



## **FOLLOWING THE MONEY:**

**TRACKING FEDERAL AIDS APPROPRIATIONS TO ADDRESS  
DISPARITIES IN HIV AND AIDS TREATMENT IN THE UNITED STATES**

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**PREPARED FOR THE JOINT CENTER FOR POLITICAL AND ECONOMIC STUDIES**

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## PREFACE

The toll of HIV/AIDS in the United States has eased in recent years, thanks to extensive efforts to combat the disease through prevention, detection, and treatment. Beginning in the mid 1990s, advances in HIV treatments slowed the progression of HIV infection to AIDS, and better treatments also led to dramatic decreases in deaths among persons with AIDS. But HIV/AIDS still disproportionately affects communities of color. African Americans accounted for over half (51%) of the estimated number of HIV/AIDS diagnoses made during 2007, followed by whites (29%) and Hispanic/Latinos (18%).

These disparities raise the question: has the federal government been responsive to the needs of communities of color? This report—*Following the Money: Tracking Federal AIDS Appropriations to Address Disparities in HIV and AIDS Treatment in the United States*—finds that there is more work to be done to ease the burden of HIV/AIDS in communities of color.

The report finds that HIV/AIDS is not one epidemic in the United States but rather has become multiple epidemics, affecting different communities at different rates and through different vectors of transmission. Tragically, some of the communities least prepared to deal with the spread of HIV are communities that are most vulnerable and have received the least federal resources to combat the disease.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 was structured to address the social and medical needs of those infected with HIV. This report finds that the Act's funding formula disproportionately favored established communities inhabited by older, white homosexual populations who were generally well-organized and politically sophisticated. And although HIV infection rates in rural, Southern communities—which are primarily African American communities—have been growing faster than anywhere else in the United States, the existing Ryan White funding structure has not addressed this phenomena, and these communities have obtained proportionately less funding than other communities with similar or smaller numbers of AIDS cases.

There are several strategies needed to ensure that resources flow to communities proportionate to need. For example, the CARE Act has retained a provision mandating that 75% of the core funding be used for “direct medical services,” which does not address the differing stages of the multiple regional epidemics. Omitting this funding limitation could provide federal leadership with greater flexibility to meet the needs of vulnerable communities. In addition, policymakers should actively assess the adequacy of funding streams to ensure that emerging epidemics are addressed.

We have seen that HIV/AIDS can be successfully curtailed, leading to the hope that the epidemic can one day be eradicated. Now we must work to ensure that all communities benefit equally from these advances.

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*Ralph B. Everett*

*President and CEO*

*The Joint Center for Political and Economic Studies*



## EXECUTIVE SUMMARY

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act 1990 was structured to address the social and medical needs of those infected with HIV. In the 20 years since the law's enactment, our knowledge and treatment of the disease have changed, the demographics of the disease have shifted, and the American epidemic has transformed into multiple epidemics. As a result, today the funding structure of the CARE Act is outmoded and antiquated.

In our effort to determine whether the CARE Act adequately addresses the needs of the minority AIDS population, we found:

1. The Minority AIDS Initiative (MAI) was established in 1998, after the introduction of highly active antiretroviral therapy (HAART), and has developed a multi-pronged approach to finding solutions that could mitigate the impact of the AIDS epidemic – HIV prevention, care, treatment and research. Since the characteristics of the AIDS epidemic had changed by 1998, the MAI approach targeted not just gay men but the entire minority community. Thus, the policy shifts expressed in the CARE Act and the MAI have been heightened through the appropriations and funding processes.
2. The funding formula disproportionately favored established, older communities inhabited by older, white homosexual communities who were generally organized and open with their orientation.
3. Although the Centers for Disease Control and Prevention (CDC) and other federal agencies have known that AIDS infection rates in rural, Southern communities, which are primarily African American communities, have been growing faster than anywhere else in the United States, the existing Ryan White funding structure has not addressed this phenomena, and these communities have obtained proportionately less funding that other communities with similar or smaller numbers of AIDS cases.
4. Initially, the demographics and care funding formulae of the epidemic favored larger, established gay communities, where those with HIV were more apt to report infections.
5. As the demographics of the disease shifted to reflect more HIV infections within the African American gay community and among African American women – communities that tend to have the shortest lifespan after reporting the infection and that are less apt to publicly report HIV – the CARE Act formulae and reporting requirements have not been able to comprehensively capture the data on these populations and provide care and education consistent with these groups' infection rates.
6. The CARE Act was originally structured to address active AIDS, not HIV cases, and the Department of Health and Human Services' reliance on CDC data for CARE Act funding does not accurately reflect the depth of the epidemic or the regions where transmission rates are surging. Even with the recent changes in state legislation to mandate names reporting, the data collected do not comprehensively reflect the breadth of the infection. Penalties applied to grant funding under the CARE Act for failure to comply with names reporting requirements are outdated and not appropriate, as all states have changed their AIDS/HIV reporting requirements and limitations on funding can impede control/containment of the epidemic.
7. Neither the CARE Act nor the standard analysis of CDC data effectively capture the multiple AIDS epidemics occurring in the United States, not to mention the differing needs of the infected populations within each of these communities. In failing to address the unique needs of each of the epidemics, the government has not been able to stem the illness.

Each component of the problem stymies the development of programs and services and the allocation of funding to address the unique needs of the minority AIDS community. This paper will address these issues with a focus on the problems associated with the demographic and epidemiological deficiencies incorporated into the Ryan White Care Act of 1990 and its successor, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act reauthorization in 2006. As many of the CARE Act formulae issues have been recently addressed in other studies and publications, we analyzed the CARE Act structure, budget, and appropriations to determine how changes in the act would ensure that MAI funding is directed to communities of color to end the epidemic. And, while the

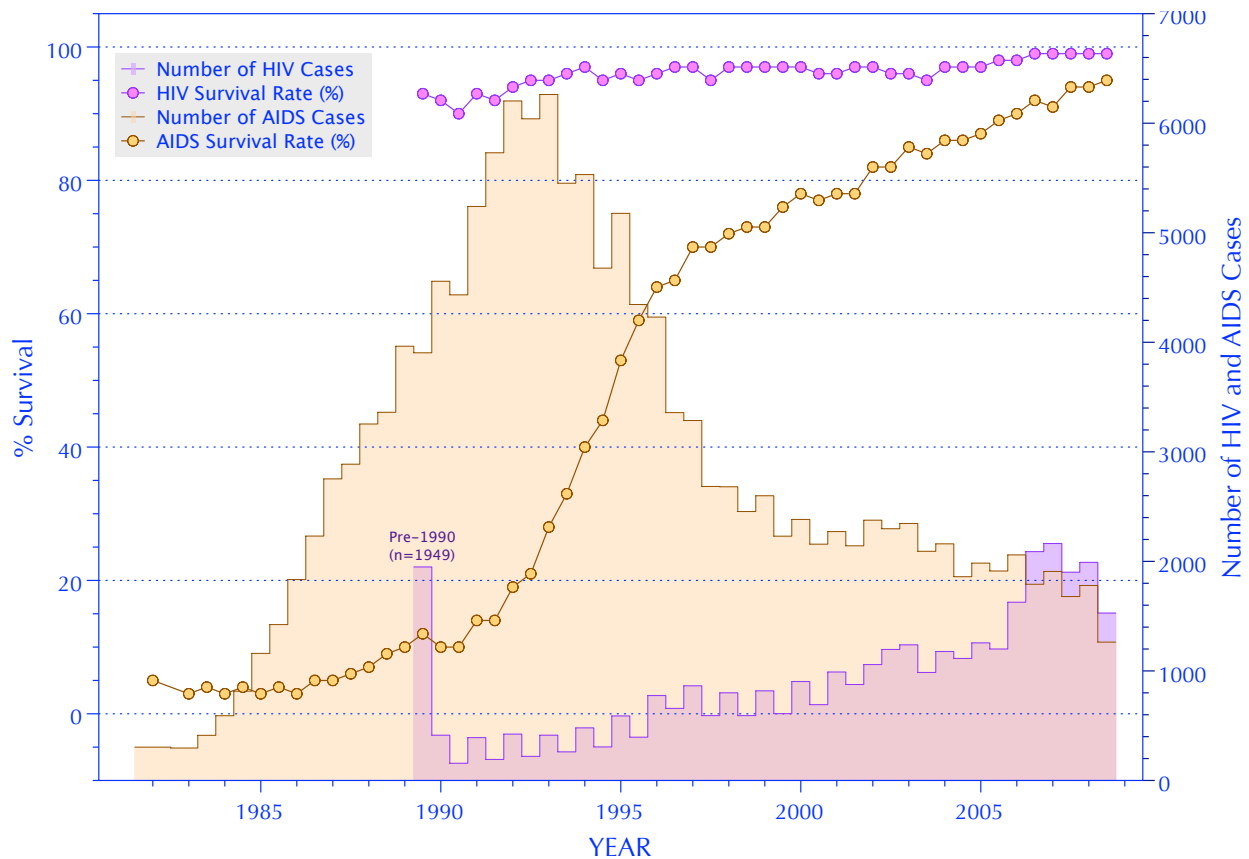
latest permutation of the act, the Ryan White HIV/AIDS Treatment Extension Act of 2009, addresses many of the issues identified, concerns still exist about MAI funding reaching minority communities.

Although we will discuss funding issues within the overall context of our analysis, much research has been conducted on the CARE Act funding formula, and additional study here would not benefit our analysis. Rather, we focus on the epidemiological base of the CARE Act, deficiencies thereto, and the relationship between those deficiencies and funding of the MAI.

- Section 1 will discuss the social and legislative context in which the CARE Act and the MAI were enacted.
- Section 2 will discuss the formulae used for disbursing appropriations under the CARE Act.
- Section 3 will discuss the deficiencies in data collection methods.
- Section 4 will discuss the changing nature and demographics of AIDS/HIV.
- Section 5 will discuss the implications and deficiencies of the CARE Act on the Minority AIDS Initiative.
- Section 6 will provide conclusions and recommendations.



**FIGURE 1: CALIFORNIA HIV AND AIDS SURVEILLANCE, 1982-2009**



## 1. THE SOCIAL, LEGISLATIVE, AND EPIDEMIOLOGICAL CONTEXT OF THE RYAN WHITE ACT<sup>1</sup> AND THE MINORITY AIDS INITIATIVE

On June 5, 1981, the federal Center for Disease Control’s *Morbidity and Mortality Weekly Report (MMWR)* published a report of *Pneumocystis carinii* pneumonia in five previously healthy young men in Los Angeles, California. These cases were later recognized as the first reported cases of acquired immunodeficiency syndrome (AIDS) in the United States. Since that time, this disease has become one of the greatest public health challenges both nationally and globally. Using comprehensive data from the state of California, **Figure 1** shows the span of the epidemic from the perspective of the initial populations affected.

Attitudes toward AIDS have gone through dramatically different phases. In the early 1980s, it was considered the “gay” disease, referred to as GRID (Gay-Related Immune Deficiency), and as such was easy for lawmakers to ignore. No one hurried to fund research into a disease that seemed to be killing only members of a historically unpopular group. Fear of the disease escalated as more homosexuals became sick. AIDS activists initiated a massive grass roots campaign highlighting the implications of the disease and the seeming epidemic. But public opinion began to shift in the late 1980s only when the infection broke out of the gay community and started to spread to other populations.

With over 307,000 cases of AIDS reported to the World Health Organization (WHO) and over 35,000 deaths reported to the Centers for Disease Control and Prevention (CDC) in 1990,<sup>2</sup> the gay and health communities fought to address the epidemic, which had escalated rampant discrimination against

1 The Ryan White Act as discussed in this paper consists of three different laws: The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, Pub.L. 101-381, 104 Stat. 576, enacted August 18, 1990, referred to as the CARE Act in this paper; the Ryan White HIV/AIDS Treatment Modernization Act of 2006, Pub.L 109-415, 120 Stat. 2767-2820, referred to here as the Treatment Act; and the Ryan White HIV/AIDS Treatment Extension Act of 2009, S.1793, signed by the president October 21, 2009, referred to here as the Extension Act.

2 “Current Trends Update: Acquired Immunodeficiency Syndrome – United States, 1989,” *MMWR Weekly*, 39(5): 81-86 (February 9, 1990).

gays<sup>3</sup> and was exacerbated by the public's skepticism about the nature of the illness and the modes of transmitting the disease. The insurance industry's response to the disease, which included testing<sup>4</sup> and cancellation of individual and group health policies<sup>5</sup> for businesses employing people with AIDS, resonated throughout the economic system. The disease affected social relations, business practices, and every aspect of life in America.<sup>6</sup> A solution was needed to stem the impact the disease had upon American business.<sup>7</sup>

The schisms and strictures of American society in relation to homosexuality were reflected in the development and structure of legislation. Intertwined in the politics of the time and the undercurrent of homophobia within American culture, Congress could not delve into the myriad of issues associated with AIDS but instead needed a sensitive, appropriate "face" to justify legislation. Ryan White provided that. A young, white hemophiliac infected with human immunodeficiency virus (HIV) through the use of infected blood products, he became well known as a result of his fight to attend public school. His infection reflected the breadth of the illness.<sup>8</sup>

In the meantime, African American gay activists and health professionals were feeling the impact of HIV/AIDS on the minority community. Even with added knowledge of methods of transmission and the development of innovative therapies, more and more black men became infected, and the CDC started to track infections transmitted to black women.

Since 1995 both the numbers of AIDS cases and the number of AIDS deaths have been higher among African Americans than whites. Additionally, since 1995 the case fatality ratios for African Americans and whites have been similarly stable, with

Latinos showing a steady improvement in case fatality rates for the period (**Figure 2**).

The minority AIDS community voiced concerns about the disproportionate impact of government-funded AIDS services in the minority community. In March 1998, African American leaders were briefed on the highly disproportionate impact of the disease in communities of color and the upward trend of minority AIDS cases. Alarmed by the numbers and projections, the U.S. Surgeon General David Satcher declared "a public health emergency," noting "the complexion of the epidemic has changed."

These leaders testified before the Congressional Black Caucus (CBC) and requested a government response to the epidemic. In FY 1999 Congress incorporated the now-named Minority AIDS Initiative (MAI) into the CARE Act funding scheme and set aside monies within the Titles I and III programs to expand funding to organizations serving communities of color so that access to HIV primary care could be increased.

Since that time, the MAI has been incorporated into the CARE Act as supplemental funding, specifically allocated to ensure that communities of color receive needed AIDS services. However, after repeated efforts to either reduce or eliminate AIDS funding during the Bush Administration,<sup>9</sup> advocates looked to Congress to ensure MAI appropriations, and the CARE Act was amended to codify the MAI initiative.

## 2. FORMULA FOR DISBURSING APPROPRIATIONS UNDER THE CARE ACT

HIV-positive individuals who do not have Medicare, Medicaid, or private insurance and meet particular income requirements may qualify for medical and social services through CARE Act funding. CARE Act funding is also used to support primary medical care and essential support services. A smaller but equally critical portion of CARE Act money is used to fund technical assistance, clinical training, and research on innovative models of care. CARE Act funding has been categorized by the services rendered:

3 "Federal Policy Against Discrimination Is Sought by AIDS Victims," *New York Times*, September 22, 1988.

4 Marilyn Adams, "Screening for AIDS Insurance: Screenings for AIDS May Become a Common Part of the Workplace of the 90s," *Miami Herald*, December 1, 1991.

5 *Doe v. Mutual of Omaha Insurance Company*, U.S. District Court, Northern District of Illinois, case no. 98C-0325 (March 1998); the Americans With Disabilities Act prohibits unjustified disability-based discrimination in insurance against individuals who have AIDS or ARC. [WHAT DOES ARC STAND FOR?] *American Council of Life Insurance v. District of Columbia*, 645 F. Supp. 84 (Dist. D.C. 1986) challenge to AIDS anti-discrimination law which prohibited AIDS testing as a requirement to obtain insurance; challenge defeated. B. Schatz, "The AIDS Insurance Crisis: Underwriting or Overreaching," *Harvard Law Review* 100(7): 1782-1805 (May 1987). Robert L. Ohsfeldt and Stephan F. Gohmann, "The Economics of AIDS-Related Health Insurance Regulations: Interest Group Influence and Ideology," *Public Choice* 74(1): 105-126 (July 1992).

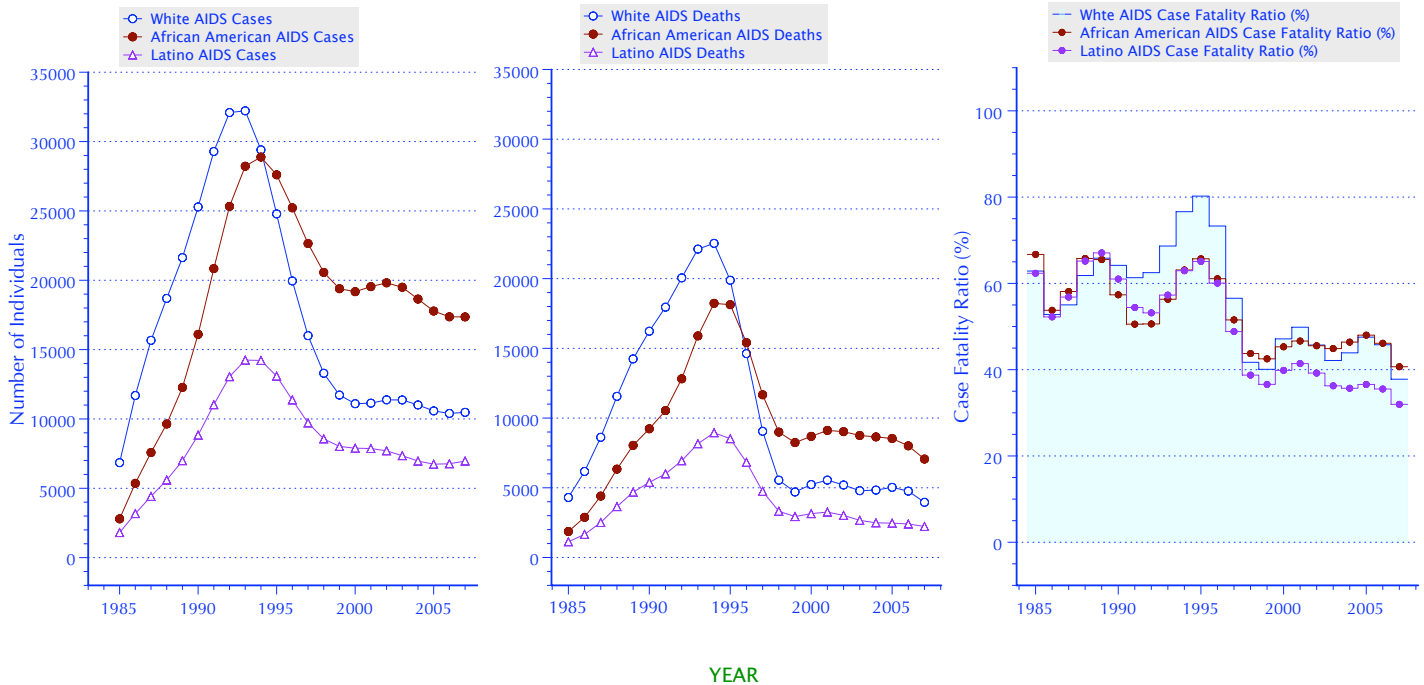
6 Morris Floyd, "The AIDS Hysteria: Threat to Justice, Civil Rights," *Engage/Social Action*, 14(2): 18-23 (1986), as quoted in "The Black Church and the AIDS Crisis" (Focus Paper #29), as found at <http://gbgm-umc.org/health/hivfocus/focus029.stm>.

