

# Delivering HIV Services to Vulnerable Populations: A Review of CARE Act–Funded Research

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## SYNOPSIS

This article summarizes key findings from evaluation and research studies that have received financial support from the HIV/AIDS Bureau of the Health Resources and Services Administration or from Ryan White Comprehensive AIDS Resources Emergency (CARE) Act grantees. These studies suggest that the CARE Act has improved but not equalized service accessibility, quality, and outcomes for different populations living with HIV disease. Evaluations of access to highly active antiretroviral therapy (HAART) found that uninsured patients, women, people of color, and injection drug users waited much longer than others to receive the new therapies. These disparities were not uniform across study sites, suggesting that clinic characteristics and geographic location have a major influence on prescribing patterns. Once patients gained access to HAART, health insurance status made little difference in clinical outcomes.

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The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was enacted in August 1990 to improve the quality and availability of care for low-income and medically underserved individuals and families affected by HIV. Since fiscal year 1991, Congress has appropriated more than \$9.7 billion for CARE Act programs.<sup>1</sup> Over this same time period, major changes have occurred in the epidemiology of HIV/AIDS, treatment regimens and standards, and health care financing. This article reviews recent evaluation and research studies that have received financial support from the HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA) or from CARE Act grantees to summarize what is known about the accessibility, quality, and outcomes of HIV services provided to vulnerable populations in rapidly changing environments.

### ENVIRONMENTAL CHANGES INFLUENCING HIV SERVICE DELIVERY

The CARE Act emphasizes the development and maintenance of coordinated systems of care that are responsive to the needs of diverse HIV populations. Three environmental forces have influenced, and will continue to influence, the services delivered through these systems:

- *Changing face of the epidemic:* The HIV/AIDS epidemic is rapidly spreading among women, people of color, adolescents and young adults, and residents of rural and small urban areas.<sup>2</sup> Increasing numbers of newly infected individuals have comorbidities, such as chemical dependence and mental illness, and are homeless or marginally housed.<sup>3</sup>
- *Changing treatment regimens and standards:* Advances in prophylactic regimens and antiretroviral therapies are slowing disease progression, improving quality of life, and reducing the frequency of opportunistic infections for many people with HIV infection. However, many HIV-positive individuals are not benefiting from these medications because they are unaware of their serostatus, forgoing medical care, or receiving substandard care.
- *Changing Medicaid policies and financing mechanisms:* Over the past decade, managed care plans that rely on utilization review and capitated payments to control costs have replaced fee-for-service reimbursement as the predominant form of health care financing. Although state Medicaid programs have lagged behind private insur-

ers in developing managed care arrangements, almost all states now have some form of managed care for Medicaid beneficiaries.<sup>4</sup> In addition, the federal Centers for Medicare & Medicaid Services has approved Section 1115 waiver proposals from Maine, Massachusetts, and the District of Columbia and is reviewing proposals from several other states to extend Medicaid coverage to low-income individuals with early-stage HIV disease who do not meet disability standards. These changing Medicaid policies and payment arrangements are likely to have a major impact on beneficiaries' access to experienced HIV service providers and clinically appropriate HIV care.

### BACKGROUND

HRSA's HIV/AIDS Bureau administers the CARE Act. Through the Special Projects of National Significance (SPNS) Program of the CARE Act, the HIV/AIDS Bureau supports projects that demonstrate and evaluate innovative methods of reaching underserved populations and delivering HIV care. The HIV/AIDS Bureau has also funded, or partnered with other agencies to co-fund, research on the service needs of emerging HIV populations, barriers to service access and utilization, and the quality and outcomes of HIV care. This article focuses on evaluation and research studies that have received financial support from the HIV/AIDS Bureau or from CARE Act grantees. To our knowledge, this is the first published review of what has been learned from CARE Act-related studies. Thus, it fills a critical gap in the literature on socioeconomic and racial/ethnic disparities in HIV service delivery.

We first reviewed all study reports, policy briefs, and written summaries of studies in progress funded by the HIV/AIDS Bureau. MEDLINE and AIDSLINE searches were conducted to identify journal articles and conference papers on SPNS- and other CARE Act-related evaluations. Because combination antiretroviral therapies have dramatically changed the standards and outcomes of HIV care, the literature review was limited to studies that have been conducted or published since the introduction of these therapies in 1996. We used a standardized abstraction form to record each study's objectives, design, setting, participants, measures, and results. Abstracts were prepared by the first author and reviewed by the second author.

Ten high-priority questions derived from the legislative language of the CARE Act served as the framework for synthesizing study findings. The studies providing evidence to answer these questions are summarized below.

## QUESTION 1: ARE CARE ACT—FUNDED PROGRAMS EFFECTIVELY REACHING LOW-INCOME AND MEDICALLY UNDERSERVED POPULATIONS WITH HIV/AIDS?

Through grants to states, eligible metropolitan areas (EMAs),<sup>5</sup> and community-based organizations, the CARE Act funds health and support services for low-income and medically underserved individuals with HIV/AIDS. HIV-affected subpopulations emphasized by the legislation include women, people of color, and adolescents and young adults, as well as people who are unstably housed and/or have comorbidities such as chemical dependence or mental illness. Four studies provide information on the sociodemographic characteristics of the general population receiving care for HIV disease and the subpopulations served by CARE Act—funded providers.

### HIV Cost and Services Utilization Study

The HIV Cost and Services Utilization Study (HCSUS), a national probability sample of HIV-positive adults receiving medical care in the contiguous United States,<sup>6</sup> offers important insights on the extent to which low-income and historically underserved populations are represented among health service recipients. The HCSUS research team conducted three waves of interviews with study participants. The baseline sample consisted of 2,864 respondents interviewed from January 1996 through April 1997. Using data from these baseline interviews, the researchers constructed an analytic weight for each respondent. This weighting process allowed them to adjust the sample to represent all HIV-infected U.S. adults receiving medical care. Of the estimated 231,400 HIV-positive adults who received medical care during the first two months of 1996, 46% had annual household incomes less than \$10,000 per year and 63% were unemployed.<sup>6</sup> Twenty percent had no health insurance. The remaining patients were covered by private insurance (32%), Medicaid (29%), or Medicare—usually in conjunction with Medicaid (19%).

