Extending the Reach of the Ryan White CARE Act:
The Minority AIDS Initiative

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Dear Friends:

On behalf of the National Minority AIDS Council, I am pleased to share with you this report, *Extending the Reach of the Ryan White CARE Act: The Minority AIDS Initiative*. The report highlights the extraordinary work that sixteen community-based organizations and states have been able to accomplish with support from the Minority AIDS Initiative (MAI) through the Ryan White CARE Act.

Our nation has made remarkable progress in combating HIV/AIDS in the past 20 years. However, the dynamic nature of this evolving epidemic presents complex challenges and requires intensified efforts to respond effectively. The disproportionate impact of HIV/AIDS on communities of color is not a new phenomenon. The trends in HIV/AIDS over the last decade clearly reflect a growing burden on ethnic and racial minorities. Consider these facts:

- People of color made up 58% of the cumulative AIDS cases and 70% of the new AIDS cases reported to the CDC at the end of 2001.
- Men of color accounted for 65% of the new AIDS cases reported among men.
- Women of color made up 81% of new AIDS cases reported among women.

First funded by the U.S. Congress in 1999, the MAI has been a critical tool for addressing the complex and expanding HIV/AIDS epidemic among communities of color. The MAI was developed by the Congressional Black Caucus, with the critical support of the Congressional Hispanic and Asian Pacific American Caucuses, to target funds to eliminate the persistent HIV/AIDS-related health disparities among ethnic and racial minorities. Now in its 4th year of funding, it is critical that as community we work to sustain and build upon its initial efforts to more fully address the health care needs of people of color living with and affected by HIV/AIDS.

NMAC was established in 1987 to promote and mobilize leadership within communities of color to combat HIV/AIDS. We work to strengthen the capacity and infrastructure of minority community-based organizations and to promote sound, national HIV/AIDS policies that are responsive to the unique needs of these communities. We hope that as you work to meet the needs of your community, this report will provide you greater insight into the kinds of success the MAI can produce.

Yours in the struggle,

Paul A. Kawata
Executive Director
Dear Reader:

It gives me great pleasure to present the enclosed report entitled *Extending the Reach of the Ryan White CARE Act: The Minority AIDS Initiative*. The report summarizes the history of the Minority AIDS Initiative (MAI) and highlights the work of several Ryan White Comprehensive AIDS Resources Emergency (CARE) Act grantees who have worked to fulfill its vision.

The Health Resources and Services Administration's HIV/AIDS Bureau (HAB) maintains its long standing commitment to addressing the needs of communities most severely impacted by HIV/AIDS. Recent surveillance data from the Centers for Disease Control and Prevention (2001) show that racial and ethnic minorities represent about 60 percent of newly reported AIDS cases. Responsive to changes in the epidemic, CARE Act funded programs in 2002 served over 70 percent persons of color.

Our commitment to addressing disparities in HIV/AIDS is strengthened by MAI funding.

Since 1999, Congress has appropriated MAI funding to the various Titles and programs of the CARE Act to increase the availability of medications, primary care, support services, and outreach services to communities of color. The AIDS Education and Training Centers program under Part F of the CARE Act, also receives funds to increase professional training opportunities for minority clinicians caring for people living with HIV/AIDS. In addition, the Secretary of Health and Human Services has allocated HAB additional MAI funding each year to increase the skills and capacity of community based organizations, support service providers, and consumers working to respond to this epidemic.

We are very proud of the grantees featured in this report. They are just a sample of the many MAI-funded CARE Act programs across the United States and surrounding territories working to address the HIV-related needs in our communities.

Sincerely,

Deborah L. Parham, Ph.D., R.N.
Associate Administrator
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HIV/AIDS in Communities of Color

People of color in the United States have been affected disproportionately by HIV/AIDS since the earliest years of the epidemic; however, this trend has grown significantly worse over time. In December 1985, 25% and 14% of cumulative AIDS cases were reported among African Americans and Latinos, respectively. In 1996, the proportion of AIDS cases among African Americans surpassed those among whites for the first time. And in 2001, African Americans and Latinos represented an alarming 49% and 19% of newly reported AIDS cases, respectively. Together, Asian/Pacific Islanders and American Indians (Alaskan Natives) represent another 1–2% of new AIDS cases. (See Table 1)

The particularly severe impact of HIV in African American and Latino communities in the U.S. is seen in all major transmission categories. Men who have sex with men (MSM) continue to represent the largest proportion of reported AIDS cases within these two groups, with young MSM of color demonstrating alarmingly high rates of new infections. Among men of color, injection drug use is the second largest risk factor. Among adult and adolescent women, who represent a growing proportion of new AIDS cases in the U.S., African Americans and Latinas represent 63% and 17% of newly reported cases in 2001, respectively. Similarly, of the 175 children with AIDS reported in 2001, 65% were African American and 15% were Latino.

The Ryan White CARE Act: A Cornerstone in America’s Response to HIV/AIDS

Next to Medicaid and Medicare, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act represents the largest source of Federal funding for HIV care in the United States. The Health Resources and Services Administration’s HIV/AIDS Bureau (HRSA/HAB) administers the many programs of the CARE Act, currently funded at $1.9 billion. The CARE Act was created in 1990 and named after Ryan White, an Indiana teenager whose courageous struggle with HIV/AIDS and against AIDS-related discrimination helped

| Table 1. Comparison of New AIDS Cases and U.S. Population by Race/Ethnicity, 2001 |
|---------------------------------------------|-----------------|--------------------|
| % of U.S. Population | % of New AIDS Cases |
| White | 69.0 | 30.7 |
| Latino | 13.0 | 19.0 |
| African American | 12.7 | 48.7 |
| Asian/Pacific Islander | 4.0 | 1.0 |
| American Indian/(Native Alaskan) | 0.9 | 0.45 |

educate the nation. The CARE Act subsequently was reauthorized in 1996 and 2000 to improve the quality and availability of care for low-income uninsured and underinsured individuals and families affected by HIV. HRSA/HAB works in partnership with cities, states, local community-based organizations and people living with HIV/AIDS to plan and provide CARE Act funded services to approximately 533,000 individuals each year. The CARE Act is considered the “payer of last resort” and the majority of funds pay for primary medical care and essential support services. A smaller portion is used to fund technical assistance, clinical training and research on innovative models of care.

For the past twelve years, the CARE Act has had great success in bringing those most severely impacted by HIV/AIDS into care. Reflecting the epidemic itself, 47% of clients served by the CARE Act in 2000 were African American and 21% were Latino. In this same year, approximately 67% of CARE Act clients were male, and 33% were female. HRSA/HAB’s diverse partnerships, along with the CARE Act’s mandate to provide HIV care to those with the greatest need, make the program well-suited to respond to the goals of the Minority AIDS Initiative.

Congressional Response to Growing Disparities
In Fiscal Year (FY) 1999, Congress created the Congressional Black Caucus (CBC) Initiative to address racial/ethnic disparities in HIV-related health outcomes, and expand community-based capacity to serve people of color living with HIV/AIDS, particularly African Americans. The following year, the CBC Initiative was broadened to include other communities of color affected disproportionately by HIV, and has since been referred to as the Minority AIDS Initiative (MAI).

Each year since 1999, Congress has appropriated funds to various Federal agencies within the Department of Health and Human Services (DHHS) to implement the MAI. (See Appendix A for total MAI funding by agency). In FY 2002, HRSA/HAB received $123.2 million to support expanded HIV service delivery, community-based organizational infrastructure and other efforts in communities of color. Organizations receiving MAI funds under all Titles and Part F of the CARE Act have expanded their services and increased their capacity in an effort to reduce racial and ethnic disparities and expand access to care for low-income, uninsured people of color living with HIV/AIDS.

Overview of this Report
Section II of this report provides an overview of the MAI, including a brief history of events leading to its development. Section III describes HRSA/HAB’s role in the Initiative, including new strategies the agency has adopted in response to the Initiative. Section IV provides examples of some of the many local CARE Act programs supported with MAI funds, illustrating in concrete ways how the MAI has made a lasting difference in local communities’ response to the epidemic. Additional MAI funding information and Congressional report language is found in the Appendices.
The Call for Immediate Action
In March 1998, the Centers for Disease Control and Prevention (CDC) convened a meeting of 33 African American community leaders and HIV service providers in Atlanta, GA. During the meeting, CDC officials presented new HIV data that demonstrated the epidemic’s overwhelming and disproportionate impact on African Americans. In outrage over these findings, the community leaders stopped the meeting. Together, they developed a Call to Action consisting of nine demands, including one that called for the President and Surgeon General to declare HIV/AIDS a “state of emergency” in the African American community. The group insisted on an immediate meeting with administrators at the CDC and presented them with this list of demands.

Later that month, representatives of the 33 African American leaders presented the list of demands to the Presidential Advisory Council on HIV/AIDS (PACHA), which also endorsed the leaders’ call for the declaration of a state of emergency.

In April 1998, the 33 African American leaders — represented by Dr. Beny Primm of New York — presented the group’s concerns during testimony before the CBC at its Health Braintrust Forum. Dr. Primm urged then CBC Chair, Representative Maxine Waters, and Health Braintrust Chair, Representative Louis Stokes, to support the call for a “state of emergency” so that all agencies of the Federal government could gather their collective expertise and resources to address the crisis. The next month, the CBC convened a forum of more than 100 African American AIDS experts — including service providers, community leaders and people living with HIV/AIDS — to hear testimony on the impact of the epidemic in their local communities. At the conclusion of the forum, the CBC held a press conference and called on the Secretary of HHS to declare a public health emergency. This request was further outlined in a letter sent by the CBC to then Secretary Donna Shalala in May 1998.

In the summer of 1998, African American HIV/AIDS advocates worked with key CBC staff to draft Congressional report language targeting new funds to the crisis of HIV/AIDS in the African American community. This report language was included in the FY 1999 Omnibus Appropriations Bill, thereby creating the CBC Initiative.

In October 1998, President Clinton declared a “severe and ongoing health care crisis” with respect to HIV/AIDS for racial and ethnic minorities, especially African Americans. Together with members of Congress, he also announced the creation of the CBC Initiative to be implemented within DHHS. The Initiative coincided with former U.S. Surgeon General David Satcher’s concerted efforts to eliminate racial and ethnic
health disparities related to six health conditions, including HIV/AIDS.

In 1999, the Congressional Hispanic Caucus (CHC) and Congressional Asian Pacific American Caucus (CAPAC) joined the CBC in strong support for expansion of the Initiative. The CHC Health Task Force held hearings on HIV/AIDS in September of that year, and the issue of HIV/AIDS was also a part of the CHC Institute’s Legislative Issues Conference. CHC Health Task Force Chair, Representative Ciro Rodriguez, also voiced strong support for the declaration of a “state of emergency” in a September 1999 press conference. All three caucuses requested increased funding for the CBC Initiative as part of their FY 2000 appropriations testimony. To acknowledge this cross-caucus support and reflect the true goals of the Initiative, it was renamed the Minority AIDS Initiative (MAI). In June 2001, the three caucuses convened an historic, first-ever joint hearing entitled, “HIV/AIDS: The State of the Epidemic within Communities of Color.”

**The Goal of the Minority AIDS Initiative**

The overall goal of the MAI is to improve HIV/AIDS-related health outcomes for communities of color. As a targeted supplement to the much larger Federal HIV/AIDS budget, the MAI essentially serves as a booster shot. It allows communities to expand local service capacity primarily through minority community-based organizations (MCBOs), improve service delivery, and support the development of new and innovative programs designed to reduce HIV-related health disparities. In its first four-year history, overall MAI funding has grown from $156 million in FY 1999 to $381 million in FY 2002.

