

The State of the HIV/AIDS Epidemic in America

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This issue brief was developed for the Kaiser Family Foundation Capitol Hill Briefing Series on HIV/AIDS. It provides an overview of the state of the epidemic and the federal funding and legislative response.

AIDS CASES AND TRENDS IN THE UNITED STATES

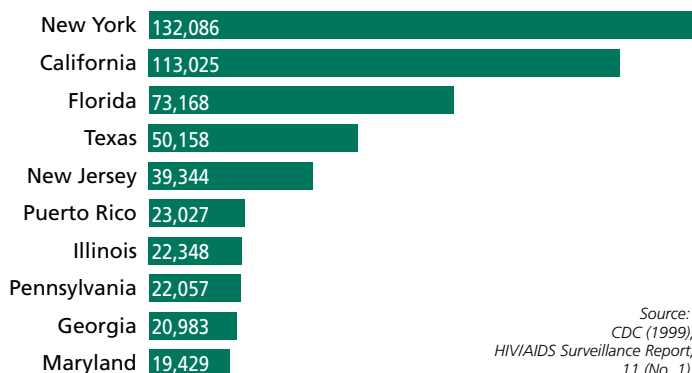
The first case of what has become known as HIV/AIDS was reported in the United States in June of 1981.¹ Between 1981 and June 1999, a total of 711,344 cases of AIDS were reported in the U.S. Most (99% or 702,748 cases) have been reported among adults and adolescents ages 13 and older; 8,596 cases have been reported among children under age 13. Between July 1998 and June 1999 alone, the most recent period for which data are available, more than 47,000 new AIDS cases were reported in this country.²

AIDS cases have been reported in all 50 states, the District of Columbia and the U.S. territories. Ten states and territories account for almost three-quarters (72%) of all AIDS cases reported since the beginning of the epidemic; these same states still rank among the top ten in newly reported AIDS cases for the most recent period. AIDS cases have been concentrated largely in urban areas and 10 U.S. metropolitan areas account for almost half (43%) of cumulative reported AIDS cases. However, because of geographic shifts in the epi-

dem, some of these metropolitan areas no longer ranked among the top 10 in the most recent period.²

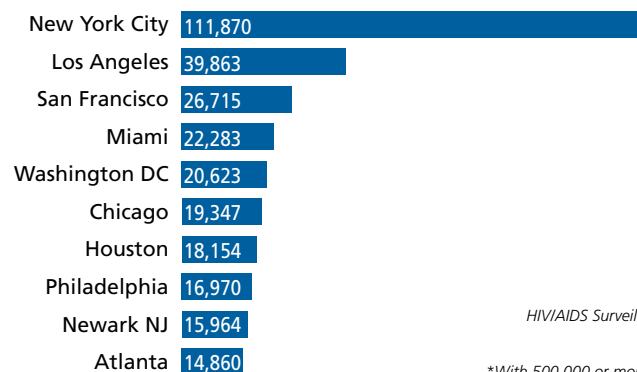
A combination of public education and prevention efforts and newer, more effective therapies have helped to slow the annual increase in the number of AIDS cases. While AIDS cases rose by 65-90% annually in the first decade of the epidemic, these rates decreased rather dramatically in the 1990s.³ In 1996, the number of new AIDS cases reported in the U.S. declined by 6% over 1995. Between 1996 and 1997, new AIDS cases

Ten States/Territories Reporting Highest Number of AIDS Cases, 1981-1999



Source:
CDC (1999),
HIV/AIDS Surveillance Report,
11 (No. 1).

Ten Metropolitan Areas* Reporting Highest Number of AIDS Cases, 1981-1999



Source:
CDC (1999),
HIV/AIDS Surveillance Report,
11 (No. 1)

*With 500,000 or more population

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What is HIV?