Women accounted for an estimated 23% of the HIV-positive U.S. adults receiving medical care in early 1996. The racial/ethnic distribution of the HIV population in care was about one-half white, one-third black, and 15% Hispanic. Although male-to-male sexual contact was the most common mode of HIV transmission (49% of patients), people exposed to HIV through injection drug use represented almost one-quarter (24%) of the medical care recipients.

Study investigators compared HCSUS point estimates of the number of HIV-positive adults seeing physicians at least every six months with Centers for

Disease Control and Prevention (CDC) estimates of the total HIV-positive population to derive a rough estimate of the number of HIV-positive adults not receiving regular medical care. They concluded that 37% to 64% of HIV-positive adults are either not in care or are not receiving medical care at recommended intervals.

### Studies of CARE Act clients

During the HCSUS baseline interviews, respondents were asked to identify their usual source of medical care. Malitz et al. used this information to assess the extent to which CARE Act—funded providers were serving socioeconomically disadvantaged HIV populations.<sup>7</sup> Sixty-five percent of respondents named a CARE Act—funded provider as their usual source of medical care. As compared to patients receiving care at non-CARE Act—funded sites, patients of CARE Act—funded providers were significantly more likely to report annual household incomes of less than \$10,000 (55% vs. 34%), Medicaid coverage (34% vs. 24%), and no health insurance (28% vs. 6%). They also were significantly more likely to be black (43% vs. 20%) and to report having less than 12 years of education (29% vs. 19%). Although a higher percentage of patients at CARE Act—funded sites than at other sites were women (26% vs. 18%), this gender difference was not significant.

Two smaller-scale studies provide further evidence that CARE Act—funded providers are reaching the vulnerable populations emphasized by the legislation. Using 1997 data from the HIV/AIDS Bureau's Client Demonstration Project, Ashman et al. compared the self-reported demographic characteristics of AIDS-diagnosed clients served by CARE Act—funded providers in four EMAs and two states ( $N = 19,291$ ) with CDC estimates of AIDS prevalence by gender, race/ethnicity, and HIV exposure mode ( $N = 41,560$ ).<sup>8</sup> The gender and race/ethnicity distributions of clients at CARE Act—funded facilities generally reflected the demographics of local AIDS epidemics. When differences were noted, CARE Act clients were more likely to be women and members of minority groups (e.g., black or Hispanic) and less likely to report histories of injection drug use.

Larson et al. assessed the extent to which 17 SPNS grantees enrolled underserved and disenfranchised populations with HIV in their programs from October 1994 through June 1999.<sup>9</sup> The grantees used a standardized form to collect data from enrollees on demographics and health risk factors. Of the 4,804 enrollees, 73% were people of color, 46% were women, and 3% were younger than 21 years of age. Eighty-six percent were unemployed, and 89% were dependent on publicly supported medical care. Relatively high pro-

portions of SPNS enrollees had histories of problem drinking (42%), crack use (34%), heroin use (22%), and other illicit drug use (45%). Fifty-seven percent reported unstable housing.

### **QUESTION 2: WHAT ARE THE SERVICE NEEDS AND THE UNMET SERVICE NEEDS OF PEOPLE LIVING WITH HIV/AIDS?**

The CARE Act provides funding for a wide array of services, including outpatient medical care, dental care, home health care, and 27 health-related support services. Three studies provide information on the service needs of HIV subpopulations and the extent to which these needs are being met.

#### **HCSUS**

Katz et al. analyzed the prevalence of need and unmet need for supportive services among 2,832 HCSUS participants interviewed from January 1996 through April 1997.<sup>10</sup> Two-thirds of participants said they had needed at least one supportive service in the previous six months. The most frequently cited service needs were benefits advocacy (43%) and emotional counseling (33%). The HCSUS researchers defined unmet need as “needing a service but not receiving it.” Among those participants reporting at least one supportive service need, unmet need was greatest for benefits advocacy (35%), substance abuse treatment (28%), and emotional counseling (25%). Although women were more likely than men to cite support service needs, they reported fewer unmet needs. Nonwhite and lower-income participants reported higher unmet needs for all supportive services. Participants who had seen a case manager in the previous six months had lower unmet needs for all supportive services.

#### **Studies of CARE Act clients**

A group of SPNS evaluators examined relationships between demographic/behavioral indicators of vulnerability and the pre-enrollment service needs reported by 478 HIV-positive individuals enrolled in five SPNS projects from October 1994 through June 1999.<sup>11</sup> When asked about health care and support services needed but not received in the six months before program enrollment, participants reported an average of 8.6 unmet service needs. Dental services and self-help groups were most frequently cited as unmet service needs. Participants with unstable housing and histories of crack cocaine use reported the greatest number of unmet service needs.

To evaluate the success of the CARE Act in meeting HIV-related service needs, Marx et al. distributed sur-

veys to 1,056 clients at 71 CARE Act-funded sites in the San Francisco Bay Area.<sup>12</sup> Almost all participants in this 1994 survey said they had needed at least one service in the previous four months. The most frequently cited service needs were medical care (86%), dental care (70%), mental health care (70%), food (57%), and money for living expenses (56%). Seventy-two percent of the clients with service needs said that at least one of their needs had not been met by CARE Act-funded programs. Unmet need was greatest for childcare (60%), household help (52%), and transportation to HIV-related services (48%). Only 6% reported an unmet need for medical care.

As compared to clients with health insurance, uninsured clients were more likely to report unmet needs for dental care and substance abuse treatment and for four support services (benefits counseling, legal advice, help with living expenses, and food). Women and men and white and nonwhite clients had similar rates of unmet service needs, leading the researchers to conclude that the CARE Act had “equalized access” for these subpopulations. Although clients sometimes gave multiple reasons for having unmet service needs, the most frequently cited reasons were: “did not try to get services” (41%), “put on a waiting list” (36%), and “specific services were unavailable” (34%).

### **QUESTION 3: WHAT ARE THE MAJOR BARRIERS TO ACCESSING HIV SERVICES?**

Four studies shed light on the sociodemographic, cultural, and organizational factors associated with reduced access to health care and support services.

