



Delivering HIV Services to Vulnerable Populations: What Have We Learned?

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The following reports address program evaluation-related issues relevant to the CARE Act community. To obtain copies, visit the HRSA HIV/AIDS Bureau web site at <http://hab.hrsa.gov/evaluation.html> or contact the HRSA Information Center at 1-888-ASK-HRSA (1-888-275-4772).

Choosing and Using an External Evaluator, Report #1, September 1997. This guide offers advice on the effective selection and use of external evaluators. It describes a seven-step process for defining the purpose and scope of an evaluation, identifying the evaluator's tasks, soliciting and selecting the evaluator, and working with the evaluator to plan and implement a methodologically sound study.

Using Data to Assess HIV/AIDS Service Needs: A Guide for Ryan White CARE Act Planning Groups, Report #2, August 1998. This guide provides materials for orienting and training members of CARE Act planning groups to read statistical reports, conduct or oversee community needs assessments, and use epidemiologic and administrative data for HIV service planning and decision making.

Cost- and Performance-Based Contracting: A Guide for Ryan White CARE Act Grantees, Report #3, October 1998. This guide defines cost and outcome effectiveness and discusses the ways in which cost and performance indicators can be incorporated into CARE Act priority-setting, resource allocation, and procurement processes. Service procurement models that link reimbursement to the accomplishment of performance targets are discussed, along with strategies for preventing and solving performance problems.

A Practical Guide to Evaluation and Evaluation Terms for Ryan White CARE Act Grantees, Report #4, September 1999. This guide is designed to help CARE Act grantees and planning groups become familiar with the "language" of evaluation. Part 1 defines evaluation and explains how evaluation differs from needs assessment, monitoring, research, and continuous quality improvement. Part 2 describes the steps involved in designing and conducting evaluations and defines the terms associated with each step. Part 3 defines terms related to quality management and improvement.

An Approach to Evaluating HAART Utilization and Outcomes in CARE Act-Funded Clinics, Report #5, June 2000. This report describes the approach used by two Title III-funded clinics to evaluate the therapeutic benefits and resource requirements of implementing highly active antiretroviral therapy (HAART). Study findings are presented, but the primary focus of the report is on the process of designing and conducting an outcomes evaluation, the problems encountered, and the "lessons learned."

Table of Contents

Preface	ii
Executive Summary	iii
Introduction	1
Overview of the CARE Act	1
Environmental Changes Influencing HIV Service Delivery	2
Methods and Scope of Review	5
Studies of HIV Service Accessibility and Utilization	6
Are CARE Act programs effectively reaching low-income and medically underserved populations with HIV/AIDS?	6
What are the service needs and unmet needs of people living with HIV/AIDS?	8
What are the major barriers to accessing HIV services?	11
How do HIV service utilization patterns vary by demographic characteristics, payor type, and source of care?	15
How does the receipt of ancillary services affect access to HIV primary care, service utilization patterns, and retention in care?	22
How are changes in systems for procuring and financing HIV care affecting access to needed services?	23
Studies of HIV Service Quality	26
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?	26
Studies of HIV Service Outcomes	31
How do clinical outcomes vary for HIV-positive individuals with different payor types and sources of care?	31
Have CARE Act-funded programs improved the health and well-being of HIV-positive individuals and populations?	32
Conclusions	37
References	40
Appendix	
Recent Research on the Accessibility, Quality, and Outcomes of HIV Services for Vulnerable Populations	44

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

Preface

This report is one of a series of publications that are being developed by the Health Resources and Services Administration's (HRSA), HIV/AIDS Bureau (HAB) to assist Ryan White Comprehensive AIDS Resources Emergency (CARE) Act grantees in designing and implementing evaluation studies. The reports provide guidance on a wide range of evaluation issues and describe evaluation studies conducted by CARE Act grantees. The goal of the series is to improve services for people living with HIV/AIDS by enhancing the ability of CARE Act grantees to conduct methodologically sound evaluations and to develop action plans based on study findings.

An Evaluation Monograph Advisory Committee, consisting of one representative from each CARE Act Title, provides guidance and oversight for the series. Committee members advise HAB staff on evaluation topics that should be addressed and the criteria that should be used to select publications. They also review draft reports to suggest ways of making the information more useful and understandable to grantees. Committee members include:

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Executive Summary

This report summarizes recent research on the accessibility, quality, and outcomes of health and support services provided to low-income and medically underserved populations with HIV disease. The focus is on evaluation and research studies that have been or are currently being funded by the Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau and studies that directly relate to the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. Additional empirical studies that have been conducted or published since 1996 are summarized in the Appendix.

What Have We Learned?

Recent studies of HIV service delivery 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, estimates from the HIV Cost and Services Utilization Study (HCSUS) indicate that 37-64 percent of HIV-positive adults still are not receiving regular medical care. HCSUS findings also suggest that the HIV-positive individuals not in care are more likely to have early (and possibly unrecognized) HIV infection, lack health insurance, and/or to be people of color. Other studies 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 of 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 (i.e., help 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 users, 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

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

users typically encountered more access barriers, 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 combination antiretroviral therapy found that, as protease inhibitors gained acceptance as the standard of care and were added to AIDS Drug Assistance Program (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 to receive the new therapies—a factor that may partially explain their higher rates of emergency room visits and hospitalizations. Disparities based on payor status, gender, race/ethnicity, and HIV exposure mode were not uniform across study sites, suggesting that clinic characteristics and geographic location may have a major influence on prescribing patterns.

Evaluations of service quality focused on the primary care component of the HIV care continuum. One study documented high rates of PCP prophylaxis, anti-*Toxoplasma* antibody testing, and Pap smears among clinically-eligible patients receiving care at CARE Act-funded clinics. Prescription of antiretroviral therapy—with and without protease inhibitors—did not differ significantly by gender, race/ethnicity, or HIV exposure mode. Variations in clinician adherence to other HIV care guidelines were better explained by “time in care” at the current facility and the frequency of medical visits than patient sociodemographic characteristics. Another study of ADAP clients in Washington State found no association between age, gender, or race/ethnicity and the type of antiretroviral therapy received. However, patients treated by physicians who had cared for ≥ 10 HIV-positive patients were significantly more likely to receive antiretroviral therapy with a protease inhibitor or nonnucleoside reverse transcriptase inhibitor.

Most of the outcomes evaluations are still in progress. Completed studies suggest that once patients gain access to antiretroviral therapy, payor status makes little difference in clinical outcomes. By December 2000, new data will be available on variations in service utilization and clinical outcomes among women, children, people of color, and patients with comorbidities.

What Questions Remain?

To date, most of the evaluation and research studies supported by the 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 HIV-positive individuals who 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 service delivery system components and the larger health policy environment. Some of the variables that should be investigated are as follows:

- **Characteristics of health/social service professionals** (e.g., knowledge and attitudes, HIV-specific training and experience, cultural competence)
- **Organizational characteristics** (e.g., eligibility requirements, convenience of location and hours of operation, average appointment waiting time, availability of on-site ancillary services, adoption and enforcement of clinical care guidelines)
- **Characteristics of the HIV service delivery system** (e.g., number of different 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 reforms, Federal guidelines for HIV/AIDS clinical 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, HIV service evaluators 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 vulnerable populations.

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

Notes:



Introduction

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was enacted in August 1990 and reauthorized in May 1996 to improve the quality and availability of care for low-income and medically underserved individuals and families affected by HIV disease. Since fiscal year 1991, Congress has appropriated more than \$7.9 billion for CARE Act programs. Over this same time period, major changes have occurred in the epidemiology of HIV/AIDS, treatment regimens and standards, and health care financing. This report reviews recent evaluation and research studies to summarize what is known about the accessibility, quality, and outcomes of HIV services provided to vulnerable populations in rapidly changing environments.

Overview of the CARE Act

The CARE Act is administered by the HIV/AIDS Bureau (HAB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS). This Act funds HIV-related health and support services under four Titles:

- **Title I** provides emergency relief funding to 51 eligible metropolitan areas (EMAs) that have been most severely affected by the HIV/AIDS epidemic. The EMAs use these funds to support outpatient primary health care; dental care; mental health counseling; substance abuse treatment; and support services, such as case management, home health care, housing assistance, and transportation.
- **Title II** awards formula funding to the 50 States, District of Columbia, Puerto Rico, and the U.S. territories to develop and operate AIDS pharmaceutical assistance programs, home and community-based services, and programs that help low-income HIV-positive individuals continue their health insurance. Most States also use Title II funds to support the planning and delivery of outpatient health and support services through regionally- and locally-based HIV care consortia.
- **Title III** awards competitive grants to community and migrant health centers, health departments, and other community-based clinics to provide “early intervention services” to medically underserved individuals with HIV disease. These services include outpatient primary health care, dental care, antiretroviral therapies, and support services such as case management and nutritional counseling.

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

- **Title IV** awards competitive grants to public and private nonprofit organizations to develop and coordinate comprehensive systems of community-based services for HIV-positive children, youth, women, and families. Title IV-funded services include primary and specialty medical care, support services such as counseling and case management, and opportunities to participate in clinical trials.

Three additional service and training programs are funded under Part F of the CARE Act:

- **Special Projects of National Significance (SPNS) Program** awards competitive grants for projects that demonstrate and evaluate innovative methods of reaching underserved populations and delivering HIV/AIDS care. Replication of effective models is encouraged through widespread dissemination of project findings.
- **AIDS Education and Training Centers (AETC) Program** supports a national network of centers that conduct multidisciplinary HIV education and training programs for health care professionals.
- **HIV/AIDS Dental Reimbursement Program** awards grants to accredited dental schools and post-doctoral dental education programs to help offset the uncompensated costs incurred in providing oral health care to patients with HIV disease and to support HIV-specific training for dental students and residents.

In fiscal year 1999, the Department of Health and Human Services, in collaboration with the Congressional Black Caucus, launched a major initiative to reduce the incidence of HIV infection and improve the accessibility and quality of HIV/AIDS care in racial and ethnic minority communities. HRSA received \$12 million in direct appropriations for Title I, III, and IV programs in “highly impacted” communities and for the establishment of a National Minority AIDS Education and Training Center. The appropriation for fiscal year 2000 is \$72.9 million.

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: (1) the changing face of the epidemic, (2) changing treatment regimens and standards, and (3) changing Medicaid policies and financing mechanisms.

Changing Face of the Epidemic

The HIV/AIDS epidemic is rapidly spreading to women, adolescents, and people of color and to vulnerable populations in smaller cities, suburbs, and rural areas. Increasing numbers of newly-infected individuals have comorbidities, such as chemical dependence and mental illness, and are homeless or marginally housed.

- **Women** - In 1990, women accounted for just 11 percent of the new AIDS cases reported to the Centers for Disease Control and Prevention (CDC). By 1998, the female proportion of incident AIDS cases (23 percent) had more than doubled (Kaiser Family Foundation, 1999).
- **Adolescents and Young Adults** - At least half of all new HIV infections in the United States occur among people under age 25, the majority of whom acquire HIV through heterosexual contact (CDC, 1999b). In 1998, 1,798 young people (13-24 years) accounted for one of every 25 adult/adolescent AIDS cases reported to the CDC.
- **African Americans** - Between 1990 and 1998, the African American proportion of newly-reported AIDS cases jumped from 30 percent to 45 percent (Kaiser Family Foundation, 1999). Almost two-thirds of all women and children reported with AIDS in 1998 were African American (CDC, 1999a).
- **Latinos** - In 1990, Latinos accounted for 17 percent of the new AIDS cases reported to the CDC. By 1998, they accounted for 20 percent of newly-reported AIDS cases but only 11 percent of the U.S. population (Kaiser Family Foundation, 1999).
- **Rural Residents** - Between 1981 and 1993, the CDC received reports of 18,308 individuals who were residing in nonmetropolitan areas of less than 50,000 population at the time of AIDS diagnosis. Over the next five years, the cumulative number of rural AIDS cases (39,856) more than doubled (McKinney, 2000). Rural residents accounted for 7 percent of the new AIDS cases reported in 1998 (CDC, 1998).

The changing profile of the HIV/AIDS epidemic will require ongoing research on the service needs of emerging populations; barriers to service access and utilization; and the timeliness, quality, and continuity of HIV/AIDS care. Further research will be needed on innovative strategies for bringing HIV-positive individuals into care at an early stage of disease, service delivery models for clients with multiple diagnoses, and effective methods of supporting and retaining clients in care. As these questions are investigated, researchers also will need to consider whether variations in resource use and associated costs are reasonable and acceptable relative to the benefits received.

Changing Treatment Regimens and Standards

Advances in prophylactic regimens and antiretroviral therapies are slowing the course of disease progression, improving quality of life, and reducing the frequency of opportunistic infections for many people with HIV/AIDS. However, many HIV-positive individuals are not benefitting from these medications because they are unaware of their serostatus, forgoing medical care, or receiving substandard care. For patients receiving combination antiretroviral therapy, treatment is complicated by HIV's ability to generate drug-resistant variants and increased risks for diabetes, heart disease, liver failure, and other comorbidities.

