Winter 1995


Scott Burris

Follow this and additional works at: http://repository.jmls.edu/lawreview

Part of the Health Law and Policy Commons, and the Medical Jurisprudence Commons

Recommended Citation

http://repository.jmls.edu/lawreview/vol27/iss2/2

This Symposium is brought to you for free and open access by The John Marshall Institutional Repository. It has been accepted for inclusion in The John Marshall Law Review by an authorized administrator of The John Marshall Institutional Repository.
PUBLIC HEALTH,  
"AIDS EXCEPTIONALISM"  
AND THE LAW  

SCOTT BURRIS*

In 1991, Ronald Bayer wrote an article for the New England Journal of Medicine in which he identified something called "AIDS exceptionalism," and predicted its demise in the second decade of the HIV epidemic.¹ In Bayer's account, the response to HIV in the 1980s had been shaped by "an alliance of gay leaders, civil libertarians, physicians, and public health officials"² who opposed applying to HIV the "broad statutory provisions established to control the spread of sexually transmitted and other communicable diseases."³

As the second decade of the epidemic began, Bayer argued, "the effort to sustain a set of policies treating HIV-infection as fundamentally different from all other public health threats will be increasingly difficult. Inevitably, HIV exceptionalism will be viewed as a relic of the epidemic's first years."⁴

Bayer's was the most elegant, but by no means the only, articulation of the idea that we could best understand the first decade of AIDS policy by calling it "different" from past public health practice. Influential doctors like Marcia Angell of the New England Journal of Medicine, public health officials like Stephen Joseph, and politicians like William Dannemeyer all made a similar suggestion, albeit from drastically different perspectives.⁵ Angell worried

---

* Assistant Professor of Law, Temple Law School. I am indebted to Robert Swenson, M.D., with whom I have been enjoying for the past year a continuing and most enlightening conversation about medicine and public health. I would particularly like to thank Daniel W. Fox, Harlon Dalton and Michael T. Isbell for helpful comments on the manuscript. Research for this essay was supported by a grant from Temple Law School.

2. Id. at 1500.
3. Id. at 1501.
4. Id. at 1503.
that we were failing to distinguish between "social" and "epidemiological" problems, the former requiring policy innovation and the latter requiring the application of proven measures. Joseph suggested that more effective treatment and even preventative interventions would soon require "a shift toward a disease control public health approach" along the lines of traditional tuberculosis control and away from voluntarism and education. Dannemeyer criticized public health officials for deploying politically-grounded educational measures instead of the "basic techniques" traditionally applied against communicable disease. The claim was more or less specific, and the blame for the phenomenon variously assigned, but the lament at the core of all these accounts of policy exceptionalism came down to this: why can't we just cut the politics and the rights talk and get back to the science, to what works, to what we used to do?

This complaint is less a justified reaction to a politics of "exceptionalism" than a form of sentimentalism, an evocation of a drastically oversimplified present in the cause of retrieving a past that never was. Yet while the "AIDS exceptionalism" most clearly delineated by Ron Bayer never quite existed, the underlying question of how AIDS policy compares to the response to other past and present health threats is well worth pursuing.

HIV is not unique among diseases in provoking controversy. It is not necessary to rehearse the many ways in which the general social response to HIV has been very much like that accorded the killer diseases of the past. The claim that the response to HIV has been different in being politicized is fundamentally ahistorical, overlooking that virtually all major public health measures have inspired political disputes at one time or another. Even the sympathetic commonplace that HIV is uniquely stigmatizing is only true relative to other present health threats; in their prime, cholera, tuberculosis, and syphilis were all badges of vice and dissipation. The passions that disease can inspire are what make public health as much a political art as a bio-medical science. HIV fits well into a tradition of vigorous policy dispute and social tension. I will elaborate this point first.

It is also interesting to consider how HIV relates to other health threats. HIV, as a virus, has properties that make it differ-
ent from other disease-causing microbes. The particular pattern of its spread depends upon contemporary social conditions that are different from conditions of the past. HIV was revealed suddenly, as an epidemic, and epidemic diseases have generally been seen as alarmingly different from more ubiquitous killers societies have learned to bear. The drama and biological peculiarity of HIV should not, however, obscure its similarity to other leading killers, like cancer, heart disease, and accidents. All of these ways of dying can be attributed to behavior, to our culture, and to its values as they are expressed in socially constructed options and individual choices. All of the ways of dying challenge public health to develop effective, long-term social learning strategies to change dangerous behavior, and in so doing all of them pose questions about the government's role in manipulating the lives of the people.

One might justly question whether it is even accurate to assert that "traditional" health measures have not been applied to HIV. As Bayer himself noted in a later article, during the HIV epidemic, twenty-five states passed revised health laws authorizing coercive action against HIV-infected people engaging in dangerous behavior, and nineteen states passed HIV-specific criminal laws. AIDS is a reportable disease throughout the country, and HIV is reportable in some way in half the states. Public health agencies in many cities have used their summary powers to close or modify bathhouses and other sites of free sexual activity. Legislation mandating screening of various sorts of people, like prostitutes and prisoners, has been common. Even if we suppose that a doctrine of exceptionalism has carried the day among health policymakers, the measures actually enacted by state legislatures across the country reflect, at best, the failure of life to match the elegance of theory.

Of course, the argument for exceptionalism does not rest on the many "traditional" measures that have been applied to HIV, but on the undeniably new ones. Even if it is correct to say that the response to HIV is unexceptional in being shaped by contemporary society, the exceptionalists are equally correct in the view that people with HIV have enjoyed unprecedented legal protection of their social status. The final portion of this essay talks about this legal

---

7. Ronald Bayer & Amy Fairchild-Carrino, AIDS and the Limits of Control: Public Health Orders, Quarantine, and Recalcitrant Behavior, 83 Am. J. Pub. Health 1471 (1993). Isbell makes the converse point, that the idea of a non-coercive, social learning strategy against HIV has been imperfectly translated into practice: "By focussing on the earlier voluntarist consensus in academic public health circles, Bayer obscures the government's failure to implement an adequate set of voluntarist policies." Isbell, supra note 1, at 165.

