

An Analysis of HRSA-Funded Services for HIV-Positive Substance Users:

**A Study of Ryan White CARE Act Title III, Title IV, and SPNS
Providers**



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INTRODUCTION

The Health Resources and Services Administration (HRSA) provides funding through the Ryan White CARE Act for services provided to individuals living with HIV. This report describes the results of a study conducted of HRSA-funded providers who deliver services to individuals with HIV who also have a substance disorder or recent history of substance use. The study was conducted by the Health and Disability Working Group at the Boston University School of Public Health in the summer of 2000 as part of a Special Projects of National Significance (SPNS) grant to develop performance standards and identify innovative practices in serving HIV positive substance users. The purpose of the survey was to:

- Understand how HRSA funding is being used by provider organizations to serve HIV positive substance users;
- Understand how programs are configured to serve HIV positive substance users; and
- Identify innovative strategies that can be explored in greater depth and be used as a basis for developing a training program.

METHODS

The survey was developed using information from the following sources:

- A literature review on HIV and substance use;
- Telephone interviews with fifty key informants who were identified as experts in the fields of HIV and substance use;
- Questionnaire responses from twenty-four HIV positive individuals with a recent or current substance use history who live in four different parts of the country;
- Suggestions from our National Advisory Committee and HRSA staff.

The survey included both closed and open-ended questions. After the survey was pilot-tested, it was distributed nationwide to all Ryan White Care Act Title III, Title IV and SPNS grantees that were identified as delivering direct care to people living with HIV. Two hundred and eighty three surveys were mailed to the grantee contacts identified by HRSA. A reminder postcard was mailed and a minimum of four telephone calls were made to non-respondents. Additional surveys were mailed, faxed or e-mailed to providers as a result of new contact information supplied during the telephone follow-up calls. Once responses were received, follow-up telephone calls were made to obtain missing data from some of the respondents.

One hundred and seventy-five surveys were returned to the Health and Disability Working Group. Some grantees, particularly those funded through Title IV, indicated that they did not specifically serve substance users. These responses are not included in our results. The results below reflect the responses of one hundred and sixty five providers (fifty eight percent of the original sample) who serve HIV positive substance users.

RESULTS

Geographic Distribution

Responses were received by grantees located in each of the ten HRSA regions. The largest number of responses was received from Regions 2, 4, and 9, and the smallest number of responses was received from Regions 7, 8, and 10.

Responses by HRSA Region

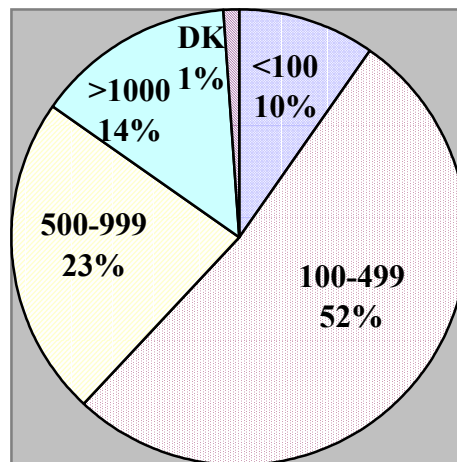
Region	States	Number	Percent
1	CT, ME, MA, NH, RI, VT	15	9%
2	NJ, NY, PR, VI	34	21%
3	DE, DC, MD, PA, VA, WV	11	7%
4	AL, FL, GA, KY, MS, NC, SC, TN	36	22%
5	IL, IN, MI, MN, OH, WI	15	9%
6	AR, LA, NM, OK, TX	12	7%
7	IA, KS, MO, NE	5	3%
8	CO, MT, ND, SD, UT, WY	3	2%
9	AZ, CA, HI, NV, AS, FM, GU, MH, MP, PW	27	16%
10	AK, ID, OR, WA	7	4%

Half of the respondents were located in cities of 100,000 – 500,000 people, and one-third were located in cities of over 500,000 people. The remaining respondents, 14 percent, were located in cities or towns with fewer than 100,000 people. Nearly 75 percent of the respondents were also located within Title I EMAs.