*In October 1998, President Clinton declared a “severe and ongoing health care crisis” with respect to HIV/AIDS for racial and ethnic minorities, especially African Americans.*
An Introduction to HRSA Programs

HRSA’s mission is to improve and expand access to quality health care for all by moving toward the goal of assuring access for all Americans. Four bureaus and one office within HRSA are responsible for several major programs through a $6.2 billion total budget. The Bureau of Primary Health Care administers the community and migrant health center program providing primary health care to the medically underserved. The Healthy Start programs and the maternal and child health block grants fall under the direction of the Bureau of Maternal and Child Health. Training and education of health care professionals is available through the Bureau of Health Professions, which also administers the National Health Service Corps program. The Office of Special Programs works to increase organ and tissue donation. Finally, the HIV/AIDS Bureau administers the CARE Act, HRSA’s highest funded program.

The CARE Act consists of several programs, including:

- **Title I**, which provides emergency relief to metropolitan areas that are disproportionately affected by HIV/AIDS;

- **Title II**, which provides assistance to states to improve the quality, availability and organization of health care and support services, as well as access to needed pharmaceuticals through the AIDS Drug Assistance Program (ADAP);

- **Title III**, which provides funding to organizations for early intervention and primary care services for people living with HIV/AIDS, in addition to funds for planning and capacity building;

- **Title IV**, which provides funding to provider networks for comprehensive care for infected women, infants, children and youth and their affected families, as well as access to clinical research;

- **Special Projects of National Significance (SPNS)**, which support the development of innovative service delivery models that have potential for replication;

- **AIDS Education and Training Centers (AETCs)**, which support training for health care providers to counsel, diagnose, treat and manage individuals with HIV infection and help prevent high risk behaviors that cause infection;

- **Dental Reimbursement Program (DRP)**, which provides support to dental schools, postdoctoral education and hygiene programs for non-reimbursed care provided to persons with HIV disease; and
✔ The new Community Dental Program designed to increase access to oral health care for underserved rural and urban HIV-positive populations, in addition to training providers in community settings.

A Shift in CARE Act Programs
In October 2000, Congress reauthorized the CARE Act for a five-year period and adopted a number of important program changes. These included an increased emphasis on individuals who know their HIV status but are not yet in care, and a specific commitment to identifying and addressing disparities in access and utilization of HIV services for historically underserved populations. These changes coincided with the MAI’s attempt to develop innovative strategies focusing on high-risk and hard-to-serve populations, which had eluded more traditional programs.

In response to reauthorization and the MAI, HRSA/HAB took a number of steps to broaden the pool of CARE Act applicants to include more minority community-based organizations. Through the DHHS Office of HIV/AIDS Policy (OHAP) Plain Language Initiative, HRSA/HAB project officers attended a series of trainings on writing in plain language. Early in 2000, project officers began to rewrite CARE Act program guidances to reduce the use of government jargon and encourage the submission of applications by new, less experienced organizations. The agency also gave the National Minority AIDS Council funds to provide pre-application technical assistance workshops for organizations interested in applying for Planning Grants under Title III of the CARE Act. Beginning in 1999, HRSA also supported a series of regional workshops for local providers. These workshops provided free training in the areas of financial management, resource development and board development.

The MAI Increases Total CARE Act Funding
The allocation of MAI funds across the CARE Act is determined largely by Congress in the annual Labor, Health, Human Services and Education Appropriations Bill. However, in addition to agency-specific allocations, and Title-specific allocations in the case of the CARE Act, each year Congress has appropriated $50 million to the HHS General Management Fund (GMF). (Previously, these funds were appropriated to the Secretary’s Public Health and Social Services Emergency Fund.) The Secretary

| Table 2: Minority AIDS Initiative Funding Appropriated to CARE Act Titles and Programs, FY 1999-2002 (in $ millions) |
|---|---|---|---|---|---|---|---|
| | Title I | Title II | Title III | Title IV | AETC | Other | Total |
| FY 1999 | 5.0 | 0 | 3.0 | 12.1 | 2.0 | 0.2 | 22.3 |
| FY 2000 | 26.5 | 0 | 27.4 | 12.2 | 6.8 | 0.2 | 73.1 |
| FY 2001 | 34.0 | 7.0 | 44.4 | 15.7 | 7.7 | 0.4 | 109.2 |
| FY 2002 | 41.8 | 7.0 | 49.4 | 17.0 | 8.0 | 0 | 123.2 |

Source: Health Resources and Services Administration.

Note: The “Other” column includes SPNS and TA set-asides, but not other MAI funds allocated to HRSA. See Appendix A for all MAI funds to HRSA. Totals in Table 2 may not equal amounts in report language in Appendix C due to the re-programming of additional funds to the CARE Act for the MAI by HRSA.
has distributed these funds across agencies for specific MAI-related programs. In FY 2002, HRSA received $123.2 million in MAI funds appropriated to specific Titles of the CARE Act, and an additional $6 million from the HHS General Management Fund for various training, education and capacity building activities. (See Appendix A for General Management Funds to HRSA, FY 1999–2002).

Each year, HRSA issues MAI guidance to current and potential CARE Act grantees. The guidance describes how MAI funds may be used, how to apply for funding, and MAI-specific reporting requirements. This guidance is program-specific, and is based on Congressional intent, as indicated in report language that Congress adopts each year during its appropriations process. (See Appendices B and C for CARE Act-specific MAI report language for FY 1999 through FY 2002).

The Role of Minority Community-Based Organizations

Because Congressional report language for the MAI has changed somewhat from year to year, HRSA requirements for MAI-funded programs and grantees also have changed. In FY 2002, Congress adopted its most detailed MAI report language yet, which states clearly that one of the central goals of the MAI is to improve the capacity of MCBOs to more effectively serve their communities. In the FY 2002 report language Congress states: “In distributing these funds, the Committee expects HRSA to tailor the portion of the Ryan White programs that are funded under the Minority HIV/AIDS Initiative as tightly as possible in order to address the growing health problem and maximize the participation of minority community-based organizations.”16
Communities in Action

Despite important increases in MAI appropriations since 1999, requests for this targeted funding continue to exceed the amount of funds available. Community-based providers have proposed a wide range of programs and services targeting racial and ethnic minorities, each of which is based on an assessment of service delivery needs in their local community. As the examples in the following section illustrate, these programs range in scope from primary medical care to targeted outreach and intensive case management.

Less tangible than direct services, yet still significant, is the way in which the MAI has focused attention on HIV/AIDS in racial and ethnic communities. In so doing, the MAI has helped community leaders and public officials ensure that this issue gets and remains on the radar screen. A recent survey by the Kaiser Family Foundation reflects a significant concern about HIV/AIDS among people of color. When asked to rank the number one health issue facing the nation in 2000, 41% of African Americans and 40% of Latinos ranked AIDS as number one, compared to 26% of whites. In this same survey, seven in ten (70%) African Americans and nearly two-thirds (64%) of Latinos viewed AIDS as a more urgent health problem for the country today than it was a few years ago. In 1997, prior to the MAI, the proportions of African American and Latinos who held this view were 58% and 67%, respectively.

The following programs illustrate some of the many successful CARE Act programs supported with MAI funds. The sixteen programs highlighted were chosen in consultation with HRSA/HAB project officers to illustrate the broad range of CARE Act services supported with MAI funds, as well as the diversity in geographic locations and populations served.

These MAI-funded CARE Act grantee programs are just a few examples of the many and varied ways in which communities have implemented the overall goal of the MAI — to improve HIV-related health outcomes for people of color — consistent with the needs of their local communities. Similar efforts are underway throughout the country. The MAI has led to new and expanded services for people of color and has strengthened the organizational capacity of community-based organizations. Given the CARE Act’s shared goal of reaching out and bringing into care hard to reach populations, the MAI has evolved into an important component of the CARE Act. It also plays a crucial role in broader efforts across all DHHS agencies to assure access to care for all Americans.
The Denver Title I Eligible Metropolitan Area (EMA) encompasses a five-county region of 2.2 million residents, including the City and County of Denver. As of March 2002, an estimated 6,900 residents of the Denver EMA are living with HIV or AIDS. The majority of these individuals are white (70%) or male (92%); however, women represent a growing proportion of reported cases (13% in the last two years, compared to 3% in 1985). African Americans, in general, bear a disproportionate burden of cases. Although they comprise just 6% of the EMA population, African Americans represent 14% of reported AIDS cases. Latinos, who comprise 19% of the population, represent 14% of people living with HIV/AIDS. Men who have sex with men (MSM) represent over two-thirds (67%) of HIV/AIDS cases in the Denver EMA, and injection drug use is associated with nearly one in five cases (18%).

The Mayor’s Office of HIV Resources (MOHR) administers the Denver EMA’s Title I funding in close collaboration with the HIV Resources Planning Council. The Planning Council establishes priorities for the use of all Title I funds, and has played an active role in shaping implementation of the Minority AIDS Initiative (MAI) locally. For example, in 1999, as part of its MAI-related planning, the Planning Council’s Needs Assessment, Cultural Competency and People of Color Committees developed a collaborative plan to identify and respond to barriers to care for people of color. As early as FY 2000, the Planning Council proposed that MAI funds be targeted to minority community-based organizations, and also required additional staff training for MAI providers.

Mayor Wellington E. Webb and the MOHR also played a leadership role in promoting AIDS awareness among African Americans. In addition to organizing four community forums, the MOHR sponsored the screening of a film entitled, “House on Fire: African Americans Respond to AIDS” at the 2000 Denver International Film Festival. Mayor Webb declared September African American AIDS Awareness Month in 2001 and 2002. And a local conference focusing on HIV and African Americans has been held for the past two years. During this same period, the MOHR has partnered with local community leaders to make presentations to various African American community groups to encourage their participation in AIDS service delivery. As a result of this outreach, two new agencies began providing HIV services in March 2002.

The Denver EMA has used MAI funds to expand its continuum of care to include two new service categories: 1) Health Care Referral and Related Support Services; and 2) Client Advocacy. Client advocacy was the first new service funded with MAI funds in FY 1999. The purpose of client advocacy is to reduce disparities in health outcomes by providing peer-based educa-
tion and support to people of color who need help navigating the continuum of HIV care. Each year, the demand for client advocacy services has exceeded available resources, and clients involved in the program demonstrate significantly improved health outcomes. In fact, the program’s success has prompted the MOHR and the Planning Council to expand funding for client advocacy services using both MAI and base Title I funding so that even more clients who are having trouble managing their HIV disease may benefit from the service.

The People With AIDS Coalition Colorado (PWACC) is a bilingual, multicultural and minority-based organization run by and for people living with HIV/AIDS. Its mission is to empower people living with HIV/AIDS through information, education and advocacy. In FY 1999, PWACC became the first MAI-funded sub-grantee to provide client advocacy services. Documented improvements in health outcomes for program participants reflect the program’s success in referring new clients into primary medical care, the AIDS Drug Assistance Program, and supportive services. For example, in the first six months of FY 2002, the program served 137 African American and Latino clients (more than 90% of whom were mono-lingual Spanish-speaking). During this period, these clients experienced an aggregate decrease of 97% in viral load (from 500,000 to 14,000) and a 46% increase in CD4 counts (from 334 to 486).

Through PWACC’s Peer Advocacy Project, trained peer advocates work with clients who may not be experiencing the same positive health outcomes as the majority of people living with HIV/AIDS. The support that peer advocates provide is based on each client’s individual needs. This often includes assistance in understanding the disease process, accessing primary medical care, and adhering to medical, mental health, or substance abuse treatment plans. Given a critical shortage of affordable housing in the EMA, peer advocates often are asked to help locate and maintain stable housing. Advocates also have helped clients through the difficult process of disclosing their HIV status to family members or friends, the fear of which can interfere with clients’ willingness to adhere to medications and access medical care consistently. The peer-to-peer nature of the program ensures that clients learn from those who share their experiences.

In FY 2002, Servicios de la Raza — a bilingual/bicultural, minority community-based organization located in the heart of Denver’s Latino community — received MAI funding to expand its five-year-old HIV case management program (La Gente) to include client advocacy. Though the agency does not limit its services to Latinos, its location and bilingual/bicultural staff, as well as its long history of providing mental health, substance abuse and social services to the Latino community, have established its strong reputation in that community. The majority of La Gente clients who receive client advocacy services are monolinguial,
Spanish-speaking immigrants. Translation assistance in accessing community-based services, including primary medical care, is therefore critical. The important bonds that have been established between La Gente case managers and clients are enabling people living with HIV/AIDS to become active participants in their own health care, and helping many address other mental health or substance abuse issues that may have interfered with consistent care in the past.
The Philadelphia Title I Eligible Metropolitan Area (EMA) extends across nine counties and two states and includes the Philadelphia, Pennsylvania, and Camden, New Jersey. The Philadelphia Department of Health’s AIDS Activity Coordinating Office administers Title I funds in the Philadelphia EMA. This is done in close collaboration with the Integrated HIV Planning Council, which serves as the planning body for AIDS care, prevention and housing services.

