WHERE THE STREETS HAVE NO NAME

Strategies & Solutions for Testing & Treating HIV in Underserved Areas of the US

This activity is jointly sponsored by Indiana University School of Medicine, Association of Nurses in AIDS Care (ANAC), and HealthmattersCME.

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Target Audience

This activity has been designed to meet the educational needs of health care providers who care for patients with HIV, including physicians, physician assistants, nurse practitioners, and registered nurses.

Program Overview

Of the approximate 1.1 million Americans living with HIV infection, an estimated 21% are unaware they are infected. An unknown but substantial proportion are aware of their status but do not receive care, or receive it only intermittently. Many of these persons live in areas of the United States where resources—human, financial, and physical—are limited. Their needs for social and economic support may be greater than those of persons who live in areas where such services are more readily available. For persons with HIV who live in rural areas, geographic location, health-system gaps, and aspects of the social environment, including stigma, are all significant challenges that must be addressed in order to provide state-of-the-art testing and care for their illness.

Where the Streets Have No Name monograph is a unique, CME/CE-certified enduring material that describes the problems in underserved areas in the United States and presents some solutions, including the experience of clinics that have overcome barriers to providing care to persons with HIV who live in a variety of resource-limited settings.

Educational Objectives

At the conclusion of this activity, participants should be able to:

- Discuss solutions to the barriers limiting the full implementation of opt-out testing in order to identify those with HIV and link patients into care
- Compare linkage to care models to determine elements that would improve access to care in their practice
- Identify HIV centers of care and HIV providers that can serve as resources in the optimal care of those with HIV in rural areas
- Describe strategies that optimize treatment in an environment with limited or diminishing resources
- Identify issues and barriers to medication adherence for long-term success of antiretroviral medications

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Physician Continuing Medical Education

INDIANA UNIVERSITY
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Accreditation Statement

This activity has been planned and implemented in accordance with the Essential Areas and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint sponsorship of Indiana University School of Medicine and HealthmattersCME. Indiana University School of Medicine is accredited by the ACCME to provide continuing medical education for physicians.

Designation Statement

Indiana University School of Medicine designates this educational activity for a maximum of *1.5 AMA PRA Category 1 Credits™*. Physicians should only claim credit commensurate with the extent of their participation in the activity.

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Note: *While it offers CME credits, this activity is not intended to provide extensive training or certification in the field.*

Nursing Continuing Medical Education

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This program is approved for 1.5 contact hours by the Association of Nurses in AIDS Care (ANAC). The Association of Nurses in AIDS Care (ANAC) is an approved provider of continuing education by the Virginia Nurses Association Continuing Education Approval Committee, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

Disclosure of Relevant Financial Relationships

The following speakers and planning committee disclosed no actual or potential conflict of interest in regard to this program:

Cyndee Burton, RN
Lanny T. Cross
Kirsten Felix
J. Jay Flicker, PsyD
James Murphy
Mary Jane Nealon, RN, MFA

Donna Sweet, MD, disclosed that she has received research honoraria from Bristol-Myers Squibb as well as speaker honoraria from Abbott, Bristol-Myers Squibb, Gilead Sciences, Inc, Pfizer, and Tibotec Therapeutics.

Samir Kumar Gupta, MD, disclosed that he has received grant support from Gilead Sciences, Inc, and Tibotec Therapeutics for unrestricted research.

Debbie P. Hagins, MD, AAHIVS, disclosed that she has received honoraria from Bristol-Myers Squibb (speakers' bureau), Gilead Sciences, Inc (speakers' bureau, advisory boards), Merck (consultant, advisory panel), and Tibotec Therapeutics (speakers' bureau, consultant, spokesperson). She also disclosed that she is a paid consultant for Health HIV.

Derek Spencer, MS, CRNP, disclosed that he has received honoraria for speaking and/or consulting from Gilead Sciences, Inc, GlaxoSmithKline, Merck, and Tibotec Therapeutics.

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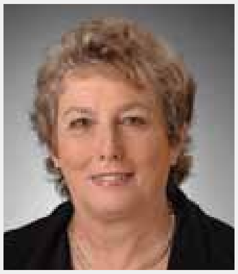
LETTER FROM THE CO-CHAIR



Donna Sweet, MD
Professor of Medicine
Department of Internal Medicine
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Dear Health Care Professional:

Although the HIV/AIDS epidemic in the United States first emerged among gay men in large urban centers, health care professionals who work in rural areas and other communities with limited resources have seen the epidemic hit close to home. In terms of numbers, the epidemic has stabilized since the start of the twenty-first century. But a growing proportion of HIV/AIDS now affects rural Americans and members of minority and disadvantaged populations. Compared to the early years of the epidemic, HIV-positive rural residents are more likely to be nonwhite, women, heterosexual, and locally infected.[1]

Rural Americans, particularly minorities and those who live in remote areas, are more likely than the population as a whole to be poor, unemployed, and underinsured or uninsured as well as to lack access to basic medical care.[2] In rural areas—and indeed in some urban populations—health care system gaps, a lack of clinicians with expertise in treating persons with HIV, and stigma are significant challenges that must be addressed in order to provide state-of-the-art testing and care for persons with HIV. Most HIV care is publicly funded; however, even as the numbers of patients who survive with HIV continues to grow, states are cutting budgets, thereby reducing funding for HIV services across the country.[3-5]

The rural HIV/AIDS epidemic is actually several epidemics. The southeastern United States has the greatest proportion of AIDS cases and deaths in the country.[6] In the rural South, HIV incidence continues to increase, African Americans account for the majority of the newly infected, a higher proportion of those infected are women, and mother-to-infant transmission still occurs.[6] Researchers suggest the epidemic in the Deep South has a great deal in common with HIV/AIDS in developing countries.[7] In other parts of the United States, persons with HIV/AIDS living in rural areas are few in number and are dispersed across large landscapes, thereby making it difficult to provide medical care as well as the support services they need in order to take advantage of it. HIV/AIDS is on the increase among migrant workers and immigrants, populations that are difficult to reach with both HIV prevention and HIV care.[8]

HIV service providers in underserved areas share the need to find ways to provide HIV care—testing and treatment—in an environment with limited or decreasing financial and human resources. This monograph is designed to provide information and examples for those who care for clients with HIV in resource-limited areas of the United States. In addition to didactic information, the program features the stories of 7 HIV service providers, 2 in poor urban areas and 5 in rural areas. These stories can serve as examples of creative approaches to addressing the needs of HIV-infected clients in areas where the challenges are many and the resources are few. It is my hope this publication will serve as a source of encouragement and a resource for clinicians across the United States who are committed to bringing the benefits of HIV treatment and support to those most in need.

Donna E. Sweet MD

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MODELS OF CARE

INTRODUCTION

Since human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) first emerged in the 1980s, it has evolved from a life-threatening emergency to a drawn-out struggle against not only a virus, but demographic, social, and economic challenges to the delivery of effective treatment. Beginning in the 1990s, new antiretroviral (ARV) drugs were introduced that precipitated a dramatic decline in AIDS-related deaths. However, while HIV mortality has plummeted, the number of persons living with HIV and requiring care is increasing. In the United States, HIV/AIDS has become a chronic disease, treatment has shifted from the inpatient to the outpatient setting, and clinicians who care for persons with HIV are now called upon to provide primary care and treatment of the concomitant illnesses of an aging population.[1]

In addition the epidemic increasingly affects minority and low-income populations—populations that historically have had poor access to health care. Persons with HIV face many other life challenges, including poverty, homelessness, drug addiction, mental illness, racism, homophobia, and AIDS stigma. Their needs include a wide range of basic support services as well as HIV treatment and primary medical care. Persons living with HIV in rural areas face additional challenges that derive from geographic isolation, lack of privacy, and limited availability of medical services.

This CME/CE-certified activity, *Where the Streets Have No Name,* describes the epidemiology of HIV in the twenty-first century, tracing the growth of the epidemic in populations with limited access to health care. We review ways to extend HIV testing, engage HIV-infected persons in care, and promote retention in treatment and medication adherence. The program is accompanied by profiles of 7 HIV programs that have adopted a variety of creative approaches to provide medical care and services for persons with HIV who live in underserved areas of the United States.

CHANGING EPIDEMIOLOGY OF HIV

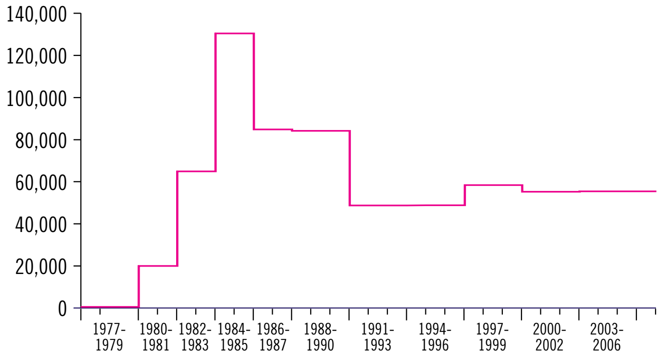
The incidence of HIV/AIDS in the United States has declined markedly since its peak in the 1990s, and antiretroviral therapy (ART) has had striking success in increasing the lifespan of those infected. Nevertheless, HIV/AIDS continues to be a major public health problem. The virus has been spreading in minority and other disadvantaged populations. The proportion of persons who do not know they are infected, those who received a diagnosis but are not in care, and those who received a diagnosis late in the course of the disease remains unacceptably high.

INCIDENCE, PREVALENCE, AND MORTALITY

An estimated total of 1.7 million Americans have been infected with HIV since the first cases of AIDS were reported in 1981. More than 580,000 persons infected with HIV have died, and 1.1 million persons infected with HIV are alive today.[2]

An estimated 56,300 new cases of HIV infection were diagnosed in the United States in 2006, according to the most recent report from the Centers for Disease Control and Prevention.[3] The annual incidence has declined markedly from its peak of >130,000 from 1984 to 1985 (Figure 1). Men who have sex with other men (MSM) remain the predominant transmission category (Figure 2). However, today MSM account for a smaller proportion of cases than in the early years of the epidemic, although HIV incidence is again on the increase in this risk group. HIV transmission via injection drug use has decreased significantly, and a small proportion of new infections occur in MSM who are also injection drug users. In about 31% of cases, HIV is acquired via heterosexual transmission.[2-4]

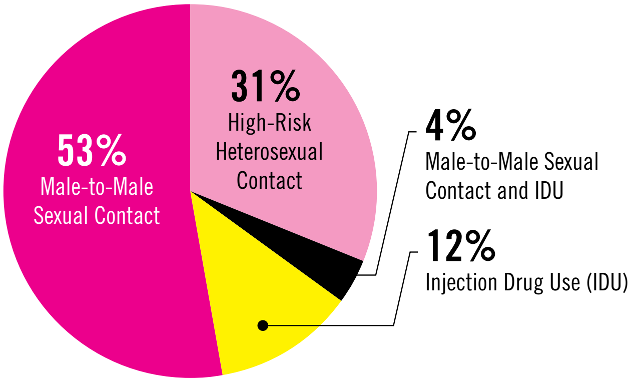
Figure 1. Estimated Number of New HIV Infections, Extended Back-calculation Model, 1977-2006



Note: Estimates are for 2-year intervals during 1980-1987, 3-year intervals during 1977-1979 and 1988-2002, and a 4-year interval for 2003-2006.

Source: Centers for Disease Control and Prevention. Estimates of new HIV infections in the United States. HIV/AIDS Fact Sheet, August 2008.

Figure 2. HIV Transmission Categories in 2006



Source: Centers for Disease Control and Prevention. Estimates of new HIV infections in the United States. HIV/AIDS Fact Sheet, August 2008.

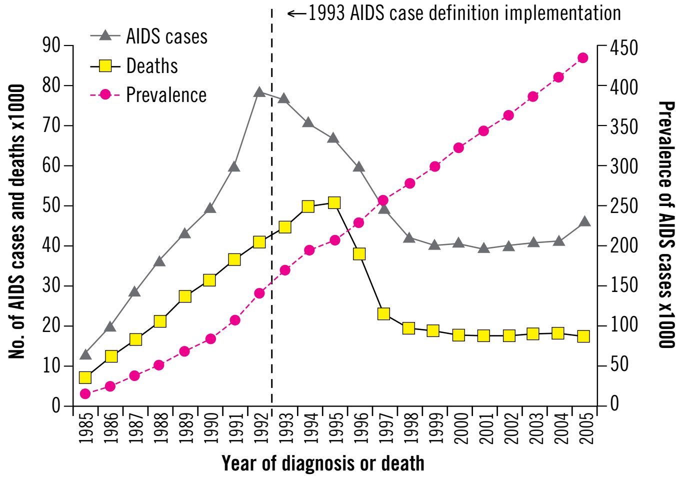
Although the annual incidence of HIV in the United States has remained stable since 2000, the number of persons reported to be living with HIV infection (prevalence) has risen because of increased detection and because HIV-infected persons are surviving longer as a result of more effective ART (Figure 3). With about only 8000 deaths per year, the number of persons with HIV/AIDS is growing at the rate of about 55,000 per year.[3,5]

Of the estimated 1.1 million Americans with HIV, more than 468,000 received a diagnosis of AIDS.[6,7] Estimated HIV prevalence among US adults in 2006, including diagnosed and undiagnosed infection, was 447.8/100,000 population (0.447%).[6]

Antiretroviral Therapy and Increased Survival

In the 1990s combination ART was adopted as the standard of care for persons with HIV infection. Continuing improvements in the effectiveness of ARV regimens have resulted in an 80% decrease in AIDS-related mortality and large reductions in the incidence of opportunistic infections that were previously the hallmark of an AIDS diagnosis.[1] According to one analysis, each of 6 successive eras of treatment was associated with a stepwise increase in patient life expectancy. The most recent era, which began in 2003, consisted of new ARV regimens with improved efficacy and tolerability and reduced complexity, the introduc-

Figure 3. Annual AIDS Incidence and Mortality (left Y-axis) and Prevalence (right Y-axis) 1985, 2005



Source: Fenton KA. Changing epidemiology of HIV/AIDS in the United States: implications for enhancing and promoting HIV testing strategies. *Clin Infect Dis.* 2007;45:S213-S220.

tion of enfuvirtide, and prophylaxis of *Pneumocystis* pneumonia and *Mycobacterium avium* complex disease. This standard of care resulted in an estimated 13.3 years of additional survival per patient compared with the absence of treatment.[8] This analysis was based on a mathematical model of all persons with AIDS who entered care from 1989 to 2003 and was designed to obtain a conservative estimate of the survival benefits of treatment.

