



## REPLY

## Medical Civil Rights as a Site of Activism: A Reply to Critics

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My respondents, Allison Hoffman, and Rabia Belt and Doron Dorfman, generously wrote their responses to my Article, *Medicalization and the New Civil Rights as the nation lurched from crisis to crisis*.<sup>1</sup> Their responses were written in the throes of the onslaught of COVID-19, the effects of which were concentrated on those who were already vulnerable. With the epidemic still raging, protests broke out over the killing of George Floyd. We live in a time when the law seems to have failed those seeking justice—and we are casting about for alternatives.<sup>2</sup>

Enter medical civil rights. In the context of the Floyd murder itself, Minneapolis City Council Vice President Andrea Jenkins, the first openly transgender Black woman elected to public office in the United States, argued that racism should be declared a public health emergency.<sup>3</sup> Analogizing racism to “cancer,” she argued, “[u]ntil we name this virus [i.e. racism], we will never, ever resolve this issue.”<sup>4</sup> The Cleveland City Council’s Health and Human Services committee met virtually (in light of the COVID-19 epidemic) to discuss a resolution declaring “Racism as a Public Health Crisis.”<sup>5</sup> The President of the American Psychological Association similarly argued, “[w]e are living in a racism pandemic, which is taking a heavy psychological toll on our African

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1. Rabia Belt & Doron Dorfman, Response, *Reweighing Medical Civil Rights*, 72 STAN. L. REV. ONLINE 176 (2020); Allison K. Hoffman, Response, *How Medicalization of Civil Rights Could Disappoint*, 72 STAN. L. REV. ONLINE 165 (2020).

2. Cf. Monica C. Bell, *Police Reform and the Dismantling of Legal Estrangement*, 126 YALE L. J. 2054 (2017) (describing legal estrangement in police contexts).

3. *Minneapolis City Council Official Calls for Racism to be Declared a Public Health Emergency*, AXIOS (May 28, 2020), <https://perma.cc/7N3K-7ULM>.

4. *Id.*

5. *Racism as a Public Health Crisis Virtual Meeting*, CLEVELAND CITY COUNCIL (May 30, 2020), <https://perma.cc/2THA-RM9W>.

American citizens.”<sup>6</sup> Over 130 localities and states declared racism a public health emergency, including the states of Michigan, Wisconsin, Nevada, and the localities of Boston, Denver, Columbus, Cook County, Pittsburgh, Minneapolis, Memphis, and Dallas, the vast majority doing so this past summer.<sup>7</sup> Many, therefore, continue to diagnose civil rights problems and their solutions using medical frames. Are these policymakers, backed by activists, wrong to do so? The answer, according to legal scholarship that has explicitly considered the question, seems to be yes.<sup>8</sup>

My ambitions are, in some ways, modest. I simply argue that while the legal scholarship has emphasized the harms of using medical discourse, it has not explicitly considered its benefits across social movements—and there are several. Rather than suggest that these activists have miscalculated, I seek to understand why activists and policymakers have deployed medical frames. Further, recognizing that medical discourse and the rights—and burdens—it produces are malleable, I seek to explore ways in which to further its social justice possibilities.

For some actors, however, the costs may still outweigh the benefits, and my interlocutors perform a valuable task in elucidating their perspective. Those calculations may change, not just from group to group, but from individual to individual, and there is substantial disagreement within groups.<sup>9</sup> Our conversation is part of a broader one among various disciplines, including medical humanities, disability theory, and health policy. While historically the relationship between at least some of these disciplines, particularly medical humanities and disability theory, was “tense and distant,”<sup>10</sup> as this engagement represents, the scholarship has moved in the direction of “bridge-building” and “cross-pollinat[ion].”<sup>11</sup>

To further that end I focus on three main questions: What benefits does medicalization provide, who is involved in offering and receiving the benefits, and why do medical frames provide these benefits? But before I do any of that, I address a fundamental question on which there is significant confusion—what is “medicalization”?

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6. ‘We Are Living in a Racism Pandemic,’ Says APA President, AM. PSYCH. ASS’N (May 29, 2020), <https://perma.cc/NZB5-HEQF>.

7. *Declarations of Racism as a Public Health Issue*, AM. PUB. HEALTH ASS’N, <https://perma.cc/KK89-CQP7> (archived Dec. 3, 2020).

8. See Craig Konnoth, *Medicalization and the New Civil Rights*, 72 STAN. L. REV. 1165, 1202-08 (2020).

9. See, e.g., *infra* text accompanying notes 78-83 (discussing diverse approaches to the transgender movement and diagnoses).

10. Carol Thomas, *Medical Sociology and Disability Theory*, in *NEW DIRECTIONS IN THE SOCIOLOGY OF CHRONIC AND DISABLING CONDITIONS: ASSAULTS ON THE LIFEWORLD* 44 (Graham Scambler & Sasha Scambler eds., 2010) [hereinafter *NEW DIRECTIONS*].

11. Simon J. Williams, *The Biopolitics of Chronic Illness: Biology, Power and Personhood*, in *NEW DIRECTIONS*, *supra* note 10, at 205, 207; Konnoth, *supra* note 8, at 1171.

