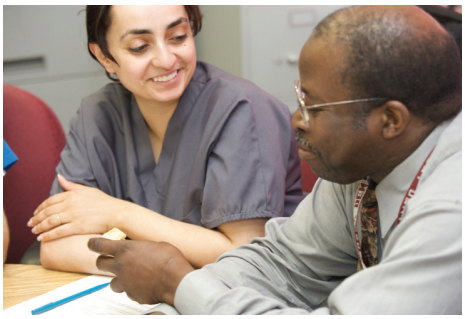
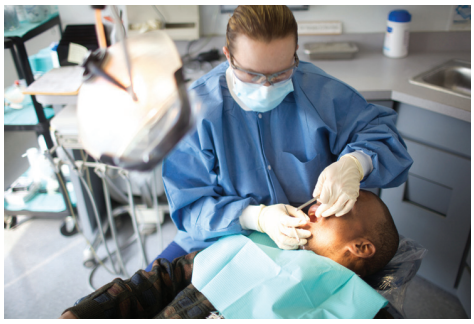
TRAINING MANUAL





Creating Innovative Oral Health Care Programs

December 2013

U.S. Department of Health and Human Services
Health Resources and Services Administration
HIV/AIDS Bureau
Special Projects of National Significance Program

Training Manual: Creating Innovative Oral Health Care Programs

U.S. Department of Health and Human Services
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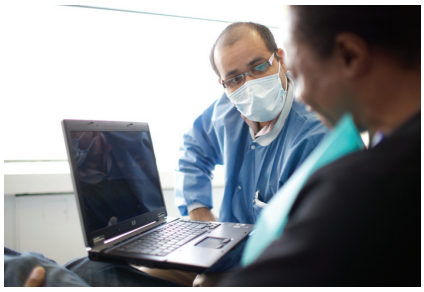
TABLE OF CONTENTS

The Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) has developed the Integrating HIV Innovative Practices (IHIP) manuals, curricula, and trainings to assist health care providers and others delivering HIV care in communities heavily impacted by HIV/AIDS with the adoption of Special Projects of National Significance (SPNS) models of care. This IHIP training manual is part of that effort. Additional IHIP materials can be found at www.careacttarget.org/ihip.



1

ABOUT THIS MANUAL

"[Receiving oral health care through Ryan White] changed everything. I was out and about in the community much more than I ever would have been before I had my teeth fixed. More exercise, more self-esteem, more food, more everything, really."

—Charles, Patient at SPNS Oral Health Initiative grantee site,
HIV Alliance of Eugene, OR

Oral health is a critical component of total health for all people. Poor oral health has serious consequences, including painful, disabling, and costly oral diseases. Gum disease, in particular, is associated with diabetes, heart disease, and stroke. Pregnant women with gum disease are more likely to give birth to children prematurely and to have children of low birth weight.[1,2]

Many of these oral diseases may be prevented with regular dental care.[3] In 2007, however, only 44.5 percent of people age 2 and older had a dental visit within the previous 12 months, a rate that has been essentially unchanged over the previous decade.[4] Despite oral health's importance, 47.2 percent of U.S. adults have some form of periodontal disease.[5]

The landmark *Oral Health in America* report by the Surgeon General makes a compelling case for the integration of oral health into overall health. The report calls out disparities in access to oral health care across the country, including socioeconomic factors, lack of transportation, presence of disability or chronic illness, lack of dental insurance, and personal factors, such as lack of awareness and education about the importance of oral health.[6]

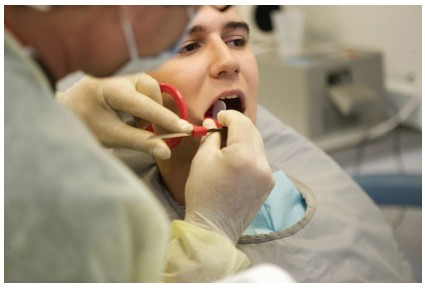
These access barriers are particularly acute for people with chronic illnesses or compromised immune systems, including people living with HIV/AIDS (PLWHA), because of the interconnection between physical health and oral health. To address unmet oral health care needs and identify strategies and treatment models, the Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB), Special Projects of National Significance (SPNS) program launched the *Innovations in Oral Health Care Initiative* (Oral Health Initiative). This initiative, which ran from 2006 to 2011, funded 15 grantee sites across 12 States and 1 U.S. Territory and included hospitals, community health centers (CHCs),

and AIDS service organizations (ASOs) in both urban and rural settings.

This training manual synthesizes lessons learned from this federally funded project and has important implications for addressing oral health care among PLWHA, one of their most frequently cited unmet needs. The objective of this training manual is to provide program-planning information. Target audiences include HIV, primary care, and dental providers interested in expanding or replicating innovative models of oral health care for PLWHA. This training manual consists of the following components:

- An overview of the importance of oral health care in total patient care and specific considerations for PLWHA,
- A discussion of the barriers to oral health care that PLWHA face,
- A synopsis of key details of the SPNS Oral Health Initiative, its grantees, and the models of care studied,
- A survey of the best practices garnered from the SPNS Oral Health Initiative, and the potential benefits and challenges associated with each model of care discussed, along with other considerations, such as costs, logistics, and sustainability, and
- A list of helpful additional resources to further assist with the replication process and the delivery of high-quality oral health care to PLWHA.

This training manual is part of the Integrating HIV Innovative Practices (IHIP) project, which promotes dissemination and replication of successful models of care. Accompanying this guide are a curriculum, pocket guide, and Webinar trainings. IHIP materials can be found at: www.careacttarget.org/ihip.



2

WHY AN ORAL HEALTH INITIATIVE?

"You don't want a healthy neck-down body.
You want a healthy top-of-the-head to the tip-of-the-toe body."

—Dr. Howell Strauss, Executive Director of AIDS Care Group of Chester, PA, a SPNS Oral Health Initiative grantee

PLWHA experience a high incidence of common oral health problems (e.g., dental decay/cavities, gingivitis), as well as other oral health problems that are directly related to HIV infection. Between 32 and 46 percent of PLWHA will have at least one major HIV-related oral health problem (e.g., bacterial, viral, and fungal infection; oral cancer; or ulcer).[7]

As with the general U.S. population, PLWHA are more likely to have an unmet need for oral health care than for medical care. According to various studies, 58 to 64 percent of PLWHA do not receive regular dental care.[8]

Poor oral health can make it difficult to chew or swallow and can impede food intake, appetite, and nutrition, leading to poor absorption of HIV medications and leaving PLWHA susceptible to progression of their disease. Poor oral health can also interfere with medication adherence. HIV medications have side effects such as xerostomia, commonly known as dry mouth or dry mouth syndrome, which further predispose PLWHA to dental decay, periodontal disease, and fungal infections.

