognize as valid, so too does science. Indeed, in some ways, there is a fundamentally democratic aspect to science. To be sure, scientists, like lawyers, engage in modes of specialized reasoning which the layperson may not fully understand. But unlike conclusions based on value judgments or divine revelation, everyone has equal “epistemic access” to the data lawyers and scientists use to reach their conclusions, and most of us buy into the respective methods of, say, precedent-based reasoning in the law, or repeatable and falsifiable empirical methods in science.<sup>403</sup>

To be sure, the losers in any legal proceeding are not likely to agree on the outcome. But sharing common premises and reasoning methods lends legitimacy to the proceeding: “[L]egal judgments that employ those tests thus partake of the authority that the scientific method confers on robust research results.”<sup>404</sup> This minimal “intersubjective validity” over shared premises and reasoning methodology is far more achievable than claiming access to some ultimate truth as to the correct outcome.

Scientific reasoning can be embedded in the law in three different ways.<sup>405</sup> The first involves ad hoc appeals to scientific evidence. *Brown v. Board of Education*’s famous reliance on the doll experiment<sup>406</sup> is an example that at least one author argues was an attempt to bolster the legitimacy of an outcome that lacked much precedential authority.<sup>407</sup>

Under the second approach, courts might use scientific evidence to help satisfy some legal standard. Thus, in upholding New Jersey’s prohibition on sexual orientation change efforts on minors, the Third Circuit held that the state had a substantial interest that the ban directly advanced.<sup>408</sup> In applying the standard, it relied in part on evidence from the American Psychological Association, the American Psychiatric Association, and the American Academy of Pediatrics, among others.<sup>409</sup> The form of First Amendment scrutiny that the

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403. *Id.* at 868-69.

404. *Id.* at 865.

405. My approach here is informed by, but departs in important respects from, the models developed in Tristin K. Green, Essay, “*It’s Not You, It’s Me*”: Assessing an Emerging Relationship Between Law and Social Science, 46 CONN. L. REV. 287, 294 (2013), and John Monahan & Laurens Walker, *Social Authority: Obtaining, Evaluating, and Establishing Social Science in Law*, 134 U. PA. L. REV. 477, 478 (1986).

406. 347 U.S. 483, 494 & n.11 (1954).

407. See Sanjay Mody, Note, *Brown Footnote Eleven in Historical Context: Social Science and the Supreme Court’s Quest for Legitimacy*, 54 STAN. L. REV. 793, 823-24 (2002).

408. King v. Governor, 767 F.3d 216, 224 (3d Cir. 2014), *abrogated by* Nat’l Inst. of Family & Life Advocates v. Becerra (NIFLA), 138 S. Ct. 2361 (2018).

409. *Id.* at 238.

court applied did not *require* medical evidence. However, it was used as an additional, “alternative . . . source of legitimacy.”<sup>410</sup>

Finally, the third approach is to deputize to science the legal standard altogether. One example of this occurs in employment discrimination law: To show disparate impact, a plaintiff must adduce sufficient empirical data—without such data, her claim fails.<sup>411</sup> Disparate impact is simultaneously a legal, scientific, and numerical standard. In that way, the third approach differs from the first two approaches, which have no intrinsic link to medical or scientific authority. The first two approaches rely on scientific authority as one among other kinds of authority invoked to justify judicial reasoning. As a doctrinal matter, however, such reliance is not necessary. Under a deputization model, however, the legal standard and the scientific standard are one and the same.

These three paradigms are archetypes. But medical civil rights approaches fall best within the third category. As Part I discusses, for its understanding of “impairment” or “serious health condition,” the law relies on medical standards and diagnoses.<sup>412</sup> The deputization, as envisaged in *Mathews*, liberates medical civil rights from the concerns that circumscribe traditional constitutional rights. Medical rights are seen as projects of an objective, easily justifiable process.

The purported objectivity of medical evidence, indeed, helped justify the underlying laws that provide medical legal rights. As benefits scholar Matthew Diller notes with respect to Social Security, “the requirement of a medically determinable source of the disability was intended to ensure that claims would be susceptible to medical evaluation,”<sup>413</sup> thus creating an objective standard that applicants could not manipulate.<sup>414</sup> Similarly, regulations implementing

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410. See Stryker, *supra* note 397, at 862 (describing “[s]cientific-technical rationality” as a “source of legitimacy for law enforcement”); see also Monahan & Walker, *supra* note 405, at 478 (suggesting that courts invoke social sciences as authorities similar to precedential reasoning).

411. See Green, *supra* note 405, at 294; see also Paul-Emile, *supra* note 259, at 316-17.

412. See 29 U.S.C. § 2611(11) (2018) (defining “serious health condition” under the FMLA as, among other things, a condition involving treatment by a healthcare provider). See generally Smith, *supra* note 77 (discussing how courts in the ADA context require medical diagnoses).

413. Diller, *supra* note 211, at 408.

414. See 102 CONG. REC. 13,038 (1956) (statement of Sen. George) (“Doctors have less confidence in themselves than I have . . . I think more of the medical profession in this country than to believe that they cannot determine when a man or a woman worker has a permanent and total disability. That fact must be medically determined for, if not medically determined, the worker cannot receive any benefit.”); see also *Social Security Amendments of 1955: Hearings on H.R. 7225 Before the S. Comm. on Finance*, 84th Cong. 517 (1956) (statement of Leo Price, Director, Union Health Center, International Ladies Garment Workers’ Union) (“Criteria can be developed, and medical knowledge and experience are available, so that the presence or absence of total and permanent disability in an applicant can be successfully adjudicated.”); DEBORAH A. STONE, *THE*  
*footnote continued on next page*

the FMLA explicitly allow the employer to seek medical certification of the employee's health condition.<sup>415</sup> These laws envisaged that courts would deputize the medical establishment to produce an unbiased determination as to whether or not an individual qualified for rights.

But even when the purported intent of the law granting medical rights is to *decrease* reliance on evidence from the medical establishment, courts nonetheless demand such evidence. Thus, activists explain that the ADA sought to disestablish the notion that the medical establishment "objectively" describes physical flaws in an individual.<sup>416</sup> Rather, as the previous Subpart explains, disability activists claim that many of the burdens PWD face are socially imposed.<sup>417</sup> Through social negligence or prejudice, PWD face barriers, architectural and attitudinal among others.

Nonetheless, courts have required "objective" medical evidence in order to award rights. Thus, in one case, a plaintiff presented uncontroverted testimony that heavy lifting caused scars from an earlier surgery to split open and bleed.<sup>418</sup> The employer knew that the plaintiff had the surgery; however, even drawing all factual inferences in favor of the employee, the court ruled against him because he "presented absolutely no medical reports or other objective evidence substantiating his claim."<sup>419</sup> To hold otherwise "would allow anyone with any kind of condition . . . to claim a physical impairment."<sup>420</sup>

Such holdings reveal that even in medical civil rights decisions, courts have similar anxieties to those they express in constitutional cases. As in constitutional cases, individuals might claim harms and discrimination. And as

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DISABLED STATE 121 (1984) (noting the hope that "objective clinical findings" used to define disability could not be manipulated even though there was some fear that such manipulation was possible).

415. 29 C.F.R. § 825.306(a) (2019).

416. *See supra* text accompanying notes 351-54.

417. *See supra* text accompanying notes 350-56.

418. *Farley v. Gibson Container, Inc.*, 891 F. Supp. 322, 325-26 (N.D. Miss. 1995) (citing *Maulding v. Sullivan*, 961 F.2d 694, 698 (8th Cir. 1992)); *see also Maulding*, 961 F.2d at 698 (noting that the plaintiff failed to support her allegation of a disability affecting her respiratory system with adequate medical documentation); *Buchanan v. Safeway Stores, Inc.*, No. 3:95-cv-01658, 1996 WL 723089, at \*3 (N.D. Cal. Dec. 6, 1996) ("Plaintiff failed to produce any objective medical evidence demonstrating a restriction of either his short or long term work capacity in any job."), *aff'd*, 133 F.3d 925 (9th Cir. 1997); *Aucutt v. Six Flags Over Mid-Am., Inc.*, 869 F. Supp. 736, 744 (E.D. Mo. 1994) (observing that the plaintiff failed to present any medical reports regarding his "alleged medical condition or any objective affirmative evidence that provides this Court with some indication as to exactly how plaintiff is allegedly impaired"), *aff'd*, 85 F.3d 1311 (8th Cir. 1996). Smith, among others, offers a comprehensive listing of these cases. Smith, *supra* note 77, at 23 n.94,

419. *Farley*, 891 F. Supp. at 326.

420. *Id.*

in constitutional cases, their claims might be denied as subjective and self-serving. But medical authority gives individuals a backstop, however precarious, that constitutional claimants lack. To be sure, in some cases, where even medical authority is conflicted (as in some of the earlier cases involving MCS), courts might disregard medical authority.<sup>421</sup> But in other cases, medical authority can infuse medical civil rights with authority that is absent in purely legal claims.<sup>422</sup>

## V. Assessing Medical Civil Rights

How should we reconcile the critiques of medical civil rights with the benefits I have described in such detail? It bears noting that many opponents of using medical discourse themselves rely on medical evidence to justify their positions.<sup>423</sup> I offer two defenses of medical civil rights. First, I recognize the harms of medical status, and the hard choices they necessitate. At the same time, I believe many of the criticisms are outweighed by the benefits medical civil rights provide. Given their benefits, medical civil rights are the best of a set of bad choices that individuals facing disadvantage have—as the expansion of these claims suggests. Second, I argue that medical status is a malleable concept which has, and can further be, transformed in ways that respect rights and preserve institutional legitimacy.

