# PENALIZING PREVENTION: THE PARADOXICAL LEGAL TREATMENT OF PREVENTATIVE MEDICINE

#### Doron Dorfman<sup>†</sup>

includes Preventive medicine. which interventions intended to preempt illnesses before they surface, has long been a priority for furthering public health goals and improving quality of care. Yet, preventive medicine also sends strong signals about the possible risks associated with the users' behavior and character. This signaling effect intersects with existing stigma and pervades law and policy. Thus, the law endorses and encourages prevention on one hand and penalizes it on the other, creating the paradoxical legal treatment of preventive medicine. A spectrum of penalties is assigned to those using preventive medicine including, for example, insurance discrimination, exclusion from civic practices or the legal profession, and stigmatization. Laws, policies, and court decisions that penalize users deter them from using life-saving

<sup>†</sup> Associate Professor of Law, Seton Hall Law School faculty. J.S.D., J.S.M. Stanford Law School; B.A., LL.B., LL.M. University of Haifa. This Article was selected for the 2021 Health Law Scholars Workshop hosted by the American Society of Law, Medicine & Ethics (ASLME) and Saint Louis University School of Law. I greatly benefited from feedback by participants at the Harvard Health Law Policy, Bioethics, and Biotechnology Workshop, Stanford's Law & Biosciences Workshop, the Regulation and Innovation in the Biosciences (RIBS) Workshop, the Virtual Health Law Workshop, the Health Law and Policy Colloquium at UCLA Law, and the faculty workshops at Fordham Law School, Brooklyn Law School, Seton Hall Law School, and Syracuse University College of Law. For constructive commentary and fruitful engagement with this research I would like to thank Leo Beletsky, Rabia Belt, Micah Berman, Michal Buchhandler-Raphael, Tom F. Burke, Vanessa Casado-Pérez, Andrea Cascarano, Liz Chiarello, Brietta Clark, I. Glenn Cohen, Yaron Covo, Corey Davis, Christine Demetros, Taleed El-Sabawi, Monica Eppinger, Rachel Fabi, Rob Gatter, Sara Gerke, Daniel Goldberg, Hank Greely, Mark Hall, Nina Kohn, Julia Mahoney, Medha Makhlouf, Maya Manian, Mason Marks, Seema Mohapatra, Jamelia Morgan, Jennifer Oliva, Elizabeth Pendo, Vanessa Casado Pérez, Nicholson Price, Anya Prince, Heather Rothman, Chris Robertson, Fred Rottnek, Ana Santos Rutschman, Rachel Sachs, Nadia Sawicki, Liz Sepper, Eileen Selogie, D'Andra Shu, Paul E. Traynor, Charlotte Tschider, Ruqaiijah Yearby, Sidney Watson, Lindsay Wiley, Kimberly T. Wilson, Megan S. Wright, and Patti Zettler. I would like to give special thanks to Leah Fowler and Asaf Kletter for their deep engagement and thoughtful advice as well as to Niloofar Abedzadeh and Julie Park for excellent research assistance. I would also like to thank the Cornell Law Review editors Kevin Corbett, Gigi Scerbo, Nicholas Serensits, Misha Spivakovsky, and Nitin Tangellamudi for their terrific work on this Article.

preventive health measures, hindering the promise of preventive medicine. This Article introduces an original typology and conducts three in-depth case studies on the regulation of the HIV prophylactic drug, PrEP, mental health treatment, and the public use of the opioid reverser naloxone to demonstrate how the law penalizes prevention. It then calls for harmonizing the legal regulation of preventive medicine to allow for preventative medicine's important goals to come to fruition.

Introi	DUCTION	313
I.	CATEGORIES OF PREVENTIVE MEDICINE, RISK	
	GROUPS, AND SIGNALING EFFECTS	317
II.	The Paradoxical Legal Treatment of	
	PREVENTIVE MEDICINE	321
III.	Penalizing Prevention: Three Case Studies	326
	A. Penalizing Sexual Health: The Case of PrEP 3	327
	1. A Primary Preventive Measure for	
	HIV Infection 3	327
	2. PrEP Insurance Discrimination	32
	3. Exclusion from the FDA's Blood	
	Donation Policy 3	35
	4. Penalizing PrEP Use in Child Custody and	
	Visitation Cases3	39
	B. Penalizing Mental Health Treatment: The	
	Case of the Character and Fitness	
	Screenings for State Bar Associations 3	642
	1. Three Decades of Mental Health	
	Fitness in the Courts and Beyond	
	a. The 1990s and the Effect of the ADA3	647
	b. The 2000s and the Rise of the	
	Behavioral Approach3	
	c. The Last Decade3	
	C. Penalizing Altruism: The Case of Naloxone 3	
	1. The Current Opioid Crisis	
	2. The Promise of Naloxone	
	3. Naloxone Insurance Discrimination	
IV.	Toward a Typology of Preventive Medicine Stigma3	
V.	NORMATIVE IMPLICATIONS AND POLICY RECOMMENDATIONS 3	575
	A. Using State and Federal Laws to	
	Combat Insurance Discrimination	576
	B. A Behavioral-Individualistic Approach to Risk:	
	Fighting Exclusion from Civic and	
	Professional Practices 3	678

C.	Destigmatizing the Multiple Aspects of	
	Preventive Measures	381
Conclusion		383

#### INTRODUCTION

Scientific advancements in health interventions can now preempt diseases before they erupt. Prevention is the crown jewel of the public health field<sup>1</sup> as well as a key component in measuring quality of health care.<sup>2</sup> Yet, the law jeopardizes the uptake of preventive medicine. This Article argues that the law penalizes prevention. It brings to light a critical barrier to implementing preventive health measures, which is what I term *the paradoxical legal treatment of preventive medicine*.

Consider Pre-Exposure Prophylaxis ("PrEP"), a novel and highly effective drug treatment that prevents sexual transmission of HIV. PrEP users, often perceived to be engaging in "risky" sexual behaviors, are penalized for taking this preventive measure. They are discriminated against in the insurance context, denied coverage, prohibited under FDA policy from the civic ritual of donating blood,<sup>3</sup> and their parental fitness is questioned in family court.<sup>4</sup> In September 2022, the U.S. District Court of the Northern District of Texas found the Affordable Care Act's ("ACA") Section 2713, which mandates insurers to cover PrEP as a preventive measure, violates employers' religious beliefs under the Religious Freedom Restoration Act ("RFRA").<sup>5</sup> This is because using the drug "facilitate[s]

<sup>3</sup> Jeffrey A. Bennett, Banning Queer Blood: Rhetorics of Citizenship, Contagion, and Resistance 118 (2009).

<sup>5</sup> Braidwood Mgmt. Inc. v. Becerra, No. 4:20-cv-00283-O, 2022 WL 4091215, at \*20 (N.D. Tex. Sept. 7, 2022).

 $<sup>^1\,</sup>$  Scott Burris, Micah L. Berman, Matthew Penn & Tara Ramanathan Holiday, The New Public Health Law: A Transdisciplinary Approach to Practice and Advocacy 6 (2018) (finding that the aim of public health is to prevent rather than treat illness).

<sup>&</sup>lt;sup>2</sup> Avedis Donabedian, who pioneered the study of quality in health care, famously recognized prevention as one of the crucial activities that constitute the process of health care and that it should be measured to determine health care quality. *See* Avedis Donabedian, AN INTRODUCTION TO QUALITY ASSURANCE IN HEALTH CARE 46 (Rashid Bashshur ed., 2003); Avedis Donabedian, *Evaluating the Quality of Medical Care*, 83 MILBANK Q. 691, 716 (2005) ("In addition to defects in method, most studies of quality suffer from having adopted too narrow a definition of quality. In general, they concern themselves with the technical management of illness and pay little attention to prevention . . . ."); *see also* David Blumenthal, *Part 1: Quality of Care—What Is It?*, 335 New ENG. J. MED. 891, 892 (1996) (discussing the factors considered in evaluating the quality of health care).

<sup>&</sup>lt;sup>4</sup> See infra subpart III.A.

and encourage[s] homosexual behavior, intravenous drug use, and sexual activity outside of marriage between one man and one woman."<sup>6</sup> In March 2023, the Texas court issued injunctive relief, enjoining the government from enforcing Section 2713 of the ACA.<sup>7</sup> Soon after, the federal government filed an appeal on these decisions, and at the time of the writing of this Article, the appeal is pending before the Fifth Circuit.<sup>8</sup> While blocking access to preventive health care for more than 230 million Americans,<sup>9</sup> these decisions also demonstrate how bias and stigma of PrEP users penetrate legal decision making.<sup>10</sup> In other words, how decisions related to public health are oftentimes colored by moral judgment.<sup>11</sup>

Now think about character and fitness evaluations by certain state bar associations that take a candidate's mental health treatment as a signal of unfitness to practice law. Preventive treatment meant to manage and control mental illness is penalized. As a result, a candidate who laudably obtains professional intervention before a mental condition emerges or worsens may be denied a license to practice.<sup>12</sup>

Finally, consider one of the latest efforts to alleviate the opioid epidemic: Naloxone, a drug that reverses the effects of an overdose and prevents death. The United States Department of Health and Human Services ("HHS") has recognized the distribution of naloxone to potential witnesses of an opioid

<sup>12</sup> See infra subpart III.B.

314

<sup>&</sup>lt;sup>6</sup> Id. at \*5, \*18.

<sup>&</sup>lt;sup>7</sup> "[T]he Court ENJOINES Defendants and their officers, agents, servants, and employees from implementing or enforcing the compulsory preventive care coverage mandate in the future." Braidwood Mgmt. Inc. v. Becerra, No. 4:20-cv-00283-O, 2023 WL 2703229, at \*1 (N.D. Tex. Mar. 30, 2023).

<sup>&</sup>lt;sup>8</sup> Paige Minemyer, *HHS Appeals Judge's Ruling on ACA Preventive Care*, FIERCE HEALTHCARE (Mar. 31, 2023), https://www.fiercehealthcare.com/regulatory/ hhs-appeals-judges-ruling-aca-preventive-care [https://perma.cc/CW7B-S6ST].

<sup>&</sup>lt;sup>9</sup> The Department of Health and Human Services ("HHS") estimates that "more than 150 million people with private insurance—including 58 million women and 37 million children—currently can receive preventive services without cost-sharing under the ACA, along with approximately 20 million Medicaid adult expansion enrollees and 61 million Medicare beneficiaries that can benefit from the ACA's preventive services provisions." *See* U.S. DEP'T oF HEALTH & HUM. SERVS., HP-2022-01, Access to PREVENTIVE SERVICES WITHOUT COST-SHARING: EVIDENCE FROM THE AFFORDABLE CARE ACT 1 (2022), https://aspe.hhs.gov/sites/default/files/doc uments/786fa55a84e7e3833961933124d70dd2/preventive-services-ib-2022.pdf [https://perma.cc/Z6G4-YYC2].

<sup>&</sup>lt;sup>10</sup> See infra subpart III.A.

<sup>&</sup>lt;sup>11</sup> Doron Dorfman, *The PrEP Penalty*, 63 B.C. L. Rev. 813, 815, 875 (2022).

overdose to be a core strategy to prevent overdose mortality.<sup>13</sup> However, good Samaritans who purchased naloxone to protect others have been denied insurance coverage because that purchase signaled to insurance companies the stigmatized use of illicit drugs and opioids.<sup>14</sup>

This Article challenges the standard associations made between preventive medicine and risk groups. The paradoxical legal treatment of preventive medicine, endorsing prevention on one hand and penalizing its use on the other, is a byproduct of strategies to implement preventive health measures. An initial step in designing such interventions is identifying the risk for acquiring the particular health condition (e.g., contracting disease) within the relevant risk group in the first place.<sup>15</sup> This categorization, I argue, gives rise to the tendency of courts, legislators, insurers, and individuals to stigmatize and penalize those in risk groups who use preventive medicine. This is because preventive measures, specifically those taken to preempt health conditions that are themselves stigmatized, raise suspicions about the users' behavior and character.

Risk assessment, specifically in insurance classification schemes, relies on correlations, not causal "but for" relationships, between the insured's predictive trait and the projected losses to the insurer for potential coverage.<sup>16</sup> As insurance

<sup>&</sup>lt;sup>13</sup> Press Release, U.S. Food & Drug Admin., FDA Approves Higher Dosage of Naloxone Nasal Spray to Treat Opioid Overdose (Apr. 30, 2021), https://www.fda. gov/news-events/press-announcements/fda-approves-higher-dosage-naloxone-nasal-spray-treat-opioid-overdose [https://perma.cc/LD6L-PD7P].

<sup>&</sup>lt;sup>14</sup> See infra subpart III.C.

<sup>&</sup>lt;sup>15</sup> See WENDY E. PARMET, POPULATIONS, PUBLIC HEALTH, AND THE LAW 20–22 (2009) (discussing how epidemiologists compare groups to isolate the risks that may cause certain illnesses).

<sup>16</sup> Ronen Avraham, Kyle D. Logue & Daniel Schwarcz, Understanding Insurance Antidiscrimination Laws, 87 S. CAL. L. REV. 195, 218 (2012). Indeed, the Supreme Court addressed a similar issue in the 1978 case City of Los Angeles Department of Water & Power v. Manhart, addressing a sex discrimination in employment claim whereby female employees were required to make larger contributions to their pension funds due to the fact that statistically, women as a class live longer than men do. 435 U.S. 702, 705 (1978). The Court decided that "[e] ven a true generalization [through correlation or by proxy] about the class is an insufficient reason for disqualifying an individual [from the discussed class] to whom the generalization does not apply." Id. at 708; see also Ramona L. Paetzold, Commentary, Feminism and Business Law: The Essential Interconnection, 31 Am. Bus. L.J. 699, 710 (1993) ("It is through Manhart that one learns that 'facts' or 'statistical truths' can still be the basis for illegal stereotypes when their use disadvantages a protected class, as when all women are asked to pay higher pension premiums because as a class, women tend to live longer than men."). Although the Court decided the case according to Title VII of the Civil Rights Act of 1964, its rationale about making a generalization based on certain traits and proxies could be applied more generally.

scholars have pointed out, the relevant trait of the insured might simply serve as a *proxy* for the risk,<sup>17</sup> which very well may be caused by other possible contributing factors.<sup>18</sup> Therefore, using such a trait can have the effect of making classifications that are neither efficient nor equitable.<sup>19</sup>

If we consider preventive medicine from a public health perspective, we are actually saving money for society and the health care system by preventing illness in the first place rather than treating it after it occurs.<sup>20</sup> Thus, it is vital to take a public health perspective when considering discrimination by proxy due to the use of preventive health measures.

In this Article, I show how structural stigma affects the legal regulation of preventive health measures. In addition, I offer an original typology of such intersections between stigma and prevention policies. Ultimately, I contend that penalizing prevention impedes major public health projects. It chills the use of preventive medicine meant to eliminate diseases.

The Article proceeds as follows: Part I describes what preventive medicine is, the concept of risk groups, and the signaling effects of preventive medicine on its users as it pertains to risk. Part II explains the paradoxical legal treatment of preventive medicine (i.e., how it is endorsed and encouraged on the one hand and penalized on the other). Part III then demonstrates the paradoxical legal treatment through three case studies of preventive medicine: PrEP to eliminate HIV, character and fitness screening of mental health treatment for bar admission, and naloxone, an overdose reverser used in response to the opioid crisis. Part IV considers stigma beyond preventive medicine's signaling effect. In this part, I introduce an original typology of preventive medicine stigma that can be attached to either the health condition we aim to prevent, the preventive measure itself, or both. This typology informs the normative implications and policy recommendations for reducing structural stigma and harmonizing the legal treatment of preventive medicine delineated in Part V.

<sup>&</sup>lt;sup>17</sup> For a discussion of "proxy discrimination," see Anya E.R. Prince & Daniel Schwarcz, *Proxy Discrimination in the Age of Artificial Intelligence and Big Data*, 105 Iowa L. Rev. 1257, 1270–72 (2020).

<sup>&</sup>lt;sup>18</sup> Avraham, Logue & Schwarcz, *supra* note 16, at 219.

<sup>&</sup>lt;sup>19</sup> *Id.* at 220.

<sup>&</sup>lt;sup>20</sup> See infra Part I.

# CATEGORIES OF PREVENTIVE MEDICINE, RISK GROUPS, AND SIGNALING EFFECTS

Preventive medicine, or prophylaxis, uses health measures to preempt illnesses as opposed to treating them after they have arisen.<sup>21</sup> There are three types of preventive medicine. In 1952, the Commission on Chronic Illness suggested two types of preventive medicine: primary prevention and secondary prevention. Primary prevention is practiced prior to the biological origin of the illness and thus includes measures to prevent the illness from occurring altogether. Primary prevention measures include immunization, health education, and stress management. Secondary prevention is practiced after the illness has been diagnosed but before it has become symptomatic (i.e., caused harm in the form of disability or suffering), to prevent the illness from progressing (e.g., testing for and medicating hypertension before it leads to heart disease).<sup>22</sup> Over the years, another type of preventive medicine emerged: *tertiary prevention*.<sup>23</sup> Tertiary prevention is practiced after the illness becomes symptomatic, with the goal of preventing further deterioration, pain, and suffering and increasing the patients' quality of life, albeit not curing the illness.<sup>24</sup> The traditional conception of preventive health uses these three categories, based on the stage of the illness or disease.

A core element of preventive medicine is identifying *the risk* of getting the illness in the first place or developing harms and complications. To accomplish this goal, insurers, legislators, and policymakers have tended to categorize individuals into risk groups for the sake of fitting them with the appropriate preventive measure.

Other scholars accordingly developed a risk-based typology for preventive medicine based on the populations for which the measures are advisable. *Universal presentation* (e.g., maintaining good dental hygiene or not smoking) is meant for everyone. *Selective presentation* (e.g., use of safety goggles for mechanics,

 $<sup>^{21}</sup>$  Lawrence O. Gostin & Lindsay F. Wiley, Public Health Law: Power, Duty, Restraint 15 (3d ed. 2016).

<sup>&</sup>lt;sup>22</sup> BURRIS, BERMAN, PENN & HOLIDAY, *supra* note 1, at 6.

<sup>&</sup>lt;sup>23</sup> Robert S. Gordon, Jr., *An Operational Classification of Disease Prevention*, 98 Pub. Health Rep. 107, 107 (1983); *see also* Barbra Starfield, Jim Hyde, Juan Gérvas & Iona Heath, *The Concept of Prevention: A Good Idea Gone Astray?*, 62 J. EPIDEMIOLOGY & CMTY. HEALTH 580, 580 (2008) (defining types of prevention).

<sup>&</sup>lt;sup>24</sup> BURRIS, BERMAN, PENN & HOLIDAY, *supra* note 1, at 6–7.

or HPV vaccines for women or men who have sex with men) is meant for members of subgroups distinguished by gender, age, occupation, and so on, whose risk of illness is statistically found to be above average. Finally, *indicated presentation* (e.g., mammograms for women under the age of fifty with a family history of breast cancer) is meant for those who were individually screened and found to have a risk factor, or conditions that manifest them as high risk.<sup>25</sup> This risk-level-based typology has not caught on in public health, which uses the stage-of-the-illness typology. However, this typology is helpful in thinking about the process of signaling that is created with preventive measures.

Focusing on those in "high-risk" groups embodies a familiar conundrum that cuts across the public health field. On one hand, preventive medicine looks into social and environmental causes of illnesses,<sup>26</sup> yet, on the other, there has long been a tendency to focus on individual behavior that creates the risk.<sup>27</sup> As renowned social policy scholar Deborah Stone observed twenty-five years ago: "the politics of preventive medicine . . . manifest the strong individualism so deeply ingrained in American politics in general. Philosophically, the whole idea of identifying high-risk individuals and highrisk individual behaviors locates the source of misfortune in the individual rather than in social structure and economic opportunity."<sup>28</sup>

318

<sup>&</sup>lt;sup>25</sup> Gordon, *supra* note 23, at 108–09.

<sup>&</sup>lt;sup>26</sup> This approach has been termed the "public health paradigm." *See* PARMET, *supra* note 15, at 159 ("[T]he population perspective reminds us that the levels of risk that an individual faces are always determined, at least in part, and often in large measure, at a population level. Thus, though an individual may be able to choose what treatment to accept or reject after a terrible car accident, the individual cannot fully control the risk he or she faces by driving. Nor can a lone individual control the risk that a natural disaster will devastate a city. As a result, the most critical choices, such as lowering the risk of disease or injury, can never be realized solely by recognizing individualistic rights.").

<sup>&</sup>lt;sup>27</sup> This focus has also been termed the "individualist/biomedical paradigm." *See* Micah L. Berman, *A Public Health Perspective on Health Care Reform*, 21 HEALTH MATRIX 353, 356–358 (2011); Starfield, Hyde, Gérvas & Heath, *supra* note 23, at 581–82.

<sup>&</sup>lt;sup>28</sup> Deborah A. Stone, *The Resistible Rise of Preventive Medicine*, 11 J. HEALTH POL. POL'Y & L. 671, 689 (1986).

The focus on risk factors, behaviors,<sup>29</sup> choices,<sup>30</sup> or lifestyle<sup>31</sup> when it comes to preventive medicine creates assumptions and perceptions regarding people who use preventive health measures. Because preventive medicine signals a message about the user, it also creates a divide between an ingroup and out-group. Members of the out-group are the ones "at risk" and thus need some intervention in the form of preventive medicine. It is thus "their problem and not ours."

Yet this type of categorization is part of a broader cognitive process of information processing. Categorization and processing of information can result in stereotyping and other forms of biased intergroup judgment without any motivation, malice, or prejudice on the part of the individual.<sup>32</sup> Stereotypes are thus part of cognitive mechanisms with which all people engage.<sup>33</sup> These mechanisms are adopted to simplify the task of perceiving, processing, and retaining information about other people through schemas or heuristics.<sup>34</sup> In the context of this Article, I argue that engaging in preventive medicine creates a stereotype against the user. Legal actors then make decisions and enact laws, regulations, and policies based on this stereotype.

Stereotypes need not be incorrect to be considered stereotypes. Occasionally, they describe real and even salient attributes about social groups and, in this context, "risk groups."<sup>35</sup> The factual validity of stereotypes, that is, the debate over whether stereotypes have a kernel of truth to them, dates back to the 1930s.<sup>36</sup> The factual validity of stereotypes has

- <sup>33</sup> *Id.* at 1188.
- <sup>34</sup> *Id.* at 1199–1200.

<sup>&</sup>lt;sup>29</sup> Lindsay F. Wiley, Shame, Blame, and the Emerging Law of Obesity Control, 47 U.C. DAVIS L. REV. 121, 166–67 (2013) (discussing how it is comforting to view a condition of another person's life as a result of controllable causes and selfdetermination); Lindsay F. Wiley, *The Struggle for the Soul of Public Health*, 41 J. HEALTH POL. POL'Y & L. 1083, 1085, 1091 (2016) [hereinafter Wiley, *Struggle*] (arguing that attributing health to individual behavior makes it difficult to target the portion caused by community and environmental factors).

<sup>&</sup>lt;sup>30</sup> Berman, *supra* note 27, at 357–58.

<sup>&</sup>lt;sup>31</sup> Stone, *supra* note 28, at 675–76.

<sup>&</sup>lt;sup>32</sup> Linda Hamilton Krieger, *The Content of Our Categories: A Cognitive Bias Approach to Discrimination and Equal Employment Opportunity*, 47 STAN. L. REV. 1161, 1187 (1995).

<sup>&</sup>lt;sup>35</sup> Charles M. Judd & Bernadette Park, *Definition and Assessment of Accuracy in Social Stereotypes*, 100 Psych. Rev. 109, 110 (1993).

<sup>&</sup>lt;sup>36</sup> The first, and most famous, study on the topic, was done by Katz and Braly in 1933. *See generally* Daniel Katz & Kenneth Braly, *Racial Stereotypes of One Hundred College Students*, 28 J. ABNORMAL & SOC. PSYCH. 280 (1933). This study was followed by others. For more on this topic, see PENELOPE J. OAKES, S.

proven elusive and extremely difficult to assess.<sup>37</sup> Nevertheless, stereotypes can have a relationship with reality because they make generic, exaggerated statements about social phenomena.<sup>38</sup> While it is therefore possible that a person taking a preventive health measure is engaging in "risky behavior," it does not mean that any person taking such measures is in fact engaging in such actions.

Stigma is an attribute that conveys devalued stereotypes. Renowned sociologist Erving Goffman classically defined stigma as an "attribute that is deeply discrediting" and causes one to be rejected by a social group.<sup>39</sup> A discredited attribute could be readily discernable (like skin color or body size) or could be hidden but nonetheless discreditable if revealed (like a criminal record, mental illness, or the use of medication like PrEP).<sup>40</sup> Stigma is a general aspect of social life that complicates everyday micro-level interactions as it negatively impacts social networks, employment opportunities, emotional well-being, and the perception of self.<sup>41</sup> The concept of stigma has been applied in an extensive array of contexts with multiple focal points,<sup>42</sup> demonstrating its complexity as a social phenomenon that does not manifest itself in one singular way.<sup>43</sup>

Structural stigma is the discrimination against stigmatized groups at the institutional level (as opposed to the individual level).<sup>44</sup> It is "embedded in and sustained by the systems and

- <sup>39</sup> ERVING GOFFMAN, STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY 3 (1963).
- <sup>40</sup> *Id.* at 4–5.

ALEXANDER HASLAM & JOHN C. TURNER, STEREOTYPING AND SOCIAL REALITY 19 (1994); David J. Schneider, *Modern Stereotype Research: Unfinished Business, in* Stereotypes AND STEREOTYPING 419, 420 (C. Neil Macrae, Charles Stangor & Miles Hewstone eds., 1996).

<sup>&</sup>lt;sup>37</sup> Richard D. Ashmore & Frances K. Del Boca, *Conceptual Approaches to Stereotypes and Stereotyping, in* Cognitive Processes in Stereotyping and Intergroup Behavior 1, 18 (David L. Hamilton ed., 1981); Oakes, Haslam & Turner, *supra* note 36, at 24.

<sup>&</sup>lt;sup>38</sup> See Erin Beeghly, What is a Stereotype? What is Stereotyping?, 30 HYPATIA 675, 677 (2015).

<sup>&</sup>lt;sup>41</sup> *Id.* at 19; *see also* Bruce G. Link, Elmer L. Struening, Michael Rahav, Jo C. Phelan & Larry Nuttbrock, On Stigma and Its Consequences: Evidence from a Longitudinal Study of Men with Dual Diagnoses of Mental Illness and Substance Abuse, 38 J. HEALTH & Soc. BEHAV. 177, 177–78 (1997).

<sup>&</sup>lt;sup>42</sup> Bruce G. Link & Jo C. Phelan, *Conceptualizing Stigma*, 27 Ann. Rev. Socio. 363, 365 (2001).

