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**SPECIAL CARE IN DENTISTRY**

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**SUPPLEMENT**



**DENTAL CARE CONSIDERATIONS OF  
SPECIAL CARE POPULATIONS**

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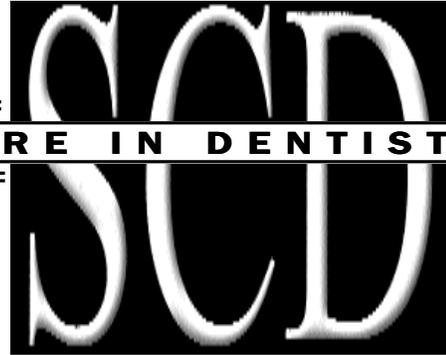
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## INTRODUCTION

*The following Introduction is reprinted from the Dental Care Considerations of Disadvantaged and Special Care Populations Preconference Briefing Materials*

*Spec Care Dentist 22(3):4S, 2002*

**T**he four articles that follow in this supplement were prepared for the Conference on Dental Care Considerations of Disadvantaged and Special Care Populations. The conference, was held in Baltimore, MD on April 18-19, 2001 and was organized by the Research Triangle Institute under contract to the Health Resources and Services Administration, Bureau of Health Professions. Each of the articles focuses on three populations; young children, disabled adults and the frail elderly with special needs that affect their receipt of oral health care. While the authors followed a common outline in preparing their presentations, they were free to draw upon whatever materials they had available, to add the emphasis they felt was appropriate, to offer any insights they could into this population's oral health and care access problems, and to propose solutions for them.

A word about the authors is in order. The Executive Summary for the three formal papers was prepared by Dr. Arthur Bonito, a health services researcher with an extensive dental research background and organizer of the conference. The first paper on young children was prepared by Dr. Burton Edelstein, an energetically outspoken advocate for this group. The paper on disabled adults was prepared by Dr. Doris Stiefel, a pioneer in the development of training for dentists to work with this very heterogeneous group. The paper on the frail elderly was a team effort lead by Dr. Michael Helgeson, who is the CEO of Apple Tree Dental, a unique private-sector organization that specializes in bringing dental care to institutionalized persons. There is no question that these authors know the dental care access issues of the groups they are writing about very well.

Finally, the papers that follow were the basis for brief presentations by the authors at the conference that stimulated small group discussions. As you will note after reading each presentation, these populations are quite different in many ways

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but share many of the same impediments to having their oral health care needs met. These include: limited mobility and dependence on others, low appreciation for oral health care on the part of their caregivers, little or no private insurance coverage and low if any public coverage for dental care, little formal contact with the dental delivery system, limited coordination between health care providers, and an inadequate supply of appropriately trained health professionals. While the oral health care access needs of these subpopulations are the focal point of the conference, the purpose of the conference was to have the conference attendees, through small group discussions, develop recommendations to the Health Resources and Services Administration, Bureau of Health Professions on how to modify its Title VII and VIII programs to better serve the needs of these vulnerable members of our nation.

## ACKNOWLEDGEMENTS

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## Disclaimer

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## INTRODUCTION

Each of the three articles in this supplement has examined the special dental care considerations of a different vulnerable subpopulation in the United States—young children, disabled adults, and the frail elderly. All three of the authors have: (1) clearly described the oral health and dental care access challenges, (2) carefully identified impediments to maintaining and improving oral health, and (3) suggested specific approaches for improving the oral health and access to dental care for the selected segment of the population. While the juxtaposition of these groups will highlight their special needs and conditions, the intent is not to pit one set of needs against another, but rather to focus on their similarities and how the oral health of all may be addressed through modifications in health professional training priorities.

## YOUNG CHILDREN

A young child is defined as being up to 6 years of age. With more than 4 million children born each year in the United States, nearly 24 million children meet this definition. This period of life is especially important because of tremendous growth in size; development in function, capacity, and sophistication; and learning of basic knowledge, attitudes, beliefs, and behaviors that can shape one's later life. Disturbances in a child's health and welfare during this period can take a toll that lasts a lifetime. Also, missed opportunities to establish good health and health behaviors can result in chronic dysfunction or disability.

All young children are not equally at risk for poor oral health and lack of access to needed care. Social determinants associated with their health include family income level, racial and ethnic status, and parental employment and educational status. Place of residence and family structure are also associated with health status and access. While the number of young children is expected to grow only slightly in the next decade, this subpopulation is expected to be composed more highly of immigrants and ethnic minorities. In addition to poor, immigrant, minority, and homeless children, a second distinct group of vulnerable young children are those with physical, mental, and emotional disabilities.

Among all young children, dental caries is the preeminent concern because of its prevalence and consequences. It is the most prevalent childhood chronic disease, five times more prevalent than asthma. Nearly one in five 2- to 4-year olds have visually evident dental caries. Decay is closely tied to social advantage, with poor children up to five times more likely to have decay than their wealthier counterparts. While

# Executive Summary: Dental Care Considerations for Vulnerable Populations

the number of young children who have had dental treatment varies little by income level, the number of teeth remaining decayed in poor children is nearly twice (75 vs. 45 percent) that of those more affluent. Among children under 6 years of age, slightly more than one in five have visited a dentist. The reasons for visits differ markedly by income, however, with nearly twice the proportion of low-income children reporting pain or something wrong as the reason for their visit as nonpoor children. Race, ethnicity, and parental education level also reflect a similar disparity, with the children of non-Whites, Hispanics, and parents without a high school education much more likely to visit a dentist due to pain or a problem. Finally, few young children appear to get any preventive services when they do visit a dentist, although the more disadvantaged get even fewer.

All low-income U.S. children up to the age of 6 have comprehensive dental coverage (at little or no cost to the parents) under Medicaid and its Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program. This coverage has been extended to near-poor children in most states through the State Child Health Insurance Program (SCHIP). Despite the coverage, utilization of the benefit is low. In no state did as many as half of the covered children receive dental care, and in three-fourth of the states, fewer than one in three did, so despite mandated coverage, access was far from universal.

Several impediments to maintaining and improving oral health in young children can be identified. One is the lack of integration between the systems that deliver medical and dental care. To change this situation will require raising the awareness of medical providers about the importance of oral health, expanding the collocation of medical and dental service delivery capabilities, increasing joint training opportunities for medical and dental professionals, and sharing dental disease detection and prevention responsibilities between dental and medical workers.

The size, distribution, diversity, and competency of the health professions workforce are also impediments to achieving better children's oral health. The number of dentists graduating from dental school annually has fallen from more than 6,300 in the 1970s to approximately 4,000 in the 1990s, despite the growing population. However, number of dentists is not the only issue, because increased access for underserved populations has not been historically associated with greater numbers of dentists. Dental schools typically provide little experience to predoctoral students in treating young children, especially those with complicated needs.

The situation is better in postgraduate training programs, but fewer than two of five graduate dentists pursue advanced

training in general dentistry or any of the seven specialties. Graduate training opportunities in pediatric dentistry have been growing but still only represented about 200 openings in 1999. In contrast, the number of hygienists graduating in the United States has been growing and they may be able to take on a greater role in patient education and prevention. However, the limits on their scope of practice often still require a dentist to be present when they practice. In addition, their training does not prepare hygienists to address the restorative and surgical needs of children who have cavities, traumatized teeth, developmental problems, or other existing pathologies.

The maldistribution of dental care providers has been recognized as an impediment for some time and, despite creative attempts to lure them to rural and other underserved areas, many areas continue to go without. Because it has been shown that minority dentists serve more minority patients, the lack of greater racial and ethnic diversity in dentistry also constitutes a barrier to caring for young Black and Hispanic children who have been shown to have disproportionate needs.

Another impediment to improving child oral health is the shrinking cadre of dental school faculty necessary to train future dentists. Nondental health professionals who come in contact with young children and often see them earlier and more regularly than dentists but do not recognize the need for dental care or actively promote the importance of oral health are another barrier to improving the oral health of young children.

The fact that there is no standard predoctoral training required for dentists treating young children is a barrier to meeting their needs. While general dentists are licensed and able to treat children, they often do not feel confident enough to do so by virtue of their limited predoctoral experience. Also, while postdoctoral pediatric specialty training provides intensive and extensive experience treating young children, not enough dentists are receiving this specialty training. This represents a real impediment because they provide a disproportionately large amount of dental care to low-income and other vulnerable children.

Although private dental insurance and public programs like Medicaid and SCHIP are intended to promote improved oral health, they serve as barriers as well. Private coverage is typically provided as a benefit of employment, and to extend it to children requires the payment of a premium. In addition, some private dental plans do not routinely cover treatment of children under 3 years of age, and others impose limits on procedures available to them. Young children with extensive dental needs may require treatment under general anesthesia in a hospital, something that is often covered by private medical rather than dental insurance, but not all states mandate such coverage. Public coverage under Medicaid and SCHIP is mandated to provide comprehensive dental treatment for young poor and near-poor children but only one of five dentists participate in the programs, and only a fraction of them provide more than \$10,000 in billings. The dental safety net providers—school-based clinics, mobile practices, migrant and community health centers with dental facilities, dental schools, and pediatric residency training programs—are far more limited in number than the medical safety net that relies on community hospitals, clinics, and other training facilities as its backbone.

The final barrier to improving the oral health of young

children is the patients themselves and their caregivers. Young children do not have the dexterity to provide their own oral hygiene and do not control their own diet, two important elements of good oral health. They depend on their caregivers to do these things for them. Many caregivers do not have the requisite knowledge or values to recognize the importance of and do not themselves practice appropriate oral hygiene behavior or choose a proper diet. It is made worse when children's attitudes toward dental care are colored by their caregivers' fears and anxieties about the pain associated with dental care.

Among the approaches advocated for improving and maintaining young children's oral health are:

- Using public education to raise awareness of the need,
- Increasing disease prevention through adoption of risk assessment methods and known effective prevention measures,
- Reforming Medicaid and SCHIP to ensure adequate financing to induce greater dentist and hospital participation,
- Increasing system capacity to address the specific needs of pediatric patients, and
- Expanding the health professions workforce including more dentists, and more training for hygienists and other primary-care providers available to deal with children's oral health problems.

## ADULTS WITH DISABILITIES

It is estimated that one in five persons in the United States has some level of disability, and that one in ten has a severe disability. More than half of the persons with severe disabilities are between 22 and 64 years of age. Nearly 2.5 million disabled adults use a mobility device.

Although adults with disabilities represent a very heterogeneous subpopulation, they can be categorized into two groups based on the time of onset of their disability. One group, those with disabilities of developmental origin, includes adults with conditions like mental retardation, cerebral palsy, epilepsy, and autism that are present at birth or that emerge in the developmental period before reaching adulthood. The second group consists of persons with acquired disabilities resulting from trauma, such as head and spinal chord injuries, or from chronic diseases including arthritis, cancer, diabetes, AIDS, degenerative neurological disorders, psychiatric disorders, and chemical dependencies.

The percentage of adults with disabilities increases with age; women are slightly more likely than men to have a disability, and the proportion of women having a disability increases as they age. There are racial and ethnic differences as well; Native Americans and Blacks are more likely to have disabilities than Asians, Hispanics, and Whites. There is also an association between disability and socioeconomic factors. Persons with disabilities are largely poor, have low levels of education, and are likely to be unemployed or only employed part-time.

Persons with disabilities account for a disproportionately large share of medical expenses. They are much less likely to have private insurance available to pay for their care and more likely to be covered by some public program. Greater severity of disability is associated with making more medical visits, and

having insurance to pay for care is also associated with making more medical visits among the disabled. But unlike their use of medical care, persons with disabilities make fewer dental visits than persons without a disability. This is due in part to having few financial resources available to purchase out-of-pocket care, little employment-based dental insurance, and very limited public dental coverage.