### A. A Foundational Defense

Recall that the critiques in Part III above faulted medical civil rights for harming individual liberty by (1) coercing individuals (especially those who are vulnerable), (2) imposing stigma, and (3) warping and assimilating nonmedical harms into medical ones. I agree that these problems are real; their implications are serious. However, *all* civil rights-seeking presents the hazards medical civil rights critics identify. At the same time, the benefits of medical civil rights often exceed those that traditional civil rights offer. Thus, while it is important

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421. See *supra* notes 99-103 and accompanying text.

422. See Stryker, *supra* note 397, at 885 (“As scientific certainty increases, the perception that relying on science will enhance effectiveness is also likely to increase. Thus, legal authorities seeking effectiveness should be more inclined to rely on science the more unambiguous and certain is the relevant science and the more consensus about it there is among scientists.”).

423. See, e.g., Richard Klein, *What Is Health and How Do You Get It?*, in *AGAINST HEALTH*, *supra* note 15, at 15, 16 (relying on medical, here “epidemiological,” evidence to show that “yo-yo dieting,” which the author traces to medicalized opposition to obesity, is bad for the immune system). Some critics are conscious of this. See, e.g., LeBesco, *supra* note 210, at 80 (discussing how the Health at Every Size movement might buy into conventional discourses that reify the distinction between sick and healthy in order to push back against obesity medicalization).



to keep the Janus-faced nature of medical civil rights in mind, at both the individual and aggregate levels, medical civil rights might be the best of a set of limited alternatives available to vulnerable individuals.

First, the costs medical civil rights impose are not unique; legal rights in general coerce and demand assimilation. Civil rights activists of all stripes have lamented how civil rights doctrine has an “assimilationist bias.”<sup>424</sup> For example, scholars have shown how gay activists have had to claim that sexuality is immutable in order to trigger suspect scrutiny; or elide, in cases involving the right to same-sex intercourse, the primarily sexual connection between the plaintiffs.<sup>425</sup> Law, like medicine, creates categories—categories of fundamental rights and categories of discrete and insular minorities with certain specific characteristics into which individuals must assimilate, or at least pretend to assimilate, in order to get rights. This sometimes produces claims with “transvestic qualit[ies]”—dressing up one kind of claim in another’s garb.<sup>426</sup> And in order to achieve such victories, *all* rights seekers must expend significant resources, as in the medical civil rights contexts.

Apart from coercing and assimilating individuals, critics claim that medical civil rights also stigmatize them. Samuel Bagenstos suggests that statutes that provide positive rights stigmatize more than those that provide negative rights. He argues that some actors who administer welfare programs, including Social Security programs, are “paternalistic, arbitrary, and oppressive,”<sup>427</sup> and that “people who accept or use social welfare rights are often treated, by society at large, as less entitled to participate fully in the life of the community than those who do not accept those rights.”<sup>428</sup> As more positive rights accompany medical civil rights than traditional civil rights, one may conclude that medical civil rights impose more stigma.

However, to the extent traditional civil rights prescribe positive-rights remedies as well, they might stigmatize just as much as positive medical civil rights. For example, in one of the Supreme Court’s most recent pronouncements on the issue, Justice Clarence Thomas repeated his observation that affirmative action stigmatizes minorities: “[I]t taints the accomplishments of all those who are the same race as those admitted as a result of racial discrimination” and

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424. See, e.g., Kenji Yoshino, *Assimilationist Bias in Equal Protection: The Visibility Presumption and the Case of “Don’t Ask, Don’t Tell,”* 108 YALE L.J. 485, 487 (1998).

425. Katherine M. Franke, Commentary, *The Domesticated Liberty of Lawrence v. Texas*, 104 COLUM. L. REV. 1399, 1408 (2004); Yoshino, *supra* note 424, at 509.

426. William N. Eskridge, Jr., *Multivocal Prejudices and Homo Equality*, 74 IND. L.J. 1085, 1110 (1999) (explaining why anti-gay discrimination comprises more than sex discrimination, even though they are undeniably and deeply connected).

427. BAGENSTOS, *supra* note 79, at 21.

428. Bagenstos, *supra* note 276, at 418-19.

imposes “stigma.”<sup>429</sup> Further, some might contest Bagenstos’s suggestion that negative rights impose less stigma. Richard Epstein suggests that traditional negative civil rights like Title VII may be seen as a “backhanded insult, as an implicit statement . . . that women and minorities cannot . . . make it on their own. [They] . . . speak[] of a perpetual state of dependence . . . .”<sup>430</sup> Given this, the stigma of pity or charity may apply to more than just medical status protections. These harms fall disproportionately on individuals who face harm and who are therefore seeking these rights—such as people of color and women.

Finally, scholars are completely correct that vulnerable populations, such as the poor and minorities, might have limited access to the liberatory power of medicine. As one scholar explains, “whites’ substance abuse is medicalized and perceived as treatable illness, while non-white substance abusers must confront criminal sanction for the very same behaviors.”<sup>431</sup> However, minorities have limited access to the liberatory power of rights-seeking more generally—and sometimes benefit less than other groups. No citation is required for the truism that minorities have a harder time finding legal representation, navigating the legal system, or getting a fair hearing.<sup>432</sup> Similarly, while it took centuries of pervasive and systematic oppression and struggle for African American claims of discrimination to be cognizable, the less extreme harms that white individuals have experienced in limited contexts, such as affirmative action, immediately yielded legal responses.<sup>433</sup> There is discrimination in the way rights are distributed—not just medical rights. This is a problem with rights claims more generally.

So much for the costs of medical protections for individual rights claims. I now turn to two of the institutional critiques: (1) that medicine can lose its

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429. *Fisher v. Univ. of Tex.*, 570 U.S. 297, 333–34 (2013) (Thomas, J., concurring) (quoting *Grutter v. Bollinger*, 539 U.S. 306, 373 (2003) (Thomas, J., concurring in part and dissenting in part)).

430. RICHARD A. EPSTEIN, *FORBIDDEN GROUNDS: THE CASE AGAINST EMPLOYMENT DISCRIMINATION LAWS* 498 (1992).

431. Erin M. Kerrison, *White Claims to Illness and the Race-Based Medicalization of Addiction for Drug-Involved Former Prisoners*, 31 HARV. J. ON RACIAL & ETHNIC JUST. 105, 107 (2015). See generally Konnoth, *supra* note 167 (explaining that minorities are often harmed by medical stereotypes such that invoking medical language might create unique harms for them).

432. But, the rigors of law review publication require that I provide one. See generally Sara Sternberg Greene, *Race, Class, and Access to Civil Justice*, 101 IOWA L. REV. 1263 (2016) (offering evidence of this and possible explanations).

433. What some call the “[t]he first affirmative action program” was established in 1965. Khaled A. Beydoun & Erika K. Wilson, *Reverse Passing*, 64 UCLA L. REV. 282, 312 & n.159 (2017). After immediate legal challenges, the Court began marching back such programs starting in 1978. See *id.* at 315–24.

legitimacy, and (2) that medicine can be co-opted. (I save my response to the third institutional critique for the next Subpart.)

I offer a similar answer to these two institutional critiques. Just as the legitimacy of medicine may suffer when it takes up unpopular causes such as poverty, so too might the legitimacy of other programs. One well-documented example is how white Americans stop supporting welfare programs when they believe that African Americans partake of them to a greater degree than whites.<sup>434</sup>

Similarly, much like medicine, the law can be co-opted for a variety of purposes—from promoting slavery to banning homosexuality. As I explain in the next Subpart, the better approach is to shape medical discourse to extract its rights-giving potential.

If the costs of medical civil rights resemble those exacted by other kinds of rights-seeking, their benefits often (though not always) exceed the benefits of traditional civil rights. These benefits exist simultaneously with medicine's costs, as medical discourse can be deployed simultaneously both to liberate and to oppress. Consider the coercive and stigmatizing interventions that Khiara Bridges documents. The individuals Bridges describes suffer "disparagement" in practice.<sup>435</sup> But this desire to enforce social norms on vulnerable groups coexists with the recognition that, as a legal and ethical matter, dignity and autonomy must be respected. Even the hospital staff members Bridges observes exchanging "disapproving glances" about certain patients seem reluctant to articulate their disapproval.<sup>436</sup> As one staff member explained, "[t]hese patients tell you this and they tell you that . . . That's not my business. My business is to help them."<sup>437</sup> This statement implicitly suggests mistrust, judgment, and dismissal of patients, possibly for lacking required paperwork—they "tell you this and tell you that"—but *explicitly*, at least, hews to the goal of the government program—to enhance the autonomy and dignity of the subject. Indeed, the reason that women are subjected to the controls in the first place is because they seek the benefits that come from assuming a medical status, and many appreciate the benefits they get.<sup>438</sup>

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434. Rachel Wetts & Robb Willer, *Privilege on the Precipice: Perceived Racial Status Threats Lead White Americans to Oppose Welfare Programs*, 97 SOC. FORCES 793, 794 (2018); see also Michele Estrin Gilman, *The Return of the Welfare Queen*, 22 AM. U. J. GENDER SOC. POL'Y & L. 247, 258-59 (2014) (roughly mapping how race and gender affected whether welfare recipients were considered deserving or undeserving).

435. Bridges, *supra* note 197, at 42-43.

436. See Bridges, *supra* note 199, at 68.

437. *Id.* at 68 n.12.

