Title II Survey: Services for HIV Positive Substance Users

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Introduction

This survey of state programs, funded under Title II of the Ryan White CARE Act, was the second in a series of surveys designed to assess the current work of CARE Act grantees in providing services for HIV positive substance users. The goal of this study was to obtain information about what services are provided to HIV positive substance users through Title II funding, in the context of the overall delivery system for substance abuse treatment services in each state. It is hoped that this information will assist HRSA in developing a technical assistance agenda to support the improvement of service delivery to HIV positive substance users, and that innovative practices identified at the state or program level can be adapted by other funders and providers to improve service delivery.

Title II Background

HRSA awards Title II grants to fifty states, the District of Columbia, Puerto Rico, Guam and the U.S. Virgin Islands on a formula basis to provide health care and support services for people living with HIV. These grants are usually administered by the state Departments of Public Health. States with more than one percent of the total AIDS cases reported nationally during the previous two years must contribute funding to match the Federal grant. States can fund a wide array of health care and support services through Title II funds, including substance abuse treatment, but must earmark a specific amount to pay for HIV medications for individuals with no or inadequate health insurance coverage.

States can either provide services directly or through Title II consortia. Consortia consist of health care and support service providers, community-based organizations, and consumers that plan and deliver services for people with HIV. In either system of service delivery, the states or consortia are required to develop a plan for prioritizing service funding based on existing data and a needs assessment process. The Title II state programs are required to develop a Statewide Coordinated Statement of Need that identifies important gaps in services for people with HIV through a review of existing needs assessments and other data. Consortia may set service priorities in a specific section of the state, but must conduct their own needs assessment.

The study described below was designed, in part, to obtain information about the extent to which Title II programs are familiar with the needs of HIV positive substance users, and the adequacy or shortcomings of the existing service delivery system in meeting their needs. We were also interested in knowing what actions the Title II programs are taking to address these needs, and to identify innovative programs or practices in serving the population.

Data Collection and Analysis Methods

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

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

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 II grantees was obtained from HRSA. Prior to survey distribution, the Director of HRSA's HIV Bureau 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.

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 the 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 II-Funded Substance Abuse Treatment Services

Forty-seven states responded to the survey, a response rate of 87 percent. Eighteen of these states (38 percent) fund some form of substance abuse treatment through Title II funds. These funds support substance abuse treatment programs provided by ninety-two provider agencies across the country. The most commonly funded Title II substance abuse treatment service is outpatient counseling, with twenty-one percent of the Title II states funding this service. Other forms of treatment funded are described in the table below.

Substance Abuse Treatment Services Funded Under Title II

Service Type	**% of States Funding Service**
Outpatient Counseling	21%
Methadone Maintenance/LAAM	13%
Residential Treatment	9%
Acute Detoxification	9%
Acupuncture Detoxification	4%
Inpatient Treatment	2%
Other (collateral, support services)	11%

Special Programs

Only 17 percent of the states (eight) use Title II funds to promote substance abuse treatment programs that target under-served populations. Programs for HIV positive women and women and their children are the most common. The table below lists the

targeted populations and the number of states that report funding special substance abuse treatment programs for these groups.

Programs For Special Populations Funded By Title II

Special Population	# of States with Programs
Women	7
Women and their children	4
Incarcerated/recently incarcerated	4
African Americans	3
Adolescents	2
Latinos	2
Other minority populations	2
Homeless	1
Mentally ill	1
Gay and/or Lesbian	0

As with Title II funding in general, the largest service category among programs for special populations is outpatient counseling. This is followed by residential treatment and detoxification. Other services provided in these targeted programs include outreach, peer support, and methadone maintenance.

Harm Reduction

Fifteen percent of the States report that they fund some form of harm reduction program through their Title II funds. A few of the states included methadone maintenance programs in their descriptions of harm reduction programs, but most did not. The most commonly described harm reduction services include pre-treatment counseling, outreach and education, and prevention case management.

Overall Substance Abuse Treatment Delivery Systems in the States

It is important to place Title II funding in the context of the overall delivery system for substance abuse treatment services in each of the states, because different funding

allocation decisions will be made based on the adequacy of other resources. We asked the Title II programs to provide a general description of the substance abuse treatment delivery system, including its strengths and weaknesses for people with HIV. In addition we asked about the general availability of harm reduction services not funded by Title II.

Eighty percent of the Title II programs provided a description of the substance abuse treatment delivery system in their state. Most of these descriptions included the types of services available and how people with HIV were accepted/not accepted by the mainstream system of care. Thirteen states described specific harm reduction programs, while three states reported that there were no harm reduction options. The remaining states (sixty-six percent) reported that they did not know about the availability of harm reduction services or were silent on this issue.

