Directions in HIV Service Delivery & Care

A POLICY BRIEF

Number 4

Reducing Barriers to Care

Health Resources and Services Administration
HIV/AIDS Bureau
Office of Policy and Program Development
www.hrsa.gov/hab

Directions in HIV Service Delivery & Care

A POLICY BRIEF

Number 4

Reducing Barriers to Care

Health Resources and Services Administration
HIV/AIDS Bureau
Office of Policy and Program Development
www.hrsa.gov/hab

Directions in HIV Service Delivery & Care

A POLICY BRIEF

Number 4

Reducing Barriers to Care

Caitlin Ryan, MSW, ACSW
Editor

Health Resources and Services Administration
HIV/AIDS Bureau
Office of Policy and Program Development

Introduction

When the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was initially authorized in 1990, lack of public infrastructure and capacity to provide services for affected persons, particularly low-income and uninsured/underinsured people with HIV/AIDS, posed profound challenges to communities throughout the country. Since that time, the CARE Act has established a critically needed planning process and infrastructure to develop and sustain essential health and social services for persons living with HIV/AIDS. These services have improved the lives of thousands of poor, uninsured/underinsured men, women, children, youth and families throughout the United States. And their effectiveness has been borne out by the reduction in HIV morbidity and mortality among the most impoverished communities.

Although substantial gains have been made, challenges remain in meeting the care and support needs of historically underserved populations, including minorities, women, families, substance users and people with mental illness. And these continuing disparities represent new challenges for the CARE Act in its second decade.

Guiding Principles

As the CARE Act entered a second reauthorization cycle last year, HRSA's HIV/AIDS Bureau (HAB) conducted a comprehensive assessment of disparities in access to services and care. This assessment was based on the policy framework established by HAB Associate Administrator, Dr. Joseph O'Neill, who identified four principles to guide the Bureau's mission. These include: 1) changes in demographics; 2) access to emerging therapies; 3) changes in health care financing; and 4) program accountability.

During a year-long review of the role and structure of CARE Act services, HAB explored various changes, issues and needs affecting HIV service delivery, using these principles as a lens by which to identify and assess current and future challenges in caring for uninsured and underinsured people with HIV/AIDS. HAB examined these issues in light of the following questions:

- How can HRSA strengthen CARE Act-funded programs to ensure that all persons with HIV/AIDS, regardless of race, co-morbidity, geographic location or income, have access to needed health and support services?

- How can HRSA ensure that CARE Act services meet current standards of quality HIV care?

- How can HRSA and CARE Act grantees help providers maintain fiscal and administrative viability within rapidly evolving health delivery and social welfare systems, while creating opportunities for new providers to care for affected and underserved populations?

- How can HRSA improve its ability and that of CARE Act grantees to monitor and evaluate services, becoming more accountable to Congress, State agencies and, most importantly, people with HIV/AIDS who depend on these services for their survival?

Program Review Activities and Policy Studies

Under the guidance of Dr. John Palenicek, Director of the Bureau's Office of Policy and Program Development (OPPD), staff engaged in extensive consultation with constituents, community members and people living with HIV/AIDS. This includes collaborating with HRSA's AIDS Advisory Committee to sponsor a series of public hearings to solicit broad feedback in preparation for reauthorization. During the past year, OPPD staff undertook a comprehensive evaluation of current program activities to understand the dynamic of HIV care within an evolving system of health care finance and delivery. And they initiated a series of targeted policy studies to more fully understand the factors that affect access to care and ability to remain in care for poor, low-income and traditionally underserved populations.

Topics selected for these studies include the following:

- The experience of vulnerable populations (e.g., minority women, children, and substance users) in accessing needed services and care;
- The changing nature of health care delivery and finance systems for HIV services and their relationship with CARE Act-funded programs; and
- The role and structure of Title I, II, III and IV programs within communities.

The goal of these studies is to expand on current knowledge and to generate findings that can inform future policy directions or suggest administrative or legislative changes for the reauthorized CARE Act. Results of these studies will be presented in a series of policy briefs—*Directions in HIV Service Delivery & Care*—to help grantees and CARE Act providers render more effective services to people with HIV/AIDS. Findings and recommendations will also help inform HRSA's administrative procedures, technical assistance and training activities, improve service delivery, and enhance inter-governmental relationships between Federal agencies and among Federal, State and local jurisdictions.

These studies are especially relevant for CARE Act providers because they focus on populations and issues that—although difficult to address—offer the greatest potential for significantly improving outcomes for the Nation's most underserved populations. HRSA grantees are encouraged to read these reports and to incorporate findings and recommendations into their ongoing planning and program activities. HRSA welcomes feedback from readers on the usefulness of these monographs for their work. Send comments to: jgrantling@hrsa.gov.

Abstracts

Use of CARE Act Funds to Purchase Health Insurance for People with HIV/AIDS

Daniel Schreiner, M.H.S.

PURPOSE: To educate CARE Act grantees and other providers on use of Title II funds to purchase health insurance for low-income PLWH. **METHODOLOGY:** The analyst reviewed insurance coverage materials and conducted interviews with public officials from selected States between February and June 2000. **FINDINGS:** As new treatment options have become available, health insurance continuation has become more cost effective for providing treatment and care. HRSA has developed three policies on use of CARE Act funds to purchase health insurance coverage for PLWH. States have four mechanisms to purchase health insurance policies for PLWH: 1) leveraging benefits under COBRA; 2) utilizing a State-run high-risk health insurance pool; 3) accessing new options in some States to assure affordable insurance in the individual market (through Individual Market Reform); and 4) accessing coverage under the Health Insurance Portability and Accountability Act. **RECOMMENDATIONS:** The author provides recommendations for assessing use of CARE Act funds to purchase health insurance for PLWH.

The Role of Legal Services in Ensuring Access to Care for People with HIV/AIDS

John-Manuel Andriote, R. Bradley Sears, J.D.

PURPOSE: To assess the role of legal services in helping people with HIV/AIDS to access health and related services. **METHODOLOGY:** Researchers interviewed legal service providers from 25 HIV-related legal service organizations located throughout the United States, and reviewed available literature and existing needs assessments during the Fall of 1999. **FINDINGS:** Legal services help PLWH to access care, use entitlement programs, and meet subsistence needs by overcoming immediate barriers to underserved populations, including families, foreign-born, and incarcerated persons. Legal services are a core component in the network of HIV/AIDS-related services. Most HIV-related legal service programs have relatively small budgets and few providers have conducted needs assessments for PLWH. **RECOMMENDATIONS:** The authors provide suggestions for expanding access to and capacity of HIV-related legal service programs.

Release Planning Needs for Federal Inmates with HIV/AIDS in Community Placement Facilities

Earl C. Huch, M.A.

PURPOSE: To assess policies, procedures, and barriers to care for releasing inmates with HIV/AIDS in community settings. **METHODOLOGY:** Site visits and interviews, together with a review of policies and procedures, were conducted in halfway houses and correctional facilities in two States and six cities during the Fall of 1999. **FINDINGS:** All inmates need more and better services to transition into community settings and avoid returning to high risk behavior. Corrections and halfway house staff face a range of obstacles in release planning for inmates with HIV/AIDS. Case managers' lack of access to inmates' HIV status poses a barrier to care. Medical management in halfway houses is inconsistent, and halfway house staff are unclear about official policy regarding client confidentiality. **RECOMMENDATIONS:** The author provides suggestions for enhancing pre-release planning and for improving care of inmates with HIV/AIDS in community settings.