The growing prevalence of HIV infection among low-income and medically underserved populations, coupled with the high cost of antiretroviral medications and associated laboratory tests, have severely strained the capacity of State and local governments to provide state-of-the-art care to all who could benefit (Doyle & Jefferys, 2000). As people gain access to combination antiretroviral therapies, feel better, and live longer, the demand for support services, such as counseling, vocational training, and housing assistance, also is increasing. Faced with the dual challenges of expanding access to antiretroviral therapies and support services while controlling costs, CARE Act grantees and planning groups are having to make difficult decisions about the types and amounts of service that will be provided and clinical and financial eligibility requirements. Ongoing evaluations of service accessibility, quality, and cost effectiveness will be needed to inform and guide priority-setting processes and resource allocation decisions.

Changing Medicaid Policies and Financing Mechanisms

Over the past decade, managed care plans that rely upon utilization review and capitated payments to control health care costs have replaced fee-for-service reimbursement as the predominant form of health care financing. Although State Medicaid programs have lagged behind private insurers in developing managed care arrangements, almost all States now have some form of managed care for Medicaid beneficiaries (Westmoreland, 1999). As States gain experience with Medicaid managed care plans for low-income women and children, an increasing number are developing managed care programs and special reimbursement strategies for people with HIV/AIDS and other chronic or disabling diseases (Conviser, Murray, & Lau, in press). Yet, little is known about how participation in Medicaid managed care affects access to HIV pharmaceuticals, outpatient health and health-support services, or the

coordination of these services. Provisions for linking patients with HIV specialists and the quality of care provided by “gatekeeper” primary care physicians also require further study. Additional areas of inquiry include the impact of managed care on patients’ health status and perceived quality of life.

The recent DHHS decision to allow Maine to extend Medicaid coverage to people in asymptomatic and symptomatic stages of HIV disease sets the stage for similar demonstration projects in other States. By providing Medicaid coverage for antiretroviral therapies and other health services earlier in the course of HIV disease, States can delay the onset of disability for many people with HIV infection. However, to expand coverage without violating Federal requirements for “budget neutrality,” States may have to limit the scope of reimbursable services, impose stricter utilization controls, and/or reduce quality standards. Given the size of Federal and State investments, the cost effectiveness of covering health services for people in earlier stages of HIV disease will receive close scrutiny.



Methods and Scope of Review

This report summarizes recent research on the accessibility, quality, and outcomes of health and support services provided to low-income and medically underserved populations with HIV disease. The focus is on evaluation and research studies that have been or are currently being funded by HRSA’s HIV/AIDS Bureau. To gather information on evaluation methods and findings, the author reviewed final study reports, policy briefs, written summaries of studies “in progress,” and journal articles on SPNS and other CARE Act-related evaluations.¹ MEDLINE and AIDSLINE searches were conducted to identify additional studies that have been conducted or published since the introduction of combination antiretroviral therapies (1996-present). The Appendix provides a tabular summary of these studies.

¹ The data collection methods used in these evaluations included surveys, medical record reviews, interviews, and focus groups. For definitions of these methods and other evaluation terms, see *A Practical Guide to Evaluation and Evaluation Terms for Ryan White CARE Act Grantees* (Report #4) in the HIV/AIDS Bureau’s Evaluation Monograph Series. This guide and descriptions of all HRSA/HAB-funded evaluations can be accessed at <http://hab.hrsa.gov/evaluation.html>.



Studies of HIV Service Accessibility and Utilization

Are CARE Act-funded programs effectively reaching low-income and medically underserved populations with HIV/AIDS?

The CARE Act funds health and support services for low-income, uninsured, and underinsured populations with HIV/AIDS. HIV populations emphasized by the legislation include women, adolescents, and people of color, as well as people who are unstably housed and/or have comorbidities, such as chemical dependence and mental illness. The HIV Cost and Services Utilization Study (HCSUS), a national probability sample of HIV-positive adults receiving medical care in the contiguous United States, offers important insights on the extent to which low-income and historically underserved populations are represented among health service recipients (Bozzette et al., 1998). Of the estimated 231,400 HIV-positive adults who received medical care during the first two months of 1996, 46 percent had annual household incomes less than \$10,000 per year and 63 percent were unemployed. Twenty percent had no health insurance. The remaining patients were covered by private insurance (32 percent); Medicaid (29 percent); or Medicare - usually in conjunction with Medicaid (19 percent).

Characteristics of HIV-Positive Adults In Care During January and February 1996 HCSUS Estimates

Gender:	77% male; 23% female
Race/Ethnicity:	49% non-Hispanic whites; 33% non-Hispanic blacks; 15% Hispanics; 3% other
Exposure Mode:	49% men who have sex with men; 24% injection drug use; 18% heterosexual contact; 9% other
Age:	34% 18-34 yrs; 54% 35-49 yrs; 11% ≥50 yrs
Region:	36% South; 28% West; 25% Northeast; 11% Midwest

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

During the HCSUS baseline interview, respondents were asked to identify their usual source of medical care. Malitz and colleagues (2000) used this information to assess the extent to which CARE Act-funded providers are serving low-income and vulnerable HIV populations. Sixty-five percent of respondents named a CARE Act-funded provider as their usual source of medical care. As compared to individuals served by physicians and clinics without CARE Act support, the patients of CARE Act-funded providers were significantly more likely to report annual household incomes of less than \$10,000 (55 percent vs. 34 percent), Medicaid coverage (34 percent vs. 24 percent), or no health insurance (28 percent vs. 6 percent). They also were significantly more likely to be black (43 percent vs. 20 percent) and to have less than 12 years of education (29 percent vs. 19 percent). Although patients of CARE Act-funded providers were more likely to be women (26 percent vs. 18 percent), this gender difference was not significant.

Two smaller-scale studies provide additional 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 and colleagues (in press) compared the 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). The gender and race/ethnicity distributions reported by CARE Act-funded providers generally reflected the demographics of local AIDS epidemics. When differences were noted, clients of CARE Act-funded providers were *more likely* to be women and people of color and *less likely* to report histories of injection drug use.

Larson and colleagues (in press) assessed the extent to which 17 SPNS grantees enrolled underserved and disenfranchised populations with HIV/AIDS in their programs between October 1994 and June 1999. Of the 4,804 enrollees, 73 percent were people of color, 46 percent were women, and 3 percent were less than 21 years of age. The vast majority were unemployed (86 percent) and dependent on publicly-supported medical care (89 percent). Relatively high proportions of enrollees had histories of problem drinking (42 percent), crack use (34 percent), heroin use (22 percent), and other illicit drug use (45 percent). Fifty-seven percent reported unstable housing. Related analyses of a subset of 2,793 enrollees revealed that 89 percent had at least four "need-vulnerability factors" that create barriers to service access and retention.²

² The SPNS evaluation center used 14 data elements to develop an index of service need-vulnerability. The need-vulnerability indicators were as follows: < 21 years of age, person of color, primary language other than English, children needing care, less than high school education, unemployed, dependent on publicly-supported medical care, history of problem alcohol use, history of heroin use, history of crack cocaine use, history of other illicit drug use, history of involvement with the criminal justice system, history of sex work, and unstable housing.

What are the service needs and unmet needs of people living with HIV/AIDS?

Five studies provide information on the service needs of people living with HIV/AIDS and the extent to which these needs are being met. Katz and colleagues (2000) analyzed the prevalence of need and unmet need for supportive services among 2,832 HCSUS participants interviewed between January 1996 and April 1997. Two-thirds of participants said they had needed at least one supportive service in the previous six months. The percentages of participants citing service needs were highest for benefits advocacy (43 percent) and emotional counseling (33 percent).

The HCSUS researchers defined “unmet need” as needing a service but not receiving it.³ Among those participants who said they needed each service, *unmet need* was greatest for benefits advocacy (35 percent), substance abuse treatment (28 percent), and emotional counseling (25 percent). Although women were more likely than men to report supportive service needs, they had lower unmet needs for all services. Nonwhite participants and participants with lower incomes had higher unmet needs for all services. Being unstably housed was associated with greater unmet need for benefits advocacy and home health care. Participants who had interacted with a case manager in the previous six months had lower unmet need for all supportive services.

A group of SPNS evaluators examined relationships between 14 indicators of need-vulnerability¹ and the service needs reported by 478 people with HIV/AIDS who participated in five SPNS projects between October 1994 and June 1999 (Melchior et al., in press). When asked about health and support services needed but not received during the six-month period prior to 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. Gender was not a statistically significant predictor of the number of service needs. However, when the statistical models were constrained to consider gender first, unstable housing and crack cocaine use were most predictive of the number of services needed by men, and crack cocaine use was most predictive for women.

To evaluate the success of the CARE Act in meeting HIV-related service needs, Marx and colleagues (1997) distributed surveys to 1,056 clients at 71 CARE Act-funded sites in the San Francisco Bay Area. Almost all clients participating in this 1994 survey said

³ Unmet need for benefits advocacy was defined as needing this service but not having health insurance and/or public income assistance at the time of the interview.

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

they had needed at least one service in the previous four months. Among clients with service needs, 72 percent reported at least one unmet need. Only 6 percent reported an unmet need for medical care.

<u>Most Frequent Service Needs (%)</u>	<u>Most Frequent Unmet Service Needs (%)</u>
Medical care 86	Childcare 60
Dental care 70	Household help 52
Mental health care 70	Transport to HIV care 48
Food 57	Dental care 41
Money for living expenses 56	Home health care 40

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. However, uninsured clients were more likely than insured clients 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). Among men who have sex with men, those with histories of injection drug use more often reported unmet needs for three health services (dental care, home health care, and substance abuse treatment) and for three support services (housing, help with living expenses, and buddy/companion services). Although clients often gave more than one reason for having unmet service needs, the most frequently cited reasons were:

- Did not try to get services (41 percent);
- Put on a waiting list (36 percent); and
- Specific services were unavailable (34 percent).

In contrast to the aforementioned client-focused studies, Finkelstein and colleagues (2000) conducted interviews and focus groups in six EMAs to assess the adequacy of Title I planning for active substance users. They found that four HIV Health Services Planning Councils lacked comprehensive assessments of the service needs of active substance users, and that most Planning Councils lacked accurate data on the services available to active substance users through *non-CARE Act* agencies and funding streams. Planning Council representatives identified lack of available slots across drug

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

treatment modalities as the most critical unmet need. Despite this recognized need, four Planning Councils funded little or no drug treatment. Planning Councils in two EMAs incorrectly interpreted the CARE Act's role as "payor of last resort" to mean that they could not fund services that had other sources of reimbursement. In other EMAs, drug treatment was viewed as "the responsibility of another funding source" or as "an expensive service without a guaranteed outcome" (Finkelstein, Greenberg, & Lubinski, 2000, p. 21).

Another qualitative study assessed the extent to which HIV Health Services Planning Councils in five EMAs had considered and responded to the service needs of HIV-positive women of color (Fullilove et al., 2000). Through interviews and focus groups with 120 Planning Council members, service providers, and HIV-infected and affected minority women, the researchers identified five critical areas of need:

- 1) Homes from which to organize family life;
- 2) Transportation to services;
- 3) Help integrating HIV-related care into daily chores;
- 4) Help coping with drug addiction, mental illness, incarceration, and victimization; and
- 5) Help addressing discrimination and immigration issues.

None of the EMAs had adequate substance abuse treatment or mental health services for HIV-positive women of color. Title I funding for transportation and childcare fluctuated from year to year, despite the critical need for these services among infected minority women. The researchers concluded that, while drug addiction, homelessness, and mental illness are common experiences for HIV-positive women of color, the service delivery systems in the EMAs were not sufficiently varied or flexible to effectively address these problems.

Studies in Progress

HRSA's HIV/AIDS Bureau is funding a new study that should further illuminate the types and levels of unmet need for HIV-related services. The Partnership for Community Health (PCH) is developing and testing a method of assessing unmet service needs based on epidemiologic and demographic trends, consumer and provider surveys, and assessments of services funded by sources other than the CARE Act.

During the first project year (October 1999-September 2000), PCH will pilot test the needs assessment methodology in Oregon and the Houston EMA. During the second project year (October 2000-September 2001), PCH will develop handbooks and other instructional materials to help Title I and II grantees replicate the methodology.

What are the major barriers to accessing HIV services?

Seven studies shed light on sociodemographic, cultural, and organizational factors that are associated with reduced access to health and support services. Using data from 2,864 HCSUS interviews conducted between January 1996 and March 1997, Cunningham and colleagues (1999) examined whether basic subsistence needs, lack of transportation, and other barriers were associated with poorer access to medical care. More than one-third of the sample said they went without or postponed care at least once in the six-month period preceding their interviews. None of the subsistence needs or barriers were significantly associated with fewer than three physician visits in the previous six months. However, participants 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, people of color, uninsured and lower-income participants, and people reporting HIV exposure modes other than male-to-male sexual contact were more likely to report “competing needs” and to postpone medical care due to illness or lack of transportation.