8. Although even this requires some qualification. While there has never before been such a wealth of positive law protecting the work, housing, and privacy rights of people with communicable disease, concern about these issues has played a role in health policy. For example, doctors who opposed reporting of tuberculosis and syphilis at the turn of the century commonly argued that
protection, focusing on antidiscrimination law following the Supreme Court's decision in *School Board v. Arline*. Conceding that this aspect of the policy response to HIV is something new, I offer a very different account of its meaning and implications than the exceptionalists. Rather than a political concession to effective advocates, the legal protection of people with HIV was an ambitious effort to control, even to change, the social fears that had traditionally made disease control more difficult. Like Justice Brennan, I believe that this is consistent with, not antagonistic to, public health, and unlike the exceptionalists, I do not believe that the public health rationale for such an approach is losing its force. My fear is not that protecting people with HIV has been a compromise with effective disease control, but that the rule of *Arline* may not be strong enough to overcome the exceptional fear and revulsion that HIV and other killer diseases traditionally inspire.

I. SOME THOUGHTS ON AIDS EXCEPTIONALISM AND PUBLIC HEALTH SENTIMENTALISM

AIDS, how is it different? how the same? What a rich vein of inquiry, running beneath so many different terrains. "For the social scientist," Charles Rosenberg wrote, "epidemics constitute an extraordinarily useful sampling device—at once found objects and natural experiments capable of illuminating fundamental patterns of social value and individual practice. Epidemics constitute a transverse section through society, reflecting . . . a particular configuration of institutional forms and cultural assumptions." Any number of people have taken Rosenberg's cue and studied the complex data. Susan Sontag has considered *AIDS and its Metaphors*. Harlon Dalton meditated upon the meaning of AIDS to African Americans. Fee and Krieger wrote of the effort to construct AIDS in the familiar form of past plagues. Mushenow and colleagues have examined judicial behavior in HIV cases. And the list could go on for pages.
The argument that HIV was being treated exceptionally appeared rather early in the epidemic as an instrument of public health politics. Alvin Novick writes:

The view that AIDS advocates had a gay agenda that was in serious conflict with a proper public health agenda permeated the policy decisions of the Reagan years and was often addressed, directly and obliquely, by Patrick Buchanan and Gary Bauer, both of whom had significant staff positions in the Reagan White House. The concept that federal health policy ought to include, or to be directed, at members of groups who were traditionally ostracized and stigmatized, who had already proved to be particularly vulnerable to HIV infection, was anathema to members of the Reagan administration.

And so they cast the battle as gay rights versus public health, an articulation now easily recognizable as radically conservative.16

Largely serving the needs of rhetoric, this brand of “exceptionalism” is not an account of HIV and its many forms of meaning and being, but an “-ism,” an enemy ideology which systematically derives a public health policy against HIV from the premise that the disease is essentially different from any other. This is a convenient rhetorical device for advocates of a return to public health “tradition,” inasmuch as the premise is so patently untenable, and the conclusion that policy must surely change follows easily. One hopes that Pat Buchanan speaks for a minority of the uninformed, but the belief that HIV has been treated “differently,” and for purely political reasons, is widely and sincerely held. But has it been? What are the chief elements of this exceptionalism, and how well do they withstand serious scrutiny?

An argument that HIV has been treated differently requires a set of disease that have been treated “the same.” There must be a norm for there to be deviance. Bayer’s history runs like this:

[I]t is necessary to recall that conventional approaches to public health threats were typically codified in the latter part of the 19th or the early part of the 20th century. Even when public health laws were revised in subsequent decades, they tended to reflect the imprint of their genesis. They provided a warrant for mandating compulsory examination and screening, breaching the confidentiality of the clinical relationship by reporting to public health registries the names of those with diagnoses of “dangerous diseases,” imposing treatment, and in the most extreme cases, confining persons through the power of quarantine.17

This account is indisputable, but on its face it is a statement about law, not practice, and so as a description of history it verges on the tautological. It captures a common sense of the past among some proponents of a “traditional” HIV policy, but this sort of memory is too short and happy, failing to recall that virtually all these supposedly well accepted measures were at one time or another vigorously

17. Bayer, supra note 1, at 1500.
disputed. This sort of memory is too fuzzy, supposing that these measures were accepted as Platonic ideals, rather than as applied in particular context to particular diseases. And thus, this sort of memory fails to reach the most important question for health policy: why are particular measures accepted as applied to some diseases and not as to others?¹⁸

The answer to this question resides in considering the complex interaction between ideas about disease, disease control, and the proper role of the state. The common practices of health agencies through most of this century reflected a certain “technology” of disease control—by which I mean a set of measures and an understanding about how, when, and to whom to apply them—and a social attitude towards that technology and its deployment by the state. Both the technology and social attitudes about its use were rooted in the revolution in biology (and the social status of medicine), entailed in the discovery of specific microbial causes of disease. The success of the germ theory over the last years of the nineteenth century was breathtaking. W.T. Sedgewick, a Massachusetts biologist and public health worker, put it this way: “before 1880 we knew nothing; after 1890 we knew it all.”¹⁹ The ability to develop vaccines, diagnostic tests, and effective treatments or cures were factors in a general trend to conceive of public health problems as susceptible chiefly to individual medical therapy, a view that “also provided a rationale for public health officials to disengage themselves from commitments to moral and social reform” that had animated the public health program of the nineteenth century sanitarions. The job of public health on this view was to find patients, and to make sure they got the necessary treatment.²⁰

This approach to public health seemed to work. One by one, diseases like tuberculosis, syphilis, polio, diphtheria, and measles were “conquered” by wonder drugs or vaccines. Smallpox was actually eradicated. So successful was this medical strategy, which was actually implemented more by doctors in the private health care system than public health care workers, that the various health laws authorizing compulsory testing, treatment, or isolation were almost never actually applied.²¹ By the 1970s, funding for venereal

---

18. Consider Rothman's explanation for the acceptance of coercive measures against tuberculosis carriers early in this century: "Almost no one protested the departments' power to incarcerate persons with tuberculosis, particularly as it became evident that they would exercise their authority almost exclusively against the vagrant and the uneducated immigrant." Rothman, supra note 8, at 292.


