

SPECIAL PROGRAMS OF NATIONAL SIGNIFICANCE

REPORT ON NEW 1999-2000 INITIATIVES

**Palliative Care
Adherence
Correctional Settings
Improving the Quality of Care
Services for Substance Users
Care along the US/Mexico Border**

UPDATE FOR RYAN WHITE CARE ACT GRANTEES

25 September 2000

SPNS REPORT ON NEW 1999-2000 INITIATIVES

TABLE OF CONTENTS

Preface	5
Overview	7
SPNS Mandate	7
New Focus for 2000	8
Summary of the Initiatives	10
Models of HIV Care Related to End-of-Life Care and Palliation	13
The Initiative	
Statement of Need	13
Goals	13
Summary of Initiative	13
The Cross-site Evaluation	14
Common Data Elements	15
Achievements in Year One	16
Plans for Year Two	17
The Demonstration Projects	18
Assessment of Efforts to Increase Adherence	23
The Initiative	
Statement of Need	23
Goal	24
Summary of Initiative	24
The Cross-site Evaluation	24
Common Data Elements	25
Achievements in Year One	26
Plans for Year Two and Three	27
The Demonstration Projects	27
Evaluation of Services to People with HIV in Correctional Settings	35
The Initiative	
Statement of Need	35
Goals	35
Summary of Initiative	36
The Cross-site Evaluation	37

SPNS REPORT ON NEW 1999-2000 INITIATIVES

TABLE OF CONTENTS (con't)

Evaluation of Services to People with HIV in Correctional Settings	
Common Data Elements	38
Achievements in Year One	39
Plans for Year Two	40
The Demonstration Projects	41
Improving the Quality of Care for People with HIV	47
Statement of Need	47
Goal	47
Summary of Initiative	47
Institute for Healthcare Improvement	48
Common Data Elements	49
Achievements in Year One	49
Plans for Year Two	50
Assessment of Innovation in Serving People with HIV who are Substance Users	51
Statement of Need	51
Goals	51
Summary of Initiative	52
The Evaluation	52
Categories of Care for Performance	
Standards	53
Achievements in Year One	53
Plans for Year Two	54
Demonstration Projects that Advance Innovation in HIV Care Along the US-Mexico Border	57
The Initiative	
Statement of Need	57
Goals	58
Summary of Initiative	58
The Cross-site Evaluation	58
Common Data Elements	60
The Demonstration Projects	60

PREFACE

“The SPNS program exists to ensure better care for People living with HIV/AIDS”

This is the first issuance in a series of SPNS grantee updates to communicate the current state of SPNS initiatives and their multi-site evaluations. While program evaluation does not happen overnight, the SPNS Branch staff are responding to the need for health care providers to receive crosscutting information from SPNS grantees. Many SPNS grantees are evaluating health care services being delivered to target populations similar to those served by other providers. This series is just one method for providers to discuss their challenges with those who are having similar experiences and to share common data instruments being developed.

Developing relationships between providers with experience and those just starting out ensures that what is being learned today can be shared today. SPNS grantees and their federal collaborators are developing innovative models using real-world problem solving to meet the changing needs of people living with HIV/AIDS. We encourage providers not only to read this document but also to dialogue with the grantees and the project officers of these initiatives. In addition to this update there is a HRSA/HAB web site with more information on other ongoing SPNS initiatives:

<http://www.hab.hrsa.gov/evaluation2c.html>.

The SPNS program exists to ensure better care for people living with HIV/AIDS, but at the fundamental level, the response is no more complicated than getting care to those who don't have it. May this series be the beginning of a continued dialogue among SPNS grantees and providers to ensure high quality care for all people living with HIV/AIDS.

Sincerely,



Barbara Aranda-Naranjo, Ph.D., FAAN
Branch Chief
Demonstration Project Development
and Evaluation/SPNS
HRSA/HAB



Richard Moore,
Branch Deputy
Demonstration Project Development
and Evaluation/SPNS
HRSA/HAB

OVERVIEW

SPNS MANDATE

The purpose of the Special Programs of National Significance (SPNS) program, which is administered by the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) is to advance knowledge and skills in the delivery of health and social services to people with HIV infection who are disadvantaged financially and medically underserved. The program's goals are to:

- Fund innovative models of care, and support the development of effective delivery systems of HIV care and services;
- Advance knowledge and skills in the delivery of health and support services to people with HIV who are underserved;
- Disseminate SPNS findings to improve CARE Act program development and implementation.

HAB has identified four factors that will impact HIV/AIDS care over the next decade. These factors form the basis for SPNS priorities:

- The HIV/AIDS epidemic is growing among traditionally underserved and hard-to-reach populations. The epidemic continues to spread among women, injection drug users and their heterosexual partners, gay and bisexual men of color and youth. HIV/AIDS is now most heavily impacting minority communities and individuals living in poverty.
- The newly emerging HIV/AIDS therapies, such as combination antiretroviral therapy, can make a difference in the lives of people with HIV disease. However, the service system must continue to meet the care needs of those who do not choose these therapies, who cannot tolerate their side effects, and for whom combination therapy is not indicated. The service system must maintain its commitment to high-quality primary health care, including palliative and end-of-life care.
- Changes in the economics of health care are affecting the HIV/AIDS care network. Many Medicaid beneficiaries are now being enrolled in managed care plans. In these plans, persons living with HIV disease may have limited access to providers experienced in HIV/AIDS care, which has a major impact on length and quality of life. CARE Act-funded AIDS service organizations have much to offer managed care plans, including the capacity to offer support services that enable people with HIV/AIDS to access primary care.
- Health policy and funding are increasingly determined by measurable outcomes. With each new budget year, funding requests and decisions about appropriations become more closely linked to achieving clear, demonstrated outcomes. HRSA must provide quantifiable outcome data that clearly demonstrate the benefits of Federal

funds. The Agency's ability to fulfill this responsibility depends upon carefully developed evaluation strategies and the data-gathering capacities of grantees. This requires close cooperation between HRSA and its grantees.

NEW FOCUS FOR 2000

SPNS under the new HIV/AIDS Bureau

The new 1999-2000 initiatives comprise the first portfolio of SPNS within the new consolidated HIV/AIDS Bureau (HAB). Previously, different Titles/programs of the Ryan White CARE Act were administered by pre-existing HRSA bureaus (e.g., the Title III programming was administered by the Bureau of Primary Health Care). With CARE Act programming now unified within a single bureau, the SPNS Branch has initiated a more integrated approach by systematically incorporating input from each CARE Act program as it has set its priorities for what are considered nationally significant projects. The SPNS initiatives also draw upon expertise of agencies outside HRSA, through active collaboration with the Centers for Disease Control and Prevention, Agency for Healthcare Research and Quality, and Substance Abuse and Mental Health Services Administration..

The new portfolio of initiatives not only draws on the broad range of expertise within HAB, but will disseminate the findings widely throughout HAB programs and grantees, assuring that the evaluation benefits are maximized. Each initiative is managed within HAB by matrix. Project officers, selected for their programmatic expertise related to a particular initiative, are based either within the SPNS branch or a particular program office. All of the new initiatives are managed by a collaborative team of project officers from throughout the Bureau. SPNS not only taps the field and professional experience of other HAB personnel for input, but uses this network to assure that the findings and resulting products of SPNS programming are rapidly and readily disseminated to HAB staff and on to CARE Act programs. SPNS uses a number of mechanisms, including its web site and newsletter, to provide preliminary findings to CARE Act grantees as they are developed rather than waiting until results are finalized and published.

The major goal of SPNS is to improve the care received by people living with HIV in all Ryan White CARE Act programs. This is the guiding principle that makes rapid dissemination of new findings to HIV providers so important.

Structure of the initiatives

A new aspect of the 1999-2000 SPNS initiatives is that, recognizing the creativity and innovation within existing CARE Act programming, they focus on evaluating existing programs as well as on developing new models of care. The initiatives usually describe the components of the innovative model and then evaluate its effectiveness, efficiency and replicability. An important corollary is an examination of the contextual issues that contribute to the success or failure of an intervention in a particular setting or with a particular population. For example, the Border Initiative not only takes into

consideration but explores the socio-political and economic context of services to at-risk persons along the border.

The initiatives have a new structure designed to collect data and evaluate interventions across sites. The projects are grouped by type of intervention or topic (eg, adherence, corrections) with the guidance of an evaluation center that facilitates cross-site evaluation. Each grantee is required to participate in development of the evaluation plan for the overall initiative and to collect uniform data that can be analyzed and compared across programs.

Evaluation Centers

Four of the six initiatives are comprised of evaluation centers and a group of grantees, and the other two initiatives are being implemented by single entities that will report on the results of efforts across multiple programs. Each Center coordinates evaluation activities of the initiative's grantees through a systematic process:

- Development of consensus on evaluation goals and questions. In addition, wherever possible, the Center encourages grantees to use standardized process and outcome measures in their site-specific evaluation plans.
- Standardization of data collection instruments. Common data elements are used for the multi-site evaluation and common codes are created for data values.
- Development of protocols for submission of data to the Center.
- Quality assurance procedures for submitted data.

Each Center also coordinates the dissemination of findings, and provides technical assistance to grantees in reporting their own findings. In doing so, the Center also addresses the issues that arise when multiple entities collaborate in an evaluation effort, such as:

- Data confidentiality
- Data ownership and data sharing
- Sequence of release of dissemination products
- Protocols for dissemination of findings
- Authorship

The Center for each initiative is also responsible for the assessment of the policy implications of study findings and the production of a report that provides policy recommendations.

At the end of their first year, the SPNS initiatives have already demonstrated that collaboration for multi-site evaluation of care programs is possible and rewarding, and that it requires time and effort on the part of all stakeholders: the Center, HRSA/SPNS, and the projects. The mechanism for establishing a collaboration partnership for each initiative was the convening of one or more meetings of the Center and the grantees. This enabled all parties to meet and become familiar with each others' projects, begin

establishment of a shared group identity and mission, and begin a dialogue about the multi-site evaluation effort. Continuation of the dialogue usually occurred through emails and regularly scheduled telephone conference calls as well as a second multi-site meeting. By the end of the first year, most initiatives have achieved consensus about their evaluation methodologies and finalized their multi-site evaluation plans. Numerous challenges have been faced and lessons learned, some of which will be discussed under individual initiatives.

SUMMARY OF THE INITIATIVES

Models of HIV Care Related to End-of-Life Care and Palliation

Although death rates from HIV/AIDS have fallen in recent years, nearly 20,000 people die from AIDS each year in the United States. SPNS is supporting innovative service models targeted to people with HIV/AIDS who are homeless, uninsured, substance users, and/or mentally ill, and individuals in or about to be released from correctional facilities. Five demonstration projects test different models of end-of-life care and palliation service delivery to various medically underserved and hard-to-reach populations with HIV/AIDS. The evaluation and technical support center provides evaluation oversight and exchange of information and expertise among the projects as well as dissemination of information to the broader service, research and funding communities, to foster replication and adaptation of viable service models for the targeted populations.

Assessment of Efforts to Increase Adherence

In order for the highly active antiretroviral therapies (HAART) to be effective, strict adherence to the regimens is essential. However, adherence to the complex regimens is challenging, particularly for people with HIV who experience other difficulties such as substance use and homelessness in their lives. Many Ryan White CARE Act-funded grantees and their contractors are funding innovative programs to increase adherence to HIV therapies. The objective of the Adherence Initiative is to evaluate existing interventions that have been designed to increase adherence to HAART among underserved populations such as women, adolescents, the homeless, substance users, and in minority and ethnic population groups. Twelve programs that span a range of target populations, adherence interventions, and client service settings have been provided the funding to evaluate their adherence support interventions. The Center for Adherence Support Evaluation (CASE) Project is supporting them in evaluating what kind of adherence support works best for whom, at what cost. CASE will also facilitate the development of a national consensus about what the best practices are to support adherence, and will broadly disseminate the findings.

Evaluation of Services to People with HIV in Correctional Settings

The goal of the Corrections Initiative is to improve access to HIV care and prevention services both inside and outside corrections institutions, and to develop model programs that assure continuity of care for incarcerated persons with HIV upon their release from jail or prison. The Initiative is a collaboration between The Centers for Disease Control

and Prevention (CDC) and HRSA that funds seven demonstration projects (State health departments or their bona fide agents) as well as the Evaluation and Program Support Center (EPSC) to assist with program implementation and evaluation. In each state, the health department and department of corrections work collaboratively with one or more community-based organizations to provide services. Projects provide a variety of service interventions, such as primary care, prevention, psychosocial support, and referral systems that link correctional and community settings. They target a range of different populations in different settings, such as youth in juvenile detention centers, women in state prisons, and drug-using inmates in city jails.