Two studies examined sociodemographic factors associated with the time interval between initial diagnosis of HIV infection and entry into primary medical care. Jefferson Comprehensive Care, Inc., a Title III-funded primary care clinic serving eight counties in central Arkansas, reviewed medical records of 162 clinic patients diagnosed with HIV between 1994 and 1998 (Sharma, Scott, & Milberg, 2000). The study’s major findings were as follows:

- The median number of weeks from an HIV-positive diagnosis to entry into primary medical care was much greater for men than women (6.5 vs. 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.

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

Albany Medical Center (AMC) reviewed medical records of 135 clinic patients who received HIV-related care during 1997 and/or 1998 (Clifford et al., 2000). AMC's AIDS Program receives funding from Titles II, III, and IV of the CARE Act and serves a 22-county region in northeast New York State. In contrast to the Jefferson Comprehensive Care study, the median time from HIV-positive diagnosis to care was about the same for men and women (4 months vs. 3 months). However, dramatic differences were noted for certain HIV subpopulations:

Hispanics - 15 months (compared to 3 months for whites and 6 months for African Americans)

Medicare beneficiaries - 50 months (compared to 1 month for HMO patients; 2 months for commercially-insured patients; and 5 months for Medicaid beneficiaries, self-pay patients, and patients receiving pharmaceutical assistance through New York's AIDS Drug Assistance Program).

Patients with injection drug use as HIV exposure mode - 31 months (compared to 2 months for patients who acquired HIV through male-to-male sexual contact or heterosexual contact with an infected partner)

Huba and colleagues (in press) examined relationships between 14 indicators of need-vulnerability¹ and barriers to service access reported by 519 HIV-positive individuals who participated in seven SPNS projects between October 1994 and June 1999. 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).

Barriers Cited by Significantly Higher Proportion of Women*

- 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
- Worrying that family or friends would not want them to receive services

* $p < .05$

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

Women with children needing care reported more access barriers than women without these responsibilities. Men of color reported more access barriers than white men. Although other studies (Marx et al., 1997; Melchior et al., in press) have documented higher levels of unmet service need among substance users, drug use was not significantly related to the number of reported access barriers in this study.

To assess the effectiveness of SPNS initiatives in reducing barriers to service access, evaluators asked project staff to rate the severity of 12 different access barriers at two time points—before the projects began and at the end of the third year. Brown and colleagues (in press) analyzed staff ratings from six SPNS projects. At the onset of these projects, the barriers with the highest mean scores (1-7 severity scale) included:

- Lack of public funding;
- Other agencies believe clients will not comply;
- Long waiting lists;
- Clients not enrolled in public assistance;
- Other agency staff are insensitive or not knowledgeable; and
- Other agencies do not provide services in an appropriate environment.

By the end of the third year, the mean severity scores for all of these barriers had declined. The barriers rated as most significantly reduced included: (1) long waiting lists, (2) lack of transportation, and (3) other agency staff feel they lack knowledge or training.

A 1996 study of 519 HIV-positive clients receiving services from 65 CARE Act-funded sites in the San Francisco EMA explored the reasons why they were not accessing the services they felt they needed (Marx et al., in press). Trained interviewers recruited from a job bank for people with HIV/AIDS queried clients on their need for and receipt of 21 different services in the past 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 percent) reported an *agency barrier*, such as eligibility requirements, inconvenient location or hours of operation, lack of bilingual staff, and being wait-listed for services. Forty-five 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 44 percent of the study

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

participants. In contrast to the Cunningham et al. study (1999) which found lower overall access to medical care among people with basic subsistence and transportation needs, only 19 percent of the participants in this study attributed their unmet service needs to *financial constraints* or *practical problems*. Another interesting contrast with the Cunningham et al. study 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 variations 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 social, psychological, and cultural factors that influence access to HIV therapies (Morin et al., 2000). A multidisciplinary research team interviewed health care professionals and a racially diverse mix of HIV-positive patients at four outpatient clinics in San Francisco and Oakland. The major access barriers identified for each racial/ethnic group were as follows:

African Americans	Latinos	Native Americans	Asian/Pacific Islanders
<ul style="list-style-type: none"> • Stigma associated with HIV disease • Mistrust of medical providers • Lack of (or conflicting) information about the benefits of HIV therapies • Drug regimens provide daily reminder of one's illness; concern about drug side effects 	<ul style="list-style-type: none"> • Stigma associated with HIV disease • Language differences • Fear and uncertainty about United States immigration policies • Recent immigrants lack information on HIV treatment options • Cultural tendency not to discuss disease 	<ul style="list-style-type: none"> • Stigma associated with HIV disease • Mistrust of government and western medicine • Taking pills is not part of traditional folk treatments • Cultural tendency to reflect for a long time on the HIV diagnosis before seeking treatment 	<ul style="list-style-type: none"> • Stigma associated with HIV disease • Diversity of language and cultures • Recent immigrants lack information on HIV treatment options • To shield family honor, A/Pis are more likely to seek care outside their own communities

How do HIV service utilization patterns vary by demographic characteristics, payor type, and source of care?

Making health and support services available to low-income, medically underserved people with HIV/AIDS does not necessarily improve service utilization (Rundall et al., 1999). Six studies offer insights on individual and organizational characteristics associated with variations in HIV service utilization patterns.

Shapiro and colleagues (1999) used data from three waves of interviews with HCSUS participants to examine variations in health services utilization, receipt of prophylaxis against *Pneumocystis carinii* pneumonia (PCP), and receipt of combination antiretroviral therapy over time. Among HIV-positive adults who received medical care in 1996 and early 1997, 15 percent made fewer than two ambulatory visits in the previous six months, 23 percent made at least one emergency room visit that did not lead to hospitalization, and 19 percent were hospitalized at least once. Thirty percent of persons with CD4+ T-lymphocyte counts < 200 cells/ μ L did not receive PCP prophylaxis in the six months prior to their interview, and 41 percent of those with CD4+ T-lymphocyte counts < 500 cells/ μ L did not receive combination antiretroviral therapy with a protease inhibitor (PI) or nonnucleoside reverse transcriptase inhibitor (NNRTI).

After adjusting for CD4 cell count, multivariate analyses of service and medication use by gender, race/ethnicity, HIV exposure mode, and payor type revealed the following:

- **Fewer than two ambulatory visits in previous six months** - significantly more likely among people of color (as compared to whites) and uninsured (as compared to privately insured)
- **At least one emergency room visit** - significantly *more likely* among women than men, people of color (as compared to whites), people with injection drug use or heterosexual mode of HIV exposure (as compared to men who have sex with men), and uninsured or Medicaid/Medicare beneficiaries (as compared to privately insured)
- **At least one hospitalization** - significantly *more likely* among women than men, blacks (as compared to whites), people with injection drug use or heterosexual mode of HIV exposure (as compared to men who have sex with men), and Medicaid/Medicare beneficiaries (as compared to privately insured)

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

- **Receipt of PCP prophylaxis** - significantly *less likely* among women than men, people of color (as compared to whites), people with injection drug use or heterosexual mode of HIV exposure (as compared to men who have sex with men), and uninsured or Medicaid beneficiaries (as compared to privately insured)
- **Receipt of PI/NNRTI regimens** - significantly *less likely* among women than men, people of color (as compared to whites), people with heterosexual mode of HIV exposure (as compared to men who have sex with men), and uninsured or Medicaid/Medicare beneficiaries (as compared to privately insured)

The researchers reassessed service and medication utilization patterns during the latter half of 1997 and early 1998. In the six-month period preceding the interviews, 16 percent of the represented population made fewer than two ambulatory visits, 16 percent made at least one emergency room visit without hospitalization, and 14 percent were hospitalized at least once. As of January 1998, 26 percent had not received indicated PCP prophylaxis and 15 percent had not received PI/NNRTI regimens.

After adjusting for CD4 cell count, many of the HIV care disparities noted at baseline still existed. However, the following improvements were noted:

- **Fewer than two ambulatory visits in previous six months** - differences between black and white patients were no longer statistically significant
- **At least one emergency room visit** - differences between people of color and white patients were no longer statistically significant
- **At least one hospitalization** - differences between patients with heterosexually-acquired HIV and men who have sex with men were no longer statistically significant
- **Receipt of PCP prophylaxis** - women, people of color, uninsured patients, and Medicaid beneficiaries still were less likely to receive PCP prophylaxis, but the differences from the withhold groups (men, whites, and privately insured) were no longer statistically significant. People with histories of injection drug use were about equally likely to receive PCP prophylaxis as men who have sex with men.
- **Receipt of PI/NNRTI regimens** - Latinos, people with heterosexually-acquired HIV, and Medicare beneficiaries were less likely to receive PI or NNRTI therapy, but the differences from the withhold groups (whites, men who have sex with men, and privately insured) were no longer statistically significant.

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

Two new disparities were noted. Uninsured patients were significantly more likely than privately-insured patients to have been hospitalized at least once during the previous six months. People with histories of injection drug use were significantly less likely than men who have sex with men to receive PI/NNRTI regimens.

Five additional studies provide clinic-specific analyses of HIV service utilization patterns. A study conducted by Johns Hopkins University researchers examined whether health service utilization patterns and access to PI/NNRTI regimens varied by payor type (Moore & Keruly, 1999). Their study population included 959 patients who made at least two visits to the Johns Hopkins University AIDS Service (JHUAS) between April 1996 and March 1999 and who had CD4+ T-lymphocyte counts < 500 cells/ μ L and/or HIV-1 RNA > 10,000 copies/ml at the start of the study period. The distribution by payor status was as follows:

- Uninsured \geq 80% of medical visits - 26%
- Uninsured for 20-80% of medical visits - 28%
- Medicaid or Medicare for \geq 80% of medical visits - 29%
- Privately insured - 17%

On average, patients in the \geq 80 percent uninsured group, made significantly fewer visits for primary and specialty medical care than patients in other payor categories. They averaged about the same number of emergency room visits as patients in the 20-80 percent uninsured group and government insured patients but significantly more visits than privately insured patients. Patients in the 20-80 percent uninsured group were two times more likely to be hospitalized than privately insured patients.

The percent of JHUAS patients on combination antiretroviral therapy steadily increased over time. Between 1996 and 1997, privately insured patients were significantly more likely to receive PI/NNRTI regimens than uninsured or government insured patients. White patients and men who have sex with men were more likely to receive these regimens than African Americans and patients who acquired HIV through injection drug use. By 1998-99, statistically significant differences in the receipt of PI/NNRTI regimens by payor status and race no longer existed. However, patients with histories of injection drug use continued to have a lower likelihood of receiving the new therapies.

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

Baker, Milberg, and Alzola (1999) examined variations in service utilization and the receipt of PI/NNRTI regimens in three groups of HIV-positive patients—privately insured patients, Medicaid/Medicare beneficiaries, and uninsured patients whose care was supported by the CARE Act. Their sample included 677 patients with CD4+ T-lymphocyte counts < 500 cells/ μ L or HIV-1 RNA > 10,000 copies/ml who visited two community-based HIV clinics in Florida and one hospital-affiliated HIV clinic in New York between January 1997 and May 1999. Of these patients, 30 percent were privately insured, 48 percent had Medicaid and/or Medicare coverage, and 22 percent were uninsured.

The researchers used baseline CD4 cell counts (< 200, 200-499, and \geq 500 cells/ μ L) to analyze variations in service use by payor type. The average number of clinic visits and viral load tests per year were about the same for privately insured and uninsured patients with CD4 counts > 200 cells/ μ L. In the lowest CD4 category, privately insured patients averaged more clinic visits per year (8.8 vs. 7.1) and more viral load tests (4.9 vs. 2.4). Rates of clinic visits and viral load tests were highest for Medicaid/Medicare beneficiaries in every CD4 category. Hospitalization rates also were much higher for Medicaid/Medicare beneficiaries than for other patients.

In January 1997, 48 percent of privately insured patients and 45 percent of Medicaid/Medicare beneficiaries were receiving PI/NNRTI regimens, as compared to 34 percent of uninsured patients. By May 1999, more than 70 percent of patients with private insurance and Medicaid/Medicare coverage were receiving combination therapies, as compared to just half of uninsured patients. Over the study period, uninsured patients were half as likely to receive PI/NNRTI regimens as privately insured patients. The likelihood of receiving these regimens was about the same for men and women and somewhat lower for African Americans than whites.

Meredith and colleagues (in press) examined health service utilization patterns and access to highly active antiretroviral therapy (HAART)⁴ among 202 women enrolled in the SPNS-funded Helena Hatch Special Care Center at the Washington University School of Medicine (St. Louis, MO). During 1997, the women averaged 2.8 clinic visits. Only 38 percent received “optimal medical care” (defined as at least one clinic visit per quarter). The number of encounters with a nurse or nurse practitioner and the total minutes per encounter were positively and significantly associated with more frequent clinic visits.⁵

⁴ The researchers do not say whether they defined HAART to include NRTI/NNRTI combinations as well as NRTI/PI combinations.

