

# **IDENTIFYING SUCCESSFUL HIV ORAL HEALTH PROGRAMS**

**FINAL REPORT**

**ORDER NUMBER 01-0322 (P)**

**TO THE**

**HIV/AIDS BUREAU  
OF THE  
HEALTH RESOURCES AND SERVICES ADMINISTRATION**

**October 2002**



**117 Jordan Taylor Lane  
Harwood MD 20776  
(443) 203-0305 (T) \* (410) 203-0306 (F)  
[www.positiveoutcomes.net](http://www.positiveoutcomes.net)**

## Table of Contents

<b>Key Findings</b> .....	<b>i</b>
A. Background.....	i
B. Study Findings .....	ii
<b>Acknowledgements</b> .....	<b>vii</b>
<b>Introduction</b> .....	<b>1</b>
<b>Background</b> .....	<b>1</b>
<b>Methods</b> .....	<b>2</b>
Table 1. Criteria for Identifying Successful HIV Oral Health Programs .....	3
<b>REVIEW OF THE LITERATURE</b> .....	<b>5</b>
A. Periodontal Disease in HIV .....	5
B. Oral Manifestations of HIV Disease in Adults.....	6
C. Periodontal Disease in Children with HIV .....	9
D. Accessibility and Use of Dental Care.....	10
1. Access to Dental Care Among Adults With HIV Infection.....	10
2. Access to Dental Care Among Children With HIV Infection .....	12
3. Barriers to Delivery of HIV Oral Health Care.....	12
4. Financing Dental Care for Persons Living With HIV (PLWH) .....	13
a. Medicaid.....	13
Table 2. Level of Dental Coverage for Adult Medicaid Beneficiaries, January 2000.....	14
E. Dental Health Indicators Among Low-Income People.....	15
F. Utilization of Dental Services Funded By Medicaid .....	15
G. Federal Efforts to Increase Medicaid Beneficiaries’ Access to Dental Services .....	17
H. State Efforts to Increase Medicaid Beneficiaries’ Access to Dental Services .....	17
I. Ryan White CARE Act.....	19
<b>PROJECT FINDINGS: ELEMENTS OF SUCCESS</b> .....	<b>23</b>
A. Factors Resulting in Start-up of HIV Oral Health Programs .....	23
B. Organizational Models .....	24
C. Physical Design and Atmosphere of HIV Oral Health Programs.....	26
D. Staffing.....	26
E. Linkages With Dental Training Programs .....	29
F. Nature of Oral Health Services Provided.....	30
G. Financing of Oral Health Services .....	32
1. RWCA-Funded Systems to Directly Purchase Dental Services .....	32
2. Third Party Reimbursement For Dental Care .....	34

3. Collection of Payments From Patients.....	38
H. Strategies for Care Coordination.....	38
1. Physical Co-Location of HIV Dental and Medical Clinics .....	40
2. Clinical Records.....	40
3. Multidisciplinary Care Management of PLWH.....	41
I. Strategies for Ensuring Accessible Services.....	41
1. Physical Location in the Community.....	43
2. Co-location With Clinical or Other HIV Care Services.....	43
3. Hours of Operation.....	44
4. Intake and Scheduling of New Patients.....	44
5. Scheduling of Ongoing Patients.....	46
6. Emergency or Urgent Care.....	47
7. Transportation.....	48
8. Linkages With Case Managers.....	49
9. Home Visits.....	49
10. Outreach to PLWH Not In Dental Care .....	49
11. Culturally Competent Services .....	51
J. Strategies for Ensuring Continuity of Care .....	51
1. Overcoming Dental Phobia or Pain Aversion.....	52
2. Physical Environment .....	52
3. Clinical and Management Information Systems .....	53
K. Patient Education Strategies.....	54
L. Infection Control Strategies.....	56
M. Quality Assurance Strategies .....	57
O. Impediments to Successful Oral Health Programs.....	59
1. Staff Recruitment and Retention.....	59
2. Funding .....	60
3. Space.....	61
<b>Other Resources.....</b>	<b>62</b>
<b>Appendix.....</b>	<b>64</b>
Table 2. Oral Health Programs Visited or Contacted.....	65
<b>Citations .....</b>	<b>67</b>

# KEY FINDINGS

The goals of this project are to assist the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA) to gain a better understanding of:

- What is known about access to and use of oral health care services by persons living with HIV (PLWH),
- Barriers to oral health care services experienced by PLWH, and
- Elements of successful oral health care programs for PLWH.

## A. BACKGROUND

While oral manifestations of HIV are generally documented in the medical literature, the periodontal conditions afflicting PLWH are not well addressed in the clinical literature. The prevalence of the various oral diseases associated with HIV also is not well documented and timely data are not available. In a survey of the reported cases of AIDS in the US through 1987, for example, oral/pharyngeal candidiasis was the second most common opportunistic infection (OI) reported. Timely data are not available about the prevalence of oral diseases in PLWH and the impact of protease inhibitors (PIs) and other changes in treatment strategies.

Studies of access to dental services by PLWH indicate that dental care is a common unmet need but that use of dental care is low. Surveys have identified socio-economic barriers, including lack of insurance or other means to pay for dental care, and personal barriers, such as fear of dentists, as factors contributing to lack of access and utilization of oral health services. Availability of dentists willing to treat PLWH is also cited as a major barrier to care.

Studies of oral health in various income groups in the US document that low-income people generally suffer from dental disease at a higher rate than people of higher incomes. Medicaid, the source of health care financing for those in poverty in this country, is a mechanism for helping to close the gap. Studies have found that while preventive and therapeutic dental services for children are covered by State Medicaid programs, utilization rates are very low. At the same time, only emergency dental care is covered for adult beneficiaries by most State Medicaid programs. The low utilization rates for dental care by children and no coverage for adults has resulted in several generations of Medicaid beneficiaries with no or minimal dental care.

Researchers have examined barriers to Medicaid participation by dentists. Reports document that dentists are unwilling to participate in the Medicaid program because of administrative complexities and extremely low reimbursement rates. Many State Medicaid programs are taking

steps to remove barriers for participation by oral health providers. The federal Medicaid program is offering incentives to states to expand dental and other Medicaid benefits to more children, as well as increased oversight of State Medicaid programs to assure that dental services mandated by law are being provided.

The Ryan White CARE Act (RWCA) has several programs that support dental services to PLWH. Oral health services are funded with Title I, II, III and IV funding. Additionally, the Dental Reimbursement Program (DRP) retrospectively compensates dental schools and post-doctoral dental programs for providing oral health treatment to PLWH. However, the relative amount of RWCA funds allocated to dental care by these RWCA programs is low, particularly in light of the high level of unmet demand for care and the importance of good oral health in sustaining high quality of life and supporting HIV treatment. RWCA dental providers report structural barriers to development and funding of dental programs.

Although successful approaches are being taken by RWCA providers to provide HIV oral health care, these efforts are not well documented. There is a dearth of articles or reports that describe successful HIV oral health projects and the elements that contribute to their success.

## **B. STUDY FINDINGS**

To address this dearth of information, HIV oral health programs and HIV dental insurance programs were contacted by telephone to learn about the services they provide and their successful strategies in meeting the oral health care needs of PLWH. Site visits were conducted to HIV oral health programs throughout the US.

HIV oral health programs were commonly established in response to significant unmet need identified by individual dental providers or through the RWCA needs assessment and planning process. The HIV oral health programs studied are designed to fit into the unique community settings of which they are a part. Numerous factors affect what organizational models are selected. Service models include provision of care in general dental settings or HIV-focused oral health programs. In some programs, HIV dental care is integrated with HIV medical services. In others, HIV dental services are integrated into HIV social services programs.

The settings in which HIV oral health programs operate vary widely and depend on such factors as local resources, agency characteristics, and target population. Programs are located in dental schools, hospital or hospital-based clinics, community-based ambulatory care clinics, publicly funded community health centers (CHCs), freestanding dental clinics, solo or group dental practices, homeless shelters, feeding programs, or city or county health departments.

The populations served by HIV oral health programs reflect the HIV epidemics in their communities. Most programs serve adults, a small number of programs serve only children, and some programs serve all age groups. Among programs serving adults, the service population may be PLWH in general, the homeless, youth, substance abusers, or a particular racial or ethnic group. Service areas range from local neighborhoods or communities to entire regions.

The physical design and atmosphere of HIV oral health programs are important to their success. Several HIV oral health programs report that they strive to create a professional atmosphere that emulates a private dental practice. An effort is made to make PLWH feel that they are not treated differently than other dental patients. Other programs report that they strive to be an integrated component of an AIDS service organization (ASO). The number of operatories range in number, based on the number of dental providers concurrently working in the clinic.

Staffing models differ widely. While some programs purchase service contracts with dentists in private practice, others employ dentists directly, pay them as contractual employees, or contract with dental outsource agencies. Additionally, some programs work with dentists who provide care in their own offices on a fee-for-service or pro bono basis. Many of the HIV oral health programs supplement their staffing with students and faculty from local dental education programs that rotate through the HIV oral health program. Staffing of clinic-based HIV oral health programs commonly includes one or more dentists, dental hygienist, dental assistant, office manager, billing clerk, and reception staff. Some programs also include dental students and fellows, a health educator, case manager, and outreach worker. The number of personnel staffing the program is determined by patient volume, the array of services provided, the number of operatories, and the hours of operation.

Dental specialists play an important role in the delivery of oral health care to PLWH. Most of the HIV oral health programs studied do not have onsite dental specialists. Instead, referral agreements have been established with community and university-based dental specialists. Programs use a variety of methods to identify specialists willing to work with PLWH. Directors of HIV oral health programs report that they commonly obtain specialty care as a result of their personal and professional relationships with dental specialists. Other programs report that they are able to gain the commitment of a few local specialists if they refer only a small number of patients to them and rotate referrals to specialists in the community. Specialists also are willing

to take referrals when they are adequately compensated for their services, billing is easy, and payment is timely.

The HIV oral health programs studied generally establish a long-term, individualized care or treatment plan. The care plan is considered long term, with full restorative and preventive care undertaken during the course of several visits. Commonly programs schedule patients for routine hygiene visits every three to four months, with more frequent visits scheduled based on the care plan, patient wishes, and availability of appointment slots. Components of the plan include: a formal intake process, review of general medical history, x-rays, and laboratory results prior to the initial examination; and ongoing comprehensive preventive care, restoration, cosmetic care, placement of prosthetics, oral surgery, and urgent and emergency care. Most of the HIV oral health programs studied identified dental education as an important aspect of their care. Dental education is often begun at the initial visit by dental hygiene personnel and conducted by dental staff at each visit.

Adequate financing of HIV oral health programs is a critical aspect of success in meeting the oral health care needs of PLWH. Lack of dental insurance among PLWH has been addressed in several ways by states, local jurisdictions, and providers. In Michigan, Massachusetts, New York, and Rhode Island, statewide dental reimbursement programs have been successful in forming networks of community-based dentists that provide services under a fee-for-service basis. Title I funds in Miami-Dade and San Diego Eligible Metropolitan Areas (EMAs) have been used to form fee-for-service and capitated dental networks. Several community-based organizations (CBOs) have successfully used Title III funds to form dental networks, including one that serves a 29 county area in the central US.

Several strategies have been identified to lower the costs of operating HIV oral health programs. Most of the programs studied actively seek laboratories and suppliers that are willing to accept lowered payments. Programs affiliated with dental education programs are able to negotiate price reductions based on volume. Equipment costs have been reduced by soliciting used equipment from private dental practices, public health dental clinics, or dental schools. Renovation costs have been funded through State construction bonds and Bureau of Primary Health Care (BPHC) 330 program funds.

In addition to RWCA funds, HIV oral health programs commonly receive an array of other funds to support their services. These sources of funding include Medicaid and commercial insurance, State and/or local government funds, charitable and corporate donations, and public

and private sector grants. Most of the programs studied report significant challenges in financing their operations and that their institutions must make up their funding deficit. Solutions identified by the HIV oral health programs studied to achieve fiscal solvency include capping the number of patients served, limiting the types of services provided, and seeking other sources of care for prohibitively expensive procedures.

Several strategies are used by the HIV oral health programs studied to coordinate dental, medical, and other HIV-related services. Co-location with medical clinics is a common strategy. Co-location enables dental providers to confer with physicians and other medical providers when medical problems are identified. Co-location also affords the opportunity for dental examinations to be conducted as part of the medical visit. Co-location also has been used to identify HIV-infected dental patients that are not in routine primary care and to arrange for primary care while the patient is onsite. Medical and dental records are integrated in several of the programs studied to further care coordination. At others, dental staff has ready access to the records.

Coordination of care is achieved in other HIV oral health programs that are not co-located with medical providers. Multidisciplinary team meetings or case conferences are routinely convened, in which dental personnel actively participate in care planning and management. In some agencies, a disease management model is used with a liaison nurse coordinating the provision and scheduling of medical and dental care.

Several strategies have been used by HIV oral health programs to ensure accessible services. Such strategies include selecting a location that is physical accessible and acceptable to patients; co-location in ASOs, offering convenient office hours, rapid intake and appointment scheduling, use of appointment reminder systems, effective methods for decreasing no-show and cancellation rates, triage procedures for walk-in and urgent patients, identifying sources of care during after-hours, provision of transportation, linkages with case managers for case finding and assistance in appointment keeping, home visiting, outreach to PLWH not in dental care, and provision of culturally competent services through staffing and materials.

The HIV oral health programs studied have developed an array of strategies for ensuring continuity of care. Dental phobia and pain aversion is widespread among their patients. An effort is made to establish a trusting relationship with the patient in a safe, comfortable atmosphere. Several programs initially focus on an oral examination, without treatment or cleaning. Alternatively, patient education may be the focus of the care plan until the patient is comfortable. Several other programs have developed pain management strategies to provide pain-averse

patients enough time to become comfortable with dental procedures. The physical organization of the programs is important in supporting this approach, with an effort made to make the environment inviting and comfortable. Even in programs with limited space and in older facilities, an effort is made to make the surroundings comfortable for their patients. Retention of staff is also important to ensure continuity. Patients in several programs can select their dental provider. Many of the HIV oral health programs studied have also been able to retain their staff over time, allowing a relationship to grow between the staff and their patients.

The HIV oral health programs studied have designed an array of infection control policies, procedures, and quality assurance models that support their success. These policies and procedures vary based on the organization of the programs and their staffing.

# ACKNOWLEDGMENTS

Several individuals were of particular assistance in conducting this project. Ms. Celia Hayes of the HAB Office of Science and Epidemiology served as project officer. Ms. Hayes provided ongoing support and helpful feedback throughout the project. Barry Waterman, DDS, of HAB, also provided invaluable guidance in the planning and conduct of this project.

Dr. Stephen Abel served as the Principal HIV Oral Health Consultant. His expertise in all aspects of HIV oral health care was of great assistance in the conduct of this assessment.

The members of the project's Advisory Work Group took time from their busy schedules to help guide the project in its planning and conduct. We thank Dr. Victor Badner, Dr. Valli Meeks, and Dr. Mark Nichols for sharing their expertise with the Advisory Work Group and participating in site visits. We also thank Ms. Kathy Treat of the HAB Division of Community-Based Programs, Primary Care Services Branch, for her participation in the Advisory Work Group.

We thank several other HIV oral health experts for their participation onsite visits: Dr. Victor Lugo and Dr. Jacqueline Plemons.

We are indebted to the staff of the HIV oral health and financing programs that we visited or consulted with by telephone conducted throughout this project. We appreciate their contributions to this project and hope that this final report reflects their important contribution to HIV oral health care in the US.

# INTRODUCTION

The goals of this project are to assist the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA) to gain a better understanding of:

- What is known about access to and use of oral health care services by persons living with HIV (PLWH),
- Barriers to oral health care services experienced by PLWH, and
- Identify and study elements of successful oral health care programs for PLWH.

# BACKGROUND

Studies of access to dental services by PLWH indicate that dental care is a common unmet need but that use of dental care is low. Surveys have identified socio-economic barriers, including lack of insurance or other means to pay for dental care, and personal barriers, such as fear of dentists, as factors contributing to lack of access and utilization of oral health services. Availability of dentists willing to treat PLWH is also cited as a major barrier to care.

Studies of oral health among the various income groups in the US document that low-income people generally suffer from dental disease at a higher rate than people of higher incomes do. Medicaid, the source of health care financing for those in poverty in this country, is a mechanism for helping to close the gap. However, studies have found that while Medicaid programs cover pediatric preventive and therapeutic dental services, utilization rates are very low. At the same time, only emergency dental care is covered for adult beneficiaries by most State Medicaid programs. The low utilization rates for dental care by children and no or limited coverage for those services for adults has resulted in several generations of Medicaid beneficiaries with no or minimal dental care.

Researchers have examined barriers to Medicaid participation by dentists. Reports have documented that dentists are unwilling to participate in the Medicaid program because of administrative complexities and extremely low reimbursement rates. Many State Medicaid programs are taking steps to remove barriers for participation by oral health providers. The federal Medicaid program is offering incentives to states to expand dental and other Medicaid benefits to more children, as well as increased oversight of State Medicaid programs to assure that dental services mandated by law are being provided.

RWCA programs support dental services to PLWH in varying ways. Oral health services are funded with Title I, II, III and IV funding. Additionally, the DRP retrospectively compensates dental schools and post-doctoral dental programs for providing oral health treatment to PLWH. However, the relative amount of RWCA funds allocated to dental care by these RWCA programs is low, particularly in light of the high level of unmet demand for care and the importance of good oral health in sustaining high quality of life and supporting HIV treatment. RWCA dental providers reported structural barriers to development and funding of dental programs.

Although successful approaches are being taken by RWCA providers to provide HIV oral health care, these efforts are not well documented. There is a dearth of articles that describe successful HIV oral health projects and the elements that contribute to their success.

