Social Risk and the Transformation of Public Health Law: Lessons from the Plague Years

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Social Risk and the Transformation of Public Health Law: Lessons From the Plague Years†

Elizabeth Cooper

INTRODUCTION

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† Many authors have used the phrase "plague years" to refer to significant medical, social, or political upheaval, including the bubonic plague, famine, the McCarthy era, and the age of HIV/AIDS. Among the most well-known references are DAVID BLACK, THE PLAGUE YEARS: A CHRONICLE OF AIDS, THE EPIDEMIC OF OUR TIMES (1986), DANIEL DEFOE, A JOURNAL OF THE PLAGUE YEAR (1722) (describing the 1665 outbreak of bubonic plague in London), and LARRY KRAMER, THE PLAGUE YEARS, in THE AIDS READER 113 (Nancy F. McKenzie ed., 1987).

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INTRODUCTION

Acquired Immune Deficiency Syndrome (AIDS) was the wake-up call that disturbed America from its mid-twentieth century slumber concerning the dangers of communicable diseases. Until AIDS was identified in 1981, most Americans felt largely impervious to health threats posed by viruses or bacteria. Polio, smallpox, and tuberculosis had been brought under control by the “magic bullets” of antibiotics and vaccines. We felt more susceptible to the ravages of cancer or the debilitation of heart disease. But, over the last twenty years, the (re)emergence of serious or life-threatening microbial-based conditions such as Ebola, hantavirus, Lyme disease, West Nile virus, among others, has brought the world back to a time when health threats were a constant concern.


With the introduction of sulfonamide drugs in the 1930s and antibiotics in the 1940s, the germ theory had spawned effective technologies to combat infection. The promise of... ‘magic bullets,’ specific chemotherapies that would root out and destroy ‘invading organisms,’ had, at last, been realized. Diseases that a mere decade earlier posed a serious threat to life now could be quickly and definitively treated; antibiotics were routinely saving those previously damned.

*Id.*; *see also Edward S. Colub, The Limits of Medicine: How Science Shapes Our Hopes for the Cure* 183 (1997) (“Between the Salk and the later Sabin polio vaccines, the children of the world can now be protected from a terribly crippling disease and the polio vaccine has become a standard against which we measure not only other vaccines but the efficacy of all medicine.”).

In 1798, Edward Jenner developed a then controversial procedure of vaccination to protect people from smallpox. *Id.* at 120. “From 1953, the year after the introduction of the antituberculosis drug, isoniazid, through 1984, the number of tuberculosis cases reported decreased from 84,304 to 22,255, an average decline of 51% per year.” Ronald Bayer & Laurence Dupuis, *Tuberculosis, Public Health, and Civil Liberties, in New Ethics for the Public’s Health* [hereinafter New Ethics] 225, 226 (Dan E. Beauchamp & Bonnie Steinbock eds., 1993) [hereinafter Bayer & Dupuis, *Tuberculosis*].


4. Ebola Hemorrhagic Fever is a virus spread through contact with an infected animal or with fluids from an infected person. Symptoms include rash, fever, and myalgia (muscle aches), leading to chest pains, shock, blindness, internal bleeding, and death. Since its recognition in 1976, there have been 1095 cases, with 803 resulting in death. All cases but one have been in Africa. *See CDC, Disease Information: Fact Sheets: Ebola Hemorrhagic Fever,*
and even newly-recognized strains of hepatitis\(^8\) have underscored our vulnerability. History teaches that new plagues will continue to emerge.\(^9\)

What does this mean for the development of public health law and policy? Each epidemic provokes legal and political challenges that raise basic questions about our conceptions of social justice and that shape the

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8. See STEDMAN'S MEDICAL DICTIONARY 784 (26th ed. 1995) (stating that hepatitis is an inflammation of the liver caused by a viral infection spread either through transfer of bodily fluids or the fecal-oral route; hepatitis A, B, and C (HAV, HBV, and HCV respectively) afflict over 500,000 people annually in the United States; HBV alone ranks as the ninth-leading killer in the world; HCV affects 150,000 Americans annually, and accounts for a large portion of cirrhosis, liver failure, and liver cancer cases; types D and E are less frequently diagnosed in the United States); CDC, HEPATITIS D (DELTA) VIRUS, available at http://www.cdc.gov/ncidod/dvbid/delta/index.htm (last modified Feb. 1, 2000) (noting that hepatitis D (HDV) requires a pre-existing HBV infection; epidemiological data suggest that HDV infects less than 10% of asymptomatic HBV carriers and less than 25% of those with chronic HBV related liver disease); Martin L. Tepper & Paul R. Gully, Viral Hepatitis: Know Your D, E, F and Gs, 156 CAN. MED. ASS'N J. 1735, 1735-36 (1997) (stating that hepatitis G (HGV) "was fully characterized in 1996 . . . and as of yet the role of HGV in fulminant hepatitis is an unresolved question") (citations omitted).

development of our public health jurisprudence.\textsuperscript{10} How do we identify those at risk or those in need of care? Is it ethical to force people to learn they are ill if no cure exists for their underlying disease? How do we protect those who are healthy from becoming ill? In a world of limited resources, how do we distribute available or emerging treatment? How do we protect those who have fallen ill from inappropriate discrimination or other harms? It is an enormous challenge to determine how these decisions should be made and who should make them.

Legislative efforts to answer these questions largely have been inadequate. Public health law has developed in piecemeal fashion, responding to each crisis as it arises,\textsuperscript{11} resulting in an amalgam of legislative provisions generally unprepared to deal with existing—or future—threats to the public health.\textsuperscript{12} Indeed, the law frequently has revealed itself to be ill-equipped to deal with the social and political issues that inevitably attach to any wide-spread medical crisis.\textsuperscript{13}


\textsuperscript{11} See Laurie Garrett, Preferring Anarchy and Class Distort, in BETRAYAL OF TRUST: THE COLLAPSE OF GLOBAL PUBLIC HEALTH 266-89 (2000) [hereinafter Garrett, BETRAYAL OF TRUST] (noting that unlike European policies, which are handed down from above, "American public health ... arose from the local level, and no two cities or states had precisely the same policies"); Lawrence O. Gostin, The Future of Public Health Law, 12 Am. J.L. & Med. 461, 476 (1986) (stating that most public health statutes are "severely outdated" and were "fashioned on an ad hoc basis"); Gostin, Burris & Lazzarini, supra note 10, at 101-02 ([S]uccessive layers of statutes and amendments, built up over one hundred years or more in response to disease epidemics[,] ... tell the history of disease control in America much as geologic strata tell the history of the earth."); supra Part II.A (reviewing existing law regarding communicable diseases).

\textsuperscript{12} See Garrett, BETRAYAL OF TRUST, supra note 11, at 266 (describing the American public health system as a "hodgepodge of programs, bureaucracies, and failings" in "dire disarray"); René Bowser & Lawrence O. Gostin, Managed Care and the Health of a Nation, 72 S. Cal. L. Rev. 1209, 1257-58 (1999) (noting the lack of resources necessary "to identify and respond effectively to the great variety of health risks facing populations"); Fidler et al., supra note 3, at 782 ("Often the flexibility needed to respond to new threats is not present within the legal system of many states . . ."); Gostin, Burris & Lazzarini, supra note 10, at 106 ("State health codes typically contain laws that are simply no longer relevant and fail to address new approaches to disease control."). For an example of an outdated statute, see N.J. STAT. ANN. § 26:4-10 (West 1999), which prohibits the use of the "common drinking cup" in public places because it is an "undoubted source of communication of infectious diseases").

\textsuperscript{13} See Gostin, Burris & Lazzarini, supra note 10, at 113 (finding public health legislation "silent on the trust, legitimacy, and stigma issues that animate health disputes today"); cf. Human Rights and Public Health, in HEALTH AND HUMAN RIGHTS 5 (Jonathan M. Mann et al. eds., 1999) ("Promoting and protecting health requires explicit and concrete efforts to promote and
Lawrence O. Gostin, Scott Burris, and Zita Lazzarini, leading public health thinkers, have authored one recent proposal to remedy this incoherence in the law by recommending that each state overhaul its communicable disease law in a manner consistent with constitutional principles of due process and equal protection. This innovative plan seeks to eliminate distinctions based on history and habit, and instead create affirmative and negative burdens based on the nature of a given disease, the severity of the harm to the infected, the likelihood and means by which it will be transmitted to others, and the harm it is likely to cause. The authors of the proposal seek to maximize protection for the healthy while preserving the individual liberties of those who are fighting disease or infection. They recognize that those who fall ill experience not only medical hardship ("medical risk"), but also extraordinary stigma, social hostility, and discrimination ("social risk").

protect human rights and dignity, and greater fulfillment of human rights necessitates sound attention to health and to its societal determinants.

14. See Gostin, Burris & Lazzarini, supra note 10, at 118 (proposing a “disease control law” that would “conform to current standards of general constitutional and statutory law”). For a more detailed description of this proposal, see infra Parts II.A-B.

15. See Gostin, Burris & Lazzarini, supra note 10, at 121 (“[S]ound public health statutes should set out a rational and reliable way both to assess risk and to establish procedures to ensure the protection of individual rights.”). These factors are rooted in the statutes and case law that have developed to protect the rights of people living with disabilities. See Americans with Disabilities Act, 42 U.S.C. §§ 12101-12213 (2000) [hereinafter ADA] (prohibiting discrimination on the basis of disability in employment, public accommodations, and public services); Rehabilitation Act of 1973, as amended, 29 U.S.C. §§ 701-796i (2000) [hereinafter Rehabilitation Act] (prohibiting discrimination on the basis of disability by federal employers or contractors); Sch. Bd. of Nassau County v. Arline, 480 U.S. 273, 289 (1987) (setting forth the factors courts should use to determine whether a person with a disability constitutes a significant risk of harm to others and therefore does not receive the antidiscrimination protection of the Rehabilitation Act); infra note 126 and accompanying text (discussing a statutory scheme that would look to the least restrictive alternative in accomplishing a public health goal).

16. See Gostin, Burris & Lazzarini, supra note 10, at 119 (proposing protection of “programs that encourage healthy choices” as well as “strong protections for privacy and security”).

17. The term “medical risk” refers to the range of disease-based sequellae an ailing individual is likely to experience, as well as the likelihood that the disease, and its attendant health-related harms, will be transmitted to others. This concept also is integral to the doctrine of informed consent, which requires a patient to give knowledgeable and voluntary consent prior to undergoing a procedure that reasonably could be expected to cause medical harm. See generally Ruth B. Faden & Tom L. Beauchamp, A HISTORY AND THEORY OF INFORMED CONSENT (1986) (reviewing the development and uses of informed consent doctrine); Jay Katz, THE SILENT WORLD OF DOCTOR AND PATIENT (1984) (discussing pragmatic aspects of seeking and obtaining informed consent in the health care setting).

18. See Scott Burris, Fear Itself: AIDS, Herpes and Public Health Decisions, 3 Yale L. & Pol'y Rev. 479, 480 (1985) [hereinafter Burris, Fear Itself] (“While it is obvious that medical knowledge has changed vastly in the past century, there is little to suggest that basic human responses to disease have changed at all. People are still afraid of both disease and the sick.”).
LESSONS FROM THE PLAGUE YEARS

Although the term “medical risk” is familiar as a concept describing the range of harms that may result from a medical disease or procedure, the term “social risk” is less well-known. As described by Scott Burris, “[s]ocial risk in health behavior may be broadly defined as the danger that an individual will be socially or economically penalized should he become identified with an expensive, disfavored, or feared medical condition.” Such penalties may include discrimination or other forms of ostracization for which no legal recourse may be available.

Social risk may be “actual” or “perceived.” Actual social risk refers to the concrete attitudes and actions that cause or genuinely threaten social harm to a person living with disease. Perceived social risk is just as tangible.


Stigma has been understood as a social relation between a stigmatized and a ‘normal’ person, based on a shared belief that some part of the stigmatized person’s Identity is, . . . ‘spoiled.’ Social hostility involves negative social attitudes towards certain individuals, but without the individual feeling any shame about his identity or condition.

See also SUSAN SONTAG, AIDS AND ITS METAPHORS 32-33 (1988) (discussing the idea of a “social death” that may accompany diagnosis of disease); Burris, Social Risk, supra at 831-32 (“Today, the notion that diagnosis or treatment of . . . [certain] conditions can trigger social harms is widely accepted”).

The AIDS epidemic is our most recent object lesson of the interaction of medical risk and social risk. Past examples include diagnoses of cancer and syphilis. See PETER LEVISE ALLEN, THE WAGES OF SIN: SEX AND DISEASE, PAST AND PRESENT 42 (2000) (“Perhaps more than any other disease before or since, syphilis in early modern Europe provoked the kind of widespread moral panic that AIDS revived when it struck America in the 1980s.”); ALLAN M. BRANDT, NO MAGIC BULLET: A HISTORY OF VENereal DISEASE IN THE UNITED STATES SINCE 1880, at 5 (1987) (hereinafter BRANDT, NO MAGIC BULLET) (describing the stigma of sexual irresponsibility attached to venereal disease); SONTAG, supra, at 16:

In recent years some of the onus of cancer has been lifted by the emergence of a disease whose charge of stigmatization, whose capacity to create spoiled identity, is far greater. It seems that societies need to have one illness which becomes identified with evil, and attaches blame to its “victims,” but it is hard to be obsessed with more than one.

Genetic testing also brings with it a host of social risks that will need to be confronted. See Elizabeth B. Cooper, Testing for Genetic Traits: The Need for a New Legal Doctrine of Informed Consent, 58 Md. L. REV. 346, 352-53 (1999) (hereinafter Cooper, Testing for Genetic Traits) (noting that genetic testing “present[s] a host of social risks related to access to health care, stigma, psychological well-being, and potential discrimination”).

20. Burris, Social Risk, supra note 19, at 862; see also infra Part II.B.1 (discussing further the concept of social risk, including the “perception of the risk, which may or may not be tied to the actual level of threat”).

to this person, who may adopt a way of thinking or pattern of behavior in anticipation of, and to protect himself from, actual social risk—usually from community, government, or bureaucratic systems. 22

The authors of this important attempt to modernize public health law are troubled by the disproportionate impact of disease on communities traditionally disenfranchised from social, political, and economic power—communities significantly defined by class, race, and, to a certain extent, gender. 23 However, despite the innovation of this model statutory scheme, it does not go far enough to recognize and mitigate the social risk that accompanies the historic, population-based, enhanced risk of disease. Its chief failing is that it is composed of a set of neutral principles that, by definition, are not likely to attend sufficiently to the needs of the disenfranchised, particularly in the context of an epidemic or other health crisis. This failing is likely to be made manifest in two important ways. First, the targeted communities 25 may decide not to comply with a legislative or policy initiative that they perceive as carrying significant social risk, 26 thus

surveillance and other possible influences on HIV prevention behavior).

22. See Burris, Surveillance, supra note 21, at S122; infra Part II.B.1 (discussing the role of perceived social risk).

23. This does not mean that the wealthy do not fall ill. However, the illnesses of the dominant culture tend to be more often associated with overindulgence (alcohol, food, or drugs) than those of the nondominant culture, which tend to be associated with poverty and a lack of access to health care. See Scott Burris, Law as a Structural Factor in the Spread of Communicable Disease, 36 Hous. L. Rev. 1755, 1767-69 (1999) [hereinafter Burris, Law as a Structural Factor] (citing Bruce Link & Mary Jo Phelan, Social Conditions as Fundamental Causes of Disease, 1995 J. Health & Soc. Behav. 80 (1995)) (noting that structural factors including money, knowledge, power, and prestige influence the outcomes of disease); see also Gostin, Burris & Lazzarini, supra note 10, at 75-76 (noting that "social institutions and activities, human equality and economic activities [may constitute] the major health risks in a population") (citations omitted).


25. I use the term "targeted communities" to refer to the people whose lives are most directly affected by a given statute or policy initiative. Cf. Robert B. Seidman, Justifying Legislation: A Pragmatic, Institutionalist Approach to the Memorandum of Law, Legislative Theory, and Practical Reason, 29 Harv. J. on Legis. 1, 5 (1992) (describing law as having a "targeted addressee"). Part III.B.1 further defines the term "targeted community."

rendering the measure ineffective. Second, the enactment of policies that increase stigma or social hostility, in the absence of a compelling state interest, constitutes an avoidable and unacceptable harm to human dignity.

To address these and other problems in the current state of public health law, I propose a Harm Assessment Protocol that will aid legislators and policymakers as they tackle the challenge of modernizing this area of law. This Protocol will allow them to avoid—or at least mitigate—the harms that otherwise might derive from implementing a health-based statutory proposal that may be attractive to or popular with the general public, but which is not, in reality, likely to benefit the public health.

Although courts have struggled for decades to find appropriate ways to implement equal protection principles as a means of redressing harm, legislatures have not carried their burden beyond the drafting of such “equality” principles. Indeed, democratic fora, by design, are not geared to attend to the needs or perspectives of the minority. Too often, pressure on legislators dissuades them from supporting legislation that is “in the public interest”—that is, legislation which may protect the interests of the disenfranchised and serve the overall greater good, but which may not be

(1997) [hereinafter Hodge, Modern Public Health] (“[A] federal court in 1900 voided a quarantine measure to control bubonic plague among Chinese immigrants, finding that the action, which actually posed a danger to the health of the community, was passed as a guise for discrimination against the Chinese community.”) (citations omitted).

27. See infra notes 88, 149, 260 and accompanying text (describing factors, such as lack of trust, that interfere with implementation of effective public health measures).

28. See infra Part III.B.3 (noting that such harm may undermine the trust between government and the governed that is necessary to preserve the public health).

29. The Harm Assessment Protocol is introduced infra this Part, described in detail infra Part III.A, and set forth in a flow chart, infra fig.1.

30. See infra Parts I.B and I.C for a discussion of the role and authority of legislators and policymakers. This Protocol is designed to assist legislators in drafting statutes, policymakers in preparing regulations and guidelines, and public health researchers and thinkers in examining of how public health law and policy can be improved.

31. See infra Part II.C (discussing the pressures that keep legislatures from addressing these problems).

32. Our democratic model is designed to ensure that minority interests do not dominate the desires of the majority. See CASES AND MATERIALS ON LEGISLATION: STATUTES AND THE CREATION OF PUBLIC POLICY 46 (William N. Eskridge, Jr. & Philip P. Frickey eds., 2d ed. 1995) [hereinafter CASES AND MATERIALS ON LEGISLATION] (“Where [a] faction remains a minority, any form of popular government is sufficient to contain it, because its views will not command the necessary majority.”); Tracy E. Higgins, Democracy and Feminism, 110 Harv. L. Rev. 1657, 1658 (1997) (discussing the inherent tension in democracies between “a democratic commitment to respect the political will of the people and a liberal commitment to respect the rights of the individual”); cf. THE FEDERALIST No. 51 (James Madison) (describing the theory of checks and balances both among the arms of the government and within a bicameral legislature).

33. See infra Part II.C (discussing “the public interest” theory of governance).
endorsed by constituents or corporate supporters.\textsuperscript{34} Notwithstanding legislators' duties to represent the needs of their constituents, there are times when they also must consider the needs of the broader community. For example, because disease disproportionately affects the disenfranchised\textsuperscript{35} and because these groups often have less of a voice in their legislatures, legislators bear a particular responsibility to ensure that the interests of these groups are protected.\textsuperscript{36}

As difficult as it may be to define what is meant by the term "in the public interest," critical thinkers seek to expand the definition to include the voices of the disenfranchised. Most begin with the fundamental concept of autonomy, particularly the autonomy of the individual to consent to be governed—a core principle underlying much democratic theory.\textsuperscript{37} Critical theorists have shown that it is virtually impossible for disenfranchised populations to function autonomously, or perhaps more accurately, to assert complete agency.\textsuperscript{38}

This critique also has been heard in the context of bioethical scholarship, which concerns itself with the development and application of public health law and policy.\textsuperscript{39} As bioethicists direct their attention to developing policies that recognize "the moral significance of groups," they assert that those in power bear responsibility for valuing the "standpoint," or life expertise, of those who identify as members of subjugated groups, thereby providing a "corrective lens for the myopia of the dominant group."\textsuperscript{40} Alleged "neutral principles" therefore do not exist: they merely reflect the interests of the dominant group.

Logic, then, directs us to theories that accept the place of group identity in developing appropriate public health law and policy. Communitarianism, as tempered by critical race and critical feminist analysis, provides one option. Other options which might be more useful rely on reconceptions of

\textsuperscript{34} See infra note 96 and accompanying text (describing pressure that may be brought to bear on legislators); infra Parts II.B.3 and III.B.3 (describing the social risk caused or exacerbated by legislators' current behavior and agendas).

\textsuperscript{35} See supra notes 23-24 and accompanying text (commenting on this disproportionate effect).

\textsuperscript{36} See infra Part ILC (observing that attending to the needs of the disenfranchised does not constitute disruptive factionalism, but is instead an appropriate area of concern for legislators).

\textsuperscript{37} See infra notes 189-92 and accompanying text (discussing autonomy and agency).

\textsuperscript{38} See infra note 195 (discussing complete and partial agency).

\textsuperscript{39} See infra Part II.B.3 (discussing autonomy and agency).

\textsuperscript{40} See infra note 208 (explaining this term); see also notes 205-24 and accompanying text (same).

autonomy based on narrative ethics, pragmatism, and even empiricism.42

The Harm Assessment Protocol proposed in this Article is designed to bring the voices of the disempowered—if not literally, then at least conceptually—to the halls of the legislature and the offices of policymakers, and it relies on these cogent critiques of the primacy of autonomy. Instead of relegating social risk considerations to the end of the process, when they often are ignored or overlooked, my multi-prong analysis begins with an inquiry into such factors.43 Under this Protocol, if the proposed policy would not increase the social risk of those groups targeted by the initiative and otherwise promotes a legitimate public health goal, it should be supported, enacted, and implemented.44 If, however, implementation of the policy proposal would have a negative impact on the lives and well-being of the disenfranchised (i.e., would increase social risk), policymakers ought not to consider the proposal unless the state’s interest in implementing it is compelling, rather than merely legitimate. Moreover, the proposal must be the least restrictive alternative available to achieve the identified public health goal. If it does not satisfy these requirements, policymakers should reject the proposal and seek more acceptable means of achieving their goal.

Finally, if the proposal represents the least restrictive alternative, but the state interest is not compelling, policymakers should conduct a balancing test to assess the strength of the state interest, the ability of the proposal to achieve the identified goal, and the anticipated harm to social risk or dignity. Without accounting for such factors, lawmakers should not presumptively support such a proposal.

It is only by privileging the inquiry on behalf of the disenfranchised that lawmakers can ensure that their interests are not inappropriately overwhelmed by the actions of the majority, no matter how well-intentioned they may be. In so doing, our legislative and policy leaders can enact and enforce public health law and policy that will increase public trust and enhance the public health.

This Article begins by reviewing historical and modern approaches to disease control, emphasizing the fact that, despite growing medical breakthroughs, we continue to face profound challenges to our national health and well-being. Part I also identifies the various governmental and

42. See infra Part II.B.3 (discussing communitarianism, pragmatism, and empiricism).
43. See infra Part III.A (describing the Harm Assessment Protocol); infra Part III.A fig.1 (providing a flowchart of the Harm Assessment Protocol).
44. Clearly, if the proposal were to harm the public health, it should be disapproved. If it is neutral, it then requires a consideration of competing interests. This Article will not address the economic or partisan political issues that may influence whether a particular legislative or policy initiative is worthy of support.
45. Courts require that a challenged measure satisfy a least (or less) restrictive alternative test, a real or substantial relation test, or a narrowly tailored test when a complaining party alleges violations of fundamental rights or incidents of invidious discrimination. See infra notes 263-65 (discussing the “least restrictive alternative” doctrine).
political actors who currently are responsible for the development of public health law and policy and explores the limits of their power. This historical and structural background provides a context for the modern questions of public health law and policy addressed later in this Article.

Part II examines in greater detail the model public health statute described earlier. It then explores the role that stigma, social hostility, and social risk play in the lives of people who experience serious illness. This Part surveys pertinent critiques of the traditional principilism of bioethics—particularly the value of autonomy—and notes that “neutral rules” often are insufficient to attend to the needs of those who are disenfranchised from wealth, power, or good health. Part II concludes with a survey of the structural influences that mitigate against legislators’ and policymakers’ attending to the interests and priorities of the disenfranchised.

Building on Part II’s observations, Part III introduces the Harm Assessment Protocol as a means of evaluating public health law and policy, including existing dominant public health law, the model public health statute, and possible future proposals. To illustrate the advantages of using the Protocol within the realm of public health law, I apply it to an important legal and policy conflict that has arisen in the context of attempting to contain the spread of communicable diseases: the reporting of names of HIV-infected people to the government (“HIV name reporting”). This application of the Protocol reveals that although conducting disease surveillance may be a compelling state interest, the gathering of names does not satisfy the least restrictive alternative prong. As it is possible to gather essentially the same information by using unique identifiers that do not reveal personal identifying information, legislative and policy leaders should reject HIV name reporting as a means of conducting disease surveillance.46

Part III will further demonstrate that the Harm Assessment Protocol is an important addition to the current state of the law because it both privileges the voices of the disempowered and simultaneously remains grounded in the legitimate governmental need to prevent and treat disease. The success of the Protocol thus challenges the accepted wisdom that protecting the public health requires minimizing individual rights and liberties.47 On the contrary, this Article demonstrates that successful public health policy requires assessing the social risk factors experienced and

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46. This result is contrary to the conclusion reached by Gostin and his colleagues. See Gostin, Burris & Lazzarini, supra note 10, at 125-26 (suggesting that HIV name reporting is an appropriate public health policy); see also Chandler Burr, The AIDS Exception: Privacy Vs. Public Health, in NEW ETHICS, supra note 2, at 211 (arguing that the public health benefits of HIV name reporting outweigh privacy interests); Lawrence O. Gostin & James G. Hodge, Jr., The “Names Debate”: The Case for National HIV Reporting in the United States, 61 ALB. L. REV. 679, 742-43 (1999) [hereinafter Gostin & Hodge, The Names Debate] (asserting that HIV name reporting is justified on public health grounds).