## I. What is Medicalization?

One fundamental concern Belt and Dorfman raise goes to the concept of medicalization. They argue, both at the beginning and at the end of their response, that by supporting medicalization, I am advancing an “older model of disability advocacy” that “perpetuate[s] dependency and charity,” that shifts power from patients to experts, and that results in societal alienation.<sup>12</sup> In particular, they suggest that I am advancing the “medical aspects” of disability, rather than the “social model.”<sup>13</sup>

The distinction they offer, presumably, tracks that of the “medical” and “social” model of disability that the Article describes at length.<sup>14</sup> Roughly speaking, in cases of disability, the medical model requires changes and “cures” to the bodily traits of the person experiencing disability, while the social model suggests changes to social circumstances that render the trait disabling—thus, instead of forcing a cochlear implant on an individual, as the medical model requires, the social model requires accessible signing services.

In their treatment of the medical and social models, Belt and Dorfman do not mention the Article’s discussion, so I cannot claim this for sure—but I suspect our disagreement is terminological. By partially defending medical discourse, I do not defend the medical model, as medical discourse and “medical model” in disability theory are not the same thing. Disability theory uses the phrase “medical model” to describe an archetype; it is a term of art that imagines a solely biological approach to curing disability, thus emphasizing the harmful possibilities of medicine.<sup>15</sup> But the on-the-ground reality of modern medicine has increasingly moved away from this sole reliance on biology, thanks in large part to the work of disability activists. Indeed, as the Article explains, medical frames today seek to advance structural solutions, such as housing and anti-racism efforts.<sup>16</sup> Medical discourse, today at least, deals heavily with the “social environment”; the “medical model” does not.<sup>17</sup> Conceptualizing medicine as involving only a certain kind of medical professional exercising biological authority imagines an ideal type of western medicine, embedded at a certain point in history.<sup>18</sup> The “medicalization” that Belt and Dorfman target is

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12. Belt & Dorfman, *supra* note 1, at 177-78, 184.

13. *Id.* at 187. See generally Ruth Colker, *Anti-Subordination Above All: A Disability Perspective*, 82 NOTRE DAME L. REV. 1415 (2013) (describing the importance of structural solutions to achieve anti-subordination).

14. Konnoth, *supra* note 8, at 1180 n.58.

15. *Id.*

16. See, e.g., *id.* at 1197.

17. Indeed, many disability scholars today protest the biological-social dichotomy as not reflecting lived experience, as the original Article notes, and I disavow that I am making claims regarding biological situatedness, explicitly, either way. *Id.*

18. See Konnoth, *supra* note 8, at 1255 n.476.

therefore a faux ami—or perhaps, a faux enemy; it is not the purely biologically based medical model that they rightly question.

In understanding how medicine came to look to (some) structural solutions, it is important to understand that medicine is a social discourse, shaped by time and place and by those who invoke it. For most of human history—from the ancient Greeks to well into the nineteenth century—medicine was generally understood as an art that sought to maintain the balance of bodily “humors” or fluids.<sup>19</sup> Both behavior, and (with Christianity’s arrival) sin, determined how the humors were balanced, but with some groups—racial minorities, women, the poor—the humors were always out of sync.<sup>20</sup> This meant that the fault for medical harm lay within the bodies or soul.

The twentieth century has generally abstracted medical fault away from the body through a process that has invited controversy and turmoil. First, the germ theory of the late nineteenth century meant that individuals were not solely responsible for ill health—tuberculosis, for example, was proven not to be the result of an imbalance in the humors, but rather the result of germs. Eugenic arguments remained—germs there may be, but the weak constitutions of certain individuals caused them to succumb; indeed, some eugenicists opposed public health programs so that those weakly constituted would die.<sup>21</sup>

Mid-century approaches turned to technical, biological remedies, and the focus was on professionals imposing cures on the patient.<sup>22</sup> This is the period which Belt and Dorfman highlight—they rely heavily on the work of pioneering medical sociologist Talcott Parsons, who emphasized the stunted power dynamics between doctor and patient.<sup>23</sup> Subsequent sociologists and disability scholars have criticized Parsons’s observations as representing an “ideal type,” and an “abstract hypothetical construct” (much like the medical model),<sup>24</sup> and have argued that patients often occupied “active,” rather than “passive” roles even then.<sup>25</sup> In any case, Parson’s observations were made in 1951—twenty

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19. See Craig Konnoth, *Medical Stereotypes* 10 (May 8, 2020) (unpublished manuscript) (on file with author).

20. *Id.* at 11.

21. Martin S. Pernick, *Eugenics and Public Health in American History*, 87 AM. J. PUB. HEALTH 1767, 1767 (1997).

22. See Nancy Krieger, *Epidemiology and Social Sciences: Towards a Critical Reengagement in the 21st Century*, 22 EPIDEMIOLOGIC REVS. 155, 159 (2000) (“[T]he bulk of early- to mid-20th century US epidemiologic inquiry either ignores social factors or treats them as nuisance variables encountered en route to ascertaining the ‘true’ etiology (read ‘biological causes’) of disease”).

23. Belt & Dorfman, *supra* note 1, at 183 & nn.40-44.

24. Kathy Charmaz, *Studying the Experience of Chronic Illness through Grounded Theory*, in NEW DIRECTIONS, *supra* note 10, at 8, 14; Carl May, *Retheorizing the Clinical Encounter: Normalization Processes and the Corporate Ecologies of Care*, in NEW DIRECTIONS, *supra* note 10, at 129, 131.

25. Graham Scrambler & Sasha Scrambler, Introduction: The Sociology of Chronic and Disabling Conditions, Assaults on the Lifeworld, in NEW DIRECTIONS, *supra* note 10, at 1, 2.

years before the birth of the bioethics movement, and forty before mainstream medical (re-)engagement with social determinants of health.