Treatable conditions, such as gingivitis or early periodontitis, can become serious quickly in PLWHA when the immune system is weak. Bacterial infections (i.e., dental decay and periodontal disease) that begin in the mouth can escalate to systemic infections and harm the heart and other organs if not treated, particularly in PLWHA.

While poor oral health can impact physical health in a number of ways, its psychosocial impact is equally significant. Poor oral health in PLWHA can adversely affect quality of life, lower self-esteem, and limit career opportunities and social contact as result of facial appearance, malodor, or pain. Paul, a patient at Special Health Resources of Texas (SHRT), a SPNS Oral Health Initiative grantee, knows firsthand the psychosocial impact of poor oral health. "When you've got bad teeth," he remarks, "you're confined."

In some cases, patients may even resort to self-medication to reduce their pain from oral disease, including the use of illicit drugs and highly addictive opiates. The use of such substances can lead to even greater psychosocial concerns.

BARRIERS TO CARE

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.[9] Many of the same barriers to oral health care for PLWHA are the same barriers that prevent them from engaging in and staying in HIV medical care.

- *Financial concerns* are the primary barrier to care. These barriers can include absence of dental insurance, insufficient insurance coverage, or the inability to pay out-of-pocket for care.[10,11]
- *Stigma* is another barrier to care for PLWHA. This can include finding a dentist who understands the needs of PLWHA and concerns about confidentiality.
- *Lack of oral health professionals* trained and willing to treat PLWHA is another barrier to care.

THE RYAN WHITE HIV/AIDS PROGRAM'S CONTINUED COMMITMENT TO ORAL HEALTH

Oral health programs are supported in all Parts (Parts A–D, F) of the Ryan White HIV/AIDS Program. Oral health care is one of multiple eligible services and is a legislative priority for funding under a group of "core" primary medical services for Parts A, B, and C.

In 2010 alone, nearly $80 million was spent on oral health within all Ryan White HIV/AIDS Program Parts, and more than 141,000 duplicated Ryan White clients received oral health care services. HRSA's dental programs include the following:

- *HRSA Dental Reimbursement Program (DRP)*
  - DRP funds institutions with accredited dental or dental hygiene education programs to help them defray the unreimbursed costs of providing oral health care to people with HIV: http://hab.hrsa.gov/abouthab/partfdental.html#2.
  - In 2011, 56 award recipients in 21 states and the District of Columbia trained over 11,700 dental students, postdoctoral dental residents, and dental hygiene students, providing oral health care services to over 37,100 HIV-positive patients. Over $9.6 million in grant monies were awarded.
- *HRSA Community-based Dental Partnerships Program (CBDPP)*
  - CBDPP was first funded in FY 2002 to increase access to oral health care services for HIV-positive individuals while providing education and clinical training for dental care providers, especially those in community-based settings.
  - The program initiates multipartner collaborations between dental and dental hygiene education programs and community-based dentists and dental clinics. Community-based program partners and consumers help design programs and assess their impact: http://hab.hrsa.gov/abouthab/partfdental.html#3.
  - In 2011 alone, 12 grantees in 11 states received funding through CBDPP and they, in turn, trained 3,300 dental students, postdoctoral dental residents, and dental hygiene students in HIV oral health care. This resulted in the provision of oral health services to over 5,800 HIV-positive patients.
  - CBDPP's success is reflected in the utilization of partnerships with dental schools as a means of expanding services and patient reach among several SPNS Oral Health Initiative grantees.
- *State Oral Health Workforce Program:* This program is just one of a number of workforce grants focused on oral health delivery that are funded by HRSA's Bureau of Health Professions. The State Oral Health Workforce Program is designed to help States address demonstrated oral health workforce needs. To learn more, visit: http://bhpr.hrsa.gov/grants/dentistry/sohw.html.

- *Patient fear of and discomfort with dentists* remains a significant deterrent to dental care for PLWHA, as with the rest of the population.
- *Low health literacy and lack of education* about the importance of oral health often prevents patients from seeking oral health care.
- *Lack of self-efficacy navigating the health care system* can make the mere task of seeking oral health care an intimidating process.

AN OPPORTUNITY: ORAL HEALTH AS A GATEWAY TO BETTER HIV CARE

Oral health professionals can help in early diagnosis of HIV infection and referral to care, as oral lesions can be the first overt clinical presentations of HIV infection. Early detection can improve prognosis and reduce transmission because infected PLWHA may not know their HIV status. Oral health professionals can also work with clients to engage them in regular HIV primary medical care and address issues such as nutrition. Dentists can control or eliminate a local infection to avoid adverse consequences such as systemic infections, eliminate pain and discomfort, and restore oral health functions.

In some cases, elimination of pain caused by alleviated periodontal disease can help patients reduce or eliminate their use of opiates or other substances used to mitigate the pain. "We had a number of clients using opiates for many years," says Amanda McCluskey, client services program manager at HIV Alliance of Eugene, OR. "They came into the clinic to treat their oral pain and then went into drug treatment because they no longer needed to use the opiates to control the pain." (To learn more about opiate addiction and buprenorphine treatment, see the IHIP materials on these topics at: www.careacttarget.org/ihip.)

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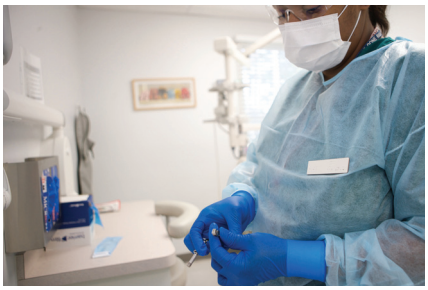


BACKGROUND OF THE SPNS ORAL HEALTH INITIATIVE

The overall goal of the Oral Health 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 of the SPNS Oral Health Initiative included integrating medical and dental care and sustaining programs beyond the life of the grant.

In order to achieve these objectives, many grantees employed dental case management with great success. In one study of a segment of SPNS Oral Health Initiative patients, the patients emphasized the importance of dental case managers as contributing to their reasons for returning to care.[12] These dental case managers coordinating their care made it easier for them to follow up on appointments, and also reduce their anxiety about dental care, making it more likely that they would be retained in care. (Dental case management is discussed in greater detail on p. 11 of this training manual).