While oral health of the average American has improved over the past several decades, the same is not true for disabled adults. Disabled adults have serious dental problems, underutilize dental services, and have limited access to dental care. The deinstitutionalization movement that occurred decades ago with the intent of normalizing the lives of persons with disabilities by placing them in the community may be a contributing cause. Regardless, the dental care that was often provided in an institution was no longer available, and oral hygiene practices and dietary controls that were easier to oversee in institutional settings were much less controlled in community settings.

More importantly, however, disabled adults require treatment from dentists with training in special care dentistry. This field of dentistry addresses the needs of persons: whose care requires accommodation to their disability; whose dental health has been neglected, with resultant widespread disease; and who have difficulty locating dentists who will treat them.

While adults with disabilities present a range of conditions and levels of impairment, they may need more support to access, use, and derive optimal benefits from treatment. Providing care may take longer, travel and other arrangements may be needed, and they may be unable to perform their own follow-up care. Dentists trained in special care assess the patient's level of functioning and medical status before beginning treatment by interacting with the patient, the physician, and the caregivers. Special care dentists know that treatment and aftercare may need to be modified to accommodate the patient's condition and living situation.

It is important to recognize that oral health is integral to overall health, and that the failure to properly maintain oral health can result in deterioration in overall physical health. Some oral infections have been associated with systemic medical conditions, some treatments for chronic conditions can predispose to oral disease, and some medical conditions may lead to dental problems. Overall, the limited literature available documents that disabled persons exhibit poorer oral hygiene, more severe periodontal disease, more decayed tooth surfaces, and greater treatment needs than persons without disabilities.

These oral conditions may result from the disabled adult's dependency on caregivers who are not well informed, not motivated to provide the hygiene care, not fully appreciating the importance of oral health, or not well trained. In addition, the disabled person's fear and anxiety about receiving dental care, whether based on prior bad experiences or not, may inhibit seeking dental care.

Among persons with disabilities, limited access to and the unmet need for dental care are reported repeatedly. Among the impediments identified as restricting their access and leading to an increased need for care are: the lack of personal financial resources, private dental insurance, and public dental

programs; the lack of properly trained caregivers and dental personnel; a failure by all parties involved to appreciate the importance of oral health; and problems of physical access and mobility for adults with disabilities.

The fact that adults with a disability are poor and often unemployed or only employed part-time means that they have few financial resources and little private insurance to cover their dental care expenses. Medicaid benefits for dental care differ by state and generally are quite limited. In addition to their service limitations, dentist participation in the program is very limited as well. Providers maintain that it is because of the low rates of Medicaid reimbursement.

Surveys indicate that only a small proportion of dentists in private practice are willing to treat patients with disabilities and that they are more reluctant to treat patients with developmental or psychiatric disabilities than those whose disability is physical. Many dental professionals in positions where they need to treat disabled patients reported being poorly or totally unprepared. In addition, the little training given in special patient care to predoctoral dental students and prebaccalaureate hygiene students is focused on providing care in private practices to mildly to moderately disabled persons. No dentists or hygienists are receiving advanced training to treat the growing number of severely disabled adults. Because many with severe disabilities may be in institutional settings, caregivers there need to be educated in the importance of maintaining the patient's oral health and correctly performing hygiene.

With respect to training in special care dentistry, the situation is troubling. Despite a growing need for increased training in special care dentistry, support has diminished. Predoctoral students typically get only didactic training and little or no hands-on experience in caring for disabled patients, and the situation is even more limited at the postdoctoral level, with only a handful of programs offering the training necessary to treat disabled adults. Not enough dental professionals are getting this training.

The failure to recognize dental care as important to and necessary for the health of disabled persons is pervasive across the health disciplines, social service agencies, state and federal legislatures and other policymakers, and third-party payers as well. This attitude must be changed if there is to be increased funding for training and to pay for care, as well as greater recognition of the importance of oral health by more health professionals.

Disabled adults must often travel some distance to locate a dentist willing and able to provide services. This places a greater burden on their family or caregivers to get them to the dentist, beyond what would be needed merely for transportation to a dentist. Lack of physical access to dentists capable of treating them is a very real barrier to care, especially for persons living in rural areas.

The oral health of adults with disabilities needs more attention; this group is often forgotten, growing in numbers, and present with extensive dental needs. However, there is great potential to improve their health, function, and quality of life. Several approaches are suggested to improve the oral health of disabled adults as well as their access to dental care. The key to all of them is for more financial resources for treatment and training, for dental care to be recognized as

important, and for enough trained providers willing to deliver care to this group.

One approach suggested is greater integration of the health care delivery system. A system in which private practices and regional centers (e.g., in universities and institutions) could be woven together to provide the full range of services needed to a full spectrum of disabled adults would help ensure that the need for care at different levels of complexity and in different geographic areas could be satisfied. This might include locating dental facilities with other health care facilities, especially in academic medical centers.

In addition to a more integrated care delivery system, more collaboration is needed between dental care and other health and social services providers. Such collaboration and appreciation of each other's roles in the care of disabled adults could be better served through interdisciplinary training. More effort is needed to reach caregivers and the disabled themselves with the information and training necessary to value and perform proper oral hygiene. More support for general practice residencies and graduate fellowships in special care dentistry as well as advanced training for hygienists are needed, along with incentives for new trainees to serve the severely disabled. These specially trained providers could form the heart of a new corp of special care teaching staff at university medical centers.

Greater use must be made of preventive procedures and materials, including adaptive techniques and tools. The reduction in disease morbidity would more than pay for the extra effort. Further research is needed into many aspects of the epidemiology, risk factors, and service delivery aspects of dental diseases in disabled adults that take into account the nature of the disability, and standards of care need to be established for this group.

Finally, more financial support is needed to help pay for the care that disabled adults require. It is needed to train and better distribute more dentists and hygienists and other health care workers who know how and are willing to provide the restorative and preventive dental services that disabled adults need. Funding is also needed to support faculty to do the training and conduct the necessary research to make improved oral health a reality for disabled U.S. adults.

## FRAIL ELDERLY

The U.S. population is aging. Today approximately 35 million persons are 65 years of age and older, a tenfold increase since 1900. By 2030, that number is expected to double to 70 million, representing about 20 percent of the U.S. population. The fastest growing segment of the elderly population is the group 85 years of age and older. Today they constitute about 4 million persons, but by 2050 this group is expected to grow to nearly 20 million. About half of the elderly reside in only nine states. California, Florida, New York, Texas, and Pennsylvania each have about 2 million or more, followed by Ohio, Illinois, Michigan, and New Jersey with over 1 million each.

The vast majority of the elderly live in the community. It is estimated that only 1.6 million, or less than 5 percent, reside in nursing homes. Fewer than 1 million others are estimated to reside in less "restrictive" institutional environments such as assisted living facilities and the like. However, the number of

such facilities has grown dramatically in the past decade or two, so the number who will be residing in them will likely increase. The proportion of the elderly who live in nursing homes increases with age, with about 1 percent of 65 to 74 year olds to nearly 20 percent of persons 85 and older.

Clearly not all of the elderly are frail, and it is difficult to estimate how many of them are. Not being able to get out to visit the dentist on one's own is used here to define the frail elderly. By this definition, the frail elderly include those community-dwelling persons 65 years of age and older whose mobility is limited by their chronic conditions, those in the community who are homebound or functionally dependent, and those in nursing homes who are functionally dependent. As many as 30 percent of the elderly may be included in this definition as frail.

The frail elderly are most often women and typically over 75 years of age. Many live alone, have few social and financial resources, and suffer from chronic conditions that limit their activities. Those in nursing homes are overwhelming non-Hispanic Whites and rely on Medicaid as their primary source of payment.

Maintaining oral health is important to good general health in the frail elderly because of its vital connection to nutrition and communication, and its association with systemic infections. For the frail elderly, good oral health also means eliminating pain and maintaining function so that their quality of life can be sustained.

However, the frail elderly have extensive oral disease in need of treatment, they have medical problems that complicate their care and, because of their age and health status, their diagnosis and treatment are more complex. Their need for dental treatment is extensive often due to a long period of neglect of their oral health since many lose their dental insurance upon retirement and the cumulative lifetime toll of oral diseases. A variety of surveys have shown dentate nursing home residents to be in particular need of treatment for dental caries, whereas those without teeth also have a variety of problems.

The presence of chronic and systemic medical problems is sometimes manifest in the oral cavity and often complicates oral health. The loss of teeth can complicate medical conditions by affecting the ability to bite, chew, swallow, and enjoy food, with a resulting adverse impact on nutritional status. In addition, the large number of medications the elderly take to control chronic conditions often have side effects that adversely affect their oral tissue.

The diagnosis and treatment of the frail elderly differs from that of younger persons because of changes that occur in the teeth and other oral tissues that require alterations in the procedures as well as materials used. Additional considerations can affect treatment decisions involved with caring for the cognitively impaired and dying patient. There are also special legal and ethical considerations that must be taken into account with respect to the use of anesthesia and restraint of patients, and dentists must also be aware of the elder abuse issue.

A variety of impediments to maintaining and improving the oral health of frail elderly persons have been identified. They include the absence of an effective dental care delivery system, the absence of adequate numbers of properly trained

health professionals, the lack of financial resources and dental insurance to pay for care, a failure to appreciate the importance of oral health, and the inability of the patient or caregivers to perform proper oral hygiene.

The inadequacy of the delivery system includes inadequate facilities and equipment to serve the frail elderly. Nursing homes and private dental offices rarely have the necessary equipment to deliver comprehensive primary care, and hardly ever have the portable dental equipment needed to provide bedside care to those who are bed-bound in nursing homes or in the community. Additionally, they may not have the special equipment (like a Hoyer lift for patient transfer) or the staff and know-how to administer sedation to patients who are profoundly confused or disoriented. Traditional dental offices typically do not have nursing staff to assist frail elderly patients with their other care needs during dental treatment. Additionally, dentists are not trained or experienced providing treatment outside of their practice confines and therefore do not feel comfortable with this. While dentists may not be trained to work comfortably in nursing homes, physicians, nurses, and aides employed in nursing homes have limited training to recognize oral problems, especially soft tissue lesions or the oral sequelae of chronic conditions.

Since most dental insurance is provided as a benefit of employment, most elderly persons lose that coverage upon retirement and are forced to pay for dental care fully out of their own pocket. As a result, many stop making regular dental visits. Public programs do not do a very good job of assuring dental care benefits for the elderly. Medicare does not cover dental treatment unless it is an integral part of treatment for a medical condition such as cancer. State Medicaid programs rarely cover adult dental care, and when they do it is often just to relieve pain. The reimbursement for dental care under Medicaid has fallen to such a low level that few dentists choose to participate in the program.

The elderly, and often their caregivers, have little understanding and appreciation for the importance of maintaining good oral health. The experience of oral pain, absence of teeth, and associated loss of function was accepted for a long time in the United States as the normal result of the aging process. Such expectations on the part of patients and caregivers have been a major impediment to providing dental care to the frail elderly. Among the elderly living alone, physical limitations due to their chronic medical conditions often prevent them from being able to perform proper oral hygiene even if they wanted to. Those living in the community with a caregiver get little better. Those living in institutions are limited in the same way, but have aides who can assist them. The evidence indicates that these caregivers do not do as good a job as is necessary and that they have little motivation to perform adequate oral hygiene on difficult patients in the community or in nursing homes.

Several approaches have been suggested for improving the oral health and dental care access of the frail elderly. Among the suggestions are a new approach to treatment planning that includes consideration of the patient's input, an objective assessment of the patient's condition and level of restorable function, the impact of the patient's medical conditions, and an assessment of the sustainability of any treatment options.

Another approach is to make it easier for elderly patients to visit a dentist and, when that is not possible, as in the case of

severely impaired frail elderly, to make it easier for a dentist to visit the patients. One important aspect of bringing the frail elderly into a private dental practice is to do a complete medical history of conditions, medications, and medical procedures that may require premedication (e.g., antibiotics or anesthesia) before treatment or suspension of medication (e.g., warfarin) before treatment. The delivery of on-site dental care to residents of nursing homes requires more than just portable equipment. On-site care requires integration of the medical and nursing staff, consideration of legal and regulatory issues, and possibly a new approach to financing care. For this approach to work will mean greater integration of medical, nursing, and dental staff, greater communication and improved understanding among them, and improved documentation for the records.

