The Americans with Disabilities Act as Risk Regulation

Samuel R Bagenstos
ESSAY

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Much disability based discrimination occurs because of fears that hiring or serving people with disabilities will pose a safety risk. Disability rights laws such as the ADA strictly regulate such risk-motivated discrimination. Many disability rights advocates and academic defenders of the ADA laud such laws as applying a “scientific” approach to risk rather than the “irrational” approach generally adopted by the public at large. That position is doubly strange: It stands in remarkable tension with disability rights advocates’ general suspicion of “experts,” and applies a technocratic approach to risk regulation—an approach that usually has politically conservative implications—to achieve the distinctly nonconservative goal of promoting the full integration of people with disabilities into our nation’s economic and civic life. In this essay, Professor Bagenstos uses the problem of risk-motivated disability discrimination as a lens through which to examine the politics of risk regulation scholarship. He argues that the easy association of technocratic approaches with political conservatism—and of democratic approaches with political liberalism or progressivism—ignores the complex ways in which technocratic and democratic institutions may serve or disserve particular political interests.

INTRODUCTION

Much (though far from all) disability based discrimination occurs because of the discriminator’s fears of safety risks. Consider a few examples drawn from prominent recent cases filed under the Americans with Disabilities Act (ADA). A dentist may refuse to treat a patient who has HIV out of fear that the disease will be transmitted by accident during the treatment process.1 A truck company may refuse to hire a driver with insulin-dependent diabetes out of fear that she will experience insulin...
shock and wreck her vehicle.\textsuperscript{2} Or a manager may fire a person with a mental illness out of fear that she will physically attack her coworkers.\textsuperscript{3}

These examples are not unusual. The Supreme Court has so far decided ten cases that have arisen under the ADA; in five of those cases, the defendant excluded the plaintiff for expressly safety-related reasons.\textsuperscript{4} Two of the leading Rehabilitation Act cases—\textit{School Board of Nassau County v. Arline}\textsuperscript{5} and \textit{Southeastern Community College v. Davis}\textsuperscript{6}—similarly involved instances where the defendants believed that the plaintiffs’ disabilities posed undue safety risks. Unlike other areas of civil rights law,\textsuperscript{7} disability discrimination law is repeatedly called upon to respond to intentional discrimination that has its genesis in a concern for private or public safety.

On one view, commonly held by disability rights lawyers and advocates, many if not most of these fears are simply irrational. The role of disability rights law is thus to require a “scientific” analysis and thereby prevent prejudice- and stereotype-fueled perceptions of risk from being translated into disadvantage for people with disabilities. In a pair of recent articles, Linda Krieger has crystallized this view well. As she puts it

\begin{itemize}
\item \textsuperscript{2} For examples of cases in which employers refused to hire people with insulin-dependent diabetes for positions that require driving, see Kapche v. City of San Antonio, 176 F.3d 840, 847 (5th Cir. 1999) (noting that time has come for “revaluation” of the per se rule established in \textit{Chandler v. City of Dallas}, 2 F.3d 1385, 1395 (5th Cir. 1993) (holding as a matter of law in Rehabilitation Act case that driver with insulin-dependent diabetes “presents a genuine substantial risk that he could injure himself and others”).

\item \textsuperscript{3} See, e.g., Palmer v. Circuit Court, 117 F.3d 351, 351–52 (7th Cir. 1997) (affirming grant of summary judgement on ground that “the Act does not require an employer to retain a potentially violent employee,” even if violence “was precipitated by mental illness”).


\item \textsuperscript{5} 480 U.S. 273 (1987) (involving school board’s discharge of teacher with tuberculosis).

\item \textsuperscript{6} 442 U.S. 397 (1979) (involving nursing program’s denial of admission to individual with serious hearing disability on grounds that she posed risk to patients).

\item \textsuperscript{7} Safety considerations have been invoked in defense of sex discrimination as well, but it is telling that in only one case—involving Alabama’s refusal to allow female prison guards to work in male maximum security penitentiaries—has the Supreme Court ever held that such concerns justified intentional discrimination. See \textit{Dothard v. Rawlinson}, 433 U.S. 321, 334–37 (1977).
\end{itemize}
approvingly, the ADA “seem[s] to require that an employer replace an ‘intuitive’ or ‘popular’ approach to risk assessment with more scientific methods and standards.”8

This position makes the prohibition of purportedly safety based disability discrimination seem obviously just and correct. Disability rights law does nothing more than replace irrationality with rationality, prejudice with science. Who could be against that?9

This invocation of “rationality” and “science” by disability rights advocates is doubly strange. For one thing, a substantial body of disability rights thought has devoted itself to attacking the legitimacy of deferring to “experts,” “science,” or “rationality” in making decisions concerning people with disabilities.10 Disability rights advocates’ embrace of such deference in the risk context seems, on the face of it, anomalous.

More broadly, the position of disability rights advocates with respect to risk-based discrimination seems to confound the usual politics of risk regulation. Krieger’s arguments for a “scientific” response to risk are not new. They resonate quite strongly with what I will call the “technocratic

8. Linda Hamilton Krieger, Foreword: Backlash Against the ADA: Interdisciplinary Perspectives and Implications for Social Justice Strategies, 21 Berkeley J. Emp. & Lab. L. 1, 6 (2000); see also id. at 5 (describing the statute as “limit[ing] an employer’s prerogative to exclude a disabled person from a particular job based on a scientifically unsound assessment of the risks to health and safety posed by the person’s disability”); id. at 5–6 (describing the statute as “potentially transformative” because “stigmatizing conditions are so often associated with irrational perceptions of danger, and because risk assessment in any context is more often based on popular myths and stereotypes than on sound scientific analysis”); Linda Hamilton Krieger, Afterword: Socio-Legal Backlash, 21 Berkeley J. Emp. & Lab. L. 476, 483 (2000) [hereinafter Krieger, Socio-Legal Backlash] (finding “a powerful tension between compliance with the statute on the one hand and popular (read, ‘irrational’) approaches to risk on the other”). Krieger is hardly alone among prominent academic defenders of disability rights law in asserting that the restrictions on risk-based discrimination simply substitute science for prejudice. The work of Peter Blanck, for example, has often sounded similar themes. See Peter David Blanck & Mollie Weighner Marti, Attitudes, Behavior and the Employment Provisions of the Americans with Disabilities Act, 42 Vill. L. Rev. 345, 385–89 (1997); Peter David Blanck & Mollie Weighner Marti, Genetic Discrimination and the Employment Provisions of the Americans with Disabilities Act: Emerging Legal, Empirical, and Policy Implications, 14 Behav. Sci. & L. 411, 426–27 (1996); see also Vicki A. Laden & Gregory Schwartz, Psychiatric Disabilities, the Americans with Disabilities Act, and the New Workplace Violence Account, 21 Berkeley J. Emp. & Lab. L. 246, 263–64 (2000) (“In contrast to the employer response encouraged by the popular account,” frequently based on subjective perceptions or irrational fears, “the ADA calls for rational scientific decision-making in the assessment of risk.”).

9. Richard Epstein, for one. See Richard A. Epstein, Forbidden Grounds: The Case Against Employment Discrimination Laws 480–94 (1992). For (to my mind convincing) refutation of Epstein’s argument, see, for example, J. Hoult Verkerke, Free to Search, 105 Harv. L. Rev. 2080, 2082 (1992) (book review) (arguing that Epstein’s theoretical arguments are unconvincing and that “even if Epstein’s theoretical arguments were convincing, his historical and empirical claims are untenable”). Rather than add more ink to that battle, in this essay I take as a given that laws prohibiting discrimination by private employers against members of stigmatized groups are justified.

10. See infra text accompanying notes 19–24.
approach to risk regulation—a body of scholarship that has devoted itself to identifying “irrationalities” in the public’s responses to risk and urging reliance on “expert,” “scientific,” “rational” processes of risk assessment and management. But that technocratic approach has not gone unchallenged in the literature. Another group of scholars (whom I will call “democrats”) has devoted considerable effort to attacking the notion that expert perceptions should govern our approach to risk. In the democrats’ view, public perceptions are neither “unscientific” nor “irrational.” They instead reflect a richer understanding of what makes risks bad—and an understanding that is, in any event, entitled to respect in a democratic polity.

In the general risk regulation debate, the technocratic position tends to have politically conservative implications. Based on their conclusions about the irrationality of public responses to risk, technocratic scholars urge the scaling back of many regulations—particularly those dealing with environmental protection and occupational safety—that are close to the hearts of many on the more liberal side of the political spectrum. Conversely, democrats who urge deference to public understandings of risk aim largely to defend aggressive government intervention through such regulations. In the disability discrimination context, however, the political valences of the democratic and technocratic positions seem to have shifted. Here, it is disability rights advocates—politically liberal proponents of aggressive government regulation—who urge deference to “scientific” decisionmaking.

I contend that this shift in political valences is instructive—both for disability rights advocates who are drawn to a technocratic resolution of risk-based discrimination cases and for contributors to general risk regulation scholarship who have come to associate technocratic and democratic arguments with relatively unchanging political positions. For disability rights advocates, the criticisms of technocracy raised by democratic adherents in the risk regulation literature—many of which dovetail with criticisms of technocracy that disability rights advocates have themselves advanced in other contexts—should suggest that the search for “expert,” “scientific,” and “rational” approaches will not always serve their interests. For participants in more general risk regulation debates, the disability context should suggest that the politics of technocratic and democratic approaches are more complicated—and more contextual—than is typically acknowledged. Whether technocratic or democratic approaches to risk will advance a particular political agenda in a particular context depends on a number of variables specific to that context. In particular, the characteristics of the technocratic and democratic institutions that might plausibly be called upon to assess and manage risk are likely to be crucial in determining the relative implications of such approaches.

In this essay, I explore these points by examining the application of disability discrimination law to various risk-based decisions. In Part I, I briefly review the technocratic and democratic positions and explain cer-
tain limitations of these positions that become evident in the disability context. In Part II, I turn to an examination of disability rights law. In Part II.A, I provide a brief overview of the relevant legal rules. I then turn, in Part II.B, to an examination of the prevailing rule that courts must defer to the reasonable determinations of public health officials in deciding what safety risks are “significant” and thus warrant the exclusion of people with disabilities from particular opportunities. Disability rights supporters like Krieger defend that rule on the basis of a technocratic notion of expertise. I contend that disability rights advocates are probably correct to believe that the rule of public health deference serves their interests, but the reason is less technocratic than political: Public health agencies appear to be institutionally well situated to take full account of the interests of people with disabilities. Technocratic approaches to risk will not always serve the interests of disability rights advocates so well. Accordingly, in Part II.C, I explore two contexts in which the courts or the political system have deferred to technocratic actors who are less well situated to take full account of the interests of people with disabilities. In the Conclusion, I consider the implications of this discussion for more general writing about risk regulation. In particular, my analysis of the proper institutional response to risk-based disability discrimination provides some support for the arguments of scholars such as Cass Sunstein and Kip Viscusi who have recently urged that technocratic tools can sometimes be the best means of achieving the politically progressive goals—like equity in the distribution of risks and benefits—articulated by risk regulation democrats. But it also suggests that democrats must be careful in choosing which technocratic tools to employ for that purpose.