47. See HUMAN RIGHTS, supra note 10, at 43 ("[T]he two compete; Human rights protect the rights of individuals, and public health protects the collective good.").
perceived by targeted groups. By so doing, we are able to shift the discussion away from competing rights and develop a more thoughtful evaluation of both existing and proposed public health policy. As a result, we have the potential to protect the public's health and well-being better than ever before.\(^\text{48}\)

I. HISTORICAL AND MODERN APPROACHES TO DISEASE CONTROL

A. HISTORICAL PERSPECTIVE: MIASMA, GERM THEORY, AND SOCIAL CONTROL

The precursor to the modern public health movement dates back to the mid-1700s. At that time, it was not fully understood how diseases were transmitted,\(^\text{49}\) and many people subscribed to a "miasma" theory, believing that disease spread through inhaling bad odors.\(^\text{50}\) Often, people associated such "odors" with the crowded and unsanitary conditions accompanying poverty, particularly in immigrant communities.\(^\text{51}\) Health advocates focused their disease control efforts on broad social and environmental goals,\(^\text{52}\) such as food safety laws, building codes, and social welfare programs.\(^\text{53}\) Despite

\(^{48}\) Id. (noting that "[e]volving approaches to public health... emphasize respect for individual rights, trust between public health personnel and the community, conditions of nondiscrimination, and adequate access to health care and education").

\(^{49}\) See ELIZABETH Fee, DISEASE AND DISCOVERY: A HISTORY OF THE JOHNS HOPKINS SCHOOL OF HYGIENE AND PUBLIC HEALTH, 1916-1939, at 19 (1987) (quoting William Sedgwick, a biologist and public health worker, as saying, "'[B]efore 1880 we knew nothing; after 1880 we knew it all").

\(^{50}\) See Wendy E. Parmet, FROM SLAUGHTER-HOUSE TO LOCHNER: THE RISE AND FALL OF THE CONSTITUTIONALIZATION OF PUBLIC HEALTH, 40 AM. J. LEGAL HIST. 476, 484 (1996) (noting that, in the early nineteenth century, with its increased urbanization, "filth and the resulting miasma was thought by public health authorities to cause disease").

\(^{51}\) See BRANDT, NO MAGIC BULLET, supra note 19, at 21 (citing W. Travis Gibb, CRIMINAL ASPECTS OF VENEREAL DISEASES IN CHILDREN, in TRANSACTIONS OF THE AMERICAN SOCIETY FOR SANITARY AND MORAL PROPHYLAXIS 2 (1908)) ("Much of the vice we see around us," noted Dr. Howard Kelly of Johns Hopkins, "is bred in the pestilential hot house atmosphere of dark, dirty, ill-ventilated homes, which induces abnormal cravings in ill-conditioned bodies."); GARRETT, BETRAYAL OF TRUST, supra note 11, at 289 ("[F]ilth [w]as generally seen to be associated with immigrants... [Nineteenth century] sanitarians blamed the poor for their own poverty; they labeled slum and tenement residents lazy, idle, and immoral."); SONTAG, supra note 19, at 42 ("The conviction that living in dark, dirty cities causes (or at least produces a susceptibility to) tuberculosis is a version of the miasma theory, and continued to be given credence well into this century, long after the actual cause of tuberculosis had been discovered.").

\(^{52}\) See generally Sylvia N. Tesh, MIASMA AND "SOCIAL FACTORS" IN DISEASE CAUSALITY: LESSONS FROM THE NINETEENTH CENTURY, 20 J. HEALTH POL. POL'Y & L. 1001 (1995) (noting the focus on "broad social factors" until the end of the nineteenth century).

\(^{53}\) See GARRETT, BETRAYAL OF TRUST, supra note 11, at 281-82 (commenting on measures that significantly enhanced public health, including "[s]ewer and privy construction, improved drinking water quality, quarantine policies, street cleaning, enforcement of safer food, meat and milk production standards, paved roads," and improved diets); BRANDT, NO MAGIC BULLET, supra note 19, at 156 ("City and state health departments continued to pass ordinances requiring the examination for venereal disease of domestics and food handlers, although it was well-known that infections were rarely, if ever, transmitted without intimate sexual contact.");
misconceptions about disease transmission, a dearth of effective treatment, and an often highly moralistic approach to their work, the nature and scope of the efforts of these "sanitarians" led to a reduced incidence of major communicable disease.

With the discovery of bacteria and viruses in the latter half of the nineteenth century, public health policy made a significant shift to belief in an "anti-disease" approach, which focused on the elimination of the germs that caused a particular disease. In contrast to the social reform efforts of early public health advocates, these interventions "[t]ended to be individualistic in orientation, often dismissive of social and cultural factors and heavily driven by technology and the market." While this anti-disease

Tesh, supra note 52, at 1004 ("The 1848 public health law in Britain—and similar industrializing countries—commanded government officials to undertake massive sanitary reforms: to pave streets, build sewers, provide clean water, establish ventilation and crowding standards for housing, and haul away garbage.") (citations omitted).  

54. See Garrett, Betrayal of Trust, supra note 11, at 296 (noting that "the sanitarians ... imposed a moralistic judgmentalism that openly expressed disdain for the religious, family, and cultural lives of the poor").  

55. See id. at 285 (noting the growth of "the sanitarians" in New York and elsewhere from the mid-1800s); George Rosen, A History of Public Health 187-92 (1958) (noting that the results of this approach "were impressive," despite the absence of effective medical treatment); see also id. at 98 n.148 (noting that "[t]uberculosis declined [in the early 1900s] because of broad improvements in general living and working conditions (and food purity measures"); Gostin, Burris & Lazzarini, supra note 10, at 77 n.54 (citing John Duffy, The Sanitarians 93-108 (1990)).  

56. See Garrett, Betrayal of Trust, supra note 11, at 292 (noting the publication in 1880 of Dr. Louis Pasteur's Germ Theory of Disease); Burris, Fear Itself, supra note 18, at 470 ("The late nineteenth century discovery that infectious diseases are transmitted by infectious agents such as viruses and bacteria revolutionized medicine. [This] was the basis for the development of precise diagnostic and curative techniques, changing the responses of doctors and public health officials to disease."); see also Sontag, supra note 19, at 41-42 (noting that by 1880, miasmic theory was replaced by the germ theory of contagion).  

57. See Garrett, Betrayal of Trust, supra note 11, at 282-83 (discussing the scientific discoveries of the late nineteenth century and developments in germ theory); Brandt, Behavior, Disease, and Health, supra note 2, at 55-56 ("With the focus on the organism as the cause of disease, the significance of the social environment diminished. Other critics suggested that medical science began to focus on the specific aspects of pathogenesis, losing a perspective on the 'whole' patient."); Charles E. Rosenberg, Framing Disease: Illness, Society, and History, in Framing Disease: Studies in Cultural History (Health and Medicine in American Society) xiii, xvii (Charles E. Rosenberg & Janet Golden eds., 1992):  

The germ theory created another kind of framework for imposing a more firmly based taxonomic order on elusive configurations of clinical symptoms and postmortem findings. It seemed only a matter of time before physicians would be able to understand all those mysterious ills that had puzzled their professional predecessors for millennia; the relevant pathogenic microorganisms need only be found and their physiological and biochemical effects deciphered.  

58. Gostin, Burris & Lazzarini, supra note 10, at 77 n.56 (citing Dan E. Beauchamp, The Health of the Republic: Epidemics, Medicine, and Moralism as Challenges to Democracy 55-57 (1988), and Rene Dubos, The Mirage of Health: Utopias, Progress and Biological Change (2d ed. 1987)). Germ theory "provided a rationale for public health officials to
approach had some positive effect for individuals where viable treatments were available, it also constituted a significant lost opportunity to focus on improving public health through systemic change.\textsuperscript{59}

It was not, however, until the mid-1900s, with the development and mass-production of antibiotics\textsuperscript{60}—medicine that could relatively easily and inexpensively cure those with bacterial infections—that this "anti-disease" approach reached its stride. Until that time, treatments for disease, particularly sexually transmitted disease, were often painful, of dubious positive effect, and sometimes more harmful than the disease itself.\textsuperscript{61} Indeed, prior to the advent of antibiotics, health advocates often were left in the uncomfortable position of knowing what caused the illness but being unable to help the individual affected.\textsuperscript{62}

Social reformers, largely in the role of "progressive physicians," stepped

disengage themselves from commitments to moral and social reform ...." Scott Burris, Public Health, "AIDS Exceptionalism" and the Law, 27 J. MARSHALL L. REV. 251, 256 (1994) [hereinafter Burris, AIDS Exceptionalism] (quoting PAUL STARR, THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE: THE RISE OF A SOVEREIGN PROFESSION AND THE MAKING OF A VAST INDUSTRY 189-97 (1984)); see also Brandt, Behavior, Disease, and Health, supra note 2, at 56 (explaining that while "the bacteriologic revolution...offered the possibility of disconnecting disease from...sin, moral turpitude, and idleness," there were still some illnesses, including those sexually transmitted, that continued to have "powerful moral meanings") (citation omitted).

59. See Brandt, Behavior, Disease, and Health, supra note 2 at 53, 55-56 ("With the focus on the organism as the cause of disease, the significance of the social environment was diminished. ... [M]edical science began to focus on the specific aspects of pathogenesis, losing a perspective on the 'whole' patient."); cf. GARRETT, BETRAYAL OF TRUST, supra note 11, at 293 (noting that germ theory allowed public health efforts to have an empirical basis, resulting in more substantial prevention programs).

60. See BRANDT, NO MAGIC BULLET, supra note 19, at 161 (describing the search for and use of the "magic bullet" of antibiotics to improve public health in the twentieth century).

61. See ALLEN, supra note 19, at 52-56 (describing the range of harsh, often toxic, treatments used on people with syphilis, including near-lethal doses of mercury); GARRETT, BETRAYAL OF TRUST, supra note 11, at 297 (observing that some physicians "were unintentionally killing their patients with toxic tinctures, salves, and poisons, and...were worsening public health catastrophes...through inept handling of patients"). Unfortunately, these "magic bullets" were not without their problems. See GARRETT, BETRAYAL OF TRUST, supra note 11, at 324 (noting that many of the new antibiotics "were ushered into clinical use after only a modicum of testing" and, as a result, "side effects were often severe and dosages uncertain").

Vaccines, some of which were developed even before germ theory was fully understood, grew in number and effectiveness throughout the nineteenth century. See supra note 2 (discussing the discovery of a smallpox vaccine in the late 1700s). However, with each new vaccine, political, community-based resistance also developed. GARRETT, BETRAYAL OF TRUST, supra note 11, at 298-99.

62. In 1882, Robert Koch discovered the bacteria responsible for tuberculosis. See N.J. MED. SCH. NAT'L TUBERCULOSIS CTR., BRIEF HISTORY OF TUBERCULOSIS, at http://www.umdnj.edu/~nhtweb/history.htm. It was not until 1943 that an antibiotic to treat tuberculosis was discovered. Id. The gap between discovery and antibiotic treatment for gonorrhea was similarly lengthy. See SUSAN POUER, CHICAGO'S WAR ON SYPHILIS, 1937-1940, at 2 (1995) (noting that the gonorrhea bacteria was identified in 1879); BRANDT, NO MAGIC BULLET, supra note 19, at 171 (stating that in 1949, gonorrhea was virtually eradicated with the widespread availability of antibiotic therapy).
into this gap. They approach combined elements of rudimentary disease control (e.g., quarantine) with a good dose of moral education. They sought to reduce the prevalence of sexually transmitted diseases “STDs” by “improving” the behavior of those prone to becoming ill—overwhelmingly perceived by society as the poor and immigrant classes. This shift in approach led to the further shaping and understanding of disease as “socially constructed”—affected by both biological and cultural factors—facilitating an interdependence of social movements and medical care that had not previously existed. While this approach was, on one level, pragmatic and appealing in its recognition of the interdependence of good health and favorable social conditions, it also facilitated development of a belief structure in which those who were ill, particularly with STDs, were

63. See BRANDT, NO MAGIC BULLET, supra note 19, at 8 (“Progressive physicians helped to pull together two of the most significant threads of the complex Progressive ideology: the desire for a rigorously defined moral order and a growing reliance on technical expertise. Indeed, Progressive physicians were quick to suggest the relationship of social pathology to medicine.”); see also DOROTHY PORTER, HEALTH, CIVILIZATION AND THE STATE 156 (1999) (“The ideological aim of the Progressive movement was to achieve scientific management in government through an increased role of specialist professionals in the construction and execution of public policy . . . . Health reform was an excellent target for Progressivism because sanitary improvement alleviated the conditions of poverty without restructuring society.”).

64. Brandt discusses the moral aspects of disease:

Venereal diseases offered physicians an opportunity to develop a comprehensive approach to health and disease, for here was a massive problem that clearly demanded the broadest possible view of the doctor’s task from an educational, social, and clinical perspective. In fact, venereal disease, as a social construct, provided a means of organizing and explaining many of the social dilemmas which Progressivism sought to address.

BRANDT, NO MAGIC BULLET, supra note 19, at 8-9.

65. See POIRIER, supra note 62, at 7 (“Because intimations of immorality and sexual lasciviousness were often part of particular racial or class stereotypes, ‘venereal disease’ was often associated with specific—usually socially oppressed or disadvantaged—groups of people . . . .”); cf. GARRETT, BETRAYAL OF TRUST, supra note 11, at 296 (noting that despite the improvements in public health achieved by the sanitarians, they also “imposed a moralistic judgmentalism that openly expressed disdain for the religious, family, and cultural lives of the poor” and immigrant communities).

66. See BRANDT, NO MAGIC BULLET, supra note 19, at 5 (remarking that illness and disease are associated with social “symbols and images” which “reflect social values . . . . Fundamental to this notion that disease is socially constructed is the premise that it is profoundly shaped by both biological and cultural variables”); Kenneth Keniston, Introduction to the Issue, 118(3) DAEDALUS, Spring 1989, at ix, x:

AIDS is socially constructed . . . in the sense that any disease is, be it typhoid fever, bubonic plague, chicken pox, Legionnaire’s disease, syphilis, or influenza. That is, we assign a meaning to the condition, including all that is implied by calling it a disease, in a broader framework of traditional meanings, appealing metaphors, and convincing theories.

See generally SONTAG, supra note 19 (arguing that images of illness and disease are social projections or metaphors).
castigated for having become ill and often blamed for their own illnesses.\footnote{See Poirier, supra note 62, at 17 (noting that one particular social reform group, the American Society for Sanitary and Moral Prophylaxis, preferred an educational approach, but the Society "usually chose its words deliberately to instill fear and revulsion for the diseases and the sexual profligacy with which they were usually linked"). The progressive movement also became known for its support of the nascent eugenics movement of the early part of the twentieth century. See Brandt, No Magic Bullet, supra note 19, at 19 ("Fears about the impact of venereal diseases on the future of the family led physicians to ally with the nascent eugenics movement in the first decades of the twentieth century"); Cooper, Testing for Genetic Traits, supra note 19, at 355 (describing the domestic eugenics movement of the early twentieth century, which endorsed "[r]estrictive immigration laws, forced sterilization, and prohibitions on interracial marriage") (citations omitted).
\footnote{See Poirier, supra note 62, at 20 ("By casting syphilis as a public health problem rather than a moral one, a matter of sound business economics rather than family righteousness, and an opportunity for scientific advancement rather than an outrage against social purity, Parran created a new realm for governmental action."). Parran, however, was not immune from permitting stereotyping to influence the development of policy, as was evident in his belief that syphilis manifested itself differently in Blacks than in whites. Id. at 139.
\footnote{See Brandt, No Magic Bullet, supra note 19, at 129 (noting that "[b]y the early 1930s...citizens of the United States contracted almost half a million new infections" each year); see also id. ("Among blacks, the poor, and the young, rates of venereal infection reached disproportionately high levels.").
\footnote{See Poirier, supra note 65, at 93 (noting that Parran, as part of the Chicago Syphilis Control Program, set up clinics where "free and secret" syphilis testing was provided to "Works Progress Administration employees and people on the city's relief roles, but the rest of Chicago's citizenry was also 'invited' to partake of the service").}
\footnote{See Gostin, Burris & Lazzarini, supra note 10, at 77-78: Surgeon General Thomas Parran pushed for the legal authority to deploy modern "epistemological methods" of disease control...The pathogen, not social conditions, was thought to be the problem, and through modern methods like these, the pathogen could be defeated. Health authorities sought the power to test}'
his five steps are still a part of public health efforts to control the spread of sexually transmitted disease today.\textsuperscript{72} Indeed, Parran's program was a vast improvement over the intertwining of morality and medicine, neither of which seemed to improve in their marriage.\textsuperscript{73} However, public health officials, including Parran, found it hard to abandon campaigns that preyed on shame and allegations of immorality,\textsuperscript{74} as it was far easier to blame the ill for their own poor condition than to accept societal responsibility for improving the state of the public's health.

As a result, the guidelines often were implemented in widely disparate manners. The poor and immigrant communities, wholly dependent on the state for health care—if any was provided—were the true targets of the new public health initiatives. Reporting regulations often were enacted or enforced for \textit{public} hospitals.\textsuperscript{75} The wealthy, who could afford health care

\begin{footnotesize}

suspected carriers, screen populations (such as marriage license applicants and newborns), trace partners, and require treatment.

\footnote{72. \textit{See infra} note 80 and accompanying text (providing statutory examples of Parran's impact).}

\footnote{73. \textit{See} ALLEN, \textit{supra} note 19, at 60 ("Those unfortunate Europeans who suffered from syphilis experienced the worst of disease, medicine, and religious condemnation all at once—a deadly mixture, and a dangerous model for the centuries ahead."); BRANDT, NO MAGIC BULLET, \textit{supra} note 19, at 147 (describing federal and state-based efforts that "had a substantial impact upon the problem of venereal disease in American life"); \textit{see also} BRANDT, \textit{supra}, at 141-50 (describing Parran's campaign against venereal disease).}

\footnote{74. \textit{See} BRANDT, NO MAGIC BULLET, \textit{supra} note 19, at 157 (describing the persistent view that disease, especially venereal disease, "particularly affected the working class, the immoral, and certain racial and ethnic groups"); \textit{see also id.} at 155-58 (describing Parran's failure to avoid a campaign based on fear and moralism). Parran perhaps unwittingly contributed to this problem by advocating that "syphilis ignorance" be replaced by "syphilophobia," which actually served to encourage "fear, stigma, and denial." \textit{Id.} at 155. Parran also commented on syphilis as a punishment:

Yet, as [Parran] continued to argue for open-mindedness, a qualification slipped in. "Before we are capable of teamwork," Parran continued, "all of us together—physician, public official, citizen—must learn to think of syphilis scientifically as a dangerous communicable disease, which it is; rather than morally as a punishment for sin, which it \textit{often} is not." Thus, Parran said, syphilis \textit{is}, sometimes, a punishment for sin.

POIRIER, \textit{supra} note 62, at 82.

\footnote{75. \textit{See} BRANDT, NO MAGIC BULLET, \textit{supra} note 19, at 42:

The New York City Board of Health enacted a regulation in February 1912 that obligated all public hospitals to report venereal cases under their care, and under which physicians were \textit{requested} to report by number . . . as it was assumed that the institutional cases constitute the poorer and more ignorant class, and the class most in need of supervision.

\textit{See also} Rosenberg, \textit{What Is an Epidemic? AIDS in Historical Perspective}, 118(2) DAEDELUS, Spring 1989, at 8 [hereinafter Rosenberg, \textit{What Is an Epidemic?}] (explaining that to combat New York's 1916 polio epidemic, prophylactic measures were enforced in the "dirty and densely populated immigrant slums . . . and not in the more prosperous, less crowded, and seemingly salubrious suburbs and middle-class areas that in fact produced so many of the cases"); GARRETT,
from private physicians, often were able to avoid these mandates.\textsuperscript{76} As a result, the disenfranchised communities, already subjected to greater intrusions by the state, were now increasingly blamed for the spread of disease—as it was their names and identities that were collected on state rosters.\textsuperscript{77} Despite objections from the beginning\textsuperscript{78} and ongoing doubts about the equity of its enforcement as well as its overall efficacy,\textsuperscript{79} Parran’s approach had a dramatic impact on the development of public health law and policy.\textsuperscript{80}

\textit{BETRAYAL OF TRUST, supra note 11, at 290 ("[T]he U.S.-born population often saw immigrants as little more than sources of disease and filth, readily blaming them for all epidemics and, indeed, supporting sanitarian interventions that prejudicially targeted the newly arrived poor.")}.

76. In 1912, New York passed an ordinance where “the implicit assumption was that patients who could afford to pay for treatment could be trusted not to spread their infections.” BRANDT, NO MAGIC BULLET, supra note 19, at 42; cf. Rosenberg, \textit{What Is an Epidemic?}, supra note 75, at 8 (noting how nineteenth-century quarantines were imposed on the poor but not on the wealthy).

77. \textit{See POIRIER, supra note 62, at 94-95, 141 (noting that data—such as patient’s name, age, race, gender, disease—gathered at free public clinics underrepresented Anglo-Americans and people from the wealthier classes so that the interpretations of these statistics were skewed). POIRIER also noted:}

Another problem with interpreting and reporting statistics had a direct impact on people’s lives. For example, from the start, the project differentiated tests and treatments by race; statistics for syphilis and gonorrhea for “white” and “Negro” men and women were a source of comment in the earliest reports, with the incidence of both diseases continually higher among African Americans. How these numbers were related to syphilis’s own relation to poverty was often not clearly discussed—nor was a comparison of the income levels of the two racial groups or the fact that most of the dragnet stations and city clinics were situated in poor, ethnic (largely African-American) neighborhoods.

\textit{Id. at 181.}

78. \textit{See Gostin, Burris & Lazzarini, supra note 10, at 82 n.73 (citing Daniel M. Fox, Social Policy and City Politics: Tuberculosis Reporting in New York, 1889-1900, 49 BULL. HIST. MED. 169, 178 (1975)) (noting that the reporting of names of people with tuberculosis to the New York health department, mandated in 1897, raised substantial negative reactions).}

79. Despite the intensive campaign against syphilis waged by Parran and other governmental officials in the 1930s, there were still more than 485,000 cases in 1941. \textit{See BRANDT, NO MAGIC BULLET, supra note 19, at app. While the discovery of penicillin lead to a significant drop in cases during the 1950s, the 1960s saw syphilis infection rates grow exponentially; the number of cases quadrupled between 1958 and 1975. Id. at 170-75. In the decade from 1965 to 1975, cases of gonorrhea more than tripled, rising to over one million per year. Id. at app.}

80. \textit{See, e.g., CAL. HEALTH & SAFETY CODE § 120520 (Deering 1999) (requiring the health department to conduct educational and publicity work); Fla. stat. Ann. § 384.26(1) (West 1999) (outlining the contact investigation program for those with sexually transmitted diseases); MD. CODE ANN., HEALTH-GEN. I § 18-307 (1999) (requiring the screening of all pregnant women for syphilis); N.J. STAT. ANN. § 26:4-30 (West 1999) (stating that health officers may order tests of any person suspected of having a venereal disease); N.Y. PUB. HEALTH LAW § 2303 (McKinney 1999) (requiring treatment or isolation for anyone infected with a venereal disease).}
Notwithstanding the more sanguine efforts of the modern public health movement and particularly effective advances in modern science since the mid-1900s, the country has continued to suffer through epidemics such as polio, syphilis and gonorrhea, AIDS, and hepatitis. Thus far, our approaches to combating public health crises have not been sufficiently effective. Before considering improvements to the public health system, however, one must understand the players within the system, their tools, and the limits on their authority.

B. MODERN THEORY AND PRACTICE OF DISEASE CONTROL

1. Who Is Responsible for Creating Public Health Policy Today?

Public health matters generally are legislated by the separate state governments rather than the federal government. Within each state, the legislature sets the overall limits on the reach of its state (or local) department of health. Despite these limits, the respective departments exercise a significant degree of autonomy in setting public health policy.


82. The ancient diseases of syphilis and gonorrhea continue to plague us, despite effective cures. See supra notes 2, 69, 79 and accompanying text (discussing the occurrence of new infections, despite the availability of treatments and cures). It is noteworthy that the CDC's most recent efforts to obtain congressional funding to try to eliminate syphilis were denied. Malcolm Gladwell, The Talk of the Town: Cheap and Easy, NEW YORKER, July 10, 2000, at 21; see CDC, TRACKING THE HIDDEN EPIDEMICS: TRENDS IN STDs IN THE UNITED STATES 2000, available at http://www.cdc.gov/nchstp/dstd/Stats_Trends/Trends2000.pdf (noting that between 1997 and 1999, gonorrhea rates increased by nine percent). Although syphilis rates around the country have experienced a decline, id., they have continued to rise in New York City. Garrett, BETRAYAL OF TRUST, supra note 11, at 476 (citing data from 1998 and 1999).

83. See supra notes 1, 4 and accompanying text (providing statistics on the effects of these and other diseases).

84. See Bowser & Gostin, supra note 12, at 1235 (noting the state governments' "near plenary authority to act for the health, safety and welfare of society"); Burris, Fear Itself, supra note 18, at 479 ("States have the authority to exercise their policy power to protect public health. The law upon which this authority rests has been well settled for decades."); Hodge, Modern Public Health, supra note 26, at 100-02 (describing the states' powers of public health regulation as "the broadest and least limiting source of authority and support for government action in the United States") (footnote omitted). Although there have been varying degrees of federal influence, public health regulations traditionally have been "considered legislative questions for local and state health authorities." James G. Hodge, Jr., The Role of New Federalism and Public Health Law, 12 J.L. & HEALTH 309, 326 (1998) [hereinafter Hodge, New Federalism]; see also Seidman, supra note 25, at 2 (describing legislation as the "principal legal device by which the organized political community attempts to resolve pervasive social problems").