The human immunodeficiency virus (HIV) is the virus that causes AIDS. HIV is found in certain body fluids and can be spread through the following: blood, semen, vaginal fluid, breast milk, and other fluids containing bloods (e.g., cerebrospinal fluid surrounding the brain and spinal cord, synovial fluid surrounding bone joints, and amniotic fluid surrounding a fetus). HIV is passed from one person to another through sexual contact and blood-to-blood contact.

dropped another 18% and between 1997 and 1998, there was another 11% decline. These data indicate that while the number of new cases each year is still dropping, the rate of decline has slowed.²

AIDS Deaths

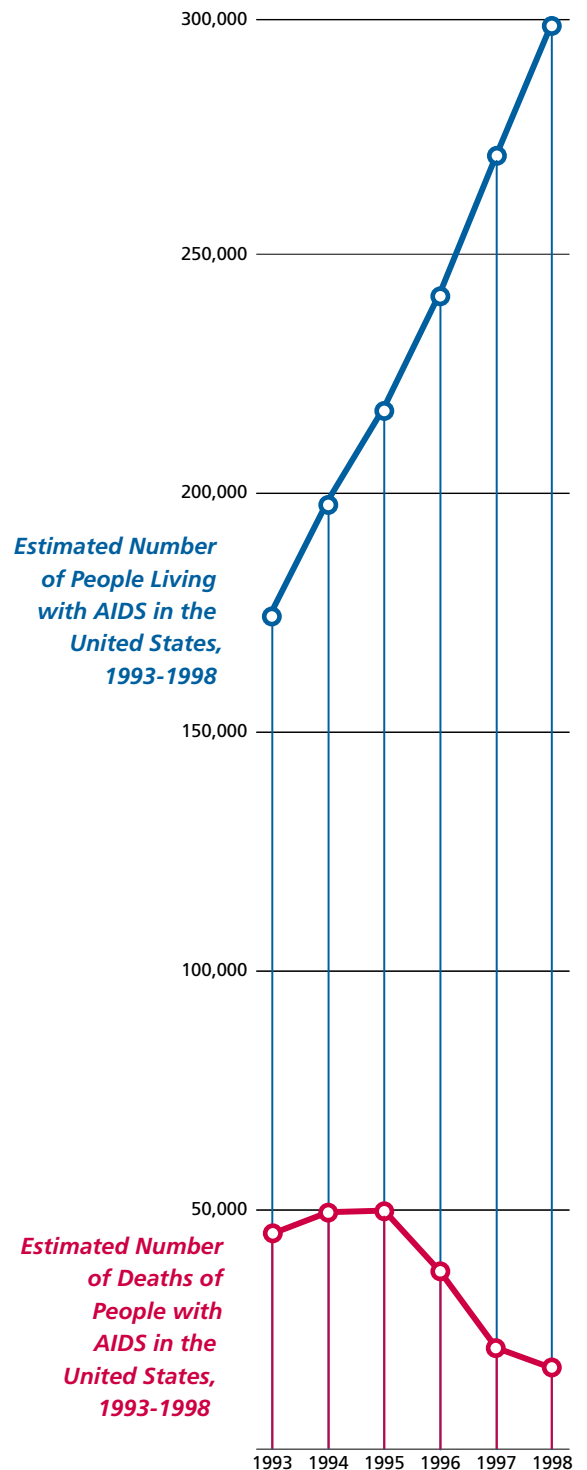
AIDS has become a leading cause of death in the U.S. for some populations and is the fifth leading cause of death among all Americans between the ages of 25 and 44.⁴ More than 420,201 Americans with AIDS have died, including 415,226 adults and adolescents and 4,975 children under age 15. Due primarily to new treatments and prevention and education efforts, AIDS-related deaths have declined in recent years, although this trend has been slowing. Between 1996 and 1997, the number of AIDS-related deaths declined by 42% followed by a 20% decline between 1997 and 1998.⁵ An estimated 17,171 persons died of AIDS-related causes in 1998 compared to 44,991 in 1993.²

People Living with HIV/AIDS

The Centers for Disease Control and Prevention (CDC) estimates that between 800,000 and 900,000 Americans are living with HIV (approximately 1 in 300 Americans) and an estimated 40,000 people become infected each year.^{5,6} New treatments have extended the lives of people with HIV leading to a rise in the number of people living with HIV/AIDS in the U.S. A record number of Americans – 297,136 – are estimated to be living with AIDS, the most advanced form of HIV infection, in this country, indicating a growing need for prevention, care and treatment services for this population.²

Modes of HIV Transmission

Primary modes of HIV transmission in the U.S. have been sexual intercourse and injection drug use. Since the epidemic began, almost half (48%) of all adult AIDS cases reported in the U.S. have been linked to sex between men and one quarter



Source:
CDC (1999),
HIV/AIDS Surveillance Report,
11 (No. 1).