Starting in the 1970s, the bioethics movement began in earnest, emphasizing the importance of informed consent and patient participation.<sup>26</sup> Further, while technical remedies have remained important, at least since the early 2000s, researchers have refocused their energies on so-called social determinants of health, which continued some threads of public health work from nearly a century before.<sup>27</sup> On this account, both material- and status-based factors in one's environment such as housing, employment, financial, family, social, and educational circumstances, all affect health.<sup>28</sup> It has only been in the last two decades or so, however, that efforts have begun in earnest to address these social determinants,<sup>29</sup> and some—such as racism, as the Article describes—are still being understood.<sup>30</sup>

As a procedural matter, bioethics has thus begun the task of seeking participatory justice. As a substantive matter, social determinants emphasize substantive goals involving equity. That bifurcated understanding can frame several movements that, in turn, affected the social role of medicine.

In the 1970s, for example, psychiatrists who became embedded in Vietnam veteran organizations “as peers”—that is, as fellow activists, rather than as distanced professionals—successfully pushed for Post-Traumatic Stress Disorder (PTSD) to be recognized as an after-effect of combat.<sup>31</sup> As the Veterans Administration notes today, this meant that “the significant change ushered in by the PTSD concept was the stipulation that the etiological agent was outside the individual (i.e., a traumatic event) rather than an inherent individual weakness.”<sup>32</sup> Participatory justice thus achieved substantive justice—the profession realized that society, rather than the individual, was responsible for trauma.

As medical sociologists describe, other movements—such as the breast cancer movement—built on these techniques seeking to emphasize social structures in medical narratives.<sup>33</sup> The Article goes on to describe in detail how

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26. See Olubukunola Mary Tawose, *The Legal Boundaries of Informed Consent*, 10 AM. MED. ASS'N J. ETHICS 521, 522 (2008).

27. Konnoth, *supra* note 8, at 1196.

28. Jeff Niederdeppe, Q. Lisa Bu, Porismita Borah, David A. Kindig & Stephanie A. Robert, *Message Design Strategies to Raise Public Awareness of Social Determinants of Health and Population Health Disparities*, 86 MILBANK Q. 481, 482-83 (2008).

29. Konnoth, *supra* note 8, at 1196.

30. *Id.* at Part IV.B.2.

31. Konnoth, *supra* note 19, at nn.423-29 and accompanying text.

32. Matthew J. Friedman, *PTSD History and Overview*, U.S. DEP'T OF VETERANS AFFS., <https://perma.cc/7FUW-AU52> (archived Dec. 3, 2020).

33. MAREN KLAWITER, *THE BIOPOLITICS OF BREAST CANCER: CHANGING CULTURES OF DISEASE AND ACTIVISM*, 165-168 (2008) (discussing how the women's breast cancer movement built directly on the AIDS movement).

today, lay individuals participate in medical narratives and knowledge making more than ever before. I discuss how medical social movements have shaped diagnoses, how “[p]atients and former patients . . . ‘sit on state mental health councils, work for mental health agencies, and serve on treatment policy committees,’” and engage with Institutional Review and governance boards of medical institutions.<sup>34</sup> I explain how outside medical institutions, lay individuals shape medical discourse through numerous means, far beyond the reach of the medical profession.

As a result, interventions are evolving. Insurance—from Medicaid to insurers like Aetna—seek to promote social and structural remedies like housing, to some degree at least.<sup>35</sup> Provider groups are hiring social workers to connect patients to remedies that would historically be considered non-medical.<sup>36</sup> These changes are desirable. Disability scholar Sam Bagenstos discusses some of these changes in explaining how disability activists on the ground rely on “the assistance and endorsement of professionals.”<sup>37</sup> He sees the incorporation of non-medical professions as de-medicalization—but I see it rather as the influence of the disability movement on medicine, precisely what disability theorists have called for.<sup>38</sup>

This discussion in the Article shows that medical discourse, in practice, increasingly reflects Belt and Dorfman’s understanding of disability as “formulated through a complex interaction between the impairment and the social environment.”<sup>39</sup> Many of these achievements derive from the efforts of lay actors. Belt and Dorfman are concerned that the Article seeks to “tak[e] the expertise and decisionmaking capacity away from patients and disabled individuals and hand[] it over to other experts to make decisions for them.”<sup>40</sup> But my Article applauds, at length,<sup>41</sup> the “‘resistance and self-defense against’ coercive medical institutions” within medical discourse and the development of “patient ‘counter-expertise’” both inside institutions and in society more

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34. Konnoth, *supra* note 8, at 1253 (quoting Nancy Tomes, *From Outsiders to Insiders: The Consumer-Survivor Movement and Its Impact on U.S. Mental Health Policy* 113, in *PATIENTS AS POLICY ACTORS* (Beatrix Hoffman, Nancy Tomes, Rachel Grob & Mark Schlesinger eds., 2011)).

35. AMANDA CASSIDY, HEALTH AFFS., MEDICAID AND PERMANENT SUPPORTIVE HOUSING 2 (Oct. 14, 2016), <https://perma.cc/5BEM-JE3Z>; AETNA, PROMOTING HEALTH EQUITY FOR LOW-WAGE WORKERS: HOW EMPLOYERS CAN REDUCE HEALTH CARE COSTS, INCREASE PRODUCTIVITY AND HELP EMPLOYEES STAY HEALTHY 4 (2019), <https://perma.cc/QBG4-B5U5>.

36. See Lindsey Getz, *Accountable Care Organizations: Social Work’s Impact on an Emerging Model*, SOCIAL WORK TODAY, Mar. 2015, at 24.