Overall, the SPNS Oral Health Initiative has demonstrated excellent patient oral health and medical care outcomes, including:

- Serving 2,500 PLWHA who had been out of oral health care for 1 year or more,
- Enabling 14,500 patient visits, and
- Performing 26,000 dental procedures.

But these numbers mean little unless considered in the context of the thousands of patients living happier and healthier lives as a result of the Initiative. "It's definitely helped me," remarks a patient at Harbor Health, a grantee in Provincetown, MA, about the care he's received. "When [my dentists] did my top teeth, I had an infection in there for about probably one-and-a-half years. So my T-cells after all this jumped nearly 100 points," he adds. "I feel a lot better."

ORGANIZATIONAL MODELS STUDIED

Each SPNS Oral Health Initiative demonstration site had to determine which organizational model(s) it

ORAL HEALTH AND NATIONAL HIV/AIDS STRATEGY

HRSA works diligently to meet the goals of the National HIV/AIDS Strategy (NHAS), designed to improve the course of the HIV epidemic in the United States. Needs assessments conducted by States and eligible metropolitan areas (EMAs) often identify oral health care as one of the greatest unmet needs among PLWHA. "The second and third goals of the NHAS have to do with increasing access, having desirable health outcomes, and reducing health disparities," explains HRSA Chief Dental Officer Dr. Mahyar Mofidi. "We know that oral health care is one of the top health care needs of patients with HIV," he adds, "so working toward expanding access to dental care and reducing oral health disparities we can make a dent in achieving the National HIV/AIDS Strategy."

The SPNS Oral Health Initiative has sought out and engaged dental providers and offered valuable training in the treatment of PLWHA and HIV stigma reduction education for dental students via those grantees that embarked on partnerships with dental teaching institutions. An implementation strategy of the NHAS involves linking patients to coordinated, continuous care—something achieved in this Initiative through dental case management services.

would use, how it would recruit and train clinical staff, and how it would recruit patients into and retain in care. Six organizational models were used across the grantee sites (many utilized various combinations):

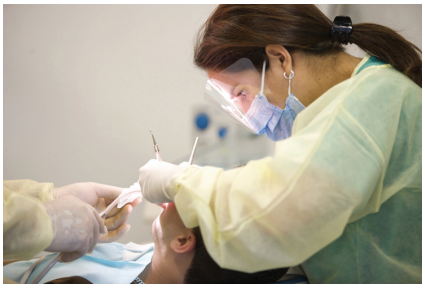
1. Increasing services at existing clinics,
2. Building satellite clinics,
3. Collaborating with clinics in dental hygiene schools or community colleges,
4. Fee-for-service dental reimbursement with contracted providers,
5. Leasing space at existing private offices/clinics, and
6. Purchasing mobile dental units.

Lessons learned around establishing various organizational models are addressed in greater detail in the following sections.

OVERVIEW OF THE SIX SPNS ORGANIZATIONAL MODELS STUDIED

Grantee Name & Location	Grantee Type	Program Model	Target Population Served
AIDS Care Group Chester, PA	ASO	• New satellite dental clinic in West Chester County, PA	PLWHA from communities of color in rural Pennsylvania
AIDS Resource Center of Wisconsin Green Bay, WI	ASO	• New satellite dental clinic in Green Bay, WI	Uninsured and underinsured PLWHA in Green Bay and rural WI
Community Health Center of Connecticut Middletown, CT	CHC	• 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	• Collaboration with rural dental satellite clinics	PLWHA in 15 counties in southern Oregon
Louisiana State University New Orleans, LA	University	• Mobile dental unit	Underserved, at-risk, and PLWHA of color in New Orleans, LA
Lutheran Medical Center New York City, NY	University	• Training program • Satellite clinic in the U.S. Virgin Islands (USVI)	PLWHA in the USVI
Montefiore Medical Center (MMC) Bronx, NY	University	• University-based dental program • 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	• Mobile dental unit	PLWHA in rural South Carolina
Special Health Resources for Texas Longview, TX	ASO	• Satellite clinics	PLWHA in rural East Texas
St. Luke's Roosevelt Hospital New York City, NY	Hospital	• Hospital-based HIV dental center expanding existing services	PLWHA in New York City not enrolled in hospital's medical program
Tenderloin Health Center San Francisco, CA	CBO	• 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 District
University of Miami Miami, FL	University	• University-based program using a mobile dental unit	PLWHA in the Miami area
University of North Carolina Chapel Hill, NC	University	• University hospital-based dental clinic expanding existing services	PLWHA patients in several counties of North Carolina
Boston University (Evaluation and Technical Assistance Center)	University	• Evaluation and Technical Assistance Center	SPNS Oral Health Initiative grantees

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



4

LESSONS LEARNED

The SPNS Oral Health Initiative allowed grantees to build or expand oral health care programs to serve their patients, and to test new models of care in an effort to identify innovative ways to do a better job of serving not only their own patients, but all PLWHA. The lessons learned from their SPNS projects are shared below to encourage implementation of best practices. They include the following:

- Considerations for getting started with establishing an oral health care program, including securing partnerships, financing, and staffing and management,
- The value of dental case management,
- Tips on integrating medical and oral care,
- Addressing patients' geographic isolation and transportation needs, and
- Pros and cons of the organizational models used by SPNS Oral Health Initiative grantees.

GETTING STARTED

Embarking on an oral health program requires careful evaluation of available resources. Oral Health Initiative grantees performed needs assessments in advance of launching their SPNS projects that took into consideration the human resources, equipment and office space, marketing, and finances needed to execute their proposed projects successfully. Creating partnerships, establishing high standards for staffing and management, and ensuring sufficient financing were important foundational activities that paved the road for successful and sustainable oral health programs, as discussed below.

Creating Partnerships

Many SPNS Oral Health Initiative grantees developed partnerships with other organizations to complement and supplement their services, as well as to help bring people into care through shared marketing resources and networks. In fact, those grantees that developed collaborative relationships with other providers offered higher levels of dental service on a whole than those that did not. (To revisit definitions for different levels of

NEW TO ORAL HEALTH OR NEED A REFRESHER?

See the glossary in Module 4 in the corresponding IHIP curriculum to brush up on key oral health terminology.

oral health care, see page 11). The types of partnerships explored by grantees ranged from collaboration with teaching institutions to partnerships with other HIV and/or community health organizations.