Before turning to the body of this essay, a word about the nature of my project is in order. I do not intend my argument to be prescriptive in a doctrinal or policy sense. That is, I do not mean to defend any general position about the shape that disability law and policy should take. Rather, I seek to highlight the heretofore poorly appreciated complexity of the politics of risk—both inside and outside of the disability context. Thus, I hope to show why disability rights advocates may be well served by putting aside their general hostility to technocratic approaches and embracing public health deference—but why those advocates will not serve the interests they seek to advance if they accept the authority of technocratic “experts” more generally. And I hope to show why political liberals would be well served by abandoning any strong rejection of technocratic approaches to risk—but why their skepticism toward such approaches might nonetheless be justified.

I. DISABILITY, TECHNOCRACY, AND DEMOCRACY

Disability rights advocates, reviewing risk regulation scholarship in search of some insight into the problem of risk-based disability discrimination, could be forgiven for reaching an uncomfortable conclusion: Both of the major approaches to risk regulation that compete in the liter-
nature seem problematic from the perspective of promoting the full access of people with disabilities to our nation’s economic, social, and civic life.\textsuperscript{11} The problem disability rights advocates might have with the technocratic position—that such a position privileges the value judgments of technocrats without sufficient normative justification—should be familiar, though the disability context does sharpen it considerably. But although democratic participants in the risk regulation literature have defended their position as a progressive alternative to the (politically conservative) institutionalization of “expert” authority, it should be apparent that their position, too, has problems from a disability rights perspective. If one’s aim is to shield a stigmatized minority group from public prejudice, a legal regime that seeks merely to implement public attitudes is rightly considered suspect.

A. The Limits of the Technocratic Approach

When scholars like Krieger argue that the ADA reflects a “scientific approach to risk,” they rely (both explicitly and implicitly) on the work of those who have elaborated a technocratic approach to risk regulation. Scholars working in this technocratic tradition argue that public policy demands irrationally large investments to reduce risks to life,\textsuperscript{12} is inconsistent in its treatment of numerically identical risks,\textsuperscript{13} and often has the perverse effect of increasing aggregate risks.\textsuperscript{14} That work traces these irrationalities to systematic cognitive errors that affect the public’s perceptions of risk: overestimates of small risks and underestimates of large

\textsuperscript{11} Although it has recently come under some criticism from some disability rights supporters, see, e.g., Mark C. Weber, Disability and the Law of Welfare: A Post-Integrationist Examination, 2000 U. Ill. L. Rev. 889, 904–21 (criticizing disability rights advocates’ focus on the goal of integration), integration has long been the expressed goal of disability rights advocates. See, e.g., James I. Charlton, Nothing About Us Without Us: Disability Oppression and Empowerment 124–27 (1998) (arguing that integration remains an important goal of the disability rights movement); Timothy M. Cook, The Americans with Disabilities Act: The Move to Integration, 64 Temp. L. Rev. 393, 397 (1991) (arguing that the ADA reflects endorsement of the goal of integration); Jacobus tenBroek, The Right to Live in the World: The Disabled in the Law of Torts, 54 Cal. L. Rev. 841, 843 (1966) (arguing that disability law “should be controlled by a policy of integration—that is, a policy entitling the disabled to full participation in the life of the community and encouraging and enabling them to do so”); see also Weber, supra, at 889–90, 890 n.8 (discussing influence of tenBroek’s argument on the development of disability rights law).


\textsuperscript{13} See, e.g., Breyer, supra note 12, at 20–27 (stating that regulations vary widely in costs they impose per life saved, from low of $100,000 to high of $92 billion); see also Viscusi, Rational Risk Policy, supra note 12, at 98 tbl.6.3 (presenting similar list of regulations and their costs).

overreaction to prominent or sensational sources of risk; status quo biases, framing effects, and the irrational desire to eliminate all risk from a given source; and fear of “new” or involuntarily imposed risks even where other risks are just as great. Like Krieger, technocratic risk regulation scholars have argued that the analysis and management of risks should be the responsibility of “expert” institutions attuned to “scientific” understandings of risk.

But these technocratic arguments have come under fire from democratic risk regulation scholars. Those scholars contend that differences between lay and “expert” perceptions of risk do not reflect public irrationality so much as different value judgments. Rather than assuming, as the technocrats do, that “a death is a death is a death,” democrats argue that people rationally distinguish among different risks based on differences of context—and that those contextual differences are the primary explanation for the supposed “irrationalities” identified by the technocrats.

Richard Pildes and Cass Sunstein have summarized some of the key factors that the public uses to distinguish among risks:

15. See Viscusi, Rational Risk Policy, supra note 12, at 6. Viscusi has at times suggested that this bias results from a lack of mathematical comprehension: “[I]ndividuals have great difficulty comprehending extremely low-probability events.” W. Kip Viscusi, Fatal Tradeoffs: Public and Private Responsibilities for Risk 150 (1992) [hereinafter Viscusi, Fatal Tradeoffs]; see also Breyer, supra note 12, at 36 (making the same point). But he has also constructed a model under which such a bias is a rational response to decisionmaking under uncertainty. See Viscusi, Rational Risk Policy, supra note 12, at 6–11. But whether or not it is rational for an individual to overestimate small risks and underestimate large risks, Viscusi and Breyer plainly believe that it is not rational to base policy on such misperceptions.


17. On the status quo bias, see Viscusi, Rational Risk Policy, supra note 12, at 16–17; on framing effects, see Breyer, supra note 12, at 36; on the zero-risk mentality, see Viscusi, Fatal Tradeoffs, supra note 15, at 151; Viscusi, Rational Risk Policy, supra note 12, at 15–16.


20. See, e.g., Paul Slovic, Perception of Risk, 236 Science 280, 285 (1987) (“[Lay people’s] basic conceptualization of risk is much richer than that of experts and reflects legitimate concerns that are typically omitted from expert risk assessments.”); see also, e.g., Gillette & Krier, supra note 20, at 1075 (“Disagreements between lay people and expert risk assessors cannot be attributed to simple ignorance or ineptitude on the part of either group. The divide, instead, results from fundamentally different world views.”); cf. Daniel A. Farber, Eco-pragmatism: Making Sensible Environmental Decisions in an Uncertain World 67 (1999) (observing that pro-environmental, pro-regulatory views are strongest among people with the most education, and arguing that it is therefore hard to write off such views as “based on ill-considered prejudices or bias”). Lisa Heinzerling has argued that the very figures that report high and disparate costs per life saved rest on assumptions that themselves reflect value judgments—often value judgments that directly contradict...
(1) the catastrophic nature of the risk; (2) whether the risk is uncontrollable; (3) whether the risk involves irretrievable or permanent losses; (4) the social conditions under which a particular risk is generated and managed, a point that connects to issues of consent, voluntariness, and democratic control; (5) how equitably distributed the danger is or how concentrated on identifiable, innocent, or traditionally disadvantaged victims, which ties to both notions of community and moral ideals; (6) how well understood the risk process in question is, a point that bears on the psychological disturbance produced by different risks; (7) whether the risk would be faced by future generations; and (8) how familiar the risk is.22

To delegate risk regulation decisions to the “experts,” democrats have argued, is to defer to the value judgments of a particular class of people. Such a regime cannot be defended by simply invoking the concept of expertise. The value judgments of the “experts” must be defended normatively.

This creates a problem for disability rights supporters who defend a technocratic approach to evaluating risk-based discrimination. Long experience has led disability rights activists to look with suspicion on the so-called “experts.” One of the most strongly held tenets of disability rights ideology is the critique of professionalism. To many disability rights advocates, “expert” professionals are more threat than help. The professional’s preferred response to disability-related issues, these advocates contend, is one of domination and dependence: The professional dominates, the person with a disability remains dependent.23 Professionals’ responses to disability, in this view, principally serve the interests of the professionals themselves, by creating a class of disabled people who must turn to the professionals for help.24 Seen from this perspective, the tech-


24. See, e.g., Harlan Lane, Construction of Deafness, in The Disability Studies Reader 153, 159 (Lennard J. Davis ed., 1997) (“In the end, the troubled-persons industry creates the disabled deaf person.”). For a particularly affecting expression of this view from a journalist and disability rights activist, see Billy Gulfus, The Do-gooder, in The Ragged
nocratic effort to institutionalize the role of “expert” professionals would thus seem more likely to reflect the self-interest of the professionals than the interests of people with disabilities.

B. The Limits of the Democratic Position

Democratic risk regulation scholars respond to the difficulties with the technocratic position by urging deference to the value judgments of the public, both for reasons of popular sovereignty and because those value judgments seem normatively attractive on their merits. Indeed, some democratic risk regulation scholars seem to assume reflexively that any particular risk regulation provision that emerges from the legislative process should be treated as embodying a deliberate moral choice by the populace that deserves respect as an expression of popular morality.

The democratic position is typically presented as a politically progressive response to the conservative implications of technocratic proposals. But in the disability context, and in the civil rights context generally, the political valence of democratic approaches may shift. Civil rights laws aim to eliminate patterns of inequality and subordination that reproduce themselves along socially salient group lines. In particular, they seek to counterbalance majoritarian bias against stigmatized groups—“discrete and insular minorities.” A basic premise of the ADA is that people with disabilities constitute just such a stigmatized group. If the goal of disability rights advocates is to impose a check on the

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26. See, e.g., Hornstein, supra note 25, at 631 (treat[ing] EPA comparative risk assessment initiative as an “attempt to sidestep the moral goals set for the Agency stautorily”); McGarity, supra note 21, at 73–74 (arguing that “[t]he cost-benefit decision criterion runs counter to many provisions in health and environmental statutes that adopt a protective risk based approach that de-emphasize regulatory costs” and that the criterion should therefore be rejected normatively as sole desideratum).

27. McGarity’s argument is an example of such political positioning. For an example of the way he characterizes Sunstein’s technocratic approach, see McGarity, supra note 21, at 11 (“While many of the solutions that Professor Sunstein and other free marketeers offer will no doubt ease the burden of regulation on private entities, they will invariably reduce the protections that the existing statutes currently afford to citizens and environment.”)

28. For further discussion of this point, see, for example, Samuel R. Bagenstos, Subordination, Stigma, and “Disability,” 86 Va. L. Rev. 397, 453–54 (2000) (discussing goals of civil rights law).


30. For an extensive attempt to demonstrate this point, see Bagenstos, supra note 28, at 418–45.
prejudices of the majority, then a regime that aims simply to transform
the majority’s views into policy seems instantly problematic.