7 Rose Knotts and J. Lynn Johnson, "AIDS in the Workplace: The Pandemic Firms Want to Ignore," *Business Horizons* (July-August 1993).

8 Dirk Johnson, "Ryan White Dies of AIDS at 18; His Struggle Helped Pierce Myths," *New York Times*, April 9, 1990.

9 "AIDS Advocates Dismayed by Bush Administration: Budget Provides Minimal Increase to AIDS Drug Assistance Program," as found at [http://www.sfaf.org/aboutsfaf/releases/fy05\\_budget.html](http://www.sfaf.org/aboutsfaf/releases/fy05_budget.html); see also Edward Epstein, "Democrats Victorious in Dodging Attempt to Cut AIDS Funding," *San Francisco Chronicle* Washington Bureau.

**FIGURE 2: NUMBERS OF AIDS CASES (LEFT PANEL) AND AIDS DEATHS (CENTER PANEL), AND AIDS CASE FATALITY RATE (RIGHT PANEL), BY RACE, 1985-2007, UNITED STATES**



1. Part A of the Ryan White HIV/AIDS Treatment Modernization Act of 2006 (Ryan White HIV/AIDS Program) provides emergency assistance to eligible metropolitan areas (EMAs) and transitional grant areas (TGAs) that are most severely affected by the HIV/AIDS epidemic.
2. Part B of the 2006 Treatment Act provides grants to all 50 states, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and five U.S. Pacific Territories or associated jurisdictions. Part B grants include a base grant, the AIDS Drug Assistance Program (ADAP) award, ADAP supplemental grants, and grants to states for emerging communities – those reporting between 500 and 999 cumulative reported AIDS cases over the most recent five years.
3. The Part C Early Intervention Services (EIS) program of the Treatment Act funds comprehensive primary health care in an outpatient setting for people living with HIV.
4. Part D grantees provide family-centered care involving outpatient or ambulatory care (directly or through contracts) for women, infants, children, and youth with HIV/AIDS. Grantees are expected to provide primary medical care, treatment, and support services to improve access to health care.
5. Under Part E, the Special Projects of National Significance (SPNS) program advances knowledge and skills in the delivery of health and support services to underserved populations diagnosed with HIV. SPNS grants fund innovative models of care and support the development of effective delivery systems for HIV care.

The AIDS Education and Training Centers (AETC) program of the Ryan White HIV/AIDS Program supports a network of 11 regional centers (and more than 130 local associated sites) that conduct targeted, multidisciplinary education and training programs for health care providers treating people living with HIV/AIDS. The AETCs serve all 50 states, the District of Columbia, the Virgin Islands, Puerto Rico, and the six U.S. Pacific jurisdictions.

Funds from all grant programs of the 2006 Treatment Act can support the provision of oral health services. Two programs, however, specifically focus on funding oral health care for people with HIV: the Dental Reimbursement Program (DRP) and the Community-Based Dental Partnership Program (CBDPP).

The Minority AIDS Initiative grants provide funding to evaluate and address the disproportionate impact of HIV/AIDS on women and minorities. As mentioned above, most Minority AIDS Initiative funding was appropriated under Titles I and III (Parts A and B) categories, and because it was a specific allocation it was separated out from Department of Health and Human Services (DHHS) and related funds and appropriated as a special program to be disbursed by the secretary between DHHS programs. However, the Congressional Budget Office identified the following agencies as receiving appropriations from MAI funding:

1. Health Resources Service Administration (HRSA)
2. Centers for Disease Control and Prevention (CDC)
3. Substance Abuse and Mental Health Services Administration (SAMHSA)
4. National Institutes of Health (NIH)
5. Minority Communities Fund (MCF)
6. Office of Mental Health (OMH)
7. Office of Women's Health (OWH)

Additionally, MAI funds disbursed by the Office of the Secretary of DHHS include funding provided to Indian Health Services, the Office of Minority Health, the Office of Population Affairs, and the Office of HIV/AIDS Policy.

With a mission to improve HIV/AIDS-related health outcomes for racial and ethnic minority communities disproportionately affected by HIV/AIDS, MAI funding has allowed communities to expand local service capacity primarily through minority community-based organizations; to increase the availability of medications, primary care, support services and outreach services to communities of color; and to support the development of new and innovative programs designed to reduce HIV-related health disparities.

Under the 1999 CARE Act legislation, the DHHS Office of HIV/AIDS Policy is responsible for convening a steering committee to coordinate MAI implementation

and evaluation.<sup>10</sup> The committee's membership includes representatives from various agencies and offices that administer MAI funded programs. And in 2003, DHHS Secretary Tommy Thompson appointed an ad hoc advisory committee on the MAI that is co-chaired by community leaders and federal officials. The charge to this group is to develop recommendations related to future funding and implementation of the MAI.

The first funding cycle, FY 1999, included over \$110 million in MAI funding and another \$46 million in reprogrammed funds to be administered primarily by DHHS. Later, DHHS reprogrammed an additional \$10 million in funding toward the MAI for a total of \$166 million allocated in FY 1999.<sup>11</sup> For FY 2008, a total of \$403 million was provided to continue these activities. For FY 2009, the Administration requested \$386.9 million.<sup>12</sup> The FY 2010 Administration budget included an estimated \$25.8 billion for combined domestic and global HIV/AIDS activities.

In December 2006 the CARE Treatment Act reauthorized CARE Act programs and established appropriate levels for fiscal years 2007 through 2009. The new law changed how Ryan White funds can be used, with an emphasis on providing life-saving and life-extending services for people living with HIV/AIDS. Key changes in the most recent legislation that impact the use of MAI funding include:

1. Spreading the MAI funding over all programs funded by the Ryan White Act; thus, five times as many people will be eligible to obtain MAI funding.<sup>13</sup>
2. A new method for determining eligibility for Part A (formerly called Title I) funds that gives priority to urban areas with the highest number of people living with AIDS while also helping mid-size cities and areas with emerging needs.
3. A new method for distributing Part A funds that directs money to metropolitan areas with the highest number of people who are HIV positive. The methods encourage outreach and testing, which will get people into treatment sooner and save more lives.

<sup>10</sup> U.S. House of Representatives Committee on Appropriations, House Report 107-229, Departments of Labor, Health and Human Services, and Education and Related Agencies Appropriations Bill, 2002, October 9, 2001.

<sup>11</sup> FY 2009 Budget of the United States; Congressional Appropriations Bills and Conference Reports; Agency Budget and Congressional Justification documents; Office of Management and Budget, personal communication, May 2009; DHHS, Office of the Budget, personal communication, August 2009.

<sup>12</sup> DHHS HRSA FY 2010 Budget Justifications, p. 182.

<sup>13</sup> Described in the notes from the Presidential Advisory Council on AIDS (PACHA) meeting, February 2008, Parham Hopson presentation.

4. The move from a formula for calculating funding based on estimated AIDS cases to a formula using counts of people living with HIV and AIDS. The previous formula counted only people with AIDS to calculate funding.
5. A move to allow the use of code-based data, with a duplication penalty.
6. More money spent on direct health care for Ryan White clients. Under the 2006 law, grantees receiving funds under Parts A, B, and C (formerly called Titles I, II, and III) must spend at least 75% of funds on “core medical services.”
7. Funding targeting Title I programs moved from formula-based to competitive grants.

With the 2006 Treatment Act scheduled to expire September 31, 2009, the Ryan White HIV/AIDS Treatment Extension Act of 2009 was introduced to amend Title XXVI of the Public Health Service Act to revise and extend the program for providing life-saving services for those with HIV/AIDS. The president signed the Act on October 30, 2009.

Incorporating substantive provisions to address some of the deficiencies of the CARE Act, the legislation:

1. Synchronized the MAI application schedules across Ryan White Parts A through D and Part F to streamline the MAI application process.
2. Reverted competitive funding under MAI Parts A and B to formula funding, with the congressional intent that the secretary distribute MAI funding for Part A and Part B based on the distribution of HIV/AIDS cases among racial and ethnic minorities.
3. Extended the exemption period for names-based reporting and maintained the code-based protections established under the 2006 reauthorization for states and jurisdictions with maturing names-based HIV case data during the first three years of the reauthorization period; it retained the 5% penalty for jurisdictions that report code-based data to the HRSA. The penalty is taken against their count of living cases of HIV and will still be subject to a 5% cap on increases in the HIV case count. In 2012, the penalty will be increased to 6%. Beginning in fiscal year 2013, code-based protections will be eliminated and all states will be required to report cases using a names-based system.
4. Added an adjustment for Part A and B jurisdictions that switched to names-based reporting early in 2007 and received a decrease in total funding of at least 30% from

2006 as a result of determinations based on the new reporting system. For those jurisdictions, the secretary shall base awards on living HIV/AIDS cases plus an adjustment of 3%.

5. Required the Government Accountability Office (GAO) to report on MAI activities across DHHS agencies. The report is to include a description of best practices in capacity building, particularly for minority community-based organizations.
6. Required the DHHS secretary to prepare a plan for the use of MAI funds for capacity building, taking into consideration the findings of the GAO report.

Guidance from the Committee on Energy and Commerce<sup>14</sup> acknowledged the prevalence of HIV in the nation’s prison systems and recommended permitted uses of Ryan White dollars to address AIDS there. The committee stated:

The Committee is concerned about the prevalence of HIV in the nation’s prison system. Disparities in the epidemic are exacerbated by the lack of access to adequate health and support services for inmates while incarcerated and upon their return to the community. The Committee notes that the Health Resources and Services Administration (HRSA) has developed guidance on the permitted use of Ryan White dollars for pre- and post-release programs for HIV-positive inmates being released back to the community, and believes that HRSA should encourage Part B grantees to develop and implement such programs as appropriate.<sup>15</sup>

Additional guidance related to the overall Ryan White funding addressing health disparities and co-morbidities. Citing the 2002 Institute of Medicine’s *Report on Healthcare Disparities and Unequal Treatment*, the committee stated:

The Ryan White Act provides the best opportunity for individuals affected by HIV/AIDS to access health care. Co-morbidities such as hepatitis C have a substantial impact on health-related quality for patients with HIV/AIDS. By ensuring patients with co-morbidities have access to care, the Ryan White Act is taking a small but necessary step in reducing the serious health disparities that

<sup>14</sup> Guidance from the Committee on Energy and Commerce on AIDS in the prison population, health disparities, AIDS prevention and testing, and national AIDS/HIV testing goals was directed at the overall Ryan White programmatic considerations; the guidance has been incorporated into this paper as it addresses minority AIDS concerns.

<sup>15</sup> House Report 111-305, Ryan White HIV/AIDS Treatment Extension Act of 2009 Committee Report (October 20, 2009), p. 6.

disproportionately affect racial and ethnic minorities.

Most low-income HIV-positive individuals co-infected with HBV or HCV [hepatitis B or C virus] can obtain services through the Ryan White Program, but coverage for HBV and HCV treatment and viral load testing, which is crucial for diagnosis and monitoring response to treatment, is limited. Unfortunately, coverage for diagnostics, monitoring, treatment and vaccination against viral hepatitis is not uniformly available through state AIDS Drug Assistance Programs (ADAPs), due to funding shortfalls. The Committee believes resources under the Ryan White Program are urgently needed for care, treatment, diagnostics, hepatitis vaccine, case management, and support services for patients undergoing hepatitis treatment, as well as to improve provider education on HBV and HCV medical management and treatment.<sup>16</sup>

And the committee acknowledged the need to address prevention. In addition to stating its support for the development of an HIV vaccine “as a solution to ending the HIV pandemic,”<sup>17</sup> the committee encouraged early identification of individuals infected with HIV. It also required the planning councils for Part A grant recipients and states, as part of their Ryan White planning process, to develop strategies, in coordination with other appropriate community strategies or activities, to identify and diagnose individuals with HIV/AIDS who are unaware of their status and link them with the appropriate care and treatment. It conditioned Part A supplement grants on the requirement that “one-third of the criteria on which allocations are made will be based on demonstrated success in identifying undiagnosed individuals with HIV/AIDS, making them aware of their status, and linking them to appropriate care.”<sup>18</sup>

Consistent with the shift to prevention, the Extension Act requires the development of a national HIV/AIDS testing goal of 5 million HIV tests provided through all federally supported HIV/AIDS programs and requires the secretary to report to Congress each year on the progress made toward achieving the goal. The secretary is also required to review each domestic HIV/AIDS prevention program to determine its effectiveness based on the program’s stated purposes and on its contributions toward the testing goal.<sup>19</sup>

16 Ryan White Committee Report, pp. 6-7.

17 Ryan White Committee Report, p 7.

18 Ryan White Committee Report, pp. 8 and 9.

19 Ryan White Committee Report, p. 10.

### 3. DEFICIENCY IN DATA COLLECTION METHODS AND ITS IMPACT ON CARE ACT DISBURSEMENTS

The epidemiology supporting successful efforts to eradicate disease is different from that used to track disease. And the CARE Act was not structured to include an infrastructure to support epidemiological control and containment of the disease. While the CDC is tasked with control and prevention, its systems for tracking HIV/AIDS patients were initially designed in response to the delicate political nature of tracking communicable disease.

With a focus on the social implications of mandated testing and reporting, the CDC initially opted for a “passive” reporting system, using data obtained from voluntary testing and anonymous reporting mechanisms. It was conducted by one individual on a case-by-case basis from reports submitted by physicians, many of whom were seeing their first AIDS cases. Because there was no approved test for HIV in the early 1980s, cases were confirmed using clinical criteria based on a crude CDC case definition of AIDS.<sup>20</sup>

In March 1985, the Food and Drug Administration approved the HIV enzyme immunoassay and Western blot test for screening blood products to ensure safety of the blood supply. Advances in early detection of HIV and HIV treatment slowed the progression of HIV disease for infected persons and contributed to a decline in AIDS incidence, thus diminishing the ability of AIDS surveillance data to represent trends in the incidence of HIV infection or the impact of the epidemic on the health care system. As a consequence, the capacity of local, state, and federal public health agencies that continued to utilize AIDS-only reporting models to monitor the HIV epidemic was compromised.<sup>21</sup>

States continued to grapple with the collection of names data on HIV, although the Council of State and Territorial Epidemiologists promulgated a position statement recommending the addition of non-AIDS HIV to the national public health surveillance system (1995), and CDC

20 “1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults. *MMWR* 41(RR-17), 1992.

21 “Guidelines for National Human Immunodeficiency Virus Case Surveillance, Including Monitoring for Human Immunodeficiency Virus Infection and Acquired Immunodeficiency Syndrome,” *MMWR* 48(RR-13): 1-28, December 10, 1999; see also “HIV Surveillance and Name Reporting: A Public Health Case for Protecting Civil Liberties,” American Civil Liberties Union, October 1997, as found at <http://www.aclu.org/technology-and-liberty/hiv-surveillance-and-name-reporting-public-health-case-protecting-civil-liber>; and “The AIDS Exception: Privacy vs. Public Health,” *Atlantic Monthly* 279(6): 57-67, June 1997, as found at <http://www.theatlantic.com/issues/97jun/burr.htm>.

**TABLE 1: STATE-LEVEL POLICIES FOR HIV TESTING**

State	Type of Setting	HIV Policy Reporting <sup>24</sup>	Date Legislation Enacted <sup>25</sup>
Alabama	Confidential <sup>26</sup>	Names	
Alaska	Confidential/anonymous	Names	
Arkansas	Confidential	Names <sup>27</sup>	
Arizona	Confidential/anonymous	Names	
California	Confidential/anonymous	Names to anonymous	April 2006 <sup>28</sup>
Colorado	Confidential/anonymous	Names	
Connecticut	Confidential/anonymous	Names/anonymous <sup>29</sup>	January 2005
Delaware	Confidential/anonymous		February 2006
District of Columbia	Confidential/anonymous	Anonymous	November 17, 2006 <sup>30</sup>
Florida	Confidential/anonymous		
Georgia	Confidential/anonymous	Anonymous	Dec. 2003 & Nov. 2009
Hawaii	Confidential/anonymous	Code	March 2008 <sup>31</sup>
Idaho	Confidential	Names	
Illinois	Confidential/anonymous	Code	January 2006

published formal guidelines for the conduct of non-AIDS HIV surveillance (1999). Additionally, the CARE Act amendments of 2000 called for an Institute of Medicine study of states' HIV surveillance systems and their adequacy and reliability for the purpose of using such data as the basis for CARE Act formula grant allocation. Subsequently, the CDC formally recommended that all states switch to confidential names-based reporting systems and offered to provide technical assistance to states in transitioning to confidential names-based AIDS/HIV surveillance systems.<sup>22</sup> And the 2006 Act requires names-based HIV case counts for determining CARE Act funding, but includes an exemption to allow the use of code-based case counts through FY 2009.<sup>23</sup>

Table 1 summarizes the state-level policies that regulate HIV reporting to the Centers for Disease Control and Prevention through the state departments of health.

24 To ensure the validity of data, the CDC includes HIV infection data from states and dependent areas that have conducted confidential names-based HIV infection reporting for at least four years (i.e., since at least 2003) to allow for stabilization of data collection and for adjustment of the data in order to monitor trends. However, data presented for a given year may include cases reported during only part of the year. Before implementing statewide HIV reporting, some states collected data on cases of HIV infection (not AIDS) in selected populations. Therefore, these states have reports that precede the initiation of statewide confidential reporting. A state with confidential HIV infection reporting also may report persons who tested positive in that state of residence, cases reported before a state initiated reporting may have been reported from a state that did have confidential HIV infection reporting.

