

HRSA Care ACTION

PROVIDING HIV/AIDS CARE IN A CHANGING ENVIRONMENT

Mental Illness and HIV Disease

Mental health has not always been a comfortable topic, with prejudices making mental illness and, often, the mentally ill themselves, taboo. The concepts of mental health and mental illness have not been well understood, and confusion about mental illness and its symptoms have resulted in fear, misunderstanding, and unnecessary suffering.

Much progress has been made in recent years. Mental health has become an acceptable topic of conversation in many social circles and, among some segments of society, reaching out for help is now interpreted as a sign of strength, not weakness. Treatment of mental illness has also improved dramatically. Mental health care increasingly is considered part of comprehensive primary care and referrals for mental health services are much more readily available. And the arsenal for fighting mental illness is larger than ever before.

Definitions

The 1999 publication *Mental Health: A Report of the Surgeon General* provides welcomed guidance for advancing our understanding of basic mental health concepts. This landmark publication provides the following definitions of mental health and mental illness:

Mental health—the successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity;

from early childhood until late life, mental health is the springboard of thinking and communication skills, learning, emotional growth, resilience, and self esteem.

Mental illness—the term that refers collectively to all mental disorders. Mental disorders are health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning.¹

“Major depression is the leading cause of disability in developed nations according to the World Health Organization’s Global Burden of Disease study”

Some common examples of mental disorders are:

Alzheimer’s disease, which is largely marked by alterations in thinking, especially forgetting;

Depression, marked by alterations in mood; and

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Attention deficit/hyperactivity disorder, marked by alterations in behavior (overactivity) and/or thinking (inability to concentrate).

Mental illness is more prevalent than many realize. One in five Americans experiences a mental disorder in the course of a year. Approximately 15 percent of all adults who have a mental disorder also experience a co-occurring substance use disorder, which complicates treatment.¹

About 10 percent of the U.S. adult population use mental health services provided by the larger health care system in any one year, with another 5 percent seeking such services from social service agencies, schools, or religious or self-help groups. Eight percent of these adults have a mental disorder; 7 percent have a mental health problem. Of children ages 9 to 17, 21 percent receive mental health services in a given year.¹

In 1996, the direct treatment costs for mental disorders in the United States was \$69 billion.

In 1996, direct treatment costs for mental disorders, including substance abuse and Alzheimer's disease, was \$99 billion.¹

There is further evidence of the pervasiveness of mental illness in the "Global Burden of Disease" study, commissioned by the World Health Organization and the World Bank, which states that mental disorders represent 4 of the 10 leading causes of disability for those age 5 and older. Major depression is the leading cause of disability in developed nations; manic-depressive illness, schizophrenia, and obsessive-compulsive disorder also figure prominently.²

The study also indicated that the impact of mental illness on overall health and productivity is seriously under-recognized, both in the United States and throughout the world. As the following table shows, mental illness is the second leading cause of disability and premature mortality.

“Ten published studies conducted between 1990 and 1995 showed HIV seroprevalence rates of between 4 and 23 percent among those with a severe and persistent mental illness.”

Disease burden by selected illness categories in established market economies, 1990²

	Percent of Total DALYs*
All cardiovascular conditions	18.6
All mental illness**	15.4
All malignant disease (cancer)	15.0
All respiratory conditions	4.8
All alcohol use	4.7
All infectious and parasitic disease	2.8
All drug use	1.5

*Disability-adjusted life year (DALY) is a measure that expresses years of life lost to premature death and years lived with a disability of specified severity and duration (Murray & Lopez, 1996).

**Disease burden associated with "mental illness" includes suicide.

The Surgeon General's report makes this recommendation to the American people regarding mental health/illness: *seek help if you have a mental health problem or think you have symptoms of a mental disorder.* Yet, there are many barriers to putting this advice into action, including the stigmatization of those with mental health disorders, and gaps in the availability of state-of-the-art mental health services for those who seek them. The report recommends courses of action in order to overcome these barriers. In summary:

- Continue to build the science base;
- Overcome stigma;
- Improve public awareness of effective treatment;
- Ensure the supply of mental health services and providers;
- Ensure delivery of state-of-the-art treatments;
- Tailor treatment to age, gender, race, and culture;
- Facilitate entry into treatment; and
- Reduce financial barriers to treatment.