Use of CARE Act Funds to Purchase Health Insurance for People with HIV/AIDS

Daniel Schreiner

Purpose:

To educate CARE Act grantees and other providers on use of Title II funds to purchase health insurance for low-income PLWH.

Background

Health insurance continuation has been an option to ensure appropriate care for people with AIDS under Title II of the Ryan White CARE Act since the law was first enacted in 1990. As new treatment options have become available, this provision has become more cost effective for providing treatment and care. Although providers and some grantees may be unaware of this funding option, the Health Resources and Services Administration (HRSA) has issued policies on use of CARE Act funds to purchase health insurance coverage for people living with HIV (PLWH). The purpose of this paper is to educate providers and grantees on this key funding option.

Since 1997, the HIV/AIDS Bureau (HAB) has issued three policies on funding health insurance premiums for low-income PLWH. These include: 1) *HAB Policy Notice 97-01*, enabling Title I and II grantees to pay family health insurance premiums to ensure health insurance continuation for a family member with HIV; 2) *HAB Policy Notice 97-02*, allowing Title I and II grantees to pay for public or private health insurance co-payments and deductibles for PLWH; and 3) *HAB Policy Notice 99-01*, allowing Title II ADAP grantees to purchase health insurance services that include comprehensive primary care and the full range of HIV treatments.

Table 1

HRSA Policies Funding Health Insurance for PLWH

- **HAB Policy Notice 99–01**
  Allows Title II ADAP grantees to purchase health insurance services that include the full range of HIV treatment and primary care services.
- **HAB Policy Notice 97–01**
  Allows payment of premiums for a family health insurance policy to provide insurance coverage for a low-income family member.
- **HAB Policy Notice 97–02**
  Allows Title I and II funds to pay for public or private health insurance co-payments and deductibles for low-income PLWH.

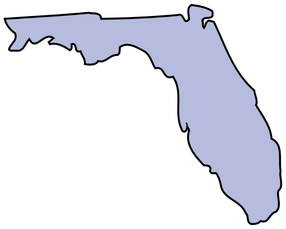
Insurance Funding Options

As grantees evaluate the use of CARE Act funds to purchase health insurance policies for persons with HIV/AIDS, they will need to consider available mechanisms to select the best funding option. These include: 1) leveraging benefits under the Consolidated Omnibus Budget Reconciliation Act of 1986 (COBRA); 2) utilizing a State-run high-risk health insurance pool; 3) accessing new options in some States to assure affordable insurance in the individual market (through Individual Market Reform); and 4) accessing coverage under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) designed to provide health insurance coverage for workers and their families when they change or lose their jobs.

Currently, 28 States report operating high-risk insurance pools. However, not all risk pools allow Federal funds, such as CARE Act dollars, to purchase policies on behalf of clients. Market Reform initiatives have shaped coverage in 42 States and enable many people to access needed health care. These initiatives include: guaranteed individual health policies regardless of previous health history, limits on the exclusion period allowed for pre-existing conditions, and limitations on premium rate increases for conversion policies. In addition, Market Reform can require that premiums are set by community rating systems (the process of determining an individual's premium rate based on the average cost of providing care to enrollees with the same demographics), rather than experience rating systems, which use an individual's previous claims history, the method used by most traditional insurers.

The Health Insurance Portability and Accountability Act includes separate provisions for group and individual markets. The group market offers health insurance coverage to individuals and their dependents through a group plan maintained by an employer, a union, or both, while the individual market offers coverage to individuals who are not connected with a group health plan.

Examples follow of States that currently operate health insurance programs using Title II and/or ADAP funding for clients with HIV/AIDS. Florida operates an Insurance Continuation Program solely through the State's Title II program, administered through a contract with the Health Council of South Florida. Indiana (in the process of selecting a contractor to administer the program) uses both Title II and ADAP funds to purchase policies for clients through the State's high-risk health insurance pool. Maryland uses a combination of Title II and ADAP funds to operate an insurance program (administered within the Department of Health and Mental Hygiene), that continues existing policies and purchases new policies through open enrollment periods.



Florida

Florida's AIDS Insurance Continuation Program (AICP) provides coverage for people with AIDS or HIV-related symptoms ("HIV symptomatic") who are unable to continue paying private health insurance premiums. The Florida Department of Health contracts with the Health Council of South Florida, Inc. to administer the program, through an agreement with 14 community-based organizations (CBOs) that serve as enrollment sites and work with local CBOs to ensure access throughout the State. The $4.6 million program currently serves approximately 1,550 clients, with funding from Title II, the State of Florida General Revenue, and the Florida Tobacco Settlement Trust Fund. AICP provides assistance with insurance premiums, co-payments, deductibles, conversion fees (fees associated with converting from group to individual policies), and policy upgrades to add services, such as prescription benefits. Florida also maintains a high-risk pool (the Florida Comprehensive Health Association), but due to continued financial losses, the Florida legislature closed new enrollments effective June 30, 1991.

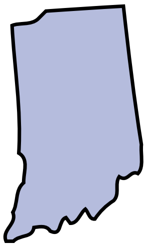
Florida Contact Information

Nicole Montgomery, Program Director
Health Council of South Florida
5757 Blue Lagoon Drive, Suite 170
Miami, FL 33126
305-263-9020, ext. 116

Patrick Daly, Bureau of HIV/AIDS
Florida Department of Health
2585 Merchants Row Blvd., Rm. 345 J
Tallahassee, FL 32399
850-245-4444, ext. 2539

The program makes direct payments (up to $650/month) to each client's employer or insurance company for continuation of medical, dental, and vision coverage. The Florida Department of Health believes that this statewide program has generated substantial savings for their Title II program and other State health programs. An important benefit for participants is to remain in the care of their personal physicians, maintaining established relationships and ensuring uninterrupted access to care. AICP clients generally have greater access to various HIV/AIDS treatments as a result of continued access to private insurance. Providers and hospitals also benefit since private health insurance companies generally offer higher payment rates than public programs.

AICP services (which include co-payment assistance) are accessed through case managers working in partnership with collaborating CBOs. Prior to receiving services—and subject to the availability of funds—clients receive a voucher from their case manager to cover the co-payment. Vouchers are submitted to a service provider, who, in turn, submits it to the local collaborating CBO for payment. Eligibility requirements include: Florida residents with AIDS or HIV-related symptoms, who are currently covered by private health insurance, who have a gross income less than or equal to 300 percent of the Federal Poverty Level, with cash assets less than or equal to $4,500 (for one person), and who are willing to sign all forms and to provide eligibility information.



Indiana

Indiana's Health Insurance Assistance Program (HIAP) provides financial assistance for eligible persons to access Indiana's Comprehensive Health Insurance Assistance Program. The Indiana Department of Health plans to move eligible Title II/ADAP clients into the program, which currently pays the premium and out-of-pocket expenses associated with enrollment in a major medical plan covered by the program. Clients generally remain in ADAP during the pre-existing condition period (approximately 4 months).

In FY 2000, Indiana expanded their Title II HIAP to include clients covered by ADAP. The cost of insurance policies purchased through the State high-risk insurance pool was found to be significantly less expensive, while providing ADAP clients with comprehensive health care. The

Indiana Department of Health recognized that increases in Federal/State funding were not keeping up with increases in the ADAP caseload. With the help and involvement of community groups, the department was able to build on the existing Title II health insurance program and provide the same services to ADAP clients. In November 1999, the health department required new and existing ADAP clients to complete an application for the high-risk health insurance pool, requiring regional training and technical assistance for caseworkers.

