ECHO
Evaluation Center on HIV & Oral Health

Expanding Access to Oral Health Services for People Living with HIV/AIDS: Lessons Learned

Boston University School of Public Health
Health & Disability Working Group

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Contents

The purpose of this report is to provide program planning information to other HIV, primary care, and dental providers interested in expanding or replicating innovative models of dental care for people living with HIV/AIDS.

Introduction

This report describes lessons learned from a national initiative to expand access to oral health services for people living with HIV/AIDS (PLWHA). It was funded by the HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA) as a Special Projects of National Significance Program Initiative from 2006-2011. This initiative was implemented by fifteen demonstration sites across the U.S. and the U.S. Virgin Islands. A multi-site evaluation and technical assistance center housed at the Boston University School of Public Health coordinated a national program evaluation. The overall goal of the initiative was to expand access to comprehensive oral health care provided in accordance with professional standards to improve oral health outcomes of PLWHA. Oral health outcomes were defined as patient experience with care, health of teeth and gums, completion of a Phase 1 treatment plan (the elimination of active disease and restoration of function), and retention in care. Other important objectives included integrating medical and dental care and sustaining programs beyond the life of the grant.

This report covers program implementation decisions and factors that contributed to success in reaching patients and sustaining programs beyond the period of grant funding. Its purpose is to provide program planning information to other HIV, primary care, and dental providers interested in expanding or replicating innovative models of dental care for PLWHA. The report is organized into four sections: background and methods, program start-up, strategies for success, and sustainability. The section on program start-up describes different decisions made about program models and challenges encountered with staff and patient recruitment. The section on strategies for success describes key interventions that contributed to patient outcomes, including dental case management, transportation, creating satellite clinics, patient education and integrated medical and dental care. The sustainability section reviews methods used by sites to continue providing oral health care to their existing patients as well as new patients beyond the conclusion of the federal funding period.

HIV Alliance dental care staff

Barriers to dental care among people living with HIV/AIDS include financial concerns, stigma, and dental fear. The Innovations in Oral Health Care Initiative was launched in response to these concerns.

Background and Methods

Despite the evidence that oral health and systemic health are interconnected, particularly among individuals with chronic illnesses such as HIV, access to oral health care remains elusive for many individuals.[1] PLWHA are more likely to have an unmet need for oral health care than for medical care, with financial concerns - absence of dental insurance, insufficient insurance coverage, or the inability to pay out-of-pocket for care – being the primary barriers to care.[2-3] Other important barriers to dental care among PLWHA include stigma - finding a dentist who is HIV-friendly or concerns about confidentiality - and dental fear.[4-7] In response to these concerns, the HIV/AIDS Bureau of HRSA launched the Innovations in Oral Health Care Initiative to implement and evaluate innovative models of oral health care in both urban and rural communities. Programs were funded to deliver comprehensive oral health care targeted to new communities or geographic areas that previously lacked access to care. In addition, it was hoped that these programs would be sustainable beyond the five-year grant period and replicable elsewhere in the country. The dental programs described below were designed to reduce disparities in accessing oral health among PLWHA, and achieve the goal of integrating oral health with comprehensive HIV care.

[1]National Research Council. "Front Matter." *Improving Access to Oral Health Care for Vulnerable and Underserved Populations*. Washington, DC: The National Academies Press, 2011. 1.

[2]Marcus, M, Maida CA, Coulter, ID, et al. A longitudinal analysis of unmet need for oral treatment in a national sample of medical HIV patients. Am J Public Health. Jan 2005;95(1):73-75.

[3]Heslin KC, Cunningham WE, Marcus M, et al. A comparison of unmet needs for dental and medical care among persons with HIV infection receiving care in the United States. J Public Health Dent. Winter 2001;61(1):14-21.

[4]Patton LL, Strauss RP, McKaig RG, Porter DR, Eron JJ, Jr. Perceived oral health status, unmet needs, and barriers to dental care among HIV/AIDS patients in a North Carolina cohort: impacts of race. J Public Health Dent. Spring 2003;63(2):86-91.

[5]Meng X, Heft MW, Bradley MM, Lang PJ. Effect of fear on dental utilization behaviors and oral health outcome. Community Dent Oral Epidemiol. Aug 2007;35(4):292-301.

[6]Rohn EJ, Sankar A, Hoelscher DC, Luborsky M, Parise MH. How do social-psychological concerns impede the delivery of care to people with HIV? Issues for dental education. J Dent Educ. Oct 2006;70(10):1038-1042.

[7]Graham MA, Logan HL, Tomar SL. Is trust a predictor of having a dental home? J Am Dent Assoc. Nov 2004;135(11):1550-1558; quiz 1622.

Information for this report was collected by the Evaluation Center for HIV and Oral Health (ECHO) at the Boston University School of Public Health through multiple site visits using a structured site visit protocol, regularly scheduled conference calls with project directors and dentists, and a focus group conducted with dental case managers and patient navigators. Project staff and dentists delivered formal presentations on program lessons at semi-annual grantee meetings, and discussed particular topics such as outreach, patient education and care retention in group sessions. Follow-up telephone interviews were conducted to obtain additional information. In addition to these qualitative data, a quantitative evaluation included patient interviews and the collection of dental service utilization data. The ECHO research team, in conjunction with a team of oral health clinical consultants, synthesized and analyzed these data to generate the program start-up categories, strategies for success, and sustainability.

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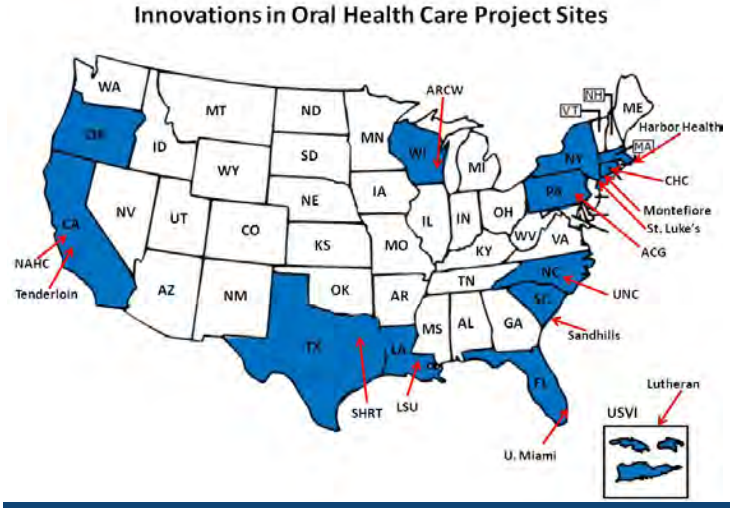


The fifteen programs provided oral health care to underserved HIV-positive individuals in twelve states and one U.S. territory and served both urban and rural populations.