438. To take one example, Bridges notes that while "many women with whom I have spoken welcome their meetings with the nutritionist and appreciate the information given to them, just as many women found the coerced consultation offensive." *Id.* at 74. Bridges does not quantify these different groups for comparison, but my reading of her overall discussion is that many of the offended women were not averse to the

*footnote continued on next page*

This dual framing—where those partaking of medical discourse experience both rights recognition as well as stigma—is apparent in other contexts. Thus, even as critics charged that soldiers diagnosed with PTSD would be stigmatized and seen as “passiv[e],” the diagnosis came with important benefits like disability payments and back pay.<sup>439</sup> Similarly, Michele Crossley explains how an HIV diagnosis can produce both discomfort with the “sick role” as well as a sense of “empowerment.”<sup>440</sup>

The task of this Article is not to deny that medicine comes with cost.<sup>441</sup> But, like any litigant, a medical civil rights claimant must consider whether, in their particular circumstance, benefits outweigh costs. There is no formulaic answer for when this will be the case—it might depend on how desperate a family is for SSDI benefits, how essential it is for a trans individual to have access to surgery, or how much distress someone with fatigue is in because of her work schedule. The analysis might hinge on the legal frame at issue, the condition involved, or personal preference.<sup>442</sup> The numbers suggest that for many, the analysis skews in medicine’s favor.

This cost/benefit analysis is precisely what happens even in the hardest examples—including, for example, medication of children to get Social Security benefits.<sup>443</sup> The parents weighed costs and benefits and did not make the choice lightly. “SSI payments can be a lifeline in a bad economy, and they beat welfare checks in almost every way”—though, in absolute terms, they may involve very limited sums of money.<sup>444</sup> Even in Massachusetts, which ranks third in the nation in per capita welfare spending according to a recent estimate,<sup>445</sup> a parent on welfare with two children doubles her benefit if just

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assistance they received but did object to the way in which it was provided. *See also* Hoffman, *supra* note 288, at 135 (offering historical evidence that poor women had both “gratitude” toward, but also concerns about the stigma of, Medicaid).

439. BLOCHE, *supra* note 46, at 68, 79. To the extent Bloche believes that moral passivity is real, he and I disagree for the reasons explicated in the next Subpart.

440. *See* Michele Crossley, “Sick Role” or “Empowerment”? *The Ambiguities of Life with an HIV Positive Diagnosis*, 20 SOC. HEALTH & ILLNESS 507, 508 (1998).

441. *See supra* Figure.

442. For examples of how some individuals and communities decide against medicalization, see Jutel, *supra* note 55, at 289 (discussing anorexia); and Konnoth, *supra* note 2, at 347–48 (describing how the early gay rights movement debated whether to examine medical etiologies of homosexuality).

443. To be clear, the parents profiled took action on the advice of medical and school officials—without which they could not have accessed prescription drugs—although the parents themselves did not believe that their children needed medication. Wen, *supra* note 223.

444. *Id.*

445. Gabrielle Olya, *States That Spend the Most and Least on Welfare*, YAHOO! FIN. (Mar. 10, 2019), <https://perma.cc/D98M-H6TR>.

one of her children qualifies for SSI.<sup>446</sup> The choice a parent makes reveals her desperation—choosing to medicate one’s child despite one’s own instincts. As one parent notes, “It’s all about surviving.”<sup>447</sup> And the medical professionals and teachers who assist these parents agree.<sup>448</sup> But this story also reveals the key importance of medical status as a source of rights—one might infer that in a bad economy, where jobs are not to be found, there is no other avenue for these families to make ends meet.<sup>449</sup>

## B. An Aspirational Defense

I am confident in my claim that medical civil rights often present relative advantages over other forms of civil rights-seeking, despite their flaws. I am less confident, but reasonably hopeful, that medical civil rights might be divested of many of their flaws altogether. Much like legal meaning, the meaning of medical status is socially constructed by numerous actors, as Part I suggests. For medical frames to extend beyond medical institutions, actors outside these institutions must engage with and shape them.

To be sure, the last few years have created setbacks for various constituencies seeking civil rights—including in medical contexts. The Trump Administration’s approval of Medicaid work requirements, the push toward high deductible health plans, and attempts to gut various salutary aspects of the ACA are just a few examples.<sup>450</sup> But taking a broader perspective, the reforms that the previous Part described over the last seventy years—the passage of Social Security, disability protections, and the like—suggest that the longer arc of medical civil rights-seeking is an encouraging one. I see even more promise—in the long term at least—in the rise of movements that seek to advance rights-based medical frameworks both inside and outside medical institutions.

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446. Wen, *supra* note 223.

447. *Id.* Another parent added: “Money determines everything . . . . It determines how much you eat, what you eat, and how you treat your kids.” *Id.*

448. *Id.*

449. A similar story might be told of the subjects of Khiara Bridges’s investigation. Those women were not subject to greater coercion because of their medical status—privately insured women, as Bridges notes, who are pregnant, are treated with a greater degree of autonomy (though they too were subject to various kinds of surveillance). Bridges, *supra* note 199, at 80-81. The greater coercion of Bridges’s subjects arose from their poverty. In the medical sphere, and in *other* spheres, from education to employment, poor people are subject to a greater degree of surveillance and control.

450. See *Gresham v. Azar*, 950 F.3d 93, 95-97 (D.C. Cir. 2020) (holding that the Administration acted in an arbitrary and capricious manner by approving work requirements); Martin McKee et al., Discussion, *What Will Donald Trump’s Presidency Mean for Health? A Scorecard*, 389 LANCET 748, 749-50 (2017) (providing a survey of some of the actions discussed above).

This Subpart outlines some of these efforts, what medical sociologists consider points of “resistance and self-defense against” coercive medical institutions.<sup>451</sup> Compared with the disempowerment of patients even just a century ago,<sup>452</sup> the changes are heartening. I begin by discussing patient empowerment within medical institutions, and continue by describing how nonpatients are engaging in medical discourse in ways that may universalize its appeal. I end by explaining the implications of these phenomena for the criticisms of medicalization.

### 1. Inside medical institutions: Patient empowerment

First, *within* medical institutions, there have been steps to make medical status designations more transparent and subject to the engagement of multiple stakeholders. At a fundamental level, ethicists have increasingly argued for lay engagement in the process of creating medical ethics that inform medical institutions. This, in turn, is reflected in greater patient engagement in the practice of medicine in two ways—*creating* medical status taxonomies and then *applying* them. These approaches promote the authority of the patient and her knowledge of her medical condition, while challenging the “authority of medical expertise.”<sup>453</sup> Such so-called patient “counter-expertise” challenges the dominance of medical professionals.

Medical ethics historically was the province of the medical profession. However, medical ethicists have increasingly argued for the involvement of

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451. See Nye, *supra* note 192, at 123-24; see also Joan Busfield, *The Concept of Medicalisation Reassessed*, 39 SOC. HEALTH & ILLNESS 759, 765 (2017) (summarizing certain sociologists’ view that “there has been a decline in the trust of expert authority” and that “present-day consumers are more active, sometimes encouraging medicalisation, sometimes resisting it,” while also noting that “some early accounts of medicalisation gave too much emphasis to medicine’s imperialistic tendencies and underplayed its benefits”). Others offer a similar recommendation as I do, that is, of reducing medical authority. See Maayan Sudai, *Revisiting the Limits of Professional Autonomy: The Intersex Rights Movement’s Path to De-Medicalization*, 41 HARV. J.L. & GENDER 1, 38-39 (2018) (suggesting “epistemic conflict” as a tool for *reducing* the authority of medicine). While Sudai considers the disestablishment of professional authority simply to be demedicalization, I would dispute this characterization. See *supra* notes 39-49 (explaining how nonmedical authorities still engage and produce medical discourse).

452. See Marc A. Rodwin, *Patient Accountability and Quality of Care: Lessons from Medical Consumerism and the Patients’ Rights, Women’s Health and Disability Rights Movements*, 20 AM. J.L. & MED. 147, 151-52 (1994) (describing incidents including nonconsensual operations and sterilizations).

453. David J. Hess, *Medical Modernisation, Scientific Research Fields and the Epistemic Politics of Health Social Movements*, 26 SOC. HEALTH & ILLNESS 695, 696 (2004). This expertise is in a “narrow-band” pertaining to a specific topic. *Id.* at 703 (quoting DAVID J. HESS, *EVALUATING ALTERNATIVE CANCER THERAPIES: A GUIDE TO THE SCIENCE AND POLITICS OF AN EMERGING MEDICAL FIELD* 229 (1999)).

lay society in developing ethical guidelines. As Robert Veatch argues, “ethics . . . must be grounded in our most fundamental beliefs and values” rather than in “the views of a . . . professional group.”<sup>454</sup> In a “democratic society,” there is an “equality of moral authority,” such that numerous different groups should be consulted and have a voice in the shape of these ethics.<sup>455</sup> Law professor and bioethicist Alex Capron similarly argues for a “dialectic” of ethics that is “socially situated [and] interdisciplinary.”<sup>456</sup>

Outside input comes from numerous sources. Medical sociologists have discussed how legal actors, including malpractice lawyers and journalists, influence the operation of medical institutions.<sup>457</sup> More importantly, the emergence of medical social movements—a broader phenomenon that has received sustained sociological attention only in the last decade, but little legal attention—has transformed medical practice.<sup>458</sup> These movements consist of patient and advocacy groups, with their own subcultures, including symbols, forms of activism, communities, and narratives. These include, for example, pink ribbons and pins in the breast cancer movement;<sup>459</sup> and AIDS rides, red ribbons, the AIDS memorial quilt, and *POZ* magazine in the HIV/AIDS movement.<sup>460</sup> These groups sometimes ally with, and sometimes combat, payers or providers. This can transform how those in, or engaged with, illness communities perceive a disease. These groups have gone from playing second fiddle to professionals, to partners—and sometimes formidable opponents—

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454. Robert M. Veatch, *Who Should Control the Scope and Nature of Medical Ethics?*, in *THE AMERICAN MEDICAL ETHICS REVOLUTION: HOW THE AMA'S CODE OF ETHICS HAS TRANSFORMED PHYSICIANS' RELATIONSHIPS TO PATIENTS, PROFESSIONALS, AND SOCIETY* [hereinafter *THE AMERICAN MEDICAL ETHICS REVOLUTION*] 158, 166 (Robert. B. Baker et al. eds., 1999).