85. See Josephine Gittler, Controlling Resurgent Tuberculosis: Public Health Agencies, Public Policy, and Law, 19 J. HEALTH POL. POL'y & L. 107, 108 (1994) (noting that "it is customary for [state governments] to delegate [their broad public health regulatory powers] to local
These factors lead to considerable inconsistency in health policy from state to state.85

Each state health department has both “actual jurisdiction,” which allows it to regulate behavior directly, and “persuasive jurisdiction,” where the department derives power from developing goodwill from work done in concert with other agencies, policymakers, and the public.87 The greater degree to which a department of health has developed a trusting relationship with the general public and with policymakers, the more likely it is to be successful in implementing effective public health strategies.83 The agency “must be willing to embrace and excel in the political process,” yet

governments”) (citation omitted); Gostin, Burris & Lazzarini, supra note 10, at 104-05 ("[G]rants of power to health officials and local governments tended to be made in broad terms."); Edward L. Rubin, Law and Legislation in the Administrative State, 89 COLUM. L. REV. 369, 369 (1989) (observing the degree to which we live in an “administrative state” in which legislative policies are implemented by “large administrative agencies”); see also CAL. HEALTH & SAFETY CODE § 120145 (Deering 1999) (“The [health] department may quarantine, isolate, inspect, and disinfect persons, animals, houses, rooms, other property, places, cites, or localities, whenever in its judgment the action is necessary to protect or preserve the public health.”); N.J. STAT. ANN. § 26:4-2 (West 1999) (delegating power to the state department of health and local boards of health to define communicable diseases, declare epidemics, require reporting of diseases, isolate and quarantine “wherever deemed necessary,” remove any infected person to a suitable place, disinfect premises, and remove and destroy articles “when in its opinion the safety of the public health requires it”).

86. See Fidler et al., supra note 3, at 781 (“No two states have a similar list of reportable conditions, and reporting is not required in all states for many of the nationally reportable diseases.”); Hodge, New Federalism, supra note 84, at 356-57 (suggesting that states might be encouraged “to enact uniform legislation at their own level” by the implementation of national incentives, such as funding and the sharing of expertise).

87. Gostin, Burris & Lazzarini, supra note 10, at 91 ("[E]very health agency faces the challenge of using its expertise and persuasive power to encourage and facilitate others to take actions that are consistent with the goals of public health."); see David P. Fidler, Return of the Fourth Horseman: Emerging Infectious Diseases and International Law, 81 MINN. L. REV. 771, 849 (1997) [hereinafter Fidler, Emerging Infectious Diseases] (noting that the issue “of whether public health authorities should coerce through law or persuade through education arises at every level of public health policy: local, national, and international”) (footnote omitted).

88. See Gostin, Burris & Lazzarini, supra note 10, at 94-95 ("[C]ompliance without enforcement is essential to public health. One of the most important determinants of voluntary compliance is the credibility of the health department." (quoting Robert A. Kagan & Jerome H. Skolnick, Banning Smoking: Compliance Without Enforcement, in SMOKING POLICY: LAW, POLITICS, AND CULTURE 69, 76-87 (Robert L. Rabin & Stephen D. Sugarman eds., 1993))); Note, Name Brands: The Effects of Intrusive HIV Legislation on High-Risk Demographic Groups, 113 HARV. L. REV. 2098, 2106-08 (2000) [hereinafter Name Brands] (discussing the distrust of public health officials “among populations now most affected by AIDS and HIV,” resulting from “the very real specter of past medical abuse,” as a significant deterrent to the effectiveness of any regulation); see also CDC, Public Opinion About Public Health—United States, 1999, 49(12) MMWR 258-59 (noting that “[s]ocietal support is critical for public health efforts”).

89. Gostin, Burris & Lazzarini, supra note 10, at 94. The authors note that it is “precisely that political involvement [which] risks weakening the impression of professional neutrality and expertise from which public health officials draw much of their political power. This is to some extent a Gordian knot that, like the original, can only be untied by inspired action.” Id.
at the same time must guard against losing its legitimacy as a moral agent.\textsuperscript{90}

2. What Are the Limits on the Power of Public Health Officials?

The broad outlines of the limits of public health law and the executing authorities are fairly straightforward. The state has the authority to limit individual liberty in the face of a public health emergency so long as its interest in doing so is compelling and it uses the least restrictive means available.\textsuperscript{91} An example of a commonly accepted exercise of this power would be the state’s use of quarantine to contain a life-threatening airborne epidemic (e.g., infectious tuberculosis).\textsuperscript{92} Similarly, courts have upheld state-mandated vaccinations of school-age children, because it is only when virtually all children are immunized that we have a chance of eradicating diseases such as measles and rubella, as we have seen with smallpox.\textsuperscript{93}

\textsuperscript{90} A department of health, as moral agent, must walk a fine line between encouraging behavior that improves the public health (e.g., not smoking, wearing seatbelts, engaging in safe sex) and functioning as a voice of moral condemnation, which may undermine its efforts. \textit{Compare supra} Part IA (discussing historic, and largely moralistic, attempts to improve public health), \textit{with infra} Part IB.3.a (discussing more modern attempts to facilitate behavior modification and thereby improve public health). \textit{See also} Gostin, Burris & Lazzarini, \textit{supra} note 10, at 94 (noting that “public health authorities must find ways of meeting objections concerning legitimacy”); Thaddeus Mason Pope, \textit{Balancing Public Health Against Individual Liberty: The Ethics of Smoking Regulations}, 61 U. Pitt. L. Rev. 419, 444 (2000) (arguing that the legitimacy of a campaign focused on the indirect social costs of smoking is belied by a positive “net economic impact” and masks a paternalistic imposition of moral values).

\textsuperscript{91} The leading case of \textit{Gibbons v. Ogden}, 22 U.S. (9 Wheat.) 1, 203 (1824), held that each state’s powers “form a portion of that immense mass of legislation, which embraces everything within the territory of the state, not surrendered to the general government . . . Inspection laws, quarantine laws, health laws of every description . . . are component parts of this mass.” In \textit{Jacobson v. Massachusetts}, 197 U.S. 11 (1905), the Supreme Court addressed the scope of the states’ powers in the case of involuntary vaccination. The Court stated: “Upon the principle of self-defense, of paramount necessity, a community has the right to protect itself against an epidemic of disease which threatens the safety of its members.” \textit{Id.} at 27. The public health regulation, however, must have a “real or substantial relation to the protection of the public health and the public safety.” \textit{Id.} at 31. This is widely regarded as a “forceful statement by the Court of the constitutional limits of the exercise of police powers in the interests of public health.” Hodge, \textit{Neo Federalism, supra} note 84, at 328. Hodge further notes that “[t]he authority of states . . . does not extend to worthless, blanket provisions restricting personal freedoms in the name of public health.” \textit{Id.}

\textsuperscript{92} \textit{See} In re Halko, 246 Cal. App. 2d 553, 558 (1966) (holding that consecutive quarantine orders were not an unjust deprivation of liberty as long as the person quarantined was still infected with active tuberculosis). However,

[b]ecause casual contact cannot spread [HIV/AIDS], infected individuals present no health hazard to anyone with whom they do not have sexual relations, exchange blood or other body fluids, or share intravenous needles. A quarantine of [people with HIV/AIDS], unlike a smallpox quarantine, would be similar to isolating people merely because they are ill, which is plainly unconstitutional.


\textsuperscript{93} \textit{See} CDC, \textit{Vaccinia (Smallpox) Vaccine Recommendations of the Immunization Practices
Achieving this compelling public health goal places only a minimal burden on schoolchildren and their families.94

Choices in the development of public health policy, however, are rarely so clear. There are difficulties inherent in both protecting the well-being of those who are healthy and safeguarding the rights of those who are ill and often stigmatized. This tension arises in numerous contexts. For example: Is it appropriate for the government to collect the names of people who have sexually transmitted diseases? Should they be permitted—or required—to contact the sexual partners of those so diagnosed? Should health care providers be required to offer—or should pregnant women be required to undergo—tests for syphilis, hepatitis, or HIV/AIDS? The options, of course, are infinite.

To complicate matters further, public health decisions rarely are made in a vacuum. Both legislators and policymakers face substantial pressure from their constituents when a community is, or perceives itself to be, faced with the threat of a health crisis.95 While it may be easy to enact laws and institute policies that appease the commonweal, public opinion—generally formed in direct response to a crisis—is not always the best guide to developing effective public health measures. Indeed, such measures may do little to protect the public health and may, in fact, ultimately cause harm.95

Advisory Committee (ACIP), 40(RR14) MMWR 1 (1991) [hereinafter Vaccinia] (“Vaccinia (smallpox) vaccine is a highly effective immunizing agent that brought about the global eradication of smallpox.”); CDC, WHAT WOULD HAPPEN IF WE STOPPED VACCINATIONS?, available at http://www.cdc.gov/nip/publications/Bgen/WhatIfStop.htm (last modified March 28, 2000) (noting the significant effectiveness of measles and rubella vaccines in helping to stem the spread of these diseases). By 1971, routine vaccination against smallpox was discontinued. Vaccinia, supra. “The last naturally occurring case of smallpox occurred in Somalia in 1977.” Id. In 1980, “the World Health Assembly certified that the world was free of naturally occurring smallpox.” Id.

94. See Jacobson, 197 U.S. at 29 (“[I]t was the duty of the constituted authorities primarily to keep in view the welfare, comfort and safety of the many, and not permit the interests of the many to be subordinated to the wishes or convenience of the few.”).

95. See Burris, AIDS Exceptionalism, supra note 58, at 257 (“As a general matter, public health controversies have little to do with the technical attributes of the measure at issue, but rather turn on more complex questions of culture, class, and power.”); see also infra Part II.C (discussing the role of the legislature in fostering and maintaining public health).

96. See Gostin, Burris & Lazzarini, supra note 10, at 89 (“While Americans are, as a group, quite as ready as public health officials to worry about threats to health, public health officials and the public rarely worry about the same ones in the same way.”). An example of a misguided policy was the decision of the Illinois legislature to test all people for HIV prior to issuing a marriage license; in the ensuing year over 40,000 people crossed state borders to get married. Elizabeth B. Cooper, Why Mandatory HIV Testing of Pregnant Women and Newborns Must Fail: A Legal, Historical, and Public Policy Analysis, 3 CARDOZO WOMEN'S L. J. 13, 21 (1996) (citing Robert Estad, AIDS Test Has 40,000 Fencing State to Wed, CHI. TRIB., Jan. 4, 1989, at Cl). Citing lost revenues and a fear of “alienating a lot of Illinoisians from the laws of this state,” the Illinois legislature repealed the act twenty-one months after passing it. Daniel Engler & Rick Pearson, Premarital AIDS Test Law Repealed, CHI. TRIB., Sept. 12, 1989, at Cl; see Hodge, New Federalists, supra note 84, at 329-30 (noting the existence of “public health actions which purported to
The following section explores in greater detail the tools—and conceptual frameworks—available to legislators and public health officials in their efforts to control disease and improve the public health.


The three essential tools that health departments rely on—prevention, treatment, and surveillance—roughly correspond to the three current models of understanding disease and health: the behavioral model, the microbial model, and the ecological model. Public health is best protected when each of these approaches is relied upon in appropriate proportion.

a. Prevention

The primacy of prevention is rooted in the behavioral model, which examines the ways in which our lifestyles expose us to pathogens or otherwise tend to cause illness or death. At the core of this model is the

protect the public, but in reality involved some arbitrary interference with private business or imposed unusual and unnecessary restrictions upon lawful activities’); cf: Burris, Social Risk, supra note 19, at 891:

Existing legal protection does not address all important social risks, and even those people whose interests are protected in theory may not wish to rely on law in practice. As a person becomes poorer and more socially marginalized, the law becomes less likely to protect key economic interests, and more likely to itself be a source of social risk.

97. See Gostin, Burris & Lazzarini, supra note 10, at 79 (“The main job of health agencies is to directly promote good health and prevent illness.”); MD. CODE ANN., HEALTH-GEN. I § 18-102(a) (2000) (“The Secretary shall adopt rules and regulations necessary to prevent: (1) The introduction of an infectious or contagious disease into this State; or (2) The spread of an infectious or contagious disease in this State.”); TEX. HEALTH & SAFETY CODE ANN. § 81.021 (Vernon 1999) (“The board shall exercise its power in matters relating to protecting the public health to prevent the introduction of disease into the state.”); cf. COMM. FOR THE STUDY OF THE FUTURE OF PUB. HEALTH, INST. OF MED., THE FUTURE OF PUBLIC HEALTH 7-8 (1988) (defining the “core functions of public health agencies” as “assessment, policy development, and assurance,” which broadly correspond to surveillance, development of regulations and programs, and implementation thereof).

98. See MD. CODE ANN., HEALTH-GEN. I § 18-103(a) (2000) (“The Secretary shall: (1) Obtain accurate and complete reports on communicable diseases in this State; (2) Determine the prevalence of each communicable disease; and (3) Devise means to control communicable diseases.”); TEX. HEALTH & SAFETY CODE ANN. § 81.047 (Vernon 1999) (“[T]he department shall require epidemiological reports of disease outbreaks and of individual cases of disease suspected or known to be of importance to the public health. The department shall evaluate the reports to determine the trends involved and the nature and magnitude of the hazards.”).

99. See Gostin, Burris & Lazzarini, supra note 10, at 64, 69-77 (describing the models).

100. Id. at 64; see also Brandt, Behavior, Disease, and Health, supra note 2, at 63:

By the early 1970s, an emerging critique of modern biomedicine and medical technology centered attention on the question of responsibility for disease and its prevention . . . . Individuals could no longer rely on public health interventions, the activities of the medical profession, or the health-care delivery system to solve
LESSONS FROM THE PLAGUE YEARS

understanding that every step each person takes to prevent individual illness or disease is a step that works to improve the public health overall. Public education campaigns to urge changes in behavior (to cease smoking, wear motorcycle helmets, or use condoms) are among the most familiar prevention tools. Other prevention tools require a deeper role of government in our lives, ranging from universal vaccination programs (to prevent measles or rubella) to temporary quarantine (to stem the spread of measles or tuberculosis). As expected, the validity of each prevention tool is highly dependent on context.

Crafting effective prevention strategies can be very difficult. Despite the broad range of available prevention tools, politics or public sensibilities may affect the degree to which public health officials are willing to be explicit about disease prevention, particularly concerning sexually transmitted conditions. Moreover, the complexity of the human psyche often renders it impervious to pragmatic suggestions about disease or accident prevention. Therefore, development of effective prevention measures is an extraordinarily challenging aspect of preserving the public health.

the problems of disease. Rather, the mantle of responsibility in the quest for health would now be carried on the shoulders of individuals.

101. See Dan E. Beauchamp, Public Health as Social Justice, in NEW ETHICS, supra note 2, at 106:

Like the other principles of public health, prevention is a logical consequence of the ethical goal of minimizing the numbers of persons suffering death and disability. The only known way to minimize these adverse events is to prevent the occurrence of damaging exchanges or exposures in the first place, or to seek to minimize damage when exposure cannot be controlled.

102. See supra note 91 and accompanying text (discussing the state's ability to limit individual liberty under certain circumstances).

103. See BRANDT, NO MAGIC BULLET, supra note 19, at 193 (noting that President Ronald Reagan did not speak the word “AIDS” until 1985, following the death of Rock Hudson, four years after the epidemic was first identified); see also Gay Men's Health Crisis v. Sullivan, 733 F. Supp. 619, 637 (S.D.N.Y. 1989) (striking down government restrictions on the use of sexually explicit AIDS education materials).

104. Public resistance to the behavioral model is expressed in two ways: (1) rejection of “an official endorsement of what they regard as deviant behavior” (e.g., harm reduction efforts concerning safer sex education and drug use) or (2) rebellion against “unacceptable paternalism” (e.g., requiring use of motorcycle helmets). Gostin, Burris & Lazzarini, supra note 10, at 64. Despite the increase in awareness of how HIV/AIDS is transmitted and the wide availability of condoms in the United States, thousands of people become infected each year. See GARRETT, BETRAYAL OF TRUST, supra note 11, at 477 (describing a study of gay men who admitted to having unsafe sex, and reporting that interviewees said that “[t]hey knew everything that the CDC and groups like GMHC . . . had to say about HIV yet they rejected the prevention campaigns, calling public health officials and prominent gay leaders ‘safer sex police’ and ‘condom police’”); GABRIEL ROTELLO, SEXUAL ECOLOGY: AIDS AND THE DESTINY OF GAY MEN 118-29 (1997) (describing various studies during the early 1990s reporting high levels of unsafe sex among gay men despite initial adoption of safer sex practices).
b. Treatment

Since the discovery of pathogens and the tools to treat them, the "microbial model" has played a crucial role in enhancing public health. This model values the production of mechanisms to kill microbes either before or after they infect human beings. We commonly think of antimicrobial treatment as something as simple as completing a round of antibiotics or being given a vaccine. In fact, it has multiple, contextually-determined definitions.

Treatment for some diseases, such as syphilis, can mean a relatively short-term course of medication with few side effects that results in both a cure and an inability to transmit the disease to others. However, treatment for other diseases, such as tuberculosis, can involve both enforced quarantine for a discrete time period and a prolonged regimen of numerous medications with significant side effects. While these treatments may heal the patient and render him noninfectious, they do not necessarily prevent a relapse. With HIV/AIDS, treatments may keep the disease in abeyance and reduce symptomatology, but they are noncurative and often involve serious, even life-threatening side effects. Moreover, anti-HIV treatments have not been found to render a person incapable of transmitting the virus.

105. See Fidler, Emerging Infectious Diseases, supra note 87, at 777 ("Once the biology and epidemiology of a disease agent are understood, public health authorities can implement treatment and control measures. Antimicrobial drugs are commonly used to kill pathogenic microbes or to prevent them from reproducing.") (footnotes omitted); Gostin, Burris & Lazzarini, supra note 10, at 64 (describing the assumptions of the microbial model).

106. See Mike Mitka, US Effort to Eliminate Syphilis Moving Forward, 283 JAMA 1555, 1555 (2000) ("Syphilis is a completely preventable disease that can be cured with one dose of penicillin.") (quoting Helene Gayle, M.D., Director, CDC National Center for HIV, STD, and TB Prevention).

107. See DIV. OF TUBERCULOSIS ELIMINATION, CDC, FREQUENTLY ASKED QUESTIONS, at http://www.cdc.gov/nchstp/tb/faqs/qa.htm (last modified Aug. 31, 1999) (stating that multiple medications must be taken for at least six months to be effective; that side effects may include loss of appetite, nausea, jaundice, fever, abdominal pain, rashes, dizziness, and blurred vision; and that the patient may no longer be contagious two to three weeks after beginning a drug regimen). After treatment is complete, it is still possible to contract TB again, especially multidrug resistant TB. Id.

108. See GARRETT, BETRAYAL OF TRUST, supra note 11, at 473 (noting the emergence of drug-resistant HIV strains that require physicians to prescribe "extraordinarily complex cocktails of ... antivirals"); DEP'T OF HEALTH & HUMAN SERV., GUIDELINES FOR USE OF ANTIRETROVIRAL AGENTS IN HIV-INFECTED ADULTS AND ADOLESCENTS, at http://www.hivatis.org/trtgdlns.html (Jan. 28, 2000) (stating that HIV is presently incurable, treatments are palliative in nature, and that the treatments' adverse effects may be fatal; treatment 'vacations' may be recommended due to intolerable side effects, unfavorable drug interaction, and during the first trimester of pregnancy; most clinicians would recommend that treatment continue indefinitely until either the patient dies or the drugs stop working).

The development of efficacious treatment—particularly in the face of life-threatening and contagious or congenital illness—can also raise troubling questions about whether and when treatment should be mandated. Although there are few instances in which mandated treatment is permitted (such as directly observed therapy (“DOT”) for people with noninfectious but active tuberculosis and prophylaxis to prevent syphilis in newborns),110 it remains a part of the microbial model’s emphasis on preserving the public health. As such, it is not surprising that the risk of mandated treatment renders this model more likely “to produce political disputes about the proper scope and exercise of the state’s power to attack the pathogen by controlling the human being who carries it.”111

c. Surveillance

Surveillance—or the collection of data about disease patterns—often is identified as a chief goal of the guardians of the public health.112 Disease surveillance permits public health officials to monitor an epidemic’s scope, thereby enabling them to engage in effective prevention efforts and target appropriate resources for treatment.113 However, because surveillance permits the government to acquire such deeply personal information about its citizens, it is vitally important that there be clear links between the surveillance activity, and the corresponding prevention and treatment goals. Surveillance is a means to achieving a goal, but ought not to be the goal itself.114

111. Gostin, Burris & Lazzarini, supra note 10, at 64.
112. See Fidler, Emerging Infectious Diseases, supra note 87, at 791 (“The first crucial step in dealing with infectious diseases is identifying the pathogenic agent, which is entrusted to public health surveillance systems.”); Gostin, supra note 85, at 116 (“The foundation of efforts of public health agencies to control TB and other communicable diseases is surveillance of these diseases.”).
113. See Nancy Krieger & Sally Zierler, What Explains the Public’s Health?—A Call for Epidemiologic Theory, in New Ethics, supra note 2, at 45, 48 (noting that epidemiologists’ use of HIV surveillance data, under a social production of disease theory, allows for research that “explicitly names social policies and political priorities (for example, availability of low-income housing, employment, and affordable education) as critical cofactors in the geographic spread of AIDS in the United States”).

[S]creening is a means, not an end. It provides information, the value of which depends on the use to which it is put. In both the legal and medical arenas, proposals for screening can be sensibly evaluated only in terms of how well they accomplish some desirable public health goal.

See also Gostin, Burris & Lazzarini, Infectious, supra note 10, at 125 (identifying the authors’ criteria to justify data collection); Kevin M. Kramer, A National Epidemic, a National Conversation,
As surveillance can take many forms, choosing a means of obtaining surveillance data can be quite complicated. Indeed, because it permits the government to learn such personal information as whether individuals are afflicted with stigmatizing conditions including HIV/AIDS, syphilis, or TB, it can be among the most politically charged activities of a health department.115

Under the rubric of surveillance, the government could—and does—require laboratories or physicians to provide names and other identifying information to their respective state health departments when people test positive for certain conditions. Many states employ this policy to monitor the scope of syphilis, gonorrhea, and HIV.116 Government officials also may collect this data using other means. For example, they could require health care providers to report all cases to the health department, but allow them to use unique identifiers instead of names or other compromising identifiers. Other means of generating surveillance data, though less comprehensive, include requiring anonymous serologic tests at various locations (such as hospitals, emergency rooms, or STD clinics)117 or requesting that physicians voluntarily report their patients’ positive test results to the department.

Surveillance has the potential of being closely aligned with the ecological model of improving public health. This model recognizes that the distribution and experience of disease is dramatically affected by “the way

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115. See, e.g., MD. CODE ANN., HEALTH-GEN. 1 § 18-201 (Michie 2000) (requiring reports including the names of all persons with infectious or contagious diseases that endanger the public health, except asymptomatic HIV, which is reported using a unique patient identification number instead of the patient’s name); MICH. COMP. LAWS ANN. § 333.5114 (West 1999) (requiring the reporting of HIV positive test results, including the patient’s name, unless the patient requests anonymity); N.J. STAT. ANN. § 26:4-38, -40 (West 1999) (requiring the reporting of all cases of venereal disease to include the name of the patient); TEX. HEALTH & SAFETY CODE ANN. §§ 81.041(e), 81.044(b)(1) (Vernon 1999) (requiring the reporting of AIDS and mandating that AIDS reports include the name of the patient). Carried to the extreme, the government could require the general population to submit to disease screening at regular intervals, with the results reported to the department of health. Under existing conditions, this would, of course, be legally suspect. It also would be a tremendous waste of taxpayer money. Cf. Ronald Bayer et al., HIV Antibody Screening: An Ethical Framework for Evaluating Proposed Programs, 256 JAMA 1768, 1768 (1986) (“Even were [mass HIV antibody] screening feasible, it would require an extraordinary and repeated intrusion into the privacy of all Americans, with little probable benefit.”).

116. See supra note 115 (providing examples of state statutes).

117. See Bayer et al., supra note 115, at 1769-74 (describing possible approaches to screening and testing for HIV); Penelope Ploughman, Public Policy Versus Private Rights: The Medical, Social, Ethical, and Legal Implications of the Testing of Newborns for HIV, AIDS & PUB. POL’Y J., Winter 1995/1996, at 182, 188-89 (discussing the pros and cons of testing newborns for HIV).
society organizes itself, produces and distributes wealth, and interacts with
the natural environment.118 Moreover, it recognizes a “collective
responsibility” for improving unhealthy behavior and therefore inevitably
serves as a means of critiquing the status quo.119 The lessons available
through such data analysis can guide us toward developing more systemic
approaches to understanding and improving public health.

Along these lines, epidemiologists Bruce Link and Mary Jo Phelan have
concluded that “fundamental causes of disease [should be] defined
‘broadly to include money, knowledge, power, prestige and the kinds of
interpersonal resources embodied in the concepts of social support and
social network.’”120 Employing this model allows one to see

that risk factors, and diseases themselves, are actually intermediate
factors in illness—pathways through which deeper social causes
operate to have their effect, and explains the durability of social
factors in health outcomes. When one intermediate factor, such as
poor sanitation, is eliminated, another, such as drug use, take[s] its
place.121

Therefore, current epidemiological thinking about disease causation
asserts that, while it is appealing to think one can improve public health by
attempting to control microbes through treatment tools such as vaccinations
or cures, and to seek to change human behavior through prevention tools
such as encouraging use of clean needles or condoms, our efforts are
doomed to be frustrated unless we look at—and try to do something
about—the systemic factors that are the primary influences on “multiple
disease outcomes.”122 By ferreting out patterns of disease and population-
based ill health (such as pockets of HIV/AIDS, asthma, or lead paint
exposure), surveillance has the potential to energize efforts to make some of
the systemic changes called for under the ecological model.123 It is

118. Gostin, Burris & Lazzarini, supra note 10, at 64.
119. Id. Not surprisingly, the public most often resists the ecological model’s method of
“pointing to such fundamental social causes of disease as poverty, racism, and severe income
inequality.” Id.; see also Jonathan Mann, Medicine and Public Health, Ethics and Human Rights, in
NEW ETHICS, supra note 2, at 83 (explaining the public’s resistance). Mann posits the limited
focus of public health education to result from a denial of “societal factors whose dominant role
in determining levels of preventable disease, disability, and premature death is beyond dispute.”
Id. at 86.
120. Burris, Law as a Structural Factor, supra note 23, at 1767-68 (citing Link & Phelan, supra
note 22, at 80, 81-83, 85-87).
121. Id. at 1768.
122. Id.
123. See id. at 1766 ("There is a growing recognition throughout the disciplines of public
health that the 'structural,' 'environmental,' and 'fundamental social' causes of disease have
a pervasive impact on disease and must be more effectively identified and addressed if substantial
improvements are going to be made in public health.") (citations omitted); David P. Fidler,
INTERNATIONAL LAW AND GLOBAL PUBLIC HEALTH, 48 U. KAN. L. REV. 1, 47-48 (1999) (reaching a similar
unfortunate that this too rarely occurs.