How Prevalent is Mental Illness Among People Living with HIV Disease?

The precise number of people living with HIV disease who suffer from mental illness is impossible to know. Disease surveillance is difficult for many reasons. Mental illness is often undiagnosed and many people are able to carry out activities of daily living despite mental health problems. Moreover, mental illnesses are points on a vast continuum, from the mildest form of short-term depression—perhaps in reaction to an HIV diagnosis—to a lifelong struggle with schizophrenia that existed long before HIV was contracted.

Common Psychiatric Disorders Among People Living With HIV Disease

Psychiatric Conditions	Examples of Symptoms
Mood Disorders	
Depression	Pervasive sadness, apathy, fatigue, suicidal ideation, hopelessness, changes in appetite and sleep patterns
Mania (Bipolar Disorder)	Increased energy, decreased need for sleep, racing thoughts, grandiosity
Psychotic Disorders	
Schizophrenia	Auditory hallucinations, delusions, thought disorders
Anxiety Disorders	
Generalized anxiety disorder, panic disorder, obsessive-compulsive disorder, post-traumatic stress disorder	Nervousness, heightened arousal, panic attacks, intrusive anxiety-provoking thoughts, obsessions/rituals, flashbacks
Adjustment Disorders	
	Depression and/or anxiety of less severity and directly related to an identifiable stressor
Personality Disorders	
	Persistent, maladaptive life behaviors that interfere with interpersonal relationships
Sleep Disorders	
	Difficulty initiating and/or maintaining sleep
Sexual Functioning Disorders	
	Diminished libido, difficulty having an orgasm, difficulty obtaining or maintaining an erection
Constitutional Problems	
Chronic fatigue	Chronic lack of energy
Wasting syndrome	Chronic muscle wasting
Pain	Chronic pain from such conditions as neuropathy

Source: Research Triangle Institute

However, studies indicate that mental illness among the HIV-positive population is significant. In a study based on telephone calls placed to the CDC National AIDS Hotline—which provides confidential HIV-related information and referrals to anonymous callers—11.3 percent were mental health-related, in that callers spoke about specific mental health-related topics or requested mental health referrals. In addition, 4.6 percent of calls included signs or symptoms from the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*, which indicate potential mental illness.³

Another study estimates that at least 30 percent of all people with HIV require mental health services to treat the emotional and cognitive sequelae of the infection.⁴

Somewhat better data are available about those individuals who suffer from "severe and persistent mental illness," or SPMI (which typically refers to schizophrenia, bipolar disorder, major depression, or schizoaffective disorders). Ten published studies conducted between 1990 and 1995 showed seroprevalence rates among those with a severe and persistent mental illness of between 4 and 23 percent.⁵

Experts speculate that several characteristics of this population may increase their exposure to HIV infection. Deficits in cognition, social skills, and problem-solving are contributing factors, as well as impulsivity, sexual acting out, and difficulty forming stable social/sexual relationships.⁶

What Mental Health Problems Do HIV-Positive People Face?

A variety of psychiatric disorders have been identified among people living with HIV/AIDS. These conditions may exist prior to and following an HIV diagnosis; whether some of these conditions are a direct result of a person's HIV diagnosis remains an unanswered question. One study speculates that depression appears to be the most common psychiatric disorder found among HIV-positive individuals.⁷

Psychiatric mental illness disorders among people with HIV disease are wide-ranging—from anxiety disorders characterized by nervousness, to psychotic conditions like schizophrenia that include auditory hallucinations and delusions. The most common are summarized in the chart above.⁸

Efforts also have been made to classify cognitive dysfunction as it pertains to HIV/AIDS. The National Institute of Mental Health convened four workgroups that addressed specific questions and made recommendations for research in both the clinical and basic science aspects of the neurological effects of AIDS. The workgroups recommended these standard classifications in order to precisely identify cognitive dysfunction:

1. Neuropsychologically unimpaired — performance at or above expected levels in all functional domains, or below expected levels in no more than one domain;
2. Neuropsychologically impaired—performance below expectations in at least two cognitive domains;
3. Mild neurocognitive/minor motor disorder — the identified impairment occurs in at least two domains resulting in mild dysfunction in everyday functioning or work performance; and
4. HIV-associated dementia — significant neuropsychological impairment occurs in at least two domains, and results in marked dysfunction in everyday functioning or work performance.