455. *Id.* at 167.

456. Alexander Morgan Capron, *Professionalism and Professional Ethics*, in *THE AMERICAN MEDICAL ETHICS REVOLUTION*, *supra* note 454, at 180, 186.

457. Robert Dingwall & Pru Hobson-West, *Litigation and the Threat to Medicine*, in *CHALLENGING MEDICINE* 40, 42 (David Kelleher et al. eds., 2d ed. 2006) (discussing this relationship in the United Kingdom); Jonathan Gabe et al., *Understanding Medical Dominance in the Modern World*, in *CHALLENGING MEDICINE*, *supra*, at xix (same).

458. See, e.g., Sandra R. Levitsky & Jane Banaszak-Holl, *Introduction to SOCIAL MOVEMENTS AND THE TRANSFORMATION OF AMERICAN HEALTH CARE* 3, 4 (Jane C. Banaszak-Holl et al. eds., 2010) (“[W]hile there is a rich literature about health systems generally and the social and political aspects of individual disease entities and disabilities, there have been few attempts to conceptually integrate this research with contemporary theories of collective action.” (citations omitted)).

459. *Breast Cancer Ribbon*, NAT’L BREAST CANCER FOUND., INC., <https://perma.cc/7APL-F58L> (archived May 9, 2020).

460. See Tracy Baim, *AIDS: The Plague Years*, WINDY CITY TIMES, Apr. 6, 2011, at 14, 14-15, 17, <https://perma.cc/9HDA-E6PL>; *About Us*, POZ, <https://perma.cc/P5G4-DT7B> (archived May 24, 2020) (“POZ is an award-winning print and online brand for people living with and affected by HIV/AIDS.”).

with forms of institutional governance, and financial support, even in situations involving great medical complexity.<sup>461</sup>

Medical social movements participate in medical institutions in various ways. First, they have engaged in developing new medical status designations and taxonomies. For example, in an unprecedented move, the World Health Organization, which puts together the ICD codes, sought out the views of the World Professional Association for Transgender Health on gender-identity-related diagnoses.<sup>462</sup> Such interventions, for some patient activists, at least, are nonpathologizing.<sup>463</sup> Similarly, veteran activism resulted in the recognition of Gulf War Syndrome as a genuine condition. A 1994 report denied “persuasive evidence that any of the proposed etiologies” caused the “chronic illness” that Gulf War veterans claimed they experienced.<sup>464</sup> By 2008, the consensus was that “Gulf War illness is a serious condition that affects at least one fourth” of the veterans who served in the Gulf War.<sup>465</sup> This shift occurred largely through patient activism. Organizations such as the National Gulf War Resource Center and Operation Desert Shield/Storm Association formed to advocate for the diagnosis, and various scientists gathered to the cause and produced a body of literature.<sup>466</sup> Finally, patients are more involved in the

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461. See, e.g., Vololona Rabeharisoa, *The Struggle Against Neuromuscular Diseases in France and the Emergence of the “Partnership Model” of Patient Organisation*, 57 SOC. SCI. & MED. 2127, 2128-33 (2003) (discussing the emergence of one such group in France).

462. Sam Winter et al., *The Proposed ICD-11 Gender Incongruence of Childhood Diagnosis: A World Professional Association for Transgender Health Membership Survey*, 45 ARCHIVES SEXUAL BEHAV. 1605, 1606 (2016).

463. GLOB. ACTION FOR TRANS EQUAL., IT’S TIME FOR REFORM: TRANS\* HEALTH ISSUES IN THE INTERNATIONAL CLASSIFICATIONS OF DISEASES 11 (2011), <https://perma.cc/GLR4-KM24> (explaining that for most trans activists represented at the meeting, introducing “trans\* experiences that intersect with the health system” through Z-codes would be “non-pathologi[zing]”). While the fact that these particular activists would not find such modifications pathologizing is not determinative—they do not necessarily speak for the community—it is at least suggestive. See *Committees*, WPATH, <https://perma.cc/HJ94-VRR5> (archived May 9, 2020) (listing—in addition to doctors—lawyers, social workers, and education specialists in committee membership).

464. OFFICE OF THE UNDER SEC’Y OF DEF. FOR ACQUISITION & TECH., U.S. DEP’T OF DEF., REPORT OF THE DEFENSE SCIENCE BOARD TASK FORCE ON PERSIAN GULF WAR HEALTH EFFECTS 2, 46-53 (1994), <https://perma.cc/2HMH-644A>.

465. RESEARCH ADVISORY COMM. ON GULF WAR VETERANS’ ILLNESSES, GULF WAR ILLNESS AND THE HEALTH OF GULF WAR VETERANS: SCIENTIFIC FINDINGS AND RECOMMENDATIONS 1 (2008), <https://perma.cc/2B2K-K5LT>.

466. Phil Brown et al., *A Narrowing Gulf of Difference? Disputes and Discoveries in the Study of Gulf War-Related Illnesses*, in CONTESTED ILLNESSES: CITIZENS, SCIENCE, AND HEALTH SOCIAL MOVEMENTS 79, 85-87 (Phil Brown et al. eds., 2012).



research process than ever before, with some researchers adopting a “community-based participatory research” model to engage with patient-activists.<sup>467</sup>

Next, medical movements participate in the *application* of medical status classifications in particular contexts and medical interventions, both at the individual and structural level. Medical institutions are taking steps to make their decisionmaking regularized and transparent.<sup>468</sup> Ethicists have advocated for, and institutions have adopted, new “shared-decisionmaking” tools that give patients a greater say at the points of diagnosis, treatment, and the development of clinical practice guidelines.<sup>469</sup> Many hospital administrative boards, Institutional Review Boards (IRBs), and others have begun to include patient representation or community members.<sup>470</sup> Patients and former patients in the mental health context “sit on state mental health councils, work for mental health agencies, and serve on treatment policy committees.”<sup>471</sup> Systematizing such steps is important as medical civil rights become entrenched in legal doctrine.<sup>472</sup>

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467. Nina Wallerstein et al., *On Community-Based Participatory Research*, in COMMUNITY-BASED PARTICIPATORY RESEARCH FOR HEALTH: ADVANCING SOCIAL AND HEALTH EQUITY 3, 3-12 (Nina Wallerstein et al. eds., 3d ed. 2018) (discussing numerous facets of a community-based approach to research); see also 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, 638 (2012) (describing the push for and difficulties of researching the impact of patient and public involvement in research).

468. Some emerging literature has begun to address this question. Govind Persad, *What Is the Relevance of Procedural Fairness to Making Determinations About Medical Evidence?*, 19 AMA J. ETHICS 183, 184-85 (2017). But see Richard Ashcroft, *Fair Process and the Redundancy of Bioethics: A Polemic*, 1 PUB. HEALTH ETHICS 3, 7-8 (2008) (arguing that a procedural approach to medical decisionmaking is insufficient).

469. See Craig J. Konnoth, *Transparency Versus Informed Consent: The Patient/Consumer Paradigms*, in TRANSPARENCY IN HEALTH AND HEALTH CARE IN THE UNITED STATES: LAW AND ETHICS 75, 79 (Holly Fernandez Lynch et al. eds., 2019). See generally Antoine Boivin et al., *Patient and Public Involvement in Clinical Guidelines: International Experiences and Future Perspectives*, QUALITY & SAFETY HEALTH CARE, Oct. 2010, at e22; P. Díaz del Campo et al., *A Strategy for Patient Involvement in Clinical Practice Guidelines: Methodological Approaches*, 20 BMJ QUALITY & SAFETY 779, 780 (2011).

470. See, e.g., Robert Klitzman, *Institutional Review Board Community Members: Who Are They, What Do They Do, and Whom Do They Represent?*, 87 ACAD. MED. 975, 975 (2012) (discussing the composition of IRBs); Zahirah McNatt et al., *Implementation of Hospital Governing Boards: Views from the Field*, BMC HEALTH SERVICES RES. 1 (Apr. 2014), <https://perma.cc/38P9-86CW> (discussing community representation on hospital boards in Ethiopia).

471. Nancy Tomes, *From Outsiders to Insiders: The Consumer-Survivor Movement and Its Impact on U.S. Mental Health Policy*, in PATIENTS AS POLICY ACTORS, *supra* note 193, at 113, 113.