<sup>&</sup>lt;sup>43</sup> Betsy L. Fife & Eric R. Wright, *The Dimensionality of Stigma: A Comparison of Its Impact on the Self of Persons with HIV/AIDS and Cancer*, 41 J. HEALTH & Soc. BEHAV. 50, 51 (2000).

<sup>&</sup>lt;sup>44</sup> Link & Phelan, *supra* note 42, at 372; Susan T. Fiske, *Stereotyping, Prejudice, and Discrimination, in* The HANDBOOK OF SOCIAL PSYCHOLOGY 357, 392 (Daniel T.

organizations that govern daily life," including law, policy, and regulations.<sup>45</sup> Penalizing prevention through law has intentional or unintentional stigmatizing consequences on marginalized groups and individuals.<sup>46</sup> The creation of structural stigma around preventive medicine arises from the process of assigning stereotypes to users, who are often themselves members of already stigmatized and disadvantaged groups, because of the information signaled to others. In other words, because stigma is a process dependent on social, economic, and political power,<sup>47</sup> the stigma around preventive medicine builds on existing stigma inflicted on those marginalized populations by more dominant groups.

Exposing and examining the stereotypes and stigmas about the risk levels possessed by those taking preventive health measures is an important endeavor, as those stereotypes stifle efforts to encourage prevention and improve population health.

In the next section, I explain how the existing endorsement of preventive medicine in laws such as the ACA clashes with other laws, policies, and decisions made by legal actors, which reflect the stereotyping of those taking preventive health measures. This clash creates what I refer to as the paradoxical legal treatment of preventive medicine.

Π

The Paradoxical Legal Treatment of Preventive Medicine

In addition to increasing the number of Americans who have health insurance,<sup>48</sup> an important objective of the ACA has been to improve the quality of covered health care and

<sup>46</sup> Patrick W. Corrigan et al., *Structural Stigma in State Legislation*, 56 Psychi-ATRIC SERVS. 557, 557–58 (2005) (discussing mental illness and AIDS).

<sup>47</sup> Link & Phelan, *supra* note 42, at 375.

Gilbert, Susan T. Fiske, & Gardner Lindzey eds., 4th ed. 1998) (concluding how within the field of social psychology, more attention needs to be given to structural issues and discrimination when studying stigma and stereotyping).

<sup>&</sup>lt;sup>45</sup> Sarah Hemeida, Hallie Conyers-Tucker, Lina Brou & Daniel Goldberg, *Structural Stigma in Law: Implications and Opportunities for Health and Health Equity*, HEALTH AFFAIRS (Dec. 8, 2022), https://www.healthaffairs.org/do/10.1377/hpb20221104.659710 [https://perma.cc/73DA-TRES].

<sup>&</sup>lt;sup>48</sup> The ACA allowed twenty million previously uninsured Americans to obtain health care coverage, yet policies weakening the ACA protections as well as job loss related to the COVID-19 pandemic have caused uninsured numbers to rise again recently. *See* Rachel Garfield & Jennifer Tolbert, *What We Do and Don't Know About Recent Trends in Health Insurance Coverage in the US*, KFF (Sept. 17, 2020), https://www.kff.org/policy-watch/what-we-do-and-dont-know-about-recenttrends-in-health-insurance-coverage-in-the-us [https://perma.cc/9XYV-FMG9].

to provide minimum essential coverage.<sup>49</sup> Preventive medicine has been an integral part of the effort to increase quality of care.<sup>50</sup> Title IV of the ACA, titled "Prevention of Chronic Disease and Improving Public Health," contains subsections setting forth the goals of "Increasing Access to Clinical Preventive Services," "Modernizing Disease Prevention and Public Health Systems," "Support[ing] . . . Prevention and Public Health Innovation," and "Creating Healthier Communities."<sup>51</sup>

To accomplish the goal of expanding preventive medicine, the ACA allocated sources of funding. One source is the *Public Health Education Fund* to establish and pay for a "national public-private partnership for a prevention and health promotion outreach and education campaign."<sup>52</sup> The campaign promotes the use of preventive medicine and encourages "healthy behaviors linked to the prevention of chronic diseases."<sup>53</sup> Another fund is the *U.S. Prevention and Public Health Fund*, which aims "to provide for expanded and sustained national investment in prevention and public health programs."<sup>54</sup> The ACA also allocates grant funding to private employers to expand workplace wellness programs, which are also seen as preventive medicine services.<sup>55</sup>

Before the ACA was enacted, insurers were not interested in covering preventive medicine due to financial considerations. In the American health insurance market, beneficiaries switch between insurers multiple times throughout their lifetime. This high turnover leaves insurers with little incentive to invest in

<sup>51</sup> Patient Protection and Affordable Care Act, Pub. L. No. 111–148, § 1(b), 124 Stat. 119, 124–25 (2010) (codified as amended at 42 U.S.C. § 18001).

- <sup>54</sup> 42 U.S.C. § 300u-11(a).
- <sup>55</sup> 42 U.S.C. § 300gg-4(j).

322

<sup>&</sup>lt;sup>49</sup> GOSTIN & WILEY, *supra* note 21, at 291; Peter R. Orzag & Rahul Rekhi, *Policy Designs: Tensions and Tradeoffs*, in The TRILLION DOLLARS REVOLUTION: HOW THE AFFORDABLE CARE ACT TRANSFORMED POLITICS, LAW, AND HEALTH CARE IN AMERICA 47, 57 (Ezekiel J. Emanuel & Abbe R. Gluck eds., 2020) ("[E]qually core to the ACA's design were reducing the cost and improving the quality of care provided by the delivery system.").

<sup>&</sup>lt;sup>50</sup> "According to Sen. Tom Harkin (D-IA), the lead author of many of these provisions, the goal of Title IV was to reorient our system from being a 'sick care system' to being a 'health care system' by 'creating a sharp new emphasis on disease prevention and public health." *See* Berman, *supra* note 27, at 354; *see also* 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, 1890, 1904–05 (2011) (discussing the preventive medicine mandate as contributing to health promotion).

<sup>&</sup>lt;sup>52</sup> 42 U.S.C. § 300u-12(a).

<sup>53</sup> Id.

preventive medicine, as they will likely not be able to reap the fruits of such measures.  $^{\rm 56}$ 

In response, the ACA mandated the vast majority of insurers to cover approved preventive health measures under their plans. Section 2713 of the ACA increases access to clinical preventive services by requiring non-grandfathered private health insurance plans to provide "first-dollar" coverage for a range of preventive services.<sup>57</sup> Accordingly, these plans may not impose cost sharing (such as copayments, deductibles, or co-insurance) on patients for approved preventive services.<sup>58</sup> The list of preventive services covered by insurers is composed of recommendations made by one of four professional-governmental bodies: Preventive Services Task Force ("PSTF"),<sup>59</sup> the Advisory Committee on Immunization Practices ("ACIP"), the Health Resources and Services Administration's Bright Futures *Project* (dealing with the health-care needs of infants, children, and adolescents) ("HRSA"), and the Institute of Medicine Committee on Women's Clinical Preventive Services ("IMC-WCPS").60

<sup>58</sup> 42 U.S.C. § 300gg-13.

<sup>&</sup>lt;sup>56</sup> Bradley Herring, Suboptimal Provision of Preventive Healthcare Due to Expected Enrollee Turnover Among Private Insurers, 19 HEALTH ECON. 438, 439 (2010).

<sup>&</sup>lt;sup>57</sup> In a recent article, Professor Jacqueline Fox demonstrated how enrollees in insurance plans that have not yet shifted to full coverage or that are enrolled in grandfathered plans had to pay a substantial amount of money, roughly \$600 a month in copayment for PrEP. She showed how even coupon and discount programs did not always make sense to those enrollees, as the discounted price for PrEP did not count towards the annual deductible in the program, making out of pocket costs remain for the enrollee. *See* Jacqueline R. Fox, *The Lived Experience of Health Insurance: An Analysis and Proposal for Reform*, 14 NE. U. L. REV. 429, 480–82 (2022).

<sup>59</sup> The Preventive Services Task Force is an independent body "composed of individuals with appropriate expertise. Such Task Force shall review the scientific evidence related to the effectiveness, appropriateness, and cost-effectiveness of clinical preventive services for the purpose of developing recommendations for the health care community, and updating previous clinical preventive recommendations." 42 U.S.C. § 299b-4(a)(1). To be included as covered preventive health services, a recommendation with an A or B rating by the Task Force is required. Under 42 U.S.C. § 300u-12(a)(2), the Task Force can determine how to recommend preventative services. See Grade Definitions, U.S. PREVENTIVE SERVS. TASK https://www.uspreventiveservicestaskforce.org/uspstf/about-uspstf/ FORCE. methods-and-processes/grade-definitions [https://perma.cc/3JAJ-QTA9] (last visited May 5, 2023). An "A" rating means that "[t]here is high certainty that the net benefit is substantial." *Id.* A "B" rating indicates that "[t]here is high certainty that the net benefit is moderate, or there is moderate certainty that the net benefit is moderate to substantial." Id.

<sup>&</sup>lt;sup>60</sup> Preventive Services Covered by Private Health Plans Under the Affordable Care Act, KFF (Apr 3, 2023), https://www.kff.org/health-reform/factsheet/preventive-services-covered-by-private-health-plans [https://perma.cc/ A7CY-T3EH].

Imposing cost sharing affects consumers' decisions of whether to consume the service and thus is known to serve a behavioral function.<sup>61</sup> By eliminating the burden of cost sharing for preventive services, the ACA endorses and incentivizes greater use of preventive medicine.<sup>62</sup>

Precisely because of this absolute endorsement of preventive medicine. Section 2713 has been under attack by those opposing the ACA and has been become "the next major challenge" to the ACA<sup>63</sup> after the Supreme Court decided to leave the law intact in California v. Texas.<sup>64</sup> In Braidwood Management Inc. v. Becerra, a decision by the U.S. District Court of the Northern District of Texas from September 2022, the court sided with the plaintiffs who wished to purchase insurance that excludes coverage for contraception, the HPV vaccine, screenings and behavioral counseling for STDs and drug use, and PrEP, all recommended preventive health measures to which plaintiffs objected to on religious and moral grounds.<sup>65</sup> The plaintiffs were not able to buy such insurance, however, due to the Section 2713 mandate for insurers to provide such recommended preventive health measures. Judge Reed O'Connor, who in 2018 declared the ACA unconstitutional in a decision later overturned by the Supreme Court,<sup>66</sup> awarded summary judgment to the plaintiff based on two grounds. First, that the binding status given to the recommendations of the four governmental bodies cannot stand, as they do not comply with constitutional requirements of the appointments clause.<sup>67</sup> Second, according to the court, even if members of PSTF had

<sup>63</sup> Nicholas Bagley, *The Next Major Challenge to the Affordable Care Act*, The Atlantic (June 18, 2021), https://www.theatlantic.com/ideas/archive/2021/06/next-major-challenge-affordable-care-act/619159[https://perma.cc/P2AE-LTBY].

<sup>66</sup> Texas v. United States, 340 F. Supp. 3d 579 (N.D. Tex. 2018). After this 2018 decision, one commentator stated that Judge O'Connor has been "blinded" by "his contempt of the ACA." *See* Nicholas Bagley, *Opinion: The Latest ACA Ruling Is Raw Judicial Activism and Impossible to Defend*, WASH. Post (Dec. 15, 2018), https://www.washingtonpost.com/opinions/2018/12/15/latest-aca-ruling-is-raw-judicial-activism-impossible-defend [https://perma.cc/GTB7-BCR3].

<sup>67</sup> Specifically, the court decided that PSTF members are superior officers who have not been nominated by the President nor confirmed by the Senate as the Appointments Clause of the Constitution requires, and thus their acts of requiring the coverage of preventive measures are unconstitutional. *See Braidwood*, 2022 WL 4091215, at \*9–12.

<sup>&</sup>lt;sup>61</sup> Christopher T. Robertson, Exposed: Why Our Health Insurance Is Incomplete and What Can Be Done About It 4 (2019).

<sup>&</sup>lt;sup>62</sup> Wiley, Struggle, supra note 29, at 1089.

<sup>&</sup>lt;sup>64</sup> 141 S. Ct. 2104, 2112 (2021).

<sup>&</sup>lt;sup>65</sup> No. 4:20-cv-00283-O, 2022 WL 4091215, at \*3 (N.D. Tex. Sept. 7, 2022).

2024]

the authority to require the coverage of PrEP and the other measures the plaintiff objected to, such a requirement imposes an impermissible substantial burden on employers' religious beliefs under RFRA.<sup>68</sup> Requiring the plaintiffs to purchase insurance that covers PrEP, the court determined, would violate their sincerely held beliefs because "providing coverage of PrEP drugs 'facilitates and encourages homosexual behavior, intravenous drug use, and sexual activity outside of marriage between one man and one woman,' and . . . providing coverage of PrEP drugs in Braidwood's self-insured plan would make him complicit in those behaviors."69 In addition, the court concluded that the government did not show a specific compelling interest in compelling religious employers to cover PrEP. Even if the government had such compelling interest the preventive medicine mandate was not the least restrictive means of furthering the government's interest. This is because the government could have simply covered the cost of PrEP for anyone working for a religious employer without imposing it on the plaintiffs.<sup>70</sup> In March 2023, the court has ruled on the remedy for the constitutional issue: enjoining the federal government "from implementing or enforcing the compulsory preventive care coverage mandate in the future" in any part of the country (not only in Texas).<sup>71</sup> As of the time of the writing of this Article, an appeal filed by the government is currently pending before the Fifth Circuit.72

This litigation over the preventive medicine mandate is projected to go on for quite a few years.<sup>73</sup> It clearly demonstrates the way decisions related to public health are colored by moral judgement, specifically when it comes to sexuality and "family values."<sup>74</sup> This Article makes a related yet independent claim never before discussed in the literature regarding the legal treatment of preventive medicine within the ACA and beyond.

- <sup>73</sup> Bagley, supra note 63 at 8-9.
- <sup>74</sup> Dorfman, *supra* note 11, at 875.

<sup>&</sup>lt;sup>68</sup> RFRA provides that the "[g]overnment shall not substantially burden a person's exercise of religion even if the burden results from a rule of general applicability," unless the government shows that it has a "compelling governmental interest" and the policy "is the least restrictive means of furthering that compelling governmental interest." *See* 42 U.S.C. § 2000bb-1(a)–(b).

<sup>&</sup>lt;sup>69</sup> Braidwood, 2022 WL 4091215, at \*18.

<sup>&</sup>lt;sup>70</sup> Id. at \*19–20.

<sup>&</sup>lt;sup>71</sup> Braidwood Mgmt. Inc. v. Becerra, No. 4:20-cv-00283-O, 2023 WL 2703229, at \*1 (N.D. Tex. Mar. 30, 2023).

<sup>&</sup>lt;sup>72</sup> Minemyer, supra note 8.

I claim that there are inconsistencies in how the law broadly treats preventive medicine. Despite the ACA's endorsement of preventive medicine, other regulations, policies, and decisions by legal actors create disincentives to use preventive services. Through a process I call penalizing prevention, those who endeavor to use preventive measures are being stigmatized and penalized in a variety of ways, including paying higher insurance premiums, exclusion from professions, the inability to take part in "civic rituals,"<sup>75</sup> and having the use of preventive measures be used against them as evidence in trials. All these penalties create structural stigma around the use of preventive health measures as well as a chilling or deterrent effect on using preventive services, thereby frustrating the goal of improving public health.

I demonstrate the socio-legal phenomenon of penalizing prevention through three case studies of preventive health measures that correspond with the traditional stages of illness typology of primary, secondary, and tertiary prevention.

#### III

#### PENALIZING PREVENTION: THREE CASE STUDIES

This section will demonstrate the primary claim about penalizing prevention using three case studies pertaining to major public health issues. The first concerns preventive measures related to sexual health. It discusses how PrEP, a primary prevention tool highly effective in preventing HIV infection, is weaponized in child custody cases to portray users as unfit parents. In this Part, I also discuss insurance discrimination against PrEP users, who are predominantly gay or bisexual men, and how FDA policy prohibits PrEP users from donating blood despite the treatment's effectiveness and ACA coverage. The second case study deals with mental health treatment for individuals without any history of a mental health episode, which aims to prevent deterioration of one's mental state before it occurs and is therefore considered secondary prevention. Patients who undergo such treatment are determined unfit to practice law pursuant to many state bar character and fitness evaluation policies. The third case study discusses insurance discrimination against good Samaritans who acquire the "opioid reverser" naloxone. This case study is different from the first two because it is aimed at using a preventive measure for the sake of a third party (and preventing one's own disease), yet 2024]

it is part of a larger public health initiative to reduce overdose deaths amid the national opioid epidemic. It is considered a tertiary prevention tool, as it is used to help people dealing with addiction and to prevent fatalities.

### A. Penalizing Sexual Health: The Case of PrEP

PrEP is a primary prevention tool, as it aims at preventing an illness, in this case HIV (an extremely stigmatized condition within of itself),<sup>76</sup> from occurring to begin with. As I will show, there currently are multiple penalties assigned to those who would like to use it, ranging from a policy of exclusion from blood donation to insurance discrimination to using the signaling effect of PrEP in custody cases in family courts.

# 1. A Primary Preventive Measure for HIV Infection

PrEP is a combination antiretroviral drug designed to prevent HIV infection through sex and keep HIV-negative individuals negative. The FDA recognized that "when used along with safer sex practices, [PrEP] can help lower the chances of getting sexually-transmitted HIV."<sup>77</sup> Clinical trials on the effectiveness of PrEP show that even with the inconsistent use of condoms, when taken daily, PrEP is up to 99% successful in preventing HIV infection.<sup>78</sup>

<sup>&</sup>lt;sup>76</sup> Many scholars have documented how the medical and legal treatment of HIV has been derived from a morality standpoint, viewing the condition as a punishment for deviant, promiscuous, sexual behavior. *See, e.g.*, GARY L. ALBRECHT, THE DISABILITY BUSINESS: REHABILITATION IN AMERICA 77 (1992); SUSAN SONTAG, AIDS AND ITS METAPHORS 26, 45–56 (1989).

<sup>&</sup>lt;sup>77</sup> Alison Hunt, FDA In Brief: FDA Continues to Encourage Ongoing Education About the Benefits and Risks Associated with PrEP, Including Additional Steps to Help Reduce the Risk of Getting HIV, U.S. FOOD & DRUG ADMIN. (July 1, 2019), https://www.fda.gov/news-events/fda-brief/fda-brief-fda-continues-encourageongoing-education-about-benefits-and-risks-associated-prep [https://perma.cc/ J2FV-M6DW].

<sup>&</sup>lt;sup>78</sup> See PrEP (Pre-Exposure Prophylaxis), CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/hiv/basics/prep.html [https://perma.cc/JRJ7-JAHU] (last updated June 3, 2022); Peter L. Anderson et al., Emtricitabine-Tenofovir Exposure and Pre-Exposure Prophylaxis Efficacy in Men Who Have Sex with Men, Sci. TRANSLATIONAL MED., Sept. 12, 2012, at 125, 127; Gus Cairns, Overall PrEP Effectiveness in iPrEx OLE Study 50%, but 100% in Those Taking Four or More Doses a Week, AIDSMAP (July 22, 2014), http://www.aidsmap.com/news/jul-2014/overall-prep-effectiveness-iprex-ole-study-50-100-those-taking-four-or-more-doses [https://perma.cc/DT2W-TXEZ]. For a review of older clinical trials showing over 90% success, see CTRS. FOR DISEASE CONTROL & PREVENTION, PREEXPOSURE PROPHYLAXIS FOR THE PREVENTION OF HIV INFECTION IN THE UNITED STATES – 2017 UPDATE: A CLINICAL PRACTICE GUIDELINE 16–20 (2017) [hereinafter CDC GUIDELINES 2017], https://www.

Gilead Sciences ("Gilead") originally developed and manufactured PrEP as an orally administered drug under the brand name Truvada. The FDA first approved Truvada in 2004 to treat HIV-positive patients in combination with other antiretroviral drugs, and in 2012, the FDA licensed it for use as a preventive measure.<sup>79</sup> In 2014, the Center for Disease Control and Prevention ("CDC") published guidelines for physicians prescribing PrEP.<sup>80</sup> In 2019, the Preventive Services Task Force recommended PrEP as a preventive measure to be covered under Section 2713.<sup>81</sup> The same year, the FDA approved Descovv. a new generation of orally administered PrEP manufactured by Gilead.<sup>82</sup> At the end of 2021, the FDA approved an injectable option for PrEP (an alternative to oral medication), taken every two months, under the brand name Apretude.<sup>83</sup> In 2020, the patents Gilead held for Truvada expired, and so in October of that year, a generic version of Truvada that Teva Pharmaceuticals manufactured for PrEP treatment came onto the market.<sup>84</sup> Having generic versions of PrEP, which are significantly cheaper, increases access to the treatment by the uninsured.

PrEP use is becoming increasingly popular. In 2017, more than 100,000 Americans used PrEP, with numbers continuing to grow.<sup>85</sup> Research by the CDC showed that the use of

<sup>79</sup> Hunt, *supra* note 77.

<sup>80</sup> The guidelines have since been updated in 2017. *See* CDC GUIDELINES 2017, *supra* note 78, at 2.

<sup>81</sup> Final Recommendation Statement, Prevention of Human Immunodeficiency Virus (HIV) Infection: Preexposure Prophylaxis, U.S. PREVENTIVE SERVS. TASK FORCE (June 11, 2019), https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/prevention-of-human-immunodeficiency-virus-hiv-infection-preexposure-prophylaxis [https://perma.cc/F3J9-9QV2]; Scott Skinner-Thompson, AIDS and the Law § 2.03[B], at 2-38 to -39 (6th ed. 2020).

<sup>82</sup> Press Release, U.S. Food & Drug Admin., FDA Approves Second Drug to Prevent HIV Infection as Part of Ongoing Efforts to End the HIV Epidemic (Oct. 3, 2019), https://www.fda.gov/news-events/press-announcements/fda-approves-second-drug-prevent-hiv-infection-part-ongoing-efforts-end-hiv-epidemic [https://perma.cc/J4W4-N3Q6].

<sup>83</sup> Press Release, U.S. Food & Drug Admin., FDA Approves First Injectable Treatment for HIV Pre-Exposure Prevention (Dec. 20, 2021), https://www.fda. gov/news-events/press-announcements/fda-approves-first-injectable-treatment-hiv-pre-exposure-prevention [https://perma.cc/GAC4-WS4L].

<sup>84</sup> Liz Highleyman, *First Generic Truvada Now Available in the United States*, POZ (Oct. 2, 2020), https://www.poz.com/article/first-generic-truvada-nowavailable-united-states [https://perma.cc/9UF7-4RHR].

<sup>85</sup> Patrick S. Sullivan et al., *Trends in the Use of Oral Emtricitabine/Tenofovir Disoproxil Fumarate for Pre-Exposure Prophylaxis Against HIV Infection, United States, 2012–2017, 28 ANNALS EPIDEMIOLOGY 833, 835 (2018).* 

cdc.gov/hiv/pdf/risk/prep/cdc-hiv-prep-guidelines-2017.pdf [https://perma.cc/T9U5-VJHG].

PrEP has increased from 6% to 35% between 2014 and 2017 in twenty selected urban areas across the United States.<sup>86</sup> This increased use was true for almost all racial-ethnic subgroups of gay and bisexual men, the main users of PrEP, although disparities in the number of White and Black PrEP users were found.<sup>87</sup> In addition, although one million Americans are at substantial risk of contracting HIV and could benefit from PrEP, fewer than 25% are actually using it.<sup>88</sup> The gap is larger among Black and Latinx individuals than among white people.<sup>89</sup>

PrEP proclaims a new dawn for HIV prevention. Consequently, HHS initiated a program to end the HIV epidemic in the United States by using the treatment to reduce new infections by 90% from 2020 to 2030, with a specific goal of increasing access to the treatment.<sup>90</sup>

PrEP can be classified as part of a collection of preventive measures associated with sexual behavior, which I call "sexually charged preventive measures." Other sexually charged

87 Differences between the use of PrEP among White men who have sex with men ("MSM"), PrEP users (42%), and Black MSM PrEP users (26%) remain statistically significant even after controlling for income, health insurance and religion. The differences between Hispanic MSM PrEP users (30%) and White MSM, as well as the differences between older and younger MSM, were not found statistically significant after controlling for these factors. See id. A 2016 CDC study finds that "at current rates, 1 in 2 African American MSM and 1 in 4 Hispanic MSM will be diagnosed with HIV in their lifetime, compared with 1 in 11 white MSM." See CTRS. FOR DISEASE CONTROL & PREVENTION, LIFETIME RISK OF HIV DIAGNOSIS IN THE UNITED STATES 1 (2016), https://www.justfacts.com/document/lifetime risk hiv. pdf [https://perma.cc/L3YP-LA4T]; see also HIV and African American Gay and Bisexual Men, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/hiv/ group/msm/bmsm.html [https://perma.cc/MQC6-6X6B] (last updated Feb. 16, 2023). For a discussion of racial disparities with regard to HIV infection, see Aziza Ahmed, Adjudicating Risk: AIDS, Crime, and Culpability, 2016 Wis. L. Rev. 627, 651-52. To compare to the historic CDC and media's portrayal of HIV as a "gay white male problem," see Russell K. Robinson, Racing the Closet, 61 STAN. L. REV. 1463, 1511 (2009).

<sup>88</sup> Off. of Infectious Disease & HIV/AIDS Pol'y, *What is 'Ending the HIV Epidemic in the U.S.'*?, HIV.Gov, https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview [https://perma.cc/T3A2-BGAU] (last updated July 1, 2022).

 $<sup>^{86}</sup>$  Teresa Finlayson et al., Changes in HIV Preexposure Prophylaxis Awareness and Use Among Men Who Have Sex with Men — 20 Urban Areas, 2014 and 2017, 68 Morbidity & Mortality WKLY. Rep. 597, 599 (2019).

<sup>&</sup>lt;sup>89</sup> Press Release, Ctrs. For Disease Control & Prevention, HIV Prevention Pill Not Reaching Most Americans Who Could Benefit — Especially People of Color (Mar. 6, 2018), https://www.cdc.gov/nchhstp/newsroom/2018/croi-2018-PrEPpress-release.html [https://perma.cc/6MQP-7WSG]; Skinner-Thompson, *supra* note 81, at 2-37.