37. SAMUEL R. BAGENSTOS, LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT 22 (2009).

38. Konnoth, *supra* note 8, at 1257 n.494.

39. Belt & Dorfman, *supra* note 1, at 187.

40. *Id.* at 184.

41. Konnoth, *supra* note 8, at 1250-57.

generally, that we are seeing today.<sup>42</sup> While new understandings of and engagement with medical discourse are layered upon older constructs instead of fully displacing them, I do not, as my interlocutors worry, seek to advance these “older models.”<sup>43</sup> Rather, I find hope in new, social, participatory models of medicine.

## II. What Benefits Does Medicalization Provide?

What then, are the benefits that this new world of medicalization brings? Hoffman and Belt and Dorfman suggest that the benefits are limited. Hoffman suggests that medical civil rights remedies are not structural: they take an “individualized patient-centric” approach and focus on changing behavior instead of background conditions.<sup>44</sup> Belt and Dorfman similarly argue that the benefits do not involve “broad-scale social reform.”<sup>45</sup>

The issue is one of perspective, and of comparativity. First, as a matter of perspective, what is structural change depends on the kinds of structure at issue. In some cases, all that happens is that an individual gets a “small-bore item[] like [an] ergonomic chair[.]”<sup>46</sup> Sometimes, an office may get a ramp that benefits those with mobility issues, or, for that matter, those pushing a baby carriage or hauling a heavy suitcase.<sup>47</sup> One level up, there might be change to the practices of an entire school district. A level above that, the practices across a global company might change.<sup>48</sup> But there are also widespread programmatic changes: those that provide housing and employment assistance under Medicaid, to take one example.<sup>49</sup> And indeed, the passage of the Americans with Disabilities Act (ADA) itself, along with other statutes that ensure that

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42. *Id.* at 1250 (quoting Robert A. Nye, *The Evolution of the Concept of Medicalization in the Late Twentieth Century*, 39 J. HIST. BEHAV. SCIS. 115, 124 (2003)). Indeed, the relevant Subpart is entitled “Inside medical institutions: Patient empowerment.” *Id.*

43. Belt & Dorfman, *supra* note 1, at 188. I recognize this potential nominal and terminological confusion when citing a source on which Belt and Dorfman subsequently rely. Konnoth, *supra* note 8, at 1250 n.451; Belt & Dorfman, *supra* note 1, at 183-84 nn.45-46 (both citing Maayan Sudai, *Revisiting the Limits of Professional Autonomy: The Intersex Rights Movement’s Path to De-Medicalization*, 41 HARV. J. L. & GENDER 1 (2018)).

44. Hoffman, *supra* note 1, at 166, 168.

45. Belt & Dorfman, *supra* note 1, at 182.

46. *Id.*

47. See Elizabeth F. Emens, *Integrating Accommodation*, 156 U. PA. L. REV. 839, 841, 846 (2008); Jamie Gold, *The ADA on Its 30th Anniversary: Looking Back and Forward*, FORBES (July 26, 2020, 8:00 AM EDT), <https://perma.cc/3E3K-JBT8>.

48. See, e.g., Alex Thornton, ‘We Are at a Crossroads’—How Microsoft’s Accessibility Team is Making an Impact that Will Be Felt for Generations, MICROSOFT (Sept. 25, 2019), <https://perma.cc/B2LR-ZH83> (providing overview of Microsoft’s accessibility initiatives).

49. Mary Crossley, *Bundling Justice: Medicaid’s Support for Housing*, 46 J. L. MED. & ETHICS 595, 595 (2018) (discussing housing as a medical necessity).

numerous individuals across the country can have access to “small-bore” benefits, constitutes a vast structural change. Such change, I would posit, is far from “granular.”<sup>50</sup>

Next, Belt and Dorfman claim that the “apparent generosity” of disability law is “belied” by the reality<sup>51</sup>—a fact that is, alas, true of civil rights law in general. Further, disability—and, more generally, medicalization—designations come with costs, such as stigmatization, that the original Article documents exhaustively. Here, the comparativity point comes into play: How do the medicalization benefits compare to those of previous years—that is, what trend is medicalization on—and how do medical rights compare to other kinds of rights?

There is no question that the benefits medicalization provides have improved drastically over a relatively short period of time. Social determinants of health literature entered the mainstream, on some accounts, in the 1990s.<sup>52</sup> Hoffman alludes to Thomas Frieden’s famous public health pyramid in describing public health measures that envisage behavioral change among individuals.<sup>53</sup> While Hoffman raises concerns that ongoing measures do not address the bottom of the pyramid, which refers to the social environment in which individuals live, public health measures are indeed moving in that direction. Researchers of public health recognize, as Hoffman notes, that unhealthy eating is not just about lack of access to food stores—“[i]t is more about who has the time and money to exercise and cook,” and “habits developed over generations of poverty.”<sup>54</sup> And that is why medical programs have recently intervened more and more in seeking to support financial, housing, and employment assistance, and even cooking classes.<sup>55</sup> Similarly, in the context of long-term care support, it is clear both that “the notion that social insurance should support the medical but not the social aspects of care endures in a deep way,” but at the same time, that “Medicaid’s institutional bias has receded in favor of home-based care.”<sup>56</sup> Things are changing.

But what about the changes in other areas of law? Changes there seem less promising, and in the original Article, I go through a litany of other possibilities, from laws prohibiting race and sex discrimination to those offering unemployment and housing benefits, which seem to have receded,

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50. Hoffman, *supra* note 1, at 169.