In 2002, the majority (82%) of reported HIV/AIDS cases in the EMA were reported in the City of Philadelphia, and the demographics of HIV/AIDS in the EMA reflect a disproportionate impact on people of color. Between January 2000 and December 2001, African Americans represented 66% of new AIDS cases, though they represented just 20% of the EMA’s general population. Another 9.7% of new AIDS cases were among Latinos, who represented just 5% of the population. During this same two-year period, women accounted for 28% of newly reported AIDS cases, with the vast majority of these cases occurring among women of color. Injection drug use (IDU) is the single largest reported risk factor in the EMA, accounting for 38% of AIDS diagnoses in this same period. This is followed...
by heterosexuals, who represent 32% of new AIDS cases, and men who have sex with men who represent 30% of new cases.

Using Title I Minority AIDS Initiative (MAI) funding, the Philadelphia EMA has embarked upon an innovative model of outreach, case management and HIV treatment advocacy through five new storefront locations. Developed in FY 2000, these street-level service sites represent important new points of access to the larger system of community-based HIV care. The primary goal of the storefronts is to identify individuals living with HIV/AIDS who are not accessing care and link them directly with primary care providers. All of the storefronts offer a range of basic support services, as well as HIV counseling and testing and substance abuse treatment either on-site or by referral. HIV and sexually transmitted disease (STD) prevention education also is provided on-site using other funding sources. In FY 2001, the five storefronts served over 1,400 clients, nearly three-quarters (1,038) of whom were served using MAI funds.

Two of the five new storefronts are the direct result of a 1999 MAI-funded Rapid Assessment, Response and Evaluation (RARE) project. Through this effort, local officials and community leaders partnered with a multidisciplinary team of federal advisors to identify strategies to improve care and enhance HIV prevention in the EMA. All five sites are located in communities of color and target African Americans and Latinos. Each involves a new partnership between two or three service providers, the large majority of which are minority community-based organizations (MCBOs). Three of the fourteen MAI-funded agencies in FY 2001 were organizations with a history of service in the African American community that had not previously provided HIV services.

Positive Effect Outreach Ministry (PEOM) is a minority, faith-based, community organization incorporated in 1998 by a group of individuals from various churches in the Philadelphia area. In partnership with Germantown Settlement and Albert Einstein Medical Center, PEOM created the Germantown storefront. Since it opened its doors in FY 2000, the storefront has served 230 clients. In addition to providing a range of social services on-site, the program uses a mobile van to bring HIV testing and other services to areas where high-risk activities, such as drug use and prostitution, occur.

While no one is excluded from care, the Germantown storefront serves primarily members of the low-income, African American and Latino communities near the agency’s location. This includes a significant number of women and families. In the past year, PEOM’s treatment outreach and primary care program expanded to include peer-based adherence counseling. A new women’s support group enables clients to help each other deal with the many non-HIV related issues, such as violence and drugs, that can interfere with treatment adherence and overall wellbeing. In this way, the storefront’s programs are building a sense of community among the participants, many of whom have been alienated from family due to drug use or other conflicts.

“The system of care in Philadelphia doesn’t fail those in care; it fails those people not yet in care. Outreach is therefore critical.”

Pat Bass, former Co-Director, Philadelphia AIDS Activity Coordinating Office
In addition to the storefronts, the Philadelphia EMA uses MAI funds to ensure continuity of care for individuals being released from state prison through the **Transition to Hope** program, which is administered by **Blacks Educating Blacks About Sexual Health Issues (BEBASHI)**. BEBASHI was established in 1987 in response to the increasing incidence of HIV/AIDS among African Americans in Philadelphia. It is now the largest minority AIDS program serving African Americans in the Commonwealth of Pennsylvania, and its services include prevention education and counseling, HIV testing, and case management.

Since FY 1999, the **Transition to Hope** program has worked with 24 correctional institutions in the state of Pennsylvania to provide discharge planning in the prisons and case management upon release in order to ensure continuity of medical care for Philadelphia-area-bound inmates who have HIV/AIDS. Through a partnership with the AIDS Law Project of Pennsylvania, the program also provides legal assistance to clients, and helps them access other support services such as health insurance, housing and employment to facilitate transition back into the community. One of the most dynamic features of the program is its use of Peer Treatment Associates — previously incarcerated, HIV-positive staff who provide intensive treatment adherence education. These peer advocates also facilitate support groups designed to help with re-entry and prevent recidivism.

Each year since FY 1999, the **Transition to Hope** program has exceeded expectations for the number of clients it expected to serve. In FY 2001, **Transition to Hope** served 98 clients. All of these individuals were linked to primary medical care, and 60% remained in care one year later. Though continuity of medical care is the primary goal of the program, important secondary goals include helping clients reclaim their lives, become part of the community and stay out of prison.

Through its experience implementing the MAI, the AIDS Activity Coordinating Office has seen how targeted efforts to bring very marginalized populations into care often requires increased spending on so-called “collateral care” — the deferred health and other needs this population requires. At the same time, they have witnessed the tangible, positive effects that such programs have on getting and keeping people in care.

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Trinity Ministries Adult Day Care Center, Incorporated (Trinity Ministries) is a minority, faith-based social services agency affiliated with the New Testament Pentecostal Church in Broward County, FL. Prior to receiving Minority AIDS Initiative (MAI) funding through the Broward County Title I Eligible Metropolitan Area (EMA) in FY 2001, Trinity Ministries provided adult day health care services for low-income seniors, including on-site vocational therapy. Since March 2001, the agency also has run a food bank, which supplies weekly food baskets to over 475 people living with HIV/AIDS throughout the county.

Broward County is the second largest metropolitan area in Florida, and its largest city is Fort Lauderdale. As of June 2001, Fort Lauderdale had the third highest AIDS incidence rate among U.S. metropolitan areas with a population of at least 500,000 (47.8 new cases per 100,000 persons). Just over half (51%) of all new AIDS cases reported in the EMA in 2000 and 2001, and 81% of new HIV cases among women, were among African Americans, though this group represents just 21% of the EMA population. Another 10% of newly reported AIDS cases were among Latinos. Women comprised 28% of AIDS cases reported in Broward County in the last two years. An estimated one in five (19%) people living with AIDS in the county were born in the Caribbean or Latin America.

As part of its 2002 Title I planning process, Broward County surveyed consumers of CARE Act services in the EMA. When asked to identify services they needed but were unable to get, 39% of clients surveyed chose food vouchers and another 17% selected food bank services, making nutritional services the number one unmet service need. This same survey asked clients to identify the main barriers to medical care. Fear of disclosure was the number one reason given and was a greater barrier for women than for men. As a group, Haitians cited fear of disclosure most often, with language identified as another significant barrier.

Almost 90% of Trinity Ministries’ HIV/AIDS clients have incomes below the federal poverty level, and the majority (70%) are either African American (56%) or Hispanic (14%). Because Broward County serves as a major gateway to the Caribbean, Central and South America, a significant number of the agency’s clients are immigrants, including a large Haitian population. Approximately 40% of the agency’s clients are women.

In FY 2001, Trinity Ministries provided nutritional counseling to 310 clients through the support of MAI funding. These services are designed to prevent severe AIDS-related weight loss (wasting), and help clients alleviate some of the side effects that can accompany HIV/AIDS medications through proper diet. Nutritional services begin with an initial assessment conducted by a certified dietician, who is a member of the agency’s staff. The dietician reviews the protocols related to a client’s medication and determines

“...The objective of our nutritional education program is to teach clients the importance of proper nutrition as a strategy to combat HIV disease.”

Gifford Louden, Administrator, Trinity Ministries
their nutritional needs. She develops a nutrition plan tailored to the client’s medical needs and cultural traditions. In the food bank, the contents of food baskets are chosen to reflect the variety of clients’ cultural traditions in order to maximize the usefulness of the service.

In FY 2002, Trinity Ministries received additional Title I MAI funding to establish client support groups. Some of the groups are designed primarily to disseminate medical and other educational information in a setting that allows clients to ask questions of experts. Other support groups that involve the sharing of more private information have a closed membership. All clients agree to respect the confidentiality of group members. Another type of support group offered by the agency targets specific populations, such as women, men who have sex with men, Haitians or Latinos. These groups are co-facilitated by an HIV-positive member of the group.

AIDS-related stigma is one of the many issues Trinity Ministries hopes to address through its HIV/AIDS programs. At the request of clients, some of the support groups specifically have involved family members in an effort to help them deal with the misconceptions of what it means to be living with HIV disease. As a faith-based institution whose focus is not exclusively AIDS, Trinity Ministries hopes that its role as a service provider also leads to greater AIDS awareness in Broward County’s African American and immigrant communities.

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In April 2002, the California State Office of AIDS (SOA) provided Title II Minority AIDS Initiative (MAI) funding to nine local health departments to expand a year-old demonstration program called the Bridge Project. This project is an enhancement to California’s Early Intervention Program (EIP), a multidisciplinary program providing care, treatment and prevention services to people living with HIV/AIDS. As its name implies, the goal of the Bridge Project is to “bridge the gap” between African American and Latino individuals’ knowledge of their HIV infection and enrollment in care, treatment and prevention services. The promise of new HIV medications available through California’s AIDS Drug Assistance Program (ADAP) further underscores the importance of early entry into care.

The Bridge Project was created in FY 2001 in response to the SOA’s concern that, for many people of color, too great a time passes between receipt of an HIV-positive test result and initiation of care and treatment. With the help of Bridge workers, this linkage takes place among clients identified as HIV-positive at testing sites, emergency rooms, or other community-based locations such as food banks or housing programs. Outreach to clients who were enrolled previously in California’s EIP program, but have dropped out of care, is also an important part of the program. Once a link to care is established, Bridge workers are available to help clients understand their treatment options, identify and resolve ongoing barriers to care, and be active participants in the development of their care and treatment plans. The Bridge Project’s dual focus on treatment outreach and HIV-prevention means that staff also engage clients in risk-reduction counseling and education.

One of California’s Bridge Project sites is Mission Neighborhood Health Center (MNHC), a 35-year old, minority community-based health center located in San Francisco’s Mission District. Each year, MNHC provides primary health care services to 12,000–15,000 individuals, most of whom are monolingual, Spanish-speaking residents of the Mission. In 1989, with state EIP funding, MNHC created Clínica Esperanza, the first HIV clinic in San Francisco dedicated to serving Latinos. Clínica Esperanza uses EIP’s comprehensive, multidisciplinary model, which combines medical care with treatment and prevention education, psychosocial support, and case management services. In 2002, Clínica Esperanza received MAI funding through the Bridge Project to create the Enlace para Tratamientos program (also known as Enlace).

The Enlace program works closely with homeless and marginally housed clients of the Mission Neighborhood Resource Center (Resource Center), a new medical and social service center established by MNHC and the San Francisco Community Clinic Consortium in March 2002. The Resource Center
provides supportive services (such as laundry, showers and storage facilities) integrated with primary medical care, mental health and substance-abuse counseling, and housing assistance. With more than 50 single room occupancy (SRO) hotels in the Mission, the Resource Center is already a service hub for many hard-to-reach clients, including young people living on the streets, in shelters and hotels. In addition to meeting and counseling clients at the Resource Center, Enlace staff work closely with MNHC’s HIV-testing program and provide in-service training for housing case managers in supportive housing programs.

