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AIDS AS A CHRONIC ILLNESS: A CAUTIONARY TALE FOR THE END OF THE TWENTIETH CENTURY

Linda C. Fentiman*

INTRODUCTION

Forecasting is always a risky business, particularly at the beginning of the year. Nonetheless I predict that 1998 will be the year that AIDS becomes a mainstream disease, no more likely to receive special legal solicitude or extra government funding than other chronic diseases which afflict a wide spectrum of American society. AIDS is ready to come of age and lose its status as a specialty disease, due to the confluence of four major phenomena. These are: (1) significant clinical innovations in AIDS treatment,¹ (2) a shift in the demographics of persons living with AIDS and HIV,² (3) a re-configured and refinanced health care delivery system,³ and (4) new legal thinking about people with disabilities.⁴ Some AIDS advo-

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¹ See Deborah Sontag & Lynda Richardson, *Doctors Withhold H.I.V. Pill Regimen from Some*, N.Y. TIMES, Mar. 2, 1997, at A1 (discussing protease inhibitors as an AIDS treatment that will prolong patients' lives).

² See David Brown, *Poverty Entangles Promise of Powerful Treatment*, WASH. POST, Sept. 1, 1997, at A1 (reporting an increase in the number of African-Americans, women, and intravenous drug users living with HIV and AIDS rather than gay white men who made up a majority of the AIDS sufferers in the 1980s); *Minorities Miss Out on AIDS Survival Increase*, AIDS ALERT, May 1, 1997, available in 1997 WL 8961938 (noting that African-Americans have AIDS at seven times the rate of whites, and Hispanics have AIDS at three times the white rate).

³ See RAND E. ROSENBLATT ET AL., LAW AND THE AMERICAN HEALTH CARE SYSTEM 12 (1997); Eleanor D. Kinney, *Medicare Managed Care from the Beneficiary's Perspective*, 26 SETON HALL L. REV. 1163, 1163 (1996) (stating that "managed care is fast becoming the predominant model for the delivery of health care services in the United States"); see also Herbert M. Dean, *As I See it*, TELEGRAM & GAZETTE (Worcester, Mass.), Sept. 29, 1997, at A7 (discussing the high rates of growth in Health Maintenance Organization [hereinafter HMO] programs and managed care).

⁴ See Arti Kaur Rai, *Rationing Through Choice: A New Approach to Cost-Effectiveness Analysis in Health Care*, 72 IND. L.J. 1015, 1016-19 (1997) (arguing for cost-effectiveness in

cates themselves are beginning to reassess the desirability of "AIDS exceptionalism," the notion that because the diagnosis of HIV is both clinically devastating and socially stigmatizing, HIV and AIDS require special status and special resources.⁵ In addition, public health specialists and some AIDS advocacy groups, including the Gay Men's Health Crisis in New York, support the idea of mandatory reporting of HIV test results to state health departments.⁶ Mandatory reporting permits the collection of more accurate epidemiological data on the incidence of HIV infection, as well as AIDS, now that HIV infection itself is recognized as a chronic health condition necessitating medical intervention.⁷ This new openness to data collection reflects a growing consensus that HIV and AIDS are less stigmatizing than they once were, as more and more Americans' lives are touched by the disease. At the same time, the urgent need for more accurate information for formulating public health policy is seen by some to outweigh the infringement of individual privacy rights and the potential deterrent effect on those seeking HIV and AIDS treatment that have traditionally been grounds for opposing mandatory HIV reporting, particularly if names are attached to positive test results.⁸

In examining the demise of AIDS as *sui generis*, it is necessary to understand the impact of converging medical, financial, and socio-political forces over the last fifteen years. During that time AIDS has evolved from a swiftly fatal illness whose etiology was unknown, to a well-studied, treatable chronic disease where death can frequently be staved off for a lengthy time, although not forestalled altogether.⁹ AIDS is thus similar to many other chronic diseases

rationing health care); Chris Watkins, Comment, *Beyond Status: The Americans with Disabilities Act and the Parental Rights of People Labeled Developmentally Disabled or Mentally Retarded*, 83 CAL. L. REV. 1415, 1430 (1995) (noting that one aim of the Americans with Disabilities Act [hereinafter ADA] is to change legal thinking about people with disabilities).

⁵ See Sheryl Gay Stolberg, *New Challenge to Idea that "AIDS is Special,"* N.Y. TIMES, Nov. 12, 1997, at A1 (emphasizing that AIDS is a special disease that requires a special response).

⁶ See, e.g., Michael Lasalandra, *Health Officials May Require Doctors To Report All HIV Patients in State*, BOSTON HERALD, Jan. 14, 1998, at 15.

⁷ See Lynda Richardson, *AIDS Group Urges New York To Start Reporting of H.I.V.*, N.Y. TIMES, Jan. 13, 1998, at A1 (noting the importance of states requiring doctors to report AIDS cases to public officials).

⁸ See *First-ever AIDS Incidence Decline Marks Start of a New Era in Epidemic*, AIDS ALERT, Nov. 1, 1997, available in 1997 WL 8961981 (stating that improving the ability to monitor HIV infection is essential to determine patterns of the AIDS epidemic and to finding cures).

⁹ See Deborah J. Cotton, *Improving Survival in Acquired Immunodeficiency Syndrome: Is Experience Everything?*, 261 JAMA 3016, 3016 (1989) (discussing the progress in treatment

for which a remarkable series of genetic, medical, and pharmaceutical advances now hold out the potential for control, if not cure.¹⁰

With AIDS, substantial treatment breakthroughs have occurred in the year and a half since the 1996 International Conference on AIDS in Vancouver.¹¹ Thousands of HIV-positive and AIDS patients across the United States have embarked upon new treatment regimens, taking protease inhibitors daily along with other drugs.¹² In many cases, these individuals have experienced significant remission in their disease.¹³ These new "cocktails" are so successful for many people that in 1996, for the first time since the AIDS epidemic began, the number of deaths nationwide due to AIDS fell compared to the year before.¹⁴ The trend has continued in 1997, with data from New York City showing that the death toll from AIDS decreased by forty-eight percent.¹⁵

Dramatic clinical breakthroughs have also changed the standard of care and quality of life for other chronic disease sufferers. The nicotine patch has helped smokers withdraw from their tobacco addiction, thus halting the onslaught of emphysema, cancer, and cardiovascular disease.¹⁶ Psychotropic drugs have shortened hospital

for AIDS). Advances in AIDS treatment helps persons primarily in the Western developed world who have access to expensive, innovative treatment, and who are lucky enough to respond well to it. This Article limits its observations to the United States.

¹⁰ See David Brown, "Triple Therapy" Doesn't Destroy HIV, WASH. POST, Nov. 14, 1997, at A4 (noting that while progress is slow, and final results are speculative, new drug breakthroughs can help to control HIV infection).

¹¹ See *AIDS Deaths Fall Sharply; New Treatments Credited*, WASH. POST, Feb. 3, 1998, at A2 (attributing the decline in AIDS deaths in 1997 to treatment breakthroughs); David Brown, *With Fanfare, Global AIDS Conference Gets Underway in Vancouver*, WASH. POST, July 8, 1996, at A4 (reporting the opening of the eleventh International Conference on AIDS).

¹² Protease inhibitors work by interfering with the HIV virus's ability to copy itself, thus limiting its spread within the body. See Thomas H. Maugh II, *Hopes Rise for Inexpensive AIDS Drug*, L.A. TIMES, Feb. 6, 1998, at A1.

