# Title I Survey: Services for HIV Positive Substance Users


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## Introduction

Substance abuse accounts for a significant proportion of transmission of HIV, either through intravenous drug use or through sexual and high-risk behaviors associated with substance abuse. Although high-quality health care, particularly primary care, is of the utmost importance for all individuals who are HIV positive, it is even more critical for HIV positive substance users, as these individuals experience greater risk of complications. Yet intravenous drug users are less likely to access health care services (NIDA, 1999a; Selwyn, 1996; Eldred and Cheever, 1998), and less likely to receive antiretroviral therapies (ART) (Celentano, et al., 1998) than other people with HIV. In addition, substance users may experience more difficulty engaging in care (Snyder et al, 1996).

Given the significance of consumer access to a full range of services, as well as the substantial CARE Act resources expended on substance abuse treatment (HRSA, April 14, 1999), it is important to assess the current work of CARE Act grantees in providing services to HIV positive substance users. The Health and Disability Working Group at the Boston University School of Public Health, funded by the Health Resources Services Administration, has conducted several surveys of CARE Act grantees to assess CARE-Act funded activities for this population.

## Title I Background

The first survey included all Title I grantees. Under Title I of the Ryan White CARE Act, 51 eligible metropolitan areas (EMAs) have been designated to receive emergency relief funding for HIV-related services, due to the high prevalence of HIV/AIDS in these cities. Title I funds are awarded to the Chief Elected Official (CEO) of the city or county that serves the greatest number of people living with HIV in the EMA. The CEO usually designates the local health department to administer Title I funds for the EMA and serve as the Title I grantee.

Each CEO must establish an HIV Planning Council. The planning council is responsible for setting service priorities and the allocation of funds within the EMA, and for developing a comprehensive plan for services. Planning councils work in partnership with the grantee to assess service needs within the EMA, but are not involved in the

selection of particular entities to receive Title I funding or in the administration of contracts with providers. These are the responsibilities of the grantee. The relationships between Planning Councils and grantees are complex, and differ from one EMA to another. However, the CEO is ultimately responsible for ensuring that federal funds are spent appropriately, collecting information about how these funds are used, and monitoring the delivery of services.

**Data Collection and Analysis Methods**

The Health and Disability Working Group developed a mail/telephone survey tool for Title I grantees. The survey tool included both closed-ended and open-ended questions. The survey was designed to obtain information about:

- Use of Title I funds to provide services for HIV positive substance users;
- The types of substance abuse treatment funded by grantees;
- The strengths and weaknesses of different metropolitan area service delivery systems for substance abuse treatment;
- The sources of information used to assess the needs of this population;
- Gaps in knowledge about the population and their service needs;
- Standards for service delivery; and
- Examples of innovative or successful programs within the EMA.

The survey was reviewed by HRSA staff and members of a national Advisory Committee assembled to advise the Health and Disability Working Group. It was pilot-tested on a small sample of grantees. Revisions to the survey were made after receiving comments from HRSA and the Advisory Committee, and again after the pilot tests. Contact information for all Title I grantees was obtained from HRSA. Prior to survey distribution, the Director of HRSA's HIV/AIDS Bureau (HAB) sent a letter to each grantee encouraging them to respond to the survey. A survey and cover letter were then sent to each grantee, along with a fact sheet describing the project. In the cover letters, the Health and Disability Working Group encouraged the Title I grantees to seek Planning Council input or information, if needed, in order to respond to the questions about service planning.

A pre-stamped, self-addressed return envelope was included in the mailing to facilitate return. Follow-up included one reminder postcard and a minimum of four telephone calls per grantee by Health and Disability Working Group staff to increase the rate of return. In the final phase HRSA staff assisted with follow-up by calling non-respondents.

Returned surveys were checked for missing data. Telephone calls were made to grantees to obtain missing information. Qualitative questions were then coded into conceptual categories. After all surveys were coded, data were entered into a Microsoft Access database for analysis. Analysis was then completed using simple descriptive techniques. Below we present the preliminary results from this survey.