Program Start-Up

The fifteen programs provided oral health care to underserved HIV-positive individuals in twelve states and one U.S. territory and served both urban and rural populations. Urban locations included San Francisco, CA (2); New Orleans, LA; Miami, FL; Chapel Hill, NC; and New York City, NY (2). Rural locations included Eugene, OR; East Texas; Green Bay, WI; Jefferson, SC; Chester County, PA; Norwalk, CT; Cape Cod, MA; and St Croix, USVI. Clinics were housed in hospitals, community health centers (CHCs), and AIDS service organizations (ASOs.) In starting up programs, each site had to address three central issues: (1) organizational model; (2) clinical staff recruitment and training; and (3) patient recruitment.

Organizational Models

The fifteen programs used six different organizational strategies to expand access to oral health care: increasing services at their existing clinics, building satellite clinics, collaborating with clinics in dental hygiene schools or community colleges, fee-for-service dental reimbursement with contracted providers, leasing space at existing private offices/clinics, and purchasing mobile dental units. Many of the programs used multiple strategies. Expanding services at existing clinics – either through clinical staff or patient recruitment – was clearly the most expedient strategy, but did not necessarily satisfy the objective of expanding oral health care access to new geographic areas or populations. Below we describe the other five strategies employed.

Satellite Clinics

Five programs, four in rural communities and one in an urban area, built satellite clinics to expand oral health access in their service areas. AIDS Care Group (ACG), a multi-service AIDS organization offering medical care, dental care, mental health and social services for PLWHA, built a three-chair dental clinic in Coatesville, Chester County, PA after initially leasing dental treatment space at a local hospital. The original plan for the satellite clinic was to serve patients from a four-county region, but as the program developed, it grew to provide care for patients in fourteen counties. AIDS Resource Center Wisconsin (ARCW) located in Milwaukee, WI built a satellite clinic in Green Bay, WI where they had an office that was used for case management services, a food pantry, and storage.

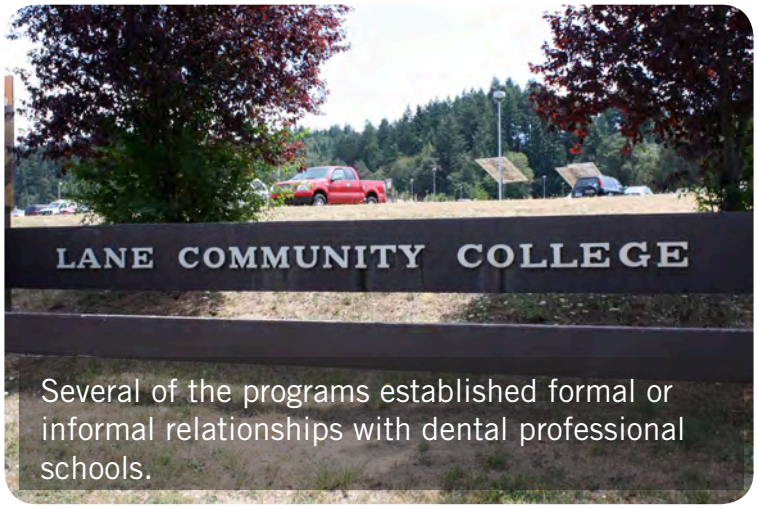
Table 1. Program Locations and Models

Program Name & Location	Program Model	Target Population Served
AIDS Care Group Chester, PA	ASO with a new satellite dental clinic in Chester County, PA	PLWHA from communities of color in rural PA
AIDS Resource Center of Wisconsin Green Bay, WI	ASO with new satellite dental clinic in Green Bay, WI	Uninsured and underinsured PLWHA in Green Bay and rural WI
Community Health Center of CT Middletown, CT	CHC with new dental clinic in Norwalk, CT	PLWHA in Norwalk, CT and surrounding areas
Harbor Health Provincetown, MA	CHC expanding dental services at existing site and creating a new clinic.	PLWHA in the mid and outer Cape Cod areas
HIV Alliance Eugene, OR	ASO /dental hygiene school collaboration with rural dental satellite clinics	PLWHA in 15 counties in southern Oregon
Louisiana State University New Orleans, LA	University based program using a mobile dental unit	Underserved at-risk and PLWHA of color in New Orleans
Lutheran Medical Center New York City, NY	University based training program creating a satellite clinic in the U.S. Virgin Islands	PLWHA in the U.S. Virgin Islands
Montefiore Medical Center Bronx, NY	University based dental program using a mobile dental unit	PLWHA receiving medical care at MMC community health centers
Native American Health Center San Francisco, CA	FQHC medical and dental program expanding existing dental services	PLWHA of color in San Francisco.
Sandhills Medical Foundation Jefferson, SC	CHC using a mobile dental unit	PLWHA in rural South Carolina
Special Health Resources for Texas Longview, TX	ASO with satellite clinics	PLWHA in rural East Texas
St. Luke's Roosevelt Hospital New York City, NY	Hospital based HIV dental center expanding existing services	PLWHA in NYC not enrolled in hospital's medical program
Tenderloin Health Center San Francisco, CA	CBO working in collaboration with SF Dept of Health to create a new dental clinic at the Tenderloin Health Center	Homeless PLWHA with substance use and mental health disorders in the Tenderloin
University of Miami Miami, FL	University based program using a mobile dental unit	PLWHA in the Miami area
University of North Carolina Chapel Hill, NC	University hospital based dental clinic expanding existing services	PLWHA patients in several counties of NC

ASO=AIDS Service Organization
CBO=Community-Based Organization
CHC=Community Health Center
FQHC=Federally Qualified Health Center

The existence of the satellite clinic meant that patients who previously had to travel two and a half hours from Green Bay to Milwaukee for dental care now could receive care close to home, and other patients who lived up to seven hours away from Milwaukee could reduce their travel time. Special Health Resources for Texas (SHRT) expanded their services in three clinics in rural east Texas, including a satellite clinic in Tyler and expansion of existing clinics in Longview and Texarkana. Community Health Center, Inc (CHC), a state-wide network of community health centers in CT, built an eight operatory dental facility in Norwalk, CT. In contrast with the other satellite clinics, the CHC clinic served a broader population not limited to PLWHA.

