

THE AGING OF THE AIDS EPIDEMIC: EMERGING LEGAL AND PUBLIC HEALTH ISSUES FOR ELDERLY PERSONS LIVING WITH HIV/AIDS

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As the elderly population continues to grow, so does a subgroup of that population—elderly persons living with HIV infection and AIDS. In her article, Professor Waysdorf, a nationally recognized AIDS law expert who has taught, published, and practiced in this area for over a decade, introduces statistics and studies that show just how quickly the HIV/AIDS-infected elderly population is growing. She analyzes which groups within the elderly population are hit hardest by this epidemic, paying particular attention to women and minority groups. The article also considers how much larger these subgroups will become in the following years. Professor Waysdorf then examines existing and proposed legislation that may help this population address the health and legal concerns it faces every day. She recommends additional measures that governmental, medical, professional, and social service agencies can take to further address the needs of the HIV/AIDS infected elderly population. Professor Waysdorf concludes that while some legal safeguards do exist, much more is needed to protect these individuals.

Professor Susan L. Waysdorf, University of the District of Columbia, David A. Clarke School of Law, received an A.B. from the University of Chicago and a J.D. from the University of Maryland. This article is dedicated to her father, Martin Waysdorf, a courageous Jewish Holocaust survivor. Like many elderly in this country, he died from undiagnosed illness, perhaps AIDS disease contracted from a tainted blood transfusion that he received during surgery in the early 1980's. She also dedicates this work to all the elderly who live with the daily challenge of an inadequate and insensitive health care system.

I. Introduction

As the AIDS epidemic has aged, so have the people it infects and affects. Striking first one population and then another, AIDS has targeted a range of vulnerable populations over the last two decades. What was once a predominately gay male disease has become an epidemic increasingly and disproportionately affecting people of color, particularly African Americans,¹ and also women, children, and their families. A great majority of those affected by the disease live in poverty and without access to adequate and affordable health care and other resources.²

While the world's attention has necessarily shifted to the global AIDS pandemic, which is devastating entire populations in sub-Saharan Africa and also parts of Asia, HIV/AIDS continues to quietly target groups in this country which remain virtually defenseless against the disease. In the United States, elderly people of all races are experiencing a proportionately greater rate of new AIDS cases than any other age groups.³ Little attention has been given to the epidemic's impact on the older adult, or geriatric population.⁴ This article seeks to drive a wedge through this wall of silence by addressing the public health, psycho-social, legislative, and legal issues associated with HIV/AIDS in aging populations.

For the first decade of the AIDS epidemic, the proportion of new AIDS cases in persons fifty years of age and older was reported as ap-

1. Sheryl Gay Stolberg, *Epidemic of Silence: A Special Report; Eyes Shut, Black America Being Ravaged by AIDS*, N.Y. TIMES, June 29, 1998 at A1 (reporting on the 12th World AIDS Conference in Geneva, Switzerland: "Black African-Americans are only 13 percent of the U.S. population. But they account for about 57% of all new infections with [HIV] . . .").

2. See generally Susan L. Waysdorf, *Families in the AIDS Crisis: Access, Equality, Empowerment, and the Role of Kinship Caregivers*, 3 TEX. J. WOMEN & L. 145 (1994) [hereinafter *Families in Crisis*].

3. Richard A. Kaye & Theodore Markus, *AIDS Teaching Should Not Be Limited to the Young*, USA TODAY (MAGAZINE), Sept. 1, 1997, available at 1997 WL 9308462.

4. For statistical and most reporting purposes, the Centers for Disease Control and Prevention defines the elderly or geriatric population as persons greater than or equal to fifty years of age. However, the U.S. Department of Health and Human Services refers to the group that has traditionally been defined as elderly in the United States as consisting of persons greater than or equal to sixty-five years of age. NAT'L CTR. FOR HEALTH STATISTICS, U.S. DEP'T OF HEALTH & HUMAN SERVS., HEALTH UNITED STATES 1999, WITH HEALTH AND AGING CHARTBOOK 17 (1999) [hereinafter CHARTBOOK]. "The definition of old age is social as well as biological. . . . Within the population 65 years of age and over, there is much variation in health and levels of activity." *Id.* In this article, unless otherwise noted, the term "elderly" will refer to those who are fifty years of age or older.

proximately ten percent on average of all new AIDS cases reported annually.⁵ However, that rate steadily increased during the 1990s. Some experts have reported that as of March 1990, AIDS cases in the age group of persons over fifty years of age already represented 12.5% of the total number of cases in the United States.⁶ The federal government reported that from 1991 through at least 1996, on average, eleven percent of persons with AIDS over the age of thirteen were fifty years of age or older.⁷ Other reports indicate that by 1998, elderly persons comprised 12.7% of all new AIDS cases, and that by 1999 that rate had increased to 13.4%.⁸

However, even these numbers do not tell the entire story because they represent cases of AIDS disease, rather than incidence of HIV infection, which is the precondition to symptomatic AIDS illness. Seniors are less likely than others to get tested for HIV. Therefore, the problem of HIV and AIDS in the elderly actually may be much larger than the raw data on AIDS cases suggests.⁹ Furthermore, between 1991 and 1996 there was a twenty-two percent rise in new AIDS cases in Americans over age fifty.¹⁰ This was actually a greater proportionate increase than the increase among persons aged thirteen to twenty-nine years.¹¹ The greatest rise in geriatric AIDS cases has been among

5. Jonathan A. Ship et al., *Epidemiology of Acquired Immune Deficiency Syndrome in Persons Aged 50 Years or Older*, 4 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 1, 85 (1991) [hereinafter *AIDS in Persons Aged 50*]; see also Michelle Nicolosi, *Never Too Old*, WASH. POST, July 17, 2001, available at 2001 WL 23181158 [hereinafter *Never Too Old*].

6. Santiago Ferro & Irving E. Salit, *HIV Infection in Patients Over 55 Years of Ages*, 5 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 348, 348 (1992) [hereinafter *HIV Infection*].

7. CTRS. FOR DISEASE CONTROL, MORBIDITY AND MORTALITY WEEKLY REPORT: AIDS AMONG PERSONS AGED > 50 YEARS-UNITED STATES, 1991-1996, (1998), available at <http://www.ama-assn.org/special/std/newsline/special/mm4702.htm> (last visited May 1, 2002) [hereinafter *MMWR*]. In 1996, of 68,473 persons aged thirteen years or older reported with AIDS, 7,459 (eleven percent) were aged greater than or equal to fifty years; this proportion has remained stable since 1991. Of those aged fifty years or older, forty-eight percent were aged fifty to fifty-four years, twenty-six percent were aged fifty-five to fifty-nine years, fourteen percent were aged sixty to sixty-four years, and twelve percent were aged (greater than or equal to) sixty-five years.

8. *Never Too Old*, *supra* note 5.

9. *Id.*

10. There was a twenty-two percent increase, from 5,260 cases to 6,400 cases, between 1991 and 1996, for persons greater than or equal to fifty years of age. *MMWR*, *supra* note 7; see also DALLAS MORNING NEWS, Feb. 9, 1998, Editorial.

11. There was a nine percent increase, from 46,000 cases to 50,300 cases among persons aged thirteen to forty-nine years of age, between 1991 and 1996. *MMWR*, *supra* note 7.

elderly women,¹² and among elderly persons of color, particularly African Americans.¹³

Although the phenomenon of geriatric AIDS was first noted by medical researchers over fifteen years ago, those responsible for the well-being of elderly persons—doctors, social workers, and public health and other governmental agencies—have only just begun to recognize the impact of the disease on our nation's senior citizens.¹⁴ This societal neglect has occurred despite the fact that incidence of HIV infection among the elderly has continued to increase at a steady and alarming pace.¹⁵ The reality of geriatric HIV/AIDS raises new social, psycho-social, economic, medical, and legal issues for both those who are infected and family members who are affected.

With the epidemic's successive attack on each population, new legal issues and public policy issues have emerged. As a result, AIDS law as a body of legal theory and practice has evolved with the expression of each affected population's legal needs. With the increased prevalence of AIDS among the elderly, once again the legal landscape of AIDS law is changing. The legal realities faced by the HIV-infected elderly population, as they face new legal challenges, barriers, and problems, have expanded the parameters of AIDS, health, and elder law.¹⁶

12. *Geriatrics AIDS Increasing Among Elderly, Particularly Women*, AIDS WEEKLY PLUS, Jan. 19, 1998, available at 1998 WL 8145541, at *1 (reporting that "about 2,500 women sixty and older have been diagnosed with AIDS in the United States, according to the Centers for Disease Control," while many more likely go undiagnosed).

13. Diane R. Brown & Andrea Sankar, *HIV/AIDS and Aging Minority Populations*, RESEARCH ON AGING, Nov. 1998, at 865.

14. The only formal report and study on geriatric AIDS by the federal agency responsible for disease monitoring and control, the Centers for Disease Control, was issued over four years ago, in January 1998. However, at the time of the writing of this article, several state health agencies (for example, Florida's Broward County and the District of Columbia), two federal agencies (the National Institute on Aging (NIA) and National Institute of Mental Health (NIMH)), several private non-profit organizations (for instance, the National Association of HIV Over Fifty, and the American Association of Retired Persons), and a handful of medical research institutes (for example, the University of California at San Francisco and the University of North Carolina) have addressed the issue, or have launched educational programs or research initiatives to study the problem of geriatric AIDS. See *Never Too Old*, supra note 5, at *1 ("And, while the government spends relatively little studying seniors with HIV, funding for such research is increasing this year: NIH and National Institute of Mental Health are jointly allotting a total of up to \$1.5 million for the first national initiative to look specifically at HIV prevention and intervention in seniors . . ."). *Id.*

15. *Id.*

16. See *id.*

This article discusses the social impact, public policy challenges, and legal issues presented by the graying of the AIDS epidemic. Part II of this article opens with an analysis of the demographic and social factors that have led to increased rates of HIV/AIDS cases among America's elderly. This section includes discussion of the impact of race, gender, and socioeconomic status on disease diagnosis, treatment, and progression, as well as the modes of transmission among the elderly. In addition, this section of the article explores various public-health initiatives, including prevention and educational programs which must be developed and undertaken now in order to curtail the spread of AIDS within this particularly vulnerable, fragile, and always growing segment of the population. The specific medical, psychological, and social needs of elderly afflicted with HIV/AIDS and the particular ways in which the disease affects older persons in our society, as well as related public policy issues are also addressed in this section.

Part III of this article outlines the legal challenges and problems facing elderly people living with HIV/AIDS. Litigation and other advocacy approaches to meeting these legal needs are explored. In addition, recent legislative proposals to reform geriatric health care, particularly Medicare, the nation's largest health insurance program for senior citizens, are discussed. During the last several years, national health care reform, the global AIDS pandemic, biotechnology growth and regulation, and the reform and survival of Medicare have become some of the most hotly debated issues in Congress, among public policy advocates, and within the body politic. For example, in the first session of the 107th Congress, dozens of bills have been introduced which are aimed at fixing the nation's health care system, providing health care for the poor and elderly, reforming Medicare, expanding or shrinking Medicaid, and responding to the global AIDS pandemic.

Although many significant health care reform bills have been proposed in Congress, this article's discussion of legislative reform focuses on two particular bills—the Medicare Wellness Act of 2001 and the Medicare Chronic Care Improvement Act of 2001.¹⁷ These two

17. See Medicare Wellness Act of 2001, S. 982, 107th Cong. (2001) (sponsored by Sen. Bob Graham); H.R. 2058, 107th Cong. (2001) (companion bill sponsored by Rep. Sander Levin, both introduced on June 5, 2001); Medicare Chronic Care Improvement Act of 2001, S. 1589, 107th Cong. (2001) (sponsored by Sen. John D. Rockefeller, IV); H.R. 3188, 107th Cong. (2001) (companion bill sponsored by Rep. Pete Fortney Stark, both introduced on Oct. 30, 2001). The Medicare Wellness Act

proposed laws are representative of the numerous Medicare and health care reform bills that have been introduced in the 107th Congress.¹⁸ The paradigm framework these two bills offer makes them particularly useful in analyzing the current Medicare reform process and in shedding light on the legislative and political process that is now ensuing in Congress. What is certain is that the final disposition of the bills will affect geriatric health care in this country for many years to come, including those elderly who are HIV-positive.

