

Changes in HIV/AIDS patterns of care and estimated costs at an urban medical center during the era of HAART

James E. Rawlings¹ J. Holmes² B. Belton² P. Selwyn³ G. Friedland². ¹20 York Street New Haven Connecticut 06515; ²Yale New Haven Hospital New Haven; ³Yale New Haven Hospital Selwyn, USA

Objective: To estimate the patterns and costs of HIV/AIDS inpatient and outpatient care at a 700 bed urban hospital in the era of highly active Retroviral therapy (HAART).

Methods: Evaluation of utilization of inpatient and outpatient hospital services; all patients with HIV/AIDS related admissions identified by ICD-9 coded discharge diagnoses; outpatients identified by attendance at hospital-based HIV-specific primary care clinic. Cost of care determined by Resource Information Management System (RIMS), a computerized fiscal data system which assigns costs for all inpatient and outpatient hospital-related services. Antiviral and nursing home costs were estimated from separate patient matched databases.

	10/94-9/95*	10/95-9/96*	10/96-9/97*
Admissions	830 (-10%)	801 (-3%)	662 (-17%)
Inpatient days	9102 (-12%)	7258 (-20%)	5368 (-26%)
Average Length of Stay	10.9 (-4%)	9 (-15%)	8.1 (-10%)
Unique outpatients	660	692 (5%)	741 (7%)
Outpatient visits	5523 (+3%)	5920 (+7%)	6522 (+9%)
Inpatient service costs	\$10,101,399	\$8,542,171 (-15%)	\$6,483,350 (-24%)
Outpatient service costs	\$1,554,761	\$1,588,857	\$1,754,634
AIDS nursing home	--	\$693,600	\$658,920
Antiviral costs (estimated)	\$1,481,000	\$1,992,000 (+35%)	\$4,039,000 (+103%)
Viral load costs	--	--	\$125,031
Total cost	\$13,137,160	\$12,816,628	\$13,060,935
Cost/patient/year	\$19,904	\$17,519	\$16,736

*Changes compared to previous year.

Conclusion: During the period of introduction and availability of HAART, acceleration of already-occurring favorable shifts in utilization of services and associated costs occurred. Outpatient and non-hospital utilization/cost and antiviral costs increased, but were offset by dramatic decreases in utilization/cost of inpatient care. Although the total number of patients in care increased, overall costs remained level and cost/patient/year decreased. Our analysis suggests that HAART is cost-effective.

NASTAD
NATIONAL ALLIANCE
OF STATE AND TERRITORIAL
AIDS DIRECTORS



**National ADAP Monitoring Project:
Interim Technical Report
March 1998**

Report By

Arnold Doyle
Richard Jefferys
Joseph Kelly

National Alliance of State and Territorial AIDS Directors
and
AIDS Treatment Data Network

Supported by a grant from The Henry J. Kaiser Family Foundation

Executive Summary

AIDS Drug Assistance Programs (ADAPs) are state-administered drug reimbursement programs that provide access to HIV/AIDS medications for low income, uninsured and underinsured individuals. Funded through the federal Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and by many states, these programs form one link in the continuum of publicly financed health care for lower income individuals living with HIV/AIDS, along with other CARE Act-funded programs, Medicaid, Medicare and local indigent health care programs. ADAPs operate in all fifty states, the District of Columbia and Puerto Rico.

These programs, initially intended to provide a safety net of temporary prescription drug coverage for lower income, uninsured or inadequately insured people living with HIV/AIDS, are now being called upon to fill a steadily growing gap in drug coverage for the HIV-infected population. Increases in numbers of clients utilizing ADAP services, the approval of new, promising and expensive anti-HIV treatments, the acceptance of combination therapy as the standard of care, rising ADAP expenditures, and restrictions on access to other public health care programs have moved ADAPs to further expand their umbrella of coverage. This raises the concern of whether ADAPs are able to adequately fill the growing gap in prescription drug coverage for people living with HIV/AIDS.

The National Alliance of State and Territorial AIDS Directors (NASTAD), in collaboration with the AIDS Treatment Data Network (ATDN), was commissioned by the Henry J. Kaiser Family Foundation to conduct a two-year National ADAP Monitoring Project. This Interim Technical Report provides an update of the data presented in the first National ADAP Status Report, released July 1997, and continues our efforts to track developments in the rapidly changing environment surrounding HIV/AIDS health care and therapy access. The update describes trends in the number of individuals served by ADAPs; drug expenditures; the fiscal status of ADAPs; and responsiveness to changes in treatment recommendations. A comprehensive update review of these programs is scheduled for release in Fall 1998.

Methods

In September 1997, a National ADAP Update survey was distributed to the 52 jurisdictions receiving Ryan White CARE Act Title II ADAP funds. The survey response rate was 100%, with all fifty-two jurisdictions reporting. Here are the major findings:

Update in the Number of Clients Served

The overall number of clients served by ADAPs continues to increase, although program growth is occurring at different rates across states, including some declines:

- Nationally, states report that 43,494 unduplicated clients were served by ADAPs during July 1997 compared to 37,506 clients in January 1997 – a 16% increase. When compared to data from the July 1996 period, there has been a 39% increase in the number of clients served.
- Thirty-nine states report increases in the number of clients served in July 1997 compared to January 1997. Six states report increases in clients served of 50% or more: Alaska, Delaware, Georgia, Louisiana, Rhode Island and South Carolina.
- Ten states report no growth or actual decreases in clients served: Connecticut, Idaho, Massachusetts, Mississippi, Montana, North Dakota, Oregon, South Dakota, Tennessee, and Virginia.

Expenditure Update

ADAP program expenditures, including expenditures for antiretroviral drugs, continue to grow as do the number of prescriptions filled by ADAPs.

- Forty-two states report increases in monthly ADAP expenditures, when July 1997 data are compared to January 1997. Fifteen of those states reporting increases of 50% or greater. Those states are Alaska, Delaware, Florida, Indiana, Iowa, Louisiana, Missouri, Nebraska, New Hampshire, North Carolina, Ohio, Rhode Island, South Carolina, Vermont and Wisconsin.
- Monthly ADAP expenditures increased 36% nationally, from \$19.5 million in January 1997 to \$26.6 million in July 1997. A comparison with data from the previous national ADAP survey indicates a 78% growth in monthly expenditures by ADAPs nationally when July 1996 are compared to July 1997 data.
- States report that the total number of prescriptions filled for all drugs on ADAP formularies increased by 24% from 105,236 in January 1997 to 130,336 prescriptions filled in July 1997. Notably, the number of protease inhibitor prescriptions filled by state ADAPs increased by 75% from 12,530 to 21,951 when comparing the same time periods.
- States report a 38% growth in expenditures for antiretroviral drugs from \$15 million in January 1997 to \$20.7 million in July 1997. There was a reported 20% growth in expenses related to other formulary drugs (including drugs for the prevention and treatment of opportunistic infections) from \$4.8 million in January 1997 to \$5.7 million in July 1997.

ADAP Budget Update Since the Last Report

The total national ADAP budget (including all sources¹) increased from \$385 million to \$422 million since the last report. This represents an overall increase of 9.6% or \$37.1 million. The increase includes a 9% increase in federal and state funds, from \$358.5 million to \$390.8 million.² Moreover, a number of state programs secured additional FY 1997 funding:

- Thirty-six states now supplement federal dollars with state-specific fiscal support (6 additional states since the last report).
- Thirteen states realized increased state/local general revenue support over the six-month period – Arizona, the District of Columbia, Florida, Indiana, Kentucky, Louisiana, Massachusetts, Minnesota, Nevada, Oklahoma, Pennsylvania, Tennessee, and Vermont.
- Six states provide the vast majority (78%) of ADAP funds provided by states—California, Illinois, Louisiana, Massachusetts, New York, and Pennsylvania.
- Sixteen states do not provide any funds specifically for ADAP and therefore rely solely on federal funding to provide ADAP services. These 16 states are: Alaska, Arkansas, Delaware, Idaho, Iowa, Kansas, Michigan, Mississippi, Montana, Nebraska, New Hampshire, North Dakota, Oregon, Rhode Island, South Dakota and Wyoming.

Emergency Cost-Containment Measures Continue

Despite an overall increase in the national ADAP budget, there continues to be disparity in the diversity of funding sources that are available to and utilized by ADAPs and many states are relying on emergency measures to continue to meet client demand and expenditures. Twenty-three states are currently curtailing ADAP services or facing budget shortages which may result in reduced services early in 1998. For example:

- Thirteen states report that they will exhaust their ADAP budgets before the next round of federal funds is available on April 1, 1998. These states are: Alabama, Alaska, Arizona, Colorado, Idaho, Kansas, Kentucky, Maine, North Carolina, Puerto Rico, Texas, West Virginia and Wyoming. At the time of the last report, eleven states reported anticipated budget shortfalls, six of which continue to do so.

¹ All sources include federal (Ryan White CARE Act Title II base and supplemental funds and Title I funds), state/local funds, and other funds such as drug rebates and insurance recovery.

² The largest category in the 1997 national ADAP funding system, the FY 1997 federal Title II ADAP supplemental funding (\$167 million), remained constant since the last report. Federal increases therefore are from increases in Ryan White Title II base funding and Ryan White Title I eligible metropolitan area (EMA) contributions.

- Fifteen states report that they are maintaining waiting lists for entry to ADAP or for access to protease inhibitors (this is the same number of states which reported such waiting lists at the time of the first report, 12 of which continue to do so and three report waiting lists for the first time). The nine states which currently report waiting lists for entry to ADAP are: Alabama, Florida, Georgia, Indiana, Mississippi, Montana, Nevada, South Carolina and South Dakota. In addition, North Carolina has stopped authorizing new clients for program participation since September 1997, although the program does not maintain a waiting list. The seven states which currently maintain waiting lists for clients to access protease inhibitors from the ADAP are: D.C., Idaho, Kentucky, Maine, Mississippi, Oklahoma, and Nevada (Nevada also has a waiting list for entry to ADAP).

ADAP Formularies and Responsiveness to Evolving Standards for Clinical Practice

At a time of rapid advances in the clinical management of HIV/AIDS³ and finite resources, states report efforts to: expand formulary coverage, broaden provider and community input in formulary development, and respond to federal treatment guidelines.

- Forty-five states report that they have formal ADAP advisory bodies in place that assist in making formulary decisions and, in some cases, decisions regarding the administration and structure of the ADAP.
- Forty-two states have changed their formularies since our previous report. Forty-nine states now cover the most recently FDA-approved protease inhibitor, nelfinavir (Viracept). Two ADAPs (Arkansas and South Dakota) currently do not cover any protease inhibitor. Forty-four states cover the first approved NNRTI, nevirapine (Viramune).
- Fifteen states report expanding the ADAP formulary to cover the eleven approved anti-viral drugs referenced in the antiretroviral guidelines, in addition to the states already providing coverage for these treatments. States have taken other actions in response to the PHS/NIH guidelines, including updating state/local treatment guidelines and developing provider education programs.
- Ten states added drugs for the treatment and prevention of opportunistic infections (OIs). However, there continues to be significant disparity among ADAPs in their coverage of OI treatment/prophylaxis. Only two state ADAPs cover the 14 drugs strongly recommended for the prevention of OIs in the PHS/IDSA guidelines.

³ In June 1997, "Draft Guidelines on the Use of Antiretroviral Agents in HIV-infected Adults and Adolescents" were released by the Public Health Service (PHS), in collaboration with the National Institutes of Health (NIH) and the Henry J. Kaiser Family Foundation. Also in June 1997, the PHS in collaboration with the Infectious Disease Society of America (IDSA) released "Guidelines for the Prevention of Opportunistic Infections in Persons Infected with HIV."

Relationship of ADAP to Medicaid and Private Insurance Coverage

The relationship between ADAP, Medicaid and private insurance has come under increased scrutiny as states seek to maximize non-ADAP sources of pharmacy benefits in order to reduce the burden on ADAP. Some states utilize insurance continuity programs to reduce the burden on their ADAP and provide stable access to health care services. In order to monitor emerging trends, states were asked to describe efforts to ensure that ADAP is the payer of last resort, discuss areas of cooperation between Medicaid and ADAP, and assess the impact of Medicaid coverage on the state ADAP.⁴ For example:

- Approximately 7 percent of ADAP clients served in July 1997 were also current Medicaid beneficiaries (including those in the spenddown process). The reported percentage of ADAP clients estimated to have Medicaid benefits varies greatly from state to state. Twenty-one states reported that no active ADAP clients were Medicaid beneficiaries.
- Thirty-nine ADAPs indicate that they have mechanisms to cross-check/coordinate client eligibility with the state Medicaid program. Twenty ADAPs report that they routinely back-bill Medicaid when an ADAP client receives retroactive Medicaid benefits.
- Approximately 7 percent of ADAP clients served in July 1997 had private health insurance that provides some level of prescription drug coverage, although this percentage varied greatly by state.

⁴ State AIDS programs were asked to identify Medicaid policies in their states that may result in increased demand on ADAP. An analysis indicates that nineteen of the twenty-three states identified as having less expansive Medicaid coverage (i.e., no medically needy eligibility category, low spenddown threshold and/or prescription drug limits) are also states with restricted access to ADAP.

Poz

7/98

THE GILDEN AGE

Penny Wise, Pound Foolish

Medicaid for HIV is an idea too simple for its time

BY DAVE GILDEN

There's an old saying that every crisis creates opportunities. But every opportunity also creates its own crises. The arrival of potent combination therapies for HIV promises to stabilize the disease for many, vastly increasing the popularity of early treatment and sparking a sharp drop in new AIDS diagnoses. At the same time, these drugs are expensive, and exacerbate the crisis in our nation's patchwork system of health care. We want people to stay healthy, yet who will pay for years of antivirals?