## **METHODS**

The project team included staff of Positive Outcomes, Inc. (POI) including Dr. Julia Hidalgo, Ms. Valerie Grosman, and Ms. Jennifer Germano. Ms. Helen Schietinger, an independent consultant, served as Project Director. Dr. Stephen Abel of the New York State AIDS Institute, served as the project's Principal HIV Oral Health Consultant. Ms. Celia Hayes of the HAB Office of Science and Epidemiology, who served as Project Officer. Dr. Barry Waterman, of the HAB Program Development Branch in the Division of Community Based Programs served as a technical advisor to the project. Ms. Kathy Treat of the HAB Division of Community-Based Programs, Primary Care Services Branch served as a liaison with staff and grantees of the Title III Program.

A Project Advisory Work Group guided the project. Participants in the Advisory Work Group included nationally recognized experts in HIV oral health care: Dr. Victor Badner of the Montefiore of the Dental Center at Jacobi Hospital in the Bronx, New York; Dr. Valli Meeks of the University of Maryland Baltimore School of Dentistry; and Dr. Mark Nichols of Bering Omega Community Services in Houston Texas. The Work Group advised the project staff in the design of the project and site visit instruments, recommended possible programs for site visits, and participated as site visit team members. Dr. Ivan Lugo of the Temple University School of Dentistry in Philadelphia and Dr. Jackie Plemons of the Texas and Oklahoma AIDS Education and Training Center (AETC) and Baylor College of Dentistry also participated in site sites.

A literature review was conducted to summarize scientific findings reported about periodontal disease in PLWH, issues regarding access to and use of health services by PLWH, including those PLWH enrolled in Medicaid, funding by the RWCA for dental care, and innovative programs that support HIV oral health services.

Based on the literature review, and in consultation with HAB staff and the Work Group, a set of criteria were established for identifying successful HIV oral health programs. These criteria are shown in Table 1.

<b>Table 1. Criteria for Identifying Successful HIV Oral Health Programs</b>
<b>Successful HIV oral health programs to be visited:</b>
<ul style="list-style-type: none"> <li>▪ Serve PLWH</li> <li>▪ Receive RWCA funds</li> </ul>
<b>Successful HIV oral health programs to be visited:</b>
<ul style="list-style-type: none"> <li>▪ Serve PLWH</li> <li>▪ Receive RWCA funds</li> <li>▪ Provide a full range of oral health services (prophylaxis and treatment), either onsite or through referral</li> <li>▪ Provide HIV oral health education to clients and staff</li> <li>▪ Link with HIV clinics and AIDS service organizations (ASOs) to assure clients with HIV have access to a continuum of comprehensive clinical and psychosocial support services</li> <li>▪ Have diverse sources of financing that ensure fiscal solvency</li> <li>▪ Have characteristics that can be replicated by other oral health providers or HIV providers</li> </ul>
<b>Sites might be selected based on the following characteristics:</b>
<ul style="list-style-type: none"> <li>▪ All regions of the US</li> <li>▪ Organizational structures including free-standing CHC, university-based dental clinic, community-based comprehensive HIV clinics</li> <li>▪ Urban and rural settings</li> <li>▪ Diverse client demographic characteristics</li> <li>▪ Approaches to organizing oral health services</li> <li>▪ Strategies for community outreach</li> <li>▪ Sources of financial support</li> </ul>

Several methods were used to identify HIV oral health programs that had the characteristics identified in Table 1: results of the literature review and referrals from the Work Group, Dr. Abel, and Title III project officers. Additionally, the Title III grantee budgets were reviewed to

identify grantees with a relatively high proportion of their award that was allocated to dental care. Sites that were identified through this process were initially contacted by telephone to gain some preliminary information and determine their interest in hosting a site visit. Table 2 in the Appendix lists the HIV oral health and dental insurance programs that were contacted.

A structured onsite assessment guide was constructed for use by the project site visit teams. The guide ensured the consistent gathering of information by the site visit team. A copy of the guide is available from the POI website: [www.positiveoutcomes.net](http://www.positiveoutcomes.net). The site visit team included an HIV oral health expert and an evaluation expert. Site visit notes were synthesized into this report.

# **A REVIEW OF THE LITERATURE**

Several methods were used to conduct a review of the literature. A number of Internet search engines were queried to identify published articles and conference abstracts. These search engines include Grateful Med and AIDSLine maintained by the National Library of Medicine and the Combined Health Information Database (CHID) maintained by the National Institute of Dental and Craniofacial Research. The searches focused on key words related to HIV/AIDS and oral health care. Internet websites maintained by federal agencies also were queried for related reports. These agencies include HAB, BPHC, the HRSA Maternal and Child Health Bureau (MCHB), and the Centers for Medicare & Medicaid Services (CMS) (formerly Health Care Financing Administration). HAB staff providing oversight of the POI project was also asked to identify unpublished agency reports, conference abstracts, or other related materials. Programmatic expenditures for dental care were abstracted from the HAB Internet website.

## **A. PERIODONTAL DISEASE IN HIV**

Early recognition and management of oral conditions associated with HIV infection are important in sustaining the health and quality of life of PLWH. Access to oral care is also important in aiding proper nutrition for PLWH. Oral care early in the course of HIV infection can help to prevent or slow wasting. Moreover, with the advent of combination ARVs, the ability to sustain proper nutrition and to ingest oral medication is critical in achieving the optimal benefit of ARV and adherence to ARV regimens.

Oral lesions are important markers in the clinical spectrum of HIV infection.<sup>1</sup> Aphthous ulceration and candidiasis, for example, indicate acute seroconversion illness. Conditions such as candidiasis, hairy leukoplakia, Kaposi's sarcoma, and necrotizing and ulcerative gingivitis suggest HIV infection in undiagnosed individuals. For those individuals in advancing stages of HIV infection, candidiasis and hairy leukoplakia indicate clinical disease progression and predict development of AIDS. Immune suppression in PLWH is also associated with candidiasis, necrotizing periodontal disease, long-standing herpes infection, and major aphthous ulcers. A review in 1996 of the literature identified 16 oral conditions that can occur in PLWH.<sup>2</sup> All of these may be seen or palpated during physical examination, and all produce subjective symptoms that are noticeable to the individual. Of the 16 conditions, seven can be suppressed by systemic drug therapies. All will recur after cessation of treatment.

Due to the association between HIV infection and oral lesions, staging systems for HIV disease progression such as that used by the CDC include oral conditions. Oral lesions are also commonly used as an entry criteria or endpoints in clinical trials of antiretroviral (ARV) drugs.

## **B. ORAL MANIFESTATIONS OF HIV DISEASE IN ADULTS**

There is a paucity of medical and dental literature describing the prevalence of periodontal disease in PLWH, but descriptive studies suggest that periodontal disease is common. There has been specific interest in the medical literature, however, in the occurrence of oral opportunistic infections indicative of an AIDS diagnosis or known to be typical of HIV disease. Therefore, what is known about opportunistic infections is more comprehensive than what is known about the general periodontal health of PLWH.

When the frequency of diseases indicative of AIDS were studied by staff of the Centers for Disease Control and Prevention (CDC) for all 30,632 people reported to have AIDS through 1987, oral/pharyngeal candidiasis was reported in 45% of cases.<sup>3</sup> *Pneumocystis carinii* pneumonia (PCP) was the only disease with a higher frequency (64%), and the next most frequent disease reported. In contrast, Kaposi sarcoma was only reported in 21% of cases.

It is unclear how accurate AIDS case surveillance data are in estimating the prevalence of oral and other manifestations of AIDS. CDC researchers point out that diseases that are not included in the AIDS cases definition are likely to be significantly under-reported since there is no legal requirement for them to be reported under State communicable disease statutes. In assessing under-reporting of oral manifestation of HIV, CDC researchers concluded that in States in which a check-off morbidity card or other form is used, oral candidiasis was reported in 45% of AIDS patients.<sup>2</sup> When physicians had to document the condition by writing it down long-hand on the surveillance form, the rate dropped to 7%.

A number of oral manifestations that are not AIDS-defining conditions are commonly diagnosed among PLWH. A cross-sectional descriptive study of 51 adult PLWH in the United Kingdom reported that 77% had one or more oral manifestations of HIV infection, including hairy leukoplakia (45%), erythematous candidiasis (22%), HIV necrotizing ulcerative gingivitis or periodontitis (16%), pseudomembranous candidiasis (14%), angular cheilitis (6%), Kaposi sarcoma (4%), and oral ulceration (4%).<sup>4</sup> Intra-oral herpes, papilloma, and non-Hodgkin's lymphoma were not identified in this sample. Dental plaque levels were low, but all individuals studied had some evidence of bleeding gums.

The Robert Wood Johnson (RWJ) Foundation funded a survey of 857 people with symptomatic HIV infection or AIDS receiving services at AIDS clinics in nine US cities.<sup>5</sup> Almost one-half (47%) reported they had an oral OI. Whites and the more severely ill patients were significantly more likely to report an infection than others surveyed were.

The relationship between the oral manifestations of HIV and the disease process has interested clinicians because not only are oral lesions a significant part of the HIV-related illness, but certain types of oral lesions play a specific part in the diagnosis and staging of HIV infection.<sup>6</sup> In surveying the literature for evidence of the utility of selected oral lesions (oral candidiasis, hairy leukoplakia, necrotizing ulcerative periodontitis, oral ulcers, and parotid swelling) as markers of HIV seroconversion, the Agency for Health Research and Quality (AHRQ) only identified one relevant study.<sup>7,8</sup> In this study, oral candidiasis was found in the majority of patients who seroconverted within three months of transfusion with HIV-infected blood, suggesting a high positive predictive value. Only a small proportion of patients who seroconverted had oral candidiasis, however, indicating that candidiasis would have a low sensitivity. The review concluded that the presence of oral conditions is of little benefit as indicators of HIV progression in a clinical setting.

In the same literature review, AHRQ sought to identify studies that had determined whether PLWH are at increased risk for complications (e.g., local infection, systemic infection, increased bleeding, delayed healing, or alveolitis) when undergoing intra-oral dental procedures (e.g., extractions, orthognathic surgery, periodontal therapy, endodontics, prophylaxis, scaling and root planning, and dental implants).<sup>7</sup> The review found few studies reporting on the risks of oral procedures among PLWH, and concluded that there is little evidence of unusual rates or severity of complications for these procedures among PLWH. A study of endodontic procedures, including root canal treatment, did not detect a clinically significant difference in the complication rates of HIV-positive and HIV-negative patients. Three studies assessing complications resulting from dental extractions found no statistically significant difference between HIV-positive and HIV-negative groups. They noted, however, that the HIV-positive group tended to have more postoperative complications. A fourth study of dental extractions found that the HIV-positive group had a significantly higher complication rate. Following adjustment for risk factors using a multivariate statistical model, however, the difference was no longer significant. Post-extraction complications included persistent bleeding, persistent pain, localized alveolitis, local wound infection, and delayed wound healing. Among the studies

reviewed by AHRQ, the postoperative complications that were experienced were minor and could be treated on an outpatient basis.

While the AHRQ has concluded that oral lesions are of little clinical use as prognostic or staging tools in HIV, the American Academy of Periodontology (AAP) recognizes that dental practitioners may be the first clinicians to identify lesions suggestive of HIV. The AAP concluded that dental practitioners must be able to treat the periodontal problems of the person living with HIV disease.<sup>9</sup> In a 1994 AAP report, “Periodontal Considerations in the HIV-Positive Patient,” a thorough discussion of the disease manifestations and treatment modalities is presented. Specific findings include the following:

- Enlarged perioral lymph nodes that may be associated with generalized persistent lymphadenopathy may be first detected by the dental practitioner during routine examination.
- People with asymptomatic HIV infection or HIV-associated persistent generalized lymphadenopathy may demonstrate an increased prevalence of several intraoral lesions including hyperplastic and/or pseudomembranous candidiasis, herpetic stomatitis, exfoliative cheilitis, depapillated tongue, and acute necrotizing ulcerative gingivitis (ANUG).
- Persons with more advanced HIV disease may present with unusual oral lesions such as hairy leukoplakia, ANUG, Kaposi sarcoma, a form of gingivitis characterized by intense marginal erythema (lineal gingival erythema, or LGE), and a form of periodontitis characterized by rapid gingival and bone necrosis (necrotizing ulcerative periodontitis, or NUP).

According to the AAP report, the data are mixed as to whether there is a correlation between the extent of periodontal disease and extent of HIV disease. The report points out that the prevalence and severity of common forms of periodontal diseases may vary among populations of PLWH due to other factors such as oral hygiene practitioners, smoking habits, and medications. The report focuses on two lesions, LGE and NUP. LGE has a reported range of 0 to 50% in PLWH. It is characterized by a 2 to 3 *mm* marginal band of intense gingival erythema with more apical focal and/or diffuse areas of erythema that may extend beyond the mucogingival line. Unfortunately, the condition does not respond to conventional scaling, root planning and plaque control. The prevalence of NUP among PLWH has been reported as 0 to 5%. NUP is characterized by marginal necrosis of the gingival and rapid destruction of the underlying alveolar bone, and is usually accompanied by severe pain and spontaneous gingival bleeding. There have been case reports of NUP involving extensive destruction as well as necrotic involvement of the adjacent mandible and maxilla. Following acute phases of HIV

periodontitis, the periodontium around remaining teeth presents with gingival blunting and marked reverse architecture.

The AAP report describes management of LGE and NUP as involving gross scaling to remove visible plaque and calculus deposits and debridement of necrotic tissue, topical antimicrobial therapy, cautious use of antibiotics due to the increased risk of overgrowth of *Candida albicans* and other microflora associated with HIV infection, and use of a concurrent antifungal agent to prevent overgrowth. Follow up visits are recommended to remove thoroughly plaque, calculus, and other deposits, and to provide plaque control instruction. Home use of an antimicrobial mouth rinse such as chlorhexidine has been effective in reducing acute symptoms of LGE and NUP as well as in preventing recurrence of lesions.

The New York State Department of Health AIDS Institute has recently published *Criteria for the Medical Care of Adults with HIV Infection*, which contains a section on oral health complications of HIV.<sup>10</sup> These clinical guidelines for oral care can be accessed from the NYSDOHAI web site:

[http://www.hivguidelines.org/public\\_html/CENTER/clinical-guidelines/adult\\_hiv\\_guidelines/supplemental\\_pages/oral\\_health\\_adults/adults\\_oral\\_health.htm](http://www.hivguidelines.org/public_html/CENTER/clinical-guidelines/adult_hiv_guidelines/supplemental_pages/oral_health_adults/adults_oral_health.htm).

### **C. PERIODONTAL DISEASE IN CHILDREN WITH HIV**

As with adults, there is a dearth of information in the published literature about the periodontal disease in children living with HIV. In one small study of periodontal disease in children with HIV, researchers followed nearly 100 HIV-infected children under 11 years of age for up to 30 months.<sup>11</sup> They concluded that primary dentition caries status (cavities in the baby teeth) in HIV-infected children is considerably greater than that for the US pediatric population. They also concluded that caries free status in primary dentition is less frequent in this population than in the US pediatric population. In their sample, caries in the primary dentition was increased substantially for those in the low CDC CD4 percentage categories and CDC moderate to severe immune suppression categories.

A longitudinal study compared 68 HIV-infected children to 53 HIV negative household peers (ranging from two to 15 years at baseline).<sup>12</sup> The periodontal findings for the medically well-controlled HIV-infected children were similar to those for their household peers, and to the general pediatric population. The only exception was that one-fourth of the HIV-infected group exhibited linear gingival erythema (LGE), or redness of the gums, both at baseline and at year

two. Although the number of children with LGE did not increase, there was an increase in the severity at year 2. Plaque assessment in HIV-infected children showed a seven-fold increase over controls for the period. However, there were no significant differences between the two groups in changes over the two years for bleeding on probing, gingival index, or pocket depths. There was virtually no recession or pathologic mobility (tooth looseness) in either group.

#### **D. ACCESSIBILITY AND USE OF DENTAL CARE**

##### **o Access to Dental Care Among Adults With HIV Infection**

Despite the importance of access to quality oral care, large numbers of PLWH have unmet need for dental care. Several articles have used data from the HIV Cost and Services Utilization Study (HCSUS) to study dental access and utilization. Coulter and colleagues estimated that only 42% of respondents had seen a dental health professional in the preceding six months.<sup>13</sup> African-Americans, individuals whose exposure to HIV was caused by hemophilia or blood transfusions, persons with less education, and employed individuals were less likely to use dental care than their counterparts were. An estimated 19% of HIV-infected medical patients had perceived unmet need for dental care in the last six months. Marcus and his colleagues reported that individuals most likely to have unmet dental needs included Medicaid beneficiaries in states without dental benefits, individuals with no dental insurance, the very poor (with incomes under \$5,000), and individuals with less than a high school education.<sup>14</sup> Stage of HIV infection was not a significant predictor of perceived unmet need for dental care.

HCSUS findings also have underscored the important link between access to dental care and use of those services.<sup>2</sup> About two-thirds (65%) of respondents with a usual source of dental care had used that service in the preceding six months. Use of dental care was reported to be greatest among patients obtaining dental care from an AIDS clinic (74%) and lowest among individuals with no usual source of dental care (12%). In a more recent article, HCSUS data were used to study the relationship between use of dental and medical care.<sup>15</sup> Heslin and his colleagues found that oral infections, mouth ulcers, and other severe dental conditions associated with HIV infection are more than twice as likely to go untreated as other HIV-related health problems. Patients were categorized as having unmet dental and medical needs if they reported needing but not receiving these services in the previous six months. Uninsured PLWH are reported to be three times more likely to have untreated dental and medical needs than those with private insurance. Medicaid enrollees report significantly more unmet dental need compared with

privately insured patients. Based on the HCSUS national probability sample, an estimated 58,000 of the approximately 231,000 people in treatment for HIV disease in 1996 had either unmet dental or medical needs or both. The investigators estimated that 14% of HIV patients as a whole had unmet dental needs in the six months prior to being interviewed, about 6% had unmet medical needs, and 5% had both unmet dental and medical needs. These findings were compared to earlier studies of the general population which found that 9% had unmet dental needs, about 6% had unmet medical needs, and 3% had both unmet dental and medical needs. The study did not examine why needs went unmet or identify specific needs that required treatment.