The reality that the percent of elders infected with HIV/AIDS is growing presents issues for those both inside and outside of the legal community. It presents significant challenges not only to attorneys, but also to legislators, public and health policy advocates, and to society as a whole. The post-war World War II "baby boom" generation is now entering middle-age. In the early part of the new millennium, this group will swell the ranks of the older population.¹⁹ Many "baby

of 2001 is a bill "[t]o promote primary and secondary health promotion and disease prevention services and activities among the elderly, to amend Title XVIII [(42 U.S.C. § 1395 et seq.)] of the Social Security Act [(Medicare)] by adding preventive health benefits coverage for a variety of purposes, conditions common to the aging process and diseases." S. 982. The Medicare Chronic Care Improvement Act of 2001 is a bill "[t]o amend Title XVIII of the Social Security Act to expand Medicare benefits to prevent, delay, and minimize the progression of chronic conditions, establish payment incentives for furnishing quality services to people with serious and disabling chronic conditions, and develop national policies on effective chronic condition care, and for other purposes." S. 1589. The two proposed acts are very similar in content and intent, and are cosponsored by many of the same members of Congress. Note, however, that they are among dozens of other similar Medicare and health care reform bills that have been introduced into Congress during the 107th session.

18. See, e.g., Medicare Reform Act of 2001, S. 1135, 107th Cong. (2001) (sponsored by Sen. Bob Graham and introduced on June 28, 2001). The Medicare Reform Act of 2001 is an even broader and more comprehensive reform package than either the Medicare Wellness Act of 2001 (also introduced by Sen. Graham, three weeks earlier), or the Medicare Chronic Care Improvement Act of 2001. To date, there is no companion bill in the House of Representatives to S. 1135. The Medicare Reform Act of 2001 would amend the Medicare program in many of the same ways that the Medicare Wellness Act of 2001 and the Medicare Chronic Care Improvement Act of 2001 would. However, the Medicare Reform Act of 2001 would do much more; it also includes a provision for coverage of outpatient prescription drugs, as well as other additional reforms. S. 1135 § 301. *For the sake of clarity and brevity in this article, discussion is focused on the Medicare Wellness Act of 2001 and the Medicare Chronic Care Improvement Act of 2001. However, much of this author's support for and criticism of those two bills could be said as well for the Medicare Reform Act of 2001, as well as for a number of other Medicare reform proposals that have been introduced into the 107th Congress. This article is not intended to be an exhaustive and comprehensive discussion of all relevant health care reform legislation introduced in the 107th Congress.*

19. As of 1997, approximately thirteen out of every 100 Americans were sixty-five years of age and over. CHARTBOOK *supra* note 4, at 17. It is estimated that in

boomers” entering the elder population will bring the HIV disease with them, having lived with it for years, as a chronic rather than an imminently terminal disease. How the baby boom generation deals with the threat and the impact of HIV infection in today’s elderly population tests society’s obligation to the courageous seniors who are confronting not only the challenges of aging, but also the stigma and ravages of the epidemic.²⁰

Elderly persons have the right, and should have the opportunities, to remain productive, secure, and in good health. Aging is a multidimensional process that is not only informed by biological aging, but also by changes in needs and wants, family roles, productivity, image, and in some cultures, by changes in respect, wisdom, and sagacity based on experience.²¹ Aging is also a process of transitions, and health is perhaps the most significant transition issue for older persons. This transition process often is severely compromised by catastrophic, terminal, and chronic disease, disability, loss of mental functioning, as well as by poverty, social isolation, and lack of health care.²²

Realistically, AIDS is not the most widespread disease among the elderly, nor the greatest cause of death or disability in this age group. Nonetheless, AIDS among younger populations has served to spotlight and to bring together some of the most compelling and troubling social issues of our time; and the same is true for elderly persons living with the disease. AIDS in this country has merged a health crisis with a rights struggle in an unprecedented way; now this development is unfolding in the fight against global AIDS. As the demographics of the disease have changed, HIV/AIDS has become increasingly intertwined with already existing social problems such as poverty, drug abuse, racism, and inadequate health care. This is in

2030, twenty out of 100 persons will be sixty-five years of age and over and two out of 100 persons will be eighty-five years of age and older. *Id.*

20. Joni Lavick, *Older Americans—An Overlooked HIV Population*, L.A. TIMES, May 25, 1998, at S8. “In addition to the isolation faced by seniors with AIDS, there are other challenges unique to this age group Older adults carry our history, and our society is judged by how we treat our elders.” *Id.*

21. UNITED NATIONS SECOND WORLD ASSEMBLY ON AGING, ELEMENTS FOR A REVISED STRATEGY AND WORLD PLAN OF ACTION FOR AGING 7 (2001), available at <http://www.aarp.org/intl/elements.pdf> [hereinafter WORLD PLAN FOR AGING]. NGO’s involved in preparation of this document included, HelpAge International, International Federation on Aging, FIAPA, the International Association of Gerontology, and the American Association of Retired Persons (AARP).

22. *Id.* at 8.

part due to the stigma AIDS carries, and in part due to the impact that socioeconomic, racial, and gender inequities and biases have had on the disease's disproportionate targeting of specially vulnerable populations.

As a result, AIDS has had a way of making its affected populations invisible and at the same time, stigmatized. This is particularly true for elderly persons with HIV/AIDS. At times other diseases and disabilities have resulted in similar treatment of particular age groups and populations. For example, in the not-too-distant past, Alzheimer's disease was a taboo subject. As with geriatric AIDS, little was known medically or scientifically about Alzheimer's.²³ Scant attention and relatively limited support was given to patients and their families.²⁴ As advocates for Alzheimer's patients began to organize and educate, public sentiment, medical knowledge of, and interest in the disease began to change.²⁵

One goal of a humane and benevolent society should be to ensure that all older persons achieve and maintain the optimum health and well-being possible, and attainable with the full support of their families and communities.²⁶ The segment of the aged population affected and infected by HIV/AIDS must not be left out and forgotten, nor be denied the right to age with dignity, respect, and the highest quality of care. Despite recent important legislative proposals promoting health care reform, geriatric AIDS continues to be an invisible problem, lacking needed recognition. This article is intended to contribute to the process of raising the public and the legal community's awareness of AIDS among the elderly and to encourage advocacy and compassionate care for all our elders, including those with HIV/AIDS.

II. The Demographics of AIDS Among the Elderly

In analyzing the demographic and other social factors that affect elderly persons with AIDS, an understanding is gained about the impact of the disease on all ethnic groups and genders. National surveillance reports indicate that AIDS hits elderly minorities and elderly

23. See Marilyn N. Larkin, *Robert Butler: Championing a Healthy View of Ageing*, LANCET, Jan. 6, 2001, at 48.

24. *Id.*

25. *Id.*

26. See WORLD PLAN FOR AGING, *supra* note 21, at 8.

women hardest.²⁷ Although the number of AIDS cases in adults fifty years and older remains highest among men, at eighty-four percent of all cases reported, compared to women, at sixteen percent, the *rates of new cases* is higher among women in this age group.²⁸

In fact, medical experts have recently reported that the growing numbers of HIV/AIDS among women fifty years and older constitute a major public health concern.²⁹ Support is growing among medical and social service providers for the position that middle-aged and elderly women with HIV/AIDS are a hidden population that needs early identification and access to care for their illness.³⁰

The Centers for Disease Control and Prevention has reported that between 1991 and 1996, cases attributed to heterosexual contact and intravenous drug use (IDU) for women aged fifty years and older “increased 106% (from 340 cases to 700 cases) and 75% (from 160 cases to 280 cases), respectively.”³¹ For men aged fifty years and older during the same period, cases attributed to “heterosexual contact increased 94% (from 360 cases to 700 cases) [and] cases due to IDU increased 53% (from 850 cases to 1300 cases).”³² At the same time, “among male recipients of contaminated blood or blood products, incident cases of AIDS decreased 48% (from 250 cases to 130 cases), [while cases among women] recipients of contaminated blood or blood products decreased only 33% (from 120 cases to 80 cases).”³³

Older women are becoming infected at increasingly higher rates than older men, and they are particularly vulnerable to transmission through risk behavior, specifically, unprotected sexual contact.³⁴ Factors that contribute to this trend include the fact that post-menopausal women are no longer afraid of becoming pregnant and have abandoned the use of condoms and other contraceptive devices.³⁵ While older women, including many widows, are becoming more sexually

27. See Brown & Sankar, *supra* note 13, at 865.

28. MMWR, *supra* note 7, at 3.

29. Farzaneh Tabnak & Richard Sun, *Need for HIV/AIDS Early Identification and Preventive Measures Among Middle-Aged and Elderly Women*, AM. J. PUB. HEALTH, Feb 1, 2000, at 287. The authors argue for the importance of health care providers directing their attention to the changing profile of middle-aged and elderly women with HIV/AIDS. *Id.*

30. *Id.*

31. See MMWR, *supra* note 7, at 3–4.

32. *Id.* at 3.

33. *Id.* at 4.

34. See *id.* at 5–6.

35. See *id.* at 6.

active with more partners, particularly in many retirement communities, they are unlikely to be informed of the dangers of HIV transmission.³⁶ Perhaps ironically, this risk factor for older women increases in proportion to the increased use of Viagra among older men, producing an unexpected consequence of the widely used and touted drug.³⁷

By race and ethnicity, AIDS is increasing faster among minorities and minority women. For men aged fifty and older, more than fifty percent of all AIDS cases occurred among minority men, including African Americans, American Indians, and Asian Americans.³⁸ Similarly, for all AIDS cases reported for women, aged fifty and older, more than two-thirds, or sixty-eight percent, were among minority women of these races.³⁹ The breakdown among the minority races for men and for women, are detailed below.

In 1996, the latest year for which the Centers for Disease Control and Prevention released data on geriatric AIDS, older African American men and women accounted for the highest proportion of AIDS cases, at 43% of all cases among the elderly.⁴⁰ Among men age fifty and older, African Americans constituted 30.8% of AIDS cases, followed by 15.1% for Hispanic men, and less than 1% each for Asian American and American Indian men.⁴¹ The figures are even more striking for women. At 48.2%, African American women represented nearly half of all AIDS cases among women fifty years of age and older.⁴² Hispanic women accounted for 18.6%, and American Indian and Asian American older women together accounted for 1.4% of all AIDS cases among older women.⁴³

As noted earlier, these data do not tell the entire story because statistics on the prevalence and incidence of HIV infection, as opposed to AIDS disease, are not uniformly reported across the states. In addition, because elderly persons do not fit the expected risk categories,

36. See Laura Engle, *Old AIDS*, BODY POSITIVE, Jan. 1998, available at http://www.thebody.com/bp/jan98/old_aids.html (last visited May 1, 2002).

37. For a detailed discussion of the drug Viagra, see David F. Chavkin, *Medicaid and Viagra: Restoring Potency to an Old Program?*, 11 HEALTH MATRIX 189 (2001). For an interesting commentary on the relationship between Viagra use and accompanying health risks to seniors, see Christopher A. Julka, *A New Sexual Revolution: Viagra as Pandora's Box for the Elderly*, 7 ELDER L.J. 409 (1999).

38. Brown & Sankar, *supra* note 13, at 865.

39. *Id.*

40. MMWR, *supra* note 7, at 2.

41. Brown & Sankar, *supra* note 13, at 865.

42. MMWR, *supra* note 7, at 6; see also Brown & Sankar, *supra* note 13, at 865.

43. Brown & Sankar, *supra* note 13, at 865.

and because their physicians are not attuned to the possibility of risky sexual or drug use behaviors, older persons are not as likely as younger persons to be tested for HIV infection.⁴⁴

Reported rates of HIV infection do indicate that the racial and gender disparities occur at even starker and disproportionate rates than AIDS disease.⁴⁵ National surveillance reports indicate that minorities comprised more than half of all reported new cases of HIV infection among persons fifty years of age and older.⁴⁶ African American men comprised nearly half of these HIV cases at 49.8%, while 4.1% were Hispanic men.⁴⁷

The reported HIV infection data for older women also showed starker disparities between the genders and races, clearly reflecting the major impact of HIV infection on women of color. Among women aged fifty years or older, minorities represented more than two-thirds of new cases of HIV infection.⁴⁸ Older African American women constituted 62.9% of all new cases of HIV infection among older women, while older Hispanic women comprised 6.6% of the total.⁴⁹

The progression of the disease and the mortality rate from AIDS also varies by racial and gender demographics, as well as socioeconomic status.⁵⁰ Social biases, access to medical care, risk and other behavioral factors which cause HIV infection and AIDS to occur at disproportionate rates among particularly vulnerable populations, like the elderly, women, and minorities are discussed in greater detail in the following sections.