<sup>&</sup>lt;sup>90</sup> Anthony S. Fauci, Robert R. Redfield, George Sigounas, Michael D. Weahkee & Brett P. Giroir, *Ending the HIV Epidemic: A Plan for the United States*, 321 JAMA 844, 844 (2019).

preventive measures include FDA-approved contraceptive methods (*e.g.*, birth control pills),<sup>91</sup> condoms,<sup>92</sup> sterilization procedures, patient education and counseling, and the Gardasil vaccine, designed to prevent human papillomavirus ("HPV") infection often transmitted via sexual contact.<sup>93</sup> In *Burwell v. Hobby Lobby Stores*, the Supreme Court held that religious employers are not required to provide coverage for contraceptives to their employees' insurance plans, as such an obligation violates the Religious Freedom Restoration Act of 1993.<sup>94</sup> *Braidwood Management Inc. v. Becerra* encounters a similar question, this time putting PrEP (and its related stigma) at the center of the discussion.<sup>95</sup>

The resistance to sexually charged preventive measures is baked into the idea of risk compensation. Risk compensation is the expectation that individuals adjust their risk-taking preferences and behaviors in response to a preventive measure. In other words, it is the expectation they will engage in more risky

<sup>92</sup> Research has found that young women who made abstinence pledges but later become sexually active before marriage have increased risks for HPV and nonmarital pregnancies, compared to young women who did not take such pledge. The explanation offered by the researchers has to do with the messages pledgers receive about using condoms or contraceptives:

Abstinence pledgers are more likely to receive cultural messages downplaying the effectiveness of condoms and contraceptives, as well as to be exposed to the framing of premarital sexual activity as a form of failure. As a consequence, girls and young women who pledge may be less "prepared" to manage the risks associated with sexual activity by obtaining condoms and contraceptives themselves, or less apt to initiate conversations about precautions with their partners.

See Anthony Paik, Kenneth J. Sanchagrin & Karen Heimer, *Broken Promises: Abstinence Pledging and Sexual and Reproductive Health*, 78 J. Marriage & Fam. 546, 559 (2016).

<sup>93</sup> Women's Preventive Services Guidelines, HEALTH RES. & SERVS. ADMIN., https://www.hrsa.gov/womens-guidelines/index.html [https://perma.cc/NL5Y-UDET] (last updated Dec. 2022).

<sup>94</sup> 573 U.S. 682, 690 (2014). For an illuminating discussion of the impact of the Religious Freedom Restoration Act on health law in the context of the Hobby Lobby case and beyond, see Elizabeth Sepper, *Free Exercise Lochnerism*, 115 COLUM. L. REV. 1453, 1496–1507 (2015).

<sup>&</sup>lt;sup>91</sup> Some have compared PrEP to the birth control pill, due to their similarity in daily dose. *See e.g.*, Ashley Henshaw, *PrEP v. PEP for HIV Prevention*, NURX: BLOG (May 15, 2019), https://www.nurx.com/blog/prep-vs-pep/ [https://perma. cc/EQU9-ZX9X] ("PrEP is sometimes compared to taking a daily birth control pill like or Aviane to prevent pregnancy. When taken correctly, it's very effective."); *see generally* Julie E. Myers & Kent A. Sepkowitz, *A Pill for HIV Prevention: Déjà Vu all Over Again?*, 56 CLINICAL INFECTIOUS DISEASES 1604 (2013) (discussing similar debates related to safety, cost, and the potential impact on sexual behavior which have been associated with both birth control pill and PrEP).

<sup>&</sup>lt;sup>95</sup> See supra text accompanying notes 63–72.

behavior because they believe they are protected.<sup>96</sup> Those concerns appear with regard to the birth control pill<sup>97</sup> and the HPV vaccine,<sup>98</sup> whereby some parents reported concern that adolescent girls who receive these measures would become more sexually active.<sup>99</sup> Similar concerns have been raised with regard to PrEP, wherein debates regarding the treatment focused on the concerns that users would have sex with more partners and would also stop using condoms.<sup>100</sup> Nevertheless, no conclusive data support these concerns about sexual risk compensation. Although some studies suggest such behavior exists to some extent among PrEP users,<sup>101</sup> specifically with regard

<sup>98</sup> Sara E. Abiola, James Colgrove & Michelle M. Mello, *The Politics of HPV Vaccination Policy Formation in the United States*, 38 J. HEALTH POL. POL'Y & L. 645, 656–57 (2013); Underhill, *supra* note 96, at 429–30.

<sup>99</sup> A 2022 qualitative study on women's attitudes toward the HPV vaccine makes this point clear. A 41-year-old participant said: "I do realize there is a stigma that some people have to deal with. When my daughter received her HPV vaccine, my husband and I questioned if she was sexually active." A 27-year-old participant said: "When I was younger the doctor tried to explain to my mother that it is necessary whether I am sexually active or not and my mom was not having it . . . she said 'no way I know my daughter doesn't need it and will never need it." And a 33-year-old woman emphasized: "Just because I get a vaccine doesn't mean I'm gonna start turning tricks." *See* Andrea N. Polonijo, Durga Mahapatra & Brandon Brown, *"I Thought It Was Just For Teenagers": Knowledge, Attitudes, and Beliefs About HPV Vaccination Among Women Aged 27 to 45, 32* WOMEN'S HEALTH ISSUES 301, 305–06 (2022).

<sup>100</sup> Underhill, *supra* note 96, at 379, 384; Oni J. Blackstock et al., A Cross-Sectional Online Survey of HIV Pre-Exposure Prophylaxis Adoption Among Primary Care Physicians, 32 J. GEN. INTERNAL MED. 62, 65 (2016) (presenting results from a survey conducted with primary care providers showing that the belief that PrEP use would lead to risk compensation was common, even more so among PrEP non-prescribers than prescribers).

<sup>101</sup> A 2023 study that surveyed sexually active gay and bisexual men from eight U.S. metropolitan areas who indicated they were interested in blood donation found that 82.5% of PrEP users "reported more than one male sex partner in the past 3 months compared with 35.5% non-PrEP users." *See* Brian Custer et al., *HIV Risk Behavior Profiles Among Men Who Have Sex with Men Interested in Donating Blood: Findings from the Assessing Donor Variability and New Concepts in Eligibility Study*, 63 TRANSFUSION 1872, 1789–90 (2023). Nevertheless, and as discussed, the fact that stereotypes have a kernel of truth to them (here, that PrEP users have sex with more partners than non-PrEP users) does not make them less of a generalization about individuals, see infra note 35-38 and accompanying text.

<sup>&</sup>lt;sup>96</sup> Kristen Underhill, *Risk-Taking and Rulemaking: Addressing Risk Compen*sation Behavior Through FDA Regulation of Prescription Drugs, 30 Yale J. on Regul. 377, 383 (2013).

<sup>&</sup>lt;sup>97</sup> Myers & Sepkowitz, *supra* note 91, at 1608; Julia L. Marcus, Kenneth A. Katz, Douglas S. Krakower & Sarah K. Calabrese, *Risk Compensation and Clinical Decision Making* — *The Case of HIV Preexposure Prophylaxis*, 380 New Eng. J. Med. 510, 510 (2019).

to less frequent use of condoms,<sup>102</sup> the research in the area is "far from conclusive."<sup>103</sup> As public health experts concluded in 2019, "Making PrEP more widely available, regardless of patients' intended condom use, won't lead to sexual anarchy."<sup>104</sup>

Risk compensation drives the signaling effect of the PrEP treatment. That is, the perception that the person who takes PrEP is promiscuous and engages in dangerous, immoral behavior.<sup>105</sup> This message converges and intersects with the stereotypes about gay men being hyper-sexual.<sup>106</sup> The next subsections will demonstrate how this signaled message, whether openly acknowledged or more tacitly received by decision makers, has informed legal and policy decisions penalizing PrEP users.

#### 2. PrEP Insurance Discrimination

Insurance law scholars have previously examined discrimination with regard to discrete and insular minorities and traditionally protected categories in American law, such as race, national origin, religion, gender, and age, along with genetic information, credit scores, and zip codes.<sup>107</sup> Yet they have not discussed the consequences that penalizing preventive medicine could have for advancing public health causes like eliminating new HIV infections. This is a new category that has serious consequences for public health, as it could have a chilling effect on using preventive medicine. It also is in direct conflict with the ACA's approach of incentivizing and promoting the use of preventive care, creating a mismatch within the legal treatment of preventive medicine.

<sup>&</sup>lt;sup>102</sup> See Erik D. Storholm, Jonathan E. Volk, Julia L. Marcus, Michael J. Silverberg & Derek D. Satre, *Risk Perception, Sexual Behaviors, and PrEP Adherence Among Substance-Using Men Who Have Sex with Men: A Qualitative Study,* 18 PREVENTION Sci. 737, 740 (2017) (showing that a qualitative study with a sample of thirty young PrEP users from San Francisco that found that "73% of participants reported a decrease in condom use after PrEP initiation . . . [though] [m] any participants (40.0%) reported that they continue to use condoms with new or *unknown* partners"); *see also* Underhill, *supra* note 96, at 394–95 (discussing examples of such research).

<sup>&</sup>lt;sup>103</sup> Craig J. Konnoth, *Drugs' Other Side Effects*, 105 Iowa L. Rev. 171, 185 (2019); Blackstock et al., *supra* note 100, at 67 (stating that there is a "lack of evidence of widespread risk compensation in studies investigating the efficacy and effectiveness of PrEP").

<sup>&</sup>lt;sup>104</sup> Marcus, Katz, Krakower & Calabrese, *supra* note 97, at 512.

<sup>&</sup>lt;sup>105</sup> Dorfman, *supra* note 11, at 864.

<sup>&</sup>lt;sup>106</sup> E. Gary Spitko, From Queer to Paternity: How Primary Gay Fathers Are Changing Fatherhood and Gay Identity, 24 St. Louis U. Pub. L. Rev. 195, 198–99 (2005).

<sup>&</sup>lt;sup>107</sup> Avraham, Logue & Schwarcz, *supra* note 16, at 231.

In 2014, a gay couple from Massachusetts tried to purchase long-term health insurance from Mutual of Omaha Insurance Company<sup>108</sup> and was denied eligibility because one of them was taking PrEP.<sup>109</sup> Even after internal appeal, Mutual maintained its decision to deny coverage.<sup>110</sup> While the medical director for Mutual speculated that using PrEP may "foster promiscuity," during his deposition, he refused to acknowledge that promiscuity was grounds for the insurance discrimination. The director even admitted that a "promiscuous" person who takes PrEP as directed is at low risk of getting HIV and that PrEP is "highly effective" against HIV,<sup>111</sup> demonstrating how moral judgments and not actual assessment of risk can often be the driving force behind health policy decision-making.<sup>112</sup> The case against Mutual was eventually settled in 2018.<sup>113</sup>

In 2018, a young, single, HIV-negative, gay physician was denied disability insurance because he was taking PrEP. Interestingly, to combat the signaled stereotype of the PrEP user, the young doctor told the *New York Times* "[he] never engaged in sexually irresponsible behavior . . . [and has] always been in longer-term monogamous relationships."<sup>114</sup> A lawyer for the GLBTQ Legal Advocates and Defenders ("GLAD") said that he identified a trend of insurers denying coverage to PrEP users and that he knows of about fourteen similar incidents, although those never reached the courts.<sup>115</sup> LGBTQ advocates say that even after they explained that PrEP is so effective that the likelihood of getting HIV is minuscule, "there seemed to be an understanding . . . . But so far [they] haven't seen any policy

- <sup>110</sup> Id. at 6–7.
- <sup>111</sup> Id. at 19–20.
- <sup>112</sup> Dorfman, supra note 11, at 818.

<sup>113</sup> Joint Status Report at 1, Doe v. Mut. Of Omaha Ins. Co., No. 1:16-cv-11381-GAO (D. Mass. Dec. 27, 2018); *see also* Valerie K. Blake, *Ensuring an Underclass: Stigma in Insurance*, 41 CARDOZO L. REV. 1441, 1468 (2020) (noting that "[o]nly after a lawsuit did Mutual of Omaha agree to revise its underwriting policy to no longer exclude coverage based solely PrEP use").

<sup>114</sup> Donald G. McNeil, Jr., *He Took a Drug to Prevent AIDS. Then He Couldn't Get Disability Insurance.*, N.Y. TIMES (Feb. 12, 2018), https://www.nytimes.com/2018/02/12/health/truvada-hiv-insurance.html [https://perma.cc/CKH3-X5EW].

<sup>115</sup> *Id.*; Press Release, GLBTQ Legal Advocs. & Defs., GLAD and Mutual of Omaha Settle HIV PrEP Case (Jan. 8, 2019), https://www.glad.org/post/glad-and-mutual-of-omaha-settle-hiv-prep-case/ [https://perma.cc/F2B7-XRF5].

<sup>&</sup>lt;sup>108</sup> Plaintiff John Doe's Statement of Undisputed Material Facts in Support of Motion for Summary Judgment at 2–3, Doe v. Mut. Of Omaha Ins. Co., No. 1:16-cv-11381-GAO (D. Mass. July 18, 2018).

<sup>&</sup>lt;sup>109</sup> *Id.* at 6.

changes."<sup>116</sup> Following the media coverage, in June 2018, the New York Department of Financial Services issued a letter to insurers prohibiting PrEP insurance discrimination according to state law.<sup>117</sup> In 2019, the New Jersey Department of Banking and Insurance issued a similar statement.<sup>118</sup> California soon followed suit.<sup>119</sup>

Around the same time, the Massachusetts attorney general was also investigating other cases against Mutual of Omaha in which the insurance company denied coverage for six Massachusetts residents based on PrEP use.<sup>120</sup> In January 2019, the parties reached an assurance of discontinuance agreement.<sup>121</sup> According to the agreement, Mutual of Omaha was forced to revise its business practice and can no longer deny or charge higher rates to PrEP users residing in Massachusetts, had to offer the consumers who were denied insurance the opportunity to reapply, and was issued a \$25,000 fine.<sup>122</sup> It is unclear, but likely, that Mutual of Omaha altered its policy nationwide following the investigation and agreement reached in Massachusetts. Such an agreement could also potentially have caused a shift in the insurance industry as a whole after other insurers became aware of the investigation. Yet, in 2022, a California resident shared his experience of being denied long-term disability insurance because of he is taking PrEP.<sup>123</sup>

<sup>120</sup> Assurance of Discontinuance at 1–2, *In re* Mut. Of Omaha Ins. Co., No. 19-0049-C (Mass. Super. Ct. Jan. 8, 2019).

<sup>&</sup>lt;sup>116</sup> McNeil, Jr., *supra* note 114.

<sup>&</sup>lt;sup>117</sup> N.Y. DEP'T OF FIN. SERVS., INS. CIRCULAR LETTER NO. 8 (June 22, 2018), https://www.dfs.ny.gov/industry\_guidance/circular\_letters/cl2018\_08 [https://perma.cc/5T84-WK9G].

<sup>&</sup>lt;sup>118</sup> Anthony Vecchione, *DOBI Issues Guidance for Naloxone, PrEP Underwriting to Insurers*, NJBIZ (June 25, 2019), https://njbiz.com/dobi-issues-guidance-Naloxone-prep-underwriting-insurers [https://perma.cc/V5RQ-D54C].

<sup>&</sup>lt;sup>119</sup> Cal. Dep't of Ins., Notice on Insurer Underwriting Practices for Truvada/ PrEP Users (June 20, 2019), https://www.insurance.ca.gov/0250-insurers/0300insurers/0200-bulletins/bulletin-notices-commiss-opinion/upload/Truvada-PrEPUsersNotice.pdf [https://perma.cc/HR8A-C4MD].

<sup>&</sup>lt;sup>121</sup> Id. at 2, 5.

<sup>&</sup>lt;sup>122</sup> *Id.* at 2–3; Press Release, Off. of Att'y Gen. Maura Healey, Major Insurance Company Settles Allegations of Discrimination for Denying Policies to Consumers Using HIV Prevention Medication (Jan. 8, 2019), https://www.mass. gov/news/major-insurance-company-settles-allegations-of-discrimination-fordenying-policies-to-consumers-using-hiv-prevention-medication [https://perma. cc/3ERB-DTHV].

<sup>&</sup>lt;sup>123</sup> Charles Orgbon III, *The Infuriating Experience of PrEP Discrimination*, S.F. AIDS FOUND. (Aug. 22, 2022), https://www.sfaf.org/collections/beta/the-infuriating-experience-of-prep-discrimination/ [https://perma.cc/5J79-9SEL].

In addition to insurance discrimination, reports have surfaced of insurers not complying with Section 2713 of the ACA regarding the dollar-first coverage of PrEP. Those are situations where insurers billed enrollees thousands of dollars for the drug and quarterly lab tests and doctor visits, which are required to keep the prescriptions.<sup>124</sup> As many enrollees are not aware that they are not supposed to pay out-of-pocket for PrEP, many of them who cannot afford the drug and tests stop taking it.<sup>125</sup> This is another way in which insurers in states like California, Florida, Georgia, Ohio, Texas, and Washington, jeopardize the national goal of increasing PrEP use.<sup>126</sup>

# 3. Exclusion from the FDA's Blood Donation Policy

Until May 2023, the FDA's blood deferral policy, colloquially known as the "blood ban," prohibited men who had have had sex with men in the last three months from donating blood.<sup>127</sup> The deferral period of three months was put in place since April 2020<sup>128</sup> and replaced a twelve-month deferral and a complete ban on gay and bisexual men giving blood that had been in place from 1983 until 2015.<sup>129</sup> The blood ban was implemented in response to the AIDS epidemic of the 1980s in a period where the risk of HIV transfusion through blood transfusion was estimated at 1 in 2,500 transfusions<sup>130</sup> and when legal restrictions on intimate relationships between two men (including anti-sodomy laws, criminalization of sex while being HIV positive, and vagrancy and perversion laws) were abundant.<sup>131</sup> Nowadays, developments in blood screening technol-

<sup>&</sup>lt;sup>124</sup> 42 U.S.C. § 300gg-13; Sarah Varney, *HIV Preventive Care Is Supposed to Be Free in the US. So, Why Are Some Patients Still Paying?*, KFF HEALTH News (Mar. 3, 2022), https://khn.org/news/article/prep-hiv-prevention-costs-covered-problems-insurance [https://perma.cc/A6RM-7W7P].

<sup>&</sup>lt;sup>125</sup> Varney, *supra* note 124.

<sup>&</sup>lt;sup>126</sup> Id.

<sup>&</sup>lt;sup>127</sup> Doron Dorfman, *Can the COVID-19 Interstate Travel Restrictions Help Lift the FDA's Blood Ban?*, 7 J.L. & BIOSCIENCES, Jan.–June 2020, at 1, 2.

<sup>&</sup>lt;sup>128</sup> U.S. Food & Drug Admin., Revised Recommendations for Reducing the Risk of Human Immunodeficiency Virus Transmission by Blood and Blood Products: Guidance for Industry 1, 9 (2020), https://www.fda.gov/media/92490/download [https:// perma.cc/4885-H4ZG].

<sup>&</sup>lt;sup>129</sup> Dorfman, *supra* note 11, at 827–29.

<sup>130</sup> U.S. FOOD & DRUG ADMIN., supra note 128, at 3.

<sup>&</sup>lt;sup>131</sup> For an historical background and description of the current status of state laws criminalizing HIV status, see generally TREVOR HOPPE, PUNISHING DISEASE: HIV AND THE CRIMINALIZATION OF SICKNESS 2–3 (2018) (describing how "[f]rom the very beginning of the epidemic, AIDS was linked to punishment" and how "[t]he war

ogy allow for all blood donations from every single donor, even those who are ineligible to give blood, to be effectively tested by blood banks for HIV and other diseases.<sup>132</sup> As a result, the chances of HIV transmission through blood donation are estimated at 1 in 1.47 million transfusions.<sup>133</sup>

Consequently, no cases of transmission of HIV, hepatitis B, or hepatitis C through blood transfusions have been documented in the United States in the past twenty years.<sup>134</sup> In addition to that, HIV testing has also become ubiquitous,<sup>135</sup> as have other means of prevention of HIV infection, including PrEP.<sup>136</sup>

Nevertheless, the blood ban's calling out of gay and bisexual men had persisted for decades without clear necessity, sending a troubling message about their status in society. As donating blood has historically been described as a "civic duty,"<sup>137</sup> this calling out also signaled to society an unsettling message

<sup>132</sup> Keeping Blood Transfusions Safe: FDA's Multi-Layered Protections for Donated Blood, U.S. FOOD & DRUG ADMIN. (Mar. 23, 2018), https://www.fda.gov/ vaccines-blood-biologics/safety-availability-biologics/keeping-blood-transfusions-safe-fdas-multi-layered-protections-donated-blood [https://perma.cc/ A9FU-73BM]. ("The FDA reviews and approves all test kits used to detect infectious diseases in donated blood. After donation, each unit of donated blood is required to undergo a series of tests for infectious diseases . . . .").

<sup>133</sup> U.S. FOOD & DRUG ADMIN., *supra* note 128, at 3; Mathew L. Morrison, Note, Bad Blood: An Examination of the Constitutional Deficiencies of the FDA's "Gay Blood Ban", 99 MINN. L. REV. 2363, 2397 (2015).

<sup>134</sup> U.S. FOOD & DRUG ADMIN., *supra* note 128, at 3.

<sup>135</sup> *HIV Testing Locations*, HIV.Gov, https://www.hiv.gov/hiv-basics/hiv-testing/learn-about-hiv-testing/where-to-get-tested [https://perma.cc/JAL3-ZN3X] (last updated June 16, 2022); John G. Francis & Leslie P. Francis, *HIV Treatment as Prevention: Not an Argument for Continuing Criminalisation of HIV Transmission*, 9 INT'L J.L. CONTEXT 520, 521–22 (2013).

<sup>136</sup> See Francis & Francis, supra note 135, at 522–24.

<sup>137</sup> Richard Titmuss famously wrote in his 1970 book *The Gift Relationship*: "The forms and functions of giving [blood] embody moral, social, psychological, religious, legal and aesthetic ideas. They may reflect, sustain, strengthen or loosen the cultural bonds of the group . . . ." RICHARD TITMUSS, THE GIFT RELATION-SHIP: FROM HUMAN BLOOD TO SOCIAL POLICY 54 (Policy Press 2018) (1970); *see also* KARA W. SWANSON, BANKING ON THE BODY: THE MARKET IN BLOOD, MILK, AND SPERM IN MODERN AMERICA 67–68 (2014) (describing how since the 1930s blood banks and the Red Cross have framed donating blood as a "civic-minded generosity").

on drugs and the punitive response to HIV [in the 1980s] are but two examples of a more seismic shift in American corrections policy; law-makers increasingly turned away from the rehabilitative spirit of the 1960s and 1970s in favor of more punitive approaches that were rooted in retribution—or punishment for punishment sake"). See also Joshua D. Blecher-Cohen, Note, Disability Law and HIV Criminalization, 130 YALE L.J. 1560, 1565–69 (2021) (describing the passing of "HIV-criminalization statutes," starting in the 1980s).

about the morality of gay identity,<sup>138</sup> and the policy had been described as discriminatory, unconstitutional, and unnecessarily stigmatizing.<sup>139</sup> Interview data have also shown how the exclusion from the "civic ritual of blood donation" by the blood ban caused feelings of isolation and alienation among gay men, making them feel like second-class citizens.<sup>140</sup>

In a recent paper, I empirically identified a PrEP penalty with regard to lay people's willingness to accept a blood donation from a potential gay donor.<sup>141</sup> I showed how despite the fact that the participants in my experiment understood that gav men on PrEP are less likely to have HIV and STIs (as mentioned, PrEP users undergo expensive tests every three months to keep their prescriptions),<sup>142</sup> participants still preferred blood from those not taking the preventive drug.<sup>143</sup> This finding is troubling, as it once again demonstrates the signaled message about promiscuous, irresponsible behavior and risk compensation by PrEP users and how such messages affect decisionmaking, similar to what happens with insurers.<sup>144</sup> The irony is that those who take PrEP and know their HIV status are the ones that need to be applauded for their contribution to the efforts to eliminate HIV. Yet instead, they are being stigmatized for using the endorsed preventive measure.

In May 2023, the FDA finally lifted the blood ban for men who have sex with men and began assessing eligibility for donation regardless of sexual orientation.<sup>145</sup> This historic

<sup>&</sup>lt;sup>138</sup> See Olivier Garraud & Jean-Jacques Lefrère, Letter to the Editor, Voluntary Non-Remunerated Blood Donation and Reasons for Donating: Is There Room for Philosophy? 12 BLOOD TRANSFUSION (SUPPLEMENT) s404, s404 (2014).

<sup>&</sup>lt;sup>139</sup> Morrison, supra note 133, at 2390–91; Brian Soucek, The Case of the Religious Gay Blood Donor, 60 WM. & MARY L. REV. 1893, 1904 (2019); Luke A. Boso, Dignity, Inequality, and Stereotypes, 92 WASH. L. REV. 1119, 1158–60 (2017); Michael Christian Belli, The Constitutionality of the "Men Who Have Sex with Men" Blood Donor Exclusion Policy, 4 J.L. Soc'Y 315, 362–75 (2003); Dwayne J. Bensing, Comment, Science or Stigma: Potential Challenges to the FDA's Ban on Gay Blood, 14 U. PA. J. CONST. L. 485, 495 (2011); Vianca Diaz, A Time for Change: Why the MSM Lifetime Deferral Policy Should Be Amended, 13 U. MD. L.J. RACE RELIGION GENDER & CLASS 134, 144 (2013); Michael Varrige, Note, Continuing Stigma: Why the FDA's Policy Deferring Men Who Have Sex with Men from Donating Blood is Unconstitutional & a Poor Policy Choice, 69 Syracuse L. Rev. 611, 614 (2019).

<sup>&</sup>lt;sup>140</sup> Bennett, *supra* note 3, at 118–20.

<sup>&</sup>lt;sup>141</sup> Dorfman, *supra* note 11, at 834–35.

<sup>&</sup>lt;sup>142</sup> *Id.* at 851; Varney, *supra* note 124.

<sup>&</sup>lt;sup>143</sup> Dorfman, *supra* note 11, at 851.

<sup>&</sup>lt;sup>144</sup> *Id.* at 852.

<sup>&</sup>lt;sup>145</sup> Press Release, U.S. Food & Drug Admin., FDA Finalizes Move to Recommend Individual Risk Assessment to Determine Eligibility for Blood Donations (May 11, 2023), https://www.fda.gov/news-events/press-announcements/

announcement, however, included a caveat for PrEP users, whose blood donation continued to be excluded under the new policy.<sup>146</sup> Underscoring this exclusion is the fear that using PrEP "may delay detection of HIV by currently licensed screening tests" and create a situation where a blood donation that initially seemed to be negative will later turn out to be positive.<sup>147</sup> And so de facto, as more and more gay and bi-sexual men take PrEP at the encouragement of the FDA, they will not be able to donate blood. A possible solution to this concern would be a "double testing system: quarantining the blood of PrEP users until it is shown to be negative for HIV", a solution done in other parts of the world, as I discuss later.<sup>148</sup>

Even under its new blood donation policy, the FDA keeps speaking in two voices with regard to PrEP: endorsing and incentivizing its use on the one hand and penalizing its users on the other.  $^{\rm 149}$ 

fda-finalizes-move-recommend-individual-risk-assessment-determine-eligibility-blood-donations [https://perma.cc/T2RL-K73S].