**Title I-Funded Substance Abuse Treatment Services**

Forty-three Title I grantees responded to the survey, for a response rate of 86 percent.[1] Nearly all of the responding grantees (88 percent) report funding some form of substance abuse treatment through Title I funds. Grantees report funding a total of 197 substance abuse treatment agencies across the country. The most commonly funded Title I substance abuse treatment service is outpatient counseling. Other forms of treatment funded are described in the table below.

**Substance Abuse Treatment Services Funded Under Title I**

| Service Type | % of Grantees Funding Service |
|---|---|
| Outpatient Counseling | 75% |
| Residential Treatment | 35% |
| Methadone Maintenance/LAAM | 28% |
| Acute Detoxification | 21% |
| Inpatient Treatment | 14% |
| Acupuncture Detoxification | 12% |
| Other (collateral, support services) | 19% |

[1] The District of Columbia, which is both a Title I and Title II grantee, was only surveyed once, through the Title II survey.

Most of the Title I Grantees provided demographic data about the clients served in these substance abuse treatment programs. Over 80 percent of the Title I grantees fund services for a diverse population, including Blacks, Hispanics, and Whites. One-third fund programs serving American Indians and one fourth fund programs serving Asian/Pacific Islanders. Three quarters of the Title I grantees also fund programs that serve women.

*Special Programs*

More than half of the grantees (60 percent) use Title I funds to promote substance abuse treatment programs that target under-served populations. Many of these grantees fund more than one targeted substance abuse treatment program; in total, 108 targeted programs are described. This means that over half of the substance abuse treatment programs funded through Title I are targeted to address the needs of special populations. Programs for HIV positive African Americans and women are the most common. The table below lists the targeted populations and the number of Title I grantees that report funding special substance abuse treatment programs for these groups.

**Programs For Special Populations Funded by Title I**

| **Special Population** | **# and % of Grantees with Programs** |
|---|---|
| African Americans | 19 (44%) |
| Women | 18 (42%) |
| Latinos | 14 (33%) |
| Women and their children | 12 (28%) |
| Incarcerated/recently incarcerated | 12 (28%) |
| Gay and/or Lesbian | 11 (26%) |
| Homeless | 10 (23%) |
| Adolescents | 7 (16%) |
| Mentally ill | 3 (7%) |
| Other minority populations | 2 (5%) |

As with Title I funding in general, the largest service category among programs targeted to serve special populations is outpatient counseling. Detoxification and residential treatment programs are the next most common programs in this category. Other services provided in these targeted programs include outreach, support services, peer support, methadone maintenance, day treatment, acupuncture, and inpatient treatment.

*Harm Reduction*

One quarter of the Title I grantees report that they fund some form of harm reduction program through their Title I funds, and nine of the grantees provided descriptions of these programs. It is interesting to note that none of the programs described were methadone maintenance programs – if these were included as harm reduction programs, the number of grantees funding harm reduction services would climb. The most commonly described programs that use a harm reduction approach include pre-treatment counseling and drop-in counseling. Outreach and education, case management, residential programs, and acupuncture are other services provided in a harm reduction model. Approximately ten percent of the programs for targeted populations described above specifically mention the provision of harm reduction services.

**Descriptions of the Overall Substance Abuse Treatment Delivery System in the Metropolitan Areas**

It is important to place the Title I funding in the context of the overall delivery system for substance abuse treatment services in each of the EMAs, as planning councils may make very different decisions based on local circumstances. We asked the Title I grantees to provide a general description of the substance abuse treatment delivery system, including its strengths and weaknesses for people with HIV, and other funding sources for substance abuse treatment. We also asked about the availability of harm reduction programs not funded by Title I.

