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March 6, 1998

Phill Wilson
Director
Southern California AIDS Social Policy Archive
University of Southern California
East Library, 354
Los Angeles, California 90089-0182

The University
Libraries

Todd A. Summers
Deputy Director
Office of National ASIDS Policy
The White House
Washington D.C.

Dear Todd,

Thank you for participating in the Oakland Conference.

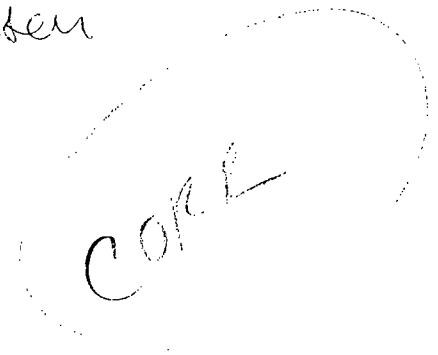
Please find enclosed a draft proposal for the African-American Treatment Advocacy, Peer Advocates Project I spoke with you about. I would appreciate your reading this proposal and giving me your comments. I would appreciate your support with this project as well.

I am in South Africa until March 17th. I will telephone you upon my return. I look forward to speaking with you soon.

Yours in the Struggle,

Phill Wilson

Phill Wilson



University of
Southern California
Los Angeles,
California 90089-0182

AFRICAN AMERICAN AIDS TREATMENT TEAM

A Strategy for Bringing African Americans with HIV/AIDS into High-Quality Care

DRAFT:
NOT FOR CIRCULATION

February 25, 1998

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EXECUTIVE SUMMARY

Black Americans bear the brunt of the U.S. AIDS epidemic, accounting for almost 45 percent all new cases, a far greater proportion than any other racial group. And yet, they have benefited the least from the powerful new combination therapies. Throughout the epidemic, African Americans have fared worse than whites and other groups on every health-care measure: Blacks are diagnosed later in the course of disease, receive worse care, benefit last from new advances in treatment, and die faster. Unfortunately, this has not changed with the advent of protease inhibitors and other potent new therapies. Although the new drugs are cutting death rates among all races, the decline in deaths among blacks lags behind the declines among whites and other groups. And thousands of blacks are continuing to get infected every year, and they will need high-quality care.

Indeed, now that effective AIDS therapies are available, one of the most critical challenges is to bring marginalized communities, especially African Americans, into care. So urgent is the need that President Clinton, Surgeon General David Satcher, and Health and Human Services Secretary Donna Shalala recently targeted HIV/AIDS as one of the six most critical health areas in which minorities suffer an intolerable gap. The Administration has vowed to close this gap, and has committed $400 million to help bring all Americans to health parity. It has asked the private sector to contribute an additional $600 million to this historic effort.

This concept paper maps out a strategy to bring African Americans with HIV/AIDS into high-quality care. The proposed strategy is a comprehensive program to train, place, and support a cadre of highly-trained African-American peer treatment educators who will arm patients with information, help them develop individualized treatment plans, and assist them in advocating for better care. Because the first step into treatment is getting tested, they will also promote HIV testing among African Americans. Finally, through a train-the-trainer process, the program will generate more than 1,000 new African American treatment advocates in two years.

Patient information is important for all diseases, but it is arguably more important for HIV/AIDS than for any other. The new drugs do not cure AIDS. They merely make it "manageable"—and, ultimately, it is patients who are responsible for managing their illness. While doctors play a critical role, patients are the ones who must adhere to the regimen, swallowing up to 20 pills a day on a strict schedule, often with special dietary requirements. Patients also have to cope with side effects, which can include chronic diarrhea and nausea. In short, quality AIDS care requires the active participation of the patient for many years, perhaps for life. Such involvement simply won't happen if patients don't understand *why* they need to shoulder these responsibilities. So patients need information—about the science and treatment of

HIV, about practical ways to improve adherence in the context of their particular lives, and about many other related issues.

Unfortunately, African American patients often have few opportunities to learn what they need to know to maximize their care, because many obstacles stymie them. The barriers include poverty, distrust of the medical establishment, stigma, lack of education, and substance abuse.

As severe as these problems are, they could be dealt with if not for another problem: the lack of an infrastructure to support treatment education. There is a dearth of African American AIDS doctors, researchers, and peer educators. Moreover, very few community-based-organizations possess the combination of expertise, commitment and, above all, resources to train, employ, and support peer educators. Of course, previous attempts to bring African-Americans into AIDS care have achieved some success, and this program incorporates their best practices, especially the proven concept of peer education. But, unfortunately, many programs have foundered because they have lacked the resources to overcome the many barriers that block African Americans from getting care.

Therefore, just as monotherapy fails against HIV, so too will one-dimensional methods fail against this multi-faceted problem. What's needed is the equivalent of combination therapy.

This program will provide exactly that. It will create a cadre of highly-trained peer educators to bring African Americans into care, and to educate them about the complexities of HIV treatment, the critical importance of adherence to their regimens, and the need to communicate with physicians to develop individualized treatment plans. These peer-educators will be superbly trained and supported through a comprehensive, two-year working internship. And their participation will depend on their meeting certain benchmarks—both academic and professional—throughout the program. In short, the standards will be high.

Like triple-combination therapy, the program consists of three interlocking elements, each of which is vital to the success of the whole.

1. **AIDS Treatment College.** Fifty, competitively-chosen peer educators will participate in a full month of intensive, state-of-the-art training in the science and treatment of HIV disease, as well as in relevant social issues such as drug adherence, substance abuse treatment, self-esteem building, HIV prevention, and presentation skills. To earn a graduation diploma from the college, the peer educators will have to pass a battery of tests. Leaders from many fields have already agreed to commit their training services. Some of these individuals include:

    - Researchers: Anthony Fauci

- Doctors: Keith Rawlings, Eric Goosby
- Community educators: Phill Wilson

2. **Working Internships**. Graduates will be dispatched into a dozen epicenter cities, where they will be supervised by carefully chosen community-based AIDS Service Organizations (ASOs). The peer educators will focus on the hardest-hit sectors of the African-American community, conducting one-on-one counseling and holding educational forums. They will reach clients at venues such as public hospitals, community clinics, STD clinics, substance abuse centers, and free clinics. In their second year, when they have field experience as well as classroom education under their belt, they will organize train-the-trainer programs. Each peer educator will commit to training an additional 10 peer educators.

3. **Support**. Treatment education is emotionally grueling and intellectually demanding. Many programs have failed because they have not offered support during the critical first years of work. This program will solve this problem in three ways:

   A. Continuing Education. The peer educators will reconvene for three advanced and intensive in-service trainings. These trainings will deepen their knowledge of all relevant issues, and keep them abreast of the latest scientific developments. Like the Treatment College, these update sessions will also feature final examinations, which participants will be required to pass.

   B. Mentoring. Each peer educator will be linked with a local mentor—a doctor, researcher, or experienced community treatment educator—who will commit to meeting with the peer educator regularly for two years. In addition, the mentor will be "on call" to answer questions during that period.

   C. Buddies. The program will link participants from the same city to form a peer-support "buddy" system. This will help participants avoid emotional "burn-out." It will also bolster their self-confidence as they work together to solve common problems.

While this program targets African Americans, it could serve as a pilot for other disenfranchised communities, such as Hispanics/Latinos.

This is a concept paper. While considerable research and planning have gone into it, this is a working document. The budget is provisional, as are some details of the program. The purpose of this paper is to explain the broad idea so that interested parties can decide how to contribute their resources and expertise.

This project was conceived by Phill Wilson, director of the University of Southern California AIDS Social Policy Archive and director of the AIDS Prevention Team of the National Black Gay and Lesbian Leadership Forum, which he founded. Mr. Wilson, who has been living with HIV for more than 15 years, has also served as the AIDS coordinator for the City of Los Angeles and as policy director for AIDS Project Los Angeles.

THE NEED

The facts about African Americans and AIDS are shocking. According to the federal Centers for Disease Control:

- Blacks comprise just 12 percent of the U.S. population but 40 percent of all AIDS cases. Blacks now account for more cases than any other racial group, whites included.