There was also agreement that the term "dementia," previously applied to subjects with a broad range of neuropsychologic functional capacity, should be reserved for only the most severe level of HIV-related cognitive impairment.

Care and Treatment of Mental Illness in Individuals Living with HIV Disease

Learning that one is HIV positive can adversely affect mental health. The need for HIV care providers to be better trained in how to help their clients cope is clear. A 1998 survey (supported in part by the Texas/Oklahoma AIDS Education and Training Center), was conducted among mental health professionals, who were asked how strongly they would recommend various topics for educational programs. "Psychological crises associated with learning that one is HIV positive" was at the top of the list of "strongly recommended" topics (as opposed to "not recommended" or "recommended"), with a full 92.8 percent among respondents citing the need.⁹

In another survey, directors of nearly 500 outpatient mental health settings in New York State were asked about HIV/AIDS services, training needs, and barriers to care. Although the number of HIV/AIDS clients served varied from site to site, 84 percent of mental health director respondents reported unmet needs for training. In this case, mental health professionals expressed their concerns about insufficient training in their centers in everything from detecting risk for HIV infection to providing services known to be effective in both HIV prevention and treatment. As the

"HIV is spread by unsafe behaviors that mental health care providers often are in the best position to address."

report states, "HIV is spread by unsafe behaviors that mental health care providers often are in the best position to address."¹⁰

1999 Ryan White CARE Act Allocations for Mental Health Counseling and Treatment

Title I
\$28,513,146, or 5.9% of all Title I funds
Title II
\$4,195,952, or 1.7% of all Title II funds
Title III
\$2,717,070, or 3.8% of all Title III funds

In collaboration with other Federal agencies, HRSA has played a role in improving services to people with HIV disease who have mental health problems. HRSA, along with the Substance Abuse and Mental Health Services Administration and the National Institutes of Health, conducted the HIV/AIDS Mental Health Services Demonstration Program, which focused on the mental health needs of people living with or affected by HIV.

Findings of this project were published in the 1999 *Mental Health Care for People Living With or Affected by HIV/AIDS: A Practical Guide*. The authors believe that the mental health needs of people with HIV are best addressed using the biopsychosocial approach to care, where providers must address this population's needs on several levels:

Social and environmental circumstances: including poverty, access to care, family relationships, housing, financial needs, food, child care, transportation, and legal status. Such concerns may be further complicated by homelessness, incarceration, and prostitution.

Psychological factors: including stress; depression; anxiety; cognitive impairments due to HIV-associated dementia; psychosis; mania; pre-existing serious mental illness, including schizophrenia and bipolar disorder; and poor judgment and impulsivity associated with personality disorders. Defense mechanisms, such as avoidance and denial, also may interfere with seeking and accepting treatment.

Biological aspects: health issues associated with HIV include the client's medical condition; health of the immune system; symptoms and common opportunistic infections (e.g., of the brain); medications prescribed both prophylactically and for symptom relief; and co-existing chronic illnesses, such as diabetes, renal and liver disease, and high blood pressure.

Further, the authors report that a key lesson learned was the importance of collaborative networks, which are vehicles to ensure that service provision systems are responsive and effective in meeting the multiple, complex needs of people with HIV/AIDS. The networks are a series of formal or informal relationships between and among individuals and organizations. They enhance the range and accessibility of services available to clients, and allow providers and administrators to benefit from the experience of other community organizations.

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Policy Notices on Utilization of CARE Act Funds

The HIV/AIDS Bureau has released two new policy notices regarding utilization of CARE Act funds.

Services for American Indians and Alaska Natives. HAB Policy Notice 00-01 states that any American Indian or Alaska Native otherwise eligible to receive CARE Act services may receive them even when eligible to receive the same services from the Indian Health Service or related providers. The new policy additionally clarifies that Indian Health Service facilities and tribally operated and urban Indian health programs may receive contracts from Title I and Title II grantees, and they may apply for Title III and Title IV funds directly.

Allowable Expenditures under the AIDS Drug Assistance Program (ADAP). HAB Policy Notice 00-02 explains the conditions under which ADAP funds may be used to ensure access to medications, and to support adherence. Expenditures for services that improve access to medications, increase adherence to medication regimens, and help clients monitor their progress in taking HIV-related medications are permitted.