The next part of this Article begins by examining a model statutory proposal that seeks to incorporate all three tools of preserving and improving public health—prevention, treatment, and surveillance—in a more thoughtful and comprehensive fashion than public health law currently reflects.

II. PROBLEMS WITH MODERN PUBLIC HEALTH LAW AND POLICY

A. A REVIEW OF COMMUNICABLE DISEASE LAW

Lawrence O. Gostin, Scott Burris, and Zita Lazzarini explore in detail the ways in which current communicable disease law fails to achieve essential public health goals. They observe that, among other flaws, public health statutes from state to state are terribly inconsistent. The "one-size-fits-all" approach to disease control and prevention found in many states' code books often is simultaneously too aggressive and ridiculously meek, and therefore unable to protect and improve the public health effectively.

To rectify these and other problems, these authors suggest that public health statutes:

- be based on provisions that apply equally to all communicable diseases;
- embrace the reality that most interventions depend on voluntary compliance by the public;
- provide health officials with the authority to use coercive public health powers when there is a demonstrated threat of significant risk to others... includ[ing] due process protections;
- offer health officials a range of measures including a graded conclusion on the international level and describing "education, housing, and employment" as "basic social determinants of human health"). Fidler concludes that "the right to health depends on the fulfillment of other economic, social, and cultural rights (for example the right to education, right to housing, right to work)." Id.

124. See Gostin, Burris & Lazzarini, supra note 10, at 102 ("[T]he [state] health codes in their entirety have evolved independently, leading to profound variation in the structure, substance, and procedures for detecting, controlling, and preventing communicable diseases.").

125. See generally id. at 101-18 (surveying state public health codes across the nation). "State health codes typically contain laws that are simply no longer relevant and fail to address new approaches to disease control." Id. at 106. They often are "arbitrary and outdated in light of current approaches to disease control and causation." Id. at 109. For example, older statutes designed to combat "venereal disease" often permit "severe restrictions on liberty, often based on vague or nonexistent criteria." Id. at 110. In the absence of appropriate statutory guidance, public health officials often tend to operate at extremes—either overusing or underusing the coercive powers available to them. Id. at 116.
series of less restrictive alternatives and require the use of the least restrictive alternative that will accomplish the public health goal; [and]

- establish strong protections for privacy and security of public health information while defining exceptions that permit disclosures necessary to protect the public.  

This approach seeks to eliminate "[s]tigmatizing, and unnecessary, distinctions between sexually transmitted and other diseases[,] . . . would add needed clarity and coherence to legal regulation, and would reduce the opportunity for politically motivated disputes about how to classify newly emergent diseases." Moreover, it incorporates the crucial notion that the finding of an actual and individualized—rather than generalized or stereotyped—"medical risk" is a prerequisite to the limitation of personal liberty. The authors import the disability discrimination principle that, absent a "direct threat," defined as "a significant risk to the health or safety of others that cannot be eliminated by reasonable accommodation," it is inappropriate to impose any limitations on a patient's liberty.  

In further deference to the presumption of liberty to which all people, including people with communicable diseases, are entitled, the model statutory scheme requires both the development of a "graded series of less restrictive alternatives" and the employment of "the least restrictive alternative that will accomplish the public health goal." The authors note that this approach "would help align communicable disease statutes with the evolving standards of both antidiscrimination law and constitutional law, by allowing only those measures that are reasonably necessary to contain a significant risk to others."  

Finally, the legislative scheme of Gostin, Burris & Lazzarini encourages the development of "strong protections for privacy and security of public

126. Id. at 119. The authors also recommend that "public health statutes define the mission of public health agencies and the scope of their activities" to include prevention and control of communicable diseases through "interventions [at] the microbial, behavioral, and ecological [levels]." Id.

127. Id. at 120.

128. Id. at 121 (citing the Americans with Disabilities Act, 42 U.S.C. § 12111(3) (1994)). This assessment of "significant risk" is based on a consideration of four factors first identified in School Board of Nassau County v. Arline, 489 U.S. 273, 288 (1989). These factors include: "(a) the nature of the risk[,] (b) the duration of the risk[,] (c) the severity of the risk[,] and (d) the probabilities the disease will be transmitted and will cause varying degrees of harm." Id. (quoting Brief of Amici Curiae American Medical Association at 19). Gostin, Burris, and Lazzarini propose a model statute that would require public health officials "to prove the existence of a health threat by clear and convincing evidence" and to provide detainees with "an immediate hearing, a showing of current infectiousness, and evidence of the need for continued detention or isolation." Gostin, Burris & Lazzarini, supra note 10, at 122-23.


130. Id.
health information with narrowly drawn exceptions for disclosure when necessary to protect the public.” 131 Under this scheme, the authors assert, “[a]cquisition of health information cannot be considered an inherent good”; rather, public health authorities should not collect personally identifiable information absent clear justification from public health authorities. 132

B. THE CRITIQUE

There are many attractive elements to this statutory scheme: it relies on essential constitutional principles of due process and individualized assessments; it strives to remove—or at least reduce—the odd stigmatizing of some diseases; and above all, it seeks to bring coherence to a system that is badly broken. 133

Unfortunately, this proposal stops short of adequately integrating concerns of “social risk” into its structure for developing public health law and policy. The heart of the problem lies in what is also the beauty of the proposal: in seeking to create a uniform system of laws, it articulates and relies upon “neutral principles” familiar from both constitutional and disability rights law. 134 As we already know from these other contexts, however, neutral principles are not enough to surmount embedded and institutionalized oppressions; indeed, they often serve to reinforce unequal assignments of power. 135 Therefore, as one might expect, the greatest problems arise when public health authorities attempt to apply this theoretical model to the lives of real people.

As noted earlier, the disenfranchised and those who have fewer resources are most likely to need public health care services. 136 Therefore, it is particularly important to assess the proposed model statutory scheme by determining its impact on those most likely to experience its effect. 137

131. Id. at 125. According to the authors, “[r]easonably justifiable criteria for data collection include: (1) preventing a significant public health risk, (2) providing a likely benefit to the subject (e.g., treatment or other services), and (3) conducting surveillance to monitor and maintain the community’s health.” Id.

132. Id. The authors identify additional privacy protections: informing subjects of the nature of data to be collected including adopting fair information practices, developing privacy and security assurances, creating established guidance concerning disclosure of data, and regular reviewing of the development and enforcement of the privacy and security measures. Id. at 125-26.

133. See supra notes 124-27 and accompanying text (providing a discussion of the proposal by Gostin, Burris, and Lazzarini).

134. See supra Part II.B.3 (discussing and critiquing the application of principles of autonomy and agency to the public health context).

135. See infra notes 204-17 and accompanying text (discussing the uses and failings of neutral principles).

136. See supra note 130 and accompanying text (arguing that fundamental causes of diseases should be defined broadly).

Fundamentally, neither traditional communicable disease law nor the proposed overhaul is complete because neither sufficiently considers the importance of social context. Therefore, the Harm Assessment Protocol focuses on the role of public health measures within the context of the communities they seek to serve.

1. Stigma, Social Hostility, and Social Risk

This section begins with an exploration of the role that stigma, social hostility, and social risk play in the lives of people who experience serious illness. Sociologist Erving Goffman and his successors have helped us to understand stigma as something beyond mere status, but rather as "a social relation between a stigmatized and a 'normal' person, based on a shared belief that some part of the stigmatized person's identity is... 'spoiled.'" The person who experiences stigma has internalized feelings of "deviance" and "shame," which may affect him as profoundly as would external threats by others. Understandably, then, people who experience stigma often are exceptionally discreet, and at times secretive, about disclosing what they perceive to be their stigmatizing condition. If their stigma cannot be

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Pragmatism, 20 Am. J.L. & Med. 395, 411 (1994) [hereinafter Wolf, Shifting Paradigms] (advocating a "rejection of theoretical elegance as the measure of good bioethics and health law, and insistence instead on evaluating what meets the needs of individuals in clinical settings is a diagnostically pragmatic move"). Wolf suggests that to have true force, theory cannot be and should not be wholly disregarded; bioethics and health law work must be linked to "the vision we ought to pursue and whether that vision is ultimately progressive." Id. at 414-15. On the interrelationship of health law and bioethics, see generally GEORGE J. ANNAS, JUDGING MEDICINE 3 (1988) and Alexander Morgan Capron & Vicki Michel, Law and Bioethics, 27 Loy. L.A. L. Rev. 25 (1993).

138. See Wolf, Shifting Paradigms, supra note 137, at 402 (discussing the failure of bioethics to consider individual characteristics such as "race, gender, or resources"). "Part of the challenge to bioethics method comes from an empirical literature provoking fundamental questions about the agreed wisdom." Id. at 403. This in turn ushers in "the rise of a new pragmatism in bioethical theory and health law development." Id. at 411 (borrowing from the title of Wolf's article).

139. Burris, Social Risk, supra note 19, at 870-71 (citing ERVING GOFFMAN, STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY (1963)).

140. Id. at 871.

141. See Barry R. Furrow, Doctors' Dirty Little Secrets: The Dark Side of Medical Privacy, 37 Washburn L.J. 283, 285 (1998) ("We are constituted of layers of group memberships, some we proudly display and some we shield from others... The protection of secrets by our silence... shields us from others' awareness of our odd traits, our deviances, behavior that may marginalize and injure us in our jobs or social spheres"); Gregory M. Herek, Illness, Stigma, and AIDS, in PSYCHOLOGICAL ASPECTS OF SERIOUS ILLNESS: CHRONIC CONDITIONS, FATAL DISEASES, AND CLINICAL CARE 107, 134 (Paul T. Costa, Jr. & Gary R. VandenBos eds., 1990) [hereinafter Herek, Illness, Stigma, and AIDS] ("[P]eople with AIDS or HIV infection may wish to hide their status from others because of a fear of straining family relationships and friendships, a wish to maintain normalcy[,]... or a desire to avoid revealing their homosexuality or use of intravenous drugs") (citations omitted).
hidden, they may make significant efforts to "manage" information about it.\textsuperscript{142}

Sources of stigma vary from community to community, but may include racial identity, gender, sexual orientation, drug use, or illness. It is important to understand that it is possible for "a stigmatized person [to] uphold the stigma relation even if she does not believe there is anything 'bad' or 'wrong' about her condition (such as deafness), as long as she still accepts that it is a deviation from a state that she accepts as normal."\textsuperscript{143}

Social hostility is closely related to stigma, but is not quite the same concept. Even if a person does not experience stigma as attendant to one or more aspects of his identity (race, gender, sexual orientation, or disease), he may be affected by the belief that external sources seek to cause him harm. This is not just paranoia, but the genuine belief—based on personal history or that of others with whom one identifies—that harm is (more or less) likely to occur based on one's social identity.\textsuperscript{144} Social hostility can include intentional, as well as nonconscious but equally painful, acts of social ostracism and discrimination.

Finally, social risk is the term that attempts to explain how individuals who experience stigma or social hostility attempt to negotiate a relatively safe place for themselves in society. As described by Scott Burris, social risk has two components: the actual threat of social risk ("attitudes and behavior that cause or threaten social harm") and the perception of social risk ("attitudes and beliefs about the threat among those who are in some way

\textsuperscript{142} See Burris, Social Risk, supra note 19, at 871 (observing that stigmatized individuals expend a great deal of effort and experience deep psychological stress as they try "to avoid rejection [and simultaneously seek] to maintain otherwise rewarding relationships"); see also Kenneth L. Karst, Myths of Identity: Individual and Group Portraits of Race and Sexual Orientation, 43 UCLA L. REV. 263, 301-02 (1995) [hereinafter Karst, Myths of Identity] (noting that multiracial individuals may choose to claim membership of one ethnic group, and that "writers on sexual orientation generally assume that even today a majority of Americans who think of themselves as gay or lesbian are 'passing,' presenting public identities that are heterosexual").

\textsuperscript{143} Burris, Social Risk, supra note 19, at 870 n.190; see Herek, Illness, Stigma, and AIDS, supra note 141, at 109 (emphasizing Goffman's theory that stigma arises in social interactions where the attribute is relevant and differs from the expected, such as an African American attending a white supremacist meeting, or conversely, a person with AIDS who normally experiences stigma in numerous settings escaping it in an AIDS support group).

\textsuperscript{144} See Karst, Myths of Identity, supra note 142, at 328:

To validate an individual's claim to equal citizenship a judge need not inquire into the validity of the person's racial or ethnic self-identification ... . It is enough to know that the official actor discriminated against the individual 'on account of' his racial identity—on the basis of his supposed membership in a racial group.

\textit{Id.} Admittedly, it is difficult to conceive of an individual who could rationally assess social hostility without internalizing it as stigma. For example, it would be an accurate perception of social hostility for a gay man or lesbian to believe that certain legislators would like to enact antigay legislation; even a person comfortable with her sexual identity would have difficulty not internalizing such expressions of social hostility over time.
tied to the trait or disease”). In many contexts, the latter is as determinative as the former.

Burris identifies the following four aspects of social risk:

- Social Vulnerability—the degree to which one’s social or economic capital is thought to be, or is, at risk;
- Psychological Vulnerability—the internalization of stigma and the ways in which it influences social interactions;
- Perceptions of Social Hostility—the extent to which one mistrusts the social, governmental, or bureaucratic systems upon which one generally must rely; and
- Perceived Probability of Harm—the factors that contribute to one’s assessment that harm is likely to occur, including optimism, pessimism, and the human tendency to expect that a risk may occur “if it is easy to imagine or recall.”

Burris further notes that is quite difficult to manage both perceived and actual social risk:

145. Burris, Social Risk, supra note 19, at 862.
146. See Burris, Surveillance, supra note 21, at 8122 (noting that human behavior is as likely to be governed by perceived threats as by actual threats); Larry G. Martin, Stigma: A Social Learning Perspective, in THE DILEMMA OF DIFFERENCE: A MULTIDISCIPLINARY VIEW OF SIGMA 145, 149-50 (Stephen G. Ainlay et al. eds., 1986) [hereinafter THE DILEMMA OF DIFFERENCE] (observing that social learning “predicates how stigmatized persons come to expect certain modes of treatment from others . . .,” affecting self conception); see also Lerita M. Coleman, Stigma: An Enigma Demystified, in THE DILEMMA OF DIFFERENCE, supra, at 211, 224 (“The most pernicious consequence of bearing a stigma is that stigmatized people may develop the same perceptual problems that nonstigmatized people have.”).
147. Burris, Social Risk, supra note 19, at 863; see infra notes 151, 153 and accompanying text (defining the term “capital”). Within the context of HIV, for example, Burris recognizes several subparts of social vulnerability, including threats of loss of confidentiality, threats to employment and health insurance, threats to other forms of economic support, fear of discrimination in housing and services, threats of violence, threats of adverse legal action, and threats to social status. Burris, Social Risk, supra note 19, at 854-70.
148. Burris, Social Risk, supra note 19, at 870-74; see also Jennifer Crocker & Neil Lusby, Stigma and the Dynamics of Social Cognition, in THE DILEMMA OF DIFFERENCE, supra note 146, at 95, 97-98 (noting that recent research has explored the ways stigmatized persons’ expectations about likely beliefs and reactions of nonstigmatized persons can affect social interaction); supra notes 139-43 and accompanying text (discussing the role and sources of stigma).
149. Burris, Social Risk, supra note 19, at 874-76; see also Herek, Illness, Stigma, and AIDS, supra note 141, at 116 (“[C]ommunities ‘at risk’ may not trust or believe medical experts and government officials . . . [and] may have different priorities for which problems must be solved.”).
To perceive a social risk is to experience one's interdependence on others—their actions and beliefs—as well as the degree to which one's own beliefs and expectations embody the norms and attitudes one's socialization has taught. It also entails an experience of one's independence from these forces, which may take the form of shamelessness, cunning or persuasiveness, or lie in more tangible assets such as wealth, professional skills, or fame. It entails, that is, an ongoing assessment of one's ability to manage social risks as one perceives them to one's advantage.151

One must negotiate social risk in the myriad settings in which one must operate—including family, work, and social networks—and in each of these settings the rules of the game may be different.152 Perhaps self-evidently, not everyone is equally able either to avoid or manage social risk. One's success depends highly on the depth and range of social skills or the available capital one possesses.153 Logically, then, those with the fewest resources are the least likely to be able to manage either actual or perceived social risk.154 This relationship between management of social risk and the availability of resources often facilitates a downward spiral as those with fewer resources continue to lose their footing, while those with greater resources may be able to negotiate a (relatively) safe or comfortable...

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152. Gaylene Becker & Regina Arnold, Stigma as a Social and Cultural Construct, in The Dilemma of Difference, supra note 146, at 59, 49-51 (discussing methods that stigmatized individuals may use to attempt to reduce their variance from cultural norms, thus making the stigma less salient); Herek, Illness, Stigma, and AIDS, supra note 141, at 132 (reviewing strategies that stigmatized individuals use to safeguard self-esteem in different situations).

153. Burris, Social Risk, supra note 19, at 856-60. Burris describes Bourdieu's concept of "habitus" as:

more than a received sense of the rules of the game, for the concept also encompasses the social skills that such an innate sense of the game provides. The habitus ... implies the individual's capacity for structured improvisation, the ability to deploy social competence to win the spoils of the social game.

Id. at 858. "Capital" is not only wealth, but also "anything socially recognized as a tradable asset in a field" (e.g., education). Id. at 859-60. As one would expect, having access to capital helps.

[Wealth as capital allows one to rig the social game—to buy better tools, practice more, purchase allies, and so on. Many forms of capital in our society also have the convenient capacity to legitimize themselves, so that they at once confer social status and justify that status by their existence.

Id. at 860.

154. See infra Part II.B.3 (discussing the correlation between increased susceptibility to social risk and a diminished capacity to exercise autonomy, or agency).
place in society.\textsuperscript{155}

2. Practical Ramifications of Stigma, Social Hostility, and Social Risk

What relevance do these concepts of stigma, social hostility, and social risk have to the development of public health law and policy? As it turns out, a great deal. As noted earlier, disease tends to aggregate in those communities with less access to wealth, power, or other resources.\textsuperscript{155} Traditionally, these communities have included poor people, people of color, and women.\textsuperscript{157} Just as gender, race, class, and sexual orientation have been recognized as markers for disenfranchisement and discrimination,\textsuperscript{123} people with disease also have experienced outright discrimination, stigma, and social hostility when trying to obtain access to jobs and services that

\begin{itemize}
  \item \textsuperscript{155} See Marcia Bayne-Smith, \textit{Health and Women of Color: A Contextual Overview, in RACE, GENDER, AND HEALTH 1, 9} (Marcia Bayne-Smith ed., 1996) ("[I]n any money-driven economy, the people on the bottom of the stratification hierarchy will experience some level of material deprivation. The unequal distribution of income from earnings and wealth creates inequality of access to everything, from basic necessities . . . to life-sustaining resources such as education and health care."").
  \item \textsuperscript{156} See supra notes 23-24 and accompanying text (describing the disproportionate incidence of disease among the disenfranchised); see also supra notes 120-22 and accompanying text (observing that fundamental causes of diseases should be understood broadly).
  \item \textsuperscript{157} Examples of the potential for disease to be experienced disproportionately include the impact of tuberculosis in poor and immigrant communities, higher rates of heart disease in African American communities, and HIV/AIDS in gay communities. See CDC, \textit{Epidemiology of Tuberculosis}, available at http://www.cdc.gov/nchstp/tb/pubs2.pdf (last modified July 7, 2000) (noting that low income groups with poor access to health care are at a higher risk of TB exposure or infection); CDC, \textit{Tuberculosis Mortality—United States, 1997}, 47(13) MMWR 253 (1998), available at http://www.cdc.gov/nchstp/tb/pubs/mmwr/mm4713.pdf (stating that the TB case rate for foreign-born persons has remained at least four to five times higher than for U.S.-born persons); OMB Watch, \textit{Paper on Health Care Reform and Low-Income Populations, October/November 1996}, available at http://www.ombwatch.org/budget/health/paper.html ("People of low income are, on average, less healthy compared with persons of higher incomes . . . . Poor people have higher rates of disease and disability; they report themselves as less healthy and have higher rates of diabetes, heart condition, HIV and tuberculosis."); American Heart Association, \textit{2001 Heart and Stroke Statistical Update} 5 (noting that the age-adjusted prevalence of cardiovascular disease in adults for non-Hispanic whites is 30\% for men and 23.8\% for women, compared with 40.5\% for non-Hispanic Black men and 39.6\% for non-Hispanic Black women); see also infra note 267 and accompanying text (providing demographic statistics on the AIDS epidemic showing the disproportionate impact of the disease on people of color).
  \item \textsuperscript{158} See Marcia Bayne-Smith, supra note 155, at 18 ("It has been documented by researchers and historians that neglect based on racism accounted for the disproportionate deaths of women of color, compared with white women . . . .")}; Rebecca Dresser, \textit{What Bioethics Can Learn from the Women's Health Movement, in FEMINISM & BIOETHICS, supra note 41, at 144, 147 (addressing the women's health movement's criticism that "physicians frequently are patronizing, detached, disrespectful, racist, homophobic, and unwilling to trust the reports of their women patients"); Lauren Jones Young, \textit{Toward an Ethic of Care and Community in Education and Medicine, in IT JUST AIN'T FAIR, supra note 24, at 244 [hereinafter Young, \textit{Toward an Ethic of Care}] (noting the effect of race, class, and gender on disparities of access to health care and education).
others often take for granted.159

Civil rights statutes—including the Civil Rights Act of 1964160 and the Americans with Disabilities Act161—have outlawed outright discrimination against people of color, women, and people with disabilities (which, in many circumstances, includes people with disease)162 in employment, public accommodations, and other contexts.163 However, the mere prohibition of discrimination does not result in its elimination.164 Moreover, while it is important for state actors and employers to ban bad acts, laws cannot ban all bad behavior and do not necessarily lead to the removal of bad thoughts, including stereotyping and stigma.165

The causes and effects of discrimination, stigma, social hostility, and stereotypical assumptions as experienced by people based on race, class,

159. See Herek, Illness, Stigma, and AIDS, supra note 141, at 116 ("AIDS-related stigma is manifested in a variety of ways. HIV-infected people continue to be rejected by friends and relatives, fired or forced to resign from their jobs. . . ."); Renslow Sherer & David Goldberg, HIV Disease and Access to Care: A Crisis Within a Crisis, in IT JUST AIN'T FAIR, supra note 24, at 149, 155 [hereinafter Sherer & Goldberg, HIV Disease] ("No discussion of access to HIV-related care would be complete without an analysis of discrimination against HIV-infected persons. . . . It manifests itself through apathy and neglect, denial of basic rights, and outright violence.").


162. Whether disease constitutes disability can be a complex determination. See generally Matthew Diller, Dissonant Disability Policies: The Tensions Between the Americans with Disabilities Act and the Federal Disability Benefit Programs, 76 TEX. L. REV. 1003 (1998) (exploring the complex tensions that may result from being found disabled under federal civil rights provisions and commenting on the ways in which this finding may, but ought not to, preclude one from being found disabled under federal benefits programs); 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 (2000) (describing difficulties that have arisen in implementation of the ADA that were not anticipated by its drafters, including defining what it means to be "disabled").

163. See 42 U.S.C. § 2000e (1994) (banning discrimination in employment on the basis of race, color, religion, sex, or national origin); 42 U.S.C. § 12101(a)(3) (1994) (acknowledging that "discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services" and explaining that the ADA is designed to eradicate this discrimination).

164. Enactment of a nondiscrimination statute merely provides someone who has experienced discrimination with a vehicle by which to seek redress, usually in the form of financial compensation.

165. See Burris, Surveillance, supra note 21, at S122 (noting that an HIV-infected church congregant who is shunned by his fellow congregants lacks a cognizable legal claim against those who shun him, as does an abandoned HIV-infected woman whose husband has left her). Burris further observes that, even when law provides a remedy in theory, it may not be effective in practice, and further that "for some people, law is a hostile or alien force that is either inaccessible or positively dangerous to encounter." Id. (citations omitted); see also Frederick X. Gibbons, Stigma and Interpersonal Relationships, in DILEMMA OF DIFFERENCE, supra note 146, at 123, 125-26 (noting that despite the enactment of progressive legislation designed to better integrate persons with disabilities in the general population, individual attitudes have been slow to change because nonstigmatized persons often avoid interaction with stigmatized individuals).
gender, or an intersection of one or more of these characteristics,\textsuperscript{166} are numerous and have been explored in detail elsewhere.\textsuperscript{167} This Article accepts the well-drawn conclusion that they continue to negatively affect poor people, people of color, and women, not only in the more obvious settings of work and public accommodations, but also in facilitating the spread of disease.\textsuperscript{168}

The spread of communicable disease is greatly facilitated when individuals do not have access to health care providers or do not go to them because of a lack of trust. When this occurs, disease is neither detected nor treated, and it remains capable of being transmitted to others.\textsuperscript{169} Access to health care in the United States is highly dependent on employment status, as it is extraordinarily difficult to gain access to health insurance in any other way.\textsuperscript{170} Whether in times of prosperity or economic hardship, women

\begin{thebibliography}{9}
\bibitem{166} Critical theorists have drawn our attention to the multiple burdens that people may experience when they do not fit within “one category” of race, gender, sexual orientation, and the like. For example, see Kimberlé Crenshaw, \textit{Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics}, 1989 U. CHI. LEGAL F. 139, 140 (1989) (“Black women are sometimes excluded from feminist theory and antiracist policy discourse because both are predicated on a discrete set of experiences that often does not accurately reflect the interaction of race and gender.”) and Dorothy E. Roberts, \textit{Reconstructing the Patient: Starting with Women of Color}, in \textit{FEMINISM AND BIOETHICS}, supra note 41, at 116, 116-22 (“Black women experience various forms of oppression simultaneously, as a complex interaction of race, gender, and class that is more than the sum of its parts.”). See also infra notes 192, 268 (discussing new theories that seek better to explain the experiences of people whose identities are not uni-dimensional, such as African American lesbians, Asian men with disabilities, and Caucasian low-income women).