Improving the Quality of Care for People with HIV

The Institute for Healthcare Improvement (IHI) is working with HAB to improve the quality of care provided by Ryan White CARE Act grantees through development and implementation of the Breakthrough Learning Series Collaborative on Improving Care for People Infected with HIV. This process teaches and applies methods for organizational change to improvement of clinical care. In the first year of this initiative, the research and development phase of applying the Breakthrough process to HIV care has been completed and 86 Title III and IV grantees have embarked on the 12-month process of the first Collaborative. They have participated in the first of three 2-day learning sessions and are engaging in making and tracking changes in clinical care in their healthcare settings. Based on their experience, the model will be revised and HAB and AETC staff will be trained in the implementation of the process. A second Collaborative will be facilitated and a National Congress will be convened to disseminate the results of the initiative.

Assessment of Innovation in Serving People with HIV who are Substance Users

Since the onset of the HIV/AIDS epidemic, a large proportion of people with HIV have become infected either through injection drug use or sexual activity with drug users. For them and for the people who provide their care, the epidemics of HIV and substance use are intertwined; neither epidemic can be addressed without addressing the other. The importance of substance users having a range of enabling services to ensure access to primary health care, and the importance of their having access to substance abuse treatment, are well understood by Ryan White providers. In 1998, 8.8 percent of Ryan White CARE Act Title I, II, and III dollars were used for substance abuse treatment and counseling. However, little research has been conducted to identify the optimal linkages and models of care to assure that people with HIV who are substance users receive the same benefit from the new HIV treatments as other people with HIV.

The Evaluation and Program Support Center (EPSC) is conducting a series of activities to identify performance standards and innovative and successful practices in serving individuals with HIV and substance abuse disorders. Based on these findings, EPSC will develop and pilot test a training program to disseminate innovative practices, engage Ryan White CARE Act grantees and providers in hands-on discussions about overcoming

barriers in serving substance users living with HIV, and provide evaluation and training and support to community-based providers.

Demonstration Models that Advance HIV Service Innovation Along the US-Mexico Border

The U.S.-Mexico border region is over 2,000 miles long, and contains some of the poorest counties in the United States. More than one-third of the families in the area live at or below the federal poverty line. Access to health care is a serious problem throughout the border region because of multiple factors including low population density in large-scale rural areas, inadequate transportation, shortages of health professionals and health care facilities, and inadequate bilingual services for a largely monolingual Spanish-speaking population. Identifying and linking people with HIV to needed health services is challenging in this context of multiple socio-economic and health systems problems. Five projects, two in Texas and one each in Arizona, New Mexico and California, were funded in FY 2000 to identify people with HIV and to develop services linking them with appropriate HIV care. The function of *El Centro de Evaluacion: HIV/AIDS Evaluation and Technical Assistance Center* is to assist each of the projects to describe its model and to evaluate its effectiveness in linking persons to care, and to conduct a multi-site evaluation as well as to disseminate the findings so that successful models can be replicated.

MODELS OF HIV CARE RELATED TO END-OF-LIFE CARE AND PALLIATION

THE INITIATIVE

Statement of need

In recent years, deaths from HIV/AIDS have decreased dramatically, due to expanded access to medical care and exciting advances in therapy, in particular highly active antiretroviral therapy (HAART). Between 1996 and 1997, the number of AIDS-related deaths declined by 42 percent, followed by a 20 percent decline between 1997 and 1998. Still, 17,171 people died of AIDS-related causes in 1998.

The HIV/AIDS epidemic has become increasingly associated with substance abuse, not among people who inject drugs and share needles, but also their sexual partners, affecting entire communities of men, women and children. HIV is yet another problem added to the multiple problems associated with substance abuse, which include mental illness, poverty, domestic violence, and crime. Thus, in addition to having substance abuse problems, people with HIV/AIDS may be homeless or mentally ill, uninsured, or recently released from correctional facilities.

People with these issues often experience barriers in accessing health care and may not be receiving primary health care, much less adequate and appropriate HIV care. They are more likely to be diagnosed with HIV later in the disease process than people receiving regular primary health care. Moreover, they may be living in shelters, substance abuse treatment programs, and hospitals. Delivering end-of-life care efficiently and effectively under these circumstances is challenging.

Goals

The goal of the End-of-Life and Palliative Care Initiative is to foster and evaluate appropriate and high quality end-of-life care for people with HIV/AIDS who have difficulty accessing the health care system.

Target populations

The target populations of the Initiative are underserved and hard-to-reach individuals with HIV/AIDS, including homeless people, individuals within and recently released from corrections facilities, people who are poor and uninsured, people with substance abuse and mental health problems, and people living in rural areas.

Summary of the Initiative

The End-of-Life and Palliative Care Initiative was developed to address the emerging challenges in providing appropriate care and services to individuals dying from HIV/AIDS who have difficulty accessing the health care system. The special requirements and characteristics of both HIV disease and the populations it affects

necessitate that care be delivered within each individual's societal context. Five demonstration projects are testing different models of palliative care delivery and service provision with various medically underserved and hard-to-reach populations dying from HIV/AIDS. In addition to the five projects, an evaluation and technical support center has been established at Columbia University to evaluate the effectiveness and efficacy of the projects and to assist in the dissemination of information to the broader service, research and funding communities to foster the replication and adaptation of viable service models for underserved people with HIV/AIDS.

Contact Information:

Victoria H. Raveis, PhD, Director
Evaluation and Support Center
Columbia University Mailman School of Public Health
100 Haven Avenue, Suite 6A
NY, NY 10032
212-304-5563
vhr1@columbia.edu

Kathy Marconi, PhD, Project Officer
SPNS Program
HIV/AIDS Bureau, HRSA
5600 Fishers Lane Rm 7A07
Rockville MD 20857
301-443-2983
kmarconi@hrsa.gov

The Cross-Site Evaluation

The Evaluation and Support Center for the End-of-Life and Palliative Care Initiative (the Center) is based at the Columbia University Mailman School of Public Health. The Center facilitates collaboration among the grantee projects delivering palliative care, supports multi-site and local evaluation, and stimulates dissemination of the findings.

The research questions being asked are:

- How effective is the program in providing appropriate palliative and end-of-life care?
- How efficient is the program in maintaining continuity of palliative care?
- What is needed to facilitate program replicability?

The goals of the cross-site initiative are to:

- Establish a research partnership among the Evaluation and Support Center, the funder (HRSA/SPNS), and the demonstration projects (grantees);
- Develop a mutually shared evaluation plan that provides insights into program replication, effectiveness and efficiency;
- Provide grantees with the necessary guidance, support and methodological tools to enable both a strong multi-site and site-specific evaluation effort; and,
- Disseminate information about the initiative and the demonstration projects to the broader service, research and funding communities.

The evaluation plan includes a quantitative component (that gathers measurable data), aimed primarily at evaluating how effective and efficient projects are in providing care, and a qualitative component (that gathers facts and information), aimed primarily at examining how replicable (reproducible) the projects are. Having both components

provides a more comprehensive and in-depth investigation, maximizing the information that can be obtained from the experiences of a small number of diverse projects.

The Palliative Care Assessment Form for HIV (PCAF-HIV) is a series of eight client interview forms and four project staff reporting forms. Client demographics, HIV status, alcohol and drug treatment history, and mental illness and treatment history are the domains that are addressed in two of the interview forms. Other domains of the evaluation assessment use measures selected or developed to reflect relevant palliative care outcomes.

The qualitative component of the evaluation will use a case study approach. An understanding of what would be needed to replicate, or reproduce, a project will be achieved by:

- analyzing the significance of project resources, such as staffing, financial, institutional, community resources;
- describing innovations or changes to the delivery care system, such as referral systems, integration of services, inter/intra-organizational linkages; and,
- identifying organizational or contextual factors that facilitated or impeded success.

A case study focus will be used because of the small number of grantee projects. Each project will be used as the unit of analysis. Data collection forms will be used to track and summarize each project's performance statistics (e.g., number of clients served and client demographics), intensity and quality of inter-agency linkages and coordination; programmatic staffing resources (e.g., coordination of services within agency; case management procedures). Projects will develop project chronologies that document their challenges, barriers, strategies, successes, and failures.

The material obtained through case studies and project chronologies will be used to analyze the significance of program resources (staffing, financial, institutional and community), describe and document innovations or changes to the delivery care system (referral systems, integration of services, and inter/intra-organizational linkages), and identify organizational or contextual factors that facilitate or impede success. The information will facilitate planning and implementation of similar service delivery models in other settings.

Common data elements

- Quality of care
- Quality of life
- Symptoms
- Psychological functioning
- Physical functioning
- Client service utilization
- Client demographics
- Client medical status
- Client medical treatment history

Achievements in Year One

The Center has facilitated the development of a mutually shared evaluation plan for all five projects through a process involving the review of each project's evaluation plan, site visits to each project, two orientation and consensus-building meetings, and regular conference calls. Consensus has been reached on the scope and content of the multi-site evaluation effort, including a mutually shared set of measures.

The quantitative component of the evaluation, the PCAF-HIV, has been developed and most projects have begun using the data collection instrument developed for this effort. In developing this instrument, the Center conducted an exhaustive review of palliative care measures, developed a manual of these instruments for grantees, and facilitated a group discussion of the measures through a meeting and conference calls that resulted in agreement as to which measures would be used for the cross-site evaluation instruments.

A number of methodological challenges were encountered as the multi-site evaluation effort progressed:

- The small number of cases anticipated at some performance sites;
- The small number of demonstration projects;
- The variability across the demonstration projects in service setting, services provided, disciplinary composition of care team, outcome impacted, type of client served, disease course at client entry, duration of contact with client, community agency linkages with formal health care agencies; and,
- The need to select appropriate population-based comparisons.

In selecting measures for the multi-site evaluation instrument, measures had to be selected that would be appropriate to administer to seriously ill clients who may be actively dying when assessed. In designing the PCAF-HIV, measures had to be:

- Reflective of the diversity of services provided;
- Relevant to the goals of palliative care;
- Appropriate for the diverse populations of people with HIV/AIDS being served;
- Appropriate for variable HIV disease states;
- Not unduly burdensome or distressful to clients;
- Able to accommodate diverse service settings;
- Able to accommodate differences in data collection;
- Not an impediment to the provision of care.

Initial experience with the data collection is requiring more staff time than anticipated:

- Clients who are in the terminal stages of AIDS are easily exhausted. Many clients were unable to fill out surveys themselves, and multiple sessions were required to complete the interview instruments.
- In some instances when the client was approached as an inpatient, it was not feasible to conduct the baseline interview as the client was either busy undergoing diagnostic

tests, or was fatigued. When this occurred, the interviews were postponed until the client was discharged either to a long-term care facility or to home.

A number of issues arose during implementation of the projects themselves that provided new insight into the challenges of providing palliative care to people with HIV who are underserved:

- Finding staff with the multiple areas of expertise needed is challenging. Personnel hired for their expertise in a particular field may lack skills or experience in other fields equally critical for their work. For example, people with hospice experience may not know how to work with addiction or mental illness; outreach workers with expertise in supporting the adherence of their clients to therapy may not easily shift to supporting their clients in stopping therapy and letting go of life.
- With clients who have multiple social problems, such as homelessness, a great deal of staff time is required to identify a patient's issues and develop a plan to address them. For example, outreach workers must make regular home visits to show interest and identify problems. Team members' activities might include assisting a patient to enter substance abuse treatment or obtain housing, visiting an individual in temporary housing, assisting with finding a lost Social Security check, or providing emotional support for families through visits or phone calls.
- Respecting client choices is often difficult for staff. Staff must learn to offer clients choices and then accept the fact that they will sometimes make "bad" decisions. According to one grantee, "We have learned to face our own feelings regarding patients who make unhealthy choices and to address the need for team support in these circumstances."
- Flexibility is required in collecting data. Staff must learn to collect data appropriate to each encounter, using instruments identified to quantify the impact made by the service provided. Timing and pacing of interviews is crucial. Social problems take priority over participating in the project, much less in disease management. The value of incorporating a chart review procedure to acquire demographic information in order to reduce the client burden is readily apparent when clients are seriously ill.
- Obtaining reimbursement for palliative care is a critical issue. Numerous barriers impede billing for palliative care services. Creative mechanisms must be developed to financially support the interdisciplinary palliative care team.