<sup>146</sup> The policy states:

Additionally, under these final recommendations, those taking medications to treat or prevent HIV infection (e.g., antiretroviral therapy (ART), pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP)), will also be deferred. Though these antiretroviral drugs are safe, effective, and an important public health tool, the available data demonstrate that their use may delay detection of HIV by currently licensed screening tests for blood donations, which may potentially give false negative results. Although HIV is not transmitted sexually by individuals with undetectable viral levels, this does not apply to transfusion transmission of HIV because a blood transfusion is administered intravenously, and a transfusion involves a large volume of blood compared to exposure with sexual contact.

Id. See also Pampee P. Young & Paula Saa, Redefining *Blood Donation—Path to Inclusivity and Safety*, JAMA (Oct. 12, 2023), https://jamanetwork.com/ journals/jama/fullarticle/2810751 [https://perma.cc/B3K3-YHBM]. For a recent study about the number of sexual partners for PrEP users vs. non-PrEP users, showing PrEP users to have more sexual partners, see Custer et al., supra note 101.

<sup>147</sup> Id.

<sup>148</sup> See infra note 386 and accompanying text.

<sup>149</sup> In its announcement of the new policy, the FDA specifically acknowledges that "these antiretroviral drugs [PrEP] are safe, effective, and an important public health tool" and that "individuals should not stop taking their prescribed medications, including PrEP, or PEP, in order to donate blood." Press Release, *supra* note 145. The endorsement of PrEP and the encouragement of more people to use it has also been clear under the HHS's plan to eliminate HIV by 2030. *See* Fauci, Redfield, Sigounas, Weahkee & Giroir, *supra* note 90 and accompanying text.

2024]

4. Penalizing PrEP Use in Child Custody and Visitation Cases

Sexuality has played a prominent role in assumptions and assessment of parenthood by courts.<sup>150</sup> In her 2012 article, Suzanne Kim demonstrates how the legal construction of parental sexuality is conceived through the paradigm of the "neutering" parents, forcing them to adhere to traditional views of sexuality (under which a husband is expected to have sex with his wife as part of the marriage contract).<sup>151</sup>

This process of regulating parental sexuality has been specifically true for LGBTQ parents who represent a deviation from traditional gender roles.<sup>152</sup> The issue of parents' sexuality has been reflected prominently in custody and visitation cases wherein family law has for decades "penalize[d] lesbian and gay parents for conduct that would be entirely unremarkable for heterosexual parents."<sup>153</sup> LGBTQ parents have been deemed by courts determining custody and visitation cases as "sexually salient" (as opposed to "sexually neutral," a category attributed to heterosexual, married parents).<sup>154</sup> This view of the gay "sexually salient" parent fits with the prominent stereotype of them being "overly sexualized and promiscuous to the point of depravity."155

153 Julie Shapiro, Custody and Conduct: How the Law Fails Lesbian and Gay Parents and Their Children, 71 IND. L.J. 623, 648 (1996); see also Kim H. Pearson, Mimetic Reproduction of Sexuality in Child Custody Decisions, 22 YALE J.L. & FEMINISM 53, 59–66 (2010) (noting the progress made by LGBT advocates in family courts, despite the fact that lesbian and gay parents remain more likely to lose custody over their children or have their visitation rights restricted).

154 Kim, supra note 150, at 4, 31.

155 Id. at 32 (quoting Kimberly Richman, Lovers, Legal Strangers, and Parents: Negotiating Parental and Sexual Identity in Family Law, 36 Law & Soc'Y Rev. 285, 294 (2002)); see also Richard E. Redding, It's Really About Sex: Same-Sex Marriage, Lesbigay Parenting, and the Psychology of Disgust, 15 Duke J. GENDER L. & PoLY 127, 159 (2008) ("A related set of concerns expressed by courts and commentators involves the perception that homosexuals are sexually promiscuous and engage in high-risk sexual behaviors . . . ."); Marc A. Fajer, Can Two Real Men Eat Quiche Together? Storytelling, Gender-Role Stereotypes, and Legal Protection for Lesbians and Gay Men, 46 U. MIAMI L. REV. 511, 538 (1992) ("In its simplest form, the sex-as-lifestyle assumption leads non-gay people to assume that sex is an element of every aspect of gay people's lives.").

<sup>150</sup> Suzanne A. Kim, The Neutered Parent, 24 YALE J.L. & FEMINISM 1, 4 (2012). 151

Id. at 7. 35.

<sup>152</sup> Dara E. Purvis, The Sexual Orientation of Fatherhood, 2013 MICH. St. L. Rev. 983, 992 (stating that gay fathers conform to the gender stereotype of fathers as breadwinners but are not thought of as caregivers). The characterization of gay fathers as sexually saliant is, likewise, comparable to the hypersexualization of Black women. See Kim, supra note 150, at 31.

To decide who is a "sexually salient" parent in custody and visitation cases, courts have used certain indicia, like having other persons in the house.<sup>156</sup> In an early case, for example, Pulliam v. Smith, the North Carolina Supreme Court upheld the trial court's decision to transfer custody from the gay father to the mother based in part on the fact that the father "was regularly engaging in sexual acts with [his male partner] in the home while the children were present."157 Similarly, in a 2007 case, A.O.V. v. J.R.V., the Court of Appeals of Virginia upheld the trial court's decision to prohibit a gay father, who shared custody with his former wife, from having his male partner stay overnight or engage in displays of affection while the children visit their house.<sup>158</sup> In a 2009 Supreme Court of Georgia case. a gay father successfully reversed visitation restrictions imposed by the trial court that "prohibited [him] 'from exposing the children to his homosexual partners and friends."<sup>159</sup>

I argue that PrEP could be weaponized by former partners in custody cases against gay parents who use it. As PrEP carries with it the stereotype of promiscuity, illustrated by the term "Truvada Whores" applied to PrEP users,<sup>160</sup> the fact that a gay father is taking the drug could be used against him to besmirch his fitness to parent in custody and visitation cases.

An example of such a situation is illustrated in the 2019 case of *Sullivan v. Sullivan*, a divorce case in Tennessee involving a heterosexual married couple with three kids. Mr. Sullivan had sex with men prior to marrying Ms. Sullivan and had participated in a conversion therapy program.<sup>161</sup> Later in their marriage, Mr. Sullivan cheated on his wife with other men. The family's nanny found PrEP pills in Mr. Sullivan's clothing.<sup>162</sup>

<sup>162</sup> *Id.* at 11.

<sup>&</sup>lt;sup>156</sup> Kim, *supra* note 150, at 32.

<sup>&</sup>lt;sup>157</sup> 501 S.E.2d 898, 904 (N.C. 1998).

 $<sup>^{158}\,</sup>$  No. 0219-06-4, 0220-06-4, 2007 WL 581871, at \*6 (Va. Ct. App. Feb. 27, 2007).

<sup>&</sup>lt;sup>159</sup> Mongerson v. Mongerson, 678 S.E.2d 891, 894–95 (Ga. 2009).

<sup>&</sup>lt;sup>160</sup> The term "Truvada Whores" originated in 2012. *See* David Duran, *Truvada Whores*?, HUFFPOST: THE BLOG (Nov. 12, 2012), https://www.huffpost.com/entry/truvada-whores\_b\_2113588 [https://perma.cc/K6QN-RM55]. Since then, the author has publicly retracted his views and endorsed a campaign to reclaim the term under the hashtag #truvadawhore. *See* David Duran, *An Evolved Opinion on Truvada*, HUFFPOST: THE BLOG (Mar. 27, 2014), https://www.huffpost.com/entry/truvadawhore-an-evolved-o\_b\_5030285 [https://perma.cc/NC6S-U2Y8]. For further discussion on the promiscuity stereotype attached to PrEP users, *see* Dorfman, *supra* note 11, at 853–54.

 $<sup>^{161}\,</sup>$  Sullivan v. Sullivan, No. 45851, slip op. at 9 (Ch. Ct. Williamson Cnty. July 11, 2018).

The trial court mentions, "Mr. Sullivan never told his wife that he has been taking Truvada or of the possible exposure to HIV. Ms. Sullivan was greatly concerned after learning these facts. She felt that her husband was very self-centered to put her in that position with no warning."<sup>163</sup>

It is true that Mr. Sullivan exhibited dishonesty throughout the trial and engaged in other questionable behaviors.<sup>164</sup> Nevertheless, it is important to emphasize the way in which the trial court and the Court of Appeals of Tennessee paid specific attention to the use of PrEP as an issue that affects Mr. Sullivan's fitness to parent:

The Court's concern has nothing to do with Mr. Sullivan's sexual orientation. Throughout the course of the trial, Mr. Sullivan was very emotional. He was emotional in discussing his dishonesty. He was emotional in discussing the children . . . [Yet,] [h]e was not bothered when he engaged in sexual activity that might expose him or potentially expose his wife to HIV by engaging in sexual relations with her without disclosing his prior conduct. *He did not fret when he started taking medication to prevent HIV* without disclosure to his wife . . . .<sup>165</sup>

Mr. Sullivan was responsible in taking PrEP and being tested for HIV to protect himself and his wife.<sup>166</sup> Taking PrEP in this situation should not be used against Mr. Sullivan like both courts did in this case. If anything, the use of PrEP should be held in his favor when determining his parental rights. The courts' argument and rhetoric send a problematic message that penalizes prevention efforts.

Empirical data also point to a similar phenomenon of penalizing gay parents who are on PrEP. In my previous experimental study, I showed that the only family status in which the PrEP penalty for accepting a blood donation applies to is

<sup>&</sup>lt;sup>163</sup> Id.

<sup>&</sup>lt;sup>164</sup> For example, Mr. Sullivan injected testosterone and illegal steroids, as part of his passion for bodybuilding, which he stored in a place accessible to the kids. Those also made him short tempered. *Id.* at 13–14. He also attempted to pit his kids against their mother. *Id.* at 18.

 $<sup>^{165}</sup>$  Sullivan v. Sullivan, No. M2018-01776-COA-R3-CV, 2019 WL 4899760, at \*7 (Tenn. Ct. App. Oct. 4, 2019) (emphasis added) (quoting *Sullivan*, slip op. at 76 (Ch. Ct. Williamson Cnty. July 11, 2018)).

<sup>&</sup>lt;sup>166</sup> Mr. Sullivan obtained a prescription for Truvada in November 2016 until January 2017 and then in October 2017 and had sex with his wife in late 2016. He also was tested for HIV and was found negative. Admittedly, it is not clear whether he was taking the drug on a consistent regimen while sleeping with his wife. *See Sullivan*, slip op. at 26 (Ch. Ct. Williamson Cnty. July 11, 2018).

single or married parents.<sup>167</sup> As parenthood is associated with both respectability and asexuality,<sup>168</sup> parents who were taking PrEP became "sexually salient" in the eyes of my study participants.<sup>169</sup> Therefore, when considering family status (whether the potential gay donor is single, married, a single father, or a married father), the participants were less willing to take blood from a gay father on PrEP than a gay father not on PrEP, and while this penalty was found on average with regard to all gay donors, it did not intersect with the two other family statuses (namely, a single or childless married gay donor).<sup>170</sup>

Custody and visitation cases are, therefore, another potential arena for penalizing PrEP use and potentially creating a disincentive to take this effective preventive measure and to help achieve the public health goal of eliminating HIV.

B. Penalizing Mental Health Treatment: The Case of the Character and Fitness Screenings for State Bar Associations

From popular culture products such as the 1973 film The Paper Chase<sup>171</sup> to studies from the 1980s finding that law students experience higher rates of psychological stress compared to other graduate students,<sup>172</sup> law school has been known for decades to be a stressful experience.<sup>173</sup> A survey by the Law School Survey of Student Engagement ("LSSSE"), which included over 2,000 law students in 2020–21, showed that nearly 77% of the sample found the level of stress and anxiety in law

342

<sup>&</sup>lt;sup>167</sup> Dorfman, *supra* note 11, at 843–44, 870–71.

<sup>&</sup>lt;sup>168</sup> Cynthia Godsoe, Perfect Plaintiffs, 125 YALE L.J.F. 136, 147 (2015).

<sup>&</sup>lt;sup>169</sup> Dorfman, *supra* note 11, at 843–44, 870–71.

<sup>&</sup>lt;sup>170</sup> Id.

<sup>&</sup>lt;sup>171</sup> Based on a 1971 novel by John Jay Osborn Jr. of the same name, the film tells of the experiences of anxious 1L law students at Harvard, written and directed by James Bridges. The PAPER CHASE (20th Century Fox 1973).

<sup>&</sup>lt;sup>172</sup> See Stephen B. Shanfield & G. Andrew H. Benjamin, *Psychiatric Distress in Law Students*, 35 J. LEGAL EDUC. 65, 66 (1985). For even earlier studies, see Lawrence Silver, *Anxiety and the First Semester of Law School*, 1968 Wis. L. Rev. 1201, 1201; see also James M. Hedegard, *The Impact of Legal Education: An In-Depth Examination of Career-Relevant Interests, Attitudes, and Personality Traits Among First-Year Law Students*, 4 AM. BAR FOUND. RSCH. J. 791, 835 (1979); KATHRYNE M. YOUNG, How TO BE SORT OF HAPPY IN LAW SCHOOL 144–45 (2018) (describing, among other studies, a study that showed that law students suffered higher rates of psychiatric distress as compared to a contrasting normative population or a medical student population).

<sup>&</sup>lt;sup>173</sup> Kathryne M. Young, Understanding the Social and Cognitive Processes in Law School That Create Unhealthy Lawyers, 89 Fordham L. Rev. 2575, 2576–57 (2021).

2024]

school to be higher than five on a seven-point Likert scale.<sup>174</sup> A 2016 survey of over 3,000 law students demonstrated that over one-third of participants screened positive for moderate to severe anxiety, and roughly one-sixth screened positive for depression.<sup>175</sup> One of the most concerning findings of that study was that while 42% of participants indicated they needed help with their mental health, just nearly half of them actually received counseling.<sup>176</sup>

Mental health intervention is an important preventive health measure that could prevent hospitalization related to mental illness<sup>177</sup> and suicide.<sup>178</sup> The U.S. Preventive Task Force recommends screening and early interventions for depression among adults to help with reduction or remission of depression symptoms.<sup>179</sup>

<sup>176</sup> *Id.* at 140.

<sup>177</sup> See, e.g., Laura N. Medford-Davis, Rohan Shah, Danielle Kennedy & Emilie Becker, *The Role of Mental Health Disease in Potentially Preventable Hospitalizations: Findings from a Large State*, 56 MED. CARE 31, 35 (2018) (finding that "the mechanisms of preventability [for mental health hospitalizations] often stem from delayed or inadequate access to preventative care for the chronic diagnoses").

178 A recent study found an association between states' implementation of Medicaid expansion to cover mental health treatment and lower rates of suicide, stating that "[o]ur results demonstrate an association between expansion and a mitigation in suicide mortality and supports the theory that expanding insurance coverage reduces mental health burden in the population and that Medicaid expansion prevented many unnecessary deaths by suicide." See Hetal Patel, Justin Barnes, Nosayaba Osazuwa-Peters & Laura Jean Bierut, Association of State Medicaid Expansion Status With Rates of Suicide Among US Adults, JAMA NETWORK OPEN: PSYCHIATRY (June 15, 2022), https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2793360 [https://perma.cc/ZU9Y-JJ6H]; see also Nicholas P. Allan, Daniel F. Gros, Cynthia L. Lancaster, Kevin G. Saulnier & Tracy Stecker, Heterogeneity in Short-Term Suicidal Ideation Trajectories: Predictors of and Projections to Suicidal Behavior, 49 Suicide & Life-Threatening Behav. 826, 827 (2019) (describing a study aimed in part at understanding the relation between previously identified risk factors for suicide ideation); Organ, Jaffe & Bender, supra note 175, at 153 n.117 (providing information on where faculty can receive training to recognize students' mental health issues and warning signs of suicide).

<sup>179</sup> Final Recommendation Statement, Screening for Depression in Adults, U.S. PREVENTIVE SERVS. TASK FORCE (Jan. 26, 2016), https://www.uspreventiveservices-taskforce.org/uspstf/document/RecommendationStatementFinal/depression-in-adults-screening [https://perma.cc/ZY5K-NXH9].

<sup>&</sup>lt;sup>174</sup> The question is taken from the "Student Stress & Anxiety Module" of the LSSSE and reads as follows: "During the current school year, how would you characterize your level of law school related stress or anxiety?" I am thankful to Meera Deo and Jacquelyn Petzold for sharing the data with me.

<sup>&</sup>lt;sup>175</sup> Jerome M. Organ, David B. Jaffe & Katherine M. Bender, *Suffering in Silence: The Survey of Law Student Well-Being and the Reluctance of Law Students to Seek Help for Substance Use and Mental Health Concerns*, 66 J. LEGAL EDUC. 116, 145 (2016).

The number one reason for not turning for help, indicated by forty-five percent of those who identified as needing that intervention, was the potential threat to bar admission.<sup>180</sup> As an anonymous law student confessed in a recent news story, he refused to seek out mental health resources when law school stress was getting overwhelming because he believed it was not worth the risk of potentially being flagged during the state bar's character and fitness evaluation. Despite having anxiety during the first year of law school, the student did not seek help and instead got drunk with his classmates on a weekly basis to relieve stress.<sup>181</sup>

To be admitted to practice law in New York, an applicant must not only pass an examination,<sup>182</sup> but also prove that he or she possesses what the New York Bar calls "good moral character and general fitness requisite for an attorney- and counselor-at-law."<sup>183</sup> While some states require affirmations by references of the applicant's character and fitness,<sup>184</sup> other jurisdictions use a questionnaire instead or in addition to these types of references.<sup>185</sup> The character and fitness evaluation includes a committee examination of the "mental fitness" of applicants to practice law informed by past mental health treatment.<sup>186</sup>

<sup>&</sup>lt;sup>180</sup> Organ, Jaffe & Bender, *supra* note 175, at 141.

<sup>&</sup>lt;sup>181</sup> Madeline Holcombe, *Law Students Say They Don't Get Mental Health Treatment for Fear It Will Keep Them from Becoming Lawyers. Some States Are Trying to Change That*, CNN (Feb. 29, 2020), https://www.cnn.com/2020/02/23/ health/law-school-bar-exam-mental-health-questions/index.html [https:// perma.cc/3KRA-FZUH]; *see also* Margaret Hannon, *Why the Character and Fitness Requirement Shouldn't Prevent Law Students from Seeking Mental Health Treatment*, A.B.A.: STUDENT LAW. BLOG (July 9, 2018), https://abaforlawstudents. com/2018/07/09/character-fitness-requirement-and-seeking-mental-healthtreatment [https://perma.cc/S2QH-JXAV] (emphasizing the importance of students being able to seek counseling without the fear of being subjected to a character and fitness inquiry).

<sup>&</sup>lt;sup>182</sup> In most states, the applicant must successfully pass three exams: The Multistate Professional Responsibility Examination ("MPRE"), a three-hour multiple-choice exam developed by the National Conference of Bar Examiners, which is administered nationally in the same format, as well as the state's Bar examination.

<sup>&</sup>lt;sup>183</sup> N.Y. COMP. CODES R. & REGS. Tit. 22, § 520.12(a) (2015). For an important critique of the moral character requirement from a criminal justice perspective, see Hadar Aviram, *Moral Character: Making Sense of the Experiences of Bar Applicants with Criminal Records*, 43 Man. L.J. 1, 3 (2020).

 $<sup>^{184}</sup>$  The New York Bar is one of those that uses affirmations by references. See N.Y. Comp. Codes R. & Regs. Tit. 22, § 520.12(b).

 $<sup>^{185}</sup>$  See, e.g., McCready v. Ill. Bd. of Admissions to the Bar, No. 94 C 3582, 1995 WL 29609, at \*5 (N.D. Ill. Jan. 24, 1995) (alleging injury to plaintiff due to the disability-related questions required for the application to the Illinois bar).

<sup>&</sup>lt;sup>186</sup> See Jon Bauer, The Character of the Questions and the Fitness of the Process: Mental Health, Bar Admissions and the Americans with Disabilities Act, 49

Law students are strategic players.<sup>187</sup> They get the message while in law school that seeking preventive treatment for mental health may cause problems in their future careers.<sup>188</sup> Therefore, as explained, the inquiry into applicants' past mental health history by state bars has created a deterrent effect on seeking preventive mental health treatment.<sup>189</sup> Some courts have recognized this problem.<sup>190</sup>

While calls to diversify the legal profession with more lawyers with disabilities have been made both historically<sup>191</sup> and more recently,<sup>192</sup> the phenomenon of penalizing prevention

<sup>188</sup> Organ, Jaffe & Bender, *supra* note 175, at 141.

189 See Alex B. Long, What the Lawyer Well-Being Movement Could Learn from the Americans with Disabilities Act, 63 WM. & MARY L. REV. ONLINE 63, 70-71 (2022). The deterrence effect on seeking mental health treatment exists in other contexts, including educational settings, outside the character and fitness evaluation for the bar exam, which are outside the scope of this Article. One recent tragic incident that is worth mentioning is that of 19-year-old pilot John Hauser who was a student at the University of North Dakota's aerospace program. In October 2021, Hauser committed suicide by crashing the plane he was flying during an exercise. Investigation after the fact found that Hauser was living with depression but did not seek treatment due to fear of jeopardizing his ability to obtain a Federal Aviation Administration ("FAA") license. Hauser's death has crystalized the urgency of discussing FAA's policies around mental illness and to ensure that there is no "penalizing prevention" issue in this context. See Cathy Wurzer & Kelly Gordon, A Student Pilot's Death Leads to Efforts to Combat Mental Health Stigma at Flight School, MPRNEWS (Feb. 1, 2022), https://www.mprnews. org/episode/2022/02/01/a-student-pilots-death-leads-to-efforts-to-combatmental-health-stigma-at-flight-school [https://perma.cc/322U-55U7]; Connor Murphy, UND Hosts Summit on Mental Health in Aviation, UND TODAY (Dec. 16, 2021). https://blogs.und.edu/und-today/2021/12/und-hosts-summit-on-mental-health-in-aviation [https://perma.cc/Y3W2-65YP]. I thank Paul Traynor for alerting me to this issue.

<sup>190</sup> Clark v. Va. Bd. of Bar Exam'rs, 880 F. Supp. 430, 437, 446 (E.D. Va. 1995) (concluding that "[q]uestion 20(b) [on an applicant's mental health history], while offering little marginal utility in identifying unfit applicants, has strong negative stigmatic and deterrent effects upon applicants"); *In re* Petition of Frickey, 515 N.W.2d 741, 741 (Minn. 1994) (finding that "as a matter of public policy, [the questions] unduly deter law students from seeking mental health counseling").

<sup>191</sup> Jolly-Ryan, *supra* note 187, at 155.

<sup>192</sup> See generally Peter Blanck et al., Diversity and Inclusion in the American Legal Profession: First Phase Findings from a National Study of Lawyers with Disabilities and Lawyers Who Identify as LGBTQ+, 23 UDC/DCSL L. REV. 23, 26 (2020) (proposing an expansion of Diversity and Inclusion into D&I+, including people with disabilities and those who identify as LGBTQ+); Peter Blanck, Fitore Hyseni & Fatma Altunkol Wise, Diversity and Inclusion in the American Legal Profession:

UCLA L. Rev. 93, 101–02 (2001) (describing the process performed by committees in the state of Connecticut as well as in other states to determine "character and fitness" of applicants for the bar).

<sup>&</sup>lt;sup>187</sup> Jennifer Jolly-Ryan, *The Last Taboo: Breaking Law Students with Mental Illnesses and Disabilities out of the Stigma Straitjacket*, 79 UMKC L. Rev. 123, 124, 128 (2010).

once again thwarts these efforts and stands as a barrier to entry of law students with mental health disabilities into the legal profession.

# 1. Three Decades of Mental Health Fitness in the Courts and Beyond

In 1957, the Supreme Court acknowledged the authority of a state to require qualifications such as proficiency and good moral character when admitting applicants to its state bar.<sup>193</sup> The Court has acknowledged that a broad discretion and power needed to be given to state bars in their determinations on admission, as long as they do not violate the Due Process Clause of the Fourteenth Amendment.<sup>194</sup> The Court also determined that overseeing bar admission is beyond the role of the courts.<sup>195</sup> Indeed, lower courts were reluctant to intervene

<sup>193</sup> Schware v. Bd. of Bar Exam'rs of N.M., 353 U.S. 232, 239 (1957) ("A state can require high standards of qualification, such as good moral character or proficiency in its law, before it admits an applicant to the bar, but any qualification must have a rational connection with the applicant's fitness or capacity to practice law."). In his concurring opinion, Justice Frankfurter emphasized what encompasses the requirement of a good moral character: "From a profession charged with such responsibilities there must be exacted those qualities of truth-speaking, of a high sense of honor, of granite discretion, of the strictest observance of fiduciary responsibility, that have, throughout the centuries, been compendiously described as 'moral character." *Id.* at 247 (Frankfurter, J., concurring).

- <sup>194</sup> *Id.* at 238–39.
- <sup>195</sup> *Id.* at 239, 248.

Discrimination and Bias Reported by Lawyers with Disabilities and Lawyers Who Identify as LGBTQ+, 47 AM. J.L. & MED. 9, 10 (2021) (conducting a study on discrimination suffered by diverse and multiple minority lawyers as an "incremental step for better understanding non-monochromatic and intersectional aspects of individual identity in the legal profession"). At the same time, scholars have criticized the suspicious, stigmatized, and ableist/sanist approach towards mental disabilities within the legal profession. See generally Michael L. Perlin, The ADA and Persons with Mental Disabilities: Can Sanist Attitudes be Undone?, 8 J.L. & HEALTH 15, 20–21 (1993–94) (arguing that the ADA's impact on people with mental illness is unfortunately small, due to "sanist" views of mental disabilities within the legal profession); Michael L. Perlin, "Baby, Look Inside Your Mirror": The Legal Profession's Willful and Sanist Blindness to Lawyers with Mental Disabilities, 69 U. PITT. L. REV. 589, 590 (2008) (describing sanism as "an irrational prejudice of the same quality and character of other irrational prejudices that cause (and are reflected in) prevailing social attitudes of racism, sexism, homophobia, and ethnic bigotry"); John V. Jacobi, Professionalism and Protection: Disabled Lawyers and Ethical Practice, 69 U. PITT. L. REV. 567, 567 (2008) (arguing that the attorney discipline system may mistreat attorneys with mental illness through ignorance). In a recent eve-opening essay, Professor Alex Long reveals how even an attempt to address lawyers' well-being through a 2017 report published by the National Task Force on Lawyer Well-Being as well as ABA and state ethics opinions actually contribute to the stigmatization of mental disabilities. See Long, supra note 189, at 74-80.

2024]

with determination related to character and fitness claims concerning mental health and fitness.<sup>196</sup> However, the passage of the Americans with Disabilities Act ("ADA") in 1990 signaled a change on this front.