New approaches are needed to finance dental care for the elderly. These could include expansion of private dental insurance after retirement, inclusion of dental services in Medicare or in supplemental plan coverage, and an expansion of Medicaid benefits for adults as well as an increase in the reimbursement levels for care provided. All of these approaches should be open to new ways of paying for care delivered beyond the typical fee-for-service approach of private practice.

Finally, it is important to provide caregivers (family and aides) and physicians, nurses, and dentists the special training and experience they need to be comfortable and competent in managing the oral health of frail elderly adults and their dental treatment. Caregivers need training in the importance and practice of oral hygiene for the elderly and the use of modified devices and methods to accomplish it. In their predoctoral and prebaccalaureate education, primary health-care providers need instruction in oral diseases, oral pharmacology, and the oral consequences of systemic diseases. Similar training is needed for physicians and nurses through continuing education courses. Predoctoral training for dentists needs to incorporate more didactic and clinical training experience in delivering care to functionally dependent and frail elderly. Opportunities for graduate and residency training in geriatric dentistry need to be expanded. More continuing education courses are needed for dentists, hygienists, and assistants in how to deliver care to residents of nursing homes.

## **SUMMARY OF CROSSCUTTING DIMENSIONS AND INTEGRATING THEMES**

The three articles clearly distinguish how each of these groups of special care patients differ from one another. The most obvious distinction is in the age of the persons who constitute the groups. The groups also differ in size, distribution, and in the types and causes of the oral problems they present for treatment. The special kinds of training required by the oral health care team also differ by group.

Yet all three groups are similar in their dependence on others for transportation to receive dental care, to decide when dental care is needed, and to assure that they receive proper oral hygiene. Furthermore, the oral health problems of all three groups are similarly worsened by their disproportionate poverty and lack of adequate dental coverage (public and private) to pay for their care. The time and distance required to find and

travel to dentists with the special training needed and the willingness to give them the care they require are similar as well.

Despite differences, the oral health and dental care access problems faced by all three are fairly similar. The need for more and better-trained dental professionals is the same as well. Although the specific training needed for dental providers to treat the oral health problems of each of the three groups vary, the approaches suggested to effectively address their problems have many similarities. These include increasing integrated medical and dental delivery systems, providing collocation of services as well as mobile services;

joint training of medical, nursing, and dental care providers so all are aware of their role in treating the total patient; greater training and experience at the predoctoral level of dental training and prebaccalaureate level for hygienists to increase the supply of providers willing and able to provide the special care; greater numbers of graduate-level and residency opportunities for advanced training; increased continuing education courses focused on each group's special needs that reach across the health professions; and an educational thrust to raise the general public's and the health profession's awareness of the importance of oral health to and its relationship with general health status.

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## ORAL HEALTH AND DENTAL CARE ACCESS CHALLENGES

**B**ecause of their developmental dependency, young children constitute a special population requiring the attention and consideration of society and its governmental policymakers. Oral health is an essential and leading component of children's overall health, functional capacity, and social welfare. This chapter focuses on young children's oral health by highlighting disparities in both health status and dental care, recognizing demographic trends that will shape policies addressing their needs, describing barriers to their care, and suggesting fruitful opportunities to enhance their oral health, particularly through health professions training.

## EARLY CHILDHOOD CHARACTERISTICS AND DEMOGRAPHY

Early childhood is the period of life from birth to age 6 that encompasses the neonatal, infant, toddler, and preschool periods. It is a time of tremendous growth in size; development in function, capacity, and sophistication; and acquisition of fundamental knowledge, attitudes, beliefs, and behaviors that largely shape an individual's subsequent life experience. While early childhood is a time of tremendous promise, it is also a time when disturbances in health or social welfare can take a toll that is expressed throughout life. It is also a period when missed opportunities to establish positive health and healthcare conditions can initiate chronic dysfunction or disability. In short, early childhood constitutes a period that starts with helplessness and ends with a dawning capacity to appreciate, organize, and confront the role of self in the larger worlds of family, community, and society.

While all young children are dependent and therefore vulnerable, there is a wide spectrum of family empowerment and advantage into which children are born. As President George W. Bush reminded the country in his inaugural address in referring to children of poverty, "children at risk are not at fault." His message defines the rightful role of government in caring for the needs of children and can serve as the basis for aggressively addressing disparities that limit some children's capacities to achieve.

### Young Children at Risk

Social determinants that correlate highly with young children's health and healthcare include family income, racial and ethnic status, parental employment status, and level of parental educational attainment. Additional factors that correlate with

# Dental Care Considerations for Young Children

many aspects of health include geographic location, family structure, sex, and age. Children of impoverished, minority, immigrant, or migrant families, and those who are homeless are particularly vulnerable because their families are often less able to provide the essential determinants of health attainment.

Another distinct group of young children who are particularly vulnerable are "children with special healthcare needs" (CSHCN), those with physical, mental, and emotional disabilities. For many of these children, every endeavor is more complex and demanding than for their less-challenged peers.

## Impact of Demography

The demography of children in the United States is a critical factor in addressing oral health and dental care because oral disease and dental treatment vary significantly by sociodemographic and general health variables. With roughly 4 million children born each year, the U.S. population under age 18 is about 72.0 million. Of these, 23.7 million are under the age of 6.<sup>1</sup>

Diversity among young children is well described in the following excerpt from the U.S. Surgeon General's Workshop on Children and Oral Health.<sup>1</sup>

According to March 1999 Current Population Survey data, children under the age of 6 comprise 9% of the population, and 39% of young children are of racial/ethnic minority status (which includes Black, Hispanic, Asian/Pacific Islander (API), American Indian), higher than any other age group. First generation immigrant children represent only 1.5% of young children, but young children of immigrants (second generation) represent 20.4% greater than the percentage of Black or Hispanic young children, 15% and 18% respectively. More racial and ethnic minority young children live in poverty than do majority White children. Children are considered as living in poverty if they reside in a household with a gross annual income below the federal poverty level (FPL). The FPL, which is determined annually, is currently \$17,650 for a family of four.<sup>2</sup> While 13% of White and 17% of API young children live in poverty, 38% of Hispanic children and 41% of Black young children are poor.

One-parent households are often unable to provide the same level of resources for children as two-parent households, with the deficiencies generally worse for female-headed rather than male-headed households. A majority of Black children ages birth through 17 years (54%) live in female-headed households versus 26% for Hispanic children and only 15% for

White and API children. The more children in a household, the greater level of competition for food, clothing, shelter and health care. Black and Hispanic children tend to live in households with more children, as do first-generation immigrant children.

Race/ethnic and generational differences for household incomes are dramatic, with median incomes for White and API children exceeding \$50,000 whereas those for Black and Hispanic children are below \$30,000. Household income also progresses upwards for immigrants from first to second to third or higher generations. Black and Hispanic children are more likely to live below the poverty line as API children (2 times) and White children (3 times). Parents of Black and Hispanic children are less likely to be highly educated or even obtain a high school diploma. Children of immigrants are 3-4 times more likely to have a high school dropout parent than children of natives.

Non-Hispanic White children have the highest proportion reporting excellent or very good health, followed by API, Hispanics, and then Blacks. While 11% of White children are without health insurance, that proportion is higher for API (16 percent), Black (20%), and Hispanic (30%) children.

In the next ten years, there will be only a slight increase in the number of children under age 18 (72 million), but racial composition of children will change. Rapid growth will occur among Hispanic and API children over the next 25 years. The new racial/ethnic composition by 2025 is estimated at 54 percent White non-Hispanic (compared to 63% in 1999), 14% Black (compared to 16% in 1999), 25% Hispanic (compared to 16% in 1999) and 7 percent API (compared to 4% in 1999). The new demography has implications for health. Intergenerational competition for health resources may intensify as there will be fewer working-age adults to provide public financing for supporting the elderly population. This may result in decreased public resources devoted to the health of America's children.

Of particular importance to oral health, the groups of children that bear the highest levels of disease burden are the same groups that are expanding most rapidly. In particular, Hispanic and API children demonstrate higher levels of dental caries than White or Black children.<sup>3</sup> As the proportion of children in the U.S. population who are Hispanic and API increases, total disease burden in young children can be expected to increase commensurately. Therefore, temporal declines in dental caries noted over the last two decades can be expected to reverse.

Seventy percent of all children are generally healthy while 20 percent require regular medical treatments for some reason and 10 percent live with chronic disease requiring more intensive healthcare.<sup>4</sup> The small numbers of chronically ill children represent a major challenge to the dental profession. Unmet need for dental care as reported by parents on the National Health Interview Survey is far higher for ill children than for their peers. While 7.3 percent of all parents report that their child is in need of dental treatment that has not been obtained, 24 percent of parents of children with special healthcare needs report such unmet need.<sup>5</sup>

### **Dental Care Considerations for Young Children**

For all young children, oral health is an essential component of overall health and dental care is an essential health service.

Oral health and dental care are important and consequential for young children because sound oral function is required for effective eating, speech development, and emergence of a positive self image and because oral and dental conditions can predispose children to significant oral and systemic consequences. These consequences include dental pain<sup>6</sup> and associated distracted and negative behaviors,<sup>7</sup> infection of the oral tissues and face, failure-to-thrive,<sup>8</sup> as well as aggravation of concomitant medical conditions such as diabetes or human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS). Additionally, early onset dental decay is a strong predictor of dental caries progression throughout life.<sup>9,10</sup>

Professional dental care is only one determinant of oral health status. Oral health is at least as dependent on parental caregiving. Health behaviors including diet and use of fluorides are also major determinants of oral health. Yet dental care remains an essential health service both for oral health promotion and for repair of damaged structures.

### **Oral Health of Young Children**

Early childhood is marked by tremendous growth and development of the face, mouth, and dentition, all of which may require the attention of a dental professional. Among the more common oral conditions of early childhood are dental caries (tooth decay), oral mucosal infections, accidental and intentional dental and oral trauma, developmental disturbances associated with teething or tooth formation, and developmental clefts of the lip and/or palate. Additionally, parents frequently request information on additional concerns including sucking habits, tooth alignment, timing and order of tooth eruption, and tooth coloration.

Among these conditions, dental caries is the preeminent concern because of its tremendous prevalence and consequences. Dental caries is the single most prevalent chronic disease condition of childhood,<sup>11</sup> 5 times greater than asthma.<sup>12</sup> Overall, nearly one in five (18.7 percent) U.S. children ages 2 to 4 have experienced visually evident tooth decay.<sup>13</sup> Decay experience is closely tied to the level of social advantage with poor children more likely to develop caries. Poor children under age 5 are 5 times more likely to have cavities than children from families with incomes 3 times the poverty level. In the National Health and Nutrition Examination Survey III (NHANES III), caries was visually evident in 30 percent of 2- to 5-year-old children in poverty, 24 percent of near-poor young children, 12 percent of middle income young children and only 6 percent of young children from families with incomes at least 3 times the poverty level. Children of poverty also experience more extensive dental disease than their higher-income peers. Children living in households below 2 times the poverty level have 3.5 times more decayed teeth than young children from more affluent families. The percentages of young children of various income levels who have experienced dental repair is far more consistent across income groups. However, since low-income children experience more disease, their unmet need remains higher than that of more affluent children. In fact, 79 percent of the decayed teeth of poor 2- to 5-year-old children were unfilled while 45 percent of decayed teeth in the highest income group were unfilled. This finding suggests both that high-income children do not access dental treatment sufficient

to meet their needs and that low-income children suffer from significant disparities in dental care. Similar statistics are reported across a wide variety of state surveys.<sup>14</sup>

Among all U.S. children under age 6, an estimated 21.5 percent experienced a dental visit. Slightly, but not statistically significantly more girls than boys had a visit, a finding that remains consistent over all ages in the United States. White children were 1.5 times more likely to have a dental visit than non-White children. High-income children (>400 percent FPL) were twice as likely to have a dental visit than poor and near-poor children.<sup>15</sup> Among young children who had a dental visit in 1996, there was little association between income or race and the number of visits obtained. This finding is unique to children under age 6. For older children, social advantage correlates strongly with larger numbers of visits even though social advantage is also highly correlated with lower levels of disease. In interpreting these data, the authors suggest that "this observation may reflect the fact that very young children are more likely to be seen episodically and experience only sufficient numbers of visits to address their clinical complaint." Since the majority of dentists are generally not well prepared by predoctoral dental education to manage the oral health care of young children, the authors believe that dentists tend to address only the primary reason the preschooler presents for care. As income levels increase, dental pathology decreases.<sup>15</sup> Thus, it is not surprising that over one-fifth (21.5 percent) of nonpoor children ages 2 to 6 who had a dental visit in 1996 were provided with a preventive service while only 8.9 percent of poor children obtained a preventive service at their visit (R. Manski, D.D.S., personal communication, December 1999).