The fifth satellite clinic was built at Tenderloin Health Center (TLH), a homeless drop-in center in downtown San Francisco. Before the satellite clinic was built, Tenderloin brought in portable dental equipment to provide oral exams and minor care in a tiny space. All other dental services were provided at the Tom Wadell Center, a clinic for homeless people, located a few blocks away. However, access to this care was problematic for PLWHA with a high rate of substance abuse and mental illness. Even though the Tom Wadell Center was close by, patients had to walk through a neighborhood well known for its drug culture. They were easily sidetracked, and many did not make it to the Center. In addition, patients needing emergency treatment often had to arrive at the clinic early in the morning and wait in line for several hours before being seen by a clinician. In 2009, a two-chair dental suite was built at the TLH drop-in center providing easy access to care. Although the building of these satellite clinics took time and required that the programs delay their start-up until regulations were navigated and construction was completed, most of the programs enrolled large numbers of new patients, and all were sustained beyond the life of the grant.



Several of the programs established formal or informal relationships with dental professional schools.

Collaborative Relationship with Dental Professional School

Several of the programs established formal or informal relationships with dental professional schools; however one program used the school as the basis for its HIV oral health care program model. The dental program established by HIV Alliance in Eugene, OR was a three-way collaboration between HIV Alliance (an AIDS Service Organization), Lane County Community College (LCC, a dental hygiene teaching institute), and the Community Health Centers of Lane County, which hired the clinical staff. LCC provided the clinical space, equipment, faculty supervision, and training. LCC hygiene students provided most of the hygiene care as part of their training. HIV Alliance managed the program, conducted the evaluation, provided dental case management and

transportation, and managed the dental clinic bank account. The Community Health Center employed and insured the dentist, hygienist and dental assistant. This collaboration required a lot of work and planning, but was successful due to the commitment of the three organizations and their flexibility to change plans and policies to make this program work. After the first year of operation, they sought space to expand this model in neighboring counties, exploring rental locations at community health centers, private practices, and community colleges. In each case, they found that community colleges with dental hygiene or dental assisting programs were the most receptive. The benefits of this model were far-reaching.

The schools and students had a steady supply of patients to fill clinics slots and an opportunity to practice their skills in working with PLWHA. Patients benefited by getting high-quality oral health care in a mixed clinic setting where PLWHA were integrated into a general dental clinic. HIV clinical providers benefited because they could refer their patients to reliable and high-quality dental providers. This program was also sustained beyond the grant period.

The Community Health Center dental care staff

Fee-for-Service Dental Reimbursement Model

Although ARCW established a satellite clinic in rural Green Bay, WI, some of their patients had to travel five or more hours to get to this clinic. In order to minimize travel time, ARCW contracted with private dentists and dental clinics in some of the outlying rural areas to provide services on a fee-for-service basis. This model was based on the Boston Public Health Commission's HIV Dental Program which recruited dentists at dental society meetings and through direct contact with private providers and clinics and reimbursed for services at Medicaid payment rates.

Leasing Private Dental Space

Several programs started out by leasing space in other clinics or private offices, but this was usually a temporary measure until a satellite clinic was built. However, this was the intended model of care for the Center for Comprehensive Care (CCC) at St. Luke's Roosevelt Hospital in New York City. CCC provides comprehensive HIV medical and dental care to PLWHA in New York City, but the results of a needs assessment suggested that many patients would not come to CCC because they did not want to receive care at a designated AIDS center and did not want to leave their neighborhood. St. Luke's leased space at two private dental offices in the Washington Heights neighborhood where they provided comprehensive oral health services, one full day at each location. This model was successful in bringing patients into dental care, but soon the number of patients

exceeded the scheduling abilities, and patients were not able to obtain follow-up care for six weeks or more. In addition, St. Luke's Roosevelt is a Medicaid-certified provider, but could not bill NY Medicaid for dental services provided in these leased locations because the leased facilities were not Medicaid-certified providers. The process to obtain certification would have required major adjustments to the program that were not deemed feasible. The billing issue, coupled with the increasing patient wait times, forced St. Luke's to abandon the private office space model. They ultimately moved their project back to the hospital location.

Mobile Dental Units

Four sites designed, purchased and implemented mobile dental units to serve patients in areas where the need for dental services was high due to geographic isolation or patient challenges in traveling to dental services in urban areas. These dental units ranged in cost from $144,000 for a one-chair unit to $330,000 for a unit with two dental chairs. The lack of uniform standards for designing mobile units made their design and implementation a time-consuming process. The design was typically provided by the purchaser without much guidance from the manufacturer. State regulations, infection control procedures, maintenance, town and county parking ordinances, medical record access and storage, scheduling and staffing and mechanical problems were a few of the many issues that needed to be researched and addressed prior to start-up. The mobile dental programs encountered multiple challenges during start-up related to design, regulatory and safety issues, parking and permits, and mechanical and maintenance issues with both the dental equipment and the actual van. Although most of the mobile dental units served a high volume of patients, only one was sustained after the demonstration program ended.

Four of the demonstration sites used mobile dental units to provide oral health services. Although most of the mobile dental units served a high volume of patients, only one was sustained after the demonstration program ended.

Sandhills Medical Center purchased a mobile dental unit to bring oral health care to PLWHA living in rural communities of South Carolina. Their two-chair mobile unit was driven to community health centers in rural South Carolina where HIV clinicians or case managers referred their patients to the van for oral health care. Initially there were multiple mechanical problems, particularly with the electrical and vacuum systems. The vendor was not helpful in addressing their problems even though they had purchased a service plan with their mobile dental unit. Ultimately they had to find a local repair shop to fix the malfunctions. Sandhills and the other mobile dental programs also faced challenges finding collaborators that had both the parking space and access to electricity that was needed to operate the van and its equipment.