An earlier longitudinal study, the AIDS Care and Services Utilization Study (ACSUS), surveyed a large heterogeneous sample of people with AIDS from several communities.<sup>16</sup> A total of 1,851 respondents from 26 medical care providers in ten US cities were interviewed. At least one unmet need was reported by 20% of the sample at baseline. Dental services were the most commonly reported unmet need, with 9% of respondents reporting unmet dental care needs. About one-half (51%) of the respondents reported one or more visits to a dentist, oral surgeon, or other professional dental care provider at some point during the 18-month study period. Dental service use was significantly more likely among more socio-economically advantaged groups: whites, homosexual or bisexual men, those privately insured, those employed, and those with relatively high education and income.<sup>17</sup>

In subsequent interviews 12 months later, 1,424 ACSUS respondents were asked if they had been treated for thrush, sores in the mouth, or other conditions.<sup>18</sup> Less than one-tenth of respondents (9%) reported that they had been treated for these oral conditions. After adjusting for CD4 cell count and other variables, African Americans and Hispanics had significantly lower odds of being treated. Respondents with more than a high school education, clinical trial participants, and those receiving counseling were more likely to be treated. The educational and racial/ethnic differences remained after controlling for socioeconomic variables such as monthly income and insurance status and for illness-related factors such as CD4 cell count. The authors concluded that the level of care received by PLWH for oral lesions is very low.

In a 1994 multi-state survey of adults infected with HIV, there were disparities and perceived barriers to seeking and receiving dental care. African Americans, Hispanics, people without a high school education, and those without dental insurance were less likely to receive care, even after accounting for symptoms.<sup>19</sup> Less than one-fifth (14%) of respondents reported having

problems obtaining satisfactory care. Inability to afford treatment was the most common reason for difficulty in obtaining dental care.

A cross-sectional survey of 213 HIV-infected women identified personal barriers experienced by some PLWH.<sup>20</sup> About one-half (43%) had not seen a dentist and 53% of dentate women reported no dental cleaning in more than a year even though 67% had dental insurance coverage, mainly Medicaid. Barriers to care included fear of and discomfort with dentists, not getting around to making an appointment, and not knowing which dentist to visit.

- **Access to Dental Care Among Children With HIV Infection**

A study of 105 HIV-infected children and 67 HIV negative household members provided an oral evaluation every six months.<sup>21</sup> Subjects received \$25 to defray travel and related expenses. Children with unmet dental needs were referred to the university pediatric dental clinic for care. Unmet dental needs were primarily dental caries, oral pain, and gingivitis. Attendance records of self-referred dental clinic patients (not in the HIV study) were examined to compare compliance rates. Results showed that 85% of the children in study followed the research protocol by attending the 6-month evaluations. However, noncompliance with referred visits for dental care among children in families with a child who was HIV positive was relatively high and was two to three times higher than noncompliance rates among regular dental clinic patients. The authors conclude that, *“We must improve our understanding about dental services, utilization practices, and barriers to care among HIV-infected and minority populations. Further, the added burden of HIV in families to comply with dental treatment needs and ways of assisting families to obtain care requires investigation.”*

- **Barriers to Delivery of HIV Oral Health Care**

In recognition of the importance of good oral health care in sustaining quality of life and assuring optimizing HIV treatment, agencies receiving RWCA funds directly provide or arrange for dental care. A recent national study commissioned by HAB found that about 20% of direct service agencies receiving RWCA funds provide oral health services.<sup>22</sup> In this study conducted by POI, we found that oral health services were primarily delivered in hospital-based HIV clinics, CHCs, local health departments, or schools of dentistry. Among agencies receiving Title III funds, 52% report that they provide oral health services directly or through contract or co-located services. There was no statistically significant relationship between whether a Title III

agency provided oral health services and their regional location, type of agency setting, or if they were a minority provider.

Barriers to organizing and financing HIV oral care were reported by agencies and oral care professionals. Structural barriers include inadequate space in HIV clinical settings and a low priority placed on oral care among agency policymakers. Dental providers also identified additional barriers. RWCA funds were commonly characterized by agencies providing dental services as being hard or very difficult to obtain. Moreover, those programs report that it is often difficult to gain representation on resource allocation decision making bodies, such as Title I planning councils. They reported that dental services commonly receive a low priority in priority setting for RWCA funds. In early analyses of responses from agencies receiving RWCA funds through the Dental Reimbursement Program, respondents report having to make substantial financial outlays to gather and report required data to HAB to document their eligibility for funds. Some agencies report that the amount received in reimbursement is far exceeded by the costs of meeting administrative and reporting requirements.

- **Financing Dental Care for PLWH**

As described in several studies, the availability and extent of third party dental insurance and government funding for dental care can significantly reduce barriers to access to dental care for PLWH. Additionally, the extent of funding for HIV dental care has been instrumental in supporting innovative oral health projects.

- **Medicaid**

Medicaid is the largest single payer of direct medical services for PLWH. The Centers for Medicare & Medicaid Services (CMS), formerly Health Care Financing Administration (HCFA), estimates that over 50% of adults and up to 90% of children with HIV are covered by Medicaid.<sup>23</sup> CMMS estimates that 116,000 PLWH will be served by Medicaid nationwide in Federal Fiscal Year (FFY) 2001. Combined Federal and State Medicaid expenditures for serving this population are estimated to be \$4.3 billion in FY 2001. Therefore, the dental services financed by Medicaid are an important component of care that needs to be understood.

States operate their Medicaid programs within broad federal requirements. They can elect to cover a range of optional populations and services, thereby creating programs that differ substantially from state to state. Dental care is an optional service for adults under Medicaid. In the 50 states and the District of Columbia, only 15 states opt to provide full dental coverage for

preventive, diagnostic, restorative, and more complex treatment. Another 18 states provide only partial dental coverage and 18 states provide no coverage at all, although some of these states do provide emergency services. Even in the states with full dental coverage, the services may only be offered to a certain segment of the eligible Medicaid beneficiaries. It should be noted that under Medicaid law, coverage for dentures for adults is a separate optional service. As of 1996, 34 State Medicaid programs covered dentures.<sup>24</sup>

**Table 2. Level of Dental Coverage for Adult Medicaid Beneficiaries, January 2000**

State	Full	Partial <sup>a</sup>	None <sup>b</sup>	State	Full	Partial <sup>a</sup>	None <sup>b</sup>
Alabama			●	Montana		●	
Alaska			●	Nebraska		●	
Arizona		●		Nevada			●
Arkansas			●	New Hampshire			●
California	●			New Jersey	●		
Colorado		●		New Mexico	●		
Connecticut	●			New York	●		
Delaware			●	North Carolina		●	
District of Columbia			●	North Dakota	●		
Florida		●		Ohio		●	
Georgia			●	Oklahoma			●
Hawaii			●	Oregon		●	
Idaho		●		Pennsylvania	●		
Illinois		●		Rhode Island		●	
Indiana	●			South Carolina			●
Iowa	●			South Dakota		●	
Kansas			●	Tennessee			●
Kentucky		●		Texas			●
Louisiana		●		Utah		●	
Maine	●			Vermont		●	
Maryland			●	Virginia		●	
Massachusetts	●			Washington	●		
Michigan	●			West Virginia			●
Minnesota	●			Wisconsin	●		
Mississippi			●	Wyoming			●
Missouri		●					

<sup>a</sup> States do not cover particular services (preventive, diagnostic, restorative, or more complex), or they impose other limitations on coverage, such as a \$475 annual ceiling on expenditures.

<sup>b</sup> None or emergency services only.

Adapted From: Government Accounting Office. Oral Health: Dental Disease is a Chronic Problem Among Low-Income Populations. April 2000. GAO-HEHS-00-72.

Dental care is a mandated service for children under Medicaid. The Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit enacted by Congress in 1967 requires that States provide comprehensive medical and dental services to all enrolled Medicaid-eligible children under the age of 21 even if the services are not normally covered by the State's

Medicaid program. Under EPSDT, these services include comprehensive, preventive, restorative, and emergency dental services to be furnished according to State-defined periodicity schedules.

States must make Medicaid coverage available to infants and to children up to six years of age living in families with incomes under 133% and to children from six to fifteen years of age living in families with incomes under 100%. In 1997, Congress created the State Children's Health Insurance Program (SCHIP) as Title XXI of the Social Security Act. With SCHIP, in return for an enhanced federal match, States can expand coverage to low-income children in families earning up to 200% of the federal poverty level.

SCHIP provides States with the opportunity to expand coverage through the expansion of existing Medicaid plans, through the adoption of a non-Medicaid plan or some combination of both. States choosing to expand existing Medicaid plans must provide standard Medicaid dental benefits for children.

#### **E. Dental Health Indicators Among Low-Income People**

Study of key health indicators demonstrates that low-income people such as Medicaid beneficiaries suffer from dental disease at a higher rate than people of higher incomes. Among adults ages 19 to 64 with family incomes less than \$10,000, one out of two had at least one untreated decayed tooth, compared to only one out of six adults with family incomes greater than \$35,000. Adults with family incomes less than \$15,000 were more than two and one-half times as likely as those with family incomes \$35,000 or greater to have lost six or more teeth. One in three children aged two to five with family incomes less than \$10,000 had at least one untreated decayed tooth, compared with only one in ten children with family incomes \$35,000 or greater.

#### **F. Utilization of Dental Services Funded By Medicaid**

In 1996, among adults enrolled in Medicaid, only 29% visited a dentist in the preceding year, which was less than one-half the rate of dental care among higher-income adults. In the same year, although 22.9 million children enrolled in Medicaid were eligible for EPSDT services, only 18% received any required preventive dental screening or services. The Government Accounting Office (GAO) conducted a review of dental services funded by Medicaid and concluded that low-income populations in general, and specifically those enrolled in Medicaid, are not receiving dental services equivalent to the services received by higher income populations.<sup>25</sup> These reports indicate that Medicaid has a significant opportunity to improve the quality and utilization rates of preventive dental care.

In response to the determination that the utilization rates of dental services among Medicaid and SCHIP beneficiaries has remained low, the GAO conducted a survey of Medicaid and SCHIP programs to identify the barriers to utilization.<sup>26</sup> In addition, GAO interviewed four federal programs whose role is to increase access to dental services for specific vulnerable populations. They found that the major factor contributing to low use of dental services among low-income persons who have coverage for dental services is finding dentists to treat them. While some low-income people live in areas where dental providers are generally in short supply, many others live in areas with readily available dental providers for the general population. Dentists' reasons for not treating more Medicaid patients include low payment rates, administrative requirements, and patient issues such as frequently missed appointments.

Systemic factors related to Medicaid compensation and provider management are likely to contribute to inadequate availability of dentists willing to treat Medicaid beneficiaries. When the GAO compared Medicaid dental payments to average dentist fees, they found that only thirteen State Medicaid programs' payments exceeded two-thirds of the average regional fees dentists charged for most of the 15 procedures examined.<sup>23</sup> The GAO identified impediments to provider participation including burdensome Medicaid administrative requirements such as unique Medicaid claim forms and codes, difficulties with claims handling, preauthorization requirements, slow payments, arbitrary denials of submitted claims, and complicated rules and eligibility verification processes for patients and providers. They also reported that Medicaid's prohibition against charging for missed appointments to cover operating costs was a problem. The effect of missed appointments by Medicaid and other low-income patients appears to be less of a problem at public health clinics and CHCs, where officials report that walk-in patients and emergency cases generally fill any open appointment times. Moreover, structural issues that affect use of dental care, such as lack of availability of dentists and the low priority that individuals assign to preventive dental care, are often more pronounced for low-income populations.

Although many states have taken action to address these concerns, use of dental services among Medicaid beneficiaries remains low.<sup>23</sup> While forty states recently raised their Medicaid dental rates, utilization rates only marginally increased. Higher rates relative to average community dental fees resulted in higher use, but only to a limited extent. Twenty states introduced managed care to provide some dental services, with mixed results. While states have not yet evaluated dental utilization under SCHIP programs, most programs are modeled after

Medicaid programs and similar utilization issues are expected. The impression of some officials in states with SCHIP dental programs is that there are fewer access problems than Medicaid programs due to the use of commercial insurance plans that pay higher rates.

### **G. Federal Efforts to Increase Medicaid Beneficiaries' Access to Dental Services**

The CMS has expressed their concern about the lack of accessible dental care for Medicaid beneficiaries and identified the need for increased oversight of the quality of services provided. HCFA will conduct assessments, including site visits, to states where the proportion of Medicaid-enrolled children who made a dental visit in the preceding year is 30% or less.<sup>27</sup> A less intense review will be conducted if 30% to 50% of enrolled children made a dental visit. The areas of compliance to be examined include outreach and administrative case management for children, adequacy of dental payments, adoption of strategies to increase provider participation, and improved claims reporting and processing systems.

### **H. State Efforts to Increase Medicaid Beneficiaries' Access to Dental Services**

A survey of State Medicaid dental program managers identified a variety of approaches to increasing access to dental services for Medicaid beneficiaries.<sup>28</sup>

- *Increasing rates.* In South Carolina, the legislature increased rates but required the dental association to add providers to the Medicaid program. In Utah, 20% of State funds granted rate increases and pay bonuses to dentists who treat a certain number of beneficiaries.
- *Streamlining administrative procedures.* Several states have adopted the American Dental Association diagnosis and procedure codes. Maine adopted a common claims form for all dentists. Illinois established electronic and batch billing that ensures faster turnaround times and simplified review strategies. Indiana eliminated prior authorization for dental services.
- *Forming coalitions:* States have established advisory committees and partnerships with professional organizations and advocacy groups to promote dialogue and positive public relations for the State Medicaid Program.
- *Educating beneficiaries:* To address the negative reputation of Medicaid beneficiaries among dentists, education has been provided to beneficiaries about scheduling and keeping appointments, proper office behavior, and the importance of good dental care.
- *Increasing the capacity and efficiency of safety-net providers:* Colorado has used State funds to create a successful Medicaid-only clinic that provides dental care.

- *Increasing use of dental hygienists:* There may be opportunities to expand the role of dental hygienists through changes in practice laws. For example, a new Minnesota pilot program allows hygienists to practice without direct dentist supervision. The dental hygienists can do oral assessments and preventive work such as administering fluoride treatments and sealants. In Nevada, hygienists can practice without an onsite dentist.
- *Using physicians:* As part of EPSDT, physicians are required to conduct oral assessments on all patients. However, dentists express concern about the quality of this care. At the University of Kentucky, oral health is part of the curriculum for third-year medical students and pediatric residents.
- *Encouraging volunteer programs:* Some dentists prefer to donate their time to charity care rather than treat Medicaid beneficiaries in their practice. In Maine, dentists treat Medicaid beneficiaries but are not listed in the Medicaid resource guide. In Connecticut, some dentists see Medicaid beneficiaries but do not submit claims. The Montana Dental Association administers a volunteer program in which a staff person connects elderly and disabled clients to dentists, who can then control their level of participation and avoid billing processes.
- *Developing programs with dental schools:* Dental schools are often an important source of care for Medicaid beneficiaries. It is hoped that dentists-in-training will continue to treat Medicaid beneficiaries when they begin practicing.
- *Reducing overhead costs:* Approaches to lower costs could close the gap between Medicaid rates and costs, though it is unclear whether reduced costs will improve access. Measures to reduce costs have included loan forgiveness, lower fees for licensure, equipment registration, and OSHA training. Other potential measures have been suggested, such as state-sponsored group purchasing of equipment and supplies or employee health and other benefits.
- *Providing services directly:* In a unique approach, Utah's Medicaid program directly provides care to Medicaid beneficiaries through three dental clinics staffed and administered by the State Medicaid Program. The clinics, which serve only Medicaid clients, manage to cover their costs solely through Medicaid reimbursement.
- *Expanding coverage:* Expanding coverage could increase access for Medicaid beneficiaries. Adults receiving care might be more inclined to bring their children in for prevention and treatment. Reducing service limits and expanding coverage might help convince dentists that they can provide quality care to Medicaid beneficiaries. Indiana, for example, covers

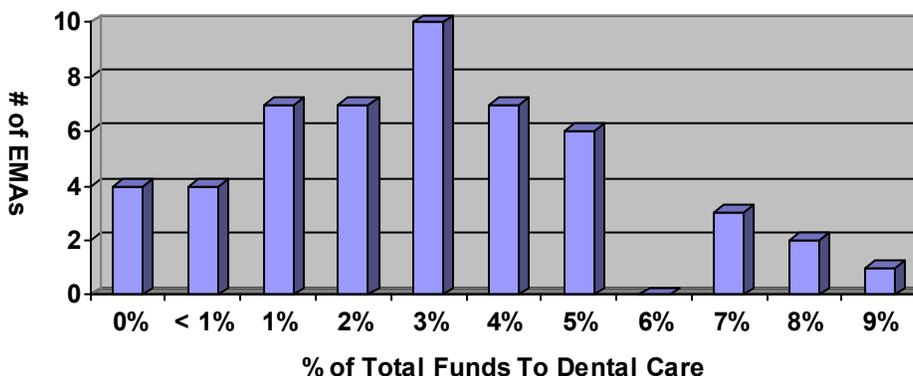
dentures in an effort to increase dentists' participation. Moreover, increasing prevention may decrease later costs for treatment or emergency procedures such as extractions.

## I. Ryan White CARE Act

Oral health services for PLWH are supported through all four titles, as well as Part F of the RWCA. Over \$16 million in Title I funds were allocated to dental care in FY 2000. Among Title I EMAs, funds allocated to dental care increased from 2.8% of total Title I funds in FY 1998 and 2.9% in FY 1999 and FY 2000, respectively.<sup>29</sup> In FY 2000, more Title I funds were allocated for ambulatory/outpatient medical care, medications, substance abuse treatment/counseling, food bank/home delivered meals/ nutritional supplements, and outreach and referral than dental care.