Low-income children are far more likely to obtain dental care because of pain or "something bothering the child" than are nonpoor children. Nearly one in five (19.4 percent) poor children who obtained a dental visit in a year did so because of symptoms while only one in ten (9.7 percent) nonpoor children did. Similar disparities are evident by race and ethnicity and parental education. More Black (1.6 times) and Hispanic (1.7 times) children obtained dental care because of symptoms than White children. More children whose parents have less than high school education (2.3 times) or only high school education (1.6 times) obtained dental care because of symptoms than children whose parents had more than a high school education.<sup>16</sup>

The Department of Housing and Urban Development reports that families with children constitute an estimated 38 percent of the U.S. homeless population and that children account for one-quarter of the homeless.<sup>17</sup> Like other poor children, homeless children were only one-fourth as likely to have a dental visit as a medical visit. While no data are available specific to young children, a study of homeless 5 to 9 year olds in Boston revealed that 96 percent were in need of dental care and 44 percent had evident pain or infection at the time of examination (M. Ramos, D.M.D., personal communication, March 2001).

### **Role of Public Insurance Programs**

Almost all low-income U.S. children are eligible for comprehensive dental coverage under Medicaid and its "Early and Periodic Screening, Diagnosis, and Treatment" (EPSDT) program.<sup>18</sup> Medicaid mandates coverage for all children under age 5 in families with incomes up to at least 133 percent of the

FPL as well as for children from age 5 to 6 from families with incomes up to at least 100 percent of the FPL. Many states extend Medicaid coverage to children from families with higher incomes. Comprehensive dental care is also generally provided to near-poor children under governmental programs in all states but Colorado through the State Child Health Insurance Program (SCHIP). Both Medicaid/EPSDT and SCHIP insurance programs prohibit or sharply limit treatment costs to parents. Both programs mandate access to care. However, dentists' familiarity with these programs and participation in them are limited, and access to care falls far short of coverage. The Department of Health and Human Services Inspector General determined in a 1996 report that only one in five Medicaid-enrolled children obtained a dental visit in a year while four in five obtained a medical visit.<sup>19</sup> In no state did more than half of children obtain a dental visit, and in nearly three-quarters of the states less than 30 percent did so. These failures to provide dental care to the most vulnerable children suggest, in part, that health professionals who attend to young children need to integrate their services and develop the capacity to address the special needs of young disadvantaged children.

In sum, young children as a class constitute a population of special concern to the health professions because of their vulnerability, lack of autonomy, and the significance of their experiences in shaping their futures. Gross disparities among young children in the existence, extent, and consequence of oral disease further substantiate that low-income, minority, immigrant, and other socially disadvantaged children bear a disproportionate burden of disease. Yet these children with greatest need access dental care at considerably lower rates decayed teeth,<sup>13</sup> twice the extent of decay when they have disease,<sup>13</sup> twice the dental pain experience,<sup>16</sup> more than twice the dental insurance coverage (R. Manski, D.D.S., personal communication, February 2001), but fewer dental visits than their higher-income peers.<sup>15</sup> Low-income and other socially disadvantaged children often present unique challenges to the dental delivery system and its workforce. Assuring that these children can access care at least to the same degree as nonpoor children and that such dental care is sufficient to comprehensively meet their needs is a significant challenge to health professions training.

### **IMPEDIMENTS TO MAINTAINING AND IMPROVING ORAL HEALTH OF YOUNG CHILDREN**

Barriers to improving oral health and dental care for young and low-income children have been extensively reviewed by federal agencies,<sup>20-21</sup> the dental profession,<sup>22</sup> the U.S. Congress,<sup>23,24</sup> multiple states,<sup>25-30</sup> groups of state policymakers including the National Conference of State Legislatures,<sup>31</sup> National Governors Association,<sup>32</sup> Association of Maternal and Child Health Programs,<sup>33</sup> and National Association of State Medicaid Directors,<sup>34</sup> public interest attorneys,<sup>35</sup> child advocates (including the Children's Defense Fund, Families USA and the National Parents Consortium) and the press.<sup>36</sup>

Barriers are multiple, multifaceted, and often complex. They arise from all concerned—families, providers, payers, government, and healthcare systems. This chapter focuses on these barriers from the perspective of medical and dental providers and recommends proposed solutions to many of the most frequently cited or best substantiated barriers.

## Barriers Related to Systems Integration and Medical Systems of Care

All who engage young children in health, nutrition, or education programs can play a significant role in promoting oral health and eliminating barriers to care.<sup>37,38</sup> Appropriate providers include lay health workers, nurses and nurse-practitioners, physicians, dental hygienists, and dentists (particularly pediatric, public health, and advanced practice general dentists). Other professionals who can promote oral health include teachers, Head Start and Women, Infants, and Children (WIC) program workers, social workers, and nutritionists.

In order to anticipate and prevent oral and dental pathologies, interventions must begin very early—preferably prenatally by including oral health screening and maternal dental services in routine pregnancy care. This is advantageous both because active periodontal disease in pregnant women has been related to the poor birth outcomes of prematurity and low birth-weight<sup>39</sup> and because maternal dental health correlates strongly with dental caries risk in their offspring.<sup>40</sup>

## Integrated Systems of Care

The American Academy of Pediatric Dentistry's "Filling the Gaps" work group on Community Integrated Systems of Care has adopted the model described in Table 1 to characterize opportunities of various health professionals to intervene at various prevention and disease management levels. These levels include anticipatory guidance, primary prevention, and disease suppression as well as dental repair for those not effectively reached through prevention. Table 1 presents potential roles for various types of health care providers in addressing dental caries in young children at various stages of disease progression. The suggested roles assume that the provider type be adequately educated and trained to deliver the particular procedure noted. The work group identified a dentist-based early dental intervention effort in Washington State entitled the "ABCD" or "Accessing Baby and Children's Dentistry" program and a pediatrician-based early dental intervention effort in North Carolina, "Into the Mouths of Babes." The work group is now developing a best practice model that would combine and integrate favorable attributes of both programs. Approaches to early childhood oral health promotion and services integration through pediatric medical care are also currently underway in California, South Dakota, and West Virginia with funding under Medicaid demonstrations and the Health Resources and Services Administration (HRSA) Office of Rural Health programs.

Raising awareness among medical providers, integrating services between medical and dental delivery systems, and demonstrating preventive strategies that engage medical as well as dental providers have been widely suggested. Such concepts have been promoted conceptually by federal agencies<sup>a</sup> discussed at stakeholder meetings and conferences<sup>b</sup> and enacted as new programs by Congress.<sup>c</sup> Moving services integration from concept to reality will require significant advancement of both science and infrastructure. These efforts will include workforce preparation, improved funding of services through Medicaid, development of information and referral systems, and funding evaluation programs that determine effectiveness. A planned Spring 2001 caries

management "Consensus Development Conference" at the National Institute for Dental and Craniofacial Research may provide the health professions with an expanded scientific rationale and armamentarium for these early integrated interventions.

Science has provided a clear understanding that tooth decay is an infectious and transmissible disease<sup>41</sup> acquired by toddlers from their mothers shortly after the first teeth erupt.<sup>40,42</sup> This single finding indicates that true primary prevention must begin in the first to second year of life. Nonetheless, leading health professional organizations differ on the recommended age for a first dental visit. The Bright Futures consortium representing 28 child health organizations<sup>43</sup> as well as dental and public health groups including the American Academy Pediatric Dentistry (AAPD), American Dental Association (ADA), American Dental Hygienists Association, and American Public Health Association all endorse initiating formal dental care at age 12 months.<sup>44</sup> In contrast, the American Academy of Pediatrics maintains a standard of referral at age 3 in its periodicity schedule, claiming that pediatricians can provide appropriate oral health guidance until that age. A recent study of pediatricians<sup>45</sup> confirms that pediatricians demonstrate willingness to provide oral health guidance but that they have little formal training or clinical knowledge of pediatric oral health. Similarly, studies of nurses<sup>46</sup> suggest that their preparation for providing dental services is also profoundly inadequate. Accreditation standards and typical curricula for educating dentists and hygienists also fail to provide substantial information and training to assure that even dental professionals are prepared to address the unique needs of young children. Within dentistry, care for young

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- a. Among federal agency programs and activities that promote shared concern by physicians and dentists for young children's oral health are the HRSA/Maternal and Child Health Bright Futures project and Community Integrated Services Systems grant program, the HRSA/Bureau of Primary Care efforts to provide "one-stop" integrated health care in community health centers, the HRSA/Bureau of Health Professions primary care training programs, the HRSA/Office of Rural Health and Health Care Financing Administration (HCFA) early childhood caries demonstration grants and a National Institute of Dental and Craniofacial Research Centers grant program to eliminate oral health disparities.
  - b. Among meetings that have considered these linkages are the 1998 "Building partnerships to Improve Children's Access to Medicaid Oral Health Services" conference convened by HRSA, HCFA and the National Center for Education in Maternal and Child Health, the 1999 Head Start-WIC-Maternal and Child Health Bureau (MCHB) conference on oral health of preschoolers, a 1999 National Institutes of Health (NIH) ethics symposium on oral health of young children, the 1999 "Achieving Improvement in Medicaid" conference convened by the American Dental Association, the 2000 "Policy Academy on Children and Oral Health" convened by the National Association and a 2000 U.S. Surgeon General's Workshop and Conference on Children and Oral Health. Additionally many state oral health summits have considered these linkages.
  - c. The Child Health Act of 2000 establishes a new early childhood caries prevention program and Congressional appropriators funded an early childhood caries demonstration project.

**Table 1 Potential provider roles for addressing dental caries in children**

Level of Caries Intervention	Procedure	Pediatric Dentists	General Dentists	Dental Hygienists	Pediatricians/ Family MDs	Nurses/ Nurse Practitioners	Obstetricians <sup>a</sup>	Dental Assistants	Lay Health Workers
Risk Assessment	Parent interview and visual screening of the child's mouth (If high risk, a complete dental diagnostic examination by a dental professional is required.)	•	•	•	•	•	-	•	•
Anticipatory Guidance	Education and preemptory counseling appropriate to the child's level of risk	•	•	•	•	•	•	•	•
Primary Prevention	Oral hygiene instruction	•	•	•	•	•	-	•	•
	Dietary counseling	•	•	•	•	•	-	•	•
	Application of topical fluorides	•	•	•	• <sup>b</sup>	• <sup>c</sup>	-	• <sup>d</sup>	-
	Application of dental sealants	•	•	• <sup>e</sup>	• <sup>f</sup>	• <sup>g</sup>	-	• <sup>h</sup>	-
Dental Prophylaxis	Mechanical removal of deposits and accretions on the child's teeth	•	•	•	-	-	-	• <sup>i</sup>	-
Disease Suppression	Tailored fluoride regimes, dietary interventions, plaque management and use of topical antimicrobial agents	•	•	•	•	•	-	•	-
Atraumatic Restorative Technique (ART)	Mechanical removal of carious tooth structure and placement of bioactive dental restorative materials	•	•	-	-	-	-	-	-
Cavity Repair	Restorative surgical	•	• <sup>j</sup>	-	-	-	-	-	-

**Key**

- Appropriate role for the provider type.
- ◐ Appropriate for the provider type under conditions specified.
- Not an appropriate role of the provider type.
- a Obstetricians can provide anticipatory guidance to pregnant women but have no direct role with young children's oral health.
- b Physicians require training to appropriately place topical fluorides.
- c Nurses require training to appropriately place topical fluorides.
- d Dental assistants' authority to place topical fluorides varies by state.
- e Hygienists' legal authority to place sealants varies by state.
- f Primary-care physicians are not trained or equipped to place sealants and doing so may be outside their legal authority.
- g Primary-care nurses are not trained or equipped to place sealants and doing so may be outside their legal authority.
- h Dental assistants' authority to place sealants varies by state.
- i Dental assistants' authority to provide prophylaxis varies by state.
- j General dentists can provide definitive reparative care to the extent of their individual technical skills and expertise.

children is generally considered the providence of pediatric dental specialists who today comprise less than 3 percent of all U.S. dental practitioners. With so few pediatric dentists, the ratio of the pediatric dentist to young child population is estimated at one pediatric dentist to more than 6000 children under the age of 6.