Indeed, in a number of circumstances it seems quite difficult to dis-
entangle the public’s views about disability-related risks from the stigma
that disability rights advocates aim to combat through the ADA. To the
extent that people find disability-related risks more salient or “available,”31 for example, that availability is likely to have a significant connec-
tion to the stigma and stereotypes that disability rights law aims to elimi-
nate. Both the fear of HIV transmission during the height of the AIDS epidemic32 and the continuing fear of violence by workers with psychi-
atric disabilities33 seem clearly to fit this pattern. Similarly, to the extent
that people fear disability-related risks because they are thought to be
new,34 that novelty is likely the direct result of past discrimination (for
discrimination has prevented people with disabilities from working in al-
legedly risky settings).35

At least in the disability context, popular distinctions among risks
should no longer seem so attractive to political progressives. Disability
rights advocates would be well advised to look beyond a democratic ap-
proach to risk that simply translates the public’s views into policy. There
is, of course, some irony in this point, for democrats often invoke the
principle of equity in defense of their position in the general risk regula-
tion debate.36 Where antidiscrimination laws are concerned, however,
the connection between equity and the public’s views is far more compli-

31. See, e.g., Timur Kuran & Cass R. Sunstein, Availability Cascades and Risk
heuristic in forming public opinion).

32. See Allan M. Brandt, AIDS: From Social History to Social Policy, in AIDS: The

33. See Jean Campbell, Unintended Consequences in Public Policy: Persons with
Psychiatric Disabilities and the Americans with Disabilities Act, 22 Pol’y Stud. J. 133, 136,
142 (1994); Caroline L. Kaufmann, Reasonable Accommodation to Mental Health
Disabilities at Work: Legal Constructs and Practical Applications, 21 J. Psychiatry & L.
155, 168 (1993); John Monahan, “A Terror to Their Neighbors”: Beliefs About Mental Disorder
191, 192 (1992); John Monahan & Jean Arnold, Violence by People with Mental Illness: A
Consensus Statement by Advocates and Researchers, 19 Psychiatric Rehabilitation J. 67,
69–70 (1996). For a discussion of this issue in the law review literature, see Laden &
Schwartz, supra note 8, passim.

34. See, e.g., Huber, supra note 18, at 1025–26 (noting differences between
regulatory responses to old and new risks).

35. This is but one illustration of the self-perpetuating nature of physical and
attitudinal barriers to the full participation of people with disabilities in public life. For
general treatment of this point, see Bagenstos, supra note 28, at 440–42.

36. See, e.g., Gillette & Krier, supra note 20, at 1078 (invoking equity as a rationale for
criticizing the technocratic approach); Hornstein, supra note 25, at 595 (urging attention
to equitable distribution of risk as a reason for adopting democratic over technocratic
approach); Pildes & Sunstein, supra note 22, at 58–59 (arguing that democratic approach
serves interests in equity). Sunstein’s views on this question appear to be evolving in a
more technocratic direction. See infra text accompanying notes 116–117.
cated. And that, perhaps, is what leads disability rights supporters like Krieger to fall back on technocratic approaches. But that move brings us full circle, for a technocratic approach remains an exceptionally problematic means of achieving the goals of disability rights advocates. How, then, are they to decide whether technocratic or democratic approaches best serve their interests? To gain some purchase on this question, it will help to consider the issue in some more concrete contexts.

II. Disability, Safety Risks, and Institutions

To this point, I have noted an anomaly: that in the area of risk-motivated discrimination, disability rights advocates—politically liberal defenders of aggressive government regulation—have endorsed the technocratic approach typically associated with conservative, deregulatory positions in the general risk regulation literature. And I have noted that the anomalies do not end there. In their more general rhetoric, disability rights advocates have made a major effort to discredit technocratic arguments—an effort that fits very well with the efforts of democratic risk regulation scholars to discredit technocratic approaches more generally. These anomalies can be explained, at least partially, by disability rights advocates’ fear that a democratic reliance on public attitudes in a context marked by stigma, prejudice, and stereotypes will lead to antiprogressive and illiberal results.

This is itself a significant point, for it suggests the insufficiency of any easy association between democratic approaches and political liberalism, technocratic approaches and political conservatism. But I want to go further. If the democrats’ (and disability rights advocates’ own) arguments against technocratic approaches have any validity at all, then a case that a technocratic approach best serves the interests of political liberals (or disability rights advocates) in a given context requires more than just an attack on democratic approaches. Such a case requires a reason to believe that the technocratic approach is better. That comparative judgment, it seems to me, depends crucially on the particular characteristics of the particular technocratic institutions that might be called upon to address risk in the particular context under study. In this Part, I hope to illustrate this point by examining three sets of technocratic institutions to which the courts and the political system have at times delegated authority to make risk-based decisions in the disability area.

After a brief overview of the legal framework in section A below, I turn in section B to an evaluation of the rule of public health deference. That rule delegates authority to determine whether risk-based discrimination is permissible to (technocratic) public health officials in many cases. I contend that a strong case can be made from a disability rights perspective for that rule. In section C, I contrast the rule of public health deference with two other instances where deference to relatively technocratic agents (here, regulatory agencies and the Oregon Health Services Commission) did not appear to serve disability rights interests as well.
A. Disability Rights Law’s Doctrinal Response to Risk-Based Discrimination

Because the tension between the imperative of public safety and the obligation to eliminate unfounded stereotypes arises repeatedly in disability rights law, the federal courts developed a set of principles under the Rehabilitation Act that have come to be known as the “direct threat” doctrine. Congress subsequently codified that doctrine in the ADA. Unlike the bona fide occupational qualification (BFOQ) doctrine applied in the sex and age discrimination areas, the direct threat doctrine does not allow employers to make a categorical judgment that a given disability is always unsafe. Rather, the employer must engage in an individualized inquiry into the plaintiff’s unique abilities, to determine whether it would be unsafe to hire her. An exclusion must meet stringent standards: A perceptible risk—even of serious harm—is not enough; the risk must be a “significant” one. And employers may not stop after determining that


39. There remains some dispute regarding whether the “direct threat” doctrine provides the exclusive means by which an employer can justify safety based discrimination. One court of appeals has held that an employer may impose “a pre-existing safety-based qualification standard [that] applies across-the-board for the position, such as a requirement that a bus driver meet certain sight requirements,” without defending that standard under the “direct threat” test. EEOC v. Exxon Corp., 203 F.3d 871, 874 (5th Cir. 2000). According to the Exxon court, such categorical exclusions may be upheld as “qualification standards” if they are “job-related and consistent with business necessity.” Id. To the extent that the Exxon decision is correct, the discussion in the text must be qualified. Even under the Exxon rule, however, a safety based exclusion may not be based on an entirely categorical judgment, for an employee who is excluded by application of a “qualification standard” must still receive an individualized “reasonable accommodation” where that will enable the employee to perform the job at issue. 42 U.S.C. § 12113(a).

40. For the statement of this principle in the case law, see Arline, 480 U.S. at 287 (noting that individualized “inquiry is essential if § 504 [of the Rehabilitation Act] is to achieve its goal of protecting handicapped individuals from deprivations based on prejudice, stereotypes, or unfounded fear”). For the statement of this principle in the regulations implementing the employment provisions of the ADA, see 29 C.F.R. § 1630.2(r) (2000) (“The determination that an individual poses a ‘direct threat’ shall be based on an individualized assessment of the individual’s present ability to safely perform the essential functions of the job.”); see also id. pt. 1630, app. § 1630.2(r) (“Determining whether an individual poses a significant risk of substantial harm to others must be made on a case by case basis. The employer should identify the specific risk posed by the individual.”). For the similar statement in the regulations implementing the public accommodations provisions of the ADA, see 28 C.F.R. § 36.208(c) (2000); id. pt. 36, app. B § 36.208.

41. See 42 U.S.C. § 12111(3) (defining “direct threat” as a “significant risk to the health or safety of others”); id. § 12182(b)(3) (same); Bragdon v. Abbott, 524 U.S. 624, 649 (1998) (“Because few, if any, activities in life are risk free, Arline and the ADA do not ask whether a risk exists, but whether it is significant.”); see also 29 C.F.R. pt. 1630, app. § 1630.2(r) (“An employer, however, is not permitted to deny an employment opportunity to an individual with a disability merely because of a slightly increased risk. The risk can
hiring the plaintiff would pose such a safety risk in the job as currently structured; they must also consider whether any “reasonable accommodation” could be implemented that would reduce the risk to insufficiency. The doctrine also protects people with disabilities against archaic stereotypes by requiring employers to rely on the best available objective evidence, and it assures that incomplete information will not lead to exclusion by forcing the employer to bear the burden of proving the existence of a significant risk.

The Supreme Court has not left judges and juries to their own devices in making the “significant risk” determination. Rather, the Court has said that “the views of public health authorities, such as the U.S. Public Health Service, CDC, and the National Institutes of Health, are of special weight and authority” in determining whether affording an opportunity to the plaintiff would pose a significant risk, and that “courts normally should defer to the reasonable medical judgments of public health officials” on these questions. If public health officials say it is safe to hire or serve a particular individual with a disability, the Court has said, that individual generally may not be excluded unless the defendant shows that the judgments of those officials are “medically unsupportable.” Although this rule of deference is not absolute, it is, at least

only be considered when it poses a significant risk, i.e., high probability, of substantial harm; a speculative or remote risk is insufficient.”

42. See 42 U.S.C. §§ 12111(3), 12182(b)(3); Arline, 480 U.S. at 287 nn.16 & 17, 289 n.19.

43. See Bragdon, 524 U.S. at 649-50; 28 C.F.R. § 36.208(c) (providing that public accommodation “must make an individualized assessment, based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence”); 29 C.F.R. § 1630.2(r) (“This assessment shall be based on a reasonable medical judgment that relies on the most current medical knowledge and/or on the best available objective evidence.”).

44. The post-ADA case law actually leaves this point unclear, but the text of the ADA’s employment discrimination title specifically identifies establishment of a “direct threat” as a defense to liability. See 42 U.S.C. § 12113(b) (stating, in statutory provision entitled “Defenses,” that “[t]he term ‘qualification standards’ may include a requirement that an individual shall not pose a direct threat to the health or safety of other individuals in the workplace”).

45. Bragdon, 524 U.S. at 650.

46. Arline, 480 U.S. at 288.

47. Id. at 286 n.15.

48. See Bragdon, 524 U.S. at 650 (“The views of [public health] organizations are not conclusive, however. A health care professional who disagrees with the prevailing medical consensus may refute it by citing a credible scientific basis for deviating from the accepted norm.”). The First Circuit in Bragdon had adopted “a rule which gives prima facie force to the views of public health authorities, but which permits a service provider to challenge those views based on contrary, properly supported opinions voiced by other recognized experts in the field (e.g., research studies published in peer-reviewed journals.”). Abbott v. Bragdon, 107 F.3d 934, 945 (1st Cir. 1997). The Supreme Court stated that “[i]n the most part, the Court of Appeals followed the proper standard in evaluating petitioner’s position,” and its remand included no instructions to alter the degree of deference accorded to public health authorities. Bragdon, 524 U.S. at 650, 655.
formally, a strong one.\textsuperscript{49}

B. A Disability Rights Case for Public Health Deference

It should be evident that the direct threat doctrine, as articulated and applied by the Supreme Court, reflects a technocratic approach to risk. Rather than resolve for itself the value question of what risks may justify disability-based discrimination, Congress (at least as the Court reads things) has largely delegated that question to “expert” public health agencies. It has done so by asking only the general question whether a risk is “significant”—itself a question of value—\textsuperscript{50}—and calling upon courts to defer to public health officials’ resolution of that question. Disability rights advocates have largely supported this doctrine, and I believe that they are correct to think that the rule of public health deference serves the interests they seek to advance. But that is because of the political balance of power in public health agencies as much as any generalized reason for deference to expertise. I elaborate this point in the subsections that follow.

