

BECOMING VISIBLE: THE ADA'S IMPACT ON HEALTH CARE FOR PERSONS WITH DISABILITIES

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I. INTRODUCTION

When Congress enacted the Americans with Disabilities Act ("ADA") in 1990, it included the underlying legislative "findings and purposes" in the statute itself and stated as one of its findings that "discrimination against individuals with disabilities persists in such critical areas as . . . health services."¹ Congress went on to announce that it was the ADA's purpose "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities."² Based on these statements, one would surmise that in 1990 Congress believed that all was not well when it came to the ability of Americans with disabilities to access and receive needed health services. Indeed, the voluminous legislative history that underpins the ADA includes ample testimony regarding the barriers that people with disabilities faced in obtaining health care.³

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1. 42 U.S.C. § 12101(a)(3) (1994).

2. *Id.* § 12101(b)(1).

3. See, e.g., 136 CONG. REC. E1839 (daily ed. June 7, 1990) (citing the need for auxiliary aids in places of public accommodation in speech by the Honorable Steny H. Hoyer); *Americans with Disabilities Act of 1988: Joint Hearing on S. 2345 Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Human Resources and the Subcomm. on Select Education of the House Comm. on Educ. and Labor, 100th Cong.* 984 (1991) (citing that health care workers and hospitals are unwilling to care or are providing substandard care for HIV-infected persons in testimony and prepared statement of Adm. James Watkins, Chairperson of the President's Comm'n on the HIV Epidemic); 136 CONG. REC. E1839 (daily ed. June 7, 1990) (citing the need for all newly constructed health care facilities above one-story tall to include elevators in speech by the Honorable Steny H. Hoyer); *Americans with Disabilities Act of 1989: Hearings on H.R. 2273 Before the House Comm. on the Judiciary and the Subcomm. on Civil and Constitutional Rights of the Comm. on the Judiciary, 101st Cong.* 269 (1989) (finding in survey published by The Research and Training Center on Independent Living at the University of Kansas that disabled persons were unable to obtain health insurance or found that health insurance did not cover sup-

As part of this Symposium's ten-year retrospective on the ADA, this Article will examine how effective the ADA has proven in addressing these barriers. What impact has the passage of the ADA had on health care for people with disabilities? The simplicity with which the question can be framed, however, belies the variety and complexity of the subject matter that potentially falls within its scope. Certainly, when we talk about the ADA's impact on health care for people with disabilities, we are talking about the physical accessibility of facilities providing health services,⁴ the availability of auxiliary aids for people with vision and hearing impairments, and the influence of patients' disabilities on providers' medical decisions. But we are also talking about whether the ADA has affected decisions by third-party payers—be they traditional health insurers, health maintenance organizations, or state Medicaid agencies—regarding health care financing and coverage available to people with disabilities. We could also talk about how the ADA affects the ability of states and localities to engage in public health regulation that limits the freedom of persons infected with communicable diseases⁵ and whether the ADA limits the ability of states to enact legislation legalizing assisted suicide.⁶ And, depending on how broadly we define the services included in "health care services," we could also talk about

plies, equipment, regular medications and therapies used by the disabled).

4. Public and private healthcare offices and facilities are subject to the same physical accessibility requirements as other public entities under Title II, *see* 42 U.S.C. §§ 12146-47 (1994), and public accommodations under Title III, *see id.* § 12183. Issues regarding the physical accessibility of health care providers have arisen in litigation under the ADA, *see, e.g.*, *Anderson v. Department of Pub. Welfare*, 1 F. Supp. 2d 456 (E.D. Pa. 1998). Because those issues are not particular to the health care setting, however, this Article will not focus on them. For a discussion of accessibility issues, both physical and attitudinal, found in the offices of primary care physicians, *see* Ellen W. Grabois et al., *Accessibility of Primary Care Physicians' Offices for People with Disabilities: An Analysis of Compliance with the Americans with Disabilities Act*, ARCHIVES OF FAM. MED., Jan./Feb. 1999.

5. *See City of Newark v. J.S.*, 652 A.2d 265, 277 (N.J. Super. Ct. Law Div. 1993) (finding that New Jersey's tuberculosis control statute did not violate the ADA); Josephine Gittler, *Controlling Resurgent Tuberculosis: Public Health Agencies, Public Policy, and Law*, 19 J. HEALTH POL., POL'Y & L. 107 (1994); Lawrence O. Gostin, *The Americans with Disabilities Act and the Corpus of Anti-Discrimination Law: A Force for Change in the Future of Public Health Regulation*, 3 HEALTH MATRIX 89 (1993).

6. *Cf. Lee v. State*, 891 F. Supp. 1429, 1437 (D. Or. 1995) (enjoining effectiveness of Oregon's Death With Dignity Act based on violation of Equal Protection Clause; declining to address ADA claim in light of constitutional holding), *rev'd*, 107 F.3d 1382, 1390 (9th Cir. 1996) (holding that plaintiffs failed to establish actual injury required for standing). For discussions of the implications of legalizing physician-assisted suicide for persons with disabilities, *see* Robert L. Burgdorf, Jr., *National Council on Disability, Assisted Suicide: A Disability Perspective*, 14 ISSUES L. & MED. 273 (1998); Mark C. Siegel, *Lethal Pity: The Oregon Death with Dignity Act, Its Implications for the Disabled, and the Struggle for Equality in an Able-Bodied World*, 16 L. & INEQ. J. 259 (1998); Stephen L. Mikochik, *Individual Rights and Reasonable Accommodations Under the Americans with Disabilities Act: Assisted Suicide and Disabled People*, 46 DEPAUL L. REV. 987 (1997). *Cf. Paul Steven Miller, The Impact of Assisted Suicide on Persons with Disabilities - Is it a Right Without Freedom?*, 9 ISSUES L. & MED. 47, 47-48 (1993) (arguing that society's growing acceptance of assisted suicide for persons with disabilities is rooted in prejudice against persons with disabilities).

what rights to placement in community-based, rather than institutional, settings the ADA gives to people with physical and mental disabilities who need various forms of assistance in performing activities of daily living.⁷

Each of the foregoing questions poses intriguing issues about the ADA's application to "the critical area of . . . health services,"⁸ and each has generated litigation and commentary in the legal literature. Analyzing the ADA's implications for various aspects of health care raises fascinating issues for several reasons. First, because many persons with disabilities have ongoing and sometimes extensive health care needs as a result of their disabilities, legal protection against discrimination in accessing health care services can be of critical importance. Health care is sometimes referred to as "special," or different from other social goods, because of its necessity in enabling individuals to maintain the health and functioning that allow them to benefit from or enjoy other social goods such as education, employment, recreation, and social activities.⁹ In addition, health care decisions—whether one considers a provider's medical treatment decisions for a patient or decisions regarding insurance coverage or the features of a state Medicaid plan—are typically complex, multifactorial decisions. As a result, trying to tease out what role disability plays in the decision-making process and whether that role should be deemed legitimate or illegitimate can be quite problematic.

Indeed, it was in part the complexity of health care decision-making and the consequent difficulty of applying disability discrimination principles to those decisions that led courts interpreting the ADA's predecessor statute, Section 504 of the Rehabilitation Act of 1973,¹⁰ to take a hands-off approach to health care issues. In two of the most significant health care cases decided under Section 504, each court effectively

7. Cf. *Olmstead v. L.C.*, 527 U.S. 581, 597 (1999) (holding that unjustified institutional segregation constitutes discrimination violating the ADA). Although *Olmstead* involved plaintiffs who were institutionalized for their mental disabilities, the issue can also arise regarding the institutional placement of individuals with physical disabilities.

8. 42 U.S.C. § 12101(a)(3) (1994).

9. See 1983 PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SECURING ACCESS TO HEALTH CARE: THE ETHICAL IMPLICATIONS OF DIFFERENCES IN THE AVAILABILITY OF HEALTH SERVICES (1983) (recognizing the unique importance of health care in people's lives); Norman Daniels, *Health-Care Needs and Distributive Justice*, 10 PHIL. & PUB. AFF. 146, 166 (1981) (describing health care as a "strategically important contributor[] to fair equality of opportunity").

10. Section 504 provides:

No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.

29 U.S.C. § 794(a) (1994).

found that the statute had limited, if any, application to health care decisions. In *Alexander v. Choate*,¹¹ the Supreme Court decided that the State of Tennessee was free to limit the days of hospital care that its Medicaid program would pay for, notwithstanding the plaintiffs' claims that the limit discriminated against persons with disabilities because of their greater need for extended hospital care.¹² The Court assumed that a disparate impact theory of discrimination could apply in at least some cases arising under Section 504,¹³ but concluded that the statute did not require Tennessee to analyze the impact of its Medicaid policy decisions on people with disabilities and then avoid decisions that would negatively impact those citizens.¹⁴ The Court rejected such a requirement as "virtually unworkable" and refused to second guess the State's judgment.¹⁵ In the same vein, in *United States v. University Hospital*,¹⁶ the Second Circuit concluded that Section 504 did not apply to medical treatment decisions for disabled infants.¹⁷ The case was one of the "Baby Doe" cases in which the federal government sued a hospital under Section 504 for failing to perform corrective surgery on an infant born with spina bifida and microcephaly.¹⁸ In finding Section 504 inapplicable, the court first rejected the government's claim that the infant was "otherwise qualified" to receive medical treatment, as required by Section 504, stating that "the phrase cannot be applied in the comparatively fluid context of medical treatment decisions without distorting its plain meaning."¹⁹ The court then went on to refute the government's contention that the infant had been subjected to discrimination under Section 504 as "tak[ing] an oversimplified view of the medical decision-making process."²⁰

11. 469 U.S. 287 (1985).

12. *Alexander*, 469 U.S. at 308-09.

13. *Id.* at 299.

14. *See id.* at 302-09.

15. *Id.* The court reasoned:

[T]o require that the sort of broad-based distributive decision at issue in this case always be made in the way most favorable, or least disadvantageous, to the handicapped, even when the same benefit is meaningfully and equally offered to them, would be to impose a virtually unworkable requirement on state Medicaid administrators.

Id. at 308.

16. 729 F.2d 144 (2d Cir. 1984).

17. *University Hosp.*, 729 F.2d at 161.

18. *Id.* at 146-48.

19. *Id.* at 156.

20. *Id.* at 157. The court reasoned as follows:

Where the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was 'discriminatory'. . . . Beyond the fact that no two cases are likely to be the same, it would invariably require lengthy litigation primarily involving conflicting expert testimony to determine whether a decision to treat, or not to treat, . . . was based on a 'bona fide medical judgment', however that phrase might be defined.

Id.

In light of this apparent judicial reluctance to apply disability discrimination law to health care decisions, scholars wondered aloud when the ADA was enacted just how much impact it would have on the health care system. In 1990, Professor Wendy Parmet noted that the ADA's likely impact beyond "the conceptually simple (albeit not trivial) cases of physical inaccessibility or irrational prejudice" remained unclear.²¹ Indeed, she found the statute "extraordinarily unclear about its impact on medical decision-making" and predicted that the statute would have little impact on health insurance for people with disabilities.²² Time has shown these observations and predictions to be quite astute, although somewhat limited in their failure to perceive the broad range of health care contexts in which the ADA would be invoked over the following decade.

Rather than attempting to address each of the previously suggested health care contexts in which the ADA has been invoked, this Article will limit its focus by adopting the perspective of individuals with disabilities²³ in their encounters with the health care finance and delivery system in the United States,²⁴ and will pose the question of what the past

21. Wendy E. Parmet, *Discrimination and Disability: The Challenges of the ADA*, 18 LAW MED. & HEALTH CARE 331, 339 (1990).

22. *Id.* at 339-40. A few years later, Professor Lawrence Gostin was in agreement:

The ADA does not completely clarify the distinction between the genuine exercise of clinical judgment and unlawful discrimination. . . . The ADA . . . tears down barriers . . . only in a limited sense. It steadfastly refuses to allow a person to be turned away because of the provider's fears and biases toward the disability. But it remains uncertain to what extent the act can help to ensure access to health care for those who arguably need it most.

Lawrence O. Gostin, *The Americans with Disabilities Act and the U.S. Health System*, 11 HEALTH AFF. 248, 251-52 (1992).

23. Of course, the scope of the Article's discussion depends to some extent on how broadly the courts read the ADA's definition of "disability." 42 U.S.C. § 12102(2) (1994). In a trilogy of cases decided in 1999, the Supreme Court substantially narrowed the prevailing view of the meaning of "disability" by holding that, in determining whether an impairment substantially limits a major life activity, courts should consider the impairment in light of any mitigating measures employed by the individual. *See Albertsons, Inc. v. Kirkingburg*, 527 U.S. 555, 565 (1999); *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 482 (1999); *Murphy v. United Parcel Serv., Inc.*, 527 U.S. 516, 521 (1999). As a consequence, many individuals with chronic medical conditions that are at least partially controlled by medication may no longer be deemed individuals with disabilities under the meaning of the ADA. *Id.* The potentially perverse implications of this holding can be spun out in a variety of hypotheticals. For example, one could imagine that persons with chronic medical conditions who cannot afford to pay out of pocket for medications could sue a state Medicaid agency for its refusal to pay for their medications as prohibited discrimination based on disability. Without medication, chronic medical conditions such as diabetes, hypertension, or epilepsy may well substantially affect an individual's major life activities. If the plaintiffs were successful and the state Medicaid agency were ordered to pay for those medications, many of the individuals (once they are able to obtain medications) might no longer qualify as individuals with disabilities because their condition is now mitigated. At that point, the state Medicaid agency could discriminate with impunity (at least under the ADA) against those individuals based on their chronic medical conditions, as long as it doesn't deprive them of access to the medicines which, in effect, render them nondisabled.