Figure 1 illustrates the percentage distribution of Title I funds allocated to dental care by Title I EMAs for FY 2000. Among EMAs, the percentage of Title I funds allocated to dental care ranged from 0% to 9%. Four EMAs did not allocate any Title I funds to dental care, while one EMA allocated 9% of their total funds.

**Figure 1. Percent of Title I Funds to Dental Care, By the Number of EMAs, FY 2000 (Anticipated)**



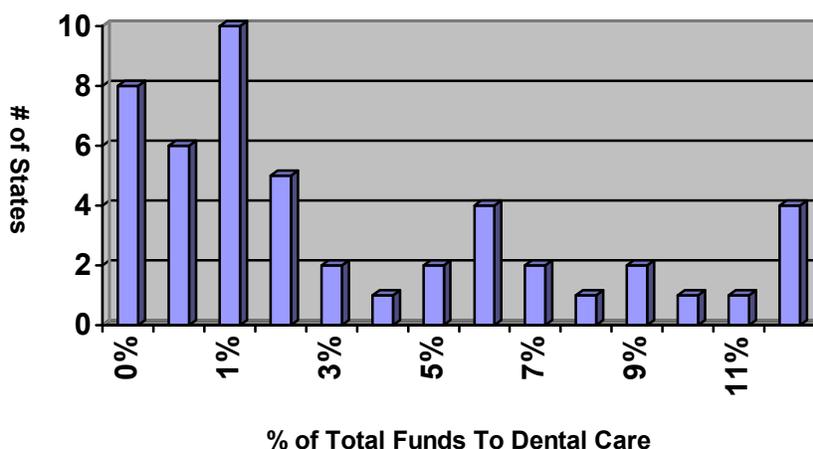
A number of factors may contribute to decisions regarding to allocate Title I funds to dental care. These factors may include demand for care, assessment of unmet need for dental care, the availability of dental providers in an EMA that may be funded to provide care supported by Title I, the extent of dental coverage by public and commercial insurers, and the amount of funds received in the EMA from the RWCA DRP.

In FY 2000, over \$5.4 million in Title II funds were allocated to dental care. Among State Title II programs, dental funds accounted for 0.7% of Title II in FY 1998. Beginning in FY 1999, supplemental Title II funds were earmarked specifically for ADAP services. After deducting

these earmarked ADAP funds from the Title II allocations, funds for dental care represented 2.0% of FY 1999 allocations and 2.2% of FY2000 allocations. In FY 2000, more Title II funds were allocated for ambulatory/outpatient medical care, medications, case management, mental health services, and food bank/home delivered meals/ nutritional supplements than dental care.

Figure 2 illustrates the percentage distribution of Title II for consortia and State direct services that were allocated to dental care by Title I EMAs in FY 2000. On average, States allocated 3.7% of their consortia and State direct services funds to dental care. The percentage of Title II funds allocated to dental care by individual states ranged from 0% to 27%. Eight states did not allocate any funds to dental care and an additional six states allocated less than 1%. In contrast, two State Title II programs allocated about 27% of their total funds to dental care.

**Figure 2. Percent of Title II Funds to Dental Care, By the Number of EMAs, FY 2000 (Anticipated)**



Over \$6 million in Title III funds in the most recent grant award cycle have been budgeted by grantees for oral health services.<sup>30</sup> About two-thirds (63%) of the 254 Title III grantees budgeted funds for oral health. Funds allocated for oral health care ranged substantially, from \$300 (0.18% of their total grant) to \$107,865 (27% of their total grant).

It is unclear how much has been awarded to dental care by the Title IV program. A study of Title IV expenditures is now underway which will provide information regarding funding of dental and other services.

The HIV/AIDS DRP under Part F of the RWCA is intended to assist accredited dental schools and post-doctoral education programs to cover their non-reimbursed costs of providing oral health care to PLWH. The objectives of the DRP are to:

- Assist in covering the rising non-reimbursed costs faced by dental education institutions that provide care to PLWH;
- Improve their access to oral health care; and
- Ensure that dental and dental hygiene trainees receive proper training in the management of oral health care for PLWH.<sup>31</sup>

The DRP is unique among RWCA programs in that it inseparably links health service delivery with the education and training of new generations of dental providers who are experienced in the management of the health care of PLWH.

The DRP is a retrospective payment program. Programs must apply to receive funds for non-reimbursed costs. Funds totaling \$41 million have been appropriated for the DRP since its initiation in FY 1997.<sup>27</sup> The DRP was initially funded at \$7.5 million in FY 1997. Funds increased to \$7.8 million in FY 1998 and 1999, respectively, \$8 million in FY 2000 and \$10 million in FY 2001. In 2001, over \$12.7 million in non-reimbursed costs was reported to DRP, with approximately 75% of those costs covered by the DRP. The DRP is funded at less than half of 1% of the entire RWCA budget. Over one-half (58%) of patients served by institutions participating in the DRP resided in New York, California, and Massachusetts. This disproportionate distribution of patients reflects the location of dental training programs in the US, the willingness of dental training programs to participate in the DRP, and the underlying distribution of PLWH in the US.

Eligibility for DRP funding was extended to dental hygiene programs in FY 2001 for the first time. Dental hygiene programs that begin collecting service data in FY 2001 will be able to apply for DRP funding in FY 2003.

Several dental training programs participating in the DRP have adopted innovative service delivery strategies such as:

- Use of innovative outreach and service-learning models (e.g., walk-in clinics for patients with acute dental needs, student and resident placement in satellite clinics or community organizations, multilingual staff, designated youth clinics, and extended service hours);
- Expanded services including language interpretation, transportation to appointments, nutritional counseling, and case management;
- Targeting specific populations including drug users, the homeless, physically challenged individuals, youth, and children;

- Offering direct enrollment in onsite clinical trials and new therapeutics;
- Incorporating sensitivity and cultural awareness training for their students and clinic staff.<sup>27</sup>

There are few descriptions in the published literature of innovative models of oral health care supported by the RWCA. Children's FACES (Family AIDS and Educational Services), a program in Ohio that receives Ryan White Title IV funds, was designated in 1997 as one of the "Models That Work" by the HRSA Bureau of Primary Health Care. One of the services that the comprehensive, family-centered program provides is dental care.<sup>32</sup>

The American Journal of Public Health featured the Columbia University School of Dental and Oral Surgery in a recent article.<sup>33</sup> The University developed a mobile program to bring dental health care services to three community-based organizations (CBOs) serving PLWH in Harlem, Washington Heights, and midtown Manhattan. The We Care Program consists of a mobile dental team that travels to the sites four days a week to provide prevention, early intervention, and linkage to comprehensive care. Personnel include the program director, primary care dentist, clinical coordinator, and dental assistant, as well as primary care postdoctoral trainees in general dentistry. They use portable equipment stationed at each site but sterilize instruments at the school. Currently the program is funded by Title I funds and the scope of services provided is limited to services not covered by Medicaid.

# PROJECT FINDINGS: ELEMENTS OF SUCCESS

## A. FACTORS RESULTING IN START-UP OF HIV ORAL HEALTH PROGRAMS

HIV oral health programs were established for a variety of reasons, with a significant unmet need for dental care for PLWH being a common theme. In some cases, the stimulus is the commitment of oral health providers who advocate for dental services because they have addressed the need in their own practices. In other cases, the stimulus is a formal needs assessment by a RWCA planning body that documents a significant unmet need for dental care. The program may be established when a group of dentists or other individuals raise funds or when a RWCA planning body makes funds available.

Several HIV oral health programs were launched by volunteer dental providers who created programs after providing care to PLWH within their own practices or in response to requests from local HIV clinics. Several examples were identified:

- The Bering Omega Community Services in Houston Texas was started by two dentists who had provided services to PLWH free of charge in the early 1980s. In 1987, they approached the United Methodist Church, which was a primarily gay congregation, to help start an HIV dental clinic. At that time, the Bering Omega Community Services was established as a non-profit agency that depended entirely on private donations and the support of local Methodist and Episcopal congregations.
- The HIV dental program of Catholic Healthcare West in Long Beach California was organized by a private practice dentist who had treated PLWH in his practice. He helped the facility recruit dental personnel and establish the clinic's operatories. He eventually was asked to direct the HIV dental program and went to work there full-time. The dental clinic at the Austin City Health and Human Services Department of Austin was initially staffed by volunteers and later operated by employed dental providers.
- A network of HIV dental clinics throughout suburban and rural Maryland was organized by a faculty member of the University of Maryland at Baltimore School of Dentistry. She and dental students staff the dental clinics at local health departments. Patients are seen during scheduled clinic hours several days per month. The goal of the network is to expand the availability of expert HIV care in local community settings, particularly in rural areas.

Some programs are a result of HIV planning bodies identifying and providing funding to meet an unmet need for HIV oral health services. Staff of several HIV oral health programs studied described long difficult processes of advocating within HIV planning bodies before funds were allocated for oral health services. Successful programs often have strong leaders who are active on university, community, or statewide committees or planning bodies. They campaigned to convince key decision makers and stakeholders that HIV dental care was needed. For example, the Massachusetts HIV Dental Program was initiated eleven years ago after multidisciplinary hearings were held at which dental care was ranked the third highest priority for PLWH.

Funds to start-up or expand HIV oral health services have been obtained from several sources: RWCA Titles I, II, or III, expanded Medicaid coverage for adults, enhanced Medicaid reimbursement for HIV-related care, or other grant funds. Programs have been able to obtain funding to build clinics, to remodel clinic space, or to purchase the necessary equipment to start clinics. Among Title III Early Intervention Services (EIS) Program grantees, Title III funds have been used to establish new dental programs in several states. Dental schools have also contributed to establish community-based practices, either within the scope of the DRP or as an extension of their existing clinical practice and/or residency programs. Examples of such programs were identified in Georgia, Minnesota, New York, and California.

## **B. ORGANIZATIONAL MODELS**

HIV oral health programs are designed to fit into the unique community settings of which they are a part. Numerous factors affect what organizational model is selected, resulting in programs with diverse organizational characteristics.

Several service models have been used, including provision of care in general dental settings or HIV-focused oral health program. In some programs, HIV dental services are integrated with HIV medical services and in others, HIV dental services are integrated with HIV social services.

The settings in which HIV oral health programs operate vary widely depending on such factors such as local resources, agency characteristics, and target populations. Programs are located in dental schools, hospital or hospital-based clinics, community-based ambulatory care clinics, publicly funded CHCs, freestanding dental clinics, solo or group dental practices, or city or county health departments. Several other unique models were identified:

- The AIDS Care Group in Chester Pennsylvania is based at a feeding program that serves indigent substance users.
- The Medical College of Georgia School of Dentistry in Augusta Georgia provides services at an HIV residence for homeless men.
- Chase Brexton Health Services in Baltimore Maryland provides onsite dental services at a health care for the homeless clinic.

While the staff members in some programs are limited to dental professionals and support staff, other programs have multidisciplinary care teams that collaborate to address the physical and psychosocial needs of their patients. In the Bellevue Hospital Pediatric Dental Clinic in New York City, for example, the oral health coordinator and a dental hygienist attend a weekly case conference with the multidisciplinary team at the Pediatric Infectious Disease Clinic. The dental providers at several other programs actively participate in weekly or monthly multidisciplinary team case conferences with medical staff.

Several of the HIV oral health programs studied established a nonhierarchical team approach in the initial design of their programs and have maintained this model. Dental providers, management, and administrative staff work together in a mutually respectful manner and work together to plan and manage the program.

The target populations of HIV oral health programs differ. Most programs serve adults, a small number of programs serve only children, and some programs serve all age groups. Among programs serving adults, outreach may be to all adults or to specific groups such as the homeless, youth, substance abusers, or a particular racial or ethnic group. Several programs, such as Chase Brexton Health Services, serve the uninfected children of PLWH in a family-centered environment.

Service areas of HIV oral health programs range from local neighborhoods or communities to entire regions. For example, the Spang Center for Oral Health in Chicago has satellite clinics at CHCs in areas of Chicago where concentrations of PLWH live, including an African American community, a Hispanic community, and a community in which gay men and homeless people live. Other programs are citywide, countywide, or cover entire states or regions. For example, the University of Alabama in Birmingham and the Medical College of Georgia School of Dentistry receives patient referrals from throughout the Southeast. Some of these programs

contract with individual dentists in private dental practices, while others provide transportation to bring patients to a centralized dental clinic.

### **C. PHYSICAL DESIGN AND ATMOSPHERE OF HIV ORAL HEALTH PROGRAMS**

The number of operatories in the HIV oral health programs studied range in number. The number of operatories is based primarily on the number of dental providers working in the clinic and the need for both dentists and dental hygienists to care for patients simultaneously to ensure optimal patient scheduling and efficiency. Additional equipment commonly in place include radiographic and sterilization equipment. The age of the equipment ranges substantially, with relatively new equipment commonly donated by community-based dental practices, schools of dentistry, or dental equipment manufacturers.

Several directors of HIV oral health programs report that they strive to create a professional atmosphere that emulates a private dental practice. An effort is made to make PLWH feel that they are not treated differently than other dental patients. Other directors report that their programs are designed to be an integrated component of an ASO.

### **D. STAFFING**

The staffing patterns of the HIV oral health programs studied vary depending on the type, complexity, and size of the program:

- In some programs in which dental care is integrated into a larger agency, the dentist is part-time and provides all oral health services. In that case, the sponsoring agency provides reception, clerical, billing, and case management staff.
- In formally organized HIV oral health programs, they commonly have one or more full or part-time dentists, and full or part-time periodontists, dental hygienists, dental assistants, receptionists, clerical and billing staff, outreach workers, and case managers.
- At several of the programs studied, dental school faculty to provide supervision, consultation, and teaching for dental students and residents who provide basic oral care, as well as services that are more specialized.
- For HIV oral health programs that contract with independent dentists to provide services in their private offices, the focus of the HIV oral health program staff may involve processing and referring patients to dentists through the provision of case management and clerical and accounting functions.

Staff at HIV oral health programs commonly includes one or more dentists, dental hygienist, dental assistant, office manager, billing clerk, and reception staff. Some programs also include dental students and post-graduate dental fellows who rotate through the program, a health educator, a case manager, and an outreach worker. Several programs, such as the Hill Health Center in Connecticut, have volunteer dental specialists that work several hours per week or month as determined by the needs of the patients of that program. The number of personnel employed by the program is determined by patient volume, the types of services provided, the number of operatories available, and the number of hours of operation.

Most of the HIV oral health programs studied identify staff recruitment and retention as a significant challenge. Contributing factors are low salaries, inadequate pools of qualified dental personnel, difficulty attracting personnel comfortable working with PLWH, and difficulty attracting individuals interested in community dentistry. Another factor described at the Spang Center for Oral Health is that they are very selective in hiring because they want personnel that are sensitive and caring in their “chair-side manner.” They avoid high turnover, with its disruptions, by carefully selecting staff that are appropriate for their clinic.

Several of the HIV oral health programs have been able to retain dental personnel since the opening of their programs, reflecting the dedication of the staff to their patients and institutions. Concerns were raised, however, at these agencies about their ability to replace those personnel if they resign. In addition to challenges regarding finding personnel willing to accept relative limited salary, benefits, and resources, the need to replace significant expertise and training was identified as daunting.

The HIV oral health programs studied apply a number of strategies to address recruitment and retention. Raising salaries is certainly the best strategy for addressing the problem of low salaries. A stand-alone community-based clinic, Howard Dental Clinic, raised private funds to supplement its RWCA funding and offers salaries competitive with the private sector for both dentists and hygienists. The clinic manager at Bering Omega Community Services justified more competitive salaries to her board of directors by conducting a local survey of agency salaries. Programs within larger agencies that have pre-existing salary scales sometimes offer generous benefit packages to offset their low salaries. Benefits not only include health insurance and vacation time, but also continuing education. Most programs offer paid time off to attend continuing education classes and conferences, as well as onsite training. At Bering Omega

Community Services, staff members participate in an annual cultural sensitivity training, as well as annual CPR and first aid. Licensed personnel receive paid days off to attend continuing education courses and are encouraged to observe the Dental Director when they have free time. Thus, they receive ongoing training as a benefit of working at the clinic.

Several difference strategies have been used by the HIV oral health programs studied to addressing the issue of a limited pool of qualified candidates. Most of the programs contacted report difficulty in hiring dental hygienists. Some programs resolve the problem by using dental students and dentists for teaching and dental hygiene. In some areas, programs have found that they can hire dentists for lower salaries than dental hygienists to provide the same services. Other creative strategies were identified:

- The director of the Spang Clinic approached the State dental director to develop a program to attract students studying at foreign dental schools. However, the program would have had to be approved by the Illinois legislature. Now she works with the Illinois Primary Care Association to attract graduates of foreign dental schools who are already in the US and seeking special status. Another very successful source of dentists for the Spang Clinic has been the National Health Service Corps (NHSC). Two positions are now filled through this program. They had to obtain Health Professional Shortage Area (HPSA) designation, which must be renewed every three years. Filing for HPSA status required two full days of research over the course of a week (collecting provider and demographics information).
- One of the objectives of providing onsite training opportunities for dental schools and other programs is that trainees will become comfortable working with PLWH and interested in employment at the site following graduation. Several programs have been able to recruit graduates that have rotated through their programs.

The programs that utilize dentists in private practice have to address a number of issues in recruiting dentists to participate. A key issue is to provide adequate and timely reimbursement based on a simple and convenient invoicing system:

- The programs in Michigan and Rhode Island use a fee schedule comparable to private dental insurance, which enables dentists to participate without financial penalty. They must follow the rules of the program, which include accepting reimbursement by the program as payment in full (they cannot bill the patient to supplement that amount). The reimbursement rate is a primary contributor to the success of the programs in recruiting dentists.