- For new cases of AIDS, the picture is even worse, with African Americans accounting for 43 percent of newly-diagnosed cases

- Blacks make up more than half of all cases among women, and more than 60 percent of all children with AIDS.

- Black men are seven times more likely to contract AIDS than white men, and black women are a staggering 20 times more likely than white women to get AIDS.

- Between 300,000 and 500,000 African Americans are estimated to be infected with HIV. More than 120,000 black Americans have died from AIDS. That's more than twice as many Americans, of all races, who died in the Vietnam War.

Based on these facts, leading black AIDS advocate Mario Cooper declared: "Except possibly for slavery, nothing in our history will have killed so many black people in such a short time as AIDS."

Combination therapy might help avert this dire fate—but only if aggressive action is taken to assure that African Americans benefit from the drugs. The new therapies have dramatically cut the death rate among all people with AIDS, African-Americans included. But a whole battery of studies document that blacks are benefiting less from these drugs, in large measure because they are not getting the drugs at all, or are getting them in substandard regimens. Consider the following:

- The CDC reports that AIDS deaths declined from 1995 to 1996 by 32 percent among whites, but only 13 percent among blacks.

- The New York City Health Department finds that death declines were about 20 percent less for blacks than for whites—and New York is widely considered to have one of the best public HIV care systems in the nation.

- A recent CDC study of more than 2000 AIDS patients found that blacks were much less likely than any other racial group to receive viral load tests. Proper use of combination therapy is impossible without monitoring viral load; therefore, access to viral load tests is a telling marker for overall access to quality care. In the study, 63 percent of white patients had received a viral load test but only 39 per cent of African Americans.

- In a study conducted by the Columbia University School of Public Health, a third of whites were receiving protease inhibitors, but only 12 percent of blacks. Clearly, blacks were less likely to be receiving the best therapies, but the study found another fact that is just as tragic: Blacks were more likely to be receiving no therapy whatsoever. More than half of the African Americans had never been on any antiretroviral medication; by contrast, only a third of whites had never been on therapy.

- The latest CDC mortality statistics are especially sobering: Even with the advances in therapy, AIDS remains the leading cause of death for blacks in the prime of their lives, age 25-44. Among men in this age group, AIDS takes more than twice as many lives as the second leading cause of death, homicide.

Many experts believe that the decline in death rates may soon level off. Mary Ann Chiasson, head of AIDS surveillance for the City of New York, says that AIDS deaths in that city appear to be stabilizing at six per day. Renslow Sherer, director of the AIDS Center at Chicago's Cook County Hospital, says that after a long decline, "We're starting to see a plateau" in the inpatient census. Partly, that's because only 60 percent of Cook County Hospital patients—most of whom are people of color—are on combination therapy. It would be tragic if the AIDS deaths leveled off in a way that left blacks to dying faster and more frequently than other races.

Look deeper, and there are more disturbing trends, especially for the long-term success of blacks who are lucky enough to receive therapy. The new drugs depend on adherence; in other words, they are effective *only* if taken on a strict schedule for years. Such adherence is not possible if patients are not prepared—intellectually, emotionally, and logistically. They also need to enlist the support of their family, friends, and medical providers. An individually-tailored, holistic treatment plan is essential for therapeutic success. Yet:

- A study from the University of Texas Health Science Center found that African Americans were half as likely as whites to discuss treatment options with their physicians.

These statistics are made vivid by the real-life stories of African Americans living with the disease. Jeannine M. Scott sought AIDS treatment in 1993. There was only one infectious disease clinic in her city of Wilmington, Delaware, and to see a doctor she would always have to wait at least an hour and a half. Sometimes she would just leave. When she stuck it out, "The doctor would see me for five minutes. He'd weigh me, take my vitals, and say, 'Here's more AZT.' I didn't feel comfortable asking questions, 'cause he was in a hurry to get me out." She also lacked the confidence to ask questions, considering her doctor "someone above me." When she left those appointments, "I felt angry with myself. I also felt helpless, very helpless. If I couldn't turn to my doctor, who could I turn to?"

Scott moved to Philadelphia, where she hooked up with an AIDS advocacy group. Now she makes her doctor explain everything to her "in words I can understand." For the drugs to work, this is the kind of transformation that must happen in patient after patient.

Unfortunately, there is a torrent of new patients. While death rates have dropped, infection rates have not. The CDC estimates that about 40,000 Americans get infected with HIV each year. That means between 16,000 and 20,000 African Americans contract the virus each year, or about two every hour.

Needle exchange has been shamefully neglected, dooming thousands of injection drug users—a disproportionate number of whom are black—to contract HIV. But even in communities with strong prevention programs, blacks have benefited least. For example, a survey of African-American gay and bisexual men in the San Francisco Bay Area found that more than half reported unprotected anal intercourse—a considerably higher percentage than among white gay men.

A plethora signs indicate that HIV will continue to infect African Americans at high rates. One of the strongest portents is the incidence of other sexually-transmitted diseases. According to the CDC, rates of gonorrhea in blacks are almost 32 times greater than in whites; for syphilis they are a whopping 50 times greater. Clearly, African Americans are going to continue to get HIV in very high numbers. Thus, the demand for high-quality treatment will not diminish, but will steeply increase.

BARRIERS TO CARE

In 1994, the CDC's *Morbidity and Mortality Weekly Report* succinctly explained why blacks suffer disproportionately from AIDS.

> Although race and ethnicity are not risk factors for HIV transmission, they are markers for underlying social, economic and cultural factors and personal behaviors that affect health. Socioeconomic status in particular is associated with premature morbidity and mortality. Unemployment, poverty and illiteracy are correlated with decreased access to health education, preventive services and medical care, resulting in an increased risk for disease. In 1992, 33 percent of Blacks and 29 percent of Hispanics lived below the federal poverty level, compared to 13 percent of Asian/Pacific Islanders and 10 percent of whites. Therefore, the social, economic, and cultural context of HIV infection should be considered when designing and implementing prevention (and care) programs . . .

The context of the passage above was prevention, but it applies with equal force to care. Many barriers block African Americans with HIV from accessing care, but the main ones are poverty, distrust, stigma, and lack of infrastructure.

Poverty

This document will not belabor the exhaustively-documented harms caused by poverty. But it is worth highlighting a recent CDC study of more than 2,000 HIV patients in three cities: Being on Medicaid—a clear marker for poverty—was a major predictor of substandard antiretroviral care. And African Americans are more likely to be poor than any other racial group.

Too often, poverty is conceptualized in terms of an individual: A particular person is poor, therefore he or she cannot afford good care. In fact, poverty is usually a communal phenomenon. Most poor people live in poor neighborhoods—for many urban African Americans, this means ghettos. When a person is trapped in the web of communal poverty, access to good care is especially difficult: There are fewer top hospitals and doctors, fewer information and education resources, fewer nearby ASOs (and certainly fewer well-funded ones). At the same time, there are more hassles—such as bad housing, higher crime, unemployment, and constant financial scrambling—that make it logistically and psychologically harder to take charge of one's health.

Unfortunately, a battery of studies shows that African Americans with HIV are most likely to be mired in communal poverty. For example, an epidemiological map of

New York, indicating which areas of the city are worst hit, shows that the South Bronx, Harlem, and East New York are epicenters of the city's epidemic. They are also three of the poorest neighborhoods, with extremely high minority populations. Similarly, a study from Los Angeles showed that living in a poor zip code was a very high predictor of contracting HIV.

One of poverty's main effects on people with HIV/AIDS is that it restricts their access to information about the disease. The internet, a major source of HIV information for middle-class white gay men, is rarely available to poor people. Basic literacy—not to mention familiarity with medical terminology—is often a problem, because schools in poor neighborhoods are often substandard. Thus newsletters, another major source of HIV information for gay white men, may be of limited value—not to mention that there are few which target African Americans. In addition, because African American ASOs are generally much smaller than their white gay counterparts, there is critical shortage of peer educators to conduct community forums or one-on-one counseling.