#### **HCSUS**

Using data from 2,864 HCSUS interviews conducted from January 1996 through March 1997, Cunningham et al. examined whether basic subsistence needs and barriers such as lack of transportation and inability to get off work were associated with poorer access to medical care.<sup>13</sup> More than one-third of respondents said they went without or postponed medical care at least once in the six-month period preceding their interviews. None of the subsistence needs or barriers were associated with the receipt of “adequate” primary medical care (defined as three or more ambulatory visits in the previous six months). However, individuals reporting at least one subsistence need or barrier were more likely to have visited emergency rooms, less likely to have ever received antiretroviral therapy, and more likely to report low overall access to medical care. Women, members of racial/ethnic minority groups, uninsured and lower-income individuals, and

people reporting HIV exposure modes other than male-to-male sexual contact were more likely to cite “competing needs” and to postpone medical care due to illness or lack of transportation.

### Studies of CARE Act clients

A 1996 study of 519 HIV-positive clients receiving services from 65 CARE Act–funded sites in the San Francisco Bay Area explored the reasons why clients were not accessing the services they felt they needed.<sup>14</sup> Interviewers queried clients on their need for and receipt of 21 services in the previous four months. Of the 283 study participants reporting at least one unmet need, 252 provided sufficient information to be included in analyses of access barriers. Just over half (54%) reported an *agency barrier*, such as difficulties with eligibility requirements, inconvenient location or hours of operation, lack of bilingual staff, and being wait-listed for services. Forty-four percent said they *lacked information* on specific services or where to get them. *Emotional barriers*, such as denial of illness, fear, and concerns about confidentiality, were cited by 45% of the study participants. In contrast to the Cunningham et al. study,<sup>13</sup> which found lower overall access to medical care among people with basic subsistence and transportation needs, only 19% of participants in this study attributed their unmet service needs to *financial constraints* or *practical problems*. Another interesting contrast is that the types of barriers cited did not differ significantly by gender, race/ethnicity, or HIV exposure mode.

As part of a larger study of racial/ethnic differences in access to HIV pharmaceuticals, researchers at the AIDS Policy Research Center and Institute for Health Policy Studies, University of California–San Francisco, used a rapid assessment approach to gather data on the social, psychological, and cultural factors that influence access to antiretroviral therapies.<sup>15</sup> In late 1999, a multidisciplinary research team interviewed health care professionals and a racially diverse mix of HIV-positive patients at four CARE Act–funded clinics in San Francisco and Oakland.

The stigma associated with HIV/AIDS created major access barriers for all racial/ethnic groups. African American respondents most frequently cited mistrust of medical providers, limited or conflicting information about the benefits of HIV therapies, and concerns about drug side effects as reasons for postponing or avoiding drug therapies. Latinos most often referred to language differences, fear and uncertainty about U.S. immigration policies, and a cultural tendency not to discuss disease. Native Americans most often cited a general mistrust of government, conflicts

between “Western medicine” and traditional folk treatments, and a cultural tendency to reflect for a long time on the HIV diagnosis before seeking treatment. Asian/Pacific Islanders most frequently described pressures to seek care outside their own communities in order to “shield family honor” and a lack of awareness of HIV treatment options on the part of recent immigrants.

Huba et al. examined relationships between demographic/behavioral indicators of vulnerability and the barriers to service access reported by 519 HIV-positive individuals who participated in seven SPNS projects from October 1994 through June 1999.<sup>16</sup> When asked about 17 possible barriers they had experienced in the six months before program enrollment, participants reported an average of 4.5 barriers. The mean number of access barriers reported by women (4.7) was significantly higher than the mean number reported by men (3.9). Much higher proportions of women cited the following barriers:

- Having to wait too long to receive the service;
- Worrying that treatment would be denied;
- Fearing the loss of child custody;
- Finding it hard to make or keep appointments;
- Having difficulty communicating needs to service providers; and
- Worrying that family or friends would not want them to receive services.

Women caring for children reported more access barriers than women without these responsibilities. Men of color, as designated by the authors, reported more access barriers than white men. Although other studies have documented higher levels of unmet service need among substance abusers,<sup>11,12</sup> drug use was not significantly related to the number of reported access barriers in this study.

### QUESTION 4: WHAT FACTORS ARE ASSOCIATED WITH DELAYED ENTRY INTO PRIMARY MEDICAL CARE?

Three studies contribute to an understanding of the factors associated with delayed receipt of primary medical care following an HIV diagnosis. To identify individual and health care factors associated with delayed entry into care, Turner et al. studied two cohorts of HCSUS participants.<sup>17</sup> Members of Cohort A ( $n = 1,540$ ) were diagnosed with HIV by February 1993 and were in care within three years. Members of Cohort B ( $n = 1,960$ ) were diagnosed with HIV by February 1995 and were in care within one year. Twenty-nine percent

of Cohort A and 17% of Cohort B waited more than three months to receive HIV-related medical care. As compared to whites, Latinos in both cohorts were significantly more likely to delay care, while African Americans in Cohort A were significantly more likely to delay care. Three factors were associated with quicker entry into medical care: (a) having a usual source of care at the time of diagnosis, (b) having Medicaid coverage rather than private health insurance, and (c) having a high level of trust in one's health care provider.

CARE Act-funded clinics served as research sites for two additional studies of the sociodemographic factors associated with the time interval between HIV diagnosis and entry into care. Study investigators at Jefferson Comprehensive Care, Inc., a primary care clinic serving eight counties in central Arkansas, reviewed the medical records of 162 clinic patients diagnosed with HIV from 1994 through 1998.<sup>18</sup> The major findings were as follows:

- The median number of weeks from HIV diagnosis to entry into primary medical care was much greater for men (6.5 weeks) than for women (2.2 weeks). One-quarter of male patients did not seek care for more than nine months.
- Uninsured patients were more likely to delay entry into primary care (median = 7 weeks) than insured patients (median = 2.9 weeks).
- Time to entry into care did not differ by racial/ethnic group.