- The Massachusetts Title II HIV Dental Program actively recruits dentists to participate, using letters of endorsement from dental leadership, brochures about the program, and outreach to dentists at the annual dental meeting. Dentists are allowed to limit the number of patients they serve through the HIV Dental Program, so that they can limit the number of indigent and/or HIV-infected patients in their practice. To prevent against the loss of other patients from their practice, the dentists participating in the HIV Dental Program are assured that their names will not be put on a public list of participating providers. Instead, the program handles referral individually on a confidential basis.

Several HIV oral health programs successfully contract with dentists for onsite services:

- Alta Med Health Services in Los Angeles contracts with a local dentist who helped to design their HIV dental clinic.
- The St. John's Riverside Hospital has been able to overcome successfully recruitment problems by using Title III funds to contract with DentServe, a dental outsourcing company. DentServe provides contract employees to staff their 2 to 2.5 day per week clinic with a dentist, a dental hygienist, and a dental assistant. This arrangement has reduced overhead and resulted in the hiring of qualified personnel that reflect the race/ethnicity of the service population. Dental performance measures have been assessed and the personnel have been found to be skilled in their work. Patients report satisfaction with their care. The hospital management hopes to support the cost of the contractual dentist to receive training to be certified as an HIV dental expert in an effort to retain him and express their appreciation for his dedication to their patients.

## **E. LINKAGES WITH DENTAL TRAINING PROGRAMS**

Many of the HIV oral health programs studied work closely with dental training programs to enhance and expand care. Some programs are set up within schools, some establish linkages that provide onsite training opportunities for students of local professional schools, and some develop systems to refer their patients to off-site professional schools for specialty care.

Numerous HIV oral health programs are affiliated with teaching institutions, which provides supervised training opportunities for students and enables patients to receive low-cost services as well as access to the expertise of faculty who supervise the work of students. For example:

- The Greenville Technical College Dental Clinic collaborates with New Horizons Family Health Services to provide services by dental hygiene students and supervising faculty. New

Horizons pays the college to treat their patients. The students provide diagnostic services (intra/extra oral care, x-rays, and oral screenings), preventive care (education, dietary information), and therapeutic services (cleanings, scaling, oral rinses, polishing, etc). New Horizons then refers patients to local community dentists for ongoing dental care, paid for by New Horizons with Title II (which supports the cost of dentures) and III funding.

- The Jackson Memorial Hospital's Department of General Dentistry and Oral Surgery has a residency program that provides services to patients of the medical HIV clinic in the hospital's outpatient ambulatory care program. The faculty members have appointments in the University School of Medicine. The hospital pays the salaries of the residents, who are graduate dentists, and the dental hygienist. The head of the dental program is able to conduct an intake on the same day each new patient receives an intake in the medical HIV clinic, and then patients are scheduled into the dental clinic.
- Chase Brexton Health Services provides externships for University of Maryland School of Dentistry students.
- The Bering Omega Community Services in Houston has dental students and residents from the local dental school. Patients are scheduled with providers best suited for their needs at each visit. Faculty supervision is provided onsite for all students and residents. A weekly oral medicine clinic is conducted by the direct of the dental clinic and faculty from the Oral Pathology Department of the University of Texas Dental Branch.
- While the Spang Center for Oral Health has the technical capacity to provide specialty care, the wait for an appointment is long. Therefore, patients who need specialty care are given the option of going to the University of Illinois in Chicago Dental School for specialty services.

#### **F. NATURE OF ORAL HEALTH SERVICES PROVIDED**

The HIV oral health programs studied generally have a long-term, individualized care or treatment plan that they establish for each patient, including:

- A formal intake process,
- Review of general medical history, x-rays, CD4 and viral load test results, and other laboratory results prior to the initial examination,
- Examination,
- Development of an individualized care plan, and

- Ongoing comprehensive preventive care, restoration, cosmetic care, placement of prosthetics, oral surgery, and urgent and emergency care.

One of the primary strategies for addressing patients' generally poor oral health care is to provide a dental hygiene examination and cleaning before the care plan is developed. The initial cleaning is needed to properly assess the patient and finalize the care plan. Most of the HIV oral health programs studied provide dental home care supplies to their patients at their initial and follow up visits, including toothbrushes, toothpaste, floss, and educational materials.

The care plan is often considered long term, with the restorative and preventive care undertaken during the course of several visits. In cases in which patients have received inadequate dental care, the care plan could take over a year to accomplish. At the end of this period, a preventive plan may be put in place to monitor the oral health of the patient and provide preventive care. The patient is viewed by many of the programs studied to be an important partner in establishing and maintaining the care plan. At the Grady Memorial Hospital Ponce de Leon Clinic and Hill Health Center, for example, the care plan is developed in collaboration with the patient.

The HIV oral health programs studied tend to vary in their ability to provide oral surgery and prosthetics, often based on the skill of the dentists working in the programs. Program staff report increased demand for restorative and cosmetic dentistry as patients begin or return to work. Restoration and cosmetic care are perceived by some of the dentists interviewed to be an important step in helping patients to enhance their self-esteem or promote their recovery from chemical dependency or mental illness.

Most of the HIV oral health programs contacted identified dental education as an important aspect of their care. Dental education is often begun at the initial visit by dental hygiene personnel and conducted by dental staff at each visit. Staff interviewed report that it is common for patients to need instruction about proper home care, including brushing and flossing. Education is an important component of care for both adults and children. With infants and young children, the intervention is called *anticipatory guidance*.

Commonly, programs then schedule patients for a routine hygiene visit every three to four months, with more frequent visits scheduled based on the care plan, patient wishes, and availability of appointment slots. The frequency of dental visits commonly varies based on the

patient's needs, but may vary based on limits placed by insurance plans, the availability of dental appointments, and the patient's wishes.

Dental specialists play an important role in the implementation of the care plan. Most of the HIV oral health programs studied do not have onsite dental specialists. Instead, referral agreements have been established with community and university-based dental specialists. Programs use a variety of methods to identify specialists willing to work with PLWH. Directors of HIV oral health programs report that they commonly obtain specialty care because of their personal and professional relationships with dental specialists. One strategy to obtain the commitment of a few local specialists to provide services to a small number of patients per month. Referrals are then rotated so that no one specialist has a disproportionate number of referred patients. Some programs work with specialists who donate their services and some with specialists who charge insurers or patients for their services. HIV oral health programs report that specialists are willing to accept referrals over time if they are paid their usual fees on a timely basis and without administrative burden.

When patients are referred to specialty providers, programs commonly have strategies to ensure that patients follow up with those specialists. Two methods that are used are to request a written report from the specialist, or to document the verbal report by the patient on their next visit. Again, if there is a financial relationship between the specialist and the clinic, obtaining follow up information is easier.

## **G. FINANCING OF ORAL HEALTH SERVICES**

### **1. RWCA-Funded Systems to Directly Purchase Dental Services**

Lack of dental insurance among PLWH has been addressed in several ways by states, local jurisdictions, and providers:

- The Michigan Dental and Drug Assistance Program uses Title II funds to reimburse dentists directly for services to PLWH. Patients must apply to the statewide program and be determined to be HIV-infected, a Michigan resident, and below 200% of FPL. Clients must apply for Medicaid enrollment within 90 days of applying to the Dental and Drug Assistance Program. Dentists must be pre-approved to obtain payment. The fee schedule is comparable to private dental insurance plans, which enables dentists to participate without financial penalty. There is no cap on the amount a dentist can invoice for the client. Dental providers

must follow the rules of the program, which include accepting reimbursement by the program as payment in full (they cannot bill the client to supplement that amount). The services covered are limited to those allowed under the Title II guidelines. So far, bills from dentists range from \$200 to several thousand dollars. The large bills are reviewed and are usually deemed appropriate because the procedures were pre-approved before care was provided.

- The Massachusetts HIV Dental Program is a statewide dental reimbursement program that uses a case management model to refer patients to private dentists throughout the state. Patients go to the HIV Dental Program office for an intake interview and then are referred directly to a provider in the community. The Program has a Title I component to serve those in the Boston EMA and a Title II component to serve the rest of the state. Medicaid and state funds supplement RWCA funds. In recognition that a more intense level of care is needed by PLWH than in general dentistry, clients can receive more services than those covered through the state's enhanced Medicaid coverage. For example, dentures may be covered more frequently than every five years. In 1994, the Program raised its fees to 30% over the State's Medicaid fee schedule (which provides \$21 for a simple visit). In 2000, however, the Medicaid Program rates went up 30% and the Program now pays equivalent fees. The scope of services covered is more expansive than that of Mass Health (e.g., four cleanings per year, root planing, tooth replacement). The dentist submits a dental claim form for payment.
- The New York ADAP Plus program purchases dental services on a fee-for-service basis. The procedures covered are based on the care plan of the patient.
- The Rhode Island Dental Program, which is operated by the AIDS Project Rhode Island (APRI), reimburses private practice dentists at the rate of one of the largest dental insurance carriers in the state. The program covers people who qualify for RWCA services who are not enrolled in Medicaid and do not have dental insurance. Patients select their own dentists. Because the reimbursement is equivalent to private dental insurance, most selected dentists do participate. The dentists submit estimates for the work to be done. After approval by APRI staff, they can complete the work and bill the Dental Program directly. Although there is a cap of \$1,000 per year per patient (the cap was just lowered from \$1,500 due to limited funding), special exceptions can be authorized on a case-by-case basis.
- The Miami-Dade County Title I program uses an RFP process to develop contracts with local CHCs, CBOs, and private providers to provide a certain dollar amount of service. Agency

contracts are renewed every five years. The agencies then use a RWCA Title I formulary and fee schedule based on Medicaid codes and rates (up to three times the Medicaid rate) to bill for services they have delivered, based on aggregated data.

- The San Diego Title I EMA Planning Council identified the need for dental care as the third highest unmet need in their EMA. To address this unmet need, basic and specialty dental care providers throughout San Diego County are supported with Title I funds. A two-tiered reimbursement system is used. Several CHCs are paid on a capitated-basis for a defined number of patients. Preventive and palliative dental care is funded. To expand access to dental services in communities outside the service areas of the capitated CHCs, fee-for-service funds are paid to community-based dentists. Specialty dental care is also funded on a fee-for-service basis.
- AIDS Project of the Ozarks in Springfield Missouri, an ASO, received Title III funds in 1991 to establish a 29 county network of medical, dental, and case management services. Dental services are purchased on a fee-for-service basis. Currently 16 dental clinics participate, representing a total of 20 dentists and one oral surgeon participate. This approach has significantly expanded access to community-based dental care.
- In Atlanta, Hemophilia of Georgia operates a network of two community-based adult dental programs that are supported by Title I and Title III funds. They plan to add an additional two clinics. The dental programs are co-located with HIV medical care. The programs also have referral relationships with the Emory University HIV clinic.

## **2. Third Party Reimbursement For Dental Care**

The HIV oral health programs studied tend to support their services through direct RWCA funding such as the dental insurance programs described above. A mix of other funding is also common including: Medicaid and commercial insurance payments, State or local government funds, charitable and corporate donations, and public and private sector grants. Management of multiple funding streams is reported to add to the administrative burden of the programs but is necessary for their solvency. Several HIV oral health programs serve as examples of the impact of multiple funding streams:

- The Bering-Omega Community Services is an example of a program that must seek multiple funding streams to cover their costs. Currently the Clinic receives funds from six separate

grants. RWCA Titles I and II, as well as private funding, provide the bulk of the dental clinic's income. RWCA funds cover 110 units of service per month, which is insufficient to cover the services provided by the Clinic. Out-of-county HIV agencies pay the clinic for the services provided to their patients, using RWCA funds. Until recently, a Title III grant also supported the dental program, however, it has recently completed its funding cycle. To receive care, patients must meet the financial criteria to receive RWCA services. If patients are ineligible for RWCA services, they may be eligible for services through Hill-Burton funds or a grant from a private local foundation. Despite these varied funding streams, the Clinic staff report that they run out of grant funds prior to the end of the contract period.

- Chase Brexton Health Services has taken a different approach to supporting its dental program. The dental clinic provides dental care to not only PLWH, but also other patients as well including the uninfected children of their adult HIV patients, commercially insured uninfected patients, and elderly patients from a senior citizens center directly across the street. This approach generates income for the clinic to support services and outlays that are not adequately supported by the grant funds and Medicaid payments received PLWH. This approach supplements funding from Titles I, II, III, commercial and Medicaid capitated and fee-for-service payments, BPHC 330 funds, and an array of grants and donations.
- The Spang Center for Oral Health provides comprehensive oral health care to low income PHWH. Their funding comes almost exclusively through RWCA Titles I and III. Almost all of their patients qualify for services without payment. While there is a handful of paying or commercially insured patients, most of these patients are referred to private dentists where the wait for services will be shorter. State dental funding and private donations provided funding to update and equip the health department dental clinics. There are very few third party payers besides Medicaid, which is the source of a small portion of their annual revenue. However, that revenue does not cover the cost of bill generation. A great deal of the care that is provided is uncompensated because there is no source of reimbursement for the services.

Other HIV oral health programs report that their third party revenue comes from the limited payments made by Medicaid programs for adult dental care, enhanced Medicaid payments such as in New York State, or expanded Medicaid dental coverage for adults. For some programs, commercial dental insurance coverage is available through employers. Payments and scope of coverage among commercial insurers is reported to be limited.

State Medicaid managed care programs provide unique issues:

- In New York, as elsewhere, children are eligible for oral health services under Medicaid. The services are covered in a separate dental managed care organization (MCO) from the medical MCO. However, parents sometime assume that if they have signed up for Bellevue Pediatric Clinic as their primary care provider, they will also be assigned there for dental care. When they bring children for visits, it is discovered that because they failed to enroll for the dental MCO, they have been auto-assigned to a different dental MCO. They are not eligible for the specialized HIV dental services at Bellevue.
- The staff of the University of Alabama dental clinic actively sought MCO network provider status. Because the MCOs do not specify in their member handbooks that the clinic be for PLWH, non-infected MCO members often call seeking dental care. The receptionist cannot disclose that the clinic is only for PLWH due to confidentiality concerns. The receptionist explains that a specialty referral is needed to get an appointment.

Most of the HIV oral health projects studied report that Medicaid payment and coverage are greatly limited for adult beneficiaries in their states. In some states with enhanced Medicaid dental coverage, HIV oral health programs are either not eligible for Medicaid reimbursement because they do not participate in MCO networks or payments are insufficient to cover the program costs. For example, the Bellevue Hospital Pediatric Dental Clinic in New York City receives less than \$6 per patient per month for their pediatric patients enrolled in Medicaid.

Most of the HIV oral health programs studied report significant challenges in financing their operations. Most programs report that they do not meet their operating costs with grant funds, insurance, and patient revenue, with their institutions sometimes making up the deficit. For example, one of the programs studied reports that only about 40 to 50% of their costs are covered by Medicaid payments.

A particularly large component of HIV oral health program costs is reported to be supplies and dental laboratory charges for items such as dentures, crowns, and bridges. Most programs studied make considerable effort to identify affordable laboratories. In some cases, reduced rates are negotiated based on the willingness of the laboratory to provide charity care or the promise of high volume from other dental programs within their organization. University and hospital-affiliated HIV oral health programs, such as the dental clinic at the University of Alabama, report

that they are able to obtain reduced pricing for laboratory services and supplies because their facilities can negotiate price reductions based on volume.

Several approaches have been used by the HIV oral health programs studied to fund the set-up and/or renovation of operatory space. Several HIV oral health programs studied are located in federally qualified CHCs funded by the 330 program of the HRSA Bureau of Primary Health Care (BPHC). Location in a 330 CHC has afforded significant funding for sites such as Chase Brexton Health Services for renovation and equipment. Chase Brexton Health Services also leveraged State construction bond funds to support its construction costs, as well as a special federal appropriation organized by a local representative. St. John's Riverside Hospital dental clinic staff reports that its hospital supported renovation costs through general revenue. One-time-only Title III funding requests have also provided support for renovation and equipment purchases at several of the other HIV oral health programs studied.

The HIV oral health programs studied identified several strategies to pay for uncovered or inadequately compensated dental care. Fundraising in the community and grant writing are the most common:

- The Howard Dental Clinic in Denver raises funds to supplement their RWCA funds, which only cover basic services, in order to provide full services including root canals and crowns.
- Bering Omega Community Services used to receive annual funding from the local hospital to cover uncompensated services, but with Medicaid cutbacks they no longer receive the funding.

Solutions that the HIV oral health programs studied use to achieve solvency include capping the number of patients, limiting the types of services provided, and seeking other sources of funding for prohibitively expensive procedures. For example, one program provides extensive oral hygiene, dentures, prophylaxis, and extraction, but not root canals and crowns. In several other programs, patients must cover the cost of dentures. Other programs will cover the cost of dentures but will not pay for the cost of replacements if patients lose their dentures (which is reported to be a frequent problem).

Several clinics report that they have significantly greater demand for their services than they can support through their various funding streams. To address this challenge, the Austin City Health and Human Services Department has set service eligibility criteria to ensure access to dental coverage for those patients who have no other source of dental care. Specifically,

individuals seeking their services must be medically indigent and have been denied access or perceive there to be a barrier to dental care. Individuals seeking care who do not meet these criteria are referred elsewhere.

Given the complexity of their various funding streams and limited revenue, the directors of several HIV oral health programs report that it is important to be able to manage their own budgets. Direct budgetary management is important for allocating resources, tracking spending, and setting priorities for expenditures.

### **3. Collection of Payments From Patients**

Application of sliding fee scales for patients whose incomes exceed RWCA limits varies significantly among the HIV oral health programs studied. Some programs refer such individuals to private sector dentists. Other programs collect sliding fee scale payments at the beginning of their visit. These programs may inform new patients when their initial visit is scheduled that a sliding fee scale will be used. Alternatively, they may be informed about the sliding fee scale as part of their income assessment during the intake process. If patients are unable to pay their out-of-pocket payments, the programs tend to establish payment agreements with the patients who are asked to make a small payment every month. Most programs that have instituted this strategy report that their patients make their payments on time. Program personnel do not perceive these policies as representing a barrier to care, since they tend to be very flexible in the amount of funds and the period required to complete the payments. Patients who do not make timely payments are not reported to collection agencies.