24. As a result of this focus, this Article will not examine the application of the ADA and Section 504 to the employment and licensing rights of health care workers. This topic is of great significance for health care workers infected with HIV, *see Doe v. University of Md. Med. Sys.*

decade has shown the ADA to mean (or not mean) for those individuals' ability to seek, receive, and pay for effective health care services. To that end, this Article will provide an overview of three broad areas on which the ADA has had varying degrees of impact. Part II of the Article will examine how the ADA has affected the rights of an individual with a disability who is seeking medical or dental treatment. Health care providers' direct refusals to treat and failures to supply necessary auxiliary aids are the most obvious instances of disability discrimination in the health care context, and it is in this context that the ADA has had probably its greatest effect. Less clear has been the Act's applicability to claims that an individual with a disability has received different and substandard medical care. Part III will discuss the ADA's impact on cost-containment efforts in the health care field, ranging from the application of the ADA to managed care practices adopted by private and public payers to the statute's implication in health care rationing schemes. Part IV will turn to attempts to apply the ADA to health insurance, an area in which the courts appear increasingly resistant to allowing the ADA a significant role in regulating health insurance. Ultimately, Part V will conclude that the ADA's impact on health care for persons with disabilities has been mixed. It has played a major role in addressing the most overt instances of discriminatory behavior, but its impact on less obvious instances of potentially discriminatory cost-cutting practices and on health insurance has been more muted and indirect. Nonetheless, I will conclude that the passage of the ADA and the mere potential of ADA liability has had the beneficial effect of compelling health care decision-makers to take the presence and needs of persons with disabilities into account; in so doing, the ADA has helped to render persons with disabilities visible in the world of health care.

Corp., 50 F.3d 1261, 1267 (4th Cir. 1995) (holding that a neurosurgery resident with HIV infection posed a direct threat to potential patients and was therefore not a qualified individual with a disability), or who have mental illness, see *Kirbens v. Wyoming State Bd. of Med.*, 992 P.2d 1056, 1057 (Wyo. 1999) (holding that state's revocation of license of physician with mental illness did not violate the ADA), or are recovering substance abusers, see *Griel v. Franklin Med. Ctr.*, 71 F. Supp. 2d 1, 13 (D. Mass. 1999) (upholding dismissal of recovering drug dependent nurse as nonpretextual), but is of relatively limited significance for persons with disabilities who are seeking treatment. For discussion of employment rights in the health care context see Mary Anne Bobinski, *Patients and Providers in the Courts: Fractures in the Americans with Disabilities Act*, 61 ALB. L. REV. 785 (1998); Laura F. Rothstein, *Health Care Professionals with Mental and Physical Impairments: Developments in Disability Discrimination Law*, 41 ST. LOUIS U. L.J. 973 (1997).

II. ACCESS AND TREATMENT FOR INDIVIDUALS SEEKING CARE

A. Denials of Access

As anticipated by commentators writing at the time of the ADA's passage, the statute generally has been a powerful tool for addressing denials of access to medical treatment for persons with disabilities, denials that often reflect health care providers' prejudices and fears. A provider's refusal to treat a person based on that person's disability is probably the most direct and overt form of disability discrimination in the health care context, and it is a form of discrimination that can predictably lead to both adverse physical consequences for the individual who may not be able to obtain needed medical treatment and psychic harm flowing from the overt rejection by the health care provider.

The Supreme Court's first case interpreting the ADA, *Bragdon v. Abbott*,²⁵ exemplifies the statute's application to this type of situation. In that case, dentist Randon Bragdon refused to fill a cavity of Sidney Abbott, a woman with HIV infection, in his office.²⁶ Abbott sued under Title III of the ADA,²⁷ which prohibits disability discrimination by the operator of a place of public accommodation,²⁸ a term that expressly includes the "professional office of a health care provider."²⁹ While the dentist argued that providing the requested services in his office would pose a "direct threat"³⁰ of HIV transmission to him, the district court rejected this reasoning and granted summary judgment to the plaintiff.³¹ The court's analysis indicates that—absent a "direct threat" or some other defense—a refusal to provide dental treatment to an individual based on the individual's disability constitutes an ADA violation.³²

25. 524 U.S. 624 (1998).

26. *Bragdon*, 524 U.S. at 628-29. This case does not involve an absolute refusal to treat, for the dentist offered to fill the cavity at a hospital. *Id.* at 629. This alternative, however, would have subjected the plaintiff to additional charges imposed by the hospital. *Id.* In addition, there was no evidence that the defendant had privileges at any hospital. *Id.* at 651.

27. *Id.* at 629.

28. 42 U.S.C. § 12182(a) (1994) provides: "No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation."

29. *Id.* § 12181(7)(F).

30. The direct threat defense is based on 42 U.S.C. § 12182(b)(3) (1994) which provides: Nothing in this subchapter shall require an entity to permit an individual to participate in or benefit from the goods, services, facilities, privileges, advantages and accommodations of such entity where such individual poses a direct threat to the health or safety of others. The term "direct threat" means a significant risk to the health or safety of others that cannot be eliminated by a modification of policies, practices, or procedures or by the provision of auxiliary aids or services.

31. *Abbott v. Bragdon*, 912 F. Supp. 580, 587-91, 595 (D. Me. 1995).

32. See *Abbott*, 912 F. Supp. at 584-85. In addition to the direct threat issue, the other issue central to the case was whether plaintiff's asymptomatic HIV infection constituted a disability

The question of when the direct threat defense may be invoked ultimately went to the Supreme Court, which addressed whether deference should be paid to the individual judgment of a health care provider regarding the existence of a significant risk of transmission.³³ The Court concluded that the existence of significant risk and direct threat, while it should be determined from the standpoint of the person who refuses to provide treatment, must be assessed based on objective medical or scientific information.³⁴ To put it simply, a health care provider cannot avoid ADA liability for refusal to treat merely by pointing to his good faith belief that treatment would pose a direct threat to him, unless that belief is also supported by objective evidence. The Supreme Court's judgment thereby reinforces the principle that subjective prejudices and irrational fears are not a legitimate basis for depriving individuals with disabilities of access to treatment.

In a number of other cases, plaintiffs with HIV infection have sued providers from whom they sought treatment, alleging that the provider violated disability discrimination law by referring or transferring the plaintiff to another, "special" provider based on the patient's HIV-positive status.³⁵ In these cases, the provider typically defends by asserting that he is not qualified to treat a person infected with HIV and that he did not discriminate against the plaintiff by making a referral to a provider with specialized training or experience. This defense has solid legal grounding in the Title III regulations issued by the Department of Justice, which make clear that the ADA in some instances allows referrals of individuals with disabilities to specialists.³⁶ Courts encountering this defense have tended to scrutinize the facts carefully to determine whether the asserted need for specialized treatment is legitimate or is instead a pretext for discrimination. So, for example, while one court

under the ADA. *Bragdon*, 524 U.S. at 628. The Supreme Court affirmed the judgment of the First Circuit and the district court in holding that the HIV infection was an impairment that substantially limited the plaintiff's major life activity of reproduction. *Id.* at 647.

33. *Id.* at 648-55.

34. *Id.* at 649. The Supreme Court was unable to determine, based on the record presented to it, whether the Court of Appeals had appropriately assessed the existence of direct threat. *Id.* at 654-55. Accordingly, the Court remanded the case to the First Circuit for a reconsideration of the evidence in light of the Court's articulated standard. *Bragdon*, 524 U.S. at 655. On remand, the First Circuit again concluded that summary judgment for the plaintiff on the question of direct threat was warranted. *Abbott v. Bragdon*, 163 F.3d 87, 90 (1st Cir. 1998).

35. See *United States v. Morvant*, 898 F. Supp. 1157 (E.D. La. 1995); *D.B. v. Bloom*, 896 F. Supp. 166 (D.N.J. 1995).

36. 28 C.F.R. § 36.302(b)(2) (1999) provides:

A health care provider may refer an individual with a disability to another provider, if that individual is seeking, or requires, treatment or services outside of the referring provider's area of specialization, and if the referring provider would make a similar referral for an individual without a disability who seeks or requires the same treatment or services. A physician who specializes in treating only a particular condition cannot refuse to treat an individual with a disability for that condition, but is not required to treat the individual for a different condition.

ruled against a dentist who claimed he was not competent to provide a routine teeth cleaning to a patient with HIV,³⁷ another court granted summary judgment to an obstetrician who referred a pregnant woman with HIV infection and other medical conditions to a specialized program for women and children with HIV.³⁸

*Bragdon v. Abbott*³⁹ and the cases involving pretextual referrals illustrate how the ADA can act as a powerful limit on the ability of health care providers to refuse to provide treatment to individuals with HIV infection. This limit holds immense meaning for persons with HIV. Surveys of providers conducted during the 1980's and well into the 1990s indicated a reluctance to treat persons with HIV,⁴⁰ a group (it should go without saying) that have significant medical needs. Thus, the consistent holdings of cases challenging refusals to treat persons with HIV, and enforcement actions taken by the Department of Justice⁴¹ send a clear message to medical and dental providers that refusals to treat are illegitimate and illegal.

While refusal to treat cases arising under the ADA have most commonly been brought by plaintiffs with HIV infection, the statute's pro-

37. *Morvant*, 898 F. Supp. at 1168. In reaching its conclusion, the court relied on the testimony of expert witnesses, including a former official at the American Dental Association, an academic authority on dentistry and HIV, and an official from the Centers for Disease Control and Prevention. *Id.* at 1163-64. See also *Howe v. Hull*, 873 F. Supp. 72, 79 (N.D. Ohio 1994) (finding the defendant's claim that the patient's diagnosis with a rare and potential fatal skin disease was the reason for his transfer to another hospital to be a pretext); *D.B. v. Bloom*, 896 F. Supp. 166, 169, 173 (D.N.J. 1995) (granting motion for default judgment against dentist who referred patient with HIV infection to "special clinic for HIV," which in fact was a facility providing services to the medically indigent and mentally ill).

38. *Lesley v. Chie*, 81 F. Supp. 2d 217, 220-21, 227 (D. Mass. 2000). In addition, the hospital at which the defendant physician had admitting privileges did not include AZT in its hospital formulary. *Id.* at 220. (AZT is a drug whose administration to a pregnant woman during pregnancy and labor significantly lowers the rate of mother-to-infant transmission of HIV. *Id.*) See also *Lasser v. Rosa*, 654 N.Y.S.2d 822, 823-24 (App. Div. 1997) (finding no evidence that referral to specialized dental clinic for persons with HIV for performance of a molar extraction was a pretext for discrimination).

39. See *supra* text accompanying notes 25-34.

40. See Robert J. Weyant et al., *Desire to Treat HIV-Infected Patients: Similarities and Differences Across Health Care Professions*, 8 AIDS 117 (1994); Charles J. Curry et al., *Willingness of Health-Profession Students to Treat Patients with AIDS*, 65 ACAD. MED. 472 (1990); see also John Gibeaut, *Lawyers are Drilling Home the Point that Dentists Who Won't Treat HIV Patients may be Practicing the Most Pervasive Discrimination of All*, A.B.A. J., July 1997, at 48 (reporting on survey published by the American Journal of Public Health).

41. The Department of Justice has undertaken a number of enforcement actions under Title III of the ADA against providers alleged to have refused treatment on the basis of a patient's disability. For example, in March 1998, the Justice Department reached an agreement settling a complaint against George Washington University Hospital. The settlement requires the hospital to take a number of steps to ensure that persons with HIV or other infectious diseases are not denied treatment or treated inappropriately. See *GWU Hospital Settles AIDS Suit*, WASH. POST, Mar. 11, 1998, at B7; *Justice Department GW University Hospital Reach Accord on Treatment of AIDS Patients*, BNA HEALTH CARE DAILY, Mar. 11, 1998. See also *United States v. Neurological Surgery Inc.*, No. 00-CV-26 (N.D. Okla. filed 1/10/00) (alleging that neurosurgeons refused to treat an individual with HIV), reported at Department of Justice, *Enforcing the ADA: A Status Report*, January-March 2000, available at <<http://www.usdoj.gov/crt/ada/janmar00.htm>>.

tection of the right of an individual not to be denied access to medical treatment based on disability has also come into play in cases involving individuals with other disabilities, including hearing impairments and Alzheimer's disease.⁴² And for the person who might be turned away from a doctor's office, dentist's office, or hospital because of a disability, this is a crucial protection that enables him to access health care treatment necessary to preserve his life or health or to increase his functioning.⁴³

B. Failure to Provide Auxiliary Aids

After flat refusals to provide care and pretextual referrals based on disability, the next most obvious violation of the ADA in the health care context is the failure of a provider covered by the ADA to provide auxiliary aids or services necessary to ensure that an individual with a disability is not "excluded, denied services, segregated or otherwise treated differently than other individuals."⁴⁴ The ADA requires hospitals and health care professionals' offices to ensure effective communication with individuals with disabilities, and a patient (or possibly a family member of a patient) who is denied necessary auxiliary aids has a claim of disability discrimination under the ADA.⁴⁵

A failure to provide auxiliary aids could act to exclude or segregate individuals with hearing impairments in many public accommodations settings, but the effect of such a failure is particularly pernicious in a health care setting because of the vital importance of timely, accurate, and confidential communication to the provision of effective medical care.⁴⁶ Ineffective communication may result in delays in treatment,

42. See *Wagner v. Fair Acres Geriatric Ctr.*, 49 F.3d 1002 (3d Cir. 1995) (woman with Alzheimer's denied admission to nursing facility); *Sumes v. Andres*, 938 F. Supp. 9 (D.D.C. 1996) (deaf woman denied prenatal care).

43. Of course, the ADA's prohibition against refusal to treat based on disability does nothing to protect individuals who are denied access to health care not because of their disability, but because they do not have health insurance coverage and cannot pay for care. See *infra* Part IV (regarding the ADA's applicability to health insurance).