Researchers at Albany Medical Center (AMC) reviewed medical records of 135 HIV-positive patients who received outpatient care during 1997 and/or 1998.<sup>19</sup> AMC's AIDS Program serves a 22-county region in northeast New York State. In contrast to the findings of the Jefferson Comprehensive Care study,<sup>18</sup> the median time from an HIV-positive diagnosis to care at AMC was about the same for men (4 months) and women (3 months). However, dramatic differences were noted for certain HIV subpopulations:

- *Hispanic patients*: median of 15 months, compared with 6 months for African American patients and 3 months for white patients;
- *Medicare beneficiaries*: median of 50 months, compared with 5 months for Medicaid beneficiaries, self-pay patients, and patients enrolled in the New York AIDS Drug Assistance Program, 2 months for privately insured patients, and 1 month for health maintenance organization patients;
- *Injection drug users*: median of 31 months, compared with 2 months for patients who reportedly

acquired HIV through male-to-male sexual contact or heterosexual contact with an infected partner.

#### QUESTION 5: HOW DO HIV SERVICE UTILIZATION PATTERNS VARY BY DEMOGRAPHIC CHARACTERISTICS, PAYER TYPE, AND SOURCE OF CARE?

Making health and support services available and accessible to low-income and medically underserved people with HIV/AIDS does not necessarily improve service utilization.<sup>20</sup> Six studies offer useful insights into individual and organizational characteristics associated with variations in HIV service utilization patterns.

#### HCSUS

Shapiro et al. used data from three waves of interviews with HCSUS participants to examine variations in health service utilization, receipt of prophylaxis against *Pneumocystis carinii* pneumonia (PCP), and receipt of combination antiretroviral therapy over time.<sup>21</sup> During each interview, participants were asked about their service and medication utilization in the previous six months. Those reporting fewer than two ambulatory visits, at least one emergency room visit that did not lead to hospitalization, multiple hospitalizations, and/or non-receipt of appropriate anti-HIV medications were considered to have inadequate access to needed health care. Of the HIV-positive adults who received medical care in 1996 and early 1997, 15% had made fewer than two ambulatory visits in the previous six months, 23% had made at least one emergency room visit that did not lead to hospitalization, and 19% had been hospitalized at least once. Thirty percent of individuals with CD4 counts <200 cells/mm<sup>3</sup> had not received PCP prophylaxis in the six months before their interview, and 41% of those with CD4 counts <500 cells/mm<sup>3</sup> had not received combination therapy with a protease inhibitor (PI) or nonnucleoside reverse transcriptase inhibitor (NNRTI).

After adjustment for CD4 cell count, multivariate analyses of service and medication use in the previous six months revealed the following:

- *Gender*: Women were significantly *more likely* than men to have made at least one emergency room visit and to have been hospitalized at least once. Women were significantly *less likely* than men to have received PCP prophylaxis and PI/NNRTI regimens.
- *Race/ethnicity*: Black and Latino study participants were significantly *more likely* than white partici-

pants to have made <2 ambulatory visits and to have had at least one emergency room visit. Black participants were significantly *more likely* than white participants to have been hospitalized at least once. Both blacks and Latinos were significantly *less likely* than whites to have received PCP prophylaxis and PI/NNRTI regimens.

- *HIV exposure mode:* People exposed to HIV through injection drug use or heterosexual contact were significantly *more likely* than men who had sex with men to have made at least one emergency room visit and to have been hospitalized at least once. They were significantly *less likely* than men who had sex with men to have received PCP prophylaxis. People with heterosexually acquired HIV infection were *less likely* than men who had sex with men to have received PI/NNRTI regimens.
- *Payer type:* Uninsured study participants were significantly *more likely* than privately insured participants to have made <2 ambulatory visits. Uninsured individuals and Medicaid/Medicare beneficiaries were significantly *more likely* than privately insured individuals to have made at least one emergency room visit and significantly *less likely* to have received PCP prophylaxis and PI/NNRTI regimens. Medicaid/Medicare beneficiaries were *more likely* than privately insured individuals to have been hospitalized at least once.

HCSUS researchers reassessed service and medication utilization patterns during the latter half of 1997 and early 1998.<sup>21</sup> After adjustment for CD4 cell count, many of the HIV care disparities noted at baseline still existed. However, the following improvements were noted:

- *Health service utilization:* Differences were no longer statistically significant for black vs. white ambulatory visits, nonwhite vs. white emergency room visits, and hospitalizations of heterosexually infected men vs. men who had sex with men.
- *PCP prophylaxis:* Women, blacks, Latinos, uninsured patients, and Medicaid beneficiaries still were less likely to receive PCP prophylaxis, but the differences from the comparison groups were no longer statistically significant. People exposed to HIV through injection drug use were about equally likely to receive PCP prophylaxis as men who had sex with men.
- *PI/NNRTI regimens:* As of January 1998, 85% of clinically eligible patients were receiving PI/NNRTI regimens. Latinos, people with hetero-

sexually acquired HIV, and Medicare beneficiaries were less likely to receive PI or NNRTI therapy, but the differences from the comparison groups were no longer statistically significant.

Analyses of survey responses revealed two new disparities. Uninsured patients were significantly *more likely* than privately insured patients to have been hospitalized at least once during the previous six months. People exposed to HIV through injection drug use were significantly *less likely* to receive PI/NNRTI regimens than men who had sex with men.

### Studies of CARE Act clients

An HIV/AIDS Bureau intramural study used Client Demonstration Project data from two states and five EMAs to examine variations in service use by race/ethnicity (Unpublished data, HRSA HIV/AIDS Bureau, Service Data Systems Branch, Office of Science and Epidemiology, 2000). Study investigators compared the service utilization patterns of clients receiving services from providers funded by Title I and/or Title II of the CARE Act in 1996 ( $N = 41,789$ ) and in 1999 ( $N = 43,160$ ). Analyses were conducted for five racial/ethnic groups: African Americans, American Indian/Alaska Natives, Asian/Pacific Islanders, Hispanics, and whites.

For all racial/ethnic groups, the proportion making at least one medical visit to a CARE Act–funded clinic was substantially higher in 1999. The medical utilization rates for each racial/ethnic group were as follows: Hispanics (58% in 1999 vs. 50% in 1996), African Americans (51% vs. 40%), Asian/Pacific Islanders (51% vs. 36%), American Indian/Alaska Natives (48% vs. 33%), and whites (47% vs. 32%). Additional analyses of 1999 data revealed that:

- About 16% to 17% of Asian/Pacific Islander, Hispanic, and white clients received dental care at CARE Act–funded sites, as compared to 10% of African American and American Indian/Alaska Native clients.
- The proportion of African American clients receiving mental health services at CARE Act–funded sites (16%) was considerably lower than the proportions for other racial/ethnic groups, which ranged from 20% to 28%. However, the proportion of African American clients receiving substance abuse treatment at CARE Act–funded sites (5%) was twice that of other groups (1% to 3%).
- Case management utilization rates were similar for all racial/ethnic groups (50% to 61%).