\bibitem{167} For a more thorough examination of these phenomena, see generally \textit{APPLICATIONS OF FEMINIST LEGAL THEORY TO WOMEN’S LIVES: SEX, VIOLENCE, WORK AND REPRODUCTION} (D. Kelly Weisberg ed., 1996); \textit{CRITICAL RACE FEMINISM: A READER} (Adrien Wing, ed., 1997); \textit{CRITICAL RACE THEORY} (Kimberlé Crenshaw et al. eds., 1993); \textit{FEMINIST LEGAL THEORY: FOUNDATIONS} (D. Kelly Weisberg ed., 1993).

\bibitem{168} See Burris, \textit{Law as a Structural Factor}, supra note 23, at 1776 (“Discrimination against women, de facto and de jure, renders them disproportionately vulnerable to HIV/AIDS. Women’s subordination in the family and in public life is one of the root causes of the rapidly increasing rate of infection among women . . .") (citation omitted); Herek, \textit{Illness, Stigma, and AIDS}, supra note 141, at 191 (asserting that “[F]ears of harassment, job discrimination, and loss of insurance coverage may deter [people at risk for HIV] from being tested [or treated]’’); Lorna Scott McBarnette, \textit{African American Women, in RACE, GENDER, AND HEALTH}, supra note 155, at 43, 65 (“[P]ersistent barriers to preventive and primary care services influenced not only the quality of life but also the patterns of illness observed among African Americans . . . After decades of access to health services, health inequalities are persisting and increasing . . .’’); Susan Sherwin, \textit{Feminism and Bioethics}, in \textit{FEMINISM AND BIOETHICS}, supra note 41, at 47, 55-56 (exploring the exclusion of women from research studies).

\bibitem{169} See \textit{Name Brands}, supra note 88, at 2106-08 (asserting that, because many of the populations most affected by AIDS and HIV generally distrust government and health officials, it is likely that these individuals will avoid seeking medical care); infra notes 109-77 and accompanying text (providing examples and a discussion of how access to health care varies based on economic class).

\bibitem{170} See Rebecca Levin, \textit{Job Locks: Will HIPAA Solve the Job Mobility Problem?}, 2 U. PA. J. L. & EMP. L. 507, 509 (2000) (“[M]ost Americans receive their health insurance through their
and people of color consistently experience the greatest amount of under-
and unemployment—and hence, less access to health insurance and health
care. Even programs such as Medicare and Medicaid, should one be
eligible for their coverage, are insufficient to meet the health care needs of
most people.

Access to health care is stymied for less obvious reasons as well. For
centuries, poor people, women, and people of color have experienced
mistreatment in health care settings. Examples abound. Historically,
doctors experimented on female slaves before using new surgical
procedures on white women. The federal government conducted the
infamous Tuskegee Syphilis Study from 1932 until 1972 to study the ravages
of untreated syphilis on Black men and continued long after antibiotics and
other treatments became available. Through the 1960s and 1970s women
of color were subjected to horrific forms of sterilization abuse, either where
doctors conditioned performing abortions or delivering babies on the
woman’s being sterilized or where government doctors threatened
withdrawal of welfare benefits unless they could perform the irreversible
procedure.

employers.... The minority of insured Americans... either purchase it individually, obtain it
through groups unrelated to employment (such as geographically-based groups or religious
and fraternal organizations), or receive it through state or federal programs, such as Medicare
and Medicaid.

171. See McNabette, supra note 168, at 61 ("[G]aps in insurance coverage restrict access to
services for growing numbers of the population, and African American women are especially
vulnerable because of unemployment and marginal employment.").

172. See Marian Gray Secundy, Lack of a Moral Consensus on Health Care: Focus on Minority
Elderly, in IT JUST AIN'T FAIR, supra note 24, at 56, 57 ("Currently, co-payments and deductibles
are rising and are increasing out-of-pocket costs so that in 1991, Medicare paid less than half of
the health expenditures of the elderly in the United States."); Young, Toward an Ethic of Care,
supra note 158, at 249 ("The 'safety net' intended by Medicaid fails millions; complex eligibility
requirements leave many poor families among the estimated 37 million uninsured.").

173. See Roberts, Reconstructing the Patient, supra note 166, at 123 ("It is well documented
that race and class differences affect the type of care patients receive.") (citing Council on
Ethical and Judicial Affairs, Black-White Disparities in Health Care, 263 JAMA 2344 (1990); Mark B.
Wennecker & Arnold M. Epstein, Racial Inequalities in the Use of Procedures for Patients with Ischemic
Heart Disease in Massachusetts, 261 JAMA 253 (1989); Robert J. Blendon et al., Access to Medical
Care for Black and White Americans: A Matter of Continuing Concern, 261 JAMA 278 (1989)).

174. See Roberts, Reconstructing the Patient, supra note 166, at 123-24 (quoting G.J. Barker-
Benfield, The Horrors of the Half-Known Life: Male Attitudes Toward Women and
Sexuality in Nineteenth-Century America 101 (1976)).

175. See Dan E. Beauchamp & Bonnie Steinbock, Introduction: Ethical Theory and Public
Health, in NEW ETHICS, supra note 2, at 3, 20 (describing the horrors of the Tuskegee study); see
also BRANDT, NO MAGIC BULLET, supra note 19, at 157-58. See generally JAMES H. JONES, BAD
BLOOD: THE TUSKEGEE SYMPHILIS EXPERIMENT (1981) (exploring in-depth the ramifications
of the Tuskegee study).

176. See Aida L. Giachello, Latino Women, in RACE, GENDER, AND HEALTH, supra note 155, at
121, 152 ("Since the mid-1930s, sterilization has been used extensively as a means of population
control in Puerto Rico. By 1982, over 40% of women aged 15 to 49 who were ever married had
Differences in treatment continue to persist, some less obviously than the historical examples, but equally pernicious in their effect. For example, one study found that poor women with cervical cancer treated by rotating residents in a community clinic were more likely to be treated surgically with hysterectomies, generally an unnecessarily drastic measure, than more affluent women who were treated by the same physician in a faculty clinic.\footnote{See Roberts, Reconstructing the Patient, supra note 166, at 123 (citing SU FISHER, IN THE PATIENT'S BEST INTEREST: WOMEN AND THE POLITICS OF MEDICAL DECISIONS (1988)).} Other studies have found that Black patients were less likely than white patients to be treated with life-saving surgeries and other aggressive treatments.\footnote{See Dula, Bioethics, supra note 176, at 12 ("The mortality rate for heart disease in black males is twice that for white males; research has shown that blacks tend to receive less aggressive treatment for this condition."); Sherer & Goldberg, HIV Disease, supra note 159, at 158 ("In one study ... whites were nearly twice as likely to have been offered AZT [(the first anti-HIV drug)] as nonwhites ....").} At least one study found that "‘the darker a woman’s skin and/or the lower her place on the economic scale’ ... [the] more likely [she was] to be considered ‘difficult’ and ‘to be talked down to, scolded, and patronized.’"\footnote{In turn, these women were given inadequate explanations about their conditions and options, and ultimately received poorer care.} Finally, clinical studies continue to exclude women, yielding skewed data about both the natural history of disease as well as the safety and efficacy of drugs being used to treat disease.\footnote{It should not be surprising that people living with disease also experience stigma, social hostility, and social risk that is linked to their disease condition—regardless of their class, race, gender, or sexual orientation. This ostracization can result in severe employment been sterilized.")}; Annette Dula, Bioethics: The Need for a Dialogue with African Americans, in IT JUST AIN'T FAIR, supra note 24, at 11, 17 [hereinafter Dula, Bioethics] (noting that "by 1965 one-third of the women in Puerto Rico had been sterilized") (citations omitted).} 

\footnote{See generally Sara Goering, Women and Underserved Populations: Access to Clinical Trials, in IT JUST AIN'T FAIR, supra note 24, at 182, 186-87 (discussing clinical trials on cardiac health and HIV infection performed on white men, the results of which proved inaccurate for women); Vanessa Merton, Ethical Obstacles to the Participation of Women in Biomedical Research, in FEMINISM AND BIOETHICS, supra note 41, at 216, 216 (discussing the negative effects of excluding women from clinical trials).}
discrimination, social exclusion, and even rejection from health care facilities and by health care providers.\textsuperscript{183} The degree of shunning often is linked to such factors as who is likely to get the disease,\textsuperscript{184} whether it is fatal,\textsuperscript{185} whether it is disfiguring,\textsuperscript{186} or whether it is sexually transmitted.\textsuperscript{187} Thus, disease is socially constructed: society creates layers of meaning about disease that extend well beyond the medical aspects of illness—and most of these meanings are not complimentary.\textsuperscript{188}

vastly different medical conditions—indeed, many may experience no medical limitations at all—they have one crucial thing in common: a socially assigned group status that tends to result in systematic disadvantage and deprivation of opportunity."). In prohibiting discrimination against people with disabilities, the ADA has provided legal protection for many people with chronic illness, including HIV. See Bragdon v. Abbott, 524 U.S. 624, 655 (1998) (holding that asymptomatic HIV can be a disability under the ADA).

183. See MARK S. SENAK, HIV, AIDS AND THE LAW: A GUIDE TO OUR RIGHTS AND CHALLENGES 86 (1996) ("Discrimination did not occur merely between individuals; whole institutions became deeply involved. Healthcare facilities, certainly insurance companies, and even government bureaucracies such as social security offices discriminated against people with AIDS in the most obvious ways . . . ."); see also Howe v. Hull, 873 F. Supp. 72, 79 (N.D. Ohio 1994) (holding a hospital liable under the ADA for a physician's refusal to admit an HIV-positive patient for treatment of an allergic reaction); Abby Ellen, Seeking Laws for Disabilities of the Attitude, N.Y. TIMES, July 26, 2000, at G1 ("[D]espite federal law to protect them against discrimination in hiring and promotion, and despite efforts by companies to recruit and train them and make job sites more accessible to them, the disabled continue to face a huge struggle for full workplace equality."). See generally Bagenstos, Subordination, supra note 182 (describing the range of social and economic exclusion experienced by people with disabilities, including those with disease).

184. See ALLEN, supra note 19, at xv ("[T]here was a long tradition in the West of seeing disease as [God's] punishment for sin—especially for sexual sins . . . . [D]espite America's apparent modernity, many people in this country—including many of those in power—were convinced that the healthy were saved and the sick were damned."); see also SONTAG, supra note 19, at 16 (1989) ("In contrast to cancer, . . . AIDS is understood in a premodern way, as a disease incurred by people both as individuals and as members of a 'risk group'—that neutral-sounding, bureaucratic category which also revives the archaic idea of a tainted community that illness has judged.").

185. See SONTAG, supra note 19, at 38 ("A fiction about soft or easy deaths [such as that which accompanied tuberculosis] is part of the mythology of most diseases that are not considered shameful or demeaning.").

186. See ALLEN, supra note 19, at 25 (discussing how leprosy and its "slow and loathsome disintegration" was among the most feared diseases of the European Middle Ages); SONTAG, supra note 19, at 40 ("And however lethal, illnesses like heart attacks and influenza that do not damage or deform the face never arouse the deepest dread.").

187. See BRANDT, NO MAGIC BULLET supra note 19, at 5:

Since the late nineteenth century, venereal disease has been used as a symbol for a society characterized by a corrupt sexuality. Venereal disease has typically been used as a symbol of pollution and contamination, and cited as a sign of deep-seated sexual disorder, a literalization of what was perceived to be a decaying social order.

188. According to historian Allan Brandt:

Fundamental to the notion that disease is socially constructed is the premise that it is profoundly shaped by both biological and cultural variables . . . . Only if we understand the way disease is influenced by social and cultural forces—issues of
In conclusion, disparities abound in many aspects of social interaction, including perception of and ability to confound instances of social risk. These disparities often cross lines of race, gender, poverty, and illness, and are compounded by socially constructed responses to multiple sources of identity. Common to all is an experience of powerlessness—an inability to create a reality devoid of such socially constructed inequities.

3. Autonomy and Agency: Bioethics and Democracy

The value of autonomy and its first cousin, agency, are dominant in theories of American democracy, as well as in American medical law and ethics. While few would dispute the importance of these values in either

class, race, ethnicity, and gender—can we effectively address its biological dimension. A 'social construction' reveals tacit values, it becomes a symbol for ordering and explaining aspects of the human experience. In this light, medicine is not just affected by social, economic, and political variables—it is embedded in them.

Id.; see also supra note 63 and accompanying text (discussing social construction of disease).

189. See IMMANUEL KANT, GROUNDING FOR THE METAPHYSICS OF MORALS 41 (James W. Ellington trans., Hackett Publ'g 9d ed. 1993) (1785) ("[Autonomy is the ground of the dignity of human nature and of every rational nature."); Daniel Callahan, Autonomy: A Moral Good, Not a Moral Obsession, 14 HASTINGS CENT. REP. 40, 40 (1984) ("Autonomy can...be understood as the basis for moral enfranchisement, establishing [one's] standing as an equal in the community and [one's] liberty to pursue [one's] own ends."); Willard Gaylin, In Defense of the Dignity of Being Human, 14 HASTINGS CENT. REP. 18, 18 (1984) ("Kant defined the special value of our species as residing in our autonomy.").

190. As described by Tracy E. Higgins, "The use of the term agency, instead of the more common autonomy, is intended to denote not simply freedom from external constraints, but an internal capacity to develop and act on conceptions of oneself that are not defined by oppressive notions of gender, race, or class."); Higgins, supra note 32, at 1664 n.31; see Kathryn Abrams, Redefining Women's Agency: A Response to Professor Williams, 72 Ind. L.J. 459, 461 (1997) (emphasizing that personal accounts of agency extend to individuals "showing alert attention to their numerous, ongoing needs—even under hideously oppressive circumstances"); Susan H. Williams, A Feminist Reassessment of Civil Society, 72 Ind. L.J. 417, 434 (1997) [hereinafter Williams, A Feminist Reassessment] ("[It is] recognition by another person with whom you need to interact that provides the experience of agency.").

191. See Higgins, supra note 32, at 1664 ("[The] assumption of agency—of citizens' freedom and ability to define their own ends—is...essential to all mainstream constitutional theory."); see also CASS R. SUNSTEIN, THE PARTIAL CONSTITUTION 176-78 (1997):

The notion of autonomy should refer...to decisions reached with a full and vivid awareness of available opportunities, with all relevant information, and without illegitimate or excessive constraints on the process of preference formation.

... Government action might...be justified on grounds of autonomy when the public seeks to implement, through democratic processes culminating in law, widely held social aspirations or collective desires.

context, some scholars critique this theoretical underpinning as insufficiently protective of the rights of those who are not part of majority culture and politics. Instead, if traditional notions of autonomy, or perhaps more appropriately agency, depend on an individual’s ability to “define her preferences free from politically relevant constraints,” it must be understood to be nearly impossible for those traditionally disenfranchised from political (or social) power to assert a pure, or full, conception of agency.

193. See, e.g., Crenshaw, supra note 166, at 140 (urging legal theorists to examine the compounded effect of race and gender on discrimination of Black women because “in race discrimination cases, discrimination tends to be viewed in terms of sex- or class-privileged Blacks, in sex discrimination cases, the focus is on race- and class-privileged women... marginaliz[ing] those who are multiply burdened...”); Angela P. Harris, Race and Essentialism in Feminist Legal Theory, 42 STAN. L. REV. 581, 615 (1990):

[Legal theory, including feminist legal theory, has been entranced for too long and to too great an extent by the voice of ‘We the People.’ In order to energize legal theory, we need to subvert it with narratives and stories, accounts of the particular, the different, and the hitherto silenced... women of color.]

See also Deborah L. Rhode, Feminism and the State, 107 HARV. L. REV. 1181, 1189 (1994) ("[T]o an important extent, women’s preferences are socially constructed and constrained. The state does not simply respond to expressed desires; it plays an active role in legitimating, suppressing, or redirecting them."); Robin L. West, Jurisprudence and Gender, 55 U. CHI. L. REV. 1, 2 (1988) ("[A]ll of our modern legal theory—by which I mean ‘liberal legalism’ and ‘critical legal theory’ collectively—is essentially and irretrievably masculine."); Williams, A Feminist Assessment, supra note 190, at 426 (observing that traditionally “[a]utonomy is a characteristic belonging to individual human beings, conceived as separate from and independent of the social context in which they exist[; yet, m]any feminists... claim that women’s desires are often not autonomous in this sense because they are the result of sexist social conditioning").

194. Higgins, supra note 32, at 1664.

195. Id. Higgins uses the term “incomplete agency” to express:

the idea that, in a range of legal contexts, women’s choices should be understood as neither fully free nor completely determined. Taking into account the ways in which women are constrained differently from men has revealed situations in which facially neutral assumptions about responsibility and choice contribute to women’s equality.

Id. (citing Kathryn Abrams, Sex Wars Redux: Agency and Coercion in Feminist Legal Theory, 95 COLUM. L. REV. 304, 346-48 (1995) (formulating a theory of “partial agency”)). Higgins notes that “[t]he term ‘incomplete agency’ is not meant to imply that complete agency is possible. Rather, it conveys the idea that women’s agency is incomplete relative to men’s agency or relative to the agency assumed by mainstream theory.” Id. at 1691 n.170; see Williams, A Feminist Assessment, supra note 190, at 432 (“[A]utonomy is neither a pre-existing condition to be assumed for all persons, nor is it an end-state that can be taken for granted once achieved. Instead, it is a process... that must be continually ongoing in order for a person to be autonomous.”) (citations omitted).

Feminist social construction theory, which is “concerned not so much by the way patriarchy limits women (implying external constraints) but by the way it creates or defines women (implying internal as well as external constraints),” also bears on this discussion. Higgins, supra note 32, at 1691, 1665 n.34 (citing Nancy J. Hirschmann, Toward a Feminist Theory of Freedom, 24 POL. THEORY 46, 51 (1996)). Higgins defined social construction as:
Scholars also traditionally have recognized the principle of autonomy as "the pivotal value"\textsuperscript{196} in bioethics.\textsuperscript{197} In the past decade, however, a growing number have critiqued the discipline's orientation around principlism\textsuperscript{198} and its insufficient attention to the social context of the people whose lives these principles have sought to guide.\textsuperscript{199} As a result, the field of bioethics has experienced a decided shift in consciousness, with increased attention being paid to empiricism,\textsuperscript{200} pragmatism,\textsuperscript{201} narrative bioethics,\textsuperscript{202} and feminist and

the idea that human beings and their world are in no sense given or natural but the product of historical configurations or relationships. The desires and preferences we have, our beliefs and values, our way of defining the world are all shaped by the particular constellation of personal and institutional social relationships that constitute our individual and collective histories.

\textit{Id.}


197. "[Bioethics] is the study and formulation of the ethics of health care and the biological sciences . . . [It is] a collaboration of several disciplines [including philosophy, law, medicine, science, theology, social science, and economics], with their relative importance shifting over time." Susan M. Wolf, \textit{Introduction: Gender and Feminism in Bioethics, in FEMINISM & BIOETHICS}, supra note 41, at 3, 7 [hereinafter Wolf, \textit{Introduction}]. The study of bioethics primarily developed out of concern for "the protection of vulnerable patients and research subjects, the relationship between medical and scientific fact and social meaning, and the ethics that should guide physicians and scientists." \textit{Id.} at 10; see also DAVID J. ROTHMAN, \textit{STRANGERS AT THE BEDSIDE: A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING} (1991) (discussing the change in relationship dynamics between doctors and patients beginning in the mid-1960s).

198. See Wolf, \textit{Shifting Paradigms}, supra note 137, at 400 ("Principlism is an approach to reasoning about ethical problems that proceeds in the main not deductively from higher-order theory, or inductively from fine-grained attention toward the situation presented, but from middle-level principles down to the case presented."); see also John D. Arras, \textit{Principles and Particularity: The Roles of Cases in Bioethics}, 69 Ind. L.J. 983, 986 (1994) (discussing the "mid-level principles" that have become "the dominant paradigm for serious work in bioethics").

199. See, e.g., \textit{AFRICAN-AMERICAN PERSPECTIVES ON BIOMEDICAL ETHICS} xxvii (Harley E. Flack & Edmund D. Pellegrino eds., 1992) ("[T]he ethical principles of health care (e.g., autonomy, justice, beneficence) are the same for all[; however,] African Americans invoke these principles differently, based on the unique historical experiences that have shaped their moral philosophy."); Rebecca J. Cook, \textit{Feminism and the Four Principles, in PRINCIPLES OF HEALTH CARE ETHICS} 193, 193-206 (Raanan Gilion & Ann Lloyd eds., 1994) (critiquing the four principles of bioethics—autonomy, beneficence, nonmalef-scale, and justice—from a feminist perspective); Annette Dula & Sara Goering, \textit{Introduction, in IT JUST AIN'T FAIR, supra note 24, at 4 (noting that "the traditional ethical framework[,] in an effort to be impartial and colorblind[,] fails to see particular groups in their unique social contexts"); Wolf, \textit{Shifting Paradigms}, supra note 137, at 400 (observing the historic "failure of bioethics to attend to differences associated with gender, race, ethnicity, and insurance status").

200. See generally Carl E. Schneider, \textit{Bioethics with a Human Face}, 69 Ind. L.J. 1075 (1994)
race-attentive critiques. 203

Why are such concerns important to consider? Indeed, why are the neutral principles of bioethics, a discipline inherently concerned with examining and correcting inequities, insufficient to correct any injustice that may exist? Traditional "principlism," 204 while useful in many ways, has been part of a deductive philosophy that favors "abstract rules and principles that disregard individual differences and context [, and that embraces a] liberal individualism that obscure[s] the importance of groups." 205 In many contexts, these neutral principles fail "to attend to differences associated with gender, race, ethnicity, and insurance status." 206

At the heart of this critique is a belief in "the moral significance of groups," 207 or perhaps more accurately, a belief in the importance of

(discussing ways in which empiricism could and should be more fully integrated into bioethical scholarship).

201. See Wolf, Shifting Paradigms, supra note 137, at 398 (observing a shift toward incorporating pragmatism into bioethical discussions).


203. See generally Dula & Goering, supra note 24 (discussing African American perspectives on biomedical ethics); Margaret Olivia Little, Why a Feminist Approach to Bioethics?, 6 KENNEDY INST. ETHICS J. 1 (1996) (describing how feminist theory makes a unique contribution to bioethics); Rosemarie Tong, Feminist Approaches to Bioethics, in FEMINISM AND BIOETHICS, supra note 41 (describing the views of feminist theorists in challenging the traditional bioethics); Wolf, Shifting Paradigms, supra note 137 (noting the increasing awareness of race and gender differences in bioethics). These shifts in bioethics mirror those that previously started to shape new ways of thinking in other disciplines, including law, jurisprudence, and philosophy of law. See Wolf, Shifting Paradigms, supra note 137, at 401 ("The new debates on method and attention to gender arrived late compared to [other] fields . . . .")

204. See Tom L. Beauchamp, Principles and Other Emerging Paradigms in Bioethics, 69 IND. L.J. 955, 955-56 (1994) [hereinafter Beauchamp, Principles in Bioethics] ("Moral principles are simply relatively general norms of conduct that describe obligations, permissible actions, and ideals of action . . . . If principles are adequately expressed, relatively more particular moral rules and judgments are supported by, though not deduced from, the principles.").


206. Wolf, Shifting Paradigms, supra note 137, at 400. The four principles become easy targets for criticism because they do facilitate deductive reasoning. In context, however, it is evident that Beauchamp and Childress "never proposed a completely deductive system whose principles were merely to be applied to specific cases." Wolf, Introduction, supra note 197, at 16; see also Beauchamp, Principles in Bioethics, supra note 204, at 959 ("Because principles are stated at a lofty level of abstraction, little practical content can be drawn directly from the principles, and that content is still subject to competing interpretations. More precision through specification is therefore essential for regulative and decision-making contexts."). Still, Wolf notes that "[w]e have developed a bioethics primarily for the person with access to health care and with a doctor likely to listen to, understand, and respect that person. It is bioethics for the privileged." Wolf, Introduction, supra note 197, at 18.

207. Susan Sherwin, Feminism and Bioethics, supra note 168, at 52 (observing that there is a "moral significance" to recognizing those who are "disadvantaged, dependent, exploited, responsible for the care of others, or otherwise limited in their ability to assert their rights in
recognizing that one’s views are shaped by one’s identity as belonging to a particular group or set of groups. Standpoint theory helps us to understand this argument. Traditional standpoint theory suggests that each person’s “point of view, expertise, and authority are situated and partial.” Critical theorists recognize both that “there is no neutral standpoint from which to impose . . . moral principles and rules” and that some standpoints, namely those of the dominant, are more valued than others. As such, “[t]he standpoints of subdued groups . . . provide a corrective lens for the myopia for the dominant group” and may provide a conceptual framework to correct past injustice.

Postmodernists are willing to take this reasoning a step further, observing that: “Otherness, for all of its associations with oppression and inferiority, is much more than an oppressed, inferior condition. Rather, it is a way of being, thinking, and speaking that allows for openness, plurality, diversity, and difference.” With these understandings of standpoint theory, the moral significance of groups—and the importance of attending to their voices and perspectives—becomes much more apparent, as does the recognition that insistence on using neutral principles is likely to disservice outsider groups and serve to reinforce the status quo.

See also Mahowald, supra note 41, at 100 ("[S]ome perspectives are privileged in comparison with others . . ."); Tong, Feminist Approaches to Bioethics, supra note 203, at 87:

> What traditional theory passed off as objective and impartial knowledge was nothing of the sort. Like all knowledge, [it] was the product of a set of experiences—. . . the experiences of mostly white, privileged men. Because women’s experiences were not encoded in traditional theory, that theory constituted itself in a very subjective, partial, ‘male’ manner.

(citation omitted).

211. Mahowald, supra note 41, at 101.

212. Id. (quoting Rosemarie Tong, Feminist Thought: A Comprehensive Introduction 219 (1989)); see also id. at 99 ("Truth as known and knowable is inevitably partial, but not relative. Although we cannot achieve omniscience, we can minimize our errors or mistakes through collaboration."). This is not an acceptance of relativism, but an acknowledgment of “the epistemological validity of standpoint theory.” Id.