44. 42 U.S.C. § 12182(b)(2)(A)(iii) (1994) (including such a failure in the ADA's definition of "discrimination"). Examples of auxiliary aids include:

Qualified interpreters, notetakers, computer-aided transcription services, written materials, telephone handset amplifiers, assistive listening devices, assisted listening systems, telephones compatible with hearing aids, closed caption decoders, open and closed captioning, telecommunications devices for deaf persons (TDD's), videotext displays, or other effective methods of making aurally delivered materials available to individuals with hearing impairments.

28 C.F.R. § 36.303(b)(1) (1999).

45. Depending on who the provider is, the individual may also have a claim under Section 504 of the Rehabilitation Act. Regulations issued under Section 504 require hospitals receiving federal financial assistance to provide auxiliary aids under some circumstances, see 45 C.F.R. § 84.52(c), (d)(1) (1999), but do not speak to the provision of aids in an office setting.

46. See Elizabeth E. Chilton, *Ensuring Effective Communication: The Duty of Health Care Providers to Supply Sign Language Interpreters for Deaf Patients*, 47 HASTINGS L.J. 871, 873

failures to obtain informed consent, and misdiagnoses. For example, in the case of *Aikins v. St. Helena Hospital*,⁴⁷ a hospital failed to provide a deaf woman with a sign language interpreter following her husband's heart attack.⁴⁸ As a result, medical personnel were not able to communicate effectively with the woman and did not learn until the day after the heart attack how much time had elapsed between the attack and the commencement of CPR.⁴⁹ Unfortunately, such instances do not appear to be unusual. A survey published in 1995 found that, while a majority of the doctors surveyed understood the appropriateness of using sign language interpreters in communicating with their deaf patients, only a minority of the doctors actually used interpreters.⁵⁰

As with cases involving denials of access, because of the ADA's relative clarity on the topic and the obvious negative impact on individual patients, courts have been willing to give some teeth to the ADA's requirement of auxiliary aids in the health care setting.⁵¹ These teeth are dulled somewhat, however, by an absence of precise rules in the ADA regarding the provision of auxiliary aids and the availability of an "undue burden" defense for public accommodations.⁵² What auxiliary aids are "necessary to ensure" that an individual with a disability is not excluded or segregated is a question of fact,⁵³ as is the availability of the

(1996).

47. 843 F. Supp. 1329 (N.D. Cal. 1994).

48. *Aikins*, 843 F. Supp. at 1332.

49. *Id.* at 1331-32.

50. See David A. Ebert & Paul S. Heckerling, *Communication with Deaf Patients: Knowledge, Beliefs, and Practices of Physicians*, 273 JAMA 227 (1995).

51. See, e.g., *Naiman v. New York Univ.*, 1997 WL 249970, *2 (S.D.N.Y. 1997) (finding that plaintiff stated a claim of disability discrimination in his allegation that defendant hospital failed to provide a qualified interpreter); *Tugg v. Towey*, 864 F. Supp. 1201, 1211 (S.D. Fla. 1994) (granting injunction requiring that mental health services be provided by counselors with sign language ability); *Mayberry v. Von Valtier*, 843 F. Supp. 1160, 1168 (E.D. Mich. 1994) (denying physician's motion for summary judgment in action by deaf woman alleging physician's refusal to provide interpreter services in the future and termination of medical care); *Cf. Anderson v. Department of Pub. Welfare*, 1 F. Supp. 2d 456, 466 (E.D. Pa. 1998) (denying plaintiff's motion for summary judgment on claim that Medicaid HMOs failed to provide all information in alternative formats; issues of fact remained regarding effectiveness of communication provided); *Aikins*, 843 F. Supp. at 1333, 1339 (denying plaintiff's ADA action for injunctive relief based on lack of standing, but finding plaintiff entitled to compensatory relief under § 504).

52. 42 U.S.C. § 12182(b)(2)(A)(iii) (1994) states that "discrimination" includes:

[A] failure to take such steps as may be necessary to ensure that no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services, unless the entity can demonstrate that taking such steps would fundamentally alter the nature of the good, service, facility, privilege, advantage, or accommodation being offered or would result in an undue burden.

53. See, e.g., *Anderson*, 1 F. Supp.2d at 466 (concluding that whether verbal assistance was a sufficiently effective means of communicating presented an issue of material fact precluding summary judgment); *Proctor v. Prince George's Hosp. Ctr.*, 32 F. Supp.2d 820, 827 (D. Md. 1998) ("Neither the precedents nor the regulations, however, establish a *per se* rule that sign language interpreters are necessary in hospital settings.").

undue burden defense.⁵⁴ As a result, plaintiffs alleging a failure to provide auxiliary aids are unlikely to prevail on summary judgment except in the clearest of cases.

An additional stumbling block for plaintiffs claiming a denial of auxiliary aids has been the limited relief available under Title III. Because a private plaintiff suing under Title III can obtain only injunctive, and not compensatory relief,⁵⁵ the plaintiff has to satisfy standing requirements.⁵⁶ A number of courts have dismissed claims based on lack of standing because of the plaintiff's inability to show that the injury complained of would likely occur again in the future.⁵⁷ Thus, a deaf person who is discriminated against by a public accommodation's failure to provide auxiliary aids on a single, isolated occasion may not be able to receive any relief under the ADA.⁵⁸ This barrier may be particularly problematic in ADA actions brought against a hospital, where care is often provided to patients admitted for acute or emergency care and who, consequently, cannot show they will need auxiliary aids from the hospital on an ongoing basis.

Because of the standing issues that may arise in private actions, the auxiliary aids provisions of Title III have proven particularly well suited to public enforcement actions brought by the Department of Justice or a U.S. Attorney. For example, in *DeVinney v. Maine Medical Center*,⁵⁹ the U.S. Attorney for the District of Maine and a private plaintiff sued Maine's largest hospital for failing to provide auxiliary aids to deaf and hard of hearing individuals.⁶⁰ The parties entered into a consent decree requiring the hospital to provide qualified sign language interpreters, assistive listening and telecommunication devices, captioned televisions and other similar aids and services to hearing impaired individuals and

54. See *Randolph v. Rodgers*, 170 F.3d 850, 858-59 (8th Cir. 1999) (reversing grant of summary judgment for hearing impaired inmate who alleged that prison's failure to provide a sign language interpreter during medical care, *inter alia*, violated the ADA and remanding for consideration of whether provision of an interpreter would be a reasonable accommodation or would impose an undue burden).

55. See *Aikins*, 843 F. Supp. at 1338 (citing 42 U.S.C. § 12188(a)(1) (West Supp. 1993) and 42 U.S.C. § 2000a-3(a) (1994)). By contrast, a plaintiff suing under Section 504 can recover compensatory damages. See *id.* at 1338-39 (citing 29 U.S.C. § 794a(a)(2) (West 1985)).

56. As articulated by the Supreme Court, in order to establish standing, a plaintiff must show that she has suffered an injury in fact (a violation of a legally protected interest) that is both concrete and particularized and either actual or imminent. *Lujan v. Defenders of Wildlife*, 504 U.S. 555, 560 (1992). The plaintiff seeking injunctive relief must face a threat of present or future harm from the illegal conduct. See *City of Los Angeles v. Lyons*, 461 U.S. 95, 103 (1983).

57. See, e.g., *Aikins*, 843 F. Supp. at 1338 (dismissing ADA claims for lack of standing); *Bravin v. Mount Sinai Med. Ctr.*, 186 F.R.D. 293, 301 (S.D.N.Y. 1999) (dismissing ADA claims for lack of standing); *Proctor v. Prince George's Hosp. Ctr.*, 32 F. Supp. 2d 820 (D. Md. 1998) (same).

58. The plaintiff may pursue compensatory damages under Section 504, though, if the provider is a hospital subject to 45 C.F.R. § 84.52(c)-(d)(1) (1999).

59. 1998 WL 271495 (D. Me. 1998).

60. 1998 WL 271495 at *1.

setting forth extensive rules governing the hospital's provision of auxiliary aids.⁶¹ Such actions take the focus away from the harm threatened to a particular individual with a disability and can provide an effective mechanism for compelling a health care provider to conform its practices more broadly to the ADA's auxiliary aids requirements.⁶²

C. Different Treatment

Once we stop talking about a health care provider's outright refusal to treat an individual with a disability or refusal to provide auxiliary aids and start looking instead at claims of discrimination in the form of differential treatment, the ADA's impact on the treatment of individuals with disabilities becomes much less clear. As discussed above, the analytical framework for a claim that a provider effectively closed the door in a patient's face is fairly straightforward. Courts are much less comfortable, by contrast, grappling with the claim of a person with a disability that she received treatment from a provider, but that the treatment was different from and inferior to the treatment provided to other patients without the plaintiff's disability.

It was this type of claim of discriminatory treatment choices that the Second Circuit rejected in the *University Hospital*⁶³ case. In that case, the government basically argued that the hospital failed to provide corrective surgery for an infant born with spina bifida and microcephaly and that the decision not to provide the surgery discriminated against the infant based on handicap in violation of Section 504.⁶⁴ Ordinarily, to prove a case of discrimination, the government would seek to put on evidence that the hospital treated other individuals, who are similarly situated except for the suspect trait, differently from the individual with the trait. The analytical difficulty arises, of course, because *only* infants who have spina bifida need surgery to correct an imperfect closure of the spinal column. How can we meaningfully compare the treatment of the infant with spina bifida with the treatment provided to her non-

61. *Id.* at *1, *3.

62. Public enforcement actions have also been brought, for example, against a group of acute care hospitals in Connecticut, see *Connecticut Ass'n of the Deaf v. Middlesex Mem'l Hosp.*, described in Department of Justice, *Enforcing the ADA: A Status Report*, April - June 1998 available at <<http://www.usdoj.gov/crt/ada/aprjun98.htm>>, an obstetrics group that had failed to provide auxiliary aids for a deaf expectant father, see *Drew v. Merrill*, described in Department of Justice, *Enforcing the ADA: A Status Report*, Oct. - Dec. 1999 available at <<http://www.usdoj.gov/crt/ada/octdec99.htm>>, and a group of neurologists, see *Neurologic Institute of the Gulf Coast*, described in *id.* In addition, in *People by Vacco v. Mid Hudson Med. Group*, 877 F. Supp. 143 (S.D.N.Y. 1995), the court held that the State of New York had *parens patriae* standing to sue a medical clinic for violating the ADA by refusing to provide sign language interpreters for patients with hearing impairments. *Vacco*, 877 F. Supp. at 149.

63. *United States v. University Hosp.*, State Univ. of N.Y. at Stony Brook, 729 F.2d 144 (2d Cir. 1984).

64. *University Hosp.*, 729 F.2d at 148.

disabled counterpart? It was based in part on this reasoning that the Second Circuit flatly concluded that Section 504 did not apply to medical treatment decisions for disabled infants.⁶⁵

The Second Circuit's reasoning and conclusion in *University Hospital* have cast a long shadow over the application of disability discrimination law to medical decision-making, and some courts continue to emphasize the need to defer to medical judgment in this arena.⁶⁶ There is some force to the argument that it is simply too complex to try to determine what role disability plays in a particular treatment decision, particularly when the condition needing treatment is somehow related to the disability itself. After all, it seems nonsensical to say that a physician cannot take a patient's disability into account at all in deciding how to treat a disability-related condition. Undoubtedly, the existence of a disability and its medical effects can be a legitimate factor in choosing appropriate medical treatment. Notwithstanding the legitimacy of considering disability in some cases, however, in other instances disability should be deemed an illegitimate consideration, as several examples will illustrate.

Imagine an oncologist who routinely recommends surgical resection for patients whose lung cancer is discovered at an early stage, but when a blind person is diagnosed with early-stage lung cancer, the oncologist recommends only chemotherapy, a less effective therapy for that cancer.⁶⁷ Assuming that the patient's visual impairment has nothing to do with his cancer and that the patient has no other comorbidities that would make surgery ill advised, the oncologist's choice would appear to be an illegitimate choice to treat that patient differently based on the patient's disability. Such a discriminatory choice ought to be covered by

65. *Id.* at 161. The Second Circuit reached this conclusion after attempting to construe Section 504's "otherwise qualified" language in this context and finding that "the phrase cannot be applied in the comparatively fluid context of medical treatment decisions without distorting its plain meaning." *Id.* at 156. Title III of the ADA, by contrast, does not require that the individual with a disability somehow be "qualified" to receive the goods and services of a place of public accommodation. *See, e.g.*, 42 U.S.C. § 12182 (1994). Professor Susan Stefan aptly notes the hidden danger in this type of reasoning when she states: "Oppressive and disadvantageous treatment based on a disfavored characteristic becomes virtually invisible to the extent that there is no comparison group." Susan Stefan, *The Americans with Disabilities Act and Mental Health Law: Issues for the Twenty-First Century*, 10 J. CONTEMP. LEGAL ISS. 131, 145 (1999).

66. *See, e.g.*, *Lesley v. Chie*, 81 F. Supp. 2d 217, 224 (D. Mass. 2000) (citing *University Hospital* as supplying the rationale for giving deference to medical treatment decisions); *Toney v. United States Healthcare Inc.*, 838 F. Supp. 201, 204 (E.D. Pa. 1993) (holding that "a determination by a physician of when her regular patient's condition warrants an additional office visit is a medical treatment decision not subject to judicial review").

67. This hypothetical is drawn from a published study showing the effect of race on surgical treatment for lung cancer. *See* Peter B. Bach et al., *Racial Differences in the Treatment of Early-Stage Lung Cancer*, 341 NEW ENG. J. MED. 1198 (1999) (finding that black patients received surgical resection 12.7% less frequently than white patients). According to the study, for patients diagnosed with non-small-cell lung cancer at an early stage, surgical resection offers a 40% chance of surviving 5 years or longer. *Id.* Patients whose cancer is discovered at a later stage or who do not have the surgery have a medical survival of less than one year. *Id.*

the ADA.