472. I do not mean to suggest that there is not much to be done. The central ICD planning task force lacks any patient representation; members consist only of experts. World Health Org., ICD-11-MMS Joint Task Force (JTF) (2018), <https://perma.cc/9BM4-43K8>. And as Sudai explains, “[a] repeated difficulty has been the lack of support and training for public representatives to meaningfully engage in such discussions” and the lack of

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## 2. Outside medical institutions

Part of the reason that outside movements are reaching into, and changing, medical institutions is the increased prevalence of medical discourse outside these institutions. Individuals who may think of themselves as healthy and do not regularly interact with medical institutions nonetheless have a greater degree of casual contact with these institutions than ever before. Further, medical discourse—and even medical status—is increasingly being used as a hermeneutic for self-understanding.<sup>473</sup>

First, individuals who do not regularly engage with the medical system come into contact with it more than before through preventative care. A well-known article, *Promoting Prevention Through the Affordable Care Act*, in the *New England Journal of Medicine*, coauthored by then-U.S. Health and Human Services Secretary Kathleen Sebelius, listed the Act's key preventative care innovations.<sup>474</sup> The Act guarantees coverage for checkups and screenings for various cancers, HIV, and depression; counseling for alcoholism; vaccinations; and more.<sup>475</sup>

But the Act also engages individuals in medical discourse outside medical institutions. It promotes workplace wellness programs that allow employers to

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"data on" what kind of involvement is effective, and toward what ends. Sudai, *supra* note 451, at 46,

473. My commentary here may have implications for disability literature regarding the so-called "contact hypothesis." See Elizabeth F. Emens, *Framing Disability*, 2012 U. ILL. L. REV. 1383, 1407 & n.138. As Elizabeth Emens notes, "[d]isability is unusual, if not unique . . . in that anyone could fall into the category at any time." *Id.* at 1402. However, this, by itself, does not create empathy. As Harlan Hahn explains, this might create "existential anxiety"; individuals who are not disabled may feel the need to create distance from PWD to ignore the precise fact that they are vulnerable to disability. See Harlan Hahn, *The Politics of Physical Differences: Disability and Discrimination*, 44 J. SOC. ISSUES 39, 42-45 (1988). Emens goes on to suggest various solutions for this problem, including educating individuals with the idea that disability can be a fulfilling existence. Emens, *supra*, at 1410-34. If individuals see themselves as part of the group already, or an adjacent group (such as those who are susceptible to a certain disability), it might increase their sense of empathy. They can no longer pretend they are separate.

474. See generally Howard K. Koh & Kathleen G. Sebelius, Perspective, *Promoting Prevention Through the Affordable Care Act*, 363 NEW ENG. J. MED. 1296 (2010) (discussing the ACA's preventative medicine strategies).

475. *Id.* at 1296-97; see also 42 U.S.C. § 300gg-13(a) (2018) (requiring coverage for immunizations and for services that have a specific rating from various standard-setting agencies). For a fuller list of these services, see *Preventive Care Benefits for Adults*, HEALTHCARE.GOV, <https://perma.cc/QQ8Q-69BX> (archived May 9, 2020). Admittedly, the uptick in use of these services two years after the passage was modest. See Xuesong Han et al., *Has Recommended Preventative Service Use Increased After Elimination of Cost-Sharing as Part of the Affordable Care Act in the United States?*, 78 PREVENTIVE MED. 85, 87 (2015).

incentivize employees to engage in healthy behavior,<sup>476</sup> from dietary habits to exercise to attending regular checkups.<sup>477</sup> There is much to criticize with wellness programs and their ilk. Writing in the context of chronic illness, medical sociologist Mike Bury argues that self-management programs shift responsibility away from medical institutions and “professionals, . . . in particular doctors,” to patients.<sup>478</sup> The same is true of wellness programs. Nevertheless, such programs enmesh patients within medical paradigms, as they are linked to medical insurance, and often, to medically measured outcomes.<sup>479</sup>

Beyond the ACA, new technologies promote medical discourse in lay contexts. For example, an increasing number of individuals use devices to get information about their bodies which, in turn, affects how they see themselves.<sup>480</sup> Self-tracking devices generate data about steps walked, heartbeat, calories burned and consumed, sleep patterns, and brainwaves,

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476. See Regulations Under the Americans with Disabilities Act, 81 Fed. Reg. 31,126, 31,140 (May 17, 2016) (codified at 29 C.F.R. pt. 1630, app. § 1630.14(d)(1) (2019)) (noting that wellness programs are permitted to require screening “for the purpose of alerting [employees] to health risks of which they may have been unaware,” and that employers may offer incentives to participate in such programs). While employers can incentivize employees to get checkups, they can only condition incentives on the outcome of those checkups in very limited circumstances. See 42 U.S.C. § 300gg-4(j)(2)(B) (permitting use of incentives for a “diagnostic testing program that provides a reward for participation and does not base any part of the reward on outcomes”).

Peter Conrad has attempted to separate out “medicalization” and “healthicization.” Peter Conrad, *Medicalization and Social Control*, 18 ANN. REV. SOC. 209, 223 (1992). The former appears to occur when medical professionals seek to medicalize; the latter, when the discourses are imbued into and promulgated by lay individuals. *Id.* However, as other sociologists have recognized, by giving a monopoly over the concept of medicalization to medical professionals, this approach denies the agency of lay individuals. This is “culturally biased,” by only treating the professionalized, Western avatar of medicalization as true medicalization, and understates the benefits of medicine. Correia, *supra* note 226, at 2-3; see also Busfield, *supra* note 451, at 765-68.

477. See, e.g., *Employee Wellness Program*, WELLABLE, <https://perma.cc/3EBY-C5FQ> (archived May 24, 2020) (listing access to dieticians and biometric screenings as part of a wellness program).

478. Mike Bury, *Chronic Illness, Self-Management, and the Rhetoric of Empowerment*, in NEW DIRECTIONS IN THE SOCIOLOGY OF CHRONIC AND DISABLING CONDITIONS, *supra* note 21, at 161, 170, 175.

479. See 42 U.S.C. § 300gg-4(j)(1)(C) (noting that insurance premium discounts may be offered for participation in wellness programs if conditioned on a participant’s satisfaction of a standard related to a “health status factor”); *id.* § 300gg-4(j)(3) (setting requirements for such wellness programs).

480. Examples of these devices include the “Fitbit Surge, Jawbone UP, Nike+Fuel, Pebble Watch, Apple Watch, and a variety of smartphone applications such as MyFitnessPal, Fitocracy, FitStar and Nudge.” Btihaj Ajana, *Digital Health and the Biopolitics of the Quantified Self*, DIGITAL HEALTH 1-2 (Feb. 2017), <https://perma.cc/FY5T-TQ6R>.

among other things; apps help analyze this data.<sup>481</sup> While accurate measures are hard to obtain, in 2014, 10% of all users of such wearables engaged with them daily;<sup>482</sup> in 2016, roughly 20% of all Americans used these devices;<sup>483</sup> and as of 2019, “nearly half of Americans (45%)” have used a fitness tracker or mobile health app, or both, at some point.<sup>484</sup> Many engage in self-tracking without a medical condition—rather, they perform such tracking because they believe that self-conceptualization and knowledge lie in medical data and discourse.<sup>485</sup>

These technologies might result in individuals seeing themselves linked to some medical status even without any interaction with medical institutions. Take consumer genetic testing technology.<sup>486</sup> Such tests provide consumers with medical information about genetic predispositions to what are understood as medical conditions today.

Medical sociologists argue that such findings transform the concept of what I call here medical status. Historically, medical statuses have been primarily characterized by certain bodily traits (such as organs perceived as malfunctioning), purported social behaviors (such as homosexuality), or a combination of both.<sup>487</sup> For many individuals, *genetic* variations and putative abnormalities will also constitute a medical status, to which they may consider themselves linked, “leading to the proliferation of [medically] at-risk groups.”<sup>488</sup> Some scholars argue that this will lead to new forms of organization:

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481. Kashmir Hill, *Adventures in Self-Surveillance, aka the Quantified Self, aka Extreme Navel-Gazing*, FORBES (Apr. 7, 2011, 11:34 AM EDT), <https://perma.cc/86UQ-AEH2>; see also *Counting Every Moment*, ECONOMIST (Mar. 3, 2012), <https://perma.cc/X6RJ-TKZ3> (exploring the concept of self-tracking and the “belief that gathering and analysing data about [one’s] everyday activities can help . . . improve [one’s] li[fe]”).

482. Jonah Comstock, *PwC: 1 in 5 Americans Owns a Wearable, 1 in 10 Wears Them Daily*, MOBI HEALTH NEWS (Oct. 21, 2014), <https://perma.cc/93UU-HJ94>.

483. Bruce Jaspen, *Wearable Fitness Devices Attract More than the Young and Healthy*, FORBES (July 11, 2016, 9:46 AM EDT), <https://perma.cc/N9KN-LUL3>.

484. Justin McCarthy, *One in Five U.S. Adults Use Health Apps, Wearable Trackers*, GALLUP (Dec. 11, 2019), <https://perma.cc/C7X9-GZXK>.

485. As anthropologist Dana Greenfield explains, this is a “utopian project[], where . . . health behaviors can be changed . . . and self-knowledge, -mindfulness, and -awareness can be achieved.” Dana Greenfield, *Deep Data: Notes on the n of 1*, in QUANTIFIED: BIOSENSING TECHNOLOGIES IN EVERYDAY LIFE 123, 126 (Dawn Nafus ed., 2016); see also Craig Konnoth, *Health Information Equity*, 165 U. PA. L. REV. 1317, 1342 (2017).

486. In 2013, 330,000 individuals were tested; this figure rose to over 12 million in 2017. Antonio Regalado, *2017 Was the Year Consumer DNA Testing Blew Up*, MIT TECH. REV. (Feb. 12, 2018), <https://perma.cc/Y53T-REYR>.