## a. The 1990s and the Effect of the ADA

The ADA is an omnibus antidiscrimination statute modeled after the Civil Rights Act of 1964. The ADA was considered a revolutionary civil rights law at the time of its enactment.<sup>197</sup> It aimed to challenge preexisting attitudes toward people with disabilities.<sup>198</sup> The ADA was signed by Republican President George H. W. Bush and was passed by a Democratic House and Senate, a bipartisan collaboration,<sup>199</sup> due to a somewhat surprising compatibility between neoliberal principles and the philosophy of the independent living movement. Both groups shared the goal of allowing disabled people to move "towards independence" through integration into the labor market and off public benefits, although this aspiration originated from different worldviews.<sup>200</sup>

<sup>197</sup> Robert L. Burgdorf Jr., *The Americans with Disabilities Act: Analysis and Implications of a Second-Generation Civil Rights Statute*, 26 HARV. C.R.-C.L. L. REV. 413, 415 (1991).

<sup>198</sup> Linda Hamilton Krieger, *Afterword: Socio-Legal Backlash*, 21 BERKELEY J. EMP. & LAB. L. 476, 480 (2000); Linda Hamilton Krieger, *Sociolegal Backlash, in* BACKLASH AGAINST THE ADA: REINTERPRETING DISABILITY RIGHTS 340, 342 (Linda Hamilton Krieger ed., 2003); Elizabeth F. Emens, *Framing Disability*, 2012 U. ILL. L. Rev. 1383, 1387. Nevertheless, as I argued elsewhere, the ADA had limited success in changing hearts and minds about disability:

Despite the ADA's transformative goal of changing social attitudes toward disability, many argue the ADA has had limited success in this regard. The ADA successfully raised *public awareness* of the topic, and now laypeople at least seem familiar with the general issues and basic concepts of reasonable accommodations. However, the statute and movement failed to change *perceptions toward disability* in courtrooms and the public sphere.

See Doron Dorfman, *Fear of the Disability Con: Perceptions of Fraud and Special Rights Discourse*, 53 Law & Soc'y Rev. 1051, 1060 (2019) [hereinafter Dorfman, Fear of the Disability Con].

<sup>199</sup> David Pettinicchio, Politics of Empowerment: Disability Rights and the Cycle of American Policy Reform 120 (2019).

<sup>200</sup> While some Republican supporters of the ADA saw it as a means to save tax money by getting people with disabilities off benefits and into the labor market, the independent living moment saw the emancipation of people with disabilities

<sup>&</sup>lt;sup>196</sup> See, e.g., Fla. Bd. of Bar Exam'rs Re: Applicant, 443 So. 2d 71 (Fla. 1983) (upholding the state bar examiners' refusal to process a bar application until the applicant answered certain questions and provided records about their mental health history); *In re* Application of Mort, 560 N.E.2d 204, 206 (Ohio 1990) (upholding the rejection of Mort's bar application, because "Mort had the burden of establishing that problems associated with his past mental health did not affect his present fitness to practice law").

The ADA thus concerned itself with eliminating barriers preventing disabled individuals from partaking in society as equal and productive citizens. Title II of the ADA protects qualified individuals with disabilities from being discriminated against, excluded, or denied participation in services, programs, or activities offered by any state or local government entity.<sup>201</sup> The fact that state bars fit neatly within the antidiscrimination mandate of Title II did not escape bar applicants.<sup>202</sup> They started challenging mental health fitness determinations made as part of the character and fitness evaluations under the new law in the early 1990s.<sup>203</sup>

The first case to use the ADA in the context of state licensing successfully challenged questions related to mental health history. This case, however, involved medical students and not law students. In Medical Society of New Jersey v. Jacobs, the court found that questions pertaining to psychiatric conditions and mental illness singled out applicants with disabilities who otherwise were qualified to practice medicine.<sup>204</sup> These questions unnecessarily burdened applicants with mental disabilities.<sup>205</sup> The questions themselves were not discriminatory; rather, the extra hurdle of contacting the treating physician imposed on those answering "yes" to the question was discriminatory under Title II of the ADA.<sup>206</sup> Two months later, questions by Maine's bar examiners were successfully challenged under the ADA for requiring information on diagnoses and treatment of mental disabilities and the release of medical records. The court emphasized that the bar may ask "questions more directly related to behavior that can affect the practice of law without violating the ADA."207 In a case filed by deans and

<sup>203</sup> Title II of the ADA became effective in January 1992. See Clark v. Va. Bd. of Bar Exam'rs, 880 F. Supp. 430, 440 (E.D. Va. 1995); see also Timeline of the Americans with Disabilities Act, ADA NAT'L NETWORK, https://adata.org/ada-timeline [https://perma.cc/6YXC-86XK] (last visited May 10, 2023) (providing an overview of the major milestones before and after the ADA was passed).

<sup>204</sup> No. 93-3670(WGB), 1993 WL 413016, at \*6 (D.N.J. Oct. 5, 1993).

<sup>205</sup> *Id.* at \*7.

<sup>206</sup> *Id.* at \*8.

 $^{207}$  In re Application of Underwood, No. BAR-93-21, 1993 WL 649283, at \*2 (Me. Dec. 7, 1993) (emphasis omitted).

as a goal in and of itself. See Thomas F. Burke, Lawyers, Lawsuits, and Legal Rights: The Battle over Litigation in American Society 77–78 (2002); Samuel R. Bagenstos, Law and the Contradictions of the Disability Rights Movement 29 (2009); Katharina Heyer, Rights Enabled: The Disability Revolution, from the US, to Germany and Japan, to the United Nations 33–34 (2015).

<sup>&</sup>lt;sup>201</sup> 42 U.S.C. §§ 12131, 12132.

<sup>&</sup>lt;sup>202</sup> Bauer, *supra* note 186, at 126.

law professors, the Supreme Court of Minnesota once again offered the need for questions to focus on conduct, although the court indicated its doubt as to whether the ADA applied to the issue.<sup>208</sup> In 1994, a Florida district court applied the same reasoning as in the *Jacobs* case to the state bar by determining that broad mental health questions discriminate against disabled applicants "by subjecting them to additional burdens based on their disability."<sup>209</sup>

Some courts determined that "narrowly focused inquiries" regarding mental health history do not violate the ADA. In Applicants v. Texas State Board of Law Examiners,<sup>210</sup> a Texas district court found that the inquiry into past mental diagnoses and illnesses is necessary to provide the board with information to assess one's capacity to practice law.<sup>211</sup> Because the board performs individualized and case-by-case investigations, and in many cases, those who answer the questions are ultimately cleared to show current fitness to practice, the board's efforts to avoid improper generalization or stereotyping of mental illness as defined by the ADA seemed evident.<sup>212</sup> Shortly thereafter, an Illinois district court relied on the Texas decision to reject claims against mental health inquiries made by applicants' references.<sup>213</sup> The Illinois court also had some strong words about how the ADA should not impede the state bars' important task of evaluating character and fitness.<sup>214</sup>

Unlike Minnesota, the Texas and Illinois courts did not account for policy considerations regarding the broader deterrent effect on the law student population. When considering

<sup>212</sup> Id.

 $^{213}\,$  McCready v. Ill. Bd. of Admissions to the Bar, No. 94 C 3582, 1995 WL 29609, at \*6 (N.D. Ill. Jan. 24, 1995).

<sup>214</sup> The purpose of the ADA is to protect disabled individuals from discrimination and to promote integration of disabled individuals into the mainstream of society. It is ludicrous, however, to propose that this purpose can only be accomplished by prohibiting a state from directly investigating and assessing an applicant's emotional and mental fitness to determine if the applicant has sufficient competence to discharge the responsibilities of a lawyer before the state warrants by licensing to the citizens that the individual has the mental and emotional fitness to fulfill a lawyer's legal, ethical, and moral responsibilities. Id. at \*7.

<sup>&</sup>lt;sup>208</sup> In re Petition of Frickey, 515 N.W.2d 741, 741 (Minn. 1994).

<sup>&</sup>lt;sup>209</sup> Ellen v. Fla. Bd. of Bar Exam'rs, 859 F. Supp. 1489, 1494 (S.D. Fla. 1994).
<sup>210</sup> No. A 93 CA 740 SS, 1994 WL 923404, at \*1 (W.D. Tex. Oct. 11, 1994).

<sup>&</sup>lt;sup>211</sup> *Id.* at \*8 ("[T]he ADA does not preclude a licensing body from any inquiry and investigation related to mental illness, instead allowing for such inquiry and investigation when they are necessary to protect the integrity of the service provided and the public.").

the problematic message that arises from the inquiry itself, it does not really matter whether the majority is "exonerated" and deemed fit to practice law. This is because such a message leads to a chilling effect on seeking mental health therapy due to the consequences of such treatment.<sup>215</sup>

Less than five months after the Texas decision and only one month after that in Illinois, both of which were hostile to challenging mental health inquires through the ADA, the most referenced case on this issue was decided, establishing the guidelines for mental health questions as part of the character and fitness requirements and recognizing the chilling effect. In Clark v. Virginia Board of Bar Examiners,<sup>216</sup> the Virginia district court was unimpressed by the fact that in twenty-three years, no applicant in the state had ever been denied the right to sit for the bar based on the mental health inquiry.<sup>217</sup> This is because the board only reviewed forty-seven applicants who answered positively to the question about mental health history out of more than 2,000 in the preceding five years. This is around one percent out of twenty percent of the expected population who have mental health disabilities, leading the court to conclude this question is ineffective in identifying applicants who might be unfit to practice due to mental health issues.<sup>218</sup>

In its analysis, the Virginia court centered the policy consideration on the deterrent effect and determined that it was adequately proven by the plaintiff's expert witness.<sup>219</sup> The court also determined that the board tacitly acknowledged the danger of a deterrent effect in its preamble to the question that warned applicants: "[Y]our decision to seek counseling should not be colored by your bar application."<sup>220</sup> The court stated that "[w]hile the Board's warning may be intended to assuage applicants' fears, it is uncertain that applicants, intimidated by the bar application process, heed such advice."<sup>221</sup> While the court did recognize that some form of mental health inquiry

- <sup>219</sup> Id.
- <sup>220</sup> Id.
- <sup>221</sup> Id. at 437–38.

 $<sup>^{215}</sup>$  Organ, Jaffe & Bender, *supra* note 175, at 141 (suggesting that "in law school, students are getting messages indicating that seeking help for mental health concerns or alcohol/drug concerns may be problematic for their academic or professional careers").

<sup>&</sup>lt;sup>216</sup> 880 F. Supp. 430, 446 (E.D. Va. 1995).

<sup>&</sup>lt;sup>217</sup> Id. at 434.

<sup>&</sup>lt;sup>218</sup> Id. at 437.

2024]

would be appropriate at some stage of the application,<sup>222</sup> it found the questions in this case were illegal. The court found them overly broad such that they impose too great of a burden on applicants with disabilities, thus violating Title II of the ADA while unsuccessfully screening out unfit applicants. Thus, the court ordered for the questions to be rewritten.<sup>223</sup>

Following *Clark*, in a case brought by the ACLU of Rhode Island, the state supreme court ordered that the bar's mental health question be modified.<sup>224</sup> The Supreme Court of Rhode Island also discussed research that showed no direct link between a history of mental health issues and one's capacity to function effectively in the workplace. The Rhode Island court, therefore, took an even more progressive approach than the Virginia court had, alluding to the fact that mental health inquiries might not need to take place at all.<sup>225</sup>

# b. The 2000s and the Rise of the Behavioral Approach

An intensive period of litigation followed the ADA's passage, but the first decade of the new millennium was far quieter. Nine years passed since the Virginia decision in *Clark* and the Rhode Island opinion were rendered, and no other federal case under the ADA was brought. A possible explanation of the dearth in litigation may potentially be plaintiffs' disillusionment with the ADA and its impact fueled by the infamous backlash against the statute in federal courts and in the Supreme Court. While the majority of cases in the context of mental health inquiries for character and fitness upheld the ADA,<sup>226</sup> generally speaking, most federal court decisions in the first twenty years after the ADA's passage were hostile to disability rights. Defendants prevailed in 92.7% of the ADA cases heard in federal district and appellate courts before 1998.<sup>227</sup> In 1999, in a series of cases known as "the Sutton trilogy," the Supreme Court ad-

<sup>&</sup>lt;sup>222</sup> *Id.* at 436.

<sup>&</sup>lt;sup>223</sup> *Id.* at 446.

<sup>&</sup>lt;sup>224</sup> In *re* Petition & Questionnaire for Admission to the R.I. Bar, 683 A.2d 1333, 1333 (R.I. 1996).

<sup>&</sup>lt;sup>225</sup> Id. at 1336.

 $<sup>^{226}</sup>$  Another exception to the trend was the 1998 case Bragdon v. Abbott, in which the Supreme Court recognized HIV infection to be a disability under the ADA, not in the employment context. 524 U.S. 624, 624 (1998).

<sup>&</sup>lt;sup>227</sup> 38.7% of the ADA cases were resolved through summary judgment and 54% were resolved through a decision on the merits. *See* Ruth Colker, *The Americans with Disabilities Act: A Windfall for Defendants*, 34 HARV. C.R.-C.L. L. REV. 99, 109 (1999).

opted a narrow reading of the threshold definition of disability and, thus, shut down claims of plaintiffs who saw themselves as part of the law's broad protected class.<sup>228</sup> In the 2002 case *Toyota Motor Manufacturing, Inc. v. Williams*,<sup>229</sup> the Supreme Court unanimously decided that the ADA's definition of disability should be "interpreted strictly to create a demanding standard for qualifying as disabled."<sup>230</sup> Scholars argued that the ADA was not meant to screen out who is a person worthy of protection in the same way that Social Security laws do, but rather to protect from discrimination. Yet the courts were unused to that mentality and used the ADA's definition of disability as a screening tool.<sup>231</sup>

The backlash against the ADA and the disillusionment that plaintiffs felt with it might explain the 2005 decision in *Strasser v. Character and Fitness Committee of The Kentucky Office of Bar Admissions*.<sup>232</sup> In this case, the plaintiff had been treated previously for alcohol and relationship problems by a therapist, which she disclosed on her bar application.<sup>233</sup> The plaintiff later met with three psychologists who recommended her admission to the bar and passed a personality test, taken at her expense, yet was nevertheless denied admission to the Kentucky bar.<sup>234</sup> The Kentucky Supreme Court took a behavioral approach to this issue, sending a clear message that prior mental health treatment, and even current counseling, do not in and of themselves deem a person unfit to practice law if

<sup>232</sup> 160 S.W.3d 789 (Ky. 2005).

<sup>&</sup>lt;sup>228</sup> See 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, 139–41 (2000); Robert L. Burgdorf Jr., "Substantially Limited" Protection from Disability Discrimination: The Special Treatment Model and Misconstructions of the Definition of Disability, 42 VILL. L. REV. 409, 438–39 (1997); Arlene B. Mayerson, Restoring Regard for the "Regarded As" Prong: Giving Effect to Congressional Intent, 42 VILL. L. REV. 587, 587 (1997); Bonnie Poitras Tucker, The Supreme Court's Definition of Disability Under the ADA: A Return to the Dark Ages, 52 ALA. L. REV. 321, 370 (2000); Kay Schriner & Richard K. Scotch, The ADA and the Meaning of Disability, in BACKLASH AGAINST THE ADA: REINTERPRETING DISABILITY RIGHTS, supra note 198, at 164, 172.

<sup>&</sup>lt;sup>229</sup> 534 U.S. 184 (2002).

<sup>&</sup>lt;sup>230</sup> *Id.* at 197.

<sup>&</sup>lt;sup>231</sup> See MARY JOHNSON, MAKE THEM GO AWAY: CLINT EASTWOOD, CHRISTOPHER REEVE & THE CASE AGAINST DISABILITY RIGHTS 11 (2003); Elizabeth F. Emens, *Disabling Attitudes: U.S. Disability Law and the ADA Amendments Act*, 60 Am. J. COMPAR. L. 205, 213 (2012) ("[The ADAAA] would, more generally, run up against the statute's explicit mandate that courts shift their emphasis from determining who is in and who is out to determining whether discrimination has occurred.").

<sup>&</sup>lt;sup>233</sup> Id. at 790–91.

<sup>&</sup>lt;sup>234</sup> Id.

there are no present behavioral issues.<sup>235</sup> The Kentucky Supreme Court decision in this case clearly goes against the tendency to penalize prevention, and no mention of the ADA can be found in this decision.

In a case from Wisconsin, a plaintiff did not challenge the questions she was asked on the application but challenged the fact that after she was screened, she had to pay for her own psychological evaluation at her own expense while dependent on Social Security benefits.<sup>236</sup> The court determined that such a requirement from disabled applicants created a burden to which the vast majority of other nondisabled applicants were not subjected.<sup>237</sup> Again focusing on behavior and not on treatment, the court concluded that the board was able to determine fitness to practice law even without a current psychological evaluation by looking at her past conduct and behavior.<sup>238</sup> What might explain the Wisconsin court's willingness to engage with an ADA analysis is the fact that the plaintiff was receiving Social Security benefits, fitting within the prominent charity model of disability as well as the public and court views of disability.239

Perhaps the ADA Amendment Act ("ADAAA"),<sup>240</sup> a direct response to the ADA backlash meant to fix the restrictive interpretation of what constitutes a disability,<sup>241</sup> inspired the next case in the saga. In 2011, an Indiana district court relied on *Clark* to send a clear message:

Notably, courts throughout the country have, with virtual unanimity, ruled that the ADA applies to questions posed to applicants by legal licensing boards. In other words, the

<sup>&</sup>lt;sup>235</sup> *Id.* at 791 ("Although Ms. Strasser sought and was treated for alcohol and relationship problems by counselor Tomeca Runyon, it does not mean that she is unfit to practice law. Moreover, Ms. Strasser is in counseling. There is nothing to suggest that her past problems with alcohol and domestic violence interfere with her present ability to practice law. The substantial fact that she has sought treatment and lack of any incidents to this date show a strong attempt to demonstrate that she is fit to practice law. Additionally, Ms. Strasser has presented evidence in the form of letters from employers and others in the legal community that she has conducted herself in a professional and competent manner.").

 $<sup>^{236}\,</sup>$  Brewer v. Wis. Bd. of Bar Exam'rs, No. 04-C-0694, 2006 WL 3469598, at \*8 (E.D. Wis. Nov. 28, 2006).

<sup>&</sup>lt;sup>237</sup> *Id.* at \*11.

<sup>&</sup>lt;sup>238</sup> *Id.* at \*13.

<sup>&</sup>lt;sup>239</sup> See Arlene S. Kanter, *The Law: What's Disability Studies Got to Do With It* or *An Introduction to Disability Legal Studies*, 42 COLUM. HUM. RTS. L. REV. 403, 419 n.51 (2011).

<sup>&</sup>lt;sup>240</sup> 42 U.S.C. §§ 12101(a)(2), 12102(4)(E)(i).

<sup>&</sup>lt;sup>241</sup> Emens, *supra* note 231, at 211–13.

Board does not have carte blanche to pry into every crevice of the bar applicant's life, as the ADA prohibits at least *some* disability-related inquiries.<sup>242</sup>

The court then decided to strike down a question it deemed as too broad and that related to a past mental diagnosis of mental impairments.<sup>243</sup> The court allowed for questions it saw as bearing on applicants' current ability to practice law,<sup>244</sup> as this may pose a "direct threat" to the public if they were admitted to the bar.<sup>245</sup> This case demonstrates how the seeds of the behavioral approach, planted by courts in the 1990s, blossomed in the 2000s. Approved questions focused on whether the mental health impairments affect, or if untreated could affect, the ability to practice law. Such questions, however, did not assume that having such an impairment or being treated would obstruct admission to the bar in a way that penalizes prevention.

## c. The Last Decade

The last decade brought with it some implementation of the court decisions against the use of overbroad, diagnosisfocused mental health inquiries, into the character and fitness screening process. In 2014, the Department of Justice ("DOJ") settled with the Louisiana Supreme Court in a manner resolving the department's investigation of the court's policies, practices, and procedures for evaluating bar applicants with

<sup>244</sup> These questions read:

Id. at \*10.

<sup>&</sup>lt;sup>242</sup> ACLU of Ind. V. Individual Members of the Ind. State Bd. of L. Exam'rs, No. 1:09-cv-842-TWP-MJD, 2011 WL 4387470, at \*7 (S.D. Ind. Sept. 20, 2011).

 $<sup>^{243}</sup>$  The question read: "[(23)] From the age of 16 years to the present, have you been diagnosed with or treated for any mental, emotional or nervous disorders?" *Id.* at \*9.

<sup>(24)</sup> Do you have any condition or impairment (including, but not limited to, substance abuse, alcohol abuse, or a mental, emotional, or nervous disorder or condition) which in any way currently affects, or if untreated could affect, your ability to practice law in a competent and professional manner?
(25) IF YOUR ANSWER TO QUESTION 24 IS AFFIRMATIVE, are the limitations or impairments caused by your mental health condition or substance abuse problem reduced or ameliorated because your [sic] receive ongoing treatment (with or without medication) or because you participate in a monitoring program?

<sup>&</sup>lt;sup>245</sup> *Id.* at \*6 ("[Q]uestions of public safety are potentially involved. Accordingly, the determination of whether an applicant meets 'essential eligibility requirements' involves consideration of whether the individual with a disability poses a 'direct threat to his own health and safety or that of others." (citation omitted)).

mental health disabilities.<sup>246</sup> According to the consent decree, the court that serves as the board in determining admission to practice in the state, would no longer be permitted to ask "unnecessary and intrusive questions about bar applicants' mental health diagnosis or treatment."<sup>247</sup> It refrains "from imposing unnecessary and burdensome conditions on bar applicants with mental health disabilities, such as requests for medical records, compulsory medical examinations or onerous monitoring and reporting requirements."<sup>248</sup> The Louisiana consent decree had an important spillover effect on other state bars.<sup>249</sup>

Yet the issue of penalizing prevention by focusing on mental health treatment and diagnosis in the character and fitness evaluation for the bar exam remains unresolved. In response to the consent decree reached in Louisiana, the National Conference of Bar Examiners ("NCBE") revised its application to focus on past conduct, a move that was inspired by the behavioral approach. Yet only twenty-six states use the NCBE forms and are directly affected by this change.<sup>250</sup> Some state courts were not convinced to move to a behavioral approach. In 2013, the Supreme Court of South Dakota rejected the claim of an applicant that the board had denied his admission based on a diagnosis of bipolar disorder, in violation of Title II.<sup>251</sup> The court did not see the applicant as a "qualified person with a disability" and ruled that the individualized assessment (not a blanket policy) regarding the history of the impairment does not violate the ADA, but rather protects the public, returning to the argument of the Texas court nineteen years prior.<sup>252</sup> In 2019, a report by the Bazelon Center for Mental Health Law reviewed all the Bar Exam Character and Fitness Questions for

<sup>251</sup> In re Henry, 841 N.W.2d 471, 478 (S.D. 2013).

<sup>&</sup>lt;sup>246</sup> For the DOJ's complaint, see U.S. DEP'T OF JUST., DJ NO. 204-32M-60, 204-32-88, 204-32-89, THE UNITED STATES' INVESTIGATION OF THE LOUISIANA ATTORNEY LICEN-SURE SYSTEM PURSUANT TO THE AMERICANS WITH DISABILITIES ACT (2014), https://archive. ada.gov/louisiana-bar-lof.pdf [https://perma.cc/8Y5C-VKVA].

<sup>&</sup>lt;sup>247</sup> Press Release, U.S. Dep't of Just., Department of Justice Reaches Agreement with the Louisiana Supreme Court to Protect Bar Candidates with Disabilities (Aug. 15, 2014), https://www.justice.gov/opa/pr/department-justice-reachesagreement-louisiana-supreme-court-protect-bar-candidates [https://perma.cc/ TC74-AADF].

<sup>&</sup>lt;sup>248</sup> Id.

<sup>249</sup> See discussion infra Part V.

<sup>&</sup>lt;sup>250</sup> David Jaffe & Janet Stearns, *Conduct Yourselves Accordingly: Amending Bar Character and Fitness Questions To Promote Lawyer Well-Being*, 26 PRo. Law., no. 2, 2020 at 3, 9, https://www.americanbar.org/content/dam/aba/publica-tions/professional\_lawyer/26-2/pln-26-2.pdf [https://perma.cc/GJ9S-FKTC].

<sup>&</sup>lt;sup>252</sup> *Id.* at 479.

all fifty states and the District of Columbia.<sup>253</sup> It showed that a number of states ask overbroad questions, not limited in time, which focus on treatment and diagnosis and not on conduct or behavior and other questions that require extensive disclosure of health information, inflicting burden on applicants with mental health impairments.<sup>254</sup> Those practices are concerning as they perpetuate stigma around mental health and penalize the use of mental health treatment.

## C. Penalizing Altruism: The Case of Naloxone

## 1. The Current Opioid Crisis

In July 2021, the CDC released preliminary data on overdose mortality rates for 2020, which showed the year as the worst on record for drug overdose deaths. More than 92,000 individuals died from drug overdoses in 2020.<sup>255</sup> In total, the current opioid crisis, which began in the 1990s,<sup>256</sup> has now taken the lives of more than half a million Americans. The overdoses involved both prescription and illegally-obtained opioids.<sup>257</sup>

The White House estimates that damage from the opioid epidemic has cost more than \$500 billion, putting a strain on the economy as well.<sup>258</sup> For these reasons, in 2017, HHS of-

<sup>258</sup> German Lopez, White House: The Opioid Epidemic Cost \$2.5 Trillion over 4 Years, Vox (Nov. 1, 2019), https://www.vox.com/

356

<sup>&</sup>lt;sup>253</sup> Bar Admissions Questions Pertaining to Mental Health, School/Criminal History, and Financial Issues, BAZELON CTR. FOR MENTAL HEALTH L. (Feb. 2019), https://secureservercdn.net/198.71.233.111/d25.2ac.myftpupload.com/wp-content/uploads/2019/12/50-State-Survey-To-Post.pdf [https://perma.cc/J47E-EAJT].

<sup>&</sup>lt;sup>254</sup> Jaffe & Stearns, *supra* note 250, at 10–11.

<sup>&</sup>lt;sup>255</sup> Provisional Drug Overdose Death Counts: 12 Month-Ending Provisional Number and Percent Change of Drug Overdose Deaths, CTRS. FOR DISEASE CONTROL & PREVENTION (June 5, 2022), https://www.cdc.gov/nchs/nvss/vsrr/drug-overdosedata.htm#dashboard [https://perma.cc/SJ6J-7T5J].

<sup>&</sup>lt;sup>256</sup> As public health scholars have pointed out "[t]he current opioid addiction crisis is, in many ways, a replay of history" as other similar epidemics have been documented in the U.S. since the second half of the nineteenth century. *See* Andrew Kolodny et al., *The Prescription Opioid and Heroin Crisis: A Public Health Approach to an Epidemic of Addiction*, 36 ANN. REV. PUB. HEALTH 559, 561 (2015); *see also* Jennifer D. Oliva, *Dosing Discrimination: Regulating PDMP Risks Scores*, 110 CAL. L. REV. 47, 61–62 (2022) (describing the current drug crisis as a "polysubstance drug crisis that has evolved over 'three phases of an intertwined epidemic").