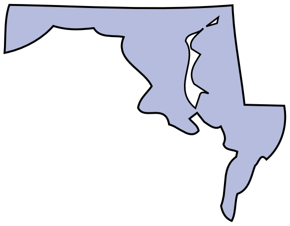
The Indiana Department of Health anticipates using about $1.1 million of FY 2000 ADAP funds, together with FY 1999 carryover dollars, to purchase insurance policies and pay co-payments, deductibles, and premiums for PLWH. Covered services include hospital expenses, skilled nursing facility and home health care, mental health treatment, surgical expenses, prescription drugs, and professional services. Indiana currently estimates the cost of providing care to clients directly from ADAP funding at $11,000 per client, with some clients accessing over $25,000 in services. By comparison, the cost of providing comprehensive health insurance through Indiana's State high-risk health insurance pool is approximately $5,100 per client.

Indiana Contact Information

Pat Reid, Director of HIV Services
Indiana State Department of Health
Suite 6C
2 North Meridian Street
Indianapolis, IN 46204
317- 233-7949

James Carr, Consultant
Indiana State Department of Health
317-251-8327

Maryland



The Maryland AIDS Drug Assistance Program (MADAP) established a health insurance program, MADAP-PLUS in FY 2000 to establish a seamless continuation of care with Maryland's existing insurance continuation program (operated mainly through State funds). MADAP-PLUS is for clients who otherwise qualify for the Maryland AIDS Drug Assistance Program but cannot afford to pay their private health insurance premiums due to illness, high costs, and/or lack of resources. The Maryland Department of Health and Mental Hygiene's AIDS Administration funds the program through a combination of State and Federal funds. The program targets employed individuals who are unable to afford health insurance premiums offered through their employers, as well as unemployed persons with coverage who have resources and assets that prevent them from qualifying for traditional public benefits. The program also assists clients who may be able to return to part-time or full-time employment as a result of successful therapy.

MADAP-PLUS provides for uninterrupted premium payments and uninterrupted access to care. By providing continuous coverage through private insurance, the program also guarantees that clients meet HIPAA requirements, and are not subsequently found to be uninsurable by private sector insurers. MADAP-PLUS ultimately provides savings to the State by allowing private companies to continue to pay for care while the State pays the premium, rather than the full cost of HIV care.

Individual and group plans issued under Maryland law by an authorized insurer, a non-profit health insurance plan, an HMO, or self-insured health benefit plan are normally covered. MADAP-PLUS pays the premiums on plans that, at a minimum, cover standard medical treatment including HIV-related care. The program makes direct payments to each client's employer or insurance company to purchase medical, dental, drug, and optical coverage. The program pays premiums of one or more policies up to $800 per month. If the plan does not provide comprehensive drug coverage equal to the MADAP formulary, a client may co-enroll in MADAP for drug coverage.

Maryland Contact Information

Coy Stout
Center for HIV Services
Department of Health and Mental
Hygiene, 5th Floor
500 North Calvert Street
Baltimore, MD 21202
410-767-5685

Eligibility is based on HIV status and income limits set by MADAP, for a 6-month period, with re-evaluation and continuing enrollment at the end of the period. The program will pay premiums regardless of whether a person is employed, as long as they are otherwise qualified. Ability to return to work is not a condition of eligibility.

Insurance Assessment Terms

The following terms are helpful in evaluating a State's health insurance market. Many of these provisions may vary by State law.

Conversion policy—refers to a group policy that can be converted to an individual policy, usually at a premium rate higher than the group premium rate.

Guaranteed issue—requires an insurance company to offer policies to an individual regardless of health status, such as HIV/AIDS, or claims experience. In the early 1990s, 11 States passed guaranteed issue laws in the individual market.

Guaranteed renewal—requires that insurance companies allow persons to renew their coverage from year to year regardless of health status, such as HIV/AIDS, or claims experience of the insured as long as the plan continues to be offered in that market.

Waiting period—generally refers to the length of time an employer may require employees to work before they become eligible for health insurance coverage. The waiting period must be applied consistently for all employees or members of a group. For CARE Act clients, the waiting period often refers to the period of time an insurance company will require clients to wait to receive covered services after purchasing a policy.

Pre-existing conditions—any condition, either physical or mental, such as HIV/AIDS for which medical advice, diagnosis, care, or treatment was recommended or received during the look-back period.

Look-back period—the maximum number of months an insurance company can go back into a person's medical history to determine if a condition such as HIV/AIDS has already been diagnosed. Look-back periods can range from 6 months to 2 years depending on the State, but are generally kept to 6 months.

continued on page 11 sidebar

Recommendations for Evaluating Health Insurance Options for PLWH

The following recommendations are provided for Title II programs to consider in determining use of CARE Act funds to purchase health insurance for persons with HIV/AIDS:

I. Determine the health insurance options available to CARE Act clients within the State.

Under COBRA, group health plans (usually sponsored through an employer, schools, unions, and other professional organizations) can be continued for up to 18 months after separation, and up to 29 months in some cases, as a disability benefit (at 102 percent of the group-rate premium). Once COBRA benefits are exhausted, the Title II program can explore the cost of a conversion policy, with an increase in the premium rate being an important consideration in deciding on a conversion policy. For example, a group policy with a premium rate of $200 per month could convert to an individual policy with a premium rate of $600 per month. In the long run, however, the higher premium rate may still prove cost effective to the Title II program and is worth exploring.

Title II programs may want to consider purchasing supplemental plans—generally purchased in the open market—which are usually available for Medicare eligible clients. Programs should determine if the State offers a high-risk health insurance pool for individuals who are uninsurable or hard-to-insure. Insurance pools often provide greater access to comprehensive, primary care services for persons with long-term illnesses, such as HIV/AIDS, who are unable to purchase individual insurance. Some States, however, may not permit State or Federal funds (e.g., CARE Act) to purchase policies for clients, so Title II/ADAP may not have access to these programs.

Title II programs should find out if the State has made legislative changes to insurance options (such as regulating premiums or requiring that policies be issued during open enrollment periods), making it cost effective to purchase health insurance policies for CARE Act clients.

II. Assess the overall budgetary impact of moving CARE Act clients into a health insurance program.

Using Title II funds for health insurance continuation can offer an important mechanism for providing uninterrupted access to comprehensive primary health care.

Title II programs that use ADAP funds to purchase health insurance policies must ensure that the policy's pharmaceutical coverage is equal to or greater than the existing State drug formulary. They must also ensure that the aggregate cost of providing services does not exceed the total cost for all clients. Programs should also assess whether other funding sources (e.g., Title I funds) can be leveraged to support the health insurance program.

III. Establish health insurance program philosophies and priorities.

Insurance programs should have a clear, overall plan and implementation strategy to ensure long-term fiscal stability. Premium payments should be made on time to provide uninterrupted access to primary care services and drug therapy. In addition, administrators should ensure that the program is accessible and available to all CARE Act clients.

IV. Consider the program's design elements.

There are several design elements that Title II/ADAP programs should consider in developing insurance purchasing programs for PLWH. These include the following:

☐ ***Scope + Coverage***
- ✔ Define the program's scope of coverage. For example, will it pay for deductibles and co-payments in addition to monthly premiums?
- ✔ Determine the best vehicles to adopt, such as a State-run high-risk health insurance pool, an insurance continuation program leveraging COBRA benefits, or individual policies purchased through the open market.
- ✔ Evaluate conversion policies and explore supplemental policies, such as the availability of Medicare supplemental policies to expand existing coverage to ensure a wider range of primary care services.

☐ ***Enrollment + Information Management***
- ✔ Modify the Title II/ADAP enrollment form to include a health insurance component.
- ✔ Expand the Title II/ADAP data system to track information on both insurance and drug purchases and to respond to rapid changes in an individual's health insurance status, including the disbursement of checks and the management of deductibles and stop-loss payments.