487. See ROSE, *supra* note 210, at 11-12.

488. Sara Shostak et al., *Sequencing and Its Consequences: Path Dependence and the Relationships Between Genetics and Medicalization*, 114 AM. J. SOC. (SUPPLEMENT) S287, S309 (2008). Nikolas Rose similarly describes the concept of “susceptibility” which “operates as a third term between the normal and the pathological” and appears to connect it to the  
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“[P]eople who identify as at risk may generate new forms of biosocial organization, as they come together ‘for mutual support, joint advocacy, and . . . activism.’”<sup>489</sup> Indeed, genetic activism has already created diverse coalitions of “consumers, professionals, public agencies, [and] biotechnology companies,” among others.<sup>490</sup> Medical discourse in turn will interpellate individuals as actors within the “national polity and its scientific institutions . . . [with] rights and responsibilities”; it will be a marker of “cultural and biopolitical citizenship.”<sup>491</sup>

### 3. Assessing the new approaches

Medical discourse on this account has moved beyond the hyperprivatized worlds of the examining room and professional groups.<sup>492</sup> It is increasingly a broad political and social phenomenon that is “co-product[ed]” through the polyphonic engagement of numerous stakeholders—courts, legislatures, patient advocates, disability activists, and even the lay public.<sup>493</sup> This has implications for the critiques from individual rights and institutional harms I outlined above.<sup>494</sup>

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notion of “predisease.” ROSE, *supra* note 210, at 84-85. Robert Aronowitz more generally argues that the concepts of disease and medicine have collapsed, such that individuals who are at risk for a disease are now surveilled and their risk itself is understood in “disease-like” ways. ROBERT ARONOWITZ, *RISKY MEDICINE: OUR QUEST TO CURE FEAR AND UNCERTAINTY* 4, 22 (2015); *see also* STEFAN TIMMERMAN & MARA BUCHBINDER, *SAVING BABIES? THE CONSEQUENCES OF NEWBORN GENETIC SCREENING* 65-68 (2013) (referring to this group as “patients-in-waiting”).

489. Shostak et al., *supra* note 488, at S309 (second alteration in original) (citation omitted) (quoting Ian Hacking, *Genetics, Biosocial Groups, & the Future of Identity*, DAEDALUS, Fall 2006, at 81, 91-92). Shostak and Peter Conrad, possibly today’s most prominent critic of medicalization, suggest that this genetic perception can “stabilize[]” into new forms of medical conditions—and thereby, medical status. *Id.* at S289, S309.

490. Deborah Heath et al., *Genetic Citizenship*, in *A COMPANION TO THE ANTHROPOLOGY OF POLITICS*, 152, 163 (David Nugent & Joan Vincent eds., 2004).

491. STEVEN EPSTEIN, *INCLUSION: THE POLITICS OF DIFFERENCE IN MEDICAL RESEARCH* 90 (2007) (describing how minority groups found inclusion within research protocols).

492. *See* Faye Ginsburg & Rayna Rapp, *Enabling Disability: Rewriting Kinship, Reimagining Citizenship*, in *THE DISABILITY STUDIES READER* 185, 188-89 (Lennard J. Davis ed., 4th ed. 2013) (suggesting that such privatized behavior prevents patients from learning of the broader resources available).

493. *See* May, *supra* note 88, at 135.

494. I am not alone in envisioning such alliances. Sam Bagenstos, for example, notes that even as many disability activists rhetorically distanced themselves from the medical profession, in practice the “disability rights movement activists . . . often relied on the assistance and endorsement of professionals who shared their views,” including “psychologists . . . [and] special-education teachers.” BAGENSTOS, *supra* note 79, at 22. Medicaid services, such as “community placements and personal-assistance services,” improved reimbursements, and access to medical care remains important. *Id.* at 25, 138-39.

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First, the broader social engagement I describe can help displace the moralistic, stigmatizing, and assimilationist tendencies of medical status.<sup>495</sup> Within medical institutions and agencies, patient movements can point to successes in pushing back against coercive and paternalistic practices, including in drug approval mechanisms,<sup>496</sup> research,<sup>497</sup> insurance,<sup>498</sup> and

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Like I explain above, Bagenstos cautions that reliance on medical programs can be a double-edged sword—we must “identify the professional communities that will prove reliable.” *Id.* at 78. For example, HIV activists worked well with public health professionals to limit the spread of HIV while still respecting individual rights. *Id.* at 83-84. He also advocates a “demedicalized” regime, where PWD have autonomy and control over the services they receive—such as being able to hire and fire personal assistance workers. *Id.* at 146-47. What Bagenstos sees as demedicalization, however, I see as a transformation of the medical discourse made possible through the sustained activism of numerous constituencies, whose ranks have the potential of growing even further in ways that this Subpart describes. *See, e.g.*, DAN GOODLEY, *DISABILITY STUDIES: AN INTERDISCIPLINARY INTRODUCTION* 105-06 (2d ed. 2017) (discussing “[c]ritical psychologists [who] confront psychological practices that sustain oppression and seek, instead, to promote an ethical and politicised psychology that works alongside activists . . . and survivors of psychology”); SHAKESPEARE, *supra* note 29, at 158-59 (discussing the changing nature of disability charities as the result of activism); *id.* at 192-93 (discussing different approaches by professionals and careworkers).

There is much work to be done in terms of understanding the full scope of disability activism, patient movements, and medical social movements in relationship to each other, both academically and through activism. *See* Levitsky & Banaszak-Holl, *supra* note 458, at 4 (discussing fragmented academic research); Michael Ashley Stein et al., *Cause Lawyering for People with Disabilities*, 123 HARV. L. REV. 1658, 1686 (2010) (reviewing BAGENSTOS, *supra* note 79) (noting that “numerous and uncoordinated strategies” sometimes harm disability activism); Stramondo, *supra* note 21, at 29 (discussing conflict and the lack of representation of PWD in bioethics contexts); *see also* Tom Shakespeare & Nick Watson, *Beyond Models: Understanding the Complexity of Disabled People’s Lives*, in *NEW DIRECTIONS IN THE SOCIOLOGY OF CHRONIC AND DISABLING CONDITIONS*, *supra* note 21, at 57, 59 (describing the social model of disability as too quick to “reject[] medical prevention, rehabilitation or cure of impairment”).

495. Admittedly, for me, the bigger threat is not a moralistic medical frame, which has been much weakened in the last century, but rather, consumerist frames. *See* DAN GOODLEY, *DIS/ABILITY STUDIES: THEORISING DISABLISM AND ABLEISM* 25-26, 30 (2014) (discussing the transhumanism movement, where medicine can create futuristic bodies as desirable “commodities”); *see also* Patricia J. Williams, *Babies, Bodies and Buyers*, 33 COLUM. J. GENDER & L. 11, 11, 15 (2016) (raising a consumerist vision of medicine where individuals could design their own babies, *inter alia*). *See generally* Konnoth, *supra* note 469 (discussing consumer and medical frames through the lens of transparency and informed consent paradigms and advocating the latter).

496. *See, e.g.*, Douglas Crimp, *Before Occupy: How AIDS Activists Seized Control of the FDA in 1988*, ATLANTIC (Dec. 6, 2011), <https://perma.cc/W6FS-AL4S>.

497. *See, e.g.*, Lori Andrews & Julie Burger Chronis, *A Pound of Flesh: Patient Legal Action for Human Research Protections in the Biotech Age*, in *PATIENTS AS POLICY ACTORS*, *supra* note 193, at 83, 90-101 (describing litigation against researchers that research subjects saw as engaging in inappropriate actions).

498. *See, e.g.*, Marc A. Rodwin, *Patient Appeals as Policy Disputes: Individual and Collective Action in Managed Care*, in *PATIENTS AS POLICY ACTORS*, *supra* note 193, at 177, 180-81.

provider care,<sup>499</sup> among other contexts. The Center for Medicare and Medicaid Services, for example, seeks to eradicate Medicaid practices that “do not meet a minimum patient-centered standard to support informed decision-making” for poor patients,<sup>500</sup> hopefully addressing some of the harms that Bridges identifies. Similarly, transgender individuals have often successfully agitated for more autonomy over medical categories that are relevant to their community, in some cases successfully countering the need to assimilate into the rigid gender binaries that concern Dean Spade.<sup>501</sup>

Finally, the involvement of outside groups in medical institutions can defuse the stigma that professional diagnosis can so often produce. Thus, after engaging with support groups, parents with gender-nonconforming children might go from feeling that gender-related conditions are stigmatizing to feeling more comfortable: “What’s it they say? It’s nothing wrong. It’s just a medical condition, like diabetes or something. Just a variation on human behavior.”<sup>502</sup>

Outside medical institutions, the stigma of medical status might also dissipate as more individuals feel linked to some kind of medical status. Several disability studies scholars have made an analogous, if contested,<sup>503</sup> point. Rather than emphasizing the distinctness of PWD as a minority group, they argue for a universalizing approach that presses the “normality of [medical] variation” among all humans across a “continuous spectrum.”<sup>504</sup> Antidisability stigma, they claim, arises in part because nondisabled individuals otherize PWD in an effort to deny that they too might one day experience an

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499. See, e.g., Hoffman, *supra* note 288, at 138-44 (describing how activism from the poverty movement and others helped spur development of the patients’ bills of rights); Tomes, *supra* note 471, 122-23 (describing how in the mental health context, patients and former patients were hired to be providers and to educate providers); see also Geoffrey M. Reed et al., *Disorders Related to Sexuality and Gender Identity in the ICD-11: Revising the ICD-10 Classification Based on Current Scientific Evidence, Best Clinical Practices, and Human Rights Considerations*, 15 WORLD PSYCHIATRY 205, 210-11 (2016) (discussing a World Health Organization working group’s recognition of the need for diagnosis codes to get access to certain procedures).

500. HARLAN KRUMHOLZ & SUSANNAH BERNHEIM, YALE NEW HAVEN SERVS. CORP./CTR. FOR OUTCOMES RESEARCH & EVALUATION, MEASURE OF QUALITY OF INFORMED CONSENT DOCUMENTS FOR HOSPITAL-PERFORMED, ELECTIVE PROCEDURES: MEASURE METHODOLOGY REPORT 8 (2018), <https://perma.cc/444U-B7UQ>.