<sup>&</sup>lt;sup>257</sup> Understanding the Opioid Overdose Epidemic, CTRS FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/opioids/basics/epidemic.html [https://perma. cc/B9TB-9JVY] (last updated June 1, 2022).

ficially declared a national state of public health emergency due to the opioid epidemic and since then has renewed its declaration every ninety days.  $^{259}$ 

Opioid addiction is attributed to both opioids for medical use (e.g., prescription medication to treat pain)<sup>260</sup> and to nonmedical use of illicit and synthetic opioids (like heroin or fentanyl).<sup>261</sup> In its early days, the current crisis was predominately driven by prescription opioids, yet by 2016, fatalities from illicit and synthetic opioids exceeded those caused by medically prescribed drugs.<sup>262</sup> Some studies have offered a "vector model" explaining how medical and nonmedical use of opioids is interconnected, arguing many heroin users first became addicted to prescription opioids before moving to use illicit drugs when they could not get further prescriptions.<sup>263</sup> Those studies, however, were later heavily criticized for suggesting a simplistic cause-and-effect model to a complex problem.<sup>264</sup>

Attributing the opioid crisis to nonmedical use of prescription medications would be a mistake. Rather, the opioid crisis is attributable to addiction more generally. As with other public health problems, the causes for addiction include genetic, behavioral, and individual factors as well as structurallyrooted factors known as the social determinants of health.<sup>265</sup>

<sup>262</sup> James G. Hodge, Jr. et al., *Exploring Legal and Policy Responses to Opioids: America's Worst Public Health Emergency*, 70 S.C. L. REV. 481, 488–89 (2019).

<sup>263</sup> *Id.* at 484.

 $^{264}$  Nicholas P. Terry, The Opioid Litigation Unicorn, 70 S.C. L. Rev. 637, 652 (2019).

policy-and-politics/2019/11/1/20943599/opioid-epidemic-cost-white-house-economic-advisers [https://perma.cc/S747-U79S].

<sup>&</sup>lt;sup>259</sup> Press Release, The White House Off. of the Press Sec'y, President Donald J. Trump Is Taking Action on Drug Addiction and the Opioid Crisis (Oct. 26, 2017), https://trumpwhitehouse.archives.gov/briefings-statements/president-donaldj-trump-taking-action-drug-addiction-opioid-crisis/ [https://perma.cc/S82G-E64D]. The declaration has been renewed every 90 days ever since. *See generally Declarations of a Public Health Emergency*, U.S. DEP't OF HEALTH & HUM. SERVS., https://aspr.hhs.gov/legal/PHE/Pages/default.aspx [https://perma.cc/3WED-HK3G] (last visited May 11, 2023).

 $<sup>^{260}</sup>$   $\,$  In what was referred to as "phase one" of the crisis. See Oliva, supra note 256, at 62–64.

 $<sup>^{261}\,</sup>$  In what was referred to as "phases two and three" of the crisis. Id. at 70–74.

<sup>&</sup>lt;sup>265</sup> See, e.g., Social Determinants of Health (SDOH), NEJM CATALYST (Dec. 1, 2017), https://catalyst.nejm.org/doi/full/10.1056/CAT.17.0312 [https://perma.cc/334W-5ZZF]; Seema Mohapatra & Lindsay F. Wiley, *Feminist Perspectives in Health Law*, 47 J.L. MED. & ETHICS 103, 103 (2019); Rachel Rebouché & Scott Burris, *The Social Determinants of Health, in Oxford Handbook of U.S.* HEALTH LAW 1097, 1097–1112 (I. Glenn Cohen, Allison K. Hoffman & William M. Sage eds., 2017); Carlyn M. Hood, Keith P. Gennuso, Geoffrey R. Swain & Bridget

The multi-decade rise in income inequality and the rise of poverty stemming from deindustrialization and cuts to the social safety net are classic examples of structural causes of addiction.<sup>266</sup> Manual labor increases the chances of physical injury and chronic pain, which in turn increases the potential opioid addiction.<sup>267</sup> Substance use has also been shown to intensify after mass traumatic events such as natural disasters, shootings, or terror attacks and in the wake of personal childhood traumas.<sup>268</sup>

Demographically, rates of overdose mortality are higher for men than for women despite the fact that women ages forty to sixty-four years are the fastest-growing population for fatal and nonfatal overdoses.<sup>269</sup> Sixty-nine percent of those who die of opioid overdose are non-Latino Caucasians, 16% are Black, and 11% are Latino.<sup>270</sup> Some attribute this to the biases of

<sup>267</sup> Nabarun Dasgupta, Leo Beletsky & Daniel Ciccarone, *Opioid Crisis: No Easy Fix to Its Social and Economic Determinants*, 108 Am. J. Pub. Health 182, 183 (2018).

<sup>268</sup> *Id.* at 184.

<sup>269</sup> Susan Salmond & Virginia Allread, *A Population Health Approach to America's Opioid Epidemic*, 38 Orthopaedic Nursing 95, 96 (2019).

<sup>270</sup> Opioid Overdose Deaths by Race/Ethnicity, KFF, https://www.kff.org/ other/state-indicator/opioid-overdose-deaths-by-raceethnicity [https://perma. cc/G92R-VLCA] (last visited May 11, 2023). Scholars pointed out how public discourse and media pretrial of the opioid crisis have been focused on white communities:

Middle-class white exceptionalism treats addiction in middle-class white communities as the exception to the deviancy narrative. It also purposefully excludes ongoing addiction and overdose crises in communities of color from the policy discourse. For example, while indigenous communities experienced overdose death rates comparable to that of white communities, indigenous people were excluded as victims in media portrayals of the overdose crisis. Black communities also have experienced dramatic increases in the rates of overdose deaths involving illicit synthetic fentanyl and cocaine. Yet media portrayals continue to brand the current crisis as an "opioid epidemic" primarily impacting white persons. Branding the current crisis as a middle-class white opioid crisis has resulted in the exclusion of discourse on increases in methamphetamine-related overdoses in predominantly poor, rural, white communities.

See Taleed El-Sabawi & Jennifer Oliva, The Influence of White Exceptionalism on Drug War Discourse, 94 Temple L. Rev. 649, 653 (2022).

B. Catlin, *County Health Rankings: Relationships Between Determinant Factors and Health Outcomes*, 50 Am. J. PREVENTIVE MED. 129, 129 (2016); Samantha Artiga & Elizabeth Hinton, *Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity*, KFF (May 10, 2018), https://www.kff. org/racial-equity-and-health-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity [https://perma. cc/3CG7-VAJN].

<sup>&</sup>lt;sup>266</sup> NAT'L ACADS. OF SCIS., ENG'G & MED., PAIN MANAGEMENT AND THE OPIOID EPIDEMIC: BALANCING SOCIETAL AND INDIVIDUAL BENEFITS AND RISKS OF PRESCRIPTION OPIOID USE 41 (Richard J. Bonnie, Morgan A. Ford & Jonathan K. Phillips eds., 2017).

2024]

health care providers who do not prescribe opioids to people of color (specifically Black people) due to their perceived higher tolerance for pain or perceived tendency to use drugs.<sup>271</sup> New research, however, has shown that, despite the surge in overdose cases during the COVID-19 pandemic, the highest rates of subsequent cardiac arrests were found among people of color and in geographic areas of concentrated socioeconomic disadvantage.<sup>272</sup>

The opioid crisis is an epidemic so widespread that a 2018 national survey showed around 45% of Americans (more than four out of ten) report they personally know someone who has suffered from opioid addiction.<sup>273</sup> This issue cannot be pushed aside as someone else's problem; it is a pervasive public health crisis requiring public policy interventions.

# 2. The Promise of Naloxone

Naloxone is an opioid overdose antidote. It is a medication that rapidly blocks the lethal effects of an opioid overdose including slow breathing and a slow heartbeat. Naloxone can be injected into the person exhibiting symptoms of overdose<sup>274</sup> or administered as a nasal spray.<sup>275</sup> Naloxone is sold under the brand name Narcan originally developed by Opiant Pharmaceuticals.<sup>276</sup> It is not a controlled substance and has no abuse potential or any serious side effects.<sup>277</sup>

The distribution of naloxone to not only first responders, but also potential witnesses of an opioid overdose, has been recognized by HHS as a core tertiary preventive strategy to

<sup>&</sup>lt;sup>271</sup> Helena Hansen & Julie Netherland, *Is the Prescription Opioid Epidemic a White Problem?*, 106 Am. J. PUB. HEALTH 2127, 2128 (2016). For an exploration of these biases see generally Maytal Gilboa, *The Color of Pain: Racial Bias in Pain and Suffering Damages*, 56 GA. L. REV. 651, 677 (2022) (describing the false belief "that Black people experience less pain than White people").

<sup>&</sup>lt;sup>272</sup> Joseph Friedman et al., *Racial/Ethnic, Social, and Geographic Trends in Overdose-Associated Cardiac Arrests Observed by US Emergency Medical Services During the COVID-19 Pandemic,* 78 JAMA Psychiatry 886, 887 (2021).

<sup>&</sup>lt;sup>273</sup> Opioid Addiction In U.S.: 7 In 10 Say It's A Very Serious Problem – CBS News Poll, CBS CHICAGO (May 8, 2018), https://chicago.cbslocal.com/2018/05/08/opi-oid-addiction-cbs-news-poll [https://perma.cc/4KPQ-ZZ8H].

<sup>&</sup>lt;sup>274</sup> The FDA approved the use of naloxone to treat drug overdose in 1971 as an injectable. *See* Corey S. Davis & Derek Carr, *Over the Counter Naloxone Needed to Save Lives in the United States*, 130 PREVENTIVE MED., no. 105932, Jan. 2020, at 1.

<sup>&</sup>lt;sup>275</sup> Press Release, *supra* note 13.

 $<sup>^{276}\,</sup>$  Until 2018, naloxone autoinjector was also sold under the brand name Evizo, but this brand has been discontinued.

<sup>&</sup>lt;sup>277</sup> Hodge et al., *supra* note 262, at 511.

combat overdose mortality.<sup>278</sup> In 2018, former Surgeon General Jerome Adams issued an advisory explaining "the importance of [the public] knowing how to use and keeping within reach this potentially life-saving medication."<sup>279</sup>

The idea of community-based naloxone rescue kits is akin to the use of publicly accessed defibrillators to help reverse sudden cardiac arrest.<sup>280</sup> The distribution of naloxone in the community has primarily been undertaken by harm-reduction organizations, state-endorsed programs,<sup>281</sup> and state laws allowing over-the-counter sale of naloxone through standing orders to increase its availability.<sup>282</sup> The year 2023 signaled a major breakthrough in increasing naloxone availability: in March of that year, the FDA approved the selling Narcan over the counter across the country and in September the drug was available for purchase at major retailers as well as online.<sup>283</sup>

Increasing lay use of the life-saving drug naloxone within the public is challenged by its association with illicit drugs and opioids and the stigmatization of the topic of opioids among lay people. The increasing prices of naloxone products ranged from 224% to 3,797% in 2006 and 2017, respectively, serve as another barrier to naloxone's wide distribution.<sup>284</sup> A third bar-

<sup>279</sup> Jerome M. Adams, Increasing Naloxone Awareness and Use: The Role of Health Care Practitioners, 319 JAMA 2073, 2073 (2018).

<sup>&</sup>lt;sup>278</sup> U.S. DEP'T OF HEALTH & HUM. SERVS., STRATEGY TO COMBAT OPIOID ABUSE, MISUSE, AND OVERDOSE: A FRAMEWORK BASED ON THE FIVE POINT STRATEGY 1, 7 (2017), https:// www.hsdl.org/c/abstract/?docid=816001 [https://perma.cc/97HF-REV2] (stating the need to "[e]xplore development of over the counter naloxone, including an assessment of its impact on availability of naloxone in the community" and "[s] trengthen education and training on overdose prevention and naloxone administration to ensure that individuals likely to respond to an overdose can take the appropriate steps to reverse an overdose").

<sup>&</sup>lt;sup>280</sup> Geoffrey A. Capraro & Claudia B. Rebola, *The NaloxBox Program in Rhode Island: A Model for Community-Access Naloxone*, 108 Am. J. Pub. HEALTH 1649, 1649 (2018).

<sup>&</sup>lt;sup>281</sup> Patricia R. Freeman, Emily R. Hankosky, Michelle R. Lofwall & Jeffery C. Talbert, *The Changing Landscape of Naloxone Availability in the United States*, 2011 – 2017, 191 DRUG & ALCOHOL DEPENDENCE 361, 361 (2018).

<sup>&</sup>lt;sup>282</sup> A standing order is a mechanism through which a health care provider with prescribing privileges or a state health officer, writes a prescription that can be used by a large group of people. Nevertheless, naloxone is not offered as an over-the-counter drug despite a push for it by public health experts. *See* Davis & Carr, *supra* note 274, at 2.

<sup>&</sup>lt;sup>283</sup> Jan Hoffman & Noah Weiland, *Narcan Is Headed to Stores: What You Need to Know*, N.Y. Times (Aug. 30, 2023), https://www.nytimes.com/2023/08/30/ health/narcan-drug-stores.html [https://perma.cc/W5ZJ-G9MY].

<sup>&</sup>lt;sup>284</sup> Matthew Rosenberg, Grace Chai, Shekhar Mehta & Andreas Schick, *Trends and Economics Drivers for United States Naloxone Pricing, January 2006 to February 2017*, 86 ADDICTIVE BEHAV. 86, 87 (2018). A positive development on pricing was announced in July 2022 when United Healthcare, one of the largest insurers

rier, not as commonly cited, relates to insurance policies that penalize those who acquire naloxone to prevent someone else's death.

# 3. Naloxone Insurance Discrimination

After witnessing her loved ones fight with opioid addiction, fifty-three-year-old realtor Sharon White of Delaware County, Pennsylvania, decided to become a recovery specialist. At that time, she purchased two doses of naloxone from her local Walgreens to carry with her. She was able to purchase the drug using a standing order, originally issued by Pennsylvania's Department of Health in 2015, in an effort to encourage members of the public to act as good Samaritans and prevent overdose deaths.<sup>285</sup> When White then tried to purchase a life insurance policy for herself, the insurance company denied coverage. The denial was based on White's medical history, which included the purchase of naloxone. This purchase signaled to the insurance company that she was using drugs herself. White tried other insurance companies, who also denied her coverage.<sup>286</sup>

Insurers distinguish between different categories on the basis of traits, a process that legal scholars have observed occurs in many other aspects of the human experience.<sup>287</sup> Engaging in the process of risk classification, meaning categorizing enrollees according to the possibility of their making future claims through actuarial calculations, is an inherent part of

in the country, announced that she will cover naloxone to its members with no cost sharing starting January 2023. *See UnitedHealthcare To Eliminate Out-of-Pocket Costs on Several Prescription Drugs, Including Insulin, for Eligible Members, UNITEDHEALTH GROUP (July 15, 2022), https://www.unitedhealthgroup.com/newsroom/2022/2022-07-15-uhg-eliminate-out-of-pocket-costs.html [https://perma.cc/C7BH-4M5X].* 

<sup>&</sup>lt;sup>285</sup> PA. DEP'T OF HEALTH, STANDING ORD. DOH-016-2021, NALOXONE PRESCRIPTION FOR OVERDOSE PREVENTION (2021), https://www.dos.pa.gov/ProfessionalLicensing/ BoardsCommissions/Pharmacy/Documents/Special%20Notices/PharmSN%20 -%20Naloxone%20Prescription%20for%20Overdose%20Prevention%20-%20 Standing%20Order%20DOH-016-2021.pdf [https://perma.cc/B47Y-HQN8].

<sup>&</sup>lt;sup>286</sup> Editorial Bd., *Saving Lives with Naloxone Shouldn't Cost You Life Insurance*, PHILA. INQUIRER (Apr. 18, 2019), https://www.inquirer.com/opinion/editorials/ naloxone-life-insurance-narcan-overdose-opioid-20190418.html [https://perma. cc/Y6UT-PDPM].

<sup>&</sup>lt;sup>287</sup> See, e.g., Krieger, *supra* note 32, at 1199–1200 (explaining "schema theory," in cognitive psychology, which provides a structure for determining what information will be encoded into memory and categorizes people according to stereotypes, which could lead to discrimination); DEBORAH HELLMAN, WHEN IS DIS-CRIMINATION WRONG? 7 (2008) (articulating how the idea of differentiating between individuals according to traits could lead to discrimination).

an insurer's job to underwrite and price insurance policies.<sup>288</sup> Risk classification avoids problems including adverse selection and moral hazard.<sup>289</sup> Adverse selection is a situation wherein low-risk individuals would not opt to purchase insurance plans in the first place and thus will not participate in the risk pooling process underlying insurance, which includes both low- and high-risk individuals, but would only do so when they are in a situation in which they need it.<sup>290</sup> Moral hazard is a situation whereby enrollees are incentivized to consume a service (such as health care) beyond a socially-optimal level, meaning that the service is no longer cost-effective.<sup>291</sup> The emerging question is whether penalizing those who acquire naloxone to prevent overdose through denving insurance coverage (at worst) or charging higher premiums (at best) should be considered discrimination. If insurers do not consider the purchase of naloxone at all, high-risk individuals with opioid-use problems would be able to purchase and carry insurance easily, taking advantage of services beyond the socially-optimal point, i.e., engaging in moral hazard. Insurance policy prices will rise as a consequence, such that low-risk individuals will opt out of carrying insurance and thus engage in adverse selection.

A similar story to Sharon White happened to Isela, a nurse at Boston Medical Center. Isela was denied life insurance after a scan of her medical records showed she had purchased naloxone. The insurance agent did not budge even after Isela tried to explain: "But I'm a nurse, I use it to help people . . . . If there is an overdose, I could save their life."<sup>292</sup> Isela then turned to another life insurance company. This one asked her to bring a doctor's note stating the reasons she carries naloxone. The irony is that Isela did not buy the drug through prescription; like White, she had purchased it through a standing order issued by her colleague in the hospital on behalf of the state of Massachusetts.

<sup>&</sup>lt;sup>288</sup> Avraham, Logue & Schwarcz, *supra* note 16, at 198.

<sup>&</sup>lt;sup>289</sup> *Id.* at 202.

<sup>&</sup>lt;sup>290</sup> Tom Baker, *Health Insurance, Risk, and Responsibility After the Patient Protection and Affordable Care Act*, 159 U. PA. L. REV. 1577, 1610–11 (2011).

<sup>&</sup>lt;sup>291</sup> Jonathan Klick & Thomas Stratmann, *Diabetes Treatments and Moral Hazard*, 50 J.L. & ECON. 519, 520 (2007).

<sup>&</sup>lt;sup>292</sup> Martha Bebinger, *Nurse Denied Life Insurance Because She Carries Naloxone*, NPR (Dec. 13, 2018), https://www.npr.org/sections/health-shots/2018/12/13/674586548/nurse-denied-life-insurance-because-she-carries-Naloxone [https://perma.cc/KW3Y-SCN9].

Isela's story demonstrates that penalizing prevention through insurance discrimination (or denial of coverage) created a chilling effect on her willingness to carry around a naloxone kit outside of work because she no longer wants the drug to show on her active medication list. She says that other colleagues feel the same, and "[s]o if something were to happen on the street, I don't have one [a naloxone rescue kit]—just because I didn't want another conflict."<sup>293</sup>

As mentioned before, insurance law scholars have not focused on insurance discrimination jeopardizing public health causes via penalizing prevention efforts. Insurers should better differentiate between situations where certain drugs are taken as a preventive and not as treatment. Regulatory interventions might be needed to ensure that a more accurate process of risk assessment could occur. With few exceptions, federal law does not usually address insurance discrimination.<sup>294</sup> This is due to the McCarran-Ferguson Act, which states that federal laws that affect insurance are deemed "reverse preempted" by any conflicting state law unless the federal law expressly provides that it is meant to apply to insurance.<sup>295</sup> The authority to regulate issues related to insurance discrimination is thus generally delegated to the states.

After Isela's story and other similar stories in the state,<sup>296</sup> in February 2019, Massachusetts' Division of Insurance issued

<sup>293</sup> Id.

<sup>295</sup> 15 U.S.C. § 1012(b).

<sup>296</sup> One of which is of Dr. Dinah Applewhite, a resident at Massachusetts General Hospital, who was denied disability insurance because she carried naloxone. In her case, the fact that Applewhite also had a short-term prescription of opioids after childbirth made things even worse. *See* Martha Bebigner, *Mass. Issues* 

<sup>294</sup> The exceptions, which are federal legislation that prohibit discrimination in insurance include: the ACA, which prohibits insurance discrimination on the basis of preexisting conditions or on the basis of sex, see Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 1557, 124 Stat. 119, 260 (2010) (codified as amended at 42 U.S.C. § 18116); The Health Insurance Portability and Accountability Act ("HIPAA"), which prohibits health insurers groups from excluding individuals on the basis of genetic predisposition to certain diseases, 29 U.S.C. § 1181(a); The Genetic Information Nondiscrimination Act of 2008 ("GINA"), which prohibits health insurers from denying coverage or charging higher premiums to enrollees based on genetic information, Pub. L. No. 110-233, §§ 101-102, 122 Stat. 881, 883, 888 (codified as amended at 29 U.S.C. § 1182(b) and 42 U.S.C. § 300gg-1(b)); and the Fair Housing Act ("FHA"), which, according to the U.S. Department of Housing and Urban Development ("HUD"), applies to insurance and prohibits housing practices that have an unjustified disparate impact on protected classes, Implementation of the Fair Housing Act's Discriminatory Effects Standard, 78 Fed. Reg. 11460, 11460 (Feb. 15, 2013) (to be codified at 24 C.F.R. pt. 100), http://portal.hud.gov/hudportal/documents/huddoc?id=discriminator yeffectrule.pdf [https://perma.cc/6UGE-L8QB].

a special bulletin urging insurance companies not to penalize prevention.<sup>297</sup> Interestingly, the bulletin mentioned both the example of naloxone and PrEP as examples of preventive medications that have caused discrimination in regard to insurance.

In 2020, after she experienced insurance discrimination due to acquiring naloxone herself,<sup>298</sup> Massachusetts State Senator Joan Lovely introduced a bill to prohibit discrimination on the basis of having purchased naloxone, which is making its way through the state House.<sup>299</sup> Similar laws were enacted in the last few years in Connecticut<sup>300</sup> Maine,<sup>301</sup> Rhode Island,<sup>302</sup> Texas<sup>303</sup> and Minnesota,<sup>304</sup> and bills were introduced

<sup>297</sup> The Division understands that in the course of reviewing an applicant for [multiple types of insurance] . . . Carriers collect and consider information about the applicant's medical history, including information about the applicant's use of prescription medications. . . . Carriers [] need to be aware that prescriptions for medications . . . may be intended to prevent, not treat an existing illness or disease.

. . . .

. . . It would defeat the Commonwealth's important public health efforts if applica[nts] . . . were unfavorably impacted [from taking preventive measures].

See Mass. Off. of Consumer Affs. & Bus. Regul., Div. of Ins., Bull. 2019-01, Information About Certain Prescriptions Used in Underwriting Analyses (2019), https://www.mass.gov/files/documents/2019/02/01/BULLETIN%20 2019-01%20%28Prescriptions-Underwriting%29\_0.pdf [https://perma.cc/ U3TL-L22H].

<sup>298</sup> Jodi Reed, *Lawmakers Fight Against Insurance Discrimination for Naloxone*, WWLP (Jan. 17, 2020), https://www.wwlp.com/news/state-politics/lawmakers-fight-against-insurance-discrimination-for-Naloxone [https://perma. cc/7TQX-CHTJ].

299 No insurer, agent or broker authorized to issue policies on the lives of persons in the commonwealth shall cancel, refuse to issue or renew, make or permit any distinction or discrimination in the amount or payment of premiums or rates charged or otherwise differentiate or discriminate against a person based solely on the person having a prescription to carry or possess the drug naloxone.

See S. 698, 192d Gen. Ct., Reg. Sess. (Mass. 2021), https://malegislature. gov/Bills/192/S698/BillHistory [https://perma.cc/PDK7-PJ3V].

- 300 CONN. GEN. STAT. ANN. § 38a-447a.
- <sup>301</sup> ME. REV. STAT. ANN. tit 24-A, § 2159-E.
- <sup>302</sup> 27 R.I. Gen. Laws Ann. § 27-4-1.1.
- <sup>303</sup> Tex. Ins. Code Ann. § 1101.253.

<sup>304</sup> MINN. STAT. ANN. § 72A.20, subdiv. 40 ("Prescription for opiate antagonist. When determining whether to issue, renew, cancel, or modify a policy of life insurance, an insurer may not make an underwriting determination based solely on information revealing that a proposed insured has a prescription for an opiate antagonist . . . .").

Guidelines After Boston Nurse Was Denied Life Insurance for Carrying Naloxone, WBUR (Feb. 13, 2019), https://www.wbur.org/news/2019/02/12/massachusetts-regulations-life-insurance-narcan [https://perma.cc/2LNM-CSKP].

in Pennsylvania,<sup>305</sup> New York,<sup>306</sup> and Illinois.<sup>307</sup> Nevertheless, as other scholars have shown, insurance antidiscrimination regulation lacks uniformity.<sup>308</sup> The main concern is that the states where the opioid epidemic is most prominent, which have been the slowest in implementing public use of naloxone,<sup>309</sup> will also fail to prohibit insurance discrimination. Thus, the progress of the public health project of decreasing the number of overdose deaths will be halted where it is most urgently needed.

In the next section, I suggest a typology of the stigma attached to preventive medicine and how it intersects with existing stigma attached to certain illnesses.

#### IV

## Toward a Typology of Preventive Medicine Stigma

Stigma is a complex process that manifests itself in multiple ways.<sup>310</sup> In this Article, I described a barrier for implementing preventive medicine attached to the signaling stereotypes linked to the use of preventive health measures and demonstrated the phenomenon through three case studies. A lingering question, however, relates to the intersection between, on one hand, the signaling effect that a preventive measure carries and preexisting structural stigma attached to the health condition to be prevented, and on the other, the population at hand, which often already suffers from structural stigma from existing societal power relations.<sup>311</sup>

In this section, I look beyond the signaling effect to examine other types of stigmas that may attach to preventive health measures and compound penalties through law and policy. This analysis should foster a coherent theoretical grasp of the topic and help expand the discussion of stigma around preventive medicine beyond the three case studies presented in this

<sup>&</sup>lt;sup>305</sup> Lloyd's Law, H.R. 2950, 2020 Gen. Assemb., Reg. Sess. (Pa. 2020), https:// www.legis.state.pa.us/cfdocs/Legis/CSM/showMemoPublic.cfm?chamber=H&S Pick=20190&cosponId=30808 [https://perma.cc/44WX-CAUY].

 $<sup>^{306}~</sup>$  S. 3159A, 2019–2020 Leg., Reg. Sess. (N.Y. 2019), https://legislation.nysenate.gov/pdf/bills/2019/S3159A [https://perma.cc/8L8Q-VPU3].