Collaboration itself can present challenges as well. It requires careful coordination and flexibility for all partners involved. SPNS grantees have shared the following lessons learned from the process of creating such partnerships:

- A partnership, like any business relationship, is built on trust and mutual accountability. Providers should carefully define each partner's responsibilities in a written agreement or contract. This written document should be revisited if disputes or misunderstandings arise regarding each partner's agreed-upon contribution to the partnership.
- Consider involving Ryan White Planning Councils or consortia in early discussions to provide guidance.
- Learn from others. Talk to other local or national HIV organizations providing oral health services and share lessons learned.
- Introduce partners to dental/medical case managers and dental/medical professionals. Encourage the parties to discuss and address questions around expectations and processes.

Staffing and Management

Health care is a "people profession," and thus it comes as no surprise that human resources are as vital for a successful oral health program as they are for any health program. Ensuring the staffing of nonjudgmental, culturally competent oral health professionals, particularly in areas with high HIV stigma, is critically important.

Some Oral Health Initiative grantees encountered challenges in recruiting staff at their sites. These included overcoming stigma and discomfort working with PLWHA, high turnover rates, and lack of education around the unique needs of PLWHA. "There's still great stigma and fear [of PLWHA] in the dental profession," shares Dr. Howell Strauss of the AIDS Care Group (ACG) in Chester, PA. Nancy Young, administrator of the SPNS Oral Health Initiative grant at SHRT, agrees. "In the first year of the grant, we struggled to find someone who was comfortable working with HIV-positive people."

Another challenge for staffing is the growing number of dental health professional shortage areas (HPSAs)—commonly called "dental deserts"—in the United States. These are areas that have a disproportionately low number of practicing dentists, based on a dentist to population ratio of 1:5,000 or more people per dentist. As of January 2013, HRSA estimates that there are currently approximately 4,600 dental HPSAs.[13] (To identify dental shortage areas across the country, please visit www.hrsa.gov/shortage/find.html).

These dental deserts are not due to a shortage of U.S.-based dentists overall. In fact, the Bureau of Labor Statistics reports that the number of dentists is expected to grow by 21 percent from 2010 to 2020, faster than the average for all occupations.[14] Rather, dental shortage areas arise, in part, because of financial disincentives for dentists to set up practice in impoverished or rural areas. Dentists often graduate from dental school with significant debt and are much more likely to set up practice in areas that are more heavily populated and lower in poverty, increasing the likelihood that they will treat higher profit-margin patients.

Dental deserts are partly why SPNS grantees in rural settings were more likely to develop comprehensive training programs for dental residents and hygienists. Training provided not only a means of strengthening the number of dental providers in the region but, at the same time, helped reduce stigma and fear of working with PLWHA.

Once a provider has addressed key staffing and training concerns and has a solid oral health team in place, the next step is providing the necessary management and reporting structure between the oral health care team and the broader clinic team. This can be accomplished by creating a set of procedures that are documented and that all stakeholders have reviewed and approved. These procedures can be especially critical in cases where low managerial supervision is provided, such as in a satellite clinic.

One grantee addressed this challenge by transferring existing staff from its primary clinic to work at its satellite clinic and, in turn, hiring new help at the primary clinic. This ensured that those working at the satellite clinic were already fully familiar with the grantee's policies and reporting structure, while giving new staff a chance to acclimate to their new roles in a more controlled setting.

Financing Oral Health Care

Navigating through policies related to payment for oral health care services is difficult. It is important for oral health and medical staff to understand the ins and outs of the funding options available for financing an oral health program for PLWHA.

Dental insurance is not as common in the private sector as medical insurance. The number of adults without dental coverage is three times as high as the number of adults without health insurance coverage.[15] In fact, more than 100 million Americans do not see a dentist because they can't afford it.[16] In some cases, State Medicaid programs for low-income and disabled individuals are able to fund dental coverage for PLWHA, but the level of coverage can vary widely—and may even be nonexistent in some States. Unfortunately, the number of States with no or reduced Medicaid dental coverage may be increasing, as dental coverage is often one of the first services to be eliminated in State budget cuts.

The Ryan White HIV/AIDS Program also has provided funding for dental care for uninsured and underinsured HIV-positive patients, as a core component of comprehensive HIV/AIDS clinical care. Parts A, B, C, D, and F of the Program all may cover dental care as part of their service mix. (To learn more about the different Parts of the Ryan White HIV/AIDS Program, please visit http://hab.hrsa.gov/abouthab/aboutprogram.html).

Alternatives to Federal funding options should also be explored. Some grantees had success accessing private foundation funding for components of their programs, such as their dental case management, or by utilizing a sliding fee scale for patient services. Other grantees recruited patients with private insurance to their practices, helping to counterbalance the cost of HIV patients who cannot afford oral health care. (To learn more about the impact of this funding approach on project sustainability, please see page 18).

The Affordable Care Act is expected to expand health insurance nationally, but will not require insurers to offer adult dental coverage as an essential health benefit.[17] As such, there remains a need for Ryan White providers to offer this care to PLWHA. In order to understand what it will cost to expand oral health services for PLWHA, administrators need to know:

- How many new people need care,
- What services should be covered (basic care, intermediate care, comprehensive care, or all of the above),
- How much providers should be paid, and
- Funds available to pay for care.

The data displayed in the table on the following page was collected by the SPNS Oral Health Initiative grantees over a 2-year period, capturing costs for services provided to 1,053 individuals and across 3 different fee schedules. During that short time, significant improvements in health and reductions in cost per person were realized. In fact, the cost of the care delivered in the second year dropped by more than two-thirds across fee schedules.

DEFINITIONS FOR LEVELS OF CARE

Services in italicized text are services that are not included in the level of care immediately below the level being described.

- **Comprehensive Care:** Nearly all dental services, including *endodontics and fixed prosthodontics*.
- **Intermediate Care:** Diagnostic care; preventive care; restorative care, excluding crowns; and periodontal care, *including surgery, oral surgery, removable prosthodontics and adjunctive services* (emergency care, consultations, night guards, etc.).
- **Basic Care:** Diagnostic services; preventive services; restorative care, excluding crowns; and periodontal care, excluding periodontal surgery and adjunctive services.

Source: Tobias CR; Fox, JE, Bachman SS, Bednarsh H, Reznik DA, Abel S, on behalf of the Evaluation Center on HIV and Oral Health (ECHO). *Expanding Access to Care for People Living with HIV/AIDS: Service Utilization and Costs.* May 2012.

DENTAL CASE MANAGEMENT

"I can't see how a dental practice right now could function without a case manager."