21. Bayer, supra note 1, at 1500.
disease and TB control began to decline. Many states repealed pre-marital screening statutes as no longer necessary.

Given the infrequency of their use, and their deep roots in a medicalized approach to public health, the acceptance of a set of measures for measles and tuberculosis and hepatitis is far more contingent than public health sentimentalists suggest. Acquiescence to inaction is hardly acceptance, particularly given the resistance that often arose when traditional measures were applied. In a larger sense, the argument that measures like screening and disease reporting have been accepted implies that the polity (or at least the targets of the measures) analyze health measures abstractly. The fact that couples took gonorrhea tests as part of getting a marriage license, or later allowed their newborns to be tested for PKU, does not constitute an acceptance of screening as a technology to be applied to any other condition; just as it is not illogical for people who do not actively oppose the reporting of measles to oppose government collection of data about sexual intercourse. 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.

The sentimental account of twentieth century public health plays on a sprightly theme of historical progress. If one were indelicate enough to mention that quarantine was vigorously opposed by anticontagionist doctors (and laypeople whose livelihood depended on unfettered commercial trade) throughout the late eighteenth and nineteenth centuries, or that disease reporting was actively or passively opposed by physicians throughout the nineteenth century, the response would undoubtedly be that "we've put all that behind us." Once a measure has won its place in the public health

---

22. Rothman writes:
[T]o review the history of policy towards tuberculosis in the period 1890-1940 is to find not department of health hegemony over the sick but protracted wars between officials and those with the disease. Regulations which gave health officials authority over persons with tuberculosis also led to a game of seek and hide. Health officials tried to identify, track and isolate patients. Sanitoriums tried to enforce a restrictive regimen for indefinite periods. Patients subverted the rules or absconded. 
Rothman, supra note 8, at 294.


24. See, e.g., Daniel M. Fox, Social Policy and City Politics: Tuberculosis Reporting in New York, 1889-1900, 49 BULL. Hist. Med. 169 (1975). Today, we continue to see major disputes about government data collection. One of the more important Supreme Court cases on privacy, Whalen v. Roe, 429 U.S. 589 (1977), concerned the reporting by pharmacists of certain drug prescriptions. For many years, there has been debate (and delay) over governmental efforts to collect data on American's sexual practices, which is nothing more than behavioral risk factor surveillance.
armamentarium, all disputes are forgiven and forgotten. But again, this is too convenient. The technology of public health has surely undergone refinement. We can collect and analyze information much better than we could in 1893, but the technology is only part of the question. The development of public health practices is neither automatic nor fixed. The same basic sort of measure may be accepted for one disease but not necessarily for another. Thus, smallpox vaccination did not automatically win public acceptance because it was an improvement over variolation, any more than the general acceptance of partner notification for venereal disease control compelled its acceptance as applied to HIV. The same or better measure, even as applied to the same disease, may have a very different meaning from one time or community to another, and the differing social constructions of different diseases may be far more powerful in shaping the acceptance of a measure than its abstract attributes or its history as applied to other conditions. The use of public education as a weapon against venereal disease in the past hundred years is a case in point.25

The notion of progress, when applied to legal doctrine, can also give a deceptive veneer of coherence to the rather disorganized legal treatment of HIV issues in state and federal agencies, courts and legislatures. Some states require HIV reporting, some do not. Some require testing of rape suspects, some virtually ban it.26 One court allows discrimination against a firefighter with HIV, another condemns it.27 One finds that firing a nurse with HIV was discrimination, another the appropriate exercise of supervisory authority.28 Legislation and adjudication reflect local passions and an uneven diffusion of or interest in information about HIV and its control. The idea that early HIV policy was systematically shaped by an ideology of exceptionalism conveniently allows the sentimentalists to declare, based on the adoption of a few screening statutes here and some HIV reporting there, that a pattern of exceptionalism is being replaced by a trend toward "same-ism."

Finally, exceptionalism allows the complexity of HIV policy to be reduced to a bilateral conflict between gay men and civil libertar-

25. See generally BRANDT, supra note 6.
28. Compare Leckelt v. Board of Comm'rs of Hosp. Dist. No. 1, 909 F.2d 820 (5th Cir. 1990) (private action under § 504 of the Rehabilitation Act) with Letter from Davis A. Sanders, Regional Manager, Office for Civil Rights, Regional Office VI, Department of Health and Human Services, to R. James Kellog, Counsel for Kevin Leckelt (Dec. 13, 1989) (on file in Re Terrebone General Medical Center, OCR Docket No. 06-87-2001) [hereinafter HHS Letter] (same complainant's administrative claim against employer).
ians, and traditionalists. Politics and rights are opposed to public health and the general welfare. The whole enterprise is cast as a zero-sum game, so that the declared trend towards more "traditional" policies at once supports and is supported by the claim that the influence of the original advocates of exceptionalism has begun to wane. Ron Bayer takes this interest group model one step further, suggesting that the steadily increasing proportion of darker and poorer people in the HIV-infected population is the epidemiological equivalent of gerrymandering: "Not only do black and Hispanic drug users lack the capacity to influence policy in the way that homosexual men have done, but also those who speak on their behalf often lack the singular commitment to privacy and consent that so characterized the posture of gay organizations.