¹³ See Lawrence K. Altman, *AIDS Deaths Drop 48% in New York*, N.Y. TIMES, Feb. 3, 1998, at A1 (analyzing data to show the progress of new AIDS treatments).

¹⁴ See Centers for Disease Control and Prevention, *Update: Trends in AIDS Incidence—United States, 1996*, 46 MORBIDITY & MORTALITY WKLY. REP. 861, 861 (1996) (noting the decline in AIDS deaths in 1996).

¹⁵ See Altman, *supra* note 13, at A1.

¹⁶ See Matthew Baldini, *The Cigarette Battle: Anti-Smoking Proponents Go for the Knock-out*, 26 SETON HALL L. REV. 348, 370 (1995) (stating that lung cancer was the most prevalent cancer linked to smoking, and noting other smoking related diseases such as chronic bronchitis, emphysema, and coronary artery disease); J. Michael McGinnis & William H. Foege, *Actual Causes of Death in the United States*, 270 JAMA 2207, 2208-10 (1993) (finding that tobacco ranks as one of the leading causes of death among Americans); Christina Del Valle, *Want to Stop Smoking? There Are More Ways than Ever To Quit*, NEWSDAY, Jan. 19, 1998, at B13 (observing the availability of nicotine patches, gums, sprays, and inhalers to help smokers quit).

stays and liberated many mentally ill people from debilitating depression, schizophrenia, and bipolar disorders.¹⁷ Similarly, pancreatic transplants (including the Islets of Langerhans, the source of insulin) are poised to radically alter the treatment of diabetes.¹⁸

During this same time period the landscape of American health care has changed dramatically. In the early 1980s, health care in the United States was largely provided within a fee-for-service system, in which eighty percent of Americans under age sixty-five had private health insurance, primarily through employment, with relatively comprehensive coverage.¹⁹ Today, managed care is the predominant form of health care delivery in the United States.²⁰ Managed care relies on new organizational delivery structures, both corporate and contractual, utilization review processes, and financial incentives to provide less care, in order to contain costs and to avoid medically unnecessary and potentially dangerous treatment.²¹ At the same time, slightly more than half of all Americans receive health care coverage through an employer who is self-insured.²² Because of the Employee Retirement Income Security Act of 1974²³ (ERISA) preemption by these employee benefit health plans are not

¹⁷ See Lou Chapman, *Fear of Mentally Ill Called Sign of Ignorance*, FORT WORTH STAR-TELEGRAM, Apr. 11, 1997, at 2 (stating that drugs reduce the need for hospitalization and counseling, and that 60% to 80% of bipolar disorders can be treated with drugs); Deborah Kelly, *Medicating the Mind: Breakthrough Drugs May Hold Promise for Many*, RICHMOND TIMES-DISPATCH, Dec. 11, 1997, at E1 (stating that new antipsychotic medications have been called miracle drugs for persons with schizophrenia and manic-depression).

¹⁸ See Kathleen Doheny, *Body Watch Zeroing in on Diabetes*, L.A. TIMES, May 28, 1997, at E2 (discussing one transplantee's foray into pancreas transplantation); David N. Leff, *French Diabetologists Couple Cholera Toxin to Insulin as Diabetes Type 1 Vaccine*, BIOWORLD TODAY, May 6, 1997, available in 1997 WL 7473764 (stating that pancreas transplants can be a successful cure for diabetes); John G. Leyden, *A Good Idea and a Lot of Sweat Led to Diabetes Treatment; Insulin Developed by Team Effort Without Team Spirit*, WASH. POST, Apr. 22, 1997, at Z18 (discussing the discovery of the Islets of Langerhans, the small microscopic cell clusters which produce insulin).

¹⁹ See ROSENBLATT ET AL., *supra* note 3, at 12 (discussing the structure of the health care delivery system).

²⁰ See Kinney, *supra* note 3, at 1163 (stating that both public and private payers are seeking to control the escalating costs of health care); see also Dean, *supra* note 3, at A7 (noting that over 70% of employer sponsored health care is in some form of managed care).

²¹ See Diana Joseph Bearden & Bryan J. Maedgen, *Emerging Theories of Liability in the Managed Health Care Industry*, 47 BAYLOR L. REV. 285, 288-89 (1995) (discussing the methods managed care organizations use to evaluate patient care); Elaine Lu, *The Potential Effect of Managed Competition in Health Care on Provider Liability and Patient Autonomy*, 30 HARV. J. ON LEGIS. 519, 521-28 (1993) (same).

²² See Alex Pham, *Aetna To Halt Some Infertility Coverage: Thousands To Be Affected in Mass.*, BOSTON GLOBE, Jan. 10, 1998, at F1 ("Approximately half of the nation's insured population belong to self-insured plans, according to insurance experts.").

²³ 29 U.S.C. §§ 1001-1461 (1994).

governed by state laws providing relief when insurance coverage is "unfairly" denied,²⁴ thus leaving many employees and their families remediless when a plan will not cover arguable medically necessary care.

Federal efforts to protect people from the most Draconian aspects of health insurance have met with limited success, and are largely incremental in nature. They include the Health Insurance Portability and Accountability Act of 1996 (HIPAA),²⁵ which was designed to limit the impact of preexisting conditions on access to insurance, and the Mental Health Parity Act of 1996,²⁶ which requires that when employee benefit plans offer coverage for both physical and mental illnesses, the total dollar value of the coverage must be the same, unless the employer demonstrates financial hardship.²⁷ There are millions of Americans who are either forced to stay in a job they don't want solely because of its health insurance coverage or who lack access to needed medical services because they happen to have the wrong disease. Nearly forty-two million Americans lack any health care insurance, even the government financed insurances of Medicare and Medicaid.²⁸ In New York City, twenty percent of the population under age 65 is uninsured.²⁹

The result of these monumental shifts in the structure and financing of health care delivery is that at the very time that medical innovations have made possible significant improvements in the quality and quantity of life for people with chronic illnesses, those who are responsible for paying for Americans' health care, in government and the private sector, seem to have finally said "Enough! We must cut costs, and cut them dramatically, and the simplest, most direct way of cutting costs is to deny coverage for certain kinds of treatments and certain kinds of illnesses." People with HIV and AIDS are among those who are struggling, often unsuccessfully, for access to medically necessary treatment, but they are no

²⁴ See Michael T. Isbell, *AIDS and Access to Care: Lessons for Health Care Reformers*, 3 CORNELL J.L. & PUB. POL'Y 7, 21 (1993).

²⁵ Pub. L. No. 104-191, 110 Stat. 1936 (1996).

²⁶ 42 U.S.C. § 300gg-5 (1994).

²⁷ See *id.*

²⁸ See PAUL FRONSTIN, SOURCES OF HEALTH INSURANCE AND CHARACTERISTICS OF THE UNINSURED 2 (Employee Benefit Research Institute Issue Brief No. 192, 1997) (demonstrating that 41.4 million non-elderly Americans have no health care insurance).

²⁹ See Ian Fisher, *Even as Economy Booms, More People Are Going Without Insurance*, N.Y. TIMES, Feb. 12, 1998, at B1 (noting that the number of people without medical insurance is rising far faster in New York State than in the rest of the country).

longer alone. Millions of other Americans living with chronic disease face similar problems as they seek medical treatment that is effective, multi-faceted, and expensive in a health care system increasingly bent on controlling both the costs the structures of health care delivery. We thus stand at the threshold of a critical question: What lessons does the AIDS pandemic provide for American health care in general?