Similarly, consider the case of Sandra Jensen, a woman with Down syndrome who developed a need for a heart and lung transplant. Both Stanford University Hospital and UC San Diego initially refused to put her on a waiting list for the transplant because the transplant surgeons believed that a person with Down syndrome lacked the mental capacity to survive the post-transplantation regimen.⁶⁸ After the case received attention from the press and advocacy groups and the Department of Justice noted the possibility of an ADA violation,⁶⁹ though, the surgeons reassessed Jensen's candidacy based on her own individual ability to handle the regimen.⁷⁰ Based on that assessment, they placed her on the waiting list.⁷¹ Only days after being put on the waiting list at Stanford, Sandra Jensen became the first person with Down syndrome to receive a heart-lung transplant.⁷² In this situation, the transplant surgeons initially viewed Jensen's disability as related to her suitability as a transplant candidate. That view, however, was based on their blanket assumptions regarding the abilities of all persons with a particular disability. Once the surgeons employed the approach prescribed by the ADA, an individualized assessment of the particular individual's abilities and needs, their view of the situation changed.⁷³

Finally, let us imagine a woman with HIV infection who visits an otolaryngologist (an "ear, nose, throat" doctor) complaining of severe pain in one ear. The doctor diagnoses a perforated ear and faces a choice between two possible treatment options: surgical repair of the perforation versus the administration of prophylactic antibiotics to ward off infection while the ear heals on its own. While this doctor typically recommends surgical repair for patients with a perforated ear, upon learn-

68. See *Down Syndrome Woman Denied Organ Transplant*, SAN FRANCISCO CHRONICLE, Aug. 12, 1995, at A19, available in 1995 WL 5294339.

69. See David A. Sylvester, *About-Face on Organ Transplant*, SAN FRANCISCO CHRONICLE, Jan. 19, 1996, at F16, available in 1996 WL 3211591; Judy Tachibana, *Alliance Drive Seeks to Register Organ Donors*, LOS ANGELES DAILY NEWS, Oct. 29, 1995, at N6, available in 1995 WL 5424624; Celeste Fremon, LOS ANGELES TIMES MAGAZINE, Apr. 14, 1996, at 18, available in 1996 WL 5259970.

70. See *After Five Month Battle, Down Syndrome Patient May Be Placed on UCSD Wait List for Heart-Lung Transplant*, TRANSPLANT NEWS, Dec. 14, 1995, available in 1995 WL 10121024.

71. See David A. Sylvester, *About-Face on Organ Transplant/Stanford to Help Woman Who Has Down Syndrome*, SAN FRANCISCO CHRONICLE, Jan. 19, 1996, at F16, available in 1996 WL 3211591.

72. See John Wildermuth, *Transplant for Woman with Down Syndrome/Heart-Lung Surgery Called a Landmark*, SAN FRANCISCO CHRONICLE, Jan. 24, 1996, at A1, available in 1996 WL 3211891.

73. For in-depth discussions of the application of disability discrimination law to the allocation of organs for transplantation, see Angela T. Whitehead, *Rejecting Organs: The Organ Allocation Process and the Americans with Disabilities Act*, 24 AM. J.L. & MED. 481 (1998); David Orentlicher, *Destructuring Disability: Rationing of Health Care and Unfair Discrimination Against the Sick*, 31 HARV. CIV. RIGHTS & CIV. LIB. L. REV. 49 (1996); Karen J. Merrikin & Thomas D. Overcast, *Patient Selection for Heart Transplantation: When is a Discriminating Choice Discrimination?*, 10 J. HEALTH POL., POL'Y & L. 7 (1985).

ing of the patient's HIV infection, he recommends the antibiotic course of treatment.⁷⁴ Is this consideration of the patient's disability in making a treatment choice legitimate?

The answer in this situation must be "It depends." Specifically, it depends on the reasoning behind the physician's choice of treatments. If the doctor based his recommendation on his judgment (supported by current medical science) that the greater risk of infection caused by surgery is not in the medical best interests of a person with HIV infection, that would seem to be a legitimate consideration of disability in medical decision-making.⁷⁵ By contrast, if the doctor believed that surgery was in the patient's best interests, but recommended antibiotic treatment out of the fear of the small and avoidable risk of patient-to-doctor transmission during surgery, that would seem to be an illegitimate consideration of disability.⁷⁶

The "it depends" analysis required in a case like this demonstrates the inadequacy of an approach that would state either that any consideration of disability in medical decision-making is illegitimate or that providers' treatment decisions are always beyond the scrutiny of the disability discrimination laws. Determining what role disability plays in medical decision-making may well continue to challenge courts, but the examples provided demonstrate that there may be instances when disability plays a role that is clearly inconsistent with both the philosophy

74. This hypothetical scenario is based loosely on the facts of *Glanz v. Vernick*, 756 F. Supp. 632 (D. Mass. 1991). See also Amir Halevy, *AIDS, Surgery, and the Americans with Disabilities Act*, 135 ARCHIVES OF SURGERY 51 (2000) (reporting anecdotally the decisions of specialists who routinely perform invasive diagnostic tests, but who decide that non-invasive radiological studies should be done on patients with HIV, and the decisions of surgeons that surgery is not necessary upon learning that a patient has HIV infection).

75. The more difficult question would arise if the patient, notwithstanding the doctor's belief that antibiotic treatment was in the patient's best interest, chose to accept the greater risk of infection and demanded that the doctor perform the surgery. In *Jairath v. Dyer*, 972 F. Supp. 1461 (N.D. Ga. 1997), the court granted summary judgment to a doctor who refused to perform Gore-tex implant surgery (a type of cosmetic surgery) at the request of a patient with HIV infection. *Jairath*, 972 F. Supp. at 1470. The court accepted the doctor's defense that performing the surgery would pose a "direct threat" to the plaintiff's own health, as opposed to the doctor's health. *Id.* A split among the Circuit Courts of Appeal has recently developed on whether the "direct threat" defense in the employment context should be construed to include threats to the health or safety of the disabled plaintiff. Compare *Echazabal v. Chevron USA, Inc.*, 213 F.3d 1098, 1104-05 (9th Cir. 2000) (holding that a direct threat that a job applicant posed to his own health or safety does not give the employer an affirmative defense in an ADA action), with *Moses v. American Non-wovens, Inc.*, 97 F.3d 447, 447-48 (11th Cir. 1996) (stating that the ADA's direct threat defense applies to threats to the disabled individual himself). The ability of a patient with a disability to demand a treatment that a physician believes is not in the patient's best interests also arises when a physician refuses to provide treatment the physician believes is futile. See Philip G. Peters, *When Physicians Balk at Futile Care: Implications of the Disability Rights Laws*, 91 NW. U. L. REV. 798 (1997); Mary Crossley, *Medical Futility and Disability Discrimination*, 81 IOWA L. REV. 179 (1995).

76. This mirrors the situation in *Abbott v. Bragdon* and other cases in which the defendant providers have unsuccessfully raised a "direct threat" defense. See *supra* text accompanying notes 25-34.

and the language of the ADA. If that is the case, the challenge is to figure out *how* it makes sense to apply the ADA to medical treatment decision-making.

Since the passage of the ADA, several courts have recognized that disability discrimination law may place some limits on the medical decisions of doctors and other health care providers.⁷⁷ Nonetheless, the law remains far from clear regarding the application of disability discrimination law to medical decision-making. This lack of resolution is likely due in part to the relative scarcity of cases litigated on this question. This scarcity is not surprising, because unless the differential treatment experienced by a person with a disability rises to the level of a denial of treatment or the patient is particularly sophisticated regarding her medical options, the patient is unlikely ever to realize that, because of her disability, she is being treated differently and less favorably in the medical advice and treatment she is receiving.⁷⁸

Notwithstanding the small number of litigated cases, how the ADA applies to medical treatment decisions is an important question, and it may become more important in the future if the responsibility for containing health care costs is increasingly left in the hands of providers facing financial incentives to provide less care rather than more. In that scenario, persons with disabilities may be particularly likely to receive suboptimal, but less expensive, medical treatments, and they may be more likely than other patients to be denied treatment altogether. This linkage between medical decision-making and cost containment presents

77. See, e.g., *Jairath v. Dyer*, 972 F. Supp. 1461 (N.D. Ga. 1997) ("Use of caution in making medical decisions is to be distinguished from situations in which doctors blatantly discriminate against patients."); *Howe v. Hull*, 873 F. Supp. 72, 78, 79, n.2 (N.D. Ohio 1994) (stating that "[d]iscrimination in public accommodation can take the form of the . . . provision of unequal medical benefits based upon the disability," but declining to address whether a provider considering whether to refer a patient to another provider "may properly consider an individual's disability when that disability complicates the medical condition for which the individual is seeking treatment"); *Lesley v. Chie*, 81 F. Supp. 2d 217, 224-25 (D. Mass. 2000) (citing to *University Hospital* and explaining rationale behind deference to medical decisions, but proceeding to scrutinize carefully facts underlying physician's claim of a nondiscriminatory basis for referral); *Sharrow v. Bailey*, 910 F. Supp. 187, 192 (M.D. Pa. 1995) (finding that HIV-positive plaintiff's claim that orthopedic surgeon conditioned performance of surgery on the use of safeguards exceeding those recommended by the CDC stated a claim for violation of the ADA); *Glanz v. Vernick*, 756 F. Supp. 632, 638 (D. Mass. 1991) (stating that courts' unquestioning deference to doctors' medical judgments "would completely eviscerate § 504's function of preventing discrimination against the disabled in the health-care context"); *Woolfolk v. Duncan*, 872 F. Supp. 1381, 1389 (E.D. Pa. 1995) (involving allegation that doctor discriminated by his failure to authorize HIV-positive plaintiff's visit to emergency room, in which the court concluded, *inter alia*, that a managed care enrollee with a disability is otherwise qualified for medical benefits "if there is no factor apart from the mere existence of disability that renders the [enrollee] unqualified for the benefit").

78. A significant number of patients are reluctant to participate actively in medical decision-making and instead trust their health care provider to make decisions regarding care and treatment for them. Cf. CARL E. SCHNEIDER, *THE PRACTICE OF AUTONOMY: PATIENTS, DOCTORS, AND MEDICAL DECISIONS* 47-49 (1998) (citing the complexity of medical decisions and the doctors' relative expertise and authority as reasons for this behavior).

a good bridge to discussing the ADA's applicability to health care cost-containment measures.

III. THE ADA AND COST CONTAINMENT EFFORTS

In this part, the focus shifts away from cases alleging a denial of treatment or the differential treatment of individual patients and toward the ADA's application to cost-containment measures employed systemically. Accordingly, this part will examine claims, not that an individual was singled out for different treatment because of a disability, but that a practice or policy that applies to everyone has a discriminatory impact on people with disabilities. The ADA clearly contemplates reaching at least some forms of disparate impact discrimination by recognizing that physical, social, or economic structures may create barriers or disadvantages for people with disabilities and that a failure to take reasonable steps to remove those barriers or remedy those disadvantages should be deemed to be discrimination.⁷⁹

The ADA's explicit recognition of so-called "structural discrimination"⁸⁰ can create some difficult line-drawing questions. One such question is just how clear must the discriminatory effect of a structure or a practice be before the law imposes any obligation to remedy the barriers or disadvantage. That was the real question the Supreme Court dealt with in addressing the fourteen-day limitation on hospitalization coverage in *Alexander v. Choate*⁸¹: Does the greater disadvantage that the limit imposes on disabled Medicaid beneficiaries mean that the limit is discriminatory in a legally actionable way?

This type of question has come up a number of times in cases challenging cost-control measures employed by either public or private payers for health care, such as state Medicaid programs and managed care plans. The ten years following the ADA's enactment were also the decade in which health care policy-makers (public and private) sought to slay the evil dragon of double-digit health care cost inflation, largely by adopting managed care methodologies. For a while, in the mid-1990s, it appeared that these efforts were largely successful, with health care cost

79. See, e.g., 42 U.S.C. §12182(b)(2)(A)(i) (1994) (stating that discrimination includes "the imposition or application of eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities" from use or enjoyment of a public accommodation) and § 12182(b)(2)(A)(ii) (stating that discrimination includes "a failure to make reasonable modifications in policies, practices, or procedures, when such modifications are necessary" to afford people with disabilities the use or enjoyment of public accommodations).

80. I borrow this phrase from Michael A. Rebell, *Structural Discrimination and the Rights of the Disabled*, 74 GEO. L.J. 1435 (1986).

81. 469 U.S. 287, 299 (1985) ("[W]e must . . . determine whether the disparate effect of which respondents complain is the sort of disparate impact that federal law might recognize").

increases in the private sector limited to the single digits⁸² and the major government programs, Medicare and Medicaid, rushing to jump on the managed care bandwagon.⁸³ But in the past few years, major managed care companies have lost money, throwing into question the ability of managed care to place any kind of sustained limits on health care cost inflation.⁸⁴

So the dragon is still alive, if temporarily subdued, and I think that, as a society, we are going to have to continue to try to figure out how we can hold health care costs to a manageable level, without unduly compromising people's access to good, quality health care services. How we answer this question has huge implications for people with disabilities, a substantial number of whom are disproportionately heavy users of health care services. This part will examine the implications of the ADA for cost-containment efforts by addressing first some of the issues associated with managed care and then touching briefly on the ADA's application to health care rationing programs.

A. *The ADA Meets Managed Care*

When we discuss managed care practices, it may be helpful to think about managed care as standing in contrast to the "good old days" of fee-for-service medicine. A sketch of the basic contours of fee-for-service medicine would look something like this: Before the advent of widespread managed care, most individuals who had private health insurance enjoyed fairly comprehensive coverage (typically provided by an employer) that allowed the insured to visit any doctor he chose at his own initiative. The insurance company would pay the doctor (or reimburse the insured) a separate fee for each service that the doctor provided to the insured. Physicians and patients generally liked this system, which maximized physician income and patient choice, but the system

82. Congressional Budget Office, *CBO Paper: Trends in Health Care Spending by the Private Sector* (Apr. 1997) at ix available at <<http://www.cbo.gov/byclasscat.cfm?class=0&cat=9>> (reporting that "the annual growth rate of private health insurance expenditures tumbled from around 14 percent in 1990 to less than 3 percent in 1994 and 1995").