What is AIDS?

AIDS stands for acquired immunodeficiency syndrome. A person who is infected with HIV receives an AIDS diagnosis in one of two ways. First, if they have been diagnosed with one or more of a group of medical conditions known as “opportunistic infections” that are closely associated with a depressed immune system. Second, even if they have not been diagnosed with one of these conditions but there is evidence that their immune systems have been depressed (this is shown by a diminished supply of CD4 cells in their blood).

(26%) have been linked to injection drug use. Ten percent of all cases have been linked to heterosexual sex, 6% to both sex between men and drug use, 1% to hemophilia/coagulation disorder, and 1% to receipt of a blood transfusion.² The remaining 9% of cases were categorized as either “other” or “risk not reported or identified.”^{2,7} More recently, however, transmission patterns have begun to shift, as an increasing proportion of HIV infections are estimated to be linked to heterosexual sex (33%) and a decreasing proportion linked to sex between men (42%). Injection drug use still accounts for an estimated one quarter of new HIV infections (25%).⁵ Patterns of transmission vary by age, race/ethnicity, and gender.

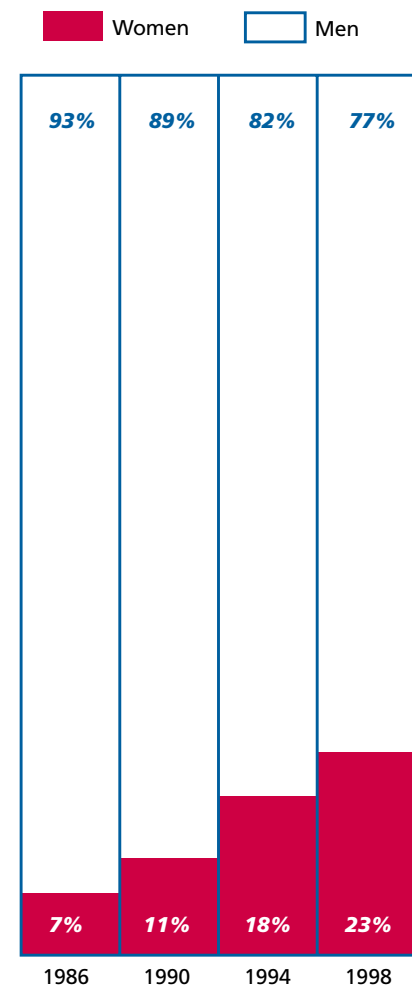
Impact of HIV/AIDS on Women

Of the more than 700,000 cases of AIDS reported among adults/adolescents since 1981, 84% have been reported among men and 16% have been reported among women. The impact of HIV/AIDS on women, however, has grown substantially since the beginning of the epidemic. The proportion of AIDS cases reported among women each year has more than tripled, from 7% in 1986 to 23% in 1998.⁸ Women represent a growing proportion of Americans living with AIDS. In 1992, 14% of Americans living with AIDS were women; by 1997, the proportion was up to 19%. CDC estimates that between 120,000 and 160,000 American women are now living with HIV.⁹

In addition, while the number of AIDS-related deaths among women is declining, as it is for the population overall, AIDS is still the fourth leading cause of death for women ages 25-44, the second leading cause of death among African-American women in this age group and third leading cause among Latinas in this age group.⁴ African American women represent a growing proportion of AIDS cases reported among women, accounting for nearly two-thirds (62%)

of new AIDS cases in 1998 compared to 52% in 1990 and 57% in 1994.⁸ African American women also represent a greater proportion of new AIDS cases reported among African Americans than white women do among white Americans; African American women accounted for almost one third (31%) of new cases reported among African Americans in 1998 while white women accounted for only 13% of cases among whites. Latinas accounted for 21% of new cases reported among all Latinos.¹⁰

Adult Women as a Proportion of Newly Reported AIDS cases



Source: CDC, HIV/AIDS Surveillance Reports

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How is HIV transmitted?