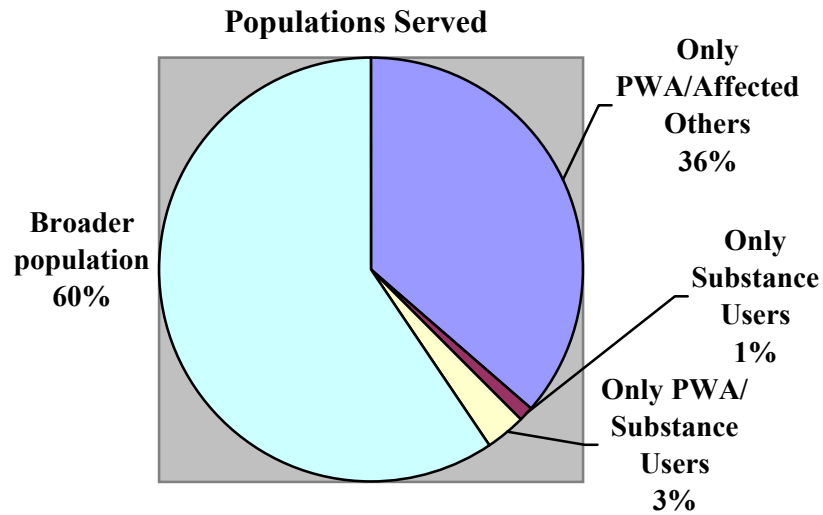
Agency Characteristics

The programs served a wide range of individuals with HIV – from less than twenty people to over four thousand people per year. Approximately half of the programs served from 100 – 500 clients/year.

Numbers of Clients Served

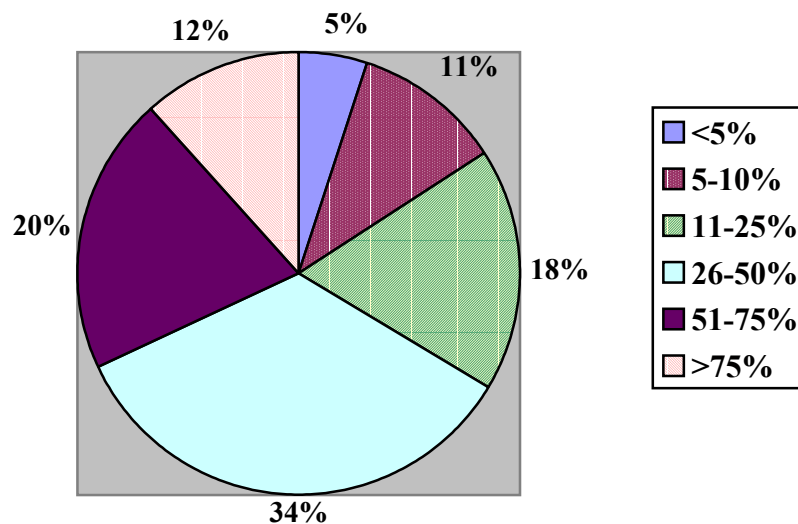


Over one-third of the programs were dedicated strictly to serving individuals with HIV, while four percent were dedicated to serving only substance users. Over half of the programs served a broader population, including programs with HIV and substance users in their client mix. These included hospital-based programs, community health centers, and local public health department programs. The chart below shows the different populations served by respondents.



Programs also varied in the percent of their HIV population that were substance users. Some programs reported that less than five percent of their HIV population were substance users, while others reported that more than seventy-five percent of their HIV population were substance users.

Percent of HIV Clients Who Are Substance Users in Programs Surveyed



Client Demographics

We asked the respondents to provide us with demographic information about their clients (age, gender, race/ethnicity). Despite our use of HRSA reporting categories, approximately twenty percent of the respondents were not able to provide us with demographic information in this manner. A significant number of agencies left the demographic tables blank or told us that they reported the information in a different format. However, we do know that twelve percent of the programs served a predominantly female population (more than 50 percent female), while the remaining programs served a predominantly male population.

It appears that the respondents also served fairly diverse ethnic/racial populations. Over half of the programs served Hispanics, and approximately three-quarters of the programs served African Americans. Several programs targeted services toward a particular racial/ethnic group, with more than seventy-five percent of their clients belonging to a single racial/ethnic group.