I. LESSON #1: PREVENTION WORKS BEST

It is always cheaper to prevent illness than to treat it.³⁰ AIDS, along with many other illnesses linked to human behavior, exemplifies the limitations of American public health policy as it is directed at chronic disease reduction. Government and private payers spend very little on cost-effective preventive public health strategies.³¹ State health departments spend only three percent of their budgets on prevention and less than one percent of government funding supports public health initiatives.³² Although approximately \$425 billion was spent in 1994 to treat the six major chronic diseases (heart disease, cancer, stroke, diabetes, chronic obstructive pulmonary disease, and chronic liver disease), less than one percent of

³⁰ See Stephenie Overman, *Managed Care Companies Still Emphasize Prevention*, L.A. BUS. J., Sept. 22, 1997, available in 1997 WL 9559235 (noting that some HMOs are starting to place more emphasis on prevention); Thomas J. Prohaska, *Health Leader Backs Needle Exchange*, BUFF. NEWS, Sept. 28, 1997, at C1 (arguing that focusing on the prevention of HIV/AIDS is cost effective).

³¹ Indeed, the publicity which has attended the successful clinical and pharmaceutical innovations in AIDS treatment in the United States and other Western countries has obscured the growing AIDS pandemic in the rest of the world, where drug therapies are far too expensive to be useful to more than a handful of those infected with HIV. Western AIDS research efforts, both publicly and privately funded, have concentrated on treatment breakthroughs, while for other countries, the only hope for limiting the spread of the disease is in prevention, through education about high risk behaviors, and the development and use of an AIDS vaccine. See Andrew Purvis, *The Global Epidemic*, TIME, Dec. 30, 1996, at 76-78 (describing recent AIDS prevention programs in African countries). In the United States Phase III clinical trials are about to begin for an AIDS virus drug. See *AIDS Vaccine Approved for Human Trials*, WASH. POST, Jan. 12, 1998, at A11 (reporting that the first AIDS vaccine has been approved by the Food and Drug Administration to move to "phase III testing"). A recent United Nations report estimated that there are 16,000 new cases of HIV infection each day. See Robert Pear, *New U.N. Estimate Doubles Rate of Spread of AIDS Virus*, N.Y. TIMES, Nov. 26, 1997, at A3.

³² See *Medical Costs To Surge for Chronic Disease Treatment*, MED. INDUS. TODAY, Apr. 7, 1997, available in LEXIS, News Library, Medtdy File; see also Edward L. Baker et al., *Health Reform and the Health of the Public: Forging Community Health Partnerships*, 272 JAMA 1276, 1277 (1994) (stating there has been an "erosion of core public health funding").

that amount (\$287 million) was spent on prevention efforts.³³ Many health care insurers and other payers do not pay for preventive health care (well-baby check-ups, mammographies, etc.), although this may change as managed care, which has marketed preventive care as one of its hallmarks, gains greater prevalence in American health care delivery.³⁴ In 1993, Drs. Michael McGinnis and William Foege estimated that approximately one half of all deaths in the United States could be forestalled by prophylactic health care measures, including changes in sexual and driving behavior, food and alcohol consumption, and the use of tobacco and other drugs.³⁵ For example, we know that more than forty percent of high school students, both boys and girls, use cigarettes and other tobacco products, and that eighty-five percent of current adult smokers began before the age of 18.³⁶ In forty years, many of these students will become sufferers from cancer, emphysema, and heart disease. Similarly, McGinnis and Foege suggested that as many as 300,000 deaths annually could be prevented if people decreased their consumption of calories, particularly animal fat, and increased their level of exercise, thus reducing their risk of developing diabetes and heart disease.³⁷

With AIDS, four effective prevention strategies have been identified: counseling individuals to change their sexual and other high risk behaviors, explicit sex education programs, condom distribution, and the provision of clean needles to intravenous drug users.³⁸ Public and private health policymakers have frequently resisted the implementation of these strategies for moral, fiscal, or political rea-

³³ See *Medical Costs To Surge for Chronic Disease Treatment*, *supra* note 32.

³⁴ See *A Managed Care Primer*, PEOPLE'S MED. SOC'Y, Oct. 1, 1997, at A1 (noting the goals of managed care are to provide services to keep people healthy); David Algeo, *Managing Medicaid HMO's New Law Presents Challenges for Health-Maintenance Organizations*, DENVER POST, June 29, 1997, at H1 (stating managed care focuses on prevention of illness).

³⁵ See McGinnis & Foege, *supra* note 16, at 2211 (linking approximately half of all deaths in the United States to identifiable factors).

³⁶ See Sheryl Gay Stolberg, *Rise in Smoking by Young Blacks Erodes a Success Story*, N.Y. TIMES, Apr. 3, 1998, at A24; Professor Richard J. Bonnie, Presentation at the Pace University School of Law Conference, Tobacco and the Public Health: Social Policy and Legal Issues (Apr. 19, 1997).

³⁷ See McGinnis & Foege, *supra* note 16, at 2208 (estimating that 35% of all cancer deaths are attributable to diet).

³⁸ See William N. Eskridge, Jr. & Brian D. Weimer, *The Economics Epidemic in an AIDS Perspective*, 61 U. CHI. L. REV. 733, 766-70 (1994); *Needle Exchange Programs Comprehensive Approach Found To Be Best Way To Prevent HIV Among Drug Users*, AIDS WKLY. PLUS, Sept. 22, 1997, at 19, available in 1997 WL 11007268.

sons.³⁹ Similar short-sightedness characterizes most states' regulation of hypodermic syringes, as they severely limit access to syringes in order to discourage drug abuse, overlooking the increased transmission of hepatitis, HIV, and other blood-borne diseases which inevitably accompanies such restrictive measures.⁴⁰

Numerous studies demonstrate that an ongoing relationship with a health care professional is crucial to changing a person's sexual behavior by influencing the individual to use condoms or to limit the number of sexual encounters, but this knowledge has not been effectively implemented due to organizational or political constraints on health care delivery.⁴¹ Although many managed care organizations endeavor to ensure continuity of care, frequently their patients do not see the same health care provider regularly, and thus lack the sort of practitioner-patient relationship which can encourage a change in high risk behavior.⁴² As governments reduce access to sexually transmitted disease clinics and other reproductive healthcare services, they lose a valuable opportunity to counsel people about the risks of unprotected sex and intravenous drug use.⁴³ Unprotected sexual intercourse accounted for more than 30,000 deaths in 1990, including 21,000 from sexually acquired HIV infections, 4000 from cervical cancer, 1600 from sexually acquired Hepatitis B infections, and 5000 deaths of infants due to unplanned pregnancies and a concomitant lack of prenatal care.⁴⁴ In almost all states possession of a hypodermic needle or syringe with the intent to use it to inject drugs is illegal.⁴⁵ Eight states additionally require a prescription to purchase a needle or syringe, although several of the states, including New York, permit syringe possession in con-

³⁹ See Lawrence O. Gostin et al., *Prevention of HIV/AIDS and Other Blood-Borne Diseases Among Injection Drug Users: A National Survey on the Regulation of Syringes and Needles*, 277 JAMA 53, 54-55 (1997).

⁴⁰ See *id.* at 54 (noting "[d]rug paraphernalia statutes ban the manufacture, sale distribution, possession, or advertising . . . of devices known to be used (or reasonably should be known to be used) to introduce illicit substances into the body").

⁴¹ See, e.g., James G. Kahn, *The Cost-Effectiveness of HIV Prevention Targeting: How Much More Bang for the Buck?*, 86 AM. J. PUB. HEALTH 1709, 1711 (1996) (suggesting that HIV prevention services help to stop the spread of HIV and reduce costs).