—Patient at Harbor Health, SPNS grantee, Provincetown, MA

AVERAGE COSTS OF SERVICES PER PERSON FOR 1ST AND 2ND YEARS OF TREATMENT

	Average Price/ Person	Very Low	Medium	High
Comprehensive Care	Year 1	$603.31	$1,271.32	$1,829.13
	Year 2	$231.67	$393.02	$546.44
	Difference Year 1 – Year 2	$371.64	$878.30	$1,282.69
Intermediate Care	Year 1	$383.24	$965.44	$1,435.09
	Year 2	$104.83	$237.02	$349.42
	Difference Year 1 – Year 2	$278.41	$728.42	$1,085.67
Basic Care	Year 1	$216.99	$541.16	$833.52
	Year 2	$55.88	$126.19	$191.89
	Difference Year 1 – Year 2	$161.11	$414.97	$641.63

Source: Evaluation Center for HIV and Oral Health, BU School of Public Health, Health & Disability Working Group. *Expanding Access to Dental Care for People Living with HIV/AIDS: Service Utilization and Costs*. P. 6–7. Available at: http://echo.hdwg.org.

While dental case management (DCM) can take different forms depending on patient needs and clinic resources, at its core it shares many similarities with HIV clinical case management, albeit with a priority placed on engaging and retaining patients in dental care as a component of an HIV/AIDS treatment plan. As with HIV clinical case management, DCM qualifies as a HRSA core medical service.

Out of 15 grantees, 9 employed a dental case manager or patient navigator to coordinate patient care. All of the dental case managers involved with the Oral Health Initiative provided some level of patient education, and were even instrumental in educating other providers involved with providing HIV care and services about the importance of oral health care for their patients. Dental case managers also handled a considerable amount of logistics for their patients, scheduling and making sure patients had a way to get to their appointments, and referring them to HIV case management, medical care, and support services.

Duties of a Good Dental Case Manager

Preparing staff for dental case management is not unlike preparing staff for medical case management. The same traits that distinguish a good medical case manager—attention to detail, strong communication skills, and ability to gain patients' trust—are the same traits evident in a strong dental case manager.

When Lucy Wright was appointed the AIDS Dental Case Manager for the SPNS Oral Health Initiative at the Native American Health Center in San Francisco, she prepared herself for her new role by speaking with and shadowing the medical case managers in her organization and in other organizations. She paid attention to the kind of notes the case managers would take and how they engaged patients to come into the clinic for various reasons. "I wanted to get a better understanding of how patients are coming in for their appointments, what the labs look like, and what I'd need to look for to keep patients current with their labs—the CD4 and viral load values."

The CDC has identified six tasks that should form the foundation of HIV case management. These include:

1. Client identification, outreach, and engagement,
2. Medical and psychosocial assessment of need,
3. Development of a service plan or care plan,
4. Implementation of the care plan by linking with service delivery systems,
5. Monitoring of service delivery and reassessment of needs, and
6. Advocacy on behalf of the client (including creating, obtaining, or brokering needed client resources).[18]

While case management skills are a must for a dental case manager, a formal background in dental care is definitely an asset. Wright is trained as a dental hygienist, and her background was an advantage for her in communicating effectively with the dental staff. It also helped her explain in detail the procedures that patients would undergo, clearly addressing any of their fears or questions to put them at ease. To learn more about skills and experience that benefit a dental case manager, see the job description detailed in Module 6 of the IHIP curriculum that complements this training manual.

One of the most valuable roles that a case manager can perform is to serve as a teacher that patients feel comfortable approaching without fear of judgment. SPNS Oral Health Initiative grantees found that patients were often afraid to ask questions of their dentist. "They're scared to ask questions because they don't want to feel like they are asking a stupid question," explains Wright. "I wanted them to feel comfortable to ask me any question that they felt was necessary so I often took care to explain dental treatment plans to the patients—a lot of hand-holding."

In some cases, Wright's handholding for patients was literal. "Some of my patients had a very strong fear of going to the dentist. Sometimes I would sit next to them during an operation so they had support when they were getting a numbing shot or a tooth extracted." One patient at Harbor Health reinforced the importance of Wright's kind of empathetic care: "When you are in pain, [the dental case manager is] someone who understands that you are in pain and they kind of guide you along, you know."

Patients are not the only ones benefitting from dental case managers. Providers have seen a marked increase in clinic efficiency and coordination with other service providers with the addition of dental case managers on staff. "Our case manager was a patient of ours for years," says Strauss. "He knew the ins and outs and many of the procedures, so he was familiar with the dental terminology."

ACG's dental case manager was responsible for all patient intake and Institutional Review Board consent forms, thus reducing the paperwork burden for ACG clinicians. The dental case manager also worked with all the other case management agencies in 16 counties across Pennsylvania to arrange appointments for patients, and even drove patients to their appointments when transportation was a challenge. "He knew every single client who was serviced—knew where they lived and their families—and we served close to 500 in this project," remarks Strauss.

Some grantees chose to provide some form of dental care coordination during the SPNS demonstration period, despite lacking a dedicated dental case manager. In these cases, grantees often chose to use an existing HIV case manager to perform dental care coordination. This usually involved the dental staff contacting a patient's HIV case manager whenever a patient required referrals to specialty care or needed help navigating available dental benefits. This practice was most common among the ASOs and university- or hospital-affiliated programs.[19] This approach can be a cost-effective way of maximizing existing resources when funding prohibits hiring and/or training a dedicated dental case manager, although special scrutiny should be given to the workload burden this may place on existing HIV case managers.

Even though HIV case managers who assume some dental case management duties will presumably already have training and experience around the principles of case management, it's nevertheless important to ensure that they receive additional training around the unique oral health needs of PLWHA. This will enable them to communicate more clearly with oral health providers as well as their patients, and be better prepared to link their patients to the right types of oral health care and services. This IHIP training manual and the other related IHIP oral health training materials provide a solid initial orientation to these issues for HIV case managers.

INTEGRATING MEDICAL AND DENTAL CARE

Just as a patient cannot be truly healthy without a healthy mouth, dental providers can't be truly successful without a healthy relationship with HIV medical care providers and case managers. Colocated medical and dental services can improve patient referrals to oral health care, as well as make it easier for patients to receive medical and dental care in one visit. This can be especially attractive when patients are traveling long distances for care.