25 Date as per the CDC recommendations. As of November 2009 only Georgia has had its database acknowledged by the CDC. Surveillance has not been implemented in Palau, the Marshall Islands, or Micronesia.

26 Alabama is the only state tracking newly diagnosed HIV cases and linking them into care.

27 Confidential names reporting for AIDS began in 1983 and for HIV in 1989.

28 SB 699 on April 17, 2006. The State Office of AIDS is currently drafting the administrative regulations required to fully implement the new reporting system. Those regulations were posted for public comment and in place by April 17, 2007.

29 Connecticut conducted pediatric surveillance and used names-based reporting for those under 13. Those over 13 years of age had the option of names or anonymous reporting.

30 Change in reporting process established through regulation.

31 State of Hawaii Department of Health, STD/AIDS Prevention Branch, "Proposed Change to Named HIV Reporting in Hawaii 2005."

22 CDC, "Dear Colleague" letter dated July 5, 2005.

23 "Ryan White CARE Act: Effects of Certain Funding Provisions on Grant Awards," GAO-09-894, September 18, 2009. CARE Act amendments of 2000 (P.L. 16-345) required the secretary of DHHS to determine no later than July 1, 2004 whether data on cases of HIV disease from all eligible areas were sufficiently accurate and reliable for use in funding distribution formulae (to replace use of AIDS cases). If not by then, the change must go into effect by FY 2007. (It was determined by July 2004 that HIV cases were not sufficiently accurate and reliable, so the latter deadline of FY 2007 went into effect.)

**TABLE 1 (CONTINUED): STATE-LEVEL POLICIES FOR HIV TESTING**

State	Type of Setting	HIV Policy Reporting	Date Legislation Enacted
Indiana	Confidential/anonymous	Names	
Iowa	Confidential	Names <sup>32</sup>	
Kansas	Confidential/anonymous	Names	
Kentucky	Confidential/anonymous	Code	October 2004
Louisiana	Confidential/anonymous	Names	
Maine	Confidential/anonymous	Name to code	January 2006
Maryland	Confidential/anonymous	Code	April 2007
Massachusetts	Confidential/anonymous	Code	January 2007 <sup>33</sup>
Michigan	Confidential/anonymous	Names	
Minnesota	Confidential/anonymous	Names	
Mississippi	Confidential	Names	
Missouri	Confidential/anonymous	Names	
Montana	Confidential/anonymous	Name to code	September 2006
Nebraska	Confidential/anonymous	Names	
Nevada	Confidential	Names	
New Hampshire	Confidential/anonymous <sup>34</sup>	Names	January 2005
New Jersey	Confidential/anonymous	Names	
New Mexico	Confidential/anonymous	Names	
New York	Confidential/anonymous	Names	
North Carolina	Confidential	Names	
North Dakota	Confidential	Names	
Ohio	Confidential/anonymous	Names	
Oklahoma	Confidential/anonymous	Names	
Oregon	Confidential/anonymous	Name to code	April 2006
Pennsylvania <sup>35</sup>	Confidential/anonymous	Names	October 2005
Rhode Island	Confidential/anonymous	Code	January 2006
South Carolina	Confidential	Names	
South Dakota	Confidential	Names	
Tennessee	Confidential	Names	
Texas	Confidential/anonymous	Names	
Utah	Confidential/anonymous	Names	

32 AIDS became reportable in Iowa in February 1983. HIV infection, including perinatal exposures to HIV, became reportable by name on July 1, 1998. Iowa codes 139A and 141A govern HIV/AIDS reporting.

33 The Massachusetts health commissioner announced on April 21, 2006 that the state would shift to confidential names-based reporting for new HIV cases.

34 New Hampshire allowed names or anonymous reporting at the option of the persons tested.

35 Philadelphia conducted anonymous reporting and switched October 2005.



**TABLE 1 (CONTINUED): STATE-LEVEL POLICIES FOR HIV TESTING**

State	Type of Setting	HIV Policy Reporting	Date Legislation Enacted
Vermont	Confidential/anonymous	Names <sup>36</sup>	April 2008
Virginia	Confidential/anonymous	Names	
Washington	Confidential/anonymous	Name to code	May 2006 <sup>37</sup>
West Virginia	Confidential/anonymous	Names	
Wisconsin	Confidential/anonymous	Names	
Wyoming	Confidential/anonymous	Names	
American Samoa	Confidential/anonymous	Names	
Guam	Confidential/anonymous	Names	
North Mariana Islands	Confidential/anonymous	Names	
Puerto Rico	Confidential/anonymous	Names	
U.S. Virgin Islands	Confidential	Names	

Compared with HIV reporting systems based on other types of identifiers (such as code or name-to-code), confidential names-based HIV reporting has proven to be more cost-effective, and it routinely achieves high levels of accuracy and reliability. Confidential names-based HIV infection reporting is consistent with reporting for other infectious diseases, including AIDS, and is now being conducted by all states, the District of Columbia, and U.S. territories. As state HIV reporting has increased, data now include states that did not previously report HIV, including tribal land and rural areas within the Indian Health Service.

<sup>36</sup><sup>37</sup>

And given the recent conversion to names-based reporting and the mandated use in CARE Act funding, federal officials are attempting to determine equitable interim methods for weighing the data until the CDC database becomes robust and reliable enough to mandate total use of reported AIDS/HIV data. The Extension Act continued the exemption period for names-based reporting by maintaining the code-based protections established under the 2006 reauthorization for states and jurisdictions with maturing names-based HIV case data during the first three years of the reauthorization period. For the first two years, jurisdictions that report code-based data to HRSA will continue to incur a 5% penalty against their

<sup>36</sup> Reported by names, but names retained by the state health department until enactment of legislation and plan in 2007.

<sup>37</sup> Changed via delegation of authority to agency responsible for AIDS collection. Washington implemented standard names reporting (retaining names) to comply with the 2005 CDC recommendation. An emergency rule was approved in March, with the final rule effective September 1.

count of living cases of HIV and will still be subject to a 5% cap on increases in the HIV case count. In 2012, the penalty will be increased to 6%. Beginning in FY 2013, code-based protections will be eliminated; all states will be required to report cases using a names-based system.<sup>38</sup>

In the interim approximately 11 states will be penalized, and some of those are in the midst of active epidemics (e.g., D.C. and Georgia.) If the District of Columbia's recount is any indication of the findings we might anticipate, it is clear that these states will reflect an undercount of active HIV cases.<sup>39</sup>

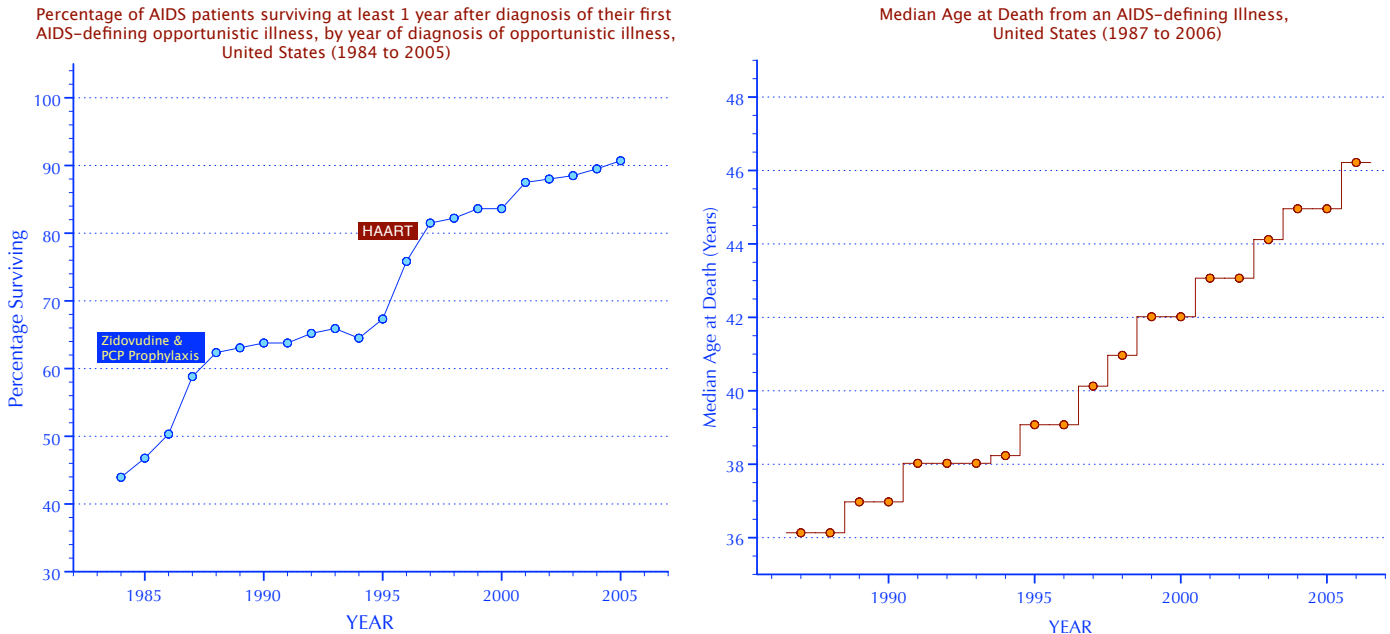
#### 4. THE EPIDEMIOLOGY OF HIV AND AIDS IN THE UNITED STATES

The original CARE Act relegated AIDS education and prevention to a secondary role and instead focused on providing care to those who were fatally ill. Shortly after the law's enactment the research community started identifying treatments that worked effectively to extend the lives of those infected with HIV and, in 1996, introduced the first highly active antiretroviral (anti-HIV) therapy. The first HAART treatments included a protease inhibitor along with two nucleoside analog drugs to fight HIV. HAART changed the

<sup>38</sup> Ryan White Committee Report.

<sup>39</sup> D.C. Department of Health, Bureau of Surveillance and Epidemiology, HIV/AIDS Administration, "District of Columbia HIV/AIDS Epidemiology Annual Report 2007"; see also Jose Antonio Vargas, "An Overwhelmed D.C. Agency Loses Count of AIDS Cases," *Washington Post*, December 30, 2006.

**FIGURE 3: PROPORTION OF AIDS PATIENTS SURVIVING AT LEAST ONE YEAR AFTER DIAGNOSIS OF THEIR FIRST AIDS-DEFINING OPPORTUNISTIC ILLNESS, BY YEAR OF DIAGNOSIS AND MEDIAN AGE OF DEATH, 1984-2005, UNITED STATES**



Note: For comparison with the data for 1999 and later, data for 1984 to 1998 were modified to account for ICD-10 rules instead of ICD-9 rules.

nature, psychology, and treatment of HIV. A few years after HAART became widely available, studies reported 60-80% reductions in new AIDS illnesses, hospitalizations, and deaths. Because of HAART, the populations supported by the CARE Act are living longer, more productive, and more normal lives. Thus, the mission of the CARE Act was altered without necessarily changing the programs or funding mechanisms and without retooling the purpose to focus on AIDS education and transmission prevention. Legislation, regulation, and administrative guidance (interpretations) have impeded not only equitable funding but also the development of an infrastructure of community-based organizations to support aggressive AIDS education and prevention services.

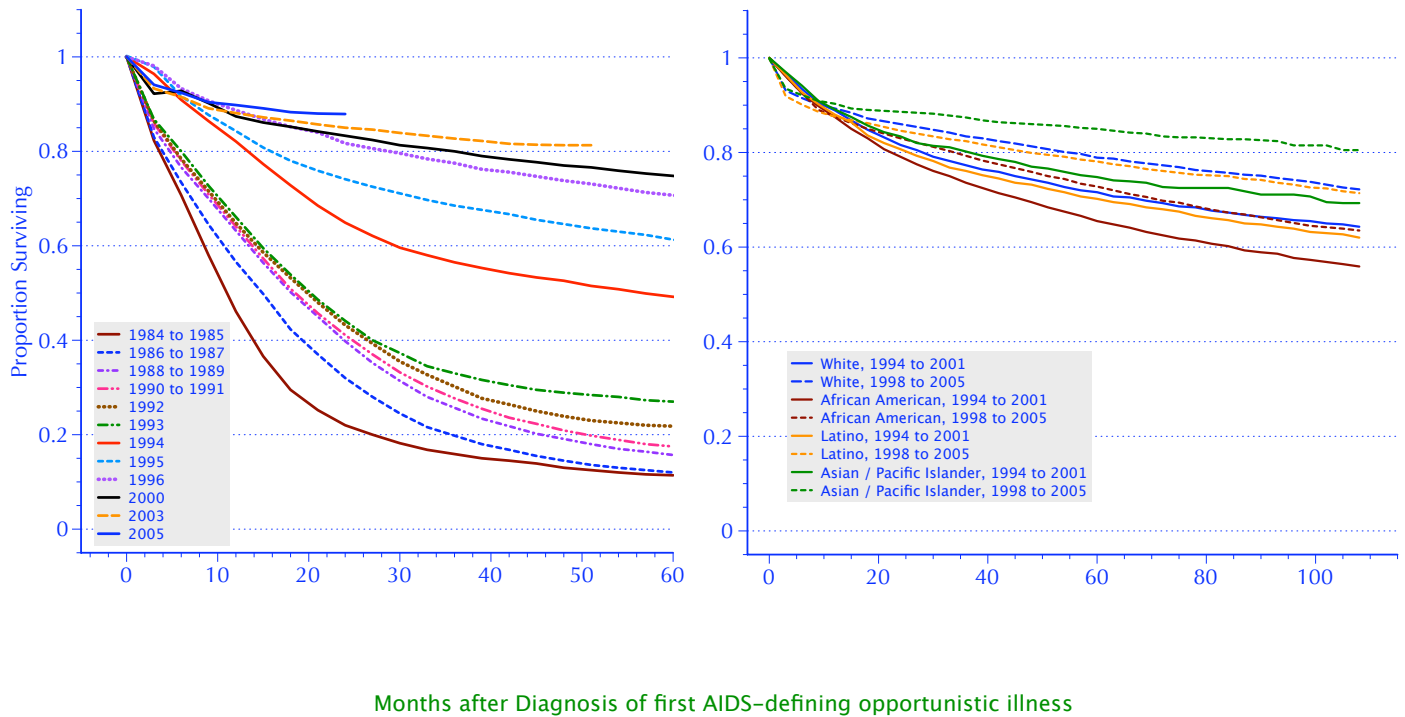
State legislative and regulatory efforts reinforced the federal approach and failed to promote the development of a culturally diverse support system for AIDS education, counseling, and care. Social and cultural norms, especially within traditional, Southern rural communities, reinforced traditions of denying

the existence of homosexuality within the African American community. Thus, the epidemiological and statistical data collected under the CARE Act framework – data upon which funding is premised – have been deficient and out of synch with the needs of the minority AIDS community.

### *Survival After AIDS Diagnosis*

AIDS survival within one year of the diagnosis of an AIDS-defining opportunistic infection improved from 43% in 1984 to 91% in 2005. Two important therapeutic innovations (the use of Zidovudine and PCP prophylaxis in 1987 and HAART in 1996), shown in **Figure 3**, appear several years after dramatic improvements in survival. The median age at death due to HIV disease increased almost linearly from 36 years in 1987 to 39 years in 1995 and to 46 years in 2006. This is a reflection of the postponement to older ages of HIV-attributable deaths that were not entirely prevented by improved treatment. The median age at death due to HIV disease varied little by racial/ethnic groups.

**FIGURE 4: CUMULATIVE PROPORTION OF AIDS PATIENTS SURVIVING, BY NUMBER OF MONTHS AFTER DIAGNOSIS OF FIRST AIDS-DEFINING OPPORTUNISTIC ILLNESS, FOR DIFFERENT YEARS OF DIAGNOSIS, 1984-2005 (LEFT PANEL), AND BY RACE/ETHNICITY, 1994-2001 AND 1998-2005 (RIGHT PANEL), UNITED STATES**



**Figure 4** pulls together survival data from 1984 through 2005. The survival data for later epochs of the epidemic are right truncated because of the delay in reporting survival data. Earlier data are right truncated to make comparisons across time easier. Survival (the estimated proportion of persons surviving a given length of time after diagnosis) increased with the year of diagnosis for diagnoses from 1984 to 2005. Year-to-year differences were small but progressive during two time periods – 1984-93 and 2001-05. There was a marked improvement in survival from 1993 to 1994 and again from 1994 through 1996. The improvement through the early 1990s predates the introduction of HAART, but improvements in survival since 1996 have been significant.