⁵ The frequency categories for 1997 included: 0 = no visits during any quarter, 1 = making visits less than half the time enrolled, 2 = making visits during half the time enrolled, 3 = making visits more than half the time enrolled, and 4 = making at least one clinic visit during all quarters enrolled.

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

Only 21 percent of the study participants received HAART during 1997. By July 1998, the proportion on HAART had increased to just 36 percent. Because most of the women had a history of substance abuse, the researchers examined how this risk behavior and other characteristics affected access to HAART. Their findings were as follows:

<u>1997</u>	<u>1998</u>
<ul style="list-style-type: none"> • After controlling for nadir CD4 cell counts, there was no relationship between a history of substance abuse and the receipt of HAART. • African American women and women who spent less time per encounter with a case manager were <i>less likely</i> to receive HAART. • Women who adhered to quarterly medical visits were <i>more likely</i> to receive HAART. 	<ul style="list-style-type: none"> • After controlling for nadir CD4 cell counts and use of HAART in the previous year, women with documented needs for substance abuse treatment were <i>less likely</i> to receive HAART. • Adherence to quarterly medical visits continued to be predictive of HAART use.

A 1993 study of 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 (Marx et al., 1998). By distributing self-administered surveys to a convenience sample of 472 patients, the researchers were able to obtain data on physician visits, emergency room visits, and overnight hospital stays during the previous year. Like Malitz and colleagues (2000), the researchers found that patients served by CARE Act-funded clinics were significantly more likely to be female, nonwhite, and uninsured. Although patients served by CARE Act-funded clinics made significantly fewer physician visits and were more likely to have visited an emergency room during the previous year, these differences were *not significant* after adjusting for sociodemographic characteristics and perceived health status. The two groups of patients 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+ T-lymphocyte count < 200 cells/ μ L were predictive of more frequent physician visits. Unemployed patients, younger patients (\leq 37 years), patients with a history of injection drug use, and those with lower health status scores reported more frequent emergency room visits. Nonwhite and unemployed patients were more likely to report hospitalizations than white and employed patients.

In Orange County, California, Akil and Pearce (1999) compared the service utilization patterns of HIV-positive adults receiving medical care in three types of settings: (1) a CARE Act-funded public health clinic, (2) a university-based HIV clinic participating in a Medi-Cal managed care program (CalOPTIMA), and (3) physician practices participating in CalOPTIMA. The researchers reviewed demographic and clinical data on 680 patients who were taking HIV antiretroviral medications and who had received at least 12 consecutive months of care from either the public health clinic or a CalOPTIMA provider between January 1996 and August 1998.

Patients receiving care in different types of settings had very different service utilization patterns. After adjusting for baseline CD4 cell count, gender, and HIV exposure mode, the *rate of medical visits per month* was four times higher for patients seeing private practitioners and 1.9 times higher for academic health clinic patients than for patients receiving services at the CARE Act-funded public health clinic. After adjusting for baseline CD4 cell count and gender, the rate of *social work/case management visits per month* was 47 percent lower for patients seeing private practitioners and 60 percent lower for academic health clinic patients than for public health clinic patients.

Studies in Progress

HRSA's HIV/AIDS Bureau currently is sponsoring two studies to increase understanding of racial/ethnic differences in HIV service utilization. Researchers in the Bureau's Office of Science and Epidemiology are using Client Demonstration Project data from two States (Michigan and Virginia) and five EMAs (District of Columbia; Middlesex County, New Jersey; and Los Angeles, San Francisco, and Orange County, California) to examine variations in service utilization patterns by race/ethnicity. The study population includes all clients who received services from providers funded by Title I and/or II of the CARE Act between 1996 and 1999. Of these 44,054 clients, 39 percent were African American, 38 percent were white, 20 percent were Hispanic, 2 percent were Asian/Pacific Islanders, and 1 percent were Native Americans.

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

Preliminary analyses of service utilization over the four years show substantial increases in the proportion of each racial/ethnic group making at least one medical visit to a CARE Act-funded clinic.

Racial/Ethnic Group	% Making Medical Visits - 1996	% Making Medical Visits - 1999
African Americans	40	50
Asian/Pacific Islanders	36	55
Hispanics	50	61
Native Americans	33	49
Whites	32	48

About 20 percent of Hispanics and Asian/Pacific Islanders received dental services from CARE Act-funded providers during the study period, as compared to 15 percent of whites and 10 percent of African Americans and Native Americans. The percentage of African Americans receiving mental health services from CARE Act-funded providers (15 percent) was considerably lower than for other racial/ethnic groups (20-25 percent). However, the percentage of African Americans receiving substance abuse treatment from CARE Act-funded providers (7 percent) was twice that of other groups (1-3 percent). Case management utilization rates were similar for all racial/ethnic groups (50-65 percent) and remained fairly stable over time.

Researchers at the AIDS Policy Research Center and Institute for Health Policy Studies, University of California-San Francisco are conducting case studies in five States (California, Florida, Illinois, New York, and Texas) to identify Medicaid and AIDS Drug Assistance Program (ADAP) policies that affect access to and utilization of HIV pharmaceuticals. They also are examining racial/ethnic variations in rates of Medicaid and ADAP participation and in receipt of HAART. The study design includes a review of 1998 Medicaid and ADAP claims data as well as interviews and focus groups with Medicaid/ADAP policymakers and program administrators, hospital and clinic eligibility workers, and AIDS benefit counselors in each State. This study should be completed by Summer 2000.

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. The contractors include: Center for Health Policy, Law and Management, Duke University (Durham, NC); CORE Center of Cook County Hospital (Chicago, IL); Family Advocacy, Care, and Education Services (FACES) Program at Children's Hospital (New Orleans, LA); Fenway Community Health Center (Boston, MA); Medical and Health Research Association of New York City, Inc. (in collaboration with Joseph L. Mailman School of Public Health, Columbia University); Office of AIDS, California Department of Health Services; Virginia Department of Health (in collaboration with Virginia Commonwealth University); and the Helena Hatch Special Care Center at the Washington University School of Medicine (St. Louis, MO). Although different groups of ancillary services are being evaluated, all or most studies address case management, transportation, mental health services, and chemical dependency treatment. Five studies are analyzing data from HIV clinics, two are analyzing client-level data reported by CARE Act-funded service providers (statewide or multi-county), and one is analyzing data from a longitudinal study of New York City residents with HIV/AIDS. With the exception of the New York City study which covers a five-year period (1994-1998), all studies are examining service utilization patterns between 1997 and 1998.

The HIV/AIDS Bureau expects to receive final reports from these studies by June 2000. Some of the preliminary findings are as follows:

- **The receipt of certain ancillary services significantly increases the likelihood of entering medical care and making regular medical visits.**⁶ 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 found that African American women entering care used significantly more emergency financial assistance, transportation, and nutrition services (Mundy et al., 2000). Women entering care with CD4+ T-lymphocyte counts < 200 cells/ μ L used significantly more mental health, peer support, and nutritional services.

⁶ Depending upon the study site, "regular medical visits" were defined as quarterly or semiannual visits for HIV primary care.

- **The receipt of ancillary services may not significantly change entry into or retention in medical care for some HIV populations.** For example, the CORE Center study found that patients who needed and received chemical dependency counseling were less likely to receive regular medical care in 1997 and any medical care in 1998 (Stieglitz et al., 2000). Five rounds of interviews with a cohort of people living with HIV/AIDS in New York City revealed that men, African Americans, and people with less than 12 years of education were more likely to lack medical care, whether or not they received ancillary services (Messerli et al., 1999).

How are changes in systems for procuring and financing HIV care affecting access to needed services?

Three studies of State Medicaid programs and one study of minority service providers' participation in CARE Act-funded services highlight structural factors that affect access to medically necessary and culturally appropriate services. Levi, Hidalgo, and Wyatt (2000) examined how interstate variations in Medicaid eligibility criteria and benefits affect eligibility criteria for CARE Act programs and the range of services offered. Their review of the "generosity" of Medicaid and 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 restrictive 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 programs⁷ or had adopted very restrictive income eligibility requirements for these programs. Using per-capita payments for disabled adults as a measure of Medicaid "generosity," seven of the nine States ranked below the national median. The eight States that restricted ADAP enrollees' access to protease inhibitors also lacked medically needy programs or had adopted very low income eligibility criteria. Six of these States placed in the bottom one-fifth of the Medicaid generosity scale.

Researchers at the Joseph L. Mailman School of Public Health, Columbia University used service utilization data from the third wave (2/96-3/97) of the Community Health Advisory and Information Network (CHAIN) Survey of HIV-positive adults to forecast the potential impact of Medicaid capitated Special Needs Plans (SNPs) on the demand for Title I-funded services in New York City (Glied, 1999). Four service categories were considered:

⁷ Medically needy programs enable disabled persons with high medical expenses to deduct these expenses from their incomes and "spend down" to Medicaid income eligibility levels.

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

- 1) Mental health services;
- 2) Substance abuse treatment services;
- 3) Case management services; and
- 4) Nutrition services.

For each service category, researchers estimated the proportion of existing Medicaid-paid services that would continue to be provided under managed care and the proportion of clients who, when discouraged from receiving SNP-funded services, would seek these services at Title I-funded agencies. Based on initial simulations that randomly assigned 40 percent of Medicaid beneficiaries to SNPs, the researchers estimated that caseloads of Title I-funded agencies providing mental health services would experience the greatest increase (about 8 percent). Additional simulations that assigned HIV-positive individuals to SNPs based on gender, race/ethnicity, HIV exposure mode, and health status suggested that changes in the demand for Title I-funded services would not be very sensitive to the composition of the SNP population.

The Maryland AIDS Administration, Department of Health and Mental Hygiene examined the impact of a new Medicaid managed care program on the services, staffing, and caseloads of 51 CARE Act-funded organizations in Maryland (Wolff, Eldred, & Weston, 1999). In addition to interviewing chief executive officers and/or program directors, the researchers reviewed quarterly administrative reports and responses to pre-interview surveys. During the first year of Medicaid managed care, only 43 percent of the sampled organizations contracted with managed care organizations to provide HIV-related services to Medicaid clients, but 63 percent 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 care. When asked about the *positive effects* of Medicaid managed care, respondents mentioned the coverage of new services, such as dental and vision care, greater access to specialists, and 24-hour access to medical care. *Negative effects* included greater difficulty enrolling clients and making service referrals. Respondents also expressed concern that the routine disenrollment of Medicaid beneficiaries every six months created gaps in service.

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

A fourth study (Hidalgo, Lewis, & Rawlings, 2000) examined the roles and levels of inclusion of minority providers in health and support services funded by the CARE Act. They defined minority providers as:

nonprofit or public agencies where 51 percent or more of board members belong to racial or ethnic minority groups; where racial/ethnic persons comprise 51 percent or more of direct service staff; or where individual providers (e.g., office-based clinicians) are members of racial or ethnic minority groups.

In 1999, 1,330 CARE Act-funded agencies provided information on their minority status, services, funding sources, participation in CARE Act planning groups, and factors that affect access to CARE Act funding. Thirty-eight percent met the study's minority provider criteria. These organizations were significantly more likely than non-minority providers to deliver case management and substance abuse treatment. They also were significantly more likely to report specific barriers to obtaining CARE Act funding (46 percent vs. 41 percent). The single most important barrier was the lack of experienced grant writers.

Through reviews of FY 1999-2000 and FY 2000-2001 grant applications for Titles I-IV and telephone consultations with key informants, the researchers discovered that grantees' ability to fund minority providers often is complicated by State and local government procurement procedures. Several EMAs and Title II grantees have formed separate corporate entities to gain greater flexibility in procurement. Other strategies include minority vendor set-asides (District of Columbia, Kansas City, and Maryland) and RFA scoring mechanisms that award extra points for demonstrating cultural and linguistic competency and organizational ability to serve clients with different languages and racial/ethnic backgrounds (Austin, Boston, Miami, and Palm Beach).



Studies of HIV Service Quality

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 valuable information on the extent to which HIV-positive patients in CARE Act-funded facilities are receiving prevention measures and treatments in accordance with professionally accepted clinical care guidelines. Kaplan and colleagues (1999) evaluated clinicians' adherence to guidelines for antiretroviral therapy and the prevention of opportunistic infections in 11 Title III-funded clinics. Between November 1996 and September 1997, medical record abstractions were performed for 1,411 HIV-positive patients who were > 13 years of age, had received a medical evaluation at the clinic within six months before record abstraction, and had CD4+ T-lymphocyte counts < 500 cells/ μ L. Of those patients meeting clinical criteria for antiretroviral therapy and prevention measures, 85 percent or more had received HIV plasma RNA testing, antiretroviral therapy, PCP prophylaxis, anti-*Toxoplasma* antibody testing, and Pap smears.⁸ Smaller percentages had received tuberculin skin tests (80 percent), pneumococcal vaccinations (70 percent), and prophylaxis against *Mycobacterium avium* complex (69 percent). Although HAART was not generally accepted as a standard of care until midway through the second phase of the study, 41 percent of patients had received protease inhibitors.