How severe is AIDS ignorance among African Americans? AZT is so well-known that it is featured in the lyrics of the Broadway musical *Rent*. But a study out of Los Angeles found that 12 percent of patients in a public health clinic, the vast majority of whom were people of color, had never even heard of AZT.

As for doctors—another major source of AIDS education—African Americans are more likely to receive care at a public hospital or clinic, where doctors are often overwhelmed, lacking the time to talk to patients. And there is a feedback loop: People without proper education and sense of self-worth will be less likely to risk appearing stupid by asking questions. Studies have documented that getting care from an experienced HIV specialist dramatically reduces the patient's risk of death—yet few such experts serve African American areas, especially poor ghettos. Indeed, many of the best doctors have set up private "consulting" practices, avoiding the restrictions of managed care, not to mention Medicaid. These doctors charge patients directly, effectively barring vast numbers of African Americans.

Finally, clinical trials—a source of state-of-the-art care for many gay men—have consistently enrolled low numbers of minorities. Few trials make a concerted effort to enroll African Americans. And black patients—often trapped in communal poverty, where their neighbors and peers are far less likely to hold professional jobs—lack the word-of-mouth network that enables many gay white men to learn about trials, good doctors, and advances in AIDS medicine.

Distrust

African American distrust of the medical establishment existed long before AIDS, but the epidemic has focused that mistrust. Emory University professor Steven Thomas has conducted numerous surveys. In a study of more than a thousand African

American church members, 35 percent believed that HIV was deployed by the government to genocidally destroy African Americans, and another 30 percent would not rule it out. Similarly, more than a third thought that HIV had been concocted in a germ-warfare laboratory—an opinion shared by 40 percent of black college students polled in Washington, DC. Another of Thomas's surveys found that 36 percent of black Americans thought the it "very likely" they would be used as guinea pigs; only 16 percent of whites felt the same.

These fears and opinions are rooted in very real history—and not only the infamous Tuskegee experiment, in which federally-funded investigators allowed black men with syphilis to die of the disease. Bloodbanks used to segregate blood given by blacks from that given by whites. Until the civil rights movement, southern hospitals were segregated—and white hospitals would turn away even critically ill African Americans. Forced sterilization—which occurred in this country until the 1970s—was inflicted disproportionately on blacks.

In the AIDS epidemic, blacks have been underrepresented in almost every clinical trial, which has fueled the notion that mainstream therapies are "white medicine." And, tragically, a 1991 study reported that AZT may have had "harmful" effects in black patients. Finally, there is a dearth of black physicians and researchers, which alienates many black patients.

Some African American leaders reinforce the distrust of mainstream medicine. On ABC's *20/20* in 1994, the Nation of Islam's Louis Farrakhan said, "Do you know where the AIDS virus was developed? Right outside of Washington. It is my feeling that the US government is deliberately spreading AIDS." The Nation of Islam still markets Kemron (alpha interferon), even though it has be proven to be ineffective, and the group actively discourages African Americans from using "white" medicine.

Farrakhan is certainly not representative of all African Americans, but distrust of and ambivalence toward mainstream medicine are real. However, the proven, undeniable success of combination therapy heralds a new opportunity for bringing African Americans into care.

Consider the story of one black AIDS activist, the Reverend Kwavena Rainey Cheeks, pastor of Interlight Unity Fellowship Church in Washington, DC. As recounted in *Positively Aware,* the newsletter of Test Positive Aware Network, a Chicago ASO, Cheeks was diagnosed with HIV in 1985. That same year, he founded Us Helping Us, an African American ASO that aggressively promoted alternative therapies and discouraged its clients from using AZT. But recently, when Cheeks himself lost 50 pounds after suffering successive bouts of PCP and CMV, he tried combination therapy. The drugs worked—his T-cells leapt by more than 160, his viral load went to undetectable, and he started training for a bicycle marathon. Recently, Cheeks appeared as a keynote speaker at a pharmaceutical company-sponsored

African American treatment conference in Oakland, California, where he talked about access to treatment, the value of the new drugs, and his journey into care.

Cheeks' story underscores the importance of peer educators. First, distrust of white medicine makes it imperative for medical information to be disseminated by black educators. But second, most peer educators trained in this program will themselves be HIV-positive. Thus, they will be able to back up their biological arguments with the power of personal testimony. In short, black Americans may have "healthy paranoia," but that distrust can be pierced by peer educators bearing news of truly effective drugs.

Stigma

Stigma interferes with care in two basic ways.

First, the health care system, dominated by white middle-class doctors, may not understand African American cultural norms. Some providers may deem African Americans—particularly IV drug users, or those who are homeless or incarcerated—as hard to deal with or even unworthy of treatment. Some doctors have reportedly been withholding combination therapy from patients based on superficial assessments of whether those patients will be able to adhere to the regimen. The CDC has found that injection drug users are more likely to receive substandard care than patients who acquired the virus sexually.

Second, stigma from within the community makes individuals with HIV afraid of seeking care. Having a lethal illness—especially an infectious one—carries a stigma on its own, turning people into pariahs. In addition, AIDS carries many more meanings, most negative. Men with HIV are assumed to be addicts or homosexuals; women with AIDS are presumed to be promiscuous or prostitutes. No wonder that, among case workers and activists, stories abound of blacks with HIV who do not seek care for fear that someone will see them walking into the clinic.

Here, too, peer educators can make a difference. By speaking openly of HIV, they can help mitigate the stigma. And since many will themselves be HIV-positive, they will provide positive role models for living successfully with HIV.

Indeed, merely seeing people with AIDS who are healthy can be a magnet into care for Africans Americans. Before effective therapies were developed, people with HIV usually sickened and died. The subliminal message was that having HIV was hopeless. But the new image of AIDS—personified by peer educators—is one of health, vitality, and hope.

Lack of Infrastructure

The problems listed above are severe, but not insurmountable. The cruelest twist, then, is that the African American community lacks the infrastructure to cope with AIDS.

There is a well-known shortage of African-American doctors and researchers, and despite long-standing epidemiological evidence that AIDS was becoming "blacker and browner," government contracts have continued to go to the largest ASOs, most of which are rooted in the gay white community.

Consider just one example: A recent report commissioned by the Pennsylvania Department of Health concluded that many people of color in Pennsylvania "do not have good access to care, information, clinical trials or related support services." Why? One of the main reasons is "the minimal amount of funding that people of color organizations receive for services and for improving their organizational capacities."

Indeed, most black ASOs are small. Located in poor neighborhoods, they lack a strong donor base. They must bid against better funded, more experienced white organizations. And many funders don't understand the African American community. The result? Many black ASOs flounder or fail. At least three went out of business last year.

In sum, African Americans face many imposing barriers to care and to information about AIDS. Even worse, there is an inadequate infrastructure to confront these problems.

PROGRAM PHILOSOPHY

Stated simply, the goal of this program is to bring African Americans with HIV/AIDS into care, and to improve the quality of care for those who are already receiving treatment.

In order to accomplish this goal, the program must address the key barriers that block African Americans from obtaining quality care. No program can be a panacea: Poverty will not vanish, and thousands of black doctors will not suddenly materialize. But there are pragmatic, workable strategies to greatly improve the HIV care of thousands of African Americans.

The best strategy is to arm patients with information about AIDS and current therapies so that they can begin to actively participate in their medical care. Patient information is always important, but it is arguably more important for HIV/AIDS than for any other disease. The available drugs do not cure AIDS. They merely make it "manageable"—and, ultimately, it is patients who are responsible for managing their illness. While doctors play a critical role, patients are the ones who must adhere to the regimen, swallowing up to 20 pills a day on a strict schedule, often with special dietary requirements. Patients also have to cope with side effects—which can include chronic diarrhea and nausea. They must navigate the maze of public-assistance benefits, which can stressful and overwhelming; they must be careful to avoid dangerous foods, such as raw eggs or contaminated water; and they must remember what secondary drugs cause harmful interactions whenever they receive medication from a doctor who isn't an HIV specialist.

In short, AIDS care is much, much more than prescribing combination therapy. It requires the active participation of the patient for many years, perhaps for life. Such involvement simply won't happen if patients don't understand *why* they need to shoulder these responsibilities. So patients need information—about the science and treatment of HIV, about practical ways to improve adherence in the context of their particular lives, and about many other related issues.