As part of the Enlace program, the Bridge worker uses an adherence model developed by MNHC through a 1999 CARE Act Special Projects of National Significance (SPNS) grant. The underlying belief of the model is that treatment adherence improves with patient readiness. The Bridge worker meets with each client to assess his/her knowledge of HIV illness, disease progression, treatments and HIV transmission. He also works with clients to identify and resolve any outstanding barriers to care. At the conclusion of this assessment, the client and Bridge worker prepare a client-centered, goal-oriented service plan, which describes how the client wishes to address their health needs. In order to encourage client participation in the assessment and development of the plan, the program uses non-cash incentives, including food and clothing vouchers.

Although the Enlace program is still quite new, preliminary evaluation data from other Bridge sites that were funded a year earlier using CDC funding appear promising. Client statistics from the initial eleven Bridge sites show that, in the first 18 months, the program served 384 clients statewide, including large numbers of African Americans (53%). African Americans represent less than 7% of the state’s population, yet accounted for almost 24% of newly reported AIDS cases in 2001. Perhaps most striking, however, is the finding that, upon entering the Bridge Project, 53% of clients reported that it had been at least one year since they learned of their HIV status (including 23% and 17% who reported that it had been five and ten years, respectively). Although some of these clients may have received care elsewhere during this period of time, it is also likely that many who were very isolated and not in care are now accessing medical care and treatment as a result of the Bridge Project.

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As the administrator of CARE Act Title II programs, the Missouri Department of Health and Senior Services (DHSS) manages the Missouri AIDS Drug Assistance Program (MO ADAP). DHSS also administers Missouri’s Title II Minority AIDS Initiative (MAI) grant, designed to increase minority participation in MO ADAP. These MAI funds support educational and outreach activities in the Bootheel region of southeast Missouri, which encompasses six rural counties with a combined population of 125,000 residents.

MAI funds were used to target Missouri’s Bootheel area for a number of reasons. First, due to the limited availability of medical and dental care services in the region, the Bootheel is a federally designated Health Professional Shortage Area. Prior to the availability of MAI-funded services, the closest HIV case management agency and disease-intervention specialists were a 1.5-hour drive away. Ability to pay for medical services also is limited in this area. Twenty percent of the region’s population has an income below the federal poverty level. The percentage of non-elderly residents enrolled in the Medicaid program ranges from 22% to 36%, compared to a statewide average of 14%.

In addition, apart from the state’s two major metropolitan areas of St. Louis and Kansas City (both of which are Title I Eligible Metropolitan Areas), three of six counties in the Bootheel region have some of the highest proportions of African American residents in the state (Mississippi-23%, New Madrid-19%, and Pemiscot-30% vs. 11% statewide). However, less than half (45%) of African Americans living with HIV/AIDS in this region were enrolled in ADAP and case management services as of December 2000.

To address these problems, the Missouri DHSS contracted with Southeast Missouri Health Network (SEMO) in December 2001 to provide outreach and educational efforts in the region. SEMO is a federally qualified, community/migrant health center located in New Madrid, MO. Established in 1978, the agency serves an estimated 15,000 patients at six clinic sites. SEMO’s mission is to deliver comprehensive primary care services to the underserved population in the Bootheel. A ten-person board of directors that includes six consumers, a migrant farmworker representative, and three at-large community members governs the agency. Five physicians, eight advanced-practitioner nurses and three dentists provide a range of primary medical care and dental services.

SEMO’s MAI-funded STD/HIV Outreach, Education and Case Management program is run by an African American registered nurse with training in HIV testing and case management. As a long-time resident of the Bootheel, she has an intimate knowledge of the geography and people of the region, and reportedly, is rarely found behind the desk in her office. Instead, she is meeting with individuals and small groups, educating them about the risk of HIV/AIDS and the benefits of early testing and treatment. Some of her outreach has targeted churches in hopes that faith-based and other community leaders will help spread the news.

“In this rural area, confidentiality is a huge issue. Fear of disclosure prevents people from getting tested. I try to teach people that, with regular care, they can have a good, healthy life.”

Marilyn Jimerson, RN, STD/HIV Outreach, Education and Case Management Program
Through word of mouth she is connected to individuals who are willing to get tested. Health fairs that use different types of incentives to encourage attendance are another strategy employed by the program. With so few health education and health care resources available in the Bootheel, SEMO coordinates its efforts with programs such as Healthy Start, and also is a part of the Southeast Missouri Minority Alliance, a coalition dedicated to improving minority health status in the region.

One unique feature of the STD/HIV Outreach, Education and Case Management Program is its seamless integration of prevention with HIV case-finding and ADAP outreach efforts targeting those living with HIV/AIDS. This integration has happened at the provider level, with SEMO staff providing both prevention and care-related counseling in its program. It also has happened at the state level. In the DHSS, for example, MAI-related planning contributed to a reorganization of the prevention and care sections under a single section chief. DHSS also initiated an effort to identify individuals who have tested positive for HIV but are not yet enrolled in state-funded case management services. When a client tests positive for HIV, the Disease Intervention Specialist who gives the test results immediately requests the client’s consent to refer them to case management services. With consent, SEMO’s MAI-funded case manager then makes contact with clients who live in the Bootheel in an effort to link them to primary medical services.

Missouri’s MAI-funded education and outreach program is relatively new. However, in the first nine months, the staff participated in trainings on case management, HIV counseling and oral testing methods. They also have begun to manage a small number of cases that previously had been managed from a great distance due to the lack of services locally. In addition, the program has reached more than 275 people through 10 group and individual outreach interventions.

Fortunately, the State of Missouri has so far avoided the need to establish a waiting list for ADAP services, as has been the case in other states. Given the goal of this program — to link HIV-positive individuals with primary medical care and enroll them in ADAP — the continued availability and stability of MO ADAP is critical.

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The Texas Department of Health’s (TDH) Bureau of HIV and STD Prevention was awarded Title II Minority AIDS Initiative (MAI) funding in FY 2002 to provide intensive case management services for minority individuals with HIV who recently have been released from city or county jails or from state prison into Dallas and Harris Counties. The overall goal of the program is to improve minority ex-offenders’ HIV-related health outcomes through increased enrollment and sustained participation in the Texas AIDS Drug Assistance Program, which is referred to as the Texas HIV Medication Program (THMP). Related goals include: ensuring continuity of primary medical care for minority ex-offenders upon release; linking clients to other community-based HIV services; and improving coordination between the prisons and jails, the TDH, and community-based service providers. TDH contracts with three community-based organizations for these services – the Urban League of Greater Dallas, Incorporated, AIDS Arms, Incorporated, in Dallas, and AIDS Foundation Houston, Incorporated.

The Texas Department of Criminal Justice (TDCJ) operates the largest corrections system in the world, composed of 114 facilities, including prisons, jails and substance abuse treatment centers. According

Inmates receive their HIV daily medication through the Texas HIV Medications Program.
to the TDCJ, the prevalence of HIV/AIDS among the incarcerated population in Texas is estimated to be more than four times higher than that of the general population. In addition, though African Americans are represented disproportionately among people living with HIV and AIDS in Texas, they are under-represented in the THMP. African Americans represent over 36% of persons known to be living with HIV or AIDS in Texas but account for only 27% of THMP enrollees. These factors make outreach to this population for THMP enrollment and provision of community-based case management an important priority.

In Houston, the Department of Health and Human Services reports that nearly three-quarters (74%) of all new HIV infections reported in the county between 1999 and 2001 were among African Americans and Latinos. Moreover, of the 1,000 inmates living with HIV/AIDS released statewide in 1999, one-third (35%) were released in Harris County alone. In fact, the Houston HIV Prevention Community Planning Group has identified incarcerated and newly released individuals as their number-one priority population for 2002–2003, and other regional planning groups in the state, including the Houston Area Title I Planning Council, continue to prioritize the unmet needs of this population.

The non-profit, community-based AIDS Foundation Houston, Incorporated (AFH) provides direct services to over 3,400 people living with HIV/AIDS in the Houston metropolitan area, and reaches an estimated 50,000 through its prevention programming. For ten years, AFH has partnered with the Harris County adult and juvenile probation systems to provide probationers with health education and risk-reduction information. In addition, since 1997, AFH has partnered with the TDCJ and other community-based organizations to train over 325 peer health educators at 22 correctional facilities across the state. In November 2001, AFH convened a statewide Public Health Corrections Leadership Forum to identify barriers to services for HIV-positive offenders.

Based on recommendations made at the Forum, AFH, the TDCJ, the University of Texas School of Public Health, Sage Associates and Management Assistance Corporation are now conducting a comprehensive needs assessment, which will include a survey of offenders. The needs assessment is funded privately by the National AIDS Fund.

In July 2002, AFH began seeing clients in the MAI-funded pilot program, Get Started. In its first year, the program hopes to meet face-to-face with 180 potential male and female clients, enroll 90% of these clients in the THMP through involvement in an intensive case management program, and ensure that at least 80% maintain THMP enrollment for at least six months. Through collaboration with prison health care providers, peer educators and other outreach efforts, Get Started staff attempt to identify HIV-positive minority offenders while they are still in prison and begin collecting documentation for THMP enrollment. Upon release, the Get Started case manager and Benefits and Resources counselors in AFH’s Client Services Department ensure that clients make contact with a primary care provider, complete the THMP

“The strength of the Get Started program is the overlay system of care it provides, with interventions during incarceration and upon transition to the free world, and intensive case management upon release.”

Michael Mizwa
Chief Executive Officer,
AIDS Foundation Houston, Incorporated

THE MINORITY AIDS INITIATIVE
enrollment process, and have access to other services available through more than 50 community-based organizations (e.g. employment training, legal services, support groups/counseling, household furnishings, etc.).

One of the more effective features of Get Started is the program’s reliance on a system of incentives to encourage clients to begin and continue meeting with program staff. For example, during their first visit with a case manager, clients are provided a one-month METRO bus pass, clothing vouchers, food vouchers and a hygiene kit. Depending on the circumstances, emergency housing also may be available to those without a place to stay. On an ongoing basis other incentives, such as a dinner or entertainment voucher, are used to encourage monthly meetings between the client and the Get Started case manager.

The direct contact between Get Started staff and clients is designed to provide them ongoing support and education to help them better understand their illness and treatment needs. Monthly meetings also offer staff the opportunity to distribute safer sex resources and counsel clients on HIV risk-reduction methods.

As a pilot program, AFH will evaluate the effect of this intensive case management model by comparing the long-term health and THMP enrollment of Get Started clients who received education and outreach while in prison and intensive case management services upon release with those of other ex-offenders who came to the program on their own. The hope is that these enhanced services will contribute to improved health outcomes for minority offenders and serve as a model for similar programs in other parts of the state.

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Beginning in FY 2000, Concilio Salud Integral de Loiza (Concilio) received Minority AIDS Initiative (MAI) funding to provide comprehensive primary medical care for people living with HIV/AIDS through the CARE Act Title III Early Intervention Service (EIS) program. Concilio is a 30-year old community/migrant health center on the northeast coast of Puerto Rico and is funded under Section 330 of the Public Health Service Act. As the major provider of primary health care services to the municipality of Loiza and the adjacent area, Concilio serves a largely Black Hispanic population with above average rates of unemployment. More than 80% of the population lives below 200% of the poverty level. Due to the limited availability of health care services in the area, the region qualifies both as a Health Professional Shortage Area and a Medically Underserved Area.

In 2001, Puerto Rico had an AIDS incidence rate (cases per 100,000 persons) of 32.3, compared with 14.9 for the United States as a whole. The island also ranks within the top 10 states and territories in terms of cumulative AIDS cases.

Concilio had provided care to people living with HIV/AIDS for more than six years prior to receiving MAI funding. However, these services were limited due to the lack of staff assigned to this population. HIV testing services were available just two mornings per week. The coordination of care for people living with HIV/AIDS often fell through the cracks due to high demands placed on the agency’s limited case management staff. Prior to FY 2000, the closest Title III EIS program was located an hour away in the San Juan area. In addition, the lack of public transportation in the area posed a significant barrier to care.

Concilio staff play an active role in HIV services planning through membership on the Board of the Metropolitan East Consortium, a Title II regional planning body whose members provide support services in Loiza and the surrounding region. To support the involvement of people living with HIV/AIDS in planning, Concilio amended its agency by-laws to designate new seats on its Board of Directors for people living with HIV/AIDS.