It has been my experience that gay and civil liberties organizations have had a certain amount of influence that has neither waxed nor waned in any dramatic way and that rights claims, both in politics and in litigation, are normally a lawyer's way of talking about bad health policy, rather than an assertion that public health must be subordinated to individual autonomy. "Privacy and consent" are also ways of discussing inclusion and social safety, and in health disputes they have often been impossible to disentangle from legal and practical concerns about discrimination. Nothing leads me to believe that advocates for Black or Latin people with HIV are not very concerned about these issues, even if they frame them in terms of empowerment or a fairer use of social resources.

The prime question the sentimentalists account begs, however, is, why have public health agencies listened to, much less negotiated with, people with HIV? The answer, of course, is not that the Lambda Legal Defense Fund and the ACLU are politically powerful enough to veto any measure they oppose—that claim is belied by the sheer number of terrible HIV policies and statutes enacted across the country. Nor is it because civil rights lawyers can credibly threaten to get undesirable HIV laws overturned after passage, because here the record is one of virtually total failure. The reason that public health policy-makers "had no alternative but to negotiate the course of AIDS policy with representatives of a well-

29. Bayer, supra note 1, at 1503.
30. Id. at 1503.
organized gay community and their allies," and that they will heed the less well-organized voices of drug users, is that health measures that inspire serious resistance among their objects are health measures that will not work. Public health agencies possess the authority, but not really the power, to coerce. Consider, for example, Illinois’s premarital HIV-testing statute, a “traditional” measure miraculously enacted over the objection of the ACLU, and rendered a nullity by the widespread willingness among the marrying kind to take their nuptials elsewhere. Developments in public health practices do not reflect the triumph of one ideology over another, but the continued working of an adaptive process of social negotiation.

Nevertheless, in some important ways, neglected in the sentimental story of exceptionalism, HIV has not challenged the traditionalists’ account of public health. For example, most of the money (and most of the advocacy) related to AIDS goes into medical research and treatment. Prevention, given lip service as the only way to stop the epidemic, remains a stepchild of medicine. To the degree the response to AIDS has challenged the medically-centered view of health, however, the challenge is not just to particular measures, but also to the cultural and technological assumptions whose imprint they bear, and indeed the challenge is not raised by HIV advocates alone. As Bayer notes, a public health strategy based on delivering a medical solution to a biological problem has far less force when applied to a behaviorally transmitted disease for which there is no cure, an inconvenience that also makes screening and partner notification less apt. But even were there a cure or vaccine, it would not follow that a traditional strategy would be in order.

Demographic research over the past thirty years has undermined the claim that medical measures were responsible for the dramatic decline of communicable disease since the eighteenth century. Experience with venereal disease and tuberculosis has

33. Bayer, supra note 1, at 1502.
34. As Starr has said, “authority signifies a potential to use force or persuasion, though paradoxically authority ends when either of these is openly employed.” Starr, supra note 20, at 9.
36. Bayer believes that the availability of early treatment is one of the forces leading to the end of exceptionalism. Unfortunately, much of the promise of early treatment apparent at the time Bayer wrote has (perhaps temporarily) dissipated.
37. See, e.g., Thomas McKeown, The Rule of Medicine: Dream, Mirage, or Nemesis? (1979); J. McKinlay & S. McKinlay, The Questionable Contribution of Medical Measures to the Decline in Mortality in the United States, 55 Milbank Q. 405 (1977) (arguing that the introduction of specific medical measures and the expansion of medical services are not responsible for most of the
driven home the point that even the best magic bullets cannot penetrate social barriers to their delivery. Commentators have recognized and wrestled with the frequent disjunction between medical measures promoting individual health and efforts to promote the health of the population as a whole. For many, the future of public health lies less in getting medicine to the sick than in changing the social and physical environment to produce fewer sick people. Instead of concentrating on the delivery of medical interventions, "Public Health, itself a broad social movement, must in turn generate a succession of specific social movements to deter addictions such as cigarette smoking, to shift cultural predilections from unhealthy to healthy foods, or to alter the intimacies of gender scripts that promote the sexual transmission of disease." For anyone who thinks this way, the tradition that produced a public health strategy focusing on the identification, control and medical treatment of sick individuals is questionable not just as applied to HIV, but also to the diseases against which it was supposedly traditionally applied.

II. AIDS AS A TYPICAL AMERICAN PUBLIC HEALTH THREAT

HIV, like all diseases, interacts with its environment in a way that reflects the peculiarities of both the virus and the community in which it exists. It is, in other words, unique but not exceptional. For all its uniqueness, however, it is important to see that HIV has much in common with other leading health threats in the United States. Rather than regarding HIV as a throwback to the communicable diseases of the past, we can profitably think of it in the company of other chronic, behaviorally linked threats of affluence—overnutrition, substance abuse, environmentally caused harms.

Public health has been dominated in this century by doctors, by people who tended to think of illness and health in individualistic, biological terms. There is an alternative view, one that under-
stands health as an attribute of communities in social and physical environments. On this view, ill health is a complex phenomenon dependant on an interaction of social, biological, genetic, and psychological factors. Improvements in the population's health can often best be achieved by promoting healthful changes in the social and physical environment.43

Applying this alternative, ecological perspective, McGinnis and Foege have recently identified the leading nongenetic causes of death in the United States.44 Their classification system looks past immediate causes of death, based on clinical criteria, to the root causes of ill-health in the social and physical environment. They found that the leading killers in the U.S. today are tobacco (400,000 annual deaths), diet and activity patterns (300,000), and alcohol (100,000). HIV disease was attributed primarily to two causes, sexual behavior (which killed 30,000 people, including most of the 25,000 annual HIV deaths), and illegal drug use (20,000 total, including approximately 9,000 from HIV).