Assuring that families can best care for their young children's oral health and utilize dental services effectively requires a seamless network of systems that already exists but that are often independent, redundant, or uncoordinated. Beyond pediatric and dental services, several other systems hold potential to enhance oral health. These include financing

systems; care coordination and case management systems; disease management systems; information systems capable of supporting evaluation, accountability, and feedback; and communication systems that can provide timely and accurate support to both beneficiaries and providers. Additional systems that can interphase with these health components include educational systems, Head Start, nutrition systems including WIC, social welfare systems including Title V Maternal and Child Health (MCH) programs, and prevention community systems including faith-based organizations and community organizing agencies. Successfully networking these systems requires competency development and adequate resources.

Some of these components are appropriately the role of government and others are appropriately developed and maintained by the professions, charitable organizations, local and national businesses, educators, the press, and community-based organizations. Toward that end, the W.K. Kellogg Foundation is supporting development of the "Public-Private-Partnership on Children's Oral Health" that works with multiple federal agencies to coordinate activities between their programs and these private-sector groups.

Hallmarks of a successful, integrated system of dental care for vulnerable young children include the following:

### **Accessibility**

A successful, integrated system will meet targeted children and their families where they live (i.e., in their communities) through agencies (e.g., social service/day care/educational/nutritional/early childhood home visitation programs, peers), and activities they typically engage (e.g., church attendance/recreation/scouts/parent-teacher associations) so that awareness (about oral health and availability of dental care) information (about what to do), and facilitation (about how to do it) are readily available.

### **Provider Engagement**

A successful, integrated system will meet targeted public and private sector healthcare providers (dentists, hygienists, dental assistants, office staff, physicians, nurses, home health workers, lay health workers) within their professional and work environments (e.g., at their offices, through their local/state/national professional associations, through their literature and continuing education programs, from their peers) so that awareness of the problem and efforts to solve it, information about how they can engage in addressing need, and facilitation (e.g., enhancing technical and cultural competencies, working with financing / information / communication / business systems) are readily available.

### **Resources**

A successful, integrated system will assure that sufficient physical (e.g., dental offices and clinics, transportation, computer networks), financial (e.g., payment streams from Medicaid, SCHIP, MCH-Title V, state/local programs, charitable foundations, businesses), and personnel (e.g., appropriately trained health professionals, educators, social workers, administrators) resources are available to meet these awareness, information, facilitation, and care delivery functions.

### **Infrastructure "Glue"**

Components of a successful system are meshed and held together by efficient information and communication systems that ensure coordination. These functions link targeted children and their families, available providers, and available resources so that redundancy and duplication are reduced, the network becomes seamless to utilizers, and feedback is assured. An example of a glue component is a referral system that effectively and efficiently links toddlers identified to be at high risk of dental caries by their medical primary care provider to a competent dental provider so that the parent's need to shift from the medical care system to the dental care system works with ease.

### **Accountability**

A successful system will hold each component accountable by clarifying roles, establishing performance goals, and providing regular and up-to-date feedback on performance and will hold the components of the network accountable for performance.

### **Barriers Related to Health Professional Workforce**

Barriers related to the health professional workforce are manifold and include issues of numbers, distribution, diversity, and competency of dentists, hygienists, and primary care health professionals. Of particular concern is the supply of dental educators to meet the training needs of current health profession trainees.

### **Numbers of Providers**

The absolute number of dentists is in decline. HRSA describes a 5 percent decline in the number of U.S. dentists between 1991 and 1998.<sup>47</sup> Combined with U.S. population increases, the declining numbers of dentists accelerate a reduction in the dentist-to-population ratio. The American Dental Education Association (ADEA) reports that dental school enrollment peaked in the 1970s under a HRSA-stimulated "capitation program" at 6301 graduating students and then declined steadily until the early 1990s when about 4000 dentists began graduating annually. Addressing the dental care needs of young children will certainly require an adequate number of dentists, but increasing numbers alone may not improve access. A 1995 Institute of Medicine review of the dental workforce<sup>48</sup> and the Pew Commission on the Health Professions study<sup>49</sup> both failed to identify a relationship between increased numbers of dentists and improvements in access for underserved populations.<sup>50</sup>

Dental education introduces students to the care of young children but generally provides little experience doing so according to initial findings of an AAPD taskforce (S. Seale, D.D.S., personal communication, March 10, 2001). Young children with advanced treatment needs are rarely managed by the predoctoral student. The likelihood of treating young children is greater in postdoctoral training but only 38 percent of dental school graduates pursue advanced training in either general dentistry or one of the seven dental specialties.<sup>51</sup>

In reviewing the role of the pediatric as well as general dentists with advanced training beyond dental school,<sup>50</sup> states that pediatric dentists are highly trained to serve the full spectrum of the pediatric population, particularly infants,

toddlers, and young children with dental disease who often present with difficult behavioral, restorative, and social needs. While there have been increases in the number of advanced general dentistry positions and the number of pediatric dentistry positions increased in 1999 to 200 (up from 180), there is continuing need to promote and increase training opportunities in these programs to further expand the core of dentists capable of serving the special needs of children.

AAPD reports that pediatric dentistry training opportunities have increased by 34 percent during the period 1989 to 2001, from 142 new trainees per year to 191 (S. Litch, J.D., personal communication, March 2001). In 1999, HRSA first awarded Title VII training grants to pediatric dentistry programs.

HRSA has recently developed but not yet released an interactive workforce model that allows states to estimate the numbers of general and pediatric dentists required to serve the dental treatment needs of children covered by Medicaid and SCHIP. The model was developed based on a series of assumptions from the ADA, AAPD, and American Society of Dentistry for Children (ASDC). The model assumes that low-income children under age 6 generally require care by pediatric dentists. As such, the model estimates a major shortfall of pediatric dentists. Even if general dentists were empowered to treat young children more effectively through advanced education programs in general dentistry, this subpopulation presents extreme challenges in clinical care that may require the specialized services of a pediatric dentist. Based on caries epidemiology, an estimated 4 to 5 million U.S. children suffer dental disease severe enough to impact their daily function.<sup>52</sup> These children more often require the specialists' care.

In contrast to dentists and dental schools, the number of dental hygienists and dental hygiene training programs is increasing. The American Dental Hygienists' Association (ADHA) reports that there are more than 100,000 registered dental hygienists in the United States with 5,000 new hygienists graduating annually from over 250 programs (A. Battrell, R.D.H., personal communication, January 2001). Dental hygienists are dental professionals who provide preventive dental services including education, instruction, and clinical preventive treatments such as dental scaling and polishing. In 15 states, hygienists are authorized to perform services only in the physical presence of dentists although 35 states allow for "general supervision." Some states, notably California, Colorado, Connecticut, Oregon, New Mexico, and New Hampshire, have developed less restrictive supervision requirements allowing hygienists to practice preventive dentistry more independently. Medicaid statutes and regulations allow direct payment to hygienists for services provided within their scope of practice in those states that authorize unsupervised hygiene practice. These efforts to expand hygienists availability, however, do not change the nature of hygienists' services. The hygiene scope of practice is determined by the nature of the profession and the content of training. For this reason, the reparative and surgical needs of young children who have cavities, broken teeth, developmental disturbances, or other existing pathologies cannot be met by hygienists. However, as preventive modalities that address disease initiation and progression are further developed and refined, hygienists can play an essential and expanded role in delivering preventive care.

### Distribution of Providers

The geographic distribution of dental providers is increasingly problematic in meeting the needs of underserved populations including young children. HRSA recognizes 1233 dental health professional shortage areas (HPSAs) and acknowledges that far more could be recognized if states endeavored to substantiate them (J. Anderson, D.D.S., personal communication, March 2001). Since many states lack full-time dental directors to engage in HPSA designations and dental HPSA processes are demanding, there has been little effort in most states to identify shortage areas. Nonetheless, the HRSA Office of Rural Health reports that a disproportionate share of dental HPSAs are in rural areas (K. Hayes, D.D.S., personal communication, March 2001). States including Maine, Texas, and Illinois have considered legislation or enacted programs to attract dentists to underserved areas through loan repayment or academic debt forgiveness. Others, including Michigan and Montana, have considered tax incentives while Maryland and Delaware have looked to licensure changes to facilitate care in underserved areas.

### Race, Ethnicity, and Gender of Providers

Racial and ethnic diversity of dental providers also constitutes a barrier to care for underserved young children. A recent report by Brown, Wagner, and Johns<sup>53</sup> substantiates that minority dentists provide a greater percentage of their care to minority patients than do White dentists. ADEA's Executive Director reports<sup>50</sup> that nearly one-third of all entering dental students in 1998 were identified as being part of a minority group, up from only about 13 percent in 1980. However, the primary increase has been among Asian/Pacific Islander students, from about 5 percent of first-year enrollees in 1980 to nearly 25 percent in 1998. At the same time, the proportion of underrepresented minorities has shown only a small 2 percentage point increase since 1980, from about 8 to nearly 10 percent of first-year enrollment. The percentage of enrolled students from each of these groups is significantly lower than the percentage of each group in the U.S. population. In 1998, the percentage of first-year enrollees was 4.4 percent for Black/African Americans, 4.9 percent for Hispanic/Latino, and 0.4 percent for Native Americans /Alaskan Natives. The U.S. population in 1998 was about 12 percent Black/African American, 11 percent Hispanic/Latino, and 0.9 percent Native American/Alaskan Natives. Since 1990 there has been a 23 percent decline in the number of dental school enrollees from underrepresented minority groups. Since 1985, the percentage of Black/African American dental school graduates has shown a slight decrease to about 5 percent. Hispanic/Latino graduates have remained at about 5 percent. And the percentage of Native American graduates has always been less than 0.5 percent.

Racial and ethnic diversity is even less evident among dental hygienists. ADHA reports that 89.8 percent of hygienists are White, 2.6 percent are Black, 4.6 percent are Hispanic, 3.2 percent are API and 0.6 percent are Native American (A. Battrell, R.D.H., personal communication, January 2001). Since underrepresented minorities constitute a larger percentage of young children than the U.S. population at large, the lack of Black, Hispanic, and Native American dental practitioners is even more problematic for assuring culturally competent and accessible care.

Gender diversity may impact service availability for more vulnerable young children if women dentists elect to serve more young children than their male counterparts have in the past. The gender of hygienists likely has less impact on the provision of dental services to young children since hygienists rarely determine the patient pool they will treat, but their gender and racial/ethnic characteristics may impact on the cultural competency of the profession. Hygienists are overwhelmingly female (97.8 percent) (A. Battrell, R.D.H., personal communication, January 2001).