HIV can be transmitted from one person to another when the blood, semen, vaginal fluid, or breast milk of an HIV-infected person enters another person's body. This can occur through a vein (during injection drug use); the vagina, anus or rectum; the mouth; or through cuts and sores. The most common ways of transmitting HIV are sexual intercourse, sharing needles or injection equipment, or during childbirth or breastfeeding. HIV can be transmitted through a blood transfusion but that risk is quite low because all donated blood in the U.S. is tested for HIV. HIV does not survive well in the environment making the possibility of casual or passive transmission highly unlikely. Unbroken human skin is an effective barrier to HIV and latex products (gloves, condoms, etc.) provide strong protection.

There has been a shift in the source of most HIV infections among women. In 1998, more women with AIDS were infected through heterosexual exposure than any other cause, followed by injection drug use. A large proportion of women were infected through having sex with an injection drug user.⁹

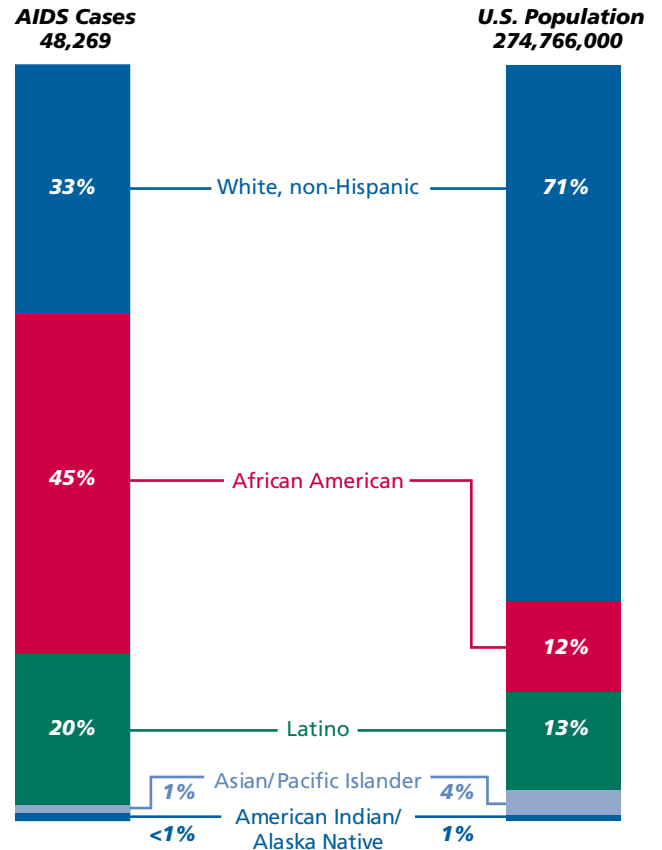
Impact of HIV/AIDS on Racial and Ethnic Minority Americans

The HIV/AIDS epidemic has had a dramatic impact on racial and ethnic minority Americans since the beginning of the epidemic. African Americans represent 37% (262,317) of all AIDS cases ever reported to CDC and Latinos represent 18% (129,555) of all cases. Less than 1% of reported cases have been among Asian/Pacific Islanders and American Indian/Alaska Natives (5,133 and 2,033 cases respectively).²

The disproportionate impact of the epidemic on racial and ethnic minorities has been increasing, and minority Americans now represent the majority of new AIDS cases and of Americans living with AIDS in the United States. African Americans represented almost half (45%) of new AIDS cases reported in the U.S. in 1998 yet only 12% of the population. Similarly, Latinos represented 20% of new AIDS cases but only 13% of the population.^{2,11} Together, African Americans and Latinos represented two-thirds of new AIDS cases but only one-quarter of the population. African Americans also represent 40% of the more than 290,000 people estimated to be living with AIDS in the U.S., and Latinos represent 20%.^{2,10}

In addition, the AIDS case rate (cases per 100,000 population, which provide a measure of the impact of the epidemic standardized to population size)

Newly Reported AIDS Cases and Estimated U.S. Population by Race/Ethnicity, 1998



Source: CDC (1998), HIV/AIDS Surveillance Report, Vol. 10, No. 2; US Bureau of the Census, 1998

among African Americans was almost 9 times the rate among whites in 1998 (84.7 per 100,000 compared to 9.9). The rate among African American men was more than 7 times higher than among their white counterparts (125.2 compared to 17.8). Among black women, the gap was even greater – 49.8 compared to 2.4 among white women – more than 20 times higher.¹⁰