83. In the Balanced Budget Act of 1997, Congress created Medicare+Choice, Medicare Part C, which allows Medicare beneficiaries a dramatically broader choice of types of managed care plans to enroll in as an alternative to remaining in Medicare's traditional fee-for-service program. 42 U.S.C. 1395w-21 (Supp. IV 1998). The legislation also contains provisions seeking to attract managed care organizations to participate in Medicare. See Lynn Etheredge, *The Medicare Reforms of 1997: Headlines You Didn't Read*, 23 J. HEALTH POL., POL'Y & L. 573 (1998). The Balanced Budget Act also loosened the criteria by which states could require Medicaid recipients to enroll in managed care plans. 42 U.S.C. 1396u-2 (Supp. IV 1998). Even prior to this loosening, Medicaid managed care enrollment expanded rapidly in the 1990s, rising from 2.7 million enrollees in 1991 to 16.8 million by the end of 1998. See Barry R. Furrow et al., HEALTH LAW 613 (2000).

84. See Eli Ginzberg, *The Uncertain Future of Managed Care*, 340 NEW ENG. J. MED. 144 (1999).

proved to be quite expensive.

The basic idea of managed care is that the medical care provided to a patient should be managed so that unnecessary and non-beneficial care will not be provided, and so that the care that is medically necessary will be provided in the most cost-effective manner or setting possible. In theory, reducing the amount of unnecessary care provided will not only decrease costs, but will also improve the quality of care received by patients. In reality, the techniques used to manage care can sometimes result in the delay or denial of needed care, a risk that is magnified for individuals with greater than average medical needs.

One broad method of managing care is for a third-party payer to use administrative limits on a patient's ability to access expensive care.⁸⁵ For example, many managed care companies will require a patient to obtain pre-authorization from the payer for any surgery or hospitalization, or will require that all visits to a specialist be authorized by the patient's primary care provider ("PCP").⁸⁶ It is easy to imagine how such administrative constraints might adversely affect individuals with disabilities that require extensive medical care.⁸⁷ Imagine a man with a chronic medical condition like diabetes, which may be most effectively managed by an endocrinologist. But the patient cannot simply make an appointment with the endocrinologist when health issues arise. Instead, in many managed care systems, the patient will have to obtain a referral from his PCP for each visit. Imposing this extra step can operate as a real barrier to accessing care in a timely and effective fashion.

In addition to administrative limits on accessing care, a managed care payer may also employ provider reimbursement methods that create financial incentives for providers to manage care. From the perspective of managed care proponents, these incentives encourage providers to practice medicine in a cost-conscious manner. From the perspective of managed care detractors, these incentives encourage providers to limit the care provided to patients. For example, to carry on the example provided above, the managed care company's payments to the PCP may be limited or decreased if the PCP makes "excessive" referrals to specialists.

Another common type of financial incentive is for the managed care entity to pay physicians on a capitation basis for caring for the plan's enrollees. Rather than paying the physician separately for each service rendered, the plan pays the physician a fixed sum of money to provide

85. For the Supreme Court's recent brief description of managed care methodologies, see *Pegram v. Herdrich*, 120 S. Ct. 2143 (2000).

86. See generally *Pegram*, 120 S. Ct. at 22-26.

87. See Nancy Ann Jeffrey, *Doctors Battle Over Who Treats Chronically Ill*, WALL ST. J., Dec. 11, 1996, at B1.

all necessary care for a managed care enrollee for a set period of time.⁸⁸ The plan then leaves it to the physician to determine what care is necessary and how to provide it in a cost-effective fashion.⁸⁹ The risk that capitation reimbursement poses is that if a physician is treating a particularly expensive patient (*i.e.*, one whose medical costs significantly exceed the capitation payment) the physician may be faced with either effectively paying for the excess care out of his own pocket or not recommending beneficial medical treatment.⁹⁰ Of course, a possible alternative to losing money or skimping on care would be for the physician to attempt to avoid altogether entering into relationships with patients with expensive medical conditions, a group that may overlap significantly with persons with disabilities.⁹¹

The possibility that managed care practices may disproportionately affect people with disabilities has not been lost on advocates for disability rights. In a handful of cases over the past several years, disabled patients have challenged managed-care type reimbursement practices as having a discriminatory impact on them in violation of the ADA. For example, in one case patients alleged that financial arrangements between a health maintenance organization ("HMO") and a physician group caused disabled patients to be more expensive to physicians than other patients and thereby violated the ADA and the Rehabilitation Act.⁹² The plaintiffs claimed that the financial arrangements led the physicians to make disabled patients wait a long time for care or to deny them care altogether, which then forced the patients to seek care from other providers.⁹³ Based on these allegations, a district court in Texas found that the plaintiffs had stated a claim of disability-related discrimination caused by the financial relationship between the HMO and the doctors.⁹⁴

In another case, individuals with disabilities whose home health care was paid for by Medicare sued a home health agency under the Rehabilitation Act for "dumping" them.⁹⁵ They claimed that a change in Medicare's reimbursement rules that capped the amount that the agency

88. See Barbara C. Colombo & Robert P. Webber, *Regulating Risk in a Managed Care Environment: Theory vs. Practice, The Minnesota Experience*, 8 ANNALS HEALTH L. 147, 155-56 (1999).

89. See *id.*

90. See generally Frances H. Miller, *Foreword: The Promise and Problems of Capitation*, 22 AM. J.L. & MED. 167 (1996).

91. See Sandra J. Tanenbaum & Robert E. Hurley, *Disability and the Managed Care Frenzy: A Cautionary Note*, 14 HEALTH AFFAIRS Winter 1995, at 213; Cf. John V. Jacobi, *Canaries in the Coal Mine: the Chronically Ill in Managed Care*, 9 HEALTH MATRIX 79 (1999) (describing the dual dangers of excluding and stinting that face the chronically ill in managed care).

92. *Zamora-Quezada v. HealthTexas Med. Group of San Antonio*, 34 F. Supp. 2d 433 (W.D. Tex. 1998).

93. *Zamora-Quezada*, 34 F. Supp. 2d at 437-38.

94. *Id.* at 446.

95. *Winkler v. Interim Services, Inc.*, 36 F. Supp. 2d 1026 (M.D. Tenn. 1999).

would be paid for providing them services led the agency to abandon them because they were "heavy service users and economically undesirable patients."⁹⁶ A district court in Tennessee found that these allegations stated a claim of discrimination based on the severity of the plaintiffs' disabilities and denied the defendant's motion to dismiss the Rehabilitation Act claim.⁹⁷

Scholars have long been concerned that the administrative and reimbursement practices employed by managed care would create substantial barriers for people with disabilities being able to access and receive necessary medical services. The cases described suggest a budding recognition by the courts that if the barriers erected by managed care are disproportionately greater for people with disabilities than for members of the general population, that disproportion may form the basis of a disability discrimination claim.

Ironically, though, while the application of managed care techniques to people with disabilities might at times give rise to a cause of action, the failure to include people with disabilities in managed care programs can also be challenged as violating disability discrimination law. Here the claim has been that the exclusion from a managed care program constitutes different treatment based on disability. This claim has come up in the context of the Medicaid program, the joint federal-state program providing medical assistance to certain categories of poor persons (namely, women and children, the aged, and the disabled). In the early to mid 1990s, many states started experimenting with enrolling Medicaid beneficiaries in managed care plans, rather than paying for their care on a fee-for-service basis.⁹⁸ These early attempts to save money for state governments were typically confined to women and children beneficiaries. Elderly and disabled Medicaid beneficiaries generally were not switched to managed care because of concerns about whether managed care could address the more complex medical needs of those populations.⁹⁹

By and large, because of their fears of the barriers imposed by managed care, Medicaid enrollees with disabilities have not objected to their exclusion from Medicaid managed care experiments. Nonetheless,

96. *Winkler*, 36 F. Supp. 2d at 1027.

97. *Id.* at 1030. *Accord* *Morris v. North Hawaii Community Hosp.*, 37 F. Supp. 2d 1181, 1189 (D. Haw. 1999) (granting preliminary injunction preventing the termination of home health benefits except in compliance with Medicare rules and state laws).

98. See John K. Iglehart, *Medicaid and Managed Care*, 332 NEW ENG. J. MED. 1727 (1995); Mary Crossley, *Medicaid Managed Care and Disability Discrimination Issues*, 65 TENN. L. REV. 419, 420 (1998) (reporting that as of June 1996, forty percent of Medicaid enrollees nationwide were enrolled in some form of managed care).

99. See U.S. Gen. Accounting Office, *MEDICAID MANAGED CARE: SERVING THE DISABLED CHALLENGES STATE PROGRAMS* 12 (1996) available at <<http://w3.access.gpo.gov/gao/index.html>> [hereinafter GAO REPORT].

Medicaid managed care enrollment may be advantageous for some individuals with disabilities, for it may offer more comprehensive coverage, better access to physicians, better continuity of care, or more liberal financial eligibility requirements.¹⁰⁰ In such a case, blind and disabled plaintiffs successfully sued the State of Hawaii for violating the ADA when it excluded them from participating in its Medicaid managed care program.¹⁰¹ The court in that case found that the plaintiffs had been categorically denied coverage under the managed care branch of Hawaii's Medicaid program solely by reason of their disabilities.¹⁰²

Since the mid 1990s, the states have increasingly sought to enroll some portion of their disabled Medicaid beneficiaries in some form of managed care. Spurring this movement has been not a fear of liability for disability discrimination, but the states' recognition that Medicaid managed care cannot reap significant cost savings for the states unless it is applied to the most costly Medicaid recipients.¹⁰³ As state policymakers consider how to include people with disabilities in Medicaid managed care programs, however, disability discrimination law may appear to present them with a "damned if you do, damned if you don't" dilemma, much as it does private managed care plans. For the ADA may have a double-edged application to issues involving managed care and persons with disabilities. If a state enrolls disabled Medicaid beneficiaries in the same managed care program as nondisabled beneficiaries (or if a private plan subjects disabled enrollees to the same managed care practices), it may face a claim of disparate impact discrimination because the managed care practices may be found to have a disproportionately adverse impact on persons with disabilities. On the other hand, though, if the state excludes disabled Medicaid beneficiaries from its managed care program (or a private plan refuses to issue a managed care coverage to a disabled applicant), it may be subject to a claim of different treatment.

From the perspective of persons with disabilities and their advocates, though, managed care companies and state health care policy-

100. See Tanenbaum & Hurley, *supra* note 91, at 215-16; Cf. Stefan, *supra* note 65, at 164 (noting mixed feelings among mental health lawyers regarding enrollment in managed mental health care programs).

101. Burns-Vidlak v. Chandler, 939 F. Supp. 765 (D. Haw. 1996). The exclusion disadvantaged plaintiffs in this case because Hawaii had established more stringent financial eligibility requirements for its traditional fee-for-service Medicaid program (which covered disabled persons) than for its Medicaid managed care program. As a result, plaintiffs were not financially eligible for the traditional program, but would have qualified for the managed care program but for their disability. Burns-Vidlak, 939 F. Supp. at 771.

102. Burns-Vidlak, 939 F. Supp. at 771.

103. See Crossley, *supra* note 98, at 422 (citing Katherine R. Levit et al., *Data View: National Health Expenditures, 1994*, 17 HEALTH CARE FINANCING REV. 205, 224 (1996)); Cf. GAO REPORT, *supra* note 99, at 14-15 (reporting that in 1994, disabled individuals constituted only about 15% of Medicaid enrollees, but accounted for 39% of Medicaid expenditures).

makers are not in an untenable situation. Instead, those decision-makers are in the exact position demanded by the ADA: They simply must take the circumstances and needs of persons with disabilities into account in deciding whether and how managed care methodologies should apply to those persons. Upon such reflection, the decision-maker could validly conclude that some persons with disabilities should be excluded from managed care enrollment because the different medical needs of that group requires the provision of a benefit that, in order to be equally effective, must be separate.¹⁰⁴ Or the decision-maker could conclude that persons with disabilities should be included in managed care enrollment, but also carefully assess whether and how managed care practices should be modified in order to avoid a discriminatory impact on those persons.¹⁰⁵ The ADA does not compel health care decision-makers to arrive at any particular substantive decision with respect to the application of managed care to persons with disabilities; what the law does do, though, is compel decision-makers to take persons with disabilities into account in their decisions. As a result, people with disabilities may be less likely to find themselves enrolled in a plan that is oblivious to or unaccommodating towards their health care needs.

Despite some of the recent faltering of the managed care industry, managed care seems certain to remain a major feature of the health care landscape in this country for the foreseeable future. Thus, figuring out how the ADA may limit the application of managed care practices to persons with disabilities is likely to be an ongoing conversation. On the other hand, because managed care appears not to be the St. George that slays the evil dragon of health care inflation, I think it likely that discussions of rationing health care as a way of containing costs will grow more frequent. Based on the past decade of experience, how would the ADA figure in these discussions?

B. The ADA and Health Care Rationing

The phrase "health care rationing" carries great political baggage and negative connotations with it, but in essence it simply refers to a process by which decisions are made regarding who will receive scarce health care resources. Although it is not commonly acknowledged, some form of de facto health care rationing has long existed in this country,

104. See 28 C.F.R. § 35.130(b)(1)(iv) (1999), which provides that a public entity may not, on the basis of disability, "[p]rovide different or separate aids, benefits, or services to individuals with disabilities or to any class of individuals with disabilities than is [sic] provided to others unless such action is necessary to provide qualified individuals with disabilities with aids, benefits, or services that are as effective as those provided to other."