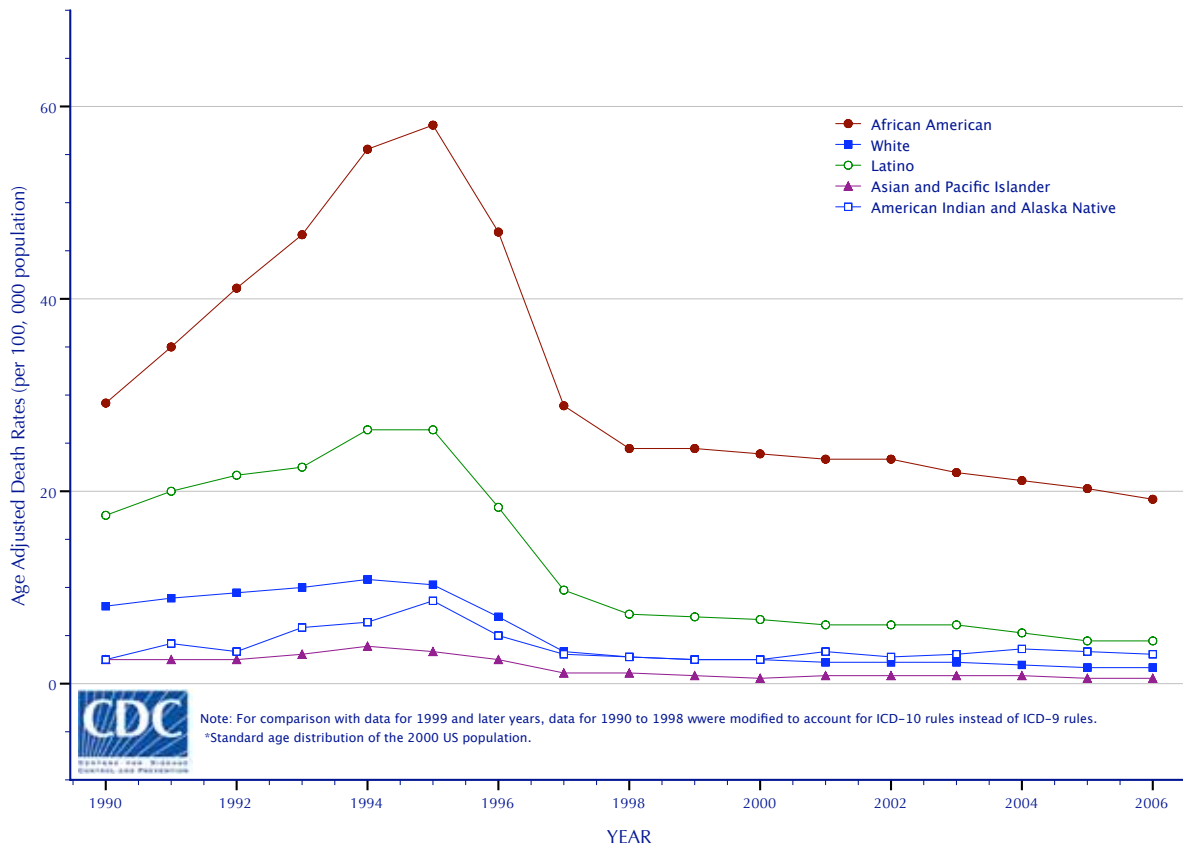
The right panel of Figure 4 shows the marked racial/ethnic disparities in survival after AIDS diagnosis. This panel shows survival for whites, African Americans, Latinos, and Asian Americans for two time periods – 1994-2001 and 1998-2005. There is an almost 10% deficit in survival for African Americans

compared to whites and a 8% deficit in survival for whites compared to Asian Americans. Whites and Latinos have similar survival curves. Results are not shown for American Indians/ Alaska Natives and Native Hawaiians/Other Pacific Islanders because the numbers of persons in these categories were too small to produce stable or consistent results. Survival differences among racial and ethnic minorities are more than likely due, in part, to late HIV diagnosis and differential access to care. The CDC suggests that comprehensive and culturally sensitive approaches to prevention, treatment, and care are needed to reduce disparities in infection rates and disease progression.

### *Mortality Due to HIV and AIDS*

These figures in this series are based on data compiled by the National Center for Health Statistics (NCHS) from death certificates of U.S. residents in the 50 states and the District of Columbia for the years 1987-2006. The underlying cause of each death is selected from the conditions reported by

**FIGURE 5: TRENDS IN AGE-ADJUSTED\* ANNUAL RATES OF DEATH DUE TO HIV DISEASE BY RACE/ETHNICITY, 1990-2006, UNITED STATES**

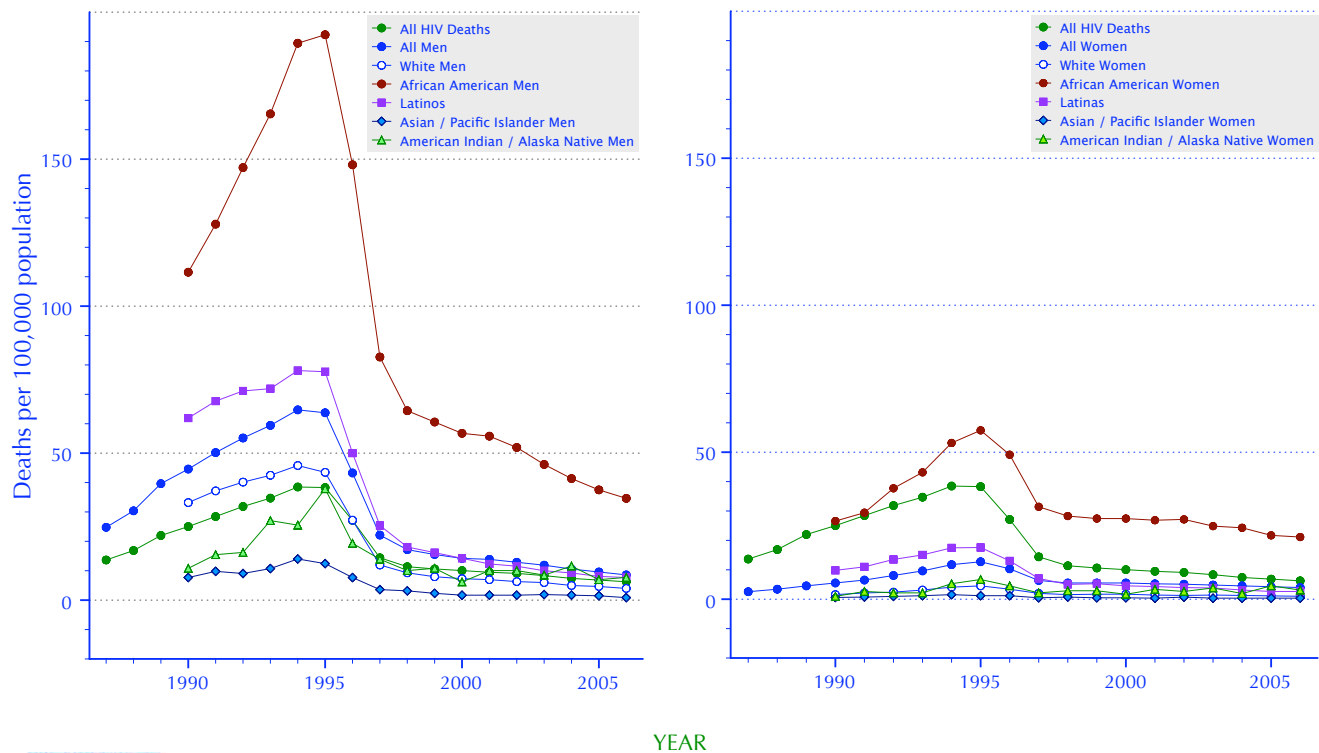


physicians, medical examiners, and coroners in the cause-of-death section of the death certificate. When more than one condition is reported, the underlying cause is determined by using a set of standardized rules promulgated as part of the International Classification of Diseases (ICD). Changes in these rules often accompany a revision of the ICD. Beginning with 1999 deaths, the 10th revision of the ICD (ICD-10) changed the rules for selecting the underlying cause of death in the United States. For these figures, to make the data for the years before 1999 comparable with the data for later years, a simplified version of ICD-10 rules was used to modify the cause-specific numbers of deaths that occurred before 1999; these had been initially determined by ICD-9 rules. Additional information on the nature and sources of death-certificate data on causes of death may be found at the NCHS website. These data from NCHS, the sole source of information on all causes of death in the national population, allow comparison of deaths due to HIV disease and deaths due to other causes.

Figure 5 shows the race/ethnicity disparity in age-adjusted mortality rates from 1990. Although each race group reflects the overall shape of the epidemic, African Americans have a more than two-fold excess in death rates due to AIDS compared to Latinos and a more than four-fold excess compared to whites and other race/ethnicity groups. Latinos, whites, American Indian and Alaska Natives, and Asian and Pacific Islanders have increasingly similar rates from 2000 onwards. Although there is a slight narrowing of the African American/other disparity, it still remains substantial.

Focusing on persons 25-44 years old emphasizes the importance of HIV disease among causes of death. Compared with rates among other age groups, the rate of death due to HIV disease is relatively high in this age group, but rates of death due to other causes are relatively low. HIV disease was the leading cause of death among persons 25-44 years old in 1994 and 1995. In 1995, HIV disease caused about 32,000 deaths, or 20% of all deaths in this age group (based on ICD-10 rules for selecting the underlying cause of death). The rank of HIV disease fell to fifth place from 1997 through 2000, and to sixth place from

**FIGURE 6: TRENDS IN ANNUAL DEATH RATES DUE TO HIV DISEASE FOR MEN AND WOMEN 25-44 YEARS OLD, 1987-2006, UNITED STATES**



Note: For comparison with data for 1999 and later years, data for 1987 to 1998 were modified to account for ICD-10 rules instead of ICD-9 rules.

Technical Notes: For the calculation of national death rates by race and ethnicity, data for a few states were excluded for the years when death certificates for those states did not collect information on Hispanic/Latino ethnicity. The states for which data were omitted were: Connecticut and Louisiana in 1990, New Hampshire through 1992, and Oklahoma through 1996.

2001 through 2006. In 2006, HIV disease caused about 5,000 deaths, or 4% of all deaths in this age group.

Among men 25-44 years old, HIV disease was the leading cause of death from 1992 through 1995. HIV disease caused about 27,000 deaths (24% of all deaths) in this group in 1995 (based on ICD-10 rules for selecting the underlying cause of death). Then the rank of HIV disease fell to fifth place from 1997 through 2000 and to sixth place from 2001 through 2006. In 2006, HIV caused about 4,000 deaths (4% of all deaths) in this group.

Among women 25-44 years old, HIV disease was the third leading cause of death in 1995, when it caused more than 5,000 deaths, or 11% of all deaths in this group. Thereafter, the rate of death due to HIV disease dropped to about the same as the rate due to suicide, and the rank of HIV fluctuated between fourth and fifth place except in 2001, when homicide jumped to fifth place (a result of the terrorist attacks of September 11). From 1998 through 2006, HIV disease caused about 2,000 deaths per year, or about 5% of all deaths in this group.

Figure 6 summarizes the epidemic trends for all race/ethnicity groups by gender. Although the rates for women are lower, the race/ethnicity disparities are as described above. Among white men 25-44 years of age, the rate of death due to HIV disease reached a peak in 1994, when HIV was the second leading cause of death, accounting for almost 14,000 deaths, or 21% of all deaths in this demographic group. The rate of death due to HIV fell during 1996 and 1997, after which HIV was the fifth leading cause of death except in 2001, when homicide rose to fifth place. In 2006, HIV caused about 1,100 deaths, or 2% of all deaths in this group. Among white women 25-44 years of age, the rate of death due to HIV disease peaked in 1995, when HIV was the fifth leading cause of death, accounting for more than 1,300 deaths, or almost 5% of all deaths in this demographic group. The rate of death due to HIV dropped during 1996 and 1997, after which HIV was either the 10th or 11th leading cause of death. In 2006, HIV caused fewer than 300 deaths, or 1% of all deaths in this group.

From 1990 through 1999, HIV disease was the most common cause of death among black/African American men 25-44 years of age. The rate of death due to HIV peaked in 1995, when HIV caused more than 9,000 deaths, or 34% of all deaths in this demographic group. The rate of death due to HIV dropped rapidly from 1996 through 1998, and more slowly thereafter. HIV was the fourth leading cause of death in 2006, when it caused about 1,800 deaths, or 10% of all deaths in this group. From 1993 through 1996, HIV disease was the most common cause of death among black/African American women 25-44 years of age. The rate of death due to HIV peaked in 1995, when HIV caused more than 3,000 deaths, or 23% of all deaths in this demographic group. The rate of death due to HIV dropped rapidly in 1996 and 1997, after which HIV disease was the third leading cause of death through 2006. In 2006, HIV caused about 1,200 deaths, or 11% of all deaths in this group.

Among Hispanic/Latino men 25-44 years of age, HIV disease was the most common cause of death from 1990 through 1996. The rate of death due to HIV peaked in 1994, when HIV caused almost 3,700 deaths, or 30% of all deaths in this demographic group. The rate of death due to HIV dropped rapidly in 1996 and 1997, and more slowly from 1998 through 2006. Rates of death due to unintentional injury and homicide also decreased substantially during the 1990s, but in 2006 these two were still the most common causes of death. Lower in rank were heart disease, suicide, cancer, and HIV. In 2006, HIV disease was the sixth leading cause of death, causing about 600 deaths, or 5% of all deaths in this demographic group. Among Hispanic/Latino women 25-44 years of age, HIV disease was the second most common cause of death from 1992 through 1996. The rate of death due to HIV peaked in 1995, when HIV caused almost 800 deaths, or 21% of all deaths in this demographic group. The rate of death due to HIV dropped rapidly in 1996 and 1997, and more slowly afterward. HIV disease was the fifth leading cause of death in 2006, when it caused about 200 deaths, or 4% of all deaths in this group.

Among Asian/Pacific Islander men 25-44 years of age, the rate of death due to HIV disease peaked in 1994, when HIV was the fourth leading cause, accounting for more than 200 deaths, or 13% of all deaths in this demographic group. The rate of death due to HIV dropped rapidly in 1996 and 1997, and more slowly from 1998 through 2006. In 2006, HIV was the ninth leading cause of death, accounting for 22 deaths, or 1% of all deaths in this group. Among Asian/Pacific Islander women 25-44 years of age, the rate of death attributed to HIV disease

peaked in 1994, when HIV was the seventh leading cause of death, accounting for 24 deaths, or less than 2% of all deaths in this demographic group. The rate of death due to HIV fell during 1995 through 1997. In 2006, HIV caused only five deaths, or less than 1% of all deaths in this group. During the entire period, the rate of death due to HIV was unstable and statistically unreliable because of small numbers (ranging from five to 24 deaths per year). In 2006, HIV disease ranked 16th among causes of death, causing five deaths or 1% of all deaths in this group.

Among American Indian/Alaska Native men 25-44 years of age, unintentional injury was the most common cause of death, responsible for about one third of all deaths – three times as many deaths as the second leading cause, heart disease. The rate of death due to unintentional injury decreased substantially during the 1990s but increased in 2002, followed by variable rates but remaining elevated in subsequent years. The rate of death due to HIV disease peaked in 1995, when HIV was the third leading cause of death, accounting for more than 100 deaths, or 10% of all deaths in this group. HIV infection was the seventh leading cause of death from 1997 through 2004. In 2005, HIV became the eighth leading cause of death, and in 2006 it was again the seventh leading cause of death, causing 25 deaths, or 2% of all deaths in this group. Diabetes and stroke were the eighth and ninth leading causes of death, respectively. Among American Indian/Alaska Native women 25-44 years of age, the rate of death due to HIV disease peaked in 1995, when HIV was the seventh leading cause of death, accounting for 20 deaths, or 4% of all deaths in this demographic group. In 2006, HIV was the ninth leading cause of death, accounting for only 11 deaths, or 2% of all deaths in this group. The rates of death due to HIV disease and septicemia during the entire period were statistically unreliable because of small numbers (20 or fewer per year). Except for 2006, the rates for diabetes were similarly unreliable.

After rapidly increasing since the 1980s, the annual rate of death due to HIV disease peaked in 1994 or 1995 (depending on the demographic group), decreased rapidly through 1997, and became nearly level after 1998. Persons dying of HIV disease increasingly consist of women (28% in 2006), blacks/African Americans (56% in 2006), residents of the South (53% in 2006), and persons 45 years of age or older (55% in 2006). HIV disease remains a leading cause of death among persons 25-44 years old, particularly among those who are African American or Hispanic.

**FIGURE 7: NUMBER LIVING WITH AIDS, NUMBER DIAGNOSED WITH AIDS, NUMBER OF DEATH DUE TO AIDS (IN THOUSANDS), AND AIDS CASE FATALITY RATES (%), 1987-2006 (LEFT PANEL), AND AIDS PREVALENCE RATES (PER 100,000 POPULATION), BY REGION, 1984-2005 (RIGHT PANEL)**

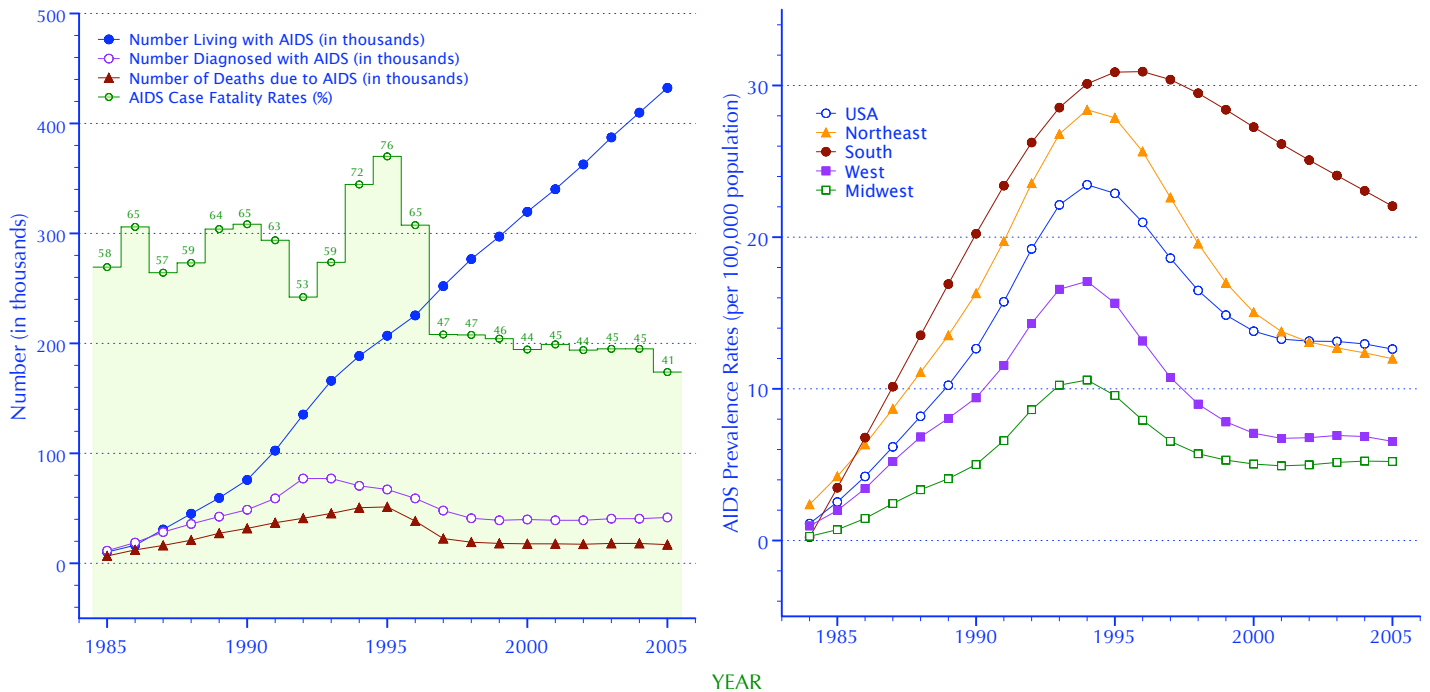
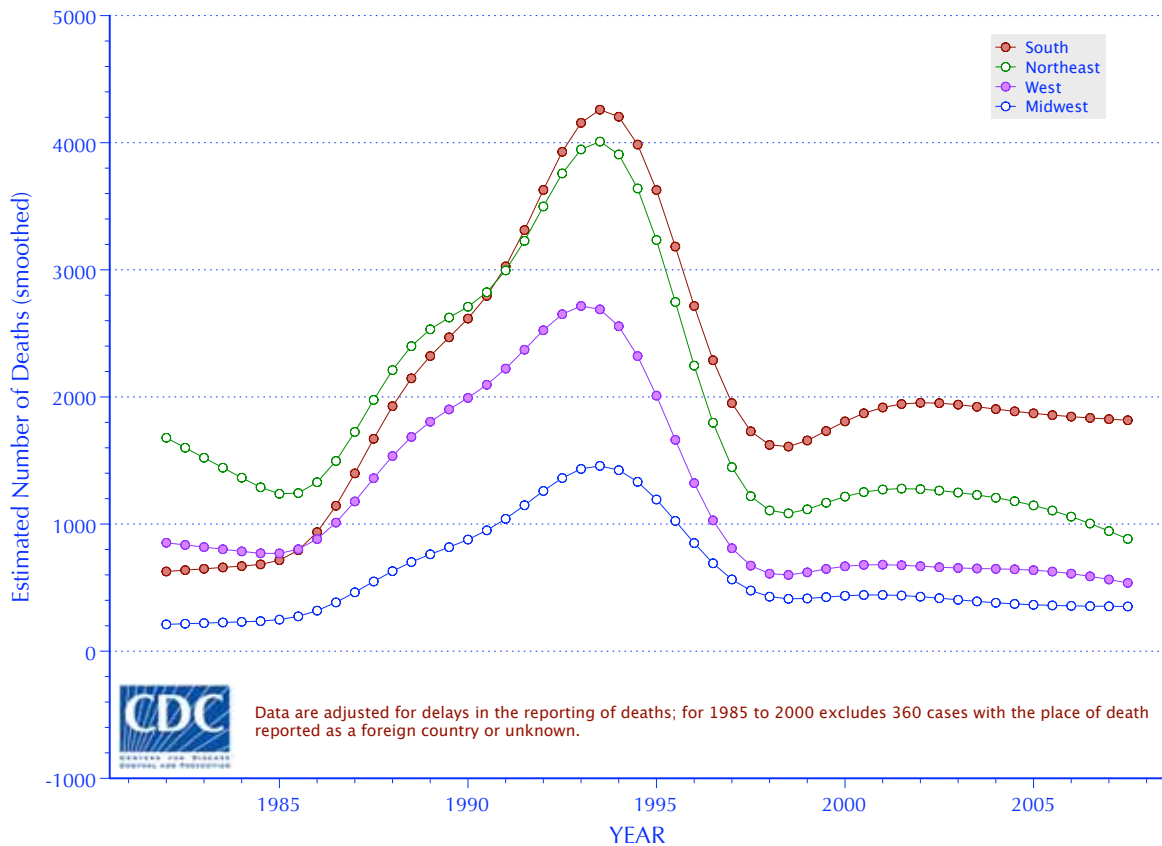