Although the number of AIDS-related deaths have declined among all racial and ethnic groups, the decline has been slower among African Americans and Latinos. HIV remains the leading cause of

death among African Americans between the ages of 25 and 44 and the third leading cause of death among Latinos in this age group.⁴

Impact of HIV/AIDS on Adolescents and Young Adults

HIV/AIDS has had a significant impact on young Americans, including teenagers and young adults. AIDS is one of the leading causes of death among people ages 25-44, many of whom were first infected with HIV when they were in their teens or early 20s. At least one-half of all new HIV infections are estimated to be among people under the age of 25 and the majority of young people are infected sexually.¹²

Most young men are infected through sex with other men. In 1998, half (51%) of all AIDS cases reported among young men ages 13 to 24 were among young men who have sex with men, 10% were among injection drug users (IDUs), and 9% were among young men infected heterosexually. Most young women in this age group are infected heterosexually. In 1998, almost half (47%) of young women were infected heterosexually and 14% were infected through injection drug use.¹²

Young women and young minority Americans have been particularly affected. Young women represented almost half (49%) of new AIDS cases reported among 13-19 year-olds in 1998. Young African Americans represented more than half (57%) of new AIDS cases reported among 13-19 year-olds in 1998 and Latinos represented almost one quarter (23%) of new cases in this age group.¹³

Impact of HIV/AIDS on Children

Since the beginning of the epidemic, 8,596 children under the age of 13 have been reported with AIDS. Almost 5,000 deaths reported have been among those under the age of 15. Minority children have been disproportionately

affected. Among AIDS cases reported in the most recent period, almost two thirds (63%) were among African American children and one quarter (25%) were among Latino children. The vast majority (92%) of children have been infected through their mothers.² During the early 1990s, an average of 1,000 to 2,000 infants were born with HIV each year. Following the discovery that treatment with zidovudine (AZT) during pregnancy, childbirth, and during a newborn's early life can reduce the chance of HIV transmission, these rates have been dramatically reduced. Between 1993 and 1998, the number of perinatally-acquired cases of AIDS dropped significantly.¹⁴

THE FEDERAL RESPONSE TO THE HIV/AIDS EPIDEMIC

The Federal government has responded to the challenges presented by the HIV/AIDS epidemic with the expenditure of Federal funds and the enactment of a series of laws authorizing activities to foster research, prevention, treatment, and care related to HIV/AIDS.

Much of the Federal response has been accomplished through the annual appropriations process and through the general authorities of the Federal agencies involved – primarily in the Department of Health and Human Services (e.g., the National Institutes of Health, the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and the Substance Abuse and Mental Health Services Administration) and also at the Departments of Defense, Veterans Affairs, Housing and Urban Development, and the Agency for International Development. In addition to these discretionary spending accounts, the Federal government has expended a significant amount through entitlement programs, including Medicaid, Medicare, Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

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Federal Spending

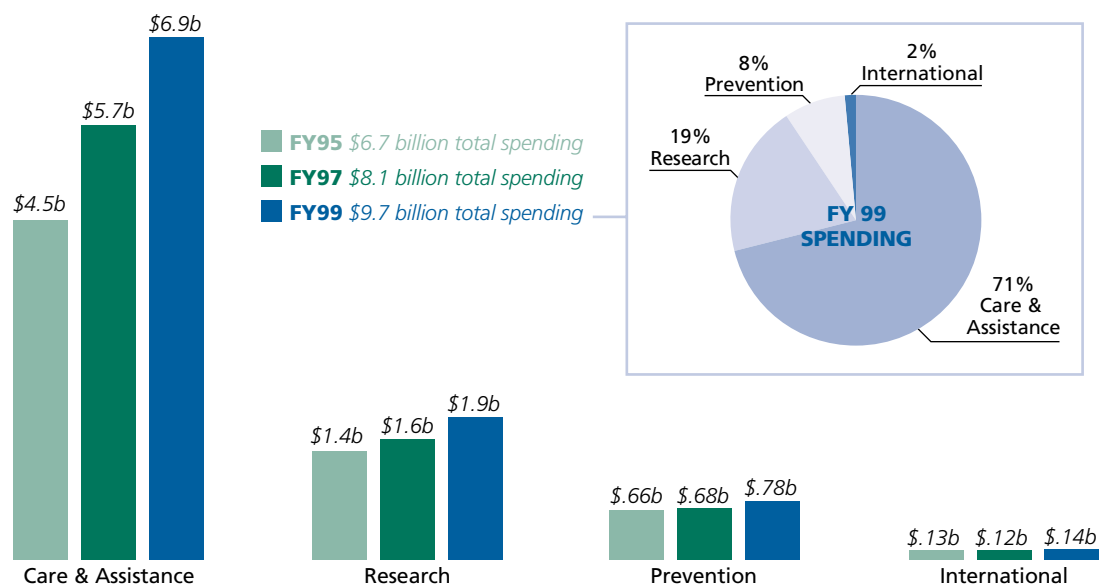
In fiscal year 1999, the Federal expenditure on HIV/AIDS related programs totaled \$9.7 billion, or 0.5% of total Federal spending.¹⁵ Of that amount, \$6.9 billion (71%) was spent on care and assistance to people with HIV/AIDS, \$1.9 billion (19%) was spent on AIDS research, \$775 million (8%) was spent on AIDS prevention, and \$142 million (2%) was spent on international AIDS efforts.