Plans for Year Two

In Year Two, project development will continue for those projects that are still getting underway, and data collection will continue or begin within each project. The Center will focus on developing and implementing the qualitative component of the multi-site evaluation.

In addition, the Center will provide guidance and technical support to individual projects through site visits, regular conference calls, and another multi-site conference; monitor the accuracy and consistency of quantitative data being collected by grantees; work with grantees to plan analytic strategies for preliminary reports of experiences and findings for

educational and/or publication purposes; and, work with grantees to identify venues for dissemination of information regarding projects, delivery of services, client populations and outcomes.

THE DEMONSTRATION PROJECTS

Grantee	Project Summary	Services Provided	Care Team
AIDS Service Center	Community-based AIDS clinic and service center delivers home- and clinic-based hospice care	Primary health care Case management Social services Counseling Housing	Physician Nurse Social worker
Catholic Community Services	A community residence provides care for terminally ill homeless people	Case management Home care Social services Family counseling Links to hospice care	Nurse Social worker Home health aide
Montefiore Medical Center	Hospital-based palliative care team delivers care to patients in clinic- and community-based settings	Primary health care Case management Counseling Spiritual support	Physician Psychologist Nurse Social worker Addiction specialist Chaplain Outreach worker
University of Maryland	Hospital-based palliative care team provides palliative and hospice care	Primary health care Hospice care	Physician Nurse Social worker Chaplain Addiction specialist Outreach Worker
Volunteers of America	Community-based organizations provide transitional case management to seriously ill inmates	Case management Links to hospice care and social services	Nurse Social worker

AIDS Services Center, Inc (Anniston, AL)

Target Populations: Poor and uninsured clients in rural Alabama, many of whom are African American, all of whom are terminally ill.

Project overview: AIDS Services Center provides HIV care to people with HIV/AIDS in a predominantly rural 14-county area of northeast Alabama. The agency uses a hospice service model to provide medical and supportive services to terminally ill people with AIDS. The multidisciplinary care team (physician, social worker, nurse) delivers both in-home and clinic-based hospice care. The ASC is building a two-unit residence beside the clinic, in collaboration with Habitat for Humanity, to enable clients and their caregivers who live far away from the clinic or who live in substandard housing to receive more intensive care as they reach the end of life.

AIDS Services Center (con't)

Contact information:

Barbara J. Hanna, MD, Principle Investigator
AIDS Services Center
PO Box 1392
Anniston, AL 16202
Phone: (256) 832-0100
E-mail: aidsserv@aol.com

Catholic Community Services (Jersey City, NJ)

Target Populations: Terminally ill, multiply diagnosed people with AIDS in an urban setting

Project overview: The St. Martin De Porres Residence offers an innovative residence-based model that takes into consideration the unique needs of terminally ill, multiply diagnosed people with AIDS. The program was developed to address both the concrete physical needs of homeless, multiply diagnosed individuals in the final stages of AIDS (shelter, physical care, access to services) and the more spiritual aspects of end-of-life care. Based on the hospice residence model, the program will provide residents with a stable place to live and obtain hospice care and personal care services 24 hours a day, seven days a week to help them transition through the final stages of life, including the psychological, social, and spiritual challenges they may encounter. All services will be provided by and coordinated with the resident's hospice care provider as well as other Ryan White CARE Act service providers in the county.

Contact information:

Elizabeth Patterson, BSN, JD, Principle Investigator
Catholic Community Services
3040 Kennedy Blvd
Jersey City, NJ 07306
Phone: (201) 798-9923
E-mail: elizpatt@excite.com

Montefiore Medical Center Comprehensive Program for HIV Palliative Care (Bronx, New York)

Target Populations: An urban population of people with AIDS who are terminally ill, including homeless people, the poor and uninsured, and substance users

Project overview: This program is a comprehensive palliative care program for patients with AIDS to be integrated into the continuum of care delivery at a large urban medical center serving the Bronx, NY and a participating institutional link to a designated AIDS Center. The program seeks to develop a model, interdisciplinary program by providing education and increasing awareness about end-of-life issues in HIV and establishing a clinical consultation program in palliative care for people with AIDS across the medical center's delivery system.

Montefiore Medical Center (con't)

Contact information:

Peter A. Selwyn, MD, Principle Investigator
Montefiore Medical Center
111 East 210th St
Bronx NY 10467
Phone: (718) 920-4678
E-mail: pselwyn@montefiore.org

University of Maryland (Baltimore, MD)

Target Populations: Terminally ill people with AIDS who are predominantly African American, poor, and have a history of intravenous drug use, and many of whom are women, homeless or extremely poor

Project overview: This model, developed at an inner city teaching hospital, assumes that a palliative approach to care is the precursor to good end-of-life care. Activities include creation of a hospice-like interdisciplinary team including a physician, nurse, social worker, and pastoral care with additional expertise in mental health, addictions, and peer outreach. Through the use of focus groups, the project will document desirable end-of-life outcomes for people with HIV/AIDS who have difficulty accessing and staying in care. The team will form relationships with people in the target population to help keep them in care particularly during the times when they are moving between care sites, for instance from hospital or long-term care facility to outpatient follow-up. The team will also operate an interdisciplinary clinic for consultation at two outpatient settings regarding the treatment of pain and other symptoms. Subsequently, the project team will evaluate the effectiveness of this service delivery model in establishing relationships that might better engage patients in care and in planning for the future with respect to advanced care planning.

Contact information:

Carla Alexander, MD, Principle Investigator
U of Maryland Medical System/ Instit. of Human Virology
29 S Greene St Suite 300
Baltimore MD 21201
Phone: (410) 328-5725
E-mail: calexand@medicine.umaryland.edu

Volunteers of America: GRACE (Guiding Responsive Action for Corrections at End-of-Life) Project in Jails

Target Populations: Incarcerated people with terminal HIV/AIDS

Project overview: This project will demonstrate how quality palliative and end-of-life care can be provided for inmates with terminal HIV/AIDS. The project will develop a case management model that reaches jail inmates while they are incarcerated and supports their transition to the community or prison. The project

will be implemented and refined in Orleans Parish, Louisiana and Los Angeles, California. Project activities include: 1) collection of information on other jail initiatives for terminally ill inmates; 2) use of a "Charette," an intensive product-oriented work session to develop a prototype program for jails; 3) development of "webs of support" in each site based on linkages and agreements with community resources; 4) case management that reaches jail inmates with terminal HIV/AIDS while incarcerated and assists the inmate to receive quality palliative and end-of-life care; and 5) utilization of Coordinating Committees at each site.

Contact information:

Margaret Ratclif, Principle Investigator
Volunteers of America
110 South Union St
Alexandria VA 22314
Phone: (703) 548-2288
E-mail: Mratcliff@voa.org

ASSESSMENT OF EFFORTS TO INCREASE ADHERENCE

THE INITIATIVE

Statement of Need

Adherence is the degree to which a person follows the instructions, proscriptions, and prescriptions associated with medical treatment. As such, adherence involves a variety of personal behaviors, social support systems, and patient/provider interactions.

Adherence is challenging under normal circumstances, but adherence to the new highly active antiretroviral therapies, or HAART, is even more critical and complex than adherence to most other medical regimens. First, with HAART, there is no room for partial adherence or lapses in taking the drugs. HIV mutates rapidly, providing opportunities for the virus to develop resistance to the drugs when they are not taken even for a short period of time. Second, the drug regimens are complicated and many of the drugs have unpleasant, sometimes toxic, side effects. Some of the factors that make HAART more difficult to take than other medical treatments include the following:

- Drug regimens may involve five or more medications and a dozen or more pills per day;
- Different medications have varying, and sometimes conflicting, dietary restrictions;
- Some medications have serious, even life-threatening, interactions with a large number of other medications taken by people with HIV;
- Many individuals experience moderate to severe side effects to the medications;
- Presently, a lifetime commitment to taking the drugs is required, as opposed to most medicine regimes, which are time-limited;
- The daily pill taking routine may conflict with other activities of daily life;
- Persons taking HIV/AIDS medications may fear social stigma associated with HIV/AIDS, and taking the medicines may threaten the confidentiality of their diagnoses;
- Presence of co-morbidities such as substance abuse, homelessness and mental illness may add complications to being adherent.

Understanding that adherence is essential to the success of the new HIV antiretroviral therapies, HIV/AIDS providers have developed and are implementing adherence support interventions as part of HIV care. However, most adherence support programs are based on experience and intuition regarding what works, not on sound research. Little is known about what factors create barriers to or promote successful adherence, either in individuals or specific populations. Research is needed to evaluate the adherence programs now being implemented and to determine which interventions are most effective with which populations.

Goal

The goal of the initiative is to assess innovative interventions being implemented to increase adherence to highly active anti-retroviral treatment (HAART) among underserved populations.

Summary of Initiative

The Adherence Initiative consists of two components:

- Twelve adherence support programs serving people with HIV receiving HAART;
- The Center for Adherence Support Evaluation (CASE) at the New York Academy of Medicine.

The twelve clinic-based programs currently deliver HIV medical care to underserved populations and have fully operational adherence support programs for their clients receiving HAART. The programs were selected to receive funding from the HRSA Special Programs of National Significance (SPNS) to evaluate their adherence programs because their adherence interventions were considered innovative.

The programs serve a variety of populations, but all target uninsured or underinsured people with HIV who have difficulty accessing care. They use a range of different adherence interventions, but all seek to improve the ability of their clients to successfully adhere to HAART. In addition, they all provide some sort of non-cash incentive for participating in the research study. No clients are prevented from receiving the services of their programs if they choose not to participate in the study. (See the Demonstration Projects section for a summary of each project)

CASE is funded to provide the programs with technical assistance in conducting local evaluations of their adherence interventions as well as to coordinate the national cross-site evaluation of all the projects. In addition, CASE and the twelve adherence programs each have the responsibility to disseminate information about “best practices,” findings, and replicable models.

Contact information:

Ruth Finkelstein, ScD, Director
Center for Adherence Support Evaluation (CASE)
New York Academy of Medicine
1216 Fifth Ave
NY, NY 10029
212-822-7266
rfinkelstein@nyam.org

Robin Cohen, Project Officer
SPNS Program
HIV/AIDS Bureau, HRSA
5600 Fishers Lane Rm 7A07
Rockville MD 20857
301-433-9088
rcohen@hrsa.gov

The Cross-site Evaluation

The cross-site evaluation is a 12-month study that measures how people’s adherence changes from the time they enroll in an adherence program, when baseline information is

collected, to specific time intervals while they are receiving the adherence intervention. The questions that have been developed for cross-site analysis include the following:

- What is the effectiveness of different interventions in supporting adherence?
- What are appropriate levels of service utilization for supporting adherence?
- What is the impact of different types of providers in supporting adherence?
- What is the duration of effectiveness of the different adherence support programs?
- What is the effectiveness of different programs in supporting adherence in different populations?
- What is the effectiveness of different programs in supporting adherence of populations facing different barriers to their adherence?
- What is the effectiveness of the different programs in supporting adherence among individuals reporting difficulties in taking their medications?

Activities of the cross-site evaluation obtain three levels of information:

- Client-level data, collected through face-to-face interviews with clients, providers' documentation of service encounters, and chart abstractions;
- Service-delivery level data, collected through site visits to each program to determine the organizational and adherence program characteristics that facilitate or impede participants' adherence to HAART regimens.

The cross-site evaluation uses the same data collection instruments at every site, according to a standard procedure that all interviewers are trained to use. Consistent measures are being used by all sites for adherence, clinical outcomes, service utilization, and demographic characteristics of clients. (For instance, the measure that has been selected for adherence is three-day recall, which is a series of questions regarding how the client took her/his medicine for each of the three past days.) Use of the same measures allows for true comparison across programs. Similarly, the site-level data collection incorporates consistent descriptions of interventions, provider characteristics, and programs. Most information is gathered quarterly, although service providers fill out an encounter form for each visit.

To protect participants' rights, the study procedures and all data collection tools have been approved and are continually monitored by the Institutional Review Boards (IRBs) that oversee human subjects research at both the New York Academy of Medicine (CASE) and at each site. All clients who are interviewed must sign a written informed consent form before participating in the research.

Common Data Elements

Client level: immune status; health and mental status; HAART regimen; knowledge of and experience taking HIV drugs; support for and effects of taking HIV drugs; adherence to medications; substance use; demographic information; adherence services provided; health care utilization;

Service-delivery level: information on the service providers, the structure of clinic services, and the context in which services are delivered; the type and level of adherence support that works best for different populations; the barriers different populations encounter in adhering to treatment.