Two-thirds of the grantees provided a description of the overall substance abuse treatment delivery system, including the range of services provided, and system strengths

and weaknesses. Not surprising, the responses varied widely. For example, some grantees report having very comprehensive substance abuse treatment systems:

> "[Our state] is fortunate to be home to a large number of substance abuse treatment centers and programs….there are numerous programs available including [one that]….targets African Americans and also has several HIV prevention and services programs.….[one program] serving gay/bisexual/ transgender individuals…..four methadone programs….[two residential programs] that target services to women. Treatment centers…will take indigent patients…Because of the widespread availability of substance use treatment, Title I has not funded treatment programs."

> "Residential detoxification services include housing, food, HIV and substance abuse counseling, alternative healing techniques, discharge planning and …referral assistance for ongoing health and social services….residential treatment includes housing, food, HIV, mental health and substance counseling, supervision of compliance to prescribed medications, ..nutritional planning….transportation services, adult education classes, and case management of primary medical care….outpatient substance abuse and methadone treatment services include individual and group counseling with attendant medication monitoring and services coordination activities…..more services are being provided with a harm reduction modality…."

> "In addition to the continuum of services available for all people with HIV/AIDS or the continuum of services for substance abusers, the following programs specifically target…HIV+ substance users….[including] services for HIV+ actively using: street outreach, needle exchange, HIV and substance abuse case management, HIV prevention counseling and education, food, housing/shelter, emergency financial assistance, links to public health and social services ...."

In contrast, other grantees report very limited delivery systems:

> "Only one agency in our EMA provides substance abuse treatment. The main weakness of this agency is that it provides a drug rehabilitation program under a quasi-military environment."

> "This is a very complicated and restricted system for…persons…who are low income and uninsured….the Regional Behavioral Health authority is responsible….they do not certify clients as eligible if they have HIV, therefore requiring the Ryan White funded system to provide these services….All services are ambulatory, none are residential or inpatient….similar exclusions occur with the state's Medicaid program."

> "The system is very fragmented and there are not enough services. That comes from the fact that harm reduction programs such as needle exchange are not well viewed in the community, and are also sometimes illegal."

Interestingly, an equal number of grantees report having a comprehensive system of care (40 percent) as report having serious service shortages (40 percent). The systems described as comprehensive include the full continuum of services from outreach, triage and referral, to residential programs, medication management, and relapse prevention. In addition, many of these grantees describe programs targeted to serve specific populations such as the homeless, African Americans, Latinos, or women. Among those grantees reporting service shortages, the most frequently mentioned problems include a shortage of detoxification beds and residential programs. Other system weaknesses include fragmentation of the delivery system, housing shortages, and a lack of harm reduction programs. Only 20 percent of the grantees mention that their delivery system includes harm reduction programs beyond those funded by Title I.

**Barriers to Care**

We asked the Title I grantees to identify all barriers to care and rank the top five barriers for HIV positive substance users in their communities. We provided a list of specific barriers and allowed the grantees to add their own barriers. The barriers were categorized into two groups: systemic barriers (e.g. lack of slots or beds, inadequate insurance) and programmatic barriers (e.g. lack of substance abuse provider knowledge of HIV, lack of walk-in services for primary care). The most highly ranked systemic barriers to care are listed below.

**Systemic Barriers to Care**

| **Systemic Barriers** | **Cited as one of top 5 barriers** |
|---|---|
| Lack of housing options | 63% |
| Too few residential programs | 58% |
| Too few detoxification programs/beds | 47% |
| Lack of transportation | 37% |
| Insurance coverage for substance abuse treatment is lacking or inadequate | 32% |
| Too few outpatient programs | 32% |
| Little capacity for after-hours HIV medical care | 29% |
| Too few methadone/LAAM programs | 24% |
| Waiting time for medical visits is too long | 16% |
| Government agencies do not collaborate in planning | 13% |

The shortage of housing and residential substance abuse treatment top the list of barriers. They are also the most commonly cited barriers by all grantees, regardless of their importance. The shortage of detoxification beds is also a major problem, as is the lack of transportation. Although less than half of the grantees report that the shortage of outpatient treatment programs is a barrier to care, in those grantees where outpatient treatment programs are lacking, it is considered to be a major problem. The absence or inadequacy of insurance coverage for substance abuse treatment is another major barrier to care. A few grantees provided additional commentary on insurance coverage, including the fact that some programs are closing or reducing lengths of stay "due to changing treatment approaches and financial constraints."