A. Misdiagnosis and the Deadly Progression of HIV-Disease Among the Elderly

Older persons with HIV and AIDS are routinely misdiagnosed, or never diagnosed as having AIDS, and they are rarely tested for HIV infection.⁵¹ Misdiagnosis by physicians of elderly persons suffering from AIDS occurs at significantly higher rates than among younger

44. *Id.*

45. *See id.*

46. *Id.*

47. *Id.*

48. *Id.*

49. *Id.*

50. Robert S. Hogg, *Epidemiology: Lower Economic Status Tied to Shorter Survival Time in AIDS*, AIDS WEEKLY, Nov. 14, 1994, available at 1994 WL 2795446.

51. *Epidemiology: U.S. Sees AIDS Rise in Older Americans*, AIDS WEEKLY, Feb. 9, 1998, available at 1998 WL 8145656.

persons who have HIV-related symptoms, due to perceptions that the elderly are not at risk.⁵² The result is that a significantly higher proportion of elderly persons who have exhibited an AIDS opportunistic infection have died within one month of their AIDS diagnosis, than younger persons with the same illness.⁵³

In general, older HIV-infected patients have a shorter observed AIDS-free, or asymptomatic interval, and a shorter survival period after diagnosis than younger HIV-infected patients.⁵⁴ HIV illness progresses significantly faster and has a more devastating impact on persons over fifty years old than for persons under the age of fifty.⁵⁵ AIDS is not an isolated event that occurs in a single moment of time in a person's body.⁵⁶ Rather, with the use of multidrug therapy that prolongs life and delays end-stage AIDS, it increasingly is a protracted and chronic disease that coincides with major portions of the infected person's life cycles.⁵⁷

Therefore, for all infected persons, no matter their age, the human immunodeficiency virus (HIV) that causes AIDS grows stronger and progresses as the infected person grows older. Those infected with HIV who are in their fifties may pass sixty before being diagnosed with AIDS; those infected in their sixties may reach seventy or even older before manifestations of the disease are apparent.⁵⁸ This is particularly true now, given the effectiveness of multidrug therapy, or

52. Paul D. Zelenetz & Marcia E. Epstein, *HIV in the Elderly*, AIDS PATIENT CARE & STDs., Apr. 1998, at 255-62.

53. *Id.*

54. See MMWR, *supra* note 7, at 5.

55. See generally CHARTBOOK, *supra* note 4, at 155-56. Note that categories for the coding and classification of human immunodeficiency virus infection were introduced in the United States beginning with mortality data for 1997. *Id.* In 1997, 4,578 AIDS deaths in persons aged forty-five to sixty-four years were reported. *Id.* Death caused by HIV infection and AIDS was the tenth leading cause of death, for persons aged forty-five to sixty-four years. *Id.* For the year 1997, other leading causes of death for persons aged forty-five to sixty-four years, in order of prevalence were: malignant neoplasms, diseases of heart, unintentional injuries, cerebrovascular diseases, chronic obstructive pulmonary diseases, diabetes mellitus, chronic liver disease and cirrhosis, suicide, pneumonia and influenza, and finally HIV infection. *Id.*

56. *Elders and AIDS: An Emerging Challenge for LTC Providers?*, BROWN U. LONG-TERM QUALITY ADVISOR, Sept. 8, 1997, available at 1997 WL 9884385 [hereinafter *Elders and AIDS*].

57. *Id.*

58. *Id.*

protease inhibitors, in combating the immediate effects of AIDS and in prolonging the lives of those infected with the HIV virus.⁵⁹

Because immune function declines with advancing age, elderly people are more vulnerable to HIV infection and its opportunistic infections than people of a younger age.⁶⁰ In general, age is an important factor in the progression of HIV infections.⁶¹ Medical studies show that the epidemiological and clinical characteristics of HIV infection in older patients differ significantly from those described for younger patients.⁶² Yet much remains unknown about the progression of the disease in the elderly. The body of medical science and knowledge concerning geriatric AIDS is very thin relative to what is understood about the disease's impact on younger persons. Until older persons with AIDS are diagnosed and treated earlier in the disease and until prospective studies are conducted on this vulnerable population, scientific knowledge and medical research will remain undeveloped and will continue to be almost entirely reactive and empirical in nature.

Due to natural age-related declines in the immune system, as noted above, the elderly are more vulnerable to infections once exposed to them, and certainly once a disease process has begun.⁶³ Moreover, mental and emotional stress have a significant impact on the immune systems of even physically healthy elderly.⁶⁴ "This recognized relationship between mental and physical health underscores

59. See William H. Adler et al., *HIV Infection and Aging: Mechanisms to Explain the Accelerated Rate of Progression in the Older Patient*, 96 MECHANISMS OF AGING & DEV. 137, 144 (1997). The Johns Hopkins School of Medicine, Gerontology Research Center reported that it is now understood that "in untreated adults the average time from HIV infection to the development of AIDS is about 10 years." *Id.*

60. A. Phillips et al., *More Rapid Progression to AIDS in Older HIV-Infected People: The Role of CD4+ T-Cells Counts*, 1991 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 970 (concluding that "age is related to the rate of progression of HIV disease and older patients appear to be at higher risk of AIDS than younger patients, even if the CD4+ T-cell counts are the same.").

61. Adler et al., *supra* note 59, at 138.

62. *HIV Infection*, *supra* note 6, at 351. The article notes that older patients (1) more frequently acquired HIV infection via transfusion of blood; (2) were more likely to have AIDS at presentation; (3) progressed to AIDS from infection more rapidly; and (4) had higher mortality rates. *Id.* In general HIV infection has a more rapid and aggressive course in older patients. *Id.*

63. Adler et al., *supra* note 59, at 137-55 (analyzing and investigating the reasons underlying the effect of age on HIV disease progression); see also Anders Blaxhult et al., *The Influence of Age on the Latency Period to AIDS in People Infected by HIV Through Blood Transfusion*, 4 AIDS 125, 125 (1990).

64. *HIV/AIDS and the Elderly*, at <http://iml/.umkc.edu/casww/hiv aids.htm> (last visited Feb. 4, 2002).

the importance of older adults maintaining good mental, as well as physical, health in order to remain resistant to infections such as HIV."⁶⁵ Thus, it is especially critical for an elderly person living with HIV to engage in good health maintenance, in order to delay progression to AIDS disease.⁶⁶

The fact is that older persons are significantly less likely to be promptly or timely tested for HIV infection, even following the onset of HIV-related illnesses and symptoms.⁶⁷ Generally, they are diagnosed with AIDS or HIV infection significantly later during the course of their illness than most younger, HIV-infected persons.⁶⁸

Delayed testing for HIV infection and delayed AIDS diagnosis is a result of a variety of factors. Physicians generally do not consider or suspect HIV infection as a possibility among the elderly. In part this is due to a lack of physician education concerning the disease and of physician ignorance about risk behavior among the elderly.⁶⁹ In addition, physicians may be blindsided because many symptoms of aging, such as weight and memory loss, mimic typical AIDS symptoms. At the same time, elderly persons do not perceive themselves to be at risk for HIV infection. They lack essential education about how the infection is transmitted, how to prevent spread of the infection, and how to distinguish AIDS symptoms from other age-related ailments.⁷⁰

In addition, the image of senior citizens with AIDS shatters cultural norms, leading physicians, nurses, nursing home workers, and others who care for the elderly to be unresponsive to HIV-related symptoms, and thus to delay diagnosis and identification of geriatric AIDS.⁷¹ Because older people are less likely to be correctly diagnosed by medical providers, they commonly suffer the effects of maltreatment, medical negligence, and untimely or lack of treatment for the disease.⁷² Tragically, the failure to diagnose HIV in its early and treatable stages results in missed opportunities for the timely use of prophylaxis for opportunistic infections or for the use of antiretroviral, multidrug therapies to prevent further progression of the disease.⁷³

65. *Id.*

66. *Id.*

67. MMWR, *supra* note 7, at 3-4.

68. *See id.* at 5.

69. Jeffrey T. Lauer, *The Aging Face of AIDS*, 50 JACKSONVILLE MED. 9, 9 (1999).

70. Engle, *supra* note 36, at 3.

71. *See id.*

72. *See id.*

73. MMWR, *supra* note 7, at 5.

Most elderly with AIDS do not learn of their HIV status until they become sick enough to be hospitalized.⁷⁴ By then the time for early intervention is long past, and chances for survival are greatly diminished.⁷⁵ Other elderly persons die of AIDS having never been diagnosed correctly. The true cause of their decline and death will never be understood completely by their families and loved ones. Elderly people who die from undiagnosed AIDS are the truly forgotten and invisible victims of the epidemic.

The fact that AIDS among the elderly is a great imitator of other geriatric conditions and diseases is another cause of delayed diagnosis or misdiagnosis.⁷⁶ The appearance of HIV-related conditions, such as AIDS-related dementia in elderly patients, can be masked by or mistaken for other similar age-related conditions, such as Alzheimer's disease, depression, and neurological malignancies.⁷⁷ The distinction is extremely important because AIDS-related dementia can be treated and reversed while Alzheimer's disease cannot be reversed.⁷⁸

Other HIV symptoms that mimic or resemble symptoms commonly associated with a number of other aging-related illnesses include: fatigue, flu-like symptoms, respiratory problems, weight loss, chronic pain, night sweats, skin rashes, and pneumonia.⁷⁹ Women with HIV/AIDS often have cervical and other gynecological cancers that are a result of the underlying condition.⁸⁰ But often these cancers are not recognized as AIDS related, and are not treated as a part of AIDS-illness.⁸¹ Frequently, these and other symptoms are treated as independent ailments when they appear in the elderly. As a result, "the possibility of HIV as a causal or related factor generally goes unexplored."⁸² Furthermore, because HIV often affects the central nervous system, many people with HIV will also develop some form of

74. *Id.*

75. *Id.*; see also Engle, *supra* note 36, at 3.

76. See MMWR, *supra* note 7, at 5; Engle, *supra* note 36, at 3.

77. *Epidemiology of HIV in Elders Appears to Be Shifting*, BROWN UNIV. LONG-TERM QUALITY LETTER, Feb. 13, 1995, available at 1995 WL 12109729 [hereinafter *Epidemiology of HIV in Elders*].

78. See Engle, *supra* note 36, at 5.

79. *HIV/AIDS and the Elderly*, *supra* note 64.

80. Allyn L. Taylor, *Women's Health at a Crossroad: Global Responses to HIV/AIDS*, 4 HEALTH MATRIX 297, 310 (1994).

81. See *id.*

82. *HIV/AIDS and the Elderly*, *supra* note 64.

neurological symptoms.⁸³ This most commonly occurs in the form of dementia, a condition also historically associated with aging.⁸⁴

Similarly, pneumocystic carinii pneumonia (PCP), which is associated almost exclusively with AIDS, may be mistaken in an elderly person for chronic heart disease or for bronchitis.⁸⁵ Even physicians who specialize in geriatric medicine and who practice in retirement communities often have little or no knowledge of AIDS or infectious disease medicine.⁸⁶ Many of these physicians may routinely mistake HIV symptoms for the inevitable signs of aging.⁸⁷

For example, once heart failure has been diagnosed, physicians may not look for any underlying cause, like HIV.⁸⁸ Congestive heart failure has become a "catch-all" symptom of the aging process, and a generic cause of death written on death certificates in areas highly populated by older and retired persons. Coronary by-pass surgery, a major medical industry in retirement communities such as South Florida, is too often seen as the routine solution to diminished health in the elderly. Yet, many of these costly operations provide minimal or no relief to the patient. Rather, the surgical trauma of by-pass surgery can lead to further decline, a diminished quality of life, and ultimately to overall medical failure.⁸⁹

In fact, in many cases unnecessary, and often extreme, surgeries are substituted for proper treatment of the underlying, yet undiagnosed, disease.⁹⁰ In short, as one noted study of geriatric health care reported, because the elderly routinely "experience chronic and acute age-related diseases to which problems can be attributed," and upon which the geriatric medical industry has come to rely, "HIV and AIDS may be the last disease considered, if considered at all."⁹¹

Whatever the reasons for late or no AIDS diagnosis, and late or no HIV-testing among the elderly, the disease has a more devastating impact on this population than on younger groups. This is in large

83. *Id.*

84. *See id.*

85. *Id.*

86. *See id.*

87. *See id.*

88. Lori D. Talarico, *Uncharted Territory: AIDS in the Older Patient; Diagnosing and Treating Those Over 50*, PATIENT CARE, Nov. 1998, at 84 [hereinafter *Uncharted Territory*].