213. See Sherwin, Feminism and Bioethics, supra note 168, at 49 ("[E]thics as it is usually
An example, borrowed from Hilde and James Lindemann Nelson, may shed light on how facially neutral rules interfere with achieving justice for outsider communities.\footnote{124} In the face of limited resources to provide health care services, some experts had proposed limiting the life-extending health care available to elderly adults by cutting off benefits at a certain age.\footnote{125} Regardless of its merits, the proposal is troublesome because of a potentially hidden problem: it would have a disproportionate impact on the ability of women—who, on the average, outlive men—to gain access to health care.\footnote{126} As such, this "neutral rule" would not, in fact, have a neutral impact.\footnote{127}

As this example reflects, "[P]ublic policies that ignore differences between a dominant group and groups with less power tend to create a false neutrality that favors the dominant group: its characteristics are taken as the norm, while groups with other characteristics are marked as deviant."\footnote{128} However, as Martha Minow has observed,\footnote{129} there is a danger that focusing

\begin{itemize}
  \item \textbf{125.} \textit{Id.}
  \item \textbf{126.} \textit{Id. at 361 (citing A Profile of Older Americans: 1992 (Am. Ass'n of Retired Persons & Admin. on Aging eds., 1992)).}
  \item \textbf{127.} Similarly, the fact that most people receive health insurance coverage from their employers has a disproportionately negative impact on women and people of color—populations that traditionally make up a greater proportion of the un- and under-employed. \textit{Id. at 362.}
  \item \textbf{128.} \textit{Id. at 355-56 (citing Martha Minow, Making All the Difference: Inclusion, Exclusion & American Law (1990) [hereinafter MINOW, MAKING ALL THE DIFFERENCE]); see Martha Minow & Elizabeth V. Spelman, In Context, 63 S. Cal. L. Rev. 1597, 1632-33 (1990) ("[T]he call to context . . . reflects a critical argument . . . that prevailing legal and political norms have used the form of abstract, general, and universal prescriptions while neglecting the experiences and needs of women of all races and classes, people of color, and people without wealth.").}
  \item \textbf{129.} \textit{See MINOW, MAKING ALL THE DIFFERENCE, supra note 218, at 20 (coining the phrase "the dilemma of difference" and noting that "]]the stigma of different may be recreated both by ignoring and by focusing on it . . . The problems of inequality can be exacerbated both by treatment members of minority groups the same as members of the majority and by treating the two groups differently."); Martha Minow, Foreword: Justice Engendered, 101 Harv. L. Rev. 10, 11 (1987) (noting that when powerful professionals use categories such as gender and race to presume objective differences in people's needs and experiences, injustice may result); Minow
\end{itemize}
soley, or excessively, on difference may actually "perpetuate the oppression and marginalization the group has experienced in the past." The key to achieving proper balance in attending to the needs of the disenfranchised, then, is to trace even facially neutral abuses of power employed to reinforce the status quo and to exploit them as the fault lines along which to challenge laws and practices that traditionally harm the disenfranchised.

How does one accomplish this balance in the context of public health law and policy? If one accepts that there is "moral significance" to inequalities based on the experiences of outsider groups, and if one believes in the importance of focusing on "those historically least served and most harmed," it is difficult to continue to subscribe to the traditional model of autonomy, which is one steeped in "liberal individualism."

Acknowledging the deficiencies in the autonomy theory and the

& Spelman, *In Context*, supra note 218, at 1598 (observing that "just treatment of all people requires us to recognize relevant differences in different contexts").


221. *See id.* at 355 (noting that a critical analysis "must put its focus first on power") (citing *Young*, supra note 210); *see also* *Wolf*, *Shifting Paradigms*, supra note 137, at 406 ([B]ioethical analysis requires attention to power in biomedical settings: who has it, how it works, and how to fix the current inequities . . . [This] analysis of power and morality cannot proceed without careful attention to context and difference.").

222. *Wolf*, *Introduction*, supra note 197, at 23; *see also* *Higgins*, supra note 32, at 1686 ([T]he enlightened perspectives of marginalized people ought to be treated as having particular authority.); *Williams*, *A Feminist Reassessment*, supra note 190, at 429 ([F]eminism must develop a model of personhood that includes some capacity to redefine ourselves and make self-conscious change in the oppressive conditions that have shaped us.).

I do not seek to undermine the importance of bolstering autonomy, or the individual exercise of agency, in the context of the doctrine of informed consent. Although efforts to improve the theory and practice of this doctrine have been incomplete, significant strides have been made. *See Katz*, supra note 17, at 82-84 (asserting that informed consent requires physician-patient dialogues where patients "are viewed as participants in medical decisions affecting their lives," but that "[t]he legal vision of informed consent, based on self-determination, is still largely a mirage"). However, one criticism of autonomy is that, once again, too many patients—due to lack of insurance, language difference, or sheer intimidation—can exercise only "incomplete agency" when faced with medical crises. Higgins, *supra* note 92, at 1691; *see* *Cooper*, *Testing for Genetic Traits*, supra note 67, at 389-86 (noting that language and cultural differences, as well as lack of trust, between patient and physician pose significant barriers to a patient's ability to give informed consent to procedures); Shervin, *Feminism and Bioethics*, supra note 168, at 58 ([P]eople who are oppressed face systemic barriers to their freedom, so the choices they are offered in medical contexts are likely to be seriously restricted by the limited choices available to them in their lives generally."). The most effective way to strengthen this exercise of individual agency is to value "the moral significance of groups." *See supra* note 207 and accompanying text (defining this concept as the recognition that individuals' perspectives are shaped by their membership in particular groups).

223. *See Shervin*, *Feminism and Bioethics*, supra note 168, at 53 ([G]reater equality is a precondition for any meaningful exercise of autonomy by seriously disadvantaged members of society.").

224. *Wolf*, *Introduction*, supra note 197, at 16 (noting the "allegiance [of bioethics] not only to Kant but to John Stuart Mill . . .").
importance of group identity, one is left groping for a suitable theory upon which to rely. This struggle logically leads to an exploration of communitarianism. Communitarians understand ethics through a lens that values “establishing and honoring the social rules and cultural ideals that motivate and regulate a group’s practices.” As such, they reject the atomistic approach fundamental to liberal individualism and its supervaluation of autonomy. Although the theory is initially attractive, it is problematic in that the communities most esteemed by communitarians—including families, religious groups, unions, and neighborhoods—have been historically recognized as being oppressive of outsider groups, including people with disabilities.

225. Tong, Feminist Approaches to Bioethics, supra note 203, at 67: 

[A] practice is ‘any coherent and complex form of socially established cooperative human activity through which goods internal to the form of activity are realized in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity, with the result that human powers to achieve excellence, and human conceptions of the ends and goods involved, are systematically extended.

Id. at 69-70 (quoting ALASDAIR MACINTYRE, AFTER VIRTUE: A STUDY IN MORAL THEORY 175 (1981)).

226. See Jennifer Nedelsky, Reconcepting Autonomy: Sources, Thoughts and Possibilities, 1 YALE J.L. & FEMINISM 7, 8 (1989) (“The now familiar critique by feminists and communitarians is that liberalism takes atomistic individuals as the basic units of political and legal theory and thus fails to recognize the inherently social nature of human beings.”).

227. See Williams, A Feminist Reassessment, supra note 190, at 422 ( remarking that “the notion of . . . constitutive communities is very attractive to some feminists because it seems to capture the more connected sense of self that many women experience and that liberal political theory has generally ignored or rejected” and because it tends to “blur[] the boundaries and significance” of the public/private distinction, which has been the subject of significant feminist criticism.).


229. See Bagenstos, Subordination, supra note 182, at 430 (suggesting that disabilities “arise[e] primarily from the human environment, rather than from anything inherent in an individual’s physical or mental condition”); Harris, supra note 193, at 613 (“At the individual level, black women have had to learn to construct themselves in a society that denied them full selves.”); Williams, A Feminist Reassessment, supra note 190, at 423-24 (noting that such institutions “have historically oppressed women and maintained gender hierarchies” and that “the potential for oppression is built into the shared identity that communitarians are celebrating”); see also R. George Wright, Consenting Adults: the Problem of Enhancing Human Dignity Non-Coercively, 75 B.U. L. REV. 1397, 1436 (1995) (citing Amitai Etzioni, On Communitarianism and Its Inclusive Agenda, TIKKUN, Sept.-Oct. 1993, at 49, 50) (“[I]t would be foolish to deny that such groups ever act coercively to enforce compliance with their norms. Groups are often the source of conformist pressures and intolerant norms.”). Notwithstanding this observation, Wright asserts that such “groups can also crucially reinforce a person’s own highest values . . .” Id. at 1436. He also notes
The question then becomes how one "combine[s] the claim on the constitutiveness of social relations with the value of self-determination." 223 Although there is no easy answer, some scholars have recommended that, by challenging some of the more rigid aspects of the conceptions of both communitarianism and autonomy and by incorporating the life experiences of the people about whom we are talking, we are more likely to facilitate the creation of more potent expressions of agency. 221

For example, Susan Williams proposes a theory of narrative autonomy that accepts a role of social construction in facilitating autonomy. Her theory calls for a modification of communitarian understanding of which groups are to be valued to include those that are "constitutive, personal, and responsive; [that] need not be found rather than chosen, nor need [to] be face to face; [but] must be multiple" and "non-oppressive." 222 Kathryn Abrams recommends "redefining and advocating new configurations of traditional communities with a potential for oppressive influence," 223 recognizing "the need for plural or multiple institutions in any given woman's life," 224 and the potential benefits of "instrumental institutions or communities" 225 as sources to support an individual's expression of agency. Others discuss the importance of narrative or case-based systems of ethics. 225

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221. See supra notes 199-94 and accompanying text (contrasting notions of incomplete or partial agency with full agency).
222. Williams, A Feminist Reassessment, supra note 190, at 441, 444.
223. Abrams, Redefining Women's Agency, supra note 190, at 462 (calling for people to "de-emphasize some of the traditional configurations that have exposed women to systematic oppressive treatment," including, for example, understanding a battered woman's commitment to protecting her children as an impetus for engaging in resistant behavior and as reflective of the potential for locating non-oppression within the mother-child dyad, which traditionally is understood as a source of women's oppression) (citing MARTHA ALBERTSON FINEN, THE NEUTERED MOTHER, THE SEXUAL FAMILY AND OTHER TWENTIETH CENTURY TRAGEDIES 230-33 (1995)).
224. Abrams, Redefining Women's Agency, supra note 190, at 462. Abrams also notes that to facilitate development and expression of agency, "a woman may need—at least temporarily—to rely on communities that did not help to foster her earlier sense of self and life story."
225. Id. Abrams continues: "A woman ... may develop important elements of ... self-understanding—particularly where it is connected with radical re-visioning or rupture—within settings that do not involve the experience of being seen and understood by others as a human being of a particular sort." Id.
226. See Arras, supra note 198, at 988, 1000, 1004 (noting "the intrinsic limitations of ethical theory for practical purposes," "[t]he renaissance of casuistry, or case-based reasoning," and the related ascendancy of "narrative ethics"). Arras also notes the similarities between "the casuistical method [and] the method of the common law," especially "given the pivotal and ubiquitous role of legal cases in the recent history of bioethics ..." Id. at 1001; see also Susan H. Williams, Bioethics and Epistemology: A Response to Professor Aras, 69 Ind. L.J. 1021, 1025-26 (1994):

[T]he narrative systems of ethics beginning to shape the field of bioethics should be seen as the vanguard of a broad epistemological movement ... [that] may carry with it the seeds of a more far-reaching change in the nature of bioethics if it leads
pragmatism, and empiricism. These approaches each emphasize that the lives of the subjects are essential starting points for conducting ethical assessments.

Where does this leave us? I do not attempt to construct new theories of autonomy or agency or to weave coherent lines of connection magically among communitarianism, standpoint theory, narrative theory, and pragmatism. I do, however, take strands of these critiques and intertwine them to form the theoretical foundation of the Harm Assessment Protocol. The critiques of autonomy, the recognition of the "moral significance of groups," and the awareness of the harms caused by social risk require that we privilege the voices of the disempowered in our struggle to create effective and sensitive public health policy. Before exploring how the Protocol accomplishes this, it is important to understand both the political context and the structural factors that historically have impeded legislators and policymakers from attending to the voices of the disenfranchised.

C. HABITS OF LEGISLATURES AND POLICYMAKERS

The problems faced by the disenfranchised must be understood in more than just the theoretical context. In the realm of public health, the legislature and related administrative agencies are the primary loci of activity. Not surprisingly, disenfranchised classes often have less ability to affect the outcome of the disputes and compromises that emanate from the practitioners to a greater recognition of the interdependence of ethics and epistemology.

237. See Wolf, Shifting Paradigms, supra note 137, at 399-408 (describing the rise in "a new pragmatism" that includes feminist, race-attentive, and empirical critiques of the traditional principism of bioethics and observing that "[t]he heart of pragmatist thought is the view that the ultimate test is always experience" (quoting Daniel A. Farber, Legal Pragmatism and the Constitution, 72 Minn. L. Rev. 1331, 1341 (1988))).

238. See Schneider, supra note 200, at 1077 ("At this stage in the history of bioethics and law, we should be ready, and we surely need, to see the core problems of bioethics in all the factual and moral complexity of reality . . . . [E]mpirical research provides one useful way to bring more of that complexity back in."); Wolf, Shifting Paradigms, supra note 137, at 403-04 (discussing the rise of empiricism in bioethical literature). Of course, not all thinkers support these changes. See id. at 413-14 (noting that pragmatism has been critiqued as potentially being "anti-theory" and "incompatible with a strong concept of rights").

239. See Arras, supra note 198, at 1001 ("Just as the casuists insist that the weight of principles resides in the details, so they insist that moral certainty resides in our responses to paradigmatic cases, rather than in appeals to theory or principle."); Wolf, Foreword, supra note 202, at 187-88 ("Bioethicists have moved from mirror to window, and now look out upon the world. We require detailed attention to the case as the ground for bioethical analysis . . . . Race, gender, insurance status, and cultural context all now demand explicit analysis."); cf. Minow & Spelman, supra note 218, at 1599 (responding to critics that attention to context does not "inexorably plop[] one into the muck of relativism").

240. See supra Part I.B.1 and note 30 (identifying the parties responsible for creating public health policy).
lesser legislative and executive branches.\footnote{Indeed, among the thousands of political action committees, lobbyists, and other advocates, it is rare to find the disenfranchised or their representatives.} Moreover, despite its pervasiveness, the problem of poverty in this country tends to be geographically confined so that few legislators represent those with the most significant needs.\footnote{Administrative bodies also do not yet reflect the diversity of the people whose lives they regulate.}

Complicating matters, legislators and policymakers are as susceptible to bias and fear as the people they serve.\footnote{Moreover, they face constant...}
pressure from their constituents, lobbyists, and legislative leaders to "do something" about the social ills they were elected or appointed to eliminate, or at least, control.\textsuperscript{246} As such, there are increasing demands on these officials to dissuade them from supporting legislation that is in "the public interest"—which may include supporting the interests of the disenfranchised, but which may not be popular with constituents, financial supporters, or the media.\textsuperscript{248}

These factors conspire virtually to ensure that those who are less powerful to begin with are not likely to be the groups and individuals with significant sway in our state or federal capitals.\textsuperscript{249} Predictably, then, those who are least able to exercise agency in their individual lives also are those who are least able to exercise agency on a broader scale: in the legislative or executive (regulatory) arenas.

To some degree, the legislature—and the administrative bodies that implement its statutory initiatives—functions as intended: it does not allow disruptive "factions" to control the outcome of debate.\textsuperscript{250} However, it is

\begin{itemize}
\item arguing that it is up to the courts to shape regulations to control biases.
\end{itemize}


While there is certainly a role for popular participation in addressing long-term problems, it is not clear that the general public is as interested in long-term issues as it is in short-term ones. Moreover, the public lacks the technical expertise to predict long-term consequences without the assistance of scientific elites.

\textsuperscript{249} See \textit{Macey, supra} note 247, at 231 (predicting that under an economic theory of legislation, "laws are likely to benefit the few at the expense of the many, because no one has an incentive to enact laws that benefit the people in general"); \textit{see also} \textit{supra} notes 241-43 (discussing limitations on the disenfranchised in the political process).

\textsuperscript{250} \textit{See supra} note 32 and accompanying text (discussing the role of the democratic model
inappropriate to characterize concern for the lives of the disenfranchised as

disruptive factionalism. For example, when disease—or other structural

harm—befalls those who already have less sway with their elected or

appointed officials, these representatives ought to bear a particular

responsibility to ensure that the interests of the disenfranchised are

protected. Indeed, I have designed the Harm Assessment Protocol to

encourage legislators and policymakers to recognize the interests of the

disenfranchised and to engage in a deliberative process that helps to ensure

that their interests are protected.

III. THE HARM ASSESSMENT PROTOCOL

A. THE ELEMENTS OF THE HARM ASSESSMENT PROTOCOL

The Harm Assessment Protocol seeks to rectify problems the
disenfranchised encounter that have been analyzed in theoretical terms
and are manifest in the practices of legislative bodies. The Protocol is
unique in that it relies on theoretical principles but provides a pragmatic

tool to affect positively the development of public health law and policy.

Building on the critique developed in Part II, the Protocol accepts that

there are limitations on the exercise of agency by disenfranchised groups

and recognizes the “moral significance” of this reality. It endorses the

notion that communities can serve as viable and important vehicles for
greater expressions of agency, but is not bound to them in a strict

communitarian sense. Finally, the Protocol privileges the voices of the
disenfranchised in the context of a debate in which their voices rarely are
heard, but does so while continuing to value the importance of preserving
the public health.

The first step of the Protocol (see infra fig. 1) requires that one identify
the “targeted population” of the legislative or policy proposal. It is important

not to fall into the trap of assuming that because one is examining a public
health proposal, the targeted population is the general public. Indeed, this
Protocol does incorporate an assessment of the needs of the general public,
but relegates this consideration to a point later in the process.

Step Two requires an assessment of whether the targeted population
would experience an increase in social risk under the statutory proposal in
question. To conduct this evaluation, one first must examine the existing
social reality of the targeted population. Does it have access to wealth or

in protecting minority interests).

251. See supra Part II.B.3 (analyzing the values of autonomy and agency).
252. See supra Part II.C (analyzing habits of legislatures regarding public health policy).
253. See supra Part II.B.3 (discussing notions of partial agency and standpoint theory).
254. See id. (discussing how communities, as understood through a lens of critical theory,
may facilitate more complete expressions of agency).
other indicia of capital? 255 Is it a group traditionally subjected to discrimination, stigma, or social hostility? Can its individual members exercise agency and enjoy self-determination, or are they more likely to exercise incomplete agency, if at all? Does the law generally protect or place further burdens on this group?

In Step Three, the lawmaker or policymaker must assess whether the proposal exacerbates the social risk already faced by the target population. The decision makers must consider the following questions:

• Will the proposal enhance rather than eliminate stigma?

• Does it exacerbate or diminish social hostility?

• Does it further disenfranchise a disempowered group?

• Does it empower a powerful group?

To answer these questions, lawmakers should determine whether the targeted population has voiced any concerns about the underlying legislative or policy proposal. 256

Surveys are one alternative to finding the answers, but they often are superficial and difficult to interpret. It may be more prudent to conduct or consult formal studies or in-depth interviews, although they too have their flaws. 257 One of the most effective ways to identify and explore the concerns of the target population is to discern whether members of the targeted population are represented by an advocacy organization. 258 Although the most disenfranchised are the least likely to be so mobilized (e.g., active drug users), many among the less-powerful regularly rely on such groups to try to protect their interests (e.g., NAACP, the Urban League, NOW, the National Gay and Lesbian Task Force). 259

255. See supra notes 146, 150, and accompanying text (discussing the term "capital in the context of stigma).

256. This element of the Harm Assessment Protocol draws heavily from the pragmatic, empirical, narrative, and communitarian critiques of bioethics in general, and autonomy more specifically. See supra Part II.B.3 (discussing these critiques).

257. See generally Burris, Social Risk, supra note 19 (discussing the problems found in many of the studies that have tried to explore influences on an individual's decision to be tested for HIV and calling for studies to be conducted that can yield more accurate data to inform the development of law and policy). Among the difficulties would be ensuring a sufficiently reliable and diverse sample, negotiating the expense, and protecting against influence by the interviewer. On balance, however, it is necessary to incur these costs to ensure an equitable result.

258. Some may be troubled by the lack of scientific rigor of this part of the inquiry. See e-mail from Scott Burris to the author (Jan. 23, 2001) (on file with author). However, so long as the organization is community-based, it is one of the most direct ways to learn the concerns of a target population.

259. I draw here from the feminist critique of communitarianism, which calls for the acceptance of constitutive communities that are nonoppressive and may be chosen, rather than found. See supra notes 251-59 and accompanying text (exploring strict communitarian
Figure 1. The Harm Assessment Protocol

Step 1
Who is the targeted population?

Step 2
What is their current experience of Social Risk?

Step 3
Does the legislative/policy proposal increase the (actual or perceived) social risk of the targeted population?

No
Does it help achieve legitimate public health goals?

Yes
Support

No
Do not support

Yes

Step 4
Does it help achieve legitimate public health goals?

Yes
Support

No
Do not support

Step 5
Is it the least restrictive alternative?

No
Do not support; reconfigure

Yes

Step 6
Is the state's interest compelling?

No
Balancing test

Yes
Support

principles through a critical theory lens).
Lawmakers and policymakers should consider both actual and perceived social risk that might be experienced by the targeted population. The presence of either danger could serve to undermine the efficacy of the proposal through noncompliance or by inflicting harm on the dignity of the targeted group. Such harm ultimately would diminish trust between the targeted group and health officials, an outcome that should be avoided when seeking to achieve effective disease control and prevention.260

If, after conducting the social risk evaluation, the lawmaker concludes that the proposal neither increases social risk nor constitutes a lost opportunity to reduce it, she should proceed to Step Four, which involves an inquiry into whether the proposal is a legitimate means of protecting the general public health.261 If it is legitimate, then lawmakers should support the proposal. If it is not, lawmakers ought not adopt it. In the unlikely event the assessment is neutral, a separate evaluation must be conducted to determine whether it is otherwise prudent to enact the proposal.262

If, however, the proposal is likely to exacerbate the social risk experienced or perceived by the target population, lawmakers must conduct a further inquiry. They first must determine whether the state has articulated a legitimate public health goal. In other words, if the proposal is properly implemented, will it improve the public health? If it will not, the proposal must be rejected.

Should the lawmaker or policymaker determine that the state interest is legitimate, the Protocol requires that the statutory proposal constitute the least restrictive alternative available to meet that legitimate public health goal. Here the Protocol borrows from constitutional doctrine, which states that if a state actor creates classifications affecting the rights of a constitutionally-protected group263 or infringes on a fundamental right,264

260. See supra Part I.B.1 (identifying the parties responsible for creating public health policy); infra Part III.B (applying the proposed Harm Assessment Protocol); see also supra note 87 and infra note 325 (discussing the relationship between trust and preservation of the public health).

261. For a discussion of what constitutes legitimate public health goals, see Whalen v. Roe, 429 U.S. 589 (1977), which upheld a computerized patient-identification requirement because it was a reasonable method of attempting to control drug abuse and did not unnecessarily infringe on any fundamental rights, and Jacobson v. Massachusetts, 197 U.S. 11, 25 (1905), which upheld a mandatory vaccination statute because "the police power of a state must be held to embrace, at least, such reasonable regulations established directly by legislative enactment as will protect the public health and the public safety."

262. This evaluation might incorporate concerns beyond the scope of this Article, including economic, environmental, or other structural political concerns external to public health issues.

263. The "least restrictive alternative" doctrine originated with a suggestion by Justice Stone in United States v. Carolene Products Co., 304 U.S. 144 (1938), where he noted that "prejudice against discrete and insular minorities may be a special condition, which tends seriously to curtail the operation of those political processes ordinarily to be relied upon to protect minorities, and which may call for a correspondingly more searching judicial inquiry." Id. at 159
courts must strike down the classification unless it both serves a compelling state interest and is the least restrictive alternative available to achieve that interest.\footnote{Since 1938, the Supreme Court has implemented a "searching judicial inquiry" in the form of a two-part "strict scrutiny" analysis. The test requires a compelling government interest and a showing that the state action in question was narrowly tailored to reach that interest. This approach is used especially to examine race-based classifications. See \textit{e.g.}, \textit{Missouri v. Jenkins}, 515 U.S. 70, 112 (1995) (O'Connor, J., concurring) (concluding school desegregation orders to be beyond a federal court’s authority because, where such efforts “classify persons on the basis of their race, we have mandated strict judicial scrutiny”); \textit{Fullilove v. Klutznick}, 448 U.S. 448, 510 (1980) (Powell, J., concurring) (noting, in the affirmative action context, that “the Judicial Branch has the special responsibility to make a searching inquiry into the justification for employing a race-conscious remedy” and that “[c]ourts must be sensitive to the possibility that less intrusive means might serve the compelling state interest equally as well”); \textit{McLaughlin v. Florida}, 379 U.S. 184, 191 (1964) (striking down Florida’s ban on interracial cohabitation after finding that the racial classifications drawn in the statute are not “reasonable in light of its purpose” but rather exhibited “an arbitrary or invidious discrimination”); \textit{Korematsu v. United States}, 323 U.S. 214, 216 (1944) (upholding the internment of Japanese-Americans while recognizing that “all legal restrictions which curtail the civil rights of a single racial group are immediately suspect” and “must [be] subject ... to the most rigid scrutiny”).} In the context of the Protocol, if the proposal does not employ

\footnote{The "strict scrutiny" standard is also employed in examining state action that restricts a "fundamental right." See \textit{Griswold v. Connecticut}, 381 U.S. 479, 485 (1965) (striking down Connecticut’s law banning the use of contraceptives because a more narrowly tailored approach was possible and “a governmental purpose to control or prevent activities constitutionally subject to state regulation may not be achieved by means which sweep unnecessarily broadly”); \textit{Skinner v. Oklahoma}, 316 U.S. 535, 541 (1942) (striking down a mandatory sterilization act for habitual criminals, the Court noted that deference to the legislature was not warranted because “we are dealing here with legislation which involves one of the basic civil rights of man” and thus "strict scrutiny of the classification" is required). State action that infringes upon voting rights has also received heightened scrutiny requiring a narrowly tailored approach. See \textit{Dunn v. Blumstein}, 405 U.S. 330, 343 (1972) (citing \textit{NAACP v. Button}, 357 U.S. 449 (1958)) (invalidating Tennessee’s durational residence requirements for voters because the State could not “demonstrate that such laws are ‘necessary to promote a compelling government interest’”); \textit{Kramer v. Union Free Sch. Dist.}, 395 U.S. 621, 623 (1969) (striking down voting restrictions in school board elections because “close scrutiny of the ... classifications demonstrates that they do not accomplish [the State’s purported compelling] purpose with sufficient precision to justify” the restrictions).}
the least restrictive means, the lawmaker or policymaker must reject the proposal, perhaps in favor of one that does adopt a more tailored approach. If the assessment reveals that the proposal seeks to use the least restrictive means, the policymaker must ask whether the state has a compelling interest in enacting the proposal. If it does, she should support the proposal, notwithstanding an increase in social risk.266

However, if the state interest is legitimate but not compelling, the lawmaker ought to employ a balancing test. The lawmaker should consider several factors, including the strength of the state interest in achieving the stated public health goal, the likelihood that the proposal reasonably will help achieve that goal, and the anticipated increase in social risk. The more diffuse the state’s goal or its means of achieving it, the more the lawmaker must yield to concerns that enactment of the statute will serve primarily to increase social risk, rather than to preserve or enhance the public health.267

By privileging the concerns of the disenfranchised and incorporating rather stringent standards borrowed from constitutional jurisprudence,268 the Protocol provides a mechanism for legislators and policymakers to incorporate a social risk assessment into their deliberations. The goal of the Protocol is straightforward: it seeks to facilitate implementation of policies that are simultaneously more just and more effective, in that they protect the interests of the minority and still safeguard the public health.