105. Cf. GAO REPORT, *supra* note 99, at 38-41 (suggesting ways that managed care methodologies could be adapted to accommodate the needs of persons with disabilities).

with the primary determining factor for the receipt of health care resources being individual wealth. From time to time, scholars, policy-makers, and politicians have engaged in spirited discussions regarding other possible systems of explicit rationing, for example, rationing based on need, rationing based on age, and rationing based on maximizing benefit to recipients.

Shortly after the ADA's passage, one of the first attempts by policy-makers in the United States to adopt an explicit rationing system directed widespread public attention to the potential connections between the ADA and the health care system. For in 1992, the Federal Department of Health and Human Services ("HHS") rejected an application for a Medicaid waiver by the State of Oregon that would allow it to implement a rationing scheme as part of its Medicaid program.¹⁰⁶ The stated reason for the rejection was the perceived conflict between the rationing plan and the ADA. Although this Article will not retrace the detailed steps by which Oregon developed its rationing scheme,¹⁰⁷ the central criterion ultimately adopted by the State for which medical services would be covered by its Medicaid program was the comparative benefit that treatments for different conditions would provide to the population of Oregon, and Oregon's citizenry had a voice—by use of telephone surveys—in what would count as a benefit.

One reason that the Secretary of HHS gave for rejecting the plan was that the use of public input and community values may have "quantifie[d] stereotypic assumptions" about the value of life with a disability as compared to life without a disability and that, as a consequence, the resulting rankings may have devalued treatments that would save life, but not return the patient to full functioning.¹⁰⁸ Although the Secretary initially rejected Oregon's waiver application, he encouraged the State to try again, pointing out that a number of factors were available for making rationing decisions that would not run afoul of the ADA. Citing *Alexander v. Choate*, he stated: "Oregon may consider, consistent with the ADA, any content neutral factor that does not take disability into account or that does not have a particular exclusionary effect on persons

106. Letter from Louis W. Sullivan, Secretary of Health and Human Services, to Barbara Roberts, Governor of Oregon (Aug. 3, 1992) (with accompanying three-page "Analysis Under the Americans with Disabilities Act ("ADA") of the Oregon Reform Demonstration"), reprinted in Timothy B. Flanagan, *ADA Analyses of the Oregon Health Care Plan*, 9 ISSUES LAW & MED. 397, 409 (1994) [hereinafter Sullivan letter].

107. For a detailed account of the process, see Michael J. Garland, *Rationing in Public: Oregon's Priority-Setting Methodology*, in *RATIONING AMERICA'S MEDICAL CARE: THE OREGON PLAN AND BEYOND* 37 (Martin A. Strosberg et al. eds., The Brookings Institution 1992).

108. The Secretary stated: "The record regarding the manner in which the list of condition/treatment pairs was compiled contains considerable evidence that it was based in substantial part on the premise that the value of the life of a person with a disability is less than the value of the life of a person without a disability. This is a premise which is inconsistent with the ADA." Sullivan letter, *supra* note 106, at 410.

with disabilities."¹⁰⁹ Because Oregon's rationing proposal already had received a great deal of attention from both health policy-makers and the general public, the Secretary's rejection of the plan based on ADA concerns spotlighted for many the potential impact of the statute on health care resource allocation questions.

For several years following the rejection of Oregon's plan, scholars, policy-makers, and commentators busily considered what limits, if any, the ADA places on the ability of public and private payers to engage in health care rationing.¹¹⁰ Because many proposed rationing schemes would allocate resources based on the benefits received from treatment or some kind of cost-benefit analysis, the fundamental question that emerged is which factors legitimately can be considered in assessing the benefit to be obtained from medical treatment and which factors, by contrast, would effectively discriminate against persons with disabilities in violation of the ADA.¹¹¹ For example, does a rationing scheme discriminate based on disability if it gives priority in funding to a treatment that statistically provides patients with seven additional years of life with no functional impairment, over a treatment that provides seven additional years of life with impairments? Does the treatment of an unimpaired life as having superior benefit constitute unlawful discrimination against persons with disabilities (persons who by definition are living with impairments)?

These discussions, while stimulating, provided no clear answers to the questions regarding the ADA's impact, and no case has yet been litigated that poses these questions directly. And as the decade following the ADA's enactment progressed, most health policy-makers and advocates for disability rights turned their attention away from explicit rationing schemes and focused instead on the issues posed by the growing prevalence of managed care, so that the discussions languished somewhat. As it becomes increasingly apparent that managed care alone is unlikely to curb health care inflation, discussions of possible rationing approaches may well revive¹¹² and again pose the question whether

109. Sullivan letter, *supra* note 106, at 411 (citing *Alexander v. Choate*, 469 U.S. 287 (1985)).

110. See, e.g., David Orentlicher, *Rationing and the Americans with Disabilities Act*, 271 JAMA 308 (1994); Philip G. Peters, *Health Care Rationing and Disability Rights*, 70 IND. L.J. 491 (1995); James V. Garvey, Note, *Health Care Rationing and the Americans with Disabilities Act of 1990: What Protection Should the Disabled be Afforded?*, 68 NOTRE DAME L. REV. 581 (1993); Nancy K. Stadel, Note, *The Use of Quality-of-Life Measures to Ration Health Care: Reviving a Rejected Proposal*, 93 COLUM. L. REV. 1985 (1993).

111. Cf. Peters, *supra* note 110, at 492 ("Any health care allocation scheme which attempts to maximize health care outcomes by giving priority to the most effective treatments has the potential to disfavor disabled patients and others, such as the elderly and the frail, whose quality of life is most impaired or whose conditions are most resistant to cure.")

112. For examples of recent discussions of health care rationing in the law review literature, see Candace J. Redden, *Rationing Care in the Community: Engaging Citizens in Health Care Decision Making*, 24 J. HEALTH POL., POL'Y & L. 1363 (1999); Mita K. Giacomini, *The Which-*

health care can be rationed in a manner that both avoids disproportionately disadvantaging persons with disabilities and comports with broadly accepted notions of distributive justice.

What role the ADA will ultimately play in such discussions is not clear. The statute itself would provide an unambiguous answer only in the grossest of cases, for example, a policy to allocate health care resources to individuals based on their existing level of physical and mental functioning, with priority being given to individuals with the highest functioning, or a policy that expressly excluded individuals from the receipt of health care resources on the basis of their disability. In most rationing proposals, though, the distinctions are likely to be far more subtle and the line-drawing questions more fine, so that the ADA is unlikely to provide any clear answers regarding the scheme's legitimacy. What is probably most significant for the health of persons with disabilities, though, is that the ADA will *play a role* in the discussions.¹¹³ The ADA again renders persons with disabilities visible and gives them leverage against any majoritarian impulses to place the burdens of health care cost containment and rationing on the backs of the minority of persons with disabilities. It demands that their dignity as persons and their health care needs be taken into account.

IV. THE ADA AND HEALTH INSURANCE

The final facet of health care that this Article will undertake to examine the ADA's impact on is health insurance. What has the ADA's non-discrimination mandate meant in the context of health insurance for people with disabilities? Now just to ask what that mandate means in the context of health insurance is to pose a real conundrum, because a seemingly fundamental conflict exists between the ADA's purpose and commonly accepted practices in the health insurance industry. The ADA, of course, basically says that public actors shall not discriminate based on disability in employing individuals or in providing individuals with goods, services, or benefits. But the ADA applies to health insurers and to employers deciding what coverage to offer in employee benefit

Hunt: *Assembling Health Technologies for Assessment and Rationing*, 24 J. HEALTH POL., POL'Y & L. 715 (1999); Arti K. Rai, *Rationing Through Choice: A New Approach to Cost-Effectiveness Analysis in Health Care*, 72 IND. L.J. 1015 (1997).

113. Health policy scholar Dr. David Hadorn recognized this even before HHS's rejection of Oregon's waiver application. He wrote:

An equally formidable challenge to the implementation of utilitarian distributions of health care has so far received much less attention: the problem of discrimination—real or apparent—against patients with disabilities. . . . [T]he 'D-word' threatens to replace the 'R-word' (for rationing) as the most feared epithet in the field of resource allocation.

David C. Hadorn, *The Problem of Discrimination in Health Care Priority Setting*, 268 JAMA 1454 (1992).

plans—entities who have traditionally made it their business on a routine basis to make decisions regarding the availability and nature of benefits by taking into account individuals' health characteristics in a fashion that could often be construed as discrimination on the basis of disability. So how does one apply a nondiscrimination mandate to an entity that says, in a sense, "it's our business to discriminate"?

To begin, the ADA clearly contemplates some application to health insurance, whether an individual receives the insurance from an employer as a fringe benefit (in which case Title I may apply)¹¹⁴ or whether the individual purchases the insurance directly from an insurance company, whose office Title III explicitly includes in its list of public accommodations.¹¹⁵ In addition, Congress made express (though not terribly clear) reference to the ADA's applicability to insurance in Section 501(c) of the ADA, known as the "insurance safe harbor" provision.¹¹⁶

One of the murkier provisions of the ADA,¹¹⁷ the insurance safe harbor basically provides that the ADA shall not be construed to prohibit an insurer from underwriting risks, classifying risks, or administering such risks as are not inconsistent with state law, unless the practice is a subterfuge to evade the purposes of the ADA. In other words, the ADA does not prohibit an insurer from continuing to use risk classification or underwriting practices allowed by state law, as long as those practices are not a subterfuge to circumvent statutory purposes.¹¹⁸ The meaning and application of Section 501(c) have been the source of much confusion and the subject of much litigation, particularly over the past several years, and the courts have reached mixed results, some of which will be discussed below.¹¹⁹ It is key to note, however, that Section 501(c) does

114. 42 U.S.C. §§ 12112(a)-12112(b) (1994).

115. *Id.* § 12181(7)(F).

116. Section 501(c) provides as follows:

(c) Insurance

Subchapters I through III of this chapter and title IV of this Act shall not be construed to prohibit or restrict -

(1) an insurer, hospital or medical service company, health maintenance organization, or any agent, or entity that administers benefit plans, or similar organizations from underwriting risks, classifying risks, or administering such risks that are based on or not inconsistent with State law;

Paragraphs (1) . . . shall not be used as a subterfuge to evade the purposes of subchapter I and III of this chapter.

Id. § 12201(c).

117. Circuit Judge Merritt has described Section 501(c) as "purposefully vague" and "totally ambiguous on its face." *Parker v. Metropolitan Life Ins. Co.*, 99 F.3d 181, 190 (6th Cir. 1996), *vacated and rev'd*, 121 F.3d 1006 (6th Cir. 1997) (en banc), *cert. denied*, 118 S. Ct. 871 (1998).

118. *Cf. Leonard F. v. Israel Discount Bank of N.Y.*, 199 F.3d 99, 103 (2d Cir. 1999) ("The plain meaning of Section 501(c) is that insurers are exempt from regulation under the ADA so long as (i) their actions conform to state law, and (ii) they do not use the exemption as a 'subterfuge to evade the purposes of [the Act].'").

119. Because of its focus on the ADA's impact on health care and health insurance for people with disabilities, this Article will not discuss the extensive litigation challenging distinctions in long-term disability insurance policies between coverage for physical disabilities and mental

not conclude that the practices of the insurance industry do not discriminate based on disability; instead, the provision states only that the ADA will not be construed to prohibit those practices.

Before discussing how courts have approached the ADA's application to health insurance, it is worth pausing to think about what disability discrimination by a health insurance provider might look like—how it might be experienced by a person with a disability. Here, one can imagine that discrimination could occur in the form of either an insurer's singling out an individual applicant or insured for different treatment or the disparate impact of an insurer's practices on people with disabilities as a group. One of the meatiest bones of contention regarding the ADA's application to health insurance is the appropriate breadth of the statute's coverage. Does the ADA provide redress only to the individual with a disability who finds that an insurance office is physically inaccessible?¹²⁰ Or does it extend broadly to protect an individual who claims that a provision or limitation of coverage received from an insurer disproportionately impacts people with disabilities, *i.e.*, that the policy discriminates in its content? Or did Congress perhaps intend some middle ground, allowing suit when an individual with a disability alleges that an insurer discriminated against her in deciding whether and on what terms to issue a health insurance policy, but not when she alleges discrimination in the content of an issued policy?

In fact, courts have taken each of the positions just suggested, and

disabilities, except to note that it appears fairly well settled by the Courts of Appeal at this point that the ADA does not prohibit such distinctions. See *Weyer v. Twentieth Century Fox Film Corp.*, 198 F.3d 1104, 1116 n.68 (9th Cir. 2000) (citing seven Circuit Courts of Appeal that have rejected such a claim); see also *EEOC v. Staten Island Sav. Bank*, 207 F.3d 144 (2d Cir. 2000) (holding that distinction not prohibited by ADA). But see *Boots v. Northwestern Mut. Life Ins. Co.*, 77 F. Supp. 2d 211 (D.N.H. 1999) (allowing claim based on such a distinction to proceed). Moreover, I will not focus on the issues regarding the proper construction of the "subterfuge" clause. Compare *Leonard F. v. Israel Discount Bank of N.Y.*, 199 F.3d 99 (2d Cir. 1999) (holding that "subterfuge" requires an intent to evade, so that plan provision adopted prior to ADA's passage cannot be a subterfuge), with *Doukas v. Metropolitan Life Ins. Co.*, 950 F. Supp. 422 (D.N.H. 1996) (finding that "subterfuge" need not be intentional, but may simply be a decision not based on either sound actuarial principles or reasonably anticipated experience). The interaction of Titles I and III of the ADA with Section 501(c) has spawned sufficient litigation to merit numerous articles on these topics. See, e.g., Bonnie Poitras Tucker, *Insurance and the ADA*, 46 DEPAUL L. REV. 915 (1997); Luke A. Sobota, Comment, *Does Title III of the Americans with Disabilities Act Regulate Insurance?*, 66 U. CHI. L. REV. 243 (1999); Nicole Martinson, *Inequality Between Disabilities: The Different Treatment of Mental Versus Physical Disabilities in Long-Term Disability Benefit Plans*, 50 BAYLOR L. REV. 361 (1998).