The University of Miami mobile dental program was a collaborative effort between the University and Jackson Memorial hospital. Jackson

Memorial Hospital purchased a one-chair van to provide screening, preventive and limited restorative care to PLWHA. The University was responsible for the dental equipment and maintenance, while the hospital maintained the mechanical aspects of the mobile unit. The Miami program also experienced start-up electrical problems on the van that needed to be repaired to ensure the equipment ran properly and safely. Care was provided three days/week, with one day devoted to maintenance and one day to administrative tasks. The van was parked outside of the Jackson Memorial hospital and patients were recruited from the HIV clinic at Jackson Memorial Hospital. Patients were able to receive preventive, restorative and periodontal care on the van, but most were referred to the hospital dental clinic for other dental services, including most of their X-rays.

Louisiana State University (LSU) purchased a two-chair mobile dental unit to serve areas of New Orleans where PLWHA were receiving other services but did not have access to dental care.

Louisiana State University (LSU) purchased a two-chair mobile dental unit to serve areas of New Orleans where PLWHA were receiving other services but did not have access to dental care. The van travelled to a variety of social service and AIDS service organizations in New Orleans. One day each week was devoted to van maintenance and paperwork. From the beginning they encountered several mechanical issues with their mobile unit, including problems with the electrical system and the vacuum system. They were unable to use any other equipment when the dry vacuum or air conditioner was in use. This van also had electrical problems and was returned to the vendor for repairs. The constant mechanical issues resulted in inconsistent delivery of oral health care when the van was not in operation.

Montefiore Medical Center used their two-chair mobile dental unit to provide oral health care to PLWHA and those at-risk for HIV infection at several of their community health centers located in the Bronx, New York. This was the last of the mobile units to be launched for a few reasons. First, the mobile unit broke down while it was being delivered and had to go back to the manufacturer to be repaired. Once all the repairs were made and the mobile dental unit was successfully delivered, the next hurdle was to install the equipment to access electronic medical records through a wireless system. This required collaboration between the hospital and the dental program Information Technology departments. There were several concerns about the confidentiality of patient data when using a wireless connection as well as limited connectivity in certain areas of the Bronx. Finally, parking proved to be a larger challenge than initially anticipated. Mobile units require a large parking area that is relatively flat. In addition, city regulations for parking the mobile

unit on city streets and property added another layer of complexity in finding suitable locations to park and provide services. With few parking lots available and street parking at a premium in New York City, the staff had to come up with alternative options to park the unit so that it was safe and stable, yet still accessible to their patient population.

All of the programs built in specific days for van maintenance which impacted the number of days during which they could provide care. In addition, patient care was not always consistent on the mobile units because of the unique equipment and staffing challenges. Care could not be provided if the driver or the dentist were not available or if the equipment was not working properly or under repair. These breaks in service were challenging for both the staff and the patients in ultimately getting patient treatment plans completed and maintaining continuity of care for individual patients. In addition, three of the programs found it difficult to navigate city or country roads with sensitive dental equipment on board because the latches were often insufficient to hold the equipment stable. One program used bungee cords to secure cabinets and equipment, and another program packed all the equipment back in its original packaging to secure it for travel daily. Overall patients were very accepting of services received in the mobile dental units. They liked that the units were new, intimate, and private. Although many patients were served on the vans and they appreciated the care they received, the majority of care provided was basic diagnostic and preventive care or minor restorative care. More complicated and time-consuming procedures were referred to stationary dental clinics.

Through new hires or transfers, CHC identified providers that had a true interest in serving PLWHA.

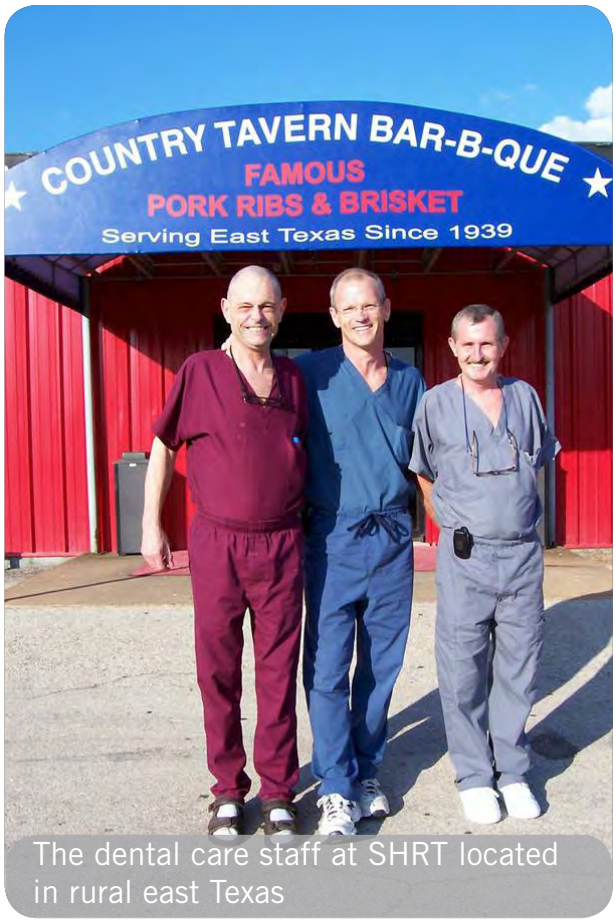
Clinical Staff Recruitment

Access to dental care can be problematic if you are one of the 49 million Americans who live in a designated dental workforce shortage area.[8] Finding dentists who are also competent and HIV-friendly and working in a rural area is even more of a challenge. The demonstration programs needed to hire clinicians who were willing to work with an underserved population in underserved communities, individuals who were not afraid to serve people living with HIV, who were willing to learn, and open to accommodating walk-in appointments and other practices that are not necessarily standard in private practice. Although important progress has been made over the years in combating overt discrimination against PLWHA, there is still room to improve

[8] http://www.hrsa.gov/publichealth/clinical/oralhealth/workforce.html HRSA Oral Health Workforce, retrieved 2/13/2012. As of Sept., 2011

education and awareness and reduce stigma among dental providers.