Other analyses suggest even greater survival benefits in HIV-infected persons who enter treatment before they receive a diagnosis of AIDS. In groups with the most favorable prognosis, the average overall life expectancy for persons who start ART is beginning to approach the life expectancy of persons who are not infected with HIV. One study included more than 43,000 adults in 14 treatment cohorts in the United States, Canada, and Europe who began ARV in 3 different treatment eras, beginning in the mid-1990s.[16] All study participants were previously untreated and began therapy with a potent combination of at least 3 antiretroviral drugs. Participants in the third treatment cohort (from 2003 to 2005), experienced a 13-year gain in life expectancy compared with those treated in the mid-1990s. For patients who began HIV treatment at age 20 years and had a CD4 count ≥200 cells/mm³, the average *additional* life expectancy was more than 50 years. Even for patients who began ART at age 35 years with a CD4 count <100 cells/mm³, the average life expectancy would be into the early 60s. The study authors point out that a gap in life expectancy still exists between persons with HIV and the general population because of both HIV and underlying lifestyle, socioeconomic, and health issues.[9]

An even more recent study from the Netherlands suggests that some groups of HIV-infected persons who are ineligible for ART can live as long as their uninfected peers. ATHENA is the Dutch national observational cohort of persons with HIV. The European HIV treatment guidelines recommend starting ART only for patients with CD4 counts <350 cells/mm³, in contrast to the 2009 US guidelines, which recommend ART initiation for persons with CD4 counts ~500 cells/mm³. The ATHENA cohort consisted of 4612 HIV-infected persons who were asymptomatic and had not yet received ART 24 months after they received a diagnosis of HIV infection. Compared with the general population, diagnosis of HIV infection at age 25 years was associated with only a 0.4-year loss of life expectancy, whereas diagnosis of HIV infection at age 35 years was associated with 1.3 years of potential life lost.[10]

TRENDS IN HIV EPIDEMIOLOGY: GREATER DISPARITIES AND UNMET NEEDS

Although the gains in survival are impressive, optimal treatment is not reaching all HIV-infected persons who may benefit from it. Until the mid-1990s, gay white men were the population most affected by the HIV/AIDS epidemic in the United States. However, the impact of HIV in minorities has been disproportionate to their numbers in the general population since the early years of the epidemic, and these demographic imbalances are increasing (Figure 2; Table 1). HIV prevalence is on the rise in harder-to-reach populations with limited access to medical care and services—notably residents of rural areas, particularly in the southern United States. With increased survival and greater opportunities to treat persons with HIV come increased demands for medical and support services. Funding and other resources have not increased to meet this expanding need.

HIV in Ethnic/Racial Minorities

Although blacks*/African Americans and Hispanics/Latinos together make up one-fourth of the US population, they account for nearly two-thirds of new HIV infections (Table 1; Figure 4) and a growing majority of persons living with HIV/AIDS (Table 1; Figure 5).[2,11] HIV incidence in blacks/African Americans is 7 times that of whites, and HIV incidence in Hispanics/Latinos is more than 2.5 times that of white Americans.[12,13] Members of these

Table 1. Estimated HIV Incidence and Prevalence in US Adult Population, by Ethnicity and Sex

HIV prevalence in 2007 (persons living with HIV/AIDS per 100,000 population)	
Black/African American	59.2
Native Hawaiian/Other Pacific Islander	22.3
Hispanic/Latino	20.4
American Indian/Alaska Native	8.6
White	6.1
Asian	4.3
Men	21.6
Women	7.5
Total	**14.4**
HIV incidence in 2006 (new infections per 100,000 population)	
Black/African American	83.7
Hispanic/Latino	29.3
American Indian/Alaska Native	14.6
White	11.5
Asian/Other Pacific Islander	10.3
Men	34.3
Women	11.9
Total	**22.8**

Source: Centers for Disease Control and Prevention. HIV/AIDS surveillance report, 2007. Vol 19. Atlanta: US Department of Health and Human Services, Centers for Disease Control and Prevention; 2009.

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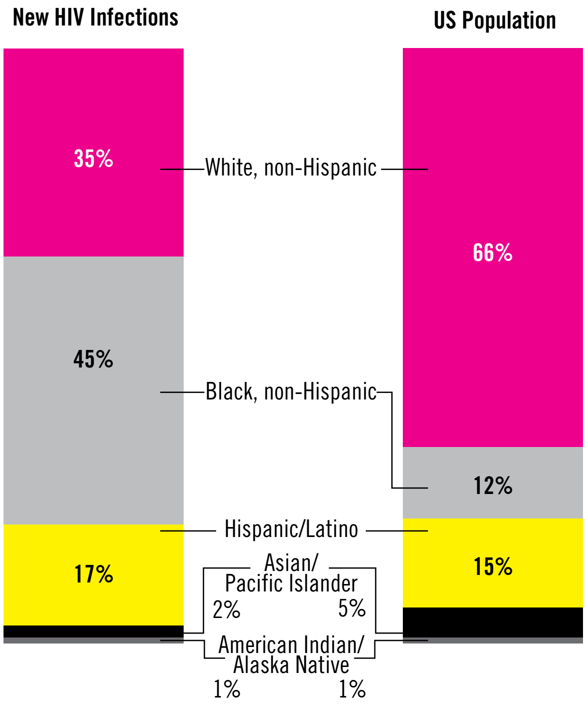
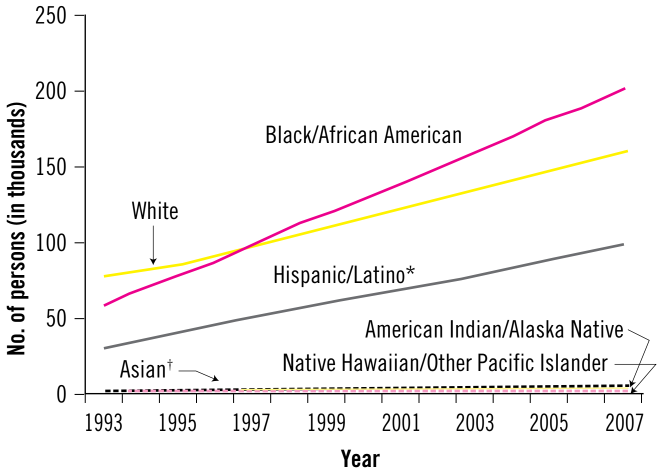
*To be inclusive of all persons of black race represented in national HIV surveillance data and HIV prevention efforts, the term "blacks" as used in this monograph includes African Americans, Caribbean Americans, Africans, and other persons of black race who may not self-identify as "African American" unless otherwise specified.

Figure 4. New HIV Infections in US Population by Race/Ethnicity, 2006



Source: Fact Sheet: Latinos and HIV/AIDS, (#6007-07). The Henry J. Kaiser Family Foundation, September 2009.

Figure 5. Estimated Number of Persons Living with AIDS, by Race and Ethnicity, 1993-2007—United States and Dependent Areas



Note: Data have been adjusted for reporting delays.
**Hispanics/Latinos can be of any race.*
[†] Includes Asian and Pacific Islander legacy cases.

Source: Centers for Disease Control and Prevention. HIV/AIDS surveillance report, 2007. Vol 19. Atlanta: US Department of Health and Human Services, Centers for Disease Control and Prevention; 2009.

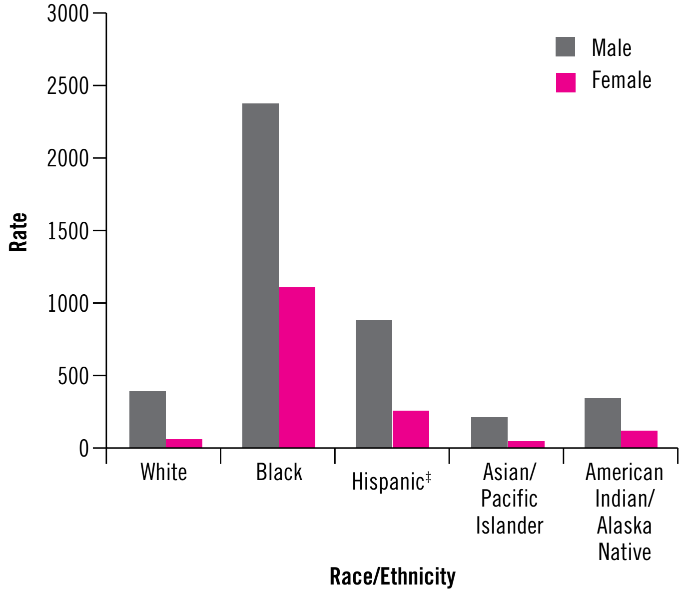
ethnic groups are also more likely than whites to report limited access to the health care system and to be uninsured or publicly insured.[12,13]

Blacks/African Americans. Forty-five percent of new HIV infections occur in blacks/African Americans, who make up 13% of the US population. The CDC estimates that more than 500,000 blacks/African Americans are HIV-infected. MSM are the predominant transmission category among black men, but black men are less likely than white men to be infected with HIV this way and more likely to be infected via injection drug use or heterosexual transmission.[12] Racism, homophobia, incarceration, and stigma are particular contributors to the growth of HIV among black men. The incarceration of black men is a significant risk factor for HIV and may serve as a link between HIV transmission among MSM and men who have sex with women.[5]

Racial and ethnic disparities in HIV/AIDS are even more pronounced among black women than black men. In 2006, 64% of US women living with HIV/AIDS were black. HIV incidence in black women is 20 times the rate in white women.[14] Women represent more than one-third of all new AIDS cases diagnosed among blacks, a higher proportion than other ethnic groups (Figure 6).[12] Three-fourths of HIV infections in black women are sexually transmitted; the remaining HIV infections are acquired via injection drug use.[14] High rates of HIV infection via sexual transmission among black women may be attributed to several potential factors: high seropositivity rates among black men; fewer available male partners for black women (and subsequently less power in relationships to demand safer sex practices); and a relatively high rate of concurrent sexual relationships.[14]

Hispanics/Latinos. Seventeen percent of new HIV infections in the United States occur in Hispanics/Latinos, who make up 15% of the population.[13] Hispanic/Latino populations in the United States are descended from diverse backgrounds, and risk factors for HIV may differ by country of heritage.[5] According to the Census Bureau's 2006 household survey, 60% of those who identify themselves as Hispanic or Latino were born in the United States.[15] In that year, 64% of Latinos living in the United States were Mexican and 9% were Puerto Rican. Counties with a high proportion of Hispanic residents (>25%) are predominantly located throughout the Southwest and California, with concentrations in some parts of the Northwest and southern Florida.[15] States with the largest absolute numbers of Latinos are California, Texas, Florida, New York, and Illinois.[15]

Figure 6. Estimated HIV Prevalence Rate* Among Persons Aged ≥ 13 years, by Race, Ethnicity, and Sex—United States, 2006



**Per 100,000 population.*
[†] HIV prevalence at the end of 2006 for the 50 states and the District of Columbia, estimated from national HIV/AIDS Reporting System data.
[‡] Might be of any race.

Source: Centers for Disease Control and Prevention. HIV Prevalence Estimates—United States, 2006. *MMWR*, 2008;57(39):1073-1076.

About 200,000 Latinos in the United States have HIV/AIDS. As with African Americans, MSM are the predominant transmission category, though less markedly so than with whites, and a relatively high proportion of transmission occurs via heterosexual sex. Infection rates in Latina women are intermediate between rates in black and white women. HIV/AIDS prevalence among Latinos is clustered in a few states, with New York, California, Puerto Rico, Texas, and Florida reporting the largest number of cases.[13]

Recently concern has been expressed about growing rates of HIV infection among Mexican migrant workers, a group which has poor access to health care and is outside the reach of conventional HIV-prevention programs. A 2005 study conducted jointly by the University of California and the Mexican Secretariat of Health found that among Mexican migrants surveyed in high-risk settings, 0.6% of those tested in California and more than 1% tested after they had returned to Mexico were HIV-infected.[16] Other studies of migrant farm workers have shown widely varying seroprevalence rates: in some groups of participants the rates ranged from as low as 2.6% to as high as 13%.[16,17] An estimated one-third of HIV/AIDS prevalence in Mexico results from migrant farm workers returning from the United States.[17] Surveyed male migrant workers have relatively high rates of such high-risk behaviors as having unprotected sex with other men, having unprotected intercourse with sex workers, and drug and alcohol use.[16] Migrant farm workers frequently have misconceptions about how HIV/AIDS is transmitted and who is at risk. They are hard to reach with prevention messages and treatment because of the language barrier, their mobility, fears of deportation, and the incorrect belief that only legal immigrants are eligible for health care services.[16]

Native Americans. An estimated 2281 American Indian and Alaska Natives were living with HIV in 2007.[18] Although the incidence and prevalence of HIV/AIDS in Native Americans and Alaskans only slightly exceed their proportion of the general population (Table 1, Figure 3), some aspects of the epidemic in this population set it apart. The great cultural and linguistic diversity among Native Americans makes it challenging to offer culturally sensitive HIV-prevention programs. Access to health care is diminished by poverty and limited education. A high proportion of Native Americans live in rural areas, further limiting their access to HIV prevention, testing, and care. Furthermore, rural residence and limited social circles amplify concerns about stigma and confidentiality.[18]