Unfortunately, those black Americans who don't actively mistrust the mainstream medical establishment often feel intimidated by it. Doctors are typically well-educated and well-heeled, whereas many African American AIDS patients are not. As Jeannine Scott, a person with AIDS, put it, patients see doctors as someone "above" them—so they're not likely to ask questions and learn what they need to know.

All this explains why peer education has been so successful: Education is critical for quality care, and peers are the best educators. A mountain of studies from many different contexts all show that peer education is effective—and this holds true for AIDS treatment education, too.

However, peer education can fail. Mainly, it can be torpedoed by inadequate training and support. Educating people about HIV is particularly difficult, for educators must master a large—and swiftly advancing—body of scientific knowledge, as well as knowledge about a wide variety of social issues that play an important role in the lives of their clients. Inevitably, they will encounter clients who ask questions to which they don't know the answers; the educators must have resources they can draw on to find those answers. Educators must also learn to cope with the emotional burden of dealing with a client population that is poor and struggling with many problems.

To ensure success, this program will accept only the most qualified and motivated applicants who have committed to the full two-year program. It will provide them with the best possible training, and it will require them to pass tests at each stage of that training. Finally, it will support participants through a working internship program that includes work supervision, continuing education, mentoring, and a peer-support buddy system.

THE PROGRAM

The African American AIDS Treatment Team will comprise 50 highly-trained peer educators who will bring African Americans with HIV/AIDS into care and help those patients already in care maximize their treatment. At least 60 percent of the peer educators will themselves be HIV-positive. Through train-the-trainer programs, each of these peer educators will commit to training an additional 10 educators.

Participants

In 15 of the top epicenter cities, the program will solicit applications from community-based counselors, advocates, and other individuals working in the field of HIV disease. (The cities are New York, Los Angeles, Chicago, Newark, Atlanta, Baltimore, Detroit, Washington, Oakland, Dallas, Jackson, San Francisco, St. Louis, Philadelphia, and Houston.) The program will be publicized through targeted advertising and by active recruitment through a network of selected ASOs that serve the African American community.

Each applicant will have to be sponsored by a community-based ASO, which will provide the first level of screening. In addition, the applicant will have to prepare an application packet which will include:

- Curriculum vitae, including education and work experience. Special emphasis will be placed on involvement in community-based AIDS work, either through paid employment or volunteer work.
- An essay explaining why the applicant wants to participate in the program, and what the applicant plans to accomplish for his or her community. The essay will help evaluate the written communication skills of the applicant.
- A brief and basic questionnaire about HIV science and treatment.
- Three letters of reference, with at least two from people working in the field of HIV.
- Applicants will be invited—but not required—to disclose their HIV status. Special consideration will be given to applicants who are HIV-positive.

The applications will be reviewed by an admissions committee comprising veteran community educators, doctors, and researchers. Finalists will be interviewed.

All participants must commit in writing to a two-year commitment that includes:

- The AIDS Treatment College
- Supervised field work with specific goals and requirements
- Continuing education through three update sessions
- Participation in mentoring and buddy programs

In addition, all participants must agree in writing that their participation in the program depends on achieving certain benchmarks throughout the two-year program. The AIDS Treatment College and each of the three update sessions will feature final examinations, which participants will be required to pass. In addition, their field work will be subject to the supervision of a certified ASO. These high standards will ensure that the program develops a cadre of superbly trained, highly motivated, and extremely effective educators.

The program will support 50 participants. However, additional participants may choose to attend the Treatment College. They will be required to pay a registration fee and cover their own travel and living expenses. These extra participants will also have to be accepted by the admissions committee.

AIDS Treatment College

For those applicants who are accepted, the first component of the program will be a month-long, intensive training called the AIDS Treatment College. It will be held on the campus of the University of Southern California (USC). Participants would be housed in the university dorms, thus lowering living expenses.

Overview

The College will be rigorous, like an AIDS education boot camp. To make sure that all students are fully prepared and get the most out of the experience, they will be assigned a College counselor, a faculty member who will live on campus with the students and whose job will be to shepherd students through the training program. No more than five students will be assigned to any one counselor. Each student will also be "buddied" with another student, from the same city if possible.

Before students arrive, they will have been sent introductory material, which they will be required to read. Buddies will meet each other, and the counselors will telephone their students (or meet in person, if they are in the same city) at least twice before the students arrive. During these pre-College phone calls, the counselor will identify

questions or concerns the student has. The counselor will also make sure the student understands the introductory material and that the buddies have met.

At the College, the counselors will meet with the students on a daily basis, track their performance on tests, tutor them in troublesome subjects (or arrange for tutoring if the subject is out of the counselor's area of expertise), and assist with any other needs that arise.

For each of the four weeks that the College is in session, Monday-Friday will be devoted to education on a variety of subjects. Saturday will be reserved for tutoring in subjects where students are having trouble, and Sunday will be a general free day, with optional group recreational activities.

The middle of last week will be devoted to final exams. These exams will include written and oral tests, a role-play in which a patient is counseled, and a one-hour treatment presentation. In order to graduate, students will have to score at least 85 percent on all these exams. The end of the final week will be used for tutoring students who fail to pass, and they will be retested. Students will also provide evaluations of the Treatment College and suggestions for how to improve it.

The College will conclude with graduation ceremonies, at which each student who passed the final exams will receive a diploma. These graduates will form the African American AIDS Treatment Team.

Faculty

Multi-disciplinary faculty will be recruited to develop the curriculum and teach at the College. Every effort will be made to recruit top researchers and doctors, such as Anthony Fauci, who has already agreed to commit his training expertise. In addition, at least 20 percent of the faculty will be African American—and here, too, top names will be sought, such as Houston doctor Keith Rawlings. A special effort will be made to ensure that all the counselors are African American, or at least people of color. While many of the faculty will be scientists or doctors, many will be experts in other areas, such as substance abuse treatment and HIV prevention. About a third will be veteran community educators from such organizations as Treatment Action Group (TAG), National Minority AIDS Council, AIDS Treatment News, and Project Inform.

At the college, there will be core faculty, who will teach over the entire one-month college, and visiting faculty, who will come for a short time. Faculty will be reimbursed accordingly. Many of the core faculty will live on campus with the students, and part of their job will be to tutor students during off-hours. Enough faculty will be hired to ensure a small student-teacher ratio.

All faculty, whether visiting or core, will agree to be available to graduates of the AIDS Treatment College for information and advice during the College *and afterwards.* The goal here is to create a lasting network of experts that the peer educators can rely on as they encounter questions and challenges in the field.

Individuals who have already agreed to serve on the AIDS Treatment College Faculty include:

- Researchers: Anthony Fauci
- Doctors: Keith Rawlings, Eric Goosby
- Community educators: Phill Wilson

Curriculum

A small, multidisciplinary team from the faculty will create the curriculum. It will cover topics such as the following:

- Basic biology of HIV disease and the immune system
- HIV treatment, including:
  - Principles of antiretroviral treatment
  - Specific drugs, including efficacy, drug-drug interactions, side effects, and on-going clinical trials
  - Pediatric treatment: principles and practice
- Adherence, including:
  - HIV resistance
  - Practical tips to help clients adhere
- Opportunistic infections, with an emphasis on prophylaxis and treatment
- Clinical trials, including:
  - Scientific theory, such as control arms, blinding, placebos, and ethics

  - Successful strategies to enroll African Americans

- Experimental therapies, including therapeutic vaccines, hydroxyurea, immune boosters such as IL2 or CD3 antibody, and new drugs such as integrase inhibitors and zinc-finger inhibitors

- Countering fringe AIDS theories, including:

  - How we know HIV is the cause of AIDS, and how to respond to the most common arguments that it is not

  - How we know that therapies like alpha interferon or DHEA don't work

- Practical peer-education advice, including:

  - How to outreach: venues and techniques

  - How to deal with challenging clients, such as those who are addicted, homeless, living in abusive situations, and those who have a history of non-adherence