The recruitment and retention of competent, HIV-friendly clinical staff in rural areas was a significant challenge for several of the programs. In Wisconsin and South Carolina the few dentists living in the community were already engaged in private practice. One site explored sharing a dentist with another public health clinic that had a part-time dentist, but the dentist was not interested in full-time employment. Program leadership in both states focused substantial efforts towards recruiting new dental graduates, traveling across the country to recruit at programs that specialized in training dentists from rural communities, advertising nationally and locally, recruiting through personal contacts and networking with dental faculty colleagues. Programs obtained designation as underserved areas and helped dental graduates qualify for loan repayment programs. On several occasions, recent graduates were hired only to decline the position to go elsewhere. In other cases they left shortly after arrival.



The dental care staff at SHRT located in rural east Texas

Both programs in WI and SC ended up hiring dentists several times over the demonstration period and faced the added challenge of finding the "right" dentist for the program. As one program director put it, they paid their dentists well but they never had any choices when hiring a dentist because they never had more than one candidate at a time. For some of these dentists, service provision was inconsistent, of lower quality, or provided in a manner that reinforced the stigma already associated with HIV.

Programs also experienced difficulty hiring dental hygienists willing to work with PLWHA. SHRT, in rural east Texas recruited applicants from a local dental hygiene school. It took several months to get any applicants, and when applications finally came in, some individuals expressed concern about contracting HIV from patients. When SHRT finally hired a hygienist, they quickly identified that she was not engaging the patients as expected and was "double gloving" to protect herself. According to the SHRT staff, this level of HIV stigma and fear is commonplace in their rural part of Texas. After a second extensive search for a dental hygienist, they interviewed a candidate who had been out of dental hygiene school for a few years and knew people who were living with HIV. She quickly became an asset to the SHRT team.

Programs where provider recruitment was not as difficult still encountered challenges in obtaining provider buy-in to serve PLWHA. For example, CHC operated a large community dental clinic for the general population. All of their clinical staff were skilled and experienced providers, but few of them had worked (knowingly) with PLWHA and were not necessarily interested in accommodating some of the changes CHC made to improve patient recruitment and retention. For example, CHC adopted open access policies and specific scheduling systems, but some of the existing staff did not buy into these practices. Through new hires or transfers CHC identified providers that had a true interest in serving PLWHA and were willing to undergo the extra training needed to update their clinical and chair side skills. They scheduled regular staff meetings to discuss the program expansion and conducted bi-weekly case reviews to encourage staff participation and create program buy-in. In addition, CHC supported providers to attend external trainings or submit journal publications in order to promote a positive attitude about the additional work the program sometimes required.

Another type of challenge was encountered in recruiting dental assistants in San Francisco. The San Francisco Department of Public Health (SFDPH), which employed the clinical staff who worked at Tenderloin Health Center (TLH), rotated its dental assistants through different city-sponsored clinics. However, the TLH dentist needed a consistent assistant who understood the homeless patient population, and knew the clinic set-up and level of care provided. The patients were distrustful and disturbed by the rotation of dental assistants. Since this was a standard practice of SFDPH, program staff had to lobby the SFDPH to assign one dental assistant to the project. Once the program was assigned a single dental assistant, the patients began to trust the dental team to provide them with consistent oral health care and were more likely to come back for subsequent care.

Patient Recruitment

While the capacity to provide free oral health care removed a major barrier to oral health care, most programs found that additional efforts were necessary to recruit patients into care. Strategies included marketing, outreach to HIV service providers and case managers, assistance with transportation, special events, providing free screening to potential patients, and word of mouth.

Each program conducted some sort of marketing activities to inform patients and providers about the availability of oral health services. This included both paid and unpaid media. Marketing materials included public service announcements, radio shows and newspaper advertising. Some programs printed materials to distribute at community events and local HIV service agencies and included announcements in HIV newsletters. One challenge to broad marketing efforts was that although dental care was provided free to PLWHA, HIV-negative individuals seeking dental care as a result of marketing efforts had to pay for services, making it difficult to explain to the general population why some people received free care and others did not.

AIDS Care Group's dentist and nurse marketed their program by providing off-site dental examinations to potential patients. They examined over 100 patients in locations including church meeting rooms, HIV/AIDS community centers, and hospital outpatient and ambulatory treatment centers. They also worked with other Ryan White Part C providers that did not have dental programs.

A primary recruitment strategy was outreach to HIV service providers, mainly Ryan White clinical staff and HIV case managers. This organizational outreach was multi-faceted and included education about the importance of oral health care for PLWHA, the availability of dental services through the program, and how to make referrals for PLWHA needing oral health care. Programs identified the following three important messages to keep in mind when conducting organizational outreach:

1. Take the time to educate case managers and other providers about the connection between HIV and oral health. They may be aware of the general importance of dental care, but not about the critical connection between medical and dental care and the impact of one on the other for people living with HIV disease.

2. Provide case managers and social workers with specific information about how to make referrals and follow up on appointments. Clarity of process and expectations helps to ease any burden associated with the new referral relationship.

3. Follow through on any promises made to HIV service providers about the timing of appointments, scheduling accommodations, and transportation arrangements. Poorly understood communications or miscommunications can filter through an agency and destroy any collaborative relationship that has been established.

To meet the needs of patients who travelled long distances and sometimes needed extended appointments to complete a large amount of dental work, two programs dedicated times/days just for PLWHA in their dental clinics. On these designated days, one program provided transportation to the dental clinic and lunch. Because the patients typically came from one or two agencies, the patients knew each other and enjoyed being there as a group. Other agencies introduced expanded hours in the evening or on the weekend for their PLWHA, recognizing that one barrier to care was that the clinic hours were during patients' working hours.

Several programs reported their existing patients were recruiting their peers for dental care.

Finally as programs got off the ground and patients began to access oral health care with positive results, the most effective outreach strategy was patient word of mouth. Several programs reported their existing patients were recruiting their peers for dental care. In addition, as patients had positive dental experiences, they shared this information with their providers and case managers who in turn were then more likely to refer other patients to the dental clinic.

Outcomes of the initiative included improved patient experience with care, completion of Phase 1 treatment plan, and retention in care over time.

Strategies for Success

As mentioned in the introduction, the goal of this initiative was to expand access to comprehensive oral health care that was provided in accordance with professional standards and resulted in improved oral health outcomes. Outcomes included improved patient experience with care, completion of Phase 1 treatment plan, and retention in care over time. Below we describe some of the strategies that were important in achieving these measures of success.

