

## **SPNS Update Report to Grantees**

# **INNOVATIVE PROGRAMS FOR HIV POSITIVE SUBSTANCE USERS**



Mari-Lynn Drainoni, PhD  
Kate Brown  
Health and Disability Working Group  
Boston University School of Public Health

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## **Summary**

The Evaluation and Program Support Center (EPSC) for Innovative Programs for HIV Positive Substance Users was established by HRSA to address the unique challenges of providing appropriate services to HIV positive people who are substance users. The four-year initiative began in October of 1999 and will be completed in September 2003. During the project's first two years, the EPSC conducted an extensive information-gathering activities culminating in the development and pilot testing of a set of guiding principles for programs serving substance users living with HIV/AIDS. A training program for Ryan White providers is now being developed in conjunction with the AIDS Education and Training Centers based on the findings of the first two years

The EPSC is based at the Health and Disability Working Group (HDWG), Boston University School of Public Health. This initiative is different from most other SPNS initiatives in that it is not a cross-site evaluation of a set of demonstration projects. Instead, the EPSC draws on the expertise of currently funded Ryan White CARE Act providers and other HIV treatment providers who serve substance users living with HIV.

## **Goals**

The goals of the initiative are to:

- ❖ Advance the body of knowledge regarding innovative interventions for HIV-positive substance users;
- ❖ Increase understanding of the interventions that improve the participation of HIV-positive substance users in obtaining primary health care, substance abuse treatment, and supportive services;
- ❖ Develop a set of guiding principles for use by HIV medical care, substance abuse treatment, care coordination, and outreach programs; and,
- ❖ Provide information about evaluation and training to assist HRSA in planning for future activities.

## **Background and Statement of Need**

Since the beginning of the AIDS epidemic, injection drug use has directly and indirectly accounted for more than one-third of AIDS cases in the United States. Of the 48,269 new cases of AIDS reported in 1998, 15,024 (31 percent) were associated with injecting drug use.

Racial and ethnic minority populations in the U.S. are most heavily affected by IDU-associated AIDS. In 1998, 36 percent of AIDS cases were IDU-related among both African Americans and Hispanic adults and adolescents, compared with only 22 percent of AIDS cases among white adults and adolescents. In addition, a larger proportion of AIDS cases among women are attributed to injection drug use (59 percent) than AIDS cases among men (31 percent).

Noninjection drugs (such as “crack” cocaine) also contribute to the spread of the epidemic when users trade sex for drugs or money, or when they engage in risky sexual behaviors that they might not engage in when sober. One CDC study of more than 2,000 young adults in three inner-city neighborhoods found that crack smokers were three times more likely to be infected with HIV than non-smokers.

The HIV/AIDS Bureau recognizes that substance abuse treatment is an important component of HIV care for a large proportion of people who are infected, especially now that the new therapies require consistent and long-term adherence to the medications. In 1998, 8.8 percent of Ryan White CARE Act Title I, II, and III dollars were used for substance abuse treatment and counseling. In addition, the importance of substance users having a range of enabling services to ensure access to primary health care is well understood by Ryan White providers. Numerous models of HIV care targeting people with HIV who are substance users are being implemented in the United States. However, little is known about the optimum substance abuse treatment modalities for people with HIV or effective interventions to assure them access to comprehensive HIV care. The EPSC is the SPNS project funded to respond to this need. The project targets HIV and substance abuse treatment providers, health care policymakers, and AETCs and other Ryan White CARE Act grantees.

### **Evaluation Program Support Center Grantee**

The Evaluation Program and Support Center (EPSC) for Innovative Programs for HIV Positive Substance Users is based at the Health and Disability Working Group (HDWG) at the Boston University School of Public Health. The HDWG is a technical assistance, research, and training center whose area of expertise is the development and evaluation of health care and support systems for individuals with disabilities, chronic illnesses, and other special needs, particularly in a managed care environment. The HDWG works with a wide range of public sector agencies, provider organizations, health plans, and consumer/advocacy groups to develop and evaluate innovative care delivery systems. Its cross-population focus includes physical disability, chronic illness such as HIV/AIDS, serious mental illness, developmental disability, children with special health care needs, and children in state custody.

### **ESPC Phase One Milestones**

The first phase of the EPSC’s work is complete. The activities of the Center culminated in the completion of several products. The activities included a review of the published and unpublished literature; surveys of over 500 CARE Act-funded grantees and HIV positive substance users; site visits to twelve innovative programs; and the development of a set of guiding principles. A series of documents are available describing the work and its findings.