HIV in Rural America

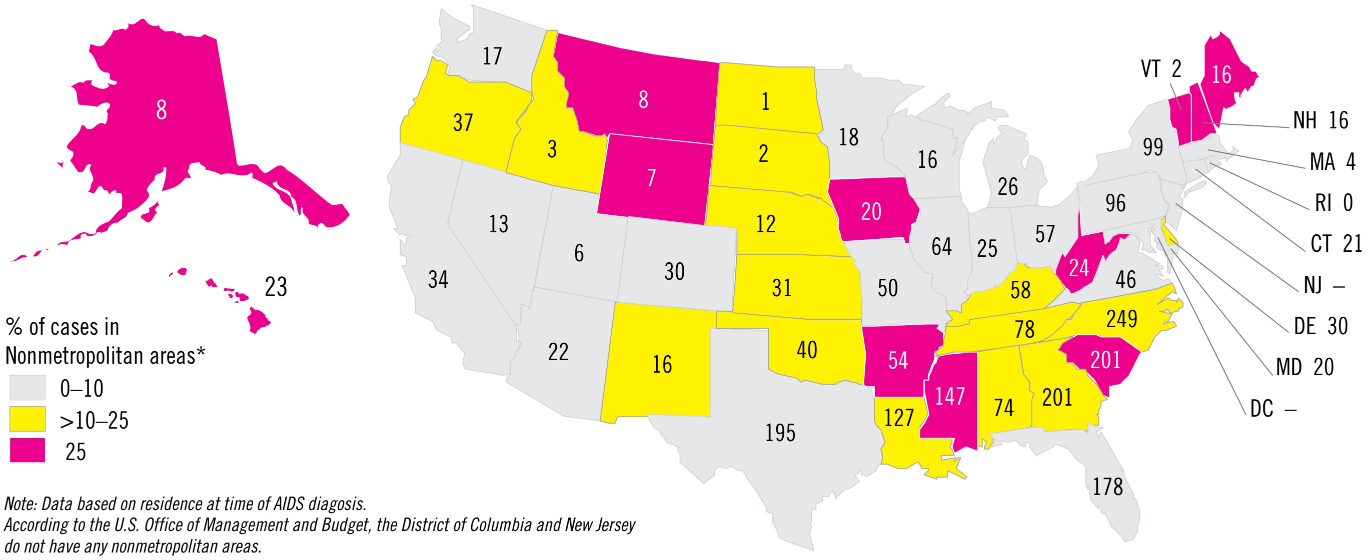
Although rural America represents a small proportion of all cases, HIV prevalence is increasing in rural areas of the country. The CDC uses the Office of Management and Budget (OMB) definition of "nonmetropolitan" (eg, rural) as an area with a population of less than 50,000 (in contrast to large metropolitan areas [greater than 500,000] or medium-size metropolitan areas [50,000 to 499,999].[19] The HIV/AIDS epidemic is still predominantly located in urban areas, with 82% of new cases occurring in large metropolitan areas and 11% in smaller cities. About 7% of AIDS cases in the United States are diagnosed in persons who live in rural areas or small towns, while 17% of Americans live in nonmetropolitan areas.[19] AIDS cases are reported by place of residence at the time of diagnosis. Thus, the incidence figures might not reflect the true disease burden or the economic impact of HIV in rural areas. The special challenges of providing HIV care and services in rural America are discussed in Barriers to HIV Treatment in Underserved Areas (see page 10).

In 2007, 2522 new cases of AIDS were reported in US adults and adolescents living in nonmetropolitan areas. The incidence (6.1 per 100,000) was about one-third that of cities with a population of at least 500,000.[20] An estimated 26,154 rural Americans were living with a diagnosis of AIDS and 17,192 were living with a diagnosis of HIV infection at the end of 2006.[19]

Rural AIDS cases have increased both numerically and as a proportion of total AIDS cases every year from 1993 to 2003. Allowing for an OMB reclassification of urban areas in 2004, which caused a dip in the ratio, it continues to increase.[21]

AIDS is diagnosed in rural areas in all regions of the United States (Figure 7).[19] The number of cases diagnosed in rural areas has increased more rapidly than the number in metropolitan areas because of 2 waves: early migration from cities and ongoing new infection in persons who already live in rural locales.[21] The number of rural AIDS cases is predicted to continue to increase for 2 reasons: persons with HIV are living longer and

Figure 7. Reported AIDS Cases Among Adults and Adolescents in Nonmetropolitan Areas, 2007—50 States and DC



Note: Data based on residence at time of AIDS diagnosis.
According to the U.S. Office of Management and Budget, the District of Columbia and New Jersey do not have any nonmetropolitan areas.
**(nonmetropolitan cases/total cases) x100.*

Source: Centers for Disease Control and Prevention. HIV Surveillance in Urban and Nonurban Areas, 2007.

a high proportion of persons who live in rural areas continues to engage in behavior that increases the risk of HIV transmission.[21]

Studies of migration of persons who have received a diagnosis of HIV infection have shown varying patterns. There is some evidence that persons move to rural areas after acquiring the infection in cities and are able to find services in these rural locations.[22] However, data from the HIV Cost and Services Utilization Study (HCSUS), based on a nationally representative sample of HIV-infected adults who receive care, suggest that a majority return or commute to the city for specialist HIV care.[23] Most of these adults said they experienced significant inconvenience in obtaining care, with long travel times, and more than 25% had put off obtaining care in the past 6 months because they did not have a way to get to their provider.

Patterns of Transmission. Men account for nearly three-fourths of reported rural AIDS cases, similar to their frequency in the overall HIV epidemic.

From 2002 to 2006 male-to-male sexual contact was the predominant mode of HIV transmission in men who lived in rural areas (Figure 8). About 20% of HIV transmission in rural men was attributed to injection drug use, and about 8% of seropositive men had both risk factors. Heterosexual transmission accounted for nearly 20% of cases.[24] In rural women, nearly all HIV infection was acquired via heterosexual contact with a man known to have or to be at risk for HIV infection (Figure 8).[24] Rural Americans may be more likely to engage in unprotected sex and to have multiple partners and less likely to have changed their sexual behavior in response to the AIDS epidemic.[24]

Racial and Ethnic Distribution of HIV in Rural Areas. Rural areas are historically less diverse than urban areas, but rural persons of color tend to be concentrated in specific geographic regions. A large majority of rural African Americans live in the South; rural Hispanics, in Texas and the West; and rural Native Americans, in Oklahoma and the West.[25]

Blacks and Latinos who live in rural areas are disproportionately affected by HIV. In 2006, 50% of all new rural AIDS cases were diagnosed in blacks, 37% in whites, 10% in Latinos, and 2% in American Indians and Alaska Natives (Figure 9).[19] Because of their higher absolute numbers in the rural Northeast, Midwest, and West, whites accounted for the largest numbers of new AIDS cases in these regions (Table 1).

In 2006 blacks/African Americans had the highest incidence of AIDS of any ethnic group in rural areas across the country (Table 2).[19] Blacks/African Americans accounted for 62% of new rural AIDS cases in the South. Nineteen percent of rural people diagnosed with AIDS in the Northeast were Latino. Among rural Latinos the incidence of AIDS was markedly elevated in the Northeast and higher than the overall rural average in the Midwest and South. American Indians and Alaska Natives accounted for 8.5% of rural AIDS cases in the West in 2006 (Table 2).[19]

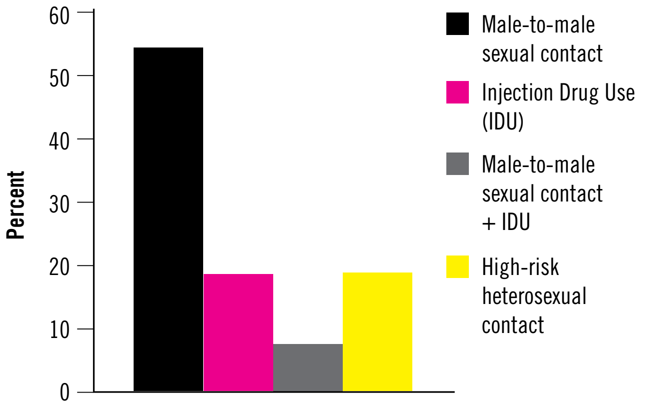
HIV in the Southern United States

The number of persons who are seropositive for HIV has increased faster in the South than in any other region of the United States, and blacks and persons who live in rural areas are disproportionately affected by the southern HIV/AIDS epidemic. Eleven of the 20 states and jurisdictions with the highest seroprevalence of HIV are in the South. With 36% of the US population, the South had half of all AIDS deaths that occurred in 2005.[26] The South is home to 65% of all rural persons with AIDS.[26]

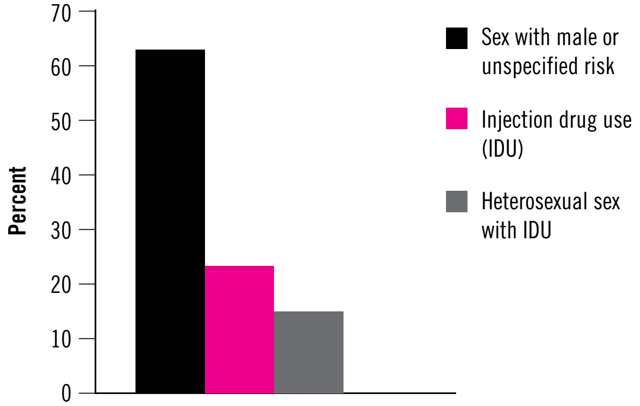
The CDC's geographic HIV reporting is based on the US

Figure 8. AIDS Diagnosed in Rural Men and Women, 2002-2006, by Transmission Category

Proportion of Rural Male Adolescent and Adult Estimated AIDS Cases by Transmission Category, 2002-2006, 50 US States and DC

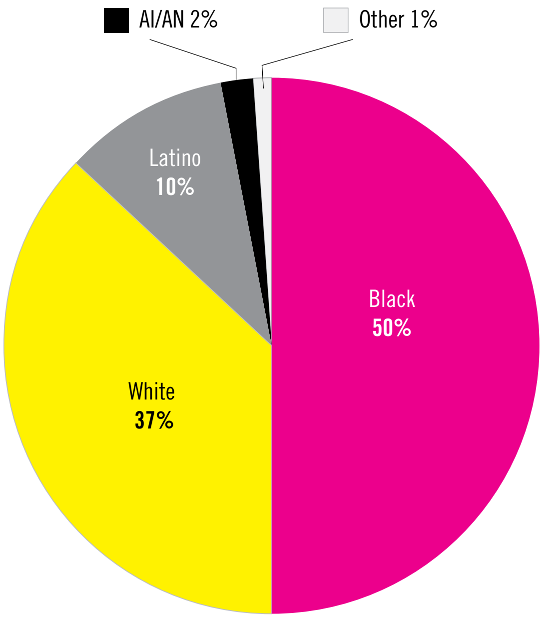


Proportion of Rural Female Adolescent and Adult Estimated AIDS Cases by Transmission Category, 2002-2006, 50 US States and DC



Source: Rural HIV/STD prevention workgroup. Tearing down fences. HIV/STD prevention in rural America. Bloomington, IN: Rural Center for AIDS/STD Prevention, 2009.

Figure 9. Racial and Ethnic Disparities in Rural AIDS Cases, US—2007



Source: Centers for Disease Control and Prevention. HIV Surveillance in Urban and Nonurban Areas, 2007.

Table 2. Incidence of AIDS Rates Diagnosed in 2006, by Race and Ethnicity, in Rural Areas in the United States

	Northeast	Midwest	South	West
White	164	224	537	126
African American	69	90	1118	15
Latino	62	43	122	37
American Indian/ Alaskan Native	2	3	12	17
Total cases	**297**	**360**	**2146**	**195**

Incidence is per 100,000 adults and adolescents.
Rural areas are defined as <50,000 population.

Source: Centers for Disease Control and Prevention. Cases of HIV infection and AIDS in urban and rural areas of the United States, 2006. HIV/AIDS surveillance supplemental report 2008;13(2).

Census Bureau's definition of the South as 1 of 4 major regions of the United States, a 16-state region that stretches from Delaware and West Virginia to Texas and Oklahoma. Within this region, different patterns of HIV infection and different social environments exist. According to 1 review, the "Deep South"—an area that comprises 6 states (Alabama, Georgia, Louisiana, Mississippi, North Carolina, and South Carolina)—is a culturally distinct area, characterized by political and religious conservatism that influences HIV-related health care policy. This region is also characterized by high levels of poverty, lack of access to health care, and high HIV prevalence in rural areas. Heterosexual contact is a primary mode of HIV transmission in the Deep South, and women are disproportionately affected. This region may account for all or most of the continuing growth of HIV/AIDS prevalence in the South, relative to the rest of the country.[27] According to another study, rural HIV incidence is elevated in two regions, the Mississippi Delta and the Southeast (which consists of the Deep South plus parts of Florida and Virginia), but is relatively low in rural Appalachia.[28]

> *"Characterized by pervasive poverty, lack of adequate services and infrastructures, unemployment, and uninsured individuals, the South is faced with a crisis of having to provide medical and support care for increasing numbers of infected individuals without adequate funding". . . . could well describe the situation of HIV care in rural areas throughout the United States.*

According to the Southern AIDS Coalition, an organization of HIV advocates, service providers, government experts, and private industry, "characterized by pervasive poverty, lack of adequate services and infrastructures, unemployment, and uninsured individuals, the South is faced with a crisis of having to provide medical and support care for increasing numbers of infected individuals without adequate funding."[26] This statement could well describe the situation of HIV care in rural areas throughout the United States.

Key Points

CHANGING EPIDEMIOLOGY OF HIV

- An estimated 1.1 million Americans live with HIV/AIDS
- Annual HIV incidence has been stable for the past decade, but HIV prevalence has risen because of increased detection of infection and improved patient survival
- Persons who are identified early in the course of HIV infection and treated appropriately can expect to survive for a near-normal life span
- Advances in treatment efficacy are offset by the growth of the epidemic in population groups who are disadvantaged in terms of access to care, including racial and ethnic minorities and rural Americans

BARRIERS TO HIV TREATMENT IN UNDERSERVED AREAS

To benefit from advances in ART, persons with HIV must be engaged in care. The Health Resources and Services Administration (HRSA) has represented engagement in HIV care as a continuum, ranging from nonengagement (ie, lack of awareness of one's HIV status) to full engagement in HIV primary medical care (Figure 10). Persons with HIV who are engaged at any point along the continuum may proceed in either direction, and it is not uncommon for an engaged person to drop out of care for long periods.[29] Persons with HIV who live in underserved areas are adversely affected by barriers that can challenge their engagement in care at any point on this continuum.

