

Oral Health Care for People With HIV Infection:

A Review of the Literature

Prepared For:
HRSA HIV/AIDS Bureau

Prepared By:
Positive Outcomes, Inc.

October 29, 2001



ACKNOWLEDGEMENTS

Helen K. Schietinger and Dr. Julia Hidalgo are the authors of this review. They would like to acknowledge the assistance of several staff members of the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau including Dr. Lois Eldred, Ms. Celia Hayes, Mr. Haslyn Hunte, Ms. Kathleen Treat, and Dr. Barry Waterman. Helpful guidance was also provided by Dr. Stephen Abel of the New York State Department of Health AIDS Institute and Dr. Don Schneider of the Centers for Medicare and Medicaid Services (CMS).

This review was supported by Purchase Order 01-0322 (P) with the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB). Its contents are solely the responsibility of the authors and do not necessarily represent the office views of HRSA or HAB.

ABOUT POSITIVE OUTCOMES, INC.

Positive Outcomes, Inc. is an independent consulting firm engaged in public health care program, financing, policy, and service system development; cost and clinical outcomes research; and program evaluation. For more information write to:

positiveout.positiveoutcomes.net *or*
115 Gibson Road Annapolis MD 21401

We can also be reached at (410) 990-9764 (T) or (410) 990-9774 (F).

TABLE OF CONTENTS

Executive Summary	ii
Introduction	1
Methods	1
Periodontal Disease in HIV	2
Oral Manifestations of HIV Disease in Adults	2
Periodontal Disease in Children with HIV	6
Accessibility and Use of Dental Care	7
Access to Dental Care Among Adults with HIV Infection	7
Access to Dental Care Among Children with HIV Infection	9
Barriers to Delivery of HIV Oral Health Care	9
Financing Dental Care for HIV-Infected Persons	10
Medicaid	10
Table 1. Level of Dental Coverage for Adult Medicaid Beneficiaries, January	11
<i>Dental Health Indicators Among Low-Income People</i>	12
<i>Utilization of Dental Services Funded by Medicaid</i>	12
<i>Federal Efforts to Increase Medicaid Beneficiaries' Access to Dental Services</i>	14
<i>State Efforts to Increase Medicaid Beneficiaries' Access to Dental Services</i>	14
Ryan White CARE Act	16
Figure 1. Percent of Title I Funds to Dental Care, By the Number of EMA, FY 2000 (Anticipated)	16
Figure 2. Percent of Title II Funds to Dental Care, By the Number of EMA, FY 2000 (Anticipated)	17
Citations	20

EXECUTIVE SUMMARY

The goals of the project, *Successful Strategies for Delivering Oral Health Care Services to Persons Living with HIV/AIDS*, 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.

This literature review, the initial phase of the project, summarizes information reported in the literature about periodontal disease in PLWH. This review also describes issues regarding access to and use of health services by PLWH, identifies access issues for PLWH enrolled in Medicaid, discusses funding by the Ryan White CARE Act for dental care, and identifies innovative programs that support HIV oral health services.

While oral manifestations of HIV are generally documented in the medical literature, the periodontal conditions afflicting PLWH are not well addressed in the medical or dental 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. In contrast, a longitudinal study of periodontal disease in children with HIV and their household peers concluded that the periodontal findings were similar in the two groups and to the general pediatric population. Timely data are not available about the prevalence of oral diseases in PLWH and the impact of protease inhibitors 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 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. 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 preventive and therapeutic dental services are covered by State Medicaid programs for children, 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 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.

The Ryan White CARE Act has a number of 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 retrospectively compensates dental schools and post-doctoral dental programs for providing oral health treatment to PLWH. However, the relative amount of CARE Act funds allocated to dental care by these CARE Act 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. Structural barriers to development and funding of dental programs have been reported by CARE Act dental providers.

Although successful approaches are being taken by CARE Act 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.

INTRODUCTION

The goals of the project, *Successful Strategies for Delivering Oral Health Care Services to Persons Living with HIV/AIDS*, 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.