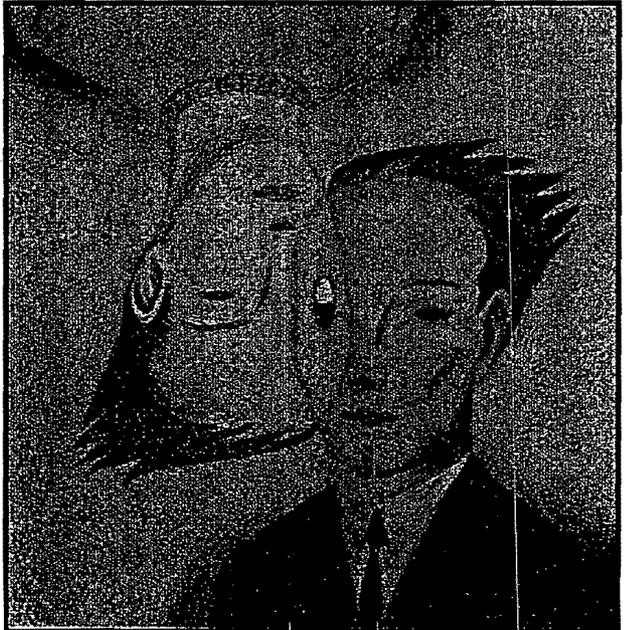
Hundreds of thousands who lack insurance but are ineligible for Medicaid fall through the cracks. The federally funded, state-run AIDS Drug Assistance Programs (ADAPs) help those not so poor, not so sick. But by failing to finance overall medical management (e.g., lab tests and doctor visits), ADAPs encourage improper use of antivirals and increase the likelihood of drug failure. And since funding does not automatically grow with demand for treatment, ADAP periodically faces bankruptcy.

In spring 1997, Vice President Al Gore endorsed a community proposal to provide coverage for most of those in medical freefall: Instead of waiting for a person to develop AIDS and qualify for disability, why not have Medicaid include everybody with HIV below a certain income level? Medicaid is more complete than ADAP and provides more care with less hassle

than the deteriorating private-insurance system.

This plan was apparently too simple for our times. Under the current balanced-budget regime in Washington, you can only save a life if you save a dollar, it seems. When health-department actuaries projected expenses over the next five years, they found that Medicaid for HIV

after the federal rejection. States can apply for waivers to add extra Medicaid coverage for HIV, so long as they promise to foot any extra bills. At present, Massachusetts is moving to apply for such a waiver, with Florida, Mississippi and Maine likely to soon follow. The state efforts would apply to people with HIV who earn less than twice the



In America, you can only save a life if you can save a dollar.

would be too costly. This conclusion was predictable enough: Even if denied treatment, most people with HIV won't require expensive medical care in this short term. More valid assumptions—for example, using a 10-year time frame—might drastically alter the financial outlook.

Advocates for this proposal turned to the states

poverty level. Most beneficiaries would be childless adults with an income of \$14,000 or less and who formerly would have been on "home relief," a program largely eliminated by so-called welfare reform. Others would be household heads cut off from temporary aid to needy families.

At best, such state programs would constitute

demonstration projects showing how a comprehensive approach to early HIV care would work. They would provide solid data on the demand for such programs and the required initial layout. Far from automatically sponsoring the most aggressive therapy, as ADAP might, their comprehensive nature would allow physicians to monitor patients and treat when their best judgment recommends it. Such systematic health care could accelerate medical research by tracking the outcome of various therapeutic strategies. Still, it sounds like the state waivers just continue the patchwork system, doesn't it?

Initial annual outlays of several billion dollars probably are needed to extend Medicaid nationally, but Clinton's 1999 budget contains only an additional \$100 million for ADAP. Daniel Zingale, director of the AIDS Action Council in Washington, says, "Everyone in the administration knows extending Medicaid makes no sense, but they think they can only make changes if they're budget neutral."

Washington's misers can quibble forever over how much money might ultimately be saved through more early treatment. It all depends on such imponderables as the rate of disease progression despite the drugs and the future costs of caring for those who get AIDS. Yet the epidemic provides a grand opportunity to recognize the social damage inflicted by death and disease. AIDS will remain a crisis until we seize that opportunity and move to control HIV in all Americans. ■

I first n was tir. relatio For th know, had at himsel But h posses and p ovary: to it. and fi just lil tionsh I de son wi doctor, malign ed, as enoug would edge. never AIDS; cancel tion t watch Call n: think pathet losing D-E op, g; and e suppo and I ready diced. down ney, I praye ating surrou ous fe attack shot i ed ba every! Aft favori

Administration Drops Effort to Extend

WASHINGTON POST

SK FRIDAY, DECEMBER 5, 1997 A23

Medicaid Coverage for AIDS Therapies

By Amy Goldstein

Washington Post Staff Writer

The Clinton administration has abandoned an attempt to use Medicaid to ensure that tens of thousands of poor, HIV-infected Americans who still are relatively healthy could afford new therapies that may prolong their lives, according to federal health officials.

The decision comes eight months after Vice President Gore announced to a roomful of AIDS activists that he had directed the U.S. Department of Health and Human Services to explore ways to "ease suffering, renew hope and ensure that good people are not priced out of life-saving medicine."

The department had hoped to cover the drugs by expanding Medicaid,

the federal health insurance program for the poor and disabled. But by law, Medicaid can start innovative experiments only if it can prove that they will not add to the program's expenditures.

Department sources said yesterday that, although officials had hoped that by paying for more people to get therapies, they could reduce the cost of their medical care in the long run, they had concluded that the drugs were simply too expensive.

"No matter how we sliced it, we could not come up with a way," said one senior department official. "We might have to take responsibility for being too optimistic at the beginning."

For AIDS activists and public health officials, the prospect had been heralded as an end to what they have com-

plained for years is a short-sighted approach to medicine: Medicaid will cover low-income AIDS patients once they become sick enough to qualify as disabled, but—in many cases—it will not cover treatments that may keep them healthier.

The issue focuses attention on a fundamental problem as the AIDS epidemic in the United States has reached a new phase. Research has made important strides lately, developing new classes of drugs and new drug combinations that have proven effective at slowing the virus's ravaging effects. At the same time, those benefits are not reaching all Americans alike, particularly as the epidemic has tilted heavily toward minorities and the poor.

Between 1995 and last year, the percentage of people who developed

full-blown AIDS decreased by 13 percent, according to the Centers for Disease Control and Prevention. But the drop was just 5 percent among Hispanics, and there was no improvement among African Americans.

To try to make drugs more accessible, the administration persuaded Congress this year to increase its funding of the AIDS Drug Assistance Program (ADAP) by 70 percent to \$285 million. But during the last two years—as word of the new, more effective drugs spread—many states ran out of their ADAP funds. Even now, AIDS activists say they are uncertain whether that infusion will cover the escalating demand for the new combinations of drugs, which cost an average of \$12,000 a year for each patient.

Yesterday, federal health officials emphasized that they would continue to search for other ways to use the Medicaid program to provide AIDS drugs to healthier people, such as encouraging individual states to apply for experiments or asking Congress to appropriate more money.

But one senior department official acknowledged, "We don't have a plan B at the moment."

Another official said that, before abandoning the nationwide expansion, the Health Care Financing Administration, which oversees Medicaid, had studied four scenarios under which Medicaid would provide the benefits to HIV-infected people at 100 percent, 200 percent, 250 percent or 300 percent of the poverty level.

They concluded that, in the first

year, that expansion would help 44,000 to 114,000 HIV-infected Americans. "Unfortunately, none of [the scenarios] are revenue neutral—or close," the source said.

According to one AIDS activist, health officials said it would cost about \$800 million a year to cover people at 100 percent of poverty.

"In the scheme of things, this isn't a whole lot of money," said Joseph Kelly, deputy director of the National Alliance of State and Territorial AIDS Directors. "What we need is the political will to do it."

But Daniel Zingale, executive director of the AIDS Action Council, said, "I still believe we can work with the administration to address the problem."

EXPANDING ELIGIBILITY FOR MEDICAID TO PERSONS WITH HIV DISEASE

More information about this project can be obtained by contacting
Christine Lubinski, AIDS Action Council of Washington, D.C. at (202) 986-1300, or
Robert Greenwald, AIDS Action Committee of Massachusetts, at (617) 450-1257.

The duplication and distribution of this report is supported in part by a generous grant from The George Gund Foundation, Cleveland, Ohio.

EXPANDING ELIGIBILITY FOR MEDICAID TO PERSONS WITH HIV DISEASE

INTRODUCTION

Recent research has shown that a long-held assumption about AIDS was wrong—there is no initial dormant phase of HIV infection. Instead, the virus attacks the body's immune system from the outset. This improved understanding of how HIV functions, along with the advent of powerful new medications, has led to new recommendations for care and treatment. Specifically, experts now advise comprehensive care and treatment, often with combination drug therapy, from the earliest stages of HIV disease.

Despite the experts' recommendations for early treatment and the existence of effective drugs, significant obstacles to accessing care and medications remain for low income people living with HIV. Existing programs cannot meet the need for comprehensive health care and preventive services. The current Medicaid requirements force most HIV positive individuals to wait until they develop full-blown AIDS to become eligible for coverage, a model which is inconsistent with clinical standards, inhumane, and costly.

EARLY INTERVENTION WORKS, SAVING LIVES AND DOLLARS

The new standard of care for people with HIV emphasizes early clinical intervention, calling for both primary care and combination drug therapy, including protease inhibitors, at earlier stages of infection. The National Institutes of Health (NIH) report that "...it has been suggested that the best opportunity to eradicate HIV infection is provided by the initiation of potent combination antiretroviral therapy during primary infection."¹ According to Dr. David Ho, director of the Aaron Diamond AIDS Research Center, mathematical models suggest that patients caught early enough and treated with combination drug therapies could be free of HIV in two to three years.²

While complete eradication of the HIV virus from the body has not yet been demonstrated, combination drug therapies have proven effective for many, driving viral loads (the amount of virus in the blood) below detectable levels, and maintaining or dramatically improving overall health. Combination therapies can slow the progression from HIV to AIDS, and can help prevent opportunistic infections (OIs). For example, researchers at NIH's National Eye Institute recently discovered that a combination of protease inhibitors and other anti-HIV drugs can prevent or delay the progression of cytomegalovirus (CMV) retinitis, a common complication of AIDS which causes blindness without proper treatment.³ Some patients in

¹ C. Carpenter, et. al., "Report of the NIH Panel to Define Principals of Therapy of HIV Infection," June, 1997.

² L. Altman, "With AIDS Advance, More Disappointment," *New York Times*, January 19, 1997.

³ NIH News Release, "Combination Drug Therapy for AIDS Found to Control Blinding

the study were able to stop standard CMV retinitis treatment, which can be cumbersome, toxic, and extremely costly (between \$50-100,000 per patient per year), without advancement of their disease.⁴

Combination drug therapies including protease inhibitors are expensive, with costs ranging from \$8,000 to \$10,000 per year. But several studies have indicated that the dollars spent "up front" on these medications are offset by later savings on hospitalizations and other expensive care and treatment for AIDS-related illnesses. A study by Dr. Peter Ruane of the Tower Infectious Disease Medical Associates in Los Angeles found that each dollar spent on combination drug therapies resulted in at least two dollars of savings on overall treatment costs, which declined 23 percent.⁵ The same study reported a 57 percent drop in the average number of days patients spent in the hospital. Data from Saint Vincent's Hospital in New York support the conclusions of the Tower study, showing a significant decrease in inpatient care, both in terms of the number of people hospitalized and the average length of stay.⁶

The findings of the protease inhibitor studies—that early intervention and treatment can prolong health and reduce the need for more expensive treatment later—are consistent with earlier studies on the cost-effectiveness and beneficial impact of preventive treatment. Researchers at Johns Hopkins Hospital compared the outcomes of patients who received prophylactic treatment for the opportunistic infection *Pneumocystis carinii* pneumonia (PCP) with those who did not receive such treatment. The patients not taking prophylaxis accounted for all of the deaths attributed to PCP, 85 percent of the hospital days, 100 percent of the Intensive Care Unit days, and 89 percent of the inpatient charges. The study concluded that those "who developed PCP despite prophylaxis had a better outcome and used fewer resources than patients not receiving preventive therapy."⁷ Another study examining preventive treatment for PCP found that prophylaxis resulted in longer life and a savings of \$16,503 for each patient, as compared with no prophylaxis.⁸

Comprehensive care and treatment which prevents or delays the progression from HIV infection to AIDS can both improve quality of life and save money. A survey of the costs of care for

Eye Infection," May 20, 1997 (reporting study results published in the *Journal of the American Medical Association*, May 21, 1997).

⁴ *Id*

⁵ P. Ruane, "Dramatic Reductions in Use of Healthcare Services by Patients with HIV Result from Use of Combination Therapy with a Protease Inhibitor," Tower Infectious Disease Medical Associates, Inc., January 23, 1997.

⁶ R. Torres, "Impact of Potent New Antiretroviral Therapies on In-Patient and Out-Patient Hospital Utilization by HIV-Infected Persons," Saint Vincent's Hospital and Medical Center, January 23, 1997.

⁷ J. Gallant, et. al., "The Impact of Prophylaxis on Outcome and Resource Utilization in *Pneumocystis carinii* Pneumonia," *Chest*, April 1995: 1018-1023.

⁸ A. Castellano and M. Nettleman, "Cost and Benefit of Secondary Prophylaxis for *Pneumocystis carinii* Pneumonia," *Journal of the American Medical Association*, August 14, 1991: 820-824.

Medicaid patients with HIV in Baltimore found that monthly costs for people with CD4+ T-cell counts under 50 (generally a sign of more advanced HIV disease) were more than twice those of people with more than 500 T-cells.⁹ Stated simply, providing care for those who are seriously ill costs more than caring for healthier people. Yet under the present Medicaid system, many living with HIV must wait for their T-cells to drop and their illness to worsen before they can receive coverage and access care.

GAPS IN HEALTH CARE COVERAGE REMAIN

The advances in overall health care and drug treatments have brought renewed health and unprecedented hope to many people living with HIV disease. For the first time in the 15 years of the AIDS epidemic, there has been a decrease in the numbers of Americans dying from AIDS. The U.S. Centers for Disease Control (CDC) reported a 13 percent decline in the number of AIDS deaths for the first six months of 1996, as compared to the same period in 1995, and attributed this decline to improved medical care, prophylaxis for OIs, and the use of combination therapies.¹⁰

In the same report, however, the CDC noted that AIDS continues to be the leading cause of death of Americans aged 25 to 44, and that the "increased prevalence of AIDS [in the U.S.] indicates the need for medical and other services for persons with HIV infection." While the new medications make obtaining care more important than ever, challenges in expanding access to primary care and treatment remain.