Physically locating dental and medical care in one place, however, does not mean that integration will be seamless. To improve team communication and cohesiveness, AIDS Resource Center of Wisconsin (ARCW) used structured activities to ensure that medical and dental providers educated each other and coordinated care on behalf of individual patients at its Green Bay clinic. At staff meetings, the dentists presented the importance of oral health care to the medical providers. In turn, the medical providers explained HIV medications and their

effects to the dentists. ARCW even had weekly integrated case conferences and a monthly review of patient medical and dental needs.

Data Management

When integrating medical and dental care, providers must inevitably share data about their patients, and this requires careful consideration of data management requirements and adherence to established privacy policies, whether institutional or Federal such as the Health Information Portability and Accountability Act of 1996 (commonly known as HIPAA). This can be especially challenging when working with providers—whether in a partner organization, or even within a different division of the same organization—that may be using different systems to make appointments and track patient data.

At Montefiore Medical Center in New York City, the initial integration of dental care and medical care data systems was somewhat problematic. "The dental appointment system was different from the medical system—different installation, different access," shares Paul Meissner, health planner and program administrator at Montefiore. Adding to the complication was the fact that the system was largely a paper system as opposed to an electronic record system. But that changed. "Over the timeframe of the SPNS grant, we went to an electronic record system, and it has been a very positive shift. It's made a huge difference in allowing our dental patient navigators to be able to communicate with doctors more effectively, and both patient navigators and doctors like it," adds Meissner.

ADDRESSING GEOGRAPHIC ISOLATION AND TRANSPORTATION NEEDS

Transportation is a key material need that can be a significant barrier to HIV care, as well as oral health care. The availability—or absence—of transportation can be the difference between making it to an appointment and not making it. Transportation becomes even more of a concern in areas where dental providers are few and far between, such as in rural areas, or when patients are otherwise geographically isolated from care.

SPNS grantees used a variety of approaches to address the challenges of transportation. Some programs arranged carpools or scheduled Medicaid-financed transportation. Some of the grantees' dental case managers even drove vans that transported patients to and from clinic visits, which provided uninterrupted time to discuss both HIV- and oral health-related issues. Other grantees introduced expanded hours in the evening or on the weekend for PLWHA, recognizing that one barrier to care was that clinic hours were during patients' working hours.

Some grantees served broad geographic areas that spanned hundreds of square miles and included many counties. Some of their patients traveled up to 5 to 8 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.

Several grantees provided transportation themselves, using a van to pick up patients and bring them into care. To address the inconvenience to patients of spending hours in a van and waiting for other patients to finish their appointments, some grantees provided meals or snacks for patients, and created comfortable waiting rooms where people could use a computer and the Internet.

A few grantee programs that offered direct patient transportation underestimated the demand it would place on the program in terms of expenses for vehicle maintenance and gas, particularly as gas prices skyrocketed during the grant period. For example, one grantee found that its van traveled tens of thousands of miles in the first year, and thus it would likely need to be replaced after a second or third year, and it still could not accommodate all their transportation needs. Providers may find that reimbursing or offering vouchers to patients for mileage, gas, or train tickets is a practical way of reducing a patient's burden of traveling that does not require the clinic to have a vehicle to transport patients directly.

Mobile Dental Units

Four grantees chose to address geographic isolation and/or transportation challenges for their patients through the use of mobile dental units. These grantees designed, purchased, and implemented mobile dental units that ranged in cost from $144,000 for a one-chair unit to $330,000 for a unit with two dental chairs.

Launching a mobile dental program requires a high degree of planning and preparation. Providers interested in developing a mobile dental program will need to address regulatory and safety issues; medical record access, storage, and privacy concerns; scheduling and

staffing issues; access to parking and permits; and be prepared for mechanical and maintenance issues with both the dental equipment and van. In fact, all of the Oral Health Initiative grantees built in specific days for van maintenance.

CLINIC MODELS

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. Grantees chose different approaches to launching their satellite clinics, including leasing treatment space from a local hospital and repurposing an existing office. In general, however, these satellite clinics enabled the SPNS grantees to enroll large numbers of new patients, and all were sustained beyond the life of the grant. Some grantees even utilized their satellite clinics to help serve a broader patient population not limited to PLWHA. (The benefits of this more inclusive approach are discussed further in the "Program Sustainability" section on page 18.) Their success is a testament to the benefits of employing this organizational model to expand care, despite any inherent challenges.

Fee-for-Service Dental Reimbursement

Despite making oral health care more accessible for many people, a satellite clinic does not guarantee that all patients will have improved access to care. One rural grantee found that, even with the addition of their satellite clinic, some of their patients who lived in very rural areas were still traveling up to 7 hours for care. To reduce their patients' travel time, private dentists and dental clinics in some of the outlying rural areas of the State were contracted to provide services on a fee-for-service basis. This fee-for-service model can be an effective way to expand care to PLWHA in hard-to-reach locations, as long as provisions are taken to ensure that the providers who are contracted are culturally competent and trained in the special oral health needs of PLWHA.

Leasing Private Dental Space

Leasing dental space can be a viable option for providers, whether they are considering it as a bridge to a satellite clinic or as a stand-alone measure for increasing access to oral health care for PLWHA. Providers considering this approach to providing or expanding oral health care services should research the implications the location of the leased space may have on billing options, as well as

CONSIDER THIS: TIPS FOR ESTABLISHING A SATELLITE CLINIC

Satellite clinics can provide significant benefits to patient care and overall clinic efficiency, but establishing them requires thoughtful preparation. Providers considering a satellite clinic should consider the following lessons learned by Oral Health Initiative grantees:

1. **Start small.** Most of the grantees that set up satellite clinics did so after less resource-intensive approaches to expanding care were tried first. For example, one grantee leased dental treatment space at a local hospital before establishing its satellite clinic. Another site brought in portable dental equipment to provide oral exams and minor care at its drop-in homeless shelter before opening its satellite clinic.
2. **Don't underestimate the time or resources needed.** All grantees experienced some delays in the startup of their programs as a result of anticipated and unanticipated regulatory requirements, construction needs, or other challenges. Plan and budget for delays in your business plan for the clinic.
3. **Communication is key.** "Build it and they will come" is unlikely to prove a successful strategy for building a satellite clinic patient base. First and foremost, ensure that all staff members, case managers in particular, are aware of the new clinic and can proactively identify and refer patients who would benefit most from the new location. All patients should learn about the clinic; word of mouth is a powerful tool for raising awareness. Staff should also be able to address any questions that may arise about the satellite clinic's services and be able to answer these questions for patients and other stakeholders. Traditional marketing methods—such as radio announcements, flyers, social media announcements, or a dedicated satellite clinic Web page on your home Web site—can also be used to get the word out about the clinic.

carefully estimate any expected increase in patients that may arise from the increased convenience of the location, and ensure enough resources are in place to continue to treat patients in a timely and effective manner.