These policy notices were mailed to all CARE Act grantees and may be downloaded from the web at: <http://hab.hrsa.gov/mission.html>.

New Treatment Guidelines for HIV and HCV Coinfection

Although the precise number of coinfecting people is difficult to pinpoint, the most conservative estimates are that 14 percent of HIV-positive individuals are also HCV-infected (see "Hepatitis C," *HRS Care ACTION*, September 1999).

HCV progresses slowly, and because individuals with HCV can remain asymptomatic for 20 years or longer, many with the disease are unaware of their condition. Chronic liver disease is the tenth leading cause of death in the United States; 40 percent is HCV related, killing between 8,000 to 10,000 individuals each year.

The U.S. Public Health Service and the Infectious Disease Society of America have issued a set of guidelines for the prevention of opportunistic infections among patients who have HIV.¹ With regard to HCV infection, the guidelines recommend the following:

1. HIV-positive persons should be screened for HCV by enzyme-linked immunosorbent assay;
2. Patients should be advised on alcohol use;
3. Patients should be screened for hepatitis A virus IgG. If negative, they should be vaccinated;
4. Patients should be evaluated for liver disease and need for treatment; and
5. Liver enzymes should be monitored after initiation of HAART.

Standard therapy for HIV/HCV is a combination of interferon alfa-2b and ribavirin: patients receive twice weekly interferon injections and daily oral doses of ribavirin for 6 to 14 months. The majority of patients concurrently receive HAART for treatment of HIV.

A recent study conducted by Douglas Dieterich, M.D., chief of Gastroenterology and Hepatology at Cabrini Medical Center in New York City, examined the efficacy of the standard interferon/ribavirin approach. Forty percent of coinfecting patients who received the therapy had a sustained virologic response. The study also demonstrated that ribavirin does not interfere with the action of certain HIV medications, as had been previously thought.

	HIV	HCV
Worldwide Prevalence	40 million ¹	170 million ²
U.S. Prevalence	800,000-900,000 ³	4 million ⁴
U.S. Annual Incidence	40,000 ⁵	36,000 ⁶
Seroprevalence among long-term injection drug users in the U.S.	15%-20% ⁷	80%-90% ⁸

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Dr. Dieterich is president of the Hepatitis Resource Network (HRN), a nonprofit alliance for research, treatment, and prevention of viral hepatitis. Dr. Dieterich, along with HRN Vice President Mark Sulkowski, M.D., Assistant Professor of Medicine at Johns Hopkins, and John Bartlett, M.D., Chief of Infectious Diseases at Hopkins, recently hosted a meeting of experts in HCV/HIV, with the intent of producing treatment management guidelines. The group produced a CME monograph entitled *Expert Perspectives: Strategies for the Management of HIV/HCV Coinfection*, which is available at www.projects.inknowledge.com.

Summary of General Recommendations for Management of HCV Infection in HIV-Infected Patients

Evaluate all HIV/HCV-infected patients for HCV therapy

Consider the following in assessing candidates for treatment and deciding how aggressively to treat

- Laboratory and histologic findings
- Severity and duration of liver disease
- Likelihood of response to treatment
- Comorbidities (e.g., chronic obstructive pulmonary disease, depression, other psychiatric illness)
- Contraindications to treatment
- Alcohol use
- Psychiatric disorders
- Status of HIV disease
- Life expectancy
- Patient attitude

Strongly advise patients with HCV infection to abstain from alcohol consumption

Vaccinate susceptible patients against hepatitis A and B viruses, pneumococcus, and influenza virus

Consider interferon/ribavirin combination therapy for HCV-infected patients with:

- Stable HIV disease (including adequate CD4 count), with the goal of viral eradication
- Advanced liver disease, with the goal of halting or delaying disease progression
- HAART hepatotoxicity, with the goal of reducing the toxicity and re-establishing aggressive treatment for HIV infection

Avoid interferon/ribavirin combination therapy for HCV-infected patients with:

- Decompensated cirrhosis (consider liver transplantation)
- Major contraindications, such as severe depression

Manage side effects of interferon/ribavirin, including depression and cytopenia

Individualize duration of therapy according to patient and viral characteristics

Evaluate response to treatment at 6 months and consider long-term treatment in nonresponders with advanced liver disease