51. Belt & Dorfman, *supra* note 1, at 181.

52. ALEC IRWIN & ELENA SCALI, WORLD HEALTH ORG., ACTION ON THE SOCIAL DETERMINANTS OF HEALTH: LEARNING FROM PREVIOUS EXPERIENCES 23 (2005), <https://perma.cc/L39C-EEUF>.

53. Hoffman, *supra* note 1, at 167.

54. *Id.* at 168.

55. See, e.g., Keith Brannon, *Tulane University School of Medicine to Open First-of-Its-Kind Teaching Kitchen*, TUL. U. (May 9, 2013, 11:00 AM), <https://perma.cc/5QUM-L5KK>; Konnoth, *supra* note 8, at 1197.

56. Hoffman, *supra* note 1, at 172.



even as medical frames have advanced more and more rights.<sup>57</sup> My claims there remain largely unchallenged.<sup>58</sup> Hoffman herself notes that civil rights law in general suffers from many of the same pathologies that she attributes to medical civil rights: Civil rights law “relies increasingly on individual legal claims and harms, and structural interventions have become increasingly difficult.”<sup>59</sup> Belt and Dorfman point to an “updated and nuanced” social conception of rights, but do not offer a concrete vehicle through which they can manifest.<sup>60</sup> Medicalization, on my account, is just that vehicle.

That said, it is true that medicine can “sit on both sides of the law in a problematic way”<sup>61</sup>—it can justify liberty deprivations as well as liberty recognition. My point, however, is that the pendulum has shifted over the last century from the former to the latter. And now, as law by itself—which also can both oppress and liberate—is proving to be a less fecund source for rights, we must ensure that the battle within and outside medicine continues to maintain its trend.

Last, Hoffman suggests that in the long run, medicalization might address only the “physical manifestations” of discrimination.<sup>62</sup> I agree that should there be a retrenchment in medical rights such that only physical harms are cognizable, it would indeed be problematic. But thanks to concerted efforts, medical civil rights have not been limited in that way. To take one example, when the ADA was proposed, Jesse Helms and his allies opposed classifying mental impairments as disabilities under the Act.<sup>63</sup> That attempt was beaten back.<sup>64</sup> Thus, both the ADA and Social Security programs, among others, cover

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57. Konnoth, *supra* note 8, at 1168-69, 1213-31; *see also id.* at 1245 (noting how positive rights claims in non-medical contexts are stigmatizing).

58. Belt and Dorfman disagree with my claim that the welfare-based predecessors of Medicaid treated their claimants worse than Social Security because it was only the *intent* of the Social Security programs to do so, and the actuality is different. Belt & Dorfman, *supra* note 1, at 181 n.29. My Article, however, makes this point. *See* Konnoth, *supra* note 8, at 1207 (noting “despite these intentions, rather than dignifying individuals, these rights can impose various kinds of stigma” and detailing stigmatic narratives). Second, in refuting my comparative point, none of their sources actually *compares* Medicaid or its predecessors to Social Security (when Medicaid is mentioned at all). *Cf.* Telephone Interview with Claire Dickson, Supervising Att’y, Colo. Legal Aid (Aug. 13, 2020) (noting that on the whole, Medicaid involves more intrusion than Social Security, but that it depends on the program at issue). Third, they raise concerns about the age of the source I rely on, but it remains the foremost comparative account of Medicaid and Social Security.

59. Hoffman, *supra* note 1, at 166.

60. Belt & Dorfman, *supra* note 1, at 187.

61. Hoffman, *supra* note 1, at 170.

62. *Id.* at 165.

63. Michael L. Perlin, *The ADA and Persons with Mental Disabilities: Can Sanist Attitudes Be Undone?*, 8 J. L. & HEALTH 15, 27 (1993).

64. *Id.* at 27-28.

both “physical or mental” conditions.<sup>65</sup> And plaintiffs have obtained concrete benefits from claiming that gender identity disorder is a “legitimate mental disorder.”<sup>66</sup> More recently, in *P.P. v. Compton Unified School District*, litigators focused on the psychological trauma caused by racism, poverty, and homelessness.<sup>67</sup> To be sure, litigators “detail[ed] the body’s response to trauma” including “neurobiological effects” that “affect[] the brain,” but the factual allegations based on which the court ruled focus on how psychological harms affect behavior.<sup>68</sup> The allegation of physical harm, in other words, is inseparable from, and arguably flows from many kinds of mental impairments.

### III. Who Is Involved?

In the first Part, I describe in detail how medical knowledge and framing is no longer the province of medical professionals alone. Sociologists like Nikolas Rose and Steven Epstein describe at length how lay individuals use medical frames as part of their self-understanding—as my Article describes at length, these new forms of engagement ground “biosocial organization” through phenomena such as the proliferation of medical devices, home medical care, and the engagement of other professions in care, as understanding of social determinants abounds.<sup>69</sup> This means that groups often understand themselves in medical terms, and engage in medical activism—including movements that pressed for diagnoses including PTSD, Battered Women’s Syndrome, coal miners’ lung, and the like.<sup>70</sup>

Similarly, today, so-called COVID-19 “long-haulers”—individuals with persistent COVID-19 symptoms have “set up their own support groups,” and are “running their own research projects, [and] form[ing] alliances with people who have similar illnesses, such as . . . chronic fatigue syndrome. A British group—LongCovidSOS—launched a campaign to push the government for recognition, research, and support.”<sup>71</sup> This has led to policy support for increased funding for research into the way we measure long-term COVID-19 outcomes.<sup>72</sup>

Hoffman, however, suggests that non-medical rights claims can more directly relate to group identity. Cases that do not (explicitly) include medical discourse, like *Obergefell v. Hodges*, “can . . . quickly translate into group-level

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65. Konnoth, *supra* note 8, at 1182.