☐ ***Client Education***
- ✔ Educate clients about new health insurance options. Inform and train case managers about enrollment options. And reallocate resources based on potential savings or demand created by implementing a health insurance program.

☐ ***Treatment Options***
- ✔ Verify that the drug purchasing and dispensing system can interact with health insurance payers. Ideally, the dispensing pharmacy should be able to split-bill for each prescription (i.e., bill 80 percent of the drug cost to an insurance program and the remaining 20 percent to Title II/ADAP).
- ✔ Create a system for providing assistance to clients who pay for prescriptions up-front and then submit paperwork to the program to request payment from the insurer (pay-and-chase).

☐ ***HRSA Notification***
- ✔ If Title II programs decide to use ADAP funds to purchase health insurance, they must submit a Notification of Intent to HRSA that addresses: the methodology that will be used, an assurance that the pharmaceutical component of the insurance policy includes a formulary equivalent to the ADAP formulary, and assurance that the cost of providing coverage to clients through the insurance program is cost neutral in the aggregate. (See HAB Policy Notice 99-01.)

Insurance Assessment Terms

continued from page 10 sidebar

Pre-existing condition exclusion period—the time during which coverage for the pre-existing condition is denied after a policy takes effect. This is typically up to 12 months. A State program may make premium payments in addition to paying for services directly from Title II and/or ADAP funds during this period.

Rating restrictions—the restrictions a State places on the premium insurance companies can charge in the individual market. Ratings are either based on *community rating* or *experience rating.* Community rating refers to premium rates that are set for the community as a whole. Rates cannot be set based on an individual's claim experience (experience rating), health status, or duration of coverage.

V. Build relationships with individuals who are integral to the success of the CARE Act-sponsored health insurance program.

Several key partners are integral to the success of any insurance program. They include individuals such as the administrators of a State-run high-risk health insurance pool, HIV/AIDS consumer groups and advocates, State insurance regulators, customer service and/or sales representatives of major insurance carriers in the State, clinical or medical providers, HIV case managers, county personnel, and other service providers.

All Title II programs should consider developing insurance coverage initiatives for PLWH. They are cost-effective, efficient and are often the best option to ensure access to care. The HIV/AIDS Bureau has undertaken additional activities to assess the effect of health insurance coverage programs on CARE Act clients and to educate grantees on the availability of these programs. HAB's Office of

HRSA Contact Information

Daniel Schreiner
HRSA, HIV/AIDS Bureau
5600 Fishers Lane, Room 7A-55
Rockville, MD 20857
Dschreiner@hrsa.gov
301-443-6396

Science and Epidemiology has funded a study to determine the impact of using ADAP funds to purchase health insurance coverage, and a primer to provide more extensive information on developing these programs will be available for grantees by the end of the year. Title II programs seeking guidance on developing insurance purchasing programs for PLWH are encouraged to contact HAB staff and States with existing programs for additional information.

The Role of Legal Services in Ensuring Access to Care for People with HIV/AIDS

John-Manuel Andriote, R. Bradley Sears

Purpose:

To assess the role of legal services in helping people with HIV/AIDS access health and related services.

Background

Recent treatment advances in HIV/AIDS have resulted in a substantial decrease in AIDS morbidity and mortality between 1996 and 1998. Also during this period, the legal needs of increasingly affected, poor, and socially marginalized populations have changed. Many of these individuals have histories of substance abuse, low income, poor housing, and limited access to health care and support services. Their legal needs are typical of those seen in poverty law practices—including advocacy for public entitlement programs such as welfare, SSI, and Medicaid; landlord/tenant law; family law; and consumer law, particularly for debt relief. Many need help with estate planning and permanency planning for care of young children.[1] In particular, women with AIDS are likely to be poor and either under- or uninsured. They have difficulty accessing legal services because of lack of childcare, and many are diagnosed at later stages of disease than men. Their legal needs often include wills, medical power of attorney, and guardianship for their children.[2,3] With an estimated 80,000 AIDS orphans in the United States from mothers who have died from AIDS, addressing the legal, social, and cultural issues related to the care and custody of children becomes an essential component of care.[4]

Results from the *HIV Cost and Services Utilization Study* (HCSUS) show that although access to HIV-related care improved overall between early 1996 and early 1997, disenfranchised populations—including Africans Americans, Latinos, women, the uninsured, and Medicaid-insured persons—all had poorer access to care.[5] In addition, more than one-third of people living with HIV (PLWH) studied went without or postponed medical care because they needed to pay for food, clothing, or housing, lacked transportation, could not leave work, or were too sick.[6] Because researchers found that competing subsistence needs and barriers frequently meant not receiving antiretroviral therapy, they concluded that PLWH require interventions aimed at alleviating their subsistence needs in addition to medical services. Most likely to be affected were non-whites, younger persons, women, injection drug users, persons with lower income or education, and the uninsured.

As people with HIV are living longer, healthier lives, more of them are returning to work. However, this positive development also requires employers to make "reasonable accommodations" for them as persons with disabilities (including HIV/AIDS), which may raise a number of potential legal issues related to the Americans with Disabilities Act (ADA).[7]

Between 1991 and 1994, four demonstration projects funded by the Special Projects of National Significance (SPNS) Program established models for providing statewide HIV-related legal services. Programs helped clients who encountered discriminatory practices requiring the assistance of legal service providers. A program assessment recommended that planning bodies should strongly consider how legal protection and advocacy services can support the mission of the CARE Act to provide a comprehensive continuum of care.[8]

Whether involving the assertion of a legal right, providing assistance in obtaining benefits, or helping with legal planning, the need for legal advocacy has been evident throughout the AIDS epidemic. These essential services improve access to health care, housing, and support services through education, empowerment, and enforcement of legal rights.

Organizational Structures of HIV-Related Legal Service Programs*

◆ Department in a general legal services organization	28%
◆ Department in an AIDS service organization	24%
◆ Clinical program at a law school	20%
◆ Protection and advocacy program	16%
◆ Impact litigation organization	16%
◆ Independent non-profit	12%
◆ State or local bar lawyer referral panel	12%
◆ Law and policy organization	12%
◆ Public/government entity	4%

**Total exceeds 100% since some respondents are represented in more than one category*

Types of Legal Services Provided in HIV-Related Legal Service Organizations

- Health care-related
- Housing landlord/tenant
- Discrimination
- Public benefits
- Employment
- Private insurance
- Confidentiality
- Testamentary documents
- Permanency planning
- Debtor/creditor & bankruptcy
- Family law
- HIV testing
- Immigration
- Tax
- Incarceration-related issues
- Criminal justice-related issues
- Other (e.g., domestic violence, mental health, and special education)

Specific Services Provided

- Brief advice and counseling
- Limited direct representation
- Referrals to other providers/programs
- Referrals to pro bono attorneys
- Client education
- Provider education
- Legislative and policy advocacy
- Litigation
- Impact litigation
- Administrative hearings/proceedings
- Preventive legal education
- Web site

Methodology

Investigators convened a panel of advisors with expertise in HIV-related legal services and advocacy in September 1999 to provide consultation and information on their organizations' experiences providing services and to help identify available resources. Researchers reviewed relevant literature, including needs assessments conducted by AIDS service providers that assessed legal service needs of clients with HIV/AIDS. Through discussions with staff attorneys and the project's advisory panel, researchers developed a list of questions for written consultation with HIV-related legal service providers. These include the following:

- What constitutes the legal service needs of PLWH, and to what extent are they addressed for diverse populations affected by the epidemic?
- In what ways do legal services help PLWH access and maintain health care?
- What types of organizations provide HIV-related legal services, and what are their characteristics (e.g., budget, staff size and composition)?
- What kinds of legal services do they provide to persons with HIV/AIDS?
- What kinds of support and resources do organizations need to provide HIV-related legal services and how can the CARE Act support them?