Use a team approach to treatment

Source: *Expert Perspectives: Strategies for the Management of HIV/HCV Coinfection*

The monograph describes what is likely to be the next advance in HCV therapy, the use of long-acting pegylated interferons. Polyethylene glycol conjugates of interferon alfa will offer greater patient convenience through once-weekly dosing (many patients experience flu-like symptom side effects on the day of dosing), and improvements in response rates compared with standard interferon monotherapy. The authors caution that pegylated interferon monotherapy will not produce response rates as high as those now achieved with interferon/ribavirin combination therapy, but that a pegylated interferon/ribavirin combination will produce sustained response

rates comparable or superior to the rates typically observed with conventional interferon alfa-2b.²

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EMAs Respond to HIV/AIDS Among Minorities: A Case Study Report

Executive Summary

HIV disease in the United States is increasing disproportionately among African Americans and Latinos, and AIDS mortality has not decreased as significantly among these populations as it has among whites.

In this study, the HIV/AIDS Bureau (HAB), and Cities Advocating Emergency AIDS Relief (CAEAR) Coalition sought to understand how Eligible Metropolitan Areas (EMAs) under Title I of the Ryan White CARE Act are responding to the HIV/AIDS epidemic among minorities.

Methodology

Telephone interviews were conducted with two individuals in each of four Title I EMAs to obtain information on responses to the epidemic among minorities.

Results

EMAs are implementing multi-faceted responses that address AIDS morbidity and mortality among minorities, and are improving capacity among minority providers, enhancing targeted outreach, and collaborating with community-based organizations. However, many HIV-positive individuals remain out of care, and the cost and complexity of serving those who are in care is high. As HIV disease increasingly expands into communities with high levels of poverty and comorbidity, managing the disease becomes more intensive, expensive, and complex.

Background

Minorities in the United States suffer higher rates of HIV disease. In the year ending June 30, 1999, 84 of every 100,000 African Americans and 34 of every 100,000 Latinos over age 13 had AIDS (excluding HIV), compared with 9 of every 100,000 whites. Among females, the dichotomy was even more pronounced.

Minorities living with HIV disease often have less access to care and, consequently, poorer health status. The decline in AIDS mortality from 1996 through 1998 was less significant among African Americans (45 percent) and Latinos (53

percent) than among whites (60 percent); and the decline among females, four out of five of whom were minority, was just 43 percent, compared with 55 percent among males.

Project Description

The HIV/AIDS Bureau and the CAEAR Coalition assessed the degree to which services to minorities have been enhanced.

This study intended to address:

What are the primary factors that affect access to services and disparities in outcomes for minorities with HIV disease in the case study EMAs?

What strategies have been developed that hold promise for reversing these access and disparity gaps?

The CAEAR Coalition is a national organization that advocates for sound public health policies and resources for the health care and supportive service needs of people living with HIV disease who receive services through the CARE Act, particularly through Title I and Title III.

Data released by the Centers for Disease Control and Prevention in spring 1998 highlighted a startling increase in new HIV infections and AIDS morbidity among African Americans. African American community representatives called on the Congressional Black Caucus (CBC) and the Administration to declare a national state of emergency to address this crisis. In October 1998, the President declared the AIDS epidemic among minorities to be a "severe and ongoing health crisis," and some months later the CBC Minority HIV/AIDS Initiative designated \$156 million in additional Federal funds to combat HIV/AIDS in minority communities hardest hit by HIV disease.

Methodology

Telephone interviews were conducted in 4 of 51 EMAs funded under Title I of the CARE Act: Cleveland, Detroit, Philadelphia, and San Antonio. These locations serve high numbers of racial and ethnic minorities and represent diverse parts of the country.

Eight individuals were interviewed for not less than 30 minutes each. Two were HIV positive. In all four EMAs, a senior official within the Title I grantee office was interviewed. Another person, knowledgeable of HIV/AIDS service implementation and actively involved in health planning and service provision, but not employed by the grantee, was also interviewed.

A standard interview protocol was used; respondents were asked to answer based on their opinions and perceptions. Participants were urged not to repeat information provided in their Title I grant applications or in the CBC Initiative applications. Respondents were advised that this research was not related to continuation of current grants received under the CARE Act, receipt of future grants, or any grants management or program implementation monitoring function.