### **Nondental Providers**

The potential contribution of nondental health professionals to advancing the oral health of young children is substantial. The supply of pediatricians, family practitioners, and primary-care nurses who see young children<sup>47</sup> is considerably greater than the supply of pediatric dentists and general dentists who see young children. Because primary-care physicians and nurses see children earlier and more regularly during critical periods of their development, they could significantly engage in oral health promotion. Because they have so little knowledge about oral health, their effective engagement will require considerable training.

### **Dental Educators**

The supply of dental educators is of particular concern to shaping future capacity of health professionals. The cadre of educators is shrinking faster than the overall supply of dentists. ADEA reports that almost 300 funded teaching slots are currently unfilled in the nation's 54 dental schools.<sup>54</sup> Dental educators are aging and are overwhelmingly White and male.

## **SUMMARY**

In sum, the supply of dentists is aging and shrinking and comprises few Black and Hispanic dentists but is experiencing a rapid increase in Asian-Americans. It is predominantly male but moving toward one-third female. Unless productivity gains can offset reductions in supply, or the demand for services decreases markedly, the nation is likely to experience an overall shortage of dentists, particularly in rural and inner-city areas where vulnerable populations are concentrated.

### **Barriers Related to Health Professional Training**

Barriers related to health profession training extend to dental and medical providers at both the pre- and postdoctoral levels. Accreditation educational guidelines for predoctoral dental education<sup>55</sup> are very general and do not specify any requirements regarding children under age 6. Pediatric dental experience in predoctoral education varies considerably across dental schools with some schools offering care only to children 6 years of age or older and others providing hands-on training in infant oral healthcare. Programs vary widely in age of child patients treated by predoctoral students and many do not see children under age 4. Similarly, dental hygiene accreditation standards provide little guidance and no requirements regarding care for children under age 6.

Postdoctoral training is not required for licensure in dentistry. For the majority of dental graduates (those who do not elect postdoctoral training or do not compete successfully for postdoctoral positions), there is no opportunity beyond elective continuing dental education to

learn about care of young children. Postdoctoral general dental education is available to approximately 1600 trainees each year through dental school-based (Advanced Education in General Dentistry) and hospital-based (General Practice Residencies) programs. These programs vary widely in addressing children at all, let alone young children or young children who are vulnerable because of health, social, or economic status.

Postdoctoral specialty pediatric dental education provides extensive and intensive training in management of infants, toddlers, and preschoolers. These programs typically bring the trainee into direct and continuous contact with poor, minority, and immigrant populations. Postdoctoral training programs in pediatric dentistry are typically 2 years in length. Roughly one-third of the 62 programs are hospital-based with an emphasis on primary care dentistry for well and ill children. The remaining two-thirds are based in dental schools (S. Litch, J.D., personal communication, March 2001).

Training programs, particularly those located in hospitals, provide a major resource for young vulnerable children in acute pain. A recent study of "emergency" dental visits in the 56 pediatric training programs showed that 37 percent of the children who presented for such care were under the age of 6. Children in pain were largely poor (54 percent) or near poor (31 percent) and from single-parent or nontraditional families (47 percent). One in five had experienced pain for longer than a week and 65 percent were reported by parents to have a functional impairment from their dental problem.<sup>56</sup>

Pediatric dentists as a group provide a disproportionate amount of care to young low-income and vulnerable children.<sup>57</sup> Although other primary-care dentists are legally authorized to provide care to young children, many generalists are not comfortable treating young children. The lack of pre- and postdoctoral training and experience in early childhood dental care combined with the unique social, communication, and behavioral demands of these patients as well as special procedures needed to provide definitive care all combine to limit many dentists' sense of competency to manage young children.

### **Barriers Related to Insurance Coverage and Safety Net Resources**

Dental insurance for young children may be private or public. Private insurance is typically employer-based while publicly funded dental insurance is primarily through Medicaid or SCHIP. Private dental plans vary widely in coverage, costs, and limitations. Many plans do not routinely pay for care of children under age 3 without a "report" from the attending dentist justifying the visit. Some plans impose limits on specific dental procedures, e.g., dental prophylaxis (cleaning) or periodic examinations, provided to young children.

Young children with extensive dental disease often require dental rehabilitation under general anesthesia in a medical facility. Since hospital care and general anesthesia are often covered by medical rather than dental policies, insurance coverage for these procedures is an important determinant of parental costs. A growing number of states, currently 31 (P. Reggiardo, D.D.S., personal communication, March 2001), mandate that medical plans provide coverage for dental-related hospital care. In states that do not assure this coverage, lacking this benefit creates a significant financial barrier to families

whose children require dental rehabilitation.

While the Medicaid program mandates comprehensive dental coverage along with comprehensive medical coverage, some parents are not familiar with the dental benefit or are unable to access dental care. Low-income families who are generally eligible for Medicaid report higher levels of medical than dental coverage<sup>58</sup> and 4 times as many Medicaid-enrolled children obtain medical than dental visits.<sup>19</sup> Although Medicaid provides ideal dental coverage from birth, the program is widely recognized as a failure in meeting beneficiaries' needs.<sup>3</sup> This is in large part because the participation of private-sector dentists is so low. A 1998 survey by the National Conference of State Legislatures suggests that fewer than one in five dentists participate in Medicaid at all and that only a fraction of these dentists provide more than \$10,000 in billings per year.<sup>59</sup> Almost all Medicaid programs are out of compliance with EPSDT law and regulations according to the HCFA.<sup>21</sup>

Children from families with modest incomes above the Medicaid threshold are eligible for the SCHIP. Under this program, each state establishes its own dental benefit. Yet, the majority of states have elected reasonably comprehensive coverage—often modeled on Medicaid. Children who lack dental coverage but have private medical coverage are ineligible for SCHIP. Since there are 2.6 children who lack dental coverage for every child who lacks medical coverage,<sup>58</sup> millions of children are excluded from SCHIP dental coverage because they are medically insured.

The dental safety net is considerably smaller than the medical safety net and comprises school-based programs, dental facilities in migrant and community health centers (CHCs), 54 dental schools,<sup>12</sup> and 62 pediatric dentistry training programs (L. Scully, AAPD, personal communication, April 2001), as well as mobile dental programs. Generally community hospitals, which constitute the backbone of the medical safety net, do not provide definitive dental care at all and would be particularly stressed to provide dental care to young children. While community hospitals typically provide for a dentist-on-call who is often an oral surgeon, they rarely maintain dental facilities or provide treatments for acute dental presentations beyond prescription of analgesics and antibiotics. Proponents of migrant and CHCs suggest that services integration, particularly for disadvantaged populations, is facilitated by "one-stop shopping" where comprehensive health services are available at one accessible site. However, HRSA's Bureau of Primary Health Care (BPHC) reports that only 58 percent of grantees and a far smaller percentage of individual CHC sites offer on-site (collocated) dental services.<sup>60</sup> Demand for dental services in CHCs is so high that routine care is often displaced by emergency care. Few CHCs and other safety-net facilities employ pediatric dental specialists. Lack of available specialists further reduces capacity to address the needs of this special population. Because the overwhelming majority of U.S. dentists practice in privately owned and operated dental offices, assuring accessible and competent care will require active engagement of the private sector.

### Barriers Related to Caretakers and Patients

As dependents, young children rely upon their parents and their parents' circle of health advisors to ensure appropriate oral health care at home, at day care, at the physician's office,

and—should they be one of the few to see an oral health professional—at the dentist's office. Yet few of these resource are well informed about infant oral health and oral health promotion for toddlers and preschoolers. As a result, parents may obtain contradictory and confusing advice, or no advice at all.

Magazines, parenting guides, and advertising aimed at young parents provide another resource for parents. Through the American Academy of Pediatric Dentistry's efforts to promote knowledge of the age-one dental visit, these resources have increasingly recommended early professional care.<sup>38</sup> A generational shift is underway on professional recommendations for dental care so that the idea of a "first dental visit at the first birthday" is still widely unexpected, unknown, and questioned by many who advise young parents including grandparents, primary medical care providers, and even dental professionals. The public has had few opportunities to learn that tooth decay is established as a disease process even as the first teeth are coming into the mouth and long before lesions are evident. The public may also be largely unaware that early trauma to the primary teeth can cause damage to the permanent teeth, that early fluoride use must balance protection with the risk for fluorotic speckling of the permanent teeth, that positive oral health behaviors need to be established early, and even that the primary teeth are important for function. Few appreciate that primary teeth remain in place until early adolescence and that these teeth are therefore critical for alignment of their successors. "They are only baby teeth" is a statement still heard often by dental providers even among parents whose children have obvious decay. A growing number of young children are cared for by people other than their parents. It is likely that the knowledge, values, and health behaviors of these supplemental caretakers will influence young children's risk of dental pathology.

Dental care and fear or anxiety have been long linked in popular culture. This linkage reflects fundamental characteristics of much dental treatment—that many procedures are essentially minor surgical procedures performed on awake patients. Equivalent medical procedures, e.g., placement of ear tubes or excision of skin lesions, are routinely performed under general anesthesia. Yet dentistry has advanced the provision of surgical care, even for most young children, in the outpatient setting using local anesthesia. While this approach eliminates risks associated with general anesthesia, it can be very demanding on the child, parent, and dentist. This approach requires intentional cooperation of patients. Dental procedures are often unpleasant to the senses with their loss of physical sensation from local anesthesia, imposing noise, unusual flavors and odors, atypical sights, and distorted visual perspective. The physical positioning of patient and dentist or hygienist is intimate and is often regarded by young children as imposing. Young children coming to dental treatment with few prior expectations can find the totality of these sensory stimuli threatening. Yet most young children are able to abide treatment for short periods of time if approached in a sensitive and supportive way.

Dental care can elicit anxiety among parents or primary caretakers. This anxiety is often evident to young children and can elicit negative expectations of dental care. Parental anxiety can occasionally translate into threats. Statements like,

“behave yourself or I’ll take you to the dentist”, are still heard by dental professionals. Threats reinforce the notion that dental care is to be avoided if at all possible.

Good personal hygiene and a healthy diet are two essential components of oral and general health. Young children have not yet developed the fine motor coordination to effectively provide self-care with toothbrush and floss. They begin mimicking parental toothbrushing as toddlers but cannot be granted full responsibility for their personal hygiene until late childhood or early adolescence. Although flossing can be particularly challenging, it is an essential element of oral hygiene wherever teeth are in physical contact with one another. Among personal hygiene practices, effective dental hygiene is perhaps the one that requires the longest period of parental supervision and intervention. During early childhood, children become increasingly engaged in dietary choices. Dietary determinants of dental disease include the quantity of sugar a child ingests as well as the frequency, timing, and duration of those “exposures.” For young children, diet and eating can fundamentally influence dental and oral health.<sup>61</sup> For this too, young children are dependent upon the knowledge and concern of their parents and caretakers.

## **APPROACHES TO IMPROVING YOUNG CHILDREN’S ORAL HEALTH AND ACCESS TO DENTAL CARE**

The goal of policies that address young children’s oral health is to eradicate disparities—to allow children who now suffer from preventable disease to be as healthy as their more fortunate and empowered peers. Accomplishing this goal is inordinately complex because it involves everything from parental knowledge and values to the capacity of dental delivery systems, from the appropriate use of toothpaste to the availability of dental insurance. Five categories of activities for improving both oral health and access to care are: public education, prevention, Medicaid and SCHIP reform, systems capacity, and workforce.

