Living With AIDS: State Programs and Communities Help Patients Prevent HIV Transmission

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More than 1 million people are living with HIV/AIDS in the U.S., and are living longer since drug treatments became available in the 1990's. African-Americans are disproportionately affected, and represent nearly half of all people living with HIV. More than half of all Americans living with HIV reside in southern states. State Medicaid and prevention programs are connecting with communities to help HIV/AIDS patients stay productive and to prevent HIV transmission. Effective policies include HIV testing as part of routine medical care and increasing public awareness of the need for HIV testing.

Gina Brown has a chronic disease that requires continuous medical treatment. She’s been infected with HIV since 1994.

Because drug treatments weren’t available then to prevent HIV from progressing to AIDS, Brown—who was diagnosed with HIV during a prenatal visit—was told she would die from the disease. Fifteen years later, Brown works for the NO/AIDS Task Force in New Orleans, has a healthy teenage daughter, and advocates that woman should take an HIV test and know their status.

She's living with HIV.

“We all start out thinking HIV is a death sentence, but it’s a chronic disease now,” Brown says in her video on the Southern AIDS Living Quilt Web site. She’s one of 30 women who share their stories on the site, an effort among several Southern states to raise awareness of HIV/AIDS and to encourage testing for the disease. The effort is called a living quilt because women living with the disease continuously add their stories, helping the site grow organically.

“The stories help to put a face on what AIDS looks like—and it looks like everybody,” said Evelyn Foust, AIDS and STD director at the North Carolina Division of Public Health and co-chair of the Southern AIDS Coalition. She helped develop the AIDS Living Quilt Web site.

“The women who tell their stories on the Living Quilt are heroes because they are going public in the face of the stigma that still exists, in order to motivate women to take charge of their own health,” Foust said.

Knowledge is a key in battling the disease. Since the advent of antiretroviral drug therapy in the 1990s, HIV/AIDS infections are no longer a death sentence. HIV patients who are diagnosed early and
receive treatment are living longer, more productive lives.

For that and other reasons, states across the country are searching for ways to raise awareness of HIV, reduce the associated stigma and encourage people to know their HIV status through testing. State health and Medicaid officials are working with people living with HIV/AIDS, community advocates and faith-based organizations to halt the spread of HIV.

Through these efforts, states are helping communities sponsor testing, providing information to individuals about how to avoid infections, getting those who are infected in treatment, and coordinating care for people who have HIV/AIDS.

An estimated 1 million people in the U.S. are infected with HIV or have AIDS, according to the Centers for Disease Control and Prevention. But one in five of those with HIV/AIDS don’t know they have it and are likely to give it to others, according to the CDC. Each year 56,000 Americans are infected with HIV that could have been prevented, according to CDC’s most recent estimates.

Twelve states have AIDS case rates higher than the national rate of 12.5 per 100,000 people. Rates are also highest in metropolitan areas, according to the Kaiser Family Foundation, and Washington, D.C., reported in March that that the severe epidemic of HIV/AIDS has infected at least 3 percent of the District’s residents.

The South has the highest estimated number of people living with AIDS.

And when it comes to the people affected by the disease, of all the HIV/AIDS racial/ethnic disparities, African-Americans are the hardest hit. (See last section of article.)

**Raising HIV Awareness and Encouraging Testing**

The CDC recommends routine HIV testing in all medical care settings for patients ages 13 to 64, and at least once a year for those at high risk of infection. But the recommendations say patients should have the choice to opt out of testing, and a majority of state laws adhere to that recommendation, according to a recent *Annals of Internal Medicine* report.

North Carolina acted on those recommendations and made HIV testing part of routine medical care in 2007. Since then, HIV testing at the state health departments has more than doubled, according to Foust. Legislators supported new funding for the expanded testing, and the efforts have paid off, she said.

“Together with increased federal funding, we have done a phenomenal job of getting more people tested and getting more patients treated who are in the early stages of HIV,” she said. “We are beginning to see progress in reduced death rates from AIDS, and now is not the time to reduce funding for these important programs.”

North Carolina isn’t alone in reaching out to communities to identify and counsel those with infected with HIV. State programs, all with CDC-funded positions, are referring HIV positive patients to treatment programs and educating them on how changing risky behavior can help avoid infecting others. And since HIV patients are living longer, programs also reinforce prevention education, motivate patients to take their medication for the rest of their lives, and refer them to sources of care and services as their medical, psychological and other needs change.