Case Study Findings

Cleveland-Lorain-Elyria OH

The Cleveland EMA comprises six counties, with Cuyahoga County accounting for 89 percent of AIDS cases in the region. About 48 percent of cases are among African Americans, who reside primarily in Cleveland. A growing number are among Latinos. The local epidemic reflects the Nation's: a growing proportion of AIDS cases are among women and individuals for whom the HIV exposure category was heterosexual contact; consumers are increasingly impoverished; and the incidence of comorbidity, especially mental illness and addiction, is on the rise.

Barriers to Care in the Cleveland EMA

Both Cleveland respondents believe that transportation is the most critical barrier to care, particularly in trying to create referral networks with rural providers. Those without access to Cleveland's public transportation system are especially vulnerable.

Poverty and lack of access to essential services such as housing is a growing problem. In Cleveland, shelters are reluctant to accept HIV-positive persons; when they do, drug policies make HIV treatment adherence complex, at best.

Stigma associated with same-sex sexual activity is strong. Low educational attainment is a significant problem—the high school drop out rate in Cleveland is 50 percent. Mistrust of the health care system is also widespread, and missed appointments have affected access to care: some organizations no longer collaborate with the grantee due to no-shows.

Respondents also discussed a lack of management skills among providers. In particular, they may lack the ability to present an organized service delivery concept or

demonstrate the use of sound financial principles. Providers find it difficult to learn from the experiences of other providers; with scarce resources, allocating staff time for communications with other providers is difficult, and few funds are available for professional development.

The Cleveland EMA's Response

Communities of faith are collaborating with the EMA. Women are especially responsive to messages from faith-based organizations, but men are less receptive, especially men who have sex with men. The region's Spanish newspaper is publishing free information about HIV disease regularly, and the local newspaper for homeless people is also providing information on prevention, counseling and testing, and HIV services.

The EMA is strengthening relationships with substance abuse treatment providers, and building relationships with correctional institutions for the first time. The grantee is also providing cultural sensitivity training.

The EMA is participating in a statewide effort to address lack of health care information among HIV-positive individuals: 125 people were trained on treatment updates, accessing entitlements, and emerging issues. Trust is a significant issue, and the EMA is involving indigenous organizations in implementing solutions.

The grantee is working with the City of Cleveland to find housing solutions. In 1992, the housing waiting list was closed, and no new housing was added until 1999.

The respondents discussed additional strategic problems: treatment failure and its impact on the demand for support services; lack of access to medications not in the ADAP formulary; lack of capacity building dollars; and the challenges of "mainstreaming" individuals who are benefiting from HAART.

Detroit MI

Respondents described a six-county EMA where 70 percent of AIDS cases are in Detroit and the majority are among African Americans.

The auto industry draws African Americans and Latinos to Detroit, particularly African Americans from the South. Latinos tend to be of Mexican, Cuban, or Haitian descent. A sizable number of Caldeans (a Christian Arab population) and migrant farm workers reside in Detroit during summer months. Most minorities with HIV disease live at 200 percent of the Federal poverty line or less. About 25 percent are female.

Respondents noted two crucial factors: (1) The EMA has an especially large deaf community due to hearing loss from work in automobile factories; and (2) some of the most stringent criteria for public assistance in the Nation.

Barriers to Care in the Detroit EMA

Lack of education, poor access to health information, and poor public transportation are significant. Poor housing and lack of access to refrigeration and storage facilities were also noted. The fear of stigma among men who have sex with men and among minority women, who fear being labeled as prostitutes, are also significant problems. Fear of losing anonymity causes some Latinos to avoid a prominent Latino provider and to travel to other neighborhoods for care. Deaf individuals are especially isolated from services.

Respondents cited a significant need for technical assistance among providers, and a propensity to compete rather than collaborate, the latter being an impediment to a "seamless" experience for consumers. Staff turnover at the grantee level, the shortage of minority providers, and the lack of cultural competency were also believed to be significant.

The Detroit EMA's Response

The Detroit EMA was one of 11 sites that received from 8 to 10 weeks of special technical assistance from Federal "Crisis Response Teams" deployed by the U.S. Department of Health and Human Services. Rapid assessment resources helped isolate the highest risk zip codes in the region, targeting two populations not in care: African American men who have sex with men and African American injection drug users.

