

HIV/AIDS, the Government, and Minorities in the United States, 1981-2001

by
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The first known cases of Acquired Immune Deficiency Syndrome (AIDS) in the United States occurred in 1981. Young Caucasian males in the United States were dying of a rare form of cancer usually found only in older Jewish men of Mediterranean descent. Something was attacking and destroying the immune system to such an extent that it was possible for young men to contract this cancer. In 1984, three years after the first reports of the new disease, researchers discovered the virus that caused the disease and named it the human immunodeficiency virus type 1 (HIV-1). By 1998, some 270,000 Americans had lost their lives to AIDS.¹ Starting in the late 1980s, however, progression of the disease through the population shifted and changed. What was once primarily a disease of young, white, gay males, became a heterosexual disease that is decreasing among Caucasians but exploding among minority populations. This explosion occurred (and continues to do so) in spite of huge federal, state, and local educational campaigns and massive amounts of money and programming that targeted these population groups.

HIV-1 is the form of the virus usually found in the United States. Scientists discovered that the virus lives in all secretions of the human body and can be easily transferred from person to person, especially by blood, semen and vaginal secretions. The virus enters the body and attacks cells in the immune system, destroying them. In 1986, a second type of HIV, called HIV-2, was found in AIDS patients in West Africa. HIV-2 infections are primarily found in Africa. HIV-2 is a slower moving virus that is less infectious in its early stages than HIV-1, though infectiousness tends to increase as the disease advances.²

Although HIV is a retrovirus, it is part of a family or group of viruses called lentiviruses. This type of virus occurs in a wide range of primates, and it is now generally accepted that HIV is a descendant of simian (monkey) immunodeficiency virus (SIV). Scientists have long known that certain viruses can pass from animals to humans through a process called zoonosis. Researchers have concluded that

HIV could have crossed over from chimpanzees when chimps were killed and eaten as food. A second possibility is contamination by the virus of batches of polio vaccine that were created using chimp kidneys. This vaccine was given to about a million people in the Belgian Congo, Ruanda and Urundi in the late 1950s, though the company which created the vaccine has claimed that all remaining samples of the vaccine have since been tested and have shown no sign of containing the HIV virus. The earliest known instances of HIV infection were found in a plasma sample taken in 1959 from an adult male living in the Congo, in a tissue sample from an African-American teenager who died in St. Louis in 1969, and in tissue samples from a Norwegian sailor who died around 1976.³

In 1985 researchers discovered that HIV targets mainly the T-cells that operate as part of the immune system. The virus attaches itself to the cell wall, discharges its DNA into the cell, and takes over the nucleus so that the cell becomes a factory for the creation of more HIV virus. In time the T-cell ruptures and dies, and the virus that has been created bursts from the dying cell to attack and take over new T-cells. By damaging and destroying the cells of the immune system, HIV interferes with the body's ability to effectively fight off viruses, bacteria and other diseases, thereby making a person with HIV susceptible to a great number of opportunistic infections that would not effect anyone with an intact immune system. When enough T-cells have been destroyed that a person's total number of T-cells fall below 200, the person is said to have AIDS. People with AIDS become weak as their bodies attempt to fight off infections like pneumonia, yeast infections, dysentery, meningitis and certain types of cancer.⁴

The HIV virus is extremely small and difficult to detect. A test was therefore developed to look for antibodies to the disease. These antibodies show that the body is under attack by the virus and is attempting to fight it off. There is a window period between initial infection and testing positive for the antibodies. Unfortunately, a person is infectious during this window period, which has been estimated at anywhere from a few weeks to six months.

The first cases clearly identified as AIDS in 1981 were traced to a Canadian flight attendant named "Patient Zero" who traveled extensively. Several of the early cases of AIDS in the United States showed

that the infected individuals had either direct or indirect sexual contact with this single source. All the early victims were young white males in their twenties. At this point, the disease seemed to be confined to the Gay community. Very soon it was discovered, however, that blood transfusions were also part of the early spread of the disease. Blood from thousands of individual donors was pooled to create a product called Factor VIII which aided blood clotting. Factor VIII was then distributed world-wide and infected hemophiliacs who became the second group to suffer heavily from the disease. Heavy drug use, particularly heroin, which followed the Vietnam War in the 1970s also contributed to the spread of the disease. Shooting galleries where people could buy drugs and rent drug equipment provided a route of disease transmission. Needles contaminated with infected blood were shared, and the disease spread. Infected women, it was discovered, could also pass the infection to their babies during pregnancy, delivery, or through their breast milk.⁵

This began the transition of the disease from a homosexual disease, to a disease that could affect everyone. The main route of transmission shifted from homosexual sexual transmission, to heterosexual transmission, transmission through contaminated needles with drug use, and transmission from mother to child.