66. *Id.* at 1191 (quoting *O’Donnabhain v. Comm’r*, 134 T.C. 34, 59 (2010)).

67. 135 F. Supp. 3d 1098, 1104 (C.D. Cal. 2015).

68. *Id.* at 1103, 1105.

69. Konnoth, *supra* note 8, at 1255, 1257.

70. Konnoth, *supra* note 19, at 8, 31, 48, 61.

71. Ed Yong, *Long-Haulers Are Redefining COVID-19*, ATLANTIC (Aug. 19, 2020), <https://perma.cc/J8DU-RHCJ>.

72. *Id.*

benefits and social understandings.”<sup>73</sup> Those cases directly target the basis of discrimination—homophobia, racism, and sexism—rather than hiding behind the “scrim” of medicine.<sup>74</sup>

But part of my claim is that rather than making medical claims disingenuously or in ways that are delinked from their realities, the “social understandings” of groups about their identities and the discrimination they experience are increasingly intertwined with medical narratives. We saw this dynamic in *Obergefell*, where Justice Kennedy relied on medical evidence to claim that homosexuality is immutable.<sup>75</sup> Similarly, our understanding of race is infused with medical understandings: Scholars such as Ruqaiijah Yearby, Lindsay Wiley, and myself have argued that medical discourse has the power to perpetuate or to help alleviate racism, especially when racism is understood as a phenomenon where social determinants of health are denied.<sup>76</sup> Discriminatory phenomena thus have their roots in various narratives of power—medicine is often one of them, and advocates may choose to emphasize its relationship to their experience.

The trans rights movement offers perhaps the most compelling example of this phenomenon. As Belt and Dorfman note, the ICD-11, which guides the diagnoses of all medical professionals, removed gender dysphoria with the support of many trans rights organizations.<sup>77</sup> But what they leave unsaid is that transgender activists see both harms and benefits to complete de-medicalization,<sup>78</sup> and the ICD replaces the term with “gender incongruence” in a separate section of the DSM, to maintain access to health services and the like.<sup>79</sup> Thus, while the claim that trans activists seek to de-pathologize trans identity is fair, the suggestion that the ICD “de-medicalizes trans identities” or

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73. Hoffman, *supra* note 1, at 166. *But see* Konnoth, *supra* note 8, at 1200 (noting how *Obergefell* relies on medical expertise for its immutability claims).

74. Hoffman, *supra* note 1, at 169.

75. *Obergefell v. Hodges*, 135 S. Ct. 2584, 2596 (2015).

76. Ruqaiijah Yearby, *Structural Racism and Health Disparities: Reconfiguring the Social Determinants of Health Framework to Include the Root Cause*, 48 J. L. MED. & ETHICS 518, 518 (2020); Lindsay F. Wiley, *Structural Racism, Social Determinants, and the Contested Scope of Public Health Law*, PETRIE-FLOM CTR.: BILL OF HEALTH (Sep. 29, 2020), <https://perma.cc/ST8W-TTHK>; Konnoth, *supra* note 19, at Part IV.B.2.

77. Belt & Dorfman, *supra* note 1, at 184-85.

78. *See generally* GLOBAL ACTION FOR TRANS EQUALITY, IT’S TIME FOR REFORM: TRANS\* HEALTH ISSUES IN THE INTERNATIONAL CLASSIFICATIONS OF DISEASES, (2011), <https://perma.cc/B85Z-U93Z> (discussing the costs and benefits of de-medicalization).

79. Geoffrey M. Reed, Jack Drescher, Richard B. Krueger, Elham Atalla, Susan D. Cochran, Michael B. First, Peggy T. Cohen-Kettenis, Iván Arango-de Montis, Sharon J. Parish, Sara Cottler, Peer Briken & Shekhar Saxena, *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).

that that move is “supported by [all?] trans rights organizations,”<sup>80</sup> disregards diverse approaches in the trans movement, many of which intertwine medicine in their narratives of identity. This allows transgender advocates to seamlessly include medical civil rights claims in their litigation strategy. For example, as counsel of record on an amicus brief in support of the transgender plaintiff in *Bostock v. Clayton County*, in which the Court held in June that Title VII prohibited anti-transgender discrimination, I engaged in deep conversations with lawyers from my days as an LGBT rights activist about ensuring that either in victory or defeat, the viability of ADA-based arguments would not be affected.<sup>81</sup> As trans rights lawyers would point out, those arguments are still important for ongoing cases.<sup>82</sup>

Notably, the dynamic here is precisely that which describes medical civil rights in general. Medical discourse remains important precisely for access to rights and benefits, and members of the relevant group support its engagement. At the same time, because of the involvement of members of these groups, medical discourse is being used descriptively, without pathologizing. The result is the use of medical discourse, but at the same time, in a way that seeks to “depathologise and destigmatise the individuals called ‘transgender.’”<sup>83</sup> Medical categories—pregnancy, genetic susceptibility to certain conditions, or categories of individuals at risk for flu—do not pathologize the groups to which they refer. Through activism, and broadening consciousness, the goal is to extend that approach to other categories.<sup>84</sup>

While groups might invoke medical discourse, it is not the case—as Belt and Dorfman claim—that I “want[] more people to use medical claiming.”<sup>85</sup> To the contrary, my Article suggests that, as the explosion in medical civil rights claims shows, counter to the consensus in the legal literature, the benefits of medical civil rights seeking may outweigh the cost: “[L]ike any litigant, a medical civil rights claimant must consider whether, in their particular

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80. Belt & Dorfman, *supra* note 1, at 185.