Figure 7 illustrates the impact of the HIV/AIDS epidemic on the nation's morbidity burden and also shows the marked differences in the epidemic in the four regions of the United States. Over the life of this epidemic the number of individuals living with AIDS has increased linearly to now exceed 400,000. This has occurred as the epidemic has waned in most communities and AIDS case fatality rates (the percent of AIDS deaths among those with the disease) have decreased from a high of 76% in 1994 to 41% in 2005. The right panel of Figure 7 shows that, although the epidemic started in the Northeast and West, the South had higher AIDS prevalence rates by the fourth year of data collection and continued to remain higher throughout the span of the epidemic. The epidemic in the West is currently approaching the low-level epidemic of the Midwest, and rates in the Northeast now mirror the national rates. What is interesting about the Southern epidemic is the slower rate of decline since 1995 when compared to the other regions; that trend leads to an increasing regional disparity in prevalence.

Figure 8 shows the estimated number of deaths by region. The Northeast had more deaths than any other region until 1989, when the number of deaths in the South began to exceed those in the Northeast. Deaths in the West exceeded deaths in the South only until 1985 and, although deaths in the Western states exceeded deaths in the Midwestern states throughout the epidemic, since 1996 the gap between the West and Midwest has remained small. It should be noted that, as the number of deaths decreased (slowly) during the 1990s in the Northeast, this decline was more rapid than the decline in the South, leading to a widening regional disparity.

Figures 9 through 12 show the epidemic by division within each region and highlight the focal point of the HIV/AIDS epidemic in the United States. Each of the figures shows the regional epidemic curve in the left panel and the divisional epidemic curves in the right panel.

**FIGURE 8: SMOOTHED ESTIMATED ADULT AND ADOLESCENT DEATHS AMONG PERSONS WITH AIDS, BY REGION OF RESIDENCE AT DEATH, 1982- 2007**



In the Northeast region (**Figure 9**) it is clear that the epidemic is mostly an epidemic of the Middle Atlantic States. The epidemic curve for the New England states is only slightly higher than that of the Midwestern States. The Middle Atlantic States include the large urban and suburban communities of the Northeast corridor (from New York City through the urban communities of New Jersey). Within New York State, the epidemic has long been recognized as being localized in the five boroughs of New York City.

**Figure 10** shows the Southern states epidemic. It is clear from the right panel that the Southern epidemic is predominantly a South Atlantic States epidemic, with the epicenter in the District of Columbia and the urban communities of Maryland. Both the East and West South Central states show a flattening of the epidemic curve, with the prevalence rates remaining relatively stable between 10 and 15 per 100,000. What is of some concern in these states is that the epidemic appears to have stabilized at a relatively high level.

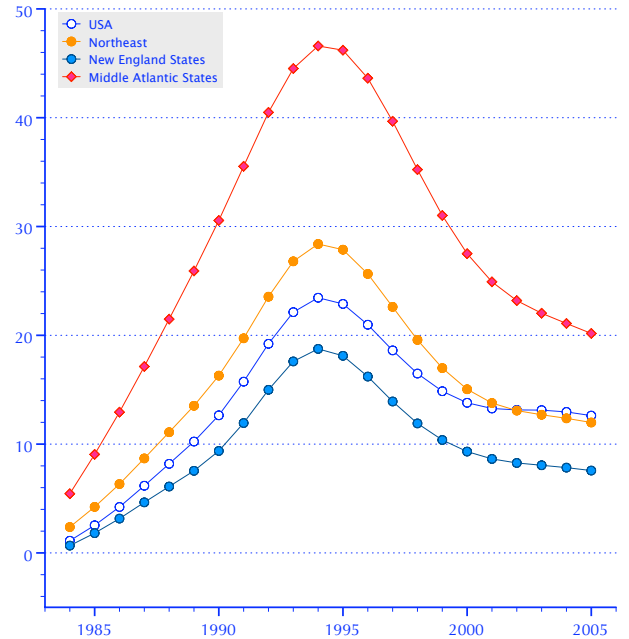
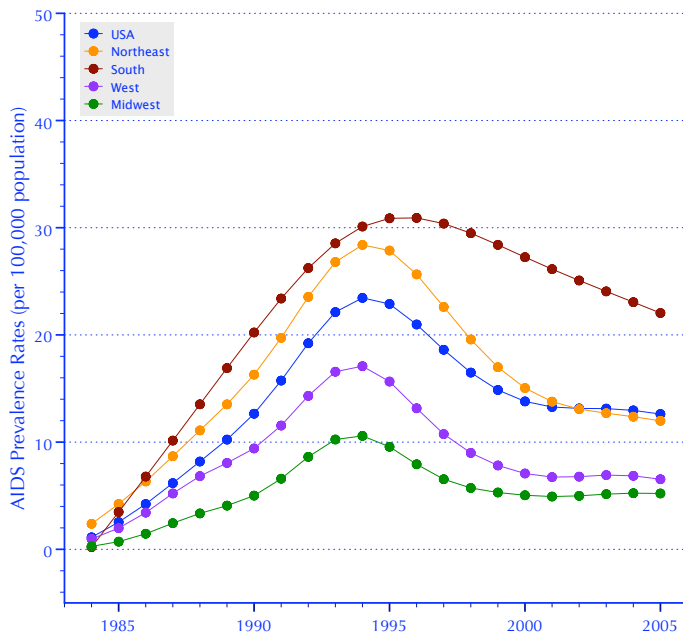
The Western United States shows three epidemics that are closely clustered, with the Pacific states having slightly higher prevalence rates throughout the epidemic (**Figure 11**). The Pacific States' epidemic is mostly a California epidemic (see **Figure 1**). All three divisions of the West have rates below 10 per 100,000 and are increasingly approximating the epidemic curves of the Midwest.

The Midwest epidemic (**Figure 12**) has the lowest prevalence rates and is mostly found in the urban communities of the East North Central states. Although the rates are all below 10 per 100,000, the East North Central states are showing a slight increase in prevalence since 2000. The causes for this increase are not clear.

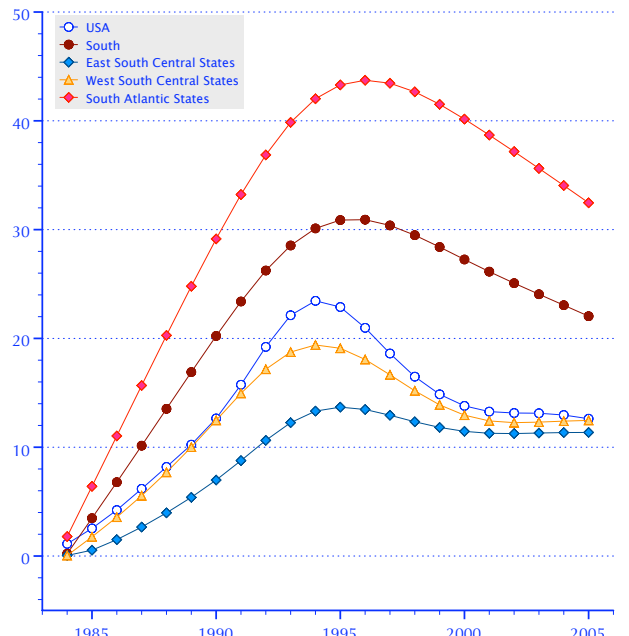
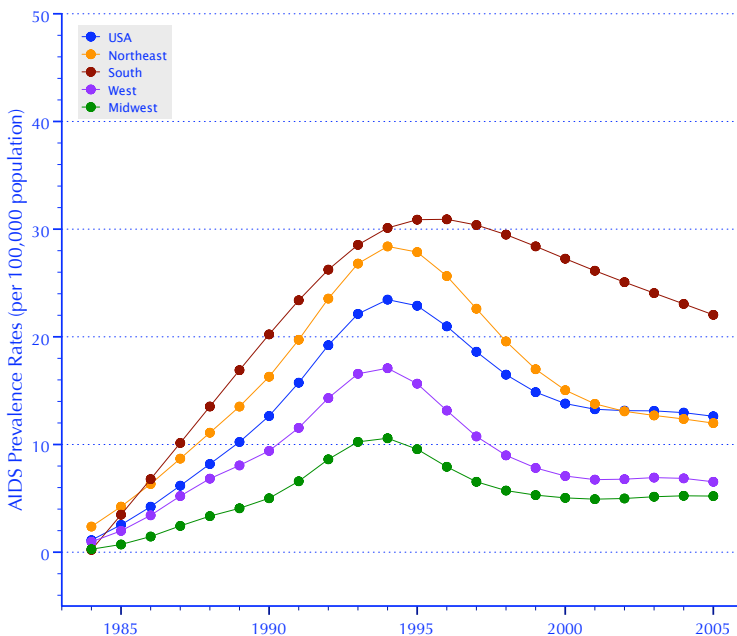
**Figure 13** shows the estimated number of AIDS cases for African Americans and whites in each of the four regions. There is a two-fold excess of AIDS cases in the South compared to the Northeast for African Americans and a two-fold excess for whites in the South compared to the Northeast. African



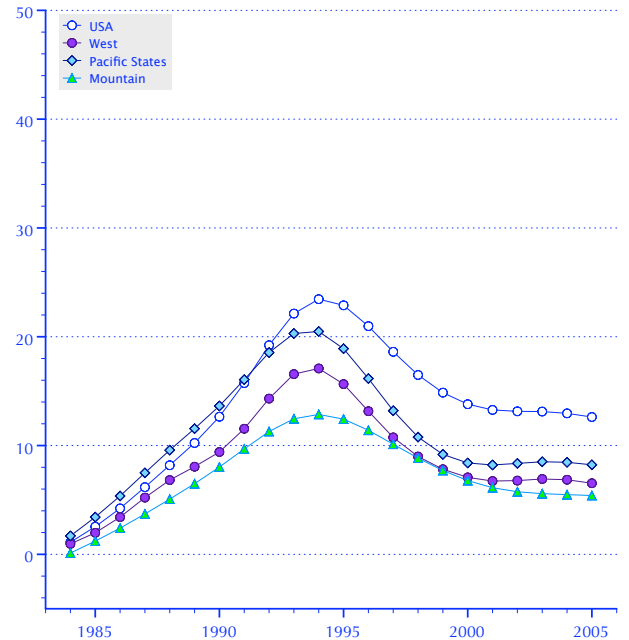
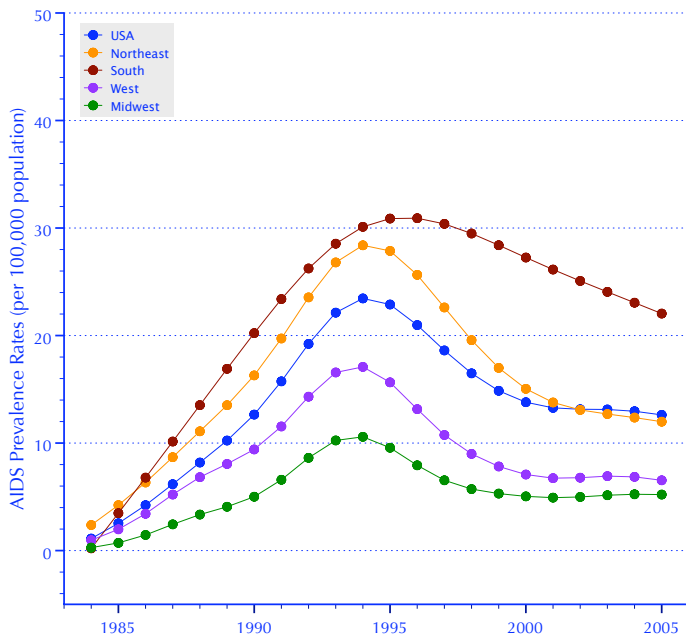
**FIGURE 9: AIDS PREVALENCE RATES BY REGION OF THE UNITED STATES 1984-2005 (LEFT PANEL), AND BY DIVISION IN THE NORTHEAST REGION, 1984-2005 (RIGHT PANEL)**



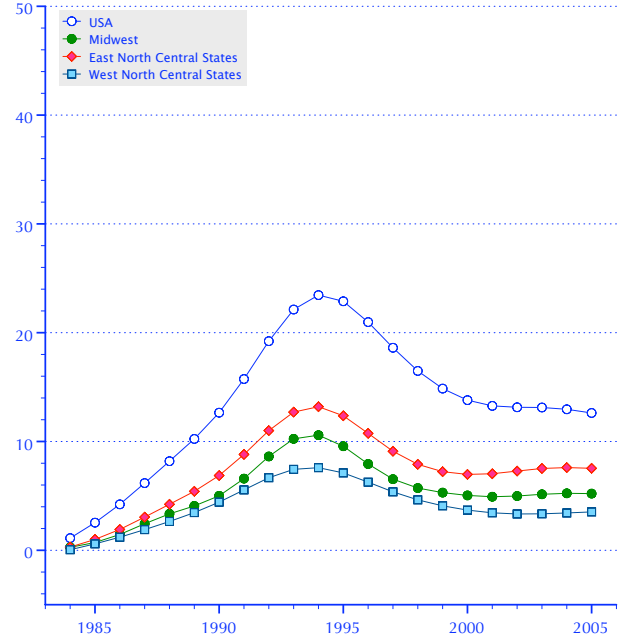
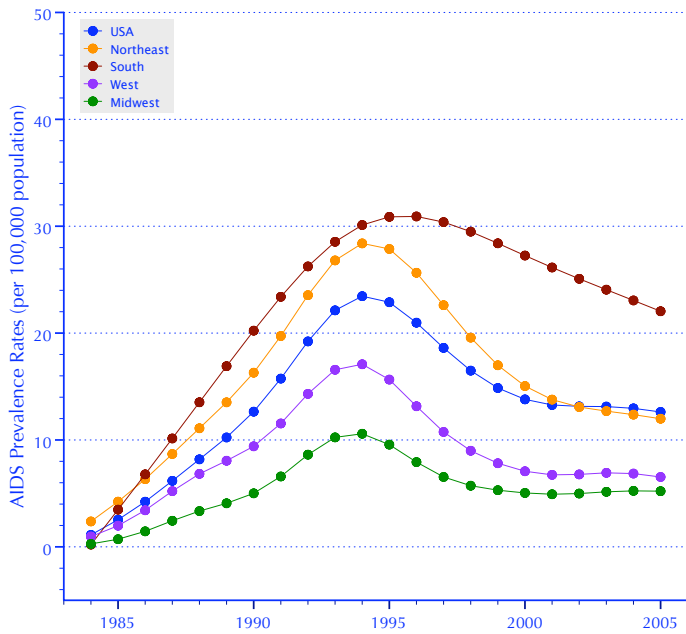
**FIGURE 10: AIDS PREVALENCE RATES BY REGION OF THE UNITED STATES, 1984-2005 (LEFT PANEL), AND BY DIVISION IN THE SOUTH REGION, 1984-2005 (RIGHT PANEL)**