1. \textit{The Beginnings of a Justification: Judges and Juries Fail People with Disabilities.} — In ordinary litigation, judges and juries have the responsibility for applying open-ended legal standards like “significant risk” to the particular facts. A natural first question to raise about the doctrine of public

\textsuperscript{49} There is always a question whether deference doctrines in fact alter the decisions of courts or, instead, simply provide a justification for decisions they would have reached in any event. My impression from litigating and following ADA cases is that the doctrine of public health deference does have real bite—though I admit that judges might be tempted to defer to public health officials out of a sense of comparative institutional competence even without a doctrinal mandate to do so. In any event, Peter Schuck and Donald Elliott’s analysis of lower court rulings following the Supreme Court’s decision in \textit{Chevron} U.S.A., Inc. v. NRDC, 467 U.S. 837 (1984), convinces me that the prospect that rules of deference will in fact alter lower court decisions must at least be taken seriously. See Peter H. Schuck & E. Donald Elliott, To the \textit{Chevron} Station: An Empirical Study of Federal Administrative Law, 1990 Duke L.J. 984, 1057 (providing data suggesting that \textit{Chevron} decision increased rate of circuit court affirmation of agency decisions).

\textsuperscript{50} The point is hardly novel, but Barry Sullivan puts it well: [T]he question whether a risk is “significant” is not simply a factual question. To ask whether a risk is “significant” is at least in part to ask whether the risk is “acceptable,” and “the issue of acceptable risk lies,” as Mary Douglas has noted, not simply within the realm of facts, but “with the principles of valuation itself, that is, with culture.” Barry Sullivan, When the Environment is Other People: An Essay on Science, Culture, and the Authoritative Allocation of Values, 69 Notre Dame L. Rev. 597, 601 (1994) (quoting Mary Douglas, Risk Acceptability According to the Social Sciences 14–15 (1985)). For recognition of this point in the risk regulation case law, see Indus. Union Dep’t v. Am. Petroleum Inst., 448 U.S. 607, 656 n.62 (1980) (plurality opinion) (agreeing that any “determination that a particular level of risk is ‘significant’ will be based largely on policy considerations”); id. at 706 (Marshall, J., dissenting) (“Factual determinations can at most define the risk in some statistical way; the judgment whether that risk is tolerable cannot be based solely on a resolution of the facts.”).
health deference, then, is why the ordinary practice should not apply in disability discrimination cases.

One reason should be obvious, for it played a significant role in molding the institutional structure for implementing Title VII of the Civil Rights Act of 196451—one of the models for the ADA. That reason is simply this: Judges and juries may be especially susceptible to the public prejudices that lead to discrimination. The same prejudices and fears that lead a restaurant to determine that it is unsafe to hire people with HIV may also influence the judge or (particularly) the jury who decides that the restaurant acted properly in refusing to hire people with that condition.52

Prejudice aside, there is a structural reason for disability rights advocates to distrust “significant risk” determinations made by actors whose focus is limited to a single case with a single defendant. Judges and jurors might agree, when considering the question in the abstract, that tradeoffs must be made between risks and opportunity—that just as we wouldn’t spend $100 million to save one statistical life, we also wouldn’t confine all people with HIV to unemployment to save one statistical life.53 But when


52. See Kathleen M. Sullivan & Martha A. Field, AIDS and the Coercive Power of the State, 23 Harv. C.R.-C.L. L. Rev. 139, 179 (1988) (warning that popular anxiety, irrationality, and hysteria about AIDS may lead to vindictive and discriminatory verdicts). The prejudice point is a commonplace in arguments about jury competence. See, e.g., Neil K. Komesar, Imperfect Alternatives: Choosing Institutions in Law, Economics, and Public Policy 141 (1994) (“The majoritarian character of the jury is sometimes unattractive. Consider for example the resolution of legal claims that members of a targeted minority have been discriminated against by the majority. A randomly chosen jury may be a subset of the injuring group.”). A similar point is likely to apply to judges, who, after all, come from the same society as juries, though we expect judges’ professional culture (and the fact that they see many cases) to constrain the influence of bias to some extent. See Lawrence O. Gostin, The Americans with Disabilities Act and the Corpus of Antidiscrimination Law: A Force for Change in the Future of Public Health Regulation, 3 Health Matrix 89, 118 (1993) (“Courts are simply unprepared to respond to th[e] dilemma [posed by low-risk, high-consequence transmission] by the application of a rational set of standards.”).

53. Although the risk regulation literature is contentious, all participants appear to agree on one point: Society cannot eliminate all risk. E.g., Farber, supra note 21, at 84 (“We may want to pretend that th[e] amount [we can spend to reduce risk] is infinite, but the harsh reality is that there are limits to the resources we can or should devote to safety.”); Viscusi, Fatal Tradeoffs, supra note 15, at 3 (“[W]e cannot eliminate risk from our lives. The difficulty of reaching a zero-risk society is universal.”); Gillette & Krier, supra note 20, at 1028 (“[T]he objective of risk management must be not the elimination of risk, but rather the minimization of all risk-related costs.”). Democrats, as might be expected,
asked whether the particular defendant sitting in the courtroom should bear the risk, it is easy to ignore this more global analysis and treat any risk to life—no matter how small—as sufficient to warrant exclusion. 54 The identification of the party who must bear the consequences only exacerbates the “zero-risk mentality” that leads people to demand an elimination of all risk. Many pre-Bragdon HIV cases provide an excellent example of this mentality. They held that any risk of transmitting the disease was “significant” and therefore warranted exclusion. Their rationale? That “the victim of infection with this rare but fatal infection can hardly be consoled by the odds,” or “[s]urely it is no consolation to the one or two individuals who become infected . . . that they were part of a rare statistic.” 55

disagree with technocrats about the point at which reduction of risk becomes infeasible. See, e.g., Hornstein, supra note 25, at 616–29 (arguing that technocrats’ focus on comparing existing risks—and the cost of existing means of eliminating those risks—understates the possibility of fundamental change that would reduce all risks). In Bragdon v. Abbott, its most important decision on the “direct threat” doctrine, the Supreme Court recognized this point. 524 U.S. 624, 649 (1998) (“Because few, if any, activities in life are risk free,” the Court said, “the ADA do[es] not ask whether a risk exists, but whether it is significant.”).

54. See, e.g., Reid Hastie & W. Kip Viscusi, What Juries Can’t Do Well: The Jury’s Performance as a Risk Manager, 40 Ariz. L. Rev. 901, 913 (1998) (“[T]he jury tends to take a very narrow view with a focus on the injured person in court, not on the invisible members of the rest of society who will be affected (often positively) by the defendant’s response to tort liability outcomes.” (paraphrasing Shirley Carroll v. Otis Elevator Co., 896 F.2d 210, 216 (7th Cir. 1990) (Easterbrook, J., concurring))). Although Hastie and Viscusi are discussing the jury’s role in tort cases, their basic point—that the individualized nature of adjudication makes it hard for the jury to deal with probabilistic risks—holds here as well. A more recent paper by Viscusi reports empirical data suggesting that judges are less likely than juries to “fall prey to the zero-risk mentality.” W. Kip Viscusi, Jurors, Judges, and the Mistreatment of Risk by the Courts, 30 J. Legal Stud. 107, 134 (2001). As the HIV cases indicate, however, judges are not immune from that mentality. See infra note 55.

55. Scott Burris, Public Health, “AIDS Exceptionalism” and the Law, 27 J. Marshall L. Rev. 251, 268 (1994) (alteration in original) (footnotes omitted) (quoting Doe v. Wash. Univ., 780 F. Supp. 628, 634 (E.D. Mo. 1991), and In re Application of Milton S. Hershey Med. Ctr., 595 A.2d 1290, 1296 (Pa. Super. Ct. 1991)); see also Bradley v. Univ. of Tex. M.D. Anderson Cancer Ctr., 3 F.3d 922, 924 (5th Cir. 1993) (“A cognizable risk of permanent duration with lethal consequences suffices to make a surgical technician with Bradley’s responsibilities not ‘otherwise qualified.’”); Estate of Behringer v. Med. Ctr., 592 A.2d 1251, 1283 (N.J. Super. Ct. Law Div. 1991) (“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.”). For other examples, see Doe v. Univ. of Md. Med. Sys. Corp., 50 F.3d 1261, 1266 (4th Cir. 1995) (“We hold that Dr. Doe does pose a significant risk to the health and safety of his patients that cannot be eliminated by reasonable accommodation. Although there may presently be no documented case of surgeon-to-patient transmission, such transmission clearly is possible.”); Leckelt v. Bd. of Comm’rs., 909 F.2d 820, 829 (5th Cir. 1990) (upholding firing of nurse who refused to take an HIV test “[e]ven though the probability that a health care worker will transmit HIV to a patient may be extremely low” because “the potential harm of HIV infection is extremely high”); Mauro v. Borgess Med. Ctr., 886 F. Supp. 1349, 1353 (W.D. Mich. 1995) (“Because there is a real possibility of transmission, however small, and because the consequence of transmission is invariably death, the threat to patient safety
In cases in which courts are called upon to adjudicate challenges to the imposition of risks by large enterprises, this judicial bias against risk might not be a major problem. Gillette and Krier contend that decisionmakers’ bias against risk producers (a phenomenon they label “process bias”) is likely to be counterbalanced or even outweighed by victims’ difficulty in getting their cases into court in the first place (a phenomenon they label “access bias”). Even if courts rule in unduly risk averse ways in cases that come to them, Gillette and Krier argue, sufficiently few cases are likely to come to the courts to dampen any overdeterrent effect on the activities that are associated with risk. Where a person with a disability must go to court to vindicate her right to engage in an activity that is feared to impose a risk on others, by contrast, the courts’ access and process biases are likely to pull in the same direction—the direction that leads to exclusion of people with disabilities. Because it is the risk producers who must seek the assistance of the courts in this context, all of the obstacles to court access that operate against risk consumers in the ordinary tort context operate in their favor here—indeed, the particular difficulties faced by discrimination plaintiffs may make those obstacles even more significant.

A strong rule of deference to public health officials can overcome the anti-risk bias discrimination plaintiffs face in challenging risk-based exclusion. If juries are particularly likely to be influenced by community prejudices, and particularly unlikely to see beyond the facts of the particular cases before them, a rule of deference should seem especially apt to disability rights advocates. Under such a rule, the judge will take the case away from the jury if the consensus of public health officials is on the plaintiff’s side and the defendant has not carried the heavy burden of showing that the consensus is “medically unsupportable.” Such a rule imposes significant constraints on the judge as well, by requiring the judge to state with some certainty that the public health consensus is wrong, rather than allowing her to indulge her own zero-risk mentality.

2. Why a Purely Technocratic Justification Fails. — There thus appear to be substantial theoretical and empirical reasons for disability rights advo-

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56. Gillette & Krier, supra note 20, at 1046–58.
57. Id. at 1055–58.
icates to shy away from leaving the determination of “significant” risk to the unfettered judgment of judges and juries. But why should such advocates think that public health officials are any better?