Dental Case Management

Nine of the programs employed staff as dental case managers or patient navigators. These staff played an important role in recruiting patients, scheduling and providing appointment reminders, and making sure clients had a way to get to their appointments. They were instrumental in following up on missed appointments and coordinating with HIV medical care and case management services. All of the dental case managers worked as part of a team to help educate other providers about the importance of oral health care for PLWHA and how to refer their patients into dental programs. Most new patients were referred from other health and social service providers. Thus dental case managers spent much time building and maintaining relationships with these referring providers. Dental case managers provided resources and materials for both providers and patients, promoted oral health assessment as a part of comprehensive case management and trained HIV case managers to advocate for oral health care for their clients.

Dental fear and anxiety were prominent among immigrant populations, who had limited experience with dental care, and homeless individuals. Dental case managers assisted these patients in overcoming fear, stigma, and other barriers that kept them from seeking oral health services. At several urban programs, dental case managers recruited patients directly by discussing dental services in a drop-in center or clinic setting, allaying patient fears about dental care and offering to accompany the patient to their first dental visit. The dental case managers helped explain what would happen and what new patients could expect when they came in for their visits. In rural areas, the dental case managers spent substantial time arranging and coordinating patient transportation. Some of the dental case managers also drove the vans that transported patients to and from clinic visits, and used this time to discuss both HIV-related and

oral health-related issues. All of the dental case managers provided some level of patient education about the patient's individual oral health treatment plan, the connection between HIV and oral health and beneficial oral health self-care practices; however, the level of education depended on the clinical background of the staff. Two of the dental case managers were dental assistants by training and were able to provide more comprehensive education about the specific dental procedures and follow-up care.

Assistance with Transportation

The demonstration programs used a variety of approaches to address the challenges of transportation, often changing strategies mid-course to try more effective or cost-efficient methods. Some programs offered gas cards as incentives for patients to come into care, while others used a van to pick up patients and drive them to the clinic. In addition, some programs arranged carpools or scheduled Medicaid-financed transportation.

HIV Alliance, ARCW, SHRT, and ACG all served a broad geographic area that spanned hundreds of square miles and included many counties. Some of their patients travelled from five to eight hours for care, and the programs provided reimbursement for gas. Considering the time and distance involved in getting patients to the dental clinic, both medical and dental services were scheduled on the same day to reduce the amount of dental visits and travel. If the care required was very labor intensive, some of the programs paid for hotel and meals so patients could spend the night and receive the care over the course of two days.

HIV Alliance established satellite clinics (described under Organizational Models on page 5) in neighboring counties, and their own dental teams travelled to these clinics to provide care, thus sparing patients the travel time and costs. ACG and SHRT provided transportation themselves, using a van to pick up patients and bring them into care. However, these programs then had to address the inconvenience of people spending hours on a van and hours waiting for everyone to have their appointments. Both ACG and SHRT provided meals or snacks for patients and created comfortable waiting rooms where people could use a computer and internet while waiting for other patients to finish their visits before the van ride home. The ACG van driver had 2,000 songs on his iPod for people to listen to during the ride.

A couple of the programs offering patient transportation underestimated the demand it would place on the program in terms of the cost of gas as prices skyrocketed during the grant period.

A couple of the programs offering direct patient transportation underestimated the demand it would place on the program in terms of the expense of vehicle maintenance and cost of gas, particularly as gas prices skyrocketed during the grant period. For example, ACG found that their van travelled tens of thousands of miles in the

first year, would probably need to be replaced after a second or third year, and still could not accommodate all the need for transportation. In addition to their van service, they started to reimburse for mileage or train tickets if the patient was travelling to the clinic from a faraway location. The vouchers or gas reimbursement model was used by many of the programs that did not have a vehicle to transport patients directly.

Connections with Dental Teaching Institutions

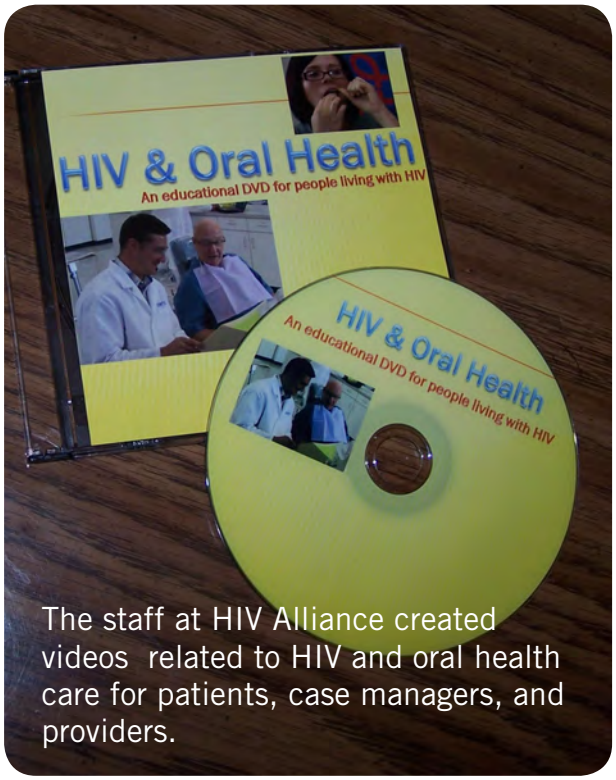
Both the University of Miami and SHRT used dental residents to provide care, which provided an opportunity for students to learn and gain valuable experience for their future careers as dentists while expanding access to care for PLWHA. HIV Alliance used dental hygiene students in a very unique care model in their collaboration with LCC as described above in Organizational Models. This program trained a new generation of hygienists to deliver comprehensive dental care in a non-discriminatory manner and was replicated as the program expanded into other counties over a geographic area the size of the state of Rhode Island. The provision of dental care in the patients' community meant that the same education and experience was gained by students across the state and moved with them into their practice settings when they were employed after graduation. In addition, because this model was affiliated with a dental teaching institution, it was eligible to receive funds under the Dental Reimbursement Program of the Ryan White Part F program (see the section on Sustainability on page 20).