Medicaid provides access to health care coverage for low income, uninsured, disabled people. Individuals who are HIV positive but have not been diagnosed with AIDS, however, are often not eligible for Medicaid, because they do not meet the program's disability standards or other categorical eligibility requirements. To qualify for Medicaid, people must meet income requirements and the disability criteria of the federal Supplemental Security Income (SSI) program. The Social Security Administration uses the CDC's definition of AIDS, along with evidence of functional impairments, as proof of disability.¹¹ **Despite the fact that early clinical intervention—including primary care, preventive services, and medication therapies—has been shown to improve health and delay the onset of expensive opportunistic infections, most HIV positive individuals must wait until they "get sicker" and develop AIDS before they can receive Medicaid.**

⁹ R. Moore and R. Chaisson, "Costs to Medicaid of Advancing Immunosuppression in an Urban HIV-Infected Patient Population in Maryland," *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*, 1997, 14:223-231.

¹⁰ Centers for Disease Control, *Morbidity and Mortality Weekly Report*, February 28, 1997, 46: 165-173. For the first nine months of 1996, AIDS deaths declined even more dramatically, by 19 percent over the same period in 1995.

¹¹ The CDC definition of AIDS for surveillance purposes is: documented CD4+ T-lymphocyte counts <200 per microliter or percent of total lymphocytes <14 percent or a variety of opportunistic infections.

This is particularly devastating because the populations in which HIV infection is increasing are the ones likely to enroll in Medicaid once their HIV infection becomes full-blown AIDS. The epidemic is growing fastest among groups which have traditionally been socioeconomically disenfranchised, including racial and ethnic minorities, injection drug users, and women. In 1996, for the first time, blacks accounted for more AIDS cases than whites (41 percent versus 38 percent).¹² Women represented 20 percent of new AIDS cases in 1996, up from seven percent in 1985. While overall AIDS deaths declined 19 percent in the first nine months of 1996, deaths among blacks decreased 10 percent and deaths among women, only seven percent.¹³

These populations are also the groups less likely to have health insurance and access to treatments, and more likely to face barriers in obtaining health care, according to a survey by the Agency for Health Care Policy and Research.¹⁴ People who are uninsured or underinsured not only lack access to expensive combination therapies, but also to basic primary care and preventive services.

Additionally, current Medicaid requirements undermine public health efforts by preventing many people with HIV from receiving care earlier in their disease. Under the present system, we are often not reaching these people to teach and reinforce behavior changes which can prevent HIV transmission. Even if people are able to obtain the new combination therapies, they may lack access to the primary care and medical case management needed to ensure that the prescribed treatment regimen is appropriate and effective, and to support them in following complex treatment plans. If patients do not strictly comply with their combination therapy regimens, they are likely to develop drug-resistant strains of HIV. The existence of such drug-resistant HIV mutations may further complicate public health efforts to combat AIDS.

Despite the existence of federal AIDS programs, such as the AIDS Drug Assistance Programs (ADAPs) and the other components of the Ryan White CARE Act, Medicaid serves as the foundation of AIDS care through its provision of both comprehensive health care and drug therapies. ADAPs provide limited prescription drug coverage for some uninsured and underinsured people with HIV and AIDS. But these programs cannot (and are not designed to) meet the need for comprehensive primary care and diagnostic services. In spite of their limited mission—to provide access to a limited formulary of proven AIDS medications—ADAPs face severe financial pressure in many states, and often cannot meet the growing demand for new combination therapies. In some states, ADAPs do not even cover protease inhibitors, and many offer a very limited formulary of antiretroviral and OI drugs. In other states, there are lotteries, long waiting lists, and increasingly restrictive eligibility criteria for ADAP participation.

While other Ryan White CARE Act programs pay for some primary care and drug

¹² Centers for Disease Control, *Morbidity and Mortality Weekly Report*, February 28, 1997, 46: 165-173.

¹³ B. Seitz, "AIDS Sufferers Living Longer," ABC News.com, July 15, 1997.

¹⁴ P. Mohr, Patterns of Health Care Use Among HIV-Infected Adults: Preliminary Results," *AIDS Cost and Services Utilization Survey*, Agency for Health Care Policy and Research, September 1994: 3.

reimbursement, they are not intended to provide widespread comprehensive health care. Ryan White funding is used for a range of care and services, including food, transportation, and case management for people living with AIDS. Additionally, many ADAPs and Ryan White-funded primary care programs have eligibility criteria which exclude people in the earlier stages of HIV disease. These programs lack the financial resources to broaden their eligibility criteria to cover such individuals.

The Medicaid eligibility framework—requiring total disability to qualify for coverage—is at odds with current clinical and public health knowledge. Many low income HIV positive individuals with relatively intact immune systems are not presently eligible for Medicaid, but will eventually qualify for Medicaid after developing AIDS. Unable to afford adequate treatment early in their HIV disease, they cannot obtain the health care services necessary to manage the disease, and will be more ill when they do enroll in Medicaid. Ironically, earlier access to these medical services and treatments would enable them to preserve their health, learn how to prevent transmission of HIV to others, and avoid more costly care such as inpatient hospitalization. For humane, financial, and public health reasons, it is time to make Medicaid's eligibility requirements consistent with the clinical realities of HIV disease.

A COLLABORATIVE RESPONSE

In response to the contradictions between current Medicaid disability criteria and AIDS clinical evidence and care standards, which call for early treatment of HIV disease, representatives from the AIDS Action Council, community-based AIDS service organizations, the Health Care Financing Administration (HCFA) and the Office of Management and Budget (OMB) have begun to work collaboratively to address these issues. Response from the administration has been unequivocally supportive, culminating in an endorsement from Vice President Al Gore, who has asked HCFA to find ways in which to expand Medicaid and allow more low-income Americans with HIV to access care and therapies. Gore is quoted as saying “[Medicaid expansion] can ease suffering, it can increase hope, and it can get new drug therapies into the hands of people who need them.” As a result of these collaborations, we are all working together under HCFA's leadership to develop a plan for expanding eligibility to Medicaid for persons who are HIV positive.

AN AIDS-SPECIFIC EXPANSION

As participants in these discussions, we have recognized several reasons for an AIDS-specific expansion of Medicaid. We believe that it serves the interests of public health, scientific knowledge, and fairness to broaden Medicaid coverage to include people with HIV.

Public health: With earlier health care and treatment, as mentioned above, people living with HIV are more likely to avoid behaviors which can spread the virus, and are more likely to adhere to complex treatment plans, which can both prolong health and prevent development of drug-resistant strains of HIV. Earlier access to care can also serve as an incentive for people to learn their serostatus for the first time, and then take steps to avoid either contracting or transmitting HIV.

Scientific knowledge: Protease inhibitors and other new medications received rapid FDA approval, have not yet been in long-term use, and have been researched mainly by studying people in more advanced stages of HIV disease. There are many remaining questions about the benefits, risks, and best way to use combination therapies in people who are HIV positive, but do not have AIDS. A Medicaid expansion demonstration project which brings people with HIV into care provides the opportunity to gather data and conduct research studies designed to answer these questions.

Fairness: The current Medicaid system requires most low-income people with HIV to develop AIDS in order to gain access to health care and new combination therapies. This is in conflict with principles and guidelines recently released by the Department of Health and Human Services and the NIH, which call for earlier intervention with combination drug therapies as the standard of care for the treatment of HIV in most cases. The government should ensure that this standard of care, endorsed by its own agencies, is accessible to those who have no other way to obtain it. Our federal government has always recognized the importance of ensuring access to treatment for other communicable diseases, such as sexually transmitted diseases and tuberculosis—it is unfair and inhumane to deny such treatment to people with HIV.

PROPOSAL DESIGN

The objective of this program is to expand Medicaid eligibility to low-income individuals who have tested positive for the presence of HIV and who would otherwise be eligible for Medicaid once their health status met an AIDS-defining diagnosis. States participating in this initiative will demonstrate that the provision of earlier access to care and treatment will extend the period of time that a person who is HIV positive remains asymptomatic, defer the onset of opportunistic infection, and delay hospitalization, all of which will result in significant cost savings and life-enhancing benefits. The following section describes what we believe are the core components of this initiative.

Eligibility

Any and all individuals who meet the following criteria will be eligible under this program:

- test positive for the presence of HIV; and
- have income at or below 200 percent of the federal poverty level.

State demonstrations will coordinate resources with other private, state, and federal programs. Individuals with private insurance can apply for and become eligible for Medicaid as a “wrap-around benefit” thereby maximizing private insurance participation. State proposals will specify the state specific eligibility guidelines and coordination of other state and federal programs.

Covered Benefits

Ideally, states will provide the full benefit package (i.e., mandatory and optional Medicaid services) to individuals eligible through this program. In any case, benefit packages must be flexible to accommodate new treatment advances and changes in standards of care that become available during the course of the demonstration. Through this project, states, at a minimum, must provide:

- primary care,
- prescription drugs,
- diagnostic and laboratory services,
- mental health services, and
- substance abuse treatment services.

Options to Participate in the Demonstration Projects

Section 1115 of the Social Security Act allows the Secretary of Health and Human Services to grant waivers from the usual federal Medicaid requirements¹⁵ to states which want to create demonstration projects to test new approaches to Medicaid. These demonstration projects must be designed to promote the objectives of Medicaid,¹⁶ and must include a research and evaluation component. Generally, demonstration projects created under a Section 1115 waiver are supposed to be “budget neutral” over the life of the project, meaning that costs under the demonstration project do not exceed what costs would have been without the waiver in place. Section 1115 also authorizes matching federal funds for certain expenditures.

This initiative will be designed to provide states with the maximum flexibility possible in participating in a Medicaid expansion demonstration project. The project does not necessarily need to meet the traditional definition of “budget neutrality,” since there can be federal and/or state subsidies. Also, budget neutrality should be measured within a time frame which is appropriate for assessing the clinical impact and cost-effectiveness of the new combination therapies (e.g., over a period of five to ten years).

Options for participation include the creation of a free-standing demonstration program or new or amended 1115 waivers. New 1115 waivers could provide the vehicle to expand Medicaid eligibility and/or allow a Medicaid buy-in option for those individuals otherwise ineligible for coverage. Amending an approved or pending 1115 waiver could also be used to expand eligibility. In addition, states could increase the income standards for their Medicaid buy-in programs, allowing more persons who are HIV positive to qualify. For example, states could set the income standard at 200 percent of the federal poverty level or they could use a graduated system to make more individuals eligible.

¹⁵ As defined in Section 1902 of the Social Security Act, and other provisions incorporated through Section 1902.

¹⁶ As set out in Title XIX of the Social Security Act.

NEXT STEPS

Over the next several months, the AIDS Action Council will work with HCFA to develop and refine a solicitation process for states to successfully participate in the HIV Expanded Eligibility Demonstration Initiative. It is important for community-based AIDS service organizations to urge their state governors and Medicaid directors to advocate for this initiative with HHS and HCFA. While we expect that this initiative will offer states tremendous opportunities to provide cost-effective access and coverage to its most vulnerable populations, we also recognize the range of development and design issues that need to be resolved. Over the next several months, the AIDS Action Council will work with states and HCFA to complete the following tasks:

- Continue to work with HCFA to design a program that includes adequate incentives for state participation in this initiative.
- Build consensus among federal and state leadership, elected officials, and government staff, including representatives from Medicaid programs, Departments of Health, and Departments of HIV Services.
- Work with HCFA to develop a process that allows states to efficiently design and implement a vehicle for eligibility expansion that responds to the unique environment and situations of each state (waiver amendment or new waiver submission).
- Design a process to solicit input from consumers, AIDS service organizations, primary care and other health care providers, and health care agencies regarding program design and program effectiveness, on an ongoing basis.
- Work with HCFA to develop a methodology that allows states maximum flexibility in measuring cost effectiveness. The goal will be to have HCFA resolve methodology issues related to baseline measurements, the measurement of savings in other government programs, and evaluation time frames.
- Work with HCFA to identify and develop data bases that provide the information needed to estimate current expenditures and projected costs for the purposes of assessment and future planning. Necessary data includes the number of newly eligible individuals by state and service area (persons who are HIV positive with incomes below state defined eligibility criteria), utilization of services, and cost.

AIDS STATISTICS

AFRICAN AMERICANS

- **Represent only 13% of total U.S. population but were 45% of the total number of reported AIDS cases in 1997.** (They are 36% of all HIV/AIDS cases which shows that these numbers are increasing).
- **62 percent of reported pediatric AIDS cases are African-American.**
- **An estimated 240,000 to 325,000 African-Americans are estimated to have HIV/AIDS.**

Men

- **AIDS is the leading killer among African American men age 25-44.**
- **1 in 50 African American men are believed to be HIV infected.**

Women

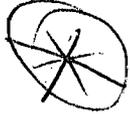
- **AIDS is the second leading killer among African American women age 25-44.**
- **African American women represent 60% of total number of reported AIDS cases in women.**
- **1 in 160 African American women are believed to be in HIV infected.**

HISPANICS

- **21% of the total number of reported cases in 1997, although 10% of the population.**

OVERALL HIV/AIDS STATISTICS

- **650,000 to 900,000 American are currently living with HIV.**
- **Since 1981 more than 640,000 American have been diagnosed and more than 385,000 have died from AIDS.**
- **Age-adjusted death rate from HIV infection dropped 47% from 1996 to 1997.**

Rich Ta 

Lynn

Dark

Model: Premium Support System
Number

No growth rates
Free for users

Swen Rose USA Today

(703) 247-3100

2530 people plus
passed on
Medicare
Universal

7:00
9:30

4:00 - 5:30

6:30 ✓

7:00

✓

9:30

(10:15)

1:30

1:00

(2:30)



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

FACSIMILE

File ~~ABC~~
AIDS/CBC

DATE 8/26/98

TO: (NAME, ORGANIZATION, CITY/STATE AND PHONE NUMBER):

Sarah Bianchi

FROM: (NAME, ORGANIZATION, CITY/STATE AND PHONE NUMBER):

Kevin Thurm
Deputy Secretary
DHHS

690-6133

RECIPIENT'S FAX NUMBER (202) 456-5557

NUMBER OF PAGES TO SEND (INCLUDING COVER SHEET): 25pg

COMMENTS:

DRAFT**QUESTIONS AND ANSWERS***HHS Discussions with the Congressional Black Caucus on HIV/AIDS*

Q. What is the status of discussions between HHS and the CBC on the CBC's call for a "state of emergency" on HIV/AIDS in the black community?