For HIV oral health programs with commercially insured patients, such as the Spang Center for Oral Health and the Hill Health Center, co-payments are collected at the beginning of the office visit. Patients may pay in cash or charge using a credit card. In other sites studied, such as at Bellevue, patients are billed.

## **H. STRATEGIES FOR CARE COORDINATION**

### **1. Physical Co-Location of HIV Dental and Medical Clinics**

Co-location with medical clinics is a common strategy used by HIV oral health programs. Co-location enables oral health providers to confer with physicians when medical problems are identified. For example, a dentist may identify a lesion or a systemic infection when the patient is

being examined and summons a physician for an assessment. Another advantage is that dental examinations can occur during the medical visit, which is convenient for the patient and enables medical and other service providers to reinforce the use of oral health services. For example:

- At the Bellevue Pediatric Infectious Disease Clinic, an operatory has been set up in an examination room in the middle of the Clinic so that children can observe the process of oral examinations and hygiene. The dentist and dental hygienist collaborate with medical and social service staff in the care of each child who attends the Clinic. Oral hygiene is provided for children during their clinic visits, allowing them and their caregivers to develop rapport with the staff and become comfortable with the experience of routine oral care. If patients require dental interventions, they are then scheduled for appointments at the pediatric dental clinic.

Several of the oral health programs studied are housed in the same building with an HIV medical clinic. For example:

- The dental and medical clinics of the Public Health Trust (PHT) North Dade Health Center are located in the same facility. Co-location affords patients the opportunity to be scheduled for back-to-back appointments on the same day. Dental clinic staff can provide education in the medical clinic.
- The Jackson Memorial Hospital General Dentistry and Oral Surgery Department has a clinic located on another floor from the HIV outpatient department. Patients are sent to the dental clinic on the same day they receive their initial intake at the HIV outpatient clinic. The HIV physician and oral surgeon then confer.

Physical co-location of HIV dental and medical care has an added benefit of identification of dental patients who are not in routine primary medical care. For example:

- The St. Joseph's Mercy Care Services Infectious Disease Dental Program serves a homeless population. They occasionally treat new patients who are HIV-infected, have painful dental problems, and have not received routine HIV care. Due to the Dental Program's physical co-location with an HIV medical clinic, the patient can be paid for dental and medical examinations on the same day. The dentist frequently consults with the physician because the operatories and examination rooms are directly across a shared hallway.
- Several other dental programs that serve both HIV-infected and other patients report that they occasionally identify HIV-infected patients through oral examination who are unaware of

their HIV serostatus. The oral health program staff can send the patient to the HIV counseling and testing unit that day.

## **2. Clinical Records**

Ideally, clinical records can integrate dental and medical providers' notes, assuring that there is a complete clinical profile available. Such integrated records are found in settings in which medical and dental providers are co-located. At the Grady Memorial Hospital Ponce de Leon Clinic, for example, a single unified record is maintained in a centralized record room.

Co-location also affords a convenient way to provide ready access to medical charts by oral health staff. This saves a great deal of staff time that is otherwise required to obtain laboratory results and other pertinent information from the patient or from a provider at a different agency. Availability of up-to-date clinical information also assures a more complete understanding of the patient's problems by the oral health staff.

Several of the HIV oral health programs studied report that they are often unable to treat new patients with urgent dental problems on the same day because their institutions' policies forbid the faxing of patient medical records. To address this barrier, outreach workers, case managers, or transportation providers may be asked to transport the patient and their records to the dental clinic. Transportation vouchers funded by the RWCA are used to pay for transportation.

## **3. Multidisciplinary Care Management of PLWH**

Even when HIV oral health providers are not co-located with other HIV services, some of the agencies studied report that their staff attends case conferences at other agencies to collaborate in the care of shared patients. For example:

- The staff at Pediatric Dental Infectious Disease Clinic at SUNY Stonybrook functions as part of the management team at the Pediatric Infectious Disease Clinic, even though they are located in a separate building.

An added benefit of multidisciplinary care management is the opportunity to educate medical providers regarding the diagnosis and treatment of HIV oral disease. For example:

- The Director of the HIV dental program at Catholic Healthcare West routinely provides dental education to hospital medical staff and the professors and students at a local school of dental hygiene. The dentist at Alta Med Health Services conducts workshops with primary

care providers regarding the identification and treatment of HIV oral conditions, including conditions that require referral to Alta Med for further care.

- At the network of agencies participating in the Title III consortia led by Hemophilia of Georgia, a liaison nurse handles referrals to dental and medical providers in the network, coordinates appointments so that patients can be seen by medical and dental providers on the same day, ensures that charts are provided to Dental Clinic staff, coordinates the services provided by medical and dental providers, and follows up with outreach workers regarding patients who are having problems in keeping appointments and adhering to medication.
- The staff of the Spang Center for Oral Health attends monthly HIV Coalition meetings to collaborate in the provision of care throughout Chicago.

Multidisciplinary care management is not always successful in ensuring care coordination.

For example:

- At APLA, dental clinic staff reports that they have experienced problems in getting feedback from dental specialists at university-based dental schools. To address this problem, the dental staff tries to provide the procedures needed by their patients onsite.

## **I. STRATEGIES FOR ENSURING ACCESSIBLE SERVICES**

The HIV oral health programs studied use an array of creative strategies to make their services easily accessible. These strategies are discussed below.

### **1. Physical Location in the Community**

A convenient location is reported to be critical by the HIV oral health care programs studied. Some programs have located themselves in an ASO. They have easy outreach to potential patients and are perceived by patients as being associated with a trusted provider. Other programs are located in a mainstream medical building such as a CHC or other ambulatory care clinic. In the statewide programs described above, contracts with community-based dentists in private practice were the solution to ensure available and accessible services.

Physical location of the HIV oral health program is important to ensure access. For example:

- For the Spang Center for Oral Health in Chicago, the key to expanding access to care was the establishment of satellite clinics at CHCs in neighborhoods with high proportions of PLWH. The Bering Omega Community Services was initially located in a neighborhood convenient to the bulk of its patients who were predominantly white gay men. Their patients are now

predominantly African American or Hispanic, and reside in another part of the city with poor public transportation links to the clinic. Therefore, the dental clinic staff is collaborating with WAM Foundation, a primarily African American agency, to raise funds to build a second clinic in a location convenient to patients. Funds have been raised to buy property and build a three operatory facility to be staffed by a dentist and dental hygienist.

- The Chase Brexton Health Services dental clinic was recently relocated to a street-level, storefront setting in a neighborhood with a high rate of PLWH. The dental clinic is designed to be inviting and does not have obvious HIV-specific signage that might make potential patients feel stigmatized about walking in for care. The dental staff also provides onsite services at a health care for the homeless program funded by the HRSA BPHC.
- Staff of the Austin City Health and Human Services Department of Health report that the proximity of their dental clinic to the University of Texas HIV clinic results in frequent walk-ins by individuals seeking dental care.
- The staff of the University of Alabama dental clinic also reports frequent walk-ins due their proximity to the HIV medical clinic.
- The dental clinic of APLA is located in a medical office building that is located near a subway line. Patients report that they like the anonymity of the location since the dental clinic is not distinctly identified by signage as an HIV program.
- The Medical College of Georgia School of Dentistry has a dental clinic managed by senior dental students five days per week. It is a general clinic, but PLWH, who have difficulty finding dentists in Augusta and the rural areas of the Southeast come from as far as three or four hours to be treated. Referrals are received from ASOs through the Southeast. Patients are cared for by either the student or resident program. There is a resident on-call after hours to triage emergencies. If a patient requires routine care, an appointment is made and the person is assigned a provider. An examination and treatment plan are implemented, followed by fillings, crowns, and cleanings. The limitation is that procedures that are not in the teaching mission of the clinic, such as surgical extractions, are not done. A specialist in oral medicine works with PLWH who have non-tooth-related problems such as KS and gum tissue disease. The program receives funding from the DRP.

## 2. Co-location With Clinical or Other HIV Care Services

Several HIV oral health programs report that co-located services provide easy initial access to oral health services and enable the patients' trusted providers to introduce oral health care as part of the package of services provided. The association of the dental clinic with other supportive services can help overcome the fear of dental care that is a common phenomenon among patients who have not had positive experiences with dental care. For example:

- The dental clinic at the University of Alabama is the only dedicated dental clinic in the state. They are physically located in an HIV-dedicated facility that affords “one-stop shopping” for PLWH. Dental clinic personnel participate in weekly lunchtime conferences along with the clinical staff to discuss patients who are unusually challenging. The dental staff often makes case presentations. The co-location of the dental and medical clinics also affords the opportunity for dental providers to go to the medical clinic if an immediate consultation is needed. Medical charts are sent to the dental clinic upon referral.
- When a county hospital with an HIV dental clinic was slated for closure, AIDS Resource Center of Wisconsin was able to hire the dentist that staffed the clinic and secure the clinic’s equipment from the hospital. The Center then established a dental clinic within their case management agency by modifying their physical space to accommodate the dental operatories. Funds from Titles II and III support the dental clinic’s operations.
- At Chase Brexton Health Services, several adjacent buildings house a wide array of medical, dental, retail pharmacy, nutrition, case management, and enabling services. Dental clinic staff has access to medical and pharmacy records. They coordinate medication management with the medical and pharmacy staff on a routine basis. Dental staff notes the importance of having a separate telephone messaging system to instruct patients what to do in case of a dental emergency.
- The dental clinic at the Grady Memorial Hospital Ponce de Leon Clinic is located in a building that houses a full continuum of HIV services including medical, dental, ancillary medical, retail pharmacy, case management, housing, and enabling services. Several ASOs have field offices in the building to ensure easy access and one-stop shopping.
- At the St. John’s Riverside Hospital, Chase Brexton Health Services, and the Grady Memorial Hospital Ponce de Leon Clinic, HIV medical clinic staff will walk patients to the dental clinic if they are encountering an urgent dental problem.

- The AIDS Project of the Ozarks contracts with a network of community-based dental providers throughout a 29 county area. They continue to recruit actively dentists to add to the network, particularly in communities in which there is patient demand and unmet dental need. The project staff uses a person-to-person approach to recruit and orient dentists to the program. Word of mouth among dentists in the area has led to the willingness of dentists to participate in the program. These efforts are enhanced by benefits coverage and a payment schedule that is significantly better than that of the Medicaid Program and a “no-hassle,” fast payment system that makes participation easy for dental providers.

### **3. Hours of Operation**

Most of the HIV oral health programs studied operate during the workday, with few programs operating evening or weekend clinics. Several programs report that they had operated evening or weekend clinics but discontinued that schedule because demand was inadequate or patients were concerned about their safety in the evening.

Several approaches are used to assist patients during non-clinic hours. Most HIV oral health programs have a recorded message on their voice mail system that directs patients to after-hours providers (e.g., emergency rooms, urgent care center, etc.). One program reports that they also used a cell phone to take urgent calls. This strategy did not work because their facility is closed in the weekends and the operatories and patient charts were not available.

### **4. Intake and Scheduling of New Patients**

Referrals to HIV oral health projects tend to come from HIV medical clinics, case managers, HIV hot lines, community-based dentists, and self-referral. Many of the HIV oral health programs studied schedule new patients as quickly as possible so they can begin receiving services in a timely manner. Several programs conduct initial intakes at the first contact to establish a relationship with the patient so that she or he returns for the first dental appointment. For example:

- At Jackson Memorial Hospital, all new HIV patients are sent to the HIV Dental Program as part of their intake visit.
- At Bering Omega Community Services, intakes are completed on a walk-in basis. An examination is then scheduled for a dental visit, usually within a week. The initial intake is completed by a volunteer or by the front desk staff, who are cross-trained to do the intake.

An intake packet includes a letter explaining eligibility, policies and procedures of the clinic, including how to access childcare, a health history form, eligibility materials, and consent for services. The intake form is in English and Spanish. Patient intake is conducted during a blocked period of four hours on two days per week. An appointment is made for the first dental visit, which includes x-rays and an oral examination. Walk-in patients are scheduled for another day.

The wait for new patients varies considerably among the HIV oral health programs studied, ranging from several weeks to three to six months. New patients with urgent problems who have been referred by their primary care provider can be seen within 24 hours at most programs studied. Their medical records are usually needed prior to the examination, however, so that their clinical status can be evaluated. Of particular interest are medical records that summarize the new patients' immunologic status, their current medications, and other clinical information that may be needed to identify clinical conditions that might compromise or complicate dental care. New patients with emergency oral health problems are referred to emergency dental centers, such as those operated by dental schools, if they cannot be seen that day.

Ability to pay may act as a barrier to care. To address this problem, Chase Brexton Health Services, patients are not charged a co-payment for the initial visit to eliminate any financial barriers to accessing initial dental assessment. Several other programs do not charge for the initial visit to their dental clinic.

Several HIV oral health programs report that they set aside visits in their schedules for walk-in or urgent patients. Some programs also will call patients who are scheduled in the future, if an appointment slot becomes available. This rapid scheduling strategy allows future visits to be freed up and care plans to be completed at a more rapid pace than initially scheduled.

No-show rates for new patients are reported to range from 20 to 50%. Factors reported to be associated with no-shows are reduction in the pain that initially precipitated the request for appointment, lack of transportation, or forgetting about the appointment. Keys to decreasing no-show rates among new patients are to: schedule their initial appointments as quickly after their initial contact with the program as possible, send reminders by mail or call the patients 24 to 36 hours before their appointment, and call them if they do not arrive on time. Several programs report that once new patients are engaged in care they tend to keep their follow up appointments and arrive on time.

## 5. Scheduling of Ongoing Patients

Some of the HIV oral health programs studied schedule appointments rather than block appointments, so patients do not have to come in the morning and wait long hours to be seen. Some programs, such as the PHT North Dade Health Center, have evening and weekend hours of operation to accommodate patients who work or care for children. Several CHCs report that RWCA funding has enabled them to expand their capacity and provide faster service for PLWH than their other dental patients. At the PHT Center, for example, PLWH only wait two weeks for an appointment compared to a six-month wait for other patients.

At several of the HIV oral health programs studied with more than one dentist, patients are allowed to select their dentist. Although selection may extend the wait-time for appointments for the dentist of their choice. In some clinics, patients are assigned the next available dentist so that wait-times are reduced for all dentists.

No-shows or cancellations of ongoing patients are a common problem in most of the HIV oral health programs. To reduce no-shows and cancellations, several programs report scheduling the next appointment while patients are at their programs for care. They then send postcards reminding the patient about their scheduled appointment. Telephone reminders are then placed 24 to 26 hours in advance of the appointment and the patients counseled about the importance of attending their appointment. Catholic Healthcare West personnel also flags the charts of repeat no-show patients and contact their case managers to ask that they ensure that transportation is arranged for the patients and/or other barriers to appointment keeping are addressed. The University of Alabama dental clinic maintains a list of “stand-by” patients who are willing to come in at short notice if there is a visit cancellation or no-show.

Another solution to the nearly ubiquitous problem of no-shows and cancellations has been active behavioral modification strategies. Some programs enter into an agreement with each patient at the intake appointment to abide by clinic rules. One rule may be that patients can schedule appointments, but if they are late for or miss a certain number of appointments, they are put on “block appointments.” They are then not scheduled for a specific time, but must arrive at the beginning of a day (or afternoon) and wait for an opening. Once they have completed a certain number of appointments in this manner, most programs will reinstate their scheduling privileges. The Spang Center for Oral Health and Bering Omega Community Services both have written guidelines for patients and an agreement for each patient to sign at intake. Several

programs report that they can readily predict which on-going patients are likely not to keep their appointments. These patients are not assigned a specific appointment slot, but are worked in to the clinic's schedule if they arrive. These patients are commonly actively chemically dependent. Dementia and other cognitive impairment have led some patients to request that they receive a telephone call on the day of the appointment to remind them to attend their appointment.

The role of parents or other caregivers is important in the appointment keeping of pediatric patients. The director of the Bellevue Pediatric Dental Clinic has a conference with the caregiver of any child who has missed two appointments. During these conferences, the director often identifies problems that require social service or other interventions or referrals. In several clinics if there is a no-show patient or cancellation, patients already in the operatory receiving care can have extended appointments to address other items in their care plan.

Dental management software is used by several of the HIV oral health programs studied to generate appointment lists for upcoming clinic sessions. Clerical personnel use the lists to contact patients by telephone or mail to remind them about their upcoming appointments. To ensure patient confidentiality, clinic personnel do not specify that the patient's appointment be at an HIV dental clinic. Commonly, HIV oral health program personnel record in the patients' charts whether they want to be contacted at their homes regarding appointment reminders.

Dental management software is also used by several of the HIV oral health programs studied to track appointment adherence and to identify patients who persistently miss appointments. Several other strategies are used to reduce no-shows and cancellations including: contacts with patients via their case managers such as patients with no telephone or unstable housing, counseling patients that repeated break appointments, and discontinuation of service for habitual no-show patients.

## **6. Emergency or Urgent Care**

All the HIV oral health programs studied have 24-hour on call service, either with beepers carried by staff or with an answering service that forwards calls to the designated person on-call. If a patient calls after clinic hours, the provider on-call assesses the situation, either instructing the person to go to the emergency room, come to the clinic on the next day, or call to schedule an appointment, as appropriate. For example:

- The staff at the dental clinic at Jackson Memorial Hospital works within a health care system that has oral surgery residents available at their emergency room. The emergency room resident can be contacted directly by the provider to ensure continuity of care.
- In Baltimore as in other cities, the University of Maryland at Baltimore School of Dentistry has a dental emergency room that can be used for after-hour referrals.
- At the Spang Center for Oral Health, all dentists are on-call for their own patients. They respond to each case individually, advising whether to go to the emergency room or come to clinic in the morning.
- At the Grady Memorial Hospital Ponce de Leon Clinic, dental clinic patients are given a card with evening and weekend telephone contact information for their dental providers in the case of an emergency. The dental clinic director also has admitting privileges to Grady Memorial Hospital for patients with complications resulting from acute dental disease.