One might attempt to answer this question in technocratic terms: The statute requires deference to public health officials because they possess the expertise necessary to undertake the “scientific approach to risk assessment.” But such a justification is quite problematic. Even if we assume that public health officials are uniquely capable of determining the “true” extent of the risk imposed by allowing a person with a disability to participate in a given opportunity, we still need to know something else: Is the risk worth running? As the democrats have shown, that is at bottom a value question. Public health officials may have unique expertise in quantifying risks, but such expertise can give disability rights advocates no normative justification for vesting those officials with authority to resolve questions of value.

The history of public health practice belies any notion that public health officials are apolitical “experts.” Public health is as political as any other government activity. Indeed, people with disabilities would seem to have a lot to fear from a policy of leaving safety determinations to the public health “experts.” Public health officials have made almost astoundingly broad claims about the reach of their jurisdiction. Because virtually everything in life may have an effect on the public’s health, the logic of public health creates a nearly irresistible pressure to expand the scope of the enterprise to regulate virtually all human activities. Within

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60. Krieger, Socio-Legal Backlash, supra note 8, at 483.
61. See, e.g., Scott Burris, Rationality Review and the Politics of Public Health, 34 Vill. L. Rev. 933, 953–54 (1989) [hereinafter Burris, Rationality Review] (arguing that the real dispute in Arline—a dispute “over the acceptability of whatever level of risk [Arline] was determined to present”—“does not become medical merely because it is placed in medical hands”).
62. See, e.g., Ronald Bayer, Private Acts, Social Consequences: AIDS and the Politics of Public Health 17 (1989) (“To speak of public health policy as if it could be apolitical represents an effort to mask the play of social forces appropriately called forth in the making of decisions affecting the communal welfare.”); Bernard J. Turnock, Public Health: What It Is and How It Works 16 (2d ed. 2001) (discussing the “inherently political nature” of public health); cf. Lawrence O. Gostin et al., The Law and the Public’s Health: A Study of Infectious Disease Law in the United States, 99 Colum. L. Rev. 59, 68 (1999) (“[P]ublic health, as both a goal and a practice, is as inherently political (i.e., concerned with the allocation of resources in society) as it is technological (i.e., concerned with the deployment of professional knowledge of illness).”).
63. For extensive and nuanced discussion of the danger faced by civil rights plaintiffs under legal standards that defer to professionals—as well as the opportunities such standards occasionally present for such plaintiffs—see Susan Stefan, Leaving Civil Rights to the “Experts”: From Deference to Abdication Under the Professional Judgment Standard, 102 Yale L.J. 639, 646 (1992).
64. Consider this description by Paul Starr, who seems largely sympathetic to claims for a broader sphere of “public health” activity: “The maintenance of the public’s health allows—some would say demands—concern with almost every aspect of life. Breathtaking definitions of public health, offered by some of the field’s own leaders, suggest how far
this potentially limitless jurisdiction, public health officials frequently have a range of discretionary coercive powers, including powers of involuntary isolation and quarantine.65 Public health officials have used their asserted expertise to perpetrate arrogant blunders like the Swine Flu vaccination fiasco.66 More important, “[s]ome of the worst abuses against vulnerable groups have occurred in the name of public health.”67 Public health measures have been marked by racism,68 classism,69 homophobia,70 and the hysteria associated with whatever epidemic is claims of its jurisdiction may reach.” Paul Starr, The Social Transformation of American Medicine 180 (1982); see also Turnock, supra note 62, at 16 (discussing the “broad and ever-increasing scope” of public health); Gostin et al., supra note 62, at 69 (“Any activity that aims to encompass environmental protection, medical care, personal behavior, and the ‘development of social machinery’ for health makes ambitious, if not hubristic, claims of jurisdiction. By this definition, the health department ought to be the biggest agency in state government.”).


67. Lawrence O. Gostin, The Future of Public Health Law, 12 Am. J.L. & Med. 461, 480 (1986); see also Sullivan & Field, supra note 52, at 155 (“There is strong evidence to suggest that similar patterns of selective enforcement have marked earlier episodes of quarantine, such as the quarantine of venereal disease toward the beginning of this century.”).

68. See, e.g., Jew Ho v. Williamson, 103 F. 10, 23–24 (C.C.N.D. Cal. 1900) (striking down San Francisco Board of Health order that imposed quarantine on the city’s Chinatown section to prevent spread of asserted bubonic plague outbreak on ground that quarantine was enforced only against Chinese residents of quarantine area); Wendy E. Parmet, From Slaughter-House to Lochner: The Rise and Fall of the Constitutionalization of Public Health, 40 Am. J. Legal Hist. 476, 495 & n.131 (1996) (discussing Louisiana Board of Health’s 1898 ban on immigrants into large areas of the state subject to a yellow fever quarantine, a ban that was upheld in Compagnie Francaise de Navigation a Vapeur v. La. State Bd. of Health, 186 U.S. 380, 385 (1902)); cf. Sheila M. Rothman, Living in the Shadow of Death: Tuberculosis and the Social Experience of Illness in American History 184 (1994) (“Explanations [by early-twentieth-century public health officials] as to why the immigrant population was most prone to tuberculosis, like the Progressive analyses of poverty itself, focused equally on underlying social conditions and on personal moral failings.”).

69. See, e.g., Parmet, supra note 68, at 501 (observing that early-twentieth-century public health interventions often focused on coercive measures directed at the poor); Sheila M. Rothman, Seek and Hide: Public Health Departments and Persons with Tuberculosis, 1890–1940, 21 J.L. Med. & Ethics 289, 290 (1993) (same).

70. See, e.g., David Charny, Economics of Death, 107 Harv. L. Rev. 2056, 2078 (1994) (book review) (discussing “the clear evidence of dilatoriness and bias in government’s initial response to AIDS” as the “public health establishment . . . decid[ed] that the lives of gays were not worth saving”). As I argue below, however, the overall picture is somewhat more complicated. Although slow to act, public health agencies became a very sympathetic forum for the claims of gay men and other groups most affected by the HIV epidemic.
most dreaded at the moment. 71 These problems do not lie wholly in the past. 72 One might wonder, then, why disability rights advocates believe people with disabilities will be well served by a regime that defers so strongly to "expert" public health officials.

3. A Political Justification for Deference. — Any justification for the doctrinal deference to public health officials must start by acknowledging the inherently political nature of the public health enterprise. Although what follows is more suggestive than conclusive, I believe that disability rights advocates can make a strong political case for public health deference in the disability discrimination context.

The public health process is certainly political, but that does not mean that public health agencies simply reflect the inclinations of the broader community. For a number of reasons, the political balance of power in such agencies is likely to make them unusually receptive to the claims of people with disabilities—though by no means a rubber stamp. For disability rights advocates, then, the best justification for public health deference is that the deference rule allocates authority to adjudicate risk-based disability discrimination disputes to an entity that is uniquely likely to act in a manner that furthers those advocates' integrationist goals. In this section, I sketch the outlines of the political case for deference; in the next section, I provide some anecdotal evidence in support of that case. Although I cannot, in this exploratory essay, finally establish that disability rights advocates should be persuaded by the political argument for deference, that argument has received insufficient attention in the literature and I hope to prompt further exploration of it.

Why might public health officials be particularly likely to take account of the interests of people with disabilities? One reason relates to institutional culture and professional norms—factors that can have a crucial effect on the actions of even the most political agencies. 73 Although public health officials come from a variety of professional disciplines, 74

71. One example: As Sheila Rothman describes, some public health officials responded to the tuberculosis epidemic in the early twentieth century by vigorously employing their involuntary commitment powers against poor people with the condition and by attempting (without success) to persuade legislatures to ban interstate travel by people with the condition. See Rothman, supra note 68, at 190–93; see also id. at 198 ("There is no overestimating the fear of contagion among both the public at large and public health officers . . . .").

72. See Jonathan M. Mann, Medicine and Public Health, Ethics and Human Rights, in New Ethics for the Public's Health 83, 88 (Dan E. Beauchamp & Bonnie Steinbock eds., 1999) (surveying the range of public health practices in developed and developing countries and concluding that "inadvertent discrimination is so prevalent that all public health policies and programs should be considered discriminatory until proven otherwise").


74. See, e.g., Turnock, supra note 62, at 20 ("[P]ublic health professionals include anthropologists, sociologists, psychologists, physicians, nurses, nutritionists, lawyers,
the institutional culture of public health agencies is distinctive in its central concern with the probabilistic nature of risks and harms. Because the culture of public health defines the enterprise as “a function of the health of populations, not individuals,” epidemiology becomes the discipline’s “mother science”—the “‘glue’ that holds public health’s many professions together.” The epidemiological-probabilistic orientation of modern public health practice exerts a strong pressure on public health officials to gather enormous amounts of information from a variety of sources and then to tally up and weigh the society-wide costs of a proposed course of action against the society-wide benefits. That tallying exercise itself operates as a guard against heuristics and biases that might otherwise result in the unjustified denial of opportunities to people with disabilities.

Moreover, the fear of driving risks underground has recently given public health officials a keen interest in eliminating unjustifiable discrim-
ination against those who might pose risks to others.\textsuperscript{80} The reason is simple: Allowing doctors to refuse treatment to people with HIV (for example) might eliminate a (tiny) risk to the individual doctors, but only at the expense of creating greater risks to society as a whole (by, for example, depriving people with HIV of the care they need for opportunistic infections that may themselves be contagious, or by eliminating other opportunities to provide people with HIV the means to mitigate the risks they might pose to others).\textsuperscript{81}

In addition, one of the aspects of public health agencies that may seem the most threatening to people with disabilities—the agencies’ potentially all-encompassing jurisdiction—may ironically provide the greatest assurance that the interests of people with disabilities will be heeded. The point connects to the argument, advanced powerfully by Gillette and Krier, that risk producers are likely to have disproportionately better access to the administrative process than are risk consumers. Gillette and Krier contend that risk producers—often a concentrated group with a large stake in agency decisions—will typically have great ability to organize and attempt to influence an agency-run risk regulation process.\textsuperscript{82}

Gillette and Krier frame their argument as a critique of proposals to vest greater authority for risk regulation in administrative agencies. But disability rights advocates may find that the point cuts in the opposite direction in the disability discrimination context. If, as disability rights advocates argue and the ADA presumes, private market decisions are likely to be driven by discrimination against and undervaluing of the interests of people with disabilities, then disability rights law should operate as a corrective to that tendency. Allocating decisionmaking authority to an institution to which people with disabilities have disproportionate access is one way to correct the anti-disability bias. Because of the expan-

\textsuperscript{80} See Mann, supra note 72, at 89 (“Again in the context of AIDS, public health has learned that discrimination toward HIV-infected people and people with AIDS is counterproductive.”); see generally Jonathan M. Mann et al., Introduction to Health and Human Rights 1, 1–2 (Jonathan M. Mann et al. eds., 1999) (“Stigmatization and discrimination thwart medical and public health efforts to help people with disease or disability.”); Turnock, supra note 62, at 14–16 (describing “social justice orientation” of public health); Gostin et al., supra note 62, at 92–93 (discussing the important role of the anti-stigma project in protecting the public health).