With MAI funding, Concilio hired two full-time staff — an HIV Program Coordinator and a Case Manager. Both the Program Coordinator and the Case Manager have completed certification in HIV counseling and testing. As a result, in March 2001, the clinic was able to make HIV testing services available five days per week. Currently, when a patient tests positive for HIV infection, the case manager enrolls the client in the EIS program, makes arrangements for an evaluation by a primary care physician, and also makes referrals to other support services the patient may need. These support services may include home health care, housing assistance, legal assistance, and/or substance abuse counseling and treatment. Clients are provided educational literature, and at each visit, receive a card containing written information regarding the results of their most recent lab tests.

“This new funding has greatly improved Concilio’s ability to provide comprehensive HIV care, and to more proactively manage the full range of services our clients need.”

Edwin Pérez Peréz, MD, Medical Director, Concilio Salud Integral de Loiza
With Title III MAI funding, Concilio also supports a half-time nutritionist who consults with clients on medication protocols and counsels them on nutrition needs that can affect their ability to adhere to HIV treatments. The nutritionist also conducts two nutritional evaluations per year for each client. Though MAI funding covers a small portion of a medical internist's time, most other clinical staff positions that support the EIS program, including dentists, are funded through other Federal sources.

In FY 2001, Concilio provided comprehensive primary medical care to 55 individuals living with HIV/AIDS, representing an increase from the previous year. By the end of FY 2002, the number of clients grew to 86 individuals. However, program staff believe that even this number is less than those with need based on HIV/AIDS surveillance data.

Providing consistent care to individuals who are homeless or marginally housed is a significant issue for the program, especially after the damage to housing caused by Hurricane George in 1998. Concern about confidentiality in this largely rural area also continues to be an issue that prevents some from getting tested and accessing care. Still, the agency has seen a real difference in quality of life for clients receiving the program’s comprehensive package of services and expects the number of clients served by the program to expand further in the year ahead.

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Through the use of Title III Minority AIDS Initiative (MAI) funding, Near North Health Services Corporation (NNHSC) has established an Early Intervention Services (EIS) program to serve predominately low-income African Americans and Latinos living with HIV/AIDS in the South Side, West Side and Near North areas of Chicago. The opening of the EIS program followed a year-long planning process, during which the agency assessed the need for additional primary care services in these communities, and identified resources needed to provide comprehensive HIV care at three of the agency’s clinic sites. This planning process included a survey of current HIV and non-HIV clients at the agency to identify unmet service needs.

NNHSC is a minority-run community health center funded under Section 330 of the Public Health Service Act. The agency has served the Chicago area for over 35 years, and in 2001, provided primary health care to over 20,000 clients. Of these clients, approximately three-quarters (73%) were African American, and 20% were Latino. Over 40% of the residents in the agency’s service area have incomes below the poverty level, and approximately 20% of the adult population is unemployed.

Prior to receiving EIS funding in FY 2002, NNHSC provided primary care services to people living with HIV/AIDS as a sub-contractor to two programs funded through Titles II and III of the CARE Act. However, as the overall need for services in
the community continued to grow, the staff increasingly felt that the complex service needs of clients required a more comprehensive and multidisciplinary approach to HIV service delivery. Title III MAI funding allowed NNHSC to hire a clinical adherence counselor to work with clients to address barriers that interfere with consistent use of medical services and adherence to treatment. Such barriers might include medication side effects, substance use, mental health issues or unstable housing. The program hired a full-time nutritionist. Also, it is now able to pay for a dentist to come to the agency to provide on-site dental services. Though NNHSC had conducted HIV testing on site for years, the availability of dedicated, EIS staff has enabled the agency to expand patient education efforts focused on the need for testing.

In addition to an increased client demand for HIV services, NNHSC staff also observes that clients new to care often require services related to other health issues that are chronic in the African American community, such as asthma, diabetes and hypertension. These needs, combined with the fact that many of NNHSC’s HIV clients often enter care in the later stages of their illness, means that providing care to clients living with HIV disease is often more costly and time-intensive than for other clients.

NNHSC is part of a network of four community health centers referred to as the Alliance of Chicago Community Health Services (the Alliance). HIV/AIDS is one of four diseases that the Alliance has prioritized for coordinated action, and NNHSC is the last of the four agencies to begin providing comprehensive HIV care. One of the efforts the Alliance has pursued is the development of a joint quality improvement plan. Using a national quality improvement program known as HIV-Qual, the four agencies collect, pool and compare client data on eleven different clinical outcome measures to monitor the quality of their programs.

NNHSC has taken further steps to improve the quality of its EIS program through staff participation in professional trainings provided through the Mid-West AIDS Education and Training Center (MAETC). To support the agency’s expansion of HIV testing services, all advanced staff were trained in pre- and post-test counseling. The nursing staff received additional training on HIV sensitivity and awareness, and several physicians, including the Medical Director, will participate in an intensive training on HIV treatments sponsored by the MAETC.

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“MAI funding has had an enormous impact on the quality of HIV care our clients receive. New case management services support clients who are struggling with treatment adherence, thereby freeing up staff time for oversight and quality improvement activities.”

Tim Long, MD, Interim Medical Director, Near North Health Services Corporation

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Tim Long, MD, Interim Medical Director, Near North Health Services Corporation
In FY 1999, Tri-County Community Health Center (TCCHC) received CARE Act Title III Minority AIDS Initiative (MAI) funding to expand Positive Life, a comprehensive, Early Intervention Services (EIS) program funded initially with Title II CARE Act funding. The program's expansion followed a two-year, Title III Planning Grant received in 1997. Positive Life serves approximately 200 people living with HIV/AIDS each year, 90% of whom are either African American (55%) or Latino (35%). Women represent over half of the program's clients, and in FY 2001, Positive Life also became a Title IV program to better address the needs of women. In addition to living with HIV/AIDS, over 75% of the clients in the HIV program struggle with mental health issues and/or substance abuse.

TCCHC is a minority-run, community/migrant health center funded under Section 330 of the Public Health Service Act. For more than 20 years, the agency has provided primary medical care to a rural, three-county area of eastern North Carolina. TCCHC is the only bilingual health care provider in the state, which enables Positive Life to fill a significant unmet service need identified in the EIS planning process. Approximately 60% of the agency's clients overall, and 40% of those in its HIV program, are migrant and/or seasonal farm workers who travel throughout the region to follow employment opportunities. The staff of the HIV clinic reflects the gender and ethnicity of the clients it serves.

Through the use of Title II and ADAP funding, TCCHC has provided primary medical and dental care to individuals living with HIV/AIDS since 1990. However, in the late 1990's, the agency began to see a significant increase in both the number and complexity of cases, particularly among women. It became increasingly clear that the agency's basic primary medical care program was unprepared to address the full range of support services that clients needed to help them adhere to treatment. TCCHC staff recognized the need to work with clients to assess their readiness prior to initiating HIV treatment, and to provide more intensive support to help them manage frequent side effects. This need led TCCHC to apply for a Title III Planning Grant. The agency used these funds to work collaboratively with other health and social service providers, as well as the county HIV Task Force, to document the range of HIV services available in the region, identify unmet need, and develop a plan for the coordination of care.

Positive Life's multidisciplinary model of care provides to clients a wide range of services, all of which are located within the clinic. The program combines primary medical care and dental services with case management, benefit counseling, pharmacy and nutritional services. The agency also runs a residential substance abuse treatment program for men. HIV testing has been available at the clinic since 1991.

The case management program has taken a number of steps to encourage the use of Positive Life services by women living with HIV/AIDS. This includes paying...
for child care during clinic visits and providing medical care to the children of HIV-infected women regardless of whether they are living with HIV/AIDS. EIS and Title II funding also has enabled TCCHC to open two half-day satellite clinics in remote areas of the region so that clients who live a great distance from the clinic itself are able to see a physician regularly.

From the agency’s perspective, Positive Life’s team approach to providing care has improved the quality of the program, and also has contributed to increased participation by clients. Many times, rather than speaking with their physicians, clients approach the case manager when they are having problems with medications. The case manager is able to help facilitate a conversation with the physician and make referrals to other community-based services, as needed. The program also has seen a dramatic increase in the active involvement of people living with HIV/AIDS in the administration of the program. In FY 2001, the program hired two part-time, HIV-positive peer advocates to assist in various capacities. In addition, a very active 25-member Consumer Advisory Board meets monthly. Periodically, these advisory board meetings are conducted in Spanish to ensure that monolingual clients are able to participate fully.

In the past year, through its involvement in Community Partners HealthNet — a network of rural community health centers — TCCHC has started planning for the expansion and improved coordination of services for people living with HIV/AIDS in eastern North Carolina.

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In FY 2000, Whatley Health Services, Incorporated (WHSI) received Title III Minority AIDS Initiative (MAI) funding to expand primary medical services provided through the HOPE Clinic, the agency’s two-year old HIV program. Since that time, the number of active clients served by the clinic has grown from 85 to 137. Approximately three-quarters of the clinic’s current clients are African American, though this group represents just 28% of the general population in the agency’s service area. Women represent 20% of all HOPE Clinic clients.

WHSI is a 25-year old federally qualified community health center whose main site is located in Tuscaloosa, AL. Each year, the agency serves nearly 11,000 patients through its eight health centers. In the agency’s ten-county service area, which encompasses more than 7,500 square miles, transportation is a major problem. In the case of HIV services, concerns about confidentiality also are an issue, and a number of clients travel significant distances to Tuscaloosa in search of confidentiality.

Beginning in 1998, HOPE Clinic operated for three hours every other week at WHSI’s main health center in Tuscaloosa. However, as the number of clients and the complexity of their HIV conditions grew, this level of service was insufficient. Title III funding has enabled the clinic to expand the number of hours the infectious disease specialist is available to spend with clients. It also allows the clinic to provide a comprehensive and multidisciplinary set of services. WHSI now operates HOPE Clinic one full day a week, and also supports services at a second site located in Walker County. Beginning in 2003, the agency will offer HIV services at a third site in the southern section of WHSI’s service area.

The comprehensive set of services available on-site at WHSI HOPE Clinic includes primary medical care, dental care, nutrition counseling, case management and pharmacy services, as well as mental health and substance abuse assessment. Referrals for legal services, as well as dental and medical subspecialty care, also are available. The clinic provides Medicaid verification services on-site, as well as housing assistance funded through the Housing Opportunities for People with AIDS Program (HOPWA).

In FY 2001, an expansion of Title III MAI funding enabled HOPE Clinic to hire an outreach worker. In the past year, she has met with other local service agencies to educate their clients and staff about the risk of HIV and inform them of the clinic’s services. Through presentations at health fairs and one-on-one meetings, the outreach worker emphasizes the importance of knowing one’s HIV status and offers HIV testing using the Orasure system. She also makes multiple attempts to contact clients who have not been to the clinic in the past six months to help them address whatever barriers are interfering with consistent care.

In many cases, lack of transportation is the major barrier in this rural area. Although the availability of the satellite

“Every day, the HOPE Clinic bridges the gap for our clients by eliminating the barriers that interfere with consistent care — whether it’s a lack of transportation, the severe shortage of health services in the area, or the cost of HIV treatments.”

Donnie Lewis, RN, Program Director, HOPE Clinic, Whatley Health Services, Incorporated
clinic has helped, many clients still must travel an hour or more to receive services, and public transportation is poor. Using MAI funds, the clinic has contracted with a local AIDS service organization to provide van service. The availability of this service has led to a reduction in the number of missed medical appointments.

Another significant barrier to consistent care is access to HIV treatments. The majority of HOPE Clinic clients are low-income and uninsured, making the cost of HIV drugs prohibitive. Were it not for the efforts of clinic staff, clients would simply go without. The high cost of drugs is made worse by the fact that, due to insufficient funding, in March 2003 the Alabama AIDS Drug Assistance Program (ADAP) has a waiting list of more than 150 persons. Even those clients who are fortunate enough to be enrolled in ADAP must deal with the program’s limited formulary that does not always cover all the HIV-related medications that clients need. By working closely with pharmaceutical companies’ patient assistance programs, and using Title III funds when necessary, WHSI staff have been able to ensure that even the most needy clients living with HIV/AIDS have access to life-saving treatments.