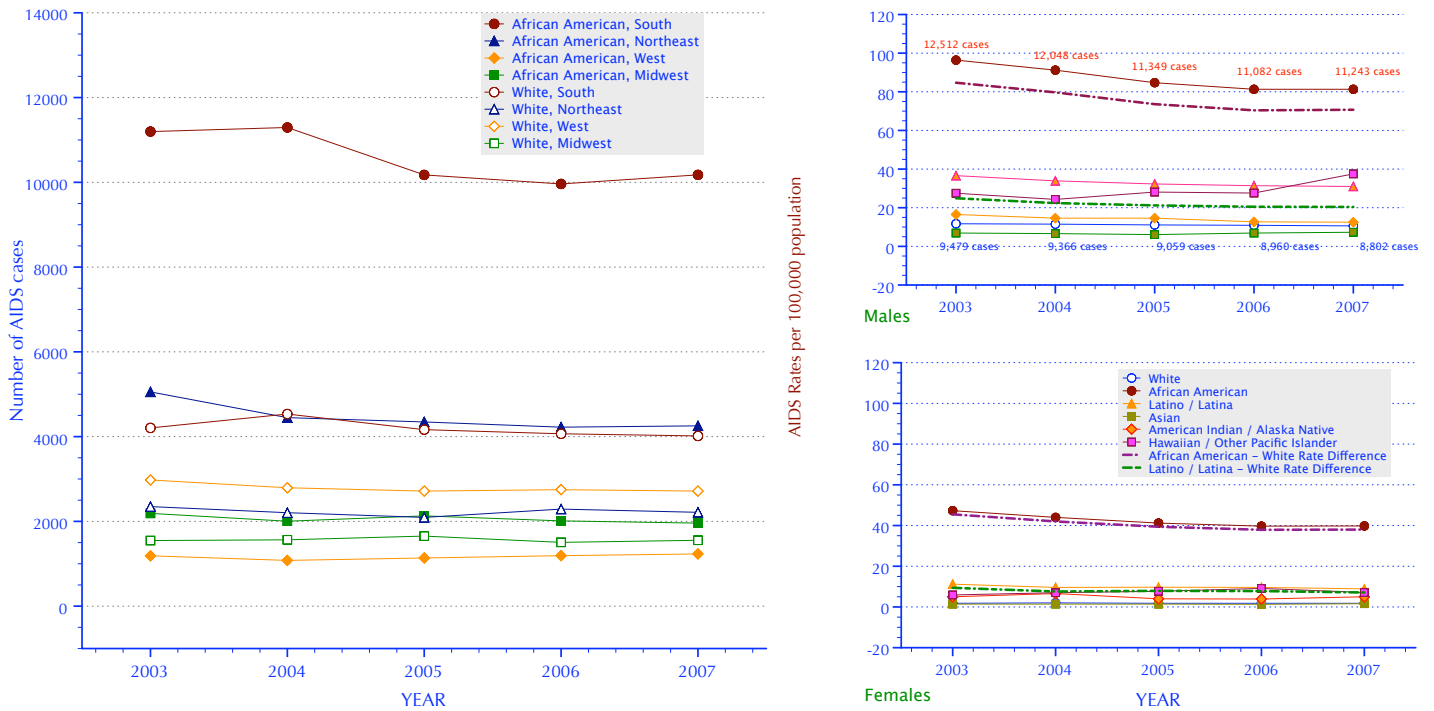
**FIGURE 11: AIDS PREVALENCE RATES BY REGION OF THE UNITED STATES, 1984-2005 (LEFT PANEL), AND BY DIVISION IN THE WEST REGION, 1984-2005 (RIGHT PANEL)**



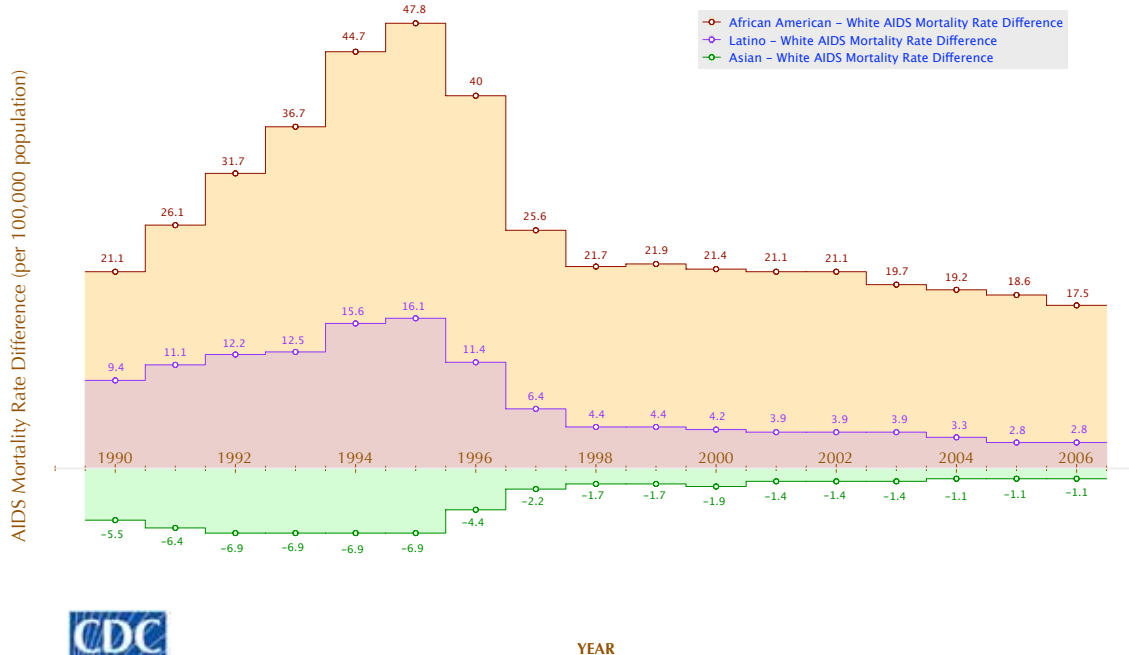
**FIGURE 12: AIDS PREVALENCE RATES BY REGION OF THE UNITED STATES, 1984-2005 (LEFT PANEL), AND BY DIVISION IN THE MIDWEST REGION, 1984-2005 (RIGHT PANEL)**



**FIGURE 13: ESTIMATED NUMBER OF AIDS CASES BY RACE AND REGION (LEFT PANEL), AND ESTIMATED AIDS RATES (PER 100,000 POPULATION), BY RACE/ETHNICITY FOR 50 STATES AND THE DISTRICT OF COLUMBIA, MEN (TOP RIGHT PANEL) AND WOMEN (BOTTOM RIGHT PANEL), 2003-07**

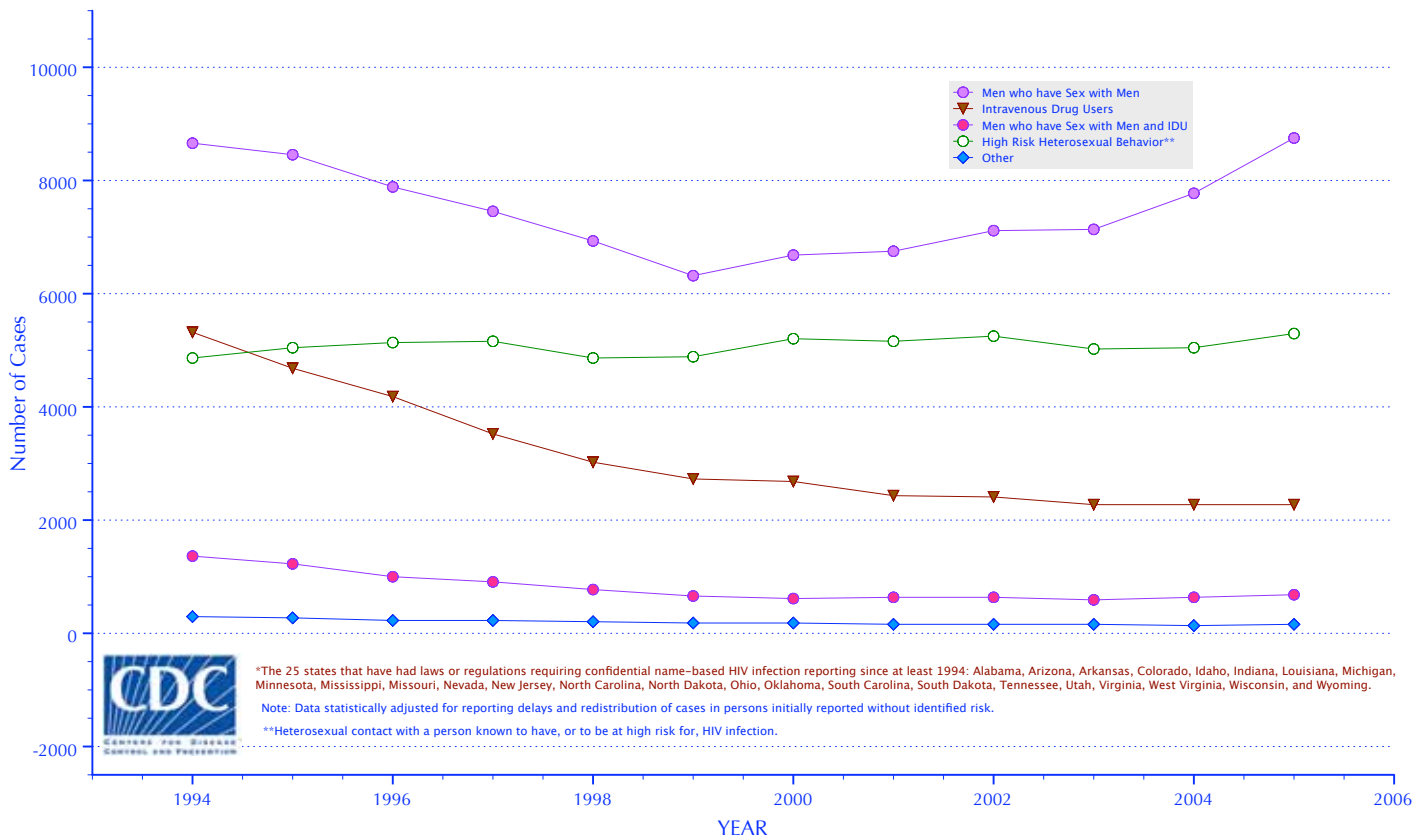


**FIGURE 14: MORTALITY RATE DIFFERENCES BETWEEN AFRICAN AMERICANS AND WHITES, LATINOS AND WHITES AND ASIAN AMERICANS AND WHITES, 1990-2006**



YEAR

**FIGURE 15: HIV/AIDS CASES AMONG ADULT AND ADOLESCENT MALES BY TRANSMISSION CATEGORY, 25 STATES\*, 1994-2005**



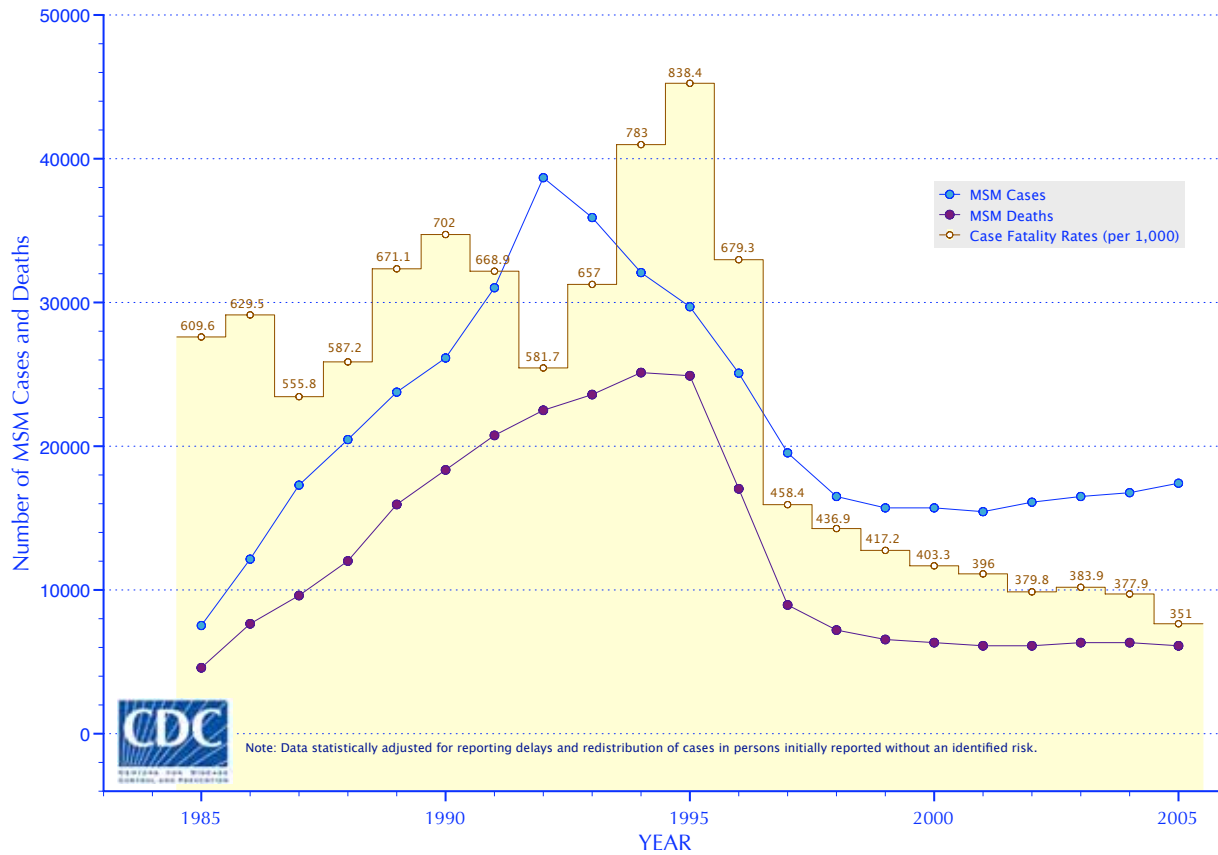
Americans in the Northeast have almost identical numbers of AIDS cases as whites in the South. African Americans in the Midwest have rates almost identical to whites in the Northeast, and African Americans in the West have rates slightly lower than whites in the Midwest. This figure clearly shows that the epidemic has become a Southern epidemic and an African American epidemic. When the regions are grouped, the excess AIDS prevalence is approximately 80 per 100,000 for African American men and 40 per 100,000 for African American women. The prevalence rates for men in all other race/ethnicity groups ranges between five per 100,000 and 20 per 100,000, with Asians having the lowest rates and American Indian/Alaska Natives and Hawaiian/Other Pacific Islander having the highest rates. Among women, the rates for groups other than African American are clustered between two per 100,000 and 15 per 100,000, with very little difference between each group but some difference between Latinas (closer to 15 per 100,000) and Asian women (closer to two per 100,000).

Figure 14 is a summary of the race/ethnicity death disparities shown as AIDS mortality rate differences. At its peak in 1995 the African American/white mortality rate difference was 47.8 per 100,000; this has declined to 17.7 per 100,000. There has been little difference in this disparity since 1998. The Latino/white disparity declined from a high of 16.1 per 100,000 in 1995 to a low of 2.8 per 100,000 in 2006. Asians had a lower AIDS mortality than whites – with a low disparity of -6.9 per 100,000 in 1995 to -1.3 in 2006.

### HIV/AIDS Among Men

Since 1994 two transmission categories have remained above 5,000 cases for men: men who have sex with men (MSM), and men who practice high-risk sexual behavior. The number of cases of MSM declined from approximately 8,500 cases in 1994 to approximately 6,250 cases in 1998 and then increased to just above 8,500 cases in 2006. There has been a slight increase in transmission among men who practice high-risk sexual behavior, from approximately 5,000 cases in 1994 to approximately 5,500 cases in 2006. Intravenous drug use

**FIGURE 16: AIDS CASES, DEATHS AND AIDS CASE FATALITY RATES (PER 1,000) AMONG MEN WHO HAVE SEX WITH MEN, 1985-2005, UNITED STATES**



transmission has declined from 5,750 cases in 1994 to just more than 2,000 in 2006 (**Figure 15**). The increasing rates among MSM and high-risk-behavior transmission groups are a cause for concern, since these are the two groups where the epidemic was initiated.

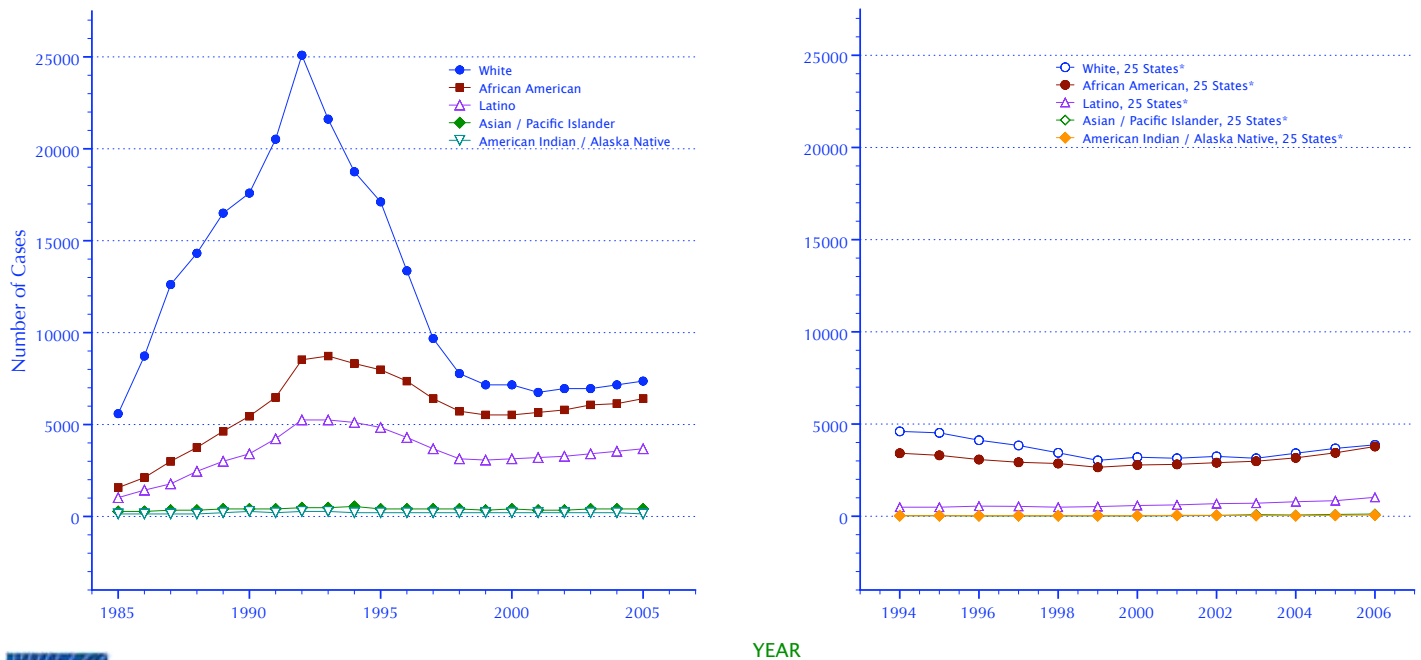
**Figure 16** shows the nature of the epidemic among MSM from 1995 to 2005. After peaking at about 40,000 cases in 1991 the number of AIDS cases declined to approximately 15,000 in 2000 and then showed a slow but steady increase to approximately 18,000 in 2005. There is lag in the curve for deaths among MSM of approximately four years, with the number of deaths reaching a peak of just above 24,000 in 1995, then declining to 6,000 in 2000 and remaining at that level. The case fatality rates (CFR) show this lag, with the peak rate of 838.4 per 1,000 in 1995 followed by a steady decline to 351 per 1,000 in 2005.