89. *See HIV Infection, supra* note 6, at 351.

90. *See HIV/AIDS and the Elderly, supra* note 64.

91. *Id.*

part the case because older patients are often farther along in the disease process, or already dying from the disease, when first seen or diagnosed.⁹² Coordination and information between medical specialties is sorely needed, for it is rare to find a doctor who is knowledgeable in both geriatrics and infectious diseases.

The federal Centers for Disease Control and Prevention and other public health agencies should take the lead in educating physicians, nurses, and other health practitioners to the reality of HIV and AIDS for seniors, and the risks that seniors face. More research needs to be undertaken and much still needs to be learned by the medical and scientific communities about the relationship between AIDS as a chronic disease, and the impact of immuno-compromised illness on the normal aging process.⁹³

B. The Impact of Race, Gender, and Poverty on Epidemiological and Mortality Factors

HIV disease epidemiology, progression, and mortality among elderly persons are further exacerbated by the impact of racial and gender differences and related socioeconomic factors. Older persons of color and older women with AIDS die more quickly, and in higher proportional numbers, from the disease than their younger counterparts.⁹⁴ Among men older than fifty-five, more than half of the deaths from AIDS have occurred in minority groups.⁹⁵ Of these, 34.4% of the deaths from AIDS among older men were among African Americans, while 16.4% occurred among Hispanic males.⁹⁶

Even more striking racial disparities exist between older white and older minority women who have died from AIDS. Older minority women had higher rates of mortality than older white women with AIDS, accounting for over seventy percent of the AIDS-related deaths

92. *Uncharted Territory*, *supra* note 88, at 85.

93. *Id.*

If scientists can find the biological link in what turns on the aging process, they may be one step closer to slowing down some of the degenerative processes of AIDS. More research may also help to identify how the natural history of HIV disease differs in older patients and who is most or least likely to benefit from new treatment regimens.

Id.

94. Brown & Sankar, *supra* note 13, at 866.

95. *Id.* at 867.

96. *Id.*

for older women.⁹⁷ National surveillance data indicates that older African American women comprised 52.4% and 56.8% in 1994 and 1995, respectively, of all older women whose deaths were AIDS-related.⁹⁸

The epidemiological, social, and economic reasons for these gender and racial disparities are multiple and interrelated. Factors include the impact of racial and gender discrimination in accessing health care and in securing health insurance, as well as differences in the mode of transmission and risk factors. In addition, the combined impact of poverty, stigma, and isolation of those who live with the disease results in further marginalization of these groups, and the exacerbation of already existing social and economic disparities, including the availability of social support, government benefits, and health care.⁹⁹

Experts have long agreed that race and socioeconomic status affect the health of people of all ages in the United States.¹⁰⁰ Both historically and currently, health status is considerably worse for elderly African Americans than elderly white persons in the United States.¹⁰¹ Studies have established the relationship between poorer health and greater vulnerability to illness and disease, as well as the fact that poverty is directly linked to poorer health.¹⁰² In the United States, where access to health care depends on access to health insurance and employment, the social stresses of lifelong poverty and low income, as well as racial and gender discrimination, further contribute to disease risk and illness.¹⁰³ In the absence of universal health care, which is the system long-adopted by other industrialized and many developing nations, in this country the type of insurance one has, and whether one has health insurance at all, affects access to, and the quality of, health care. These factors are magnified for the elderly, particularly

97. *Id.*

98. *Id.*

99. See generally *Families in Crisis*, *supra* note 2, at 173–75.

100. See Steven P. Wallace et al., *The Consequences of Color-Blind Health Policy for Older Racial and Ethnic Minorities*, 9 STAN. L. & POL'Y REV. 329, 331 (1998); see also CHARTBOOK, *supra* note 4, at 28. See generally M. Gregg Bloche, *Race and Discretion in American Medicine*, 1 YALE J. HEALTH POL'Y L. & ETHICS 95 (2001).

101. Wallace et al., *supra* note 100, at 331. See generally Marian E. Gornick et al., *Understanding Disparities in the Use of Medicare Services*, 1 YALE J. HEALTH POL'Y L. & ETHICS 133 (2001).

102. See generally Susan L. Waysdorf, *Fighting for Their Lives: Women, Poverty and the Historical Role of United States Law in Shaping Access to Women's Health Care*, 84 KY. L.J. 745 (1995–96).

103. See generally *id.*

persons of color, causing them to be more vulnerable to disease and disability, including HIV infection and AIDS.¹⁰⁴

Although poverty rates among the elderly have declined somewhat since the 1960s, in 1997 one out of ten persons sixty-five years of age and over was living in a family with income below the federal poverty threshold.¹⁰⁵ As has been the case historically, in 1997 the poverty rate was higher among elderly African Americans and Hispanics, as compared with older white persons.¹⁰⁶ More older women than men live in poverty, with thirteen percent of women at and over the age of sixty-five living in poverty, and seven percent of men at and over the age of sixty-five living in poverty.¹⁰⁷

In short, poverty is often more severe and has wider implications for elderly persons, particularly minorities. For example, some evidence suggests that elderly minorities have faced discriminatory barriers in accessing nursing homes and assisted-living facilities.¹⁰⁸ This is due at least in part to economic disparities, language and cultural differences, location of facilities, as well as racial bias and discriminatory practices on the part of nursing homes' staff and administrators.¹⁰⁹ Health policy-makers and legislators must respond to the impact of poverty, and to racial and gender disparities among our nation's elders. This can be done at least in part by increasing levels of support available through the Medicare and Medicaid programs, as well as low-income housing programs, and by implementing stricter oversight and regulation of geriatric health and nursing facilities.¹¹⁰

104. Wallace et al., *supra* note 100, at 330–31. “The evidence has consistently shown African-American elderly to be disadvantaged compared to whites in life expectancy, chronic illness rates and levels of disability. Mortality rates in 1990 were higher for African-Americans than whites among all age brackets except the very oldest.” *Id.*

105. CHARTBOOK, *supra* note 4, at 28. “Poverty rates among the elderly have been declining as older persons have benefited from Social Security payments and health insurance through Medicare and Medicaid. In 1959, 35 percent of persons 65 years of age and over lived in poverty compared with nearly 11 percent in 1997.” *Id.*

106. *Id.* at 3, 28. “In 1997 among persons 65 years of age and over, black persons were 2.9 times as likely and Hispanic persons were 2.7 times as likely to live in poverty as white persons.” *Id.* at 28; *see also* Wallace et al., *supra* note 100, at 330; WORLD PLAN FOR AGING, *supra* note 21, at 17.

107. CHARTBOOK, *supra* note 4, at 28. “Part of the sex difference in poverty rates is due to the effects of widowhood. Older women are particularly vulnerable to declines in economic status after the death of their spouse.” *Id.*

108. *See* Heather K. Aeschleman, *The White World of Nursing Homes: The Myriad Barriers to Access Facing Today's Elderly Minorities*, 8 ELDER L.J. 367, 369 (2000).

109. *Id.* at 368–69.

110. *Id.*

C. AIDS Prevention, Isolation and Stigma for the Elderly Living with HIV

HIV prevention is a uniquely difficult challenge among the elderly due to isolation, the stigma attached to the disease, and the fact that until recently very limited government resources have been directed to AIDS prevention, education, and support for the nation's elderly. Few of the nation's AIDS prevention programs target adults over fifty years of age. Many older persons live in assisted-living and retirement communities where the stigma attached to HIV/AIDS—usually associated with homosexuality and illegal, intravenous (IV) drug use—forces the issue of AIDS education and prevention underground. Without increased public health and educational initiatives, management of these geriatric facilities and communities is likely to remain resistant to providing HIV/AIDS educational materials or presentations or to allow open meetings of HIV support groups.¹¹¹

Traditional senior-citizen programs and support groups, aimed at relieving the common problems of isolation, fear, and other aging-related issues, are generally not developed with HIV-positive people in mind. These existing programs might themselves be adversely impacting elderly persons with HIV/AIDS. As with society as a whole, personnel of some geriatric facilities and residences, retirement communities, and nursing homes might engage in stereotypical or biased thinking about persons with HIV/AIDS.¹¹² In addition, many older persons might be less comfortable talking about their sexual activities or drug use to others, including to their physicians. Therefore, cultural, educational, and generational issues need to be far more closely considered in developing and tailoring HIV prevention programs and policies for seniors.¹¹³

Older adults also are likely to have fewer surviving friends and more limited social networks available to provide them with support and care. Many are caregivers themselves, looking after their own adult children or their grandchildren who are ill or orphaned due to

111. Pamela DeCarlo & Nathan Linsk, *What Are HIV Prevention Needs of Adults Over 50?*, UCSF CENTER FOR AIDS PREVENTION STUDIES AIDS RESEARCH INSTIT., U. OF CALIFORNIA-SAN FRANCISCO (1997), at <http://www.caps.ucsf.edu/over50.html> (last visited Apr. 1, 2002).

112. *Id.*; see also Aeschleman, *supra* note 108, at 369.

113. DeCarlo & Linsk, *supra* note 111.

the AIDS epidemic.¹¹⁴ In addition to experiencing the normal aging process, these elderly persons also balance numerous obligations and emotions, and juggle the needs and demands of family members who rely on them. Too often, these elder-led families receive little or no support, recognition, or publicly financed resources.¹¹⁵

Because older persons are vulnerable to other age-related chronic and debilitating diseases and disabilities, AIDS plays a significant role in further diminishing their quality of life. Often this occurs for the HIV-infected elderly person without their having the necessary medical, social service, financial, and other support systems in place to serve their rapidly multiplying needs. Developing comprehensive and supportive intervention plans, including medical and psychological assessments, case management, and linkages to community services for seniors are critically important.

To date, most HIV educational and support resources for the elderly have been very limited or not easily accessible. Existing programs have received meager state or federal funding, and this has had a negative impact on the elderly population.¹¹⁶ Responding to the need for these programs and services, public agencies in the nation's major retirement areas are only now beginning to sponsor critically needed programs for seniors.¹¹⁷

For the large percentage of seniors who live in poverty or survive on fixed incomes, the problem of accessing educational, prevention, and social services, as well as appropriate HIV-medical care is particularly problematic. In addition, given the particular stigma historically associated with HIV/AIDS in minority communities, and the lower use and accessibility of formal social and medical services, there

114. See *Families in Crisis*, *supra* note 2, at 188–207; see also Engle, *supra* note 36 at 3.

115. See generally *Families in Crisis*, *supra* note 2 (discussing the difficulty of kinship caregiving for families with AIDS).

116. See Kaye & Markus, *supra* note 3.

117. Sue Sanders, Editorial, *Passion Among Older Folks Has Drawback*, FT. LAUDERDALE SUN-SENTINEL, Oct. 30, 1997, at 18A (noting programs in South Florida sponsored by the Florida Department of Elder Affairs and the Broward County Health Department, where there are more senior citizens with AIDS than anywhere else in the nation). Other elder AIDS prevention programs exist in New York, California, Illinois and Arizona. See VANDERBILT MED. CTR., HIV/AIDS IN THE ELDERLY: NATIONAL ORGANIZATIONS (2002), available at <http://www.mc.vanderbilt.edu/adl/pathfinders/elderly/national.html> (last visited May 1, 2002).

exist additional barriers to overall services for older minority persons infected and affected by the disease.¹¹⁸

In addition, some geriatric health care facilities and residences, most notably nursing homes, may deny access and services to HIV-infected seniors due to AIDS discrimination. Elderly minorities with HIV/AIDS face multiple biases, as described earlier in this article. Empirical evidence strongly suggests that nursing facilities rationalize that they are not equipped to deal with the disease, even when HIV-positive seniors and others affected by this stigma have appropriate health care coverage.¹¹⁹ This will continue to be a legal and civil rights problem, as increasing numbers of elderly persons become residents in nursing homes and seek access to long-term nursing care.¹²⁰ Such discriminatory policies and practice, coupled with the stigma associated with AIDS, have not been effectively monitored or targeted.

Most HIV-infected persons experience the impact of AIDS-related stigma. This stigma is characterized by a level of discrimination and prejudice that is deeper than that experienced by persons with other types of illnesses and disabilities. Seniors with HIV, many of whom already live in isolation, with little or no contact with their families and former communities due to the aging migration process, experience a heightened form of AIDS stigma.¹²¹ AIDS, fear of AIDS, and the stigma which usually accompanies the disease can bring a shattering silence and debilitating isolation to the older person who learns she is HIV-infected.