81. I received permission from counsel to disclose this fact. See Email from Jon Davidson, Chief Counsel, Freedom for All Ams., to Craig Konnoth, Assoc. Professor of L., Univ. of Colorado Sch. of L. (Aug. 24, 2020) (on file with author).

82. Email from Kevin M. Barry, Assoc. Dean for Acad. Affs. and Professor of L., Quinnipiac Univ. Sch. of L., to Craig Konnoth, Assoc. Professor of L., Univ. of Colorado Sch. of L. (Aug. 12, 2020) (on file with author) (noting that the ADA reaches contexts that Title VII does not reach, and that the reasonable accommodations mandate of the ADA offers protections that Title VII—and in this author’s opinion, the Equal Protection Clause, should it be extended—does not provide).

83. Rebeca Robles García & José Luis Ayuso-Mateosb, *ICD-11 and the Depathologisation of the Transgender Condition*, 12 REVISTA DE PSIQUIATRÍA Y SALUD MENTAL (ENGLISH EDITION) 65, 66 (2019).

84. Maria Elisa Castro-Peraza, Jesús Manuel García Acosta, Naira Delgado & Ana María Perdomo-Hernández, *Gender Identity: The Human Right of Depathologization*, 16 INT’L J. ENV’T RSCH. PUB. HEALTH 978, 978 (2019).

85. Belt & Dorfman, *supra* note 1, at 179.

circumstance, benefits outweigh costs.”<sup>86</sup> At the same time, “[t]here is no formulaic answer for when this will be the case . . . . The analysis might hinge on the legal frame at issue, the condition involved, or personal preference” and, as the example of transgender rights shows, individuals in the same group will take different tacks.<sup>87</sup> Our task going forward, however, is to limit the costs.

Interestingly, even as Hoffman points to the many advantages of group-based claims, Belt and Dorfman point to the gatekeeping concerns group claims create,<sup>88</sup> which plague traditional civil rights groups as well as those who claim medicalization discourse.<sup>89</sup> Scholars like Bagenstos thus also support universal approaches to addressing harm, such as universal healthcare, that remove the focus on people with disabilities (and medicalized populations, as well) as uniquely needy.<sup>90</sup> Indeed, some disability theorists, I note, argue for emphasizing that we are all on a “continuous spectrum”—there is no clear line between disability and non-disability.<sup>91</sup> In the Article, I emphasize that the normalcy of medical discourse, as all individuals increasingly understand themselves through paradigms mediated by medical devices, genetic profiles, and “risk” analyses, can also create a form of “interest convergence.”<sup>92</sup> Yes, specific groups will continue to agitate for medical rights. But as legal scholar Martha Albertson Fineman and medical sociologist Simon Williams have argued, our material frailty demonstrates our common “vulnerability,” “dependence,”<sup>93</sup> and indeed, our humanity.

#### IV. Why Do Medical Civil Rights Provide Benefits?

In the Article, I explain that health policy today often provides medical civil rights. My key point—which my respondents do not deny—is that most appear to agree that shifting risk for a particular condition upon individuals expresses that, at a society-wide level, we assign blame to them for that condition. When we relieve risk from them, we are expressing that they should not be blamed for that harm. And as I document in detail, American history for the last seventy years has—not without the conflict that all social change attracts—involved dramatic reduction in medical risk with the passage of social security, the ADA,

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86. Konnoth, *supra* note 8, at 1248.

87. *Id.*

88. Belt & Dorfman, *supra* note 1, at 179.

89. Jessica A. Clarke, *Protected Class Gatekeeping*, 92 N.Y.U. L. REV. 101, 102-04 (2017).

90. Konnoth, *supra* note 8, at 1260 n.507 (quoting SAMUEL R. BAGENSTOS, *LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT* 145 (2009)).

91. Konnoth, *supra* note 8, at 1259 (quoting James C. Wilson, *Disability and the Human Genome*, in *THE DISABILITY STUDIES READER* 52, 59 (Lennard J. Davis ed., 3d ed. 2010)).

92. Konnoth, *supra* note 8, at 1261-62.

93. Martha Albertson Fineman, *The Vulnerable Subject and the Responsive State*, 60 EMORY L.J. 251, 255 (2010); Williams, *supra* note 11, at 209.

and the Affordable Care Act.<sup>94</sup> While society has shifted risk for other misfortunes—poverty, unemployment, and the like—back onto individuals, similar attempts in the medical context have failed.<sup>95</sup> And when tasks are framed as medical, assistance is forthcoming. To take one example from Hoffman’s response, as long as long-term care by family members was seen as “custodial,” Medicaid did not pay for it; as it began to be framed as medical, Medicaid stepped up.<sup>96</sup>

I do not deny that scattered exceptions exist—even while these programs offered protections for certain conditions, they left certain groups, such as those addicted to drugs, smokers, kleptomaniacs, and the like, out of their protections.<sup>97</sup> But—and I emphasize again—these were exceptions. My interlocutors do not deny that the broad rule over the last seventy years has been to move risk away from patients. Rather, they seek to add three additional exceptions to the list. Even if correct, these exceptions do not disprove the rule, but I have concerns even over these claimed exceptions.