Four additional studies provide clinic-specific analyses of HIV service utilization patterns by payer type, demographic characteristics, and source of care. A study conducted by Johns Hopkins University researchers examined whether health service utilization patterns and access to PI/NNRTI regimens varied by payer type.<sup>22</sup> Their study population included 959 patients who made at least two visits to the Johns Hopkins University AIDS Service from April 1996 through March 1999 and who had CD4 cell counts  $<500$  cells/mm<sup>3</sup> and/or HIV-1 RNA  $>10,000$  copies/ml at the start of the study period. Twenty-six percent of these patients had no health insurance for  $\geq 80\%$  of their visits. Another 28% were uninsured for 20% to 80% of their visits. Twenty-nine percent were government insured (i.e., covered by Medicaid or Medicare) for  $\geq 80\%$  of their visits, and 17% were privately insured.

On average, patients with  $\geq 80\%$  uninsured visits made *significantly fewer* visits for primary and specialty medical care than patients in other payer categories. They averaged about the same number of emergency room visits as government-insured patients and patients in the 20%–80% uninsured visit group but significantly more visits than privately insured patients. Patients in the 20%–80% uninsured visit group were twice as likely to be hospitalized as privately insured patients.

The percent of study patients on combination antiretroviral therapy steadily increased over time. In 1996–1997, privately insured patients were significantly more likely to receive PI/NNRTI regimens than uninsured (RR = 0.60) and government insured (RR = 0.63) patients. White patients were twice as likely to receive these regimens as African American patients. Injection drug users were significantly less likely than men who had sex with men to receive combination antiretroviral therapy (RR = 0.58). By 1998–1999, statistically significant differences in the receipt of PI/NNRTI regimens by payer type and “race” no longer existed. However, patients with histories of injection drug use continued to have a lower likelihood of receiving the new therapies than men who had sex with men (RR = 0.65).

Meredith et al. examined health service utilization patterns and access to highly active antiretroviral therapy (HAART) among 202 women enrolled in the SPNS-funded Helena Hatch Special Care Center at the Washington University School of Medicine.<sup>23</sup> During 1997, the women averaged 2.8 clinic visits. Only 38% received “optimal medical care” (defined as one or more clinic visits per quarter). From 1997 to July 1998, the proportion on HAART increased from 21% to 36%.

Because most of the women had histories of substance abuse, the researchers examined how this risk behavior and other characteristics affected access to HAART. Their findings were as follows:

- *1997:* After controlling for nadir CD4 cell counts, the researchers found no relationship between a history of substance abuse and the receipt of HAART. African American women were less likely than white women to receive HAART. Women spending less time per encounter with a case manager were less likely to receive HAART than those who spent more time. Women who adhered to quarterly medical visits were more likely than their non-adherent counterparts to receive HAART.
- *1998:* In analyses that controlled for nadir CD4 cell counts and use of HAART in the previous year, women with documented needs for substance abuse treatment were less likely to receive HAART than those without documented needs. Adherence to quarterly medical visits continued to be predictive of HAART use.

A 1993 study of 472 HIV-positive adults receiving medical care at nine CARE Act–funded clinics and four non–CARE Act–funded clinics in San Francisco evaluated whether the CARE Act had “equalized” use of medical services.<sup>24</sup> Data were gathered through self-administered questionnaires. Like Malitz et al.,<sup>7</sup> the researchers found that patients served by CARE Act–funded clinics were significantly more likely to be female than male, nonwhite than white, and uninsured than insured. Although patients at CARE Act–funded facilities made fewer physician visits than patients at non–CARE Act–funded clinics and were more likely to have visited an emergency room during the previous year, these differences were not statistically significant after adjustment for sociodemographic characteristics and perceived health status. Patients treated in CARE Act and non–CARE Act settings were equally likely to have been hospitalized during the previous year.

Of the patient characteristics studied, only unemployment, lower perceived health status, and having a CD4 cell count  $<200$  cells/mm<sup>3</sup> were predictive of more frequent physician visits. Unemployed patients, younger patients ( $\leq 37$  years), patients with histories of injection drug use, and those with lower health status scores reported more frequent emergency room visits. Nonwhite patients were more likely than white patients to report hospitalizations, and unemployed patients were more likely than employed patients to report hospitalizations.



Akil and Pearce compared the service utilization patterns of HIV-positive adults receiving medical care in Orange County, California, in three types of settings: (a) a CARE Act–funded public health clinic, (b) a university-based HIV clinic participating in a MediCal managed care program (CalOPTIMA), and (c) physician practices participating in CalOPTIMA.<sup>25</sup> The researchers reviewed demographic and clinical data on 680 HIV-positive patients who were taking antiretroviral medications and who had received at least 12 consecutive months of care from January 1996 through August 1998.

Patients receiving care in the three types of settings had very different service utilization patterns. After adjustment for baseline CD4 cell count, gender, and HIV exposure mode, the rate of medical visits per month for patients seeing private practitioners was four times that of public health clinic patients. Among academic health clinic patients, the rate of medical visits per month was 1.9 times that of public health clinic patients. The rate of social work/case management visits per month was 47% lower for patients seeing private practitioners and 60% lower for academic health clinic patients than for public health clinic patients. In models that adjusted for baseline CD4 cell count and the rate of medical visits, patients of CalOPTIMA private practitioners and public health clinic patients were equally likely to have a CD4 cell count increase of at least 50 from baseline to final count. Patients receiving care at the university-based clinic were 67% less likely than public health clinic patients to achieve an increase of 50 or more.