The data on the epidemic among adolescent and adult males reflect some aspects of the changing nature of the AIDS

epidemic in the United States. There has been an increase in the number of women being infected with the HIV; a question that must be addressed is whether the increase is a function of the resurgent epidemic among MSM. The extraordinary public health interventions of the early 1990s may be reversed by a concentration only on improving the access to antiretroviral treatment among those who are infected. It is vital that primary prevention through education and access to prevention strategies be given equal (or increased) weight. If this is not attended to, we are likely to see a resurgent epidemic, especially among those truly disadvantaged communities of color that already have reduced access to public health and medical services.

When one compares the data for MSM from all 50 states and the District of Columbia with those 25 states that have had laws and regulations requiring names-based HIV infection reporting since at least 1994, it becomes clear that the HIV and AIDS surveillance system still has some way to go to be fully operational in those communities, divisions, and regions of the

**FIGURE 17: AIDS CASES AMONG ADULT AND ADOLESCENT MEN WHO HAVE SEX WITH MEN, BY RACE/ETHNICITY, 1985-2005, UNITED STATES**



\*The 25 states that have had laws or regulations requiring confidential name-based HIV infection reporting since at least 1994: Alabama, Arizona, Arkansas, Colorado, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming.

Note: Data statistically adjusted for reporting delays and redistribution of cases in persons initially reported with identified risk.

United States at the epicenter of the epidemic (Figure 17). The fundamental concern of the lag in implementing a names-based HIV surveillance system is that a critical number of those states that most need such a system have deficits in systems-based funding. Careful screening and rigorous surveillance systems are the first step in managing an epidemic and identifying those most in need of public health services.

## 5. IMPLICATIONS OF THE CARE ACT APPROPRIATIONS ON MINORITY AIDS INITIATIVE FUNDING

Changes have occurred during the history of Ryan White funding to dilute direct funding to minority organizations providing AIDS education, treatment, and care. Scholars have noted that the overall federal AIDS budget has not kept up with the growth of the epidemic. Holtgrave et al. (2001) and

Valdiserri et al. (2004) noted that in 2007 the CDC's HIV prevention budget shrunk in real dollar terms (and the fourth year in a row in nominal terms). The average annual decrease during the last five fiscal years has been 4.15%, and there has been a 19.3% decrease between FY 2002 and FY 2007. This figure is just slightly larger than CDC's adjustment for inflation between FY 2001 and FY 2007, which used a different inflation index that focuses on research activities (Holtgrave 2007). The CDC budget for the Minority AIDS Initiative dropped from \$96 million in FY2007 to \$76 million in FY 2009, and a year of zero funding is projected for FY 2010.<sup>40</sup>

Additional substantive funding has not been redirected to the Minority AIDS Initiative to address AIDS budget contraction in other agencies. Like the overall federal AIDS budget, there have not been increases in funding to compensate for AIDS budget contractions elsewhere. Combined with the undesignated disbursements of MAI funding, the transition to

40 Judith Johnson, "AIDS Funding for Federal Government Programs: FY1981-FY2009," Congressional Research Service, April 23, 2008, and estimates provided from the Congressional Budget Office.

a competitive grant-making process, and changes in the formula for Parts A and Part B funding made in response to mandates in the CARE Act of 2007, there was a substantial reduction in targeted funding between 2007 and 2009.

Funding to some states that typically received MAI funding has also diminished. During hearings on the bill, grantees noted that the change in the grants process made the competitive grant process extremely cumbersome and did not provide reliable funding levels; thus, some states opted not to apply for grants.

Commentators and others indicated that MAI funding for 2009 increased in response to the longstanding disparity between MAI funding and the reality of the epidemic's impact on communities of color. However, the 2009 Senate Appropriations Committee report recommended funding the Minority AIDS Initiative at \$386.9 million in the request, slightly less than FY 2008 levels, and directed the transfer of \$2 million from HRSA operating division to address "high-priority HIV prevention and treatment needs of minority communities."<sup>41</sup> The total amount represents a decrease in actual funding when compared to preceding years, and clearly does not address the disproportionate gap between the AIDS epidemic in communities of color and federal AIDS spending levels.

Instead, the actual adjustment for inflation shows a substantial decrease in real dollar terms for the Minority AIDS Initiative budget. At the micro level, we can see the impact flattened funding has had on the Office of Women's Health.<sup>42</sup> The office, established in 1991 within DHHS, has a stated vision to ensure that "all women and girls are healthier and have a better sense of well being." Its mission is to "provide leadership to promote health equity for women and girls through sex/gender-specific approaches." The strategy OWH uses to achieve its mission and vision is the development of innovative programs to educate health professionals and to motivate behavior change in consumers through the dissemination of health information. OWH is responsible for funding a number of programs to address minority women's health issues. These include:

1. HIV Prevention for Young Women Attending Minority Institutions – 12 projects; a three-year evaluation began in 2007.

<sup>41</sup> Departments of Labor, Health and Human Services, and Education and Related Agencies, "Report of the Committee on Appropriations to Accompany H.R. 3293," No. 1-220, July 22, 2009.

<sup>42</sup> Office of Women's Health, "OWH and Minority AIDS Initiative Funded Programs: 2007-2008."

2. In Community Spirit: HIV Prevention for American Indian, Alaskan Native, and Native American Women Living in Rural and Frontier Indian Country – three projects.
3. National Women and Girls HIV/AIDS Awareness Day – a national HIV/AIDS/STDs and violence prevention education program targeted at minority women ages 18-25 to increase HIV and violence prevention knowledge and reduce the risk of contracting HIV. Regional and national events are held on March 10.
4. HIV Prevention for Women Living in the U.S. Virgin Islands – one project (funds for two).
5. HIV Prevention for Women Living with HIV/AIDS in Puerto Rico – two projects.
6. Prevention and Intervention AIDS-Related Services for Girls at Risk for Juvenile Delinquency – 10 projects.
7. Intergenerational Approaches to HIV/AIDS Prevention With Women Across the Lifespan – five projects.
8. HIV/AIDS and Women in the Rural South Program – funds demonstration projects for women-based organizations to provide HIV/AIDS prevention education services to women living in the rural South; five projects for three years.
9. Evaluation of OWH Women and HIV/AIDS Programs, REDA International (Wheaton, MD).

OWH received funding from the Minority AIDS Initiative to develop the following two demonstration projects to address persistent gaps in HIV/AIDS health care needs and services for women:

1. The Model Mentorship Program for Strengthening Organizational Capacity funds demonstration projects for mentorship between minority health organizations and women's organizations and/or community-based organizations delivering HIV/AIDS services, particularly to minority women. Both mentoring partners receive funding. Programmatic, administrative, fiscal, and technical assistance is provided to expand organizational capacity for improved delivery of HIV/AIDS services. Through mentoring, small organizations become better prepared to operate their agencies and implement successful HIV/AIDS programs independently.

2. The Incarcerated and Newly Released Women With HIV/AIDS/STDs Program funds demonstration projects to build a continuum of health care and support services for incarcerated and newly released minority women living with HIV/AIDS/STDs – five programs for three years.

Women represent a growing number of individuals living with AIDS in the United States; in 2007, they accounted for 55% of all new AIDS cases reported. Consequently, HIV/AIDS continues to be one of the leading causes of death for women age 25-44. Even though CDC calculates that the annual estimated rate of HIV diagnosis for black women has decreased significantly – from 82.7 per 100,000 population in 2001 to 60.2 per 100,000 population in 2005 – it remained 20 times the rate for white women.<sup>43</sup> Overall, the rates of HIV diagnosis are much higher for black and Hispanic women than for white, Asian and Pacific Islander, or American Indian and Alaska Native women. The rates for black women are higher than the rates for all men except for black men (see Figure 13). Yet, MAI funding for the program within the Office of Women’s Health has remained at \$1-2 million a year since the inception of the MAI, and it has not increased with the codification of the program. The fact that an estimated 94,000 black women live with AIDS while OWH programs touch the lives of only 5,000 of them highlights the disproportionality between the federal and Minority AIDS Initiative funding and the minority AIDS epidemic. OWH was also affected by the 2007 Care Act changes. The CARE Act amendments capped at 10% the amount that Part D grantees could spend on administrative expenses.<sup>44</sup> In testimony about the application of the changes it was noted that: “A majority of grantees also reported that the cap has had a negative effect on their Part D programs, even if it has not changed client services, because it has, for example, made it necessary for clinical staff to perform administrative tasks. In addition, about half of the grantees reported that not all of their Part D administrative expenses were covered by the 10% allowance.”<sup>45</sup>

Moreover, the GAO also indicated that CARE Act defined administrative expenses for Part D grantees as grant

management and monitoring activities. These expenses would include costs related to any activity unrelated to services or indirect costs (that includes in a federally negotiated indirect rate).<sup>46</sup> HRSA interprets administrative costs as excluding indirect costs. The legislative history indicated that, in defining administrative expenses, Congress departed from the standard definition of the term.<sup>47</sup>

### *Grant-Making Process Under the 2006 Act*

All Part A and B grantees that applied for MAI funding received it, but some Part B potential grantees decided that the administrative requirements, including a separate application for MAI funds, were not worth the amount of funds that they expected to receive and therefore chose not to apply. Moreover, grantees said that they generally funded the same service providers and initiatives to reduce minority health disparities as they had in prior years.<sup>48</sup>

The overall 2010 Minority AIDS Initiative was funded at \$143 million, a slight increase of 1 % over FY 2009 levels; and the Office of Women’s Health retained a \$1 million funding level in the FY 2010 appropriations.<sup>49</sup> To date, we have not been able to ascertain the OWH MAI appropriations levels. However, the 2011 Ryan White appropriations were increased \$39.5 million over FY 2010. Additional increases were provided to other areas of Ryan White programs, including resources to reduce health-related disparities in communities of color; and a \$53 million increase for minority AIDS prevention and treatment activities. How this funding will be allocated has not been published, but the increased funding – for the first time in Ryan White history – should provide for a clear increase in program funding availability above inflation levels.

43 CDC. HIV/AIDS Surveillance Report, 2007; Vol. 19. U.S. Department of Health and Human Services, CDC: 2009:1–63.

44 GAO, Ryan White Care Act: First-Year Experiences under the Part D Administrative Expense Cap, <http://www.gao.gov/products/GAO-09-140> (Washington D.C.: Dec. 19, 2008).

45 Testimony before the Committee on Energy and Commerce, Subcommittee on Health, Ryan White Care Act, “Program Changes Affecting Minority AIDS Initiative and Part D Grantees,” GAO-0901027T, September 9, 2009, as found at <http://www.gao.gov/htext/d091027t.html>.

46 42 U.S.C. § 300 ff-71(h)(1-2).

47 H.R. Rep. No. 109-695, at 11 (2006), reprinted in 2006 U.S. C. C.A.N. 1650, 1660.

48 Testimony before the Committee on Energy and Commerce, Subcommittee on Health, Ryan White Care Act, “Program Changes Affecting Minority AIDS Initiative and Part D Grantees,” GAO-09-1027T, September 9, 2009, as found at <http://www.gao.gov/htext/d091027t.html>.

49 President Releases Fiscal Year 2011 Budget Request, February 11, 2010 <http://www.siecus.org/index.cfm?fuseaction=Feature.showFeature&featureID=1870&noheader=1>



**TABLE 2: MINORITY AIDS INITIATIVE FUNDING, 1999-2010 (\$ MILLIONS)<sup>50</sup>**

Program	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
HRSA	\$24	\$74	\$110	\$124	\$130	\$130	\$129	\$129	\$131	\$135	\$139	\$146.55
CDC <sup>51</sup>	\$48	\$61	\$88	\$96	\$103	\$103	\$94	\$96	\$96	\$96	\$76	\$0 <sup>52</sup>
NIH <sup>53</sup>	\$8	\$9	\$7	\$5	\$15	\$0						
SAMHSA <sup>54</sup>	\$26	\$48	\$92	\$105	\$111	\$110	\$112	\$112	\$111	\$112	\$112	\$0 <sup>55</sup>
MCF <sup>56</sup>	\$50	\$50	\$50	\$50	\$50	\$50	\$52	\$52	\$52	\$52	\$52	\$52
OMH <sup>57</sup>	\$10	\$10	\$10	\$10	\$11	\$11	\$8	\$10	\$9	\$7	\$7	\$7+ <sup>58</sup>
OWH	\$0	\$0	\$0	\$1	\$1		\$1	\$1	\$1	\$2	\$1	\$1
Total	\$166	\$251	\$358	\$391	\$421	\$404	\$397	\$399	\$400	\$403	\$387 (\$410.6)	\$206.55 (\$414.5) <sup>59</sup>

50 Compiled from multiple charts developed by the Congressional Research Service, based on analysis from the DHHS Budget Office, February 1, 2008, and the DHHS website on Ryan White funding. Includes competitive proposals to various agencies within DHHS, such as the CDC, HRSA, the Substance Abuse and Mental Health Services Administration (SAMHSA), and the Indian Health Service. Project proposals are subject to three levels of review: peer review by fellow agency representatives who make up the MAI Steering Committee; secondary review by a committee of senior OPHS staff led by the director of OHAP; and final review by a team comprising the assistant secretary for health (ASH) and a few of his key advisors. Following approval from the ASH, agencies then award the funds through grants, cooperative agreements and/or contracts. In FY2009, MAI funds also support projects to: (1) improve outreach and testing for HIV, tuberculosis and sexually transmitted infections in the U.S. Pacific Jurisdictions where it helped create a Pacific Resource and Training Center and trained health departments and CBOs, (2) strengthen CBO outreach and improve data collection and analysis on HIV infection in African immigrant communities, (3) develop a formal mentoring and training program for Latino leaders of community organizations working on HIV/AIDS, and (4) initiate a collaboration with the Indian Health Service to strengthen community-based and Tribal work on HIV/AIDS.

51 Previously the CDC attributed partial funding to MAI for community-based organizations' capacity building and for testing; however, there is no mention of MAI funding in the FY2009 budget justifications of MAI funding, and there is no mention of a request for such funding. As indicated, the Ryan White 2007 amendments spread the MAI funding throughout the budget, so there may have been a decision within the budget office to not attach the spread of the fund to a specific program.

52 Previously the Centers for Disease Control and Prevention attributed partial funding to MAI for CBO capacity building and for testing, however, there is no mention of MAI funding in the FY 2009 budget justifications of MAI funding and there is not a mention of a request for such funding. As indicated the Ryan White 2007 amendments spread the MAI funding throughout the budget, and Congressional Budget Office cost estimates for H.R. 6143, the Ryan White Modernization Act, indicated that no intergovernmental mandates were incorporated into the new act, thus the program might be retained by the CDC without the MAI funding mandate. Senate Report 109-287 – Departments of Labor, Health and Human Services, and Education, and related agencies Appropriations Bill, 2007.

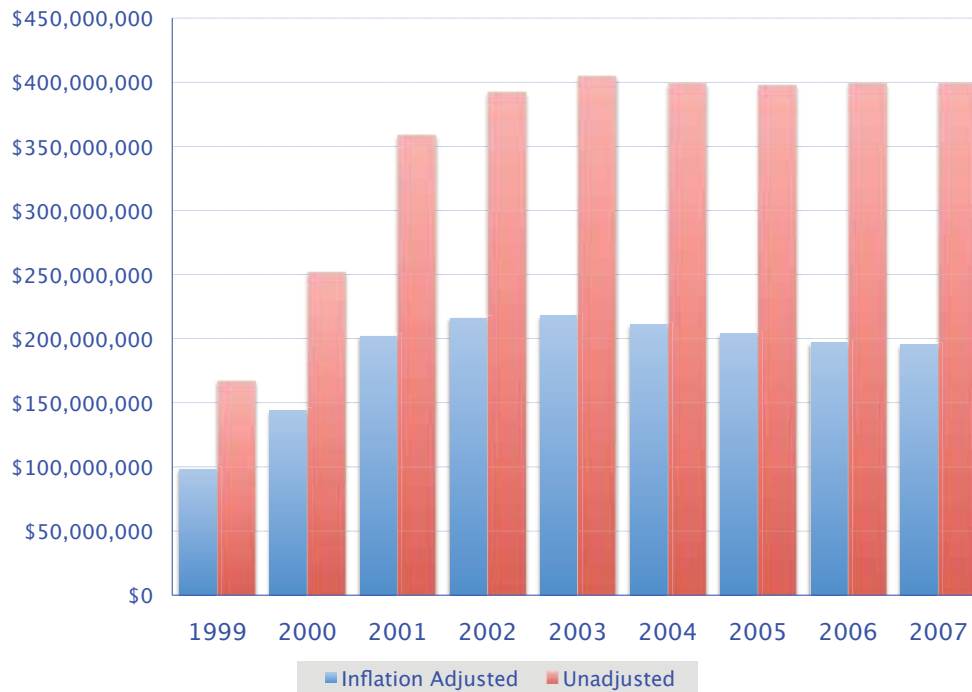
53 MAI funding to NIH is mentioned in the 2005 budget justifications submitted to Congress. The 2007 Appropriations Committee language reads as follows: "The Committee recommendation does not include a direct appropriation for the Office of AIDS Research [OAR]. Instead, funding for AIDS research is included within the appropriation for each Institute, Center, and Division of the NIH. The recommendation also includes a general provision which directs that the funding for AIDS research, as determined by the Director of the National Institutes of Health and the OAR, be allocated directly to the OAR for distribution to the Institutes consistent with the AIDS research plan. The recommendation also includes a general provision permitting the Director of the NIH and the OAR to shift up to 3 percent of AIDS research funding among Institutes and Centers throughout the year if needs change or unanticipated opportunities arise. The Committee requests that the Director provide notification to the Committee in the event the Directors exercise the 3 percent transfer authority. ...The NIH Office of AIDS Research [OAR] coordinates the scientific, budgetary, legislative, and policy elements of the NIH AIDS research program. Congress provided new authorities to the OAR to fulfill these responsibilities in the NIH Revitalization Act Amendments of 1993. The law mandates the OAR to develop an annual comprehensive plan and budget for all NIH AIDS research and to prepare a Presidential bypass budget."