To meet these goals, Positive Outcomes, Inc. (POI) has prepared this literature review. POI will also convene a work group of HIV oral health experts. Based on the results of the literature review and the guidance of the work group, ten to fifteen oral health programs supported by the Ryan White CARE Act will be visited to identify successful strategies that may be used to stimulate development of oral health infrastructure and service capacity elsewhere in the US. A final report to HAB will summarize the findings of the literature review and site visits and highlight successful oral health program strategies.

METHODS

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, the HRSA Bureau of Primary Health Care (BPHC), the HRSA Maternal and Child Health Bureau (MCHB), and the Centers for Medicare & Medicaid Services (CMMS) (formerly Health Care Financing Administration). HAB staff providing oversight of the POI project were 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.

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.¹ 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.² 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.

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.³ *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.² 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 HIV-infected adults 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%).⁴ 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 Foundation funded a survey of 857 people with symptomatic HIV infection or AIDS receiving services at AIDS clinics in nine US cities.⁵ 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.

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.⁶ 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.^{7,8} 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 are of little benefit in a clinical setting as indicators of HIV progression.

In the same literature review, AHRQ sought to identify studies that had determined whether people with HIV/AIDS 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).⁷ The review found few studies reporting on the risks of oral procedures among persons with HIV/AIDS, and concluded that there is little evidence of unusual rates or severity of complications for these procedures among persons with HIV/AIDS. 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.⁹ 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 people with HIV 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 people with HIV. 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 people with HIV 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 thoroughly remove 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.¹⁰ 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.

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.¹¹ 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 2 to 15 years at baseline).¹² 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.

ACCESSIBILITY AND USE OF DENTAL CARE

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.¹³ 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. 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.¹⁴ 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.² 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.¹⁵ 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 reported 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.¹⁶ 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.¹⁷

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.¹⁸ 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.¹⁹ 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 people with HIV.²⁰ 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.²¹ 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 CARE Act funds directly provide or arrange for dental care. A recent national study commissioned by HAB found that about 20% of direct service agencies receiving CARE Act funds provide oral health services.²² In this study conducted by POI, we found that oral health services were primarily delivered in hospital-based HIV clinics, community health centers, 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. CARE Act 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 CARE Act funds. In early analyses of responses from agencies receiving CARE Act 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 HIV-INFECTED PERSONS

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.²³ 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.²⁴

Table 1. Level of Dental Coverage for Adult Medicaid Beneficiaries, January 2000

State	Full	Partial ^a	None ^b	State	Full	Partial ^a	None ^b
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		●					

^a 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.

^b 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.

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.

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.²⁵ 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.²⁶ 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.²³ 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 community health centers, 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.²³ 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.

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.²⁷ 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.

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.²⁸

- *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 on-site 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

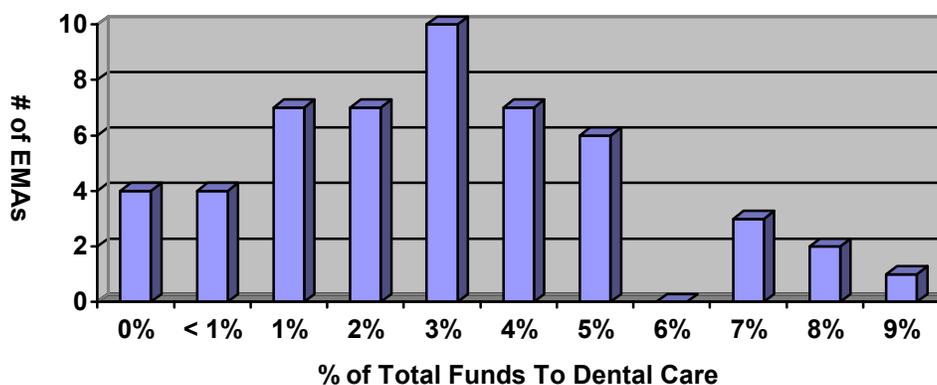
dentures in an effort to increase dentists' participation. Moreover, increasing prevention may decrease later costs for treatment or emergency procedures such as extractions.