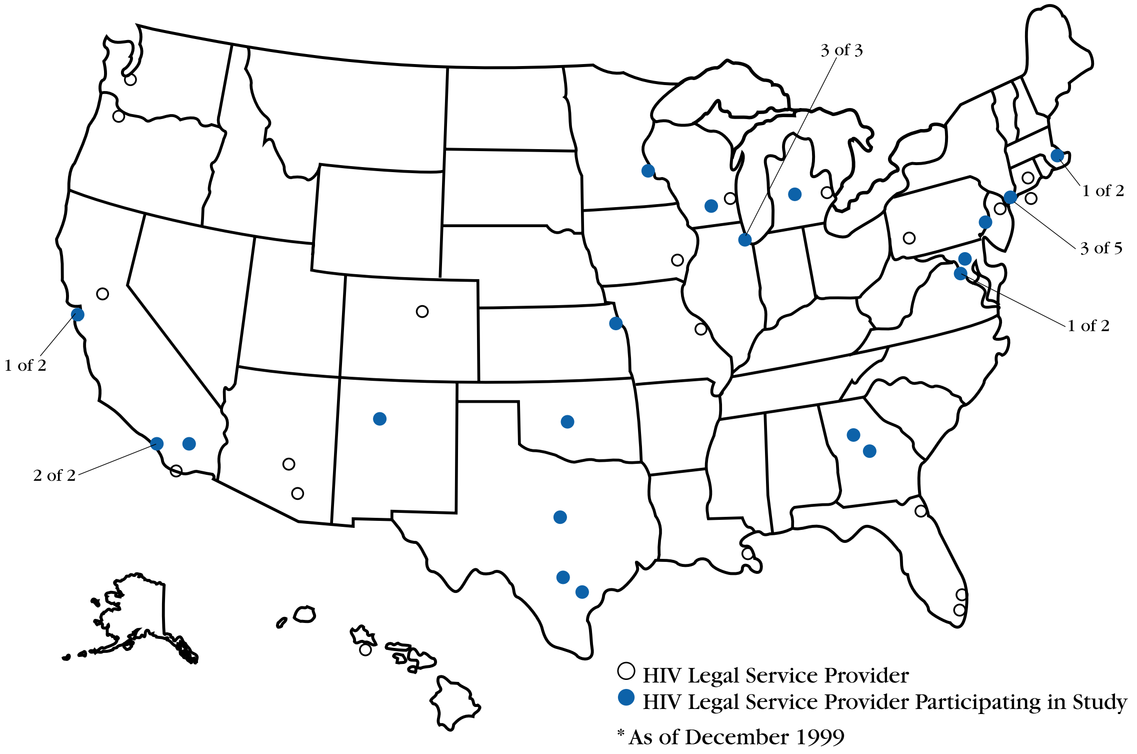
In addition, researchers included questions about legal service providers' funding sources, access to the Internet, use of volunteer legal help, evaluation procedures, use of needs assessments to assess clients' needs, client eligibility requirements, characteristics and utilization patterns, and information on case summaries.

Researchers contacted all organizations listed in the American Bar Association's (ABA) *Directory of Resources for People with AIDS & HIV* to identify organizations with at least one full time staff attorney providing HIV-related legal services and to check their contact information. Using this resource, they identified 44 organizations located throughout the country that met this criteria (see figure 1). They also contacted seven protection and advocacy organizations known to focus on HIV/AIDS issues and/or located in States with a high prevalence of HIV infection that were recommended by the National Association of Protection & Advocacy Systems. This provided a sample of 52 HIV-related legal service providers who received a written consultation form by mail in October 1999. By December 1999, 25 or nearly one-half of HIV-related legal service providers who were contacted had responded. This includes 21 providers listed in the ABA directory and four protection and advocacy organizations.

Because each provider had different organizational structures, definitions, and methods for collecting data, the researchers defined primary terms and asked providers to apply these terms to their own experiences. For example, they defined an *HIV legal service program* as any freestanding legal service program or a legal program within an organization serving clients living with or affected by HIV/AIDS. *HIV cases* were defined as any legal service provided to a client with or affected by HIV/AIDS (including brief advice and counseling), and referrals to other agencies.

FIGURE 1

HIV LEGAL SERVICE PROVIDERS IN THE U.S.*



* As of December 1999

Limitations

The investigators noted the following limitations in conducting the study:

- Although the sample includes HIV-related legal providers from all regions except the Northwest, the sample only includes about one-half of all known providers throughout the United States (as of December 1999), and thus may under represent some issues.

- This is the first study of HIV-related legal issues and was conducted in a relatively short period of time. A more comprehensive study that includes a larger sample and case studies of clients with HIV/AIDS will provide more substantial information.

Major Findings

People with HIV/AIDS have a range of care-related health and support needs that often require legal assistance.

◆ Legal services help people living with HIV/AIDS to access health care services by helping them overcome immediate barriers to care.

Barriers to care for people with HIV/AIDS account for the single largest area of legal services provided by respondents. Programs offer a broad range of health-related legal services, including brief advice and counseling, limited direct representation (short of litigation), and referrals to other legal and non-legal service providers and programs. Common barriers to care include discrimination and breaches of confidentiality by health care providers, problems in accessing and using public benefits and private health insurance, and provision of inadequate medical care. For PLWH who are able to work, balancing job responsibilities and medical care is a major challenge—even with the protections of the ADA. And despite a landmark 1998 Supreme Court ruling (*Bragdon v. Abbott*) confirming that asymptomatic HIV infection is a covered disability under the ADA and other statutes including the 1973 Rehabilitation Act, many PLWH are still denied services and care by medical providers.

Funding Sources* for HIV-Related Legal Services

CARE Act – Title I	48%
Private foundations	44%
Individual donations	40%
State/local bar associations	36%
CARE Act – Title II	24%
State government	24%
Local government	24%
HUD/HOPWA	16%
Protection & Advocacy funding	12%
Other Federal government sources	8%
Client fees	8%
Attorneys' fees	4%
Other	24%

**Total exceeds 100% since many respondents receive funds from more than one source*

◆ Most HIV-related legal service programs were founded in the late 1980s and early 1990s and many have relatively small budgets.

Of the 21 organizations providing financial information for this study, the average reported budget was $310,000 for the programs' fiscal, calendar, or contract year. However, nearly one- half had reported budgets of $200,000 or less, and one-third had budgets of $100,000 or less.

Most HIV legal service programs are housed within a parent organization; programs structured as independent non-profit organizations have the largest budgets. Predictably, programs located in high incidence areas also have the largest budgets, while those in smaller cities (e.g., Kansas City, Madison WI, Macon GA) have much lower budgets. Public funding (Federal, State and local governments) is the primary funding source for nearly two-thirds (63 percent) of legal service programs, while private foundations and individual donations provide support for about one-third. Nearly two out of three organizations with separate HIV legal services budgets receive CARE Act funds.

◆ Very few HIV-related legal service providers have conducted needs assessments of the legal needs of PLWH.

About one in six HIV-related legal service providers had conducted client needs assessments, and only one had conducted comprehensive needs assessments, despite the broad range of legal service needs demonstrated by PLWH and their reliance on legal assistance to access health and support services.