#### **QUESTION 6: HOW DOES THE RECEIPT OF ANCILLARY SERVICES AFFECT ACCESS TO HIV PRIMARY CARE, SERVICE UTILIZATION PATTERNS, AND RETENTION IN CARE?**

In 1998, HRSA's HIV/AIDS Bureau awarded eight contracts for studies of the relationship between the receipt of ancillary (supportive) services and access to and retention in HIV primary care. Although different groups of ancillary services are being evaluated, most studies address case management, transportation, mental health services, and chemical dependency treatment. Five studies are analyzing data from HIV clinics, two are analyzing statewide or multi-county data on clients at CARE Act–funded facilities, and one is analyzing data from a longitudinal study of HIV-positive New York City residents. With the exception of the New York City study, which covers a five-year period (1994–1998), all studies are examining service

utilization patterns for 1997–1998. Some of the preliminary findings from these studies are as follows<sup>26</sup>:

- The receipt of certain ancillary services significantly increases the likelihood of entering medical care and making regular medical visits. Case management and transportation show particularly strong associations with medical service utilization.
- The types of ancillary services associated with entering and receiving regular medical care may vary for people with different demographic and clinical characteristics. For example, the Helena Hatch Special Care Center at the Washington University School of Medicine found that African American women entering care used significantly more emergency financial assistance, transportation, and nutrition services than white women.<sup>27</sup> Women entering care with CD4 cell counts <200 cells/mm<sup>3</sup> used significantly more mental health, peer support, and nutrition services than women with higher CD4 cell counts.
- The receipt of ancillary services may not significantly change entry into or retention in medical care for some HIV subpopulations. For example, the CORE Center of Cook County Hospital (Chicago) found that patients who needed and received chemical dependency counseling were less likely to make regular medical visits (defined as one or more primary care visits per six months) than those needing chemical dependency services.<sup>28</sup> Five rounds of interviews with a cohort of HIV-positive New York City residents revealed that men, African Americans, and people with <12 years of education were more likely to lack medical care, whether or not they received ancillary services.<sup>29</sup>

#### **QUESTION 7: HOW ARE CHANGES IN SYSTEMS FOR PROCURING AND FINANCING HIV CARE AFFECTING ACCESS TO NEEDED SERVICES?**

Two studies of State Medicaid programs highlight structural factors that affect access to medically necessary and culturally appropriate services. Levi, Hidalgo, and Wyatt examined how interstate variations in Medicaid eligibility criteria and benefits affect the eligibility requirements of CARE Act programs and the range of services offered.<sup>30</sup> Their review of the “generosity” of Medicaid and AIDS Drug Assistance Program (ADAP) coverage in 50 states and the District of Columbia revealed that states imposing *non-income-related* restrictions on ADAP access were most likely to have restric-

tive Medicaid eligibility criteria and/or low per capita payments for disabled adults.

As of March 1999, nine states had active waiting lists for new ADAP enrollees. These states either lacked medically needy programs that enable disabled persons with high medical expenses to deduct these expenses from their incomes and “spend down” to Medicaid income eligibility levels, or they had adopted very restrictive income eligibility requirements for these programs. Using per capita payments for disabled adults as a measure of Medicaid “generosity,” these researchers found that seven of the nine states ranked below the national median. The eight states that restricted ADAP enrollees’ access to protease inhibitors either lacked medically needy programs or had imposed very stringent income eligibility criteria. Six of these states placed in the bottom one-fifth of the Medicaid generosity scale.

The AIDS Administration of the Maryland Department of Health and Mental Hygiene examined the impact of a new Medicaid managed care program on the services, staffing, and case loads of 51 CARE Act-funded organizations in the state.<sup>31</sup> During the first year of Medicaid managed care, only 43% of the surveyed organizations signed contracts with managed care organizations to provide HIV-related services to Medicaid beneficiaries, but 63% said their services had changed. The largest source of change was a shift in case manager responsibilities from addressing psychosocial needs to coordinating and authorizing all needed medical and health-support services. When asked about the *positive effects* of Medicaid managed care, respondents mentioned coverage for new services (e.g., dental and vision care), greater access to specialists, and 24-hour access to medical care. *Negative effects* included difficulties enrolling clients in managed care, navigating managed care organizations’ policies and procedures, and getting clients referred to needed services. About half of the respondents expressed concern about beneficiaries’ access to experienced HIV service providers and clinically appropriate HIV care.

**QUESTION 8: ARE LOW-INCOME AND MEDICALLY UNDERSERVED INDIVIDUALS WITH HIV/AIDS RECEIVING PRIMARY CARE THAT MEETS OR EXCEEDS U.S. PUBLIC HEALTH SERVICE STANDARDS AND PROFESSIONALLY ACCEPTED CLINICAL CARE GUIDELINES?**

Three studies provide useful information on the extent to which HIV-positive patients in CARE Act-funded facilities are receiving prevention measures and treat-

ments in accordance with professionally accepted clinical care guidelines. Kaplan et al. evaluated clinicians’ adherence to guidelines for antiretroviral therapy and the prevention of opportunistic infections in 11 clinics funded by Title III of the CARE Act.<sup>32</sup> From November 1996 through September 1997, the research team abstracted medical records for 1,411 HIV-positive adults and adolescents with CD4 cell counts <500 cells/mm<sup>3</sup> who had received medical evaluations at study clinics within six months before record abstraction. Among those patients meeting the clinical criteria for antiretroviral therapy and prevention measures, ≥80% had received HIV plasma RNA testing, antiretroviral regimens, PCP prophylaxis, anti-*Toxoplasma* antibody testing, tuberculin skin tests, and Pap smears. Smaller percentages had received pneumococcal vaccinations (70%) and prophylaxis against *Mycobacterium avium* complex (69%). Although HAART was not generally accepted as a standard of care until midway through the second phase of the study, 41% of patients had been treated with protease inhibitors.

Prescription of antiretroviral therapy—with and without protease inhibitors—did not differ significantly by gender, race/ethnicity, or HIV exposure mode. However, patients with histories of injection drug use received HIV plasma RNA tests less often than men who had sex with men and patients with heterosexually acquired HIV infection. Patients treated at urban clinics were less likely to receive HIV plasma RNA tests and protease inhibitors than patients treated at rural clinics.