Prescription of antiretroviral therapy—with and without protease inhibitors—did not differ significantly by gender, race/ethnicity, or HIV exposure mode. However, HIV plasma RNA testing was significantly less frequent for patients with histories of injection drug use than for patients who acquired HIV through male-to-male sexual contact or heterosexual contact. Patients in urban facilities were less likely to receive protease inhibitors and HIV plasma RNA tests than patients in rural facilities.

Analyses of the receipt of prevention measures revealed the following differences:

- Women were less likely than men to receive tuberculin skin tests, and white women were less likely than Hispanic women to receive Pap smears.

⁸ Both monotherapy and combination therapies were included in the definition of antiretroviral therapy. However, only 5 percent of patients received nucleoside monotherapies.

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

- Patients with histories of injection drug use were less likely to receive tuberculin skin tests, Pap smears, and tests for anti-*Toxoplasma* antibodies.
- Rates of tuberculin skin testing, pneumococcal vaccinations, and anti-*Toxoplasma* antibody testing were significantly lower in rural than in urban facilities.

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. The HIVQUAL project team makes regular monitoring visits and provides on-site coaching to help clinics develop and integrate continuous quality improvement activities into their routine procedures. Data collected from each site are used to compare performance among facilities and different HIV populations.

During the first wave of data collection (7/97-12/98), the HIVQUAL project team analyzed 1,921 patient records (Agins, 2000). Like Kaplan and colleagues (1999), they found that high percentages of clinically-eligible patients had received PCP prophylaxis (87 percent) and semiannual HIV plasma RNA testing (82 percent) and CD4+ laboratory tests (83 percent). About two-thirds of clinically-eligible patients (64 percent) had received HAART, but only half had received prophylaxis against *Mycobacterium avium* complex (51 percent) or annual tuberculin skin tests (53 percent). 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 conducted by the Office of Infectious Disease and Reproductive Health, Washington State Department of Health and the Harborview Medical Center AIDS Program, University of Washington Center for AIDS Research examined changing patterns of antiretroviral treatment provided to Washington State ADAP clients after the introduction of protease inhibitors (Kitahata, Van Rumpae, & Shields, 2000). The study sample included 833 ADAP clients who received treatment between December 1995 and May 1997 and who consented to external reviews of their outpatient records. During the last quarter of 1996, only 27 percent of ADAP clients were receiving protease

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

inhibitor-based regimens. This percentage rose to 49 percent in the first quarter of 1997 and 64 percent in the second quarter of 1997. Adjusted analyses showed no association between age, gender, or race/ethnicity and the type of antiretroviral therapy received. However, the use of PI/NNRTI regimens increased significantly with decreasing CD4 cell count.

Because most ADAP clients receive HIV primary care from physicians who contract with the Department of Health to provide these services at a set fee schedule, the researchers were able to identify physicians for 356 study participants. These clients were included in a subset analysis to determine whether individual physicians' experience in providing HIV/AIDS care was associated with greater adherence to U.S. Department of Health and Human Services guidelines for the use of antiretroviral agents in adults and adolescents. Patients being treated by physicians who had cared for ≥ 10 HIV-positive patients were significantly more likely to receive PI/NNRTI regimens than patients being treated by less experienced physicians (41 percent vs. 30 percent). After controlling for CD4 cell count and the calendar period of treatment, increasing physician experience continued to be predictive of receiving a PI or NNRTI therapy. In contrast to findings from the Kaplan et al. (1999) study, the urban or rural location of a physician's practice was not associated with the type of antiretroviral therapy received.

Studies in Progress

HRSA's HIV/AIDS Bureau currently is sponsoring four projects to evaluate and improve the quality of HIV primary care for low-income and medically underserved populations. All of these projects have financial and/or technical support from additional Federal agencies.

Use of Multi-Phase Cluster Sampling to Evaluate the Quality of HIV Care

Through a collaborative effort with the CDC's National Center for HIV, STD, and TB Prevention, the HIV/AIDS Bureau is testing the feasibility of using multi-phase cluster sampling to estimate the utilization of preventive and antiretroviral regimens and the incidence of preventable illnesses in the adult population receiving medical care for HIV disease. The methodology will be tested in two phases. Phase I will involve four study sites (Houston, southern Louisiana, Michigan, and Washington State). Each site will

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

construct a sampling frame of all clinicians reporting cases of HIV infection or AIDS to CDC's surveillance program during a specified year. After dividing the clinicians into six strata based upon the number of HIV/AIDS cases reported and receipt/non-receipt of CARE Act funding, the sites will randomly select clinicians from each stratum. The patients reported by each selected clinician will be stratified by gender and race/ethnicity and then randomly selected from each stratum. Once the patient samples are selected, the sites will use a standardized data collection instrument to abstract data on the medical care that these patients received from sampled clinicians during 1998. During Phase II, six sites (Florida, Louisiana, Maryland, Missouri, Ohio, and Washington State) will select patient samples using the same methodology and abstract data from 1999 medical records.

HIV Cost and Resource Evaluation (HIVCARE) Study

HRSA's HIV/AIDS Bureau has joined with the Agency for Healthcare Research and Quality, the Substance Abuse and Mental Health Services Administration, and the Assistant Secretary for Planning and Evaluation to fund a national network of HIV medical care providers to collect and analyze data on the resources being used to treat HIV infection, the costs associated with resource use, and indicators of quality care. Johns Hopkins University School of Medicine is serving as the coordinating center for this HIV Cost and Resource Evaluation (HIVCARE) project. During the pilot phase, 16 provider sites tested the feasibility of collecting standardized data on patient demographics, payor source, clinical markers of disease stage and progression, HIV drug therapies, and service/resource utilization for a six-month period (January-June 1998). The second phase of the project, now in progress, involves 20 provider sites and the collection of an expanded data set for January-June 1999 and July-December 1999. The ultimate objective is to develop an ongoing infrastructure for tracking and analyzing changes in the use, costs, quality, and outcomes of HIV services and resources.

The PCP Index: An Access and Quality of Care Indicator for HIV Disease

Under the co-sponsorship of HRSA's HIV/AIDS Bureau and CDC's National Center for HIV, STD, and TB Prevention, researchers at Montefiore Medical Center, Albert Einstein College of Medicine are developing and testing a population-based PCP hospitalization index. This index is based on the following formula:

$$\frac{\text{No. of PCP hospitalizations by zip code of residence}}{\text{No. of people living with AIDS by zip code of residence}}$$

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

Because PCP can be prevented with timely and appropriate use of prophylactic drugs, high hospitalization rates in certain zip code areas may be indicative of undetected HIV infection, poor access to HIV primary care, and/or HIV primary care that does not meet quality standards. The researchers are using data from Los Angeles, Miami, and New York City to map zip code areas with excess PCP-related hospitalizations between 1996 and 1998. They also are reviewing hospital records for a sample of New York City patients to confirm PCP diagnoses and to determine what proportions were admitted due to (1) previously undiagnosed HIV infection, (2) poor access to HIV primary care (as measured by previous PCP-related hospitalizations), and (3) poor quality medical care (as measured by non-receipt of PCP prophylaxis). The anticipated project completion date is September 2000.

Improving Quality of HIV Medical Care for Underserved Populations

In September 1999, the HIV/AIDS Bureau awarded a four-year contract to the Institute for Healthcare Improvement (IHI) to help CARE Act grantees plan and implement “breakthrough improvements” in HIV/AIDS care. Each year, an expert panel selected by Bureau staff will work with a group of approximately 60 grantees to define specific outcomes that can be used to evaluate the quality of HIV/AIDS care. At learning sessions conducted by IHI staff, grantees will learn how to institute “rapid improvement cycles,” track improvements in the agreed-upon outcome measures, and overcome barriers to change. They also will participate in regular conference calls and a collaborative listserve. The Agency for Healthcare Research and Quality has awarded a grant to a team of Harvard Medical School researchers to evaluate the effectiveness of this rapid-cycle quality improvement strategy. Although representatives of all CARE Act Titles will participate in the Breakthrough Series, the evaluation will be limited to a sample of Title III-funded clinics.



Studies of HIV Service Outcomes

How do clinical outcomes vary for HIV-positive individuals with different payor types and sources of care?

Three studies provide useful insights on relationships between payor type or source of care and clinical outcomes. Moore and Keruly (1999) examined how the payor status of patients in care at the Johns Hopkins University AIDS Service affected survival, progression from HIV to AIDS, and achieving an undetectable viral load. (See p. 17 for a more complete description of this study.) In a Cox proportional hazards analysis, a low CD4 cell count (< 200 cells/ μ L) was the only variable significantly associated with increased hazard for death. After adjusting for CD4 cell count, no differences were noted among payor types.

An analysis of variables associated with progression from HIV to AIDS showed an increased hazard for disease progression among patients with a lower CD4 level (201-350 cells/ μ L) and a reduced hazard among patients receiving PI/NNRTI regimens or having lower viral loads (HIV-1 RNA $< 10,000$ copies/ml). After adjusting for these variables, the researchers found no association between payor type and disease progression.

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 PI/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. Patients with CD4+ T-lymphocyte counts < 50 cells/ μ L and patients who had missed one-quarter or more of their scheduled visits were less likely to achieve undetectable viral loads. After adjusting for these variables, there was no significant difference by payor type.

Baker, Milberg, and Alzola (1999) examined the same clinical outcomes in their study of privately insured, government insured, and uninsured patients treated at two Florida HIV clinics and one New York HIV clinic. (See p. 18 for a more complete description of this study.) In a Cox proportional hazards analysis, Medicaid/Medicare beneficiaries died more quickly than privately insured patients. Uninsured patients whose care was supported by the CARE Act died less quickly than privately insured patients, but the 95 percent confidence intervals were large and not statistically significant.⁹ An analysis of

⁹ Covariables were not added to the model due to the small number of deaths ($n=51$) during the study period.

variables associated with progression from HIV to AIDS showed somewhat faster progression for Medicaid/Medicare and uninsured patients, but the differences among payor types were not statistically significant.

To identify the variables associated with achieving an undetectable viral load, the researchers chose a subset of 105 patients who had detectable viral loads and an indication for HAART at baseline. In contrast to the Johns Hopkins University study, they did not limit the analysis to patients on PI/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 the payor types.

A study in Orange County, California (Akil & Pearce, 1999) evaluated clinical outcomes for patients receiving HIV primary care in three types of settings: (1) a CARE Act-funded public health clinic, (2) a university-based HIV clinic participating in a Medi-Cal managed care program (CalOPTIMA), and (3) physician practices participating in CalOPTIMA. (See p. 20 for a more complete description of this study.) Because viral load measurements were not included in the university clinic’s database, the researchers used “change in CD4 cell count” as the sole outcome measure. After adjusting for baseline CD4 cell count and the rate of medical visits, patients of CalOPTIMA private practitioners were no more likely than public health clinic patients 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 percent less likely than public health clinic patients to achieve an increase of 50 or more.

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 studies examined the impact of Title I funding on the use of health-related services and the prevalence of HIV risk behaviors among 777 HIV-positive drug users in five new EMAs (Booth, Kwiatkowski, & Weissman, 1999). The researchers conducted three waves of

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

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). Rather than 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 as follows: medical services (74 percent), case management (62 percent), drug treatment (54 percent), mental health services (37 percent), and housing assistance (20 percent). By the second year of Title I funding, the percentages reporting service use were significantly higher only for housing assistance (40 percent) and case management (~72 percent).

With one exception (exchanging sex for drugs or money), the percentages of study participants reporting sex- and drug-related HIV risk behaviors declined linearly across the three interview waves. In all waves, and for all service categories except housing assistance, study participants who received services reported fewer HIV risk behaviors.

Studies in Progress

State and Local Outcomes Evaluations

Through an interagency agreement with CDC's National Center for HIV, STD, and TB Prevention, HRSA's HIV/AIDS Bureau currently is funding a longitudinal evaluation of the impact of Title I funding. This study is assessing changes in the availability and accessibility of HIV services, the quality and continuity of care, and HIV-related morbidity and mortality in two EMAs (Las Vegas and Norfolk-Virginia Beach-Newport News) that first received Title I grants in March 1999. Cooperative agreements have been awarded to State Health Departments in Nevada and Virginia to collect data on service utilization, preventive and antiretroviral regimens, service referrals, and clinical outcomes for the following samples and time periods:

Phase I (Pre-Title I funding) - The sampling frame for each EMA includes all people ≥ 13 years who were diagnosed with HIV and/or AIDS between September 1996 and November 1997. Data will be abstracted from their medical records for the period March 1998 - February 1999.

Phase II (Post-Title I funding) - The sampling frame for each EMA includes all people ≥ 13 years who were diagnosed with HIV and/or AIDS between March 1999 and February 2000. Data will be abstracted from their medical records for the period June 2000 - May 2001.