A. Secretary Shalala and the Department are in discussions with the CBC about the severe impact of HIV/AIDS in the African-American community. We are not prepared to make an announcement at this time. The Department has chosen not to address those discussions publicly.

Let me add that our efforts to address the CBC concerns build on what we're already doing and reaffirm our commitment in response to HIV/AIDS in communities of color. Already, a substantial portion of our federal dollars are serving persons of color. For example, 63 percent of participants in NIH-sponsored AIDS clinical trials are minorities, of whom 40 percent are African-American. Some 42 percent of clients served by Title I of the Ryan White Care Act are African-Americans and 24 percent are Hispanic, and some 80 percent of Title IV Ryan White clients are racial and ethnic minorities. However, it is imperative that we continue to define effective strategies and target investments to better prevent and treat HIV disease among racial and ethnic minority communities.

The response to HIV/AIDS in racial and ethnic minorities has been helped by an 86 percent increase in overall funding for AIDS-related programs in the Clinton Administration, with Ryan White funding increasing by 230 percent and assistance for the purchase of AIDS drugs increasing by 449 percent during that same period.

Q. Do you believe the Secretary should declare a "state of emergency" and will she do so?

A. Regardless of what terms or language is used to describe the effort, what we all should strive for is a response that treats HIV/AIDS in the African-American community as the very severe and ongoing crisis that it is.

We fully recognize that the epidemic continues to shift within communities and that African-Americans are disproportionately affected by HIV/AIDS, accounting for 44 percent of AIDS cases reported in 1997 despite comprising only 13 percent of the U.S. population.

Q. If the Secretary does not declare a "state of emergency," can we assume that the Administration is reluctant to do so?

A. I think you can assume that we undoubtedly consider this to be a very important issue and a severe and ongoing crisis, which is why we're engaging in discussions with the CBC.

Q. Is there any deadline for wrapping up these discussions – when can we expect to hear something?

A. I'm not aware of any deadline. I do know, however, that Secretary Shalala, in cooperation with the CBC, is working to develop a plan of action as quickly as possible. She is extremely concerned about this issue.

DRAFT

Q. Why haven't you addressed this crisis before ?

A. The Clinton Administration has long been concerned about HIV/AIDS, especially the impact it has had in the African-American community and among other racial and ethnic populations. In February, President Clinton announced to the American people the Initiative to Eliminate Racial and Ethnic Disparities in Health. The goal of that initiative is to draw together resources from government and private sources to eliminate, by the year 2010, serious gaps between racial and ethnic minority groups and white Americans in six key areas of health. HIV/AIDS is one of those six areas.

In fact, our FY 99 budget request proposes resources targeted directly at communities of color as part of trying to achieve this goal -- an additional \$10 million for the Centers for Disease Control and Prevention (CDC) to conduct HIV/STD demonstration projects, an additional \$30 million for a CDC community-based demonstration program in 30 communities of which \$5 million is specifically earmarked for HIV/AIDS; and an increase of \$15 million for Community Health Centers to enhance services aimed at reducing racial and ethnic health disparities including HIV/AIDS.

Q. What's the status of extending Medicaid coverage to people with HIV?

A. We have received a number of letters from CBC members and other Members of Congress on this issue and we're currently reviewing the matter. The Department is interested in providing technical assistance to any state that wants to consider pursuing a waiver to extend Medicaid coverage for HIV infection. Our Health Care Financing Administration is prepared to assist those States that want to explore this objective.

Q. How much money has the Clinton Administration targeted for HIV/AIDS in the black community?

A. A substantial portion of our federal dollars are serving persons of color. For example, 63 percent of participants in NIH-sponsored AIDS clinical trials are minorities, of whom 40 percent are African-American. Some 42 percent of clients served by Title I of the Ryan White Care Act are African-Americans and 24 percent are Hispanic, and some 80 percent of Title IV Ryan White clients are racial and ethnic minorities.

Overall, the Clinton Administration has responded aggressively to the significant threat posed by HIV/AIDS with increased attention to research, prevention, and treatment. Overall funding for AIDS-related programs has increased by 86 percent in this Administration, with funding for AIDS care under the Ryan White Care Act increasing by 230 percent and assistance for the purchase of AIDS drugs increasing by 449 percent.

The President's FY 1999 budget for HHS includes \$7.4 billion in HIV/AIDS funding compared to \$6.8 billion in the current fiscal year. We are also requesting \$30 million for a CDC community-based demonstration program in 30 communities of which \$5 million is in our AIDS request, and an increase of \$15 million for Community Health Centers to enhance services aimed at reducing racial and ethnic health disparities including HIV/AIDS.

Chronology of CBC Request for State of Emergency on HIV/AIDS

Background

Racial and ethnic minorities together account for more than 54 percent of the total AIDS cases reported since the beginning of the epidemic. We recognize that the epidemic continues to shift within communities and that African-Americans are disproportionately affected by HIV/AIDS, accounting for 44 percent of AIDS cases reported in 1997 despite comprising only 13 percent of the U.S. population.

- ▶ **April 29.** Secretary Shalala and Deputy Secretary Thurm met with Congressional Black Caucus (CBC) to discuss the Department's legislative agenda for the second session of the 105th Congress. At this meeting, Representative Waters criticized the Administration's decision not to permit federal funding of needle exchange programs and stated the CBC will be holding an emergency meeting to discuss the state of the HIV/AIDS crisis in the African American community.
- ▶ **May 11.** At the request of the CBC, a team of HIV/AIDS experts from the Department met with CBC members and minority community based organizations to discuss the HIV/AIDS crisis in the African American community. After the meeting, the CBC issued a press release calling for Secretary Shalala to declare a "Public Health Emergency" to combat the HIV/AIDS crisis in minority communities.
- ▶ **May 15.** CBC sent a letter to the Secretary requesting that she declare the HIV/AIDS crisis in the black community a "public health emergency." Since then, in letters and phone calls, the CBC and Representative Waters have continued to urge the Secretary to present a substantive response and to make the public health emergency declaration. The Secretary has kept Representative Waters updated on progress with letters and phone calls.
- ▶ **July 30.** HHS staff met with CBC staff to discuss an HHS draft proposal in response to the CBC request.
- ▶ **August 3.** CBC sent letter to HHS stating that they are pleased to see that the agency has done some preliminary work to further address the epidemic. The letter termed our proposal a good beginning, but said that a few other points must be addressed.
- ▶ **August 7.** Secretary's call to Representative Waters was postponed due to scheduling conflicts.
- ▶ **August 7.** HHS announced \$17.5 million in health care and dental care grants through the Ryan White CARE Act targeted to women, children, youth, and families and others living with HIV/AIDS. The new grants directly address HIV/AIDS in providing critical health and dental services, support services and access to research opportunities.

- ▶ August 12. HHS staff met with CBC staff to answer/clarify additional questions about the Department's draft proposal.
- ▶ Further meetings on the proposal are planned at staff level; on September 11, there is a meeting scheduled with principals (Secretary Shalala, Deputy Secretary Thurm, Surgeon General Satcher, Representatives Waters, Stokes and Christian-Green). The Secretary has been invited to participate in the CBC's Town Hall meeting on HIV/AIDS during the CBC's 28th Annual Legislative Conference on September 17.



OFFICERS

Maxine Waters
Chair

Earl Hilliard
First Vice Chair

Eddie Bernice Johnson
Second Vice Chair

Corrine Brown
Secretary

Shella Jackson Lee
Who

MEMBERS

U.S. House of Representatives

John Conyers, Jr., MI '65
William Clay, MO '69
Louis Stokes, OH '69
Ronald V. Dellums, CA '71
Charles B. Rangel, NY '71
Julian C. Dixon, CA '79
Major R. Owens, NY '83
Edolphus Towns, NY '83
Floyd Flake, NY '87
John Lewis, GA '87
Donald M. Payne, NJ '89
Eleanor Holmes-Norton, DC '91
William Jefferson, LA '91
Maxine Waters, CA '91
Eva Clayton, NC '92
Sanford Bishop, GA '93
Corrine Brown, FL '93
Jim Clyburn, SC '93
Alcee Hastings, FL '93
Earl Hilliard, AL '93
Eddie Bernice Johnson, TX '93
Cynthia McKinney, GA '93
Carlo Mack, FL '93
Bobby Rush, IL '93
Robert C. Scott, VA '93
McMinn Wolf, NC '93
Albert Wynn, MD '93
Bennie G. Thompson, MS '93
Chaka Fattah, PA '95
Shella Jackson Lee, TX '95
Jesse Jackson, Jr., IL '95
Juanita Millender-McDonald, CA '96
Ellen C. Curran, MD '96
Julia M. Carson, IN '97
Donna Christian-Groen, VI '97
Danny K. Davis, IL '97
Harold E. Ford, Jr., TN '97
Carolyn Kilpatrick, MI '97

U.S. Senate
Carol Moseley-Braun, IL '93

NOT PRINTED OR MAILED
AT PUBLIC EXPENSE

Congressional Black Caucus

Congress of the United States

2344 Rayburn Building • Washington, DC 20515 • (202) 225-2201

FOR IMMEDIATE RELEASE
May 11, 1998

CONTACT
Leah D. Allen
(202) 225-2201

CBC Calls for Secretary Shalala to Declare "Public Health Emergency" to Combat HIV/AIDS Crisis in Minority Communities

Rise of Minority HIV/AIDS Infection Alarming

Washington, D.C. -- Today, Congresswoman Maxine Waters, Chair of the Congressional Black Caucus (CBC) and CBC Members, alarmed at the rate of increase of HIV/AIDS in the black community, called for Secretary Donna Shalala to declare a "public health emergency" to eliminate HIV/AIDS crisis in the African American community.

"According to the Kaiser Family Foundation, blacks now represent 35 percent of all reported cases and 43 percent of new cases, even though African Americans comprise only 12 percent of the population. The annual AIDS case rate for African American men is 6 times that of white men and for African American women it is 16 times that of white women. AIDS is now the leading cause of death among African Americans, age 25 to 44," stated Rep. Waters.

"Today, the CBC brought together over 20 public health workers, AIDS activists and representatives from all over the country, including from Los Angeles, San Francisco, New York, and Atlanta, and the Department of Health and Human Services to assess where we are and what steps we need to take to deal with this crisis," added Rep. Waters.

"During our meeting, we agreed to call on Department of Health and Human Services Secretary, Donna Shalala, to declare HIV/AIDS a public health emergency in this country. We also identified the following problems in the AIDS healthcare delivery system that impede the ability to adequately address the crisis:

- There is a need to integrate substance abuse treatment with HIV prevention and care;

- There currently is no strategy to deal with HIV infected prison populations either inside of prison or after they are discharged.
- The resources are not connected with the epidemic. There needs to be technical assistance and a reform of the planning process so that the funding follows the epidemic.
- There is a need to spearhead a comprehensive strategy to engage our leadership and the federal government to combat anti-gay bias.
- African American women and children make up the fastest growing AIDS/HIV caseload. AIDS/HIV resources and strategies must be targeted towards them.
- There is an absence of healthcare professionals and researchers with an interest and commitment to serve African American communities.

"This is only the beginning of our efforts," stated Rep. Waters. "Enough is enough. We must exert the political will necessary to take on HIV/AIDS in those communities where it is reaching epidemic proportions. This is a national crisis. We will not rest until the crisis is acknowledged and strategies and resources are directed to eliminate it."

###



105th Congress

OFFICERS

Maxine Waters
Chair

Earl Hilliard
First Vice Chair

Eddie Bernice Johnson
Second Vice Chair

Corrine Brown
Secretary

Sheila Jackson Lee
Whip

MEMBERS

U.S. House of Representatives

John Conyers, Jr., MI '65
 William Clay, MO '69
 Louis Stokes, OH '69
 Ronald V. Dellums, CA '71
 Charles B. Rangel, NY '71
 Julian C. Dixon, CA '79
 Major R. Owens, NY '83
 Ecolphus Towns, NY '83
 Floyd Flake, NY '87
 John Lewis, GA '87
 Donald M. Payne, NJ '89
 Eleanor Holmes-Norton, DC '91
 William Jefferson, LA '91
 Maxine Waters, CA '91
 Eva Clayton, NC '92
 Sanford Bishop, GA '93
 Corrine Brown, FL '93
 Jim Clyburn, SC '93
 Alcee Hastings, FL '93
 Earl Hilliard, AL '93
 Eddie Bernice Johnson, TX '93
 Cynthia McKinney, GA '93
 Carrie Meek, FL '93
 Bobby Rush, IL '93
 Robert C. Scott, VA '93
 Melvin Watt, NC '93
 Albert Wynn, MD '93
 Bennie G. Thompson, MS '93
 Chaka Fattah, PA '95
 Sheila Jackson Lee, TX '95
 Jesse Jackson, Jr., IL '95
 Juanita Millender-McDonald, CA '96
 Elijah Cummings, MD '96
 Julia M. Corson, IN '97
 Donna Christian-Green, VI '97
 Donny K. Davis, IL '97
 Harold E. Ford, Jr., TN '97
 Carolyn Kilpatrick, MI '97

U.S. Senate

Carol Mosley Braun, IL '93

Congressional Black Caucus

Congress of the United States

2344 Rayburn Building • Washington, DC 20515 • (202) 225-2201

May 15, 1998

The Honorable Donna Shalala
 Secretary
 Health and Human Services
 200 Independence Avenue, S.W.
 Washington, D.C. 20201

Dear Secretary Shalala:

Pursuant to 42 U.S.C. § 247(d), the Congressional Black Caucus (CBC) hereby requests that you declare the HIV/AIDS crisis in the black community a "public health emergency." By making such a declaration, you, as the Secretary acting through your agency heads, "may take such action as may be appropriate to respond to the public health emergency...."