As expected, there was variation across states in describing system strengths and weaknesses. Examples of statements about some of the stronger systems include:

> "…we use a combination of state and federal grant funds as well as Medicaid reimbursement to support HIV prevention, primary care, and support services in substance abuse treatment settings. This…program..offers a range of HIV services that are co-located with substance abuse treatment in varied modalities (e.g. methadone maintenance, MTA, drug-free residential, outpatient, harm reduction). The majority of clients served through this initiative are minorities, and approximately 40 percent are women."

> "In FY99, state-funded substance abuse providers reported over 70,000 admissions. Clients were admitted to outpatient, intensive outpatient, and residential services….[The state agency] also provides $2.3 million in funding for thirteen HIV early intervention projects covering the entire state….services include HIV counseling and testing, HIV case management, medical care services, mental health treatment, outreach and other prevention services….a communicable disease specialist…supports six regional training centers."

> "[The state] offers a complete array of substance abuse services for HIV positive persons, all of which are available only through non-CARE Act funding….One of the significant factors in placement decisions is the health status of the individual, so HIV is always taken into consideration. Persons with HIV are a priority population for detox, methadone, and inpatient care….[The state] has had a harm reduction program since 1993."

Other states report a very different situation:

> "Medicaid will pay for two outpatient chemical dependency services: individual and group, but only for youth and only through state-approved chemical dependency programs….Medicaid does not cover inpatient treatment….It does pay for four days of detox for adults. Other resources include….an intensive outpatient program….[and] a methadone pilot program….there is a two to three week wait if the patient can not pay."

> "The issues for [the state] are geographic. Where there is population, there are treatment options. Where the population is widely distributed, the service options are few if non-existent."

> "Treatment agencies provide residential (on a more limited basis) and outpatient services….We do not have Medicaid benefits for substance users other than pregnant women. Harm reduction services are hard to describe."

> "[The state agency] is the primary funding source for substance abuse treatment. Limits to its usefulness include a set limit of visits and set reimbursement rates which don't seem to allow flexibility in serving HIV clients. Harm reduction programs…are primarily funded through housing sources, e.g. Shelter Plus Care."

Some of the more common weaknesses include insufficient treatment capacity, difficulty obtaining any services in rural areas, program siting problems, and the lack of different options such as residential care or detox. Strengths include comprehensive

systems of care, integration of HIV medical care and substance abuse treatment, and the use of Title II funds to provide wrap-around services for HIV positive substance users. One quarter of the states report that people with HIV receive priority status for entering treatment or the existence of specialized HIV substance abuse treatment programs in the state.

Barriers to Care

We asked the Title II programs to identify and rank the top five barriers to care for HIV positive substance users in their state. We provided a list of specific barriers and allowed the programs 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 commonly cited systemic barriers to care are listed below.

Systemic Barriers to Care

Systemic Barriers	Cited as one of top 5 barriers
Lack of housing options	55%
Insurance coverage for substance abuse treatment is lacking or inadequate	53%
Too few residential programs	53%
Too few detoxification programs/beds	42%
Lack of transportation	37%
Duration of treatment is too short	34%
Too few outpatient programs	29%
Too few methadone/LAAM programs	29%
Government agencies do not collaborate in planning	24%
Little capacity for after-hours HIV medical care	16%
Waiting time for medical visits is too long	13%

Inadequate insurance coverage and the lack of housing and residential substance abuse treatment are reported to be one of the top five barriers by more than half of the states. In addition, the shortage of detoxification beds is very common, mentioned as a barrier to care by more than three quarters of the states, and ranked as one of the top five barriers by 42 percent. In the comments section of the survey, some states report that

they had no methadone programs, and only one publicly-funded inpatient or detoxification program. Other states mention insurance limits and the inadequacy of Medicaid funding.

The shortage of transportation and outpatient programs are cited as barriers to care in more than half of the states, but do not rank as highly when ordered for importance. One third of the states report that the short duration of treatment was a major barrier to care. The two issues specific to HIV medical care, after-hours services and the waiting time for medical visits, are reported as barriers to care in many states, but do not rank as highly in importance. However, the inadequacy of insurance coverage and lack of treatment slots are viewed as bigger problems than the health care capacity barriers.

For programmatic problems, the most commonly cited barriers to care are listed below.