120. Cf. *Ford v. Schering-Plough Corp.*, 145 F.3d 601, 613 (3d Cir. 1998) ("[A]n insurance office must be physically accessible to the disabled but need not provide insurance that treats the disabled equally with the non-disabled."); *Pappas v. Bethesda Hosp. Ass'n*, 861 F. Supp. 616, 620 (S.D. Ohio 1994) (finding Title III's applicability limited to actions related to the physical use of a place of public accommodation). It is worth noting that, while the ADA specifically addresses physical accessibility issues, see 42 U.S.C. § 12183 (1994), claims based on physical inaccessibility are by their nature in fact disparate impact claims. The person in a wheelchair who complains about the lack of a ramp or elevator complains not that the public accommodation singled him out for different treatment, but that its exclusive reliance on stairs disproportionately burdens wheelchair users.

the question remains far from judicial resolution. Although some courts have been willing to scrutinize insurance practices to protect the interests of people with disabilities, the trend of the case law over the past several years has been for courts to take a fairly hands-off approach, allowing suits to proceed only when the plaintiff can show that he was singled out for different treatment by an insured because of his disability. A recently decided case, *Doe v. Mutual of Omaha Insurance Co.*,¹²¹ illustrates this approach.

In *Doe*, the plaintiffs challenged Mutual of Omaha's practice of employing AIDS caps in its health insurance policies: the company issued policies that imposed both a general limit on lifetime benefits of \$1,000,000 and a separate, lower limit of \$25,000 (in the case of one plaintiff) or \$100,000 (in the case of the other) on coverage for treatment of AIDS or AIDS-related condition ("ARC").¹²² The plaintiffs' argument was that, by imposing lower caps only with respect to treatment for the disabling condition AIDS, Mutual of Omaha was discriminating based on disability.¹²³ Although the plaintiffs survived a motion to dismiss in the district court,¹²⁴ the Seventh Circuit, in an opinion written by Chief Judge Posner, reversed the district court and granted the motion.¹²⁵ Some of his reasoning in doing so demonstrates the conceptual difficulties that courts encounter in applying the ADA to health insurance.

First, Judge Posner is careful to distinguish the plaintiffs' claim from a claim that an insurance company had refused to issue a policy based on disability or had charged higher premiums to an individual based on disability.¹²⁶ Such a claim would clearly constitute an allegation of different treatment, which the court assumed would fall within the scope of Title III's requirement that public accommodations, including insurance companies, not deny individuals with disabilities the full and equal enjoyment of their products and services.¹²⁷ Instead, the court pointed out, Mutual of Omaha sold policies to the plaintiffs, apparently on the same terms and with the same coverage limitations provided to other insureds—the policies were simply *less valuable* to the plaintiffs because of the cap on AIDS coverage.¹²⁸

121. 179 F.3d 557 (7th Cir. 1999), *cert. denied*, 120 S. Ct. 845 (2000).

122. *Doe*, 179 F.3d at 558.

123. *Doe v. Mutual of Omaha Ins. Co.*, 999 F. Supp. 1188, 1191 (N.D. Ill. 1998).

124. *Doe*, 999 F. Supp. at 1197-98.

125. *Doe*, 179 F.3d at 564.

126. *Id.* at 559.

127. *Id.* at 558-59; *accord* Winslow v. IDS Life Ins. Co. 29 F. Supp. 2d 557 (D. Minn. 1998) (finding that insurer's policy of denying coverage to any applicant treated for a mental condition within the past year violated the ADA); *but see* Chabner v. United of Omaha Life Ins. Co., 225 F.3d 1042 (9th Cir. 2000) (holding that discrimination in premium charged based on disability did not violate the ADA).

128. *Doe*, 179 F.3d at 559.

Without discussing the point explicitly, the court thus implicitly recognizes that the plaintiffs are complaining of the AIDS cap's disparate impact on people with the disabling condition AIDS. Other courts, in suits challenging as discriminatory a provision uniformly included in insurance policies have reasoned explicitly that, because all insureds are subject to the same provision, no discrimination has occurred.¹²⁹ Such courts fail to recognize the application of disparate impact theory to insurance practices; just because everyone is treated the same does not mean that a practice is nondiscriminatory.

A reluctance to apply disparate impact theory to facially neutral distinctions in health insurance policies is understandable. All coverage limitations will burden some policyholders and one could argue that it is too much to ask of insurance companies to make sure that the group of burdened policyholders is not congruent with disabled individuals.¹³⁰ This reluctance is reminiscent of the Supreme Court's concern in *Alexander v. Choate*¹³¹ that requiring a state to avoid all Medicaid policy decisions that would adversely impact persons with disabilities would impose too great a burden on the states.

This reluctance seems misplaced in the context of AIDS caps. In refusing to apply Section 504 of the Rehabilitation Act to Tennessee's limitation of coverage under its Medicaid program, the Court emphasized that the reduction in coverage "[did] not invoke criteria that [had] a particular exclusionary effect" on persons with disabilities and was "neutral on its face."¹³² In a footnote, the Court further noted that the limitation at issue did "not apply to only particular handicapped conditions."¹³³ By contrast, the Mutual of Omaha policies at issue in *Doe* ex-

129. See, e.g., *McNeil v. Time Ins. Co.*, 205 F.3d 179, 185 (5th Cir. 2000) (finding that AIDS cap did not violate Texas disability discrimination statute because "Time offered Dr. McNeil the same policy on the same terms that it offered everyone else. It did not treat him differently because he was handicapped, which is what we understand 'discrimination' to mean."); *Weyer v. Twentieth Century Fox Film Corp.*, 198 F.3d 1104 (9th Cir. 2000) (stating that "there is no discrimination under the [ADA] where disabled individuals are given the same opportunity as everyone else, so insurance distinctions that apply equally to all employees cannot be discriminatory."); *Kimber v. Thiokol Corp.*, 196 F.3d 1092 (10th Cir. 1999) (finding no discrimination when every employee was offered the same plan).

130. Indeed, the Equal Employment Opportunity Commission ("EEOC"), the agency charged with enforcing Title I's employment provisions, has taken the stance that disparate impact theory is not available to plaintiffs challenging distinctions in employer-provided health insurance. See EEOC's Interim Enforcement Guidance on the Application of the ADA, Sept. 9, 1993, at n.2, reprinted in RUTH COLKER, *THE LAW OF DISABILITY DISCRIMINATION* 469-78 (1995). The EEOC makes clear, however, that this limitation does not preclude a challenge to a distinction that is based on disability. See *id.* at 472. In an amendment to its Compliance Manual issued after this Article was written, the EEOC takes the position that a health insurance policy containing an AIDS cap would be an unequal benefit, potentially violating the ADA, if provided by an employer. See EEOC COMPLIANCE MANUAL, Chapter 3: *Employee Benefits* (Oct. 3, 2000), available at <<http://www.eeoc.gov/docs/benefits.html>>.

131. 469 U.S. 287 (1985). See discussion *supra* text accompanying note 11.

132. *Alexander*, 469 U.S. at 302.

133. *Id.* at n.22.

plicitly limited coverage based on a subscriber's need for treatment for the disabling condition AIDS.¹³⁴ The coverage limitation may well have been evenhandedly included in all policies, but it was not "neutral on its face" and thus was evidence of intentional discrimination against persons with that disability. To point out, as Judge Posner does, that persons with AIDS have medical needs unrelated to their infection and will receive the same coverage for those needs as persons without their disability¹³⁵ does not adequately answer the objection. Mutual of Omaha's policy effectively means that persons who do not have AIDS will have all their medically necessary care fully covered, up to the \$1,000,000 limit, but that persons with AIDS will have care for their most necessary, life-prolonging care limited to a fraction of that amount.

Judge Posner, however, does not explicitly reject the claim of the plaintiffs in *Doe* on the grounds that it alleges disparate impact. Instead, he rejects the claim based on the conclusion that Title III of the ADA does not reach the content of the goods and services offered by places of public accommodation.¹³⁶ For example, the court reasons by analogy, a camera store cannot refuse to sell a camera to a disabled person, but the ADA does not require the store to stock cameras specially designed for persons with disabilities.¹³⁷ The ADA prohibits denials of access or refusals to deal with persons with disabilities and prohibits dealing with such persons on terms different from non-disabled persons, but, according to the court, it does not regulate what goods and services the public accommodation chooses to provide, so long as it provides them evenhandedly.¹³⁸ In the context of health insurance, this means that the content of a policy, *e.g.*, its coverage limitations, is not regulated by the ADA, even if those limitations make the policy less valuable to a person with a disability. The court fails to see any basis for making a principled distinction between AIDS caps and other product characteristics that a disabled person might wish to have altered.¹³⁹ Patently underlying Judge Posner's analysis is a fundamental skepticism that Congress would place the federal judiciary in the role of supervising either the inventory mix

134. *Doe v. Mutual of Omaha Ins. Co.*, 179 F.3d 557, 558 (1999).

135. *Doe*, 179 F.3d at 559.

136. *Id.* at 560.

137. *Id.*

138. *See id.* at 559-60. *Accord* *McNeil v. Time Ins. Co.*, 205 F.3d 179, 186-87 (5th Cir. 2000) ("Title III does not . . . regulate the content of goods and services that are offered. . . . [T]he goods and services referred to in the statute are simply those that the business normally offers."); *Lenox v. Healthwise of Ky., Ltd.*, 149 F.3d 453, 457 (6th Cir. 1998) (rejecting plaintiff's challenge as "complaining about the mix of goods and services offered by an insurance company").

139. *See Doe*, 179 F.3d at 560-63. Posner rejects the contention that Section 501(c) of the ADA, with its express reference to insurance practices, should be seen as signaling a Congressional intent that Title III extends to the content of insurance policies. He reasoned that, because the insurance safe harbor provision could well play a role in claims involving denials of access or dealing on different terms, the provision need not be read to extend to the content of policies in order to avoid finding it superfluous. *See id.* at 561-63.

of retail stores or the actuarial fairness of the content of insurance policies.

Now, this makes a fair amount of sense. After all, I am not aware of any serious argument that the ADA requires retail stores to stock their shelves with products catering to the needs of people with disabilities. But I think that Judge Posner's concern about the implications of finding that the ADA regulates the content of insurance policies is overblown and that the nature of the health insurance market and the nature of health insurance as a product itself provide principled bases for distinguishing between health insurance and cameras, or between other products and services offered by public accommodations.¹⁴⁰

First, the market in health insurance in the United States is distinguishable from the market for other goods and services. Over the past half century in the United States, the market for health insurance has developed, notwithstanding recent state and federal legislative efforts to the contrary, in a manner such that health insurers' competition has focused not primarily on product quality and cost and service, but on the identification of risk. This has led to segmentation of the market for health insurance as insurers seek to enroll profitable, low-risk enrollees and avoid high-risk enrollees. While the correlation is far from exact, in many cases those high-risk enrollees whom insurers try to avoid are individuals who have a chronic medical condition or some other disabling condition. A situation results in which the profit motive drives insurers in many cases to actively avoid persons with disabilities as customers, a phenomenon that does not generally occur with retail goods and services.

Instead, the profit motive spurs businesses in most retail sectors to develop new products and technologies to compete for business from disabled consumers. In December 1999, the *Wall Street Journal* described the increase in targeting persons with disabilities as a niche market for consumer products, a phenomenon the *Journal* calls "handicapitalism."¹⁴¹ The article describes a variety of products developed for persons with disabilities, not because a law required it, but because companies saw a market opportunity.

Health insurers, however, have not rushed to supply innovative policies providing comprehensive coverage for persons with HIV or AIDS.

140. Two district courts have questioned the usefulness of the distinction between regulating access and regulating content. See *Walker v. Carnival Cruise Lines*, 63 F. Supp. 2d 1083, 1094 (N.D. Cal. 1999) (stating that "the plain language of section 12182(b) . . . casts doubt on the notion that, under all circumstances, the nature of the services provided need not be modified for disabled persons"); *Boots v. Northwestern Mut. Life Ins. Co.*, 77 F. Supp. 2d 211, 215 (D.N.H. 1999) (noting that "[t]his distinction between access and content . . . is not always clear").

141. See Joshua Harris Prager, *People with Disabilities are Next Consumer Niche*, WALL ST. J., Dec. 15, 1999, at B1.

Most persons who desire such coverage would be unable to afford it if the insurer priced it in an actuarially sound manner to cover claims. Because many people perceive AIDS (unlike heart disease or cancer) as "someone else's problem,"¹⁴² the buyers of a comprehensive or specialized AIDS policy would disproportionately be persons who believe themselves at risk of contracting AIDS. As a result, the policy price would be adjusted to reflect the high expected level of claims, and through the process known as adverse selection, lower risk enrollees would seek other, less expensive coverage as the price goes up, leaving only the highest risks in the pool. Moreover, unlike other product developers, health insurers are not in a position to develop the improved technology, such as new drugs, vaccines, or transplants, that would lower the cost of the product. In short, the phenomenon of handicapitalism does not apply to health insurance.