\textsuperscript{81} See Gostin et al., supra note 62, at 107–09 (detailing other ways in which driving risks underground increases risks to society at large). This is a specific instance of the general phenomenon of “health-health tradeoffs,” a phenomenon to which public health officials are particularly likely to be attuned. See generally Cass R. Sunstein, Health-Health Tradeoffs, 63 U. Chi. L. Rev. 1533 passim (1996).

\textsuperscript{82} See Gillette & Krier, supra note 20, at 1068 (“The diffuseness of public risks, coupled with the fact that materialization of any physical injury will usually be remote in time (latent) and in probability, reduces incentives to contribute much to the common cause. So does the nonexclusive nature of favorable agency action.”). For other writers similarly emphasizing the skewed distribution of stakes in affecting regulatory outcomes, see, for example, Komesar, supra note 52, at 53–97; James Q. Wilson, The Politics of Regulation, in The Politics of Regulation 357, 369 (James Q. Wilson ed., 1980).
sive, society-wide jurisdiction of broad-based public health agencies like the Centers for Disease Control and Prevention (CDC), people with potentially risky disabilities are particularly likely to have disproportionate access to them. People with potentially risky disabilities like HIV and insulin-dependent diabetes have an enormous stake in making certain that public health officials are fully informed of and sensitized to their conditions. If those officials overstate the risks, any individual person with such a disability will likely be excluded from a very broad array of activities. Private employers or places of public accommodation, by contrast, lack a similar incentive to become involved in the public health decisionmaking process. If public health officials understate the danger associated with hiring or serving individuals with particular disabilities, any given private business—indeed, any given sector of the economy—is likely to bear only a small part of the risk. Depending on the impairment at issue, any given private business may be unlikely ever to encounter an individual with that condition. These facts suggest that people with disabilities (and disability rights organizations) will have a strong incentive to monitor and become involved in the decisionmaking processes of public health agencies.

4. An Illustration—HIV/AIDS in the 1980s. — There are good reasons in the abstract, then, to believe that public health agencies are likely to act in a manner that is generally consistent with the integrationist goals of disability rights advocates—at least that they are more likely to act in such a manner than are judges and juries in risk-based discrimination cases. But my argument is not merely abstract. The public health response to the first decade of the HIV/AIDS epidemic, carefully chronicled by Ronald Bayer, provides strong (if anecdotal) empirical support. Keenly attentive to the health-health tradeoff entailed by the use of coercive measures to attack the epidemic—even when those measures might have had some short-term payoff—public health officials rejected broad scale mandatory HIV screening, opposed calls for mass quarantine of people infected with HIV, and generally shied away from targeted isolation of specifically identified infected individuals who deliberately engaged in repeated

83. There are obviously some exceptions. Some industries may be disproportionately affected by the risks associated with people with particular disabilities. The medical industry, for example, is likely to bear the brunt of any risk of transmission associated with HIV, for medical settings are the ones in which contact between body fluids is particularly likely in the above-ground economy. Similarly, the transportation industry is likely to be disproportionately affected by the safety risks associated with insulin-dependent diabetes, because insulin shock poses a particular risk when it affects a person who is driving or operating heavy machinery. These industries are likely to mobilize to participate in the public health decisionmaking process as well, but—unlike in the regulatory agencies—they are less likely to overwhelm the influence of the disability groups. Where agencies stand between well matched interest group antagonists, they are often free to pursue the course that is consistent with agency operators’ professional norms. See, e.g., Wilson, supra note 73, at 81–82 (giving examples of agency behavior when confronted with well matched interest groups).

84. See Bayer, supra note 62, at 134.

85. See id. at 174–75.
high risk behavior. \textsuperscript{86} Despite the array of coercive powers that were at their disposal, public health officials typically sought out alternative means of addressing the problem “even in the face of the challenge of individuals whose deliberate behavior posed a threat of HIV transmission.” \textsuperscript{87} As Bayer and Amy Fairchild-Carrino have noted, “public health officials from states bearing the greatest burden of the AIDS epidemic” tended to view restrictive measures “as a kind of ‘fool’s gold’—costly, time consuming, and ultimately of little public health significance.” \textsuperscript{88}

The restraint of public health officials was not limited to their own response to the epidemic. Rather, because unjustified discrimination against people known to have HIV threatened the public health regardless of who perpetrated the discrimination, public health agencies like the CDC took a strong stand against exclusion of people with HIV (or restriction of their activities) by schools and workplaces. \textsuperscript{89} As Gillette and Krier’s more theoretical argument suggests, moreover, public health officials remained in close contact with gay community groups and other representatives of people with HIV throughout this process. Nearly all observers acknowledge that this relationship had a significant effect on public health policy. \textsuperscript{90}

To be sure, some have seen the public health response to the HIV epidemic as an example of unjustified capitulation to or capture by supposedly powerful gay rights and civil liberties groups. \textsuperscript{91} Bayer himself criticizes public health officials for their apparent timidity in pressing policy positions at odds with those urged by gay community leaders in some instances. \textsuperscript{92} But the overall picture of a public health establishment held

\begin{itemize}
\item \textsuperscript{86} See id. at 190–206.
\item \textsuperscript{88} Id.
\item \textsuperscript{89} See Bayer, supra note 62, at 138–42.
\item \textsuperscript{90} See id. at 69–71, 100, 104–06, 205; see also, e.g., Mary Anne Bobinski, Risk and Rationality: The Centers for Disease Control and the Regulation of HIV-Infected Health Care Workers, 36 St. Louis U. L.J. 213, 219 n.20 (1991) (observing that CDC solicited participation from a number of groups—including gay rights groups—when it crafted its guidelines on HIV in the workplace and at school); Michael C. Musheno et al., Court Management of AIDS Disputes: A Sociolegal Analysis, 16 Law & Soc. Inquiry 737, 770 (1991) (“[P]ublic health agencies and other state parties, like human rights’ [sic] commissions, are forming effective alliances with AIDS parties, including gay rights organizations.”). But see Leonard Robins & Charles Backstrom, The Role of State Health Departments in Formulating Policy: A Survey on the Case of AIDS, 84 Am. J. Pub. Health 905, 908 (1994) (reporting results of survey of state public health officials, in which “[a]ffected groups such as persons living with AIDS and organized gays were seen by fewer than 1 in 10 health departments as being very influential.”).
\item \textsuperscript{91} See, e.g., Chandler Burr, The AIDS Exception: Privacy vs. Public Health, in New Ethics for the Public’s Health, supra note 72, at 211 (providing a classic expression of this view).
\item \textsuperscript{92} See, e.g., Bayer, supra note 62, at 71 (asserting that public health officials’ failure to appreciate the symbolic contribution that closing bathhouses would make to
captive to the desires of gay groups does not ring true.\textsuperscript{93} For one thing, public health officials took positions opposed to those of gay community leaders on some high-profile issues in responding to the AIDS epidemic—notably the questions of blood donations by members of high risk groups before the development of an effective HIV antibody test\textsuperscript{94} and of widespread HIV testing of members of such groups.\textsuperscript{95} More fundamentally, when public health officials forewent coercive measures in their responses to AIDS, their position reflected less a capture by an important interest group than a hardheaded calculation that an epidemic spread by the intimate conduct of particular segments of the community simply could not be brought under control by measures that failed to pay attention to the interests of those segments of the community.\textsuperscript{96}

The example of HIV, then, provides support for the more abstract argument I advanced in the previous sections: Disability rights advocates seem justified, notwithstanding their general critique of technocracy, in supporting the rule of public health deference. Of course, a single example—even one that has defined public health agencies’ understandings of their own practice as much as has the HIV/AIDS epidemic—cannot conclusively prove that disability rights advocates are correct in that judgment. But it does suggest that the political case for public health deference must be taken seriously by those advocates.

C. Where Technocracy Does Not Serve Disability Rights Interests

I have argued that disability rights advocates seem correct to embrace the technocratic rule of public health deference as a means of advancing their goal of full integration of people with disabilities into our nation’s civic, economic, and social lives. I have sought to explain the encouraging a public culture of sexual restraint and responsibility “was a profound misjudgment” that was “conditioned by the political forces evoked by the AIDS epidemic”; id. at 206 (making similar point about public health officials’ rejection of “carefully defined sanctions” imposed against identified infected individuals who persistently engaged in high risk conduct).

\textsuperscript{93} See Charny, supra note 70, at 2078 (“As is well documented, the public health establishment suppressed knowledge about the disease and stymied research, consciously deciding that the lives of gays were not worth saving. Thousands of gay men died, and continue to die, as a result. Where was the politically powerful gay cabal?” (footnote omitted)).

\textsuperscript{94} See Bayer, supra note 62, at 73–89 (describing controversy surrounding Public Health Service recommendations regarding exclusion of blood donations by members of high-risk groups).

\textsuperscript{95} See id. at 103–15 (describing controversy surrounding public health officials’ advocacy of such widespread HIV testing).

\textsuperscript{96} See id. at 15 (“Rigorous surveillance and attempts at the regulation of the private acts linked to AIDS—were they possible—would not only entail morally repugnant invasions of privacy, evoking images from Orwell, but would be counterproductive as well.”); id. at 240 (arguing that “public health officials have so universally argued in favor of education as the preeminent line of social defense against the epidemic” because of “the very limited rational role that coercive measures might play in the control of AIDS”).
apparent inconsistency between this conclusion and the generally conservative reputation of technocratic approaches to risk regulation (not to mention the general hostility of disability rights advocates to technocratic arguments) by pointing to factors specific to public health agencies that indicate that those entities are particularly likely to be solicitous of the interests of people with disabilities. As the discussion of “the scientific approach to risk” quoted in the introduction suggests, embrace of the technocratic rule of public health deference can easily slide into an endorsement of technocratic decisionmaking processes more generally. But such a general endorsement of technocratic approaches would ignore the highly contextual and institution-specific nature of the disability rights case for public health deference. To the extent that disability rights advocates sweepingly embrace technocracy, they may disserve their own purported goals. In this section, I illustrate that point by examining two instances in which courts and the political process have delegated disability related decisions about risk to “expert” bodies. In these instances, the general skepticism of disability rights advocates toward technocratic approaches (and the parallel skepticism of democratic risk regulation scholars) seems to have been entirely justified.