Achievements in Year One

Nearly all activities scheduled for the first year of the initiative have been accomplished. The CASE team has established strong collaborative relationships with and among the grantees by convening two grantee meetings, work groups and regular conference calls. CASE has facilitated communication and grantee access to information, encouraging the grantees to share their instruments, methods and databases and using a consensus process to develop the cross-site evaluation instruments.

The CASE team has reviewed the individual site evaluation plans to make certain that the evaluation research will answer the questions each site is asking. Although sites will be provided feedback regarding the plans in Year Two, sites with design problems needing to be resolved prior to data collection have already been given and adopted recommendations for change. For example, at one site, one of the comparison groups was determined to be inappropriate and therefore was deleted, and at another site, the method used to assign clients to various interventions was modified. Based on the information it has collected, CASE has developed a matrix of the grantees describing and comparing their programs.

The test instruments for the cross-site evaluation have been designed, developed and piloted, as well as translated into Spanish. In addition, all grantees have agreed upon an outline for site-level data collection and the qualitative interview and are continuing to refine the instruments. The New York Academy of Medicine Institutional Review Board (IRB) has approved the cross-site evaluation instrument and interviewers have been trained to utilize the instrument. Finally, all sites have received local IRB approval, have begun their local evaluations, and have begun enrollment in the national cross-site study.

During the first year of the initiative, grantees have also received technical assistance from CASE regarding issues such as: obtaining IRB approval (locally); identifying personnel with appropriate training to conduct the study; data entry and data management; data transfer (especially for those sites who store data in existing systems) and data storage. CASE made special efforts to help the grantees design their site-specific data management systems, developing Access programs that enable grantees to conduct simple data analysis themselves. CASE receives the data from all the sites, prepares the data for analysis, and sends it back to the sites, assisting them in analyzing their local data. CASE has also designed a program that enables sites to extract data elements relevant to the study from their existing electronic databases rather than duplicating data collection efforts. In addition to ongoing site-specific technical assistance, during its site visits CASE provides consultation on evaluation to staff around data collection and data management so as to ensure the collection of high quality data.

The CASE website is up and running and provides: bibliographic listings, abstracts, and full text articles relating to adherence support; the matrix of adherence sites; local and cross-site data collection instruments; communications about conference call and meeting schedules; information memos for members; a chat room for communication; and CASE staff and adherence support evaluation grantee rosters (www.case.nyam.org).

Plans for Years Two and Three

In Years Two and Three, as enough data is assembled to begin to draw conclusions about successful adherence programs or adherence program elements, there will be increasing emphasis on data analysis and various forms of presentation and dissemination of results. Specifically, the following activities are planned:

- Continued enrollment and interviewing of clients at each site and sending of data to CASE. Every two months, CASE will analyze the data and disseminate the results to both the grantees and HRSA.
- Service-delivery-level assessment of organizational characteristics, program features, design and implementation, and clients' and providers' perceptions of the program. CASE will provide evaluation consultation to all staff during their site visits.
- Analysis and dissemination workgroups to pinpoint further data that should be collected, decide how the data will be analyzed, and determine how to disseminate the findings of the Initiative.
- A best practices manual to provide guidelines for health care providers and lay persons based on the lessons learned from the research.

THE DEMONSTRATION PROJECTS

AIDS Services Center, Inc (Anniston, AL)

Target Population: People with HIV who are poor and uninsured and who live in rural northeast Alabama, many of whom are African American

Project overview: AIDS Services Center (ASC) provides HIV care to people with HIV/AIDS in a predominantly rural 14-county area of northeast Alabama. The adherence program ASC has developed provides three different interventions, including a modified directly observed therapy intervention, that differ in intensity to meet the specific need of the client. The baseline interview is used as a screening tool to assess which of the three interventions is most appropriate for each client. Clients enrolled in the most intense intervention will be paired with a trained buddy or buddy team. The buddy makes contact with the client daily by phone, and provides support for taking his or her medication. Clients enrolled the directly observed therapy intervention will come to either ASC or a local health department five days a week to pick up their medications. Clients enrolled in the

lease intense interventions will meet with a clinic adherence panel monthly at the time of their clinic visits. Periodic re-evaluation occurs, and if the needs of a client change, s/he can be moved to a different level of intervention.

Contact information:

Barbara J. Hanna, MD, Principle Investigator
AIDS Services Center
P.O. Box 1392
Anniston, AL 36202
Phone: (256) 832-0100

Chase Brexton Health Services (Baltimore, MD)

Target Populations: People with HIV who are substance users or at high risk for depression, including women

Project overview: Chase Brexton Health Services, Inc. (CBHS), a large comprehensive community-based provider of primary HIV care to underserved populations in Maryland, has recently developed a system-wide comprehensive program designed to improve client adherence to HAART regimens. Central components of the adherence program are: periodic screening for substance use and depression risk for early intervention and follow-up; proactive multi-departmental coordination of intervention plans and follow-up for those identified as high risk; and, standardization and integration of HAART education and other adherence support into the care provided by CBHS. The goal is to develop new standards for provision of HAART and adherence support for substance users and those at high risk for major depression.

Contact information:

David Butcher, M.D., Principle Investigator
Chase Brexton Health Services
1001 Cathedral Street
Baltimore, MD 21201
Phone: (410) 837-2050 x215
Email: dbutcher@chasebrexton.org

Harlem Adherence to Treatment Study, Columbia University Harlem Hospital Center (NY, NY)

Target Populations: People with HIV who are predominantly persons of color, a large proportion of whom are women, substance users, homeless, and/or marginally housed

Project overview: The Harlem Adherence Treatment Study (HATS) is a study that randomly assigns subjects to either a group that receives an enhanced adherence intervention or the current clinical practice for adherence. The experimental (enhanced) intervention consists of two main components: peer-centered social support and assistance in overcoming barriers to adherence. The intervention is based on the Transtheoretical Model of Change. Each subject is

assessed and identified as being in a specific stage of behavior change, and provided interventions designed for that stage. The interventions are provided by study peers workers, social workers, and support groups. The program evaluation involves two components: a self-administered touch-screen adherence questionnaire with an audio component; and, a qualitative assessment of the peer-client interaction. The study will compare two data collection methods, a face-to-face interview and the touch-screen computer interview.

Contact information:

Sharon Mannheimer, MD, Principle Investigator
506 Lenox Avenue, Room 3101-A
New York, NY 10037
Phone: (212) 939-2948
E-mail: sbm20@columbia.edu

Northern Manhattan Women and Children HIV Project, Columbia University School of Public Health (NY, NY)

Target Populations: HIV-infected women, including adolescents, and caregivers of HIV-infected children

Project overview: The Northern Manhattan Women and Children HIV Project (NMWCHP) is conducting the Northern Manhattan Adherence Initiative. The initiative is based upon the framework of the Transtheoretical Model of Stages of Behavior Change. The goals of the program are to: 1) integrate adherence boosting services into the comprehensive medical care and social support services being provided to HIV-infected women, adolescents, and caregivers of HIV-infected children; 2) provide appropriate information and support to clients according to their stage of readiness for taking/administering these medications; and 3) improve adherence among clients already on antiretroviral therapy.

Contact information:

Nancy VanDevanter, DrPH, Principle Investigator
Columbia University
Evaluation of the Northern Manhattan Adherence Initiative
600 West 168th Street
New York, NY 10032
Phone: (212) 305-1166

Project LINK, The Moore Clinic, Johns Hopkins University Hospital (Baltimore, MD)

Target Populations: People with HIV who have poor medical adherence, active substance use problems and mental illness, high rates of unstable housing and poverty, and low educational level

Project overview: Project LINK is an intervention program to increase adherence with HAART at the Moore Clinic, the Johns Hopkins Hospital HIV specialty clinic. This program specifically targets patients who are HAART

candidates but are not prescribed or are failing HAART therapy. The intervention has four components: intensive case management, one-on-one nursing education, peer advocate support, and group education/support sessions. Clients are assigned to receive two, three, or four of the intervention components, with all clients receiving case management and nurse education. Adherence of the clients receiving different combinations of interventions will be compared with each other as well as with a separate comparison group.

Contact information:

Richard D. Moore, M.D., Principle Investigator
Project LINK, a Medication Adherence Intervention
1830 East Monument Street, 4th Floor
Baltimore, MD 21287
Phone: (410) 955-2144
E-mail: rdmoore@jhmi.edu

Clinica Esperanza, Mission Neighborhood Health Clinic (San Francisco, CA)

Target Populations: People with HIV who are predominantly Hispanic, many of whom speak no English and experience multiple psychosocial barriers

Project overview: Clinica Esperanza is an HIV clinic with an interdisciplinary team that provides medical and psychosocial services, health and nutrition education, treatment advocacy, peer support, and complementary therapies to its clients. The Clinic has developed an adherence intervention, the Medication Adherence Protocol, or MAP, which: emphasizes the client's readiness to take HAART by having multiple discipline assessments; integrates cultural competency, social support and patients' belief systems; and builds in a system of checks and balances. Clients are prepared to begin taking HAART through a series of meetings with the medical provider, case manager/social worker, and nurse or treatment advocate. When they are determined to be ready, they fill their prescriptions and return to the clinic for an assessment of their understanding of the medicines and how to take them, as well as for assistance with putting the medications in a multi-chambered container with dividers for times of day and days of the week (a medi-set). Ongoing appointments with medical providers, case managers and peers provide continued adherence support for clients.

Contact information:

Brenda Storey, LCSW, Principle Investigator
Mission Neighborhood Health Center
240 Shotwell Street
San Francisco, CA 94110
Phone: (415) 552-1013
E-mail: estorey 359@aol.com

HIV/AIDS Health Services Center, Multnomah County Health Department
(Portland, OR)

Target Populations: People with HIV who have problems with substance use, mental illness, or homelessness

Project overview: The Multnomah County Health Department HIV/AIDS Health Services Center developed the Multidisciplinary HAART Adherence Assistance Program in June of 1998 to increase client acceptance of and adherence to HAART. The cornerstone of the program is its multidisciplinary approach. A clinical pharmacist, health care professionals, and social workers jointly address the adherence needs of HAART clients. The pharmacist coordinates the program and serves as an integral part of the care of HIV clients. The pharmacy intervention is a series of educational interventions in which the pharmacist provides education, counseling, and adherence tools such as multi-sectioned plastic boxes, or Medisets, for storing a week's supply of medicine. The program works to improve client readiness for antiretroviral treatment prior to prescription, and support client adherence to antiretroviral treatment after prescription.

Contact information:

John Dougherty, MD, Principle Investigator
Multnomah County Health Department
426 SW Stark Street
Portland, OR 97204
Phone: (503) 248-3674

Dimock Community Health Center (Roxbury, MA)

Target Populations: People with HIV, including women, African Americans, Hispanics, and people who have problems of mental health and/or substance use

Project overview: The adherence project at the Dimock Community Health Center works to ensure treatment with and adherence to HAART for HIV infected individuals, comparing a standard adherence strategy to an intensive strategy that involves community-based care. Patients are randomly assigned to receive either the standard or the intensive strategy. The standard strategy, which includes multidisciplinary care as coordinated by an HIV nurse, HIV specialty care, use of literacy-leveled educational materials, peer counseling, use of a programmable watch, and tailored interventions, is provided at both study sites. In the intensive strategy, an HIV home care nurse also visits patients once or twice weekly for four to six weeks in their identified community setting, addressing specific barriers to adherence in coordination with the multidisciplinary team.

Contact information:

Lisa Hirschhorn, MD, MPH, Principle Investigator
Dimock Community Health Center
55 Dimock Street
Roxbury, MA 02119

Dimock Community Health Center (con't)

Phone: (617) 442-8800 x1255
E-mail: hirschhorn@mediaone.net

North Broward Hospital District (Ft Lauderdale, FL)

Target Populations: People with HIV, including women and African American and Hispanic people

Project overview: North Broward Hospital District is implementing three outpatient interventions of increasing intensity to improve medication adherence: Standard, Provider Enhanced Intervention (PEI), and Home-based. The standard intervention is comprised of the interventions everyone attending the clinic receive, including a psychosocial assessment by a case management and a clinical assessment by a health care provider. The PEI is comprised of the standard intervention plus two or three sessions with the pharmacist, who provides counseling, reminder tools, and training videos. The Home-based intervention is comprised of all the previous components plus two or three home visits by a pharmacist or nurse, medicines delivered to the home, and training of the client's caregivers to help with adherence.