⁴² See Isbell, *supra* note 24, at 27-28.

⁴³ See Jim Yardley, *Breaking the H.I.V. Chain: Clinic Battles Spread of Infection—and Despair*, N.Y. TIMES, Jan. 25, 1998, at K27.

⁴⁴ See McGinnis & Foegen, *supra* note 16, at 2210.

⁴⁵ See Gostin et al., *supra* note 39, at 54 ("Forty-seven states, the District of Columbia, and the Virgin Islands have enacted drug paraphernalia laws; only Alaska, Iowa, South Carolina, and four territories have no state—or territory—wide drug paraphernalia statute.").

nection with a state-approved syringe exchange program.⁴⁶ These programs have been shown to cut the rates of HIV infection substantially.⁴⁷

Aggressive interventions to reduce the incidence of other chronic diseases have been proposed, including the Food and Drug Administration's (FDA) regulations banning most advertising of tobacco products to children under eighteen,⁴⁸ and screening of high risk groups for diabetes.⁴⁹ Other preventive public health measures, which have not generally been implemented with AIDS, but have been used historically with other diseases, include isolation and quarantine.⁵⁰ Some communities have invoked the public health police power to limit the opportunities for high risk activities by prohibiting the use of closed video booths in adult bookstores and entertainment centers,⁵¹ and closing bathhouses and other locations where there are opportunities for high risk sexual activity.⁵² More recently, the question of whether there should be mandatory contact tracing and/or reporting of persons who test HIV positive has been hotly debated in the wake of highly publicized allegations that

⁴⁶ See *id.* at 56.

⁴⁷ See Felicia R. Lee, *Needle Exchange Programs Shown To Slow H.I.V. Rates*, N.Y. TIMES, Nov. 26, 1994, at A4 (noting that intravenous drug users who are not involved in a needle exchange program have a two percent to five percent higher rate of HIV infection than those in a needle exchange program).

⁴⁸ See Regulations Restricting the Sale and Distribution of Cigarettes and Smokeless Tobacco to Protect Children and Adolescents, 21 C.F.R. § 897.2 (1996) (noting the purpose of the regulation is to prohibit the sale of nicotine cigarettes and smokeless tobacco products to children).

⁴⁹ See Geraldine A. Collier, *Battling Diabetes, the Silent Killer*, TELEGRAM & GAZETTE (Worcester, Mass.), Jan. 20, 1997, at C1 (discussing the need for intensive intervention and/or medication to decrease the risk of diabetes); Kamilla Kuroda McClelland, *New Baseline Formed for Diabetes: High-Risk; Nikkei Are More at Risk than Japanese in Japan*, N. AM. POST, June 27, 1997, at 1 (encouraging Japanese-Americans to be screened earlier and more often to catch and treat the disease earlier).

⁵⁰ See *Jew Ho v. Williamson*, 103 F. 10, 26 (N.D. Cal. 1900) (noting the quarantine of San Francisco's Chinatown, because of an ostensible outbreak of bubonic plague, was invalid under the Fourteenth Amendment); *Kirk v. Wyman*, 65 S.E. 387, 388 (S.C. 1909) (upholding a lower court's grant of a preliminary injunction to restrain the removal of a woman with leprosy to the city "pesthouse" because of the asserted contagious nature of her disease). Cuba is the only nation to seriously attempt isolation of all HIV-positive patients achieving a very low rate of HIV infection, but Cuba abandoned its isolation program due to its high costs. See Juanita Darling, *New Day for AIDS Policy in Cuba*, L.A. TIMES, July 24, 1997, at B2 (discussing the Cuban government's approach to AIDS infected people).

⁵¹ See *Doe v. Minneapolis*, 898 F.2d 612 (8th Cir. 1990).

⁵² See *New York v. New St. Mark's Baths*, 497 N.Y.S.2d 979 (Sup. Ct.), *aff'd*, 505 N.Y.S.2d 1015 (App. Div. 1986).

a young man from New York City has been the source of a one man AIDS epidemic in Jamestown, a small town in upstate New York.⁵³

II. LESSON #2: AIDS AS A CHRONIC ILLNESS AND ACCESS TO HEALTH CARE

The most salient feature of the evolution of AIDS over the past decade and a half is that it has become a chronic illness. Today, cases involving HIV-positive individuals and persons with AIDS are paradigms for the problems that many people with chronic diseases face in receiving care. The issues of access arise in a variety of contexts, including the ability to secure primary health care, to receive emergency medical treatment, to obtain quality specialist care, and to receive innovative, and often expensive treatment.

A. Access to Primary Care

People who are HIV positive or who have AIDS, or are suffering from diabetes, lupus, or hepatitis B, require primary medical and dental care in addition to specialty healthcare. Frequently those who have the HIV or AIDS disease find it difficult to find a provider who will treat them. In *Abbott v. Bragdon*,⁵⁴ an asymptomatic HIV-positive woman who sought routine dental treatment to fill a cavity disclosed that she was HIV positive.⁵⁵ The dentist, Dr. Bragdon, refused to treat her, except in a hospital setting, where the cost of treatment would be greater.⁵⁶ After declining this offer, Ms. Abbott brought suit under the Americans with Disabilities Act of 1990⁵⁷ (ADA). The First Circuit Court of Appeals held that Ms. Abbott was disabled within the meaning of the ADA because she was a person with asymptomatic HIV who was limited in a major life activity, i.e., reproduction.⁵⁸ The court held that the burden was therefore shifted to Dr. Bragdon to show that he was not obligated

⁵³ See Jane Gross, *Trail of Arrests, H.I.V. Fears and a Woman's Tale of Love*, N.Y. TIMES, Oct. 29, 1997, at A1; Tom Precious, *HIV Proposals Call for Testing, Disclosure*, BUFF. NEWS, Dec. 18, 1997, at A16.

⁵⁴ 107 F.3d 934 (1st Cir.), cert. granted, 118 S. Ct. 554 (1997).

⁵⁵ See *id.*

⁵⁶ See *id.* at 937.

⁵⁷ 42 U.S.C. § 12101 (1994).

⁵⁸ See *Abbott*, 107 F.3d at 939, 941. A plaintiff suing under the ADA is required to prove three things: (1) that the plaintiff has a physical or mental impairment; (2) that such impairment adversely affects a "major life activity"; and (3) that the limitation is significant. See *id.* at 938-39.

to treat her because she posed a direct threat to his health and safety.⁵⁹ *Abbott* marked the first time that a court held that asymptomatic HIV status alone was sufficient to qualify as a disability under the ADA, and was also important in recognizing that physicians and dentists offices are places of public accommodation within the protection of the ADA.⁶⁰

Other commentators, including Professor Scott Burris, have noted the significant difficulties that HIV-positive individuals and persons with AIDS have in gaining access to routine dental care.⁶¹ Similar difficulties in obtaining routine primary care are faced by persons with hearing impairments, blind persons who rely upon guide dogs for assistance in gaining access to a physician's office, and those whose mental impairments make them unpopular patients with primary care providers.⁶²

B. Access to Emergency Care

Individuals who are HIV positive or who suffer from AIDS have often found it difficult to receive emergency medical care because of the concern of hospitals and physicians, whether or not well-founded, that the patient's illness is too complex to be readily treated in an emergency room and that an AIDS patient, once admitted, may prove to be a costly admission.⁶³ The practice of refusing admission to an uninsured or otherwise undesirable patient

⁵⁹ See *id.* at 948 (finding the evidence offered to buttress his claim was "too speculative or too tangential").