Older persons with HIV infection actually suffer from a double stigma, a punitive bias for living with the disease, and the marginalizing stigma of being older and of appearing to be dispensable in our society.¹²² Fear of disclosure, embarrassment, and economic instability

118. Cynthia Cannon Poindexter & Nathan L. Linsk, *HIV-Related Stigma in a Sample of HIV-Affected Older Female African American Caregivers*, 44 SOC. WORK 46, 56 (1999); see also Brown & Sankar, *supra* note 13, at 877.

119. Michael T. Isbell, *AIDS and Access to Care: Lessons for Health Care Reformers*, 3 CORNELL J. L. & PUB. POL'Y 7, 44-45 (1993). See generally *Uncharted Territory*, *supra* note 88.

120. See CELIA S. GABREL, NAT'L CTR. FOR HEALTH STATISTICS, CTRS. FOR DISEASE CONTROL, CHARACTERISTICS OF ELDERLY NURSING HOME CURRENT RESIDENTS AND DISCHARGES: DATA FROM THE 1997 NATIONAL NURSING HOME SURVEY (2000), available at <http://www.cdc.gov/nchs/data/ad/ad312.pdf> (last visited May 1, 2002). In 1997, an estimated 1.5 million persons over sixty-five years of age lived in the nation's nursing homes. *Id.*

121. Poindexter & Linsk, *supra* note 118, at 48-49.

122. Steve Sternberg, *Age Isn't a Vaccine Against HIV*, USA TODAY, Oct. 16, 2000, at 1, available at 2000 WL 5792665.

can further traumatize an older person infected with HIV.¹²³ Also, AIDS-related isolation, stigma, and fear help to further undermine the health of the elderly person living with HIV infection or AIDS; it can also lead to the loss of social and familial support.¹²⁴

In addition, HIV-infected elderly persons may face particular stigmatization among their own peers because of the lack of information about the disease and its relatively recent appearance in senior communities.¹²⁵ As forceful as external AIDS stigma is, there is also evidence of damaging internalized stigma among people with HIV, as well as their caregivers.¹²⁶ This may cause the elder person to anticipate and expect discrimination and ostracism if they disclose the presence of HIV, or suspicion of HIV, including to their physician.¹²⁷ Accordingly, without social awareness, respect, and tolerance, as well as widespread education about the disease, an AIDS diagnosis will further isolate the infected senior from his or her community, family, and health care providers.

D. Transmission of HIV Among Elderly Persons

The demographic changes in the AIDS epidemic reflect the changes in prevalence of the infection's transmission modes.¹²⁸ Risk factors for elderly persons have included unprotected homosexual sexual activity, shared use of tainted needles by intravenous drug users, blood transfusions, and unprotected heterosexual sexual activity.¹²⁹ This last factor is the mode that is increasingly responsible for the greatest number of transmissions among elderly persons today.¹³⁰

Senior citizens should be considered at risk for HIV infection and AIDS because they have been or are sexually active, may be or may have been intravenous drug users, may have received blood transfusions, or may already have a compromised immune system due to other age and health-related conditions. While our society tends to assume that the elderly are without risk for HIV infection,

123. Poindexter & Linsk, *supra* note 118, at 46.

124. *Id.* at 48.

125. *See id.* at 47.

126. *See id.* at 46.

127. *Id.*

128. Charles A. Emlet & Kathleen J. Farkas, *A Description Analysis of Older Adults with HIV/AIDS in California*, HEALTH & SOC. WORK, Nov. 2001, at 226.

129. *Id.*

130. Poindexter & Linsk, *supra* note 118, at 46.

they are actually subject to the same risk factors as the rest of the population. Furthermore, seniors are subject to increased risk because of the general lack of AIDS prevention and education in senior communities.

1. BLOOD TRANSFUSIONS

Transmission of the HIV virus through tainted blood transfusions has significantly affected America's senior citizens.¹³¹ Early in the epidemic, tainted blood and blood products transfusions were a primary cause of HIV transmission in the elderly population.¹³² Although transmission among the elderly through tainted transfusions is no longer the greatest risk factor for HIV, elderly persons as a group are still more affected by this mode of transmission than other groupings targeted by AIDS.¹³³ Today we still are witnessing the impact of tainted transfusions, which occurred in the late 1970s and early 1980s, among a final wave of survivors who are elderly persons living with HIV/AIDS.

After 1985, when the test for the HIV antibody was discovered, the nation's blood banks were basically cleared of tainted blood used for transfusions, thus significantly reducing the risk of HIV transmission through tainted blood transfusions among all populations. However, it is now known that the infection has a relatively long incubation period and that often there is a resultant lag time before presentation of symptoms in individuals who are infected with the HIV virus.

Tainted blood transfusions have had a disproportionate impact on the elderly, despite the screening of blood donations for HIV antibodies since 1985.¹³⁴ Those who received tainted blood transfusions during routine and elective surgeries in the years before 1985 may not have shown symptoms of the disease until years later.¹³⁵ In the period before 1985, adults who today are age sixty-five and over were those

131. *Id.*

132. *See id.*

133. *HIV Infection, supra note 6, at 348.*

134. *AIDS in Persons Aged 50, supra note 5, at 85; see also MMWR, supra note 7, at 4.* "Through 1989, receipt of contaminated blood or blood products accounted for only one percent of cases among persons aged thirteen to forty-nine years; in comparison, this risk factor accounted for six percent, twenty-eight percent, and sixty-four percent of cases among persons aged fifty to fifty-nine years, sixty to sixty-nine years, and greater than or equal to seventy years, respectively." *Id.*

135. *AIDS in Persons Aged 50, supra note 5, at 85.*

in greatest need for transfusions, due to both elective and nonelective surgeries.¹³⁶ As a result of their being frequent recipients of infected blood almost two decades ago, many elderly contracted HIV infection and subsequently exhibited AIDS-related symptoms.¹³⁷

Diagnosis and treatment of transfusion-related cases is made more complicated by the fact, recently reported, that an average of sixteen to eighteen years can pass between initial transmission and the onset of AIDS-related symptoms.¹³⁸ Furthermore, many elderly may not even have been aware of having been administered a transfusion during surgery. Neither hospitals nor insurance companies are required to report transfusions to their patients, and many therefore do not disclose this critically important information.¹³⁹ One important medical study has shown that the proportion of patients who acquired the infection from HIV-tainted blood transfusions is significantly higher in the older population than among younger HIV-infected groups.¹⁴⁰ The highest proportion of these transfusions in this age group occurred during the peri-operative period of coronary bypass surgery.¹⁴¹

The impact of tainted blood transfusions on the elderly, and all age populations, has clearly diminished over time. Specific data on the number of older recipients of transfusions who became infected with HIV have been difficult to determine. However, some estimates suggest that more than 250,000 people age fifty and older received blood transfusions during the critical period from 1978 to 1985, the seven years during which the U.S. blood supply was contaminated.¹⁴²

The majority of those who were infected by tainted blood transfusions prior to 1985 were seniors living in areas of high HIV infection, particularly California, New York, and Florida.¹⁴³ For a variety of reasons discussed previously, AIDS illness in many of these seniors

136. *HIV Infection*, *supra* note 6, at 351. "Transfusional transmission represents an important risk factor for acquisition of HIV infection in this age group, because transfusions are more frequently required in this population." *Id.*

137. *Elders and AIDS*, *supra* note 56, at 1-2.

138. *HIV/AIDS and the Elderly*, *supra* note 64.

139. *Id.*

140. *HIV Infection*, *supra* note 6, at 351. The results of the authors' clinical tests showed that twenty-one percent of patients over fifty-five years of age received HIV infection through blood transfusions, as compared to only three percent in the under fifty-five year population. *Id.*

141. *Id.*

142. *Elders and AIDS*, *supra* note 56, at 1-2.

143. *Id.*

remained undiagnosed, or was diagnosed only when the illness had reached an advanced stage or after the patient had already died. Transmission through tainted blood transfusion thus has been historically the most distinctive and perhaps uniquely tragic mode of transmission among the elderly. However, as described below, the number and proportion of persons with AIDS in this same age group now appears to be increasingly caused by other transmission modes.¹⁴⁴

2. HIGH-RISK, UNSAFE SEXUAL ACTIVITY

While transmission of HIV infection through blood transfusions has declined in recent years, behavioral risk factors among seniors have increased, particularly unsafe sexual activity.¹⁴⁵ The reality of sexual activity and late-life romancing among seniors, both homosexual and heterosexual, is now a predominant factor in increased transmission of HIV infection among today's senior citizens.¹⁴⁶

Medical studies have indicated that the greatest incidence of HIV transmission among the elderly now occurs as a result of homosexual or bisexual contacts¹⁴⁷ among older men, or a result of heterosexual contact, for older women with AIDS.¹⁴⁸ Alarming statistics indicate that among older women, the number of new AIDS cases linked to unprotected heterosexual activity more than doubled between 1991 and 1996, from 340 to 700 cases.¹⁴⁹ Not surprisingly, older men experienced a similar rise in incidence of AIDS due to unprotected sex—homosexual, bisexual, and heterosexual—during that same period.¹⁵⁰

144. MMWR, *supra* note 7, at 1.

145. *Epidemiology of HIV in Elders*, *supra* note 77. Both the results of the authors' study and data from the Centers for Disease Control indicate that while in the period from 1982 to 1988, thirty-seven percent of AIDS patients older than sixty contracted the infection from blood transfusions, for the period 1989–1991, only twenty percent of elderly AIDS patients listed transfusions as their risk factor. *Id.* Again, this is due to the fact from 1985 forward, all blood donations in the United States were strictly screened for HIV infection, almost (but not entirely) eliminating the risk of transmitting the infection through blood transfusions. *Id.*

146. *Id.*

147. *HIV Infection*, *supra* note 6, at 351.

148. *Providers Not Diagnosing HIV in Older Women: Females over Fifty Are the Invisible Victims*, AIDS ALERT, June 1995, at 77 (cases in seniors, but that today heterosexual contact now is responsible for sixty-nine percent of the cases in older women, according to the Centers for Disease Control).

149. *AIDS Cases Increasing Among the Elderly Causes Shift from Transfusion to Sex, Drugs While Early Symptoms Often Go Unrecognized*, STAR-LEDGER NEWARK, Jan. 23, 1998, at O35.

150. *See id.*

The reality is that late-life romances are increasingly accepted and common in our society, particularly in retirement communities. The prevalence of Viagra use by older men has further augmented the possibility of sexual activity in this age group. Yet, most seniors do not consider that they may be medically at risk for AIDS as much as their children or their grandchildren.¹⁵¹ In general, seniors are living longer and more healthy lives and are turning to new companionship after the loss of a longtime spouse; yet they are doing so without taking the necessary precautions. In addition, cultural barriers and long-standing habits among seniors restrict partners from receiving accurate sexual histories and disclosure of possible risk factors from their new companions.¹⁵²

3. UNSAFE INTRAVENOUS DRUG USE AND OTHER UNIDENTIFIED RISK FACTORS

The percentage of persons over fifty who report intravenous (IV) drug use has also increased significantly in the last several years.¹⁵³ Therefore, the risk of transmission through the sharing of "dirty" needles poses another risk factor for older adults, whether the IV drug use took place several years ago or is current.

Generally, older persons with AIDS are more likely than younger ones to have undetermined means of HIV exposure.¹⁵⁴ This is in part because older persons may be more hesitant to disclose sexual behavior or intravenous drug abuse to their medical providers. Also, statistics indicate that older persons are likely to have died before an accurate AIDS diagnosis is made, and without having been questioned about their risk behaviors and possibility of exposure.¹⁵⁵

151. *Geriatrics AIDS Increasing Among Elderly, Particularly Women*, AIDS WEEKLY PLUS, Jan. 19, 1998, available at 1998 WL 8145541 (quoting Debby Elliott of HIV Care Directions, of Phoenix, "[n]ot fearing pregnancy or believing themselves to be at risk for AIDS, only twenty percent of sexually active seniors use condoms.").

152. See *Uncharted Territory*, *supra* note 88, at 84.

153. *HIV/AIDS and the Elderly*, *supra* note 64; see also 5 CDC HIV/AIDS SURVEILLANCE REP. 11 (1993).