<sup>&</sup>lt;sup>307</sup> H.B. 4000, 101st Gen. Assemb., Reg. Sess. (Ill. 2020), https://www.ilga. gov/legislation/BillStatus.asp?DocTypeID=HB&DocNum=4000&GAID=15&Sessi onID=108&LegID=122647 [https://perma.cc/A2XB-LR53].

<sup>&</sup>lt;sup>308</sup> Avraham, Logue & Schwarcz, *supra* note 16, at 231.

<sup>&</sup>lt;sup>309</sup> Freeman, Hankosky, Lofwall & Talbert, *supra* note 281, at 363.

 $<sup>^{310}</sup>$  Link & Phelan, supra note 42, at 365; Fife & Wright, supra note 43, at 51.

 $<sup>^{311}</sup>$  On the relationship between stigma and power, see Link & Phelan, supra note 42, at 375.

Article. Yet it is important to note that this is a fluid, rather than fixed, typology: the health conditions and preventive measures may fall in more than one category depending on context.

The idea is to help decipher the complexity of stigma, power, and penalties around preventive medicine, even outside the signaling effect they send. This richer understanding of the phenomenon will help guide the normative and policy implications I suggest in the final section of the Article.

I suggest a 2x2 model which examines stigma around the underlying health condition as separate from stigma around the actual preventive measure:<sup>312</sup>

	Stigmatized Measure	Non-Stigmatized Measure
	Double Stigma of Prevention	Singular Stigma of Prevention
Stigmatized Health Condition	Examples: PrEP, naloxone	Examples: Workplace wellness programs, mental health treatment in the context of character and fitness evaluations
	Singular Stigma of Prevention	No Stigma Associated with Measure or Health Condition
Non-Stigmatized Health Condition	Examples: Colonoscopy in certain populations, medical marijuana to treat cancer related pain	Example: Disease-modifying therapy (DMT) for Multiple Sclerosis (MS)

 $<sup>^{312}</sup>$   $\,$  By stigma around the preventive measure, I mean situations in which there is some negative cultural meaning associated with a medical treatment.

In the first scenario, the double stigma of prevention, both the underlying health condition and the preventive measure itself are stigmatized. The case study of PrEP provides a classic example of this phenomenon: HIV is already a heavily stigmatized condition;<sup>313</sup> taking PrEP as a preventive measure adds a second layer of stigma, as it signals promiscuity. Because the stigma is so strong in this situation, it is not surprising it has affected the law in several contexts in which we can detect penalties for PrEP use, as I described earlier. The fact that the majority of PrEP users are part of the LGBTQ community, and the fact that the treatment is meant to treat a highly stigmatized disease, contributes to stigma against all PrEP users.<sup>314</sup>

Naloxone offers another such double stigma of prevention. Addiction to opioids and substances is a highly stigmatized health condition. Using naloxone has also become stigmatized, as this treatment is perceived to be used by those with addictions. The stigma around naloxone leads to insurance discrimination against good Samaritans, who are perceived by insurers to be using illicit drugs or opioids.

In the second and third scenarios, only one of the characteristics is actually stigmatized: either the health condition we try to prevent or the preventive measure, creating a situation I refer to as the singular stigma of prevention.

An example of a stigmatized preventive measure for a nonstigmatized health condition is the use of a colonoscopy to detect colorectal cancer. Having colorectal cancer is not stigmatized in and of itself, specifically as compared with HIV/ AIDS in the previous example.<sup>315</sup> It has even been character-

<sup>315</sup> Nevertheless, decades ago, cancer used to be considered a stigmatized condition. SUSAN SONTAG, ILLNESS AS METAPHOR 57–58 (1978); SONTAG, *supra* note 76, at 24–26, 45. For example, in a 1996 case regarding physicians' duties to warn third parties from hortatory diseases, the wife of a colon cancer patient testified:

[N]either her husband nor Dr. Pack had ever told her that Mr. Batkin suffered from cancer; and that, throughout the courses of surgery and treatment, Dr. Pack advised her that he was treating a "blockage" or an unspecified "infection." On the one or two occasions when Mrs. Batkin inquired of Dr. Pack whether the "infection" would affect her children, she was told not to worry.

Safer v. Est. of Pack, 677 A.2d 1188, 1190 (N.J. Super. Ct. App. Div. 1996). Concealing the fact that the husband had colon cancer may have arisen from stigma. *Id.* For a comparison between HIV and cancer stigma, see Fife & Wright, *supra* note 43, at 52 ("[T]he stigma associated with cancer is thought to be driven primarily by fear of the illness itself, or a perception that 'it could

<sup>&</sup>lt;sup>313</sup> In fact, HIV has been considered "*the* stigmatizing condition of our time." ALLY DAY, THE POLITICAL ECONOMY OF STIGMA: HIV, MEMOIR, AND CRIP POSITIONALITIES 3 (2021). For a fascinating discussion on the similarities of the stigma of HIV as compared to stigma related to other chronic illnesses, see *id.* at 150–54.

<sup>&</sup>lt;sup>314</sup> Dorfman, *supra* note 11, at 49.

ized as a "sympathetic diagnosis."<sup>316</sup> Nevertheless, the preventive procedure to detect cancer is the one that is stigmatized.

Colonoscopy is an invasive screening procedure aimed at detecting colorectal cancer that has been covered under Section 2713 of the ACA since 2013.<sup>317</sup> The preventive procedure, which is done under anesthesia, involves the insertion of a tube into the colon through the rectum with a small video camera that allows doctors to detect polyps.<sup>318</sup> Due to the colonoscopy's high potential for early detection of colorectal cancer, celebrities and public figures have been used to promote the procedure. An early example is TV host Katie Couric, who documented her colonoscopy on the Today show following her husband's death from colorectal cancer two years earlier.<sup>319</sup> A study showed that Couric's public documentation and endorsement of the procedure led to a boost in the number of procedures conducted, a rise known as "The Katie Couric Effect."320 Almost two decades later, in 2018, Couric continued her efforts to raise awareness of this preventive measure by convincing talk show host Jimmy Kimmel to also document a colonoscopy on TV.321

<sup>316</sup> Godsoe, *supra* note 168, at 146.

<sup>317</sup> Am. Soc'y for Gastrointestinal Endoscopy, *Media Backgrounder: Colorectal Cancer Screening*, ASGE, https://www.asge.org/home/about-asge/newsroom/ media-backgrounders-detail/colorectal-cancer-screening [https://perma.cc/ S5AZ-9PCM] (last updated July 2017).

<sup>318</sup> Polyps are abnormal tissue growths that could become cancerous. *Id.*; *Colorectal Cancer Screening Tests*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/cancer/colorectal/basic\_info/screening/tests.htm [https://perma.cc/E4RQ-2DAW] (last updated Feb. 23, 2023).

<sup>319</sup> *Katie Couric Gets a Colonoscopy*, TODAY (Mar. 21, 2018), https://www.today. com/video/katie-couric-gets-a-colonoscopy-1191167555989 [https://perma.cc/J8RK-P7J4].

<sup>320</sup> Peter Cram et al., *The Impact of a Celebrity Promotional Campaign on the Use of Colon Cancer Screening: The Katie Couric Effect*, 163 Archives Internal Med. 1601, 1603 (2003).

<sup>321</sup> Ree Hines, *Jimmy Kimmel Gets a Colonoscopy with Help from Katie Couric*, ToDAY (Mar. 21, 2018), https://www.today.com/health/jimmy-kimmel-gets-colonoscopy-help-katie-couric-t125453 [https://perma.cc/3355-5HRZ]. More recently, actor Ryan Reynolds joined the rank of celebrities endorsing a public awareness campaign for colon cancer after his doctor detected a benign polyp during a colonoscopy. *See Juliana Kim, Why Ryan Reynolds Is Telling People to Get a Colonoscopy*, NPR (Sept. 19, 2022), https://www.npr. org/2022/09/19/1123661163/ryan-reynolds-colon-cancer-colonoscopy-awareness-rob-mcelhenney [https://perma.cc/W4ZT-S9S9].

happen to me' and the concept of a 'just world.' While it is associated with severe physical limitations and suffering, cancer is not associated with social groups considered to be morally reprehensible.").

Colorectal cancer disproportionally affects Black people. According to the American Cancer Society, Black people are 20% more likely to get colorectal cancer than Whites and 40% more likely to die from it.<sup>322</sup> Colorectal cancer also affects young adults.<sup>323</sup> In 2020, the death of Black actor Chadwick Boseman from the disease at the age of forty-three shocked Black communities across the nation and brought awareness to the health disparities with regard to colorectal cancer.<sup>324</sup> In 2021, twenty-nine-year-old Black journalist Nicholas St. Fleur documented his colonoscopy in an attempt to raise awareness of this important and effective preventive measure.<sup>325</sup> This awareness of the importance of colonoscopy among young people, especially among young Black individuals who are disproportionally affected by the disease, is important, as it works to combat stigma around the preventive procedure.

Colonoscopy is an uncomfortable and fraught procedure because it involves the rectum. As Susan Sontag famously wrote, "cancer is notorious for attacking parts of the body (colon, bladder, rectum, breast, cervix, prostate, testicles) that are

<sup>323</sup> The American Cancer Society found a "steep rise in rectal cancer incidence among younger adults" in recent years and estimates that 12% of the diagnoses in the U.S. will be of younger individuals under fifty. Am. Cancer Soc'y, Colorectal Cancer Facts & Figures 2020–2022, at 3 (2020).

324 Ifeanyi Nsofor, Africans Mourn Chadwick Boseman: 'A Great Tree Has Fallen', NPR (Sept. 1, 2020), https://www.npr.org/sections/goatsandsoda/2020/09/01/908471876/africans-mourn-chadwick-boseman-a-greattree-has-fallen [https://perma.cc/9Q2X-D25S]; Lydia A. Flier, Gabriela Rico & Yamicia D. Connor, Did Disparities Kill the King of Wakanda? Chadwick Boseman and Changing Landscape of Colon Cancer Demographics, STAT (Aug. 31, 2020), https://www.statnews.com/2020/08/31/disparities-kill-king-of-wakandachadwick-boseman-changing-landscape-colon-cancer-demographics [https:// perma.cc/VL6F-BYMD]; Nicholas St. Fleur, Chadwick Boseman's Tragedu Is America's Tragedy: In Colorectal Cancer Hot Spots, Young Men Are Dying at Higher Rates, STAT (June 22, 2021), https://www.statnews.com/2021/06/22/ colorectal-cancer-hot-spots-young-men-dying-higher-rates [https://perma. cc/83VD-EJ52].

<sup>325</sup> Nicholas St. Fleur & Hyacinth Empinado, *Watch: An Unusual 30th Birthday Gift: Why I Got a Colonoscopy So Young — And Documented Every Step*, STAT (June 22, 2021), https://www.statnews.com/2021/06/22/why-i-got-a-colonoscopy-so-young-and-documented-every-step [https://perma.cc/J4JH-RKE4].

<sup>&</sup>lt;sup>322</sup> ACS Medical Content and News Staff, *Colorectal Cancer Rates Higher in African Americans, Rising in Younger People*, AM. CANCER Soc'y (Sep. 3, 2020), https://www.cancer.org/latest-news/colorectal-cancer-rates-higher-in-african-americans-rising-in-younger-people.html [https://perma.cc/9QX4-PJZ9]. According to the American Society for Gastrointestinal Endoscopy, Black people are also more likely to have advanced colon cancer when it is diagnosed and to have polyps deeper in the colon, where they can be harder to detect. *See* Am. Soc'y for Gastrointestinal Endoscopy, *supra* note 317.

embarrassing to acknowledge."326 Studies have shown that colonoscopy is particularly stigmatized among young straight men.<sup>327</sup> While early research focused on the persistence of stigma around colonoscopy among Black men,<sup>328</sup> later research showed that the stigma also manifested itself among White males<sup>329</sup> who participated in studies and expressed reluctance in engaging in any medical exam involving the rectum. Many study participants saw such medical intervention as a threat to male sexuality, as they associate this body part with homosexuality and gay sex.<sup>330</sup> The stigma is so strong that very few Black men from across educational and income levels "could objectively discuss colonoscopy as a scientific and preventive medical procedure independent of the sense of violation [to their hegemonic masculine identity] that they felt was inherent in the experience."<sup>331</sup> Such stigma associated with the actual preventive measure creates a barrier for implementation outside of the stigma around the health condition or around the signaling effects of being at an increased risk.

Another example of a stigmatized preventive measure for a non-stigmatized health condition is the use of medical marijuana as tertiary prevention for pain management among cancer patients. Studies found that medical marijuana users are deemed irresponsible and unreliable "potheads" by employers, colleagues, and even health care providers.<sup>332</sup> Another

<sup>329</sup> Winterich et al., *supra* note 327, at 301; Charles R. Rogers, Jamie A. Mitchell, Gabriel J. Franta, Margaret J. Foster & Deirdre Shires, *Masculinity, Racism, Social Support, and Colorectal Cancer Screening Uptake Among African American Men: A Systematic Review,* 11 Am. J. MEN'S HEALTH 1486, 1490 (2017).

<sup>330</sup> Winterich et al, *supra* note 327, at 304–05; Chanty R. Webb, Linda Kronheim, James E. Williams, Jr. & Terryl J. Hartman, *An Evaluation of the Knowledge, Attitudes, and Beliefs of African-American Men and Their Female Significant Others Regarding Prostate Cancer Screening*, 16 ETHNICITY & DISEASE 234, 236–37 (2006); Allen, Kennedy, Wilson-Glover & Gilligan, *supra* note 328, at 2194.

<sup>331</sup> Rogers, Mitchell, Franta, Foster & Shires, *supra* note 329, at 1490.

<sup>&</sup>lt;sup>326</sup> Sontag, *supra* note 315, at 17.

<sup>&</sup>lt;sup>327</sup> Julie A. Winterich et al., *Masculinity and the Body: How African American and White Men Experience Cancer Screening Exams Involving the Rectum*, 3 Am. J. MEN'S HEALTH 300, 303 (2009).

<sup>&</sup>lt;sup>328</sup> See, e.g., Jennifer D. Allen, Mark Kennedy, Athene Wilson-Glover & Timothy D. Gilligan, *African-American Men's Perceptions About Prostate Cancer: Implications for Designing Educational Interventions*, 64 Soc. Sci. & Med. 2189, 2194 (2007); K. Allen Greiner, Wendi Born, Nicole Nollen & Jasjit S. Ahluwalia, *Knowledge and Perceptions of Colorectal Cancer Screening Among Urban African Americans*, 20 J. GEN. INTERNAL MED. 977, 980 (2005).

<sup>&</sup>lt;sup>332</sup> Joan L. Bottorff et al., *Perceptions of Cannabis as a Stigmatized Medicine: A Qualitative Descriptive Study*, 10 HARM REDUCTION J., no. 2, 2013, at 1, 4; Yuval Zolotov, Simon Vulfsons, Dana Zarhin & Sharon Sznitman, *Medical Cannabis: An Oxymoron? Physicians' Perceptions of Medical Cannabis*, 57 INT'L J. DRUG POL'Y

qualitative study found that "[a]lmost every respondent acknowledged the stereotype that 'patients' were viewed by many as simply 'stoners' who took advantage of the law."<sup>333</sup> This is a phenomenon I refer to in previous work as internalized fear of the disability con.<sup>334</sup> The stigma was so profound that it actually prevented patients from asking to use marijuana in the first place<sup>335</sup> and to keep it a secret from others.<sup>336</sup> A somewhat similar process of stigmatization around the use of psychedelics to treat mental illness has also emerged,<sup>337</sup> yet in that case, the stigma around the health condition treated plays a role in the process (making it fit under the double stigma category).

An example of a singular stigma of prevention whereby the health condition is stigmatized, rather than the preventive measure is workplace wellness programs to fight against obesity. Workplace wellness programs may include a variety of preventative measures to fight obesity and promote a "healthy lifestyle" ranging from programs on the worksite (like a company gym, introducing healthy foods in the cafeteria, or smoking cessation classes in the workplace), support for activities taken place off-site (e.g., discounts for gym memberships or for weight loss programs), or other clinical preventive services (like

<sup>334</sup> Fear of the disability con is "the cultural anxiety that individuals fake disabilities to take advantage of rights, accommodations, or benefits." *See* Dorfman, *Fear of the Disability Con, supra* note 198, at 1053; Doron Dorfman, *[Un] Usual Suspects: Deservingness, Scarcity, and Disability Rights,* 10 U.C. IRVINE L. REV. 557, 559 (2020) [hereinafter Dorfman, *[Un]Usual Suspects*]; Doron Dorfman, *Suspicious Species,* 2021 U. ILL. L. REV. 1363, 1366; Doron Dorfman, *Pandemic* "*Disability Cons*", 49 J.L. MED. & ETHICS 401, 402 (2021). For other examples of internalized fear of the disability con stigma that leads to a chilling effect on the use of a right or practice see Dorfman, *Fear of the Disability Con, supra* note 198, at 1077–78; *see also* Dorfman, *[Un]Usual Suspects, supra*, at 603.

<sup>335</sup> Satterlund, Lee & Moore, *supra* note 333, at 15.

<sup>336</sup> *Id.* at 16.

<sup>337</sup> Mason Marks, *Psychedelic Medicine for Mental Illness and Substance Use Disorders: Overcoming Social and Legal Obstacles*, 21 N.Y.U. J. LEGIS. & PUB. POL'Y 69, 93 (2018).

<sup>4, 5, 7–8 (2018);</sup> David Victorson et al., *Exploring Cancer Survivors' Attitudes*, *Perceptions, and Concerns About Using Medical Cannabis for Symptom and Side Effect Management: A Qualitative Focus Group Study,* 47 Complementary Therapies IN MeD., no. 102204, 2019, at 5, 7.

<sup>&</sup>lt;sup>333</sup> Travis D. Satterlund, Juliet P. Lee & Roland S. Moore, *Stigma Among California's Medical Marijuana Patients*, 47 J. PSYCHOACTIVE DRUGS 10, 12 (2015); *see also* Sukvinder Kaur Bhamra, Ankita Desai, Parmis Imani-Berendjestanki & Maeve Horgan, *The Emerging Role of Cannabidiol (CBD) Products; A Survey Exploring the Public's Use and Perceptions of CBD*, 35 PHYTOTHERAPY RSCH. 5734, 5739 (2021) ("Some of the key barriers to using CBD, identified by participants, were the association of CBD as a recreational drug and the fear of the stigma of using an illicit substance . . . .").

free health screenings).<sup>338</sup> The ACA allocates up to \$200 million in grant funding to private businesses to initiate and expand workplace wellness programs.<sup>339</sup> In addition, the ACA has expanded the "wellness program exception" under the Health Insurance Portability and Accountability Act ("HIPAA") nondiscrimination rule. Generally, the HIPAA nondiscrimination rule prohibits insurers to discriminate on the basis of health status when determining premiums. This rule, however, originally included a "wellness program exception" allowing employers to reward some employees for participating in the wellness programs with discounts that rise up to 20% of the cost of the employee's premium.<sup>340</sup> The ACA has expanded this reward allowing discount of up to 30% of the cost of the employee's insurance premium,<sup>341</sup> with the possibility of increasing this reward to 50% of the premium in the future.<sup>342</sup>

While exercise, nutrition and weight loss programs, and other types of health screening, all part of the wellness program, are not within themselves stigmatized preventive measures, they are in place to combat the highly stigmatized health condition that is obesity or fatness,<sup>343</sup> alongside other health conditions.

<sup>&</sup>lt;sup>338</sup> Berman, *supra* note 27, at 375. For a comprehensive overview of the health reform around wellness programs see generally Lindsay F. Wiley, *Access to Health Care as an Incentive for Healthy Behavior? An Assessment of the Affordable Care Act's Personal Responsibility for Wellness Reforms*, 11 IND. HEALTH L. REV. 635 (2014); Karen Pollitz & Matthew Rae, *Trends in Workplace Wellness Programs and Evolving Federal Standards*, KKF (June 9, 2020), https://bimgroup.us/wp-content/uploads/2021/01/Trends-in-Workplace-Wellness-Programs-and-Evolving-Federal-Standards-\_-KFF.pdf [https://perma.cc/JSW5-3NFD].

<sup>&</sup>lt;sup>339</sup> Patient Protection and Affordable Care Act, Pub. L. No. 111–148, § 10408, 124 Stat. 119, 977–78.

<sup>&</sup>lt;sup>340</sup> 45 C.F.R. § 146.121(f) (2009).

<sup>&</sup>lt;sup>341</sup> 42 U.S.C. § 300gg-4(j) (2010).

 $<sup>^{342}~</sup>$  Id. § 300gg-4(j)(3)(A) ("The Secretaries of Labor, Health and Human Services, and the Treasury may increase the reward available under this [section] to up to 50 percent of the cost of coverage if the Secretaries determine that such an increase is appropriate.").

<sup>&</sup>lt;sup>343</sup> As Professor Rabia Belt states: "Discussing fatness can be tricky. The lack of uniform terminology and two clashing models to describe weight [a disease model that uses the descriptor "obese" and an advocacy model that uses the descriptor "fat"], complicate the discussion." *See* Rabia Belt, *The Fat Prisoners' Dilemma: Slow Violence, Intersectionality, and a Disability Rights Framework for the Future*, 110 Geo. L. J. 785, 790 (2022). For discussions of fat stigma see, e.g., Cat Pausé, Borderline: The Ethics of Fat Stigma in Public Health, 45 J.L. MED. & ETHICS 510, 510 (2017); Anna Kirkland, Think of the Hippopotamus: Rights Consciousness in the Fat Acceptance Movement, 42 Law & Soc'y Rev. 397, 421–422, 427 (2008); Jennifer Bennett Shinall, Distaste or Disability? Evaluating the Legal Framework for Protecting Obese Workers, 37 BERKELEY J. EMP. & LAB. L. 101, 137

Indeed, as legal, public health, and disability studies scholars point out, by increasing the financial pressure around weight loss and health outcomes, wellness programs have a role in exasperating the stigma around fatness, shifting the focus on individual behavior, choice, and lifestyle and not facilitating any environmental changes.<sup>344</sup> The financial incentives in this context are even more problematic, as being overweight or disabled is closely associated with socioeconomic status: obese Americans are disproportionately poor,<sup>345</sup> and the same goes for individuals with disabilities.<sup>346</sup>

Mental health treatment in the context of legal practice also serves as an example in this category: although mental illness is a very stigmatizing condition, at least in the context of the bar exam, treatment is not generally shameful (however, getting mental health treatment in other contexts and in different

(2016); Yofi Tirosh, *The Right to Be Fat*, 12 YALE J. HEALTH POL'Y L. & ETHICS 264, 272 (2012); Rebecca M. Puhl & Chelsea A. Heuer, *Obesity Stigma: Important Considerations for Public Health*, 100 Am. J. PUB. HEALTH 1019, 1024 (2010); HELENE A. SHUGART, HEAVY: THE OBESITY CRISIS IN CULTURAL CONTEXT 17 (2016); Wiley, *supra* note 29, at 142. The connections between stigmatization of fatness/obesity and ableism, that is the stigmatization of disability, has been made in the literature. *See*, *e.g.*, Jess L. Cowing, *Occupied Land Is an Access Issue: Interventions in Feminist Disability Studies and Narratives of Indigenous Activism*, 17 J. FEMINIST SCHOLARSHIP 9, 10 (2020) (critiquing Michelle Obama's *Let's Move!* campaign as "just one example of how anti-obesity rhetoric demands an examination for the ways in which discourses of health and fitness rely on ableism"); Anna Mollow, *Disability Studies Gets Fat*, 30 HYPATIA 199, 200 (2015) ("Why should disability scholars care about fat? Because the modes by which fat people are oppressed are indistinguishable from ableism . . . .").

344 See Berman, supra note 27, at 377; Wiley, supra note 29, at 157-58; Wiley, supra note 338, at 645–46; Carrie Griffin Basas, What's Bad about Wellness? What the Disability Rights Perspective Offers About the Limitations of Wellness, 39 J. HEALTH POL. POL'Y & L. 1035, 1037, 1049 (2014); Anna Kirkland, What is Wellness Now?, 39 J. Health Pol. Pol'y & L. 957, 961 (2014); Jessica L. Roberts & Eliza-BETH WEEKS, HEALTHISM: HEALTH-STATUS DISCRIMINATION AND THE LAW 83-84, 194 (2018); Frank J. Cavico & Bahaudin G. Muitaba, Health and Wellness Policy Ethics, 1 INT'L J. HEALTH MGMT. 111, 111–113 (2013); Heather Baird, Note, Healthy Compromise: Reconciling Wellness Program Financial Incentives with Health Reform, 97 MINN. L. Rev. 1474, 1481 (2013); Camila Strassle, How Workplace Wellness Programs Harm People with Disabilities, JUST. EVERYWHERE (Sept. 17, 2018), http://justice-everywhere.org/health/how-workplace-wellness-programs-harm-people-with-disabilities [https://perma.cc/K8V7-DEKS]; Lydia X. Z. Brown, Ridhi Shetty, Matthew U. SCHERER & ANDREW CRAWFORD, ABLEISM AND DISABILITY DISCRIMINATION IN NEW SURVEILLANCE TECHNOLOGIES 55 (2022), https://cdt.org/wp-content/uploads/2022/05/2022-05-23-CDT-Ableism-and-Disability-Discrimination-in-New-Surveillance-Technologies-report-final-redu.pdf [https://perma.cc/7X43-8EV4].

<sup>345</sup> Michael Correll, Getting Fat on Government Cheese: The Connection Between Social Welfare Participation, Gender, and Obesity in America, 18 DUKE J. GENDER L. & POLY 45, 46 (2010).

<sup>346</sup> Rabia Belt & Doron Dorfman, *Reweighing Medical Civil Rights*, 72 Stan. L. Rev. Online 176, 182 (2020).

communities would be considered stigmatizing). The signaling mechanism about being at an increased risk for dangerous behavior, as a consequence of a mental health episode, drives the stigma and certainly the penalties in this context.

The last scenario involves no stigmatization of the health condition nor the preventive measure. An example of such preventive interventions would be cancer detection via mammograms. Patients using the measure do not generally face stigma or penalties for doing so. Nevertheless, there could be situations where a penalty is being imposed on users of a nonstigmatized preventive measure or medical condition. Such is the example of the coverage of disease-modifying therapy ("DMT") for multiple sclerosis ("MS"). MS is a chronic neurological illness that affects the central nervous system, causing symptoms like fatigue, numbness, and weakness. It is an unpredictable and degenerative condition wherein patients experience relapses and remission of their symptoms.<sup>347</sup> DMTs are drug treatments (via pills, injections, or infusions) that reduce the progression and activity of MS; they are considered a secondary prevention health measure.<sup>348</sup>

MS DMTs are very costly, with prices increasing rapidly over the last few decades. In addition, despite the ACA's commitment to preventive medicine, MS DMTs are not covered under the ACA or its marketplace insurance plans.<sup>349</sup> Insurance companies, in response, have imposed exclusions and limitations on DMT coverage. Those include prior authorizations, requiring patients to meet certain criteria as a prerequisite for payment during their utilization review, along with significant cost-sharing (mainly through copayments that could amount to \$6,000 a year),<sup>350</sup> all of which render DMT medications

<sup>&</sup>lt;sup>347</sup> *Multiple Sclerosis*, Johns Hopkins Med., https://www.hopkinsmedicine.org/ neurology\_neurosurgery/centers\_clinics/multiple\_sclerosis/conditions [https:// perma.cc/67QX-KUG5] (last visited May 12, 2023).