To demonstrate the potential success of the Protocol in practice, I now apply it to an issue that is currently the subject of significant debate in the

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266. For example, quarantine of people with infectious tuberculosis would increase social risk, but must be tolerated, as the state’s interest in limiting the spread of this airborne and potentially deadly disease is, in fact, compelling.

267. Although this balancing test is somewhat diffuse, it should be applied in the spirit of the Harm Assessment Protocol: sensitivity to increased social risk and specificity of an achievable state interest must be given prime consideration.

268. Cf Ross, supra note 241, at 313 (“Legislators should not adopt wholesale the rational basis standard used by the courts to evaluate equal protection challenges. Rather, they should test statutory classifications against different, stricter standards.”).
context of HIV/AIDS public health policy: HIV name reporting.

B. THE APPLICATION OF THE HARM ASSESSMENT PROTOCOL: HIV NAME REPORTING

1. Who Comprises the Targeted Population?

The first step of the Protocol requires that decision makers identify the targeted population of the proposed legislation. In the case of HIV name reporting, the targeted group consists of those infected with HIV, those who engage in activity that could cause them to become HIV-infected, and, to a lesser extent, those who identify their interests in concert with these populations (e.g., through demographic, political, or emotional connections). This group traditionally is composed of gay or bisexual men and injection drug users. Increasingly, this group also includes people of color, women, and the poor, as well as those that ally with them (such as the broader gay/lesbian or minority communities or family members).

269. Even though we are analyzing a public health proposal, it would be inappropriate to identify the “targeted population” as the general public. To do so would turn the Protocol on its head, causing one to conduct the “legitimate public health” inquiry first, leaving behind the social risk analysis that serves as the linchpin to the Protocol.

270. HIV can be transmitted only in utero or through an exchange of bodily fluids involving blood, semen, vaginal secretions, or breast milk. See generally Gerald H. Friedland et al., Lack of Transmission of HLV-III/LAV Infection to Household Contacts of Patients with AIDS or AIDS-Related Complex with Oral Candidiasis, 314 NEW ENG. J. MED. 334 (1986) (finding that HLV-III/LAV—now known as HIV—is not transmissible through casual contact); Gerald H. Friedland & Robert S. Klein, Transmission of the Human Immunodeficiency Virus, 317 NEW ENG. J. MED. 1125 (1987) (identifying the modes of potential HIV transmission, which include transfusion by blood, intravenous drug use, sexual transmission, and perinatal transmission).

271. In 1983, 3064 cases of AIDS were reported to the CDC; 93% were men, 7% were women; 58% were white, 26% were Black, 14% were Hispanic, <3% were other or unknown; 71% were homosexual or bisexual, 17% were intravenous drug users, and <1% were hemophiliac. CDC, AIDS WEEKLY SURVEILLANCE REP. 1 (Dec. 22, 1983). At the end of 1999, the CDC had received reports of 733,374 cases of AIDS; 82% of which were men, 18% were women; 43% were white, 37% were Black, 18% were Hispanic, <1% were Asian/Pacific Islander, <1% were American Indian/Alaskan Native; 47% were men who have sex with men, 25% were injection drug users, 10% were persons infected heterosexualy, and 25% were persons infected through blood or blood products. CDC, SURVEILLANCE REP., supra note 1, at 5. “During the 1990s the epidemic shifted steadily toward a growing proportion of AIDS cases in Blacks and Hispanics and in women and toward a decreasing proportion in [men who have sex with men], although this group remains the largest single exposure group.” Id.; see also Bob Herbert, The Quiet Scourge, N.Y. TIMES, Jan. 11, 2001, at A31 (noting the surging rates of HIV/AIDS in Black communities and stating that “[y]ou can put away the notion that AIDS is a disease that primarily affects gay white males; that story has changed”).

Further, most people are “multidimensional” and do not fit easily within one demographic category: one may be a low-income gay (white) man who injects drugs, a wealthy woman who has engaged in risk behavior, or a middle-class gay man of color. See Darren Lenard Hutchinson, “Gay Rights” for “Gay Whites”?: Race, Sexual Identity, and Equal Protection Disourse, 83 CORNELL L. REV. 1398, 1999 (2000) (developing the framework of multidimensionality analysis to understand “the diverse effects of heterosexism and other forms of oppression on personal
2. What is the Current Experience of Social Risk of the Targeted Populations?

The Protocol's second step requires lawmakers to learn about the current social risks faced by the groups identified in Step One. It makes sense to start with an understanding of the history of AIDS-related law and policy in the United States, as it has gone through several stages. The first stage occurred from the early to mid-1980s and was characterized by ignorance, coupled with a naïve belief that the epidemic could be contained within certain "other" communities—namely gay men (often perceived of as white) and injection drug users. During this time, most legislatures did nothing to respond to the epidemic. Indeed, the New York State HIV/AIDS testing and confidentiality statute, long regarded as a model for others to follow, was not enacted until 1988—seven years after the first cases of what later became known as AIDS were diagnosed.

identity and well-being" within the context of civil rights law); Peter Kwan, *Complicity and Complexity: Cosynthesis and Praxis*, 49 DePaul L. Rev. 673, 689 (2000) (using a theory of cosynthesis to "move beyond a single axis or unidimensional view of identity to one that reconceives individuals as made up of many axes all supporting the others and together constituting the whole"); see also supra note 166 and accompanying text (discussing multiple burdens and oppressions). See generally Francisco Valdes, *Sex and Race in Queer Legal Culture: Ramifications of Identities & Inter-Connectives*, 5 S. Cal. Rev. L. & Women's Stud. 25 (1995) (using an interconnectivity analysis to illuminate the complexities of multiple group identities in the law).

272. Cf. D. Zeegers Paget, *HIV/AIDS and the Legislature: An International Comparison*, 10 AIDS Care (Supp 1) S65 (identifying a chronological pattern of legislative reaction to AIDS: denial, recognition, and mobilization). Of the 208 jurisdictions studied, by the end of 1995, 11 countries were still in the stage of denial, 99 countries evolved from denial to recognition, and 88 countries had already evolved from denial to recognition to mobilization. Id.

273. See *Update on Acquired Immune Deficiency Syndrome (AIDS)—United States*, 31 MMWR 507, 513-14 (Sept. 24, 1982) ("Only a small percentage of cases have none of the identified risk factors (male homosexuality, intravenous drug abuse, Haitian origin, and perhaps hemophilia A.").

274. See Garrett, *Betrayal of Trust*, supra note 11, at 400-01 ("Bigotry against homosexuals and injecting drug users had blinded the general public, politicians, the medical community, and sadly, many public health leaders to the urgency of responding to AIDS when effective action might have had a profound impact: between May 1981 and the end of 1984.").

275. This Article uses the phrase "HIV/AIDS" to refer to the spectrum of HIV-related medical experiences—from being HIV-infected and asymptomatic to having full-blown AIDS. Admittedly, the social-medical experiences of the epidemic vary widely depending on at which end of the spectrum one lives. Indeed, it may take a decade or longer to press from initial infection to full-blown AIDS and its corollaries. Still, the term "HIV/AIDS" often is used to reinforce the spectral nature of infection with the human immunodeficiency virus and its progression to acquired immune deficiency syndrome. The Article does make some distinctions, however, such as between HIV-related name reporting and AIDS-based name reporting. See infra Part III.B.4 (discussing the differences between HIV- and AIDS-based name reporting). Other distinctions, as necessary, are noted throughout the text.


277. See supra note 1 (providing sources showing that AIDS first was recognized in 1981).
The second stage of the development of AIDS-related law and policy, running from the late 1980s until the early 1990s, was characterized by the enactment of many privacy and consent-to-testing statutes. By creating explicit counseling and consent prerequisites to testing, and by establishing firm protections of confidentiality, lawmakers were doing all they could to encourage people "at risk" for HIV/AIDS to get tested. During that era, lawmakers by-and-large did not yet perceive either themselves or most of their constituents to be at risk for HIV. Perhaps because of this, they were able to follow a "public interest" model of legislating, heeding the advice given to them by both public health experts and the gay male communities who, by this time, were increasingly well-organized.

278. See Senak, supra note 183, at 175 (noting that during the earlier years of the epidemic, state legislatures enacted stringent confidentiality requirements, "prohibiting the disclosure of HIV test results to unauthorized persons"); Scott Burris, Testing, Disclosure, and the Right to Privacy, in AIDS LAW TODAY, supra note 114, at 115, 121:

The public health consensus in support of privacy protections and against coercion led a majority of states to adopt measures in the late 1980s governing HIV testing and confidentiality. By the end of 1991, thirty-six states had enacted legislation requiring informed consent for HIV testing, and virtually every state provided some degree of protection for the confidentiality of HIV information.


280. See Garrett, Betrayal of Trust, supra note 11, at 401 (noting that in order to counter the public's ignorance and prejudice towards persons with AIDS, "disease surveillance and identification of infected individuals was made confidential or anonymous, [in an attempt to protect] individuals from societal discrimination"); Nancy Krieger & Rose Appelman, Chapter One, The Politics of AIDS, in AIDS: THE POLITICS OF SURVIVAL 3, 22 (Nancy Krieger & Glen Margo eds., 1994) (observing that the "social consequences of even taking a test—that is, the implications of being labeled a 'queer' or a 'junkie'" were extraordinary). Lack of available care made people especially suspicious of being tested. See Dennis Altman, AIDS IN THE MIND OF AMERICA 78 (1986) ("So great were the fears, both of false results and of their consequences, that various gay groups urged people not to take the test except for research purposes ... "); Rotello, supra note 104, at 107 ("[I]nitially most gay AIDS groups advised gay men to avoid the test.").

281. Senior Reagan Administration officials did not discuss the AIDS epidemic until September 1985, four years after the disease first was identified. At the time, they labeled the disease "an epidemic of fear," but stated "that there was no need to panic because AIDS remained confined to the gay and IVDU population." Krieger & Appelman, supra note 289, at 25 (citing Phillip M. Boffey, U.S. Counters Public Fear of AIDS, N.Y. TIMES, Sept. 20, 1985, at A15).

282. See supra Part IL.C (describing the "public interest" model of legislating and the obstacles to adopting this approach).

283. See Nat'l Research Council Panel on Monitoring the Soc. Impact of the AIDS Epidemic, THE SOCIAL IMPACT OF AIDS IN THE UNITED STATES 41 (1993) (noting that, in the early stage of the AIDS epidemic, U.S. public health officials "had to negotiate the course of the public health strategy with representatives of a well-organized gay community and their allies in the medical and political establishments"); Rotello, supra note 104, at 277 ("Gay men, with the strong support of lesbians, of civil liberties organizations, and of liberal and progressive groups and leaders, managed to stave off almost all of the worst scenarios ... ").
Two factors facilitated this collaboration. First, the interests of the public health officials and of the AIDS advocacy community overlapped to a great extent.\textsuperscript{284} Their goals were two-fold—to encourage people to engage in less risky behavior and to begin to trust a government that had not previously been an ally.\textsuperscript{285} Second, and just as important, despite the outrageous stigma that accompanied either an AIDS diagnosis or being gay (particularly during the mid-1980s), enough lawmakers recognized in AIDS advocates, who were by and large gay men, a mirror of, if not themselves, then perhaps their brothers, their uncles, their cousins, or even their college roommates. Although the advocates often belonged to at least two "outsider" groups,\textsuperscript{286} they were sufficiently familiar to the lawmakers that, during this period, their concerns were integrated into some of the earliest, most progressive, and most effective AIDS-related legislation.\textsuperscript{287}

\begin{footnotesize}
\textsuperscript{284} See, e.g., Gostin, Burris & Lazzarini, supra note 10, at 90 n.112:

People with and at risk of HIV banded together to work the political process for greater spending on research, prevention, and care. Although nominally acting in opposition to bureaucratic delay and neglect, blamed in part on health officials, in practice HIV advocates and health officials have been allies more often than antagonists.

\textit{See also} Krieger & Appelman, supra note 280, at 18 (noting that, although "[t]he scientific community's reaction to AIDS was also initially hostile and inadequate," this started to change earlier than that of the general population). "This shift is due in part to scientists' growing understanding of the disease and their recognition that the spread of AIDS cannot be halted without cooperation of those at risk." \textit{Id.}

\textsuperscript{285} The federal government has had a long history of discrimination against gay people. See John Charles Hayes, \textit{The Tradition of Prejudice Versus the Principle of Equality: Homosexuals and Heightened Equal Protection Scrutiny After Bowers v. Hardwick}, 31 B.C. L. REV. 375, 378-79 (1990) (listing the various ways that the federal government has discriminated against homosexuals, including explicit discrimination by the military, the Central Intelligence Agency, the Federal Bureau of Investigation, the National Security Agency, and the State Department, and discrimination in its immigration policy). This type of mistreatment led to serious mistrust of government actions surrounding the HIV/AIDS epidemic, particularly in the early years. See Burris, \textit{Social Risk}, supra note 19, at 874-75 (describing a study of gay men and their motives for taking or not taking the HIV antibody test, which revealed "a mistrust of government and its motives, particularly a fear that over the long term HIV test information would be subject to misuse").

Elements of this distrust began to shift over time. See Krieger & Appelman, supra note 280, at 22 (citing COMMITTEE ON A NAT'L STRATEGY FOR AIDS, INST. OF MED., CONFRONTING AIDS: DIRECTIONS FOR PUBLIC HEALTH, HEALTH CARE AND RESEARCH 15 (1986) [hereinafter IOM REPORT]). As of 1986, there was agreement between scientists and activists that explicit AIDS education (about sex and drug use) was essential: more drug treatment programs were necessary, substantially more resources should be allocated for biomedical and social science research, discrimination against persons with or at risk for AIDS should be banned, and coercive measures—such as forced antibody testing or quarantine—could not be used. \textit{Id.} at 23 (citing IOM REPORT, supra, at 1-3). Krieger and Appelman attribute this to an "increased understanding of the disease [and a] common opposition to the simultaneously inadequate and reactionary response of the federal government." \textit{Id.}

\textsuperscript{286} They were "outsiders" as gay men or as people living with or at risk for HIV/AIDS.

\textsuperscript{287} Although this may seem incongruous, or unexpected, this is indeed what occurred in
\end{footnotesize}
LESSONS FROM THE PLAGUE YEARS

The third era of AIDS legislation was ushered in through the mid-1990s and continues today. This era is marked by two developments. The first is the discovery of protease inhibitors and other anti-HIV medications that make it increasingly possible to treat HIV as a long-term illness. The second development concerns the shifting demographics of the epidemic. The epidemic looks significantly different now than it did almost twenty years ago when the first cases were identified, as the number of women

New York, California, and a handful of other states, many of which were experiencing the greatest concentration of people living with HIV/AIDS. See generally supra note 183 at 166 (noting that, early in the epidemic, state legislatures around the nation, particularly in epicenters of the AIDS epidemic, enacted laws providing for the confidentiality of people who stepped forward to take an HIV-antibody test); cf. Elinor Burkett, The Gravest Show on Earth: America in the Age of AIDS 305 (1993) (noting that "gay men were parts of families and churches and workplaces that embraced and supported the sick more frequently than they rejected them"). Legislators did not, of course, accept all of the recommendations of AIDS advocates, choosing to close bathhouses in the face of opposition by many in the AIDS and gay communities. See Garrett, supra note 11, at 402-03 (citing such actions by the New York State legislature).

288. See Burkett, supra note 287, at preface (citing Andrew Sullivan, Fighting the Death Sentence, N.Y. Times, Nov. 21, 1995, at A2 ([D]octors are now treating HIV as a chronic but manageable condition.)); Gostin & Hodge, The Names Debate, supra note 46, at 698-99 ("Medical advances may change our conception of HIV/AIDS from a terminal disease to a chronic treatable condition, akin to diabetes, which can be controlled in individuals for decades."). Although such drugs may not work for everyone and increasing numbers will develop resistance to them, they are responsible for a precipitous drop in the AIDS death rate since the start of their use in 1996. See Garrett, Betrayal of Trust, supra note 11, at 468-69 ("From 1997 to 1998 the U.S. HIV death rate dropped by 20 percent ... and that was a 42 percent AIDS death rate decline from 1996 to 1997.").

289. See CDC, Surveillance Rep., supra note 1, at 5:

In absolute numbers, blacks have outnumbered whites in new AIDS diagnoses and deaths since 1996 and in the number of persons living with AIDS since 1998. The proportion of women with AIDS increased steadily, reaching 23% in 1998, and the proportion infected heterosexually also increased, surpassing in 1994 the proportion infected through injection drug use. See also supra note 271 (providing additional demographic information about HIV/AIDS).

Reports tended to undercount women and people of color for the first decade or more of the epidemic. Although these populations were dying of AIDS from the very beginning, doctors did not always recognize the disease. Gay men generally were of a social and economic class that facilitated their maintaining good health; the sudden decline in health wrought by AIDS was noticed. Early in the epidemic, low-income men and women, often drug users or partner of drug users, did not necessarily have ready access to health care and also were not so generally healthy; the epidemic was not noticed as quickly in these quarters. See Corea, supra note 24, at 29 ("None of the physicians or scientists talked about the women with AIDS being sick themselves. They all saw women simply as vectors or disease to men and fetuses, as organisms, like insects, that transmit a pathogen."); Sally Zierler & Nancy Krieger, Reframing Women's Risk: Social Inequalities and HIV Infection, 18 ANN. REV. PUB. HEALTH 401, 402 (1997) [hereinafter Zierler & Krieger, Social Inequalities] ("Unlike white gay men diagnosed with AIDS, sickness among these women was not unexpected. It was just a part of the ongoing, usual excess morbidity and mortality among the poor and racially oppressed.").

Compounding this problem was that the initial definitions of AIDS did not recognize the symptoms that were occurring in these populations. Women, poor people, and people of
and people of color living with HIV/AIDS continues to grow at a disproportionate rate.\textsuperscript{290}

This third era of AIDS is marked by a frustration that this disease seems as if it is here to stay. It is not a momentary crisis. We have no magic bullets. Protease inhibitors help but do not cure,\textsuperscript{291} are expensive, and can have horrible side effects.\textsuperscript{292} Moreover, AIDS is creating an increasing drain on public coffers and has spawned a multi-million dollar industry.\textsuperscript{293} Many people, including legislators and policymakers, frustrated and frightened by the seeming failure of medicine to find a cure, just want this disease to go away. Many feel that if doctors cannot control the disease, the government ought to do something to control people living with HIV/AIDS.\textsuperscript{294} Indeed,
this frustration appears to be manifesting itself in an increasing number of legislative and policy initiatives that seek to do just that. Advocates for such measures describe themselves as seeking to end “HIV exceptionalism.”

Calls for more aggressive control measures sound off warning bells to most in the targeted population in light of their ongoing experiences of stigma, social hostility, and discrimination. As the epidemic continues to


296. See Bayer, HIV Exceptionalism, supra note 294, at 1500 (defining “HIV exceptionalism” as a term that indicates that public health officials have not adopted “the [conventional] policies developed to control sexually transmitted diseases or other communicable conditions,” such as mandatory screening, treatment, health registries, and quarantine to help monitor and control the HIV/AIDS epidemic). Those who criticize decisions not to test, identify, or report the names of people living with HIV often claim that they are based on a supervaluation of civil rights and civil liberties and a devaluation of society’s obligation to protect the public health. See Tom Coburn, Round Two-Concluding Remarks: June 1997 Roundtable on AIDS: Privacy Vs. Public Health, at http://theatlantic.com/unbound/forum/aids/cobu3.htm (last visited Jan. 26, 2001) (stating that “[e]very day that we delay implementing [traditional] public health measures we allow the disease to claim more lives”); see also Burr, supra note 46, at 218 (“However legitimate the civil-liberties issues it sought to address may have been more than a decade ago, the exceptionalist orthodoxy is now fundamentally wrongheaded as a matter of good public health and medicine.”). The basis for this differential treatment, such advocates assert, is the influence of the “gay lobby” and the “AIDS lobby,” that has exerted undue influence on our legislators and public health officials—to the detriment of the general public. See Bayer, HIV Exceptionalism, supra note 294, at 1500 (noting that, “in the first decade of the AIDS epidemic, an alliance of gay leaders, civil libertarians, physicians, and public health officials began to shape a policy for dealing with AIDS that reflected the exceptionalist perspective”); Burr, supra note 46, at 220 (noting that attempts to alter the “exceptionalist” approach to AIDS were met with fierce opposition from “virtually every gay and AIDS group”). Such assertions of HIV exceptionalism, however, raise concerns in light of the spotty historical record of implementation, the dubious success of more intrusive public health measures, and the disenfranchisement and oppression that characterize the experiences of most people living with HIV/AIDS. Supra notes 293-94 and accompanying text; infra notes 302-08 and accompanying text.

move at full force into marginalized communities that still include gay men and injection drug users, but which increasingly include the low-income and poor, people of color, adolescents (gay and straight), and older adults—communities too often characterized by extraordinary disempowerment, regardless of HIV status—there appears to be no lessening in the experiences of oppression.  

This assessment and analysis informs the response to Step Two of the Protocol: social risk is alive and well among the targeted populations of an HIV name reporting proposal.

3. Does the Legislative Proposal Increase the (Actual or Perceived) Social Risk of the Targeted Populations?

Step Three of the Protocol further opens the door to debate. There is active dispute as to whether instituting a plan to report the names of people living with HIV would pose an actual increase in social risk to the targeted populations. A number of studies have been conducted in the fifteen years
since the test for HIV antibodies first became available to attempt to determine the importance of confidentiality or anonymity to people considering being tested. It is difficult to draw definitive conclusions from these studies, but we can discern a few messages.

First, it is critically important that a state make available anonymous testing sites. This resource has encouraged people to get tested earlier, which is an essential predicate to getting care and often increases the probability that the person will engage in fewer activities likely to transmit HIV. Second, if given a choice, most people who test positive for HIV would prefer that their names not be transmitted to the government. Some people have delayed getting tested for fear that their confidentiality will be breached—casually or intentionally, by private actors or by

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301. See Andrew B. Bindman et al., Multistate Evaluation of Anonymous HIV Testing and Access to Medical Care, 280 JAMA 1416, 1416-20 (1998) (describing studies in various states to determine if the availability of anonymous testing increases the number of people who get tested for HIV); Burris, Social Risk, supra note 19, at 843-56 (reviewing and critiquing many of the studies concerning attitudes toward testing).

302. At anonymous test sites, the person seeking to be tested either provides or is given a code with which she can obtain her test results and be given post-test counseling. She need not provide her true identity nor that of any partners with whom she may have engaged in risk activity. See Bindman et al., supra note 301, at 1416 (detailing how anonymous testing is done); Burris, Social Risk, supra note 19, at 834 (noting the attraction of anonymous testing); Alvin Novick, Yale Univ. Ctr. for Interdisciplinary Research on AIDS (CIRA), HIV Case Reporting (May 4, 1998), at http://cira.med.yale.edu/hiv.case.reporting.update.html ("Some CDC spokespersons currently favor allowing states to continue to offer anonymous HIV testing and counseling to those who fear having their identities revealed. If anonymous testing were to be banned, some people would be unwilling to be tested at all."). Anonymous testing differs from confidential testing. The latter requires one to identify oneself (and depending on the state, perhaps to identify one's partners); still, the test results are not to be disclosed to anyone except the testee, her health care provider, and perhaps a government office, if HIV name reporting is in effect. See Kramer, supra note 114, at 185 (describing how HIV reporting is conducted at a confidential test site).

303. See Bindman et al., supra note 301, at 1418 ("Persons tested anonymously presented earlier in the course of HIV disease for testing and care than did persons tested confidentially."); CDC, Guidelines for National Human Immunodeficiency Virus Case Surveillance, Including Monitoring for Human Immunodeficiency Virus Infection and Acquired Immunodeficiency Syndrome, 48 (RR-13) MMWR 1, 9 (hereinafter CDC, Guidelines for National HIV Case Surveillance) ("In a companion survey of persons reported with AIDS ... participants who had recognized their HIV risk and sought testing at anonymous testing sites reported entering care at an earlier stage of HIV disease than persons who were first tested in a confidential setting.").

304. See CDC, Adoption of Protective Behaviors Among Persons with Recent HIV Infection and Diagnosis—Alabama, New Jersey, and Tennessee, 1997-1998, 49 (23) MMWR 512, 514 (2000) ("The findings in this study suggest that a high proportion of infected persons adopted safer sexual behaviors following diagnosis of HIV infection.").

305. See CDC, Guidelines for National HIV Case Surveillance, supra note 203, at 8 ("Concern about name-based reporting of HIV infections to the government was a factor for not testing for HIV for 13% of heterosexuals, 18% of injecting-drug users, and 28% of men who have sex with men.") (citations omitted).
government officials. 306 Third, although some may not even know their state's policy concerning HIV name reporting when they go to get tested, 307 many carry fear that the results will be disclosed to unauthorized persons. 308

There have, in fact, been breaches of confidentiality by both government 309 and private actors. 310 Private actors tend to disclose HIV status in the course of everyday conversation (gossip) or because they (falsely) believe they have to disclose it to protect others. 311 Gaffes by government actors largely have been caused by unintentional gaps in security, but are significant nonetheless. 312

More threatening, though, than the aberrant leak by government agents, is the legislature's power to change the rules of confidentiality. Because lawmakers were the ones who created the rules, they also can

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306. See Name Brands, supra note 88, at 2106 ("[D]istrust can stem from doubts about the government's ability to keep certain information private . . . .") (citations omitted).