Contact information:

G. Stephen Bowen, MD, MPH, Principle Investigator
North Broward Hospital District
303 SE 17th Street, Suite 100
Ft. Lauderdale, FL 33316
Phone: (954) 355-4952
E-mail: Sbowen@NBHD.org

Action Point Adherence Project, University of California, San Francisco (San Francisco, CA)

Target Populations: People with HIV who are homeless or marginally housed, many of whom have mental health or substance use issues

Project overview: The city of San Francisco has established an adherence support program targeting the homeless or marginally housed called the Action Point Adherence Project (APAP). APAP is open seven days a week in a storefront, street-based facility located in an area with large numbers of indigent HIV-infected persons. The APAP offers a wide range of support services including medication management, food, case management referrals to primary medical care, face-to-face pharmacy consultations, beeper reminder systems, financial incentives, and acupuncture. Up to 150 clients who give their consent to participate in the study will be followed from the time they enroll to up to two years later.

Contact information:

Brian R. Edlin, M.D., Principle Investigator
University of California, San Francisco

Action Point Adherence Project (con't)

Action Point Adherence Project (APAP) Evaluation
3180 18th Street, Suite 302
San Francisco, CA 94110
Phone: (415) 476-3400
E-mail: bredlin@itsa.ucsf.edu

Take Charge ADHERE Program, Washington University/Hospital (St Louis, MO)

Target Populations : Adolescent and adult women with HIV, many of whom are African American

Project overview: The Helena Hatch Special Care Center (HHSCC) offers one-stop comprehensive HIV services, including primary HIV medical care, OB/GYN services, social work and nursing case management, patient education, and psychosocial and spiritual support. The Take Charge ADHERE Program is the Center's structured adherence program. The adherence program consists of the following components: Assessment of patients' readiness for taking HAART; Selection of the best Drug regimen for each patient; Development of tailored Helping strategies; Evaluation of adherence and regimen effectiveness based upon current treatment guidelines; Reinforcement or Readjustment of treatment or adherence strategies; and, Development of Endurance strategies.

Contact information:

Linda Mundy, MD, Principle Investigator
Washington University School of Medicine, Campus Box 8051
660 S. Euclid Ave.
St. Louis, MO 63110
Phone: (314) 747-1026
E-mail: kmeredit@imgate.wustl.edu

New York Health Department AIDS Institute (Renssalaer, NY)

Target Populations : A wide range of people at the various sites

Project Overview: The Institute has funded ten comprehensive adherence support programs throughout New York State. The programs all aim to increase adherence through the following measures: development of partnerships among clinical and non-clinical providers and clients; development of collaborative management and operational structures; empowerment of clients to make informed treatment decisions; integration of treatment into the continuum of care; enhancement of client skills; provide access to support services tailored to clients' needs. Data are already being gathered from the sites for evaluation, and for the purposes of the SPNS initiative, these data are now being statistically manipulated and combined with the data from the other SPNS sites for the national cross-site evaluation.

New York Health Department AIDS Institute (con't)

Contact information:

Bruce D Agins, MD, MPH, Principle Investigator
Health Research, Inc
1 University Place
Renssalaer, NY 12144-3456
518-431-1212

EVALUATION OF SERVICES TO PEOPLE WITH HIV IN CORRECTIONAL SETTINGS

THE INITIATIVE

Statement of Need

Over two million people are currently incarcerated in jails and prisons in the United States, and African Americans and Hispanics constitute an overwhelming three-quarters of all new admissions. In 1997, an estimated 8,900 inmates had AIDS and 35,000 to 40,000 inmates had HIV in the United States, representing a prevalence of infection and disease five times higher than that of the total population. The HIV rate among inmates disproportionately affects racial and ethnic minorities: HIV rates were found to be as high as 11.3 percent and 11.1 percent among Hispanic and African American inmates, respectively, compared to 3.7 percent among white inmates.

Inmates living with HIV face challenges in obtaining medical treatment for their disease both within correctional institutions and when they return to the community. Particularly since the advent of highly active antiretroviral treatment (HAART), they often have complex treatment protocols that require close medical monitoring as well as adherence support, neither of which is usually available within jails and prisons. Even if they are available, accessing health care frequently and taking medication two or three times daily threaten the confidentiality of their HIV status within the institution. In the transition from correctional facilities back into the community, health care is usually not coordinated. Moreover, many inmates with HIV return to the community never having received counseling and HIV testing, and thus continue to be unaware of their HIV status. Thus, the opportunity for early intervention with HAART is lost, as well as the opportunity to prevent further spread of HIV through prevention education. Linkages need to be strengthened between correctional health and community-based primary health care systems in order to provide not only continuous medical care but also preventive, substance abuse, and social services.

Goals

The goal of this initiative is to improve access to care and prevention services for soon-to-be or recently released inmates by:

- Increasing access to HIV/AIDS primary health care and prevention services;
- Improving HIV transitional services between corrections and the community; and,
- Developing organizational supports and linked networks of comprehensive HIV health and social services.

The specific goals of the initiative are to:

- Increase inmate/detainee access to HIV/AIDS testing, prevention and care services;
- Improve transitional services for inmates/detainees as they are released;

- Improve community-based services to recently released inmates so they can make and maintain connections to health and social services;
- Develop organizational supports and linked networks of comprehensive HIV health and social services from correctional facilities to the community;
- Expand disease screening within correctional facilities; and,
- Provide training to corrections and community-based organization (CBO) staff.

Target Populations

Individuals, specifically racial minorities, in correctional settings, who are disproportionately affected by the HIV/AIDS epidemic.

Summary of Initiative

The Corrections Initiative is jointly funded by the Centers for Disease Control and Prevention (CDC) and the Health Services and Resources Administration (HRSA) and comprises seven demonstration projects and the Evaluation and Program Support Center (EPSC), which is implementing a cross-site evaluation of the grantees' activities. State health departments for California, Georgia, Florida, New York, Massachusetts, and New Jersey, and the Chicago Center for Health Systems Development, have been awarded cooperative agreements by the CDC to develop model programs to enhance prevention and care services to incarcerated people at risk for HIV or living with HIV. The grantees were eligible to compete for the funding under this initiative because they were designated priority areas based on: total prison population; percentage of African American AIDS cases; percentage of HIV-infected inmates in U.S. state prisons. These states also represent 26 of 30 highly affected metropolitan areas for African Americans. The EPSC received funding from HRSA to assist in the local and cross-site evaluation of the demonstration projects.

Contact information:

Ronald Braithwaite, PhD
Principle Investigator
Rollins School of Public Health, Emory University
1518 Clifton Road, Suite 564
Atlanta, GA 30322
404-727-1895
rbraith@sph.emory.edu

Theodore Hammett, PhD
Co-Principle Investigator
Abt Associates, Inc
55 Wheeler St
Cambridge, MA 02138
617-349-2734
ted_hammett@abtassoc.com

John Miles, MPA, CDC Project Officer
Corrections and Substance Abuse Activities
National Center for HIV, STD and TB Prevention
Centers for Disease Control and Prevention
1600 Clifton Road, NE, Mail Stop E-07
Atlanta GA 30333
404-639-8629
jrm2@cdc.gov

Melinda Tinsley, MA
HRSA Project Officer
SPNS Program
HIV/AIDS Bureau, HRSA
5600 Fishers Lane Rm 7C07
Rockville MD 20857
301-443-3496
mtinsley1@hrsa.gov

The Cross-site Evaluation

The EPSC, the evaluation center for the grantees, received funding from the Special Projects of National Significance (SPNS) in the HIV/AIDS Bureau (HAB) of HRSA to assist in the local and cross-site evaluations of the demonstration projects as well as to provide technical assistance regarding program issues. The EPSC has a multidisciplinary team of behavioral scientists from the Emory University Rollins School of Public Health in Atlanta, Georgia, and researchers from Abt Associates in Cambridge, Massachusetts.

The process evaluation questions being asked about each demonstration project are:

- Is the program being implemented as planned?
- What services are being delivered?
- What are the costs of the services?
- What are the service utilization trends prior to and after incarceration?

The interim outcomes being examined include:

- Is disease screening identifying more cases?
- Are target populations being reached with planned services?
- Are clients satisfied with services?
- Are releasees accessing needed services in the community?
- Are inmates/releasees adhering to prescribed regimens?

The final outcomes being examined include:

- Do program participants receive discharge planning services and get connected to community services prior to release from jails and prisons?
- Do program participants engage in case management services after they are released from jails and prisons?
- Do program participants successfully link to services in the community (e.g., medical, mental health and substance abuse treatment, housing and benefits)?
- Do program participants maintain their participation in care, especially medical care, after intensive case management services cease?
- Do program participants in case management and prevention interventions have reduced recidivism rates?

Client-level data collection will occur in the discharge planning/case management program component only. This is because the bulk of the funding and thus energy of the grantees is devoted to these interventions, and because they are, for the most part, the most innovative programs. Finally, findings in regard to discharge planning/case management programs will have important policy implications because they are innovative, staff-intensive and complex, and thus challenging to fund and to implement.

The cross-site evaluation uses a matrix evaluation design that examines common program elements across grantees. Both aggregate data (eg, number of clients completing all

sessions of a program) and client-level data (eg, engagement in case management services) are being collected at each site. While it is not possible to have control groups for this study, several of the States will collect information from comparison groups (people who are similar to those receiving the services/interventions) to strengthen the findings.

**SPNS CDC/HRSA Corrections Initiative
Forms for Data Collection**

Form	Completed by	Administered to (Respondent)	Frequency Schedule
1. Baseline Interview	Corrections Case Manager	Client in facility	1 time (1 st , 2 nd , or 3 rd contact)
2. Inside Facility Event Form	Corrections Case Manager	N/A	Every significant client contact
3. Staff Report at Release	Corrections Case Manager	N/A	1 time (within week of release)
4. Post-Release Services/Status	Community Case Manager	N/A	Every 30 days for 6 months
5. Post-Release Interview	Staff other than corrections or community case manager	Client outside facility	1 time 3 months after last contact or 6 months after release
6. HIV Treatment, Case Management	Corrections/Community Case Manager → State Evaluator	N/A	Determined by States
7. HIV Prevention Education Programs	Prevention Provider → State Evaluator	N/A	Determined by States
8. Peer Educator Training Process Data Report	Peer Education Provider → State Evaluator	N/A	Determined by States
9. Disease Screening	Screening Personnel → State Evaluator	N/A	Determined by States
10. Corrections & CBO Staff Training	Training Provider → State Evaluator	N/A	Determined by States

The State demonstration projects have access to three additional sources of technical assistance funded through CDC and HRSA as well:

- The **Southeast AIDS Training and Education Center (SEATEC)** provides training to corrections staff and evaluates the effectiveness and replicability of different models of correctional HIV training and education.
- The **National Minority AIDS Council (NMAC)** provides technical assistance to grantees regarding community capacity building and linkage development.
- The **Hampden County Correctional Center** serves as a model to grantees for providing high quality medical care to inmates and establishing partnerships between local health systems and correctional facilities.

Common Data Elements:

HIV prevention
Case management
HIV treatment issues
Continuity of care/transitions/linkages
Training

Achievements in Year One

Although it has only been a year since the projects were funded, a number of milestones have been achieved:

- The grantees have formalized contracts with community-based organizations.
- The EPSC has convened the grantees for two national meetings at which: the grantees networked; technical assistance was provided; and in-depth discussion resulted in consensus regarding the evaluation design and instruments.
- Four workgroups have been established to focus on key areas of the demonstration projects: Prisons; Jails; Juvenile facilities; and, Policy issues.
- A set of core indicators and an evaluation matrix have been finalized.
- The evaluation instruments have been piloted and finalized.
- All states have begun implementing at least one of their program components, including HIV treatment, HIV prevention, disease screening and staff training.
- Aggregate data are being collected by all States.

Each project grantee has worked on developing collaborative partnerships with correctional institutions at the administrative level, and with target sites including prisons, jails, juvenile facilities, and community corrections. In addition, grantees have funded community-based organizations and/or correctional institutions to provide or coordinate one or more of the following interventions for correctional institutions (Note: for more detail, see Matrix of Interventions by Grantee in the Demonstration Projects section):

- HIV treatment (including medical treatment, discharge planning, and case management);
- HIV prevention (including peer education and prevention case management);
- Disease screening (including screening for HIV, STDs, TB, and hepatitis);
- Staff training;
- Community capacity building.

The first intervention category, a cluster including HIV treatment, discharge planning and case management, is the most common type of intervention, with all States developing such a program in a jail setting and all except New York and Georgia developing a program in a prison setting. The States contract with CBOs to provide discharge planning and case management services inside facilities and case management follow-up in the community. Most of these case management programs will exclusively target HIV positive inmates. California will also offer prevention case management for high-risk HIV negative female inmates in a jail setting.