PARTNERSHIPS WITH TEACHING INSTITUTIONS

Two of the biggest barriers to care for PLWHA are the lack of oral health providers trained and willing to treat PLWHA, and the lack of funding to hire oral health staff. Partnerships with teaching institutions are an excellent way to address both of these issues directly. Working with dental students also offers the opportunity to reduce the stigma associated with HIV, paving the way for a generation of dental providers that is more sensitive to the unique needs of PLWHA and more open to treating them in a sensitive, culturally competent manner.

The grantees that developed either formal or informal partnerships with dental schools or dental programs in their communities all have been able to sustain their programs beyond the life of the SPNS grant, in part, because of their fruitful partnerships with these teaching institutions. Providers interested in collaborating with dental teaching programs will need to delineate clearly the program elements for which each partner is accountable. This can include providing clinical space and equipment, program management and evaluation, dental case management, transportation, and finances.

Despite the benefits that dental students can provide, grantees found that it was important for interested students to undergo an interview process just like any other staff hire. For one grantee, the interview process for the students included writing essays about why they wanted to work with PLWHA and why they wanted the extra clinic experience. "We wanted to make sure they were doing it because they have a passion to treat people with HIV," stressed the administrator of the organization's Oral Health Initiative grant.

PATIENT EDUCATION

"Once you build that trust with a patient, they will always come back to care."

—Lucy Wright, patient navigator,
Native American Treatment Center,
San Francisco, CA

Offering patient education was one of the factors most highly correlated with patient retention among SPNS Oral Health Initiative grantees. Providers can have a strong influence on patient education and oral health literacy.

Compassion is at the core of what drives effective patient education. There are simple things a dental case manager or patient navigator can do to demonstrate compassion and facilitate patient education.

SPNS grantees found that listening closely to patient stories and concerns, as well as their fears about dental work, was invaluable in helping to address questions and alleviate uncertainties. "I think listening was key," says Wright. "Some patients don't have anybody else to turn to, talk to, or provide companionship. Just being able to have somebody hear them out was a wonderful experience for them."

Fear and anxiety around dental care is a big barrier to care for PLWHA that can often be effectively addressed by patient education. This anxiety was especially prominent among homeless individuals and immigrant populations who had limited experience with dental care. At several urban programs, dental case managers recruited patients directly by discussing dental services at a drop-in center or clinic setting, allaying patient fears about dental care, and offering to accompany patients to their first dental visit. They also helped explain what would happen and what new patients could expect when they came in for their visits.

For some patients treated as part of the Oral Health Initiative, a visit to the dentist was their first ever, and thus, step-by-step guidance on what to expect was all the more critical to allay their fears. "Many of our patients had never been to a dentist and their parents had never been to the dentist," shares Young. "This was their heritage, no dental care."

Others had gone without care for long periods of time or received only episodic emergency care. In fact, 20 percent of Oral Health Initiative patients had not received any dental care in the previous five years or longer. Fourteen percent of the patients who came into care at one of the programs were there only once and did not return.

All of the grantees provided some level of patient education about the patients' individual oral health treatment plans, the connection between HIV and oral health, and beneficial oral hygiene practices. Several programs took extra steps to engage patients in care, and encourage them to return for follow up, and establish a dental home.

Many grantees drafted patient education materials to address the concerns, questions, and barriers to oral health care discussed by patients. When preparing education materials, providers should make sure that their messages are understood by their target audiences by taking into consideration their optimal reading levels and preferred languages. For example, one grantee developed patient education materials in both Spanish and English, and hired bilingual staff to review the materials with individual patients.

Patient education can be approached in many ways. Some grantees educated patients on a one-on-one basis, in which a dental assistant or hygienist provided chairside education to patients around ideal oral health practices. At other grantees, patient education was provided in a group setting. Patient videos and demonstration materials were created for use in patient waiting rooms, and while patients were waiting to be seen for care the dental case manager engaged them in group discussions about good oral health practices.

Even with patient education, however, some patients will still not care for their teeth properly, once initial oral pain and infection are alleviated. Months later, this can result in patients returning to their dental hygiene clinic with new but preventable oral health problems. To overcome this hurdle, providers can use consumer focus groups to identify and test new patient education messages and methods.

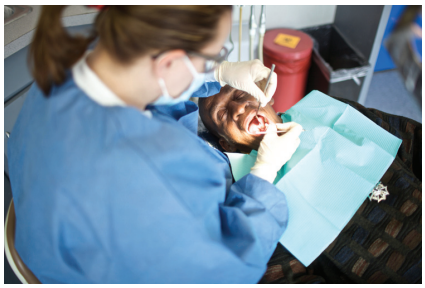
Motivational interviewing can also be instrumental in inspiring patients to change their behaviors and helping to direct provider-patient education efforts. Motivational interviewing is defined as a "collaborative, person-centered form of guiding to elicit and strengthen motivation for change."[20] Because of its proven effectiveness in driving behavior change, ECHO offered motivational interviewing training for Oral Health Initiative grantees, with very positive feedback. "Motivational interviewing training really helped our dental hygienist get people to reduce smoking and dipping, which is high in Texas; increase flossing; and reduce sugar intake," says Young. "It made a big difference." (To learn more about motivational interviewing and to access motivational interviewing training tools, please see Module 8 in the corresponding curriculum).

Peer Involvement

Peers can be powerful influencers of behavior in PLWHA, and are well positioned to educate PLWHA about the importance of oral health care. Peers may be able to gain a patient's trust more readily than a provider might, and they can utilize this relationship to help reduce patient fears of dental care and to share their own personal positive experiences with oral health care. They can also play important support roles in getting patients into and retained in care by helping to:

- Provide transportation to and from appointments,
- Connect patients with other social services,
- Accompany patients to dental visits, and
- Remind patients of appointments.

To learn more about peer-patient education and access related training tools, please see Module 9 of the corresponding curriculum.



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PROGRAM SUSTAINABILITY

All grantees were asked to consider and prepare for project sustainability from the very beginning of the Initiative, and several grantees have been successful in sustaining some or all of their grant programs beyond the SPNS grant period. These programs all depended on different factors to sustain their programs, but were unified in their adaptability and creativity in approaching the challenges inherent in funding their programs.