DIAGNOSIS OF HIV

The first step in engagement in care is awareness of one's HIV status. Clearly there is a need to improve the early detection of HIV infection; in 2009 an estimated 21% of persons with HIV in the United States were unaware of their infection.[30] Among persons who received a diagnosis of AIDS, one third had received a diagnosis of HIV infection within the previous 12 months. These "late testers" may have been infected as much as 5 to 10 years before they tested positive for HIV infection.[5]

Early detection of HIV and engagement in care have clinical benefits: the provision of ART as well as prophylaxis of opportunistic infections and treatment of concomitant sexually transmit-

Figure 10. Continuum Engagement in HIV Care, as Represented by the Health Resources and Services Administration

Not in care		↔			Fully engaged
Unaware of HIV status (not tested or never received results)	Aware of HIV status (not referred to care; didn't keep referral)	May be receiving other medical care but not HIV care	Entered HIV primary medical care but dropped out (lost to follow-up)	In and out of HIV care or infrequent user of HIV care	Fully engaged in HIV primary medical care

Source: Cheever LW. Engaging HIV-infected patients in care: their lives depend on it. *Clin Infect Dis.* 2007;44:1500-1502.

ted infections (STIs). For many patients who previously lacked access to health care, engagement in HIV treatment can be a bridge that links them to providers of other medical and support services.[31] Engagement in HIV treatment also has public health benefits: it reduces the transmissibility of HIV and exposes HIV-infected persons to messages about safer-sex practices.[31]

There have been few studies of diagnostic delays specific to rural areas. A survey of South Carolina residents in the early 2000s found that persons who live in rural counties were more likely than those who live in counties with a city of 25,000 population or larger to be diagnosed late (47% vs 42%). Late diagnosis (and, therefore, indirectly, rural residence) was associated with a lower CD4 count at diagnosis.[32]

ENGAGEMENT, RETENTION, AND MEDICATION ADHERENCE

The term "unmet need" in the field of HIV/AIDS has been defined by the HRSA as the need for HIV-related health services by persons with HIV who are aware of their HIV status but do not receive regular primary medical care.[33] Although recent nationwide data are unavailable, it is generally recognized that a large unmet need exists for HIV treatment for persons who are aware that they are seropositive.[34]

Some 20% to 40% of patients do not show up for their first clinical appointment after a positive HIV test.[34] The reasons for the "no-show phenomenon" have not been well studied because clinics do not obtain data on patients until they have appeared for their first visit. In a study from Birmingham, Alabama, researchers found persons who did not keep their appointments to establish HIV primary care were more likely to be African American, female, and uninsured, as well as to live at a distance from the clinic. A longer waiting time for the first appointment was also associated with failure to engage patients in care.[34] These investigators suggest that distrust of the health care system and stigma play a role in failure to engage in care, and their review of other research suggests a lack of transportation, substance abuse, and behavioral health and housing needs also play a role.

Persons with HIV require lifelong care. Retention is important not only to receive ART, but to receive additional treatment for medical and psychiatric conditions and interventions to improve adherence to therapy. Poor retention in care and nonadherence (or incomplete adherence) to ART is common among HIV-infected persons and is associated with increased mortality.[35] In a widely cited nationwide study based on 2003 data, only slightly more than half of adults eligible for ART received it.[29,36]

Research has identified four factors that contribute to poor retention in care and poor medication adherence, according to a review by AIDS Action, an advocacy organization.[38] Poor client-provider relationships that are characterized by a lack of trust and meaningful communication cause many clients to disengage from care. The difficulty of maintaining adherence to complex, challenging medication regimens and the disruptions caused by adverse effects and stringent dosing schedules cause some patients to discontinue ART altogether. Patients' competing needs, including family, housing, and employment, may conflict with the need for HIV primary care and receive a higher priority. Providers indicate that a lack of resources contributes to the inability to connect to underserved and hard-to-reach populations.[38]

BARRIERS TO CARE IN RURAL AMERICA

Persons with HIV who live in rural America, as well as their providers, face daunting challenges. Access to care is limited by distance, the lower availability of expert medical care and social services, and high rates of poverty and medical disenfranchisement. Difficulty maintaining confidentiality, stigmatization, and prevailing social conservatism pose additional challenges.[25,39-41]

Rural areas disproportionately lack adequate numbers of primary care physicians, a well-developed health care infrastructure, and providers who have cared for enough HIV-infected patients to develop expertise.[25] According to nationwide surveys conducted in the mid-2000s, nearly two-thirds of rural counties in the United States are designated health-professional-shortage areas, and the disparities are worse in counties where blacks or Hispanics are the majority population.[42] As a group, rural residents are somewhat more likely than urban residents to be uninsured, to lack a primary care physician, and to defer obtaining health care for lack of money. Disparities increased in minorities who live in rural locations and with the remoteness of the area. Of rural Hispanics, 41% to 56% lacked insurance coverage, with the highest rates in remote counties.[42] States in the South, Midwest, and West with predominantly rural populations have among the highest rates of medical disenfranchisement—defined as uninsured and with no regular access to primary medical care[43]—and the lowest rates of private and public insurance coverage.[42]

HIV-infected rural persons have complex mental-health needs and stressors that may reduce their adherence to complex ART regimens. Compared to urban HIV-infected persons, they have greater difficulty coping with life stressors, more experience of discrimination, and higher rates of depressive symptoms and suicidal ideation.

Because HIV-infected persons may be widely dispersed in rural areas, it can be impractical to deliver services that require home visitation and equally difficult for patients to travel to a central location. Public transportation is unlikely to be available, and for some, private transportation is unaffordable.[25]

Rural residents may lack access both to social services and client support and to behavioral health and substance abuse services. Unmet psychosocial needs adversely affect medication adherence and treatment outcomes. In a study of persons with HIV in the rural South, service needs—such as help with housing and clothing; a support group; behavioral health, drug, and/or spiritual counseling; and financial assistance—were highly prevalent, frequently went unmet, and were associated with poor medication adherence.[44]

HIV-infected rural persons have complex mental-health needs and stressors that may reduce their adherence to complex ART regimens. Compared to urban HIV-infected persons, they have greater difficulty coping with life stressors, more experience of discrimination, and higher rates of depressive symptoms and suicidal ideation.[45]

Aspects of the rural social environment also pose barriers to effective HIV care.[25,26,39,40,46,47] In small communities, persons with HIV have greater difficulty maintaining anonymity and confidentiality. The threat of being identified when buying a condom or seeking HIV testing or treatment for an STI or a substance abuse problem can be enough to keep persons from pursuing these appropriate behaviors. The threat of being identified visiting an HIV care provider can cause persons with HIV to delay seeking treatment or to travel a distance in order to obtain medical care. Prejudices and denial about HIV infection in rural areas may render it difficult for HIV care providers to make their services known and to find a location to serve their clients. Persons with

HIV who live in rural areas may be widely dispersed and find it difficult to connect with one another for social support.

The major mechanisms for HIV transmission are associated with behaviors that are stigmatized in settings where “traditional values” prevail. Social conservatism is typically greater in rural areas than in cities, leading to enhanced fears of stigmatization. The prominence of the church in rural settings, particularly in the South, intensifies fear of stigma. (However, churches can also be allies in identifying and caring for persons with HIV; see HIV Service Profile 5 and HIV Service Profile 6 on page 19.)

Poverty rates are usually higher in rural areas than urban areas. Poverty limits a person’s ability to pay for medical care, but it also has less direct effects, ranging from increased-risk behaviors—such as nonuse of condoms or exchanging sex for money—to HIV-infected women having to choose between the needs of their families and their own needs for care.

Key Points

BARRIERS TO HIV TREATMENT IN UNDERSERVED AREAS

HIV care can be viewed as a continuum, with multiple opportunities to improve client engagement. Areas in need of improvement include:

- Early detection of HIV. About one-fifth (21%) of persons with HIV in the United States are unaware of their infection, and one-third of persons receive a diagnosis of HIV infection a year or less before they receive a diagnosis of AIDS.
- Engagement in care. Between 20% and 40% of patients do not show up for their first clinical appointment after a positive HIV test
- Retention in care and medication adherence. Contributing factors are poor client-provider relationships, complex medication regimens, clients’ competing needs, and a lack of resources

The difficulty of providing services for persons with HIV in rural areas is exacerbated by such factors as distance, less availability of expert medical care and social services, poverty and medical disenfranchisement, and adverse aspects of the social environment

ROUTINE OPT-OUT TESTING FOR HIV

HIV testing is crucial to efforts to prevent and treat HIV infection. In response to the reduced effectiveness of using risk-based testing to identify HIV-infected persons, the CDC in 2006 recommended a new approach to HIV testing, designed to improve the rate of early detection by making testing routine in primary care clinical settings. The traditional approach, risk-based testing, was thought to be losing its effectiveness in identifying HIV-infected persons because of the changing epidemiology of HIV: many of the newly identified (persons who live in rural areas, persons who identify their risk factor to be heterosexual sex, women, and racial and ethnic minorities) are not aware they are at risk for HIV infection.[48]

CDC RECOMMENDATIONS FOR ROUTINE OPT-OUT HIV SCREENING

The CDC recommends HIV screening (see Routine Opt-Out Screening: Key Elements) for all persons aged 13 to 64 years. “Opt-out” testing requires a patient to be notified that they will be tested and given the opportunity to decline. With opt-out testing, the patient has given general consent for medical care; separate written consent for HIV testing is not required (but it is important to document a patient’s oral acceptance or decline of testing in the medical record). “Opt-in” testing refers to testing that is offered and the patient must voluntarily agree to testing. The concept of routine testing involves offering HIV testing to everyone, not just to persons in traditionally high-risk groups, as well as offering HIV testing on a regular basis. The CDC recommendations state that testing should be offered at least once, and patients at elevated risk should be screened annually. State laws dictate whether opt-out testing may take place (some states still require separate written consent for HIV testing). Even if opt-out testing is not legally possible, testing may still be offered on a routine basis in the health care setting.

HIV screening in health care settings is encouraged because it provides the opportunity to link patients immediately to clinical care. The CDC recommendations for routine testing destigmatize the testing process, in part because there is no longer any need to ask about risk behaviors.

The CDC recommendations also call for routine opt-out screening as part of the standard panel of prenatal tests in pregnant women (see Routine Opt-Out Screening: Key Elements). Women should be provided with additional oral or written information about HIV infection and how it can be transmitted from mother to infant.

HIV screening in health care settings is encouraged because it provides the opportunity to link patients immediately to clinical care. The CDC recommendations for routine testing destigmatize the testing process, in part because there is no longer any need to ask about risk behaviors. Discontinuation of the requirement for pretest risk assessment and prevention counseling removes a burdensome logistical barrier.

The CDC recommendations apply to all providers in public

ROUTINE OPT-OUT SCREENING: KEY ELEMENTS

- All health care settings
- All patients aged 13-64 years
- Notification *and* opt-out
- Separate written informed consent not required
- Counseling about HIV prevention not required
- Exception: Diagnostic yield ≤0.1%
- Pregnant women: part of routine prenatal panel
- Annual screening in persons at high risk of HIV

Source: Centers for Disease Control and Prevention. Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. *MMWR.* 2006;55(RR-14):1-17.

and private settings, including not only the primary care office, hospital, and emergency room, but also community and public health clinics; tuberculosis (TB), STI, and substance abuse clinics, and prison health clinics. The recommendations make an exception for clinicians whose patient populations have a documented prevalence of undiagnosed HIV of less than 0.1%—that is, 1 case per 1000 patients. In practices in which such data are lacking, providers should initiate screening and discontinue it later if warranted.

Although routine opt-out screening is recommended as a normal part of medical practice, there is still a role for HIV screening in nonmedical settings. Community programs make an important contribution to HIV detection. They can reach persons who do not receive medical care on a regular basis. These programs can also provide a vital educational opportunity and a chance for HIV programs to engage community groups.[48]

The Role of Rapid Testing. Before the introduction of rapid HIV tests, the CDC estimated that 31% of persons tested at publicly funded testing sites did not return for their results.[49] Several rapid-test kits are now available that are approved for use in point-of-care settings that do not have laboratories (see Steps to Implement HIV Testing in Primary Care on page 14). The tests yield results in less than 30 minutes. Persons can learn their results during the same office visit and be given an immediate link to treatment.[50] Rapid tests are as sensitive and specific as the older enzyme immunoassays, so a negative result does not require confirmation. However, because test results are negative in persons who have been exposed to HIV but who have not yet seroconverted, those with a suspected recent exposure to HIV and a negative test should be retested within 3 months. Reactive tests should be confirmed with a Western blot or indirect immunofluorescence. Persons should be counseled about steps to reduce the risk of HIV transmission while awaiting the confirmatory result.[50]

State Testing and Reporting Policies. Clinicians who offer routine opt-out testing should be aware of their state's laws regulating informed consent and partner notification. The laws are available in the Compendium of State HIV Testing Laws, available at http://www.nccc.ucsf.edu/StateLaws/index.html

With the goal of more accurate determination of HIV epidemiology, US states and territories are moving to HIV name reporting. If a person tests positive for HIV infection, their name is reported to the state, which determines if this is a unique result and then after removing the name or other personally identifying information, reports the aggregated information to the CDC.[30] Anonymous testing, in which the patient's name is not recorded, is available as an option in many states: all but 11 states offered anonymous testing in 2008.[30]

Economic Issues: Reimbursement, Cost-Effectiveness, and Impact

The primary potential adverse economic impacts of expanded HIV testing are the costs to providers (eg, for unreimbursed tests) and the cost to insurers and other payers for providing medical care to patients who would otherwise have remained undiagnosed.