The prison programs tend to emphasize HIV prevention programs, whereas the jail programs focus more on disease screening and staff training interventions. The HIV prevention programs typically include: group health education and HIV prevention classes, health education at admission and encouragement of HIV counseling and testing. At least 3 states will also provide peer-based education programs. The disease screening

component usually focuses on HIV counseling and testing, but STD, TB, and hepatitis are sometimes included as well. Some initiatives include an emphasis on partner notification, and at one jail, chlamydia screening has been expanded to include men as well as women.

As none of the States have high known rates of HIV infection among juvenile inmates, the current priorities in juvenile facilities are disease screening and HIV prevention. Four States will extend to juveniles the community case management services offered to jail and prison releases in certain areas, and two States plan to provide staff training.

Even though it is too early in the data collection process for any findings to be gleaned from the data, the initiative has faced a number of challenges that provide valuable information for agencies seeking to develop care and prevention services to incarcerated and recently released individuals. The scope, complexity and time requirements of program implementation depend upon a number of factors:

- Whether the new services are being built into an existing service system or a program is being started from scratch;
- The extent of bureaucratic procedures required for processes such as contract letting and personnel hiring (particularly within state health departments, perhaps because the larger the bureaucracy, the more complex the structure);
- Whether there are existing relationships between public health and corrections systems, especially on a state level;
- Whether prison inmates or ex-offenders are geographically dispersed, both in terms of the location of the facilities and the locations of the communities of return (in fact, prisons do not release inmates as frequently as do jails and have a lower volume of HIV-positive releasees, so fewer inmates are being released to more geographically dispersed areas, creating challenges in designing organizational linkages and services).

Plans for Years Two and Three

In years two and three of the initiative the projects will continue to conduct their interventions and collect process data and will begin to collect client-level data. EPSC will continue convening meetings and facilitating regular conference calls to enhance collaboration and communication among the projects as well as to provide technical assistance to individual projects regarding data collection and management. Site visits and trainings will be provided as needed. As data are gathered and analyzed, EPSC will stimulate the development of technical papers, articles, and presentations at professional meetings regarding the findings.

THE DEMONSTRATION PROJECTS

Matrix of Interventions by Setting and Grantee

As of September 2000

Setting	HIV Treatment	HIV Prevention	Disease Screening	Staff Training
California*				
Prisons	X		X	
Jails	X	X	X	X
Florida				
Prisons	X	X	X	X
Jails	X	X	X	X
Juvenile Facil's	X			
Georgia				
Jails	X		X	X
Juvenile Facil's		X	X	
Illinois*				
Prisons	X			
Jails	X	X	X	X
Juvenile Facil's		X	X	X
Massachusetts**				
Prisons	X			
Jails	X		X	
Juvenile Facil's	X		X	
New Jersey				
Prisons	X	X	X	X
Jails	X	X	X	X
Juvenile Facil's	X	X	X	
New York				
Prisons		X	X	X
Jails	X	X	X	X
Juvenile Facil's		X	X	X

* General capacity building, CBO and corrections training

** HIV prevention in community corrections program

California

Project overview: The overall project is organized as a consortium with central administration and communication coordinated by the state health department's Office of AIDS. Each major component operates with substantial autonomy. Centerforce, a CBO, provides peer education, health education, and aftercare support services for state prison inmates in three facilities. The Forensic AIDS Project, at the San Francisco Department of Public Health, and Continuum, part of a consortium of providers called Tenderloin Cares, will provide case management and housing placements to soon-to-be-released HIV-positive inmates in San Francisco county jails. The Los Angeles County Health Department will be assessing the needs of HIV-positive inmates in the Los Angeles jail system and implementing programs based on these assessments.

California (con't)

Contact information:

Reggie Caldwell, M.S.W.
Office of AIDS State of California
P. O. Box 942732
Sacramento, CA 94234-7320
(916)324-6783
E-mail: rcaldwe2@dhs.ca.gov

Florida

Project overview: The project, named Linking Inmates to Needed Care (LINC), has three distinct components, all of which provide discharge planning and case management services: a prison program based in the Florida Department of Corrections; a jail program in the Jacksonville/Duval County Jail; and a juvenile component in the Hernando facility. The prison project provides HIV treatment as well as discharge planning and case management services in a specific facility. In addition to the inmates who live at that facility, inmates with HIV are transported from five other facilities, including the juvenile facility, to receive the care provided here. Transportation is provided so that inmates who are released may continue to receive HIV treatment from the health professionals who are located at this facility. Secondary prevention and staff training are being planned. The jail program contracts with a CBO to provide case managers both inside the jail and in the community to ensure tight linkages. Transitional housing is also being planned, and beds have been reserved for releasees at various community facilities.

Contact information:

Priscilla H. Wood
Special Projects Coordinator
Florida Department of Health/Bureau of HIV/AIDS
4052 Bald Cypress Way, Bin A09
Tallahassee, FL 32399-1715
(850)245-4444, ext, 2568
E-mail: priscilla_wood@doh.state.fl.us

Georgia

Project overview: The Georgia Program has jail and juvenile components, both serving the Atlanta/Fulton County area. The adult program includes: discharge planning, case management, disease screening, and staff training at Fulton County Jail. The juvenile component includes HIV prevention, disease screening, and staff training at the Metro Regional Detention Center, and HIV prevention for youth probated through the DeKalb County Juvenile Court. The jail program is the most developed of the three components, with plans for expanding HIV counseling and testing as well as for establishing case management services. The youth component will focus on prevention education groups for high-risk or infected offenders, as well as on peer education and chlamydia and gonorrhea screening and treatment.

Georgia (con't)

Contact information:

Judith Byrnes, Education and Information Officer
Georgia Department of Human Resources Prevention Services
2 Peachtree Street, NW
10th Floor, Suite 400
Atlanta, GA 30303
(404)657-3110
E-mail: jbyrnes@dhr.state.ga.us

Illinois

Project overview: The Illinois Public Health, Corrections and Community Initiative has prison, jail and juvenile components. In all 3 settings, the interventions consist of HIV treatment, discharge planning, and case management for HIV-positive inmates, as well as HIV prevention for all inmates, and staff training for corrections case managers. The prison component, planned for two or three facilities, will have two prison-based case managers to provide discharge planning and connect inmates to services in the communities of their release. In the jail component, a clinical coordinator develops medical treatment plans for HIV-positive inmates, and connects them with treatment and medications on release. In addition, two jail-based case managers provide discharge planning with linkages to community-based services. The staff of juvenile detention facilities develop discharge plans and connect HIV-positive youth to intensive community-based case management. In addition, increased voluntary HIV counseling and testing as well as staff training in HIV prevention are being planned.

Contact information:

Kendall Moore, Project Director- Illinois
Chicago Department of Public Health
2160 W. Ogden Avenue
Chicago, IL 60612
(312) 746-6235
E-mail: kendallm@attglobal.net

Massachusetts

Project overview: In Massachusetts, the Department of Public Health is implementing three programs under its grant. The largest, the Transitional Intervention Program, is a state-wide community-based transitional case management program for inmates released from all county jails, state prisons, and youth facilities. The state is divided into six regions, in which CBOs provide corrections-based and community-based services. Each region has a team of one social worker and one case manager, who develop discharge plans for HIV-infected inmates. On release, the inmate is assigned to the team in her/his home region, and that team follows up on the discharge plan, also providing mental health, substance abuse and other counseling for up to six months. The other two programs are the expansion of a chlamydia screening program to men as well as

women in a jail and a peer-based HIV education and prevention program at all Offices of Community Corrections statewide.

Contact information:

Carmen Rosa
HIV/AIDS Bureau
Massachusetts Department of Public Health
250 Washington Street, 3rd Floor
Boston, MA 02108-4619
(617) 624-5218
E-mail: carmen.rosa@state.ma.us

New Jersey

Project overview: The New Jersey Department of Health contracts with five CBOs to provide HIV treatment, discharge planning and case management, HIV prevention, enhanced HIV counseling to supplement the additional testing that is needed as a result of this initiative, and staff training. These interventions will be provided in a county jail, half-way house, juvenile facility, men's prison, and women's prison. In most cases, clients will receive in-facility and post-release services from different organizations. An important criterion in the selection of CBOs was their ability to work in correctional settings. The health department plans to monitor the organizations' performance carefully, hold regular conference calls with all partners, and visit all facilities on a regular basis.

Contact information:

Laurence E. Ganges, MSW, Director, Counseling and Testing Services
Department of Health & Senior Services
Division of AIDS Prevention and Control
P. O. Box 363
50 East State Street, 3rd Floor
Trenton, NJ 08625
(609)984-6125
E-mail: lganges@doh.state.nj.us

New York

Project overview: The New York Department of Health has a complex and multifaceted project. HIV prevention services, including peer education, are being provided at four state prison facilities, and disease screening services, including HIV counseling and testing and linking HIV-positive individuals with services, are being provided at two prisons. HIV prevention and disease screening as well as a transportation service to link releasees with services in the community, are being provided in a jail facility. Prevention case management will be provided for high-risk women inmates in another jail. The juvenile prevention program involves providing prevention services to at-risk youth recruited from residential programs to which they are assigned. Youth are identified at the reception center through STD screening, with those who test positive for an STD being enrolled in a follow-up behavioral intervention.

New York Health Department AIDS Institute (con't)

Contact information:

Dan O'Connell, M.A., M.L.S, Associate Director

Division of HIV Prevention

New York State Department of Health

Empire State Plaza

Corning Tower, Room 308

Albany, NY 12237

(518)473-2300

E-mail: dao03@health.state.ny.us

IMPROVING THE QUALITY OF CARE FOR PEOPLE WITH HIV

Statement of Need

Marked reductions in HIV morbidity and mortality have been reported in recent years, yet there are inequities in the distribution of these gains. The decreases in mortality among African Americans and Hispanics with HIV are lower than the decreases among white persons with HIV. In addition, in spite of all that is known about effective HIV care, recent studies have documented significant deficits in the quality of care received by a substantial proportion of HIV-infected persons. Mechanisms for promoting improvements in the care received by people with HIV need to be developed and implemented in order to close the gap between the science (what is known) and the care being delivered.

Goal

The goal is to improve health status and outcomes in order to maximize the length and quality of life for people with HIV/AIDS and to satisfy patient and caregiver needs, while maintaining or decreasing the total cost of care.

Target Population

Ryan White CARE Act-funded grantees and care providers

Summary of Initiative

The HIV/AIDS Bureau in partnership with the Institute for Healthcare Improvement (IHI) is conducting the Collaborative for Improving Care for People with HIV/AIDS, in which Ryan White CARE Act grantees and providers participate in a process aimed at improving the quality of care provided to their clients. The first step of the initiative was for an expert panel of clinicians, academicians, administrators, consumer representatives, and researchers to convene to identify cutting edge approaches to HIV care that can be used by grantees/providers to deliver state of the art clinical care to their clients. In the next step, selected representatives of CARE Act grantee/provider organizations are participating in a year-long collaborative that involves learning the best available scientific knowledge on the care for people with HIV/AIDS, and learning and applying methods for organizational change.

The organizations' activities include planning, attending learning sessions, implementing changes in their organizations' clinical practice, collecting data to document the impact of the changes, and sharing information with the Collaborative regarding the process and its impact on care delivery. The HIV Collaborative will culminate in a National Congress for the dissemination of results to the larger CARE Act and health care community.

The success of the collaborative will depend on how well participating organizations can integrate knowledge that currently exists once they are given strong examples of practitioners and organizations that have already applied such knowledge to achieve unprecedented results in improving the quality of HIV care. This effort is designed to achieve rapid improvement the delivery of care and health outcomes for people living with HIV/AIDS in participating organizations.

Institute for Healthcare Improvement (IHI)

The IHI, which is funded to manage the Collaborative, is a not-for-profit organization designed to accelerate improvement in health care systems. The IHI designed the Breakthrough Series, a process that brings together groups of health care organizations that share a commitment to making major, rapid changes that will produce “breakthrough” results: lower cost and better outcomes at the same time. The philosophy of the Breakthrough Series is that sound science can greatly improve the costs and outcomes of current health care practices, but that much of this science is unused in daily work.

The goal of IHI is to facilitate improvements in the quality of care within HIV clinical care organizations by implementing a system-wide improvement process that focuses on assuring the delivery of evidence-based clinical care and strong support for self-management. Specifically, the goals of the Collaborative are to:

- Achieve measurable and dramatic improvements in health outcomes;
- Develop leadership capabilities and infrastructure for the rapid spread and continuous improvements in care to grantees;
- Disseminate models of improvement developed in this project to non-participating providers and populations.