RYAN WHITE CARE ACT

Oral health services for PLWH are supported through all four titles, as well as Part F of the Ryan White CARE Act. Over \$16 million in Title I funds were allocated to dental care in FY 2000. Among Title I Eligible Metropolitan Areas (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.²⁹ 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)



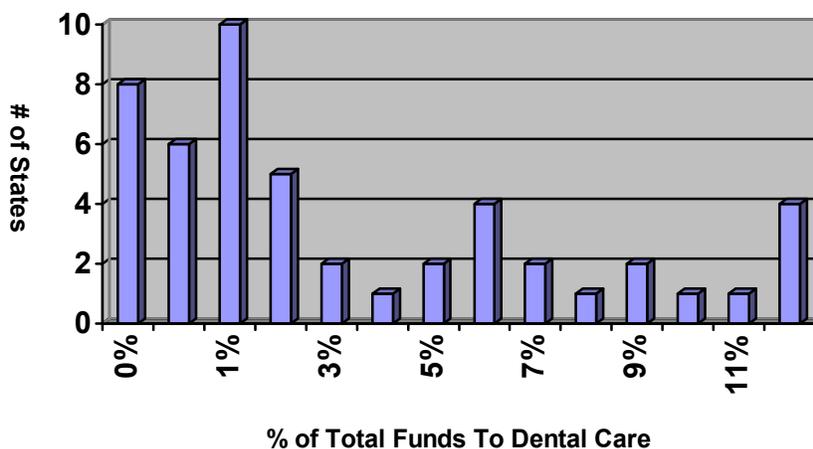
A number of factors may contribute to decisions regarding to allocate Title I funds to dental care. These factors may include demand for care, assessment of unmet need for dental care, the availability of dental providers in an EMA that may be funded to provide care supported by Title I, the extent of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

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.³⁰ 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 Dental Reimbursement Program (DRP) under Part F of the CARE Act 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.³¹

The DRP is unique among CARE Act 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 1997.²⁷ 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 CARE Act 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 on-site clinical trials and new therapeutics;
- Incorporating sensitivity and cultural awareness training for their students and clinic staff.²⁷

There are few descriptions in the published literature of innovative models of oral health care supported by the CARE Act. 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.³²

The American Journal of Public Health featured the Columbia University School of Dental and Oral Surgery in a recent article.³³ The University developed a mobile program to bring dental health care services to three community-based organizations serving people with HIV/AIDS 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.

CITATIONS

- ¹ Patton LL; van der Horst C. Oral infections and other manifestations of HIV disease. *Infect Dis Clin North Am.*13(4):879-900, 1999.
- ² Weinert M, Grimes RM, Lynch DP. Oral manifestations of HIV infection. *Annals of Internal Medicine.* 125: 485-496, 1996.
- ³ Selik RM, Starcher ET, and Curran JW. Opportunistic diseases reported in AIDS patients: Frequencies, associations and trends. *AIDS I*(3):175-182, 1987.
- ⁴ Marcenes, W, Pankhurst CL, Lewis DA. Oral health behaviour and the prevalence of oral manifestations of HIV infection in a group of HIV positive adults. *International Dental Journal.* 48(6):557-562, 1998.
- ⁵ 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.
- ⁶ Greenspan D and Greenspan JS. HIV-related oral disease. *Lancet* 348:729-733. 1996.
- ⁷ 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. <http://www/ahrq.gov/clinic/denthivsum.htm>.
- ⁸ 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.
- ⁹ American Academy of Periodontology Committee on Research, Science and Therapy. *Periodontal Considerations in the HIV-Positive Patient.* Chicago IL: AAP. April 1994.
- ¹⁰ AIDS Institute. *Criteria for the Medical Care of Adults with HIV Infection.* New York: NYSDOH AIDS Institute. March 2001. http://www.hivguidelines.org/public_html/CENTER/clinical-guidelines/adult_hiv_guidelines/supplemental_pages/oral_health_adults/adults_oral_health.htm.
- ¹¹ Hicks MJ, et al. Dental caries in HIV-infected children: A longitudinal study. *Pediatric Dentistry.* 22(5):359-364, 2000.
- ¹² 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.

-
- 13 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.
 - 14 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.
- ³² *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.
- ³³ 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.