Of the one hundred sixty-five programs:

- Twenty programs targeted a Black population;
- Fourteen programs targeted a Caucasian population;
- Eight programs targeted a Hispanic population;
- One program targeted an Asian population; and
- One program targeted a Native American population.

Services

The agencies provided a range of on-site services to HIV positive substance users, including medical care, mental health care, substance use treatment, and support services. The following table shows the types of services provided on-site by survey respondents.

On-Site Services

Services Offered On-Site	Number	Percent
Medical, mental health, and substance use treatment	62	38%
Medical and mental health services	31	19%
Medical and substance use treatment	13	8%
Mental health and substance use treatment	2	1%
Medical services (no mental health or substance use treatment)	43	26%
Mental health services (no medical or substance use treatment)	3	2%
Substance use treatment (no medical or mental health)	4	2%
Support services only	4	2%
No on-site services ¹	3	2%

¹ Some respondents provided services such as outreach, case management, and transportation, but only at off-site locations.

A summary of these service categories shows that:

- Ninety percent of the programs provided medical services;
- Fifty-nine percent provided mental health services;
- Forty nine percent provided substance use treatment²; and
- Four percent did not provide any medical, mental health, or substance use treatment, but instead provided support services/and or served as a coordinating center for subcontracted service providers.

Cultural and Linguistic Capacity

The programs answered a series of questions about how they addressed the cultural and linguistic diversity of their clients. Sixty percent of the programs reported that they offered access to culturally sensitive services and provided examples of how they addressed diversity. All of these providers reported that some of their staff received training in cultural sensitivity or diversity issues in the past three years. Common topics included:

- Basic diversity training;
- Training that focused on the culture of specific populations served by the agency; and
- Training about substance use issues as they relate to culturally diverse populations.

Fifty nine percent of the respondents described other ways in which they addressed the cultural and linguistic needs of their clients. The most common way of addressing cultural issues was to hire clinicians from different racial or ethnic backgrounds who reflected the diversity of the agency’s clients. Activities used to address cultural and linguistic issues – in addition to staff training – are described in the chart below.

Other Ways of Addressing Cultural and Linguistic Needs

Strategy	# of agencies	%
None	97	41%
Hiring clinicians of different cultures	89	38%
Ensuring that translators/interpreters are available	32	14%
Making referrals to/having contracts with culturally specific orgs.	20	8%
Translating patient materials into different languages	16	7%
Hiring peer educators/counselors of different cultures	12	5%
Meetings/coalitions with minority organizations	7	3%
Seeking client input about services	6	3%
Hiring ASL interpreters	5	2%

² A follow-up study of a sample of these programs revealed that most of the agencies that reported they provided substance use treatment provided counseling services, but often did not employ certified or licensed addictions counselors in this role.

Most respondents reported that some of their HIV positive clients spoke a language other than English. Seventy-seven percent of the agencies served Spanish-speaking clients and 13 percent served Haitian Creole-speaking clients. Some agencies also served clients whose primary languages were Chinese, French, Portuguese, or a variety of African languages. One percent of the agencies reported that some of their HIV positive clients used American Sign Language.

Most of the respondents also reported that they employed staff who spoke languages other than English. Eighty-four percent of the agencies employed Spanish-speaking staff and 11 percent employed Haitian Creole-speaking staff. Some agencies had staff who spoke Chinese, Vietnamese or other Asian languages. Four percent of the agencies had staff who used American Sign Language. In general, the agencies employed staff who spoke most of the primary languages spoken by clients, with the exception of less common African, European, and Asian languages.

Program Models

One of the primary objectives of the survey was to identify programs that have implemented innovative strategies to serve HIV positive substance users. The different strategies can be grouped into the following general categories:

- Services that lower the threshold for HIV positive substance users to access care, such as drop-in services, extended hours, or home/shelter-based services;
- Services designed to engage and retain people in care, such as street outreach, mobile vans, peer support services and harm reduction programs; and
- Integrated services that facilitate the referral process, such as one-stop shopping for medical care, mental health and substance use treatment services; using multidisciplinary teams; and case conferencing.