501. See *supra* text accompanying notes 194-95.

502. Rosin, *supra* note 375 (quoting a parent).

503. Several scholars emphasize the importance of maintaining a defined disability identity. See, e.g., Simi Linton, *Reassigning Meaning*, in THE DISABILITY STUDIES READER, *supra* note 82, at 223, 225.

504. James C. Wilson, *Disability and the Human Genome*, in THE DISABILITY STUDIES READER, *supra* note 82, at 52, 59.

impairment they see as disabling.<sup>505</sup> “[F]orc[ing]” these fears “out into the open for examination” through universalizing arguments can address this stigma.<sup>506</sup> Disability law scholars similarly almost uniformly endorse universal remedies to emphasize the common bond between PWD and nondisabled individuals.<sup>507</sup>

Similar reasoning applies here. As more individuals become invested in medical discourse and medical status, its stigma might dissipate to some degree at least—if everyone considers themselves invested in medical discourse or linked to some community imbued with medical status, then the space in which stigma may operate could begin to shrink.<sup>508</sup>

Polyphonic engagement with medical discourse helps address other medicalization critiques beyond stigma. Although there is some way to go, the legal backstops and wide-ranging engagement with medical discourse address some of the democracy and legitimacy concerns medicalization raises.<sup>509</sup>

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505. Ato Quayson, *Aesthetic Nervousness*, in THE DISABILITY STUDIES READER 254, 255 (Lennard J. Davis ed., 5th ed. 2016). See generally Emens, *supra* note 345 (discussing hedonic costs).

506. Quayson, *supra* note 505, at 256; see also Susan Wendell, *Toward a Feminist Theory of Disability*, in THE DISABILITY STUDIES READER, *supra* note 82, at 336, 339–41.

507. Sam Bagenstos emphasizes how advocacy for “universal . . . health insurance” would benefit PWD “disproportionately,” but would “not send the message that people with disabilities are uniquely in need of caretaking; it would send the message that we all need insurance against contingencies in life.” BAGENSTOS, *supra* note 79, at 145. Michael Stein, Anita Silvers, Bradley Areheart, and Leslie Francis suggest an approach where we focus on “accommodating every body,” such as aging workers, rather than subjecting individuals to the vicissitudes of disability definition in the law. See Michael Ashley Stein et al., *Accommodating Every Body*, 81 U. CHI. L. REV. 689, 693 (2014). And Elizabeth Emens provides typologies of “third-party benefits,” such as employer-offered telecommuting, that can benefit PWD and other groups of stakeholders. Elizabeth F. Emens, *Integrating Accommodation*, 156 U. PA. L. REV. 839, 841–43 (2008). But see SHAKESPEARE, *supra* note 29, at 47–50 (arguing the limit of universal design); Shakespeare & Watson, *supra* note 494, at 62–63 (cautioning the limits of a universal approach).

508. “[T]he argument that mental disorders are universal would” render it “normal[] as one dimension of the human experience.” Victoria Costello, *What If Mental Illness Is a Universal Experience? A Path Away from Stigma to Timely Treatment and Prevention*, CTR. FOR HEALTH JOURNALISM: MEMBER POSTS (Mar. 3, 2012), <https://perma.cc/83Y9-KQHK>.

509. See, e.g., Hoffman, *supra* note 288, at 143–45; Mark Schlesinger, *The Canary in Gemeinschaft Using the Public Voice of Patients to Enhance Health System Performance*, in PATIENTS AS POLICY ACTORS, *supra* note 193, at 148, 155–62 (discussing how patient movements’ victories have been watered down and patient complaints have been ignored). But see Steven Epstein, *Measuring Success: Scientific, Institutional, and Cultural Effects of Patient Advocacy*, in PATIENTS AS POLICY ACTORS, *supra* note 193, at 257, 260 (noting the ways in which patients have contributed to change, while at the same time seeking not to overstate the effects of patient advocacy); Rachel Grob & Mark Schlesinger, *Epilogue to PATIENTS AS POLICY ACTORS*, *supra* note 193, at 278, 280–89 (offering solutions to enhance patient engagement more generally); Rodwin, *supra* note 498, at 183–88 (expressing both concerns regarding and solutions for patient complaints in insurance

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Constitutionally designated institutions, such as courts and legislatures, act as important checks on the power of medical institutions, and they help shape the content of medical discourse, especially to the extent medical status leverages *legal* rights. Courts, after all, decide among warring medical expertise in particular cases. The metes and bounds of medical statuses that yield legal rights are set by legislatures, as Part I describes. When medical professionals have sought to challenge these legislative guidelines, they have generally lost.<sup>510</sup> Thus, a rights-giving medicalization frame itself increases medicine's enmeshment and reliance upon democratically legitimate backstops. This, in itself, reifies medicine's legitimacy, both as a delegate of the law, and on its own terms.

But even beyond drawing legitimacy parasitically from the law, as more individuals see themselves linked to medical status, medical rights will develop their own independent legitimacy. Medical institutions are facilitating this shift self-consciously: In the research context, as one medical sociologist observes, "[t]he advocacy goal . . . is to move toward more democratic participation,"<sup>511</sup> and "redress[] a kind of 'democratic deficit' . . . said to exist when citizens do not actively participate in shaping scientific and technological futures."<sup>512</sup> Legal scholars have explained how the law (in particular the Constitution) derives its legitimacy from individuals and groups situating themselves and making rights claims within legal and constitutional narratives, even in resistance to judicial authority.<sup>513</sup> Similarly, even as individuals seek independence from the medical profession and develop their own subjectivity, they do so only by "behaving like [doctors]."<sup>514</sup> To go toe-to-toe with professional opponents, advocates often educate themselves; even lay individuals use diagnostic techniques

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contexts); Schlesinger, *supra*, at 168-72 (offering solutions to take into account patient complaints).

510. See, e.g., *Pickup v. Brown*, 728 F.3d 1042, 1055-56 (9th Cir. 2013) (upholding a legislative ban on efforts to change sexual orientation against free speech challenges), *amended on denial of reh'g en banc*, 740 F.3d 1208 (9th Cir. 2014), *abrogated by Nat'l Inst. of Family & Life Advocates v. Becerra*, 138 S. Ct. 2361 (2018).

511. See *Andrews & Chronis*, *supra* note 497, at 84.

512. ROSE, *supra* note 210, at 140.

513. See, e.g., Robert Post & Reva Siegel, Essay, *Roe Rage: Democratic Constitutionalism and Backlash*, 42 HARV. C.R.-C.L. L. REV. 373, 375 (2007) ("When citizens speak about their most passionately held commitments in the language of a shared constitutional tradition, they invigorate that tradition. In this way, even resistance to judicial interpretation can enhance the Constitution's democratic legitimacy.").

514. Enrico Maria Piras & Alberto Zanutto, "One Day It Will Be You Who Tells Us Doctors What to Do!": Exploring the "Personal" of PHR in Paediatric Diabetes Management, 27 INFO. TECH. & PEOPLE 421, 424 (2014); see, e.g., Annemarie Mol, *What Diagnostic Devices Do: The Case of Blood Sugar Measurement*, 21 THEORETICAL MED. & BIOETHICS 9, 17-19 (2000) (describing how blood sugar measurement technology allows the patient to behave like a doctor).

and equipment that were once available only to medical professionals.<sup>515</sup> As they enhance individuals' independence from the medical profession in practical terms, these technologies nevertheless represent a buy-in to medical forms of understanding. This may help dissipate the stigma that has historically come with a medical status designation, increasing its legitimacy.<sup>516</sup>

This creates a form of interest convergence—in medical rights discourse at least, even as different constituencies vie for different medical rights claims,<sup>517</sup> and as patients, individually or as a group, disagree with professionals (and even each other) as to desirable outcomes and strategies.<sup>518</sup> Even when individuals do not themselves occupy any medical status, they are likely to defer to the designations of medical status produced by the social processes I describe—and to the rights they yield. Rather than disestablish these rights, this kind of contestation enhances the symbolic and material investment of all social constituencies in the project of medical civil rights.<sup>519</sup>

### Conclusion

Many may find the explosion of medical civil rights claims ominous. It might signal to them that individuals who might be facing contracting social safety nets and less sympathetic courts must resort to illegitimate tools which subject them to stigma and control, that force them to shoehorn claims into

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515. See *supra* notes 480-85 and accompanying text.

516. See *supra* note 508 and accompanying text.

517. For concerns about interest convergence in this and related contexts, see Emens, *supra* note 345, at 916-19. For a response to such concerns, see Adrienne Asch, *Critical Race Theory, Feminism, and Disability: Reflections on Social Justice and Personal Identity*, 62 OHIO ST. L.J. 391, 401 (2001).

518. See Elizabeth Mitchell Armstrong & Eugene Declercq, *Is It Time to Push Yet? The Challenges to Advocacy in U.S. Childbirth*, in PATIENTS AS POLICY ACTORS, *supra* note 193, at 60, 65 (discussing how women might choose different strategies for delivering their babies); Tomes, *supra* note 471, at 118, 123-24 (describing how different groups might ally with, or oppose, medical discourse and the medical professions).

519. Paul-Emile argues that it is precisely because legislators recognize that they might end up disabled one day that they are more sympathetic to disability rights than to rights remedying racial inequality:

Legislators were probably well aware that any able-bodied person, themselves included, could at any time become physically or mentally disabled due to chance, age, illness, or accident. But these same legislators were likely quite certain that they would not become black . . . . Thus, many legislators' interests converged with the interests of individuals with disabilities to the extent that these legislators likely understood that they may have to seek the protections of disability laws one day.