54 Again, no reference is made to MAI funding in the SAMHSA 2010 budget justifications.

55 Again, no reference is made to MAI funding in the SAMHSA 2010 budget justifications. However, we find the MAI Initiative funding mentioned in the 2005 budget justifications submitted to Congress. The 2007 Appropriations Committee language reads as follows: "The Committee recommendation does not include a direct appropriation for the Office of AIDS Research [OAR]. Instead, funding for AIDS research is included within the appropriation for each Institute, Center, and Division of the NIH. The recommendation also includes a general provision which directs that the funding for AIDS research, as determined by the Director of the National Institutes of Health and the OAR, be allocated directly to the OAR for distribution to the Institutes consistent with the AIDS research plan. The recommendation also includes a general provision permitting the Director of the NIH and the OAR to shift up to 3 percent of AIDS research funding among Institutes and Centers throughout the year if needs change or unanticipated opportunities arise. The Committee requests that the Director provide notification to the Committee in the event the Directors exercise the 3 percent transfer authority. SAMHSA 2005 Budget FY 2005 Justification of Estimates for Appropriations Committees as found at <http://www.samhsa.gov/budget/b2005/spending/index.aspx> Department of Health and Human Services, FY 2010, SAMSHA Justifications as found at [http://www.samhsa.gov/Budget/FY2010/SAMHSA\\_FY10CJ.pdf](http://www.samhsa.gov/Budget/FY2010/SAMHSA_FY10CJ.pdf) The NIH Office of AIDS Research [OAR] coordinates the scientific, budgetary, legislative, and policy elements of the NIH AIDS research program. Congress provided new authorities to the OAR to fulfill these responsibilities in the NIH Revitalization Act Amendments of 1993. The law mandates the OAR to develop an annual comprehensive plan and budget for all NIH AIDS research and to prepare a Presidential bypass budget.

56 Minority Communities Fund, administered by the Office of the Secretary, HHS. Appropriations allocated to the Secretary are used to fund the Office of HIV/AIDS Policy, which was created after MAI funding initiative was created. Funds received by the Office of the Secretary for the MAI are disbursed to the Public Health Service agencies in HHS, as well as the Centers for Disease Control and Prevention; the Health Resources and Services Administration; the Substance Abuse and Mental Health Services Administration; and the Indian Health Service, on a competitive basis. Project proposals are subject to three levels of review, including peer review by fellow agency representatives who comprise the MAI Steering Committee; secondary review committee of senior OPHS staff lead by the Director of OHAP; and final review team comprised of the Assistant Secretary for Health (ASH) and a few of his key advisors. Following approval from the ASH, agencies then award the funds through grants, cooperative agreements, and/or contracts to support hundreds of organizations and entities across the country. Judith A. Johnson, Congressional Research Service Report to Congress, AIDS Funding for Government Programs: FY 1981-2009, updated April 23, 2009, CRS-8.

**FIGURE 18: FEDERAL FUNDING FOR THE MINORITY HIV/AIDS INITIATIVE BY AGENCY  
(IN US \$MILLIONS), 1990-2006**



57 Reference is made to MAI funding in budget justifications for the OMH, but it is difficult to pinpoint an amount actually spent on MAI programs. However, extensive DHHS Budget Justification Narrative reflects substantial MAI work and use of MAI funds. "OMH also supports HIV/AIDS programs, some of which are funded by the Minority HIV/AIDS Initiative (MAI). These programs include the Collaborative Technical Assistance and Capacity Development (CTA/CD), a three-year grant program initiated in FY2008 which supports 13 projects designed to develop and improve the coordination and continuum of HIV prevention, treatment and support services provided by organizations closely interfaced with targeted minority populations impacted by HIV/AIDS. In a collaborative partnership with primary care service sites and substance abuse and/or mental health treatment and prevention programs, grantees provide technical assistance and capacity building services to those organizations based on their identified needs. ...In FY2009, OMH also received MAI funds for two new programs. The first, Curbing HIV/AIDS Transmission among High Risk Youth and Adolescents by Utilizing Peer-to- Peer Interaction Using New Application Technologies (CHAT), is a partnership with HRSA and SAMHSA to support ongoing HIV/AIDS prevention, education and testing initiatives aimed at youth who are currently in alternative education settings; juvenile detention facilities; and alternative living arrangements ordered by the courts. The project will use innovative approaches such as texting and tweeting as a tool to support instant communication with the target population to increase access to AIDS information and prevention through these application technologies. The second is the HIV/AIDS Health Improvement for Re-entering Ex-offenders Initiative (HIRE). OMH, in partnership with the Substance Abuse and Mental Health Services Administration, Centers for Medicare and Medicaid Services, Administration for Children and Families, Health Resources and Services Administration, Indian Health Service, and the Department of Justice seeks to improve the HIV/AIDS health outcomes of ex-offenders re-entering the mainstream population (reentry population) by supporting community-based efforts to ensure the successful transition of ex-offenders as they complete their state or federal prison sentences and return to the community. Under a comprehensive umbrella demonstration grant, OMH will target the re-entry population affected by HIV/AIDS."

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59 Figure in parenthesis is taken from Kaiser Family Foundation 2010 MAI Fact Sheet.

## CONCLUSIONS AND RECOMMENDATIONS

The revelation of deficiencies in the legislation and regulatory framework, combined with the levels of appropriations, informed our analysis of the disconnection between the policy and regulatory infrastructure and the epidemiology of HIV and AIDS. We believe that HIV and AIDS epidemiology could contribute much to the advocacy needs of communities of color. Policies and regulations should reflect the changing nature of the multiple epidemics of HIV and AIDS.

Without a shift in the regulatory framework (as well as the appropriations formulae), the Ryan White programs retain a mission out of synch with the current manifestations of the descriptive epidemiology of HIV and AIDS. The Extension Act Committee Report provides extensive direction to move toward the MAI goals of prevention, education and testing, but as long as the mandate to spend 75% of these resources on treatment, the recommendations set out by the Report will not be met. More dollars are being spent on fewer terminally ill, who live in regions where the epidemic is stable or on the decline, and on those individuals who are experiencing shorter periods of illness. Proportionately fewer dollars are being spent on prevention and education and in regions of the country where the epidemic is at its height.

### THIS REPORT OFFERS THE FOLLOWING RECOMMENDATIONS:

1. Since its inception the CARE Act has retained a provision mandating that 75% of the core funding be used for “direct medical services.” This legislative mandate colors the approach taken to all funding, including the MAI funds. The act is not designed to address the differing stages of the multiple regional epidemics. We believe the 75% funding limitation should be taken out, and funding decisions should be left to the secretary and to the MAI planning committee.
2. Complete and accurate demographic data will not be available to the CDC for use by DHHS for funding decisions until around 2012, as the states did not comply with the Ryan White names reporting requirements until 2007. Under the 2007 amendments, states could receive up to a 30% penalty for anonymous reporting. Although this provision has been removed in the CARE Act extension legislation and the 3-5% penalty as incorporated

in the original CARE Act now applies, there needs to be additional development of the demographic data and the removal of the penalty, especially in those regions that have been identified as the epicenter of the epidemic.

3. DHHS and minority AIDS advocates have known that there has been a shift in the center of disease transmission from the urban areas initially identified with the epidemic, e.g. San Francisco and New York, to include the rural South; however, politics has played a role in the failure to equitably transfer funding. We believe that without the transfer of proportional funding to address the epidemic in the South, additional epidemics will emerge. Transfer of funding best serves national interests.
4. Though the CARE Extension Act includes a mandate for AIDS testing and the development of a national AIDS testing plan (by the secretary of DHHS), neither the Ryan White appropriations nor the CARE Act extension includes funding for the rollout of a national AIDS testing plan. We support the development of a national testing plan and recommend including an appropriation to cover the costs of the proposed 5 million tests for 2010, with a continuing appropriation to cover testing until 90% of the U.S. population has been tested at least once for the disease.
5. The CARE Act extension includes language directing the secretary to provide pre- and post-conviction AIDS support and education programs for inmates. However, no funding is included in the legislation. We recommend additional funding to address this need as the release of the prison population and the incumbent infection and transmission risks associated with convict re-entry disproportionately impact minority communities.

Central to our efforts to track the effectiveness of the funding sources have been the government’s efforts to address the inequity of the formulae used to disburse CARE Act funding. Numerous scholars have challenged the funding formulae and determined the formulae deficient; however, we believe that the formulae could provide a fairly equitable funding base for medical/health care, housing, and other support services if the data used to evaluate funding were accurate. It is not.

The CARE Act does not address the characteristics of the epidemic and transmission rates. The central mission of the act has been to provide the initial framework for federal and state care of persons living with AIDS. Designed to create a comprehensive network of services, the regulations and

interpretive guidance issued under the Care Act have and continue to serve as the standard for providing care, treatment services, and housing and prescription services. Although the mission does not conflict with the alternative goal of tracking transmission, the CARE Act was not designed to fund ancillary efforts needed to control transmission.

The CARE Act was enacted to address the needs of jurisdictions, health care providers, and people with HIV/AIDS and their family members. The Ryan White HIV/AIDS Treatment Modernization Act of 2006, which reauthorized CARE Act programs for fiscal years 2007 through 2009, changed how Ryan White funds can be used, with an emphasis on providing life-saving and life-extending services for people living with HIV/AIDS. Key changes in the most recent legislation included:

1. A new method for determining eligibility for Part A (formerly called Title I) funds that gives priority to urban areas with the highest number of people living with AIDS while also helping mid-size cities and areas with emerging needs.
2. A new method for distributing Part A funds that directs money to metropolitan areas with the highest number of people who are HIV-positive. The methods encourage outreach and testing, which will get people into treatment sooner and save more lives.
3. More money spent on direct health care for Ryan White clients. Under the 2006 law, grantees receiving funds under Parts A, B, and C (formerly called Titles I, II, and III) must spend at least 75% of funds on “core medical services.”
4. The codification of the Minority AIDS Initiative for HRSA’s Ryan White programs.

With changes in the law have come changes in the HIV/AIDS demographics. In August 2008, the CDC released updated national estimates of the annual number of new HIV infections that occur in the United States. The new analysis found there were about 56,300 new HIV infections in 2006 (the most recent year for which data are available), about 40% higher than CDC’s long-standing estimate of 40,000 for each of the last several years<sup>60</sup>.

With the new law, DHHS also amended the Ryan White data collection process. The federal government is including CDC-confirmed HIV case data in the Ryan White CARE Act funding formula and mandating the use of a names-based reporting system.

As of January 2005, 38 states and five territories had adopted names-based HIV reporting systems; five states had adopted name-to-code-based systems; and seven states, Philadelphia and the District of Columbia continued use of systems that use coded identifiers. In the 14 areas using codes, 13 different codes are used. Several of the latter, including California, are changing to named reporting. Those states not using names-based systems have not been included in CDC AIDS surveillance reports or in the allocation of Ryan White funds. In 2008, only two states continued to use code-based systems. This change in state public health reporting processes has radically impacted the data collected by the CDC and used in Ryan White Act appropriations process.

60 Lawrence K. Altman, New York Times August 3, 2008; “HIV Rates 40 % Higher than Estimated”. Original source, Centers for Disease Control and Prevention, CDC Facts: Estimates of New HIV Infections in the United States, August 2008.

## ABOUT THE JOINT CENTER AND ITS HEALTH POLICY INSTITUTE

The Joint Center for Political and Economic Studies is one of the nation's leading research and public policy institutions and the only one whose work focuses primarily on issues of concern to African Americans and other people of color. For nearly 40 years, our research and policy analysis have informed and influenced public opinion and national policy, while contributing to a wider understanding of the role of black civic and political participation in making America a better place for all its citizens.

The Joint Center Health Policy Institute, one of its four “centers of excellence,” plays a leadership role in reframing policy debates on health and focusing attention on existing health disparities. Our ongoing research and analysis are helping to generate policy recommendations and solutions for longstanding health equity concerns. The Institute strives to identify the complex underlying causes of health disparities and to develop strategies to address them, with the understanding that targeting the social determinants of health can lead to positive changes in patterns of health and well-being.

**Ralph B. Everett, Esq.** is President and CEO of the Joint Center for Political and Economic Studies, widely acknowledged as the nation's leading think tank for policy analysis and research on issues of concern to African Americans and other people of color. A native of Orangeburg, South Carolina, he has a 30 year track record of pioneering leadership in the nation's capital, having served in the 1980s as Staff Director and Chief Counsel of the U.S. Senate Committee on Commerce, Science and Transportation, and subsequently for more than 17 years as a partner at the international law firm of Paul, Hastings, Janofsky & Walker. A Phi Beta Kappa graduate of Morehouse College, Mr. Everett earned his J.D. from Duke University Law School.

**Brian D. Smedley, Ph.D.** is Vice President and Director of the Health Policy Institute of the Joint Center for Political and Economic Studies in Washington, DC. Formally, Smedley was Research Director and co-founder of a communications, research and policy organization, The Opportunity Agenda. Prior to helping launch The Opportunity Agenda, Smedley was a Senior Program Officer in the Division of Health Sciences Policy of the Institute of Medicine (IOM), where he served as Study Director for the IOM reports, *In the Nation's Compelling Interest: Ensuring Diversity in the Health Care Workforce* and *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, among other reports on diversity in the health professions and minority health research policy.

## ABOUT THE AUTHORS

*Allen A. Herman, MD, Ph.D.* – Dr. Herman is a native South African and an experienced consultant in health care, public health and Epidemiology. Currently Dr. Herman is the Project Director for Diabetes Self-Management Education (DSME) Projects funded by the Centers for Medicare and Medicaid Services (CMS). The first project is located in western Tennessee and focuses on improving the secondary and tertiary health outcomes of Medicare diabetics with and without chronic kidney disease. The second project covers the entire state of Mississippi and addresses the key educational problems of Medicare, Medicaid, underinsured and uninsured persons diagnosed with diabetes through the implementation of a comprehensive Diabetes Self-Management Education program.

Prior to his work in Tennessee and Mississippi, Dr. Herman spent eight years as the foundation Dean of the National School of Public Health of the Republic of South Africa. Dr. Herman was the architect and designer of the first e-learning Masters degree program in Public Health in Africa. He designed and developed the computing, physical and virtual infrastructure of the e-learning program at the National School of Public Health, coordinated the development of the two-year Masters degree program, and created both the Epidemiology and Biostatistics curricula. This program served students in twenty-six countries across Africa. Additionally, Dr. Herman helped develop the first e-learning program in HIV/AIDS Management in the World of Work. Now in its fifth year this one-year certificate program identified managers at all levels in the workplace and still graduates more than 200 students each year.

Dr. Herman has extensive experience in developing large-scale research projects in the fields of health services research, mother and child health, AIDS, cancer and mental health. He developed and led research projects in a number of states and the District of Columbia, in Scandinavia and Africa. He has written extensively on the role of race, social identity and economic status on the health of populations.

His work in HIV/AIDS included being the principal international advisor to the Hon. Ronald V. Dellums during his term as Chairman of the U.S. Presidential Committee on HIV/AIDS. Dr. Herman also advised the South African National Defense Force and helped bring a substantial antiretroviral treatment program to the South African military. The treatment program was developed in partnership with the United States Department of Defense and the National Institute of Allergy and Infectious Diseases of the National Institutes of Health.

Dr. Herman graduated in Medicine from the University of Natal in 1977 and completed his doctoral work in Epidemiology at the University of the Witwatersrand in 1989. He was a postdoctoral research fellow at Columbia University.

***Winifred Carson Smith, Esq.*** – Windy Carson-Smith, attorney, consultant and entrepreneur, has worked in various capacities throughout her career. Presently, chief operating officer and owner of Carson Company, a health care consulting policy concern, she brings over 25 years of senior association, legislative, policy and regulatory experience at the state, federal and national levels to her national consultancy. Her clients include the American Nurses Association, the National Association of Clinical Nurse Specialists, the Joint Center for Political Studies state nursing associations and individual health clients.

Over the years, Windy has lobbied, testified and drafted laws and regulations for registered nursing, advanced practice nursing, prescriptive practice and other regulatory matters. She has worked on major nursing policy national and state initiatives to include legislative and regulatory barriers to practice for clinical nurse specialists, advanced practice nursing reimbursement, nursing ANA standards and guidelines, and barriers to advanced nursing practice. One of her history making endeavors includes the initiation of the lobbying campaign which led to independent DEA registration of advanced practice nurses. Windy authored numerous articles on nursing issues for numerous academic and professional journals to include *The American Nurse*, *Nurse Practitioner*, *NP World News*, *American Journal of Nurse Practitioners*, *Advanced Practice Nursing Quarterly*, *Advance for Nursing Practice*, *The American Journal for Nursing*, *The Online Journal for Nursing*, *The NBNA News*, and *Kango* (the journal of the Japanese Nurses Association). Windy has also authored chapters on advanced nursing practice and nurse prescriptive authority in the following books: *Health Law Handbook*, *Nurses*, *Nurse Practitioners: Evolution to Advanced Practice*, and *Nursing Clinics of America*. Frequently quoted in mainstream and nursing press on nursing issues, especially nurse prescribing, Windy writes a regular column for *NP World News*. She sits on the editorial advisory boards of *Health Law Week* and *The American Journal for Nurse Practitioners*. Windy was the only non-nurse recognized for her advocacy on advanced practice nursing issues by *Nurse Practitioner* magazine (2000) on the anniversary of nurse practitioner practice. Windy served on the National Practitioner Data Bank Advisory Committee (HHS) and as a nursing liaison to the DEA. Windy is also involved in community affairs. A fundraiser for District of Columbia candidates, she recently completed her tenure as President of the LeDroit Park Civic Association. She serves on the Board of Directors of the Duke Club of Washington, JPM and Associates, the Wright Family Foundation and Random Acts Foundation.

Windy received her undergraduate degree in History and Political Science from Duke University and her law degree from George Washington University. She is the wife of Frank Smith, Jr., PhD., a civic rights activist, scholar, former D.C. Councilmember and Director of the African American Civil War Freedom Foundation, the only national organization dedicated to recognition of the achievements of black soldiers who fought in the civil war.

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