1. Deferring to Federal Regulatory Agencies. — In Albertson’s, Inc. v. Kirk- ingburg, the Supreme Court held that no “direct threat” inquiry was necessary when an employer refused to allow a person with monocular vision to work as a truck driver.97 Federal Highway Administration (FHWA) regulations, in force since 1971, require drivers of commercial motor vehicles in interstate commerce to have corrected vision of 20/40 or better in both eyes.98 Although the regulations allowed the FHWA to grant waivers to people with monocular vision who had good driving records, and the FHWA had in fact granted the plaintiff such a waiver, the Court held that the employer was entitled to rely on the basic vision standard set forth in the regulation.99 Accordingly, the Court held that the plaintiff was not a “qualified” individual, and that he was not entitled to demand that the employer make an individualized showing that hiring him would pose a significant risk.100

Simply from the standpoint of proper interpretation of the ADA, the Albertson’s opinion seems exceptionally problematic.101 What is notable

98. Id. at 558–59.
99. Id. at 577–78.
100. Id. at 567–78.
101. The Court rested its conclusion that the employer need not accept the waiver the FHWA had given the plaintiff on the ground that “[t]he waiver program was simply an experiment with safety, however well intended, resting on a hypothesis whose confirmation or refutation in practice would provide a factual basis for reconsidering the existing standards.” Id. at 576. There is no doubt that that the program was experimental, as the tortured administrative process attending its adoption demonstrated. See Advocates for Highway and Auto Safety v. Fed. Highway Admin., 28 F.3d 1288, 1291–94 (D.C. Cir. 1994) (vacating and remanding the waiver rule on the ground that the agency lacked sufficient
here, however, is the Court’s willingness to defer to the FHWA’s determinations regarding whether people with monocular vision could be excluded from truck driving jobs. If one is making a general case for deference to expertise, that willingness seems unexceptionable. Who, after all, is likely to have more specialized knowledge about the kinds of medical conditions that create a risk on the roads than the regulatory agency that has been protecting roadway safety for decades?

Yet disability rights advocates could legitimately argue that deference to such front-line regulatory agencies, no matter how expert, is far less likely to advance their interests than is deference to public health agencies. Unlike with broad-portfolio public health agencies, people with disabilities are likely to have disproportionately little access to industry- or subject matter-specific agencies like the FHWA. Such industry-specific agencies are most likely to be responsive to the concerns of the industry, labor union, and public interest groups (in this instance, “safety” organizations) that confront them on a daily basis.102 And their organic statutes may bar them from considering (or be read to bar them from considering) the effect that their decisions will have on people with disabilities.103

data to show that the rule was consistent with the safe operation of motor vehicles); see also Albertson’s, 527 U.S. at 576 n.21 (noting that on remand from the Advocates decision, the Federal Highway Administration reinstated those waivers it had already issued). But that is hardly a reason to allow employers to ignore it. As the Court itself observed, the Department of Transportation began the experiment with a waiver program precisely because its own studies had found a “lack of empirical data to establish a link between vision disorders and commercial motor vehicle safety.” Albertson’s, 527 U.S. at 575 (quoting Advocates, 28 F.3d at 1293 (quoting Qualification of Drivers; Vision Waivers, 57 Fed. Reg. 31,458 (Jul. 16, 1992))). In other words, the Department’s longstanding visual acuity standard appeared to be excluding many people with visual impairments on the basis of unfounded fears and stereotypes; and the Department decided, in the interest of developing more reliable information, to give drivers with visual impairments who had good driving records the benefit of the doubt for a while. The ADA’s “significant risk” rule, with its requirement of an individualized inquiry and its placement of the burden of proof on those who would deny opportunities to people with disabilities, was crafted for just such a situation. See supra text accompanying notes 38–44. Where the Department of Transportation regulation itself allowed for an individualized inquiry, the Court’s refusal to require such an inquiry under the ADA seems particularly hard to justify.

102. Cf. Turnock, supra note 62, at 147 (describing subordination of public health to regulatory goals in shift of environmental health responsibilities from health agencies to environmental regulatory agencies).

103. For example, the Motor Carrier Safety Act of 1984, Pub. L. No. 98-554, tit. II, 98 Stat. 2892 (1984)—under which the FHWA adopted the visual acuity regulations at issue in Albertson’s—has been read to resolve all uncertainty in favor of the safe operation of motor vehicles; it thus allocates the risk of uncertainty to those, like people with monocular vision, who would seek an exception to an existing safety regulation. See Advocates, 28 F.3d at 1294 (concluding that the Department’s statement that it lacked sufficient evidence to enable it to determine riskiness of visual impairments disentitled it to enact waiver program to obtain that evidence because the statute requires that the agency have sufficient evidence to demonstrate safety of its actions before it may go forward). The court concluded:

[W]e are fully aware of the difficulties that the FHWA undoubtedly faces in acquiring the data on which to make an informed judgment as to whether the
As a result, it seems quite likely that they will take actions that fail to account for—and may even affirmatively disserve—the interests of people with disabilities.

Paula Berg has illustrated this point by examining decisions made by the Occupational Safety and Health Administration (OSHA). Berg identifies several instances in which the exclusive focus on the interests of employers and employees has led OSHA to disregard the interests of—and even encourage discrimination against—people with disabilities. Most notably, the agency allows employers to escape the most costly aspects of its tuberculosis (TB) standard if they simply forbid people with actual or suspected TB from entering their facilities. Such a rule serves the interests of employees in OSHA-covered workplaces, but it encourages covered employers to exclude people with TB even in cases where reasonable accommodations could eliminate any safety risk. A case like *Albertson’s*, which holds that the regulations adopted by industry- or subject matter-specific regulatory agencies displace the ADA’s direct threat requirement, might simply encourage businesses to seek the promulgation of such regulations as a shield against ADA liability. In short, while public health agencies “such as the U.S. Public Health Service, CDC, and the National Institutes of Health” appear to possess existing vision standards may safely be relaxed. The requirements of the Motor Carrier Safety Act’s waiver provision, however, must be satisfied; and because the FHWA has failed to meet its requirements, we vacate and remand the rule.

Id.

104. Summarizing her argument, Berg states that OSHA’s:

failure to identify any goals other than the protection of employee health (such as the protection of the public health generally) and to explicitly value the rights of other parties affected by contagion regulations creates the risk that OSHA will routinely value the rights and interests of employers and employees at the expense of PWIDs [people with infectious diseases], perceived PWIDs, and the public.


105. See id. at 1391–92.

106. See id. at 1392.

107. Walter Olson predicted this phenomenon even prior to *Albertson’s*:

A few businesses and trade associations, alarmed at the wave of ADA demands and looking for some line of defense, are beginning to think about working to get the various federal personnel safety regulations tightened in hopes of tying their own hands and requiring them to reject applicants with borderline physical capacity. Since such regulations inevitably tend to be somewhat overbroad, an ironic result would be to bar an occasional individual with compromised vision from particular jobs even though the employer in question, left to its own discretion and knowing in some detail what the job does and does not require, would have judged him an acceptable risk.


institutional attributes that make them particularly likely to take seriously the interests of people with disabilities, there is strong reason to believe that other regulatory agencies do not. Disability rights advocates should pause, then, before allowing their embrace of the technocratic rule of public health deference to extend unquestioningly to deference to other “expert” agencies.

2. The Oregon Health Plan. — A second example of a technocratic process that seemed to disserve the interests of people with disabilities has more complex implications for the choice between technocratic and democratic processes. In its ambitious attempt to reform its health care system in the early 1990’s by covering more people but limiting the treatments for which people would be covered, Oregon followed an approach that incorporated both democratic and technocratic elements. Indeed, Pildes and Sunstein have identified that approach as a promising experiment in participatory risk regulation practices.109 The Oregon experience certainly provides evidence to support disability rights advocates’ fear of allowing public attitudes—which may be shaped by stigmas, prejudices, and stereotypes—to exclude people with disabilities from opportunities. At the same time, however, it illustrates that disability rights advocates have substantial grounds for skepticism of technocratic processes as well.

In its deliberations regarding what conditions and treatments to cover under the reformed Oregon health plan, the “expert” Oregon Health Services Commission made a crucial decision—to rank treatments on the basis of the number of quality-adjusted life years (QALYs) they would save. Thus, a treatment that would save a person’s life and restore that person to complete well being would be given funding priority over a treatment that would save another person’s life while leaving her with a continuing impairment or disability.110 Rationing life-saving health care based on such quality-of-life measures tends to disfavor people with disabilities, because a life with a disability is measured as having a lesser “quality” than one without it.111

109. See Pildes & Sunstein, supra note 22, at 92–94.
111. See Dan W. Brock, Health Care Resource Prioritization and Discrimination Against Persons with Disabilities, in Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions 223, 226–27 (Leslie Pickering Francis & Anita Silvers eds., 2000); Philip G. Peters, Jr., Health Care Rationing and Disability Rights, 70 Ind. L.J. 491, 501 (1995). As Peters points out, it is possible that the use of quality-of-life measures for allocating resources for addressing nonfatal conditions may favor people with disabilities. See Peters, supra, at 544–45; see also Brock, supra, at 227 (“[I]t would be a mistake to believe that persons with disabilities will always fare worse in prioritization of health resources, but the ways and frequency with which they will fare worse are extensive.”). Moreover, a quality-of-life calculus that ignored the quality-of-life effects of disabilities other than those being treated would significantly alleviate the concern that such a calculus discriminates against people with disabilities. For scholars advocating such an approach to QALY analysis, see Einer Elhauge, Allocating Health Care Morally, 82 Cal.
Oregon’s Commission exacerbated matters by measuring “quality of life” based on the results of a public survey that almost certainly incorporated the nondisabled population’s biases regarding the undesirability of living a life with a disability.112 But the basic problem lay at the feet of the technocrats—the Commission’s decision to use the concept of “quality of life” as a key determinant in ranking treatments in the first place.113 Although the Health Services Commission determined, through an extensive process of soliciting public opinion, that the public believed quality of life to be an important value in allocating health care resources, participants at community meetings listed a number of other values as well, including prevention, effectiveness of treatment, mental health care, and community compassion.114 Any number of ranking methodologies might have been consistent with some combination of these values, but the “expert” Commission chose one that emphasized the role of the public’s judgments about only one of them—quality of life—even though those judgments may well have been inconsistent with the public’s judgments about other important values such as equity and community compassion.115

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112. This was a principal basis for the Department of Health and Human Services’ rejection of the request for a Medicaid waiver to allow Oregon to carry out its experiment. See ADA Analyses of the Oregon Health Care Plan, 9 Issues L. & Med. 397, 410 (1994) (reprinting letter from then-HHS Secretary Sullivan to then-Governor Roberts rejecting the waiver). Defenders of the QALY approach would contend that relying on the views of people with disabilities is just as likely to be problematic; people with disabilities, in this view, may have psychologically adjusted to their conditions and thus may underestimate the negative quality-of-life effects they experience. See John McKie et al., The Allocation of Health Care Resources: An Ethical Evaluation of the ‘QALY’ Approach 34 (1998).

113. See Caitlin J. Halligan, Note, “Just What the Doctor Ordered”: Oregon’s Medicaid Rationing Process and Public Participation in Risk Regulation, 83 Geo. L.J. 2697, 2705–17 (1995); see also Michael J. Astrue, Pseudoscience and the Law: The Case of the Oregon Medicaid Rationing Experiment, 9 Issues L. & Med. 375, 381 (1994) (stating that, from the perspective of the Health and Human Services General Counsel at the time of initial submission of Oregon’s plan, “the most troubling element of the process was the use of so-called quality of life factors—both as part of the subjective manipulation of categories by the Commission and the more quantitative calculation of the rankings”).