As discussed more fully below, the CBC in consultation with HIV/AIDS activists and HIV/AIDS healthcare providers nationwide, believe that the AIDS crisis in the black community must be addressed as a public health emergency.

The Crisis

AIDS is now the leading cause of death among African Americans, age 25 to 44. According to the Kaiser Family Foundation, blacks now represent 35 percent of all reported cases and 43 percent of new cases, even though African Americans comprise only 12 percent of the population. The annual AIDS case rate for African American men is 6 times that of white men and for African American women it is 16 times that of white women.

Moreover, an alarming 1 in 50 African American men and 1 in 60 African American women are infected with HIV. The numbers are even more devastating when we look at HIV infection from the use of tainted

needles. Of the 8 persons who are directly or indirectly infected with HIV through the use of contaminated needles every day, 5 are African Americans or Latinos.

Racial and ethnic minorities together account for over 54% of the total AIDS cases reported since the beginning of the epidemic. Latinos account for 18% of the total AIDS cases. Sixty-three percent of new AIDS cases in children under 13 years of age are African American.

CBC Meeting with AIDS/HIV Organizations

On May 11, 1998, the CBC called an emergency meeting with over 60 HIV/AIDS Activists and HIV/AIDS healthcare providers from around the country, including San Francisco, Los Angeles, Atlanta and New York, to hear first-hand the impact HIV/AIDS is having on our communities, the nature of their programs and the services they provide to their HIV/AIDS clients and the steps they believed were necessary to address the HIV/AIDS crisis in our communities.

The organizations were elated that the CBC called this national meeting to sound the alarm over the crisis. They all agreed with your assessment that there, indeed, is an emergency regarding the AIDS crisis in the black community. They also agreed that the statistics are consistent and reflect the experiences they encountered in trying to serve their clients.

We also identified the following problems in the AIDS healthcare delivery system that impede the ability to adequately address the crisis:

- There is a need to integrate substance abuse treatment with HIV prevention and care.
- There currently is no strategy to deal with HIV infected prison populations either inside of prison or after they are discharged.
- The resources are not connected with the epidemic. There needs to be technical assistance and a reform of the planning process so that the funding follows the epidemic.

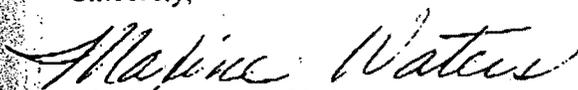
- There is a need to spearhead a comprehensive strategy to engage our leadership and the federal government to combat anti-gay bias.
- African American women and children make up the fastest growing AIDS/HIV caseload. AIDS/HIV resources and strategies must be targeted towards them.
- There is an absence of healthcare professionals and researchers with an interest and commitment to serve African American communities.

Next Step

Our meeting concluded with 100 percent agreement that there is an HIV/AIDS emergency in our communities. Therefore, we believe it is urgent and necessary for a formal declaration of a public health emergency.

We are prepared to meet with you to further discuss what we believe are steps necessary to address the crisis.

Sincerely,



Maxine Waters, Chair
Congressional Black Caucus

cc: President Clinton
Vice President Gore
Members of Congress
Members of Black Leadership Forum
Meeting Attendees
Mr. Erskine Bowles
Mr. Thurgood Marshall, Jr.



105th Congress

OFFICERS

Maxine Waters
Chair

Earl Hilliard
First Vice Chair

Eddie Bernice Johnson
Second Vice Chair

Corrine Brown
Secretary

Sheila Jackson Lee
whp

MEMBERS

U.S. House of Representatives

John Conyers, Jr., MI - '66
William Clay, MO - '69
Louis Stokes, OH - '69
Ronald V. Dellums, CA - '71
Charles B. Rangel, NY - '71
Julian C. Dixon, CA - '79
Major R. Owens, NY - '83
Edolphus Towns, NY - '83
Floyd Flake, NY - '87
John Lewis, GA - '87
Donald M. Payne, NJ - '89
Eleanor Holmes-Norton, DC - '91
William Jefferson, LA - '91
Maxine Waters, CA - '91
Eva Clayton, NC - '92
Sanford Bishop, GA - '93
Corrine Brown, FL - '93
Jim Clyburn, SC - '93
Alcee Hastings, FL - '93
Earl Hilliard, AL - '93
Eddie Bernice Johnson, TX - '93
Cynthia McKinney, GA - '93
Carrie Meek, FL - '93
Bobby Rush, IL - '93
Robert C. Scott, VA - '93
Melvin Watt, NC - '93
Albert Wynn, MD - '93
Bennie G. Thompson, MS - '93
Chaka Fattah, PA - '95
Sheila Jackson Lee, TX - '95
Jesse Jackson, Jr., IL - '95
Juanita Millender-McDonold, CA - '96
Elijah Cummings, MD - '96
Julio M. Carson, IN - '97
Donna Christian-Green, VI - '97
Danny K. Davis, IL - '97
Harold E. Ford, Jr., TN - '97
Carolyn Kilpatrick, MI - '97

U.S. Senate

Corol Moseley-Braun, IL - '93

NOT PRINTED OR MAILED
AT PUBLIC EXPENSE

Congressional Black Caucus

Congress of the United States

2344 Rayburn Building • Washington, DC 20515 • (202) 225-2201

June 1, 1998

The Honorable Donna Shalala
Secretary of Health & Human Services
200 Independence Ave., SW
Washington, D.C. 20201

Dear Secretary Shalala:

On May 15, 1998, we sent the attached formal request to you to request that you declare the HIV/AIDS crisis in the black community a 'public health emergency.' To date, I have not received a response from your office.

Please advise me of your decision or when your decision will be made so that I may let the organizations know the results. As you can imagine, we are anxiously awaiting your response to this correspondence.

Thank you in advance for your swift attention to this matter.

Sincerely,

Maxine Waters, Chair
Congressional Black Caucus



105th Congress

Congressional Black Caucus

Congress of the United States

2344 Rayburn Building • Washington, DC 20515 • (202) 225-2201

May 15, 1998

OFFICERS

Maxine Waters
Chair

Earl Hilliard
First Vice Chair

Eddie Bernice Johnson
Second Vice Chair

Corrine Brown
Secretary

Shella Jackson Lee
Whip

MEMBERS

U.S. House of Representatives

- John Conyers, Jr., MI - '65
- William Clay, MO - '69
- Louis Stokes, OH - '69
- Ronald V. Dellums, CA - '71
- Charles B. Rangel, NY - '71
- Julian C. Dixon, CA - '79
- Major R. Owens, NY - '83
- Edolphus Towns, NY - '83
- Floyd Flake, NY - '87
- John Lewis, GA - '87
- Donald M. Payne, NJ - '89
- Eleanor Holmes-Norton, DC - '91
- William Jefferson, LA - '91
- Maxine Waters, CA - '91
- Eva Clayton, NC - '92
- Sanford Bishop, GA - '93
- Corrine Brown, FL - '93
- Jim Clyburn, SC - '93
- Alcee Hastings, FL - '93
- Earl Hilliard, AL - '93
- Eddie Bernice Johnson, TX - '93
- Cynthia McKinney, GA - '93
- Carrie Meek, FL - '93
- Bobby Rush, IL - '93
- Robert C. Scott, VA - '93
- Melvin Watt, NC - '93
- Albert Wynn, MD - '93
- Bennie G. Thompson, MS - '93
- Chaka Fattah, PA - '95
- Shella Jackson Lee, TX - '95
- Jesse Jackson, Jr., IL - '95
- Juanita Millender-McDonald, CA - '96
- Elijah Cummings, MD - '96
- Julia M. Carson, IN - '97
- Donna Christian-Green, VI - '97
- Danny K. Davis, IL - '97
- Harold E. Ford, Jr., TN - '97
- Carolyn Kilpatrick, MI - '97

U.S. Senate

Carol Moseley-Braun, IL - '95

The Honorable Donna Shalala
Secretary
Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Shalala:

Pursuant to 42 U.S.C. § 247(d), the Congressional Black Caucus (CBC) hereby requests that you declare the HIV/AIDS crisis in the black community a "public health emergency." By making such a declaration, you, as the Secretary acting through your agency heads, "may take such action as may be appropriate to respond to the public health emergency...."

As discussed more fully below, the CBC in consultation with HIV/AIDS activists and HIV/AIDS healthcare providers nationwide, believe that the AIDS crisis in the black community must be addressed as a public health emergency.

The Crisis

AIDS is now the leading cause of death among African Americans, age 25 to 44. According to the Kaiser Family Foundation, blacks now represent 35 percent of all reported cases and 43 percent of new cases, even though African Americans comprise only 12 percent of the population. The annual AIDS case rate for African American men is 6 times that of white men and for African American women it is 16 times that of white women.

Moreover, an alarming 1 in 50 African American men and 1 in 60 African American women are infected with HIV. The numbers are even more devastating when we look at HIV infection from the use of tainted

needles. Of the 8 persons who are directly or indirectly infected with HIV through the use of contaminated needles every day, 5 are African Americans or Latinos.

Racial and ethnic minorities together account for over 54% of the total AIDS cases reported since the beginning of the epidemic. Latinos account for 18% of the total AIDS cases. Sixty-three percent of new AIDS cases in children under 13 years of age are African American.

CBC Meeting with AIDS/HIV Organizations

On May 11, 1998, the CBC called an emergency meeting with over 60 HIV/AIDS Activists and HIV/AIDS healthcare providers from around the country, including San Francisco, Los Angeles, Atlanta and New York, to hear first-hand the impact HIV/AIDS is having on our communities, the nature of their programs and the services they provide to their HIV/AIDS clients and the steps they believed were necessary to address the HIV/AIDS crisis in our communities.

The organizations were elated that the CBC called this national meeting to sound the alarm over the crisis. They all agreed with your assessment that there, indeed, is an emergency regarding the AIDS crisis in the black community. They also agreed that the statistics are consistent and reflect the experiences they encountered in trying to serve their clients.

We also identified the following problems in the AIDS healthcare delivery system that impede the ability to adequately address the crisis:

- There is a need to integrate substance abuse treatment with HIV prevention and care.
- There currently is no strategy to deal with HIV infected prison populations either inside of prison or after they are discharged.
- The resources are not connected with the epidemic. There needs to be technical assistance and a reform of the planning process so that the funding follows the epidemic.

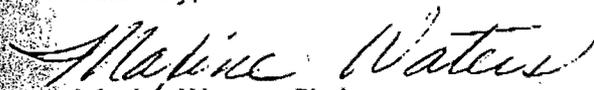
- There is a need to spearhead a comprehensive strategy to engage our leadership and the federal government to combat anti-gay bias.
- African American women and children make up the fastest growing AIDS/HIV caseload. AIDS/HIV resources and strategies must be targeted towards them.
- There is an absence of healthcare professionals and researchers with an interest and commitment to serve African American communities.

Next Step

Our meeting concluded with 100 percent agreement that there is an HIV/AIDS emergency in our communities. Therefore, we believe it is urgent and necessary for a formal declaration of a public health emergency.

We are prepared to meet with you to further discuss what we believe are steps necessary to address the crisis.

Sincerely,



Maxine Waters, Chair
Congressional Black Caucus

cc: President Clinton
Vice President Gore
Members of Congress
Members of Black Leadership Forum
Meeting Attendees
Mr. Erskine Bowles
Mr. Thurgood Marshall, Jr.



JUN 10 1998

The Honorable Maxine Waters, Chair
Congressional Black Caucus
U.S. House of Representatives
2344 Rayburn Building
Washington, DC 20515

Dear Representative Waters:

Thank you for your letter of May 15, 1998 in which you raised a number of issues concerning HIV/AIDS and its impact on the African-American community. I want to provide you and the Congressional Black Caucus with an update in response to the request that the Department re-examine its current response to the HIV/AIDS epidemic with a particular focus on the needs of the African-American community.

There is no question that the face of HIV/AIDS has changed, and that HIV/AIDS in the African-American and other minority communities warrants a special and unique response. The Department is in the process of taking a hard look at all of its HIV/AIDS-related programs with a particular focus on CDC's HIV/AIDS/STD prevention initiatives, HRSA's Ryan White care and treatment programs, and SAMHSA's substance abuse prevention and treatment efforts in order to more accurately assess our response.

Our goal is a candid review and assessment of what is happening on the State, local and community levels given the changing nature and demographics of HIV/AIDS. In addition, the Department's review will take into consideration factors other than funding and infrastructure, such as those related to social conditions, economic and community resources, cultural beliefs and perceptions about the health care system in the African-American community. The linkages and collaborations between HIV/AIDS prevention, treatment and substance abuse providers will also be examined.

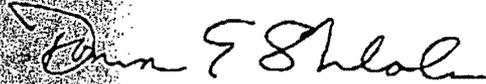
New technical assistance resources may need to be carefully designed in order to help community based organizations develop the necessary capacity to enhance services to those individuals infected and affected by HIV/AIDS in the African-American community. New partnerships and expanded community collaborations may need to be formed.

page 2

Within the next several weeks we plan to discuss with you a detailed strategy which will outline the Department's response. The response will include a two-pronged approach--those items immediately implementable and those items which will require more long-term planning. The scope of what we are undertaking is comprehensive and requires that we take the necessary time to accomplish our shared goals.

I look forward to continuing our dialogue and working with you and the Congressional Black Caucus as we address the HIV/AIDS crisis in the African-American community.

Sincerely,



Donna E. Shalala

HIV/AIDS in the black community is a crisis. Again, we request that you make a speedy public health emergency designation. The time to act is now.