An evaluation is being conducted of the Collaborative Breakthrough Series rapid learning strategy. Through funding provided by the Agency for Healthcare Research and Quality, the Harvard Medical School is studying the effectiveness of this intervention on participants as compared to non-participating CARE Act funded organizations. Researchers collected information at the first learning session and are conducting their evaluation as the collaborative progresses.

Contact information:

Project Director: Penny Carver
HIV/AIDS Breakthrough Series Collaborative
Institute for Healthcare Improvement
Project Director: Penny Carver 135 Francis Street
Boston, MA 02215
617-754-4814
E-mail: PCarver@IHI.org

Magda Barini-Garcia, MD, MPH,
Chief Medical Officer
Div Training and Technical Assistance
HIV/AIDS Bureau, HRSA
5600 Fishers Lane, Room
Rockville MD 20857
301-443-6366
Mbarini-garcia@hrsa.gov

Common Data Elements

Each participant organization monitors Key Measures described in the table below.

KEY MEASURES OF QUALITY OF HIV CARE (As of 6/16/00)			
Category	Measure	Goal	Data Gathering Plan
Access and Retention	% patients with visits in last 3 months	85%	At the end of each month, count the number of patients with at least one visit in the last 3 months; divide by the total number of patients in the patient database system (multiply by 100)
Viral Load and CD4 Count	% patients with CD4 count less than 200	25% decline	At the end of each month, count the number of patients on HAART whose last CD4 count was less than 200; divide by the total number of patients on HAART (multiply by 100)
	% patients with undetectable viral load	60%	At the end of each month, count the number of patients on HAART whose last viral load was undetectable (less than 50 copies); divide by the total number of patients on HAART (multiply by 100)
Clinical Care	% patients on HAART	75%	At the end of each month, count the number of patients who are currently on HAART; divide by the total number of patients in the patient database system (multiply by 100)
Self-Management and Adherence Support	% HAART patients with adherence counseling intervention at last visit	75%	At the end of the month, count the number of patients with documented adherence counseling intervention at last visit; divide by the total number of patients on HAART (multiply by 100)

Achievements in Year One

The research and development phase: In the first year of the Collaborative, IHI worked with HAB staff and expert faculty to develop Collaborative goals, the elements of a system of care that would achieve those goals (The Change Package) and a measurement system to measure the changes and the overall performance of the new system. The Co-Chairs of the Collaborative are Renslow Sherer, MD, Director of Coordinated HIV Services, The CORE Center, Cook County Hospital, and Joseph O'Neill, MD, MPH Associate Administrator of the HIV/AIDS Bureau. The length of the collaborative was increased from 6-8 months to 12-13 months in order to provide teams with sufficient time to demonstrate improved outcomes for their pilot populations.

Breakthrough Series One: Eighty-five Title III and Title IV teams, rather than the 40 to 60 expected teams, were selected as participants in the first Breakthrough Series Collaborative. The teams attended the first of three two-day Learning Sessions. They are now testing changes and reporting on their progress monthly to their Senior Leaders and the Collaborative leadership, supported by a system of regular conference calls and internet discussions on the "Extranet."

Development of a Data Registry: A system was developed for tracking patient care activities for those participants who do not have one already.

Plans for Year Two

Transfer of Breakthrough Series Methodology and Developing Capacity: IHI will transfer the Breakthrough Series methodology to the HIV/AIDS Bureau and its selected partners through training, coaching and guidance. Staff will acquire the skills needed to apply the model for improvement and run subsequent Collaboratives with minimal IHI support. Deliverables will include:

- A two-day training on the Breakthrough Series and Model for Improvement for staff of the AIDS Education and Training Center, Title I and II Program Officers, and HAB staff and key project officers;
- Training of staff of the AIDS Education and Training Center and the Title I and II Programs to spread the improvements and to assure sustainability;
- Breakthrough Series training kit, including all planning documents and implementation tools;
- Copies of IHI training materials related to the Breakthrough Series.

A team of eight to ten early adopters from the first Collaborative will receive an ongoing training, mentoring and coaching experience to develop their competency to spread improvements in HIV care to other providers and provide technical support to HAB staff and future Collaborative teams.

Refinement of System Design for HIV Care: The knowledge base (the Change Package) will be reviewed and revised by June 2001.

Breakthrough Series Two: A second cohort of HAB teams will participate in the Breakthrough Series, taking advantage of the infrastructure, training, experiences, case examples, tools and lessons learned from the first Collaborative.

National Congress Event: A national Congress event may be held to showcase the best achievements within the Collaborative and to disseminate the improvement knowledge gained during the Collaborative to a much larger audience.

ASSESSMENT OF INNOVATION IN SERVING PEOPLE WITH HIV WHO ARE SUBSTANCE USERS

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. The importance of substance users having a range of enabling services to ensure access to primary health care, and the importance of their having access to substance abuse treatment, are 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 research has been done to determine the optimum substance abuse treatment modalities for people with HIV. Performance standards and best practices for treatment and care of substance users with HIV have yet to be identified and disseminated for use by other practitioners.

Goals

The goals of the initiative, Assessment of Innovation in Serving People with HIV who are Substance Users, 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 primary health care, substance abuse treatment, and supportive services;

- Identify particularly innovative programs that serve substance users and determine what makes the programs successful;
- Develop a set of integrated performance standards for primary care, substance abuse treatment and support services that can be used by programs that serve substance users; and,
- Provide information about how to replicate innovative program models.

Target Population

Substance users with HIV/AIDS

Summary of Initiative

This initiative, unlike most of the initiatives, is being conducted by a single evaluation center, the Evaluation and Program Support Center (EPSC), and has no funded demonstration projects. Instead, the EPSC draws upon the expertise of currently funded Ryan White CARE Act and other HIV providers who already serve substance users living with HIV. The initiative is comprised of a series of information-gathering activities culminating in the development of a set of performance standards for programs serving substance users with HIV/AIDS, a description of best practices based on existing innovative programs, and a training program. Information is being gathered through: reviews of the published and unpublished literature and existing performance standards specific to the care and treatment of HIV-positive substance users; surveys of Ryan White CARE Act providers and their clients who are substance users; key informant interviews with experts in the fields of HIV care and substance abuse treatment; and, surveys of and site visits to innovative programs. A national expert Advisory Committee has been convened to guide the work of the EPSC.

The Evaluation

The task of this initiative is to answer the following questions:

- What additional standards need to be set in order to ensure that HIV positive substance users are able to access the same standard of care as other people living with HIV or other substance users?
- What standards should be set to address the interaction between HIV and substance abuse (topics that may be missing from existing standards)?
- What are the most pressing barriers to care for this population, and is there evidence in the literature that these barriers can be overcome by establishing certain performance standards?
- What are the barriers to care for different under-served populations of HIV positive substance users, including women, racial/ethnic minorities, adolescents, people who are homeless, rural populations, gay men/lesbians, and individuals who are incarcerated?

The EPSC is based at the Medicaid Working Group at the Boston University School of Public Health in Boston.

Contact information:

Mary-Lynn Drainoni, PhD
Medicaid Working Group
Boston University School of Public Health
374 Congress St, Suite 502
Boston MA 02210
Phone 617-426-4447
Email drainoni@bu.edu

Karen Brown
HRSA Project Officer
5600 Fishers Lane, Room 7A32
Rockville MD 20857
301-433-3577
kbrown1@hrsa.gov

Categories of Care for Performance Standards

- HIV primary medical care
- Acute detoxification
- Outpatient substance abuse treatment
- Residential substance abuse treatment
- Methadone maintenance programs
- Supported/transitional housing
- Case management services

Achievements in Year One

During Year One, the EPSC conducted a review of the published and unpublished literature regarding treatment of substance users with HIV infection and completed the first draft of the report.

The EPSC team has also 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 reports are being drafted. The first draft of the report of the key informant survey contains 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. It also contains a list of 69 programs identified by key informants as successful. Based on the recommendation that more experts be interviewed, additional key informant interviews have been conducted and the results will be incorporated in the second draft report.

Based on the work that has been accomplished, a number of lessons have already been learned:

- Performance standards are needed: Very few existing performance standards discuss the issues of substance users living with HIV. Most of the HIV primary and specialty care standards that were reviewed recommended that patients be screened for substance abuse upon their first visit, but few discussed the specifics of caring for those with substance abuse problems. For substance abuse treatment in general, few

standards exist apart from those published by Substance Abuse and Mental Health Services Administration (SAMHSA), and even fewer are specific to HIV-positive substance users.

- Equity in care must be emphasized. HIV positive substance users should receive the same standard of medical care provided to anyone with HIV, as established by the United States Public Health Service and the Infectious Disease Society of America. They should also receive the same standard of substance abuse treatment as other substance users, in accordance with guidelines established by the American Society of Addiction Medicine and SAMHSA.
- The scope of the performance standards must include process standards. Care delivery strategies that enhance access to care, and treatment adherence for substance users, are needed for substance users with HIV, and must be considered as an equal partner with clinical standards of care. These process standards include screening processes, provider training, continuity of care across disciplines, ease of access to services, outreach strategies, cultural capacity and competence, and the availability of support services. These standards are less likely to have been tested and evaluated, but are considered vital to client outcomes. Therefore development of performance standards for programs serving HIV-positive substance users must address both clinical standards and process standards.
- Some issues are controversial. It may not be possible to achieve consensus on all controversial issues, and at the end of the initiative it may be necessary to identify areas that require further discussion. The two topics that have surfaced so far are:
 - Performance standards that address access to HAART therapy for active substance users; and
 - Performance standards that address the reality of relapse or the lack of readiness to undergo substance abuse treatment among people with HIV (i.e., harm reduction).

Plans for Year Two

- **Report of the literature review:** The first draft of the report has been reviewed by HRSA and the Advisory Committee; the second draft will be completed and again reviewed, and the final report completed by the end of Year Two.
- **Report on the key informant interviews:** The results of additional interviews are being incorporated into the first draft of the report; a second draft will be reviewed and finalized.
- **Typology of current program models:** The typology of program models will be developed based on the information gathered from the surveys.

- **Performance standards** : Three subcommittees have been selected to assist EPSC staff with the development of performance standards for HIV Medical Care, Substance Abuse Treatment, and Support Services. The final standards are anticipated to be completed by April 2001.

- **Identification of innovative program models**: An operational definition of “innovative programs” will be developed and 50 programs identified that meet the definition. A telephone survey will be conducted with these programs and 12 programs selected for site visits. These will 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 enabling services; and how the program outcomes compare with the identified performance standards. A report of the findings will be written that makes recommendations for future SPNS projects.

- **Replication training program**: A training program will be developed and conducted that includes:
 - Presentations by innovative programs from across the country;
 - A panel discussion with local providers that have implemented successful interventions;
 - “How-to” discussion groups that focus on overcoming barriers;
 - A panel discussion with consumers to address their own experiences with barriers to care; and,
 - A session on evaluation methods that introduces the performance standards developed earlier in the project and suggested methods for measuring performance against these standards.

DEMONSTRATION PROJECTS THAT ADVANCE INNOVATION IN HIV CARE ALONG THE US-MEXICO BORDER ¹

THE INITIATIVE

Statement of Need

The U.S.-Mexico border region, over 2,000 miles long, spanning 4 states in the United States and 6 states in Mexico, is one of the poorest areas of the U.S. The unemployment rate along the 62-mile wide stretch is 250 to 300 percent higher than in the overall United States. More than one third of the families live at or below the federal poverty line. An estimated 350,000 people live in *colonias* – un-zoned, semi-rural communities with no access to public drinking water or sewage systems. The border area experienced a 25 to 30 percent increase in population in the 1980's compared to less than 10 percent for the overall U.S. population. This rapid population growth, due to high fertility rates and a high rate of immigration of people from Mexico seeking employment, compounds the economic and social problems. There is a steady flow of migrants back and forth across the border to seeking both seasonal and permanent work in the United States. Within this context, access to health care is limited by numerous factors including inadequate transportation and long distances between urban communities, a scarcity of health care professionals and health care facilities, and inadequate bilingual services for a large monolingual Spanish-speaking population.

With the capacity of the health care system already limited along the border, Given conditions along the border that access to health care system The opportunities for people with HIV to learn their status are limited, as are the sites for comprehensive health care. Although a number of health outreach and community health models are being implemented along the border, including the use of *promotores* (health educators) for HIV prevention education, and resources of the Ryan White CARE Act provide HIV care programming along the border, much remains to be done. Overcoming the structural, socio-economic and cultural barriers that limit early identification of HIV disease among permanent and migrant residents along the border is a large task.