### **Categories of Activities**

#### **Public Education**

To act in its own best interest, the public needs to engage pediatric oral health issues at both a policy and a personal level. Policy-level involvement translates this little-known public health problem into a political agenda by raising awareness and perception of the problem and bringing it to the attention of public officials. For example, dental insurers, academic policy analysts, and grassroots organizations in Washington State are currently engaged in a policy campaign entitled “Watch Your Mouth” that seeks to energize public sentiment around children’s oral health. Once raised, this focus can influence a range of public policies including public investment in training more dental professionals. Similarly, fluoridation campaigns engage the public in ways that both inform people and empower them to act through public referenda. At the personal level, public information campaigns are employed to promote essential oral health behaviors including quitting smoking, rejecting “spit tobacco,” eating healthy, consuming sufficient calcium (“Got Milk?”), using fluorides properly, practicing

good oral hygiene, and taking young children to their first dental visit at age 1.<sup>62,44</sup>

#### **Prevention**

Disease prevention holds great promise for attaining and maintaining oral health. Because dental caries is established as a disease process during infant and toddler years, there is a strong justification for starting dental treatment at age 1.<sup>62</sup> Preventive approaches are generally cost effective, can be provided by a range of lay and professional advisors, and tend to benefit general as well as oral health. Tailoring the intensity of preventive interventions to a child’s risk for disease can maximize cost-benefit and effectiveness.<sup>63</sup> Strategies to assess caries risk in young children can be based on previous caries experience, presence of precavitated “white spot” lesions, visible plaque in young children, and the perception of experienced examiners.<sup>64</sup> Recommended preventive strategies for young children include daily toothbrushing using fluoridated toothpaste, application of fluoride varnishes, use of antimicrobials to reduce cariogenic flora, and placement of dental sealants in high-risk locations.<sup>64</sup> Effective implementation of this approach, however, requires extensive education and training of lay and professional health advisors, widespread acceptance of early dental interventions, acknowledgement of the utility and methods of assessing risk, and development of risk-specific preventive clinical protocols.

#### **Medicaid and SCHIP Reform**

High-risk young children are generally from low-income families and are therefore eligible for dental coverage through Medicaid and SCHIP. Unless these programs become more functional and widely accepted by dental providers so that enrolled children can readily access care, opportunities to improve beneficiaries’ oral health will be stymied. The U.S. Surgeon General reports<sup>12</sup> that “Medicaid has not been able to fill the gap in providing dental care to poor children. Fewer than one-in-five Medicaid-covered children received a single dental visit in a recent year-long study period.”

When young children do obtain dental care, many present with advanced disease that requires treatment under general anesthesia. HCFA estimates that Medicaid expends at least \$100 million annually for hospitalization costs associated with dental treatment of young children (D. Schneider, D.D.S., personal communication, February 2001). Linking meaningful and timely preventive care to an effective Medicaid program that assures access could markedly reduce these necessary but avoidable expenditures.

#### **Systems Capacity**

Low-income young children often obtain health care services in “safety-net” facilities described above. These sites often lack a dental program. The HRSA Bureau of Primary Health Care is now actively supporting expansion of these facilities. As these facilities increase in number, it is important to assure that their professional staffs have the capacity to treat young children.

The public-sector dental delivery system similarly also lacks a robust supply of pediatric dentists and the capacity to manage young children. The inequitable geographic distribution of dental care providers results in logistical barriers for many vulnerable families. Few practitioners are trained in infant dental care or are experienced in treating children under

the age of 6. The ADA 1990 Survey of Dental Practice reports that only 2.6 percent of all patients seen by dentists are under the age of 5.<sup>65</sup>

### **Workforce**

As detailed above, shortcomings in dentist workforce numbers, geographic distribution, diversity, and competency to manage young children constitute a structural barrier to enhancing dental care for young children. Although the dental hygiene workforce is growing, hygienists cannot function like nurse practitioners providing comprehensive primary care because their professional scope of practice is limited to preventive services. Hygienists may play an increasingly important role in capitalizing on the preventive potential to limit disease burden if they become well trained in infant oral health care. Successfully engaging primary care physicians and nurses will similarly require extensive education and training as well as incentives to incorporate oral health counseling, risk assessment, and effective referrals in standard medical practice.

### **Improving Quality of Life**

Any strategy that successfully reduces disease occurrence, progression, or consequences will improve young children's quality of life. By limiting children's experience of dental pain and infection, their capacity to function well, grow normally, and engage in normal activities will be enhanced.

### **Bringing Dental Care to Vulnerable Children**

Bringing comprehensive dental care to young children can be logistically challenging. Mobile vans, dental facilities in or near Head Start and WIC centers, and dental facilities in neighborhood schools can enhance geographic access.<sup>44</sup> Young children often need to be treated early in the day when both they and their dental providers are more resilient. Many of these facilities are of necessity smaller than typical dental offices and CHC clinics. The time required to comply with infection control requirements can markedly limit the efficiency of small facilities.

An alternative approach is to "link" dental services to places where high-risk young children congregate. Head Start and WIC programs provide locations where screenings, risk assessments, and preventive education can be provided. Children in need of more extensive care can then be referred to or transported to suitable locations. Case management services required by Medicaid can provide the social and logistic support needed to connect the child with care.

When dealing with young children, it is particularly important to involve parents both to provide assurance to the child and to capitalize on an opportunity to encourage parents to ensure appropriate home care, diet control, and use of fluorides. Bringing care to children should be arranged in a way that does not exclude parents and limit the potential to engage them in their children's oral health.

Primary-care medical providers including nurses, nurse practitioners, pediatricians, and family practitioners should become a major resource for risk identification and timely referral, especially for high-risk children. For their referrals to be effective, however, requires that parents are carefully informed about where and how to obtain care. Referrals need to be tracked in order to determine whether children actually

obtain care. States may consider EPSDT tracking systems linked to case management services in order to effect successful referrals.

### **Special Measures to Accommodate Young Children**

A great advantage of providing dental care to young children is that no special armamentarium is required. To accomplish an effective examination, nothing more than good illumination and a dental mirror is required. The child can be effectively positioned on the parent's or dentist's lap,<sup>66</sup> eliminating even the need for a dental chair. When more intensive dental treatment is required, the equipment and materials employed are the same as for older children and adults. It is the capacity of the provider to relate to and successfully engage the young child, not the physical equipment, that is critical.

### **Necessary Training for Providers and Families**

Significant training in oral health is needed by both medical and dental providers since health professional education to date has generally ignored the dental component of early childhood. Needed are new curricula and educational experiences for dentists, hygienists, physicians, and nurses in training at both the pre- and postprofessional degree level. Also needed are continuing education programs for existing providers. Core educational elements include components on common oral diseases of young children, risk assessment, anticipatory guidance, conducting an oral examination, preventive interventions, and disease suppression strategies. For dentists, additional training is needed in management of common dental presentations and customizing care to very young children. Dentists also need information and practical training regarding young children's development and communications skills as well as issues of cultural competency.

Increasing public awareness that early dental care is important in limiting lifelong oral disease will require significant education of families. Adoption of the "age-one dental visit" as promoted by the Bright Futures coalition and professional groups will require a fundamental change in widely accepted public norms. The idea of individualized oral health care that tailors intensity of treatment to a child's level of risk is also novel and will require acceptance to be effective. Balancing the benefits and risks of home therapies including use of topical and systemic fluorides or use of prescribed antimicrobial agents will require that parents acquire sophisticated information. Prevention can be significantly enhanced if the public can become better informed about the impact of dietary and hygienic choices, use of protective devices to limit accidents, and impact of maternal oral health on the health of young children.

### **Expanding Dental Insurance Coverage**

Dental insurance coverage is important because it helps reduce financial barriers to care.<sup>4</sup> Many children, even those who enjoy medical coverage, do not benefit from dental coverage.<sup>58</sup> Even when commercial dependent dental coverage is available, it may not be extended to very young children. Dental benefits are comprehensive for low-income young children covered by Medicaid or SCHIP, but these children frequently have difficulty accessing care. Dental coverage is generally not coordinated with medical coverage under private-and

employer-based plans. As a result, many medical plans have refused coverage for physician and hospital services related to dental care. This problem has been increasingly addressed by modifying state law to mandate that medical services ancillary to dental treatment be covered.

### **Strategically Improving Title VII and VIII Programs**

The Health Professions Training Act provides funding for a variety of programs to improve education and training in the service of disadvantaged populations. To date, this program has not been focused on preparing the health workforce to effectively manage oral health needs of young children but many opportunities could be pursued.

## **DENTISTS AND HYGIENISTS**

Approaches that can enhance training of dentists and hygienists include the following listed below.

### **Predoctoral Pediatric Dentistry Training**

Analogous to the "Undergraduate Medical Education for the 21<sup>st</sup> Century" ("UME 21") program, a UDE 21-type predoctoral program can prepare future dentists in infant oral health, increase cultural competency, address the care of children with special healthcare needs, and assure a more extensive grounding and experience in clinical pediatric dentistry.

### **Postdoctoral Training Availability for All Dentists**

Learning to provide technical dental services for young children is more readily accomplished after the new dentist becomes reasonably familiar with dental procedures. Only after technical comfort is attained by working with cooperative and passive patients can the dentist shift focus to the patient whose behavior or developmental competencies are more distracting and demanding. Thus, the postdoctoral training period provides an especially rich time for teaching dentists to treat young children. However, with less than half of dental students pursuing postdoctoral training, it will be necessary to significantly increase the number of training slots to accommodate a majority of dental trainees.

### **"PGY 1" Pediatric Dentistry Training**

Not all first year postgraduate education programs (PGY1) in general dentistry provide significant training in pediatric dentistry and many may not address young children at all. To develop a workforce competent to treat young children, Title VII-funded primary care dental programs need to mandate significant experience in pediatric dentistry including encounters with young children.

### **Postdoctoral Pediatric Dentistry Training Expansion**

Because young children will always present age-specific challenges to dentists, meeting the needs of young children will require a substantial increase in the number of qualified pediatric dentists. Title VII programs began funding pediatric dentistry training in 1999 and will need to considerably expand the program while leveraging its commitment with other funding sources so that the specialty can grow commensurate to need and demand.

## **Creating Incentives for Academic and Research Careers**

Even more alarming than shortcomings in preparing dentists to treat young children is the paucity of academic dentists to train the next generation.<sup>54</sup> In the last 6 months alone, nearly one in four dental schools has advertised to fill a vacant pediatric dentistry position (S.Litch, J.D., personal communication, March 2001).

## **Continuing Dental Education**

The majority of potential dentists and hygienists available to treat young children are established practitioners who are often unprepared to manage their needs. Use of health profession straining resources to "retrofit" existing practitioners with skills needed to treat young children may be an effective approach to enhancing care availability.

## **Curriculum and Faculty Development**

All of the above approaches to enriching the availability of providers require development of curricula and faculty capable of implementing these novel teaching materials.

## **Diversity Incentives**

Evidence<sup>53</sup> that minority providers treat higher percentages of minority patients suggests that dental access for predominantly minority low-income young children will be improved by training more minority dentists. Extensive efforts to recruit minority candidates to dental school suggest that programs need to begin at least at the level of high school if not earlier.<sup>54</sup>

## **Team Education**

The greatest potential to improve children's oral health lies in coordinated systems of care that reach children early with effective primary prevention. This approach requires competency of dentists and hygienists as well as physicians and nurses. Title VII and VIII programs should be designed to encourage team education that focuses on the overall health care of young, vulnerable children and includes a fully integrated oral health component.

## **Promotion of a Hygienist-Caries Manager**

The growing disciplines of caries management, caries suppression, and risk-based individualized dental preventive care all suggest increasing opportunities for dental prevention professionals to expand their knowledge and skills to better serve young children. Health professions training programs need to consider how to bolster the transfer of science to practice while generating incentives for hygienists who can function as "disease managers" by providing preventive and suppressive care. One evident opportunity is to develop curricula for baccalaureate-level dental hygiene programs so that the 2 years customarily committed to liberal arts education can be focused on coursework in education, early childhood development, microbiology and caries pathology, and caries management.

## **NONDENTAL PERSONNEL**

Additional opportunities to enhance oral health services for young children through health professions training programs should be targeted to nondental personnel. The goal of such

training will be to enhance the capacity of nondental providers to assess risk, examine the oral cavity, make and assure referrals, and provide basic counseling. Opportunities include those listed below:

### Educational Infrastructure

Curriculum development, faculty development, and training experiences for primary-care physicians, nurses including nurse practitioners, and physicians assistants.

### Team Training

Team-based education that extends beyond dentists and hygienists to include the range of primary-care medical providers.