154. *AIDS in Persons Aged 50*, *supra* note 5, at 85. "The proportion of cases with undetermined means of HIV exposure was almost three times as great among persons aged greater than or equal to fifty (7.6%) as among persons aged thirteen to forty-nine (2.8%)." *Id.*

155. Jonathan Ship et al., *Epidemiology of AIDS in Older Persons*, 4 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 84, 87 (1991). For example, a person over fifty-five who received HIV-infected blood through a transfusion during surgery may later infect his or her partner through sexual intercourse and later die of another age-related illness without ever knowing he or she was HIV-infected. The partner,

HIV infection is not a static variable, and risk factors are less likely to exist in isolation from others. Often infection is the result of a combination of variables and factors.

In fact, national surveillance data indicate that the numbers of persons older than fifty with AIDS whose transmission risk category is unidentified are increasing and multiplying with the aging process.¹⁵⁶ Of those age fifty to fifty-four years, ten percent were found to have no identifiable risk factor at the time of their AIDS diagnosis.¹⁵⁷ This figure increased to twelve percent in those fifty-five to fifty-nine years old, and then to seventeen percent in those sixty-five years and older.¹⁵⁸ As one geriatric policy expert has noted, these numbers appear to indicate that “many older adults with HIV are unaware of when or how they were infected, or are reluctant to provide this information because of stigma” in the form of further marginalization, isolation, or loss of services.¹⁵⁹

The epidemiological and demographic particularities of AIDS among the elderly point to the need for new services and targeted medical care to this already vulnerable segment of our society. As the above discussion indicates, AIDS and other geriatric chronic diseases, such as Alzheimer’s and cardiac disease, are defining the reality of aging and disease in America. Geriatric AIDS raises important questions about the quality of life among the elderly and the ability to medically extend life. The aging of the epidemic points to the critical need for preventive programs and medical services necessary to address and protect the special needs of elderly AIDS patients, particularly those requiring nursing home and long-term care. Existing AIDS service agencies, elder care programs, and government entitlement programs, most notably Medicare, must be reformed and expanded in order to meet these growing needs and priorities. These and other emerging legal, legislative, and public policy issues will be discussed below.

now HIV-infected, may never suspect the presence of the disease and its transmission. *Id.*

156. *Uncharted Territory*, *supra* note 88, at 84.

157. *Id.*

158. *Id.*

159. *Id.*

III. Facing the Reality of AIDS Among the Elderly

When a senior is diagnosed with AIDS, the medical transition he or she undergoes will occur at a time when he or she is most vulnerable and in need of multifaceted support—financial, medical, social, psychological, familial, as well as legal. In this context, respect, care, support, and empowerment for all elderly, and more specifically, for the chronically ill elderly person with AIDS emerges as a significant “rights” question. This is an issue that the legal community, particularly those who practice elder law and health care law, must address. In this section, attention is turned to the emerging legal and public policy issues facing elderly persons living with HIV/AIDS.

In addition to new social, economic, emotional, and medical challenges, infected and affected elderly with AIDS are faced with daunting legal problems. These legal problems are a product of both the aging process and also the particularities of AIDS-associated disability and illness, with their ensuing economic costs and social stigma. While senior citizens living with AIDS face many of the same legal problems as younger persons with AIDS, such as discrimination from health and life insurance companies, they also face unique age-related legal challenges and barriers to entitlements and care.

Furthermore, many of the legal issues that the great majority of elderly persons routinely face, such as Medicare coverage and estate planning, are exacerbated by an AIDS diagnosis. The nation’s elderly represent a growing segment of the population experiencing unmet legal needs, many of which are particularly complex and challenging.¹⁶⁰ Legal concerns typically faced by elderly persons include problems in the areas of family law, consumer protection, and housing law; issues related to health, including advance directives; Medicare coverage and Medicaid eligibility; the protection of income and assets; guardianships and conservatorships; elder abuse and age discrimination; estate planning; and eligibility for government and employer benefit programs.¹⁶¹ Effectively addressing the legal needs and concerns of the elderly client has presented ethical quandaries for the elder law attorney and has required novel interdisciplinary ap-

160. Mary Helen McNeal, *Redefining Attorney-Client Roles: Unbundling and Moderate-Income Elderly Clients*, 32 WAKE FOREST L. REV. 295, 299 (1997). A variety of developments common to the process of growing old can complicate a person’s ability to secure legal representation. *Id.*

161. *Id.* at 299–300.

proaches which are sensitive to the special problems of the elderly in our society.¹⁶²

Elderly persons with HIV/AIDS face these as well as additional legal problems which are a product of their special circumstances. These circumstances present additional barriers to their ability to live safely, healthily, and with effective control over their destinies and decision making. Such additional legal problems include lack of Medicare coverage for long-term care and AIDS medications, and assistance accessing specially funded AIDS medication programs.¹⁶³ HIV-positive seniors also face legal problems with nursing home discrimination; stigma-generated abuse and neglect by family members and institutions; AIDS illness quality of care issues; personal injury and medical malpractice issues stemming from misdiagnosis of their AIDS illness; access to AIDS screening, testing, and prevention programs; and time-sensitive estate planning and advance directive matters.¹⁶⁴ Moreover, not only elderly AIDS patients, but also their fami-

162. *Id.* at 301. See generally Matthew R. Dubois, *Legal Planning for Gay, Lesbian, and Non-Traditional Elders*, 63 ALB. L. REV. 263 (1993); Heather A. Wydra, *Keeping Secrets Within the Team: Maintaining Client Confidentiality While Offering Interdisciplinary Services to the Elderly Client*, 62 FORDHAM L. REV. 1517 (1994).

163. THE AIDS DRUG ASSISTANCE MONITORING PROJECT, STATE AIDS DRUG ASSISTANCE PROGRAMS: A NATIONAL STATUS REPORT ON ACCESS, available at <http://www.aidsintonyc.org/adap/report.html> (last visited Feb. 4, 2002). The AIDS Drug Assistance Program (ADAP) is a state-administered program that provides access to FDA-approved drugs used to treat HIV illness and "to prevent the onset of related opportunistic infections" for low-income people with HIV/AIDS who do not have adequate private or public health insurance. *Id.* This program has been particularly important to HIV-positive Medicare beneficiaries, because traditional Medicare (non-Medicare Plus Choice HMOs) does not include coverage for prescription medications, but Medicaid programs generally do. ADAP programs are available in all fifty states, the District of Columbia and Puerto Rico, and are funded primarily by the federal Ryan White CARE Act. *Id.* In 1997, thirty states provided supplementary funding, with total federal and state ADAP spending of \$385 million. *Id.* Each state sets the income and medical eligibility requirements, determines which drugs will be covered, the monthly caps on amount of drugs, and how they will be distributed. *Id.* In most states, ADAP provides many antiretroviral therapies (protease inhibitors). *Id.* During 1996, the national estimate of the total number of persons served by ADAP was 80,000. *Id.* However program officials indicated that the number of people who could be eligible for the program ranged between 140,000 and 280,000 nationally. *Id.* In order to qualify for the ADAP program, a person must complete an application, be approved and verified by the state administrative agency, and a cross-match with the Medicaid database is done to ensure that the applicant is not eligible for that program. *Id.* Applicants must meet health, financial, legal residency, and insurance requirements. *Id.* Historically, the application process in some states has been difficult to access and navigate, as well as time-consuming. *Id.*

164. *Uncharted Territory*, *supra* note 88, at 84.

lies, face new legal problems due to AIDS, particularly in the areas of family law and public benefit issues.

The many legal issues which elderly persons with HIV/AIDS face can be sorted into three categories of legal services, each of which are discussed below. First, because medical providers often fail to timely diagnosis HIV infection in seniors for a variety of reasons, legal causes of action for medical malpractice and negligence may become increasingly important.¹⁶⁵ These problems may be addressed by remedies in tort, as well as by protections under federal and state disability rights laws.

Second, elderly persons living with HIV/AIDS face unique legal issues of confidentiality and discrimination in nursing homes, hospitals, senior residences, and retirement communities. Evidence indicates that HIV-positive elderly persons in nursing homes face particular quality of care issues, as well as AIDS discrimination, as they deal with or reside in these facilities.¹⁶⁶

Third, faced with this highly incapacitating, increasingly chronic, and in the vast majority of cases, ultimately deadly disease, seniors will have significantly increased medical needs which Medicare does not routinely cover. Already existing shortcomings in the federal Medicare program are exacerbated for AIDS patients. Furthermore, as Medicare partners with health maintenance organization (HMOs) in Medicare Plus II Choice managed-care arrangements, the legal issues of right to coverage and against denial of necessary medical care will become increasingly important to the elderly.

A. Legal Protections Against Failure to Diagnose and to Treat

As discussed in Part II of this article, HIV-positive seniors are routinely misdiagnosed or not timely diagnosed by medical personnel. Left undiagnosed and untreated, AIDS accelerates the aging process and ravages the declining health of affected elderly. Allowed to run its course, without medical treatment now available that can significantly prolong life, AIDS will take its toll of irreversible illness and death. Families of afflicted seniors are left with the questions whether death could have been delayed and whether quality of life

165. See Brown & Sankar, *supra* note 13, at 865; see also *Epidemiology of HIV in Elders*, *supra* note 77, at 8.

166. See *Epidemiology of HIV in Elders*, *supra* note 77, at 8.

could have been maintained at acceptable levels, if the illness had been correctly and timely diagnosed. Others, for whom a correct AIDS diagnosis of their loved one is never made, are left with the enduring uncertainty about the true cause of their relative's illness and death.

Clearly, AIDS is not the only disease that often is not diagnosed correctly or diagnosed in a timely manner by medical providers. Much can be learned about how to remedy the widespread failure to diagnose HIV illness in the elderly by examining systemic medical errors that have afflicted people suffering from other diseases and conditions. Medical errors at the diagnosis stage, and the resultant failure to provide appropriate AIDS treatment, occur in the context of a virtual *medical errors epidemic* that has plagued the medical system. These medical errors, recently documented in a National Institute of Medicine report, have resulted in numerous deaths, permanent disabilities, and unnecessary suffering.¹⁶⁷

Families of elderly persons with HIV/AIDS should be aware that medical malpractice lawsuits, a form of personal injury tort action, could be an appropriate legal recourse. However, this after-the-fact remedy will do little to reverse the impact of the medical error, unless intervention is made on behalf of the patient while appropriate treatment can still have an effect. The dangers of misdiagnosis will in actuality only be abated when the silence surrounding the medical error of misdiagnosis for elderly persons with HIV/AIDS is broken. This will occur only when doctors and other health care professionals are educated about the needs of geriatric patients and the realities of HIV risk among senior citizens. Seniors themselves, with the help of family members and patient advocates, can influence the quality of care they will receive, and with the necessary resources can lead the way in improving communication and accessing appropriate treatment.

167. See INST. OF MED., NAT'L ACAD. OF SCI., *TO ERR IS HUMAN: BUILDING A SAFER HEALTH SYSTEM*, (1999). The report cites medical errors as one of the nation's leading causes of death and injury, and it outlines a comprehensive strategy for government, industry, consumers, and health providers to reduce medical errors. *Id.* The report also calls upon Congress to create a national patient safety center in order to address the persistent problems that are estimated to cause the death of some 44,000 to 98,000 persons in the United States annually. *Id.*

B. AIDS Discrimination and the Elderly

Elderly people living with HIV/AIDS face important legal issues related to protection from discrimination by medical providers and in nursing homes, senior residences, and retirement communities. HIV status and AIDS illness are disabilities protected from discrimination, under federal statutes, some state and local laws, as well as case law.¹⁶⁸

Since almost the beginning of the AIDS epidemic, when AIDS and HIV infection were recognized as significant medical problems and disabilities, legal advocates sought to address the crisis through both public health and civil liberties law.¹⁶⁹ The result is a complex set of interlocking statutes that has the potential to effectively protect a person with HIV/AIDS from discrimination by employers, public accommodations, including medical providers, and by public entities, including government-funded organizations, and government agencies.¹⁷⁰

In the first ten to fifteen years of the AIDS epidemic, enforcement of these laws, particularly the federal Americans with Disabilities Act (ADA) and the Rehabilitation Act of 1973, has primarily occurred in the context of employment discrimination against persons with HIV/AIDS.¹⁷¹ However, more recent legal challenges have been waged successfully in the context of access to medical care and public entitlements.¹⁷² Such cases open the door for potentially successful litigation by elderly persons with HIV/AIDS seeking legal recourse against medical personnel who delay or refuse treatment due to their HIV status or who violate their rights to confidentiality.