Reimbursement for Routine Testing. Medicare now pays for routine HIV testing, as do a growing number of private insurers and state Medicaid programs. More insurers are expected to reimburse for testing as the CDC recommendation becomes more widely accepted.[51]

Cost-Effectiveness of Routine Testing. The CDC recommendation of a threshold screening prevalence of <0.1% (1 in 1000) is about one-fourth the estimated prevalence of HIV (diagnosed and undiagnosed) in the US population. The CDC recommendation is based on the cost-effectiveness literature,[6] which suggests that routine opt-out testing according to the CDC guidelines is economically justified in terms of the value it provides.[52] An independent cost-effectiveness analysis determined that routine screening for HIV is cost-effective as long as the prevalence is greater than 0.2%. This result essentially confirms the CDC's estimate and suggests that, at this prevalence level, screening for HIV delivers value comparable to other commonly accepted medical screening tests.[53]

According to one economic simulation study, the benefit of screening is closely related to a program's rate of successfully linking patients to medical care. The results suggest that if HIV-testing funds are limited, resources should be focused on getting more persons who test positive into care rather than on launching new testing initiatives.

Economic Impact of Large-Scale Testing. One economic challenge to implementing large-scale HIV testing is the uncertainty of funding for HIV treatment in settings with limited resources. The economic impact of identifying large numbers of persons who require treatment is feared.[54]

According to one economic simulation study, the benefit of screening is closely related to a program's rate of successfully linking patients to medical care. The results suggest that if HIV-testing funds are limited, resources should be focused on getting more persons who test positive into care rather than on launching new testing initiatives.[52,55]

IMPLEMENTING HIV TESTING IN THREE SETTINGS

Whether offered in the clinic or a community setting, HIV testing can be made more acceptable by offering it routinely, using a simple conversation starter to heighten awareness among clients, increasing the profile of testing among clinic staff, and seeking potential allies in the community. In this section, faculty representing 3 screening settings share some of their approaches.

Primary Care Office Settings

Routinizing HIV testing in the primary care setting is important because it removes a source of stigma, according to Donna Sweet, MD, professor of medicine in the Department of Internal Medicine, director of HIV programs at The Medical Practice Association of the University of Kansas School of Medicine, and co-chair of this CME activity. Persons who do not want to be seen walking into an HIV clinic can be tested where they go for their routine medical care; the test can be offered as part of a general screening panel, so that they do not have to ask for it specifically. In Dr Sweet's general internal medicine practice, a sign, displayed prominently, reads, "We offer HIV testing to all patients. If we fail to ask, ask us."

Community Health Center Settings

Partnership Health Center (PHC), a community health center (CHC) in Missoula, Montana, serves the western half of the state (see HIV Service Profile 4 on page 18). Because western Montana is a low-prevalence area, the center offers targeted HIV testing. According to case manager Mary Jane Nealon, RN, MFA, the clinic carried out a campaign in which all employees who knew their HIV status wore a pin that read, “I know.” When clients asked what they knew, staff members would reply, “Our HIV status. Everyone should know that.” They then explained the clinic offered free HIV testing virtually whenever it was open.

The PHC also scanned the electronic medical records of all patients who had a test for another STI or hepatitis B and flagged them so that patients were offered a free HIV test during their next clinic visit. This effort increased the staff’s awareness of HIV infection; as a result, they increased the number of tests they offered across the board, not just to persons at increased risk.

Community-Based Screening Programs

The JACQUES Initiative, a comprehensive HIV prevention, care, treatment, and support program located in Baltimore, Maryland, operates in an urban, underserved community. A community-based outreach and screening project uses volunteers from the faith-based community to educate, test, and reduce stigma and offers community members a chance to impact the local response to HIV infection (see HIV Service Profile 2 on page 16).

Project SHALEM was designed to provide a “safe place” for HIV testing and linkage to care in places of worship and to involve members of these religious organizations directly in testing, according to Derek E. Spencer, MS, CRNP, executive director of the JACQUES Initiative.

The project’s launch in July 2009 was carried out on a single day with the participation of more than 200 volunteers recruited from the local faith-based community, students from local colleges and universities, and other community members. Before Project SHALEM’s launch, 49 members of the faith-based community were trained to perform HIV testing and counseling in the community. The project tested 900 people in one day at 11 sites across Baltimore. Thirty-seven people were identified as HIV infected, and one-third were linked to HIV primary care. The project has since launched 4 sustainable HIV-testing and linkage-to-care sites in the faith-based community in Baltimore.

STEPS TO IMPLEMENT HIV TESTING IN PRIMARY CARE

- **Choose a test.** Three rapid HIV tests that have been approved by the Food and Drug Administration (FDA) have received a Clinical Laboratory Improvements Amendments (CLIA) waiver that allows them to be used in nonlaboratory settings, including medical offices as well as such settings as health fairs and homeless shelters. To perform the tests, an organization must obtain a waiver from the CLIA[57]
- **Determine which laboratory you can use to conduct confirmatory testing**
- **Research your state’s laws regarding pretest counseling, informed consent, and partner notification**[51]
- **Establish patient-information and consent procedures.** Scripts are available for language to use when informing patients about screening; sample consent forms are also available.[51,57] If allowed by state law, use an opt-out procedure. Be prepared to discuss and document a patient’s refusal of screening[51,57]
- **Decide what your role as the primary care clinician will be in caring for your patient, what the role of your staff is, and what services will be provided by other clinicians**
- **Research available local HIV/AIDS services, including infectious-disease or HIV specialists, case management and support services, and patient support groups.** State and local health departments can provide this information and can be reached via a central CDC website, http://www.cdc.gov/mmwr/international/realres.html Useful links to providers can also be found on the website of the American Academy of HIV Medicine, http://aahivm.org[56]
- **Once you identify these providers, establish referral relationships and methods to communicate with them**
- **Educate yourself and the appropriate members of your staff about the best ways to discuss a positive HIV screening test result**

Key Points

ROUTINE OPT-OUT TESTING FOR HIV

- The CDC recommends routine opt-out screening for HIV in primary care clinical settings
- Rapid-test kits are available that yield results within 30 minutes. Persons can learn their results and be linked to treatment without delay
- Clinicians who offer routine opt-out testing should be aware of their state’s laws regulating informed consent and partner notification
- Implementing routine opt-out testing in clinical practice requires a plan: learn the local laws, choose a rapid test and a laboratory for confirmatory testing, establish referral links, and learn how to discuss a positive HIV test result

ORGANIZATION OF CARE IN UNDERSERVED COMMUNITIES

Care for persons with HIV infection can be organized in many ways, ranging from simple specialist referrals to complex organizations and referral networks designed to bring care to persons who live in remote and/or underserved locations and provide a full range of medical, case management, and ancillary services. (Organizations that provide HIV services to persons who live in underserved areas are described in the accompanying HIV Service Profiles [beginning on page 16].)

Shared Care. In this traditional arrangement, a primary care physician and an HIV specialist provide patient care jointly. Involvement of the primary care physician may vary from caring for non-HIV-related medical problems to monitoring the HIV treatment regimen prescribed by the specialist, to managing all aspects of HIV care with consultation.[1] Primary care clinicians who would like to be in charge of their patients’ HIV care, but who might need some assistance on occasion, can take advantage of a new "Clinical Consult" program offered by the American Academy of HIV Medicine (see The Clinical Consult Option for Low-Volume Providers below).

Traveling Clinics. This approach brings expert clinicians to provide care for persons with HIV infection who live in remote areas, thereby reducing—though not eliminating—patients' need to travel long distances. One example of a traveling clinic is the Ryan White Programs of The Medical Practice Association of the University of Kansas School of Medicine, Wichita, Kansas (see HIV Service Profile 1 on page 16).

THE CLINICAL CONSULT OPTION FOR LOW-VOLUME PROVIDERS

Among its many efforts to educate clinicians who care for persons with HIV/AIDS, the American Academy of HIV Medicine (AAHIVM) certifies physicians, nurse practitioners, and physician assistants as HIV Specialists. It also offers a "Clinical Consult" program as an option for clinicians who practice in low-volume and nonurban areas and who see few patients with HIV infection but would like to develop expertise in treating them.

HIV Specialists are required to have 30 or more hours of CE activity, pass an exam every 2 years, and provide HIV care for 20 or more patients. The "Clinical Consult" program enables low-volume providers, who care for fewer than 20 patients, to pair with a certified HIV Specialist, who will provide consultation on HIV treatment. To enroll in the program, low-volume providers must meet the CE requirement and pass the certifying examination. The AAHIVM tries to pair clinicians geographically and encourages them to have face-to-face meetings.[58] More information is available on the AAHIVM website, http://www.aahivm.org

Central Clinics. Comprehensive HIV services may be provided by programs with a highly staffed central location. Two examples of central clinics serving urban populations with limited resources are Baltimore's JACQUES Initiative (see HIV Service Profile 2 on page 16) and the Chatham CARE Center, organized as a patient-centered medical home, that serves persons living with HIV in Savannah, Georgia (see HIV Service Profile 3 on page 17).

Expanded Community Health Centers. Some rural areas have built on the capacities of existing CHCs, adding expertise to provide HIV treatment and case management services. An example of an expanded CHC is Partnership Health Center in Missoula, Montana (see HIV Service Profile 4 on page 18).

Other programs serving rural populations with limited resources are organized as single or multiple clinics that provide some combination of medical care, case management, and support services. Central Florida's Hope and Help Center, located in Orlando/Sanford, consists of a central location that offers case management and ancillary services, along with a satellite center that offers substance abuse and behavioral health services in an area of special need (see HIV Service Profile 5 on page 19). Matthew 25 AIDS Services, Inc., which serves rural Kentucky, consists of a central location in Henderson, with 2 satellite clinics and provides a full range of services (see HIV Service Profile 6 on page 19). AIDS Resource Alliance and West House Personal Care Home provides case management and support services from a single center in Williamsport, Pennsylvania (see HIV Service Profile 7 on page 20).

OPTIMIZING TREATMENT RETENTION AND ANTIRETROVIRAL MEDICATION ADHERENCE IN UNDERSERVED POPULATIONS

Retaining HIV patients in care and enabling medication adherence are major priorities in HIV care that pose difficult problems in underserved areas. This section examines how these variables are defined and measured, and discusses some tactics to optimize them.

RETENTION IN CARE

The definition of "retention in care" is based on whether a patient uses the recommended number and type of medical services. Patterns of use of medical services described in the literature include regular use, sporadic or cyclical use, and nonuse. The recommended interval between primary care visits depends on the stage of HIV infection, but the maximum interval is 6 months.[61] Typically a "retained" patient is one who completes a medical appointment every 6 months, or more often if appropriate, and who appears for other scheduled appointments. "Partial retention" may describe patients who make fewer primary care visits, are frequent no-shows for scheduled appointments, or inappropriately use emergency HIV services. A third category comprises patients who come for their initial primary care visits but then drop out of care.[61,62]

For research purposes, patient retention is measured as the number of missed appointments, which may include appointments for phlebotomy and infectious-disease-specialist and nursing services in addition to primary care. In the literature, missed appointment rates for HIV care consistently range from 25% to 35%, regardless of which types of visit are included in the analysis.[61] Nonretention in HIV care is more prevalent in areas with limited resources.

Risk Factors. Identification of groups at elevated risk for nonretention can be the basis for targeted interventions. Groups at increased risk to withdraw from HIV care include African Americans, younger adults, heterosexuals, injection drug users, the unemployed, and those with less education, no health insurance, or lower household income. Missed appointments are associated with injection drug use, mental illness, a lack of social support, and less engagement with the provider. Difficulties with transportation, child care, or job conflicts may also interfere with keeping appointments.[61,62]

A survey of members of socially marginalized populations—minorities, women, youth, and the recently incarcerated—found that nonengagement with HIV care was more likely in persons with unmet needs for financial assistance, housing, assistance with obtaining benefits, transportation, food, and behavioral-health and substance abuse treatment. Nonengagement was also associated with practical barriers, including not having a telephone and such beliefs as mistrust of the health care system and the idea that faith will help with AIDS.[62]

continued on page 21

Profile 1: Traveling HIV Clinics

The Ryan White Programs, The Medical Practice Association of the University of Kansas School of Medicine, Wichita, Kansas

Organization: University-based clinic, plus 3 outreach clinics in rural Kansas; visited once a month by a traveling team with expertise in HIV care

Services: Comprehensive HIV specialist care, primary care for HIV patients' general medical conditions, dental assistance and care, transportation assistance

Clients: Roster of more than 1000 HIV patients at the central clinic, with about 30 HIV patients seen per visit by the traveling team. In the southwestern rural clinic, more than one-third of patients are Hispanic; this population is largely non-English-speaking, and many are undocumented. The southeastern clinic serves a high proportion of women with sexually acquired HIV infection.

HIV Service Description: The program supplies the only Ryan White services to rural Kansas and has 4 of the 5 HIV specialist physicians in the state. The central clinic employs 4 AAHIVM-certified HIV specialists and provides HIV primary care, other Ryan White services, HIV testing and counseling, and housing assistance. In addition, one part of the program's mission is to bring HIV/AIDS education and training to rural providers (physicians, mid-level providers, nurses, pharmacists, dentists, dental office staff) who have limited opportunities for education.

The outreach clinics were initiated 10 years ago to alleviate the need for HIV patients to travel long distances for care. The clinics are staffed by a group of professionals with expertise in HIV care, including not only a physician, but also a nurse practitioner or physician assistant, case manager, medical assistant, and phlebotomist, as well as residents and medical students. Clinics are held every 4 to 6 weeks. The client base has grown from an average of 5 HIV patients per visit to an average of 30 HIV patients today. Clients are offered a standing appointment so they know they can obtain care if they show up on the appointed day and hour. ■

Profile 2: Centrally Located HIV Clinics

JACQUES Initiative
Baltimore, Maryland

Organization: Central hub with multiple outreach and satellite sites

Services: HIV testing and linkage to care, primary care, case management, referral for behavioral health and substance abuse treatment, transportation, adherence interventions

Clients: 88% African American, 18% MSM, 37% women, 30%-40% are homeless, 52% used drugs in the past 6 months, 42% have history of mental illness

HIV Service Description: The JACQUES Initiative provides health care for persons with HIV who live in Baltimore. The project was initiated by the Institute of Human Virology at the University of Maryland and serves a poor, urban, African American population.