The grantee is changing how services are delivered. Mobile services are offered during expanded business hours, and case managers are working in the streets to link individuals to care and assist with adherence. Discharge planning is being improved, so that recently released individuals are not required to navigate a complex system of unfamiliar providers.

The EMA is improving management outcomes, adopting a common data system and a higher quality needs assessment process. Foundation funds are supporting capacity building at five minority organizations. The grantee has changed its grants management approach from project monitoring to technical assistance, reflected in a range of initiatives, from evaluation and case management training to a new Community Primary Care Network. The Network is credited with improving drug formularies and access to dental care.

Case management outcomes are being improved through an approach that empowers clients to manage all aspects of their lives. "We are moving to a paradigm of partnership with the consumer," says one respondent.

Respondents credit insightful leadership from health care providers and case managers and the implementation of sound client health and social service care plans with improving outcomes among minority clients.

Philadelphia PA

The Philadelphia EMA covers suburban and rural areas across nine counties in Pennsylvania and New Jersey. Minorities represent a majority of AIDS cases, including African Americans and Latinos, as well as Caribbean and recent immigrants from Africa, especially Liberia. The epidemic reflects national trends: women, along with substance abusers and their sexual partners, represent a growing proportion of new AIDS cases. Poverty is a key factor. Providers care for a large migrant farm worker population.

Barriers to Care in the Philadelphia EMA

Stigma is the most significant barrier, preventing individuals from accessing health information, and keeping them out of clinics and organizations known to be HIV providers. A lack of stable minority providers is also a critical problem.

Housing and lack of transportation are problematic. Inadequate financial resources are the most important barrier to delivering services; some organizations can survive in a given fiscal period but cannot repay loans, and most Federal, State, and local funds can't be used to retire debt.

One respondent cited a profound dichotomy of need between suburban and inner-city communities. Using organizations with community relationships to reach HIV-positive individuals is important, but finding organizations that meet fiscal and organizational management requirements is a challenge. Technical assistance and training helps, but implementing solutions is slow and costly.

The Philadelphia EMA's Response

The grantee is funding five new "storefront" sites in areas with high concentrations of HIV infection, substance abuse, and prostitution. Counseling and testing, referrals, and some primary medical care are available. Funding providers that offer social services is a priority.

The grantee is funding a short-term inpatient substance abuse treatment program targeting mentally ill substance abusers at risk for homelessness; clients' basic needs are met before they are tested for HIV. With the planning council's support, the grantee continues to encourage the funding of minority controlled service providers.

Services are being regionalized to help overcome barriers related to transportation and trust, and monitoring mechanisms are being implemented.

Consumers are very involved in planning processes, and the support of the Mayor of Philadelphia, the City's Social Services Director, and the Commissioner of Health are also crucial.

Community-based organizations need help honing their skills, defining their service lines, and coping with more stringent requirements for documented outcomes and improvements in quality of care. The continuous quality improvement (CQI) process is one management tool, with technical assistance and capacity building as important components.

San Antonio TX

The San Antonio EMA covers four counties, and Spanish is the primary language of about one-half of the population. Incomes are low and the number of uninsured residents is high; three of four individuals living with AIDS receive care at a publicly funded site. Providers also serve outlying rural populations.

About one-half of all AIDS cases are among Latinos, almost one-quarter among African Americans, and the remainder among whites. Men who have sex with men is the predominant risk factor for HIV transmission, but many do not identify as gay or bisexual. The proportion of cases among women is increasing and almost all are among minorities. Access to substance abuse treatment is a significant problem.

Barriers to Care in the San Antonio EMA

Poverty is the most significant barrier to care, exacerbated by an erosion of State programs and a lack of awareness—especially among women—that public services are available through CARE Act providers.

Stigma is a substantial problem. Women fear being labeled as injecting drug users or prostitutes, while men fear being labeled gay or bisexual. HIV-related stigma is also a problem among potential providers.

An under-funded safety net system has resulted in poor access to HIV care. Lack of State funds for primary health care means that a higher proportion of CARE Act resources goes to medical services. State and locally funded health care services are increasingly inaccessible; the region's public mental health treatment facility recently closed.