168. Americans with Disabilities Act, 42 U.S.C. §§ 12101–12301 (1994 & Supp. III 1997); Federal Rehabilitation Act of 1973 § 504, 29 U.S.C. § 794 (1994). See, e.g., CAL. HEALTH & SAFETY CODE §§ 199.20–23 (West 1989); MASS. GEN. LAWS ANN. ch. 111, § 70 (West 1989); N.Y. PUB. HEALTH LAW § 2782 (McKinney 1994).

169. See generally Donald H. J. Hermann, *The Development of AIDS Federal Civil Rights Law: Anti-Discrimination Law Protection of Persons Infected with Human Immunodeficiency Virus*, 33 IND. L. REV. 783 (2000).

170. 42 U.S.C. § 12101 (1990) (see Titles I, II, & III).

171. See, e.g., Arthur S. Leonard, *AIDS and Employment Law Revisited*, 14 HOFSTRA L. REV. 11 (1985); Arthur S. Leonard, *Employment Discrimination Against Persons with AIDS*, 10 U. DAYTON L. REV. 681 (1985).

172. See generally *Bragdon v. Abbott*, 524 U.S. 624 (1998); *Henrietta D. v. Giuliani*, 246 F.3d 176 (2d Cir. 2000) (holding New York City violated rights of city residents with HIV/AIDS under the ADA and the Rehabilitation Act, by failing to provide meaningful access to public assistance programs, benefits, and services).

Evidence indicates that HIV-positive elderly persons in nursing homes face particular quality of care issues, as well as AIDS discrimination by these facilities, and that the ADA might be an effective tool in challenging that discrimination. Examples of discriminatory practices might include a nursing home's refusal to admit an HIV-positive applicant because that person may be considered difficult to manage or a threat to other residents. Similarly a facility might segregate an HIV-positive resident, discharge a resident diagnosed with AIDS or another communicable disease, or isolate or discharge a resident with a mental disability.¹⁷³ Effective enforcement of federal and state anti-discrimination laws is needed to protect the rights of persons with HIV/AIDS, so that they may be free of this type of public accommodation bias.¹⁷⁴ Also, stricter government regulation of nursing homes, other geriatric health care facilities, and also assisted-living residential centers would help to eliminate such discriminatory practices.

However, utilization of the ADA and the Rehabilitation Act of 1973 to counter nursing home and assisted-living center discrimination of residents and applicants has to date been limited.¹⁷⁵ In cases that have been brought under the ADA and the Rehabilitation Act, the results have been mixed.¹⁷⁶ Providing seniors with HIV/AIDS legal protection against nursing homes and similar facilities under these laws is a relatively novel litigation strategy, but certainly one worth exploring.

The ADA in particular has the potential to be a very effective tool in protecting elderly disabled nursing home residents on at least two fronts: first, the mental and physical impairments normally associated with the aging process, and second, the disability related to infectious disease status. The ADA can be used to protect the disabled

173. Elizabeth Schneider, *The ADA—A Little Used Tool to Remedy Nursing Home Discrimination*, 28 U. TOL. L. REV. 489, 504 (1997).

174. *See id.* at 514 (reporting that in the early 1990s there were numerous reports of nursing homes refusing to accept AIDS patients. Yet, nursing facilities that receive Medicare or Medicaid funding are prohibited under 504 from refusing to admit people with AIDS).

175. *Id.* at 489 (arguing that the ADA does cover nursing homes and that its potential for combating disability discrimination by nursing homes needs to be explored by attorney-advocates).

176. *See, e.g.,* *Winkler v. Interim Servs.*, 36 F. Supp. 2d 1026 (M.D. Tenn. 1999) (favorable under Rehab Act). *But see* *Easley v. Snider*, 36 F.3d 297 (3d Cir. 1994); *Wagner v. Fair Acres Geriatric Ctr.*, 49 F.3d 1002 (3d Cir. 1995) (addressing discriminatory admission policies against elderly persons with Alzheimer's disease); *Rodriguez v. DeBuono*, 197 F.3d 611 (2d Cir. 1999).

from being denied admission to a nursing home, from impermissible transfers or discharges on the basis of the resident's AIDS illness or diagnosis, and from discrimination stemming from segregated or disparate treatment in the receipt of services.¹⁷⁷ Advocates for the elderly should begin using these laws more frequently to protect the rights and needs of this vulnerable population.

C. Added Challenges to the Medicare and Medicaid Programs

As more senior citizens are correctly diagnosed with HIV infection and AIDS illness, Medicare and Medicaid programs will be further stretched to their limits. The existing gaps in the Medicare program, particularly failure to cover medications and long-term nursing care, as well as gaps in coverage of many necessary screening, testing, and prevention services, adversely affect all elderly Medicare recipients, and particularly those with HIV/AIDS and other chronic and terminal illnesses.¹⁷⁸

Because Medicare does not cover medications, most elderly Medicare recipients with HIV/AIDS cannot afford the life-prolonging and exorbitantly expensive medications required for AIDS treatment, unless they can access and qualify for the AIDS Drug Assistance Programs (ADAP).¹⁷⁹ Elderly AIDS patients thus are dependent on subsidized support or charity, unless they have enough resources to locate and purchase care and medications privately.¹⁸⁰ Seniors are forced to "spend down" whatever assets they have in order to qualify for Medicaid, which covers the costs of medications in most states.¹⁸¹

Furthermore, Medicare recipients who are members of Medicare-health maintenance organizations (HMOs) in managed-care arrangements may face further legal challenges in order to receive coverage and to access AIDS-specific health care providers within their HMO program. Some studies suggest that managed-care systems have the potential to provide worse health care than fee-for-service plans, like traditional Medicare.¹⁸² This may be because HMO doctors

177. Schneider, *supra* note 173, at 518.

178. See generally Harry Margolis, *A Proposal for Reform of Medicaid Rules Governing Coverage of Nursing Home Care*, 9 STAN. L. & POL'Y REV. 303 (1998).

179. See David Pratt, *Health Care Policy: What Lessons Have We Learned from the AIDS Pandemic?*, 61 ALB. L. REV. 671, 674-76 (1998).

180. *Uncharted Territory*, *supra* note 88, at 5.

181. See 42 U.S.C. § 1396(a) (1996).

182. Wallace et al., *supra* note 100, at 333.

are pressured to undertreat patients and to limit access to specialists, thus maximizing profits.¹⁸³ The continued congressional delay in passage of an effective Patients' Bill of Rights prevents elderly people from securing their legal rights under the Medicare program, particularly those who are members of Medicare-HMOs, in the Medicare Plus II Choice program.¹⁸⁴

The need for long-term care coverage also comes into sharper focus as elderly Medicare recipients living with AIDS need to access and secure such care. Indeed, as AIDS continues to spread through the elderly population at the rates discussed in this article, the epidemic will dramatically stretch the long-term care industry far beyond its current capabilities. Long-term nursing home care is also generally covered by Medicaid but not by Medicare, creating another major gap in care for many elderly persons with HIV/AIDS. In addition, most preventive health services and many screening tests are not covered under the Medicare program.

Only systemic change in the Medicare program, particularly toward coverage for medications, for nursing home and long-term care, as well as for preventive and chronic care services, will effectively respond to the impact of HIV/AIDS and other chronic and terminal illnesses and conditions on the elderly. In addition to legislative reform of Medicare, discussed below, ultimately only enactment of universal national health coverage that would provide for and protect people of all ages and incomes will eliminate the gaps, inequities, and disparities that currently exist in the nation's health care system.

D. Legislative Advocacy—Reforming Medicare

Recently, a number of legislative reforms have been introduced in Congress that call for providing preventative and chronic care to Medicare beneficiaries. If enacted into law, these reforms would transform Medicare from an "outdated sickness program to a modern wellness program."¹⁸⁵ The Medicare Wellness Act of 2001¹⁸⁶ and the

183. *Id.*

184. See Dean M. Hashimoto, *The Proposed Patients' Bill of Rights: The Case of the Missing Equal Protection Clause*, 1 YALE J. HEALTH POL'Y L. & ETHICS 77 (2001).

185. 147 CONG. REC. S5833-01 (June 5, 2001) (statement of Sen. James M. Jeffords). Senator James M. Jeffords, one of the bill's cosponsors, is quoted as saying, "[i]t is my hope that my colleagues will examine this legislation and realize the inadequacy of the current package of preventive benefits in the Medicare program.

Medicare Chronic Care Improvement Act of 2001¹⁸⁷ are two important examples of these legislative proposals. These laws would have a wide-ranging impact on seniors at-risk for and suffering from chronic and disabling conditions and diseases, including HIV/AIDS. However, while other chronic and serious geriatric illnesses are named in both of the pieces of legislation and their legislative histories, HIV/AIDS is not specifically mentioned.¹⁸⁸

On June 5, 2001, Senator Bob Graham (D-Fla.) introduced the Medicare Wellness Act of 2001 in the U.S. Senate, with the support of twelve Senate cosponsors.¹⁸⁹ That same day, U.S. Representative Sander M. Levin (D-Mich.) introduced a companion bill of the same name in the U.S. House of Representatives, which has the support of thirty-four congressional cosponsors.¹⁹⁰ The purpose of the legislation is to promote primary and secondary health promotion and disease prevention services and activities among the elderly, by amending Title XVIII of the Social Security Act.¹⁹¹

This would be accomplished by adding preventive health benefits coverage for a variety of conditions and diseases common to the aging process to the Medicare program. Under the legislation, the Department of Health and Human Services (DHHS) would establish an interagency *Working Group on Disease Self-Management and Health Promotion* that would create policies and criteria for the DHHS Secretary to make grants to eligible entities for health promotion and dis-

We have the opportunity to transform Medicare from an out-dated sickness program to a modern wellness program." *Id.*

186. S. 982, 107th Cong. (2001); H.R. 2058, 107th Cong. (2001).

187. S. 1589, 107th Cong. (2001); H.R. 3188, 107th Cong. (2001).

188. See generally sources cited *supra* notes 186 & 187.

189. Senator Graham was joined by the following U.S. Senators in introducing S. 982 in the Senate: Mr. Bingaman, Mr. Corzine, Mr. Hollings, Mr. Kennedy, Mrs. Lincoln, Mrs. Murray, Mr. Chafee, Mr. Durbin, Mr. Jeffords, Mr. Levin, Mr. Lugar, and Mr. Rockefeller IV. S. 982, 107th Cong. (2001). Senator Graham had previously introduced this bill, with some technical differences, titled the Medicare Wellness Act of 2000, in the 106th Congress.

190. See S. 982, 107th Cong. tit. 2, § 102 (2001). U.S. Representative Levin was joined by the following Representatives of Congress in sponsoring the bill, H.R. 2058, 107th Cong. (2001): Mr. Abercrombie, Mr. Baldacci, Mr. Cardin, Mr. Crowley, Mr. Foley, Mr. Gutierrez, Mr. Hoeffel, Mr. Kildee, Mrs. Lee, Mr. Matsui, Mrs. Roybal-Allard, Ms. Sanders, Mr. Simmons, Ms. Thurman, Mr. Waxman, Mrs. Woolsey, Mr. Ackerman, Mr. Baldwin, Mr. Coyne, Ms. DeGette, Mr. Frost, Mr. Hinchey, Mr. Horn, Mr. McNulty, Mrs. Maloney, Mrs. Morella, Mr. Pascrell, Jr., Mr. Owens, Mr. Pastor, Mr. Rush, Mr. Serrano, Mr. Stark, Mr. Udall, Mr. Wexler, and Mr. Leach.

191. H.R. 2058, 107th Cong. (2001); S. 982, 107th Cong. (2001).

ease prevention among Medicare beneficiaries.¹⁹² The Secretary also would conduct demonstration projects to promote disease self-management for conditions identified by the *Working Group*, for targeted elderly populations.¹⁹³ In addition, the legislation would establish within the Medicare program an awareness and educational campaign to help prevent falls by seniors, a demonstration project to screen for clinical depression, and a health education and risk appraisal program to identify target groups with special behavioral risk factors for health problems and disease.¹⁹⁴

Finally, the Medicare Wellness Act of 2001 would amend the Medicare program to cover or to expand existing coverage of various specified preventive health services for elderly persons.¹⁹⁵ In some cases, the deductibles and coinsurance payments for Medicare beneficiaries would be waived for certain existing preventive health services, which in recent years have been added to Medicare coverage.¹⁹⁶

In essence, the proposed law would shift the focus of Medicare from a "program that simply treats illness to one that promotes wellness."¹⁹⁷ Medicare beneficiaries with HIV/AIDS, or at risk for

192. See S. 982, 107th Cong. tit. 1, § 102 (2001) (Working Group on Disease Self-Management and Health Promotion).

193. See S. 982 tit. 1, § 104 (Disease Self-Management Demonstration Projects).

194. See S. 982 tit. 3 (National Falls Prevention Education and Awareness Campaign), tit. 4, (Clinical Depression Screening Demonstration Projects), and tit. 5 (Medicare Health Education and Risk Appraisal Program).