⁶⁰ See *id.* at 939 (stating that both symptomatic and asymptomatic HIV-positive persons are covered by the Act). The Supreme Court has granted certiorari in *Abbott*. See 118 S. Ct. 554 (1997). A decision in *Abbott* will likely have an impact on another key decision involving an HIV-positive employee who was terminated. See *Runnebaum v. Nationsbank of Md.*, 123 F.3d 156 (4th Cir. 1997). It is noteworthy, however, that *Runnebaum* arose in the context of employment discrimination and the court found no evidence that the plaintiff's HIV positive status limited him in his procreative functions, thereby offering a possible distinction from *Abbott*. See *id.* at 169-70.

⁶¹ See Scott Burris, *Dental Discrimination Against the HIV-Infected: Empirical Data, Law and Public Policy*, 13 YALE J. ON REG. 1, 4 (1996) (analyzing empirical studies on dentists' attitudes toward patients with HIV and concluding that many dentists are uncomfortable treating such patients).

⁶² See *Tugg v. Towey*, 864 F. Supp. 1201, 1211 (S.D. Fla. 1994) (granting a preliminary injunction under the ADA to deaf and hearing-impaired plaintiffs seeking mental health counseling from therapists who used sign language, rather than relying on sign language interpreters); *Mayberry v. Von Valtier*, 843 F. Supp. 1160 (E.D. Mich. 1994) (involving a deaf patient whose physician no longer wanted to pay for an interpreter to be present during appointments).

⁶³ See *Howe v. Hull*, 874 F. Supp. 779, 783 (N.D. Ohio 1994) (claiming that a patient was transferred to another hospital because of his HIV status).

is known colloquially as "patient dumping."⁶⁴ It has been addressed by some state courts which have found a common law duty to treat,⁶⁵ and, on the federal level, by the Emergency Medical Treatment and Active Labor Act⁶⁶ (EMTALA), which requires that all patients who arrive at a hospital emergency room shall receive an appropriate medical screening examination to determine if they are in the midst of a medical emergency or active labor, and prohibits their transfer in a medically unstable condition, unless the physician certifies in writing that the benefits of the transfer outweigh its potential risks.⁶⁷ The exemplary AIDS case is *Howe v. Hull*.⁶⁸ Fred Charon, a patient with AIDS, sought treatment at the emergency room of a community hospital when he suffered a severe prescription drug reaction unrelated to his underlying AIDS condition.⁶⁹ Charon was denied admission to the hospital and transferred to a nearby academic medical center.⁷⁰ Although the transfer was ostensibly due to the treating physician's concern that Charon was suffering from a complicated drug reaction, requiring treatment at the academic medical center, ample evidence suggested that the drug reaction was simple and readily treatable at the community hospital, and that the transfer was motivated by Charon's AIDS status.⁷¹ A suit followed, asserting claims under state tort law for the infliction of emotional distress, the ADA, the Federal Rehabilitation Act of 1973⁷² and EMTALA. The defendant-physician and hospital were found liable for intentional infliction of emotional distress, and violating the ADA and the Rehabilitation Act, but the claims under EMTALA were rejected.⁷³ Still, as an allegedly "dumped" patient, Charon symbolizes the growing number of Americans with socially disfavored chronic diseases who have difficulty gaining access to vitally necessary hospital emergency care.

⁶⁴ See *id.* at 784.

⁶⁵ See *Thompson v. Sun City Community Hosp., Inc.*, 688 P.2d 605 (Ariz. 1984) (involving a hospital's transfer of an unstable patient to another hospital for surgery); *Wilmington Gen. Hosp. v. Manlove*, 174 A.2d 135 (Del. 1961) (involving a hospital transfer of an infant in a potentially emergent situation, who later died due to a lack of care).

⁶⁶ 42 U.S.C. § 1395dd (1994).

⁶⁷ See *id.* § 1395dd(c)(1)(A)(i)-(iii).

⁶⁸ 874 F. Supp. 779 (N.D. Ohio 1994).

⁶⁹ See *id.* at 783.

⁷⁰ See *id.* at 783-84.

⁷¹ See *id.* at 786.

⁷² 29 U.S.C. § 701 (1994).

⁷³ See *Howe*, 874 F. Supp. at 791.

C. Access to Specialty Care

HIV-positive individuals and AIDS patients exemplify the problems of many sufferers from chronic diseases who need specialized medical care, but have difficulty in gaining access to it due to the limited knowledge of their primary care providers. In some cases, the primary care provider is not sufficiently knowledgeable to recognize the disease and provide the necessary care. People with Sjogrens Syndrome, a disease of the autoimmune system that causes a loss in moisture functions in the tear ducts and the salivary glands, leading to vision and oral hygiene problems, are often undiagnosed because of a lack of awareness in the general medical and dental communities.⁷⁴ In other cases, the primary care provider lacks the knowledge to make an appropriate referral. This was a common experience among HIV-positive and AIDS patients, particularly in the early stages of the AIDS epidemic. At that time, many physicians and AIDS activists believed that people living with HIV and AIDS were not receiving sufficient referrals to specialists and subspecialists, which were desperately necessary because generalist physicians were frequently unqualified to deliver care.⁷⁵

A different concern in the debate about access to specialty care is that patients suffering from a particular disease, such as AIDS, may become isolated in special treatment units as the pariahs of the patient community. Today, this discussion about the "ghettoization" of AIDS plays itself out in the controversy surrounding New York State Health Department regulations mandating HIV testing for all newborns, which require that infants and their mothers diagnosed as HIV positive be referred to AIDS specialists.⁷⁶ Opponents of the regulations argue that all primary health providers should be able to provide appropriate care for AIDS patients, and that mandating specialty referrals may lead again to the medical and social isolation of HIV-positive individuals

⁷⁴ See Joyce Howard Price, *Ailment Keeps Millions in Misery: Sjogren's Syndrome Goes Undiagnosed for Most Sufferers*, WASH. POST, Dec. 28, 1997, at A2.

⁷⁵ See *New York City HMOs Not Ready To Serve HIV-Positive Women, Children, Study Says*, Health Care Daily (BNA) (Oct. 13, 1995), available in LEXIS, BNA Library, Bnahlt File.

⁷⁶ See N.Y. COMP. CODES R. & REGS. tit. 10, § 69-1.3 (1995) (mandating newborn testing); Charles W. Henderson, *Transmission Baby AIDS Testing Law Faces Legal Challenge*, AIDS WKLY. PLUS, July 28, 1997, available in 1997 WL 11006861 (discussing both support and opposition to the mandatory newborn testing law).

and AIDS patients.⁷⁷ However, to the extent that there is any consensus in the HIV-positive and AIDS community, it is that people living with AIDS and HIV, as with any chronic disease, need to have their health care overseen by a practitioner with sufficient expertise to manage a complex treatment regimen, who is able to make immediate and competent referrals should the disease progress beyond his or her capabilities to treat it.

For the increasing numbers of Americans with chronic diseases who receive their health care through a managed care organization, there is an additional concern: that the constraints of the "gatekeeper" system, in which all care is "managed" by a primary care practitioner, will lead to medically harmful delays in, and denials of, treatment. Whether the patient is identified as being HIV positive, or diagnosed with diabetes or hepatitis, the need is for immediate referral to an appropriate specialist, who can initiate effective treatment, including the appropriate drug therapy. With HIV-positive individuals, as well as sufferers from other chronic diseases, the concern is always that a delay in treatment may lead to irreversible deterioration in the patient's condition.