Lowering the Threshold

All of the medical programs and almost three quarters of the mental health programs offered services that lower the threshold for accessing care. The table below describes how programs provided these services.

Service Accessibility

Program Type	Service	Percent
Medical Programs N=149	Walk-in services or same-day appointments	97%
	Home-based medical services	35%
	24-hour coverage	100%
Mental Health Programs N=98	Walk-in services or same-day appointments	90%
	Home-based mental health/support services	71%
	24-hour coverage	47%

Engagement and Retention in Care

Eighty-one programs provided substance use treatment services, usually outpatient counseling on-site. Of these, 90 percent took a harm reduction approach to treatment. However, of the programs that did not provide on-site substance use treatment, only 65 percent stated that they had a formal relationship with a substance use treatment program that offered a harm reduction approach.

Many of the respondents provided services that were designed to engage and retain clients. The table below describes these strategies.

Strategies for Engagement and Retention

Strategy	Percent
Street/neighborhood outreach to engage new clients or retain clients	54%
Mobile van for outreach, education, medical care, support services	22%
Peer advocacy or education	50%

Coordination and Integration

Finally, a substantial number of agencies operated programs that integrate medical, mental health, and substance use treatment services.

Strategies for Coordination and Integration of Care

Strategy	Percent
“One-stop shopping” for HIV medical care, mental health, and substance use treatment	38%
Multi-disciplinary team approach to care	95%
Case conferences with referral agencies	77%

When asked to describe other innovative or effective features of their agency’s service delivery program, respondents mentioned a wide range of services and strategies. These included:

- Support services such as clothing, food, childcare, and transportation;
- Money management training;
- Housing advocacy;
- Services and strategies to support adherence to antiretroviral therapy;
- Recreational activities;
- Complimentary therapies such as acupuncture or massage;
- Strategies to provide services in rural or geographically distant areas;
- Domestic violence education, counseling, and services; and
- Prison linkages.

A few programs also mentioned their work in systems advocacy to change laws, regulations and funding priorities as program innovations.

Barriers

Respondents noted many significant challenges to providing services to HIV positive substance users. We asked respondents to rank the five most important barriers to care that they encountered as they developed and implemented their programs. Nearly half of the respondents reported that they encountered difficulty in referring clients to substance use treatment because there were insufficient substance use treatment services for their HIV positive clients. In addition, providers stated that once people were receiving treatment, it was difficult to retain them in care.

A host of other barriers to care were described by respondents. The table below describes the barriers encountered and the percent of respondents who listed each barrier as one of their top five obstacles to care.

Top Five Barriers to Care in Order of Rank

Barrier to Care	Percent of Respondents
Difficulty retaining people in substance use treatment	47%
Lack of substance use treatment slots	45%
Difficulty retaining substance users in medical care	38%
Lack of housing	34%
Duration of treatment is too short	33%
Lack of treatment programs for women and children	26%
Medical and substance use treatment services are not co-located	25%
Lack of harm reduction programs	24%
Fear of HIV disclosure in substance use treatment programs	22%
Lack of insurance coverage	21%
Limited transportation	18%
Clients get lost between referrals	16%
Lack of primary care provider expertise in substance use	13%
Substance use treatment providers lack HIV expertise	13%
Lack of outreach	12%
Substance use treatment providers are judgmental	7%
Difficult to recruit/retain bilingual staff	7%
Primary care providers are judgmental toward substance users	6%
Substance use treatment providers lack cultural sensitivity	6%

The survey offered respondents the option of ranking barriers that are attributable to the attitudes and skills of providers, such as judgmental attitudes, the lack of cultural sensitivity, or the fact that primary care providers are not sufficiently knowledgeable about substance use. Only a few of these provider-specific issues were reported by respondents, and they were not ranked highly.

Program Funding

The sample for this study consisted of programs that receive funding from Titles III, IV, and SPNS of the Ryan White CARE Act. However, many of the agencies also received Title I and II funding. The table below shows the percent of respondents who received funding from each of the CARE Act Titles.