<sup>&</sup>lt;sup>348</sup> Ulrik Dalgas, Martin Langeskov-Christensen, Egon Stenager, Morten Riemenschneider & Lars G. Hvid, *Exercise as Medicine in Multiple Sclerosis—Time for a Paradigm Shift: Preventive, Symptomatic, and Disease-Modifying Aspects and Perspectives*, 19 CURRENT NEUROLOGY & NEUROSCIENCE REPS. 88, 88 (2019).

<sup>&</sup>lt;sup>349</sup> Gregory J. Esper, Daniel Hartung & Orly Avitzur, *The Patient Protection and Affordable Care Act and Chronic Neurological Illnesses: Benefits and Challenges*, 72 JAMA NEUROLOGY 739, 739 (2015).

<sup>&</sup>lt;sup>350</sup> Daniel M. Hartung, *Health Economics of Disease-Modifying Therapy for Multiple Sclerosis in the United States*, 14 Therapeutic Advances in Neurological Disorders, Feb. 2021, at 4.

unaffordable, despite the generally generous coverage of preventive medicine in the ACA.  $^{\rm 351}$ 

The lack of sufficient insurance coverage has a grave effect on the usage of DMTs among patients diagnosed with MS.<sup>352</sup> A 2019 survey with a sample of 578 MS patients shows that more than one-third of them reported struggles in obtaining DMTs coverage due to insurer restrictions. Nearly half of respondents noted that they had altered their DMT use (by skipping doses or delaying treatment) and made other lifestyle changes that affect their quality of life.<sup>353</sup> Delayed treatment has been shown to deteriorate the health of MS patients, putting much more strain on the health system for treatment in the long run.<sup>354</sup>

In conclusion, the legal or policy considerations necessary to address the stigma surrounding preventive measures could, in most cases, depend on whether the health condition we aim to prevent is stigmatized or the preventive measure is stigmatized. Such typology, therefore, provides a tool to analyze the stigma surrounding health conditions and preventive measures and provides insight into what kind of legal or policy consideration could effectively fight such stigma. I now turn to the policy and normative implications of this research.

## V

NORMATIVE IMPLICATIONS AND POLICY RECOMMENDATIONS

This Article has identified the phenomenon of penalizing prevention due to signaling effects in a variety of contexts, including insurance discrimination, exclusion from civic practices like blood donation, exclusion from legal practice, or stigmatization affecting legal rights (such as custody cases involving PrEP use). The normative implications for the phenomenon accordingly takes many forms as well.

<sup>&</sup>lt;sup>351</sup> *Id.* at 2–3.

<sup>&</sup>lt;sup>352</sup> James M. Stankiewicz & Howard L. Weiner, *An Argument for Broad Use of High Efficacy Treatments in Early Multiple Sclerosis*, 7 NEUROLOGY: NEUROIMMUNOL-OGY & NEUROINFLAMMATION e636, e639 (2020); Ana L. Hincapie, Jonathan Penm & Craig F. Burns, *Factors Associated with Patient Preferences for Disease-Modifying Therapies in Multiple Sclerosis*, 23 J. MANAGED CARE & SPECIALTY PHARMACY 822, 828 (2017).

 $<sup>^{353}\,</sup>$  Nat'l Multiple Sclerosis Soc'y, Quantifying the Effect of the High Cost of DMTs: Market Research Report (2019).

<sup>&</sup>lt;sup>354</sup> Hartung, *supra* note 350, at 4.

A. Using State and Federal Laws to Combat Insurance Discrimination

Regulatory interventions should be implemented to proscribe insurance discrimination against individuals who use preventive health measures, whether those are primary prevention measures like PrEP or tertiary prevention measures like naloxone. Several states have implemented or have considered implementing regulatory interventions. In 2020, Maine joined the efforts in Massachusetts and New York<sup>355</sup> to end PrEP insurance discrimination by amending its state insurance policy to prohibit discrimination on the basis of PrEP use.<sup>356</sup> Similarly, the New Jersey's Department of Banking and Insurance promulgated a bulletin prohibiting insurance discrimination concerning PrEP and naloxone.<sup>357</sup> New York's Department of Financial Services issued guidance to insurance companies, opining that denying insurance due to prescriptions of naloxone violates state law that prohibits insurance discrimination.<sup>358</sup> Colorado's Division of Insurance has expressed a similar position to New York in a bulletin addressed to insurers.<sup>359</sup>

Leaving regulatory intervention to state legislators could present political hurdles. Perhaps counterintuitively, research has shown that at least until 2017, states with high rates of overdose deaths are not the ones dispensing the most naloxone.<sup>360</sup> Political reasons cause the mismatch between overdose mortality and naloxone distribution in certain states. First, community use of naloxone is not only a preventive measure, but also is considered a harm-reduction strategy unpopular with conservatives.<sup>361</sup> Second, as with other preventive measures like PrEP, some critics of expanding community-based naloxone have expressed concerns about risk compensation. They argue that the

<sup>&</sup>lt;sup>355</sup> See supra notes 114–122 and accompanying text.

<sup>&</sup>lt;sup>356</sup> Me. Rev. Stat. Ann. tit. 24-A § 2159(7).

<sup>&</sup>lt;sup>357</sup> Vecchione, *supra* note 118.

<sup>&</sup>lt;sup>358</sup> N.Y. DEP'T OF FIN. SERVS., INS. CIRCULAR LETTER NO. 9 (Sept. 6, 2019), https://www.dfs.ny.gov/industry\_guidance/circular\_letters/cl2019\_09 [https://perma.cc/KY4C-WJX5].

<sup>&</sup>lt;sup>359</sup> COLO. DEP'T OF REGUL. AGENCIES, DIV. OF INS., BULL. NO. B-4.103, INSURERS' CONSIDERATION OF NALOXONE PRESCRIPTIONS IN THE UNDERWRITING PROCESS (Jan. 31, 2020), https://drive.google.com/file/d/1S8KHDAMr3qog2b91zwNPbQwFHS4gOp0A/ view [https://perma.cc/P7YV-8E7A].

<sup>&</sup>lt;sup>360</sup> Freeman, Hankosky, Lofwall & Talbert, *supra* note 281, at 362.

<sup>&</sup>lt;sup>361</sup> Alexander R. Bazazi, Nikolas D. Zaller, Jeannia J. Fu & Josiah D. Rich, *Preventing Opiate Overdose Deaths: Examining Objections to Take-Home Naloxone*, 21 J. HEALTH CARE POOR & UNDERSERVED 1108, 1109 (2010); Kolodny et al., *supra* note 256, at 569.

life-saving drug's distribution would send a message that using opioids is no longer as dangerous as it was and would potentially encourage users to continue or even increase their risky behavior.<sup>362</sup> This risk compensation claim, however, has been refuted by a 2021 empirical study analyzing national data.<sup>363</sup> In addition, studies have shown that the availability of naloxone via state law distribution has decreased the number of opioid overdose deaths and that this positive effect stemming from laws enabling easier access to naloxone increases over time.<sup>364</sup> A recent study found that naloxone availability had a strong negative association with overdose mortality in White and higher socioeconomic neighborhoods, but it did not find such an effect in Latino or Black neighborhoods.<sup>365</sup> Possible explanations for the racial disparity include barriers to access to naloxone in communities of color. lack of education and awareness, and the fear of incarceration because of involvement with a stigmatized practice of opioids.<sup>366</sup>

Litigating insurance discrimination in federal courts through the robust antidiscrimination mandate of Section 2590.702 to the ACA regulations could be another solution.<sup>367</sup> Section 2590.702 is arguably the linchpin of the ACA, as it prohibits discrimination in insurance on the basis of health factors like health status, medical condition, medical history—all of which can be interpreted to mean taking preventive health measures. Litigation in federal courts could provide an effective avenue to address insurance discrimination related to preventive medicine even if a state law does not provide such protection.

<sup>&</sup>lt;sup>362</sup> Bazazi, Zaller, Fu & Rich, *supra* note 361, at 1109 ("One common objection to distributing naloxone to opiate users is that doing so might encourage increased drug use."); Jennifer L. Doleac & Anita Mukherjee, *The Effects of Naloxone Access Laws on Opioid Abuse, Mortality, and Crime*, 65 J.L & ECON. 211, 212 (2022).

<sup>&</sup>lt;sup>363</sup> Brian C. Kelly & Mike Vuolo, *Do Naloxone Access Laws Affect Perceived Risk of Heroin Use? Evidence from National US Data*, 117 ADDICTION 666 (2021), https://onlinelibrary.wiley.com/doi/epdf/10.1111/add.15682 [https://perma. cc/Q922-HFGZ].

<sup>&</sup>lt;sup>364</sup> Davis & Carr, *supra* note 274, at 1–2; Rahi Abouk, Rosalie Liccardo Pacula & David Powell, *Association Between State Laws Facilitating Pharmacy Distribution of Naloxone and Risk of Fatal Overdose*, 179 JAMA INTERNAL MED. 805, 806–09 (2019). Although this 2019 study did find an association between an increase in nonfatal incidences of overdose in states with increased access to naloxone, the authors attribute this evidence to other reasons other than risk compensation.

<sup>&</sup>lt;sup>365</sup> Amir M. Forati, Rina Ghose & John R. Mantsch, *Examining Opioid Overdose Deaths Across Communities Defined by Racial Composition: A Multiscale Geographically Weighted Regression Approach*, J. URB. HEALTH 551, 556 (2021).

<sup>&</sup>lt;sup>366</sup> Id.

 $<sup>^{367}</sup>$   $\,$  29 C.F.R § 2590.702 (2021).

As reports of insurers across the country charging thousands of dollars in cost sharing from enrollees, steps to enforce the Section 2713 rule for dollar-first coverage of preventive measures like PrEP should also be bolstered.<sup>368</sup> The insurance commissioners in every state as well as the Department of Labor (which oversees employer-based health plans through which most Americans are insured) are responsible for such enforcement of insurance coverage rules. This enforcement, however, is dependent on reporting from enrollees who are being wrongly charged. Yet many times, those enrollees are not aware they are not supposed to pay and thus do not report.<sup>369</sup> Educating the public on their rights under Section 2713 to the ACA, so they can report such incidents, as well as enforcing civil monetary penalties and other serious sanctions, are key to fight such illegal practices by insurers.

B. A Behavioral-Individualistic Approach to Risk: Fighting Exclusion from Civic and Professional Practices

As I have shown, the signaling effect of taking a preventive measure, meaning the perceptions of a heightened risk derived from lifestyle and choices others attribute to the individual, affects decision-making in regard to all sorts of civic, professional, and even legal decisions within courts. To combat this, behavioral approaches should be adopted that look at individuals and assess risk based on multiple criteria. Such a perspective focuses on actual conduct and not on specific signaled messages that may not be accurate about an individual who uses preventive health measures.

Such an approach was adopted by some state courts with regard to the character and fitness evaluations starting in the early 2000s with cases such as *Strasser v. Character and Fitness Committee of Kentucky Bar Admissions*<sup>370</sup> and continuing after the Louisiana Bar consent decree.<sup>371</sup> In 2019, the

<sup>&</sup>lt;sup>368</sup> Varney, *supra* note 124.

<sup>&</sup>lt;sup>369</sup> Id.

 $<sup>^{370}</sup>$  160 S.W.3d 789 (Ky. 2005). Nevertheless, a 2020 case reveals that the Kentucky character and fitness committee is still imposing significant burden on bar applicants because of their mental health history. The case involved an applicant who had to go through two years of bureaucracy and endless disclosers of her mental health records (including one interrogation held on the day of the swearing-in ceremony at the State Capitol) before finally being admitted to the Kentucky bar. *See* Doe v. Sup. Ct. of Ky, 482 F. Supp. 3d 571, 577–79 (W.D. Ky. 2020).

<sup>&</sup>lt;sup>371</sup> See discussion supra subpart III.B.1.c.

Connecticut Bar Examining Committee voted to remove mental health diagnosis questions from the state's bar application altogether<sup>372</sup> and adopted a behavioral/conduct approach instead.<sup>373</sup> A similar approach has been taken by Virginia, which also no longer requires disclosure of mental health diagnoses, taking the *Clark* decision a step further.<sup>374</sup> California enacted a law prohibiting the state bar or members of its examining committee from reviewing or considering a candidate's mental health medical records unless the records are being used to show good moral character or to demonstrate a mitigating factor to a specific act of misconduct.<sup>375</sup> Similar approaches to California were taken by Virginia, Michigan, and Florida, which revised their mental health questions to better align with the Louisiana consent decree.<sup>376</sup> In February 2020 New York implemented such changes, when it announced that mental health questions were to be removed from the state bar application, effective immediately.<sup>377</sup> New Jersey is the latest state to revise its mental health inquiry to reflect a behavioral/conduct approach in September 2023.<sup>378</sup>

A similar perspective has been taken with regard to blood donation bans for men who have sex with men around the world and most recently, in May 2023, albeit in a different format, by the FDA.<sup>379</sup>

<sup>374</sup> Kristen Clow, Note, *Mental Health and the Character and Fitness Examination: The Tide Is Shifting*, 95 N.D. L. Rev. 327, 337 (2020).

<sup>&</sup>lt;sup>372</sup> Conn. Editorial Bd., *Long Overdue Step Taken to Remove Mental Health Stigma in Law*, Conn. L. TRIBUNE (Apr. 12, 2019), https://www.law.com/ctlawtribune/2019/04/12/long-overdue-step-taken-to-remove-mental-health-stigma-in-law [https://perma.cc/8QG7-5XEG].

<sup>&</sup>lt;sup>373</sup> The Connecticut Bar Examining Committee now has a "protocol for inquiry into health diagnosis or drug or alcohol dependence" which clarifies that they are looking to instances where conduct is involved and disclosed. *See* Reguls. of The Conn. Bar Examining Comm., art. VI-9, https://www.jud.ct.gov/cbec/regs.htm [https://perma.cc/5S29-JEAP].

<sup>&</sup>lt;sup>375</sup> CAL. BUS & PROF. CODE § 6060(b)(2).

<sup>&</sup>lt;sup>376</sup> Clow, *supra* note 374, at 336.

<sup>&</sup>lt;sup>377</sup> Marilyn Cavicchia, A New Look at Character and Fitness: Bar Leaders, Lawyers, Others Urge Elimination of Mental Health Questions, 44 Bar Leader, Jan.–Feb. 2020, https://www.americanbar.org/groups/bar\_services/publications/bar\_leader/2019\_20/january-february/a-new-look-at-character-and-fitness-bar-leaders-lawyers-others-urge-elimination-of-mental-health-questions [https://perma.cc/N2YK-2DVF].

<sup>&</sup>lt;sup>378</sup> N.J. Supreme Ct., Notice to the Bar: Supreme Courts Limits Inquiries About Mental Health on the Character and Fitness Questionnaire (Sept. 21, 2023), https://www.njcourts.gov/sites/default/files/notices/2023/09/n230921b.pdf [https://perma.cc/M7DU-GYMT].

<sup>&</sup>lt;sup>379</sup> Press Release, *supra* note 145.

In previous years, European countries like Italy, Spain,<sup>380</sup> Hungary,<sup>381</sup> England,<sup>382</sup> and Israel<sup>383</sup> adopted systems using an "individual risk assessment" of "risky behaviors." It assesses each potential donor's risk using a detailed questionnaire whereby "sexual orientation" or PrEP use are not automatic disqualifiers but instead are components of a more elaborate individualized risk assessment.<sup>384</sup>

Nevertheless, unlike other countries, the FDA has chosen in 2023 to exclude PrEP users in its revised policy because of the fear of late detection of HIV because the use of the preventive drug.<sup>385</sup> This type of individual risk assessment, which excludes PrEP use, creates the exact paradoxical legal treatment of preventive medicine presented in the Article. A way to resolve the problem of possible later detection of HIV is using a method of "double testing" the blood.<sup>386</sup>

This approach, which has been taken by Israel, Spain and Italy,<sup>387</sup> tested plasma from men who have had sex with men; if found negative, the plasma was "separated, frozen and kept in cooled quarantine for four months."<sup>388</sup> Following the quaran-

<sup>&</sup>lt;sup>380</sup> Ruth Offergeld, Christel Kamp, Margarethe Heiden, Rut Norda & Marie-Emmanuelle Behr-Gross, *Sexual Risk Behaviour and Donor Deferral in Europe*, 107 Vox SANGUINIS 420, 421–22 (2014).

<sup>&</sup>lt;sup>381</sup> Mikelle Street, *Hungary Removes Ban on Gay and Bi Men Donating Blood*, Our (May 8, 2020), https://www.out.com/health/2020/5/08/hungary-removesban-gay-and-bi-men-donating-blood [https://perma.cc/57Y8-VNB5].

<sup>&</sup>lt;sup>382</sup> Elizabeth Kuhr, *U.K. to Allow Sexually Active Gay and Bisexual Men to Donate Blood*, NBC News (Dec. 14, 2020), https://www.nbcnews.com/feature/nbcout/u-k-allow-sexually-active-gay-men-donate-blood-n1251095 [https://perma. cc/45DT-QPBA].

<sup>&</sup>lt;sup>383</sup> Ido Efrati, Israel Ends Ban on Blood Donations from Homosexual Men, HAARETZ (Aug. 19, 2021),

https://www.haaretz.com/israel-news/.premium-health-minister-endsban-forbidding-homosexuals-to-donate-blood-1.10132071 [https://perma. cc/5KDG-R928].

<sup>&</sup>lt;sup>384</sup> I. Glenn Cohen, Jeremy Feigenbaum & Eli Y. Adashi, *Reconsideration of the Lifetime Ban on Blood Donation by Men Who Have Sex with Men*, 312 JAMA 337, 338 (2014).

<sup>&</sup>lt;sup>385</sup> Press Release, *supra* note 145.

<sup>&</sup>lt;sup>386</sup> Varrige, *supra* note 139, at 630 (citing Grace Guarnieri, *Gay and Bisexual Men in Israel Can Now Donate Blood Without Delay, but Not in the U.S.*, NEWSWEEK (Jan. 10, 2018), https://www.newsweek.com/gay-bisexual-blood-donors-israel-delay-776679 [https://perma.cc/FL9B-DB66]].

<sup>&</sup>lt;sup>387</sup> Offergeld, Kamp, Heiden, Norda & Behr-Gross *supra* note 380, at 421–22.

<sup>&</sup>lt;sup>388</sup> Judy Siegel-Itzkovich, *Gay Men Allowed to Donate Blood Through Magen David Adom in New Policy*, JERUSALEM POST (Jan. 10, 2018) https://www.jpost. com/Israel-News/Gay-men-allowed-to-donate-blood-through-Magen-David-Adom-in-new-policy-533355 [https://perma.cc/Z73J-CL6D]; Varrige, *supra* note 139, at 630 (citing Guarnieri, *supra* note 386).

#### 2024]

tine period, the donor gave blood again, and if it was also found negative, both the frozen and the new blood were approved for transfusion.  $^{\rm 389}$ 

Research on the Italian system found that the move to individualized risk assessment based on behavior did not have an effect on the incidence of HIV infection among blood donors.<sup>390</sup>

Such individual assessments that allow PrEP users to donate are more equitable policy approaches in terms of debunking structural stigma and improving the expressive function of the law,<sup>391</sup> but in contexts like the blood donation bans, could promote important public health goals like fighting chronic scarcity in the American blood supply and eliminating HIV through PrEP.<sup>392</sup>

# C. Destigmatizing the Multiple Aspects of Preventive Measures

Stigma is a dynamic and complex phenomenon, specifically when it relates to health conditions and illness.<sup>393</sup> As I have shown in Section IV, newly discovered illnesses and health

<sup>390</sup> Barbara Suligoi et al., *Changing Blood Donor Screening Criteria from Permanent Deferral for Men Who Have Sex with Men to Individual Sexual Risk Assessment: No Evidence of a Significant Impact on the Human Immunodeficiency Virus Epidemic in Italy, 11 BLOOD TRANSFUSION 441, 448 (2013).* 

<sup>391</sup> The expressive function of the law means the ways in which law and policy signal and construct public meanings about norms and values. *See* RICHARD H. MCADAMS, THE EXPRESSIVE POWERS OF LAW: THEORIES AND LIMITS 11–12 (2015); Cass R. Sunstein, *On the Expressive Function of Law*, 144 U. PA. L. REV. 2021, 2022 (1996); Lawrence Lessig, *Social Meaning and Social Norms*, 144 U. PA. L. REV. 2181, 2185 (1996); Deborah Hellman, *The Expressive Dimension of Equal Protection*, 85 MINN. L. REV. 1, 3 (2000); Elizabeth S. Anderson & Richard M. Pildes, *Expressive Theories of Law: A General Restatement*, 148 U. PA. L. REV. 1503, 1571 (2000); Richard H. McAdams & Janice Nadler, *Coordinating in the Shadow of the Law: Two Contextualized Tests of the Focal Point Theory of Legal Compliance*, 42 LAW & Soc'Y REV. 865, 867 (2008); Dorfman, *supra* note 11, at 867-69; Sara Emily Burke & Roseanna Sommers, *Reducing Prejudice Through Law: Evidence from Experimental Psychology*, 89 U. CHI. L. REV. 1369, 1372-1374 (2022).

<sup>392</sup> Lifting the blood ban has been estimated to increase yearly donations by 4% or more. See Ayako Miyashita & Gary J. Gates, UPDATE: Effects of Lifting the Blood Donation Ban on Men Who Have Sex with Men, UCLA: WILLIAMS INST. (Sept. 2014), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Blood-Donation-Ban-MSM-Sep-2014.pdf [https://perma.cc/V7ZH-JQTN]; see also, Dorfman, supra note 11, at 860.

<sup>393</sup> Fife & Wright, *supra* note 43, at 52.

<sup>&</sup>lt;sup>389</sup> Siegel-Itzkovich, *supra* note 388; Guarnieri, *supra* note 386; Itzchak Levy et al., *Attitudes and Perceptions Among Men Having Sex with Men Towards a New Non-Deferral Blood Donation Policy in Israel*, 114 Vox SANGUINIS 310, 311 (2019); *see also supra* note 383 and accompanying text (discussing Israel's current blood donation policy as changed in 2021).

conditions, new treatments, and intra-group norms and values all influence the ways stigma evolves. This in turn, affects the ways law and policy are developed and implemented.

This Article takes the first step to introduce the signaling effects of preventive measures that create stigma around their users and impose penalties on them. The Article also draws attention to how stigma can attach to the health condition we aim to prevent (like HIV infection) and to the preventive measures (such as a colonoscopy).

Fitting within the goal of destigmatizing preventive medicine, a concrete blood donation policy would ideally give gay and bisexual donors who are PrEP users preference, as this population is less likely to have transmissible HIV or STIs. This approach, however, was rejected by the FDA in 2023. Such a policy change would communicate that PrEP is a reliable preventive tool and combat decision-making clouded by moral judgment. As qualitative research shows, many gay men want to donate blood and see it as a civic duty; therefore, such a policy would likely encourage individuals to take PrEP where needed and promote the goal of eradicating HIV.<sup>394</sup>

The blood ban for men who have had sex with men has been rightfully abolished, as there is no medical-scientific reason to single out sex between men while downplaying or ignoring similar risks undertaken by heterosexual couples, a distinction that has been considered unconstitutional.<sup>395</sup> Yet a policy that prioritizes donation by PrEP users through "double testing"<sup>396</sup> is a missed opportunity to promote cohesion and consistency concerning the legal treatment of preventive medicine.

A multifaceted approach should be implemented to educate legal actors including legislators, policy makers, and courts about preventive measures as an important health issue—moving beyond an individualistic approach to a broader view of how preventive medicine can promote public health goals. Legal and educational tools can be used to help bridge the gap between the law on the books that encourages preventive medicine and the law in action that penalizes it.

Another example of working to prevent penalties upon those who use preventive measures is Rule 8.3(c) to the American Bar

<sup>&</sup>lt;sup>394</sup> BENNETT, *supra* note 3, at 117–18.

 $<sup>^{395}</sup>$  Russell K. Robinson & David M. Frost, *The Afterlife of Homophobia*, 60 Ariz. L. Rev. 213, 217, 234–36 (2018).

<sup>&</sup>lt;sup>396</sup> See infra note 386 and accompanying text.

Association's Model Rules of Professional Conduct.<sup>397</sup> This rule exempts members of the legal profession from reporting misconduct of other members if the information was gained "while participating in an approved lawyers assistance program."<sup>398</sup> The rationale behind the exemption is not to deter judges or lawyers from taking part in assistance programs helping with substance use condition or mental health issues because of the fear they may be reported and suffer consequences to their careers—meaning this rule is meant to avoid penalizing prevention.<sup>399</sup>

Notably, the ACA established the Public Health Education Fund to fund public-private partnerships for outreach and education campaigns around preventive health.<sup>400</sup> This fund will benefit from the insights this Article outlined. Educating legal actors on health stigma related to preventive health could influence how the law treats populations using preventive health measures and a means to harmonize the legal treatment of preventive medicine.

## CONCLUSION

This Article is the first to expose and describe a central dilemma in the field of public health law: the paradoxical legal treatment of preventive medicine, meaning how structural stigma stands in the way of successfully implementing preventive interventions through laws, policies, and court decisions. The case studies around PrEP, state bar associations' character and fitness evaluations penalizing mental health treatment, naloxone, and other examples discussed, clarify the need to ensure laws and policies fit with the ACA's goal of encouraging and expanding preventive medicine.

Taking steps to destignatize preventive medicine and ensure there are no penalties imposed on those using preventive health measures would provide the means to a better quality of care as the ACA envisioned, creating a healthier society.

<sup>&</sup>lt;sup>397</sup> I thank Russell Pearce for this point.

<sup>&</sup>lt;sup>398</sup> Model Rules of Pro. Conduct r. 8.3 (Am. Bar Ass'n 2021).

<sup>&</sup>lt;sup>399</sup> *Id.* cmt. [5] ("[P]roviding for an exception to the reporting requirements of paragraphs (a) and (b) of this Rule [requiring report of misconduct] encourages lawyers and judges to seek treatment through such a program. Conversely, without such an exception, lawyers and judges may hesitate to seek assistance from these programs, which may then result in additional harm to their professional careers and additional injury to the welfare of clients and the public.").

<sup>&</sup>lt;sup>400</sup> 42 U.S.C. § 300u-11(a).