## **7. Transportation**

Because transportation is often a problem for indigent patients, several of the HIV oral health programs studied integrate the provision or arrangement of transportation into their services. Some HIV oral health programs are co-located at ASOs with a van service. In some cases, these programs provide transportation to their clinics for patients in surrounding jurisdictions. For example:

- Transportation is provided from Lancaster County Pennsylvania to the clinic in Chester.
- The staff of Bering Omega Community Services arrange for transportation from three surrounding counties and Galveston to the clinic in Houston.
- Transportation is arranged for patients living in outlying parts of Westchester County New York to the St. John's Riverside Hospital.

Ordinarily, services for one individual are spread over several weeks or months. However, when people are transported from outside of the county, every effort is made to complete the work in a single visit. For example:

- The dental clinic operated by the Austin City Health and Human Services Department in Texas serves patients from Travis County and nine surrounding counties. The clinic coordinates appointment scheduling and transportation services with the rural health clinics in the surrounding counties to ensure that patients are transported to Austin for dental visits.

Parking was identified by several HIV oral health programs to be a problem because there is no or limited free parking. To address this problem, the programs obtain free parking permits or taxi, bus, or subway vouchers or tokens funded by Titles I or II.

## **8. Linkages With Case Managers**

Most of the HIV oral health programs studied coordinate with clinic and community-based case managers to ensure that appointments are kept. They also arrange with case managers to do case finding when patients are lost to follow up. For example:

- In Davenport Iowa, Community Health Care provides oral health services to PLWH. Each patient has a case manager from Quad Cities Regional Virology Center, an HIV medical clinic.
- At the St. John's Riverside Hospital, case managers routinely receive a list of no-show patients for follow up and encouragement to reschedule their appointment. Dental personnel at the hospital also participate in case conferences with case managers.

## **9. Home Visits**

In the pediatric setting, the relationship with the caregiver and involvement with the family are especially important factors in successful management of oral health among children. At the Pediatric Dental Infectious Disease Clinic at SUNY in Stonybrook NY, the play therapist from the Pediatric Infectious Disease Clinic and the coordinator of the pediatric dental clinic sometimes make home visits to provide teaching and support for the caregiver and to work with the child.

## **10. Outreach to PLWH Not In Dental Care**

Some of the HIV oral health programs studied state that their outreach to PLWH not in dental care is minimal because they do not have sufficient capacity to add new patients or because there is currently a substantial waiting time for new patients. Other programs use creative and aggressive outreach strategies to attract PLWH who are not receiving oral health care. These strategies include advertisements, patient education programs in HIV medical settings, local educational programs in community-based settings, and brochures. Recruitment of patients often involves dentists and dental hygienists who attend HIV medical clinics to meet patients and provide educational presentations.

Informal outreach occurs in many settings with people who are not accustomed to accessing dental care except when they are in acute pain. For example:

- The dental hygienist at Bellevue Hospital Pediatric Infectious Disease Clinic is active in the community where she attends health fairs and conducts dental education in schools.
- At the AIDS Care Group in Chester Pennsylvania, the dentist is actively involved other services provided, such as the breakfast program that feeds indigent, chemically dependent individuals. The dentist knows and is trusted by patients and encourages them to receive care at the dental clinic.
- Staff of the Austin City Health and Human Services Department conducts street outreach to injecting drug users and the homeless. They encourage staff of the local HIV hotline to refer individuals to them for care and they post brochures at local HIV clinics, ASOs, the Salvation Army, and the City's indigent clinic.
- Outreach workers are employed by the network of providers funded by the Title III project awarded to Hemophilia of Georgia. The outreach workers conduct case finding activities and help patients to address problems regarding appointment and medication adherence. They work closely with liaison nurse and dental providers.

Outreach to HIV medical providers is equally important, not only to make them aware that oral health services are available, but to educate them about the importance of referring their patients to oral health care. For example:

- The Massachusetts HIV Dental Program conducted an intensive outreach promoting the dental program to 200 agencies in the HIV provider community in 1995. The Program is now well known among community dental providers and receives frequent referrals.

Many HIV dental providers working in the HIV oral health programs studied are active with their local AETCs. For example:

- The staff of the Spang Center for Oral Health conducts regular outreach to health care providers for referrals and staff recruitment. They visit HIV-related agencies to describe their program's services and to provide agencies with brochures. The director also works with the AETC and provides continuing education for dentists and other health care providers.
- Dental staff of the AIDS Resource Center of Wisconsin actively conducts outreach to community-based dentists and local correctional facilities.

- The Hill Health Center conducted screening at an HIV hospice. This outreach effort had to be discontinued, however, because the patients were too ill to receive dental care.
- The dental hygienist at St. John’s Riverside Hospital routinely visits the HIV medical clinic there to conduct education workshops and outreach in the waiting room. The objective to the outreach is to provide individuals with a “connection with a friendly face” so that their concerns about initiating dental care are ameliorated.
- At the Bellevue Hospital Pediatric Dental Clinic AIDS Program and the Pediatric Dental Infectious Disease Clinic at Stonybrook New York, education of pediatric medical staff has been so effective that outreach by the oral health clinicians is no longer the initial oral health intervention for patients. The medical staff incorporates oral hygiene into their routine education of caregivers. However, in both programs, the dental hygienist and dentist work as part of the interdisciplinary team providing services in the medical clinic. They develop relationships with all the caregivers and their children to promote the likelihood that they will take advantage of the oral health services.
- Staff of the Chase Brexton Health Services dental clinic participates in community health fairs and local gay pride events where they distribute dental supply “goody bags.”

### **11. Culturally Competent Services**

One of the important aspects of care that enables patients to feel sufficiently comfortable to access services is that it be culturally competent. HIV oral health programs providing services to Latino populations have materials written in Spanish and hire Spanish-speaking staff. Bering Omega Community Services in Houston has annual training for its staff in cultural competence. Several programs have made strong, successful efforts to hire staff that reflects the patient population ethnically and culturally, such as the Bering Omega Community Services, the Austin City Health and Human Services Department, the Grady Memorial Hospital Ponce de Leon Clinic, and St. Joseph’s Mercy Home Care.

### **J. STRATEGIES FOR ENSURING CONTINUITY OF CARE**

The HIV oral health programs studied have developed various strategies to ensure continuity of care. The staff of the Spang Center for Oral Health allows patients to choose their providers and Bering Omega Community Services assigns a specific provider to each patient. Both strategies attempt to build a relationship between the patient and provider that will motivate the

patient to continue obtaining care. Because routine oral health care for PLWH usually involves oral hygiene every three months, frequent appointments can be a burden for the patient, but the opportunities for relationship building are frequent.

### **1. Overcoming Dental Phobia or Pain Aversion**

Dental personnel at the HIV oral health programs studied report that dental or pain aversion is widespread among their patients. The programs have adopted a number of strategies to overcome dental aversion, or “dental phobia.” Most programs slowly introduce the patient to the dental setting to demonstrate that it is a safe environment. The development of a trusting relationship with the providers is important. The initial visit might only involve an oral examination, without any treatment or cleaning. Teaching may be the focus of the care plan until the patient becomes comfortable. Several programs report that they do not engage in any potentially painful procedures for several visits to provide time for pain-averse patients to become comfortable with dental care. Several other strategies are used:

- The dental program at Jackson Memorial Hospital uses sedation for major procedures that might be conducted under local anesthetic in other settings. Strategies to distract the patient from the procedure are also used.
- At the Ponce de Leon Clinic in Atlanta, music is piped into the examination rooms and attention is paid to creating a pleasant ambience for patients including individualized thematic operatories.
- In pediatrics, it is often the parents or other caregivers who are dental phobic. Efforts are made to prevent the child from adopting the parent’s fear. At both the Bellevue Hospital Pediatric Dental Clinic AIDS Program and the Pediatric Dental Infectious Disease Clinic at Stonybrook New York, a play therapist is enlisted to work with the child. The parent or other caregiver is encouraged to leave the room while the dental hygienist or dentist is working with the child.

#### **○ Physical Environment**

The physical environment of the HIV oral health programs studied varies widely depending on the level of funding and physical location of the clinic. Some programs are spacious, well-ventilated, well lit, with up-to-date equipment, and pleasant waiting rooms. For example:

- Bering Omega Community Services has modern operatories, a complete laboratory, up-to-date x-ray equipment, and brightly painted walls. While the clinic has nearly outgrown its physical space, it is attractive and has state-of-the-art equipment.
- Several programs, including Houston’s Bering Omega Community Services, Chase Brexton Health Services, and the Community Health Center in Davenport Iowa, are building new dental clinic facilities. Others are in the process of raising capital funds, purchasing equipment, renovating facilities, or building new or additional clinics.

Many clinics, however, operate out of CHCs or other community-based agencies whose buildings are dingy and overcrowded. They struggle with inadequate space and outdated equipment but make the most of the resources available to them. For example:

- The Spang Center for Oral Health functions in a small space that shares a waiting room with a CHC’s dental clinic. Overall, space is very limited in the clinic area. Despite these limitations, the reception area and treatment rooms have subtle reminders that the clinic is HIV-friendly. In addition, subtle non-confrontational ways of educating patients include a bowl of condoms on the desk (which is refilled regularly) and copies of the HIV referral guide to other HIV services in Chicago. Thus, even under difficult circumstances, the ambiance can be pleasant and inviting to patients.

- **Clinical and Management Information Systems (MIS)**

The record keeping systems maintained by the HIV oral health programs studied run the gamut from paper charts to sophisticated electronic dental management systems. Most programs maintain paper records and then use clerical staff to input information into databases used for billing and tracking purposes. Other approaches are also taken:

- The Palm Beach County Dental Program in Palm Beach Florida has an integrated MIS that enables them to obtain documentation of patient HIV status and medical history. Dental services provided are entered into the MIS for use by the clinical staff of the Dental Program and County’s HIV primary care clinic.
- The Bellevue Hospital Pediatric Dental Clinic in New York City is part of a large system-wide automated MIS that can be used to obtain financial eligibility information to determine where to refer patients for specialty care.

- The Pediatric Dental Infectious Disease Clinic at SUNY uses a system-wide MIS to record patient visit information.

Several of the HIV oral health programs studied report that they would like to move to an automated, paperless record keeping system. Their institutional MIS cannot support and/or interface with such software for cross-institutional information systems management and have not approved the adoption of new software.

Several of the HIV oral health programs studied that are co-located with HIV medical clinics report that automated medical management software tends to be inadequate for dental management because the procedure and billing coding systems are different. To address this problem, several HIV dental clinics have adopted dental management software designed for private dental practices. In some cases, dental management software has been modified to reflect the unique needs of an HIV-dental clinic, such the need to document supplemental laboratory results. At Chase Brexton Health Systems, for example, they used several software systems before designed their own software screens to meet the unique needs of their dental clinic.

It was noted by several of the HIV oral health programs studied that a drawback of some dental software is its inability to interface with the other software used to manage other HIV services or meet RWCA reporting requirements. To complete their CARE Act Data Reports, for example, separate database software such as MS Access had to be used.

## **K. PATIENT EDUCATION STRATEGIES**

The HIV oral health programs studied have developed creative patient education strategies. The purpose of patient education is to motivate patients who do not access oral health care, to enhance patient adherence to personal oral hygiene and appointment keeping, and to address issues such as fear of dentists or pain aversion.

Patient education is common in pediatric oral health settings. Pediatric oral health providers consider teaching caregivers about proper oral hygiene to be an important aspect of medical care, calling the intervention “anticipatory guidance.” For example:

- At the Pediatric Dental Infectious Disease Clinic at SUNY, oral health is perceived by the dental staff as not being related to dentistry but to life dynamics. Care giving determines whether children with HIV have healthy mouths: they are all born orally healthy. The Clinic dental staff works closely with the staff at the HIV medical clinic to reach mothers and other caregivers as early as possible in each child’s life. Caregiver empowerment is considered

key, and the pitch made to the families is that while they cannot control much of what happens with their HIV-infected child, they can control what goes in his or her mouth. The dental and medical staff teaches parents and other caregivers about how to give oral medications and nutritional supplements and about appropriate use of bottles for nutrition and not as pacifiers. They clinicians encourage the use of food as nourishment, not as a reward or comfort. This educational intervention is considered the most important oral care in the child's early life. With appropriate early teaching, the first time when it is critical for a child to have an oral health visit is when the molars come in and fissure sealants should be applied.

For HIV oral health programs serving adults, education is integrated with oral care in the clinic or with outreach into the medical setting. In general, programs have two kinds of patients: those in episodic care and those in continuing care. Patients in episodic care are perceived as the ones in need of education about the importance of preventive care as well as restorative care, but they are often the most difficult to convince that regular oral care will be beneficial. At the University of Alabama dental clinic, for example, patients are educated about the importance of not waiting until there is a problem before having a dental examination. The context of the education and the relationship with the educator are both considered factors that contribute to successful education. The objectives of education must be limited and incremental, whether they are to convince patients to seek oral health care in the first place or to support adherence to dental treatment plans.

The HIV oral health care programs studied report numerous opportunities for patient education. During dental visits, patient education is integrated into care. Educational materials and videos are commonly available in the programs' waiting rooms. Dental hygienists are reported to incorporate commonly basic dental education into their assessment and treatment. Dentists and hygienists spend considerable amounts of time during initial visits dispelling myths about dental procedures and allaying fear regarding pain. Patient education may be provided in other settings as well. Several programs report that informal patient education is provided at HIV medical clinic waiting rooms by dental hygienists or dental assistants who will visit the clinics on a regular basis. At Alta Med Health Services, the dentist routinely conducts dental education at patient support groups.

The HIV oral health programs studied have developed an array of patient education materials regarding basic self-care and explanations of common dental procedures. These materials tend to be pictorial, to address illiteracy that is common among the patients of some programs. These materials are also distributed at local HIV clinics as an educational and outreach strategy.

Dental education is reported by the HIV oral health programs studied to be most effective in warm, friendly environments in which the patients feel welcome. Such an environment is also conducive to appointment keeping.

## **L. INFECTION CONTROL STRATEGIES**

Appropriate infection control is now commonly integrated into the HIV oral health programs studied. In the early years of the HIV epidemic, however, what are now accepted measures were considered an overreaction to contagion. For example:

- Bering Omega Community Services was the first dental facility in Houston to apply universal precautions in its practice. The dental director reports receiving negative communication from the American Dental Association (ADA) for initiating universal precautions in the years prior to the upgrading of the ADA's infection control guidelines in response to HIV and hepatitis.
- The Hill Health Center also reports independently adopting infection control practices in the absence of guidelines from the ADA.

Protocols for infection control vary in the HIV oral health programs studied. All the programs contacted, however, report that they follow appropriate OSHA and ADA guidelines. Additionally, several programs have established their own infection control policies. For example:

- At the Spang Center for Oral Health, a dental assistant is responsible for completing a set of tasks weekly and initialing a task sheet. Tasks include maintenance of the sterilizer, developer, operatories, sterilizing and laboratory space, break room, and sterilized cassettes/pouches.
- At the St. Joseph's Mercy Care Services Infectious Disease Dental Program, clinic personnel have a routine set of infection control procedures that they undertake every morning prior to patient appointments, at mid-day, and in the evening. These procedures are considered a high priority responsibility of the staff.

- At Bering Omega Community Services, the dental director provides the staff training, including information about HIV and hepatitis. He is the OSHA officer and conducts an annual review of the clinic's policies and procedures. He watches each staff person practicing. The most common infractions he finds are staff not wearing masks properly or not wearing goggles. Staff members wear gowns for patient care and there are sharps containers with needle recapping devices in every room. Rather than using paper drapes, the rooms are disinfected with a phenol-based spray between patients.
- At the Grady Memorial Hospital Ponce de Leon Clinic, the dental clinic dedicates one day per week in which no patients are scheduled. On that day, all clinic lines are sterilized. Personnel use that day to get caught up on their charting and other non-treatment activities.

The balance between resources versus staff time seems to determine whether clinics wipe down their equipment with disinfectant or “wrap” it with plastic for each patient. Some programs have instituted routines such as assignment of staff to check autoclaves and equipment on a regular basis. Staff training about infection control is an important component of continuing education within the programs.

At several HIV oral health programs located in sites with other clinical programs, the HIV oral health programs' infection control policies are reported to exceed policies and practices of other departments. This has led to the need to justify greater budgetary outlays for infection control by the oral health program's staff.

Infection control is reported by the HIV oral health program studied to be expensive. One clinic reports that it costs between \$17 and \$20 per visit to undertake infection control procedures. Latex allergies are reported among some staff of HIV oral health programs that must re-glove repeatedly throughout their day, requiring additional outlays for non-latex gloves.