Even for those who are not infected with the disease, state prevention efforts focus on teaching behaviors to protect people from becoming infected and emphasizing periodic re-testing for HIV.
Mississippi, for example, has seen a dramatic increase in HIV infections in recent years. So the state’s Department of Health STD/HIV Office is working to reach people in nontraditional ways, said spokesperson Juanita Davis. She said there is a greater need for more “culturally sensitive programs and activities that bring about awareness in order to make more people more aware, particularly those most susceptible to infection.”

Mississippi is targeting young people through teen summits and addressing cultural barriers that hinder education, awareness and testing, Davis said. “The perception of the community is so important when addressing this issue,” she said.

State health departments have found willing partners in faith-based organizations on many health issues, and particularly on preventing HIV/AIDS. The Rev. J. Lee Hill, an associate pastor at The Riverside Church in Manhattan who helps coordinate HIV/AIDS awareness and prevention programs for youth in New York City, said HIV/AIDS “is no longer consigned to a particular group or population.”

Hill believes it is imperative that everyone from government officials to everyday citizens participate in this important fight. “It’s an issue that affects us all,” he said.

And that’s a reason behind the Southern AIDS Living Quilt Web site, launched last October. The stories emphasize that ordinary women, especially women of color, can be affected by HIV and live normal lives. In addition, health professionals, advocates and clergy deliver messages that many women can have HIV and not be aware of their status, and all need to be tested and take precautions against HIV infection.

“The reason we are targeting women in the South is that when you look at new AIDS cases, they represent the biggest disparities in the South, and new AIDS cases are still over-represented in the South,” said Foust.

Tanya Bass, an HIV/AIDS health educator in North Carolina, has used the Living Quilt stories as a teaching tool in her work with college students.

“The students said the stories made HIV infection real for them,” Bass said. “By presenting the information in the way students are accustomed to learning, with a real person telling their story, they learned about the impact of HIV in our community much better than they would from reading a report.”

When the Southern AIDS Living Quilt was launched, state health department events focused on HIV/AIDS in Southern states, particularly how the disease affects women. In Florida, which ranks third behind New York and California in the number of AIDS cases since the beginning of the epidemic, the Living Quilt was presented at the University of Miami medical school where Florida women told their stories publicly, some in Spanish.

Tom Liberti, the HIV/AIDS bureau chief in the Florida Department of Health and one of the founders of the Southern AIDS Coalition and the Living Quilt, said the presentation was important in addressing the problem. “It is critical that we turn the tide on the 56,000 new HIV infections annually. These women’s stories will motivate women to be tested and others to stay on their medication,” Liberti said.

Florida is making progress in controlling HIV infections. The state in 2007 saw a 13 percent decline in the number of AIDS deaths, consistent across all groups including African-Americans, he said.

“We continue to build on existing relationships with church and other community leaders to include AIDS prevention activities in their work,” Liberti said. “Prevention grant funding is being targeted to
specific communities such as African-American women, Haitian communities or men who have sex with men. Finally, expanded testing programs funded by the CDC African-American initiative reached over 370,000 people in Florida for 2008, representing the largest publicly funded testing program in the United States.”

**Medicaid Covers Treatment and Prevention**

Those who test positive for HIV/AIDS need treatment, experts say. States help provide some of that treatment. Medicaid is the largest health insurance coverage program for people with HIV in the United States. According to the Kaiser Family Foundation, total Medicaid spending for HIV reached $7.5 billion in the 2008 fiscal year, with states providing $3.4 billion of that. Although Medicaid HIV costs have increased, they represent less than 2 percent of all Medicaid spending, according to Kaiser.

Most HIV/AIDS patients qualify for Medicaid because they are low-income, disabled and receiving Supplemental Security Income benefits, according to Kaiser. A few states have also implemented federal Medicaid waivers to cover low-income people with HIV before they become disabled. Coverage of HIV/AIDS medications may be available through Medicare Part D for dually eligible disabled Medicaid recipients, and also through AIDS Drug Assistance Programs in all states; the programs are supported by a combination of federal and state funding.

For state Medicaid programs, patients living longer with HIV/AIDS result in increased costs for long-term antiretroviral drug therapy medical treatment. A 2006 Cornell University Medical School study reported in *Medical Care*, the journal of the American Public Health Association, estimated that lifetime medical costs for HIV exceed $600,000.