Programmatic Barriers

Programmatic Barriers	**Cited as a barrier**	**Cited as one of top 5 barriers**
Women with children are not supported in programs	57%	47%
Harm reduction/recovery readiness services are not provided	57%	38%
Substance abuse treatment providers need more HIV training	57%	35%
Lack of outreach to bring people into care	70%	35%
HIV positive substance users fall through the cracks between services	70%	35%
HIV primary care clinics lack walk-in services	55%	29%
Primary care providers do not screen for substance abuse	62%	24%
Language barriers	62%	24%
Support services are not linked to HIV medical care or substance abuse treatment	60%	21%
Substance abuse treatment programs are not culturally sensitive	53%	21%
Primary care providers do not know about substance abuse treatment options	62%	21%
Problems siting substance abuse treatment programs	30%	18%
Primary care providers lack cultural sensitivity	66%	18%
Long waits at HIV primary care sites (when a person presents for care)	40%	9%
Substance abuse treatment programs ignore the medical issues	30%	6%

The most commonly cited barriers to care revolve around engaging and maintaining people in care – the lack of outreach to engage people in care, and the frequency with which people fall through the cracks between systems. Problems within health care programs – the lack of cultural sensitivity, lack of knowledge about substance abuse, language issues, and the absence of linkages to support services – are also common barriers to care, cited by more than 60 percent of the states. However, when we look at the significance of certain problems, as opposed to the frequency, the absence of programs to support women and children ranks first, followed by the absence of harm reduction/recovery readiness programs.

Other important barriers include issues related HIV knowledge among substance abuse treatment providers, culturally sensitive substance abuse treatment, and the lack of walk-in services for medical care.

Sources of Information for Planning and Decision-Making

We asked a series of questions to determine what information about services for HIV positive substance users Title II programs use for planning purposes. Most of the states (81 percent) have information on the epidemiology of HIV in the state, and three quarters of the states conduct consumer surveys or focus groups to supplement this information. Sixty percent also conduct provider surveys, but less than half of the states receive data about the number of substance abuse treatment slots available or the lengths of waiting lists for treatment. A little more than half of the states receive data about other funding streams for medical or substance abuse treatment services as part of the planning process.

Gaps In Knowledge

There are substantial gaps in the information about the unmet needs of HIV positive substance users available to Title II programs for their needs assessments. For example, as part of the barriers to care section of the survey, we asked Title II programs if any of their information about barriers comes from a needs assessment. Only fifteen to twenty-five percent of the states respond that *any* of the issues cited as barriers are documented through a needs assessment. The barriers to care most likely to be documented include transportation, housing options, detoxification beds, inadequate health insurance, and the

absence of harm reduction services. However, even these barriers are only documented by five to seven states. Many of the barriers to care are documented by only one state. These include most of the primary care capacity issues, including waiting time for medical visits, walk-in services, primary care provider capacity to screen for substance abuse, and the absence of linkages between primary care, substance abuse treatment, and mental health. Other barriers documented by only one state include many of the substance abuse treatment issues, including the ability of substance abuse treatment providers to address HIV and medical issues, the lack of outreach to engage people in care, and problems in siting substance abuse treatment services. Cultural sensitivity barriers among primary care providers and substance abuse treatment issues are only documented in two states.

Many states also report that they do not know if certain issues are barriers to care. For example, half of the states do not know if there are problems in siting substance abuse treatment programs, and one third of the states do not know if there are sufficient methadone maintenance slots, or if insurance coverage is adequate. One third of the states also do not know if the duration of treatment is sufficient in most programs, if there are long waits for medical visits, or if substance abuse treatment providers have the capacity to address HIV medical issues.

Although half of the states report receiving information about other funding streams for services in general, many do not know about funding for substance abuse treatment services in specific detail. For example, one third of the Title II programs do not know if Medicaid pays for detoxification services or residential treatment in their state, or if another state agency funds detoxification services. Title II programs are even less knowledgeable about city, county, Medicare, or Center for Substance Abuse Treatment funding for substance abuse treatment. This lack of knowledge or information points to important gaps in the planning process for serving HIV positive substance users. The table below summarizes the level of knowledge among Title II programs about other funding sources for substance abuse treatment.

Percent of Title II Programs That Do Not Know About Funding Sources for Substance Abuse Treatment

Funding Source	Detox	Outpatient	Methadone	Residential
Medicaid	32%	23%	26%	30%
Other State funds	36%	28%	36%	32%
County funds	49%	45%	47%	45%
City funds	49%	43%	45%	43%
Other CARE Act	43%	38%	38%	38%
Medicare	51%	47%	49%	47%
Private Insurance	38%	32%	38%	32%
CSAT	45%	38%	38%	38%
Veterans Admin.	40%	32%	45%	32%

Standards of Care

More than two-thirds of the states (68 percent) have developed standards of care for some of the services they fund through Title II. Although most of these states have standards of care for case management services, only one quarter have standards of care for substance abuse treatment, and one third have standards of care for HIV medical care. Very few of the standards for case management and medical care specifically address services for HIV positive substance users.