- **Literature review:** The EPSC conducted a review of the published and unpublished literature regarding treatment of substance users with HIV infection. The report contains discussions of: the epidemiology of substance use and HIV;

the relationship between substance abuse and HIV treatment delivery systems; the status of performance standards for care people with HIV who are substance users; barriers to care for demographic groups of people with HIV who are substance users; and, innovative programs and interventions that have been developed for people with HIV who are substance users. The report is available at the Health and Disability Working Group web site: [www.hdwg.org](http://www.hdwg.org)

*Performance Standards, Barriers to Care and Innovative Program Models for HIV-Positive Substance Users: A Review of the Literature*

- **Surveys and key informant interviews:** The EPSC team surveyed more than 400 CARE Act-funded grantees and more than 100 providers funded by other sources, surveyed approximately 40 HIV-positive substance users, and completed interviews with more than 50 key informants. The results of all the surveys have been analyzed and written up. The reports contain sections on successful program models and strategies, barriers to care for people with HIV who are substance users, the performance standards that have been identified, and program evaluation. The reports are available at the Health and Disability Working Group web site: [www.hdwg.org](http://www.hdwg.org)

*Title I Survey: Services for HIV Positive Substance Users*

*Title II Survey: Services for HIV Positive Substance Users*

*An Analysis of HRSA-Funded Services for HIV Positive Substance Abusers: A Study of Ryan White CARE Act Title III, Title IV, and SPNS Providers*

*Professional Expert Key Informant Report on HIV and Substance Abuse*

*Consumer Key Informant Findings on HIV and Substance Abuse*

- **Identification of innovative program models:** Based on the results of the survey work, the EPSC developed a set of criteria for defining innovative models of care and identified over 50 programs that met the criteria. An in-depth telephone survey was developed and conducted with these programs. Twelve of the programs were selected as representing an important range of innovations. Site visits were conducted to these sites to examine the range of innovations in different program models; interventions for different populations; specialized case management systems; linkages between primary medical care, substance abuse treatment, and support services. A summary of common themes and individual case studies of the findings will soon be available on the HDWG website.
- **Guiding principles:** Working with a series of experts, and based on the body of knowledge gained from the phase one activities, a set of guiding principles have been developed for primary HIV care, substance abuse services, outreach services, and care coordination. These principles were developed to assist HRSA

and other purchasers of service to establish a standard of care for the delivery of services to HIV positive substance users. They supplement existing standards by addressing the special needs of people with HIV who also have substance use issues. The standards are currently under review by HRSA and other federal agencies, and will be made available by HRSA.

## **Phase Two Initiative**

Using the knowledge gained from the first phase of work, the EPSC is developing and will pilot test a training program and a training curriculum for providers of services to HIV positive substance users. The program takes a train-the-trainer approach. The objectives of the training program are to:

- Provide training to substance abuse treatment providers, HIV medical care providers, and HIV support service providers that enhances their capability to serve HIV positive substance abusers;
- Encourage Title I and Title II grantees to collaborate with state and local agencies responsible for the funding of substance abuse treatment services in order to promote policies and funding initiatives that support collaboration and service integration at the provider level;
- Provide specific assistance to programs in evaluating their performance in serving HIV positive substance abusers, and using this information to improve performance; and
- Promote the capacity to sustain this level of technical assistance by engaging AETCs and local experts in curriculum development and a train-the-trainer program.

The training program will offer providers in the field, including AETCs, HIV medical care, substance abuse treatment providers, and Title I and II grantees the opportunity for cross-training in important issues to address in serving HIV positive substance users. The training programs will include several different modules and offer the trainees an opportunity to discuss barriers to care in their own communities and think about solutions. Approximately 60 individuals across six AETC regions nationally will be trained by a group of nationally recognized expert trainers in the following topics during January of 2003:

- An Overview of HIV and Substance Abuse: The Indisputable Connections
- Harm Reduction
- Outreach and Engagement in Care
- Adherence and Retention in Care
- A Multidisciplinary Approach to Care

Learning from innovative programs elsewhere and determining how to apply these lessons to specific programs requires both a national and a local perspective. The series of training programs will achieve a balance between the desire to disseminate successful

practices as broadly as possible, and the need to address very local concerns in order to effect meaningful change.

Following the national training, the train-the-trainer component will be incorporated through collaborations with local AETCs, who will serve as the convener of a local training session. HDWG will work with HRSA and each AETC to ensure that that the training programs can be sustained within the region beyond the grant period.

EPSC has worked with HRSA and the national AETC program to identify participating areas and select the sites for planning and implementing the train-the-trainer program and the local training sessions. A final curriculum will include a facilitator's manual and resource material that will be useful to other AETCs and in other parts of the country.

**Contact information:**

Mari-Lynn Drainoni, Ph.D., Principal Investigator  
[drainoni@bu.edu](mailto:drainoni@bu.edu)

Karen Brown, HRSA Project Officer  
[kbrown1@hrsa.gov](mailto:kbrown1@hrsa.gov)

Carol Tobias, Co-Investigator  
[tcaryl@bu.edu](mailto:tcaryl@bu.edu)

5600 Fishers Lane, Room 7A32  
Rockville, MD 20857  
Phone: 301-443-3577

Kate Brown, Project Director  
[kbrown@bu.edu](mailto:kbrown@bu.edu)

Health and Disability Working Group  
Boston University School of Public Health  
374 Congress St, Suite 502  
Boston, MA 02210  
Phone: 617-426-4447