D. Access to Experimental Treatment

HIV and AIDS are similar to many chronic diseases in which the standard of care for medical and drug treatment is rapidly evolving, leading to major gaps in access to quality health care. Three big picture questions have emerged. First, can the process of experimentation be expedited, so that definitive results can be obtained about the efficacy of a particular innovative treatment? Second, how soon is it reasonable to expect success at an academic medical center to be translated into a standard of treatment that is available to patients across the nation at an affordable price? Third, should everyone have access to the new standard of care, regardless of the type or amount of health care insurance they have?

In the early stages of the AIDS epidemic, the controversy over access centered around participation in randomized clinical trials for experimental drug treatments.⁷⁸ The FDA asserted that before a drug could be approved and marketed, a new drug must go through

⁷⁷ See Henderson, *supra* note 76.

⁷⁸ See, e.g., *Testing Testing: Clinical Trials Are an Essential and Expensive Part of Drug Development*, *ECONOMIST*, Feb. 1, 1997, available in 1997 WL 8136413 (noting the process for drug development).

a lengthy series of animal studies and human studies in order to be certain that a drug was both safe and effective for its intended use.⁷⁹ Clinical trial guidelines required all testing to be conducted via randomized clinical trials, meaning that one could not receive an experimental drug, no matter how promising, without participating in a clinical trial, and even then, one would not be guaranteed the drug, since the essential nature of a clinical trial requires that some persons be in the control group.⁸⁰ Aggressive protests by "Act Up" and other AIDS activist groups led the FDA to promulgate "Fast Track," "Parallel Track," and other expedited access regulations, which have substantially decreased the time necessary to gain FDA approval for new pharmaceutical treatments for all patients affected with "immediately life-threatening" or "serious" diseases.⁸¹ Recently enacted legislation codifying the FDA's regulatory approaches is expected to shorten the drug and medical device approval process even more.⁸²

Today, there is a significant drug arsenal available to combat HIV and AIDS, yet access problems remain. Three protease inhibitors—saquinavir, zidovudine, and didanosine—have proven successful in combination with nucleoside analogues in clinical trials and clinical practice in interfering with the HIV virus' ability to replicate itself.⁸³ Early data show that the use of these "combination therapies" can halt the progression from HIV positive status to full-blown AIDS,—help prevent the opportunistic infections which ultimately cause death in AIDS patients, and generally improve the quality of life of HIV-positive and AIDS patients.⁸⁴ Many patients

⁷⁹ See *id.*

⁸⁰ See, e.g., Stephen Fried, *Cocktail Hour*, WASH. POST, May 18, 1997, at W10 (discussing the access problems arising from clinical guidelines).

⁸¹ See Sheila R. Shulman & Drusilla S. Raiford, *FDA Regulations Provide Broader Access to Unapproved Drugs*, 30 J. CLIN. PHARMACOLOGY 585, 585 (1990) (noting that the goal of new FDA procedures is to facilitate the availability of new medications, and obtain additional data on their safety and efficacy); Lawrence M. Fisher, *Hope Near the End of the Pipeline*, N.Y. TIMES, May 1, 1997, at D1 (discussing the introduction of new cancer treatments); Gina Kolata, *Interest Grows in Licensing Shortcut for 2 AIDS Drugs*, N.Y. TIMES, Sept. 25, 1990, at C3 (noting the effects of AIDS activists in advancing the licensing process).

⁸² See Ronald Rosenberg, *Biotech Firms Praise FDA Legislation: Bill Streamlines Drug Approval Process*, BOSTON GLOBE, Nov. 11, 1997, at D5 (discussing the favorable reception given to the more streamlined approval process contained in the FDA legislation).

⁸³ See, e.g., Grace Brooke Huffman, *Review of Protease Inhibitors for Use in HIV-1 Infection*, AM. FAM. PHYSICIAN, June 1, 1997, available in 1997 WL 10150889 (analyzing the success of the protease inhibitors saquinavir, zidovudine, and didanosine).

⁸⁴ See Lawrence O. Gostin et al., *National HIV Case Reporting for the United States*, 337 NEW ENG. J. MED. 1161, 1162-63 (1997) (discussing the advances in HIV treatment).

have experienced a substantial decrease in the "viral load" of HIV in their bloodstream, a recognized biological marker for the advance of HIV disease.⁸⁵

However, these potent drugs are not available to everyone. The primary barrier is financial. It costs \$10,000 to \$15,000 annually just for the drugs for the combination therapy "cocktail," and many HIV-positive and AIDS patients require other drugs as well.⁸⁶ Recent data show that this is money well spent, because increased costs for drug therapy are offset by declines in the number of inpatient hospital admissions and the length of those stays as well.⁸⁷ However, private and government insurers have been reluctant to incur the up-front costs of combination therapy treatment, illustrating some of the inherent weaknesses of our multi-payer, fragmented health care system, in which different types of health care needs are treated differently.⁸⁸

Many insurers and managed care organizations place annual caps on each patient's drug expenses, leaving patients with AIDS and HIV, as well as sufferers from other chronic diseases, with the sole option of paying for their necessary pharmaceuticals out of pocket if they want to stay healthy.⁸⁹ In some managed care organizations, only a limited group of drugs is on the approved drug formulary. If protease inhibitors and other AIDS treatment drugs are not on the formulary, the patient is simply out of luck.

Because many HIV/AIDS patients lose their health insurance when they become sick enough to lose their jobs, eventually many patients turn to the government to pay for their health care. More

⁸⁵ See *id.*

⁸⁶ See Diane Targovnik, *Success of New AIDS Drugs Imperils Tax-Funded Program: Pharmaceutical "Cocktail" So Costly that State-Federal Assistance Plan Going Broke*, NEWS TRIB. (Tacoma, Wash.), Jan. 26, 1997, at A5 (noting that the cost of HIV drugs makes them out of reach of some persons).

⁸⁷ See Joan Stephenson, *Paying Now for Costly AIDS Drugs May Save Money Later* (visited Feb. 8, 1998) <<http://www.ama-assn.org/special/hiv/newsline/conferen/retrocon/js0126.htm>> (arguing that the decline in hospitalizations justifies the costs of protease inhibitors).

⁸⁸ See Charles W Henderson, *Quality of Life: AIDS Patients Living Longer While Money Problem Grows*, AIDS WKLY. PLUS, July 28, 1997, available in 1997 WL 11006856 (observing that hospitals and outpatient AIDS clinics are receiving less reimbursement from private insurance companies); *How Each State Is Faring with Demand for New HIV Drugs*, AIDS POL'Y & L. (BNA) 1, 5 (Oct. 4, 1996) (noting that 22 states are expected to limit access to protease inhibitors, due to rising costs).