Standards of Care

Service Area	Any Standard of Care	Standards Specific to Substance Use/Users
Substance Abuse Treatment	26%	N/A
HIV Medical Care	34%	4%
Case Management	62%	9%
Supported Housing	30%	2%

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

- Expectations regarding referrals and linkages;
- Expectations regarding assessment, particularly of readiness for change;
- Provision of harm reduction counseling;
- Annual assessment of provider skills; and
- Assessing the effectiveness of outreach and obstacles active users face in getting into treatment.

Innovations

Six of the Title II programs reported that they made special attempts to assess the needs of HIV positive substance users. These included several surveillance studies and focus groups, one of which trained outreach workers to interview active injection drug users. Four of the programs have initiated specific outreach projects to engage people in treatment and care, including poster campaigns, promoting early intervention and outreach programs, and implementing a service fund to pay for the treatment of choice as requested by individual consumers.

Discussion

The state agencies responsible for Title II funding are uniquely positioned to identify system strengths and weaknesses in serving HIV positive substance users for several reasons. Most of them reside within state Departments of Public Health, and have access to planning resources and other state funding for HIV-related services. Some of them are also located in the same state agencies as the state authority for substance abuse treatment. However, the structure of the Title II funding and service allocation process puts many of the Title II grantees at a disadvantage. For example, many funding priority decisions are made at the local level by HIV consortia who may or may not have sufficient planning information or resources to conduct planning activities.

What stands out about these results is the general strength of Title II grantees in describing the overall service delivery system for HIV positive substance users. This contrasts with the absence of hard data for planning, and the small percentage of grantees

who use Title II funds to address gaps in care for this population. Given the many barriers to care cited and system weaknesses described by grantees, it is surprising that only one third of the Title II programs fund substance abuse treatment. And only eight states use Title II funds to support substance abuse treatment programs for under-served populations.

This conclusion is further supported by the fact that many of the states had difficulty supplying demographic data about people receiving substance abuse treatment services through Title II funds. Only 56 percent of the grantees that fund substance abuse treatment services could supply racial/ethnic data on the populations served, and only fifty percent could supply information on gender. In several cases, we were referred to consortia subcontractors for this information.

Another possible explanation for the lack of activity at the state level is that this survey included all states, territories and the District of Columbia. The states with the highest prevalence of HIV are also home to Title I EMAs that receive separate funding from HRSA. Thus, the states may rely upon the Title I programs to focus on substance abuse treatment and medical/support services for substance users, while the Title II programs focus on rural populations and smaller cities. In states with smaller populations and lower HIV prevalence, substance abuse may not be as big an issue as access to basic medical care and medications.

Regardless, the fact remains that there are serious gaps in the information available to states and consortia when they make decisions around funding priorities. Information about funding streams, insurance coverage (especially Medicaid), treatment slots, and waiting lists need to be available and considered by all states and consortia. Specific questions about primary care program capacity to serve substance users and substance abuse treatment capacity to address HIV-related issues needs to be incorporated into provider and consumer surveys. Similarly, specific questions about outreach strategies, linkages, and support services needs to be incorporated into surveys. Finally, each state and consortium needs to identify strategies for obtaining information about the needs of special populations in accessing services. Based on the survey results, they appear to do a better job of assessing the needs of women with children, but not as well at assessing

the needs of African Americans, Latinos, other racial/ethnic minorities, the homeless, adolescents, recently incarcerated individuals, or the gay/lesbian population.

It is also important to acknowledge that some states have been very innovative in targeting resources to support HIV positive substance users. Eight states have used Title II funds to support dedicated programs for special needs populations. Seven states have funded harm reduction strategies, and in some cases this has resulted in broader provider acceptance of this approach. Other states have been creative in targeting limited resources to enhance services at substance abuse treatment programs by funding HIV medical care or support services. A few states have used Title II funds to purchase dedicated slots within mainstream substance abuse treatment programs or to provide HIV support service capacity in these programs.

Although most of the work in designing and implementing innovative programs for HIV positive substance users rests with the actual service providers, it is essential for these providers to have public policy support and funding. The experiences of states that have provided this support, and have engaged in the collaborations necessary to make program implementation possible, may contain valuable lessons for other Title II programs.