  - Common questions and answers

- Epidemiology, including

  - How AIDS is affecting African Americans

  - What proportion of African Americans with AIDS acquired their infection through injection drug use, homosexual sex, heterosexual sex, or vertical transmission

  - The link between STDs and AIDS

- Substance abuse treatment, with an emphasis on:

  - Harm reduction techniques

  - The effect of drug abuse on the immune system and on other diseases

- Building self-esteem, including:

  - The link between self-esteem and adherence

  - Racism, homophobia, sexism, and negative stereotypes of addicts

  - The importance of non-judgmental, empathetic, client-focused education

- Optimizing the doctor-patient relationship, including:

  - How to find an HIV specialist

  - How to prepare for appointments

- Presentation skills, emphasizing

  - One-on-one counseling, including listening and trust-building skills

  - Public presentations

- Computer skills, including how to use the internet to obtain the latest HIV information

- Public assistance, including:

  - An overview of federal programs, such as ADAP and Ryan White

  - How to learn about state and local programs

  - How to learn how to link clients to local case management services

- HIV Prevention, including:

  - Vertical transmission and prophylaxis

  - The importance of HIV-positive people protecting themselves from other viruses, such as hepatitis and herpes

  - Safer sex guidelines, and how to negotiate safer sex

  - Safer drug use

In addition to the mandatory curriculum, there will also be the opportunity to "major" in particular elective fields, such as pediatric care, research advocacy, legislative issues, prevention, or substance abuse treatment.

The curriculum will be codified into a binder, including worksheets and self-tests, so that participants will have a comprehensive, written resource that they can refer to throughout their training and afterwards.

Education techniques will involve traditional lectures, multi-media presentations, small group seminars, and, where appropriate, role-playing.

Working Internships

Graduates of the AIDS Treatment College will immediately begin bringing African Americans with HIV/AIDS into care, through working internships at selected ASOs.

The ASOs will be responsible for supervising the treatment educators. They will manage them, provide administrative and logistical support, and log their accomplishments (for example, keep records of how many clients were served.)

Most of the peer educators will be employed by the ASOs, with their salaries split 50-50 between the ASO and this program. But some peer educators, especially those who are themselves HIV-positive, may want to volunteer rather than work for a salary, in order to preserve their health and public-assistance benefits. Either way, however, their work will be supervised and logged by the ASOs.

The ASOs will be chosen before the AIDS Treatment College begins, so that the peer educators can start their working internships immediately after graduation.

The ASOs will be selected through two separate processes, which together will guarantee placing the treatment educators. First, program organizers will select one or two highly-qualified, African American-based ASOs in each of the 15 target cities. These ASOs will have agreed to use graduates of the Treatment College as peer educators.

Second, a request for proposals (RFP) will be sent to all major ASOs serving the African American community in the target cities. The RFP will ask the ASOs to detail how they will use one or more of the peer educators who graduate from the Treatment College.

In either case, during the first year, the salary will be split 50-50 between the ASO and this program. In the second year, the ASO will assume responsibility for the full salary.

During the first year after graduation, peer educators will concentrate on educating African Americans with HIV/AIDS about treatment, adherence, the importance of getting into care, and so forth. They would accomplish this through:

- One-on-one counseling
- Community forums
- facilitating support groups
- Organizing treatment hotlines

They would find clients through outreach at venues such as:

- Public hospitals
- Community clinics
- STD clinics and HIV testing sites
- Substance-abuse centers
- Free clinics
- Homeless shelters

If each of the 50 peer educators shepherds just one person a week into care, then 2,500 African Americans will be brought into care during the first year alone. If each peer educator helps just one patient a week adhere to therapy for an extra six months, then they will probably have added 1,250 person-years of life to the African American community.

During the peer educators' second year, when they have had a year of experience and two additional update-training sessions under their belts, they would conduct train-the-trainer courses, using the AIDS Treatment College Curriculum. Each peer educator would commit to training a minimum of 10 additional peer educators. Thus, the graduating classes of the first two AIDS Treatment Colleges would train an additional 1,000 African American peer educators, an invaluable resource for an information-starved community.

Support

Treatment education is emotionally grueling and intellectually demanding. Especially during the first years, ongoing support is crucial. Many programs have failed because,

when the initial training program was completed, they left employees to sink or swim. Not this program. It will leverage the investment in the Treatment College through three kinds of on-going support: Continuing education, mentoring, and peer-support buddies.

Continuing Education

Graduates of the Treatment College will reconvene three times for in-service update training sessions. These will occur at 6, 12, and 24 months after the College. They will be structured as mini-versions of the original Treatment College: Students will receive intensive trainings by top faculty, and students will be required to pass tests on the material. These updates review key subjects, present new scientific and treatment information, and plan the next update session.

At months 12 and 24, the update session will coincide with the next class of the Treatment College. The experienced peer educators will receive an update session, and they will help train the next class of peer educators. At month 24, qualified graduates may be hired as full faculty members for the Treatment College.

Mentoring

Each graduate of the Treatment College will be linked with a doctor, researcher, or veteran community educator in the graduate's home city. It is expected that most mentors will have also served as faculty, to enhance continuity. Mentors will commit to meeting regularly with their peer educators. Mentors would also agree to be "on call" to answer any questions the peer educator might have. Finally, the mentor will complete a quarterly progress report.

Buddies

Countless studies have documented the power of peer-support to help people learn, work productively, and, in short, maximize their effectiveness. The buddies formed during Treatment College will continue to work together during the two-year internship program. They will commit to meeting once a month for both years, and they will each submit quarterly reports on what they have learned from each other, which will help in program evaluation. In the second year, buddies will be urged to work together on the train-the-trainer program.

CONCLUSION

This program attacks one of the main challenges of the AIDS epidemic—bringing African Americans into care. So great is this challenge that the President has identified it as one of the six most important racial health-care gaps, launching a billion-dollar public-private initiative to close it. This program can play a major part in that endeavor.

Finally there are other communities that also need special attention. This program could serve as a pilot program for other marginalized populations, such as Hispanics/Latinos (especially those who do not speak English) and Native Americans. We therefore that observers participate in the first Treatment College, so that they might create similar programs.

END

Budget Summary
and
Budgets for Management and Internship Matching Grants

Budget Summary		
Description	**Cost**	**Total Cost**
YEAR ONE		
Management	$175,000	
AIDS Treatment College	$470,650	
Internship Matching Grants	$750,000	
6-Month Update Training Session	$73,710	
12-Month Update Training Session	$113,790	
TOTAL YEAR ONE PROGRAM COST		$1,583,150
YEAR TWO		
Management	$175,000	
Second AIDS Treatment College	$470,650	
Internship Matching Grants (for grads of 2nd Treatment College)	$750,000	
6-Month Update Training Session (for grads of 2nd Treatment College)	$73,710	
12-Month Update Training Session (for grads of 2nd Treatment College)	$113,790	
24-Month Update Training Session (for grads of 1st Treatment College)	$113,790	
TOTAL YEAR TWO PROGRAM COST		$1,696,940
Management		
One program director, full-time	$50,000	
One meeting planner, full-time	$25,000	
One Administrative assistant,, part-time	$20,000	
Payroll, health insurance, etc.	$20,000	
Two program consultants	$12,000	
One fiscal agent	$10,000	
Office equipment (computers, fax, copier) and supplies	$20,000	
Rent ($1,500 per month)	$18,000	
Total Managment Cost		$175,000
Working Internship Matching Grants		
(Half of first-year salary)		
50 interns @ $15,000	$750,000	$750,000