195. See S. 982 tit. 2 (Medicare Coverage of Preventive Health Benefits). The legislation allows for coverage and waiver of the Medicare deductible for the following specified health services: (1) therapy and counseling for cessation of tobacco use (Section 201); counseling for post-menopausal women (Section 202); screening for diminished visual acuity (Section 203); screening for hearing impairment (Section 204); screening for cholesterol (Section 205); screening for hypertension (Section 206); expansion of eligibility for bone mass measurement (Section 207); and coverage of medical nutrition therapy services for beneficiaries with cardiovascular diseases (Section 208).

196. See Medicare Wellness Act of 2001, S. 982, 107th Cong. tit. 2, § 209 (2001) (discussing the elimination of deductibles and coinsurance for existing preventive health benefits). The specified preventive health items and services are: blood testing and outpatient self-management training services for persons with diabetes; pneumococcal, influenza, and hepatitis B vaccines and administration; screening mammography; screening pap smear and screening pelvic exams; bone mass measurement tests; prostate cancer screening tests; cervical cancer screening tests; screening for glaucoma; and medical nutrition therapy services. These services are already partially covered services under Medicare (with deductibles and coinsurance payments currently required).

197. 147 CONG. REC. S5833-01 (June 5, 2001) (statement of Sen. Bob Graham).

For too long, the Medicare approach to health care has been wholly reactive. Benefits are designed to treat illness and disability once a recipient is already suffering. This approach is outdated. It is time for

HIV/AIDS need exactly these types of counseling, screening, wellness, and preventive services proposed under the Medicare Wellness Act of 2001. Yet, while HIV-positive elderly Medicare recipients are not explicitly excluded from receiving some of the services proposed, nowhere in the legislative history of the Act, nor in the Act itself, is HIV/AIDS mentioned.¹⁹⁸

The Medicare Chronic Care Improvement Act of 2001 was introduced in Congress on October 30, 2001.¹⁹⁹ The Senate bill, sponsored by Senator John D. Rockefeller IV and three cosponsors,²⁰⁰ and its companion House bill, sponsored by Representative Pete Fortney Stark and thirteen cosponsors,²⁰¹ contain many of the same provisions concerning disease risk and prevention as the Medicare Wellness Act.²⁰²

However, this more recent piece of legislation has a different focus. While the Medicare Wellness Act of 2001 focuses on coverage of health prevention and risk programs for the elderly, the Medicare Chronic Care Improvement Act of 2001 aims to provide coverage for

Medicare to become pro-active. It is time to focus on helping people to prevent disease in the first place so that they may live not just longer, but more fulfilling lives.

Id.

198. For example, under Title V of the Medicare Wellness Act of 2001, the Medicare Health Education and Risk Appraisal Program, risk behavior factors among the elderly which are articulated in the proposed bill for further study, assessment, and demonstration projects are: (A) lack of proper nutrition; (B) use of alcohol; (C) lack of regular exercise; (D) use of tobacco; (E) depression; and (F) any other risk factor identified by the Secretary (DHHS). S. 982, 107th Cong. § 501 (2001). Unsafe sexual practices of seniors that put them at risk for HIV infection should be included in this list.

199. Medicare Chronic Care Improvement Act of 2001, S. 1589, 107th Cong. (2001); H.R. 3188, 107th Cong. (2001). The Act would amend the Medicare program to expand benefits to prevent, delay, and minimize the progression of chronic conditions. S. 1589, 107th Cong. (2001).

200. Joining Senator Rockefeller, in cosponsoring S. 1589 are Senators Wellstone, Baucus, and Graham (the chief sponsor of the Senate's Medicare Wellness Act of 2001).

201. Cosponsors of H.R. 3188 are Reps. Becerra, Eshoo, Hinchey, Lewis, McNulty, Schakowsky, Wynn, Brady, Frank, Kucinich, McGovern, Roybal-Allard, and Weiner.

202. Disease risk and prevention is covered under Title I, Subtitle A—Improving Access to Preventive Services. H.R. 3188, 107th Cong. §§ 101–121 (2001). Much of this subtitle closely mirrors the language in the Medicare Wellness Act of 2001, Title II, Medicare Coverage of Preventive Health Benefits, Section 209, Elimination of deductibles and coinsurance for existing preventive health benefits.

coordinated care of chronic disease for all Medicare recipients.²⁰³ This law would expand Medicare benefits to prevent, delay, and minimize the progression of chronic conditions among all Medicare beneficiaries, both seniors and younger, retired workers who are deemed disabled.²⁰⁴ Specifically, the bill provides for assistance to Medicare beneficiaries with a serious and disabling chronic condition to obtain appropriate levels of care, as well as services and programs to prevent, delay, and minimize the progression of chronic conditions.²⁰⁵ This would be accomplished by expanding Medicare coverage to include chronic care assessment, care-coordination, self-management services, and patient and family caregiver education and counseling.²⁰⁶

As HIV/AIDS increasingly has become a chronic, rather than an imminently terminal disease, Medicare beneficiaries diagnosed with HIV/AIDS should be eligible for the significantly expanded benefits proposed under the Medicare Chronic Care Improvement Act of 2001.²⁰⁷ Under the bill's structure and the definitions incorporated

203. Medicare Chronic Care Improvement Act of 2001, S. 1589, 107th Cong.; H.R. 3188, 107th Cong. (2001). The Act expands Medicare benefits to prevent, delay, and minimize progression of chronic conditions, as well as develop national policy and effective care. *Id.*

204. Medicare is available not only to retired workers age sixty-five and over, but also to medically eligible adults under the age of sixty-five who are retired workers who have paid Social Security taxes over the required quarters. Seniors, however, make up the vast majority of Medicare recipients.

205. In introducing S. 1589, Senator Rockefeller stated:

[A]n estimated [eighty] percent of Medicare beneficiaries suffer from at least one chronic condition and those beneficiaries account for an astounding [ninety-five] percent of Medicare spending. But Medicare does not provide many of the health care services that people with chronic conditions need. For example, current Medicare data show that, on average, people with chronic conditions see eight different physicians. Medicare does not compensate these physicians for communicating with one another, nor are they paid for care coordination, monitoring medications, early detection, or for educating or counseling patients and caregivers. . . . To meet the needs of these individuals, our health care system must embrace a person-centered, system-oriented approach to care. Payers and providers who serve the same person must be empowered to work together to help people with chronic conditions prevent, delay, or minimize disease and disability progression and maximize their health and well being.

147 CONG. REC. S11,206-07 (daily ed. Oct. 30, 2001) (statement of Sen. Rockefeller).

206. Benefits under this section would provide a "person-centered, system-oriented approach to care for this extremely vulnerable segment of our population by expanding Medicare coverage." 147 CONG. REC. S11,206-07.

207. In introducing S. 1589 to the Senate Committee on Finance, Senator Rockefeller defined chronic conditions as encompassing "an array of health conditions that are persistent, recurring, and cannot be cured." 147 CONG. REC. S11,206-07.

into the bill, chronically ill persons with HIV/AIDS should not be excluded from the proposed coverage of chronic care benefits.²⁰⁸ However, as with the Medicare Wellness Act of 2001, HIV/AIDS is nonetheless absent from the bill's language and from the list of conditions presented in the legislative history.²⁰⁹

The Medicare Wellness Act of 2001 and the Medicare Chronic Care Improvement Act of 2001 strongly reinforce and complement one another. Together, the proposed laws promote and provide coverage for preventative health and coordinated, patient-centered care for chronic disease. The laws bridge existing significant gaps in the program that have adversely affected millions of seniors and other Medicare recipients. If passed by Congress and signed into law by President George W. Bush, the Medicare reforms would, according to one of the bill's chief sponsors, Senator Rockefeller, "provide a comprehensive solution to improving the quality of life and health for millions of Americans who are struggling with serious and disabling chronic conditions."²¹⁰ However, these two bills alone will not solve all the serious shortcomings in the Medicare program. Legislative reforms that would expand Medicare to cover medications, long-term care, and other services must also be promoted and supported.²¹¹

The Medicare Wellness Act of 2001 and the Medicare Chronic Care Improvement Act of 2001 are long-overdue and welcome legislative initiatives. They also are completely consistent with much of the public policy that is advocated for in this article on behalf of elderly persons, as they face declining health in the aging process. However, perhaps due to lack of knowledge about the geriatric AIDS problem on the part of its drafters and the national health care agencies which advised the Congresspersons in drafting the bills, as noted above both

208. The proposed law incorporates a definition of a "serious and disabling chronic condition" that is very similar to that utilized by DHHS in determining "disability" under the Social Security Disability Insurance program (SSDI) for retired disabled workers. This test includes the application of Activities of Daily Living (ADLs) measures. Many persons with AIDS illness would qualify under this test if they qualify for SSDI and are recipients of Medicare. Medicare Chronic Care Improvement Act of 2001, S. 1589, 107th Cong., tit. I, subtit. C, § 121(f) (2001).

209. Senator Rockefeller explained that these conditions "include severely impairing conditions like Alzheimer's disease, congestive heart failure, chronic obstructive pulmonary disease, diabetes, depression, hypertension, and arthritis." 147 CONG. REC. S11,206-07.

210. *Id.*

211. *See, e.g.*, Medicare Reform Act of 2001, S. 1135, 107th Cong. (2001) (introduced by Senator Bob Graham in the Senate on June 28, 2001).

pieces of legislation omit specific reference to the health needs of HIV-positive seniors—references to prevention, counseling, testing, and chronic care services related to HIV/AIDS.

Although the door is left open in both proposed laws for extending Medicare coverage to include many HIV/AIDS related services, these items should be specifically articulated and included in the laws at this stage of the legislative process. The fact that these two very expansive pieces of legislation are silent about HIV/AIDS, yet are sponsored by Congresspersons who are some of the strongest supporters of Medicare reform and the health care rights of the elderly, is a stark indication that much still needs to be done to educate and advocate about the problem of geriatric AIDS. As these and other proposed Medicare reform bills go forward, their congressional sponsors should amend them to include recognition of and services for Medicare beneficiaries with HIV/AIDS. Articulating the reality of geriatric AIDS in these acts also would go far toward advancing public awareness of this growing problem.

IV. Conclusion

The legal realities faced by HIV-infected elderly as they encounter these new, additional legal challenges have expanded the parameters of AIDS law, health law, and elder law. Some of these emergent issues raise the need for expanded and additional direct legal services programs. Due to the myriad social problems raised by the challenges of our aging society, the legal needs of the elderly will be best served by a holistic approach of service providers, working together across professions to provide support and services.

Many of these legal needs can be addressed through already existing elder law and AIDS law service agencies and advocacy programs. Some legal problems, such as nursing home discrimination against HIV-infected seniors and medical misdiagnosis of geriatric AIDS, may require new and more focused litigation, particularly under the Rehabilitation Act and the Americans with Disabilities Act.

However, issues stemming from shortcomings and inadequacies in the Medicare and Medicaid systems are questions of public policy that will require legislative changes by Congress. The Medicare Wellness Act of 2001 and the Medicare Chronic Care Improvement Act of 2001 are excellent examples of many legislative initiatives recently proposed which would reform and expand the nation's health care

systems, including Medicare. Although these two bills in particular are positive and important steps in the right direction, they urgently need to be amended so that they specifically include HIV/AIDS screening, testing, risk assessment, counseling, and education programs, as well as chronic care services, for Medicare beneficiaries who are at risk for or suffering from HIV/AIDS. In addition, other critically important Medicare reforms need to be supported, particularly those which would provide for coverage of medications and long-term care.

The growing phenomenon of elderly people with HIV/AIDS jars the illusion about the sanctity of aging in our society and removes yet another defensive barrier against the disease. The graying of the AIDS epidemic presents a challenge of immense proportions to the public health and legal communities and to society as a whole. The reality of being elderly and having HIV/AIDS highlights some of the most compelling and controversial contemporary social issues.

How we respond to this aspect of the AIDS epidemic will be a test of our social fiber, as we necessarily turn our attention to this most vulnerable population. We can help to ensure that our elders are protected and treated, that they achieve and maintain their health, and that they age with dignity, rather than being silently ravaged by this disease, with its related stigma and burdens.