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

System-level changes will be tracked through ongoing reviews of each EMA's Title I grant applications, HIV/AIDS surveillance reports, and other secondary documents. The anticipated study completion date is September 2001.

In October 1999, the HIV/AIDS Bureau awarded four one-year contracts for State and local evaluations of the impact of CARE Act-funded services on client-level and system-level outcomes. The HIV populations and outcomes being evaluated are as follows:

New York University Medical Center

This study is investigating the impact of Title IV-funded services on clinical outcomes, immunologic markers, and access to social services in three cohorts of HIV-positive infants and children served by the Lower New York Consortium for HIV-Affected Families Network between 1985 and 1999. Cohort 1 consists of 351 children served in the years before the Consortium received Title IV funding. Cohort 2 consists of 523 children served during the initial years of Title IV funding. Cohort 3 consists of 303 children served during the "program maturity stage" of Title IV funding. Changes in outcomes will be assessed within and between the three time periods.

Office of AIDS, California Department of Health Services

This study is examining changes in immunologic markers and HIV-related morbidity (i.e., frequency of opportunistic infections, non-injury-related emergency room visits, and hospitalizations) in a random sample of 425 clients who received medical care from four CARE Act-funded clinics between 1998 and 1999. The impact of case management and other ancillary services on clinical outcomes also is being investigated. The study sites include two large urban clinics in northern and southern California, a large suburban clinic in the central valley, and a small rural clinic in northern California. Statistical analyses will control for demographic variables, payor status, and comorbid conditions.

University of Pittsburgh

This study is assessing the extent to which a Title III-funded program operated by the Pittsburgh AIDS Center for Treatment (PACT) has served patients from subpopulations and groups disproportionately affected by HIV, provided timely and appropriate antiretroviral treatments and preventive care, removed barriers to care, and reduced morbidity and mortality. The study population includes all patients (N > 800) seen at PACT between 1997 and 1998.

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

Washington University School of Medicine

This study is assessing the extent to which the CARE Act-funded HIV Care Center at Washington University School of Medicine has served patients from subpopulations and groups disproportionately affected by HIV, delivered high-quality care, removed barriers to care, and reduced morbidity and mortality. The study population includes all patients (N~650) enrolled in the Center between 1997 and 1998. Patients will be stratified by “markers of vulnerability” (e.g., female, person of color, unstable housing, need for substance abuse treatment, need for mental health treatment) for purposes of analysis. Focus groups with clinicians will explore how they are adapting to changes in antiretroviral treatments and the growth of managed care.

Evaluations of Health-Related Quality of Life

Three groups of SPNS grantees are evaluating the impact of service delivery models and interventions on health-related quality of life. Twenty-seven grantees with “Partnership Cooperative Agreements” from HRSA’s HIV/AIDS Bureau and the Department of Housing and Urban Development are using the Medical Outcomes Study Short-Form Health Survey (SF-36) and an assessment tool developed by the Columbia University Evaluation and Technical Assistance Center (ETAC SF-24) to track quality-of-life improvements among a cohort of clients receiving integrated medical care and housing/support services. Twelve SPNS grantees are evaluating relationships between adherence interventions and perceived quality of life, and five grantees are assessing changes in psychological, emotional, and spiritual health among a cohort of clients receiving palliative care.

Evaluations of Outcomes for HIV-Positive Women and Children

Two studies of Title IV-funded programs are nearing completion. The first study is analyzing changes in perinatal HIV transmission rates and related variables (e.g., rates of prenatal HIV counseling and testing, prenatal care, and AZT use during pregnancy) at 27 Title IV-funded sites between 1996 and 1998. Title IV grantees are conducting retrospective medical record reviews for all infants who received care at these sites, whether or not their mothers were enrolled during pregnancy. Preliminary findings for 1996-1997 indicate that 58 percent of the mothers received prenatal care at Title IV sites, 33 percent received prenatal care from other service providers, and 8 percent did not receive any prenatal care. Overall rates of perinatal HIV transmission were the same each year (~9 percent). However, over the two-year period, the perinatal HIV transmission rate was significantly lower for women receiving prenatal care at Title IV sites (4.9 percent) than for women receiving prenatal care at non-Title IV sites (11 percent) or not receiving prenatal care (22 percent).

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

The second study is analyzing changes in morbidity and mortality among a random sample of 545 HIV-positive children who received services at 27 Title IV-funded sites between 1996 and 1998. Relationships between specific services and clinical outcomes are being explored, along with factors that explain differences in clinical outcomes among Title IV sites.

Evaluations of Outcomes for People with HIV/AIDS and Comorbidities

The HIV/AIDS Bureau has awarded three contracts for evaluations of HIV service utilization and health outcomes among people who have HIV/AIDS and comorbid conditions. The contractors include:

Joseph L. Mailman School of Public Health, Columbia University

Researchers are using data from the Community Health Advisory and Information Network (CHAIN) longitudinal study of New York City residents with HIV/AIDS to evaluate service utilization patterns and health outcomes among HIV-positive individuals with tuberculosis, sexually transmitted diseases, chemical dependencies, mental illness, and unstable housing.

Johns Hopkins University

Researchers are evaluating service utilization patterns and health outcomes among Johns Hopkins University AIDS Service patients with hepatitis C, chemical dependencies, and mental illness.

Helena Hatch Special Care Center, Washington University School of Medicine

Researchers are evaluating service utilization patterns and health outcomes among HIV-positive adult and adolescent women with diabetes, hypertension, hepatitis B and C, tuberculosis, sexually transmitted diseases, chemical dependencies, mental illness, and unstable housing.

Each study will analyze data for at least a three-year period (1996-1999) and will include an assessment of the costs and benefits of integrating treatment for comorbidities with HIV primary care. Final reports are anticipated in December 2000.



Conclusions

Recent studies of HIV service delivery 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 indicate that 37-64 percent of HIV-positive adults still are not receiving regular medical care (Bozzette et al., 1998). HCSUS findings also suggest that the HIV-positive individuals not in care are more likely to have early (and possibly unrecognized) HIV infection, lack health insurance, and/or to be people of color. Other studies (Clifford et al., 2000; Sharma, Scott, & Milberg, 2000) 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 of 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 (i.e., help 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 users, 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/low-income individuals, and injection drug users typically encountered more access barriers, 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 combination 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 to receive the new therapies—a factor that may partially explain their higher rates of emergency room visits and hospitalizations. Disparities based on

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

insurance status, gender, race/ethnicity, and HIV exposure mode were not uniform across study sites, suggesting that clinic characteristics and geographic location may have a major influence on HAART prescribing patterns.

Evaluations of service quality focused on the primary care component of the HIV care continuum. Kaplan and colleagues (1999) documented high rates of PCP prophylaxis, anti-*Toxoplasma* antibody testing, and Pap smears among clinically-eligible patients. Prescription of antiretroviral therapy—with and without protease inhibitors—did not differ significantly by gender, race/ethnicity, or HIV exposure mode. Variations in clinician adherence to other HIV care guidelines were better explained by “time in care” at the current facility and the frequency of medical visits (as measured by number of CD4 tests in the past year) than patient sociodemographic characteristics. Another study of ADAP clients in Washington State (Kitahata, Van Rempaey, & Shields, 2000) found no association between age, gender, or race/ethnicity and the type of antiretroviral therapy received. However, patients treated by physicians who had cared for ≥ 10 HIV-positive patients were significantly more likely to receive PI/NNRTI regimens. New data being collected by the HIV Cost and Resource Evaluation project should enhance understanding of the factors associated with better quality care.

Most of the outcomes evaluations described in this report are still in progress. Completed studies suggest that once patients gain access to PI/NNRTI regimens, payor status makes little difference in clinical outcomes. By December 2000, new data will be available on variations in service utilization and clinical outcomes among women, children, people of color, and patients with comorbidities. Forthcoming reports from SPNS grantees will provide useful assessments of the impact of specific service delivery models on physical and mental health, role functioning, and perceived quality of life. SPNS grantees also are collecting extensive data on access and quality-of-care issues faced by HIV populations that have not been systematically studied—active injection drug users, incarcerated individuals, people living along the southwestern border of the United States, and people requiring end-of-life AIDS care who are homeless, chemically dependent, and/or mentally ill.

The expanded Behavioral Model of Health Services Utilization (Aday, Andersen, & Fleming, 1980) offers a useful framework for assessing the research that has been conducted to this point. This model posits that access to services and the types and levels of service utilization are influenced by the health policy environment, characteristics of health service organizations and health care delivery systems, and

*Delivering HIV Services to Vulnerable Populations:
What Have We Learned?*

characteristics of the populations at risk.¹⁰ To date, most of the evaluation and research studies supported by the 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 HIV-positive individuals who 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 service delivery system components and the larger health policy environment. Some of the variables that should be investigated are as follows:

- **Characteristics of health/social service professionals** (e.g., knowledge and attitudes, HIV-specific training and experience, cultural competence)
- **Organizational characteristics** (e.g., eligibility requirements, convenience of location and hours of operation, average appointment waiting time, availability of on-site ancillary services, adoption and enforcement of clinical care guidelines)
- **Characteristics of the HIV service delivery system** (e.g., number of different 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 reforms, Federal guidelines for HIV/AIDS clinical 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, HIV service evaluators 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 vulnerable populations.

¹⁰ Characteristics of the populations at risk include: (1) *predisposing variables* (e.g., age, gender, race/ethnicity, HIV exposure mode, educational attainment, beliefs about the value of health services and/or clinicians' knowledge of disease, and knowledge of health care resources), (2) *enabling variables* (e.g., health insurance status, employment status, household income, housing status, and perceived ease of accessing health care), and (3) *need* (e.g., disease stage, HIV-1 RNA level, and medical symptoms).



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What Have We Learned?*

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What Have We Learned?*

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*Delivering HIV Services to Vulnerable Populations:
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A p p e n d i x

Recent Research on the Accessibility, Quality, and Outcomes of HIV Services for Vulnerable Populations

<i>Reference</i>	<i>Study Objectives</i>	<i>Methods</i>	<i>Findings</i>
Studies of HIV Service Accessibility and Utilization			
Palacio, H., Shiboski, C.H., Yelin, E.H., et al. (1999). Access to and utilization of primary care services among HIV-infected women. <u>Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology</u> , 21(4), 293-300.	To identify factors associated with the use of medical services among HIV-positive women	Conducted a telephone survey of 213 HIV-positive women in the San Francisco Bay Area between May 1995 and August 1996. Survey respondents were recruited from the Northern California Women's Interagency HIV Study Cohort, a multi-site longitudinal study of HIV infection in U.S. women.	<ul style="list-style-type: none"> 93% of respondents had a primary care provider. Factors associated with a greater number of primary care visits: > 45 years, having AIDS, perceiving greater benefits from medications, lack of problems with appointment times, and shorter appointment waiting times Factors associated with greater likelihood of missed appointments: lack of health insurance, current injection drug use, and difficulty remembering appointments
Shiboski, C.H., Palacio, H., Neuhaus, J.M., et al. (1999). Dental care access and use among HIV-infected women. <u>American Journal of Public Health</u> , 89(6), 834-839.	To identify predictors of dental care use in HIV-positive women	Conducted a telephone survey of 213 HIV-positive women in the San Francisco Bay Area between May 1995 and August 1996. Survey respondents were recruited from the Northern California Women's Interagency HIV Study Cohort, a multi-site longitudinal study of HIV infection in U.S. women.	<ul style="list-style-type: none"> 43% of respondents had not visited a dentist in more than a year. Factors associated with lack of dental care in the past year: current unemployment, greater concern about non-HIV-related problems, annual income ≤ \$6,000, perception of poor oral health, and edentulism Reported access barriers: fear of and discomfort with dentists, "not getting around to making an appointment," and not knowing which dentist to visit

Reference	Study Objectives	Methods	Findings
Davidson, A.J., Bertram, S.L., Lezotte, D.C., et al. (1998). Comparison of health status, socioeconomic characteristics, and knowledge and use of HIV-related resources between HIV-infected women and men. <u>Medical Care</u> , 36(12), 1676-1684.	To compare socioeconomic characteristics, measures of health status, and knowledge and use of HIV-related resources between HIV-positive women and men registered with the Denver Health and Hospitals health care system	Linked data from Adult Spectrum of Disease (ASD) medical record abstractions with data from Surveillance to HIV/AIDS Surveillance (SHAS) interviews. Of the 1,199 HIV-positive patients enrolled in the ASD, 52 women and 367 men (n=419) participated in SHAS interviews between February 1991 and December 1993. The Medical Outcomes Study Short Form was used to assess perceived health status.	<ul style="list-style-type: none"> • Women were more likely to be minority, injection drug users, and at earlier stages of HIV disease. Also were more likely to receive public assistance and have health insurance while still in early-stage disease. • No significant differences were noted for physical and social function, mental health, pain, or general health perceptions. • Both women and men demonstrated high awareness of available services. • Service utilization patterns were similar; however, women used support services, social work, and shelter assistance less often than men.
Kaiser Family Foundation. (1998, March). <u>The Kaiser Family Foundation Survey of African Americans on HIV/AIDS</u> . Available at: < http://www.kff.org/content/archive/1372/ >	To examine the knowledge, attitudes, and perceptions of African Americans and subgroups within the African American community (i.e., women, young adults, parents, opinion leaders, and people with less education and lower incomes) with respect to HIV and AIDS	Conducted a telephone survey of a national probability sample of African American adults (n=811) between September and October 1997	<ul style="list-style-type: none"> • 52% of African Americans had never talked to a health care professional about any aspect of HIV or AIDS. • 55% of African Americans wanted information on where to go for help if exposed to HIV. The percentages of each subgroup citing this need were as follows: Women - not reported Young adults (18-24 years) - 51% < 12 years of education - 70% < \$20,000 annual income - 63%