307. See Burris, Social Risk, supra note 19, at 846 & n.78 (describing a study of sexually active teenagers in Massachusetts that found that thirty-five percent believed that HIV test results were not confidential; eighty-one percent believed that their partners would not be notified in the case of a positive result) (citations omitted); DIV. OF STD PREVENTION, MASS. DEPT' T OF PUB. HEALTH, HIV PARTNER NOTIFICATION, at http://www.magnet.state.ma.us/dph/cdc/hivpn.htm (last visited Aug. 15, 2000) (hereinafter HIV PARTNER NOTIFICATION) (describing Massachusetts' voluntary partner notification program and strict confidentiality regulations).

308. See HIV PARTNER NOTIFICATION, supra note 307 (noting that thirty-five percent of respondents thought test results were not confidential).

309. See Sonia Bhatnager, Note, HIV Name Reporting and Partner Notification in New York State, 26 FORDHAM URB. L.J. 1457, 1476 (1999) (describing how employees of the Pinellas County Health Unit in Florida inadvertently leaked a list of names, addresses, birth dates, and the means by which approximately 4000 HIV-positive people contracted HIV); Name Brands, supra note 88, at 2105 n.50:

In 1997, for example, a Florida state health worker was charged with downloading confidential databases containing the names of people with AIDS. He used the information to screen potential dates for himself and his friends; eventually his partner sent copies of the AIDS list to various newspapers. The story was widely publicized.

(citations omitted).

310. See Herring v. Keenan, 218 F.3d 1171, 1180-81 (10th Cir. 2000) (holding that a probation officer violated probationer's constitutional right to privacy by telling his employer and his sister of his HIV infection); P.F. v. Mendres, 21 F. Supp. 2d 476, 484 (D.N.J. 1998) (holding that a father's right to privacy was violated when a police officer disclosed the father's AIDS status to his neighbor, who then divulged the information to other parents and the media); Doe v. Borough of Barrington, 729 F. Supp. 376, 391 (D.N.J. 1990) (holding that disclosure of a father's AIDS status by a police officer to a neighbor violated his right to privacy, noting that the neighbor, who both worked for the school district and had children in the same school, had alerted other parents and the media).


312. See Bhatnager, supra note 309, at 1476 (describing a health department's inadvertent leak of confidential information).
change them.\footnote{313} For example, the state of Illinois did just this when it
decided that health officials should inform all patients of their health
practitioner’s HIV status—and vice versa.\footnote{314} Although advocates ultimately
persuaded lawmakers to withhold funding for this mandate, the law was
passed and remains on the books.\footnote{315} Similarly, legislatures can choose to
amend confidentiality laws to track HIV-infected people (such as health care
providers or public school teachers) or to determine whether they should be
prosecuted under HIV/AIDS criminalization statutes.\footnote{316}

One could assert that the actual risk of disclosure described herein is
not likely to occur and that if it does, legal recourse would be available. Or,
were the government to misuse lists of HIV-infected individuals collected for
surveillance purposes, its actions would be enjoined were there no
compelling reason for it to do so.\footnote{317} Under this reasoning, the actual social
risk attendant to adopting HIV name reporting might be calculated as not
being terribly significant.\footnote{318}

\footnote{313} See Anna Forbes, Myths and Facts about HIV Case Reporting by Name Versus by Unique Identifier, at http://hiinsite.ucsf.edu/topics/testing/2093.33br-ltml (Oct. 16, 1997) [hereinafter Forbes, Myths and Facts about HIV]:

State privacy laws are only as strong as the legislatures’ will to uphold them. States
can, and do, change their laws regarding privacy all the time. If a state Health
Department has a name-based registry listing people with HIV, it can be forced at
any time to open that registry by either legislative mandate or court order.


\footnote{315} 410 ILL. COMP. STAT. ANN. § 325/5.5(c) (West 2000).

\footnote{316} See Gostin & Hodge, The Names Debate, supra note 46, at 732 (“South Carolina health authorities legislatively are required to cross-check prospective and existing public school teachers against state HIV/AIDS databases.”); Alvin Novick, HIV Surveillance: What’s Hot, What’s Not, 13 AIDS & PUB. POL’Y J., Summer 1998, at 52, 52-53:

Access to a list [(of names)] could be [(and has been)] gained by state law or by
other legal authority. A state might for example pass legislation that anyone
accused of rape or convicted of rape would be checked against a list of persons
reported with HIV disease so that law enforcement authorities could decide
whether to enhance the criminal charges.

\footnote{317} See also Doughy, supra note 295, at 165 (1994) (“[A] legislature (or the voters by referendum) might determine that the welfare of children demands that they not be in the custody of HIV-infected parents, who could be identified using state lists. Prisoners might make another inviting target.”); supra notes 313-14 (discussing how legislators can change confidentiality rules for HIV/AIDS records).

\footnote{318} See supra note 300 (comparing views on whether the potential negative effects of HIV
The Protocol, however, requires law and policymakers to look not just to actual social risk, but also to perceived social risk, as the line between the two is narrow, particularly in terms of how it affects behavior. As described by Scott Burris, "[P]eople's behavior is likely to be governed by the perceived risk," which may or may not be "particularly sensitive to actual probabilities of harm." In other words, at least in the realm of social risk, perception creates the reality. There is little doubt that the identified target populations perceive significant social risk attendant to the adoption of an HIV name reporting proposal. Indeed, there is virtual unanimity among people living with HIV/AIDS and the advocacy organizations representing their interests: they do not trust HIV name reporting and they do not want it implemented.

This increase in perceived social risk may cause significant damage in two ways. First, it may affect decisions to be tested. Second, and perhaps more profoundly, members of the targeted population may understand it as an affront to their human dignity. This type of harm can only serve to undermine the necessary relationship of trust between the government that is seeking to contain epidemics and preserve the public health and its populace.

Application of this step of the Protocol has yielded important information. However, an increase in (actual or perceived) social risk is not reason enough to reject a proposal for HIV name reporting. Rather, lawmakers must proceed to Step Four of the Protocol: determining the legitimacy of the state's interest in enacting such a policy.

name reporting outweigh the positive results).

319. See Burris, Surveillance, supra note 21, at S122 ("The distinction between the threat and the perception of risk emphasizes that the actual danger of harm coming from surveillance is largely irrelevant."); supra text accompanying note 146 (noting that informing a person that it is unlikely that surveillance data will be disclosed may minimize the actual risk, but the perception of risk remains significant).

320. Burris, Surveillance, supra note 21, at S122.

321. Id.


323. See supra notes 299-304 (analyzing the ramifications of HIV name reporting).

324. See supra note 87 and accompanying text (discussing the relationship between trust and enhancing the efficacy of public health programs).
4. Does the Proposal Help Achieve Legitimate Public Health Goals?

Before inquiring about the particular proposal to report the names of people living with HIV, it is important for lawmakers to revisit the state’s interest in surveillance in general. Many public health officials consider surveillance to be the cornerstone of their disease prevention and treatment activities.325 Their primary concern is: how can we know what to prevent or treat, and in which populations, absent using surveillance tools?250 Therefore, when used affirmatively to affect allocation of health care resources, and when appropriate privacy protections are in place, surveillance can help achieve legitimate public health goals.257

AIDS surveillance has been conducted from the very beginning of the epidemic.258 Indeed, it was through the reporting of cases to the Centers for Disease Control and Prevention (“CDC”) that we even learned of this disease.329 For the first years of the epidemic, there generally was very little time from date of diagnosis to death.359 The only way epidemiologists could learn about AIDS was by assessing the patterns of disease manifestation reported to the CDC, which served as an information bank.

The CDC, and other advocates who support a system of HIV surveillance, assert that the development of new drugs, in particular, has rendered AIDS surveillance somewhat anachronistic.331 They maintain that

325. See Garrett, Betrayal of Trust, supra note 11, at 280 (“[A]s early as 1629 American colonists in Virginia realized that they couldn’t protect their people’s health unless they had numbers—hard facts, entered dutifully by quill into log books: births, deaths, illnesses, and marriages were, by law, recorded, chronicling the vital statistics of the colony.”); see also supra Part I.B.3.c (discussing the use of surveillance as a tool for achieving public health goals).

326. See Patricia L. Fleming et al., Tracing the HIV Epidemic: Current Issues, Future Challenges, 90 AM. J. PUB. HEALTH 1037, 1037 (1998) (stating that surveillance of HIV and of AIDS “can improve the allocation of needed prevention and treatment resources to communities”).

327. See Gostin, Burrus & Lazzarini, supra note 10, at 125-26 (setting forth criteria to permit surveillance data collection); Gostin & Hodge, The Names Debate, supra note 46, at 743 (noting that effective surveillance is essential when public health needs are compelling and the practice is mindful of the privacy of the individual).

328. See The Ass’n of the Bar of the City of N.Y., Committees on AIDS, Civil Rights, Health Law, Legal Issues Affecting People with Disabilities and Sex and Law, Name Reporting of HIV Cases 3 (June 1998) [hereinafter ABCNY, Name Reporting] (“Surveillance of AIDS cases including reporting of names of persons diagnosed with AIDS to public health authorities, began almost immediately with little fanfare, as it was a traditional public health approach to learning more about little-understood and serious medical conditions.”); see also supra Part I.B.3.c (discussing the public health tool of surveillance).

329. See CDC, Pneumocystis Pneumonia, supra note 1, at 3 (describing the discovery of the disease).

330. See ABCNY, Name Reporting, supra note 328, at 3 (describing how in the early years of the epidemic, “the harsh reality was that persons with AIDS usually died quickly”).

331. See CDC, Guidelines for National HIV Case Surveillance, supra note 303, at 2 (“With the advent of more effective therapy that slows the progression of HIV disease, AIDS surveillance data no longer reliably reflect trends in HIV transmission and do not accurately represent the need for prevention and care services.”); AIDS Action Council, Creating an Effective Public Health
only by measuring disease distribution from an earlier point and then continuing to monitor disease progression will we be better able to understand patterns of illness and rates of disease progression, and therefore be able to improve both our HIV-related prevention and treatment efforts. Although some question the ability of the government to attain these goals, there is little doubt that achieving them would constitute a legitimate state interest.

5. Is the Proposal the Least Restrictive Alternative?

Since surveillance generally qualifies as a legitimate public health goal, the focus of Step Five of the Protocol is whether HIV name reporting constitutes the least restrictive alternative, or a sufficiently narrowly tailored means, to accomplish legitimate public health goals. As discussed earlier, epidemiologists have a range of surveillance tools available to them to understand the scope of an epidemic. To understand the distribution of a bloodborne disease, they can conduct anonymous tests on blood samples collected at any number of sites, including inpatient hospitals, outpatient treatment centers, sexually transmitted disease clinics, or anonymous testing sites, all of which can be performed in a nonintrusive manner.

However, because the tests by law are conducted on anonymous blood samples, it is

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Response to the Changing Epidemic: Moving to HIV Surveillance by Unique Identifier and Other Non-Name Based Surveillance Systems 4 (Oct. 1997), at http://hivsite.ucsf.edu/topics/testing/2098.347b.html [hereinafter Creating an Effective Public Health Response] ("Because of changes in the epidemic, AIDS Action [a Washington, D.C.-based advocacy group] believes that AIDS surveillance can no longer provide as timely, complete, representative, and accurate a reflection of the epidemic as we need.").

332. See Gostin & Hodge, The Names Debate, supra note 46, at 699 ("HIV, once believed to be a latent infection, has medically been shown to be active from the point of infection. Early detection and treatment is critical to providing individuals infected with HIV the opportunity to live longer without visible symptoms"); Creating an Effective Public Health Response, supra note 331, at 3 ("If planned and implemented carefully and thoughtfully, HIV surveillance can be a valuable tool in fighting HIV and AIDS.").

333. See supra notes 264-65 and accompanying text (providing cases discussing the least restrictive alternative).

334. See supra Part I.B.3.c (discussing the public health tool of surveillance).

335. These tests are conducted on blood collected from patients who otherwise would be having blood drawn. Before the tests are performed, all information that might identify the patient is removed. Only demographic data, such as gender, age, and race of the patient are noted, as well as the identity of the institution where the test was conducted. These tests cannot be conducted unless all identifying information is removed. See ACLU, HIV Surveillance, supra note 300 ("[N]ame reporting is not essential to effectively monitor the epidemic, target prevention, link individuals with HIV to health care, and allocate funding. Existing HIV tracking mechanisms, including sentinel studies and incidence and prevalence surveys, help to accomplish these goals."); Lambda, Comments on the CDC's Draft Guidelines, supra note 297 ("Other established methods of surveillance, such as anonymous seroprevalence surveys of newborns or clients in family planning or STD clinics (where demographic data can be obtained without linking a test result to a particular name), would better determine the extent of HIV infection.")
inherently impossible to conduct follow-up with patients to inform them of their disease condition, to try to facilitate their getting into care, or to learn about their disease progression.

It also is possible to conduct surveillance studies by requiring testing facilities to report data by using a unique identifier, rather than by using a name or other identifying information. Under this type of system, data particular to the individual (such as initials, parts of the social security number, date of birth, race, and gender), and perhaps the identity of the health care provider, are combined in an algorithm that yields an encrypted code; this code is then used to submit disease-related information to government officials without providing any identifying information about the tested individual.

The beneficial aspects of successful unique identifier programs are many; they yield a code either that the individual can recall or that often can be regenerated with that person’s assistance; they cannot be readily decoded, thereby protecting the anonymity of the person who has been tested, and they make it possible continually to update the “person’s” file with information about disease progression. Because epidemiologists have indicated that it would be very helpful to have data indicating how HIV disease progresses, particularly in this relatively new age of effective medications, there is no reason why they could not use the unique identifier for this purpose—posing little to no threat to patient confidentiality.

There are, though, disadvantages to using unique identifier systems. According to some studies, they can be both more expensive and yield less

336. See CDC, Guidelines for National HIV Case Surveillance, supra note 203, at 9-10 (outlining unique identifier surveillance programs). In early 1994, both Texas and Maryland implemented HIV case surveillance through the use of non-name unique identifiers. See CDC, Evaluation of HIV Case Surveillance Through the Use of Non-Name Unique Identifiers—Maryland and Texas, 1994-1996, 46 MMWR 52 (Jan. 9, 1998) [hereinafter CDC, Evaluation of HIV Case Surveillance]. Currently four states use this approach to HIV surveillance. See infra note 341 (listing these states).


338. See Blayer, But Names Will Never Hurt Me, supra note 317, at 1213 (“With unique identifiers, the public health need for HIV information can be fulfilled with less risk to individual confidentiality.”); Anna Forbes, An Activist’s Guide to Unique Identifiers (Nov. 26, 1997), at http://hivinsite.ucsf.edu/topics/testing/2098.331F.html (discussing the high level of privacy afforded by unique identifiers).

339. See CDC, Guidelines for National HIV Case Surveillance, supra note 203, at 4 (concluding that as a result of the advent of more effective medications that slow the progression of HIV disease, states should extend AIDS case surveillance activities to include HIV case surveillance and should improve surveillance of disease progression).

340. See CDC, Evaluation of HIV Case Surveillance, supra note 336, at 1 (noting that Maryland enacted a statute in 1993 requiring health care providers to construct the unique identifier code and record it in a surveillance log for purposes of case investigation and follow-up).
complete results than name reporting systems.\textsuperscript{341} However, states currently using this approach have claimed that any additional expense, excluding start-up costs, is minimal to non-existent.\textsuperscript{342} Moreover, they have concluded that, following an initial period of adjustment, the unique identifier system yields data that are at least as complete as that produced by a name reporting system.\textsuperscript{343}

Some flaws in name reporting systems also are to be expected. As with unique identifiers, it is impossible to rule out both under- and over-reporting.\textsuperscript{344} Also some advocates allege that implementation of a name

\textsuperscript{341} See id. (noting that the implementation of unique identifiers in Texas yielded higher rates of incomplete case reporting, as compared to name-based HIV surveillance); see also AIDS Action Committee of Massachusetts & AIDS Action Council of Washington D.C., Creating an Effective Public Health Response to the Changing Epidemic: Moving to HIV Surveillance by Unique Identifier and Other Non-Name Based Surveillance Systems (Nov. 14, 1997), at http://hivisite.ucsf.edu/topics/testing/2098.347b.html [hereinafter AIDS Action Committee of Massachusetts & AIDS Action Council of Washington D.C., Creating an Effective Public Health Response] ("Unique identifier reporting systems are more expensive and will take more time to successfully implement than name reporting systems . . . . [they] are inherently more complex than name reporting systems, and thus more costly to operate."). Texas ultimately ceased using unique identifiers and adopted HIV name reporting. CDC, 11(1) HIV/AIDS SURVEILLANCE REP. 3 (1999).

\textsuperscript{342} See Forbes, Myths and Facts about HIV Case Reporting, supra note 913:

HIV case reporting costs money to implement, whether names or unique identifiers are used. Maryland and Texas set up their systems after receiving one-time CDC grants of $600,000, allocated to evaluate the systems over three years. Both states report that the difficulty of mounting a unique identifier system was exacerbated by the total lack of state funding, among other factors.

\textsuperscript{344} See also Blayer, But Names Will Never Hurt Me, supra note 317, at 1212 ("[W]hile unique identifier systems have been criticized as cumbersome and expensive, federal funding could make them more effective and cost-efficient. HIV case reporting costs money to implement regardless of the type of scheme used.").

\textsuperscript{343} See News Release, Md. Dep't of Health & Mental Hygiene, HIV Reporting System Found To Be Highly Accurate (Aug. 31, 1999) (announcing the finding that "Maryland's non-name based HIV reporting system has been found to provide a highly accurate and unduplicated count"); Forbes, Myths and Facts about HIV Case Reporting, supra note 313 (noting that the Maryland Health Department reports a 96.6% completeness rate in reporting by state-funded HIV test sites, and that completeness from other testing sites is steadily improving); cf. TEX. DEP’T OF HEALTH, BUREAU OF HIV AND STD PREVENTION, RECOMMENDATIONS ON HIV INFECTION REPORTING, http://www.tdh.state.tx.us/hivstd/facts.htm (abandoning a unique identifier system of HIV name reporting because of insufficient data collection).


With one unique identifier composed of intimate information (so the individual remembers it), a repeat tester can be identified as such and not double counted. The accuracy of names-based reporting, by contrast, depends upon whether the testee uses his or her real name, and the available evidence suggests that many people who are required to give their name when taking an HIV test use a pseudonym to hide their identity.
reporting system will drive people away from being tested or will cause them to seek testing in a non-name-reporting state, resulting in an undercounting or inaccurate understanding of HIV infection patterns.345

It is not necessary to resolve every dispute about the pros and cons of every means of conducting HIV-related surveillance. It is important, however, that the CDC, the widely recognized arbiter of public health standards, accepts unique identifier systems as a legitimate means of gathering HIV-related surveillance data.346 In light of the availability of alternatives to name reporting and the CDC's acceptance of unique identifier systems, a lawmaker or policymaker must conclude that HIV name reporting cannot qualify as the "least restrictive alternative" under the Harm Assessment Protocol.

6. The Outcome of the Harm Assessment Protocol as Applied to HIV Name Reporting

If a proposal does not satisfy the least restrictive alternative prong of the inquiry, it must be rejected. However, this does not mean the state must give up on its attempts to satisfy a particular legitimate public health goal—in this case, HIV case surveillance. Rather, the proposal should be reconfigured to incorporate a less restrictive, or more narrowly tailored, alternative and then run it through the Protocol.347

It is evident that, although any form of HIV-related surveillance is likely to cause some increase in or perception of social risk, a unique identifier system is not nearly as threatening as name-based reporting. Indeed, use of unique identifiers has been endorsed by the vast majority of organizations representing the interests of the populations targeted by this legislative proposal.348 It further is clear from the prior analysis that a unique identifier

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*Cf. Blayer, But Names Will Never Hurt Me, supra note 317, at 1211 ("[T]here will likely be fewer duplication problems with a unique identifier system than with name reporting.").

345. *See supra note 300 (providing differing views on whether HIV name reporting would harm the target population).

346. *See CDC, Guidelines for National HIV Case Surveillance, supra note 303, at 10 (noting that the CDC will continue to assist four states—Illinois, Maine, Maryland, and Massachusetts, along with Puerto Rico, in establishing unique identifier systems). Indeed, the CDC has employed a unique identifier-type system (Soundex) for reporting the names of people diagnosed with AIDS from state health departments to its offices in Atlanta for almost twenty years. See HEALTH INFORMATION AND SURVEILLANCE SYSTEMS BOARD, CDC, SOUNDEX—REFERENCE GUIDE 2, available at http://www.cdc.gov/od/hsinh/docs/Soundex.pdf (Version 1.0, 1999) (explaining the Soundex system). However, the CDC states that it historically has found HIV name reporting to be more accurate than HIV case reporting through unique identifiers. CDC, Guidelines for National HIV Case Surveillance, supra note 303, at 10.

347. *See supra Part II A (setting forth the Protocol); supra fig.1 (graphically depicting its contents).

348. *See generally ACLU, HIV Surveillance, supra note 300 (advocating for a unique identifier system of reporting); Letter from Ad Hoc Committee on Smart AIDS Laws, to Antonia C. Novello, Commission of the N.Y. State Dep't of Health (Jan. 14, 2000), at
system would satisfy the least restrictive alternative inquiry.

The only remaining question under Step Six of the Protocol, then, is whether the state has a compelling interest in conducting HIV case surveillance. We already have accepted that HIV surveillance satisfies a legitimate state interest. Most people (and most courts) would be comfortable concluding that the government's interest in conducting this type of surveillance is compelling because it is expected to lead to a superior understanding of disease progression, improved means of treating the disease, better formulated prevention efforts, and a more accurate allocation of resources for prevention and treatment purposes.\(^349\) It is important, though, that lawmakers conduct ongoing assessments to ensure that the data yielded from the surveillance mechanism are being used to accomplish these important goals. Should surveillance efforts deteriorate to the mere collection of data, without more, the question of whether the government's interest in collecting the data remains compelling, and therefore whether it is appropriate to conduct HIV-related case surveillance, would have to be revisited.\(^350\)

This demonstration of the Harm Assessment Protocol has permitted us to preference the assessment of social risk as experienced by the targeted populations of two modes of disease surveillance: HIV name reporting and

\(\text{http://www.lambdalegal.org/cgi-bin/pages/documents/record?record=556}\) (noting that fifteen organizations, including the Latino Commission on AIDS, LeGaL (Lesbian and Gay Law Association of Greater New York), New York AIDS Coalition, HIV Law Project, Housing Works, and South Brooklyn Legal Services endorsed the use of a unique identifier system for HIV case reporting); AIDS Action Committee of Massachusetts & AIDS Action Council of Washington D.C., Creating an Effective Public Health Response, supra note 331 (supporting HIV surveillance system over an AIDS surveillance system); Tammy Vitano & Marina Gomez, Naming Names: Why We Don't Want Names Reporting, WOMEN ALIVE, Winter 2000, at 8, available at http://thebody.com/wa/winter00/kick.html (summarizing a debate between proponents and opponents of name reporting);

\(^349.\) See supra note 326 and accompanying text (discussing the benefits of HIV surveillance). See generally supra Part I.B.3.c (describing surveillance as a means of achieving public health goals).

Some representatives of people living with HIV would assert that conducting HIV surveillance does not constitute a compelling state interest because surveillance data are rarely put to effective use in disease prevention and treatment. In this instance, they would wish to push the Protocol to its final inquiry: a balancing test between the state’s interest in conducting a particular type of surveillance and the increase in social risk articulated by the targeted populations as attendant to adoption of that approach. Other factors, including pertinent economic ramifications, also are likely to come into play at this point. See supra Part III.A for a description of this stage of the Protocol and supra fig. 1 for a flow chart reflecting this stage of the inquiry.

\(^350.\) Such ongoing assessments likely would be costly. However, without such verification, there is a risk that surveillance could become an end unto itself, rather than a means to an end of reducing disease incidence as well as its attendant morbidity and mortality. See supra Part I.B.3.c (discussing the function of surveillance). Should this occur, the government’s interest in collecting the data would no longer be compelling and, as such, this surveillance activity ought to cease.
HIV case reporting through unique identifiers. Absent this process, it is more likely that public pressure would lead to selection of HIV name reporting as the mode of conducting surveillance.\footnote{See CDC, SURVEILLANCE REP., supra note 1, at 5 (noting that thirty-four jurisdictions in the United States have HIV name-based reporting, including Connecticut and Oregon, where only pediatric cases are reported by name).} Using this Protocol, we have been able to identify a form of surveillance that is substantially equivalent in its effectiveness and significantly preferable to the targeted population than the original proposition. Moreover, by moving the concerns of the traditionally disempowered to the forefront we have enhanced the relationship between state officials and the people who often are most vulnerable to them. Equally important, all of these goals have been met while still protecting the public health.

CONCLUSION

Modern public health law has many failings. It often is inconsistent, mired in historical anachronisms, and insufficiently attentive to constitutional standards. Policymakers must undertake efforts to create coherence with an awareness that experience of social risk—both actual and perceived—plays a crucial role in determining the ultimate effectiveness of public health law and policy.

The Harm Assessment Protocol provides a pragmatic tool for legislators and policymakers to incorporate a social risk assessment into their deliberations. Acknowledging the critiques of autonomy, the recognition of the “moral significance of groups,” and the awareness of the harms caused by social risk, the Protocol seeks to privilege the voices of the disempowered—people who already carry a disproportionate burden of social risk. Indeed, only by engaging in this process are we able to ensure that the interests of the disenfranchised are not overwhelmed by the actions of the majority, no matter how well-intentioned they may be.

Fundamentally, though, the Protocol works because it both attends to the concerns of the disempowered and remains grounded in the legitimate governmental need to prevent and treat disease.\footnote{Indeed, the Protocol could be used not only within the realm of public health law and policy, but also in other substantive areas where there is concern that the voices of the disenfranchised have been displaced from the halls of our legislatures and the offices of our policymakers.} Indeed, it is only by adopting this approach that we can devise and implement public health law and policy that both increases the public trust and enhances the public health.