⁸⁹ See, e.g., *Managed Care Executives Cite Drug Costs as a Barrier to Profits*, MANAGED CARE OUTLOOK, Aug. 8, 1997, available in 1997 WL 8469939 (observing that HMOs pursuing short term budget goals are having problems with the rising costs of medications).

than 100,000 AIDS patients receive at least some of their drugs through Medicaid.⁹⁰ Under Title II of the Ryan White Care Act,⁹¹ AIDS Drug Assistance Programs (ADAPs) are established in each state to assist indigent patients in paying for necessary drugs.⁹² Under this federal-state partnership, each state seeks approval for its own ADAP program, choosing to cover those drugs which it believes it can afford.⁹³ This has led to wide variations in each state in the number of patients served and the particular drugs available. For example, New York State's program, which serves more than 10,000 patients, is one of the most generous in the nation, which is perhaps to be expected given the state's significant AIDS population, and the political clout of AIDS advocacy groups.⁹⁴ Many other states do not provide coverage for protease inhibitors, the most effective and expensive of the anti-HIV drugs, underscoring that a person's access to effective health care can depend significantly on the accident of geography.⁹⁵ In addition, a significant limitation of all ADAP programs, and of Medicaid in general, is that they cover only persons who have been diagnosed with AIDS, rather than the larger group of those who have tested HIV positive, perhaps reflecting a political decision that the AIDS/HIV dividing line is an appropriate way to apportion scarce government resources.⁹⁶

However, this decision is unsound both medically and fiscally. Protease inhibitors and other advanced anti-AIDS drugs are a significant breakthrough precisely because they can prevent the advance of HIV disease to AIDS, thus providing a cost-effective means of limiting the spread of AIDS and the concomitant costs of AIDS treatment. Viewing the ADAP program as a separate "pot" of

⁹⁰ See Deborah L. Shelton, *Rising Hopes—Rising Costs* (visited Feb. 8, 1998) <<http://www.ama-assn.org/special/hiv/newsline/special/amnews/-amn0916.htm>> (stating that as many as 50,000 additional HIV-infected patients are likely to seek prescription drugs through Medicaid).

⁹¹ See 42 U.S.C. § 300ff (1994) (establishing the framework for federal assistance to be made available to states to provide services for HIV-positive individuals and their families).

⁹² See *id.*

⁹³ See *id.* § 300-ff-22 (describing how states may use the federal grants).

⁹⁴ See David Brown, *AIDS Toll Falls by Half in New York; Health Officials Say New Funds, Drugs May Drive Trend*, WASH. POST, Jan. 25, 1997, at A1 (discussing the positive impact of the New York State ADAP, particularly in New York City).

⁹⁵ See *Study Details Limited Reach of ADAPs Despite Funding Jump*, MED. & HEALTH, July 14, 1997, available in 1997 WL 8689240 (noting that Arkansas, Nevada, Oregon, and South Dakota do not cover the approved inhibitors).

⁹⁶ See *AIDS Lobbies Push for Expanded Care Coverage*, AIDS ALERT, Jan. 1, 1998, at 6 (noting the legislatively imposed dichotomy between AIDS and HIV).

money, to fund AIDS treatment rather than AIDS prevention, will ultimately prove extremely short-sighted.

E. Denial of Access Due to Noncompliance

One of the most poignant ways in which AIDS patients both experience and symbolize the problems of patients with chronic illnesses is in compliance. While compliance means different things in different disease contexts, it generally refers to the ability and willingness of a patient to adhere to the treatment plan developed by the physician, including refraining from medically injurious behavior and taking prescription drugs at intervals that will maximize their efficacy. For an obese patient with high blood pressure and cardiovascular disease, compliance means quitting smoking, changing eating habits, taking medication to lower blood pressure, and learning to exercise in moderation. For a patient who is diabetic, it means eating appropriate meals on a regular basis, monitoring blood glucose levels regularly, and taking oral or injectable insulin at prescribed levels. For an HIV-positive or AIDS patient, compliance requires adhering to a strictly-timed regimen of taking as many as twenty pills a day, some on an empty stomach and some after a meal, as well as meeting the requirements for good health in everyone: eating nutritious meals, getting a good night's sleep in a safe place, and refraining from use of alcohol and other drugs. The latter requirements may be difficult to meet for many HIV-positive and AIDS patients, who may be homeless, poor, and using drugs.

With the advent of combination drug therapies, compliance for patients with HIV and AIDS has become particularly complex.⁹⁷ On the one hand, these new pharmaceutical interventions promise significant remission in disease symptoms for many individuals, allowing them to return to work and to their normal lives. On the other, preliminary data make clear that even occasional lapses in compliance may nullify the efficacy of these drugs in halting the onslaught of AIDS, when patients develop a drug-resistant strain of the HIV virus.⁹⁸ Even more troubling, if the noncompliant patient

⁹⁷ See generally Sontag & Richardson, *supra* note 1, at A1 (discussing the "minefield of ethical, legal and public health concerns" and how strict compliance is necessary with combination drug therapies or else the virus may become resistant to treatment).

⁹⁸ See DAVID A. MORTON III, MEDICAL PROOF OF SOCIAL SECURITY DISABILITY § 2.15 (Supp. 1996) (stating that noncompliance by persons with tuberculosis has resulted in the development of drug-resistant strains of the disease and that poor compliance by persons with AIDS may have the same effect); see also Jennifer L. Rosato, *The Ultimate Test of*

transmits this new version of the virus to others, through sexual contact or intravenous drug use, the new virus can spread widely throughout the population.

Thus, practitioners caring for an HIV or AIDS patient have competing obligations, to the patient and the community, in deciding whether to prescribe a regimen of combination therapies to a patient whom they suspect may have compliance difficulties. First, can the patient's compliance be predicted? Studies of AIDS and other diseases suggest that physicians are poor predictors of compliance, and that it is important to disregard stereotypes based on race, gender, social class, or drug use.⁹⁹ Second, in light of the expense of combination therapies and the potential for the patient to develop drug-resistance, it is critical that the practitioner spend ample time discussing possible pitfalls with the patient and consider delaying, for a short while, the implementation of drug therapy, because the patient has only one chance to make it work.¹⁰⁰

Broader public health concerns are even more difficult to resolve. The lessons of dealing with non-compliant patients with active, drug-resistant tuberculosis (TB) may be useful, although they are not strictly parallel. With active TB, it is possible to mandate a short course (twice a week for two to four weeks) of directly observed therapy to ensure that a patient is taking the medication and thus eliminate the risk of transmission of active, drug-resistant TB.¹⁰¹ With AIDS and HIV, the requirement of combination therapy is expected to be indefinite, and the patient monitoring required to ensure compliance around the clock impracticable. The incredible success of combination therapy itself may provide the necessary "carrot" to encourage compliance, as patients who feel healthier are much more likely to continue treatment. In this view, it would be beneficent parentalism at its worst to prejudge the likely outcome for a particular patient who could be given the op-

Autonomy: Should Minors Have a Right to Make Decisions Regarding Life Sustaining Treatment?, 49 RUTGERS L. REV. 1, 61 n.265 (1996) (noting that drug resistant strains of HIV may result from poor compliance).

⁹⁹ See *Clinicians Explore Ways To Ensure Compliance: More Counseling Needed*, AIDS ALERT, Feb. 1, 1997, available in 1997 WL 8961919 (suggesting that physicians should design a medication schedule tailored to a patient's lifestyle).

¹⁰⁰ See MORTON, *supra* note 98, § 2.15 (stating that physicians should provide patients with suggestions for remembering medication regimens as well as maintain contact with the patient to monitor compliance); Sontag & Richardson, *supra* note 1, at A1 (noting the dilemmas physicians face when deciding whether to treat patients with combination drugs).

¹⁰¹ See *Newark v. J.S.*, 652 A.2d 265, 269 (N.J. Super. Ct. 1993) (stating that non-compliance may lead to relapse and development of a drug resistant strain of tuberculosis).

portunity to try protease inhibitors. Thus, all patients must be given a chance to benefit from the new therapies, as well as the support system necessary to make a chance worth taking.