Reference	Study Objectives	Methods	Findings
<p>Kaiser Family Foundation. (1998, March). <u>Kaiser Family Foundation National Survey of Latinos on HIV/AIDS</u>. Available at: http://www.kff.org/content/archive/1392/</p>	<p>To examine the knowledge, attitudes, and perceptions of Latinos* and subgroups within the Latino community (e.g., women, young adults, parents, opinion leaders, and people with less education and lower incomes) with respect to HIV and AIDS</p> <p>* Researchers used the term "Latino" to describe U.S. residents of Hispanic origin regardless of race.</p>	<p>Conducted a telephone survey of a national probability sample of Latino adults (n=802) between September and October 1997</p>	<ul style="list-style-type: none"> 69% of Latinos had never talked to a health care professional about any aspect of HIV or AIDS. 63% of Latinos wanted information on where to go for help if exposed to HIV. The percentages of each subgroup citing this need were as follows: Women - not reported Young adults (18-24 years) - 58% < 12 years of education - 70% < \$20,000 annual income - 69%
<p>Kass, N., Flynn, C., Jacobson, L., et al. (1999). Effect of race on insurance coverage and health service use for HIV-infected gay men. <u>Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology</u>, 20(1), 85-92.</p>	<p>To determine whether race is associated with health insurance coverage and health service use among gay and bisexual men in the Baltimore Center of the Multicenter AIDS Cohort Study (MACS)</p>	<p>Between 1991 and 1996, participants in the Baltimore Center of MACS made semiannual visits for physical examinations, laboratory work, and structured interviews. Data for this analysis were taken from the most recent visit that each man made during the five-year period. Analyses are based on a sample of 307 HIV-positive men.</p>	<ul style="list-style-type: none"> Controlling for CD4 cell count, education, income, and employment, black and white men were equally likely to have health insurance and to have private rather than public health insurance. Race was not a significant predictor of emergency room use, hospitalization, or the use of antiretroviral therapy. White men were more likely to have had a dental visit in the last six months (despite the higher % of black men with dental insurance) Among men with CD4 cell counts > 500, white men were 10 times more likely to have seen a physician in the last six months.

Reference	Study Objectives	Methods	Findings
Stone, V.E., Mauch, M.Y., Steger, K., et al. (1997). Race, gender, drug use, and participation in AIDS clinical trials. <u>Journal of General Internal Medicine</u> , 12(3), 150-157.	To determine whether participation rates of women, people of color, and injection drug users in AIDS clinical trials are similar to those of other HIV/AIDS patients and to investigate reasons for different participation rates	Interviewed a convenience sample of 260 HIV-positive patients receiving ongoing ambulatory care at Boston City Hospital clinics between September 1993 and August 1994	<ul style="list-style-type: none"> • 22.3% of respondents had participated in an AIDS clinical trial. • Women, people of color, and people with a history of injection drug use were significantly less likely to have ever participated in a clinical trial. • Women and people of color reported less knowledge of clinical trials and were less likely to have been informed about clinical trials for which they were eligible. • People of color were half as likely as whites to cite ineligibility as the reason for non-participation and were more likely to view clinical trials unfavorably.
Bing, E.G., Kilbourne, A.M., Brooks, R.A., et al. (1999). Protease inhibitor use among a community sample of people with HIV disease. <u>Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology</u> , 20(5), 474-480.	To examine the sociodemographic factors associated with use and perceived knowledge of protease inhibitors and whether use of these medications is associated with changes in perceived health status	Mailed questionnaires to 3,730 clients of a large Los Angeles-based AIDS service organization in November 1996. Analyses are based on 1,034 completed questionnaires.	<ul style="list-style-type: none"> • Two-thirds of survey respondents were taking protease inhibitors (PIs), and 52% reported being “very knowledgeable” about these antiretroviral agents. • People not receiving PIs were more likely to be African American, non-English speaking, earning < \$9,600 annually, and uninsured. • PI users reporting less knowledge about the drugs were more likely to be nonwhite, earning < \$9,600 annually, and lacking a college education.

Reference	Study Objectives	Methods	Findings
Celentano, D.D., Vlahov, D., Cohn, S., et al. (1998). Self-reported antiretroviral therapy in injection drug users. <u>JAMA</u> , 280(6), 544-549.	To assess the extent to which injection drug users, who were clinically-eligible for protease inhibitor-based combination therapy between July 1996 and June 1997, actually received such treatment	Analyzed data from a longitudinal study of the natural history of HIV infection in injection drug users in Baltimore, MD. Analyses are based on semiannual interviews (July 1996-June 1997) with 404 HIV-positive injection drug users with CD4 cell counts < 500 cells/ μ L.	<ul style="list-style-type: none"> 49% of respondents reported no recent antiretroviral therapy (ART). The percentages on various types of ART were as follows: monotherapy (14%), combination therapy without a PI (23%), and PI-based triple therapy (14%). Factors associated with ART: CD4 cell count < 200, recent HIV-related outpatient visit, continuity of care, no current injection drug use, drug abuse treatment, and unemployment Factors associated with receipt of PIs: recent incarceration and current injection drug use (lower likelihood); AIDS diagnosis (higher likelihood)
Cox, C. (1999). Hospice care for injection drug using AIDS patients. <u>The Hospice Journal</u> , 14(1), 13-24.	To determine the level of hospice involvement with injection drug using patients with AIDS and the factors associated with the provision of care to this population	Conducted a mail survey of all hospices in the United States and Puerto Rico between January and March 1993. Responses were received from 957 hospices (62% of the final estimated sampling frame).	<ul style="list-style-type: none"> 65% of the hospices had cared for AIDS patients in the previous fiscal year, but only 24% had cared for injection drug using (IDU) AIDS patients. Blacks accounted for 51% of IDU-related AIDS cases in 1993 but only 32% of the IDU AIDS patients in hospices. Hospices providing care to IDU AIDS patients had been in operation longer, had twice as many staff and volunteers, and had > 3 times as many patients as hospices not caring for IDU AIDS patients.

Reference	Study Objectives	Methods	Findings
Osmond, D.H., Bindman, A.B., Vranizan, K., et al. (1999). Name-based surveillance and public health interventions for persons with HIV infection. <u>Annals of Internal Medicine</u> , 131(10), 775-779.	To determine whether name-based surveillance of HIV infection leads to more timely receipt of medical care and/or more persons being notified of exposure to an HIV-positive partner	Interviewed a probability sample of people with AIDS in five States with name-based surveillance of HIV infection (n=388) between May 1995 and December 1996. To evaluate the effect of type of HIV surveillance on the timeliness of receipt of medical care and partner notification, only people who had tested positive for HIV before the date of their AIDS diagnosis were interviewed.	<ul style="list-style-type: none"> • Most participants began medical care soon after receiving a positive HIV test result. • The percentages seeking timely medical care in States with and without name-based HIV surveillance differed only slightly (66% vs. 67% at two months) • Receiving information on available HIV/AIDS resources from health department personnel was not associated with more timely receipt of medical care. • Variables most strongly associated with seeking timely medical care: (1) having symptoms at the time of HIV testing and (2) having a regular source of care.
Mueller, K.J., & Beavers, S.L. (1998). Insurance status among HIV+ Nebraskans. <u>Journal of Health & Social Policy</u> , 10(1), 53-64.	<p>To measure the rates of insurance among HIV-positive Nebraskans and to test two hypotheses:</p> <p>H1: People with AIDS are more likely to be uninsured than people with asymptomatic or symptomatic HIV.</p> <p>H2: HIV-positive individuals experience difficulties maintaining their health insurance.</p>	<p>Conducted a mail survey of a sample of clients from University of Nebraska Medical Center, Nebraska AIDS Project, and the Regional West Medical Center in Scottsbluff during the spring and summer of 1993. Of the 480 people surveyed, 238 returned completed questionnaires, reflecting ~10% of the estimated number of HIV-positive people in the State.</p>	<ul style="list-style-type: none"> • 43% of respondents were covered by private insurance; 22% were uninsured. • Among people with AIDS, 22% of the women and 15% of the men were uninsured. Among people in earlier stages of HIV disease, 6% of the women and 31% of the men were uninsured. • As compared to people with asymptomatic and symptomatic HIV, people with AIDS were less likely to be uninsured.

Reference	Study Objectives	Methods	Findings
Studies of HIV Service Quality			
Yedidia, M.J., & Berry, C.A. (1999). The impact of residency training on physicians' AIDS-related treatment practices: A longitudinal panel study. <u>Academic Medicine</u> , 74(5), 532-538.	To evaluate the effects of different aspects of residency training on AIDS-related treatment practices	Conducted a longitudinal panel study of physicians who graduated in 1989 from six medical schools in New York State. The physicians were surveyed during the fourth year of medical school, the third year of residency training, and six years after graduation from medical school. Analyses are based on responses from 394 physicians who participated in the second and third waves of the survey.	<ul style="list-style-type: none"> Aspects of residency training had a sustained effect on how physicians cared for patients with HIV/AIDS but not on the number of HIV/AIDS patients treated. Physicians choosing less invasive procedures for HIV/AIDS patients than for other seriously ill patients tended to have been high in cynicism about patient care and low in willingness to care for HIV/AIDS patients during their residencies and to rate their training as oriented toward memorizing. Physicians seeking to minimize physical contact with HIV/AIDS patients tended to have been homophobic and averse to IDUs as residents and to have had high proportions of IDUs in their caseloads.
Jones, J.L., Hanson, D.L., Dworkin, M.S., et al. (1999). Surveillance for AIDS-defining opportunistic illnesses, 1992-1997. <u>Morbidity and Mortality Weekly Report</u> , 48(SS-2), 1-22.	To examine aggregate data and trends for 1992-1997 to determine the frequencies at which opportunistic infections (OIs) occurred first, the incidence of OIs, the percentage of deceased patients who had experienced a given OI during their course of AIDS, and the frequency of prescriptions for antiretroviral therapy and prophylaxis for PCP and MAC	Analyzed data from the Adult/Adolescent Spectrum of HIV Disease (ASD) sentinel surveillance project, a prospective medical record review of HIV-positive patients ≥ 13 years conducted in ~ 100 medical facilities in 11 U.S. cities. Standardized ASD data to national AIDS surveillance data for 1992-1997 by age, race, gender, year of AIDS diagnosis, HIV exposure mode, and—for incidence calculations—by CD4+ T-lymphocyte distribution. Overall, 22,558 patients were followed.	<ul style="list-style-type: none"> Of the 22,558 patients followed, 6,113 (27%) had incident OIs. Among patients with CD4+ T-lymphocyte counts < 500 cells/μL, prescription of triple combination therapy increased from zero in 1992 to 40% in 1997. Among patients with CD4+ T-lymphocyte counts < 200 cells/μL, prescriptions to prevent PCP remained relatively stable over the study period (75% - 80%). Among patients with CD4+ T-lymphocyte counts < 50 cells/μL, prescriptions for MAC prophylaxis increased from 9% in 1992 to 44% in 1997.