The most commonly cited programmatic barriers to care are listed below.

**Programmatic Barriers to Care**

| **Programmatic Barriers** | **Cited as one of top 5 barriers** |
|---|---|
| Women with children are not supported in programs | 47% |
| Harm reduction/recovery readiness services are not provided | 38% |
| Substance abuse treatment providers need more HIV training | 35% |
| HIV positive substance users fall through the cracks between services | 35% |
| Lack of outreach to bring people into care | 35% |
| HIV primary care clinics lack walk-in services | 29% |
| Language barriers | 24% |
| Primary care providers do not screen for substance abuse | 24% |
| Primary care providers do not know about substance abuse treatment options | 21% |
| Support services are not linked to HIV medical care or substance abuse treatment | 21% |
| Substance abuse treatment programs are not culturally sensitive | 21% |
| Primary care providers lack cultural sensitivity | 18% |
| Problems siting substance abuse treatment programs | 18% |
| Long waits at HIV primary care sites (when presenting for care) | 9% |
| Substance abuse treatment programs ignore the medical issues | 6% |

The most significant programmatic barrier to care reported by grantees is that women with children are not supported in substance abuse treatment programs. It is interesting to note that this shortcoming was only mentioned by half of the grantees. However, when it was mentioned, it was clearly one of the most significant problems. It is possible

that the other grantees do not find this to be a barrier because they use Title I funds to support treatment programs for this population. The same thing may be true of the lack of harm reduction/recovery readiness programs which ranks eleventh in the list of barriers to care reported by grantees, but ranks second when grantees list the top five barriers to care.

One third of the grantees reported that the lack of HIV knowledge among substance abuse treatment providers, insufficient outreach to bring people into care, and the fact that substance users often fall through the cracks between systems of care are major barriers to care. Other provider issues such as the shortage of HIV medical care walk-in services, the absence of substance abuse screening in primary care sites, and provider inability to address language barriers, are also significant barriers to care.

Although provider capabilities – or the lack thereof – did not make it to the top of the list in terms of their overall importance, they are among the barriers cited by the largest numbers of grantees. More than two-thirds of the grantees report the following barriers to care:

- Substance abuse treatment providers need more training in HIV (72 percent);
- Primary care providers lack cultural sensitivity (67 percent);
- Primary care providers do not know about substance abuse (67 percent); and
- Both primary care sites and substance abuse treatment sites do not have sufficient capacity to address language barriers (65 percent).

**Sources of Information for Planning and Decision-Making**

We asked the Title I grantees to identify the types of information available to make decisions about resource allocation for HIV positive substance users and the representation of people knowledgeable about substance abuse on the planning councils. All of the grantees report receiving epidemiological data and most receive data on other funding streams for services. In addition, 98 percent of the grantees conduct consumer surveys or focus groups, and 79 percent conduct provider surveys. Over two-thirds of the grantees receive data on the number of substance abuse treatment slots and the length of waiting lists for substance abuse treatment.

Most of the HIV planning councils have some form of representation from the substance abuse treatment sector. Nearly all of the grantees have a substance abuse treatment provider representative on the Council, but only half have a representative of a

governmental substance abuse treatment bureau at the city, county or state level. Three quarters of the planning councils report at least one consumer representative who is an active user or in recovery.

**Knowledge Gaps**

Although responses varied significantly among grantees, certain gaps in knowledge stand out. For example, one-third of the Title I programs were not able to provide any description of the overall substance abuse treatment delivery system in the metropolitan area, beyond those services funded by Title I. This conflicts with the data cited above about the information grantees receive for planning purposes. If that data is available, the grantees should have been able to provide some description of their delivery system. In addition, among those who did provide a description of the delivery system, 70 percent of the grantees reported they did not know about the availability of harm reduction services or were silent on this issue.