◆ Assistance with accessing and using entitlement programs is an important service provided by all legal service providers.

People with HIV/AIDS frequently rely on public benefits programs to help pay for essential services and expensive HIV-related treatment options. Often they need help in obtaining these benefits, including assistance obtaining Medicaid. All HIV-related legal service programs report assisting clients in applying for State and Federal public benefits, including Medicaid and Medicare. Programs also help clients access State AIDS Drug Assistance Programs (ADAPs) and ensure that low-income clients can use and receive quality care from free and low-cost public clinics. Programs help clients appeal denials of their benefits claims, handle improper delays in receiving public benefits, and deal with such matters as charges of overpayment and inappropriate termination of benefits. For many clients, qualifying for public benefits is a route to accessing other health-related benefits. For example, access to SSDI benefits for 2 years is a requirement for Medicare eligibility. For many women with children, obtaining Temporary Assistance for Needy Families (TANF) means that they also receive Medicaid benefits. However, women and children who lose TANF benefits also improperly lose Medicaid coverage, even though they are still Medicaid-eligible. Legal advocacy programs can help them appeal inappropriate termination and ensure access to care.

Legal service providers also help PLWH obtain health insurance coverage and fight unlawful termination or denial of health insurance benefits, a service provided by nearly three-fourths of providers participating in the study. As HIV infection progresses to AIDS, people tend to lose their jobs and, as a result, also lose their health insurance.[9] Access to health care coverage is crucial for maintaining health and capacity for self-care. Nearly all legal service programs (22 of the 25 contacted) provide legal services in the area of employment.

◆ Legal service programs provide essential support to address barriers to care for HIV- affected families, foreign-born, and incarcerated PLWH.

Nearly three-fourths of participating programs provide assistance with permanency planning to help families plan for a child's care when parents become incapacitated or die from AIDS. Legal assistance is also needed to facilitate access to care for foreign-born and legal aliens with HIV/AIDS since public health and medical benefits are available to some, but not all, non-citizens living in the United States. Nearly one-half of legal service programs participating in the study provide legal services related to immigration. Of these, nine programs reported a total of 3,557 immigration-related cases for their most recent year—the second-highest number of cases reported for general legal support. This includes helping non-citizens apply for temporary visas, permanent resident status, and naturalization, which enables them to work legally in the United States, to obtain jobs and private health insurance, and to be eligible for public benefits. About one-third of participating legal service programs also provide assistance to incarcerated PLWH. Despite a smaller number of cases, the impact of legal services on incarcerated PLWH may be much broader since a reported "case" may actually represent an effort to change an entire penal system's delivery of care for PLWH.

- **Legal services also help PLWH meet subsistence needs—food, clothing, and shelter—that can compete with and prevent them from accessing essential health care services.**

Legal service programs help clients eliminate barriers to care by addressing employment-related issues, problems with obtaining or maintaining public benefits, life and disability insurance, debtor/creditor and bankruptcy issues, and tax problems. By ensuring that clients have quality housing, for example, they can provide a stable living environment that is essential for adequate health care. Legal service programs can also help gain access to temporary housing, shelters, residential drug treatment programs, and residential health care facilities on a non-discriminatory basis.

- **Nearly all legal service providers have access to the Internet, and more than one-half have a Web site for client access and information. Most providers track client cases electronically and providers use a wide range of methods to assess quality and effectiveness of services.**

All but one legal service provider in the sample has Internet access; of these nearly two-thirds have a Web site to provide information about their services. Nearly three-fourths use computer software to track client cases, which helps programs share information about legal services with other HIV-related legal providers. All but one provider has at least one method for evaluating client satisfaction with their services; on average, providers use four to five types of assessment, including client surveys (71 percent), case reviews (50 percent), follow-up calls (33 percent), and outside evaluations (17 percent).

Recommendations

Findings demonstrate that legal services for people with HIV/AIDS play a central role in their ability to access and maintain health care services.

I. Legal services should be considered a core component in the network of services needed by people living with HIV/AIDS.

Basic needs such as housing, employment, and access to public benefits are critical to the health and well-being of PLWH. Through effective protection and advocacy-related legal services, the subsistence needs of PLWH can be met and better access to health care ensured.

Suggested Options:

1. Change guidance that severely limits the types of legal services that can be provided with CARE Act funds.
2. Develop strategies to fund legal services through Title I and II programs.
3. Commission a policy paper on the laws protecting people with HIV/AIDS, based on the premise that legal advocacy is a "mainstream" essential service.

II. Expand Federal and other sector funding for HIV/AIDS legal services.

Legal service providers strongly support increased funding for legal services and free access to general legal research resources, such as Westlaw and Lexis.

Suggested Options:

1. Gain recognition for PLWH in Protection & Advocacy statutes and existing legal program report language, and among the Legal Services Council, long term care and nursing home ombudsmen, and education advocates (for children).
2. Develop group discounts to enable a national network of HIV/AIDS legal services

providers to obtain key services such as Westlaw and malpractice insurance at substantial savings to individual organizations.

III. Promote needs assessments to determine HIV/AIDS clients' legal needs.

Few communities or legal service providers have conducted formal needs assessments of legal services or HIV/AIDS clients' needs to ensure that services meet clients' needs. Since most legal programs use computer software tracking programs, it is possible to conduct a national needs assessment of HIV-related legal needs. Planning for legal support needs should routinely be incorporated into CARE Act planning.

Suggested Options:
1. Contract out for legal services needs assessments using CARE Act funds.
2. Include HIV-related legal services as a component of ongoing CARE Act needs assessments.

IV. Support the development of attorney training and client legal education materials.

Client education and attorney training materials are needed in the areas of tax and immigration law. Establishing a mechanism to share attorney training and client education materials is cost effective and will prevent unnecessary duplication.

Suggested Options:
1. Use SPNS funding to develop a clearinghouse for HIV-related legal resources.
2. Create an electronic list serve on HIV-related legal issues.

V. Initiate a project to facilitate formal networking and sharing of HIV-related legal materials.

Legal service programs need a formal mechanism to facilitate information sharing, including a clearinghouse for attorney and client educational and training materials. Given the widespread use of computer tracking software, data about the types of HIV-related legal services can be collected and shared relatively easily, and the Internet provides an effective means of networking and sharing this information.

Suggested Options:
1. Fund national activities including networking, list serves, conference calls, and meetings.

References

1. Rivera R. Lawyers, clients, and AIDS: Some notes from the trenches, 49 *Ohio State Law Journal*, 1989: 891- 911, 921-925.
2. Sarmiento MT. The legal needs of women with HIV, 9 *Berkeley Women's Law Journal*, 1994; 155.
3. Bunting SM, Bevier DJ, Baker SK, Poor women living with HIV: Self-identified needs, *Journal of Community Health Nursing*, 1999; 16(1):41-52.
4. Lazzarini Z, Lopomo F, Reiter GS, Flaherty K, Chandler C. Integrating Legal Options for Guardianship and Adoption Into Comprehensive HIV-Related Social Services. *HIV Infection and Women Conference*, 1995 February 22-24; S64.
5. Shapiro MF, Morton SC, McCaffrey DF, et al. Variations in the Care of HIV-Infected Adults in the United States: Results from the HIV Cost and Services Utilization Study. *Journal of the American Medical Association*, 1999; 281(24): 2305-2315.
6. Cunningham WE, Anderson RM, Katz MH, Stein MD, Turner BJ, Crystal S, Zierler S, Kuromiya K, Morton SC, St. Clair P, Bozzette SA, Shapiro MF. The impact of competing subsistence needs and barriers on access to medical care for persons with human immunodeficiency virus receiving care in the United States. *Medical Care*, 1999;37:1270-1281.
7. Hassner M. The law and the workplace. *Body Positive*, 1999;12(1):19-22.
8. Hines R, Decker CL, Witt WP, Marconi K, Singer B, and the Four Special Projects of National Significance HIV Advocacy Projects. Demand for and use of advocacy services for persons living with HIV/AIDS, *AIDS & Public Policy Journal*, 1997;12(2):89-101.
9. Kass NE, Munoz A, Chen B, Zucconi SL, Bing EG. Changes in employment, insurance, and income in relation to HIV status and disease progression: The multicenter AIDS cohort study, *Journal of Acquired Immune Deficiency Syndrome*, 1994;7(1):86-91.