In 1997, HRSA’s HIV/AIDS Bureau funded the New York State Department of Health AIDS Institute to expand its HIV quality-of-care program (HIVQUAL) to Title III-funded clinics in seven states (Colorado, Connecticut, Massachusetts, New Jersey, Oklahoma, Pennsylvania, and Rhode Island) and Puerto Rico. Using a customized software package provided by the AIDS Institute, each of the 40 participating clinics tracks HIV ambulatory care indicators for a stratified random sample of active patients over time. Data collected from each site are used to compare performance across facilities and different HIV subpopulations.

During the first wave of data collection (July 1997 through December 1998), the HIVQUAL project team analyzed 1,921 patient records.<sup>33</sup> Like Kaplan et al.,<sup>32</sup> they found that most clinically eligible patients had received PCP prophylaxis (87%) and semiannual HIV plasma RNA testing (82%). About two-thirds of clinically eligible patients (64%) had received HAART, but much smaller percentages had received prophylaxis against *Mycobacterium avium* complex (51%) or annual tuberculin skin tests (53%). Multivariate analyses of

performance rates by gender, racial/ethnic group, HIV exposure mode, and geographic region found no statistically significant differences. However, the individual facility providing care proved to be an important explanatory factor.

A third study examined changing patterns of antiretroviral treatment provided to Washington State ADAP clients after the introduction of protease inhibitors.<sup>34</sup> The study sample included 833 ADAP clients who received treatment from December 1995 through May 1997 and who consented to external reviews of their outpatient records. During the last quarter of 1996, only 27% of these ADAP clients were receiving protease inhibitor-based regimens. This percentage rose to 49% in the first quarter of 1997 and 64% in the second quarter. Adjusted analyses showed no association between age, gender, or race/ethnicity and the type of antiretroviral therapy received. However, the use of protease inhibitor/NNRTI regimens increased significantly with decreasing CD4 cell counts.

Because most ADAP clients receive HIV primary care from physicians who contract with the Washington State Department of Health to provide these services, the researchers were able to identify physicians for 356 of the study participants. Using this subsample, the researchers examined whether patients treated by physicians with greater HIV care experience were more likely to receive protease inhibitor/NNRTI regimens. After controlling for CD4 cell count and the calendar period of treatment, the researchers found that patients treated by physicians who had cared for  $\geq 10$  HIV-positive patients were significantly more likely to receive protease inhibitor/NNRTI regimens than patients treated by less experienced physicians. In contrast to findings from the Kaplan et al. study,<sup>32</sup> the urban or rural location of a physician's practice was not associated with the type of antiretroviral received.

#### QUESTION 9: HOW DO CLINICAL OUTCOMES VARY FOR HIV-POSITIVE INDIVIDUALS WITH DIFFERENT PAYER TYPES AND SOURCES OF CARE?

Two studies provide useful insights on the relationships between payer type or source of care and clinical outcomes. Moore and Keruly examined how the health insurance status of patients of the Johns Hopkins University AIDS Service affected survival, progression from HIV to AIDS, and achieving an undetectable viral load.<sup>22</sup> In a Cox proportional hazards analysis, a low CD4 cell count ( $< 200$  cells/mm<sup>3</sup>) was the only variable significantly associated with increased hazard for death. Patients with lower CD4 cell counts (201–350

cells/mm<sup>3</sup>) had an increased hazard for progression from HIV to AIDS. Patients on protease inhibitor/NNRTI regimens or with lower viral loads (HIV-1 RNA  $< 10,000$  copies/ml) had a reduced hazard for disease progression. In adjusted models, no differences were noted among payer types.

To identify the variables associated with achieving an undetectable viral load (i.e., HIV-1 RNA  $< 400$  copies/ml), the researchers analyzed a subsample of 632 patients who received protease inhibitor/NNRTI regimens and for whom a repeat viral load measurement was available. Patients with lower baseline viral loads (HIV-1 RNA  $< 10,000$  copies/ml) were *more likely* to achieve undetectable viral loads than those with HIV-1 RNA  $> 100,000$  copies/ml. Patients with CD4 counts  $< 50$  cells/mm<sup>3</sup> were *less likely* to achieve undetectable viral loads than those with CD4 counts  $> 350$  cells/mm<sup>3</sup>. As compared to patients who kept most of their medical appointments, those who had missed one-quarter or more of their scheduled visits were less likely to achieve undetectable viral loads. After adjustment for these variables, no differences were noted among payer types.

Baker, Milberg, and Alzola examined the same clinical outcomes in three groups of HIV-positive patients: (a) privately insured patients, (b) Medicaid/Medicare beneficiaries, and (c) uninsured patients whose care was supported by the CARE Act.<sup>35</sup> Their study sample included 677 patients with CD4 cell counts  $< 500$  cells/mm<sup>3</sup> or HIV-1 RNA  $> 10,000$  copies/ml who visited two community-based HIV clinics in Florida and one hospital-affiliated clinic in New York from January 1997 through May 1999. A Cox proportional hazards analysis found that Medicaid/Medicare beneficiaries died more quickly than privately insured patients. An analysis of variables associated with progression from HIV to AIDS showed somewhat faster progression for Medicaid/Medicare and uninsured patients, but the differences among payer types were not statistically significant.

To identify the variables associated with achieving an undetectable viral load, the researchers analyzed a subsample of 105 patients who had detectable viral loads and an indication for HAART at baseline. In contrast to the Johns Hopkins University study,<sup>22</sup> they did not limit the analysis to patients on protease inhibitor/NNRTI regimens. Viral loads were considered to be undetectable if the values were less than the lower limit of detection or if they were coded as undetectable. Lower detection limits differed, depending on the test type and year. In a model that adjusted for demographic variables, baseline viral load, and HIV exposure category, Medicaid/Medicare beneficiaries were significantly less likely to achieve undetectable

viral loads than privately insured patients. However, when site (Florida or New York) was added as a covariable, there were no significant differences among payer types.

#### **QUESTION 10: HAVE CARE ACT-FUNDED PROGRAMS IMPROVED THE HEALTH AND WELL-BEING OF HIV-POSITIVE INDIVIDUALS AND POPULATIONS?**

A series of studies have evaluated or are currently evaluating the CARE Act's impact on individual clients, populations, and service delivery systems. One of the earliest evaluations examined how Title I CARE Act funding had affected the use of health-related services and the prevalence of HIV risk behaviors among 777 HIV-positive drug users in five new EMAs.<sup>36</sup> The researchers conducted three waves of interviews to assess service utilization patterns and HIV risk behaviors before Title I funds were awarded (September 1993) and in the first two years of Title I funding (1994 and 1995). Instead of following the same cohort over time, they chose to interview a new group at each wave so that study participants could be referred to services following their interviews.