The first example involves the opioid crisis. I follow a swathe of scholars in arguing that the medicalization of the opioid epidemic has resulted in a far more lenient approach to opioid addicts than to crack addicts who were criminalized.<sup>98</sup> Hoffman, who questions this conclusion, presents no comparative data to counter this comparative claim.<sup>99</sup> But she raises two fair alternatives to the medicalization explanation for why we blame opioid addicts less: (a) we blame doctors more because they were more to blame, and (b) they are more likely to be white than crack addicts.<sup>100</sup>

On the first possibility, the fact that we appropriately blame doctors has no clear bearing on the blame opioid addicts should carry. As Khiara Bridges notes, just as opioid addicts were subject to social forces (such as unscrupulous doctors) that led to addiction, so too were crack addicts.<sup>101</sup> Yet we are more likely to blame those social forces in cases involving opioid addiction.

Second, Hoffman is quite right that the blame game in these respective addiction epidemics has a lot to do with race. But, as I explain in a working draft, race has a lot to do with medicalization.<sup>102</sup> It is harder for Black people to medicalize problems in ways that seek rights—a problem I engage with in this

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94. Konnoth, *supra* note 8, at 1227-34.

95. *Id.* at 1228.

96. Hoffman, *supra* note 1, at 172.

97. Konnoth, *supra* note 8, at 1227 n.322, 1229, 1233.

98. *Id.* at 1194-95.

99. Hoffman, *supra* note 1, at 173-74.

100. *Id.* at 174.

101. Khiara M. Bridges, *Race, Pregnancy, and the Opioid Epidemic: White Privilege and the Criminalization of Opioid Use During Pregnancy*, 133 HARV. L. REV. 770, 791 (2020).

102. Craig Konnoth, *Race and Medical Double-Binds*, 120 COLUM. L. REV. F. (forthcoming 2020-2021) (manuscript at 1) (on file with author).

separate work—and the issue has to do with the fact that “[t]here is discrimination in the way rights are distributed—not just medical rights.”<sup>103</sup> And the issue of race is deeply intertwined with the issue of medicalization.

Finally, and most importantly, Hoffman does not engage with the statements of policymakers I quote that specifically invoke the medicalization frame to justify different treatment of opioid and crack addicts.<sup>104</sup> The ultimate animating factor may be racism, but medicine has the rhetorical and legitimizing power to produce the racist outcomes that benefit whites and harm Black people.

Hoffman next argues that the case of undocumented immigrants also shows our lack of empathy for harms framed as medical: “medical need could limit someone’s ability to come to the United States legally under public charge rules.”<sup>105</sup> Further, the Trump administration has not released immigrants in detention camps under the COVID threat.<sup>106</sup> Yet both her points in fact demonstrate the power of medicalization. The public charge rules are an acknowledgement that we do, as a society, take solicitude of individuals—once in this country—when they suffer medical misfortune. Medicalization is not a miracle frame—it will not persuade an administration like the current one to do justice on all fronts. And yet, on some fronts, it has been surprisingly effective.

Finally, Belt and Dorfman describe a series of cases at length that showed a Court unsympathetic to the ADA, demanding that people, for example, “mitigate[]” disabilities.<sup>107</sup> I describe these cases only in a footnote<sup>108</sup>—because in 2008, President George W. Bush (in his second term) signed a law, passed by unanimous consent in the Senate, overturning these cases.<sup>109</sup> That saga appears to reinforce my claims regarding the power of medicalization in the halls of policy. And while many Americans evince hostility to people living with disabilities—as a comparative matter, and given the policy changes I describe, attitudes towards medical misfortune in general remain unclear, contextual, and complex. When we speak as a society, however, our message is usually quite clear.

### Conclusion

There remains a lot to do. As Belt and Dorfman note, many medical civil rights remedies exact harm, and are not as effective as they could be. Medical

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103. Konnoth, *supra* note 8, at 1246.

104. *Id.* at 1194-95.

105. Hoffman, *supra* note 1, at 174.

106. *Id.*

107. Belt & Dorfman, *supra* note 1, at 179-80.

108. Konnoth, *supra* note 8, at 1233 n.360.

109. *Id.*; ADA Amendments Act of 2008, Pub. L. No. 110-325, § 2, 122 Stat. 3553, 3553-54 (codified at 42 U.S.C. § 12101 note).

rights, as the Article admits, are “Janus-faced.”<sup>110</sup> And Hoffman quotes my claim that “[m]edical claims are malleable [and] contingent . . . social phenomena” with concern—medical civil rights can be changed for the worse.<sup>111</sup>

And yet individuals seek these rights in growing numbers. Indeed, while the Trump years have exacted damage across all forms of rights-seeking, the longer trend and “broader perspective” of medical rights-seeking has been promising.<sup>112</sup> The task then, is not to tell individuals, activists, and groups that they are wrong, but to seek how to use these rights’ malleability to co-opt, shape, and transform medical civil rights to limit their harms and maximize their promise. The efforts of scholars and activists—among which the scholarship and work of my respondents are among the foremost—have helped move the needle in that direction. And we must continue onward. My respondents are correct that my Article is a (limited) defense of the phenomenon of medical civil rights. But it is more than that. It is also a call to arms.

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110. Konnoth, *supra* note 8, at 1245.

111. Hoffman, *supra* note 1, at 173 (quoting Konnoth, *supra* note 8, at 1174).

112. Konnoth, *supra* note 8, at 1249.