Paul-Emile, *supra* note 259, at 350. Thus "[i]n the disability context, although people may associate modifications with more costs than gains, they do not believe that the gains come at their expense." *Id.* at 361.

unnatural vessels. As valid as these concerns may be, they do not diminish the power of these rights for the lives of the actual people who are responsible for the explosion of claims.

These concerns also ignore the ever-changing nature of these rights and the valence of medical discourse. Some conditions fall within the core of the law's conception of medical status; some squarely outside. But the battle to claim medical civil rights in contestable areas demonstrates their malleability and their promise. As the figure in Part II.A above suggests, medical civil rights rely on both medical recognition and legal rights-giving. They are a site of dialogue between law and medicine, where law can extract from medicine its liberatory power, where medicine can harness law's rights-giving features. Law helps define medical status in popular consciousness, telling us which medical statuses are serious as is and which need to be more narrowly defined; it recognizes or denies recognition for certain medical conditions.

More importantly, however, the law helps infuse medical status with normative content in a way that medicine by itself is often ill equipped to do. That normative content might be punitive and reinforce the hierarchy of doctor and patient. But as medical civil rights show, it may also be liberatory. It might yield powerful formal rights mechanisms and reinforce normative views about who or what should be blamed for medical harm—in most cases, fate and society. It also creates a starting point to think about new forms of rights—positive rights, rights that extend to family caretaking, and social transformation. But while it gives, it also takes from medicine legitimating power to shore up its own security.

But when I speak of “the law” in this way, I do not refer to some brooding omnipresence in the sky. Rather, “the law” must be invoked in the visions of real litigants, of desperate parents, and distressed employees, who invoke medicine not simply for the cures it might provide, but for the rights it might yield. In so doing, it is these individuals and their claims that shape our understanding of medicine, the law, and their enduring relationship.

### **Methodological Appendix**

This Appendix provides the raw figures for the figure in Part II.A above for claims with respect to Social Security, ADA, FMLA, ERISA, and, for some conditions, IDEA cases drawn from Westlaw searches. I counted all mentions of the specific condition as they appeared with the relevant statutory term or appropriate variations.<sup>520</sup> This Appendix is simply meant to establish the proposition that it is more likely than not that claims in cases of so-called contested diagnoses increased over time, rather than to provide specific figures for that increase. Accordingly, some limitations should be noted with these figures.

While I did not review every case, every case that appeared in sample sets of cases that I examined involved the relevant condition and the relevant statutory claim. The numbers do not include several cases in which medical conditions were misspelled or varied by name (fibromyalgia, for example is also known as fibromyocitis). I did, however, check for variations on the name of certain conditions such as hyperkinetic impulse disorder, an early, alternative name for ADHD. The numbers also do not include the limited number of cases in which a court does not spell out a certain statute's name in full and merely uses an acronym (like ADA or SSDI). Note, however, I did include common errors in statutory naming—for example, “social security income” for “supplemental security income.” Disability claims in this table include veterans’ disability benefits, as I saw no principled reason to exclude them, and excluding them was impractical. I reviewed every case when the number of hits was under one hundred, to ensure that the claimant did indeed claim the particular condition under the particular statute. Thus, for example, in a case not involving fibromyalgia, a court might still mention fibromyalgia when discussing as precedent a case involving the condition. I removed those cases. These occurrences were few enough that once results exceeded one hundred, I only conducted spot checks, as those occurrences would not disturb the overall trend. Finally, research results might vary slightly as Westlaw adjusts its database over time.

While I believe my approach strongly suggests an explosion of claims, it cannot rule out other possibilities. This includes the possibility that the symptoms individuals exhibited were previously captured by other diagnoses, based on which they filed claims, and that as newer terminology came into vogue, those diagnoses were displaced by the new ones, leaving the total number of claims constant. However, while there is some evidence of

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520. Thus, one typical example of a search would be: *adv*: (“Americans #with Disabilities Act” “Rehabilitation Act”) & “Multiple Chemical Sensitivity” & *DA*(aft 12-31-2010 & bef 01-01-2015) or *adv*: (SSI SSDI “social security”) & “Multiple Chemical Sensitivity” & *DA*(aft 12-31-2005 & bef 01-01-2010).

terminological change with these conditions,<sup>521</sup> I know of no such large-scale displacement with respect to most of the listed conditions. I also tested for variation for conditions with known terminological changes, such as ADHD.

It is also possible that the number of claims did not increase, but rather only the number of Social Security denials increased as to these conditions, which produced more appeals. I also include cases where individuals made claims to both controversial as well as uncontroversial medical statuses (fibromyalgia as well as osteoarthritis for example). That seems appropriate as my primary interest here is *that* they made the claim, not that the claim was recognized or proved valid (though the increase in awarded claims suggests that many of them did indeed prove valid). There is also double counting of cases where two of the conditions I list here are mentioned. These double counts are removable, but it is unclear whether such removal would be appropriate. Further, I effectively double count cases where there is both a lower and appellate court decision or multiple dispositions in different procedural postures in the same court. However, there is no reason to believe that this double counting affects certain decades more or less than others. Finally, I double count cases where individuals make more than one statutory claim (IDEA and ADA claims for example) as again, it did not seem appropriate to remove such claims. Checks, however, suggested that such overlaps were minimal. Indeed, as the table shows, because of the greater overlap of ADA claims with IDEA claims specifically in the case of ADHD (compared to other conditions), I created a separate table showing ADA claims and Social Security claims that do not include terms like “IDEA,” “FAPE” (Free Appropriate Public Education), or “IEP” (Individualized Education Program). However, that removal did not disturb the trend, and only slightly reduced (approximately 10%) the absolute number of cases.

Finally, I exclude statutes and programs under which litigation is limited, such as the Fair Housing Act, IDEA claims for conditions that affect primarily older individuals (like fibromyalgia), and Medicare and Medicaid, as the searches in those cases are more likely to be contaminated with irrelevant cases.

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521. See, e.g., Klaus W. Lange et al., *The History of Attention Deficit Hyperactivity Disorder*, 2 ATTENTION DEFICIT HYPERACTIVITY DISORDER 241 (2010) (explaining the changing terminology as it applies to ADHD).

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**Data Appendix**

**Table 1**

Contested Illness Claims, 1990-2014

<b>Claim</b>	<b>1980-1984</b>	<b>1985-1989</b>	<b>1990-1994</b>	<b>1995-1999</b>	<b>2000-2004</b>	<b>2005-2009</b>	<b>2010-2014</b>
<i>Fibromyalgia</i>							
Social Security	0	13	23	151	466	1,869	4,642
ADA/Rehab Act	0	0	8	29	57	126	143
FMLA	0	0	0	5	9	10	11
ERISA	0	0	2	45	167	474	284
<b>Total</b>	<b>0</b>	<b>13</b>	<b>33</b>	<b>230</b>	<b>699</b>	<b>2,479</b>	<b>5,080</b>
<i>Chronic Fatigue Syndrome</i>							
Social Security	0	0	31	100	173	424	533
ADA/Rehab Act	0	0	3	25	24	30	32
FMLA	0	0	0	5	7	22	17
ERISA	0	0	8	45	85	187	109
<b>Total</b>	<b>0</b>	<b>0</b>	<b>42</b>	<b>175</b>	<b>289</b>	<b>663</b>	<b>691</b>
<i>Multiple Chemical Sensitivity Disorder</i>							
Social Security	0	0	3	16	5	29	26
ADA/Rehab Act	0	0	3	21	13	6	9
FMLA	0	0	0	1	0	5	2
ERISA	0	0	0	6	2	8	2
<b>Total</b>	<b>0</b>	<b>0</b>	<b>6</b>	<b>44</b>	<b>20</b>	<b>48</b>	<b>39</b>
<i>ADD/ADHD</i>							
Social Security	0	1	6	66	126	500	2,135
ADA/Rehab Act	0	1	14	122	110	277	370
FMLA	0	0	0	4	11	16	47
ERISA	0	0	0	3	8	29	32
IDEA	1	4	25	73	96	262	385
<b>Total</b>	<b>1</b>	<b>6</b>	<b>45</b>	<b>268</b>	<b>351</b>	<b>1,084</b>	<b>2,969</b>
<i>ADD/ADHD ( Without IEP, FAPE, IDEA)</i>							
Social Security	0	2	6	62	115	467	1,986
ADA/Rehab Act	0	1	5	86	79	180	271
<b>Total</b>	<b>1</b>	<b>3</b>	<b>11</b>	<b>146</b>	<b>194</b>	<b>647</b>	<b>2,257</b>

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Claim	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009	2010-2014
<i>PTSD</i>							
Social Security	0	3	16	32	99	532	2,772
ADA/Rehab Act	1	2	5	30	37	160	281
FMLA	0	0	0	1	6	44	79
ERISA	0	0	0	4	10	53	61
IDEA	0	0	0	0	2	11	38
<b>Total</b>	<b>1</b>	<b>5</b>	<b>21</b>	<b>67</b>	<b>154</b>	<b>800</b>	<b>3,231</b>

**Table 2**  
Increase in Contested Illness Claims from 1990-1994

Claim	1995-1999	2000-2004	2005-2009	2010-2014
Fibromyalgia	597%	2,018%	7,412%	15,294%
Chronic Fatigue Syndrome	317%	588%	1,479%	1,545%
ADD/ADHD	496%	680%	2,309%	6,498%
PTSD	219%	633%	3,710%	15,286%