During the pre-Title I interviews, the percentages of study participants saying they had received services in the previous six months were: medical services (74%), case management (62%), drug treatment (54%), mental health services (37%), and housing assistance (20%). By the second year of Title I funding, the percentages reporting service use were significantly higher only for housing assistance (40%) and case management (approximately 72%). With one exception (exchanging sex for drugs or money), the percentages of study participants reporting sex- and drug-related HIV risk behaviors declined linearly over the study period. In all interview waves, and for all service categories except housing assistance, people who received Title I-funded services reported fewer HIV risk behaviors.

Title IV of the CARE Act awards competitive grants for the development and operation of comprehensive systems of primary medical care and support services for women, children, adolescents, and families infected and affected by HIV. Twenty-five Title IV grantees recently completed a longitudinal study of the effectiveness of their programs in reducing perinatal HIV transmission.<sup>37</sup> Retrospective medical record reviews were conducted for all infants enrolled in Title IV programs who were born to HIV-positive mothers in 1996, 1997, or 1998.

Of the 2,989 HIV-positive mothers whose Title IV

enrollment status during pregnancy could be determined, 1,733 (58%) were enrolled in Title IV programs before giving birth. Preliminary analyses of the services provided to Title IV enrollees indicate that 98% received prenatal care, and 97% of those in prenatal care received zidovudine. Of the 1,256 HIV-positive mothers who were not enrolled at Title IV sites, only 80% received prenatal care. Once in prenatal care, 86% of non-Title IV enrollees received zidovudine. Over the study period, the perinatal HIV transmission rate was significantly lower for women receiving prenatal care at Title IV sites (5%) than for women receiving prenatal care at non-Title IV sites (11%).

#### **CONCLUSION**

The 32 evaluation and research studies reviewed in this article suggest that the CARE Act has improved but not equalized service accessibility, quality, and outcomes for different populations living with HIV disease. Although CARE Act-funded providers are reaching many low-income and medically underserved individuals, HCSUS estimates suggests that 37% to 64% of HIV-positive adults are still not receiving regular medical care.<sup>6</sup> HCSUS findings also suggest that the HIV-positive individuals not in care are more likely than individuals in care to have early (and possibly unrecognized) HIV infection, to lack health insurance, and/or to be people of color. Other studies reviewed in this article suggest that these same characteristics, along with male gender and injection drug use, are associated with delayed entry into care.

Because most Bureau-supported studies investigated the service needs and access barriers for people already receiving health services, primary medical care did not emerge as a major service need. The services most frequently cited as unmet needs included benefits advocacy (help in obtaining health insurance and/or public income assistance), substance abuse treatment, emotional counseling, and oral health care. Unmet service needs were most prevalent among people of color, individuals with lower incomes, substance abusers, and people who were unstably housed. However, the types of service needs varied from one subpopulation to another.

Studies of access barriers tended to focus on individual characteristics (e.g., gender, race/ethnicity, health insurance status) rather than characteristics of health care providers, service delivery systems, and policy environments that might affect service utilization. Although women, people of color, uninsured individuals, and injection drug users typically encountered more access barriers than comparison groups,

these barriers were not necessarily the same. Nonetheless, several studies documented the effectiveness of case management in reducing unmet service needs and linking clients with regular medical care.

Evaluations of access to antiretroviral therapy found that, as protease inhibitors gained acceptance as the standard of care and were added to ADAP and Medicaid formularies, increasing percentages of clinically eligible patients received these regimens. Uninsured patients, women, people of color, and injection drug users waited much longer than others to receive the new therapies—a factor that may partially explain their higher rates of emergency room visits and hospitalizations. Disparities based on health insurance status, gender, race/ethnicity, and HIV exposure mode were not uniform across study sites, suggesting that clinic characteristics and geographic location have a major influence on prescribing patterns.

Evaluations of the quality of CARE Act–funded services focused on the primary care component of the HIV care continuum. Although study sites varied in the extent to which they prescribed protease inhibitor/NNRTI regimens, patient demographic characteristics were not significantly associated with the type of therapy received. Variations in the receipt of combination antiretroviral therapy were better explained by physicians' experience providing HIV care, CD4 cell counts, and the frequency of medical visits. Preliminary findings from outcomes evaluations suggest that, once patients gain access to HAART, health insurance status makes little difference in clinical outcomes.

To date, most of the evaluation and research studies supported by HRSA's HIV/AIDS Bureau have investigated how the sociodemographic characteristics of HIV-positive individuals already in care are related to service utilization, service quality, and clinical outcomes. Little is known about the service needs and access barriers experienced by people who know their HIV serostatus but are not in care. Relationships between cultural beliefs and service utilization patterns also require further exploration.

When evaluating the accessibility, quality, and outcomes of HIV services, researchers need to consider the independent and interactive effects of multiple levels of influence. Some of the variables that should be investigated are:

- *Characteristics of health and social service professionals* (e.g., HIV-specific training and experience, attitudes and perceptions, communication and interpersonal skills, cultural competence);
- *Organizational characteristics* (e.g., eligibility requirements, convenience of location and hours

of operation, average waiting time for appointments, co-location of health and support services, adoption and enforcement of clinical care guidelines);

- *Characteristics of the HIV service delivery system* (e.g., number of organizations providing services, number of different services offered, extent to which service organizations maintain regular contact with each other, adoption of system-wide standards of care);
- *Health policy environment* (e.g., level of federal and state funding for HIV-related services, interstate variations in Medicaid and ADAP eligibility criteria and benefits, immigration and welfare policies, Federal guidelines for HIV care).

While disparities in HIV care appear to be narrowing, they continue to exist in some geographic areas and medical care settings. Much can be learned about these variations from local evaluations that are being conducted or sponsored by CARE Act grantees. By integrating qualitative and quantitative results from local and larger-scale evaluations, health services researchers can build a comprehensive knowledge base that explains variations in care; informs health policy; and guides federal, state, and local efforts to improve HIV service delivery to poor and historically underserved populations.

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