115. See generally Brock, supra note 111, at 224 (“[S]ince the principles and values developed in the public meetings were quite general, their impact on the process appears to have been limited.”). The Commission ultimately made substantial changes in the priority condition-treatment list that had been compiled on the basis of the public survey. Although the public’s quality-of-life ratings retained some role in determining the place of treatments on the list, the Commission’s adjustments substantially reduced that role. Halligan, supra note 113, at 2712–16. Those “expert” adjustments introduced additional biases of their own, however. In particular, by according treatments for more common conditions priority over those for less common conditions, the Commission made it less likely that people with disabilities would receive the treatments they need. Such a decision might (or might not) be justified on economies-of-scale grounds. “But OHSC [Oregon Health Services Commission] offered no such explanation, nor did it provide any rationale for its decision, other than labeling it ‘reasonable.’” Id. at 2722. By unreflectively
In short, the technocrats who made up the Oregon Health Services Commission chose to prioritize quality-of-life factors, which could be quantified through the QALY technique, over the other, harder-to-quantify public concerns that emerged from the community meetings it held. That decision may have had a significant effect on the rankings ultimately produced by the Commission—an effect that likely disfavored people with disabilities. Like the Albertson's decision, then, the Oregon experience provides a cautionary lesson for disability rights advocates who believe that a *general* deference to expertise will reliably serve their interests.

**CONCLUSION: LESSONS FOR RISK REGULATION**

My major goal in this essay has been to highlight the complexity of the politics of technocratic and democratic approaches to risk regulation. I have done so by examining a context—risk-based disability discrimination—where the usual political positions have shifted: Disability rights advocates, politically liberal proponents of aggressive regulation, are the champions of "expert" "scientific" "rationality." My examination of this area has obvious implications for more general discussion of risk regulation. In particular, it lends support to those who argue generally that technocratic tools may be the best way of serving the politically liberal goals democratic risk regulation scholars purport to favor. For example, as Sunstein's work on risk regulation has moved away from a more purely democratic approach toward a more technocratic one, he has increasingly come to emphasize this benefit of using technocratic methods of regulatory analysis. Sunstein has argued that comparative risk analysis and cost-benefit analysis can play a crucial role in forcing deliberation and assuring that democratic processes act in accordance with considered public judgments rather than hysteria, heuristics, or biases.  

After the Department of Health and Human Services twice rejected Oregon's request for a Medicaid waiver, the state submitted a revised plan that complied with various conditions set by the federal government. See ADA Analyses of the Oregon Health Care Plan, supra note 112, at 423–24. Ultimately, the Oregon plan resulted in virtually no rationing. Lawrence Jacobs, Theodore Marmor, and Jonathan Oberlander persuasively contend that such a result was what the plan's political proponents wanted all along. See Lawrence Jacobs et al., The Oregon Health Plan and the Political Paradox of Rationing: What Advocates and Critics Have Claimed and What Oregon Did, 24 J. Health Pol'y, Pol'y & L. 161, 170–74 (1999). But the political vision of the people who drafted, lobbied for, and enacted the Oregon plan hardly resolves the concerns that the initial implementation of the plan raises for the allocation of disability related decisions to technocratic processes. If anything, it suggests the superiority of democratic political processes.

116. See, e.g., Kuran & Sunstein, supra note 31, at 736–60 (arguing that cost-benefit analysis should be encouraged as a check against misperceptions rooted in independent learning and preference falsification); Pildes & Sunstein, supra note 22, at 72–86 (arguing that, although a "rough" tool, cost-benefit analysis is preferable to allowing "interest group power and sensationalist anecdotes, rather than deliberation to determine regulatory
argues that the process of cost-benefit analysis should be “softened” to incorporate public values by, for example, measuring benefits in terms of QALYs rather than a simple “body count” of lives saved. But, he contends, cost-benefit analysis should nonetheless remain the basic tool for making risk regulation decisions. Although Sunstein has not focused on the problem of bias against disadvantaged minorities in risk regulation,¹¹⁷ his argument for technocratic tools as an aid to democratic deliberation certainly seems apt here.

Unlike Sunstein, Viscusi has not staked out a position as an advocate of deliberative democracy in risk regulation, but he has recently sought to emphasize that technocratic tools may be the best means of satisfying concerns with equity.¹¹⁸ In his study of the Superfund program with James Hamilton, Viscusi compiles a strong case that the current politically driven process for cleaning up Superfund sites affords poor and minority communities less protection than more well-off majority-white communities.¹¹⁹ Although they do not examine local political processes in great detail, Hamilton and Viscusi suggest that this pattern results from the lower levels of political mobilization in poor and minority communities.¹²⁰ A greater reliance on cost-benefit analysis, they argue, “would promote environmental equity by making expected cancer cases among minorities and the poor count just as much as illnesses of the wealthy.”¹²¹ Experience with the disability context suggests that the point is a more general one: Advocates of a democratic approach to risk regulation—

¹¹⁷. Sunstein’s broader work has emphasized the role of deliberative institutions in protecting disadvantaged minorities against bias. See, e.g., Cass R. Sunstein, Public Deliberation, Affirmative Action, and the Supreme Court, 84 Cal. L. Rev. 1179, 1197±99 (1996) (arguing for increased public deliberation over issue of affirmative action).


¹¹⁹. See James T. Hamilton & W. Kip Viscusi, Calculating Risks? The Spatial and Political Dimensions of Hazardous Waste Policy 188 (1999) (“As the minority percentage in the one-mile ring around a site increased, EPA regulators spent less per cancer case averted, were more likely to choose the cheapest alternative in dealing with soil contamination, and were less likely to invoke the more stringent cleanup standards provided by state environmental laws.”).

¹²⁰. See id. at 183–86.

¹²¹. Id at 188. As Viscusi summarized his conclusions in a more recent article: Minorities would fare much better under a benefit-cost regime than under the current EPA cleanup policy strategy, which purports to advance environmental equity. Notwithstanding the agency’s politically correct declarations, the driving force behind hazardous waste cleanup is the political clout of the affected populations. The powerless, the disenfranchised, and the less politically sophisticated fare much worse under the current regime than they would if policy choices were driven by evaluation of policy benefits and costs.

Viscusi, Risk Equity, supra note 118, at 871.
who purport to share a strong concern with distributive justice—should be drawn to a more technocratic process in instances where the public’s views are likely to be driven by bias against, or “selective sympathy and indifference” to, members of socially salient, systematically disadvantaged groups, and where the technocratic process is structured in a way that makes it more likely to avoid that bias.

It should not be surprising that disability rights laws use technocratic doctrines like public health deference to serve the democratic goal of equity. An important building block of modern antidiscrimination doctrine has long reflected a similar insight. In the employment discrimination area in particular, civil rights lawyers have long been concerned that the use of traditional hiring criteria may simply reflect unexamined bias and stereotypes. Accordingly, they have attempted to use disparate impact doctrine—which requires employers to provide more or less technocratic validation of criteria that have a disproportionately harmful effect on minorities and women—to objectify those processes. The rule of public health deference applied under the direct threat doctrine serves roughly the same purpose. These quite technocratic aspects of established civil rights law should give democratic risk regulation advocates pause before they suggest that the general public’s views about risk should be translated directly into policy. Where public risk perceptions are affected by social stigmas, technocratic processes can provide a counterbalance that helps to advance the substantive interests that democratic scholars seem to support.

But the examples of Albertson’s and the Oregon Health Plan raise a caution: Deference to “expert” agencies should not simply be assumed to serve the goal of equity. A determination as to whether technocratic tools can serve such a goal may depend on a careful analysis of the political forces operating on the particular “experts” to whom deference is sought.

This point has significant implications for the proposals of those who advocate a hybrid of technocratic and democratic decisionmaking processes. The Oregon experience in particular suggests that no perfect balance can be achieved between these two types of processes. Sunstein, for example, has suggested that political liberals can achieve the benefits of both public participation and technocratic rationality through the QALY device. But in Oregon the attempt to use QALYS as a means of incorporating public values into a process that remained ultimately technocratic distorted rather than reflected deeply held public values—a result that may be inevitable in areas like risk regulation where people’s


123. For discussion of this purpose of disparate impact doctrine, see Elizabeth Bartholet, Application of Title VII to Jobs in High Places, 95 Harv. L. Rev. 947, 950–52 (1982).
own intuitions and values often conflict. The decision to privilege “quality-of-life” measures through the QALY device thus reflects a normative choice among values—and one with significant distributive consequences. Political liberals must squarely confront these issues before they decide that such a hybrid provides an effective means of achieving their goals.

The results of the various uses of technocracy in the disability-related risk context suggest that politically liberal advocates of equitable responses to risk are not well served by simply embracing technocratic processes or using them as the presumptive framework for policymaking. Nor, however, are they well served by rejecting technocratic tools outright. Technocratic approaches seem likely to serve the cause of equity when the relevant technocratic decisionmakers are well positioned to hear and take seriously the interests of disadvantaged groups, when general public attitudes or imbalances of political power would otherwise lead to an inequitable distribution of the benefits and burdens of risk, and when political and legal avenues provide a check on inequitable actions by the technocrats themselves. Those factors seem to be present in the case of public health officials and people with assertedly risky disabilities; they do not appear to have been present in the construction of the Oregon Health Plan. What should be clear, however, is that the associations between technocratic positions and political conservatism, and between democratic positions and political liberalism, are entirely contingent. As I have tried to illustrate by considering the case of risk-based disability discrimination, the politics of different approaches to risk will necessarily vary with context. Risk regulation scholarship is best served by

124. That experience thus lends some support to the criticisms that other democrats have leveled against Sunstein’s hybrid of technocratic and democratic positions. See, e.g., McGarity, supra note 21, at 62 (“When push comes to shove, Professor Sunstein sides with the experts, assigning to them the primary role in regulatory decisionmaking and relegating the citizens’ role to that of ‘input.’”); id. at 77 (“In the final analysis, Professor Sunstein’s ‘soft,’ deliberative model for employing cost-benefit analysis in regulatory decisionmaking is so close to the ‘hard,’ efficiency-driven model that the distinction will probably be lost in the real world.”); see also Farber, supra note 21, at 96 (“What Sunstein proposes is a moderate, humane form of cost-benefit analysis, a distinct improvement over the blunter versions proposed in Congress. Yet even this version is flawed.”). Although Farber focuses his discussion on environmental law, his argument applies to the relationship between Sunstein’s proposal and public values more generally.

125. Lisa Heinzerling has recently commented on the “parade of normally equality-minded writers extolling the virtues of evaluating regulatory action on the basis of the number of ‘quality-adjusted life-years’ saved by it.” Lisa Heinzerling, The Rights of Statistical People, 24 Harv. Envtl. L. Rev. 189, 195 (2000). Heinzerling is explicit about the risks such measures pose to people with disabilities:

One’s age, health, and disability status suddenly have become good grounds for distinguishing the value of one’s life from another, for the explicit reason that the lives of those situated on the undesirable side of the statuses of age, health, and ability (the elderly, the sick, and the disabled) are worth less than the lives on the desirable side.

Id.
paying careful attention to the particular contexts in which the political system is called upon to respond to risk and the institutions that might plausibly be employed in those contexts.126

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