FY 1999 HIV/AIDS spending included the following:

- \$2.1 billion (22%) for the Federal share of Medicaid spending on people with HIV/AIDS¹⁶;
- \$1.8 billion (19%) for AIDS research at the National Institutes of Health;
- \$1.5 billion (15%) for Medicare spending on people with HIV/AIDS;
- \$1.4 billion (15%) for the Ryan White CARE Act;
- \$776 million (8%) for Social Security Disability Insurance (SSDI);
- \$678 million (7%) for AIDS prevention and surveillance at the CDC;
- \$403 million (4%) for HIV/AIDS care for veterans at the VA;
- \$360 million (4%) for Supplemental Security Income payments;
- \$225 million (2%) for the Housing Assistance for People with AIDS (HOPWA) program; and,
- \$463 million (5%) for other care, assistance, research, prevention, and international programs.

Between FY 1995 and FY 1999, Federal HIV/AIDS spending increased by almost \$3 billion. Over the five-year period, total HIV/AIDS spending was \$40.6 billion.

Total Federal HIV/AIDS Spending by Category, FY1995 - FY1999



Source: Kaiser Family Foundation (1999), *Federal HIV/AIDS Spending: A Budget Chartbook*, August.

Major HIV/AIDS-Related Laws

Congress has acted to authorize activities related to HIV/AIDS through a series of laws. Major HIV/AIDS laws passed by Congress include:

- **The Health Omnibus Programs Extension Act of 1988** authorized the use of Federal funds for AIDS education and prevention as well as HIV-antibody testing at anonymous testing sites.
- **The Ryan White Comprehensive AIDS Resources Emergency Act of 1990** (Public Law 101-381) authorized funds to "improve the quality and availability of care for individuals and families with HIV disease." The CARE Act included emergency relief grants to metropolitan areas with high numbers of AIDS cases; grants to States to improve the quality, availability, and organization of services to individuals and families with HIV disease; and grants for HIV early intervention services. **The Ryan White CARE Act Amendments of 1996** (Public Law 104-146) reauthorized the CARE Act for an additional five years and modified the formulas used to allocate funds to cities and states.
- **The Housing Opportunities for People with AIDS (HOPWA) Act of 1991** (Public Law 101-625) created a new program to provide housing assistance to low-income people living with AIDS. HOPWA funds are allocated to states and cities based on a formula keyed to the number of AIDS cases and the incidence of AIDS. Another 10% of HOPWA funds are awarded competitively.
- **The National Institutes of Health Revitalization Act of 1993** (Public Law 103-43) created a permanent, independent Office of AIDS Research at NIH and required the director of that office to "act as the primary Federal official with responsibility for overseeing all AIDS research conducted or supported by NIH."

- **The Ricky Ray Hemophilia Relief Fund Act of 1998** (Public Law 105-369) mandated a single payment of \$100,000 to any individual infected with HIV if the individual has any blood-clotting disorder and was treated with blood-clotting agents between July 1, 1982, and December 31, 1987 (or if the person is the lawful current or former spouse of such an individual, or acquired HIV infection from a parent who is such an individual).