Reference	Study Objectives	Methods	Findings
Sackoff, J., McFarland, J., Su, S., et al. (1998). Prophylaxis for opportunistic infections among HIV-infected patients receiving medical care. <u>Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology</u> , 19(4), 387-392.	To evaluate implementation of U.S. Public Health Service (USPHS) guidelines for primary prevention of PCP, MAC, and toxoplasmosis and to determine whether prescriptions vary by demographic and clinical factors, HIV exposure mode, and by clinic	Evaluated implementation of USPHS prophylaxis guidelines among patients at four hospital-based HIV clinics in New York City who initially met the CD4 criteria for prophylaxis between January 1995 and April 1997. Medical records were reviewed at six-month intervals to identify the drugs prescribed. Study samples included 149 patients (PCP), 130 patients (MAC), and 138 patients (toxoplasmosis)	<ul style="list-style-type: none"> • The proportion of eligible patients receiving PCP prophylaxis increased from 88% to 100% over the study period. • The proportion of eligible patients receiving MAC prophylaxis increased from 22% to 62%. • Toxoplasmosis prophylaxis was prescribed in 73% of intervals and did not differ significantly by antibody status. • Prescribing patterns were uniform across gender, HIV exposure mode, and age for PCP and MAC prophylaxis but differed by clinic and race for MAC prophylaxis (black patients less likely to receive).
Turner, B. J., Markson, L., Cocroft, J., et al. (1998). Clinic HIV-focused features and prevention of <i>Pneumocystis Carinii</i> pneumonia. <u>Journal of General Internal Medicine</u> , 13(1), 16-23.	To examine associations between clinics' experience with HIV care and clinic HIV-focused features and two outcomes: (1) delivery of PCP prophylaxis and (2) development of PCP as the initial AIDS diagnosis	Obtained clinical and health care data on Medicaid enrollees whose first AIDS-related diagnosis occurred between 1990 and 1992 from a New York State Medicaid database. Conducted telephone interviews (December 1993 - April 1994) with medical directors of clinics identified as the "usual source of care" for one or more Medicaid enrollees. The final study cohort included 1,876 patients treated by 125 clinics.	<ul style="list-style-type: none"> • 44% of clinically-eligible patients received PCP prophylaxis in the six months before AIDS diagnosis. • The adjusted odds of receiving PCP prophylaxis increased with the number of HIV-focused clinic features. Features showing significant associations: (1) case management, (2) aerosolized pentamidine available on-site, and (3) multidisciplinary conferences on HIV care. • 38% of patients had PCP as the initial AIDS-defining diagnosis. No clinic features were significantly associated with patient risk of developing PCP.

Reference	Study Objectives	Methods	Findings
<p>DeRiemer, K., Daley, C.L., & Reingold, A.L. (1999). Preventing tuberculosis among HIV-infected persons: A survey of physicians' knowledge and practices. <u>Preventive Medicine</u>, 28(4), 437-444.</p>	<p>(1) To assess physicians' knowledge and practices for preventing tuberculosis among HIV-positive individuals. (2) To compare physicians' practices with the practices recommended by the American Thoracic Society and the U.S. Public Health Service/Infectious Diseases Society of America. (3) To identify the characteristics of physicians who should be targeted for further information, medical education, and training on TB-related care.</p>	<p>Mailed questionnaires to a random sample of physicians in San Francisco, Alameda, and Contra Costa Counties (CA) during late 1995 and early 1996. Of the 1,300 internists, family practitioners, infectious disease specialists, and pulmonary medicine specialists surveyed, 630 (53%) responded.</p>	<ul style="list-style-type: none"> • 65% said they routinely provide information to HIV-positive patients about the risks of exposure to Mycobacterium tuberculosis. • 39% said they provide annual tuberculin skin testing (TST) to HIV-positive patients without a history of a positive test. • 47% provide a 12-month regimen of chemoprophylaxis for HIV-positive persons who have a positive TST but not active tuberculosis. • Physician experience treating HIV-positive patients (as measured by the cumulative number of patients seen in past two years) was a better predictor of correct knowledge and practices than physician specialty.
<p>Chong, C., & Husson, R.N. (1998). Lack of acceptance of guidelines for prevention of disseminated <i>Mycobacterium avium</i> complex infection in infants and children infected with human immunodeficiency virus. <u>The Pediatric Infectious Disease Journal</u>, 17(12), 1131-1135.</p>	<p>To determine the extent to which the U.S. Public Health Service/Infectious Diseases Society of America (USPHS/IDSA) guidelines for prophylaxis against disseminated Mycobacterium avium complex (DMAC) infection are being followed and current practices for preventing and managing DMAC infection in HIV-positive children</p>	<p>Mailed questionnaires in February 1998 to all sites participating in HIV clinical research through the National Institutes of Health-sponsored Pediatric AIDS Clinical Trials Group. Forty-one of 65 centers (63%) responded.</p>	<ul style="list-style-type: none"> • Most respondents said they would follow USPHS/ISDA guidelines for children ≥ 2 years old. Very low percentages said they would consistently follow these guidelines for the < 1 year old and 1-2 year old age groups (34% and 39% respectively). • Reasons for lack of adherence: (1) youngest age groups perceived to be at low risk for DMAC and (2) concern that compliance would be poor because children with AIDS already are taking multiple drugs • Researchers concluded that clinicians will not accept expert guidelines that are inconsistent with their personal experiences.

Reference	Study Objectives	Methods	Findings
Brogart, C.L., Mitchell, T.F., Coleman, R.L., et al. (1999). Clinical experience and choice of drug therapy for human immunodeficiency virus disease. <u>Clinical Infectious Diseases</u> , 28(1), 14-22.	To examine differences in choice of drug therapy between providers experienced in the management of HIV disease and those with less experience	Mailed questionnaires in May 1996 to 1,166 physicians affiliated with AIDS community-based clinical trials networks funded by the National Institute of Allergy and Infectious Diseases or the American Foundation for AIDS Research. Of the 524 returned questionnaires, 343 were evaluable. Most respondents were infectious disease specialists, internists, or family practitioners.	<ul style="list-style-type: none"> • Found a statistically significant association between the number of HIV-positive patients cared for and the likelihood of prescribing HAART • There were no differences among physicians regarding prophylaxis for PCP. • Physicians with > 50 HIV-positive patients were more likely than physicians with 6-20 HIV-positive patients to report use of multi-drug combinations for treatment of opportunistic infections.
Willard, C.L., Liljestrand, P., Goldschmidt, R.H., et al. (1999). Is experience with human immunodeficiency virus disease related to clinical practice? <u>Archives of Family Medicine</u> , 8(6), 502-509.	To investigate the depth of HIV experience in a sample of rural primary care physicians and to determine whether experience is associated with use of newer management strategies, confidence in care, and consultation needs	Conducted a telephone survey of a random sample of general internists, general practitioners, and family physicians practicing in nonmetropolitan counties of California. Interviews were conducted with 102 physicians between November 1996 and February 1997.	<ul style="list-style-type: none"> • Most physicians were low-volume providers of HIV care. (Only 35% had treated a patient with HIV in the previous six months.) • Physicians with more HIV experience (as measured by number of HIV-positive patients treated) were more likely to report use of PIs and viral load tests and familiarity with vertical transmission prophylaxis. • Physicians with more HIV experience expressed greater confidence about HIV care and less need for consultation.

Reference	Study Objectives	Methods	Findings
Fairfield, K.M., Libman, H., Davis, R.B., et al., (1999). Delays in protease inhibitor use in clinical practice. <u>Journal of General Internal Medicine</u> , 14(7), 395-401.	To examine the factors associated with delays in protease inhibitor use for patients with elevated viral loads	Conducted medical chart reviews for all patients with HIV treated at a general internal medicine practice at Beth Israel Deaconess Medical Center (Boston, MA) between July 1, 1995 and June 30, 1997. Analyses are based on 190 patients with a viral load > 10,000 copies/ml. Socioeconomic data on a subset of 129 patients were gathered through telephone interviews. Main outcome measure - time to first PI prescription after first elevated viral load.	<ul style="list-style-type: none"> • In multivariate models adjusted for secular trends in PI use, the following factors were significantly associated with delay in PI initiation: higher CD4 cell count, higher viral load, history of pneumocystis pneumonia, history of depression, and history of injection drug use. • Socioeconomic factors, including race, educational attainment, work status, insurance type, and income, were not significantly related to delayed PI initiation.

Reference	Study Objectives	Methods	Findings
Studies of HIV Service Outcomes			
McLaughlin, T.J., Soumerai, S.B., Weinrib, D., et al. (1999). The association between primary source of ambulatory care and access to and outcomes of treatment among AIDS patients. <u>International Journal for Quality in Health Care</u> , 11(4), 293-300.	(1) To examine the association between AIDS patients' primary source of ambulatory care and access to ZDV antiretroviral treatment and PCP prophylaxis. (2) To estimate the effects of delays in antiretroviral treatment and PCP prophylaxis on rehospitalization and death rates.	Used a linked Medicaid-AIDS surveillance database to examine access to and outcomes of treatment among New Jersey adults (> 12 years) diagnosed with AIDS between January 1989 and March 1991. The study sample included 366 patients who had at least one year of continuous Medicaid enrollment before AIDS diagnosis, survived at least two weeks following AIDS diagnosis, and who had received no antiretroviral agents or PCP prophylaxis in the year prior to the AIDS-defining illness.	<ul style="list-style-type: none"> • 49% of the AIDS patients had no primary source of ambulatory care (PSAC). • Patients with a PSAC were more likely to have received ZDV and PCP prophylaxis. • Increased age, female gender, nonwhite race, and history of injection drug use were associated with a reduced likelihood of receiving ZDV and PCP prophylaxis, although these differences were not always significant. • Lack of a PSAC predicted shorter survival but not increased risk of hospitalization.
Palella, F.J., Delaney, K.M., Moorman, A.C., et al. (1998). Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. <u>The New England Journal of Medicine</u> , 338(13), 853-860.	To evaluate the impact of combination antiretroviral therapy on morbidity and mortality among HIV-positive patients with advanced immune depletion	Conducted medical record reviews on patients seen between January 1994 and June 1997 at nine HIV clinics in eight U.S. cities. All of these clinics participate in the ongoing HIV Outpatient Study. The researchers limited the study sample to 1,255 HIV-positive patients with at least one CD4+ T-lymphocyte count < 100 cells/ μ L since they wanted to evaluate morbidity and mortality among patients at greatest risk for illness or death.	<ul style="list-style-type: none"> • Between 1995 and the 2nd quarter of 1997, mortality rates declined from 29.4 per 100 person-years to 8.8 per 100 person-years. Reductions occurred regardless of gender, race, age, or HIV exposure mode. • Privately insured patients were more likely to receive PI-based combination therapy than patients with other payor types. By the 2nd quarter of 1997, the vast majority of patients in all payor groups were receiving PIs. • In a preliminary failure-rate model, mortality differed significantly according to payor type. When type of antiretroviral therapy was added to this model, the effect of payor type was no longer significant. • Patients with a history of injection drug use were less likely than other patients to receive PIs, but IDU was not significantly associated with morbidity or mortality.

Reference	Study Objectives	Methods	Findings
Whitman, S., Murphy, J., Cohen, M., et al. (2000). Marked declines in human immunodeficiency virus-related mortality in Chicago in women, African Americans, Hispanics, young adults, and injection drug users, from 1995 through 1997. <u>Archives of Internal Medicine</u> , 160(3), 365-369.	To examine Chicago's HIV-related mortality trends through 1997, with specific attention focused on women, people of color, adolescents and young adults, and injection drug users	Abstracted data from State mortality files on Chicago residents whose deaths were attributed to HIV between 1980 and 1997. To classify HIV-related deaths by mode of exposure, the researchers matched the mortality files with the HIV/AIDS Reporting System database. Numbers, proportions, and rates of declines in HIV-related deaths were analyzed for the city as a whole and for patients who received their AIDS diagnosis at Cook County Hospital (as a proxy for marginalized populations).	<ul style="list-style-type: none"> Between 1995 and 1996, the number of HIV-related deaths in Chicago decreased by 19%, but marginalized populations experienced small or no declines. Between 1995 and 1997, HIV-related mortality declined by 61%. Although percentage declines were greatest for men, whites, and MSM, declines also were observed for women (35%), Hispanics (61%), blacks (52%), IDUs (47%), and adolescents/young adults (63%). Among Cook County Hospital (CCH) patients, the percentage decline in HIV-related mortality was smaller than at other Chicago facilities (49% vs. 64%) Percentage declines for women, people of color, and injection drug users treated at CCH were not significantly different than at other Chicago facilities.
Wilson, I.B., Sullivan, L.M., & Weissman, J.S. (1998). Cost and outcomes of AIDS care: Comparing a health maintenance organization with fee-for-service systems in the Boston Health Study. <u>Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology</u> , 17(5), 424-432.	To compare four-month costs of care, physical functioning, and satisfaction between a health maintenance organization (HMO) and fee-for-service (FFS) systems, adjusting for patient sociodemographic and clinical characteristics and functional status at baseline	Compared the costs of AIDS care, health outcomes, and patient satisfaction at a staff model HMO and two hospital-based FFS systems in Boston. All AIDS patients receiving care at these sites between February 1990 and March 1991 were eligible to participate. Interviews were conducted with patients at study entry and four months later. Medical bills and medical records were reviewed for the four-month follow-up period. Study sample - 255 patients for whom both baseline data and four-month interview data were available.	<ul style="list-style-type: none"> After adjusting for sociodemographic characteristics, baseline functioning, HIV exposure mode, and clinical variables, total four-month costs at the staff model HMO were significantly lower than those in FFS settings (\$4,799 vs. \$8,540). Outpatient costs also were significantly lower (\$1,131 vs. \$1,614). The largest component of HMO cost savings came from reduced spending on inpatient care, but the HMO also spent less on outpatient and home care. Neither adjusted physical functioning scores nor adjusted satisfaction scores differed significantly between HMO and FFS patients.



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