Only half of the grantees reported that *any* of the barriers described in the survey such as lack of slots, availability of insurance, provider knowledge, or people falling through the cracks, were documented in their needs assessments. The lack of transportation, residential programs, housing programs, and language barriers were the most likely to be documented. However, none of the grantees had any documentation about primary care provider knowledge of substance abuse treatment, and only one grantee reported any documentation about provider screening for substance abuse treatment, or substance abuse treatment program handling of medical issues. Some of the grantees indicated that they did not know if a particular issue was a barrier to care. The table below lists those barriers about which the grantees know the least.

**Knowledge Gaps Around Barriers to Care**

| Potential barrier to care | % of grantees with no information about issue |
|---|---|
| Difficulty siting programs | 40% |
| Too few methadone/LAAM slots | 33% |
| Lack of harm reduction/recovery readiness programs | 33% |
| Duration of treatment is too short | 26% |
| Insurance coverage is inadequate | 23% |
| Lack of walk-in primary care services | 23% |
| Lack of outreach to clients | 23% |
| Substance abuse treatment programs are not culturally sensitive | 23% |
| The waiting time for an HIV primary care visit is too long | 23% |

**Standards of Care**

Most of the Title I grantees (86 percent) have developed standards of care for at least some of the services they fund through Title I. A little more than half of the grantees (58 percent) have standards of care for substance abuse treatment. Seventy percent have standards of care for HIV medical care, however only 14 percent report that the HIV medical care standards address issues specific to substance abuse such as the need to screen for substance abuse or make referrals to appropriate treatment. Fourteen percent of grantees also have case management standards that address substance abuse issues, and four percent of grantees have supported housing standards that address substance abuse issues.

**Standards of Care**

| Service Area | Any Standard of Care | Standards Specific to Substance Use/Users |
|---|---|---|
| Substance Abuse Treatment | 58% | not applicable |
| HIV Medical Care | 70% | 14% |
| Case Management | 74% | 14% |
| Supported Housing | 35% | 9% |

Some grantees suggested areas in which performance standards for serving substance users might be developed. These included:

- Enhanced case conference between substance abuse, mental health, and primary care providers;

- Co-locating substance abuse treatment and mental health staff and primary care, supported housing, and other support service sites; and
- An annual assessment of provider competency in service provision for this population.

**Innovations**

The grantees were asked to report any innovative attempts to assess the needs of HIV positive substance users, or to conduct outreach to this population. Thirty percent described their specific needs assessment procedures as innovative, and 20 percent described specific innovative outreach measures. Nearly all of the needs assessments included face-to-face interviews or focus groups with HIV positive substance users. Many of the grantees engaged consumers to conduct these interviews, often under the aegis of a university or research group.

Outreach methods included:

- Using peer advocates to conduct outreach and provide support services;
- Assigning an individual to keep track of people who abandon treatment and conducting street outreach to bring them back in;
- Making a targeted effort to engage recently released incarcerated individuals to connect them with services;
- Providing services through outreach and education vans;
- Opening harm reduction drop-in centers;
- Providing transitional housing for people in active user support groups; and
- Establishing a harm reduction planning process to address this issue.

Two of the grantees specifically mentioned using Congressional Black Caucus funds to conduct outreach activities.

**Discussion**

Most of the grantees are using Title I funds to support some form of substance abuse treatment for people with HIV. Furthermore, over half of the grantees are funding targeted programs for under-served populations such as women with children or racial/ethnic minorities who may be overlooked in mainstream treatment programs. Most of the Title I substance abuse treatment funding is directed toward outpatient treatment, with residential services running a distant second. These are all positive signs that

grantees are using a portion of their HRSA funding to provide essential services for HIV positive substance users.