F. Denial of Access Because of Lack of Insurance: The Limitations of an Employment-Linked Health Care System

The evolution of AIDS over the last fifteen years is a lens through which to examine the strengths and weaknesses of the American health care system. The most significant weakness is that for people under 65 health care coverage is tied closely to employment status.¹⁰² It is largely an historical accident that health insurance coverage became employment-based, due to World War II price controllers who determined to exempt employee benefits from wage and price controls.¹⁰³ Today, as more Americans are aging out of the ranks of the employed, and many Americans are working part-time, or at low wage jobs that do not provide health insurance benefits, the wisdom of this decision is being reexamined.¹⁰⁴ In the case of people with HIV and AIDS, as with many other chronic diseases, most people try to work until they are too sick to continue, often seeking reasonable accommodation in employment tasks along the way. One of the most significant barriers to adequate health care is the trend of employers to self-insure for the health care needs of their employees rather than purchase insurance on their employees' behalf.¹⁰⁵ Under ERISA, self-insured employee benefit plans are not subject to state laws whose purpose is to guarantee minimum access standards to workers and their dependents.¹⁰⁶ Thus, employers are free to impose disease specific caps on coverage, or re-

¹⁰² In 1996, 64% of Americans were covered by employment-based health insurance. See FRONSTIN, *supra* note 28, at 3-4.

¹⁰³ See Dayna Bowen Matthew, *Controlling the Reverse Agency Costs of Employment-Based Health Insurance: Of Markets, Courts, and a Regulatory Quagmire*, 31 WAKE FOREST L. REV. 1037, 1041-42 (1996).

¹⁰⁴ Indeed, President Clinton's proposal to expand Medicare to include people aged 55-64 reflects this new economic reality. See Robert Pear, *Clinton Plan To Widen Medicare Can't Pay for Itself, Experts Say*, N.Y. TIMES, Jan. 20, 1998, at A1 (critiquing a plan that would allow persons under 65 to buy full Medicare coverage).

¹⁰⁵ See Thomas E. Bartrum, *Fear, Discrimination and Dying in the Workplace: AIDS and the Capping of Employees' Health Insurance Benefits*, 82 KY. L.J. 249, 253-54 (1994) (explaining that such a tactic allows employers to cut administrative costs while circumventing state insurance laws).

¹⁰⁶ See 29 U.S.C. §§ 1001-1461 (1994).

quire greater co-payments for certain illnesses than others.¹⁰⁷ The question of whether an insurer's decision to discriminate against individuals with certain types of illnesses in its underwriting violates the ADA is a complex issue that has received little attention from the courts until recently. In *Parker v. Metropolitan Life Insurance Co.*,¹⁰⁸ the Sixth Circuit Court of Appeals held, over a strong dissent, that the distinction between mental and physical illness in the length of coverage provided by an employer purchased disability policy did not violate Title III of the ADA.¹⁰⁹ The Court found that the ADA was not violated because Title III (governing places of public accommodation) applies only to physical structures, and thus the ADA does not govern insurance policies which were purchased by the employer for the benefit of its employees, as opposed to an individual entering into an insurance company's office.¹¹⁰ The Court further reasoned that providing disability policies with different benefits depending on the nature of the disability did not run afoul of the ADA because the ADA was denied to remedy discrimination between the disabled and the non-disabled, and *not* discrimination between individuals with different disabilities.¹¹¹ Thus, it would appear under the *Parker* court's reasoning, that a self-insured employer could distinguish among diseases, insuring HIV and AIDS, in the amount of health care coverage it provided.

Another court has held that where an employer purchased health insurance from a company that refused to offer *any* insurance to an employee with AIDS, the ADA was violated.¹¹² It is as yet unclear what the impact of HIPAA will be on the question of permissible discrimination on the basis of HIV positive or AIDS status, as the avowed purpose of HIPAA was to ensure that people should not be denied insurance coverage due to a preexisting condition.¹¹³ How-

¹⁰⁷ See *McGann v. H & H Music Co.*, 946 F.2d 401 (5th Cir. 1991) (affirming summary judgment for an employer who changed health plans to reduce maximum benefits for employees suffering from AIDS from \$1 million to \$5000, holding that such actions are not prohibited by ERISA).

¹⁰⁸ 121 F.3d 1006 (6th Cir. 1997).

¹⁰⁹ See *id.* at 1015 (stating "[t]he disparity in benefits provided in the policy at issue is also not prohibited by the ADA because the ADA does not mandate equality between individuals with different disabilities").

¹¹⁰ See *id.* at 1011 n.3.

¹¹¹ See *id.* at 1015.

¹¹² See *Anderson v. Gus Mayer Boston Store*, 924 F. Supp. 763, 781 (E.D. Tex. 1996) (holding that choosing an insurer that would never cover an employee because of his disability denied the employee equal access to insurance, thus discriminating against him).

¹¹³ See Eric Mills Holmes, *Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project*, 85 Ky. L.J. 503, 657-58 (1997) (stating that a

ever, in *Parker* the court rejected this argument. It reasoned first that the enactment of the Mental Health Parity Act of 1996 as an amendment to HIPAA reflected congressional understanding that the ADA did not apply to insurance policies.¹¹⁴ Second, it concluded that the limitation of the Mental Health Parity Act to health insurance (as opposed to disability) policies demonstrated a collective congressional belief that there was not a strong need to provide parity between mental and physical disabilities in this realm of insurance coverage or in the realm of disability insurance coverage.¹¹⁵

Once employees become too disabled to work, many will try to exercise their options under the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA)¹¹⁶ to continue their work-based insurance coverage for the eighteen month maximum period, and then seek coverage under the employer's disability insurance plan. Ultimately, persons with HIV/AIDS and other chronic diseases are likely to seek government assistance through Medicaid, spending themselves into poverty in order to qualify. However, current Medicaid eligibility criteria limit coverage to persons who have full-blown AIDS, excluding persons who are HIV-positive.¹¹⁷ Many AIDS advocates have questioned the wisdom of these criteria arguing that the need for health care services is equally great at the moment of initial HIV diagnosis, because many prophylactic strategies are most successful then, and will thus decrease the costs of AIDS treatment overall.¹¹⁸

CONCLUSION

AIDS has come of age in the 1990s. It has undergone a dramatic metamorphosis from a little understood, often unspeakable, and rare disease, affecting a relatively small number of people who were already socially stigmatized. AIDS is now a mainstream disease, affecting people across the nation, from all segments of society,

"goal of the Act is to improve portability and continuity of an employee's group health insurance coverage under ERISA when an employee . . . with a pre-existing condition changes employers").

¹¹⁴ See *Parker*, 121 F.3d at 1018.

¹¹⁵ See *id.*

¹¹⁶ 29 U.S.C. § 1161 (1994).

¹¹⁷ See Isbell, *supra* note 24, at 32 (noting that most HIV-infected adults obtain Medicaid through supplemental security income, requiring a physician's diagnosis of full-blown AIDS to meet disability regulations).

¹¹⁸ See *id.* at 33 (discussing a study estimating that 60% of people infected with HIV could benefit from early intervention).

even as its sufferers are primarily the poor and persons of color, who are most likely to have difficulty in gaining access to quality health care.

Because of the recent dramatic advances in the clinical treatment of AIDS, and the potential of forestalling many cases from advancing from HIV to AIDS, people with AIDS are now living with a chronic disease. AIDS, like all chronic diseases, needs medical management that is continuing, aggressive, expensive, and complex. The problems faced by persons with HIV and AIDS are the same as those confronted by other Americans with chronic diseases, despite the media attention that AIDS has received which has often made AIDS appear *sui generis*, a disease unto itself. As we near the close of the twentieth century, it is worth reflecting on the lessons we have learned from the AIDS epidemic, to consider how we might transform the American health care system to serve the needs of all its citizens—the healthy, the chronically ill, and the acutely ill and injured.