A Jeopardy-style game was developed as part of a module to train HIV-positive peers to engage their clients in oral health care. The module is available at http://peer.hdwg.org/training_toolkit/hiv_and_oral_health

Patient Education

Many patients will come in for care and treatment to alleviate pain or infection, but it can be challenging to convince them to complete their treatment plan and receive preventive or maintenance care once their pain or infection is addressed. PLWHA are not unique in this regard. Many of the patients served in this initiative went without care for long periods of time - 20% had not received any dental care in the previous five years or longer - or received episodic emergency care. Fourteen percent of the patients who came into care at one of the programs only attended one visit and did not return. Several programs took extra steps to engage patients in care, encourage them to return for follow-up, establish a dental home, and understand and practice sound oral hygiene.

CHC solicited input from patients to draft educational materials that addressed the concerns, questions and barriers to oral health care discussed by the patients. After realizing their messages were not well understood, the first draft was revised to reflect a middle-school reading level. These materials were distributed at public events. CHC also employed the traditional chair-side education approach in which a dental assistant or hygienist provides education on good oral health practices such as brushing, flossing, reducing sugar intake, and smoking cessation.



The staff at HIV Alliance created videos related to HIV and oral health care for patients, case managers, and providers.

At ACG and SHRT, patient education was provided in a team approach. Dentists and/or hygienists provided oral health self-care instruction and one-on-one education at each visit. ACG developed patient education materials in Spanish and English, and hired bilingual staff to review the materials with individual patients. ACG also created patient education materials, such as videos and demonstration materials for use in patient waiting rooms. While patients were waiting their turn to be seen, the dental case manager engaged them in group discussions about good oral health practices. Patients were transported over long distances to the program on a van, and at SHRT the dental case manager used the travel time in the van as an opportunity to reinforce the oral health self-care messages provided by the dental staff. He also answered specific questions about self-care, dental procedures that were done that day, follow-up appointments, and general HIV care.

At HIV Alliance, although hygienists provided chair-side patient education and the dental case manager also provided education, they found that patients were not necessarily taking care of their teeth once initial pain and infection were alleviated. Months later, patients returned to the dental hygiene clinic with new, preventable oral health problems. The staff used consumer focus groups to identify and test new approaches to patient education. This resulted in the creation of three videos: (1) For patients on basic oral hygiene and home care; (2) For case managers on the value of dental care as part of a comprehensive health plan; and (3) For providers to standardize important information across sites and provider types, especially once the service area expanded and multiple provider sites were secured. This novel approach did not just focus on patients, but on all of those engaged in referral and treatment with a consistent message across all videos.

Integrated Care

One of the goals of this initiative was to promote the integration of medical and oral health care. Co-located medical and dental services at sites such as ACG, SHRT, and TLH certainly improved patient referrals to oral health care. The one-stop-shopping model was particularly important for patients in East Texas who might need to spend an entire day traveling on a van to get either medical or dental care. Now they could receive both, as well as case management and other services, with care coordinated by the dental case manager. This integrated model was just as important in urban San Francisco, where dental appointments were rarely made for homeless patients who used the TLH drop-in facility. Instead, staff recruited patients through the morning breakfast that was provided to TLH clients and walked them over to the clinic space. Eventually, TLH medical providers and case managers increased their patient referrals to dental care as well. The integration of dental care services into this existing social service structure was key to its success with this population.

Even when services were located under a single roof, however, service integration was not automatic. At ARCW's Green Bay site, medical services were added to the existing dental services. Through structured activities, medical and dental providers educated each other and coordinated care on behalf of individual patients. At staff meetings, the dentists presented about the importance of oral health care to the medical providers. Medical providers talked with the dentists about HIV medications and how they work. ARCW had integrated case conferences weekly and conducted a monthly review of patient medical and dental needs.

The navigators and case managers worked to develop a good rapport with patients, taking the time to build trust and provide information, which in turn made the patient more likely to return for follow-up services.

Because the HIV Alliance model was affiliated with a dental teaching institution, it was eligible to receive funds under the Dental Reimbursement Program of the Ryan White Part F Program.

Developing a plan for sustainability was a major project consideration from the beginning. Just as there were various models for expanding care, plans for sustainability were different at each site.

Keeping it Working—Program Sustainability

This five-year oral health initiative was successful in creating several innovative programs which increased access to oral health care for thousands of HIV-positive patients in the U.S. Developing a plan for sustainability was a major project consideration from the beginning. Just as there were various models for expanding care, plans for sustainability were different at each site. The main funding options for sustainability included some combination of (1) Medicaid reimbursement, (2) reimbursement/contracts from Ryan White programs or private foundations, (3) sliding fee scales for patient payment, and (4) cross-subsidization from billing private dental insurance (and clinic outreach to expand this market).

When the initiative began in 2006, Medicaid coverage for adult dental services ranged from non-existent to almost comprehensive depending on the state. Of the fifteen programs, three were in states with no adult Medicaid dental coverage other than emergency care and four programs were in states with very limited coverage, mostly for preventive care or dentures. At that time, billing Medicaid was a feasible sustainability option for at least half of the sites with broader Medicaid coverage. Over the course of this initiative, however, Medicaid coverage for adult dental care was reduced or eliminated in several states. Both Massachusetts and California have severely reduced adult dental Medicaid coverage. The three programs in those states that were counting on Medicaid as a revenue source had to rework their sustainability plans. Another program could not access Medicaid reimbursement because it was not part of the Medicaid managed care network in the state, and existing managed dental plans were not particularly eager to contract with providers that serve potentially expensive populations. As of publication of this manual in 2012, five programs have incorporated billing Medicaid for adult dental as a major component of their sustainability plans.

Table 2. Patient Enrollment, Services and Sustainability

Program Name	Patients enrolled in the evaluation and care	Mean # services provided to patients	Patients with completed Phase I treatment plans	Plans for post – project continuation*
AIDS Care Group	206	11	71	Yes
AIDS Resource Center of Wisconsin	55	24	40	Yes
Community Health Center of CT	208	14	103	Yes
Harbor Health	74	12	29	Yes
HIV Alliance	205	21	126	Yes
Louisiana State University	291	n/a**	n/a**	No
Lutheran Medical Center	90	16	22	No
Montefiore Medical Center	58	13	14	Yes
Native American Health Center	99	20	61	Yes
Sandhills Medical Foundation	140	13	50	No
Special Health Resources for Texas	187	17	120	Yes
St. Luke's Roosevelt Hospital	289	25	136	Yes
Tenderloin Health Center	173	13	62	Yes
University of Miami	265	13	8	No
University of North Carolina	129	26	75	**

* This program plans to continue serving PLWHA with oral health services in some capacity after the grant ends using their SPNS model.