Today, HIV infection is the fifth leading cause of death for people who are 25-44 years old in the United States. It is the leading cause of death for African American men in the same age group. In the United States, the cumulative number of reported AIDS cases from the beginning of the epidemic in 1981 through June 1996 was 548,102. In 1996 alone, 148,705 cases were reported, and 343,000 deaths from AIDS had occurred. In 1996, 47 percent of AIDS victims were Caucasian, 34 percent were African-American, 17 percent were Hispanic, and 1 percent were Asian or Native American. Women accounted for only 14 percent of the total case count and men accounted for 84 percent. Adult infections accounted for 98 percent of all cases, and pediatric and adolescent cases were rare at less than 2 percent. From 1996 to 1998, overall AIDS incidence (the number of people with HIV who progress to AIDS each year) declined rapidly, falling 38 percent among Caucasians and 23 percent among African Americans. AIDS deaths during those years showed a similar pattern, declining

58 percent among Caucasians and 44 percent among African Americans.⁶

The number of individuals living with the disease, however, has increased with the introduction of antiviral drugs that slow the progression of the disease. Since 1998, the falling rates of AIDS cases have stalled among African Americans. In 2001, the AIDS rate among African Americans was 9 times that reported among Caucasians. The rate of infection among other minorities, women, and young people is also increasing at an alarming rate. The rate of new infection among Hispanics in the year 2000 was 22.5 per 100,000 population, three times the infection rate for Caucasians. Though African Americans and Hispanics represent about one-quarter of the country's population, more than 50 percent of the new AIDS cases in 2000 were among these populations. In 2001, African Americans accounted for 50 percent of the new infections reported, and Hispanics accounted for another 19 percent. Males still account for the largest proportion of AIDS cases among both Hispanics (81%) and African-Americans, but the number of women in both these population groups is growing quickly. Among children, the disparities are even greater, with African American and Hispanic children representing more than 80 percent of pediatric AIDS cases in 2000. Approximately 78 percent of HIV-infected women are minorities and most become infected through heterosexual transmission and drug use.⁷

African-American women accounted for nearly 64 percent of HIV cases reported in 2001. They are becoming infected at a rate four times greater than Hispanic women, and 16 times greater than Caucasian women. An increasing number of women contracting the virus in the African-American community are getting the disease from husbands and boyfriends, who, though they consider themselves to be heterosexual, are having sex with other men or are participating in other high risk activities (bi-sexuality, multiple partners and drug use). African Americans have been reluctant to acknowledge and deal with sensitive issues, such as homosexuality and drug use, that are associated with HIV infection. From 1989-1996, racial minority men who have sex with men accounted for only 31 percent of the AIDS cases in that group. By 1998, AIDS cases from racial/ethnic minorities infected through homosexual acts had increased to 52 percent. Women

are not protecting themselves. It is possible that women who suspect that their partners are at risk for HIV infection may be reluctant to try to negotiate condom use for fear that the man will physically abuse them or withdraw financial support. These women in turn are passing the disease on to their children.⁸

Heterosexual contact also accounts for the largest proportion of Hispanic women contracting AIDS. These infections have been linked largely to women having sex with injection drug users. Transmission related to substance abuse is a significant problem among Hispanics in the United States. Some high-risk behaviors associated with drug abuse (such as shooting galleries) may be more prevalent among this population.⁹

The increasing incidence and prevalence of HIV/AIDS in minority populations was noted, and in 1985, the U.S. Department of Health and Human Services, (HHS) created the Office of Minority Health. The Centers for Disease Control and Prevention (CDC) created its own Office of Minority Health (OMH) in 1988, and in 1990, Congress passed the "Disadvantaged Minority Health Act of 1990" to improve the health status of underserved populations, including racial and ethnic minorities. In spite of all these new offices and programs, a 1991 study in Connecticut that surveyed 800 Hispanics and African Americans found that that only 35 percent of those surveyed were aware of AIDS services, that only 10.6 percent had utilized these services, and only 23.5 percent had been tested for HIV. Among all respondents, women were more likely to have received services than men (13.4% vs. 7.2%), and Hispanics were more likely to have received services than African Americans (18.5% vs. 5.4%).¹⁰

The government increased its efforts. In 1997, the Health Resources and Services Administration (HRSA) announced a formal consolidation of the major federally funded HIV/AIDS programs for low-income and uninsured persons under a new HIV/AIDS Bureau. This bureau houses \$1 billion in programs authorized under the Ryan White Comprehensive AIDS Resources Emergency Act. These activities include early intervention services, pediatric AIDS demonstration projects and training for health care and social-service professionals.¹¹

Another major initiative was launched in 1999. This initiative, called REACH 2010 (*Racial and Ethnic approaches to Community Health*) is a cornerstone of the CDC's efforts to eliminate racial and ethnic disparities in health. One of the six agenda items for REACH is to decrease HIV infections/AIDS among minority groups (about minority health). The Healthy People Initiative, which has been the Nation's main prevention and health promotion agenda for the last two decades, now has as its second goal for Healthy People 2010, to eliminate health disparities among different segments of the population that occur by gender, race or ethnicity, education or income, disability, geographic location or sexual orientation.¹²