CARE Act Funding

Funding Source	# of Respondents	% of Respondents
Title I	68	41%
Title II	100	61%
Title III	130	79%
Title IV	44	27%
SPNS	32	19%

In addition to CARE Act funding, the respondents reported many other funding streams. The table below describes the percent of programs that received funding from these other sources.

Funding Sources

Funding Source	# of Programs	% of Programs
Medicaid	128	78%
Private insurance	103	62%
Medicare	102	62%
State funding	87	53%
Self-pay	83	50%
Non-government grants	46	28%
Fundraising	41	25%
County funding	33	20%
City funding	20	12%
CSAT/SAMHSA funding	15	9%

Medicaid was the most common source of funding for the respondents. The majority of the agencies provided medical care to low-income people, and Medicaid typically covers these services. Approximately one third of the programs reported that they have contracts with managed care plans to pay for services. Nearly all of the managed care contracts included HIV medical care, and approximately half covered mental health services and/or substance use treatment.

Many of the respondents described the challenges of funding their services and programs. One of the biggest concerns was the lack of awareness of, or interest in, the needs of HIV positive substance users among legislators, government agencies, and private foundations. This lack of awareness or interest resulted in the absence of funding for

substance use treatment, outreach and retention programs, and support services for HIV positive substance users.

Closely linked to this challenge, and the second most commonly mentioned funding issue, was the absence or inadequacy of Medicaid funding. Some states do not provide Medicaid coverage for substance use treatment and many states under-fund this service. A few programs also mentioned inadequate Medicaid reimbursement rates for HIV medical care.

Approximately ten percent of the respondents reported that they had been unable to access funding sources other than HRSA, such as Medicaid, state funds, block grants, or SAMHSA funding. Related to this, an equal number of respondents stated that they were too busy with direct care to write grants, or they were too dependent on grant funding cycles to ensure continuity of services.

DISCUSSION

The respondents to this survey were very diverse, representing organizations that ranged from very small community-based organizations to major medical centers. They were located in all regions of the country, including major cities and rural areas, and served anywhere from 15 to 4,000 people living with HIV per year. Their client populations were diverse in race, ethnicity, and culture. Although one third of the programs exclusively served people with HIV, over half served a much broader population and provided services to HIV positive substance users in the context of a broader patient mix. The services provided by the respondents included every conceivable combination of HIV medical care, substance use treatment, mental health, and support services.

While the respondents to this survey were diverse, it is important to acknowledge that they were not necessarily representative of the medical care or substance use treatment systems in general. Rather, they represent the cutting edge of the provider community as they had made a conscious decision to serve HIV positive substance users, and had successfully obtained CARE Act funding for these services. Thus, they were more likely to reflect best practices than the provider community in general. However, there is much that can be learned from their program models, interventions, and ongoing challenges that may be useful to the service delivery system in general.

Some of the features that made these programs stand out were their efforts to create culturally sensitive services; to integrate medical, mental health, and substance use treatment services; and to integrate harm reduction principles into their service delivery approach. In addition, most programs recognized the important role of outreach and support services in retaining clients in care. At the same time, there was some variability in provider performance in these areas. This variability points to areas in which HRSA might promote improved service delivery to HIV positive substance users among their grantees.

Sixty percent of the agencies provided some form of cultural sensitivity training for their staff, and 59 percent addressed cultural issues in other ways, such as collaborations with community-based organizations that provide culturally competent services. On the other hand, 40 percent of the agencies did not provide any staff training in cultural issues, suggesting there is still much work to be done in this area.

Most respondents recognized the importance of providing services in an integrated manner, and they used several different strategies to accomplish this goal. For example, many of the agencies that provided medical services also provided mental health and/or substance use treatment services on-site. Some of the substance use treatment providers also provided on-site HIV primary care. Many of the agencies provided support services on-site. Almost all of the agencies used a multi-disciplinary team approach to care. On the other hand, 25 percent of the agencies stated that the absence of co-located services or the fact that many people got lost in the referral process were major barriers to care for their clients. This suggests that HRSA should consider funding strategies that enhance the capacity of grantees to offer one-stop shopping for HIV medical care, mental health services, substance use treatment and support services. It is important to note that substance use treatment is the service least likely to be provided in settings that are otherwise fairly well integrated.