Health providers at many rural community health centers (CHC's) are unfamiliar with HIV clinical care, and even if they were to identify a patient with HIV, would prefer to refer the person to a specialty HIV clinic rather than provide ongoing primary care themselves. Some providers feel their training is inadequate to treat HIV disease, for which the treatment guidelines are constantly being updated. Moreover, they feel unable to take the time to stay up to date on current treatments. Other providers fear that if they care for people with HIV, other patients may stop coming to clinic because of the stigma associated with HIV.

¹ Unlike the other initiatives, the Border Initiative was not funded until the summer of 2000, and therefore at the time of this report grantees are only in the initial phases of program development.

Goals

The overall goal of the initiative is to develop models of community-based health care networks that effectively reduce barriers to early identification of HIV disease and assure entry to high quality primary health care for individuals who live and/or work in the U.S. region of the U.S./Mexico border area.

Target Populations:

People at high risk for HIV and people with HIV/AIDS who live and/or work along the U.S. side of the Mexico/U.S. border

Summary of Initiative

The U.S./Mexico Border Initiative consists of five demonstration projects in four states and the *Centro de Evaluacion* or HIV/AIDS Evaluation and Technical Assistance Center (The Center). The demonstration projects are developing unique models of HIV/AIDS care for high-risk populations living along the US/Mexico border, including Hispanic and Native American people. Each project will establish a network of coordinated services linking people at high risk for HIV to counseling and testing and people with HIV to primary care and other services. The projects, which altogether create a border-wide presence, strive to be responsive to regional issues that are relevant to the local area. The models of care generally focus on two themes. The first is to improve access to HIV/AIDS care through the use of local, culturally relevant models that use indigenous workers to conduct outreach activities. These activities are designed to reduce barriers for access to HIV/AIDS care. The second theme is to use innovative and culturally relevant models of case management to support primary medical care for HIV-infected individuals.

Each project has subcontracted with a local university to assist in its local evaluation, including development of process and outcome evaluation goals and methodologies for the project. The Center is funded to coordinate the cross-site evaluation, to provide the projects with technical assistance, and to develop and disseminate information and findings about the demonstration projects.

Two important components of the initiative are supported by HRSA entities outside of SPNS. The Bureau of Primary Health Care has funded each of the five demonstration projects to improve the capacity of the area community health centers (CHC's) to serve people with HIV. In addition, the AIDS Education and Training Center nearest to each project is working with that project to train health care providers at the CHC's in HIV clinical care.

The Cross-site Evaluation

The HIV/AIDS Evaluation and Technical Assistance Center, based at the University of Oklahoma, will examine the important issues that are generally relevant to all five of the

demonstration service projects. The "cross-cutting" issues that all of the projects must address to enable successful delivery of HIV/AIDS care services include concerns about limited English proficiency, the influences of poverty, a trans-border population that often receives much of their medical care in Mexico, and a population that is composed approximately of 40 percent migrant workers who travel throughout the United States.

The primary evaluation research question for this study is, "To what extent are RWCA programs providing services that remove barriers to primary care access so as to ensure that clients enter into and remain in care?" To address this question, information will be gathered on the factors that influence individuals to enter into HIV/AIDS primary care, and to stay in primary care. Clients will be interviewed about their perceptions of the cultural, psychological and social factors that affect their access to HIV information and testing, health and social services, and adherence to HIV care.

Specifically, the goals of the initiative are to:

- Develop demonstration projects to organize community-based health care networks consisting of HIV counseling and testing services in formal collaboration with primary health care services;
- Conduct multi-site evaluations of cross-cutting issues for the demonstration projects;
- Provide the demonstration projects with technical assistance in conducting local program evaluation;
- Provide limited assessment of local evaluation efforts; and,
- Disseminate the findings regarding successful models of health care networks.

The cross-site evaluation will use a matrix design that requires each of the demonstration projects to provide client-level data on certain components of its intervention. Instruments will be developed to measure the components of the service delivery models.

The Center will coordinate the cross-site evaluation as well as provide technical assistance in the areas of data management, information technology, evaluation design, and analysis, and training of grantee staff in evaluation procedures. The Center will develop and maintain a common data repository. The five demonstration projects and Center will meet twice annually to work on development of the evaluation modules and variable refinement. The web site of the Center is: www.ou.edu/border

Contact information

David Barney, MSW, MPH, PhD
University of Oklahoma School of Social Work
Rhyne Hall
Norman, OK 73019
405-325-1398
Dbarney@ou.edu

Barbara Aranda-Naranjo, PhD
Project Officer for the Evaluation Center
Director, SPNS Project, HAB, HRSA
5600 Fishers Lane Room 7C07
Rockville MD 20857
301-443-4149
BAranda-Naanjo@hrsa.gov

Wayne Sauseda, Project Officer for the Demonstration Projects
Deputy Director, Division of Community-based Programs, HAB, HRSA
5600 Fishers Lane Room 7-
Rockville MD 20857
301-443-0127
wsauseda@hrsa.gov

Common data elements

Basic demographics
 Health status
 Housing status
 Access to HIV care services
 Intervention outcomes (e.g., satisfaction with case management, knowledge gained in prevention education)

THE DEMONSTRATION PROJECTS

SPNS Projects that Advance Innovation in HIV Care Along the US-Mexico Border

Grantee	Goals and Objectives	Interventions
<i>Camino de Vida Center (NM)</i>	Determine HIV patterns of unmet HIV care	Conduct a needs assessment of patterns of access and utilization of health care among border Latinos
	Develop culturally appropriate, early HIV detection and referral services for Latinos	Provide outreach through peer health outreach workers (promotores)
	Improve the system of care to improve continuity and quality of care	Provide counseling, testing, early intervention nursing; Provide medical care; Provide training and coordination services
<i>Centro de Salud Familiar La Fe (TX)</i>	Create multidisciplinary care teams to offer combined social and medical case management	Create two disease management teams composed of nurses (HIV Care Managers) and peer advocates (HIV Case Workers) and a nutritionist to provide social and medical case management
	Focus on treatment adherence assessment, education and counseling	
<i>El Rio Santa Cruz (AZ)</i>	Increase HIV counseling and testing	Provide outreach services
	Engage people with HIV in primary health care services	Enhance primary care system through co-management and training; Increase inter-agency coordination to ensure coordination of care
	Enhance system capacity to provide local access to primary care providers	
<i>Proyecto Juntos (Valley AIDS Council) (TX)/</i>	Increase access to primary health care	Create a rotating HIV primary health care: a nurse at each CHC to coordinate care and referrals; MD to visit each CHC every other week
	Increase capacity of primary health system to meet HIV health care needs of poor, underserved populations	
	Organize health care networks	
<i>San Ysidro Care Center (CA)</i>	Increase early detection of underserved Latino/as with HIV	Five CHCs are service delivery hubs to conduct outreach and coordinate systems of health care
	Increase access to HIV/AIDS primary care services	
	Enhance capacity of CHCs to provide culturally sensitive care	

The New Mexico Border Health Initiative
Camino de Vida Center for HIV Services (Las Cruces, New Mexico)

Project overview: The Camino de Vida Center for HIV Services is implementing the New Mexico Border Health Initiative. The goals of the project are to: 1) determine the patterns of unmet HIV care among Latinos living in the border area of New Mexico; 2) develop culturally appropriate early HIV detection and referral services for Latinos; and, 3) improve the system of care to provide better continuity and quality of care for Latinos with HIV.

The activities of the project are to: conduct a needs assessment to examine the patterns of access and utilization of health care among Latinos living along the border; use a *promotores* program (health educator program) to conduct outreach to specific segments of the Latino population, including: men who have sex with men; injection drug users; women at risk of becoming infected with HIV; and, enhance and monitor the current system for continuity and quality of care for HIV-infected Latino clients.

The lead agency of the project is the *Camino de Vida* Center for HIV Services, but there are numerous other agencies in the network of services. The U.S.-Mexico Border Health Association provides training and coordination of services. The New Mexico Department of Health provides counseling and testing. Clinical care is provided at three primary care health centers (CHCs): Ben Archer Health Center, *la Clinica de la Familia*, and Memorial Medical Center's Family Practice Residency Program.

Contact information:
Kari Maier, MSW, LISW
Camino de Vida Center for HIV Services
P.O. Drawer 2827
Las Cruces NM 88004
505-532-0202
kmaier@zianet.com

Centro de Salud Familiar La Fe (El Paso TX)

Project overview: The comprehensive AIDS service provider for this area of the Texas border closed in December of 1998, and no public or non-profit agency has licensed staff for case management of people living with HIV. The goal of the demonstration project is to develop and evaluate an enhanced case management model of primary care to people with HIV.

The project will create two multidisciplinary care teams composed of nurses, peer advocates living with HIV, and a nutritionist to offer combined social and medical case management. The teams will provide treatment adherence support as well as education and counseling related to substance abuse, mental health, nutrition, and other health issues. Services will be provided at multiple sites, and project staff will be on call by pager and mobile phone. Project staff will accompany newly

diagnosed clients to all clinic visits during their first month. Staff will make monthly home visits to clients during the first quarter of their enrollment. The model will be compared to the existing case management model for Medicaid managed care beneficiaries with HIV/AIDS.

Contact information:

Ray Stewart, Project Director
Centro de Salud Familiar La Fe
608 S St Vrain
El Paso TX 79901
915-534-7979
lafe2@mail.htg.net

**Arizona Border HIV/AIDS Care Project
El Rio Santa Cruz Neighborhood Center (Tucson, AZ)**

Project overview: The goals of the initiative are to: 1) improve capacity to provide targeted outreach and counseling to at-risk border populations resulting in increased HIV testing and counseling; 2) engage clients who test positive for HIV in primary health care services; and, 3) enhance capacity of accessible primary care providers to provide care to local people with HIV. Collaborative partners include local community health centers, county health services, and programs of *promotores* (health educators) from each of the counties along the Arizona/Mexico border. Staffing expansion and training will be provided to increase identification of people with HIV and subsequent counseling and referral to services. El Rio Health Center will provide a physician with extensive background in HIV care to work with the Arizona AIDS Education and Training Center to develop and implement an integrated co-management/training system that will provide HIV primary care skills to each local border community. The Arizona Border HIV/AIDS Care Project will provide the organizational structure to further integrate services of participating agencies with ancillary services and HIV care systems in Mexico's Sonoran district.

Contact information:

Ken Burton, Project Director
El Rio Santa Cruz Community Health Center
839 West Congress
Tucson AZ 85749
520-792-9890
grants1@elrio.org

***Proyecto Juntos (Project Together)*
Valley AIDS Council (Harlingen TX)**

Project overview: The goals of *Proyecto Juntos* are to: 1) increase access to HIV primary health care; 2) increase the capacity of the primary health care system to effectively meet the HIV health care needs of poor, under-served people living with HIV who reside along the Texas/Mexico border; and, 3) organize care

networks by linking Valley AIDS Council with community health centers providing primary care in the area.

The activities of the project will include a rotating HIV primary health care component designed to move HIV/AIDS care closer to where persons with HIV live and into the three health centers that until now have limited HIV capacity. Nurses will be located at each center to coordinate care and referrals across the partner agencies. The capacity of the area network of health and human service agencies will be strengthened to provide a comprehensive and coordinated array of care and services to the target population.

Contact information:

Charles Robert Smith
Valley AIDS Council
418 East Tyler
Harlingen TX 78550
956-428-9322
vac@xanadu2.net

**Borderlands HIV/AIDS Care Innovations
San Ysidro Health Center (San Ysidro, CA)**

Project overview: The goals of the demonstration project are to: 1) increase early detection of the underserved Latino/a population; 2) increase access to comprehensive HIV/AIDS primary care services; and, 3) enhance the capacity of community health centers (CHC) to provide culturally sensitive care.

Five CHC's are the service delivery hubs that will conduct outreach and coordinate systems of care. In addition, county health departments, health providers in Tijuana and Mexicali, local and statewide HIV/AIDS organizations, and a variety of other public and community-based organizations will be part of the network. Border competent outreach workers and case managers will assure that high-risk Latino populations are reached and linked into care. A binational program will be established to connect Latinos/as with providers either in Tijuana or Mexicali or in San Diego or Imperial County as necessary.

Contact information:

Terry Whitaker, Director of Program Development
San Ysidro Health Center
4004 Beyer Boulevard
San Ysidro CA 92173
619-662-4114
syhcdds@ixpres.com