## **M. QUALITY ASSURANCE (QA) STRATEGIES**

QA strategies used by the HIV oral health programs studied range from formal continuous quality improvement (CQI) programs to informal rounds to review staff performance. Chart audits tend to focus on verifying completeness of chart documentation (e.g., completed forms, updated medication lists and radiographs, and identification of the patient's primary care clinician). Other audits involve comparing provider performance with standards established by the clinic or HIV dental guidelines. Examples of the approaches taken to QA include:

- At APLA, the dental clinic personnel meet on a monthly basis to conduct chart reviews and discuss ways in which they can improve their services.
- The Spang Center for Oral Health is part of the Chicago Health Outreach and Heartland Alliance's quality improvement team and has selected a set of process indicators to assess its performance.
- The director at Bering Omega Community Services informally reviews charts periodically, as well as conducts a formal annual chart review. Dental school faculty also review patient charts and supervise the work of residents working at the clinic.
- At Chase Brexton Health Services, dental clinic staff participates in monthly performance improvement coordination meetings, management team meetings, clinical operations teams, and professional team meetings that address various aspects of quality improvement.
- The dental director of the AIDS Resource Center of Wisconsin conducts quarterly dental chart audits to identify patients whose dental care plan indicate that they are overdue for care. Dental management software is used to monitor treatment plans and ensure that high quality care is provided.
- The St. Joseph's Mercy Infectious Disease Dental Program uses a standardized documentation assessment sheet has been developed to evaluate various aspects of chart completeness, that documentation supports the diagnoses and care plan, that there is follow up between visits to ensure continuity, and that appropriate referrals were made. The Dental Program's policies and procedures manual is also reviewed at least every two years and updated as needed.
- At the Grady Memorial Hospital Ponce de Leon Clinic, a dentist working in another department of the Hospital conducts chart audits on quarterly basis. A sample of 25 charts is reviewed per provider. CQI projects are conducted based on the results of the audits.

Several strategies for gaining the feedback of the patients of HIV oral health programs were identified:

- At the Bering Omega Community Services, where the patient satisfaction survey is in both English and Spanish, patients are surveyed when they are first seen and then every three months. Results are aggregated routinely and reported to the staff, board of directors, and the faculty at the dental school that supervise dental studies onsite.

- At the St. Joseph's Mercy Infectious Disease Dental Program, patients may complete a satisfaction survey on an ongoing basis.
- At the Grady Memorial Hospital Ponce de Leon Clinic, a patient grievance process is in place for patients who are dissatisfied with their care. A patient advocate and peer educator are available to assist the patient to resolve their complaint.

At several HIV oral health programs studied, one dentist staffs the clinic. Since self-assessment may not provide optimal QA, these clinics arrange for other dentists located in the community or at a neighboring dental school to conduct routinely scheduled QA processes such as chart audits and quality improvement activities. For example:

- Alta Med Health Services contracts with a local dentist to review annually patient charts using a set of performance measures.

Among HIV dental reimbursement programs, patient satisfaction surveys are routinely used to gather feedback from patients. Additionally, AIDS Project of the Ozarks annually surveys the dental providers in their fee-for-service network to assess their satisfaction with their program. They also routinely visit the participating dental offices to review policies and procedures.

## **O. IMPEDIMENTS TO SUCCESSFUL ORAL HEALTH PROGRAMS**

### **1. Staff Recruitment and Retention**

A significant impediment reported by HIV oral health programs studied is the challenge of recruiting and maintaining staff. Many of the programs studied include dental hygienists in their care team. Those programs report that it is increasingly difficult to recruit and retain dental hygienists. The market for dental hygienists is extremely competitive and hygienists are in high demand by private dental practices. Dental hygienists can command relatively high salaries, sometimes higher than those paid to dentists can. Several of the HIV oral health programs studied report that they have a difficult time recruiting dental hygienists not because they serve PLWH but because they are located in inner-city neighborhoods or because their physical plant is not as appealing as suburban private practices.

Retention of experienced reception personnel is reported to be a challenge. Burnout is reported to be an ongoing problem caused by the fast pace and continual high patient flow of many of the HIV oral health programs studied. There is a growing demand among private dental practices experienced dental reception personnel. Several programs report that they cannot meet

the salaries offered by private dental practices. Other programs report that they need clerical and reception personnel but they have insufficient grant funding or third party revenue to support additional positions. To address the lack of clerical support, some dental professionals undertake clerical activities including correspondence, chart automation, and record keeping.

The salary structures of parent facilities or systems are reported to be a barrier to increasing salaries at several of the HIV oral health programs studied. It is often impossible to offer salaries that are competitive with the private sector for HIV oral health programs located in systems with collective bargaining, non-profit salary structures, or government merit system wage scales. Such organization barriers are commonly present even when funds are available to increase the salary of personnel in the HIV oral health program to make cost of living adjustments or promote personnel. At least one program studied was able to address this organizational barrier by outsourcing their dental personnel to a dental employment service.

Several HIV oral health programs studied who report that they do not have retention problems state that the key to retaining dental hygienists and other staff is to ensure that they are happy, that they feel they contribute as care team members, have opportunities for training and career advancement, and that they feel they are adequately compensated both monetarily and non-monetarily in their jobs.

- **Funding**

Obtaining initial and ongoing sources of funding is an ongoing challenge for the HIV oral health programs studied. Downturns in the economy and reduction in the public tax base have impacted HIV oral health programs. Recent cutbacks in services and sources of funding for indigent care in the US (especially in Medicaid) have had significant repercussions for HIV oral health programs. Several free-standing clinics that depend upon additional donations of funds from local hospitals to help cover the costs of providing care to PLWH that are not eligible for Medicaid or RWCA funding have had this support reduced. Several university or hospital-based programs report that their institutions have notified them that they must rapidly work towards financial self-sufficiency because the institutional funds available will be reduced in the future. Other community-based programs report that they must find alternative sources to replace funding previously obtained through charitable giving, such as AIDS walks. Several Statewide dental reimbursement programs may not be able to retain the level of funds previously contributed by the State

Dental reimbursement programs face several other challenges. It is often unclear how much the programs should pay dental providers in fee-for-service arrangements. Program staff may not be privy to usual and customary rate (UCR) payment structures used by dental benefit plans or other funders. Additionally, it is unclear if those UCR structures are adequate to meet the additional clinical challenges of PLWH. Fee-for-service programs also report that they commonly use all available funds prior to the end of the funding period.

- **Space**

A common impediment to program functioning and growth is lack of space. Many of the HIV oral health programs studied are located in crowded HIV clinics or CHCs that cannot accommodate their needs. Programs located in multidisciplinary HIV one-stop shopping settings report that lack of space is becoming a problem as new patient services are added.

## OTHER RESOURCES

***HIVDent Website: <http://www.hivdent.org/>***

HIVDENT is a not-for-profit coalition of concerned health care professionals committed to assuring access to high quality oral health care services for adults, adolescents, and children living with HIV disease. HIVDENT disseminates state-of-the-art treatment information and shares expertise in advocacy, development, training, integration, and evaluation of oral health services for PLWH. The HIVDENT web site provides several sections on the oral manifestations of HIV disease and a large picture gallery, information on infection control, post-exposure protocols, pediatric/adolescent care, medications, funding and other resources. Through an easily accessible e-mail system, health care professionals and consumers alike are able to communicate directly with the HIVDent faculty, some of the foremost international experts in these fields.

### ***HIV Dental Guidelines***

- *Oral Health Care For People With HIV Infection: Clinical Guidelines For The Primary Care Practitioner.* These guidelines have been developed by the New York State Department of Health AIDS Institute. They can be obtain from:

[Hppt://www.hivguidelines.org/public\\_html/center/clinical-guidelines/oral\\_care\\_guidelines/oral\\_health\\_intro.htm](http://www.hivguidelines.org/public_html/center/clinical-guidelines/oral_care_guidelines/oral_health_intro.htm)

- *Management of Dental Patients Who Are HIV Positive.* Summary, Evidence Report/Technology Assessment: Number 37. AHRQ Publication No. 01-E041, March 2001. Agency for Healthcare Research and Quality, Rockville, MD.  
<http://www.ahrq.gov/clinic/denthivsum.htm>

### ***RWCA Dental Reimbursement Programs***

A fact sheet describing the RWCA DRP operated by HAB is available at:

<http://www.hab.hrsa.gov/programs/factsheets/drpfact.htm>

Contact information for the participating DRPs is available at:

<http://www.hab.hrsa.gov/programs/dentallist.htm>

### ***Dental Education Programs***

The American Dental Association (ADA) maintains a web-based searchable database of:

- Dental schools,
- Training programs for dental assisting, dental hygiene, and dental laboratory technology, and
- Advanced specialty and general dentistry education programs.

<http://www.ada.org/prof/ed/programs/index.html>

### ***Bureau of Primary Health Care***

The Bureau of Primary Health Care (BPHC) maintains a web-based searchable database of federally qualified health centers that provide dental care services:

<http://ask.hrsa.gov/pc/>

BPHC also maintains a web-based searchable database that can be used to determine if your HIV program is located in a Health Professional Shortage Areas (HPSA):

<http://bphc.hrsa.gov/databases/newhpsa/newhpsa.cfm>

# APPENDIX

<b>TABLE 2. ORAL HEALTH PROGRAMS VISITED OR CONTACTED</b>		
<b>SITE</b>	<b>CITY, STATE</b>	<b>REGION</b>
AIDS Care Group*	Chester PA	Mid-Atlantic
AIDS Project Los Angeles	Los Angeles CA	West
AIDS Project of the Ozarks	Springfield MO	Midwest
AIDS Resource Center of Wisconsin	Milwaukee WI	Midwest
Alta Med Health Services	Los Angeles CA	West
Austin City Health and Human Services Department	Austin TX	West
Bellevue Hospital Pediatric AIDS Program	New York NY	Northeast
Bering Omega Community Services	Houston TX	Southwest
Broward County Health Department	Ft. Lauderdale FL	Southeast
Catholic Healthcare West	Long Beach CA	West
Central Health Center Dental Clinic	Atlanta GA	Southeast
Chase Brexton Health Services	Baltimore MD	Mid-Atlantic
County of San Diego Office of AIDS Coordination	San Diego CA	West
Grady Memorial Hospital Ponce de Leon Clinic	Atlanta GA	Southeast
Hemophilia of Georgia	Atlanta GA	Southeast
Hennepin County Medical Center	Minneapolis MN	Midwest
Hill Health Center	New Haven CT	Northeast
Howard Dental Clinic	Denver CO	West
Jackson Memorial Hospital	Miami FL	Southeast
Lower New York Consortium for Families with HIV and Bellevue Pediatric Infectious Disease Clinic	New York NY	Northeast
Massachusetts Department of Public Health HIV Dental Program	Boston MA	Northeast
Medical College of Georgia School of Dentistry	Augusta GA	Southeast
Miami-Dade County Office of Management and Budget	Miami FL	Southeast
Michigan Department of Community Health HIV Dental and Drug Assistance Program	Lansing MI	Midwest
New Horizons Family Health Services	Greenville SC	Southeast
Oregon Health Sciences University School of Dentistry	Portland OR	West
Palm County Health Department	Palm Beach FL	Southeast
Prevention, Education, and Treatment (PET) Center	Miami FL	Southeast
Public Health Trust (PHT) Center	Miami FL	Southeast
Quad Cities Virology Center	Davenport IA	Midwest
Rhode Island Department of Health	Providence RI	Northeast
Riverside Health System, St. John's Riverside Hospital	Yonkers NY	Northeast

<b>TABLE 2. ORAL HEALTH PROGRAMS VISITED OR CONTACTED</b>		
<b>SITE</b>	<b>CITY, STATE</b>	<b>REGION</b>
Spang Center for Oral Health for Oral Health	Chicago IL	Midwest
St. Joseph Hospital and Medical Center	Paterson NJ	Northeast
St. Joseph's Mercy Care Services Infectious Disease Dental Program	Atlanta GA	Southeast
SUNY Stony Brook	Stony Brook NY	Northeast
University of Alabama, Birmingham	Birmingham AL	Southeast
University of Florida General Practice Residency Program	Gainesville FL	Southeast
University of Maryland At Baltimore School of Dentistry	Baltimore MD	Northeast
University of Minnesota School of Dentistry	Minneapolis MN	Midwest
University Southern California	Los Angeles CA	West

\* Pilot Site Visit

# CITATIONS

---

- <sup>1</sup> Patton LL; van der Horst C. Oral infections and other manifestations of HIV disease. *Infect Dis Clin North Am.* 13(4):879-900, 1999.
- <sup>2</sup> Weinert M, Grimes RM, Lynch DP. Oral manifestations of HIV infection. *Annals of Internal Medicine.* 125: 485-496, 1996.
- <sup>3</sup> Selik RM, Starcher ET, and Curran JW. Opportunistic diseases reported in AIDS patients: Frequencies, associations and trends. *AIDS I*(3):175-182, 1987.
- <sup>4</sup> Marcenes, W, Pankhurst CL, Lewis DA. Oral health behavior and the prevalence of oral manifestations of HIV infection in a group of HIV positive adults. *International Dental Journal.* 48(6):557-562, 1998.
- <sup>5</sup> Capilouto EI, Piette J, White BA, and Fleishman J. Perceived need for dental care among persons living with Acquired Immunodeficiency Syndrome. *Medical Care.* 29(8):745-754, 1991.
- <sup>6</sup> Greenspan D and Greenspan JS. HIV-related oral disease. *Lancet* 348:729-733. 1996.
- <sup>7</sup> Agency for Healthcare Research and Quality. *Management of Dental Patients Who Are HIV Positive.* Summary, Evidence Report, Technology Assessment: Number 37. AHRQ Publication No. 01-E041. March 2001. US Department of Health and Human Services: Rockville MD.
- <sup>8</sup> The full AHRQ report was prepared by the Research Triangle Institute-University of North Carolina at Chapel Hill Evidence-Based Practice Center (RTI). Their final report, including accompanying citations, has not been released. The citations in this literature review will be updated upon the receipt of the report from RTI.
- <sup>9</sup> American Academy of Periodontology Committee on Research, Science and Therapy. *Periodontal Considerations in the HIV-Positive Patient.* Chicago IL: AAP. April 1994.
- <sup>10</sup> AIDS Institute. *Criteria for the Medical Care of Adults with HIV Infection.* New York: NYSDOH AIDS Institute. March 2001..
- <sup>11</sup> Hicks MJ, et al. Dental caries in HIV-infected children: A longitudinal study. *Pediatric Dentistry.* 22(5):359-364, 2000.
- <sup>12</sup> Schoen DH et al. Comparison of periodontal disease in HIV-infected children and household peers: A two-year report. *Pediatric Dentistry.* 22(5):365-369, 2000.
- <sup>13</sup> Coulter ID; Marcus M; Freed JR; Der-Martirosian C; Cunningham WE; Andersen RM; Maas WR; Garcia I; Schneider DA; Genovese B; Shapiro MF; Bozzette SA. Use of dental care by HIV-infected medical patients. *Journal of Dental Research.* 79(6): 1356-61, 2000.
- <sup>14</sup> Marcus M; Freed JR; Coulter ID; Der-Martirosian C; Cunningham W; Andersen R; Garcia I; Schneider DA; Maas WR; Bozzette SA; Shapiro MF Perceived unmet need for oral treatment among a national population of HIV-positive medical patients: social and clinical correlates. *American Journal of Public Health.*;90(7):1059-63, 2000.

- 
- 15 Heslin KC, Cunningham WE, Marcus M. A comparison of unmet needs for dental and medical care among persons with HIV infection receiving care in the United States. *Journal of Public Health Dentistry*. 61:14-21, 2001.
  - 16 Bonuck KA, et al. Self-perceived unmet health care needs of persons enrolled in HIV care. *Journal of Community Health*. 21(3):183-198. 1996.
  - 17 Fleishman JA et al. Dental service use among adults with HIV infection. *Medical Care*. 35(1):77-85, 1997.
  - 18 Mascarenhas AK and Smith SR. Factors associated with utilization of care for oral lesions in HIV disease. *Oral Surgery, Oral Medicine, Oral Pathology, Oral Radiology, and Endodontics*. 87(6):708-713, 1999.
  - 19 Greene VA, et al. Oral health problems and use of dental services among HIV-infected adults. *Journal of American Dental Association*. 128(10):1417-1422, 1997.
  - 20 Shiboski CH, et al. Dental care access and use among HIV-infected women. *American Journal of Public Health*. 89(6):834-839, 1999.
  - 21 Broder HL, et al. Compliance is poor among HIV-infected children with unmet dental needs. *Pediatric Dentistry*. 18(2):137-138, 1996.
  - 22 Unpublished results from the CARE Act Agency Database Project conducted by Positive Outcomes, Inc. Results are based on agencies receiving CARE Act funds in Federal Fiscal Year 1999-2000.
  - 23 Centers for Medicaid and State Operations, *Medicaid and Acquired Immunodeficiency Syndrome (AIDS) and Human Immunodeficiency Virus (HIV) Infection*. Baltimore: Health Care Financing Administration. February 2001.
  - 24 Division of Intergovernmental Affairs. *Medicaid Services State by State*. Baltimore: Health Care Financing Administration. October 1, 1996.
  - 25 Government Accounting Office. Oral Health: Dental Disease is a Chronic Problem Among Low-Income Populations. GAO-HEHS-00-72. April 2000.
  - 26 Government Accounting Office. Oral Health: Factors Contributing to Low Use of Dental Services by Low-Income Populations. GAO-HEHS-00-149. September 2000.
  - 27 Westmoreland, Tim. *Letter to State Medicaid Directors*. Baltimore, MD: HCFA Center for Medicaid and State Operations. January 18, 2001.
  - 28 Epstein, Camm A. *States' Approaches to Increasing Medicaid Beneficiaries' Access to Dental Services*. Washington, DC: Center for Health Strategies, Inc. October 2000.
  - 29 Ryan White CARE Act funding history data are available from the HRSA HAB website: <http://hab.hrsa.gov/care.html>.
  - 30 Personal communication, Haslyn Hunte, HRSA HIV/AIDS Bureau, August 2001.
  - 31 Dental Reimbursement Program. *Ryan White CARE Act Dental Reimbursement Program: 1999 Data*. Rockville: HIV/AIDS Bureau. 2000.

- 
- <sup>32</sup> *Children's Faces (Family AIDS Clinic and Education Services)*. Strategy Transfer Guide: Models That Work. Rockville MD: HRSA/Bureau of Primary Health Care. August 1997.
- <sup>33</sup> Zabos GP, Trinh C. Bringing the mountain to Mohammed: A mobile dental team serves a community-based program for people with HIV/AIDS. *American Journal of Public Health* 91(8):1187-1189. 2001.