Organizations either focus on or are perceived to focus on one population's needs over another's. Moreover, the service system is fragmented: "I work with 12 organizations, but they do not work with each other," noted one respondent. A lack of professional resources is also a critical problem, as educational attainment is low and demand for skills is greater than supply.

The San Antonio EMA's Response

Funding increasingly targets African Americans. A weekly providers' meeting identifies potential lapses in services

delivery, and a case manager or social worker works with consumers to resolve barriers.

Few local resources are available in San Antonio. Educating key decision-makers about HIV disease and unmet need is critical. While advocacy has helped, adequate resources are still lacking.

The EMA is grappling with caring for its incarcerated population, who have minimal services. The Internet is helping relay information to correctional caregivers.

The EMA is increasing access to medical care, but without improvements in access to Medicaid, progress will be difficult.

Discussion

The External Environment

Title I communities face daunting circumstances:

EMAs must cope with the erosion of the public social service safety net. Due to changes in State eligibility criteria, HIV-positive adults have uneven access to Medicaid, housing, and food, and the epidemic is spreading most rapidly among poor people with multiple diagnoses.

Community-based health care systems must cope with an explosion of co-morbidity—substance abuse, mental illness, and hepatitis C—while access to treatment is not keeping pace with need.

EMAs battle long-held distrust of the medical establishment by populations that need care.

EMAs must address these challenges despite rising health costs and a lack of resources for basic services.

Cost and Complexity of HIV Care

The costs of responding to the AIDS epidemic reflect the significant effort required to reach the most vulnerable people. Responding to an epidemic is generally least expensive among motivated individuals who have access to information, and no barriers to using it. When barriers exist, costs are higher. And where significant behavioral change is required, costs are still higher. When disease and behaviors are associated with stigma or addiction, they rise still higher.

A Multifaceted Response

EMAs are implementing activities on several fronts to respond to the epidemic among minorities:

Linking with communities of faith;

Increasing the number of providers in underserved communities;

Enhancing capacity building, technical assistance, and training; and

Being attentive to outcomes.

Activities that address barriers to care are labor and time intensive, and grantees face difficult choices about what to fund. Moreover, determinants of success are not always in the grantees' control. For example, partnering with communities of faith can improve outreach outcomes, but churches may not want to be involved. Grantees face difficulties in locating community-based providers to serve HIV-positive individuals. Ensuring that services meet quality standards and that reporting data and fiscal controls are in place is equally challenging.

Barriers to HIV Care

EMAs reported that transportation, stigma, poverty, and lack of trust are significant problems. How consumers will get to a service provider remains paramount 20 years after the onset of the epidemic and 10 years after passage of the CARE Act. Its resolution will directly influence reduction in AIDS mortality and comorbidity, improvements in quality of life and well-being, and total costs of care.

Stigma, particularly among men who have sex with men who do not identify as gay or bisexual, received substantial attention. Societal homophobia and internalized homophobia are critical issues because they result in self-loathing, denial, and fear. EMAs face a monumental communications challenge: they must overcome vociferous messages from society-at-large that can increase risk-taking, estrangement from health care, and premature death.

Poverty is stressing the CARE Act-funded network, and it is exacerbated by an eroding public health and social service safety net and rising HIV treatment costs. Every respondent

observed the vast difference between affected populations 10 years ago and today. The potential for meaningful HIV therapy has increased while co-morbidity and the need for support services has skyrocketed.

What of the hundreds of thousands of individuals who remain outside the health care system? The learned response is that community organizations should endeavor to meet all needs simultaneously. The reality is that EMAs do not have the resources.

Challenges for the Future

EMAs are managing their resources with increasing efficiency and implementing new approaches with promise for reaching vulnerable populations. Each respondent discussed the importance of improving management capabilities, efficiency, and outcomes. Each discussed increasing capacity in indigenous minority organizations. But financial resources are limited and EMAs must make increasingly difficult choices in an increasingly demanding environment.

Greater awareness of the needs and perceptions of those not in care and among those receiving services intermittently is critical. Increased financial resources are important, but other barriers to care associated with stigma and behavioral change require more than money. While progress is being made, many with HIV remain out of care and 40,000 new HIV infections occur in the United States every year. The AIDS crisis among minorities demands adequate resources for a comprehensive approach that includes communication and collaboration with those in need.

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