Release Planning Needs for Federal Inmates with HIV/AIDS in Community Placement Facilities

Earl C. Huch

Purpose:

To assess policies and procedures and barriers to care for releasing inmates with HIV/AIDS in community settings.

Background

More than two million persons are incarcerated in U.S. prisons and jails. Both male and female inmates have a range of long-term health and mental health needs, suffer disproportionately from chronic medical conditions, substance abuse and multiple social problems, and are more likely to be African American and Hispanic than the general population.[1] According to a 1999 Department of Justice report, the incidence of AIDS is 8-10 times higher among prisoners than among the total population.[2] Moreover, in most prison systems, HIV prevalence among women is two-to-three times higher than for men.[3]

The Federal Bureau of Prisons (BOP) has responsibility for management of correctional programs for all persons convicted and sentenced under Federal law. Currently, the BOP maintains 95 institutions throughout the country with a total inmate population of over 135,000—1,000-1,200 of whom have HIV/AIDS. Individuals sentenced by Federal Court are placed in a BOP correctional facility designed to meet their security, program, and medical needs. Health care needs are managed in both traditional institutional settings (e.g. prisons) and specialized medical care facilities. Together with private contractors, the BOP also operates a community-based program of halfway houses to transition inmates back into the community where high-risk behaviors place others at risk. While most inmates transition through halfway houses, some are released directly to their home communities.

Inmates' medical care and medication are covered by the BOP while they are in Federal custody, including placement in affiliated halfway houses. But some gaps have been identified as they transition out of prison. Inmates need more services and more effective services to help them successfully transition to their home communities, to resist substance abuse relapse, and to prevent return to criminal and other high risk behavior.[4] For example, although a majority of State and Federal prison systems and three-quarters of city and county jail systems provide at least some discharge planning for inmates with HIV/AIDS, a much smaller proportion (31 percent of State/Federal systems and even fewer city/county systems) actually schedule appointments for them, thus ensuring that they are more likely to receive essential care and support services (table 1).

Because inmates released from prison face many competing needs, such as housing, food, employment, and substance abuse treatment, well designed discharge planning programs are especially important. Findings from Rhode Island's prison release program for women with HIV reported that recidivism rates were significantly lower than among recently released female inmates with HIV who did not have access to the program.[5] In addition, the program had a positive impact on former inmates' high-risk behaviors. Results from four demonstration projects (funded by the Special Projects of National Significance (SPNS) Program), which are designed to link incarcerated and recently released inmates with HIV/AIDS to community services, found that pre-release planning was vital for negotiating referrals, setting up medical appointments, and continuing contacts after discharge.

However, since Federal prisoners placed in halfway houses are still in custody, they are not eligible for CARE Act services that are otherwise provided by the BOP. These concerns underscore the need for engaging CARE Act providers in pre-release planning and for developing programs that provide linkages for inmates who are transitioning back to the community to ensure access to care and to promote treatment adherence. To discuss ways of addressing these and other care-related concerns of inmates released from Federal correctional facilities, the Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau (HAB) and BOP staff began a series of meetings during the summer of 1999.

Methodology

The investigator conducted site visits to halfway houses and Federal correctional facilities in two States and six cities—Maryland and Texas, and Baltimore, Chicago, Dallas, Fort Worth, New York City, and Washington, D.C.—to review BOP policies and procedures related to release planning and community linkages, and to assess implications for CARE Act programs. In addition, the researcher interviewed top BOP medical staff and key staff at correctional facilities and halfway houses. Sites were selected based on: 1) access to correctional facilities; and 2) the proportion of inmates with HIV/AIDS being released to the community. Site visits were conducted during a 3-month period in the Fall of 1999. Although this study focused on inmates with HIV who are placed in halfway houses, the same issues apply to those who are directly released to the community.

Selected Sites

Baltimore ◆ Chicago ◆ Dallas
Fort Worth ◆ Maryland ◆ New York City
Texas ◆ Washington, DC

Goals include the following: 1) to assess policies and procedures for release and discharge planning and dispensation of medication to Federal inmates with HIV in community placements; 2) to identify successful models for release planning and care throughout the country; 3) to assess inmates' ability to address barriers to HIV-related care, substance use treatment, and necessary support services following release; 4) to review policy options for CARE Act programs to enhance the quality of care for recently released Federal prisoners with HIV; and 5) to develop recommendations for a release planning program for the BOP and HAB.

Limitations

The investigator noted the following limitations in conducting the study:

- The small sample of four correctional facilities and eight halfway houses in two States and six cities limits the investigator's ability to observe a diverse sample of facilities in different geographic areas; and

- This is an exploratory study to assess policies and procedures; additional assessment in a wider range of facilities is suggested to expand on this study and to further clarify inmates' needs and experiences related to transitional and community-based care.

Major Findings

- **Although staff at BOP institutions and community programs face a variety of obstacles in planning for the release of inmates with HIV/AIDS, many of them are still managing to find ways to develop linkages and to help inmates transition to the community.**

Some case managers and social workers assist inmates who disclose that they have HIV/AIDS if the inmates request their assistance; however, many case management and social work staff are not informed of the inmate's HIV status. Halfway house staff often provide HIV prevention education and assist inmates with linkages to care and social services if they are aware of an inmate's HIV status. Similarly, in addition to providing medical care, a physician in a Federal correctional facility assumed primary responsibility for developing community linkages, making clinic appointments and establishing community contacts for inmate followup after release.

- **The standing policy at the time of the study—not to directly inform social workers and case managers of an inmate's HIV status—serves as a barrier to effective community release planning.**

Although both case managers and social workers can be informed of an inmate's HIV status on a need to know basis, most social work and case management staff interviewed for this study expressed great frustration at their inability to provide appropriate care for clients when information about their health status was not available. Staff felt that this policy, in essence, "tied their hands." As a result of this study, BOP officials subsequently revised their policy to permit social work and case management staff to learn about inmates' HIV status.

- **Although BOP policy regarding confidentiality calls for halfway house directors and probation officers to be notified of an inmate's HIV serostatus, staff are uncertain about what the policy is and how it should be enforced.**

Inmate confidentiality is a concern and should be maintained; however, staff are unable to provide effective case management services when they are uninformed of the clients' needs and uncertain of agency procedures and practice. Some center directors receive information on an inmate's HIV status and put it in a desk drawer, while others actively engage the inmate and case management staff in addressing the inmate's needs. All halfway house staff who were interviewed reported confusion and concern regarding the implementation of BOP's confidentiality policy.

- **Medical management in halfway houses is inconsistent due to lack of information sharing and lack of clarity about procedures.**

When staff were aware that a halfway house resident had HIV disease, some case managers arranged for care in community clinics or referred inmates to substance abuse treatment programs. However, procedures varied and medical management was inconsistent. Some inmates made their own arrangements for care without staff involvement. Others were released to the halfway house without a 30-day supply of medication or found that they needed additional medication to cover longer periods required to schedule initial medical appointments at community clinics. Correctional health staff reported that it was the inmate's responsibility to obtain his or her medication prior to release and some failed to do so. Although programs made efforts to obtain medication when residents were in need, systematic procedures are required to secure and dispense medication at halfway houses to ensure continuity of care.