In addition, aside from the peculiarities of the market for health insurance, the nature of health insurance as a special good with public importance distinguishes health insurance from cameras and most other retail products. I would speculate that at least forty-four million Americans do not own a camera. But that is not seen as a social problem, as is the forty-four million Americans who have no health insurance coverage. I have heard no politician spinning forth elaborate and expensive proposals to increase camera ownership by Americans. Recent legislation seeking to increase public and private health insurance coverage amply evidences a widespread recognition of the social importance of health insurance that is particularly acute for people with disabilities.¹⁴³ This social importance of health insurance, coupled with the particular characteristics of the market for health insurance, provide a principled basis for reading Title III of the ADA to extend to terms in an insurance policy, without compelling that the statute be read to regulate the product and service mix of other public accommodations.¹⁴⁴

142. John V. Jacobi, *The Ends of Health Insurance*, 30 U.C. DAVIS L. REV. 311, 365 (1997).

143. See, e.g., Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (increasing rights to maintain private insurance coverage); Balanced Budget Act of 1997, Pub. L. No. 105-33, 111 Stat. 251 (1997) (creating, inter alia, State Children's Health Insurance Program).

144. In *Doe*, though, the court concluded that even if it read Title III to extend to the content of insurance policies, applying the ADA in such a fashion would violate the McCarran-Ferguson Act, which generally reserves to the states the ability to regulate insurance. See *Doe*, 179 F.3d at 564. But see *Pallozzi v. Allstate Life Ins. Co.*, 198 F.3d 28, 33-35 (2d Cir. 1999) (holding that the McCarran-Ferguson Act does not bar the application of Title III to insurance). Of course, even if Judge Posner had concluded that Title III regulates the content of insurance policies, the court then would have had to determine whether the AIDS cap fell within the ADA's insurance safe harbor provision, a task that would have required the court to determine the cap's consistency with state law and whether it could be seen as a subterfuge to evade the ADA's purposes. In *Doe*, the conclusion of this inquiry would have been foregone, for Mutual of Omaha had stipulated that it could not show that the AIDS cap was actuarially justified or consistent with state law. *Doe*, 179 F.3d at 558. In other such cases, such an inquiry could be a formidable task.

Ultimately, I find the reasoning and outcome in *Doe v. Mutual of Omaha Insurance Co.* disturbing because the court's deceptively simple logic and analogies serve to obscure the complexity of the issues involved and the oppressive impact that AIDS caps in health insurance policies can have on people living with HIV/AIDS. The case also well reflects a more general retrenchment by the federal courts in the late 1990s and at the turn of the century in their willingness to apply the ADA to insurance policies. This retrenchment may be seen in cases refusing to find discrimination in the absence of differential treatment,¹⁴⁵ cases refusing to find discrimination in the different treatment of persons with different disabilities,¹⁴⁶ and cases interpreting the insurance safe harbor provision quite broadly so as essentially to give insurers free rein to discriminate.¹⁴⁷ To be fair, at least on the last count, the legislative history of the ADA contains some indication that Congress did indeed include the safe harbor in order to make perfectly clear that the ADA would not require insurance companies to change how they conducted their underwriting or risk classification practices.¹⁴⁸

Even if leaving the insurance industry alone was what Congress intended, though, that decision leaves us with an uncomfortable question: Why, if our society is truly committed to a clear and comprehensive mandate to end disability discrimination, is it still okay for insurance companies to engage in disability discrimination? The answer provided by the insurance industry (and adopted by a number of federal courts) is that to subject health insurers to liability under the ADA for their prac-

145. See *supra* note 129. *But cf. Pallozzi*, 198 F.3d at 31-33 (finding, in context of claim alleging refusal to issue policy, that Title III reaches an insurer's underwriting practices). *Doe* itself represents a view of the ADA's applicability to AIDS caps that is more restrictive than prior analyses. Prior to the Seventh Circuit's 1999 decision, a federal district court had struck down a \$5,000 AIDS cap as violating Title III, see *World Ins. Co. v. Branch*, 966 F. Supp. 1203 (N.D. Ga. 1997), and the First Circuit had allowed a plaintiff's Title III challenge to a \$25,000 AIDS cap in a medical reimbursement plan to proceed, see *Carparts Distrib. Ctr. v. Automotive Wholesaler's Ass'n of New Eng.*, 37 F.3d 12 (1st Cir. 1994). In addition, the EEOC had successfully settled a number of suit challenging AIDS caps. See Bonnie Poitras Tucker, *Insurance and the ADA*, 46 DEPAUL L. REV. 915, 929-31 (1997).

146. See, e.g., *Lewis v. Kmart Corp.*, 180 F.3d 166, 171-72 (4th Cir. 1999) (reasoning that federal disability statutes were not designed to ensure that persons with one type of disability are treated the same as persons with another type of disability).

147. See, e.g., *Leonard F. v. Israel Discount Bank of N.Y.*, 199 F.3d 99, 104 (2d Cir. 1999) (holding that "subterfuge" requires an intent to evade); *Krauel v. Iowa Methodist Med. Ctr.*, 95 F.3d 674, 678-79 (8th Cir. 1996) (holding that "subterfuge" requires employer to intend to use plan provision to discriminate in a non-fringe-benefit-related aspect of the employment relationship).

148. See S. REP. NO. 101-116 (1989), Blue 33-34 (stating in part that the Committee added Section 501(c) to make it clear that the ADA would not disrupt the current nature of insurance underwriting or insurance regulation), cited in *Leonard F.*, 199 F.3d at 105 n.4. Other portions of the legislative history, however, indicate that Congress intended that underwriting practices be judged by their consistency with "sound actuarial principles" or basis in "actual or reasonably anticipated experience." H.R. REP. NO. 101-485, pt. 3, at 71 (1990), reprinted in 1990 U.S.C.C.A.N. 267, 494.

tices that discriminate based on disability would "destabilize the insurance industry."¹⁴⁹ Undoubtedly, broadly subjecting insurers to ADA liability for their practices that discriminate against individuals with disabilities would require insurers to adjust both their coverage policies and rate-making practices in order to ensure both the legality and the actuarial soundness of their enterprise. Congress' decision not to require such adjustments, however, likely had more to do with the industry's political clout and less with concern about the industry's ability to adjust to new legal requirements.¹⁵⁰

On a philosophical level, the question of the ADA's applicability to health insurance is fundamentally a question regarding what kind of social function we expect health insurance to perform. Do we see health insurance as a way of preserving social solidarity by pooling and sharing the risk of health expenses among all members of the community? Or do we understand health insurance more properly as a mechanism for simply identifying each individual's expected health risks and enabling the individual to prepay her expected expenditures (if she can afford it)?¹⁵¹ A decision to limit the ADA's application to health insurance reflects a willingness to accept the effective exclusion of some individuals with disabilities from the social pool—as in the case of AIDS caps—as long as insurers can accomplish this exclusion by means of coverage limitations "evenhandedly applied." The practical result, from the perspective of the individual with a disability seems less evenhanded: the person with AIDS ends up with tens or potentially hundreds of thousands of dollars in uncovered health care costs, while his coworker with heart disease or cancer has similarly extensive medical costs fully covered by insurance.

V. CONCLUSION

Now that we have examined the ADA's impact on health care for persons with disabilities in terms of the statute's application to individual medical treatment encounters, cost-containment mechanisms, and health insurance coverage, we are left with the question: How much of a difference has the ADA made with respect to health care for people with disabilities? A frank assessment shows that, aside from its impact on the

149. See, e.g., *Ford v. Schering-Plough Corp.*, 145 F.3d 601, 608 (3d Cir. 1998). *Accord* *Kimber v. Thiokol Corp.*, 196 F.3d 1092, 1101-02 (10th Cir. 1999).

150. See *Americans with Disabilities Act of 1988: Oversight Hearing of H.R. 4498 Before the Subcomm. on Select Educ. of the House Comm. On Educ. And Labor*, 100th Cong. 72 (1988) (statement by Rep. Major Owens, in response to request that the ADA address inequities in the health insurance available to persons with disabilities, that a decision had been made not to "take on the insurance industry" so that the ADA would have a better chance of passage).

151. See *Jacobi*, *supra* note 142; Deborah A. Stone, *The Struggle for the Soul of Health Insurance*, 18 J. HEALTH POL., POL'Y & L. 287 (1993).

individual encounters between patient and provider, the ADA's application has to date been neither forceful nor sweeping. The ADA has indeed sent a clear message and proved enforceable as a means of attacking denials of care and failures to provide auxiliary aids, but its application to medical decision-making has been less clear. The statute has shown some promise over the past decade as a mechanism for challenging managed care practices or other cost-containment methodologies that have an adverse disproportionate impact on people with disabilities. It remains to be seen, however, how litigation in this area will play out and how willing the courts will be to scrutinize and place limits on cost-containment strategies. Indeed, if challenges to these strategies multiply, it would not be surprising to see courts following the path trod by courts addressing challenges to health insurance practices, where courts have limited the ADA's applicability to blatantly discriminatory refusals to cover and different treatment of disabled individuals in the provision of coverage.

Our retrospective examination of the ADA's application to these areas has uncovered complex questions about the proper meaning of disability discrimination in the field of medical care and how far the rights of persons with disabilities should be extended, if that extension entails the disruption of existing structures and practices in the health care financing and delivery system. Fundamentally, though, these hard questions about how the ADA applies to health care end up sounding a lot like the hard questions currently posed in the field of health policy more generally: questions about the social function of health insurance, how to contain medical costs without negatively affecting quality and access, and how to ensure that individual medical treatment decisions are made in patients' best interests. For the life span of the ADA, the health care field has itself been in a state of flux, with substantial changes occurring in delivery systems, payment mechanisms, and governmental regulations, and this state of flux appears likely to continue for the foreseeable future. Consequently, it is not as if the challenge has simply been to figure out how a new civil rights statute applies to a fairly stable, well functioning system. Instead, advocates for disability rights have struggled to figure out how to hit a moving target, as public and private health policy-makers have tinkered with the system to try to improve access for all members of society while still ensuring that quality care is received at a price that society can live with and without excessive governmental involvement. And as we have experimented and we continue to experiment with different policies and practices to try to solve the problems of our health care system, the impact of those policies and practices on people with disabilities is only one piece of the puzzle we are trying to solve.

One thing seems clear, though, a decade after the ADA's enactment: health care remains a critical area of need for persons with disabilities. Although disabled individuals as a group may be better protected from having the door to a doctor's or dentist's office, or to the hospital shut in their faces, people with disabilities still face substantial barriers to health care access. Indeed, a 2000 survey found that people with disabilities were almost three times as likely as people without disabilities to report that they had not received the medical services they needed in the last twelve months, and the gap between people with and without disability in terms of receipt of needed medical services was found to be increasing rather than decreasing.¹⁵²

These disheartening figures, however, do not necessarily mean we should view the ADA as a failure when it comes to impact on health care for persons with disabilities. Indeed, I would speculate with some confidence that the health care status of people with disabilities might well be worse today had the ADA not been passed. Certainly, the right of people with HIV and other disabilities not to be turned away by a provider based on disability has been established. And the very existence of the ADA (despite the lack of clarity regarding the scope of its application) has—particularly following the federal rejection of Oregon's rationing proposal on ADA grounds—compelled health care policy-makers and third-party payers to take the presence and needs of persons with disabilities into account in their decision-making. The work of advocates who have exposed the disproportionate impact that cost-containment practices can have on persons with disabilities has warned public and private policy-makers to ignore persons with disabilities at their peril.¹⁵³ Thus, the ADA has rendered persons with disabilities eminently visible in the boardrooms, legislative chambers, and bureaucratic offices where decisions impacting their health care are made. Similarly, the ADA's passage has lent support and legitimacy to the burgeoning field of disability studies, which seeks, among other things, to raise the consciousness of health care providers regarding the cultural and social aspects of disability in order to enable physicians to provide more sensitive and competent care to their patients with disabilities.¹⁵⁴

Moreover, it is not fair to judge the ADA as a failure in the realm of health care, for the ADA is a civil rights statute, not a health care reform

152. 2000 N.O.D./Harris Survey of Americans with Disabilities, Executive Summary *available at* <<http://www.nod.org/attitudes.html>>. The poll found that nineteen percent of persons with disabilities, as compared to six percent of persons without disabilities, reported not having received needed care, and that the gap between reporting groups increased from five percent to thirteen percent in the 1994 to 2000 period. *Id.* The survey also reported that persons with disabilities are four times as likely as persons without disabilities to have special needs that are not covered by their health insurance. *Id.*

153. See, e.g., *supra* text accompanying notes 92-94.

154. See Mike Mitka, *Enabling Students to Deal with the Disabled*, 281 JAMA 595 (1999).

statute.¹⁵⁵ Although persons with disabilities may face barriers to accessing health care to a greater extent than the general population, the barriers posed by lack of insurance, underinsurance, and administrative constraints on accessing care are certainly not unique to persons with disabilities. Consequently, health care reform that addresses these barriers may play a greater role in improving the health care received by persons with disabilities than the ADA ever can.¹⁵⁶ Although comprehensive reform of the health care system in the United States that would ensure universal health coverage does not appear on the current political horizon,¹⁵⁷ incremental measures—such as the recent Ticket to Work and Work Incentives Improvement Act of 1999¹⁵⁸—can expand the numbers of persons with disabilities with effective coverage. Thus, those who are dedicated to improving the level and quality of health care services received by persons with disabilities should not only continue to pursue creative theories that use the ADA to challenge health care practices and policies that disadvantage persons with disabilities, but should also press for health care reform to address the growing number of uninsured persons in our society.

155 See Andrew I. Batavia, *Health Care Reform and People with Disabilities*, 12 HEALTH AFFAIRS 40, 46 (1993).

156. Cf. Matthew Diller, *Judicial Backlash, The ADA and the Civil Rights Model*, 21 BERKELEY J. EMPLOYMENT & LAB. L. 19, 52 (2000) (suggesting that a more universal approach to workers' rights could complement the ADA's protection of workers with disabilities).

157. See David Blumenthal, *Health Care Reform at the Close of the 20th Century*, 340 NEW ENG. J. MED. 1916 (1999).

158. Pub. L. No. 106-170, 113 Stat. 1860 (1999) (allowing disabled individuals receiving Social Security Disability Insurance or Supplemental Security Income to obtain employment without sacrificing their Medicare or Medicaid coverage).