Sincerely,



Maxine Waters, Chair
Congressional Black Caucus

cc: President William Clinton
Vice President Albert Gore
Surgeon General David Satcher
Mr. Erskine Bowles, Chief of Staff
Ms. Sandra Thurman, Director of AIDS Policy
Ms. Clara Bloom, Acting Director, CDC
Ms. Nelba Chavez, Director, SAMHSA
Mr. Rahm Emanuel, Senior Advisor to the President
Ms. Minyon Moore, Deputy Assistant for Political Affairs
Ms. Janet Murgia, Deputy Assistant for Legislative Affairs
Mr. Broderick Johnson, Special Assistant for Legislative Affairs
Ms. Maria Echaveste, Director of Public Liaison
Mr. Ben Johnson, Deputy Director for Public Liaison



105th Congress

OFFICERS

Mazine Waters
Chair

Earl Hilliard
First vice Chair

Eddie Bernice Johnson
Second vice Chair

Corrine Brown
Secretary

Sheila Jackson Lee
 Whip

MEMBERS

U.S. House of Representatives

- John Conyers, Jr. MI - '65
- William Clay, MO - '69
- Louis Stokes, OH - '69
- Ronald V. DeLuca, CA - '71
- Charles B. Rangel, NY - '71
- Julian C. Dixon, CA - '79
- Major R. Owens, NY - '83
- Edolphus Towns, NY - '83
- Floyd Flake, NY - '87
- John Lewis, GA - '87
- Donata M. Payne, NJ - '89
- Eleanor Holmes-Norton, DC - '91
- William Jefferson, LA - '91
- Mazine Waters, CA - '91
- Eva Clayton, NC - '92
- Sanford Bishop, GA - '93
- Corrine Brown, FL - '93
- Jim Clyburn, SC - '93
- Alice Hastings, FL - '93
- Earl Hilda, AL - '93
- Eddie Bernice Johnson, TX - '93
- Cynthia McKinney, GA - '93
- Clayton Kopp, FL - '93
- Bobby Rush, IL - '93
- Robert C. Scott, VA - '93
- Melvin Watt, NC - '93
- Albert Wynn, MD - '93
- Bernie G. Thompson, MS - '93
- Chaka Fattah, PA - '95
- Sheila Jackson Lee, TX - '95
- Jesse Jackson, Jr., IL - '95
- Lontra McIsaac-McDonald, CA - '96
- Egon Cummings, MD - '96
- Júlio M. Carson, IN - '97
- Donna Christian-Green, VI - '97
- Danny K. Davis, IL - '97
- Harold E. Ford, Jr., TN - '97
- Carolyn Kaptick, MI - '97
- U.S. Senate
- Carol Mosley-Braun, IL - '93

NOT PRINTED OR MAILED AT PUBLIC EXPENSE

Congressional Black Caucus

Congress of the United States

2344 Rayburn Building • Washington, DC 20515 • (202) 225-2201

August 3, 1998

SPECIAL

VIA TELECOPIER AND U.S. MAIL

The Honorable Donna Shalala
Secretary
The Department of Health and
Human Services
200 Independence Avenue, SW
Washington, D.C. 20201

Dear Secretary Shalala:

I have reviewed the proposals your agency submitted for discussion in response to the Congressional Black Caucus' call for a "public health emergency" designation of HIV/AIDS in the African American community. I am pleased to see that your agency has done some preliminary work to further address this dreaded epidemic. While your proposal is a good beginning, I believe there are a few other points that must be addressed

I understand from your staff that you do not want to simply declare a "public health emergency" and be bound by the short term nature of a statutory designation. I suggest that you declare a "public health emergency and beyond." By using this phrase, you can explain to the American people, through the media, the horrors of the HIV/AIDS epidemic in our country. This allows you to give HIV/AIDS the same attention that President Clinton gave the nursing home issue earlier this month.

I am also interested in a direct mail campaign in the regions highly impacted with the disease. A piece of mail in every mailbox will help to educate the community and help increase discussions between neighbors and families about the HIV/AIDS epidemic.

In addition, I suggest that the Department develop an advertising campaign with ads in all of the African American newspapers and many mainstream newspapers to make communities aware that HIV/AIDS is a

SPECIAL

90 AUG -5 11:24 AM

public health emergency. The ads also should tell individuals where they can obtain treatment.

The Department also needs to develop a working model to show organizations and communities how to run a testing site for HIV/AIDS. The model should be replicated across the country in every community and neighborhood. It can be finely tuned in identified high impact areas. CBC Members also can help promote the issue by attending public meetings and appearances in each of five targeted areas.

I look forward to working with you on the fight to get the HIV/AIDS crisis in the African American community under control in this country.

Sincerely,



Maxine Waters, Chair
Congressional Black Caucus

08-05-98-0011

HHS NEWS

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

FOR IMMEDIATE RELEASE
Friday, Aug. 7, 1998

Contact: HRSA Press Office
(301) 443-3376

HHS ANNOUNCES \$17.5 MILLION IN GRANTS FOR HIV/AIDS CARE

HHS Secretary Donna E. Shalala today announced \$17.5 million in health care and dental care grants through the Ryan White CARE Act targeted to women, children, youth and families and others living with HIV/AIDS. The new grants directly address HIV/AIDS in underserved areas and racial and ethnic minority communities, providing critical health and dental services, support services and access to research opportunities.

The awards are funded under Title IV of the Ryan White CARE (Comprehensive AIDS Resources Emergency) Act, the Coordinated Care and Access to Research for Children, Women, Youth and Families program (\$10.2 million); and Part F of the Act, the HIV/AIDS Dental Reimbursement Program (\$7.3 million). They bring to 49 the number of projects funded under Title IV. The Part F program funded dental care for 69,000 patients in 1997, covering about 47 percent of the unreimbursed costs of this care.

"The awards we announce today are a critical component of our targeted assistance designed specifically to serve our most vulnerable citizens and communities, particularly women, youth, and families in minority communities in both urban and rural settings," said Secretary Shalala. "These funds help ensure that low-income uninsured individuals living with HIV/AIDS have access to high quality care."

Racial and ethnic minorities together account for more than 54 percent of the total AIDS cases reported since the beginning of the epidemic.

In 1997, the fastest growing proportion of new AIDS cases was reported among women of color. African American and Latina women accounted for 80 percent of new AIDS cases reported among women. Sixty three percent of new AIDS cases among children under 13 are among African Americans, and 23 percent are among Hispanics.

- More -

- 2 -

"The AIDS epidemic is increasingly becoming a disease of people of color, of the young, of minorities -- people who often do not have access to quality care and treatment," said Surgeon General Dr. David Satcher.

"Improving access to HIV/AIDS care is essential and a key objective of the Ryan White CARE Act programs," said Claude Earl Fox, M.D., Administrator of the Health Resources and Services Administration, the HHS agency that oversees the CARE Act. Nearly 80 percent of clients served through the Title IV program in 1996 were from racial and ethnic minorities.

The Department has been working within its HIV/AIDS programs to develop a focused response to the changing demographics of the epidemic and the special concerns which these changes present. Last February, President Clinton announced a six-point initiative to help close the health gap between racial and ethnic minorities and non-minority Americans. The initiative includes a specific focus on HIV/AIDS.

In addition, HHS has been working with the Congressional Black Caucus to expand its ongoing dialogue with minority community leaders, community representatives and AIDS activists to develop a sustained and coordinated strategy to respond to the severe and ongoing HIV/AIDS crisis in communities of color. Particular issues of concern have been the need to mobilize effective prevention efforts in minority communities and bring about equal benefits for minority populations from available therapies. HHS is developing a set of immediate strategic responses to support essential infrastructure capacity within these communities.

Today's awards are among many designed to increase the availability of prevention and treatment services, support community-based outreach and infrastructure, and expand research opportunities in racial and ethnic minority communities. In addition to resources in FY 98, the Department is committed to sustaining and expanding this investment in future years.

In recognition of the important role played by community based organizations and religious and faith institutions in preventing HIV/AIDS and providing vital support services, the Department will be investing an additional \$375,000 in FY 98 in technical assistance resources to enable these communities to better respond to the HIV/AIDS crisis. These include partnerships with the National Minority AIDS Council and the Congress of National Black Churches:

- More -

- 3 -

- A \$225,000 initiative with the Congress of National Black Churches to mobilize a variety of HIV/AIDS education and outreach projects through black churches. The Department's Office of Minority Health, Substance Abuse and Mental Health Services Administration (SAMHSA) and the NIH Office of Research on Minority Health are collaborating on this project;
- An additional \$100,000 from HRSA to the National Minority AIDS Council, as part of an existing agreement, for technical assistance to minority community-based organizations so that they can better compete for government dollars to serve people with HIV/AIDS. This strategy is being developed through public and private sources;
- An investment of \$50,000 from SAMHSA toward the development of a strategic plan that will guide coordination of HIV/AIDS activities with specific components geared to racial and ethnic minorities.

###

Note: HHS press releases are available on the World Wide Web at:
<http://www.hhs.gov>.

Title IV FY 1998 New Grant Awards
Grantee

Grantee	Award
Albany Medical College, Albany, N.Y.	\$250,000
Maricopa Integrated Health Systems, Phoenix, Ariz.	252,000
Methodist Healthcare - Memphis Hospital, Memphis, Tenn.	277,400
Metropolitan Low Income Housing, Washington, N.C.	378,894
University of Florida, Jacksonville, Fla.	242,194
University Medical Center of South Nevada, Las Vegas, Nevada	250,000
	\$1,650,488

- More -

- 4 -

Title IV FY 1998**Competing Continuation Awards**

Albert Einstein College of Medicine, Bronx, N.Y.	\$1,647,692
Georgia Dept. of Human Resources, Atlanta, Ga.	537,000
Medical College of Wisconsin, Madison, Wis.	405,443
Public Health Foundation Enterprises, Inc., Los Angeles, Calif.	950,000
Research Foundation of SUNY, Brooklyn, N.Y.	1,447,000
The Family Center, Inc., New York City, N.Y.	494,743
University of Colorado Health Science Center, Denver, Colo.	532,000
University of South Florida, Tampa, Fla.	880,000
University of Texas Southwestern Medical Center at Dallas, Dallas, Texas	872,714
Washington University School of Medicine, St. Louis, Mo.	720,000
	\$ 8,486,592
Total	\$10,137,080

HIV/AIDS Dental Reimbursement Awards**Grantee****Award**

University of Alabama School of Dentistry, Birmingham, Ala.	\$ 23,769
University of Southern California School of Dentistry, Los Angeles, Calif.	\$330,552
University of California, San Francisco, San Francisco, Calif.	\$154,087
Highland General Hospital, Oakland, Calif.	\$159,964
King/Drew Medical Center, Los Angeles, Calif.	\$160,583
University of California Los Angeles School of Dentistry, Los Angeles, Calif.	\$102,709
University of the Pacific, San Francisco, Calif.	\$ 69,908
Loma Linda University, Loma Linda, Calif.	\$ 893
University of Colorado School of Dentistry, Denver, Colo.	\$ 4,937
Childrens Hospital, Denver, Colo.	\$ 10,492
University of Connecticut Health Center, Farmington, Conn.	\$107,906
Yale New Haven Hospital, New Haven, Conn.	\$159,889
Saint Francis Hospital, Hartford, Conn.	\$ 33,656
Washington Hospital Center, Washington, D.C.	\$115,459
Childrens National Medical Center, Washington, D.C.	\$ 65,980
Howard University School of Dentistry, Washington, D.C.	\$ 36,571
University of Miami/Jackson Memorial Hospital, Miami, Fla.	\$251,882
Dade County Dental Research Clinic, Miami, Fla.	\$ 16,543
University of Florida School of Dentistry, Gainesville, Fla.	\$ 47,287
Medical College of Georgia, Augusta, Ga.	\$ 48,058

- More -

- 5 -

University of Iowa College of Dentistry, Iowa City, Iowa	\$ 17
Northwestern University Dental School, Chicago, Ill.	\$247,613
University of Illinois, Chicago, Ill.	\$ 73,056
University of Louisville School of Dentistry, Louisville, Ky.	\$ 46,620
University of Kentucky College of Dentistry, Lexington, Ky.	\$ 9,072
Louisiana State University School of Dentistry, New Orleans, La.	\$125,165
Boston University Goldman School, Boston, Mass.	\$351,143
Boston Medical Center, Boston, Mass.	\$125,767
Tufts University School of Dental Medicine, Boston, Mass.	\$225,782
Beth Israel Deaconess, Boston, Mass.	\$ 3,460
Harvard School of Dental Medicine, Boston, Mass.	\$ 20,881
University of Maryland, Baltimore, Md.	\$ 33,678
Johns Hopkins University, Baltimore, Md.	\$ 55,457
University of Michigan, Ann Arbor, Mich.	\$ 52,593
University of Detroit Mercy, Detroit, Mich.	\$ 56,791
Ann Arbor V.A. Medical Center, Ann Arbor, Mich.	\$ 10,250
University of Minnesota, Minneapolis, Minn.	\$ 36,903
Hennepin County Medical Center, Minneapolis, Minn.	\$ 24,235
University of Missouri-Kansas City, Kansas City, Mo.	\$ 7,878
Truman Medical Center, Kansas City, Mo.	\$ 3,143
University of Mississippi, Jackson, Miss.	\$ 10,143
University of North Carolina, Chapel Hill, N.C.	\$ 42,371
Wake Forest/Bowman-Gray, Winston-Salem, N.C.	\$ 3,578
University of Nebraska, Omaha, Neb.	\$ 5,064
UMD New Jersey, Newark, N.J.	\$248,728
St. Joseph's Hospital & Medical Center, Patterson, N.J.	\$ 60,368
Hackensack University Medical Center, Hackensack, N.J.	\$ 23,149
St. Mary's Hospital of Brooklyn, Brooklyn, N.Y.	\$343,512
Saint Barnabas Hospital, Bronx, N.Y.	\$126,386
Lutheran Medical Center, Brooklyn, N.Y.	\$254,647
Woodhull Medicine & Medical Health Center, Brooklyn, N.Y.	\$264,206
Montefiore Medical Center, Bronx, N.Y.	\$185,576
Interfaith Medical Center, Brooklyn, N.Y.	\$175,800
Kings County Hospital Center, Brooklyn, N.Y.	\$223,914
Coney Island Hospital, Brooklyn, N.Y.	\$129,720
Bronx-Lebanon Hospital Center, Bronx, N.Y.	\$ 92,383
Brooklyn Hospital Center, Brooklyn, N.Y.	\$ 57,816
Columbia University, New York, N.Y.	\$ 72,019
Our Lady of Mercy Medical Center, Bronx, N.Y.	\$ 82,101
New York University Kriser Dentistry Center, New York, N.Y.	\$132,349
Morrisania D&TC, Bronx, N.Y.	\$ 99,661
University of Rochester, Strong Memorial Hospital, Rochester, N.Y.	\$ 70,229
North Central Bronx, Bronx, N.Y.	\$ 35,288
Erie County Medical Center, Buffalo, N.Y.	\$ 68,459
Segundo Ruiz Belvis/Lincoln Hospital, Bronx, N.Y.	\$ 89,483

- More -



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Assistant Secretary
for Public Affairs

Washington, D.C. 20201

AIDS Ask

Prepared Videotaped Statement of
Donna E. Shalala, Secretary
U.S. Department of Health and Human Services
to the Congressional Black Caucus Health Braintrust Town Hall Meeting on
HIV/AIDS and the African-American Community
September 17, 1998

Good morning.