Seen in this light, HIV seems much less exceptional than when we think of it as a sudden viral invader, a throwback to the bubonic plague. It is one of a number of causes of death, like cancer or stroke or heart attack, which medical care alone can do relatively little to prevent or cure, and which can itself be attributed to culturally determined patterns of behavior. That HIV is lethal and incurable makes it like, not unlike, the other leading sources of mortality in America. The focus on behavior change as a primary means of reducing the toll of HIV is likewise unexceptional. Once we accept that ill-health is caused as much by the social and physical environment as by particular microbes or mutations, it follows that reducing ill-health depends heavily on "social learning" strategies, interventions that aim to change the values, preferences, and behavior of the population.45

Disputes between the ecological and medical models of disease are quite common today, at all levels from methodology to the competition for funding. Surgeon General Elders, for example, has made a point of exposing the statistic that only three percent of the

---

43. Whether or not, for example, there are genetic co-factors for lung cancer, the most significant cause by far is smoking and the social forces that encourage it. Preventing smoking is, thus, more important to public health than treating cancer. This is not to suggest that medical care is not a concern of public health. Rather, the example serves to challenge the notion, so painfully prevalent in the current medical care reform debate, that health care is a proxy for public health.


money spent on "health" care goes to preventive measures.\textsuperscript{46} There is debate about the success of particular interventions, like blood pressure screening and treatment, in reducing particular conditions, and about how to measure their success.\textsuperscript{47} In research that finds a link between political empowerment and health, the imperative for social change over medical treatment becomes overwhelming.\textsuperscript{48} Insofar as the twentieth century public health tradition to which Bayer refers takes a more individualistic, medical view of disease, all the leading modern killers challenge that tradition.

This view of disease and health implies a role for government in the shaping of healthier behavior along the full spectrum of social activity. Publicly-funded HIV education has provoked strong reactions among people who think that it endorses (homo)sexuality or drug use,\textsuperscript{49} but this is not really so different a sort of objection than the claim that measures against smoking infringe upon individual choice, or that limits on violent television would be an impermissible intrusion into freedom to offer or receive ideas. Just as nineteenth century sanitary measures required unfamiliar government meddling with property rights, confronting the problem of unhealthy behavior infringes upon the presently privileged realms of "privacy" and "speech."\textsuperscript{50} Perhaps even more unsettling than that, the prospect of the government purposefully manipulating our personal behavior offends the notion that we are autonomous beings making free choices in a marketplace of lifestyles (and, still, occasionally, an idea).\textsuperscript{51}

There are good reasons to continue to propose and debate measures to change social values and behavior in a healthy way. My own view is that this sort of government manipulation of our desires is a proper use of collective power in a culture where commercial manipulation of individual desires is a billion dollar business. But whether we are talking about AIDS, smoking or bacon double cheese burgers, the same sorts of issues arise. Here, too, HIV is unexceptional.

\textsuperscript{46} Elders, supra note 40, at 2293.
\textsuperscript{48} Thomas A. LaVeist, Segregation, Poverty and Empowerment: Health Consequences for African Americans, 71 MILBANK Q. 41 (1992). If people are sick, in part, because of social injustice, then perhaps medical care is the opium of the secular masses.
\textsuperscript{49} See Scott Burris, Education to Reduce the Spread of HIV, in AIDS LAW TODAY: A NEW GUIDE FOR THE PUBLIC, supra note 26, at 82.
\textsuperscript{51} HOWARD LEICHTER, FREE TO BE FOOLISH: POLITICS AND HEALTH PROMOTION IN THE UNITED STATES AND GREAT BRITAIN (1991).
III. EXCEPTIONALISM REVISITED: THE LAW

In the *Arline* decision, Justice Brennan eloquently described an exceptionalism whose essence is the different treatment of the sick based on the unique terrors they inspire rather than on the actual risks they pose. This, *Arline* held, was a traditional evil Congress had remedied in the Rehabilitation Act. Henceforth, sound medical judgments would replace reflexive fears and mythologies. In rejecting this unique mode of discrimination in a tuberculosis case, the Court set the standard for HIV litigation and provided a mode of analysis that Congress adopted in a series of civil rights statutes culminating in the Americans with Disabilities Act. But the force and clarity of the *Arline* rule may not be enough to overcome the fear that HIV provokes, at least under some circumstances. Recent cases involving health care workers with HIV suggest that this form of exceptionalism is not coming to an end but thriving.

Like many famous Supreme Court decisions, *Arline* offered a "test." Discrimination would only be allowed in the presence of a "significant risk" to the health or safety of others, which the court left undefined but which depended on the analysis of four factors extracted from the brief of the AMA: "(a) the nature of the risk (how the disease is transmitted), (b) the duration of the risk (how long is the carrier infectious), (c) the severity of the risk (what is the potential harm to third parties) and (d) the probabilities the disease will be transmitted and will cause varying degrees of harm."53

In the context of an opinion that acknowledged that people with communicable diseases had traditionally faced discrimination because of irrational fear, and talked about replacing "such reflexive reactions to actual or perceived handicaps with actions based on reasoned and medically sound judgments,"54 this test seemed clear enough. A risk would not be significant unless, as a threshold matter, the activity at issue posed a real chance of HIV transmission. If the chances of transmission were de minimis, or compared favorably with other fatal risks that are generally accepted in daily life, then the fatal consequences and the perpetual duration of the risk would be irrelevant. In most cases, the four part test would boil down to one issue, "the probabilities the disease will be transmitted."55

---

53. *Id.* at 288 (quoting Brief for the American Medical Association as Amicus Curiae, at 19).
54. *Id.* at 285.
55. This reading was supported by other specific locutions in the decision, such as a note that a person "who poses a significant risk of communicating an infectious disease" would not be protected. *Id.* at 287 n.16. Furthermore, it conformed with the overall logic of the decision: nothing in the Court's interpre-
Courts applying section 504 in schools and workplaces seemed to read Arline this way, and so did Congress in its subsequent disability legislation. In the legislative history of the ADA, for example, the standard was phrased as a significant probability of substantial harm. Most recently, the EEOC's regulations for Title I of the ADA defined a direct threat (the ADA's formulation of significant risk) as a "high probability of substantial harm." In the District of Columbia, a court has followed this approach in a case involving an HIV-infected health care worker.