NOTE: These budgets are provisional

Budget for the AIDS Treatment College

Description	Cost	Total Cost
Advertising & Recruitment		
15 cities, $10,000 per city	$150,000	$150,000
Materials		
Design (logo, letterhead, signage, binders, etc.)	$6,000	
Printing	$10,000	
Postage	$5,000	
Total Materials		$21,000
Audio Visual		
Projectors, screens, video, audio, technical time	$15,000	$15,000
Classroom Rental		
University classrooms	$5,000	$5,000
Curriculum Development		
6 faculty @ $500 per person	$3,000	$3,000
Honoraria		
(Visiting faculty: $200 per day. Core faculty: $300 per day)		
8 visiting faculty for 3 days	$4,800	
4 visiting faculty for 5 days	$4,000	
4 visiting faculty for 12 days	$9,600	
10core faculty for 28 days	$84,000	
Total honoraria		$102,400
Travel		
(Air: one round-trip coach ticket)		
25 students @ $700 each	$17,500	
25 students @ $400 each	$10,000	
13 faculty @ $700 each	$9,100	
13 faculty @ $400 each	$5,200	
4 staff @ 700	$2,800	
Ground transfers: 80 people @ $30 each	$2,400	
Total Travel		$47,000
Accommodations		
(University dorm rooms: $30 per day, per person)		
50 students for 28 nights	$42,000	
8 faculty for 3 nights	$720	
4 faculty for 5 nights	$600	
4 faculty for 12 nights	$1,440	
10 faculty for 28 nights	$8,400	
4 staff for 32 nights	$3,840	
Total Accomodations		$57,000

NOTE: This budget is provisional

Budget for the AIDS Treatment College

Meals		
($35 per day per person)		
50 students for 28 days	$49,000	
8 faculty for 3 days	$840	
4 faculty for 5 days	$700	
4 faculty for 12 days	$1,680	
10 faculty for 28 days	$9,800	
4 staff for 32 days	$4,480	
Graduation banquet: 75 people at $50 per person	$3,750	
Total Meals		$70,250
TOTAL TREATMENT COLLEGE COST		**$470,650**

NOTE: This budget is provisional

Budget for the 6-Month Update Training

NOTE: The 6-month update will last for four days.

Description	Cost	Total Cost
Materials		
Design (logo, signage, binders, etc.)	$2,000	
Printing	$5,000	
Postage	$2,500	
Total Materials		$9,500
Audio Visual		
Projectors, screens, video, audio, technical time	$5,000	$5,000
Classroom Rental		
University classrooms	$1,500	$1,500
Curriculum Development		
3 faculty @ $250 per person	$750	$750
Honoraria		
(All honoraria: $200 per day)		
6 faculty for 4 days	$4,800	$4,800
Travel		
(Air: one round-trip coach ticket)		
25 students @ $700 each	$17,500	
25 students @ $400 each	$10,000	
6 faculty @ $700 each	$4,200	
4 staff @ 700	$2,800	
Ground transfers: 60 people @ $30 each	$1,800	
Total Travel		$36,300
Accommodations		
(University dorm rooms: $30 per day, per person)		
50 students for 4 nights	$6,000	
6 faculty for 4 nights	$720	
4 staff for 5 nights	$600	
Total Accomodations		$7,320
Meals		
($35 per day per person)		
50 students for 4 days	$7,000	
6 faculty for 4 days	$840	
4 staff for 5 days	$700	
Total Meals		$8,540
TOTAL 6-MONTH UPDATE COST		**$73,710**

NOTE: This budget is provisional

Budget for the 12-Month Update Training

NOTE: The 12-month update will coincide with the second Treatment College. First-year graduages will spend one week participating in their own update training, and one week tutoring the new Treatment College students.

Description	Cost	Total Cost
Materials		
Design (logo, signage, binders, etc.)	$2,000	
Printing	$5,000	
Postage	$2,500	
Total Materials		$9,500
Audio Visual		
Projectors, screens, video, audio, technical time	$5,000	$5,000
Classroom Rental		
University classrooms	$2,500	$2,500
Curriculum Development		
3 faculty @ $250 per person	$750	$750
Honoraria		
(All honoraria: $200 per day)		
8 faculty for 5 days	$8,000	$8,000
Travel		
(Air: one round-trip coach ticket)		
25 students @ $700 each	$17,500	
25 students @ $400 each	$10,000	
8 faculty @ $700 each	$5,600	
2 staff @ 700	$1,400	
Ground transfers: 60 people @ $30 each	$1,800	
Total Travel		$36,300
Accommodations		
(University dorm rooms: $30 per day, per person)		
50 students for 14 nights	$21,000	
8 faculty for 5 nights	$1,200	
2 staff for 28 nights	$1,680	
Total Accomodations		$23,880
Meals		
($35 per day per person)		
50 students for 14 days	$24,500	
8 faculty for 5 days	$1,400	
2 staff for 28 days	$1,960	
Total Meals		$27,860
TOTAL 12-MONTH UPDATE COST		**$113,790**

NOTE: This budget is provisional

Budget for the 24-Month Update Training

NOTE: The 24-month update will coincide with the third Treatment College. First-year and second-year graduates will spend one week recieving their own update training, and one week tutoring the new Treatment College students.

Description	Cost	Total Cost
Materials		
Design (logo, signage, binders, etc.)	$2,000	
Printing	$5,000	
Postage	$2,500	
Total Materials		$9,500
Audio Visual		
Projectors, screens, video, audio, technical time	$5,000	$5,000
Classroom Rental		
University classrooms	$2,500	$2,500
Curriculum Development		
3 faculty @ $250 per person	$750	$750
Honoraria		
(All honoraria: $200 per day)		
8 faculty for 5 days	$8,000	$8,000
Travel		
(Air: one round-trip coach ticket)		
25 students @ $700 each	$17,500	
25 students @ $400 each	$10,000	
8 faculty @ $700 each	$5,600	
2 staff @ 700	$1,400	
Ground transfers: 60 people @ $30 each	$1,800	
Total Travel		$36,300
Accommodations		
(University dorm rooms: $30 per day, per person)		
50 students for 14 nights	$21,000	
8 faculty for 5 nights	$1,200	
2 staff for 28 nights	$1,680	
Total Accomodations		$23,880
Meals		
($35 per day per person)		
50 students for 14 days	$24,500	
8 faculty for 5 days	$1,400	
2 staff for 28 days	$1,960	
Total Meals		$27,860
TOTAL 24-MONTH UPDATE COST		**$113,790**

NOTE: This budget is provisional

Data Entry Form

Letter ID	Writer First Name	Writer Last Name	Received Date	Subject
10607	Richard	Gordon	3/9/98	Meeting Aids Action 3/11

√ Response Required?

Response Type	Response Date	Responder ID	Responder Name	Action Promised
			TSummers	

Action Completed	Action Date	Addressed To

Notes

meeting to take place 9:30 to 10:30 at the AIDS Action Council 1875 Connecticut ave

Sender's Organization	Sender's Street1	Sender's Street2
Att. Gen Harshbarger		

Sender's City	Sender's State	Sender's Zip
Boston		

Scott Harshbarger
GOVERNOR ✶ 98

March 5, 1998

Mr. Todd Summers
Deputy Director
White House Office of National AIDS Policy
808 17th Street NW, Suite 820
Washington, DC 20006

Dear Mr. Summers,

Please join Massachusetts Attorney General Scott Harshbarger and other leaders of national gay and lesbian and AIDS organizations on Wednesday, March 11, 1998, from 9:30 to 10:30 a.m. at the Aids Action Council, 1875 Connecticut Avenue NW, Suite 700. Scott would like to meet with you to discuss issues that concern the gay and AIDS communities and how he can continue to have a national impact on these issues as Governor of Massachusetts.

I have enclosed for your review copies of Scott's record on gay and lesbian and disability issues, as well as a news release issued today regarding the Attorney General's support for the Hate Crimes Prevention Act of 1998.

Please feel free to call me at the number below if you have any questions or concerns, and to let me know if you will attend the meeting on March 11th. I look forward to seeing you next week.

Sincerely,

Richard I. Gordon
(617) 482-8710

Enclosures

148 State Street, 2nd Floor • Boston, MA 02109 ✶ Tel: (617) 725-1998 ✶ Fax: (617) 725-2819 ✶ Mailing Address: P.O. Box 9042 • Boston, MA 02114

SCOTT HARSHBARGER
ATTORNEY GENERAL
(617) 727-2200

The Commonwealth of Massachusetts
Office of the Attorney General
One Ashburton Place
Boston, MA 02108-1698

NEWS RELEASE

FOR IMMEDIATE RELEASE
MARCH 4, 1998

CONTACT: DEBBIE BANDA
(617) 727-2543

HARSHBARGER, 21 A.G.s URGE CONGRESS TO STRENGTHEN FEDERAL HATE CRIMES LAW

Attorney General Scott Harshbarger and 21 other attorneys general today called on the U.S. Senate to strengthen the federal law against hate crimes to include protection for people who are victimized because of their gender, sexual orientation or disability.