I regret that I'm unable to be with you in person. But I am certainly there in spirit.

And I am there in solidarity with your efforts, your energy, and your call to action on the severe and ongoing crisis of HIV/AIDS in the African-American community.

This is an emergency in many communities of color.

You've chosen to hold this town hall meeting on a notable day in American history.

Today -- September 17th -- is a day of milestones -- and miles to go.

On this day in 1787, the US Constitution was approved -- but with three clauses protecting slavery.

On this day in 1861, the first day school for freedmen was founded -- but almost a century would pass before *Brown versus Board of Education*.

And on this day, today, we can celebrate living in a nation with the best health care in the world -- but not for everyone.

Because our nation continues to suffer from persistent and unforgivable racial health disparities.

The HIV/AIDS epidemic among African Americans is Exhibit A.

On behalf of the entire Clinton-Gore Administration, I appreciate what the Congressional Black Caucus is doing to sound the alarm about this deadly epidemic.

Working together, we've made real progress on critical issues for all of us -- and all of the nation.

Together, we've fought racism, advanced racial diversity and pursued greater unity.

Together, we've given our nation a new Surgeon General – Dr. David Satcher – who has the wisdom, heart and courage to improve the health status of all Americans.

Together, we've stepped up the fight against HIV/AIDS, with an 86 percent increase of overall funding for AIDS-related programs since 1993.

And together, we've devoted a substantial portion of our federal AIDS dollars to serve racial and ethnic minorities.

63 percent of participants in AIDS clinical trials sponsored by our National Institutes of Health are minorities – 40 percent are African-American.

And 42 percent of our clients served by Title I of the Ryan White Act are African-Americans.

Last month, we released 17.5 million dollars in Ryan White grants targeted to address HIV/AIDS in underserved areas and racial and ethnic minority communities.

Today, I am pleased to announce an additional 4.9 million dollars in end-of-the-year funds that will be devoted to HIV/AIDS related services.

These funds will be directed through community health centers and organizations, state and local health departments, and through Healthy Start to help one million African-American women of childbearing age.

These are important steps.

But like the other historic milestones of September 17th, we still have miles to go before we close the racial divides in our nation and our health.

We certainly haven't done enough to fight the HIV/AIDS epidemic in the African American community.

Not when more than four out of 10 new AIDS cases strike African Americans.

Not when six out of 10 new AIDS cases among women strike African American women.

And not when the decline in AIDS deaths in our nation is much smaller among African Americans than whites.

This is not only a crisis for African Americans.

It is a crisis for all Americans. For all communities. For all children. For all of our futures.

Every American must know about it. And no American should stand for it.

The Congressional Black Caucus is right to hold our feet to the fire.

Earlier this year, the Caucus challenged the Clinton Administration to escalate our fight against HIV/AIDS among minorities.

And for the past several months, we've been discussing with Chairwoman Waters and the Caucus the best ways to do that.

Today, I have a brief status report.

Right now, the Department of Health and Human Services, in conjunction with the CBC, is developing better strategies to better target our current resources in response to the HIV/AIDS epidemic in the African American community.

Where possible, we will build up our resources and tools -- from education to prevention to treatment and support.

And we are well on the path toward an agreement with the Caucus that will set a new course in our fight.

We hope to make a formal announcement about this new effort soon.

We especially need the Congressional Black Caucus to help us to make this happen.

We appreciate the leadership of Chairwoman Maxine Waters and Congressman Louis Stokes.

They have been clear, consistent and committed voices in this fight for a very long time.

Their determination, dedication and diligence has helped to educate all Americans about HIV/AIDS.

And their leadership in Congress has helped to direct more federal resources to this fighting HIV/AIDS in the African-American community.

More than ever, we need their leadership to take this fight to a new level and to win it.

Finally, I want to thank every member of the Congressional Black Caucus Health Braintrust, as well as the many HIV/AIDS activists and health care providers who are here for this forum.

Your strong, clear voice has raised public awareness about the devastation of HIV/AIDS in the African-American community.

On this day -- September 17th, the day the US Constitution was approved -- let us rededicate our quest to fulfill its promise.

If we are going to form a more perfect union ... establish justice ... insure domestic tranquility and promote the general welfare, then we must secure the blessings - not only of liberty -- but of good health for every American.

Thank you.

HHS NEWS

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

FOR IMMEDIATE RELEASE
Thursday, Sept. 17, 1998

Contact: HHS Press Office
(202) 690-6343

FEDERAL HEALTH AGENCY ANNOUNCES ADDITIONAL FY 1998 FUNDS TO ADDRESS HIV/AIDS AMONG RACIAL AND ETHNIC MINORITIES

The U.S. Department of Health and Human Services announced today that an additional \$4.9 million is being directed to supplement existing FY 1998 departmental efforts to address HIV/AIDS prevention and outreach services in racial and ethnic minority communities.

The funding will be used to support a variety of programs aimed at reducing the spread of HIV/AIDS in minority communities, including community-based prevention services, targeted HIV/AIDS outreach services for African-American women already in a federally sponsored prenatal care program, and a model program in Los Angeles County that integrates HIV/AIDS-related health, substance abuse and other services for racial and ethnic minorities.

"I am pleased to be able to announce these new grants as part of our continuing response to the growing HIV/AIDS crisis in communities of color," Secretary Donna E. Shalala said. "HIV/AIDS is becoming more prevalent in racial and ethnic minority communities, especially among African-Americans and Hispanics. This is a severe, ongoing crisis that calls for a long-term response that is comprehensive and sustained."

The bulk of the resources is coming from the Centers for Disease Control and Prevention which is providing \$3 million in fiscal 1998 funds for this effort including:

- \$2.1 million to support 30 community-based organizations providing high-priority HIV prevention services in African-American and Latino communities;
- \$900,000 for three state and city health departments to increase access to prevention services for HIV-infected individuals, especially African-Americans and Latinos, to prevent further spread of the disease.

The remaining \$1,875,000 of the funding is being provided by the Health Resources and Services Administration, and will be used in the following ways:

- \$950,000 for HIV/AIDS outreach activities targeted to African-American women of childbearing age through the Healthy Start program;

- More -

- 2 -

- \$790,000 to bolster HIV/AIDS related activities available through community health centers, and in public housing programs serving low-income, medically underserved people; and
- \$135,000 for a Los Angeles County project that could serve as a national model for targeting the African-American community through linking health care, mental health, substance abuse treatment and other critical HIV/AIDS services.

HHS has been working with the Congressional Black Caucus to expand its ongoing dialogue with minority community leaders, community representatives and AIDS activists to develop a sustained and coordinated strategy to respond to the severe and ongoing HIV/AIDS crisis in communities of color. Particular issues of concern have been the need to mobilize effective prevention efforts in minority communities and bring about equal benefits for minority populations from available therapies. HHS is developing a set of immediate strategic responses to support essential infrastructure capacity within these communities. An announcement on these targeted strategies is expected soon.

Under the Clinton Administration, HHS has increased overall funding for HIV/AIDS related programs by 86 percent, and stepped up its commitment to addressing the HIV/AIDS concerns of racial and ethnic minority communities.

Already, a substantial portion of federal dollars are serving racial and ethnic minority populations. For example, 63 percent of participants in NIH-sponsored AIDS clinical trials are minorities, of whom 40 percent are African-Americans and more than 20 percent are Hispanic. Also, some 80 percent of clients of Title IV of the Ryan White CARE Act are racial and ethnic minorities.

Earlier this year, the Clinton Administration unveiled the Initiative to Eliminate Racial and Ethnic Disparities in Health. This \$400 million initiative over five years gives special attention and resources to closing the gaps between African-Americans and other racial and ethnic minorities and white Americans in terms of HIV/AIDS and several other major illnesses. The goal is to close these gaps by the year 2010.

###

Note: Fact Sheets are available on HIV/AIDS and the African-American and Hispanic populations. HHS press releases are available on the World Wide Web at: <http://www.hhs.gov>.



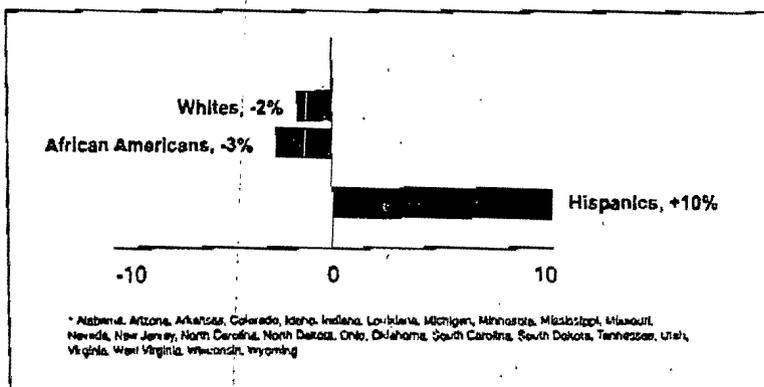
June 1998

Impact of HIV/AIDS on Hispanics in the United States

Hispanics in the United States include a diverse mixture of ethnic groups and cultures. With more than 25 million Hispanics, the United States has the fifth largest Hispanic population in the world, following Mexico, Spain, Argentina, and Colombia. Although Hispanics represent an estimated 10% of the total U.S. population, they account for 18% of the 641,086 AIDS cases reported in the United States through December 1997.

In 1997, 60,634 new AIDS cases were reported to CDC. Of these, 12,466 (21%) occurred among Hispanics. The AIDS incidence rate (the number of new cases of a disease that occurs during a specific time period) among Hispanics was 37.7 per 100,000 population in 1997, almost 4 times the rate for whites (10.4 per 100,000) and almost half the rate of African Americans (83.7 per 100,000 population).

A recent CDC study examined data from the 25 states* that had integrated HIV and AIDS surveillance from January 1994 through June 1997. This study showed that HIV diagnoses increased 10% among Hispanics between 1995 and 1996 (the most recent year for which overall trends can be examined). However, the number of cases reported among Hispanics was relatively small, since many states with large Hispanic populations have not implemented integrated HIV and AIDS reporting and were not included in the study. At the same time, HIV diagnoses declined slightly among African Americans (-3%) and among whites (-2%) in these states. Of the 7,200 young people ages 13-24 years who were diagnosed with HIV from January 1994 to June 1997, 5% were Hispanic.



* 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, Wyoming

Historical Trends in HIV and AIDS Cases

Most HIV and AIDS cases reported to date among Hispanics have been among men, although the proportion of cases among women is rising. Among Hispanic men, the majority of reported cases have been among gay and bisexual men and injection drug users. Among Hispanic women, most cases have been the result of heterosexual exposures, although drug use also plays a major role in the spread of infection to women. A large proportion of Hispanic women were infected through injection drug use or by having sex with an injection drug user. To reduce the toll of the epidemic among Hispanic men, women, and children, prevention programs must address the intersection of sexual and drug-related risks.

CDC's HIV Prevention Efforts Targeting Hispanic Populations

Since early in the HIV/AIDS epidemic, CDC recognized that Hispanic populations were being disproportionately affected and took a number of steps to better target HIV prevention efforts in these communities. The following is a brief overview of some of those activities.

- CDC currently provides \$253 million in funding to state and local health departments for HIV prevention programs. Since December 1993, CDC has funded a process designed to put more of the decisions about how these prevention funds are directed in the hands of the communities affected. Under this process, HIV Prevention Community Planning, health departments are required to establish priorities in conjunction with a planning group that brings together health department staff, representatives of affected populations, epidemiologists, behavioral scientists, service providers, and other community members to identify prevention needs and interventions to meet these needs. This process helps ensure that HIV prevention efforts are locally relevant and address the unique epidemic and prevention needs of each community.

CDC has conducted several recent assessments to determine what proportion of these funds are used to reach minority populations. While not all programs are targeted by race (some, for example, target high-risk communities such as injection drug users or people being treated in STD clinics, which include individuals from multiple races), it is clear that a significant proportion of funding for major programs, such as counseling and testing and risk-reduction programs, are targeted to Hispanics. Of programs identified as specifically targeting a racial/ethnic group (representing \$143 million), 22% of funds (\$31.4 million) target Hispanics.

- CDC also directly funds minority and other community-based organizations to design and implement HIV prevention programs that are highly targeted to high-risk individuals within racial and ethnic minority populations. Many serve gay and

bisexual men of color or injection drug users as their primary focus. CDC currently provides \$18 million to fund 94 community-based organizations through this program. Sixty-four of these organizations direct their programs to Hispanics. CDC recently announced the availability of an additional \$4 million in fiscal year 1998 for community-based organizations for HIV prevention activities directed to African-American and Hispanic populations.

- CDC funds a \$9.5 million program to assist National and Regional Minority Organizations in building capacity to deliver HIV prevention programs and services within minority communities. Of these 22 organizations, 8 exclusively serve Latino/Latina populations and 3 others serve several minority populations including Latino/Latinas.
- Additionally, CDC conducts a number of behavioral research projects aimed at reducing HIV infection in the Hispanic community.
 - ▶ The *People of Color Initiative*, designed to reduce the disproportionate spread of HIV/AIDS among minority populations, will develop, strengthen, support, and, as needed, redesign HIV prevention strategies targeting racial and ethnic minority communities.
 - ▶ The *Women and Infants Demonstration Project* is a community-level behavioral intervention research project targeting young women ages 15 to 34, most of whom are members of racial/ethnic minority populations. This project is designed to improve understanding of factors influencing women's behavior changes regarding condom and contraceptive use and to improve the development and delivery of interventions.
 - ▶ The *Prevention of HIV Infection in Youth at Risk* project focuses primarily on young men of color. This program is developing and evaluating approaches to encourage young African-American and Hispanic men who have sex with men to reduce behaviors that put them at risk for HIV.