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Since FY 1999, the Washington, D.C.-based Family Connections program has used MAI funding to expand outreach and strengthen the role of consumers in HIV planning and services received through Title IV of the CARE Act. The primary goal of Family Connections is to prevent perinatal transmission of HIV and increase access to and improve the quality of care for HIV-infected or affected children and pregnant women in the District of Columbia. The program also seeks to provide women living with HIV/AIDS information about HIV research and clinical trial opportunities.

The District of Columbia has the highest AIDS incidence rate (new cases per 100,000 population) of any large metropolitan area in the country. According to the D.C. Department of Health, the proportion of new AIDS cases that occurred among women tripled between 1990 and 2001, from 11% to 33%. Over three-quarters of recently reported AIDS cases in the District of Columbia were among African Americans, who represented approximately two-thirds (63%) of D.C. residents in the year 2000.

Each year, the Family Connections program provides comprehensive, family-
centered case management and support services to more than 600 clients. The program's four partner agencies are: Children's National Medical Center; Washington Hospital Center; the D.C. Department of Health; and Howard University Hospital. Another nine community-based agencies throughout the District provide a range of support services to clients based on referrals from the program.

In 1999, Family Connections used Title IV MAI funding to hire two advocates to expand outreach in the African American community through D.C.'s Healthy Start program. Given both programs' emphasis on targeting high-risk pregnant women, co-locating staff was viewed as a way of targeting efforts to the population in greatest need of HIV prevention and care. Through the screening of all Healthy Start clients in areas of the city with the highest AIDS incidence rates, Family Connections staff have been able to identify women who are not yet aware of their HIV status or are not yet in care. These women are then linked to care and informed of treatment options to reduce the risk of perinatal transmission. The one-on-one support provided by staff makes a huge difference in the lives of pregnant women and families, many of whom are struggling with other non-health related issues, in addition to HIV/AIDS.

Through Family Connections' linkage with Healthy Start, the program reaches a significant number of pregnant adolescents and young women. In the past year, this success has led the program to seek other Federal funding to expand its outreach and education efforts in local high schools and youth halfway houses.

Title IV MAI funding also has enabled Family Connections to create a consumer involvement coordinator (CIC) position to strengthen consumer ownership of the program. The CIC oversees the work of eight consumer staff, and also supports the work of the program's Consumer Advisory Board. The CIC initiated a women's group that is very well attended. This group is an opportunity for women living with HIV/AIDS to share information and provide peer support to newly diagnosed women. The CIC is currently working with families who come to the clinic to determine how best to design a new family resource center.

In FY 2001, Family Connections expanded the scope of its Title IV MAI-funded services to include the use of advocates to work with clients on keeping medical appointments. Staff proactively remind clients about upcoming appointments, and assist with transportation or other service needs that interfere with consistent care. Following implementation of this initiative, the rate of kept appointments for referred Family Connections clients exceeded 70% at Children's National Medical Center and was 80% at Howard University Hospital.

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“Family Connections has successfully blended MAI and other funding streams to provide outreach services that are fully integrated into the local Healthy Start program.”

Ann Scher, LICSW, Director, Family Connections

34 EXTENDING THE REACH OF THE RYAN WHITE CARE ACT
Since FY 1999, the **Memphis HIV Family Care Network** has used Minority AIDS Initiative (MAI) funding received through Title IV of the CARE Act to fund a part-time consumer advocate and support the public education and outreach efforts of the African-American Pastors’ Consortium (AAPC).

The Memphis HIV Family CARE Network (the Network) is a coalition of five social service and four health care providers that offer HIV services to women, children and families in the Memphis area. Services provided through the Network include primary medical care, case management, transportation, health education, support groups and day care for children. The Network’s fiscal agent is the Methodist Healthcare Foundation, which received Title IV funding for the first time in FY 1998.

The AAPC is a network of more than 45 pastors whose mission is to provide HIV education, assist and encourage the development of AIDS ministries, and provide pastoral counseling and support to individuals living with HIV/AIDS. The AAPC serves the Memphis Metropolitan Area, which includes the city of Memphis and five surrounding counties.

African Americans now represent the largest racial and ethnic group in the Memphis area. African Americans represented 90% of newly reported AIDS cases in the five-county Greater Memphis region in
2001. Over 90% of the 602 clients served through the Network in FY 2001 were African Americans.

Seven pastors established the AAPC in 1995. By 2002, the organization had grown to more than 45 member churches. According to the Network, the approval and acceptance of faith leadership has been extremely important to congregants.

One of the goals of the APPC is to encourage the early identification of HIV infection by promoting HIV testing. In 1999, APPC members met with the Shelby County Health Department to request assistance in making HIV testing available through their churches on a quarterly basis. Meeting this request was the first time that the health department had provided off-site testing. The AAPC has since expanded its efforts to encourage HIV testing beyond church locations to health festivals and other community events. Members also are actively involved in National HIV Testing Day activities.

One of the specific challenges the Network and AAPC are addressing together is the stigma, denial and isolation that many women living with HIV/AIDS face. These conditions often contribute to clients dropping out of care. As the mother of an HIV-positive woman, the Consumer Advocate hired by the Network is able to speak with others about how HIV has affected her life. She encourages and supports consumers to learn more about their conditions, adhere to treatment and take an active role in their care.

Although the MAI-funded outreach and public education activities that the Network and AAPC provide have focused on women and families broadly, the efforts have served a significant number of young women. In FY 2001, more than 17% of the Network’s clients were young women between the ages of 13 and 24.

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Since FY 2001, the San Diego Family Comprehensive AIDS Resources Emergency (CARE) Partnership (CARE Partnership) has used Minority AIDS Initiative (MAI) funding received through Title IV of the CARE Act to strengthen existing and develop new collaborations with African American community and faith leaders in the San Diego area. Through such efforts, the CARE Partnership hopes to broaden awareness of the epidemic’s disproportionate impact on African Americans and expand access to testing, treatment and research. The CARE Partnership is a network of primary health care and support service providers funded through Title IV of the CARE Act. Its goal is to provide a comprehensive, culturally competent system of HIV care for families living with HIV/AIDS, the large majority of whom are African American (23%) or Latino (60%). The University of California, San Diego Mother, Child & Adolescent HIV program serves as the lead agency.

The CARE Partnership’s expanded effort to increase AIDS awareness and strengthen collaboration with African American community leaders began with a series of outreach efforts in FY 2000. These were led by a newly funded community liaison position, which was filled by an African American woman with professional training in social work. The community liaison works closely with an African American peer advocate to increase awareness of the disease and link women and families living with HIV to care. The peer advocate position was an important addition to the program, given concerns that many African American women have about disclosing their HIV status publicly. She has served as an effective spokesperson and role model, helping other women to accept their HIV-positive status and teaching them how to advocate for the needs of families living with HIV/AIDS.

In January 2000, the CARE Partnership co-hosted a community-wide roundtable on AIDS prevention, care and treatment in the African American community, which was attended by 35 leaders. During the discussion, a number of barriers to prevention and care were identified, including: denial, silence, homophobia, distrust of institutions, and the competing demands of other health, economic and psychosocial issues affecting this population. During this same year, the CARE Partnership reached over 1,100 individuals through outreach at church fairs and youth group activities. More than 1,500 community members attended the play “Before It Hits Home,” which illustrated the importance of HIV issues for African American families, and was promoted by the community liaison. The CARE Partnership also co-sponsored a conference on women and HIV with the San Diego Black Nurses’ Association. Sixty-five health care workers attended the conference, many of whom were African Americans or provided healthcare to African Americans.

The community liaison also began conducting outreach to traditional community leaders, including African American faith leaders.

“The Minority AIDS Initiative has helped our program address the pervasive denial and apathy that exists in our community. By working with community leaders, we have been able to reach and serve greater numbers of individuals and families living with HIV.”

Mary Caffery, Program Coordinator, UCSD Mother, Child & Adolescent HIV Program
leaders. Written information on HIV/AIDS was distributed to over 200 congregations in 2000. That year, more than 35 churches participated in at least one AIDS awareness activity, including 16 ministers who addressed the issue of AIDS in church bulletins or from the pulpit that year. Several local ministers attended The Balm in Gilead’s 2001 Black Church HIV/AIDS Training Institute, held symbolically in Tuskegee, AL. These ministers subsequently formed a group called Concerned African American Clergy and Laity. The CARE Partnership continues to work with this group, providing technical assistance with programs, workshops, information sessions and materials development. Later that year, nine ministers and five local African American leaders met with clinicians and researchers to discuss issues related to African Americans’ participation in clinical trials.

These new collaboration and outreach efforts have led to increased involvement of minority community-based organizations in the CARE Partnership’s strategic planning process and in monthly network meetings. In FY 2001, MAI funding was provided to expand HIV service delivery to families through the Southeast Abundant Resource Center (SEAR) and the Center for Supportive Service and Education’s Women of Glory program. SEAR is an African American, faith-based agency that provides HIV testing, peer advocacy, and emergency and permanency planning services in San Diego’s southeast neighborhood. The agency’s trusted reputation in the community and its convenient location on the trolley line has helped facilitate the use of its services by people living with HIV/AIDS. Women of Glory is a faith-based outreach and education program that provides prevention information to small groups within women’s homes. As a result of MAI funding, these programs were able to obtain additional educational materials and expand support staff to reach more women.

The CARE Partnership also used MAI funding to improve access to care for immigrant populations in the San Diego area through outreach and an expansion of translation services. In an effort to ensure that monolingual Spanish-speaking consumers are involved in service planning, the CARE Partnership provides simultaneous translations at its meetings, and produces materials in both English and Spanish. The CARE Partnership also provides translation services for African immigrants living with HIV/AIDS to ensure that these women receive consistent health care.

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Since its creation in FY 1999, the National Minority AIDS Education and Training Center (NMAETC) has provided training in the clinical management of HIV disease to primarily African American health care practitioners across the country. The NMAETC was created and funded by HRSA/HAB through Minority AIDS Initiative (MAI) funding allocated to the agency from the Secretary's General Management Fund. The goals of the program are twofold: (1) to improve the quality of care for people of color living with HIV/AIDS; and (2) to strengthen the HIV/AIDS capacities of Historically Black Colleges and Universities (HBCUs). In the past year, the NMAETC has expanded its initial partnerships to include other universities and national organizations that target providers who serve large numbers of Latinos and Native Americans.

While less than 4% of U.S. physicians are African American, these providers often practice in settings that serve large numbers of African American and other minority patients. These clinicians may not care for large numbers of minorities living with HIV/AIDS currently, but they are in a position to identify new cases of infection and encourage newly diagnosed patients to engage in ongoing care and treatment. A central component of the NMAETC’s training is the provision of culturally competent care that respects the traditions and social environments of patients’ racial or ethnic backgrounds.

At the request of Congress, the NMAETC has partnered with four HBCU medical schools: Howard University in Washington, D.C.; Drew University of Medicine in Los Angeles, CA; Meharry Medical School in Nashville, TN; and Morehouse School of Medicine in Atlanta, GA. Each of these partners has established a local network of primarily African American providers, which meets at least monthly. These local networks allow the NMAETC to interact with providers on a regular basis to identify training and information needs and barriers to patient care. The NMAETC offers members continuing education opportunities on such topics as treatment adherence, antiretroviral therapies, opportunistic infections, and co-morbidities such as substance abuse and hepatitis. In FY 2001, approximately 1,725 clinical providers received training through the four provider networks.

In order to respond to the need for training of minority providers nationally, in FY 2000, the NMAETC expanded its program beyond the four areas served by the HBCUs through additional partnerships with the National Medical Association, the National Dental Association, the National Black Nurses Association, and the National Pharmaceutical Association. In collaboration with these organizations, the NMAETC held trainings at the associations’ national conventions and hosted regional trainings on HIV care in cities with the highest numbers of AIDS cases reported among African Americans.