Project sustainability has proven to be, above all else, dependent on funding. The main funding options that grantees utilized to sustain their projects included some combination of the following:

- Medicaid reimbursement,
- Reimbursement/contracts from Ryan White programs or private foundations,
- Sliding fee scales for patient payment, and
- Cross-subsidization from billing private dental insurance (and clinic outreach to expand this market).

Among the Oral Health Initiative grantees, 10 of the 15 were able to leverage Ryan White funding through various Ryan White Program Parts (2 with Part A; 3 with Part B; 3 with Part C; and 2 with Part F Dental Reimbursement Program). See page 4 to learn more.

Some grantee clinics utilized the cross-subsidization approach to great success. These grantees were able to expand their respective services to PLWHA in part because they opened their practice to non-HIV-positive, private dental patients as well. "If you look at the holistic approach to care, for a provider to say, 'Well, you know, I'm just a Ryan White clinic, and that's all I see here,' is pretty much the beginning of a shutdown of their program," adds the director of one of these grantees. "That's just another barrier to services. Our goal was to find barriers and remove them."

This same grantee was not just able to not only remove barriers, but to turn them into opportunities. The grantee recognized that there was an unmet need for private dental care in the community it serves, not just dental care for PLWHA. Now, the grantee operates its own private dental clinic to service private paying and insured patients, who bring in a steady income stream that supports its ability to sustain its program while still providing quality care to PLWHA with lesser means.

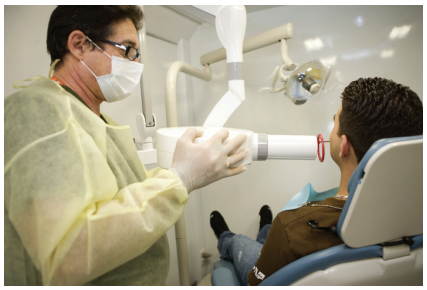
For some grantees, the organizational model they chose to implement greatly promoted sustainability. Those grantees that were able to develop fruitful partnerships with dental schools, who can provide a steady stream of low-cost staff support to a clinic, have demonstrated success in maintaining their oral health care programs. In addition, all of the grantees that established satellite clinics have been able to not only enroll large numbers of patients through their expanded services,

PROGRAMS WITH PLANS FOR POST-EVALUATION PROJECT SUSTAINABILITY

Program Name	Patients enrolled in the evaluation and care	Mean # of services provided to patients	Patients with completed Phase I treatment plans
AIDS Care Group	206	11	71
AIDS Resource Center of Wisconsin	55	24	40
Community Health Center of Connecticut	208	14	103
Harbor Health	74	12	29
HIV Alliance	205	21	126
Montefiore Medical Center	58	13	14
Native American Health Center	99	20	61
Special Health Resources for Texas	187	17	120
St. Luke's Roosevelt Hospital	289	25	136
Tenderloin Health Center	173	13	62

but also to sustain their programs beyond the SPNS grant period.

As any SPNS grantee can tell you, there's no need to reinvent the wheel to build and sustain a successful program. One of the biggest benefits of being part of the Ryan White community is learning from other Ryan White providers' experiences and adopting their best practices. While the goal of this training manual—and of the IHIP project as a whole—is to facilitate this sharing of best practices as they relate to oral health for PLWHA, valuable oral health information is being shared across the Ryan White community in many ways. To learn more, please see the "Online Resources" section on page 21.



6

CONCLUSION: CARRYING THE TORCH FORWARD

This training manual is just one of several interconnected resources available to providers seeking to enhance their delivery of oral health care for PLWHA. Providers are encouraged to review all of the training materials available on this topic—which include a curriculum, pocket guide, and Webinars—on the IHIP page of the TARGET Center Web site at: www.careacttarget.org/ihip.

Together, these IHIP materials make it abundantly clear that not only does oral health care play a critical role in overall health of PLWHA, but it also can be delivered through innovative, tailored, and tested models of care. SPNS grantees from all over the country, serving very different populations of PLWHA with varying levels of resources, have given the Ryan White community the gift of proof around what works when it comes to developing an oral health care program for PLWHA—and what doesn't, which can often be even more important.

Now, however, it's your turn to carry the torch forward. Put these lessons to work in your own practices and spread the knowledge you've gained among your colleagues, partners, and patients.

ONLINE RESOURCES

ECHO Reports (http://echo.hdwg.org/)

- *Expanding Access to Oral Health Outcomes for PLWHA—Lessons Learned:* http://hdwg.org/sites/default/files/lessonslearned-final.pdf.
- *Expanding Access to Dental Care for PLWHA—Service Utilization and Costs:* http://hdwg.org/sites/default/files/OHinClinical Care-final.pdf.
- *If You Build It, Will They Come? And if They Come, Will They Stay?: Lessons Learned in Engaging and Retaining People Living with HIV/AIDS in Oral Health Care:* http://hdwg.org/sites/default/files/ECHO engagementandretention.pdf.

HIVDent, featuring up-to-date treatment information and expertise in development, training, integration, and evaluation of oral health services for PLWHA: www.hivdent.org.

Inception of Part F dental programs explored on HRSA's *The Ryan White Program: A Living History* Web site: http://hab.hrsa.gov/livinghistory/programs/Part-F-pg3.htm.

"Increasing Access to Dental Care," *HRSA CAREAction* Newsletter, August 2008: www.hab.hrsa.gov/newspublications/careactionnewsletter/june2008.pdf.

Oral Health Screening in the Primary Medical Care Setting, presentation for clinicians by HRSA HIV/AIDS Bureau's Chief Dental Officer, LCDR Mahyar Mofidi, DMD, PhD: https://careacttarget.org/library/oral-health-screening-primary-medical-care-setting.

Public Health Reports Oral Health Supplement: http://echo.hdwg.org/news/now-available-public-health-reports-oral-health-supplement.

Ryan White HIV/AIDS Program Oral Health and HIV Fact Sheet: http://hab.hrsa.gov/abouthab/files/oral_health_fact_sheet.pdf.

"SPNS Innovations in Oral Health: Something to Smile About," *What's Going on @ SPNS* Bulletin, September 2009: http://hab.hrsa.gov/abouthab/files/cyberspns_oralhealth.pdf.

TARGET Center Oral Health Care Technical Assistance Resources: https://careacttarget.org/category/topics/oral-health-care.

The New York State Department of Health AIDS Institute's Oral Health Care Resources: www.health.ny.gov/diseases/aids/about/hlthcare.htm#ohc.

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