In a letter to Senators Orrin Hatch, R-Utah, and Patrick Leahy, D-Vermont, chairman and ranking Democrat, respectively, of the Senate Judiciary Committee, Harshbarger and the other attorneys general express their enthusiastic support for Senate Bill No. 1529, the Hate Crime Prevention Act of 1998.

"An expanded federal role in investigating and prosecuting serious forms of hate crimes is critically needed if we are to be successful in addressing and deterring these crimes in our nation," said Harshbarger, who drafted the letter to Leahy and Hatch.

"Although most states have responded to the rising tide of hate crimes by enacting state criminal civil rights laws, a number of states do not have laws addressing violence based on the victim's gender, sexual orientation or disability. The Hate Crimes Prevention Act of 1998 is a necessary supplement to state hate crime enforcement efforts to address bias-motivated victimization," Harshbarger added.

Current federal hate crimes law only offers protection for individuals based on race, color, religion or national origin.

(more)

In Massachusetts, gender, sexual orientation and disability are also protected categories under various criminal civil rights statutes.

The bill also allows federal funding for state and local programs designed to combat hate crimes committed by juveniles and directs the U.S. Sentencing Commission to study and, if appropriate, implement increases in penalties for adults who recruit juveniles to commit hate crimes.

In addition to Harshbarger, who is immediate past-president of the National Association of Attorneys General, the letter was signed by the attorneys general of Arizona, Connecticut, Florida, Maine, Maryland, Minnesota, Mississippi, Montana, Nevada, New Hampshire, New Jersey, North Dakota, Oklahoma, Rhode Island, Texas, Vermont, Washington, West Virginia and Wisconsin, plus Guam and Puerto Rico.

(end)

Community Education to Increase Understanding of and Compliance with Disability Rights Laws

Based upon the notion that most businesses and governmental agencies want to do the right thing, the Disability Rights Project has strongly emphasized community education. Project staff have participated in numerous seminars and trainings and published many booklets on the legal rights of individuals with disabilities. In addition, as industry-specific problems are identified, the Project has issued legal advisories to maximize compliance with the law. Such advisories have been directed to:

- The funeral home industry, informing them that they may not refuse to provide funeral services to people who have died of AIDS, nor assess a surcharge for such services;
- All institutions of higher education in Massachusetts, informing them that they may not ask questions concerning an applicant's physical or mental disability on their applications;
- Working jointly with the Department of Justice, Attorney General Harshbarger sent an advisory to the retail store and restaurant industries, explaining the legal rights of individuals who use service animals;
- Employers' organizations, informing them of the nondiscrimination requirements of state and federal law as they pertain to employees with serious illnesses, such as cancer and AIDS; and
- Cities and towns, discussing the legal principles concerning "handicapped" plates and placards.

This brochure is available in alternative formats.

Printed in-house.

Scott Harshbarger for Governor
148 State Street
Boston, MA 02109
(617) 725-1998

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SCOTT HARSHBARGER

Safeguarding The Rights of Individuals with Disabilities

As Attorney General, Scott Harshbarger has used the full range and power of his Office to protect the legal rights of Massachusetts citizens with disabilities.

Within months of being sworn in as Attorney General, Scott Harshbarger, along with the Director of the Massachusetts Office on Disability, sent a letter to every city and town in Massachusetts, informing them that they were required to hold their meetings in accessible locations. The letter predated the effective date of Title II of the ADA, and resulted in many municipalities either renovating their town halls or moving their meetings to accessible locations.

In June 1993, recognizing the need for a strong state-level enforcement effort, Scott Harshbarger established the **Disability Rights Project** within his Civil Rights Division, underscoring the point that **disability rights are civil rights.** As the first such project, it serves as a national model for other states. Working in partnership with the disability community, the Project has accomplished significant results in each of its three priority areas.

Ensuring that Businesses are Fully Accessible to Individuals with Disabilities

Physical Access

- Brought suit against a major hotel and trade center for widespread violations of state and federal access laws. Obtained a court order which required the defendants to remedy more than 80 violations within a strict time line and to pay $10,000 to the state for the production of consumer information materials in accessible formats;
- Achieved a far reaching settlement with a major food store chain which required it to remedy access violations in all of their newly built stores, resulting in a new standard of physical accessibility for the food store industry;
- Required several regional bus companies to change their policies and practices to ensure that they make lift-equipped buses available and provide appropriate accommodations for passengers with physical and visual impairments;
- Reached an agreement with a newly built theme park to ensure that all of its rides and attractions are fully accessible to patrons with disabilities.

Communication Access

- Negotiated a settlement with New England Telephone which required that the company install TTYs in each of its 21 customer service centers throughout its five-state service area;
- Secured settlement agreements with several movie theaters and live theaters to install assistive listening devices;
- Required a summer camp to hire a sign language interpreter for a camper who needed interpreter services to attend her local camp;
- Prosecuted a complaint against MCI for its failure to properly operate the Massachusetts Relay Service.

Protecting the right of Individuals with Disabilities to Live in the Community of their Choice

Scott Harshbarger filed a friend of the court brief in the United States Supreme Court on behalf of Massachusetts and 12 other states, arguing that the federal Fair Housing Act (FHA) must be liberally interpreted to ensure that local zoning ordinances are not used to exclude residences for individuals with disabilities. The Supreme Court's decision, which was its first consideration of the FHA after individuals with disabilities were included as a protected category, was a significant victory for the disability community.

In more than eighteen instances where local officials or neighbors attempted to block housing for people with disabilities, the Attorney General's Disability Rights Project successfully intervened to safeguard the right of individuals with disabilities to live in the neighborhood of their choice. The following are examples of such housing:

- A hospice for individuals with AIDS in Fall River;
- A residence for people with mental illness on the Cape;
- A house for young people with emotional disabilities on the North Shore;
- A mixed-use facility, containing one-bedroom condominiums for people with AIDS, individuals with mental impairments, and the working poor;
- A nursing home for individuals with mental disabilities in a western suburb of Boston;
- A residence for individuals with mental disabilities on the South Shore threatened with the imposition of onerous safety requirements not applied to other residences;
- A residence for individuals with mental retardation on the South Shore which needed a reasonable modification of the local zoning requirements in order to comply with licensing requirements;
- An apartment in Arlington in which a group of young tenants with disabilities wished to live, but, whose landlord attempted to renege on his agreement to rent to them; and
- A building which was to be used for housing for individuals with mental disabilities that a city on the North Shore refused to remove from its demolition list -- despite a developer being willing and able to rehabilitate the property.

In addition, Scott Harshbarger's Civil Rights Division has filed suit on behalf of individuals with disabilities who experienced housing discrimination due to landlords' unwillingness to afford a reasonable accommodation -- such as the installation of a ramp, or modifying a no-pet policy -- which were needed for individuals with disabilities to enjoy an equal housing opportunity.

Ensuring Full and Equal Access to Municipal Meetings and Services

Building upon the May 1991 letter, which notified every Massachusetts municipality that their public meetings had to be held in accessible locations, the Disability Rights Project expanded this effort to address not only physical access, but also communication access, and not only municipal meetings but the full range of municipal services. The Project has successfully resolved more than three dozen municipal access complaints.

Combating Hate Crimes Against Individuals with Disabilities

Harshbarger's Civil Rights Division has brought cases under the Massachusetts Civil Rights Act to obtain injunctions to protect individuals with disabilities, including:

- A woman with a visual impairment who was verbally assaulted, and whose guide dog was injured, by a taxicab driver; and
- Two men in Provincetown who were subjected to violence, harassment and property damage based upon their HIV/AIDS status.
- With strong leadership from Attorney General Harshbarger, the Legislature passed an amendment to the civil rights statute to include disability as a protected category, increase criminal penalties for violations, and provide financial restitution directly to victims.