“Many participants are drawn towards the NMAETC’s trainings in part because they are peer-based and emphasize the use of African American faculty.”

John McNeil, Principal Investigator, NMAETC, Howard University
Americans. Representatives from the regional AIDS Education and Training Centers (AETCs) also participated in planning for these regional trainings.

The NMAETC provides five levels of training designed to meet the varied needs of providers including lectures, clinical trainings or preceptorships, clinical consultations and on-site technical assistance. Lectures help to strengthen providers' skills related to HIV testing and counseling and the development of patient care plans, including the use of referrals. Three of the four HBCU partners also offer on-site preceptorships ranging in length from one day to one week. These preceptorships provide more advanced training in the clinical management of HIV disease and opportunities for hands-on observation of direct patient care. Clinical consultations are available to assist individual providers with specific questions related to an actual patient. Finally, on-site technical assistance is made available to help clinics and other provider groups develop quality improvement plans and strengthen physicians' ability to provide care that conforms to HHS Guidelines for the Use of Antiretroviral Agents in a culturally competent manner. This technical assistance often includes training on adherence strategies, treatment and prevention of opportunistic infections, and linkages to clinical trials and new therapies. In FY 2001, a total of 3,235 clinicians participated in the NMAETC's training programs.

The direct training of medical providers is the NMAETC's primary activity. However, it recently revamped its website to enhance its educational capabilities. Posted on the site are actual clinical cases, descriptions of models of care and a clinician's pocket guide on working with African Americans living with HIV/AIDS, which was developed by NMAETC staff. The NMAETC hopes to reproduce and expand this guide in the coming year to include additional information related to the care and treatment of Latinos and Native Americans.

Serving African American providers continues to be the main focus of the NMAETC. However, in the past year, it has also begun to work more closely with Latino medical providers in Washington, D.C. and Los Angeles, and has participated in efforts to address poor access to health care, including HIV care, along the U.S.-México border. Through its longstanding partnerships with HBCUs and national African American organizations — as well as more recent collaborations with such groups as the National Hispanic Medical Association, the National Native American AIDS Prevention Center and several Hispanic colleges and universities — the NMAETC hopes to continue providing culturally competent training that contributes to improved clinical care for all people of color living with HIV/AIDS.

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Beginning in FY 2002, HRSA/HAB in collaboration with the Indian Health Service (IHS), used Minority AIDS Initiative (MAI) General Management Funds allocated to HRSA to support the development and implementation of the Phoenix Indian Medical Center’s (PIMC) Fundamentals of HIV/AIDS Preceptorship for American Indian/Alaska Native Communities. The preceptorship is a hands-on, three-day training for health care providers working in American Indian/Alaska Native communities.

As one of the three largest medical centers in Indian country, the PIMC’s mission is to offer quality health care that is uniquely tailored to American Indian and Alaska Native people. PIMC is a 127 bed general medicine and surgical hospital that serves an estimated 50,000 American Indians and Alaska Natives from the metropolitan Phoenix and central Arizona area. Because of PIMC’s size and scope, it provides specialty care for over 100,000 others from IHS Tribal or Urban Indian health programs across the southwest. In 1996 PIMC established an HIV Center of Excellence to provide preventive, clinical and educational programs for this special population. As part of the Center, primary care physicians, dentists, nurses and a pharmacist provide clinical services, and a director and two case managers coordinate a variety of other HIV-related services. As of July 2002, PIMC provided direct services to 110 active clients living with HIV/AIDS.

According to the CDC, American Indians and Alaska Natives accounted for 2,537 of cumulative AIDS cases through December 2001. While relatively small in number, these figures are widely considered to underestimate the magnitude of the problem. The rate of increase in this population also is alarmingly high. For example, according to the Arizona Department of Public Health Services, while the proportion of AIDS cases among Native Americans in Arizona has remained fairly constant for some time (at 2–3% of reported cases), Native Americans represented 6% of reported AIDS cases in 2000 and 2001. Moreover, the rural, isolated location of many people living on reservation communities and the displacement experienced by many urban-living people may result in limited testing and counseling practices and create additional barriers to appropriate HIV care.

One challenge faced by the IHS is how to train providers working in local communities to provide high quality, state of the art care for a small number of patients living with a complicated and evolving disease. PIMC’s Fundamentals of HIV/AIDS Preceptorship is designed to address this challenge by teaching IHS, Tribal or Urban health care providers — including physicians, nurses, physician assistants and case managers — how to identify new cases of HIV, provide basic medical care and use information technology to assist in patient care after patients return to their communities. The training is designed specifically to be peer-based, utilizing clinician mentors with more experience in the treatment of HIV/AIDS.

“By giving practitioners a chance to observe HIV care in a clinical setting, we hope to demystify it and break down barriers that may exist in smaller communities with lower prevalence.”

Charlton Wilson, MD
Associate Director,
Phoenix Indian Medical Center
PIMC’s preceptorship consists of three half-day lectures on the epidemiology and fundamentals of HIV disease, the components of counseling and testing and legal issues surrounding patient consent and confidentiality. A second component of the program teaches participants how and where to access expert consultation on HIV care and treatment using the Internet and/or telephone consultation lines. Use of a state of the art computer lab gives participants an opportunity to test new skills by conducting on-line research. In the third component of the preceptorship, each afternoon participants choose from a variety of opportunities to observe their peer-clinicians as they provide pre- and post-test counseling or HIV care. These sessions take place at PIMC, the Maricopa County Health Department Sexually Transmitted Disease Clinic, Phoenix Children’s Hospital, the Veteran’s Administration HIV Clinic, or the McDowell Comprehensive Health Care Center—a CARE Act-funded clinic specializing in the care of people living with HIV/AIDS.

In FY 2002, PIMC’s Fundamentals of HIV/AIDS Preceptorship program held four sessions for more than 32 trainees from six different states. In the future, in addition to repeating the Fundamentals courses for more clinicians, PIMC will provide an advanced level preceptorship for those who seek more experience in the clinical management of American Indian and Alaska Native people living with HIV disease.

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TPED was designed to fill a gap in existing HIV/AIDS training opportunities that targeted clinical practitioners. Given the important role of non-clinical health and support service professionals in the overall coordination of care for people living with HIV/AIDS, as well as their increasing importance in efforts to ensure treatment adherence, TPED targeted a broad array of non-clinical professionals working primarily in communities of color. Staff targeted by the program included case managers,
social workers, health educators, peer counselors, substance abuse providers and mental health professionals. Minority providers funded through the CARE Act and programs serving the incarcerated were two priority groups targeted by the program.

The New York State TPED (NYS TPED), one of nine TPED sites across the country, was administered by the New York State AIDS Institute (AI) — the agency responsible for state AIDS programming in New York. AI formed partnerships with 16 other agencies, including five academic medical centers, ten MCBOs and the New York Academy of Medicine. The goal of the program was twofold: (1) to improve the quality of HIV care provided to people of color through the training of non-clinical staff; and (2) to build MCBOs’ internal capacity for training on an ongoing basis.

To recruit participating MCBOs, the NYS TPED targeted areas of the state with high HIV prevalence, namely Harlem, Brooklyn, Manhattan, the Bronx and Buffalo. All of the MCBOs served primarily communities of color and included a provider serving migrants in the rural Rochester/Finger Lake area of the state, two programs targeting the incarcerated and those recently released from prison, as well as substance abuse service providers.

The program consisted of three main components. The first was a series of two-day workshops for health and social service providers at MCBOs designed to teach these individuals how to train others in their agency and/or community. In addition to developing training skills, these train-the-trainer workshops provided instruction in three substantive areas: HIV treatment education, mental health and HIV, and substance abuse and HIV. The second component of the program consisted of work-site-based training conducted by staff from five participating academic hospitals. Hospital staff traveled to participating community-based organizations (CBO) to train non-clinical staff in various subjects determined through a needs assessment conducted at the CBO. Through the third component, the NYS TPED used distance learning tools, such as satellite videoconferences, audio conferences and tapes of each, to expand the reach of the program to providers located in more rural or remote areas of the state.

In recognition of the limited staff resources and service demands placed on community-based service providers, one of the features of the TPED model was the provision of financial support to participating MCBOs to partially offset the cost of staff participation. Despite this feature, the time and organizational commitment required was significant. This, combined with high turnover among providers involved in the training program, was a challenge for the NYS TPED in its first year. In subsequent years, the AI attempted to help agencies address other organizational capacity issues that affected their ability to participate in the program, and encouraged the participation of more than one representative from each agency to ensure continuity.

In its three years of existence, the NYS TPED sponsored five trainings for

“This peer-based, train-the-trainer model was designed to develop internal training capacity within minority community-based organizations to ensure that future training is provided in a culturally competent manner.”

Alvaro Carrascal, MD, MPH
Deputy Medical Director,
AIDS Institute
13 train-the-trainer programs involving 147 health and social service providers from MCBOs. These trained staff in turn conducted 170 trainings for 1,368 providers, thereby demonstrating the power of the train-the-trainer model. In the same period, the program also supported 135 hospital-sponsored, on-site trainings involving an additional 2,070 participants and five distance learning events reaching 1,228 providers. According to evaluation data collected by the New York Academy of Medicine, participants felt the program yielded a number of benefits, including: increased knowledge, skills, and confidence; improved linkages to other community-based organizations; and greater understanding of client issues.

At the conclusion of the demonstration project, a streamlined version of the NYS TPED’s train-the-trainer program was transferred to a state-run program that authorizes the delivery of select AIDS-Institute certified training programs (the Authorized Training Agency Initiative). This transfer ensures that the trainings continue in communities where they are most needed and participating agencies receive seamless support from the AI. As evidence of its lasting effect, some elements of the NYS TPED model for developing training capacity within community-based organizations have since been incorporated in HRSA guidance for the national AIDS Education and Training Centers program.

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### Minority AIDS Initiative Funding by Agency, FY 1999-2002
(in $ millions)

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*Some of these funds are used by the Office of the Secretary for Minority AIDS Initiative programs such as The Leadership Campaign on AIDS and Crisis Response Teams. However, the majority of these funds are distributed by the Office of the Secretary to other DHHS agencies for minority-specific programming including: the CDC, HRSA, SAMHSA, OMH, Office of Women’s Health, and the Office of Population Affairs. Agency-specific allocations of these emergency funds vary from year to year. In FY 2002, Congressional report language for the MAI refers to these funds as “General Department Management,” or GDM funds.

Source: Health Resources and Services Administration. Totals for HRSA do not equal those in Table 2 due to additional MAI funds allocated to HRSA for non-CARE Act programs such as Community Health Centers and Head Start. Totals in above table may not equal amounts in report language in Appendix C due to the reprogram of additional funds to the CARE Act for the MAI by HRSA.

*Some of these funds are used by the Office of the Secretary for Minority AIDS Initiative programs such as The Leadership Campaign on AIDS and Crisis Response Teams. However, the majority of these funds are distributed by the Office of the Secretary to other DHHS agencies for minority-specific programming including: the CDC, HRSA, SAMHSA, OMH, Office of Women’s Health, and the Office of Population Affairs. Agency-specific allocations of these emergency funds vary from year to year. In FY 2002, Congressional report language for the MAI refers to these funds as “General Department Management,” or GDM funds.
The conference agreement provides $12,000,000 in additional funding to be targeted to addressing treatment outcome disparities in communities of color, and will complement existing and previously planned targeted HIV/AIDS minority activities. In allocating these funds, consideration should be given to the territories, such as in the Virgin Islands, where, for example, the HIV/AIDS case rate is more than twice the national case rate of 24.1 per 100,000.

**FY 2000**
The conference agreement includes a total of $74,100,000 for Ryan White AIDS activities that are targeted to address the trend of the HIV/AIDS epidemic in communities of color, based on rates of new HIV infections, minority AIDS prevalence and mortality from AIDS. These funds are allocated as follows: [see Appendix C for Title-specific allocations.]