The AIDS Drug Assistance Program (ADAP) is now available to provide medications for the treatment of HIV disease, and program funds may be used to purchase health insurance for eligible clients. Approximately 128,078 people received medications through ADAP in 2000. None had adequate health insurance or the financial resources necessary to cover the cost of medication. Highly Active Antiretroviral Therapy (HAART) is the standard of care for the majority of people living with HIV/AIDS. It costs approximately \$12,000 per year or more, in addition to the costs of addressing opportunistic infections, side effects, and other treatment issues. Many clients are enrolled in ADAP temporarily while they wait to be accepted for Medicaid. The demand is growing rapidly among minorities as the epidemic among minorities increases. Minorities have historically experienced higher risk for poverty, lack of health insurance, multiple diseases, and are less likely to use the health care system. The result is a growing number of individuals living with AIDS who need public support.¹³

Medicaid is the largest single payer of direct medical services for people living with AIDS. It serves 55 percent of all people and up to 90% of children with the disease. It is estimated that 218,000 people with AIDS in the United States were served by the Medicaid program in 2002. Expenses for servicing this population were \$7.7 billion dollars.¹⁴

Of the \$744 million that the CDC received for domestic HIV/AIDS prevention in 2001, over 40 percent supported activities targeted to reduce HIV/AIDS among African Americans. The CDC

also funds hundreds of community-based organizations for HIV prevention programs designed to reach African Americans across the nation.¹⁵

Research efforts are also increasing. The National Institute of Allergy and Infectious Diseases (NIAID) is the lead component for AIDS research at the National Institutes of Health (NIH). NIAID is leading the war against this continuing health crisis that is disproportionately affecting minority populations. NIAID supports scientific research at universities, medical schools, hospitals, and research institutions. NIAID's AIDS research agenda includes conducting clinical trials that address the specific needs and concerns of minority populations, ensuring that minority patients have access to all clinical trials and to the latest information on AIDS treatment and prevention. In addition, NIAID's Office of Special Populations Research and Training encourages research aimed at improving the health of minority populations and also works to increase the effectiveness of outreach and education programs. Through the Office of Communications and Public Liaison and the Dale and Betty Bumpers Vaccine Research Center, NIAID also works with community-based organizations to disseminate information about HIV infection, AIDS, and NIAID research activities, especially HIV vaccine development, to minority groups.¹⁶

NIAID has several specific programs doing HIV/AIDS research. The Adult AIDS Clinical Trials Group (AACTG) and the Pediatric AIDS Clinical Trials Group (PACTG) have been researching ways to interrupt mother-to-infant transmission. In 2002, 6,191 individuals were enrolled in AACTG. Of these, 26 % were African American, 19 % were Hispanic and 1% were Asian/Native American. Also in 2002, 7,764 participants were enrolled in PACTG. Of these, 47 % were African American, 25% Hispanic, and 1% were Asian/Native American.¹⁷

The Terry Bein Community Programs for Clinical Research on AIDS (CPCRA) is a network of community-based health centers and clinics that support clinical research in community settings. CPCRA conducts large comparative studies that examine ways to use available therapies more effectively and examines the long term consequences of different treatments. In 2002, 3,444 people participated

in CPCRA studies. Of these, 49% were African American, 13% were Hispanic, and 1% were Asian/Native American.¹⁸

The HIV Prevention Trials Network (HPTN) is doing research on microbicides, designed to kill the HIV and other sexually transmitted viruses. It is looking at disease prevention and treatment, behavioral and barrier interventions, antiretroviral drugs, intervention related to drug abuse, and methods for reducing mother to child transmission. They have directed their educational outreach efforts to minority communities. In the HPTN program, 57% of the participants were African American, 5% were Hispanic and 9% were Asian/Native American.¹⁹

NIAID also conducted and supported research through the Women and Infants Transmission Study (WITS/WITSII), and the Women's Interagency HIV Study (WIHS). Ninety percent of the women in these studies were from minority populations.²⁰

For 2010, Public Health agencies are planning new ways to reduce HIV infection among minority populations. They plan to increase services to diagnose HIV early. They also want to make appropriate health services more available, provide early and equal access to health care and drugs for at least 75 percent of low-income people living with HIV/AIDS, and educate medical providers so that Medicaid-eligible women and HIV-infected children can receive clinical care. Providers must ensure that more people in minority populations know if they are HIV positive, receive appropriate counseling and treatment, and have early access to medical care to prevent or delay AIDS. It has been determined by government agencies that information on AIDS also needs to be made available in languages other than English and in low literacy formats.²¹

In spite of these continuing efforts in diagnosis, treatment, research and accessibility for minorities, the number of new HIV/AIDS cases, the number of individuals living with the disease, and the number of deaths from AIDS among minorities continues to grow (Table 1).

Table 1

AIDS Cases in the United States as of December 31, 2000^{1,2}

<i>Number of Cases</i>	<i>Caucasian</i>	<i>African-American</i>	<i>Hispanic</i>	<i>Asian/ Native American</i>
Number of New Cases	11,953	20,048	6,820	560
Living with AIDS	126,772	136,160	55,561	3,986
Deaths from AIDS	5,083	8,490	2,372	162

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