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SCOTT HARSHBARGER

6/3.

SCOTT HARSHBARGER

PROTECTING THE RIGHTS OF LESBIAN AND GAY CITIZENS

Did you know that Scott Harshbarger spoke on the State House steps during Gay Pride week in June, 1991, about the importance of protecting the rights of gay and lesbian citizens?

Are you aware that Scott Harshbarger has supported such initiatives as domestic partner benefits for gay and lesbian public sector employees, the repeal of archaic sex laws, establishing gay/straight alliances in all of our public schools and protecting people with HIV/AIDS from fraud and abuse?

Did you know that the Supreme Judicial Court of Massachusetts recently relied on Scott Harshbarger's position in support of a lesbian couple's right to adopt a child?

If you answered "No" **to any of these questions, then there is probably a lot more about Scott Harshbarger that you don't know. Here is just a selection of Scott Harshbarger's record on behalf of the lesbian and gay community. . . .**

APeB
AIDS Project East Bay

March 2, 1998

Todd Summers, Deputy Director
Ofifce of National AIDS Policy
808-17th Street, N.W. #820
Washington, DC 20006

Dear Mr. Summers,

I would like to take a moment to thank you for speaking at the ACA's "Empowering the African American Community Treatment Awareness Conference" on February 26, 1998.

I want you to know that I really appreciate the fact that within your busy schedule you were able to make yourself available to this project. Your involvement added to what resulted in being one of the most successful HIV/AIDS "client targeted" conferences presented in Alameda County.

On the behalf of our clients, service providers, family and friends, all of whom were empowered by your words, I would like to extend my deepest gratitude.

Thank You Very Much !!!!

Bill Stewart/Treatment Advocate

651 20th Street • Oakland, CA 94612 • Phone: 510.834.8181 • Fax: 510.834.0442

Data Entry Form

Letter ID	Writer First Name	Writer Last Name	Received Date	Subject
10660	John	Barnes	3/31/98	ANSA

☐ Response Required?

Response Type	Response Date	Responder ID	Responder Name	Action Promised

Action Completed	Action Date	Addressed To

Notes

Sender's Organization	Sender's Street1	Sender's Street2
AIDS Nutrition Services Allian		

Sender's City	Sender's State	Sender's Zip

File
Corres

ANSA
AIDS Nutrition Services Alliance

March 30, 1998

Todd Summers
White House Office
On National AIDS Policy
808 17 Street NW, Suite 820
Washington, DC 20006

Via fax, 202 632 1096
1 page total
original to follow by mail

Dear Mr. Summers,

This letter is to introduce a newly incorporated, non-profit organization: the AIDS Nutrition Services Alliance (ANSA). Formed by a group of community-based AIDS nutrition programs, ANSA provides a vital link among providers in the US and abroad. ANSA's primary goals are to provide information sharing, technical assistance, education and advocacy.

This September, ANSA will produce its fifth annual HIV nutrition conference to be held in San Francisco. Also this year, ANSA will launch its national newsletter and website, in order to further enhance networking among HIV nutrition providers.

As you are no doubt aware, the role of the AIDS nutrition provider is evolving rapidly. In just a few short years, our purpose has gone from comforting the dying, to providing a critical co-therapy in the fight against AIDS. In these rapidly changing times, the role of ANSA is more critical than ever -- helping agencies to brainstorm, share hard-learned lessons, and chart the course for the future.

On Monday, May 18, 1998, ANSA's Board of Directors will be in DC for a planning meeting. We would like to invite Ms. Thurman to have lunch with us at the Crowne Plaza at noon.

ANSA is comprised of a wide variety of organizations – geographically, financially, and programmatically. From God's Love We Deliver, in New York City, to the Care Coordination Team, in Wichita Kansas; from nutrition-focused meal providers to multi-service AIDS organizations with food cupboards, the common threads of ANSA member agencies are their commitment to nourishing people with AIDS, and their recognition of the benefits of networking with colleagues.

All of our member organizations provide vital, life-sustaining services to persons living with HIV. I am certain they would be thrilled to have an opportunity to hear from Ms. Thurman about her agenda for HIV related services. We hope she will join us on May 18, and look forward to your response.

Warmest regards,

John L. Barnes
Executive Director

John L. Gile
Board Chair

1400 I Street NW • Suite 1220 • Washington, DC 20005-2208
(202) 289-5650 phone (202) 842-3323 fax ANSAoffice@aol.com email

Joseph J. D'Amour, Esq.
Springfield Mayor Michael J. Albano's Liaison
to the Gay Community
NEW Tel. 413-592-9440 FAX 413-592-9435

COVER SHEET

To: TODD SUMMERS
From: Joseph J. D'Amour
Date: March 8, 1998
RE: AIDS REPORT

ANNUAL AIDS REPORT	one

AIDS, HOMOPHOBIA AND SPRINGFIELD: *'UNHOLY ALLIANCE'*

* plus cover

SPRINGFIELD MAYOR MICHAEL J. ALBANO'S AIDS LEGACY

- 25TH HIGHEST AIDS INFECTION RATE IN THE NATION;
- MARKET FOR THE CHEAPEST AND PUREST HEROIN IN THE WORLD;
- 55% OF AIDS CASES FROM SHARED DIRTY NEEDLES BY HEROIN ADDICTS;
- MAYOR AND CITY COUNCIL OPPOSE CLEAN NEEDLE EXCHANGE PILOT PROGRAM DESPITE POPULAR SUPPORT. MAYOR WON'T SIGN ORDER;
- CITY RECEIVES NO FEDERAL 'TITLE I' FUNDS UNDER THE RYAN WHITE CARE ACT (HARTFORD GETS $2.67 MILLION EVERY YEAR);
- MAYOR APPOINTS 'WINDOW DRESSING' AIDS ADVISORY BOARDS WHICH NEVER PRODUCE REPORTS;
- MAYOR'S HEALTH DIRECTOR INEFFECTUAL;
- MAYOR SAYS 'THE FACTS DON'T MATTER';
- MAYOR PROMISES REP. DENNIS MURPHY THAT HE WILL KILL ALL EFFORTS TO REVIVE CLEAN NEEDLE ORDINANCE; ###

PhillTracy@aol.com
03/23/99 03:48:17 PM

Record Type: Record

To: Todd A. Summers/OPD/EOP

cc:
Subject: Fwd: White House delegation to Africa

Todd-
I thought you should see this. I think it's right on the money. I don't know what can be done at this late date. But I think it's worth the fight. After all this is the second trip in just a few months. Were there any pwa's included in the first delegation. Why couldn't USAID (or who ever is covering the cost for the members) cover the cost of a pwa to join the delegation? There's got to be some pwa in DC who could pass the security stuff and fits the bill of "the caliber to
participate in a presidential delegation." Whatever that means. Good luck
phill
In a message dated 3/23/99 12:21:35 PM, Savrett writes:

<< FYI -
The White House-sponsored delegation on AIDS in Africa, due to leave for Africa this Saturday will be including no community rep and no PWA on the trip.
The White House says it is not trying to exclude anyone from participating, but the trip was "not designed in a way to have NGO participation".
The Africa trip is designed to "get Congressional leaders on board" (on board for what? asking for smaller increases in global AIDS funding like the White House does?!?) and is to focus on Orphans issues (after all, most of our NGOs are only concerned with gay and other un-PC communities that we wouldn't have anything to offer....).
After stalling for weeks on community representation, the White House AIDS office offered this week that if a community representative "from a major NGO or community AIDS organization" would like to be considered before Saturday by the White House AIDS Office for participation in the delegation, their costs for travel ($7,500) would not be covered by the White House, they must pass all security and other clearances before departure, and they must be "of the caliber to
participate in a presidential delegation."
Another stellar example of the ways the White House is making an effort to include community. >>

Return-path: <Savrett@aol.com>
Date: Tue, 23 Mar 1999 15:21:35 EST
From: Savrett@aol.com