Building Better Prevention Programs for Hispanics

While race and ethnicity alone are not risk factors for HIV infection, underlying social and economic conditions (such as language or cultural diversity, higher rates of poverty and substance abuse, or limited access to health care) may increase the risk for infection in some Hispanic-American communities.

In addition to addressing these underlying conditions, improved prevention efforts for Hispanics will require focusing on several key challenges. To reduce the risk of infection for Hispanic women, efforts to prevent drug use and HIV must be better integrated. And to adequately address the prevention needs of Hispanic gay and bisexual men, homophobia must be confronted on a national, societal, and community

level. Finally, we must apply lessons learned in designing culturally appropriate prevention efforts to developing effective programs for communities not yet effectively reached. Despite successes to date, this epidemic is far from over. As long as we continue to see preventable infections occur each year, we can and must do better.

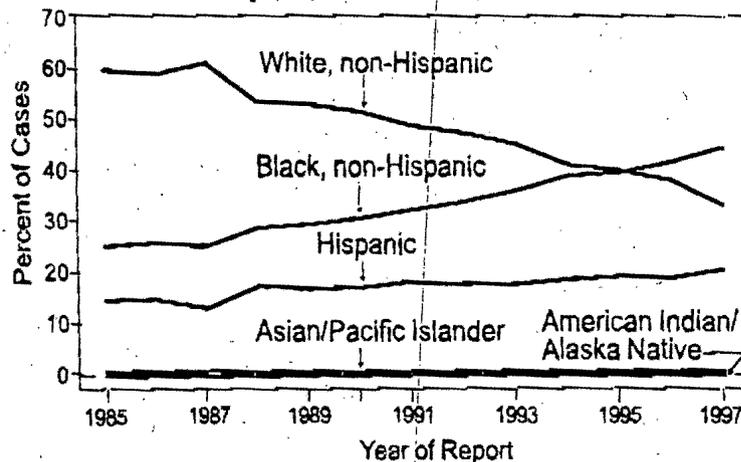
Critical Need to Pay Attention to HIV Prevention for African Americans

In the United States, African Americans have been disproportionately affected by HIV and AIDS. Through December 1997, CDC had received reports of 230,029 cases of AIDS among African Americans. Although that is 36% of the 641,086 cases reported, African Americans represent only an estimated 13% of the total U.S. population.

Researchers estimate that 240,000-325,000 African Americans are infected with HIV. Approximately 1 in 50 African-American men and 1 in 160 African-American women are believed to be infected with HIV. Of those infected with HIV, it is estimated that 93,000 African Americans are living with AIDS.

In 1997, more African Americans were reported with AIDS than any other racial/ethnic group. Of the total AIDS cases reported that year, 45% (27,075) were reported among African Americans, 33% (20,197) were reported among whites, and 21% (12,466) were reported among Hispanics. Among women and children with AIDS, African Americans have been especially affected, representing 60% of all women reported with AIDS in 1997 and 62% of reported pediatric AIDS cases for 1997.

Proportion of AIDS Cases by Race/Ethnicity and
Year of Report, 1985-1997, United States



HIV Data Show These Trends Are Continuing

HIV data from a recent CDC study comparing HIV and AIDS diagnoses in 25 states with integrated reporting systems, provide a much clearer picture of recent shifts in the epidemic, with a larger percentage of HIV than AIDS cases diagnosed among African Americans, especially women. During the period from January 1994 through June 1997, African Americans represented 45% of all AIDS diagnoses, but 57% of all HIV diagnoses. Among young people (ages 13 to 24), 63% of the HIV diagnoses were among African Americans.

CDC's HIV Prevention Efforts Targeting African Americans

The disproportionate impact of HIV/AIDS on African Americans underscores the importance of increasing prevention efforts in this community. HIV prevention efforts must take into account cultural issues, as well as social and economic factors - such as poverty, underemployment, and poor access to the health care system - that impact many U.S. minority communities. For over a decade, CDC has worked closely with national-, regional-, and community-based organizations to design and implement HIV prevention efforts directed to African Americans. Clearly, the most effective programs are those designed and implemented by the African-American community itself.

CDC is currently supporting, directly or indirectly, hundreds of community-based organizations across the United States to implement programs and provide HIV prevention services to the African-American community. Programs focus on a wide range of activities, including risk-reduction counseling, street and community outreach, prevention case management services, and efforts to help individuals at risk gain access to HIV testing and treatment and related services.

Additionally, to help establish greater capacity within the African-American community to provide HIV prevention services, CDC has instituted a program to assist national and community-based organizations serving these communities in building the infrastructure needed to deliver HIV testing, counseling, health care, and support services. And because of the critical role the faith community plays in mobilizing community leaders and in reaching and serving the community at large, CDC established a collaboration with the faith community in 1987 as part of multi-sectoral program to encourage positive response to, and participation in, HIV prevention. While the effort began modestly, with direct funding to faith organizations of roughly \$100,000 the first year, the program had grown to \$500,000 annually by 1994 and to the current funding level of \$900,000 in 1997. Roughly half of this initiative currently targets the African-American faith community.

CDC has several major initiatives and numerous research projects designed to reach the African-American community including:

- CDC currently provides \$253 million in funding to state and local health departments for HIV prevention programs. Since December 1993, CDC has funded a process designed to put more of the decisions about how these prevention funds are directed in the hands of the communities affected. Under this process, HIV Prevention Community Planning, health departments are required to establish priorities in conjunction with a planning group that brings together health department staff, representatives of affected populations, epidemiologists, behavioral scientists, service providers, and other community members to identify prevention needs and interventions to meet these needs.

This process helps ensure that HIV prevention efforts are locally relevant and address the unique epidemic and prevention needs of each community.

CDC has conducted several recent assessments to determine what proportion of these funds are used to reach minority populations. While not all programs are targeted by race (some, for example, target high-risk communities such as injection drug users or people being treated in STD clinics, which include individuals from multiple races), it is clear that a significant proportion of funding for major programs, such as counseling and testing and risk reduction programs, are targeted to African Americans. Of programs identified as specifically targeting a racial/ethnic group (representing \$143 million), 36% of programs (\$52 million) target African Americans. By comparison, 36% target Caucasians, and 22% target Hispanics.

- CDC also directly funds minority and other community-based organizations to design and implement HIV prevention programs that are highly targeted to high-risk individuals within racial and ethnic minority populations. Many serve gay and bisexual men of color or injection drug users as their primary focus. CDC currently provides \$18 million to fund 94 community-based organizations through this program. Seventy-one (76%) of these organizations direct their programs to African Americans.
- CDC funds a \$9 million program to assist National and Regional Minority Organizations in building capacity to deliver HIV prevention programs and services within these communities. Of these, many organizations directly serve the African-American community. Organizations supported through this initiative include the National Organization of Black County Health Officials (\$450,000), the National Minority AIDS Council (\$455,000), the Association of Black Psychologists (\$320,000), the National AIDS Minority Information and Education Program (\$291,000), and the National Council of Negro Women (\$451,000).
- Last year, to further evaluate the current capacity of community-based organizations serving minority organizations, CDC funded the Harlem AIDS Directors (\$400,000) to conduct an assessment to identify unmet needs.

- Additionally, CDC conducts numerous behavioral research projects aimed at reducing HIV infection in the African-American community. For example, the prevention of HIV in Women and Infants Project is a community-level behavioral intervention research project targeting young women ages 15-34. The project is designed to improve the understanding of factors influencing women's behavior changes regarding condom and contraceptive use and to improve the development and delivery of prevention interventions. Another example is the Young African-American Men's Study. This study is a 2-year formative study to prevent HIV/AIDS in young African-American men. Data are being collected in Chicago and Atlanta through interviews, observations, and group discussions with community leaders, health care providers, and young men who have sex with men. In addition to these examples, there are numerous research projects designed to better understand risk behaviors and design effective interventions for African Americans at highest risk for HIV infection, including injection drug users, women who are partners of injection drug users, individuals with high rates of STDs, and young gay and bisexual men of color.

There is no question that as long as the epidemic continues to spread in the African-American community, these programs must continue, and even more must be done. It is also clear that the public sector alone can not successfully combat HIV and AIDS in the African-American community. Overcoming the current barriers to HIV prevention and treatment in this community requires that leaders in the community acknowledge the severity of the continuing epidemic among African Americans and play an even greater role in combating HIV/AIDS in their own community.

PRESIDENT CLINTON DECLARES HIV/AIDS IN RACIAL AND ETHNIC MINORITY COMMUNITIES TO BE A "SEVERE AND ONGOING HEALTH CARE CRISIS" AND UNVEILS NEW INITIATIVE TO ADDRESS THIS PROBLEM

October 28, 1998

Today, the President will declare HIV/AIDS in racial and ethnic minority communities to be a "severe and ongoing health care crisis" and will unveil a series of initiatives that invest \$156 million to address this urgent problem. Citing the chronic and overwhelmingly disproportionate burden of HIV/AIDS on minorities, the President will outline a new comprehensive initiative that includes unprecedented efforts to improve the nation's effectiveness in preventing and treating HIV/AIDS in the African-American and Hispanic communities. The President will also highlight other important increases to fight HIV/AIDS in the budget as well as new funding for his initiative to address racial health disparities for a range of diseases, including HIV/AIDS.

HIV/AIDS in the minority community is a "severe and ongoing health care crisis." While overall AIDS deaths have declined for two years in a row, AIDS remains the leading killer of African American men age 25-44 and the second leading killer of African American women in the same age group. African Americans comprise more than 40 percent of all new HIV/AIDS cases, and African-American women make up 60 percent of female cases. Hispanics represent over 20 percent of new HIV/AIDS cases and only about 10 percent of the population. This is also a critical concern in Asian American communities, as well as Native American communities, where many are high risk and hard to reach.

Historic initiatives invest \$156 million for HIV/AIDS prevention and treatment in the minority community. During the recent budget negotiations, the Clinton Administration and the Congressional Black Caucus fought successfully to secure a major commitment of funds to address the urgent problem of HIV/AIDS among minorities through new prevention efforts, improved access to HIV/AIDS drug treatments, and training for health professionals who treat this disease. Over two-thirds of this funding is from new resources appropriated through the Omnibus Appropriations Act. The rest will be dedicated from the Department of Health and Human Services' budget.

- **Crisis response teams.** HHS will make available Crisis Response Teams to a number of highly affected areas. These teams of public health and HIV prevention and treatment experts, doctors, nurses, and epidemiologists -- from a range of agencies including the Substance Abuse and Mental Health Services Administration, the Health Resources and Services Administration, the Centers for Disease Control and Prevention -- will help assess existing prevention and treatment services for racial and ethnic minorities and develop innovative, effective strategies that best meet the needs of these communities. This effort will take place within a period of several weeks after a request for a crisis response team is received.

- **Enhanced HIV/AIDS prevention efforts in racial and ethnic minority communities.** These funds will be used for HIV prevention purposes at the Centers for Disease Control such as grants for minority, community-based organizations to work with local health clinics, make testing and counseling available, conduct community workshops, and develop HIV and substance abuse prevention programs on the campuses of Historically Black Colleges and Universities and in institutions of higher learning that predominantly serve Hispanics. The funding also will help provide comprehensive substance abuse treatment programs for African American and Hispanic women with or at risk for HIV/AIDS and their children.

- **Reducing disparities in treatment and health outcomes for minorities with HIV/AIDS.** Studies show that African Americans and Hispanics are much less likely to receive treatments that meet federally recommended treatment guidelines. This new funding, which supplements the already large increase in the Ryan White program, will help minorities get access to cutting-edge HIV/AIDS drug treatments as well as the range of primary health services needed to treat this disease. Funds also will be used to educate health care providers who treat largely minority populations on treatment guidelines for HIV/AIDS.

Unprecedented Increases in Effective HIV/AIDS Treatment, Prevention, and Research Programs. Substantial and critical funding increases in a wide range of effective HIV/AIDS programs, include:

- **An historic \$262 million increase in the Ryan White Care Act,** which provides primary HIV health care services, treatments, and training for health care professionals on HIV treatment guidelines. The treatment funding in this investment includes a more than 60 percent increase for the AIDS drug assistance program that provides protease inhibitors and other life-saving HIV/AIDS treatments to those who cannot afford the cost, which can run as high as \$20,000 a year.
- **A 12 percent increase for HIV/AIDS research at NIH.** In FY 1999, research on HIV/AIDS at the National Institutes of Health (NIH) will total \$1.8 billion, a 12 percent increase. This increase will enhance both basic research to further our understanding of the HIV virus as well as applied research that includes clinical testing of new HIV/AIDS pharmacological therapies.

A Commitment to Eliminate Racial Health Disparities. Minorities suffer from a number of critical diseases, including HIV/AIDS, at higher rates than white Americans. Hispanics are more than four times as likely to get HIV/AIDS than whites, while African Americans are more than eight times as likely. The Congress has taken a first step in investing in the President's proposal to address racial health disparities by funding \$65 million of this initiative. Congress partially funded the proposed grants for communities to develop new strategies to address these disparities and for increases in other critical public health programs, such as heart disease and diabetes prevention at CDC, that have shown promise in attacking these disparities.

Calling on Congress to Pass an Unfinished Agenda for People With HIV/AIDS.

- **A Patients' Bill of Rights.** The President and Vice President have repeatedly urged the Congress to pass a strong, enforceable Patients' Bill of Rights that contains critical protections for people with HIV/AIDS, including access to specialists and continuity of care to prevent abrupt changes in critical treatment when an employer changes health plans.
- **A Work Incentives Bill for People with Disabilities.** Congress also failed to pass the bipartisan Jeffords-Kennedy bill that would have enabled people with disabilities and other disabling conditions, such as HIV/AIDS, to return or to remain at work by expanding options to buy into Medicaid and Medicare and by offering other pro-work initiatives. This bill was on the list of top Administration priorities in the final budget negotiations.