**These data were not available for this site.

The Ryan White HIV/AIDS Program has provided millions of dollars annually to fund health care to uninsured and underinsured HIV positive patients, including several million for dental care as a core component of comprehensive HIV/AIDS clinical care. This federal program, administered by HRSA, consists of several parts. Part A provides funding to support HIV primary care and supportive services to Eligible Metropolitan Areas (EMAs) that have been disproportionately impacted by HIV/AIDS. Part B is formula funding that is awarded to all fifty states and the U.S. Virgin Islands and Puerto Rico. Part A and B programs, in turn, subcontract with providers in their EMA or state to provide essential HIV-related services that may include dental care. Part C funds providers directly to provide HIV testing and counseling, HIV primary medical care, and case management services. Part D supports health care and support services targeting women, children, and families. Both Parts C and D may also cover dental care as part of their service mix. The final part of the Ryan White program is Part F. Part F funds the AIDS Education and Training Centers; the Special Projects of National Significance (SPNS) Program, including the oral health initiative; and the Community Based Dental Partnership and the Dental Reimbursement programs.

Three demonstration programs were successful in accessing Part B funds, and an additional two programs received Part A funds to continue their oral health programs. Three programs have Part C funding for HIV primary care and included oral health services in their most recent continuation applications. Two programs accessed funding through the Part F Dental Reimbursement program. This program covers a portion of the uncompensated care provided by accredited dental education programs to PLWHA. Finally, several programs have also successfully accessed private foundation funding for components of their program, such as the dental case manager.

> This five-year oral health initiative was successful in creating several innovative programs which increased access to oral health care for thousands of HIV-positive patients in the U.S.

Many of the sites are considering the implementation of a sliding-fee scale for patient care to sustain their programs. Programs are also looking at ways to recruit new patients from surrounding areas with private insurance. Private insurance can provide an income that would be able to offset the cost of HIV patients who cannot afford oral health care.

The resources listed in this section, such as the video pictured here, were created to disseminate the findings of the HRSA SPNS Innovations in Oral Health Care Initiative and are available free of charge.

Resources

Public Health Reports Oral Health Supplement: **Innovations in Oral Health Care for People Living with HIV**
This special supplement to *Public Health Reports* presents findings from the Special Projects of National Significance Innovations in Oral Health Care Initiative. "The articles in this special issue represent the most comprehensive additions to the body of knowledge about oral health care for people living with HIV/AIDS since the HIV Cost and Services Utilization Study conducted nearly a decade ago," according to PHR.
http://echo.hdwg.org/phr

Expanding Access to Dental Care for People Living with HIV/AIDS: Service Utilization and Costs
This report derives utilization and cost estimates from service utilization data collected by demonstration sites that participated in the SPNS Innovations in Oral Health Care Initiative. This information may help policymakers and providers plan for the expansion of oral health services for PLWHA in their state, city, region, or service area.
http://www.hdwg.org/sites/default/files/resources/utilization.pdf

Video: Changing Lives Through Good HIV Oral Health
This digital story demonstrates the positive impact that the HRSA SPNS Innovations in Oral Health Care Initiative has had on the lives of three HIV-positive clients.
http://vimeo.com/13917365

Factors Associated with Preventive Dental Care-Seeking Among PLWHA
Journal of Public Health Dentistry, Winter 2012. This article examines factors associated with preventive dental care-seeking behavior among over 2,000 adults living with HIV across fifteen sites in the U.S. who were enrolled in free dental care as part of the HRSA SPNS Innovations in Oral Health Care Initiative.
http://echo.hdwg.org/preventive

A Typology of Models for Expanding Access to Oral Health Care for PLWHA
Journal of Public Health Dentistry, Summer 2011. This article describes a typology of program models for expanding access to dental

services for PLWHA, based on the work of the HRSA SPNS Innovations in Oral Health Care Initiative.
http://echo.hdwg.org/typology

Lessons in Engaging/Retaining PLWHA in Oral Care
This report describes the lessons learned about outreach and retention in oral health services over the first two years of the HRSA SPNS Innovations in Oral Health Care Initiative.
http://echo.hdwg.org/retention

Increasing Access to Oral Health Care for PLWHA: The Role of Dental Case Managers, Patient Navigators, and Outreach Workers
This report provides an informative perspective on the role of dental case managers, patient navigators, and outreach workers in the oral health care setting.
http://echo.hdwg.org/dentalcasemanagers

HIV and Oral Health for Peers Training Curriculum
This training module was a collaboration between two projects at the Health & Disability Working Group at Boston University School of Public Health: the PEER Center (Peer Education & Evaluation Resource Center, designed to help organizations develop peer programs to support HIV-positive individuals, http://peer.hdwg.org) and the ECHO (Evaluation Center for HIV and Oral Health, http://echo.hdwg.org) multi-site evaluation of the HRSA SPNS Innovations in Oral Health Care Initiative. The goal of the HIV and Oral Health module is to acknowledge the importance of oral health as part of overall health for people living with HIV, and to train peers on how to engage clients in oral health care. This three-and-one-half-hour lesson plan includes Powerpoint presentations on Oral Health and culminates in a Jeopardy-style game to solidify participants' newly acquired knowledge and skills.
http://peer.hdwg.org/training_toolkit/hiv_and_oral_health

Case Study: Florid HPV Oral Lesions
This case study examines the case of an HIV-positive patient with a complex medical history who complained of oral warts and was treated for Florid HPV oral lesions.
http://echo.hdwg.org/teaching-tools/case-study-florid-hpv-oral-lesions

Case Study: Kaposi Sarcoma
This case study examines the case of an HIV-positive patient who complained of sore gums and presented with a lesion that was subsequently diagnosed as Kaposi Sarcoma.
http://echo.hdwg.org/teaching-tools/case-study-kaposi-sarcoma

The multi-site evaluation was conducted by the Health & Disability Working Group at the Boston University School of Public Health under the project titled ECHO (The Evaluation Center on HIV and Oral Health).

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