DISCHARGE PLANNING SERVICES PROVIDED IN STATE/FEDERAL PRISON SYSTEMS, 1997

Service	Referral Made	Appointment Made
HIV medications	82%	31%
Medicaid/related benefits	78%	35%
Substance abuse treatment	75%	22%
HIV counseling	73%	27%
Psychosocial support	73%	24%
CD4 monitoring	71%	24%
STD prevention + treatment	65%	22%
Viral load monitoring	61%	22%

[6] Hammett & Harmon, 1996-1997 Update: HIV/AIDS, STDs, and TB in Correctional Facilities, 1999

- **All inmates need more and better services to help make successful transitions to the community, to resist substance abuse relapse, and to avoid returning to high-risk behavior and criminal activity.**

Community studies have demonstrated the importance of providing pre-release services and community linkages. But to be effective, these activities must begin in prisons and jails and must continue after release. While all inmates need these programs, persons with HIV/AIDS need a range of services, including HIV prevention, continuity of health care, substance abuse treatment, support services, housing, job training, and assistance with benefits eligibility.

- **The BOP does not currently have a policy regarding HIV prevention case management.**

Targeting prevention activities to inmates in correctional facilities and halfway houses is important to help them develop positive life and self care skills, to learn how to negotiate safer sex, and to decrease HIV transmission in the community. Although some halfway house staff invite outside groups to conduct HIV prevention workshops, and some programs include HIV prevention as part of routine curricula, the BOP currently does not have a policy regarding HIV prevention case management.

- **The BOP substance abuse education and treatment program should incorporate comprehensive HIV prevention education and should be proactively linked to case managers in correctional facilities and community settings.**

Since a very high proportion of inmates with HIV disease are also substance users, a significant number are also enrolled in the BOP substance abuse education and treatment program—a comprehensive 500-hour program that enables inmates who graduate to be eligible for early release (in tandem with a mandatory community program). The program includes some HIV prevention material. Moreover, some halfway houses conduct the community substance abuse treatment component, while others are conducted at the institution or other locations. More comprehensive HIV prevention education should be incorporated into the program's curricula and the program should be proactively linked with case managers in both correctional facilities and community settings.

Recommendations

I. The unit management case manager should have primary responsibility for release planning for inmates with HIV, together with medical staff.

Inmates are assigned to housing units (self-contained areas that include cells, dormitories, bathroom facilities, common areas, and staff offices) with a unit team responsible for all inmates in each unit. Unit management teams include a unit manager, case manager, and a correctional counselor, with input from the inmate's work supervisor, education department, and psychology services department. Although the unit case manager is responsible for developing an inmate's release plan, he or she is not typically informed of the inmates' HIV status. This information should be shared by medical and case management staff, taking appropriate confidentiality safeguards, when release plans are being developed. The availability of a system-wide BOP telemedicine program to provide access to medical and treatment information should also be used to assist social workers and case managers in caring for inmates with HIV/AIDS.

II. Change the current policy covering the amount of medication permitted upon release to ensure that recently released inmates have an adequate supply until follow-up care is ensured.

The current BOP policy permits inmates being released from correctional facilities to receive a 30-day supply of medication to ensure continuity of care until follow-up medical appointments can be made in the community. At times, however, appointments may take longer to schedule, and inmates are left without needed medication. This policy should be changed to allow recently released inmates to obtain adequate medication to meet their needs. In doing so, medical staff should ensure that inmates follow the correct regimen and do not experience adverse side effects.

III. Appropriate community linkages should be made during release planning, and CARE Act programs should assist with release planning in Federal institutions, and provide halfway houses with educational and linkage services.

While all inmates can benefit from assistance transitioning out of correctional facilities, those with HIV/AIDS have additional care and support needs that must be addressed. Community linkages should begin to be made when release planning begins. Approximately 70 percent of inmates are released through halfway houses so case managers have time to plan for a range of re-entry services. Close collaboration between institutional case managers and CARE Act programs is needed both for inmates released through halfway houses and directly to their home communities.

IV. HAB and BOP should work with the Social Security Administration and the Health Care Financing Administration to change eligibility guidelines to allow inmates to apply for Medicaid and Medicare while in Federal custody.

Some inmates are eligible for Medicaid and Medicare when they leave Federal custody. However, applying for public benefits is difficult for most people with HIV/AIDS, and newly released inmates face a range of other challenges that may further complicate the process. Allowing inmates to apply for Medicare and Medicaid eligibility while in Federal custody will permit coverage to begin immediately upon release and will ensure continuity of care.

V. HAB should support development of a resource manual to help with release planning and increase access to services and care for newly released inmates.

Many release planners may not be aware of the range of community services, including CARE Act programs, available for people living with HIV (PLWH). A resource manual for case managers, release planners, and inmates listing community resources and programs can help them access services and obtain needed care.

VI. HIV prevention and education programs should be increased in correctional facilities and halfway houses, and an HIV cross-training program should be developed for BOP staff.

Only 10 percent of State and Federal prisons and 5 percent of the Nation's 50 largest jail systems had comprehensive AIDS education and prevention programs in 1997, although about two-thirds of correctional facilities provide basic AIDS education for inmates.[4] Access to comprehensive information can help inmates initiate and sustain difficult behavioral changes that can reduce transmission of HIV and other infectious diseases. This includes promoting relapse prevention and avoiding other high risk behaviors.

Several Federal agencies—HRSA, the Centers for Disease Control and Prevention (CDC) and the Substance Abuse and Mental Health Services Administration (SAMHSA)—have initiated a joint cross-training activity for HIV/AIDS, tuberculosis, and infectious diseases. This initiative should include training for BOP staff and should be linked to BOP's Substance Abuse Treatment Program to increase the knowledge and sensitivity of BOP employees on issues related to HIV/AIDS.

VII. Case managers in halfway houses should be made an integral part of the release planning process, and should provide case management services for inmates with HIV/AIDS.

Linkages and collaboration between institutional and halfway house case managers should be increased to ensure effective release planning and implementation. Case managers in halfway houses should be made an integral part of the release planning process and should have responsibility for ensuring that inmates keep medical appointments, make appropriate community connections, and receive needed support.

References

1. Hammett T.M. Public health/corrections collaborations: Prevention and treatment of HIV/AIDS, STDs and TB. *Prevention Research in Brief*, July 1998.
2. National Prisoner Statistics: U.S. Department of Justice, Bureau of Justice Statistics, Washington, 1999.
3. HIVinfection among incarcerated women. *HIV Education Prison Project News*, 1999.
4. Hammett T.M. Prevention and treatment of HIV/AIDS and other infectious diseases in correctional settings: An opportunity not yet seized. *HIV Education Prison Project News*, 1999; 2(11):1-2.
5. Skolnick A. Correctional and community health care collaborations. *Journal of the American Medical Association*, 1998;279:98-99.
6. Hammett & Harmon. Medical treatment and a continuum of care. In 1996-1997 Update: *HIV/AIDS, STDs, and TB in Correctional Facilities*. Washington, D.C.: National Institute of Justice, Centers for Disease Control and Prevention, Bureau of Justice Statistics; July 1999.


DEPARTMENT OF HEALTH & HUMAN SERVICES · USA


DEPARTMENT OF HEALTH & HUMAN SERVICES · USA