Other Key Laws & Initiatives

In addition to these AIDS-specific laws, several more general laws are particularly important to the lives of people with HIV/AIDS. They include:

- **The Americans with Disabilities Act of 1990** (Public Law 101-336) prohibited discrimination against any qualified individual with a disability in employment, public services, telecommunications, or public accommodations. People living with HIV and AIDS have been protected against discrimination under the terms of the ADA.
- **The Health Insurance Portability and Accountability Act of 1996** (Public Law 104-191) regulated the sale of private health insurance in the small group and (to a lesser extent) individual policy markets by requiring insurers to offer insurance to anyone willing to purchase a policy, requiring the renewal of those policies, and limiting the amount of time a person's "pre-existing medical condition" – including HIV – can be excluded from coverage.
- **The Work Incentives Improvement Act of 1999** (Public Law No. 106-170) expanded State options under Medicaid by creating new Medicaid buy-in options for working individuals with disabilities and extended Medicare coverage for working individuals with disabilities. The Act also authorized state demonstration programs to provide Medicaid to workers with

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potentially severe disabilities – including HIV/AIDS – who are not yet disabled but whose health conditions could be expected to cause disability.

Finally, in addition to these major pieces of legislation, there have been several important national initiatives designed to address the HIV/AIDS epidemic. These include **HIV Prevention Community Planning**, which established community planning bodies and processes at the state, regional, and local levels throughout the United States, and the **HIV/AIDS Vaccine Initiative**, which increased funding for and focused on the development of an HIV vaccine. Most recently, the Congressional Black Caucus' **Minority AIDS Initiative** secured additional appropriations to address the disproportionate impact of HIV/AIDS in minority communities.

CONCLUSION

In its nearly 20-year history, the HIV/AIDS epidemic has presented the U.S. with enormous challenges

that have required the combined efforts of Federal, State and Local government; health care professionals, public health professionals and medical researchers; community-based and international organizations; patient advocates; private charities and foundations; and many others. These efforts have produced tremendous progress in the fight against HIV/AIDS and offered some optimism in the context of the epidemic. However, despite the benefits presented by new treatments, many face financial and other access barriers to HIV care. In addition, 40,000 Americans still become infected with HIV each year and the number of people living with HIV/AIDS is rising. Moreover, communities of color, women, and young people continue to be impacted by HIV/AIDS at alarming rates. Together, these trends create new challenges for policymakers, program administrators, health care professionals, advocates, and others and underscore the need to continue national, state, and local efforts to address the epidemic in the United States.



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End Notes

- ¹ Centers for Disease Control and Prevention (1981), "Pneumocystis Pneumonia - Los Angeles," *Morbidity and Mortality Weekly Report*, June;30.
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- ⁴ National Center for Health Statistics (1999), "Deaths: Final Data for 1997," *National Vital Statistics Reports* Vol. 47, No., 19, June.
- ⁵ Centers for Disease Control and Prevention (2000), *CDC Update: A Glance at the HIV Epidemic*, February.
- ⁶ Centers for Disease Control and Prevention (1999), "CDC Guidelines for National HIV Case Surveillance, Including Monitoring for HIV Infection and AIDS", *Morbidity and Mortality Weekly Report*, 48:RR-13, December.
- ⁷ Such cases refer primarily to persons whose mode of exposure was not reported and who have not been followed up to determine their mode of exposure.

- ⁸ Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Reports*.
- ⁹ Centers for Disease Control and Prevention (1999), "HIV/AIDS Among U.S. Women: Minority and Young Women at Continuing Risk," August.
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- ¹² Centers for Disease Control and Prevention (1999) "Young People at Risk: HIV/AIDS Among America's Youth," August.
- ¹³ Center for Disease Control and Prevention (1998), *HIV/AIDS Surveillance in Adolescents*, L265 slide series.
- ¹⁴ Centers for Disease Control and Prevention (2000), "Status of Perinatal HIV Prevention - U.S. Declines Continue: Hope for Extending Success to Developing World", January.
- ¹⁵ Kaiser Family Foundation (1999), *Federal HIV/AIDS Spending: A Budget Chartbook*, August.
- ¹⁶ An additional \$1.8 billion was spent by states on Medicaid services for people with HIV/AIDS, for a combined total of \$3.9 billion federal and state Medicaid spending.

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