However, it is interesting that many of the grantees are not using their Title I funds to address those barriers to care that they identify as most significant for substance users with HIV. For example, more than three quarters of the grantees cite the lack of residential treatment programs as a major barrier to care, but only one-third of the grantees use Title I funds to support this service. Similarly, two-thirds of the grantees report that there are too few detoxification programs, but only 20 percent fund detoxification services. The lack of services for women and children is ranked as the most significant barrier to care, yet less than one third of the grantees use Title I funds to address this gap. Finally, the absence of harm reduction options was cited as a major problem by over half of the grantees, but only one quarter of the grantees fund harm reduction services.

These results suggest the importance of conducting a comprehensive needs assessment of the current care delivery system, complete with the necessary data to identify service gaps, as well as consumer surveys or focus groups to better understand the barriers to care faced by different subsets of the HIV population. While two thirds of the grantees report that they receive information about waiting lists and the number of treatment slots, and nearly all receive data about other funding sources, one third of the grantees are unable to describe the current substance abuse treatment delivery system and how people with HIV are served within it.

In addition, although nearly all of the grantees conduct some form of consumer survey or interviews, it is not clear how these tools address the particular barriers to care faced by HIV positive substance users in the community. Less than half of the grantees report that barriers to care have been substantiated by the needs assessment process, indicating that these questions are not being asked of either consumers or providers. It is important to find ways to incorporate the issues described above into the needs assessment and service prioritization process.

Lack of provider knowledge, expertise, and awareness, were cited as important barriers to care by a majority of the grantees. Both health care and substance abuse treatment provider groups also need to address language barriers and cultural differences.

It would appear that Title I programs, perhaps in collaboration with other funding agencies such as the state departments of health, could support this type of cross-discipline training and cultural awareness training to great advantage.

The availability of harm reduction approaches to care is an area in which there is wide variability among grantees. One fourth of the grantees fund harm reduction programs with Title I funds, but over half cite the lack of harm reduction options as an important barrier to care. Most of these grantees do not fund harm reduction options themselves. Furthermore, there appears to be some confusion about harm reduction, with several grantees reporting that it is illegal in their state. It can be inferred from this statement that they are describing needle exchange, which is, in fact, only one type of harm reduction approach. However, several grantees provided extensive descriptions of harm reduction approaches that were used in settings other than needle exchange programs.

Finally, it appears that several Title I programs have supported innovative programs for HIV positive substance users that could be used elsewhere as program models. Grantees provided descriptions of many of these programs, including programs designed specifically for women with children, recently incarcerated individuals, racial/ethnic minorities, and people triply diagnosed with HIV, substance abuse, and mental health disorders.

Other innovative programs included those where Title I funds were used to support one-stop shopping, by adding substance abuse treatment staff to primary care programs, or HIV medical staff to substance abuse treatment programs. Other variations included strengthening collaborations between substance abuse treatment, mental health, and medical providers through mechanisms such as case conferencing, or assigning specific individuals to follow up on patients lost to care or who appeared to fall through the cracks. In some cases, Title I funds supported an entire program, while in other cases the Title I funds were used to supplement other funding streams for substance abuse treatment or primary care.

A third type of innovation included programs that can be loosely described as incorporating harm reduction principles. Examples include drop-in centers for active users where they can receive counseling and be linked to care, or street outreach and

counseling programs that link people to medical care or substance abuse treatment. Some case management and support service programs play a similar role, although these programs often require clients to play a more active role in presenting initially for services. Finally, some transitional/supported housing programs accept people with different levels of substance use, and encourage them to obtain medical care and consider substance abuse treatment.

Although most of the work in designing and implementing innovative programs for HIV positive substance users rests with the actual service providers, public policy-makers and funders play an important role in supporting innovation. The experiences of the Title I grantees that have supported these innovations through their planning process, training programs, collaborations, and funding decisions may contain valuable lessons for other grantees.

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