In addition to Project SHALEM's faith-based HIV-testing initiative, several satellite-testing and linkage-to-care sites direct clients to the JACQUES Initiative services:

- Education of hospital staff and patient linkage in an inpatient setting. HIV-infected JACQUES Initiative staff and volunteers make rounds with hospital staff members and encourage newly and previously diagnosed HIV patients to get into care
- HIV screening in the emergency departments of 3 urban academic medical centers—about 750 tests per month. Of those tested, the incidence is 1%, with an average CD4 count of 449 cells/mm^3 at diagnosis. In contrast, historically the average CD4 count in HIV patients beginning treatment as part of the JACQUES Initiative was 145 cells/mm^3
- Outreach and testing in transitional houses, drug treatment centers, and historically African American colleges

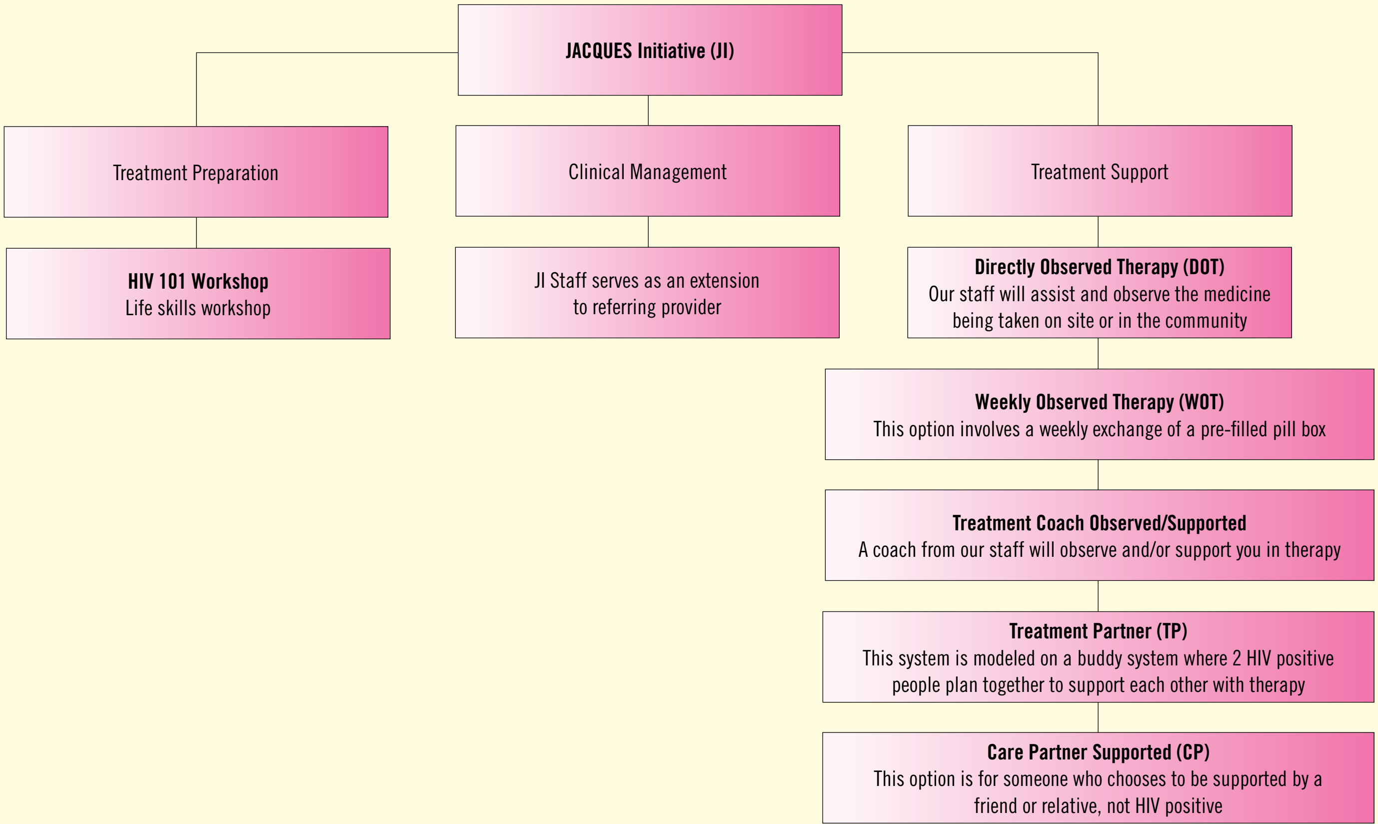
Through these efforts, between 150 and 200 HIV-infected patients are linked to care each year.

When clients are referred to the JACQUES Initiative from one of the satellite programs, they receive education about HIV, support from a staff member who is living well with HIV infection, linkage to HIV primary care as well as referral to any other support services that they need.

The JACQUES Initiative employs a treatment adherence model developed specifically for the urban poor and includes 3 components: treatment preparation, clinical management, and treatment support (see Figure opposite). When HIV clients are medically ready to start treatment, they receive peer counseling and support in preparation for treatment. Patients who are about to start ARV drug therapy are referred to a regularly scheduled evening workshop, cofacilitated by a JACQUES Initiative staff member and 1 or more persons who are living well with HIV infection. Clients are encouraged to bring family members with them to the workshop. For clinical management, JACQUES Initiative staff members provide support to the referring provider.

Treatment support is based on directly observed therapy. Options include weekly observation at the clinic, a buddy system with an HIV-infected treatment partner, and support by a non-HIV-infected family member or friend. Weekly observed therapy is encouraged for patients with high viral loads in induction therapy, until the load can be lowered. Once this occurs, the patient and their provider may consider a less intensive treatment option. ■

Figure. Integrating Treatment Preparation, Clinical Management, and Treatment Support for Maximizing Long-term Adherence to ART



Source: The JACQUES Initiative.

Profile 3: Patient-Centered Medical Home

Chatham CARE Center
Savannah, Georgia

Organization: Ryan White clinic located in a small city, plus an urban outreach clinic

Services: HIV primary care, behavioral health and substance abuse counseling, pharmacy, nutrition, surgical clinic, hepatitis B and hepatitis C management, transportation (van and vouchers)

Clients: More than 700, 77% African American, 37% women, 62% uninsured, 33% Medicare or Medicaid, 14% homeless

HIV Service Description: The Chatham CARE Center is a Ryan White clinic that serves clients in the small city of Savannah, the center of the third-largest metropolitan statistical area in Georgia. The federally funded clinic is based on the model of a patient-centered medical home (PCMH), according to clinic director Debbie P. Hagins, MD, AAHIVS.

The PCMH concept was introduced by the American Academy of Pediatrics and has been adopted by most major primary care physician organizations as well as many other specialist physician organizations. The Patient-Centered Primary Care Collaborative (PCPCC) is a coalition of more than 260 patient-advocate groups, major employers, health plans, and physician membership organizations that have come together in an effort to advance the PCMH concept. Information can be found about the PCPCC on its website, www.pcpcc.net

In the PCMH model, medical care is organized around the patient and is longitudinal, rather than the conventional episodic illness-oriented, complaint-based care model, according to an “advanced medical home” model developed by the American College of Physicians.[59] The PCMH concept is based on seven principles (See Table on page 18). First, each patient has an ongoing relationship with a personal provider trained to provide first-contact, continuous, and comprehensive care. The physician leads a team of individuals who collectively take responsibility for the patient’s ongoing care. The personal provider is responsible for addressing all the patient’s health care needs or taking responsibility for appropriately arranging care with other qualified professionals and coordinating care among specialists, hospitals, nursing homes, home health agencies, and other providers.

The PCMH model ensures quality and safety through a care planning process that incorporates evidence-based medicine, clinical decision-support tools, performance-measurement and quality-improvement activities, information technology, and active participation of patients in decision making. Patient access

Table. Principles of the Patient-Centered Medical Home
Personal provider
Physician-directed medical practice
Whole person orientation
Coordinated and integrated care
Quality and safety
Enhanced access
Appropriate payment

Source: Patient-Centered Primary Care Collaborative. Joint principles of the patient-centered medical home.

to care is enhanced by, for example, open scheduling, expanded hours, and communication via telephone and email. Another key aspect of the PCMH is that payment must appropriately recognize the added value that having a medical home offers patients, Dr Hagins says.[59,60]

Some clinicians may find it uncomfortable to involve the patient in important treatment decisions as described by the PCMH model, Dr Hagins notes. However, "when you show a patient the options for what they can do and you let them choose . . . that's how you get a buy-in." For example, in a treatment-experienced patient whose infection is showing some resistance to their current ART, Dr Hagins may offer a choice among all the different drug combinations that are effective at that point. Patients may select or even modify a regimen based on pill count or adverse effects, or simply because someone they know is following the regimen: "We construct regimens for them based on their buy-in . . . just to let them know that we care about them and that their voice matters." If the regimen is not exactly as medically indicated, the reasons for the compromise are documented in the patient's record and the patient is monitored especially closely.

The Chatham CARE Center's large staff, which represents many disciplines, enables the clinic to take a comprehensive approach to clients' medical and social services needs, Dr Hagins says. Although she is ultimately responsible for patient care and prescribing, AAHIVM-certified nurse practitioners provide much of the direct clinical care. The 28 full- or part-time staff members include, in addition to medical clinicians and support personnel, a substance abuse and mental-health counselor, a dentist, a dental hygienist, a pharmacist, a registered dietician, a health educator, peer advocates, and a van driver. To maximize access, the clinic is centrally located in an area with high HIV prevalence and has extended hours as well as round-the-clock telephone coverage that is provided by specially trained nurses. The clinic offers transportation vouchers as well as van transportation from patients' homes to the clinic and to outside medical appointments.

Peer advocacy is an important component of the Chatham CARE Center's program, as it is for many other programs. The clinic employees and volunteers include many peers who are vocal about their HIV-infected status and provide clear examples of living well with HIV. Peers serve as speakers at the clinic's screening initiatives. There is a peer-run support group, and peer conferences are scheduled periodically. ■

Profile 4: Enhanced Clinic

Partnership Health Center
Missoula, Montana

Organization: CHC in Missoula, Montana, and 3 satellite locations

Services: Physician support, physician assistant (PA) for HIV-specific urgent care, oral health, behavioral health, case management, lab services, clinical pharmacy, HIV counseling and testing, hepatitis C clinics

Clients: 187 persons with HIV who live in western Montana: 16 counties that cover 44,000 square miles. In this region 6% of the Ryan White clients are Native American, 1.6% are African American, and the remainder are white. The HIV population in Montana is aging, with 53% of clients aged 45 to 64 years. A majority (88%) of the population are at less than 200% of the federal poverty level (FPL); the remaining 12% are between 200% and 330% of the FPL. Only 33% of all clients have no insurance at all, and the remaining 67% of clients have a mix of Medicare, Medicaid, and private insurance.

HIV Service Description: Partnership Health Center is a CHC that expanded its HIV services as part of a statewide initiative. Before the initiative, the program had 48 active patients enrolled in the Ryan White program who were seen by 14 private physicians in the region. The community physicians had no particular expertise in treating HIV/AIDS. A statewide needs assessment for the initiative, conducted by the University of Montana, identified the primary concerns of persons with HIV as stigma, isolation, limited local resources, and fear of disclosure. Today the program serves 187 patients, most of whom receive their medical care at the CHC in Missoula and 3 other locations.

The program contracted with physicians who leave their offices to see their patients with HIV at the CHCs. A PA who is a specialist in HIV/AIDS care is available on-site to provide any urgent care needed. The PA is paid a flat fee, so the CHC retains some of the income generated by billing. The program provides the physicians with support, whereas before the initiative they were isolated in their private practices. At the CHCs, the physicians have access to various services, including oral health, behavioral health, case managers, labs, and clinical pharmacy.

Physicians have no overhead for providing HIV services and no extra costs for staffing or billing. Clinical pharmacy students rotate through the CHCs and provide support. The arrangement also gives infectious-disease specialists who are primarily hospitalists an opportunity to remain active in HIV outpatient care. ■

Profile 5: Regional Satellite Clinics/Case Management and Support Services

Hope and Help Center
Orlando/Sanford, Florida

Organization: Main office, with multiple case management and education satellites

Services: Medical case management, nonmedical case management and eligibility, psychosocial support and peer mentoring, AIDS Insurance Continuation Program, food pantry, HIV prevention and education, Sanford HIV/AIDS Outreach and User Treatment (SHOUT) program

HIV Service Description: The Hope and Help Center provides medical case management and other support services to a medically underserved population in central Florida.

In an effort to combat the spread of HIV/AIDS, the Hope and Help Center has SHOUT, a substance abuse outreach program. Sanford is a small town about 30 miles northeast of Orlando. Goldsboro, the Sanford neighborhood served by the program is not only poor, but also politically disenfranchised, medically underserved, and troubled by such serious problems as high rates of crime, infant mortality, and substance abuse.

The goals of the SHOUT program, which is funded by the federal Substance Abuse and Mental Health Services Administration, are to increase participation in substance abuse treatment for persons who are HIV-infected and to reduce alcohol and drug use by persons with HIV or are at high risk for contracting HIV. The program also focuses on HIV counseling and testing for HIV in the local population.

The SHOUT program owes its success to many factors, says J. Jay Flicker, PsyD, clinical director of the Hope and Help Center. The outreach and case management staff includes 2 members of the community; they and their families are well known, have “walked the walk and talked the talk,” and are gifted storytellers. The center has an enduring commitment to the Sanford community and has operated despite funding fluctuations.

The SHOUT program is consistent in terms of the messages its staff delivers to patients, stable service locations, and regular hours. The program links with community networks for such services as housing and a food pantry.

Local churches were first involved when the SHOUT program director asked a pastor to bless the center’s new mobile testing unit. Today the local churches support the program more directly by, for example, inviting the testing unit to church-run health fairs.