But, early treatment with antiretroviral drug therapy can delay the onset of AIDS with its debilitating effects that often cause people to leave the work force. A recent CDC study, completed in collaboration with Emory University’s Center for AIDS Research and Georgia State University, found that productivity losses were up to five times higher than the direct costs of medical care for people with HIV/AIDS. According to the authors, the additional years of productivity in those receiving antiretroviral drug therapies far outweigh the additional costs of treatment.

States are taking notice.

In Florida, the Medicaid program addresses prevention as part of care management for AIDS patients. The Project AIDS Care Medicaid waiver “promotes, maintains and optimizes the health of persons living with AIDS to delay or prevent institutionalization,” said Sue Conte of the Florida Agency for Healthcare Administration.

AIDS patients are assigned nurse case managers who provide health, education, custodial and support services. The case managers “work with state, county and local community agencies to make sure that services are provided regardless of the funding source,” Conte said.

Florida also provides disease management services for patients with HIV/AIDS who don’t qualify for the waiver program; those services also incorporate prevention activities. These programs coordinate with county health department HIV/AIDS programs and offer free HIV screening, education, counseling and referral programs that are open to anyone, regardless of whether they are eligible for Medicaid.

“The Project AIDS Care waiver and disease management program have fostered a collaborative and coordinated approach to providing care for Medicaid beneficiaries with HIV/AIDS in our state,” said Melanie Brown-Wofter, bureau chief for the Florida Medicaid Health Systems Development.
And the programs are paying off.

“As a result, we are seeing an improvement in health status,” Brown-Woofter said.

**1 Million With HIV/AIDS and Counting**

More than 1 million people in the U.S. have HIV/AIDS, and about 56,000 Americans are infected with HIV each year, according to the Centers for Disease Control and Prevention. But, one in five is not aware of their disease and likely to spread it to others.

More than half of the newly infected are men who have sex with men (including all racial and ethnic groups).

Although African-Americans made up only 12 percent of the U.S. population, nearly half of all people living with HIV/AIDS were African-American in 2007.

A similar disparity exists for Hispanics and Latinos. With only 15 percent of the population from these groups, 18 percent of all people living with HIV/AIDS are Hispanic or Latino.

Disparities are most pronounced among women. The new HIV infection rate in African-American women is 15 times that of white women, and the rate among Hispanic women is four times the rate in white women.

Among men, new HIV infection rates in African-Americans are six times those of whites, and Hispanic men are infected twice as often as whites. Young African-American men have experienced the highest increases in HIV infection rates in recent years.

**Risky Behaviors Lead to Infection**

Men living with HIV/AIDS most often contracted the disease through male-to-male sexual contact. As for women, nearly three-fourths of women were infected through high-risk heterosexual contact.

Sixteen percent of all men and 26 percent of all women with HIV contracted the virus through injection drug use and sharing dirty needles, and fewer cases involve transmission between mother and child before or during childbirth or through breastfeeding.

**HIV/AIDS in the South**

A nearly 26-percent increase in HIV/AIDS cases has been reported in the South since 1996, the greatest increase of any region.

Although only 36 percent of the nation’s population live in the South, the region accounted for approximately one-half of all AIDS deaths in 2005, and more than one-half of all Americans living with HIV live in the South.

More than one-half of African-Americans living with AIDS and 58 percent of new AIDS cases reported in 2006 among African-Americans occurred in the South.

Over the past 15 years, the greatest increases of HIV for Hispanics or Latinos have been in rural areas of the South.
Lack of increased federal funding for the region despite increased diagnoses and generally underfunded health care throughout the region is becoming increasingly problematic. According to the Southern AIDS Coalition, the South had the highest number of people living with AIDS in 2005 (approximately 170,000), but it ranked last in per-person spending ($6,565/person--$1,082 in CDC HIV/AIDS funding and $4,548 in Ryan White funding.

Southern states comprise approximately 65 percent of all AIDS cases among rural populations in the U.S., according to the Southern AIDS coalition. This is particularly significant because problems with screening and treatment for HIV/AIDS are exacerbated in rural areas.

Higher rates of poverty and unemployment compared to the rest of the country entail greater levels of homelessness, another major factor affecting the success of treatment and prevention programs.

The highest rates of uninsured and underinsured residents in the country cause limited access to advanced treatments such as antiretroviral drug therapy, drastically reducing their life expectancy and, in turn, the years of productivity that they would otherwise contribute to the work force.

Sources: Centers for Disease Control and Prevention, Southern AIDS Coalition

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