**FY 2001**
The conference agreement includes $109,200,000 for Ryan White AIDS activities that are targeted to address the trend of the HIV/AIDS epidemic in communities of color, based on the most recent estimated living AIDS cases, HIV infections and AIDS mortality among ethnic and racial minorities as reported by the Centers for Disease Control and Prevention. These funds are allocated as follows: [see Appendix C for Title-specific allocations.]

**FY 2002**
Within the total provided, $123,200,000 is for Ryan White AIDS activities that are targeted to address the growing HIV/AIDS epidemic and its disproportionate impact upon communities of color, including African Americans, Latinos, Native Americans, Asian Americans, Native Hawaiians, and Pacific Islanders. Department statistics show that racial and ethnic minorities represent the highest number of new AIDS cases. While African-Americans and Hispanics are only 12 percent and 13 percent of the U.S. population respectively, they account for at least 55 percent and 20 percent, respectively, of all new AIDS cases. In addition, more than 60 percent of people living with AIDS are racial minorities. Congress began funding the Minority HIV/AIDS Initiative in fiscal year 1999. It was designed to focus special attention on solving a growing public health problem as well as develop and improve the capacity of minority community based organizations to more effectively serve their communities. This approach was tailored to yield innovative and successful strategies specifically targeted to the highest risk and hardest to serve populations, which for the past two decades have
eluded more traditional HIV/AIDS prevention, treatment and education efforts.

In distributing these funds, the Committee expects HRSA to tailor the portion of the Ryan White programs that are funded under the Minority HIV/AIDS Initiative as tightly as possible to address the growing health problem and maximize the participation of minority community based organizations. In evaluating organizations' capacities, HRSA should take into consideration that the board, management and key staff are representative of the minority communities served, be situated closest to the targeted problem, have a history of providing services to these communities and have documented linkages to the targeted populations, so that they can help close the gap in access to service for the highly impacted communities of color in the interest of public health.

These funds are for activities that are designed to address the trends of the HIV/AIDS epidemic in communities of color based on the most recent estimated living AIDS cases, HIV infections and AIDS mortality among ethnic and racial minorities as reported by the Centers for Disease Control and Prevention. Consistent with this overall direction, these funds are allocated as follows: [see Appendix C for Title-specific allocations.]
Title I
The conference agreement designates $5,000,000 in Title I supplemental funding and directs that these funds be allocated to eligible metropolitan areas that have 30% or more African American and Latino HIV/AIDS cases in an effort to improve the quality of care and health outcomes for African Americans living with HIV/AIDS.

Title II
No MAI funds were allocated for Title II in FY 1999.

Title III
$3,000,000 in Title III to be used for targeted planning grants designed to build the HIV primary care capacity of indigenous organizations serving African American communities highly impacted by HIV/AIDS.

Title IV
$2,000,000 in Title IV to address the prevalence of HIV and AIDS among African American children.

AETC/PART F
$2,000,000 for subcontracts awarded through the AIDS Education and Training Centers to the Historically Black Colleges and Universities for the education of health care providers serving African American communities on the Guidelines for the Use of Anti-retroviral Agents in HIV-Infected Adults and Adolescents as developed by the Department of Health and Human Services.

**FY 2000**

Title I
Within Ryan White Title I, the conference agreement includes $26,500,000 for supplemental funding and directs that these funds be allocated to eligible metropolitan areas targeting African Americans, Latinos, Native Americans, Asian Americans, Native Hawaiians and Pacific Islanders in highly impacted communities. These funds are expected to expand service capacity in communities of color, assist children orphaned by AIDS, and expand peer education to individuals living with HIV/AIDS.

Title II
No MAI funds were allocated to Title II in FY 2000.
Title III
Within Ryan White Title III, the conference agreement includes $27,400,000 for planning grants, direct service grants and targeted technical assistance and capacity building grants to minority community-based health care and service providers with a history of service provision to communities of color. Funds should also be made available to national, regional and local organizations representing people of color to provide technical assistance collaborations, and linkages designed to strengthen HIV/AIDS systems of care.

Title IV
Within Ryan White Title IV, the conference agreement includes $12,200,000 to fund traditional minority community-based providers of services to minority children, youth and families to develop and implement culturally competent research-based interventions that provide additional HIV/AIDS care, services and linkages.

AETC/PART F
Under AIDS education and training centers, the conference agreement includes $6,800,000 to increase training and recruitment of community-based minority health care professionals in AIDS-related treatments, standards of care, guidelines for the use of anti-retroviral and other effective clinical interventions, and treatment adherence for HIV/AIDS infected adults, adolescents and children, as developed by the U.S. Public Health Service. Within the funds available for education and training centers, $350,000 is included for the AIDS Education Training Center at the University of California at San Francisco to establish a national hotline for health care providers.

Title I
Within Ryan White Title I, the agreement provides $34,000,000 to the competitive supplemental allocation targeted to minority community-based organizations, as defined by the Centers for Disease Control and Prevention, and directs that these funds be allocated through the established planning council processes of eligible metropolitan areas. These funds are designed to reduce the HIV-related health disparities and improve the health outcomes for HIV-infected African Americans, Latinos, Native Americans, Asian Americans, Native Hawaiians and Pacific Islanders. These funds are expected to expand medical and supportive service capacity in communities of color, and expand peer treatment education that is both culturally and linguistically appropriate to individuals living with HIV/AIDS.

Title II
Within Ryan White Title II, the agreement provides $7,000,000 for State HIV care grants to support educational and outreach grants to minority community-based organizations to increase the number of minorities participating in the AIDS Drug Assistance Program (ADAP). The continuing under representation of African Ameri-
cans, Latinos, Native Americans, Asian Americans, Native Hawaiians and Pacific Islanders in state run ADAP contributes to their persistently poor health outcomes in comparison to other communities.

**Title III**

Within Ryan White Title III, the agreement provides $44,400,000 for planning grants, early intervention service (EIS) grants to minority community-based health care and service providers with a history of service provision to communities of color. Funds should also be made available to national, regional and local organizations representing people of color to provide technical assistance collaborations and linkages designed to strengthen HIV/AIDS systems of care. Funds are intended to support the implementation of the plans developed by minority community-based and health care organizations. The conferees expect that fiscal year 2001 increases to Title III should be directed primarily towards providing early intervention service grants to those organizations that received Title III planning grants in the previous fiscal year and enhancing the service capacity of existing minority EIS providers.

**Title IV**

Within Ryan White Title IV, the agreement provides $15,700,000 to fund traditional minority community-based providers of services to minority children, youth and families to develop and implement culturally competent and linguistically appropriate research-based interventions that provide additional HIV/AIDS care, services and linkages. Funds are also intended to directly fund minority community based organizations and providers to expand or implement programs specifically designed to provide youth, adolescent, and young adult-focused HIV/AIDS care and services. The conferees intend that at least ninety percent of total Title IV funding be provided to grantees. The conferees expect the agency to use the funding increases for Title IV, with the exception of any increases provided through the CBC/Minority AIDS Initiative, to provide, at a minimum, additional funds to existing grantees to reflect the increases in the costs of providing comprehensive care. The agency should use a significant portion of the remaining funds to expand comprehensive services for youth, both through existing and new grantees. The conferees believe that the agency should expand efforts to facilitate ongoing communication with grantees so that prospective changes in the administration of the program can be discussed.

**AETC/PART F**

The agreement provides $7,700,000 to AIDS education and training centers. These funds are intended to increase training of community-based minority health care professionals in AIDS-related treatments, standards of care, guidelines for the use of antiretroviral and other effective clinical interventions, and treatment adherence for HIV/AIDS infected adults, adolescents and children, as developed by the U.S. Public Health Service. The training of minority providers is to be implemented through collaboration with Historically Black Colleges and Universities (HBCU), Hispanic Serving Institutions and Tribal Colleges. These efforts are designed to increase the treatment expertise and HIV knowledge of minority front-line providers serving
individuals living with HIV/AIDS. Funds are also intended to support minority community-based organizations to train minority providers to deliver culturally competent and language appropriate treatment education services.

**Title I**
Within the total provided, $41,800,000 is for competitive, supplemental grants to improve the HIV-related health outcomes for communities of color and reduce existing health disparities. Funds should be allocated through the established planning council processes of Title I eligible metropolitan areas. The Committee strongly urges the Planning Councils to maximize the participation of minority community based organizations as defined above. These funds are expected to improve and develop the capacity of these organizations to deliver HIV-related treatment and supportive services within communities of color, that are both culturally and linguistically appropriate to individuals living with HIV/AIDS.

**Title II**
Within the total provided, $7,000,000 is for State HIV care grants to support educational and outreach services to increase the number of eligible minorities who access HIV/AIDS treatment through AIDS Drug Assistance Programs (ADAP). The Committee strongly urges states to maximize the participation of minority community based organizations in delivering these educational and outreach services. The Committee is concerned that the continuing under representation of African Americans, Latinos, Native Americans, Asian Americans, Native Hawaiians, and Pacific Islanders in state-run ADAP contributes to their persistently poor HIV/AIDS health outcomes in comparison to other populations.

**Title III**
Within the total provided, $49,400,000 is for planning grants and Early Intervention Service (EIS) grants to health care providers with a history of serving communities of color. The Committee strongly urges HRSA to maximize the participation of minority community-based organizations as defined above in planning and delivering EIS. Funds should also be made available to regional and local technical assistance organizations to assist service providers in identifying and increasing the retention of minorities in care with an emphasis on women and gay men of color in highly impacted and underserved areas. Within the increase provided, HRSA is urged to make enhancing the service capacity of existing minority EIS providers a priority.

**Title IV**
Within the total provided, $17,000,000 is to sustain and expand efforts to deliver comprehensive, culturally competent and linguistically appropriate research-based intervention and HIV care services to minority women, infants, and children. The Committee strongly urges HRSA to maximize the participation of minority community-based organizations as defined above in delivering these services. Priority should be
given to these organizations and providers with a history of effectively providing services to communities of color to expand or implement programs specifically designed to provide youth, adolescent, and young adult-focused HIV/AIDS care and services. These funds will help to bridge targeted prevention and medical care and treatment services to youth and young adults.

**AETC/PART F**

Within the total provided, $8,000,000 is to increase the training capacity of AETCs to expand the number of community-based minority health care professionals with treatment expertise and knowledge about the most appropriate standards of HIV/AIDS-related treatments and medical care for HIV infected adults, adolescents and children as developed by the US Public Health Service. The training of minority providers is to be implemented through collaborations with Historically Black Colleges and Universities (HBCU), Hispanic Serving Institutions and Tribal Colleges. These efforts are designed to increase the treatment expertise and HIV knowledge of minority front-line providers serving individuals living with HIV/AIDS. Funds are also intended to support minority community based organizations to train minority providers to deliver culturally competent and linguistically appropriate treatment education services.

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* The FY 2002 Labor, Health, Human Services and Education Conference Agreement states that the $123.2 million appropriated to the CARE Act for MAI is to be used consistent with language contained in the House report, which is provided here. Additional text is available in the FY 2002 Conference Agreement.


4. Ibid.


8. Ibid. Table 11.

9. Ibid. Table 15.


11. Ibid.

12. Ibid.

13. PACHA members Debra Fraser-Howze and Alexander Robinson, both of whom participated in the April meeting at the CDC, presented the list of demands to the Council during its March 15–18, 1998 meeting.

14. Beny Primm, MD is Executive Director of the Addiction Research and Treatment Corporation in Brooklyn, NY. At the time of the CBC Health Braintrust Forum, Dr. Primm was Vice-Chair of the Board of Directors for the National Minority AIDS Council (NMAC).

15. The individuals who drafted the FY 1999 Congressional report language included Fredette West of former Representative Louis Stokes' office; Debra Fraser-Howze of the National Black Leadership Commission on AIDS (BLCA); and Miguelina Ileana Leon formerly of the National Minority AIDS Council's Government Relations staff. Others who were also involved in MAI advocacy later in the FY 1999 appropriations process include Cornelius Baker, formerly of the National Association of People With AIDS (NAPWA) and current director of Whitman Walker Clinic, and Ernest Hopkins of the San Francisco AIDS Foundation.