This is not to say there were not early departures from this view of the rules. A telling example was the district court opinion in Chalk v. United States District Court, an HIV-infected teacher's effort to enjoin his employers to allow him to return to classroom teaching. The teacher, Vincent Chalk, presented a great deal of evidence, including publications of the Surgeon General and the Centers for Disease Control, that there was "no known risk of non-sexual infection in most of the situations we encounter in our daily lives," including school. Against this, the defendant had only the concern of its experts that there might be as-yet-undetermined modes of transmission. The district court sided against Chalk, trying at least two routes around Arline:

Now, here, according to present knowledge, the risk probably is not great because of the limited ways that medical science believes the disease is transmitted. But, of course, if it is transmitted the result is horrendous.

... [T]he problem is that we simply do not know enough about AIDS to be completely certain. The plaintiff has submitted massive documentation tending to show a minimal risk. But I think it's too early to draw a definite conclusion.


58. 29 C.F.R. § 16.02(r) (1993).


60. The unreported opinion is quoted in Chalk v. United States Dist. Court, 840 F.2d 701, 707 (9th Cir. 1988).

61. Id.
Reversing, the Court of Appeals emphasized the unfairness and irrationality of requiring complete certainty. The appellate court did not mention that the notion that there are modes of casual HIV transmission somehow undiscovered is a serious distortion of the epidemiological evidence, nor that to require the plaintiff to prove that transmission cannot happen ignores the case law placing a burden on defendants to produce reasonable evidence that the plaintiff poses a significant risk.62

Interestingly, the appellate panel also elected to ignore the district judge’s comment about the horrible consequences of infection—which was, at least, a consideration in the Arline test. For the panel in Chalk, there was evidently no doubt that Arline required a threshold finding of a significant risk of transmission before evaluating the other factors. But while the argument that “we don’t yet know enough about AIDS” has proven to be a consistent non-starter in litigation, the argument from the third prong of Arline has found a firm, if undeserved, place in the law.

This prong was seized upon later by courts searching for a rationale for banning HIV-infected health care workers.63 Kevin Leckelt was a licensed practical nurse whose employers at the Terrebone General Medical Center ("TGMC") suspected of being HIV positive. They demanded a test, and, fearing for his job, Leckelt refused to comply. He was fired “for insubordination” and sued.64 An investigation by the office for civil rights of the Department of Health and Human Services concluded that Leckelt had been discriminated against in violation of the Rehabilitation Act.

It is evident . . . that, upon learning of the situation, the TGMC contemplated the option of terminating the complainant.

That option was never dismissed; had the complainant presented positive results, the TGMC planned to place him on leave “pending further review and advice from legal counsel and the Hospital Board.” This plan differs from the various infection control procedures submitted [to investigators] by the TGMC and underscores the fact that the TGMC viewed this as a special or unusual circumstance. . . . There is

62. If a plaintiff makes out a prima facie case of discrimination, the burden shifts to the defendant to show that the plaintiff was not “otherwise qualified,” i.e., that the plaintiff poses a significant risk. See, e.g., Pushkin v. Board of Regents, 658 F.2d 1372, 1387 (10th Cir. 1981); Doe v. District of Columbia, 796 F. Supp. at 570.


64. My ill opinion of the Leckelt decision is a matter of personal experience as well as detached analysis. I was one of the attorneys who represented Leckelt in his appeal to the fifth circuit.
no indication that the TGMC at any time suggested that his concerns [about discrimination] were not valid or that it was only following its stated infection control procedures.\(^{65}\)

The district court saw things differently and, in a confused opinion that among other things determined that the CDC had recommended mandatory testing of health care workers and that changing an intravenous needle was an invasive procedure within the meaning of the CDC guidelines, found no violation of the law. On appeal, the fifth circuit treated the case as one about the right of a hospital to enforce its infection control procedures, casting Kevin Leckelt as a deceitful and disease-ridden homosexual who refused to comply with a reasonable request for necessary information.\(^{66}\)

Though the opinion could thus be read as a narrow one, with the firing deemed to have been based on the "insubordination" rather than on the protected disability, the decision logically depended on the hospital needing to know if Leckelt was HIV-positive. If in fact he did not pose a significant risk, then it would presumably be discrimination to subject him to a unique testing requirement based solely on his perceived HIV status. (Of course, if he did pose a significant risk, he could be fired even if he did tell his employers of his HIV status—this was the opinion's covert catch-22.) So the opinion had to deal with, if not literally decide, the significant risk issue, and it was stuck with one of the district court's most accurate (but, as to its decision, incongruous) findings of fact, that the risk of HIV transmission from health care worker to patient was "extremely low" and "can be further minimized with the use of appropriate universal precautions":

Leckelt contends that it was not necessary for TGMC to require that he submit the results of his HIV antibody test because even if he were infected with HIV, he would not have posed a significant risk of transmission as a licensed practical nurse. At first glance, Arline seems to require that district courts make a specific finding in this respect. ("A person who poses a significant risk of communicating an infectious disease to others in the workplace will not be otherwise qualified for his or her job if reasonable accommodation will not eliminate that risk." (emphasis added)). It is clear, however, that the probabilities of whether an infectious disease will be transmitted is but one of four relevant factors.

\[\ldots\]

\[\ldots\] Even though the probability that a health care worker will transmit HIV to a patient may be extremely low \ldots, there is no cure for HIV or AIDS at this time, and the potential harm of HIV infection

\(^{65}\) HHS Letter, supra note 28, at 8.