The SHOUT program’s reputation in the Sanford community is enhanced by its support groups, involvement on advisory boards, and ability to work constructively with law enforcement. Clients are offered useful incentives, such as backpacks, hygiene packets, gift cards, clothing, and rescued bicycles. ■

Profile 6: Main Clinic and Satellites

Matthew 25 AIDS Services, Inc.
Hendersonville, Kentucky

Organization: Main clinic in Henderson, Kentucky, and 2 satellite clinics in rural Kentucky and Indiana. Nondenominational

Services: Clinical services and support

Clients: > 400 HIV-infected clients in 27 counties

HIV Service Profile: Cyndee Burton, RN, founded Matthew 25 AIDS Services, Inc., after very ill persons with HIV began returning home to die in the 1980s. Ms Burton, who worked in intensive care at the time, says, “I was astounded that the nurses that I worked with refused to take care of these individuals, partly out of fear and partly because we are the ‘buckle of the Bible Belt.’ It was very difficult for them to leave their moral judgments at the door of the intensive care unit and come in and provide care.”

A decade later Ms Burton established the Matthew 25 organization to serve persons with HIV who had to travel great distances for care. Although Matthew 25 was founded in a liberal-leaning local church, it has since become a secular nonprofit organization.

A crucial decision for Matthew 25 was “for our organization to not take on the same stigma as our clients,” Ms Burton says. Some HIV service providers attempt to occupy the same social and geographic niche as their clients and isolate themselves from the larger community. Instead, she established contacts with the business community; she is a Rotarian and a board member of the chamber of commerce. Members of business and fraternal organizations are represented on the Board of Directors of Matthew 25.

When Matthew 25 needed a new clinic, the organization purchased a building on the edge of town. However, the building’s unique location made it easy for clients to be identified while coming and going. Then the facility added other tenants, including a high-traffic clinical laboratory, and rented out space for Chamber of Commerce meetings, Girl Scout meetings, and church group activities, among other purposes. Today it is much more difficult to tell who is going to Matthew 25 for HIV services.

As a result of an HIV speaker program in local churches, church members continually volunteer to help Matthew 25 clients. Drivers take them to appointments, knitters make them hats and gloves, and gardeners donate their work to the community garden that supplies produce to Matthew 25’s food pantry. Church volunteers have produced Christmas food boxes for HIV-infected clients and delivered the parcels to their homes.

The Gifts of Grace program matches church members anonymously with clients. The client is given a Biblical name, and all the donors are called “Grace.” The Gifts of Grace volunteers are asked to support their client with prayers, letters, and small gifts. They are also asked to contact their clients at least once a month, and clients are urged to write back to their volunteers.

Fundraising programs for Matthew 25 are another way to engage the community; for example, a fashion show was hosted at a local Baptist church. ■

Profile 7: Central office With Mobile Case Management and Support Services

AIDS Resource Alliance and West House Personal Care Home
Williamsport, Pennsylvania

Organization: Nonprofit HIV/AIDS service organization serving 3 rural Pennsylvania communities from a single location

Services: Case management, medical and dental care, food, nutritional supplements, housing and utilities assistance, treatment education, outreach and testing

Clients: About 150 persons with HIV who live in northeastern Pennsylvania. African Americans make up 41% of clients—in counties in which at least 90% of the population is white. Women account for 55% of clients. A majority (81%) of clients live at or below the FPL compared with 11% to 14% of residents of the 3 rural counties, and 8% of clients do not have permanent housing.

HIV Service Profile: Like other rural HIV programs, AIDS Resource Alliance is beset by many challenges. Transportation is “a huge problem for us,” says executive director Kirsten Felix. Two of the 3 counties served by the agency have no public transportation. In the third county, the closest infectious-disease specialist cannot be reached via the available public transit. The program’s case managers must make house calls to clients who live outside the small city of Williamsport (population 30,000), where the clinic is located, and must transport clients to medical appointments using their own vehicles. As a result valuable time and resources are lost. The clinic spends about 8% of its budget on transportation, thereby reducing the amount that could otherwise be spent on medication and support services, Ms Felix says.

Funding is another challenge. The program has suffered state and federal budget cuts for years. A 2010 state budget crisis resulted in a months-long hold-up of both state and federal Ryan White funding and 6 months without receiving any income for the program. Although the program raises funds by reaching out to the community, this is a difficult enterprise given the current economic downturn and the stigmatization of HIV.

The AIDS Resource Alliance has had to fight HIV stigma on many fronts. One such battle ended in a clear victory. In the past assisted living facilities accepted the program’s clients, only to renege once they saw the medical forms of persons who had received a diagnosis of HIV/AIDS. One facility openly admitted it would never admit a person with HIV because doing so would make its staff “uncomfortable.”

By admitting to discrimination, the facility gave the AIDS Resource Alliance an opening to file a complaint with the Department of Public Welfare and the federal Office of Civil Rights and Office of Fair Housing and Equal Opportunity. The program won the complaint; however, the facility did not admit the patient out of concern that he would not receive quality care. Determined to prevent future denials of admission to assisted living for HIV-infected persons, Ms Felix, along with the clinic’s staff and board of directors, founded a new nonprofit organization and raised enough funds to get a mortgage and acquire the assisted living facility. They renamed it West House in honor of the client who was refused admission.

The 18-bed licensed home provides personal care in a home-like setting.

To preserve client confidentiality, West House was not made an AIDS-specific home, but rather a home where everyone is welcome. Since its founding in 2007 West House has provided quality care for 10 persons with AIDS in addition to its other clients. Involvement of a case manager from the AIDS Resource Alliance ensures that these clients receive the best care possible. ■

Improving Retention. Research on effective ways to improve patient retention in HIV is limited. Some useful approaches include:[29,61]

- Multiple contacts, including reminder calls before appointments, frequently updating patients' contact information, attempting to reach patients through community contacts after they have missed an appointment, and contact with a peer educator after several missed appointments
- Contact person to help navigate the health care system
- Support services, such as behavioral health and substance abuse treatment and help with transportation
- Strategies that have proven effective in other chronic diseases, such as exit interviews (to confirm the patient understood the visit), patient orientation to the clinic, open-access scheduling, contracting with the patient, social support, and case management

The Role of Case Management and Outreach. Among HIV patients who fall outside the traditional health care system, studies show that such support services as case management, outreach, and group visits can have a positive effect on the use of medical services. In a randomized study of a case management intervention in patients who recently received a diagnosis of HIV infection, a higher proportion of patients who had the intervention visited a clinician at least once within 6 months and at least 2 times within 12 months, compared with those who received standard care without the case management intervention.[63] A study of outreach programs reported that participants who received 9 or more contacts during the first 3 months of a treatment program had fewer gaps in medical care.[64]

More research is needed in order to better understand how support services can be integrated into health care to help facilitate the provision of medical care to underserved HIV patients.

MEDICATION ADHERENCE

Nonadherence to ART is widespread; in the United States and Europe, only 60% to 70% of prescribed doses of ART are taken.[65] In the United States, rates of nonadherence in rural areas may be at least as high as those in urban areas. A nationwide survey of rural residents in 12 states found that only 50% of those on ART took all their prescribed medication in the past week. Ten percent deviated from their ARV drug regimen at least once a day. Rural patients offered several reasons for skipping medication doses: wanting to avoid adverse effects, being unable to take medication at specific times, feeling depressed or overwhelmed, being away from home, not having their medication with them, and simply forgetting—all reasons that urban patients also give. This research suggests that interventions that are likely to succeed are those that will help HIV patients improve the stability of their living situation, establish consistent patterns of eating and sleeping, organize complicated medication schedules, and improve their recall of when to take their ART.[66]

Improving Adherence. In contrast to retention, many studies have tested strategies for improving HIV medication adherence. A meta-analysis of 19 such studies, each with a randomized control arm, indicates that varied approaches are effective.[65] The programs increased medication adherence, which was defined as taking at least 95% of prescribed medication, from 50% in the control arm to 62% in participants who received the study intervention. The increase in average adherence in control groups may have been the result of other interventions they received, such as pill diaries and education. However, the control groups in these studies sometimes received some type of intervention, suspected to be less active than the study intervention. The meta-analysis does not identify any particular program content or format that was more effective than another. The most common delivery method was individual counseling, usually provided by a physician, nurse, or behavioral health counselor. Patients received a median of 2 hour-long sessions. Most programs provided didactic information on ART; interactive discussions of beliefs, motivation, and expectations; and behavioral strategies. Pagers and similar devices were used, though infrequently.[65]

The following checklist (see below) for improving medication adherence was developed using both the 2009 Department of Health and Human Services Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents[67] and the American Public Health Association's recommendations to improve adherence.[68]

CHECKLIST FOR OPTIMIZING MEDICATION ADHERENCE[67,68]

✓ **Assess strengths and barriers**
Comorbid substance abuse, psychiatric, or medical illness
Financial and employment status
Need for support: housing, food, transportation
Health beliefs and cultural background
Family and social support

✓ **Establish therapeutic alliance**
Assure readiness to begin treatment
Choose the first treatment regimen carefully

✓ **Prescribe a simple drug regimen**
Low pill count
Less frequent dosing
No food requirements
Less frequent/severe adverse effects

✓ **Monitor adherence**
Self-report
Pill counts
Prescription tracking
Bottle cap devices
Viral load measurements

✓ **Steps to improve faltering adherence**
Review the patient's treatment goals and beliefs
Simplify the regimen
Adapt regimen to the patient's situation
Address need for support services
Treat side effects
Problem solving
Reminder devices: pagers, pillboxes with alarms (sometimes help)
Directly observed therapy

Key Points

OPTIMIZING TREATMENT RETENTION AND MEDICATION ADHERENCE

HIV care can be viewed as a continuum, with multiple opportunities to improve client engagement. Areas in need of improvement include:

- "Retention in care" describes the degree to which a patient keeps primary care appointments and other scheduled medical services
- Interventions likely to improve retention are those that would help patients organize their lives and medication schedules and remember when to take their ARV drugs
- Groups at elevated risk for nonretention and poor medication adherence may be identified for targeted interventions. These groups include women, minorities, the poor, the uninsured, persons with substance abuse or behavioral health disorders, and persons who need basic support services
- A variety of interventions are effective in improving medication adherence. Approaches are usually based on individual counseling with education, discussions, and behavioral strategies

PUBLIC FUNDING FOR HIV CARE

Insurance status is a strong predictor of utilization of HIV care. According to a literature review, persons with HIV who have health insurance, whether public or private, are more likely than uninsured persons to receive treatments for HIV and its symptoms and to exhibit favorable patterns of health care utilization (ie, more outpatient care, less emergency room use).[69] Evaluation research has shown that once HIV-infected persons gain access to ART, their clinical outcomes are not dependent on the source of their coverage.[70]

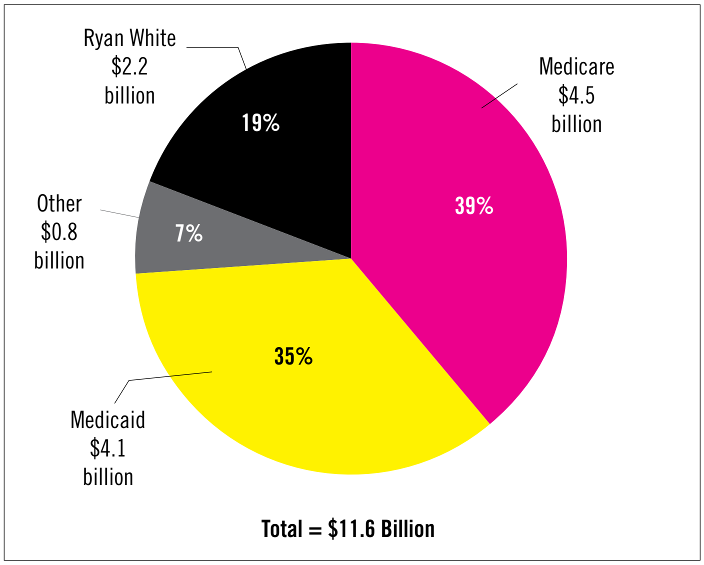
The major sources of funding for HIV care are public and include Medicaid, Medicare, and the Ryan White Program.

> *States vary in the services they allow Medicaid to cover and the reimbursement rates they pay. Some states also place limits on the number of prescriptions or physician visits covered.*

Funding for the Ryan White Program covers AIDS Drug Assistance Programs (ADAPs) and other services vital to persons with HIV who live in areas with limited resources.

Medicaid. Before the implementation of Medicare Part D prescription drug coverage in 2006, the largest source of funding for HIV/AIDS care in the United States was Medicaid, the principal safety-net health insurance program for low-income Americans. Federal Medicaid spending (Figure 11) is matched by state spending. In 2008 total Medicaid spending on HIV care was about $7.5 billion, of which the federal share was $4.1 billion. An estimated 200,000 to 240,000 persons with HIV are covered, or about 4 in 10 of Americans with HIV.[71]

Figure 11. Federal Funding for HIV/AIDS Care by Program, FY 2008



Source: Fact Sheet: Medicare and HIV/AIDS, (#7171-04). The Henry J. Kaiser Family Foundation, February 2009.

Medicaid is a means-tested program. Some eligibility requirements apply nationally, while others vary from state to state. To qualify, persons must be low-income (thresholds vary but typically are 74% of the FPL) and disabled (either unable to work for a year or more or affected with a condition expected to result in death).[71] Most persons with HIV who receive Medicaid qualify for it because they are both poor and permanently disabled. Persons with HIV are 3 to 4 times more likely than the overall US population to be covered by Medicaid. A large proportion of persons who are newly diagnosed with HIV are already on Medicaid. The program is a particularly important source of coverage for both minorities and women with HIV.

Shortcomings in the Medicaid program include difficulty in applying and the requirement to document citizenship and financial need. Furthermore, being HIV-infected does not automatically qualify as a disability, which can prevent persons from being eligible to receive coverage to pay for treatment until it is too late to prevent or postpone disability.

States vary in the services they allow Medicaid to cover and the reimbursement rates they pay. Some states also place limits on the number of prescriptions or physician visits covered.[71]

Medicare. Medicare covers approximately one-fifth of those with HIV infection who receive care, an estimated 100,000 people. With the implementation of the Medicare Part D prescription drug benefit in 2006, Medicare became the largest source of federal funding for HIV treatment.