The majority of respondents to the survey made their services easily accessible. For example, nearly all of the agencies offered same day appointments for care or walk-in services, and nearly 75 percent of the mental health providers offered home-based services. However, a much smaller number of agencies (35 percent) offered home-based medical services. Although challenging, this strategy may be very effective in reaching HIV positive substance users who live in rural areas, or shelters and single room occupancy hotels.

Most of the respondents viewed harm reduction as an important service delivery approach. Nearly all of the HRSA-funded programs that provided substance use treatment services, half of the study sample, offered a harm reduction approach or model of care. However, 35 percent of the other programs stated that the lack of access to harm reduction approaches was a major barrier to care for their clients. This suggests that the substance use treatment programs in the broader community were not as likely as CARE Act grantees to integrate harm reduction approaches into their programming. Therefore, HRSA may want to consider investing in harm reduction training and programming to expand access to these services for HIV positive substance users.

Many respondents realized that outreach and support services were key to the process of engaging clients in care and keeping them engaged. Approximately half of the programs conducted street outreach and 22 percent operated mobile vans. More than half of the programs provided one or more of the following support services – transportation, housing assistance, or peer support. However, there were still significant gaps in programs' ability to conduct outreach or provide the support services that are critically important to people living with HIV who have substance use disorders.

One of the study limitations is that all data was self-reported. This limitation assumes particular importance when assessing barriers to care for HIV positive substance users. The barriers reported were the barriers as experienced and reported by providers in trying to access services for their consumers, rather than the barriers experienced by consumers themselves. For example, the survey offered respondents the option of ranking barriers that are attributable to the attitudes and skills of providers, such as judgmental attitudes, the lack of cultural sensitivity, or provider expertise in substance use. Respondents did not commonly mention these issues, and when they were mentioned, they were not ranked highly.

However, issues of provider attitudes and skills appear frequently in the literature, and were also reported by our consumer key informants as barriers to care. The fact that respondents did not often report these issues may be due to a reluctance to acknowledge shortcomings, or may be due to the sample selection. It is possible that the study sample may, in fact, perform better around provider-specific issues because they have chosen to address the needs of HIV positive substance users, and have developed the skills to do so.

Finally, it is important to review the financing issues for the study respondents. Many of the respondents reported difficulties in financing integrated models of care. Insurance coverage and entitlements such as Medicaid or Medicare were common sources of funding for medical services, but did not pay for outreach, case management, adherence support, or treatment readiness assessments. Coverage for outpatient substance use treatment was more problematic. In some states, Medicaid does not cover substance use treatment other than detoxification in an inpatient facility. However, even in states where substance use treatment is a Medicaid-covered service, providers faced barriers, especially in integrated programs. For example, a program that employs a certified addiction counselor to provide treatment readiness services and outpatient counseling is not able to access Medicaid or insurance payments unless the host organization holds a substance use treatment license, and is credentialed by the purchasing authority.

Furthermore, many states offer medical care or substance use treatment for low-income individuals eligible for Medicaid under managed care arrangements. However, only one fifth of the respondents had contracts with managed care organizations, which could be an important funding sources for services designed to respond to the needs of HIV positive substance users. Many of the respondents reported that they were dependent upon grant cycles, but were often too short-staffed to write proposals. Nearly half of the programs depended on client payments, and over one quarter of the programs relied upon non-governmental grants and private fundraising to provide the funding to support services for HIV positive substance users.

There is still a major role for HRSA funding to fill in the gaps in services. These gaps include:

- The time for staff training in HIV and substance use;
- The time for staff training in cultural issues;
- The time for case conferencing;

- The time for home visits;
- The administrative and clinical effort needed to integrate health care with addiction and mental health services;
- Services and staff to support adherence to HIV treatment;
- Services and staff to assess readiness for substance use treatment;
- The availability of substance use treatment programs that accept and are responsive to individuals with HIV; and
- Financial support for substance use treatment integration with HIV medical care.

Furthermore, there is a technical assistance role for HRSA in helping programs to develop the skills to access other funding streams, and in supporting training around the development of integrated and innovative models of care.