\(^{66}\) The hospital's suspicion of Leckelt was based on the death of his roommate from AIDS. A hospital employee knew "that Leckelt was known to be homosexual. It is undisputed, and indeed virtually common knowledge, that homosexuals are a high risk group for contracting HIV and AIDS." Leckelt, 909 F.2d at 826. Thus, it was "reasonable" to make the exceptional demand that he be tested to confirm his HIV status (and, presumably, his homosexuality).
is extremely high.\textsuperscript{67}

With that bold statement of the obvious, the court blustered its way past the absence of any evidence, or even a serious claim, that any patient of Leckelt's was ever going to get HIV.

The same court took a similar tack more recently in a case involving a surgical technician with HIV, Thomas Bradley. "While the risk is small, it is not so low as to nullify the catastrophic consequences of an accident. A cognizable risk of permanent duration with lethal consequences suffices to make a surgical technician with Bradley's responsibilities not 'otherwise qualified.'"\textsuperscript{68}

This doesn't reflect a very careful reading of \textit{Arline}, and as risk assessment it is aggressively simpleminded. In this logic, the horror of an AIDS death makes statistics irrelevant: an oft-repeated riposte to the evidence of low risk is that "the victim of infection with this rare but fatal infection can hardly be consoled by the odds,"\textsuperscript{69} or "[s]urely it is no consolation to the one or two individuals who become infected after innocently consenting to medical care by an unhealthy doctor that they were part of a rare statistic."\textsuperscript{70} The consequences of a risk are certainly a factor in a sensible risk assessment: the more terrible they are, the lower the possibility of occurrence must be to make the risk worth running.\textsuperscript{71} But fatality per se hardly requires a conclusion that a risk is significant. All fatal risks pose a risk of fatality, and every rare event takes its toll on someone who, gets no comfort out of the awful extent of their rotten luck. The notion that the mere possibility of fatality equates

\textsuperscript{67.} Id. at 828. Cf. HHS Letter, \textit{supra} note 28, at 8 ("While the potential harm of infection is great, the probability of transmission is not significant. There are no indications that the essential functions of the complainants job involved the types of procedures that might have justified work restrictions.").

\textsuperscript{68.} Bradley v. University of Texas, 3 F.3d 922, 924 (5th Cir. 1993).


\textsuperscript{71.} Consider the analysis in \textit{Roe v. District of Columbia}:

Because the nature of the risk and the probability that HBV will be transmitted are both so low as to be classified as theoretical, the importance of the second and third \textit{Arline} factors, although meriting some discussion, fades. Despite the minuteness of the risk of salivary transmission of HBV, the risk is of permanent duration: Roe is a chronic carrier of HBV, accordingly, the potential risk of transmission will not disappear over time. In terms of the severity of the risk, HBV carries a significantly lower mortality rate than does HIV—one tenth of one percent. Yet, HBV can cause liver damage, including cancer, and even death. Furthermore, if a person becomes a chronic carrier of the infection, that person will have to change his or her lifestyle so as not to infect others, inter alia, through sexual conduct.

Nonetheless, all four factors balance heavily in Roe's favor. The overwhelming evidence that HBV is not transmitted through saliva, the permanent duration of the risk of transmission and the severity of the risk do not support a finding that Roe's restriction is warranted.

with significance is a requirement that the world be perfectly safe.\textsuperscript{72} If this is the rule, then risk assessment becomes a matter of spinning scenarios, and any disabled person who might cause a death under some implausible but not inconceivable chain of events could be subject to discrimination: "[A] visually impaired employee could knock a flowerpot off a workplace window sill, or a mobility impaired employee could block an exit in a fire: either could result, in remote, theoretical ways, in workplace fatalities."\textsuperscript{73}

If I don't take these strained interpretations of the Arline test very seriously as legal work, I take them in dead earnest as reflections of the "real" risk assessment that drives them. People do not judge risk by the numbers, but by their taste and feel, by factors like control, dread, the alternatives to running the risk, the reversibility of the consequences, and the sense of having a fighting chance.\textsuperscript{74} And as one judge was frank enough to acknowledge "[t]he public clearly believes that . . . HIV-positive health care workers should not perform invasive medical or dental procedures."\textsuperscript{75} The risk of HIV transmission may be too low to quantify, but it is unacceptable at any level. Yet while this is how most of us analyze risk, it is not the risk assessment proffered by Arline.

There is a defense of discrimination against HIV-positive health care workers that at least does not embarrass the principle relied upon to support it. Some have argued that autonomy requires, in this instance, that the patient should be able to decide whether to run the risk of treatment by an HIV-infected health care worker, whatever it is.\textsuperscript{76} It is flirted with in Rehabilitation Act cases like Leckelt and Bradley and Doe v. Washington University, but cannot be shoehorned into the required legal analysis even by the most determined judges. It is stated most clearly in Estate of Behringer v. Princeton Medical Center, an opinion applying the

\textsuperscript{72} Barnes makes the point that the Arline Court could have chosen lower standards like "potential risk" or "appreciable risk," or, presumably, even the "any risk" standard the A.M.A. itself later applied to HIV. Barnes et al., \textit{supra} note 63, at 316.

\textsuperscript{73} \textit{Id.} at 317. I once had an anonymous caller who told me he understood that HIV could not be transmitted in casual workplace conduct, but asked if he might legally fire an HIV-infected employee based on this scenario: he and the employee often had to drive together in the course of their work; the car might crash; the employer might have to offer first aid to the employee; the employee might be bleeding; the blood might get into a cut or mucous membrane of the employer, and that would very likely transmit HIV.


\textsuperscript{75} Doe v. Washington Univ., 780 F. Supp. at 634.

New Jersey Law Against Discrimination to a surgeon’s claim that it was discrimination to require him to notify his patients of his infection. Although the New Jersey statute is similar to the Rehabilitation Act, the New Jersey court felt free to explicitly balance the surgeon’s right to be free of discrimination against the patient’s supposed right to know of a surgeon’s infection under the doctrine of informed consent. Despite a continued flirtation with a low “any risk” standard, and a rather crafty restructuring of the risks at issue to include the risk of being exposed but not infected (with the attendant fear pending a negative test), the Behringer opinion finds its legs in the indisputable proposition that a “reasonable” (meaning an “average”) patient would want to know, and the assertion that “[i]f there is to be an ultimate arbiter of whether the patient is to be treated invasively by an AIDS-positive surgeon, the arbiter will be the fully-informed patient.”