Medicare is an entitlement program whose main eligibility criteria are age (≥ 65 years) and disability. The majority (93%) of persons with HIV who receive Medicare are younger than 65 years and qualify because they are disabled. Disabled nonelderly applicants can begin receiving Social Security Disability Income (SSDI) payments after a 5-month waiting period once disability has been determined and if they have a sufficient number of lifetime work credits to qualify. This is followed by a 2-year waiting period before the applicants qualify for Medicare.[72]

Low-income persons with HIV face challenges when applying for Medicare, including lengthy waiting periods and the same double-bind involved in applying for Medicaid: not qualifying for reimbursement for treatments that can prevent disability.

Because the SSDI benefit level is based on income history rather than current need, it limits the benefits that are available to many low-income persons.

In general Medicare has higher reimbursement rates than Medicaid, thereby offering more flexibility to patients and providers. However, Medicare has cost-sharing requirements and does not pay for all necessary services, such as dental care and long-term care. Medicare recipients often have supplemental coverage, from Medicaid, Ryan White Program funds, or private insurance.

KEY ATTRIBUTES OF AN AIDS DRUG ASSISTANCE PROGRAM

A number of attributes contribute to a successful ADAP, according to ADAP Program consultant Lanny Cross. Eligibility criteria for the program must be inclusive, with financial criteria that allows for the cost of living in the state. An ADAP must be a low threshold program with a simple application that is easily understandable and permits quick processing by program staff. The documentation required must be flexible in order to accommodate applicants' various situations; for example, extensive documentation should not be required to meet residency requirements for persons who are undocumented or have unstable living arrangements. Confidentiality is a high priority for many persons with HIV/AIDS, and it must be guaranteed to encourage application to the program. The ADAP must also provide convenient access to medications, which may include local pharmacies and a mail order option.

Because the US health care system is very fragmented, ADAPs must be structured to interact with other health care payers whenever possible, Mr Cross says. ADAPs should be Medicaid-compatible, assisting patients in Medicaid spend down and easing their transition to Medicaid whenever possible. ADAPs should also coordinate benefits with Medicare Part D and private insurance companies to leverage maximum coverage from these sources and conserve scarce ADAP funding.

Treatment of HIV infection requires a comprehensive formulary, including all ARV drugs, treatment and prophylaxis of opportunistic infections, and treatment of medication adverse effects and toxicities. Behavioral health drugs and treatments for comorbidities, such as TB and hepatitis, are important for maintaining clients' health and medication adherence.

Policies and processes that are user-friendly and staff who are client-oriented are also important. ADAP staff should always be courteous and caring when dealing with clients. Ideally ADAPs should have multilingual staff when serving non-English-speaking clients.

ADAPs also should strive to be nonintrusive in terms of the physician/patient relationship and provide access to a range of treatment options and exceptions, thereby facilitating individualized care.

An advisory workgroup composed of providers and consumers can serve as a mechanism for active community involvement and program support; the workgroup can also ensure that the ADAP remains aware of and responsive to the changing and emerging needs of its clients, Mr Cross says.

Prescription ARV drugs are covered by Medicare Part D, but the coverage includes a "doughnut hole," a period during which Medicare coverage stops and does not resume until beneficiary expenses reach a catastrophic level—currently $4550. Low-income Medicare beneficiaries typically receive some type of subsidy to cover this gap, usually Ryan White ADAP funding.[72]

The Ryan White Program. The Ryan White Program is the third largest source of federal funding for HIV/AIDS care, providing 19% of federal funding for HIV care ($2.2 billion) in 2008. Enacted in 1990, it is the only federally funded program designed specifically for persons with HIV. It is estimated to reach more than 500,000 clients each year. Most recipients are low income and uninsured (33%) or underinsured (56%).[73]

The Ryan White Program is not an entitlement program; thus, states can specify their own eligibility requirements. Eligibility is usually based on income, and state thresholds vary. States can also choose the services they provide, within certain limits.

Ryan White Program funding is divided into "parts." Part A funding is provided to metropolitan or other areas with a high cumulative number of reported AIDS cases. Part B funding, which includes ADAPs and other services, accounts for 55% of all Ryan White Program spending. Part B funds are distributed by formula to all 50 states, the District of Columbia, Puerto Rico, Guam, the US Virgin Islands, and 5 territories and associated jurisdictions based on their number of persons who live with either HIV (non-AIDS) or AIDS. Parts C, D, and F fund various service providers and special projects. Some states and localities provide matching funds. Ryan White Program funds support medical care, dental care, behavioral health and substance abuse care, case management, and a variety of other support services.

The Ryan White Program is not an entitlement program; thus, states can specify their own eligibility requirements. Eligibility is usually based on income, and state thresholds vary. States can also choose the services they provide, within certain limits.

The Ryan White Program is viewed as the "payer of last resort," playing a crucial role in supporting HIV care and services in underserved populations. It is an important source of support for HIV care for persons who await eligibility for Medicare and Medicaid. Funding depends on annual appropriations by Congress. The rate of increase in Ryan White Program funding has not kept pace with the growing demand for HIV services and with the stresses on the economy and other elements of the health care system.[73]

Providing such support services as transportation and behavioral health care increases the likelihood that patients will continue HIV primary care. At least one author suggests that the increasing pressure on the Ryan White Program to fund care for more persons with HIV means that fewer support services will be provided and a smaller proportion of patients may stay in care.[74]

AIDS Drug Assistance Programs. ADAPs exist to provide prescription drug coverage. The ADAP budget was $1.59 billion in 2009. The program is jointly funded by the federal Ryan White Program (about 49% in 2009), the states (14%), and by pharmaceutical manufacturer rebates (31%); the remaining share is made up by other federal sources.[75] Federal funding has held steady over 2009 while state funding has decreased significantly (34%) since 2008, and pharmaceutical manufacturer drug rebates to states have increased by 52%.[75] In 2008, the most recent year for which this information is available, 87% of funds were spent on prescription drugs, and the rest on administration.[75]

With about 201,000 enrollees nationwide in 2009, ADAPs provided HIV-related medications to about 125,000 in June of that year, or about one-third of patients who received HIV care nationally (fewer clients are served than are enrolled in ADAPs at any given time). Five states accounted for 59% of all ADAP drug spending: California, New York, Texas, New Jersey, and Pennsylvania. The top 10 states accounted for 75% of spending.[75]

ADAPs are administered on the state level. States are given flexibility to design many aspects of their ADAP programs. Eligibility criteria vary by state within certain constraints. Recipients must document they are HIV-infected. Some states also include CD4 counts, viral load, or clinical criteria. There is no standard income eligibility level; instead, thresholds to qualify for ADAP range from more than 200% to 500% of the FPL.[7]

State ADAPs may determine their own drug formularies, but they are required to have a minimum drug formulary that includes at least 1 agent from each ARV drug class. Formularies range from 28 to more than 466 ARV drugs, with many states covering all FDA-approved ARV drugs as well as drugs used to treat HIV-related opportunistic infections.[14]

State ADAP funding is highly variable and depends in large part on local resources and priorities. At a time of increasing demand for funding, ADAP funding is vulnerable. ADAP enrollment grew by unprecedented amounts in 2008-2009 as the country's economic crisis forced more Americans to rely on safety net programs. Many ADAPs are under considerable fiscal stress.[75] Some states have reduced funding for ADAPs and instituted such cost-cutting measures as waiting lists, reduced income thresholds for program eligibility, client cost-sharing, and restricted drug formularies.[75,76] As of July 29, 2010, a total of 2359 persons in 13 states were on ADAP waiting lists, a 65% increase from June 2010.[76] Most states with ADAP waiting lists are located in the South and the West, and many of these states have predominantly rural populations. Thirteen states have instituted cost-cutting measures in the past year, and other states are considering new or additional steps to minimize costs. Although reduced formularies are the traditional approach to cutting costs, a few states have implemented lower income thresholds for eligibility or cost-sharing. Frequent updates on ADAP waiting lists and other state cost-cutting measures are published in "The ADAP Watch" from the National Alliance of State and Territorial AIDS Directors, which is available at http://www.nastad.org

Key Points

PUBLIC FUNDING FOR HIV CARE

- Once HIV-infected persons gain access to ART, clinical outcomes are not dependent on the source of their coverage

The major sources of funding for HIV care are public:

- Medicaid is the principal safety net health insurance program for low-income Americans
- Medicare is a federal entitlement program whose main eligibility criteria are age and disability. Part D prescription drug coverage has become an important source of payment for ARV drugs
- ADAPs are part of the Ryan White Program. ADAPs are administered and designed by the states, within certain restrictions. Today many state ADAP programs are under financial stress

FIGHTING HIV STIGMA IN UNDERSERVED AREAS

Stigma is frequently mentioned as an additional barrier to HIV care, an additional burden to be borne by HIV-infected persons, and an additional challenge to HIV service providers, particularly in rural areas of the United States.[1,47,77-80]

> *Stigma can negatively affect preventive behaviors, such as whether a person at risk for HIV seeks testing or whether a person who tests positive for HIV seeks medical care. Stigma can also adversely affect the quality of that care as well as how others treat the HIV-infected person.*

DEFINITION, CAUSES, AND CONSEQUENCES OF STIGMA

Stigma can be defined as an attribute possessed by a person, labeled by others as "undesirable," which sets that person apart from others and diminishes his or her value in the eyes of society.[77] Stigma can be caused by a negative reaction to a particular characteristic, such as HIV infection, or from negative attitudes toward a group (eg, homosexuals, racial minorities) or a behavior (eg, homosexual sex, sex with multiple partners, injection drug use).[77]

Persons with HIV who live in rural areas have a greater chance of being stigmatized than persons with HIV who live in urban areas for several reasons: the small size of communities, limited social networks, greater visibility, a lack of access to HIV-infected peers, and social and religious conservatism.[47] Stigma can negatively affect preventive behaviors, such as whether a person at risk for HIV seeks testing or whether a person who tests positive

HOW HIV PROGRAMS PREVENT STIGMA[24]

HIV programs that operate successfully in underserved areas, such as those profiled in this educational program, have adopted multiple approaches designed specifically to reduce stigma in vulnerable client populations.

- **HIV-infected peers.** Many HIV programs utilize persons who are willing to identify themselves as HIV-infected and who provide clinical care, volunteer to help their peers, or act as spokespersons on behalf of the program. They can be role models who demonstrate how to live successfully with HIV
- **Support groups** can help clients overcome feelings of isolation
- **Enlisting churches** to help persons with HIV can help minimize the prejudices associated with a "traditional values" moral mindset
- **Recommendations to protect client privacy and confidentiality**
    - Ask clients how best to protect their confidentiality
    - Ask clients and volunteers to sign a pledge of confidentiality
    - Offer programs at sites that are not identified with HIV/AIDS or health care
    - Be sensitive about the way programs are advertised and marketed
    - Clean up and put away HIV-related materials after participants have left the site
    - Do not record a client's HIV status in open medical records or program records
    - Carefully select transportation services to preserve confidentiality
    - Provide gas vouchers to help with transportation
    - Do not discuss the program or participants in a public place, including by cell phone

Adapted from Rural HIV/STD Prevention Workgroup. Tearing down fences. HIV/STD prevention in rural America. Bloomington, IN: Rural Center for AIDS/STD Prevention, 2009.

for HIV seeks medical care. Stigma can also adversely affect the quality of that care as well as how others treat the HIV-infected person.[77]

Stigma is associated with reduced engagement and retention in HIV care and reduced medication adherence; for example, a person's fear of stigma may result in their missing doses of medication to avoid disclosing their HIV status.[78] Internalized stigma, which occurs when a person internalizes cultural norms that label them as deviant, was present in one-third of an underserved urban population and associated with poor access to care and poor adherence to ART.[81]

Rural providers are vulnerable to ethical conflicts related to stigma.[79] The providers often know or are related to their patients, which may prevent a patient from seeking care for a stigmatizing condition. In addition, maintaining confidentiality is difficult in small communities where many residents know and gossip about each other.

Providers described in this monograph have taken steps to protect their clients from stigmatization (see Sidebar: How HIV Programs Prevent Stigma). For a glimpse of 2 rural HIV service providers who have dealt with stigma in creative ways, see Matthew 25 AIDS Services, Inc., and AIDS Resource Alliance and West House Personal Care Home on pages 19 and 20, respectively.

Key Points

FIGHTING HIV STIGMA IN UNDERSERVED AREAS

- Stigma, which can result when a person possesses an attribute that others consider to be undesirable, can set that person apart from others and diminish his or her value in the eyes of society
- Persons with HIV who live in rural areas have a greater chance of being stigmatized than persons with HIV who live in urban areas for several reasons: the small size of communities, limited social networks, greater visibility, a lack of access to HIV-infected peers, and social and religious conservatism
- Stigma can negatively affect preventive behaviors, such as whether a person who is at risk for HIV seeks testing, or whether a person who tests positive for HIV seeks medical care, takes measures to prevent transmission, engages with and stays in care, and takes their HIV medications
- Rural providers are vulnerable to ethical conflicts related to stigma

CONCLUSION

Changes in the epidemiology of HIV/AIDS pose new challenges to providers whose mission is to care for infected persons. Major advances in treatment have resulted in significant increases in survival among infected persons, thereby transforming HIV/AIDS from a rapidly fatal illness into a chronic disease. HIV incidence has stabilized over the past decade as mortality rates declined, leading to a steady increase in the number of persons living with HIV/AIDS. HIV prevalence continues to rise disproportionately in populations that have limited access to health care services and increased need for other support services: ethnic and racial minorities, persons who live in rural areas, and residents of the rural South. The current financial crisis and cuts in program funding place these groups in further jeopardy. There is a continuing need to improve prevention and early detection of HIV, extend the delivery of effective treatment to poorly served groups, and provide the full range of support services they need.

This program highlights 7 HIV service providers with different approaches to caring for those most in need. What these providers have in common is a flexible, proactive approach grounded in a working knowledge of their communities as well as respect and empathy for their clients. It is likely that the lessons learned from this experience will continue to be important as the HIV/AIDS epidemic enters its fifth decade.

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Strategies & Solutions

- Focus on identifying solutions to the barriers limiting the full implementation of opt-out testing
- Focus on reviewing successful models of care from underserved areas
- Focus on issues and barriers to medication adherence for long-term success of antiretroviral therapy

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