The court was candid enough to admit that the requirement of notification would effectively terminate the surgeon’s career, and even to entertain the plaintiff’s argument that the patients’ reaction would be based “more on public hysteria than on a studied assessment of the actual risk involved.” The opinion continued:

The answer to these arguments is two-fold. First, it is the duty of the surgeon utilizing the informed consent procedure to explain to the patient the real risk involved. If the patient’s fear is without basis, it is likewise the duty of the surgeon to allay that fear. The court recognizes that the burden imposed on the surgeon may not be surmountable absent the further education of both the public and the community about the realities of HIV and AIDS. Second, the difficulties created by the public reaction to AIDS cannot deprive the patient of the ultimate decision where ‘the ultimate risk is so significant.

These answers do indeed suffice as an application of patient autonomy. Obviously, however, they also take us straight back to Ar-

79. “Where the ultimate harm is death, even the presence of a low risk of transmission justifies the adoption of a policy which precludes invasive procedures when there is ‘any’ risk of transmission.” Behringer, 592 A.2d at 1283.
80. Id.
81. Id at 1280.
82. Id.
83. It is ironic that the Behringer court looked to public education as a means of overcoming the discrimination against surgeons with HIV, given the obvious role of antidiscrimination law in not only setting forth norms of behavior but also validating risk assessments. See Burris, supra note 49.
The "difficulties created by the public reaction to AIDS" are the domain of disability discrimination law. Why is it that patients want to know about HIV? Not because it is a significant risk in quantifiable terms. Not because it is higher than many other risks accepted in the health care setting without notification.\footnote{See Steven Eisenstat, \textit{The HIV Infected Health Care Worker: The New AIDS Scaregoat}, 44 Rutgers L. Rev. 301, 314, 320 (1992) (noting that surgeons are not required to inform patients of their alcoholism or drug addiction); Michael T. Isbell, \textit{The AIDS-Infected Surgeon—No: Don’t Scapegoat Doctors}, A.B.A. J., Oct. 1991, at 47 (stating that the law does not require physicians to disclose a history of drug abuse).} No, notification is required—autonomy is implicated—precisely because reflexive reactions based on fear have crowded rational medical judgments out of the popular assessment of the risk. The patient desires—and in the reasoning from autonomy is entitled to—this exceptional notification of a low-risk characteristic of a medical provider because HIV is uniquely horrifying. \textit{Arlene} refutes, but apparently cannot control, that reasoning.

This body of law says a great deal about the exceptional legal protection afforded people with HIV. First, the protection is not merely a product of vocal gay activism. While political advocates for people with HIV played major roles in the passage of the Americans with Disabilities Act and state privacy laws, the essential construction of HIV as a disability was the work of the judiciary interpreting statutes written before HIV. Moreover, while many public health officials were undoubtedly happy to be allies rather than opponents of AIDS advocates, the idea of protecting people with communicable disease from discrimination was consistent with what health agencies had learned from past experience.\footnote{The Supreme Court in \textit{Arlene}, agreeing with a group of Amici states that: \textit{[c]onstruing section 504 not to exclude those with contagious diseases will complement rather than complicate state efforts to enforce public health laws. . . . Indeed, because the Act requires employers to respond rationally to those with handicapped by contagious disease, the Act will assist local health officials by removing an important obstacle to preventing the spread of infectious disease: the individual’s reluctance to report his or her conditions.} \textit{Arlene}, 480 U.S. at 286 n.15 (citing Brief of the State of California joined by Maryland, Michigan, Minnesota, New Jersey, New York, and Wisconsin as Amicus Curiae).} Once we recognize the similarities of HIV and other leading killers, and appreciate the role of behavior in their occurrence, the legal protection of people with HIV melds into a larger change in public health practice. Changing socially mediated behavior requires changing cultural attitudes about risk and responsibility. It requires people to be more sophisticated about the actual dangers they face, and to avoid comforting but confounding responses to risks, such as stigmatizing the sick. A rule of non-discrimination in
the absence of a significant risk normalizes a more quantitative approach to assessing risk that excludes many of the criteria that individuals normally use. It moves responsibility for fear off the shoulders of those who inspire it and onto those of the people that feel it. It is part of the process of centering the battle against ill-health in the population as a whole, rather than the subset in whom the risk actually becomes a reality.

This development is crucial to the process of behavior change, which depends very much on efficiently focusing anxiety on healthful changes. It is also exceedingly ambitious. The law can state norms, and teach by example, but alone it can no more change how people think about illness than it can change how they think about race. The health care worker cases illustrate the tenacity of "society's accumulated myths and fears about disability and disease." Like the exceptionalists, I fear that the social commitment to protecting people with HIV may be flagging, but if it does the loss will be as much to the public's health as anyone's civil rights.

V. CONCLUSION

In almost all the ways that matter, HIV has not been treated all that differently from comparable health threats. All diseases that become important (i.e., feared) get their own, "different" response. We expect that each generation will develop a particular response to the particular health threats it faces.

In this generation, at this time, it is important to deemphasize the difference between communicable and non-communicable health threats. In a society where the leading killers, even the leading communicable killers, are strongly linked to behavior, it is misguided to adhere to a traditional set of public health policies based on killing germs. Our response to HIV is part of a paradigm shift in public health away from a microbial to an environmental model of disease causation and control, not just for HIV but for all health threats.

Part of this change is a far greater attention to the mass psychology of epidemic disease. In so strongly protecting people with serious communicable diseases from the effects of fear, we are undoubtedly doing something substantially new in the history of public health policy. If all goes well, this exception will, in time, become the tradition.

86. Id. at 284.