### Cross-Training during Residencies

Both pediatric and family medicine residents could learn experientially about young children's oral health by rotating through a pediatric dentistry clinic as an integral portion of their training program. Providing support for medical rotations by pediatric dentists in training would similarly enhance pediatric dentists' capacities to deal with the complex medical problems of the chronically ill and handicapped.

### Innovative Integration Models

Title VII funding could challenge medical and dental schools, hospital residencies, CHCs, and other training sites to develop innovative models of health services integration. Development of functional models could lead to identification of "best practices" that could be widely replicated with federal or private support.

### SUMMARY

Although the majority of America's children enjoy remarkably good oral health, a significant subset of low-income, minority, medically and developmentally compromised, and socially vulnerable children continue to suffer significant and consequential dental and oral disease. Most of this inequitably distributed disease burden is preventable through early and individualized preventive care. Yet the primary-care medical and dental workforce is ill-prepared to manage the oral health needs of young children.

Demographic trends suggest that the problem of disparities in both oral health status and access to competent dental services will continue to worsen for young children. Impediments to improving the oral health of young children include barriers between medical and dental systems of care, paucity of private and safety-net facilities and providers in many areas where vulnerable children reside, and dysfunctional Medicaid insurance programs. Barriers are generated by parents, providers, payers, and systems of care as well as by the age-appropriate behaviors of young children. Vulnerable families often do not access the case management services and disease control information needed to effectively address their young children's needs.

Approaches to improving the oral health of young children therefore include enhancing public education about oral health, the appropriateness of early and periodic dental care, and

primary prevention. Improvements in workforce numbers, distribution, diversity, and competency are needed. Attention to delivery systems and public insurance capacities are also necessary to effectuate improvements.

HRSA's Title VII and VIII health professions training programs could potentially address many of these barriers and shortcomings. Training enhancements for predoctoral, postdoctoral, and graduate dentists and hygienists as well as for primary-care medical providers hold the key to marked improvements in the oral health of young children. Enhanced training of health care providers is the necessary if not sufficient condition to children whose daily life experiences are compromised by dental and oral diseases that are overwhelmingly preventable.

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**O**ral health care for adults with disabilities is a health care area that has received scant attention. It is estimated that one out of two persons with a significant disability cannot find a professional resource to provide appropriate and necessary dental care.<sup>1</sup> Lack of access to dental services for this growing segment of our population is reaching critical levels and is a national dilemma.

### ORAL HEALTH AND DENTAL CARE ACCESS CHALLENGES

About one in five Americans have a disability and one in ten have a severe disability.<sup>2</sup> Adults with disabilities comprise a heterogeneous population manifesting a wide array of disabling conditions and degrees of severity of impairment. Disability status can be determined according to a variety of criteria, including limitation in function and activity, work disability, specific conditions such as mental retardation or mental illness, or by receiving selected federal program benefits. The Americans with Disabilities Act of 1990 specifies that an individual has a disability if the person has a physical or mental impairment that substantially limits one or more major life activities, has a record of such impairment, or is regarded as having such an impairment.

Three major demographic developments account for an increase in the number of adults with disabilities living in the community:

A higher initial survival rate and increased life expectancy for persons with disabilities<sup>3</sup>

A concomitant increased likelihood of acquiring a chronic disability later in life<sup>4</sup>

The deinstitutionalization of adults with severe disabilities from large state institutions and their placement in the community in group homes, foster homes, with their families, or in independent living arrangements with minimal assistance.<sup>5,6</sup>

### CLASSIFICATION

The disabilities affecting adults may be grouped according to time of onset into two major categories: disabilities of developmental origin and those acquired later in life. The former category comprises conditions such as mental retardation, cerebral palsy, epilepsy, and autism that are present either at birth or are incurred during the developmental period (before age 22). Acquired disabilities generally result from trauma, such as spinal cord and head injury, or from chronic diseases, including arthritis, cancer, diabetes,

## Dental Care Considerations for Disabled Adults

Acquired Immune Deficiency Syndrome (AIDS), degenerative neurologic disorders, psychiatric disorders, and chemical dependencies.<sup>7</sup> Census information indicates that the most frequent causes of functional limitation in 15- to 64-year-old persons are arthritis/rheumatism, back or spine, heart, lung, or respiratory conditions.<sup>8</sup>

### DEMOGRAPHICS

According to the U.S. Bureau of the Census data for 1994, 54 million persons (20.6 percent of the noninstitutionalized population) have some level of disability; of these, 26 million (9.9 percent) have a severe disability. Among those with a severe disability, 14.1 million are 22 to 64 years old. The likelihood of having a disability increases with age, ranging from 14.9 percent for persons 22 to 44 years old to 36.3 percent of those 55 to 64 years old. In the adult population, disability rates are slightly higher for females (20.2 percent) than for males (18.7 percent), and with advancing age the gender difference widens. Prevalence of disability in persons 15 to 64 years old also varies by racial and ethnic background. Native Americans have the highest rate (26.9 percent), Asian/Pacific Islanders have the lowest rate (9.6 percent), with intervening frequencies of 16.9 percent for persons of Hispanic origin, 17.7 percent for Whites, and 20.8 percent for Blacks.<sup>8,9</sup>

There are strong associations between socioeconomic status and disability, particularly for those with severe disabilities, although causality remains unclear. People with disabilities are overwhelmingly poor; their level of education tends to be low and they are more likely to be unemployed or employed only part-time; many depend on public programs for much of their income and services. The rate of severe disability for adults who have not completed high school is reported at 22.8 percent, compared to 8.7 percent for high school graduates and 3.2 percent among college graduates. Compared to an employment rate for persons with no disability of 82.1 percent, the rate for persons with a mental disability is 41.3 percent, and for persons with severe functional limitations only 26.1 percent. For the 22 to 64 year age group, the proportion with a low relative income is 25 percent among those with a nonsevere disability and 35.5 percent with a severe disability.<sup>8,9</sup> In the decade since passage of the Americans with Disabilities Act, persons with disabilities have shown little improvement in economic well-being; they continue to be disadvantaged, have a lower rate of exposure to computer technology, and live in relative isolation.<sup>10,11</sup>

Based on the National Health Interview Surveys on Disability of 1994 and 1995, 2.3 million persons aged 18-64

use a mobility device. Among mobility device users, 68.3 percent report having difficult and 45.2 percent report very difficult access to public transportation.<sup>12</sup>

## UTILIZATION OF MEDICAL / DENTAL SERVICES

In terms of health care, people with disabilities account for a disproportionately large share of medical expenditures for every age group. Thus among 45-to 64-year-old adults, those with disabilities represent 24 percent of the population but account for 54 percent of medical expenditures.<sup>13</sup> They are much more likely than those without disabilities to depend on public programs (Medicaid or Medicare) to pay for their health care. It is estimated that 75 percent of people with developmental disabilities rely on government funding for dental and medical services.<sup>14</sup> Whereas 79.9 percent of adults with no disability are covered by private health insurance, of those with a severe disability only 43.7 percent have private insurance, 39.6 percent have government insurance only, and 16.7 percent have no insurance.<sup>9,15</sup> Physician contacts increase with severity of disability and having insurance is significantly associated with more physician contacts among people with disabilities.<sup>16</sup>

Factors governing utilization of dental services differ from those for medical care. For the population at large, dental utilization is associated with income, educational level, and dental insurance. In 1993, almost twice as many adults 25 years of age and older living at or above the poverty line had a dental visit than did those living below the poverty line (64.3 versus 35.9 percent). Similarly, almost twice as many individuals with 13 years or more of education had a dental visit than did those with fewer than 12 years of education (73.8 versus 38.0 percent). A larger proportion of individuals without private dental insurance had not had a dental visit in 5 years or more compared to those with private dental insurance (14.2 versus 6.6 percent).<sup>17</sup>

National survey information that bears directly on dental care of persons with disabilities is scant. Per capita expenditures for dental care are nearly the same for noninstitutionalized persons with and without disabilities. However, the census data that are available indicate, in contrast to medical care, a lower utilization of dental services by persons with disabilities. On an annual basis, 36.5 percent of severely disabled persons 15 years and older reported a dental visit, compared to 53.4 percent of those with no disability [J. McNeil, personal communication].<sup>18</sup>

Low utilization of dental services is not surprising because persons with disabilities are deprived socioeconomically. Payment for dental care by the average patient is made from the patient's private resources or through employment-based dental insurance. Persons with disabilities, particularly those with a severe disability, have a low income and a high rate of unemployment, or only part-time employment that does not offer dental insurance. They are less likely than the average person to be able to pay for dental care out of their own resources or through dental insurance. Moreover, persons with severe disabling conditions as well as their families may be so overwhelmed by the physical and financial demands of the disability that dental care ranks low in priority.

## DISADVANTAGED STATUS

While the oral health of the average American adult has improved significantly in the past several decades, persons with disabilities have not seen the same improvements. This segment of the population continues to have serious oral health problems, is underserved in terms of dental care, and disadvantaged in gaining access to dental services. Multiple factors contribute to poor oral health in persons with disabilities: deprived socioeconomic status, limited mobility, insufficient numbers of qualified dental providers, absence of appreciation for the importance of oral health, lack of motivation and inadequate training of general caregivers in oral health issues, and lack of aggressive oral disease prevention protocols.

Adults with disabilities are probably the most disadvantaged of this vulnerable segment of the population. While priority is rightly given to providing oral health care for children with disabilities, and the concerns of the frail elderly are also being addressed, little attention has been given to the oral health needs of the middle generation of disabled adults whose numbers are growing.

A major underlying concern is the negative effect of deinstitutionalization on access to dental services for persons with mild, moderate, and severe disabilities. The underlying philosophy of moving persons out of institutions and into smaller residential settings was to normalize their lives. This has been disadvantageous as far as oral health care is concerned. Persons who previously were treated by the dental and dental hygiene staff of large state and regional institutions now find that professional dental resources to serve them are not available in the community.<sup>19,20</sup> Moreover, there is evidence that "normalization" in living arrangements and greater independence may lead to an increase in dental disease due to less rigorous daily oral care and less supervision of diet.<sup>21</sup>

## NEED FOR SPECIAL DENTAL CARE

Special care dentistry is the field of dental practice that addresses the needs of patients who require treatment accommodation to their physical, mental, or medical problems, whose dental health has been neglected, with resultant extensive oral disease, and who have difficulty in locating dentists to treat them. Special dental care for adults takes in a diverse patient population. Examples of such patients include persons with severe movement disorders who present as moving targets for the clinician, people with chronic mental illness who may be delusional and hear voices, persons who are adults chronologically and physically but who function at a child's level, and patients with serious medical conditions who are at risk for adverse outcomes in the dental setting unless treated by a knowledgeable practitioner.

Persons with disabilities present with a range of conditions and levels of impairment. They need special dental care because they may require extra support to access dental services, partake in treatment, and derive full benefits from oral care. It may take more time to complete treatment for them.<sup>22</sup> Whereas the average person without a disability is expected to take responsibility for seeking dental care, keeping appointments, making payments, and complying with instructions in the dental chair and with home care, many

persons with disabilities are incapable of carrying out these normal obligations of a dental patient. They are dependent to a varying degree on others to make dental care decisions for them, to transport them to the dental office, and to perform or assist them with daily oral hygiene.

The provision of oral care to patients with severe disabilities requires empathy, patience, and a high degree of knowledge and skill. Quality oral health care for special needs patients is defined as a program that is person-centered, provides individualized treatment with comprehensive continuous care, provides access to specialized care when necessary, and uses the least restrictive approach to gaining patient cooperation.<sup>14</sup>

## DENTAL TREATMENT CONSIDERATIONS

The dental care provider must manage the disabling condition and modify treatment as necessary in order to deliver quality dental care and preventive oral health protocols. Special management considerations encompass pretreatment, clinical treatment, and posttreatment phases of care. The following treatment modifications illustrate the numerous issues that must be addressed in dental care of special needs patients.

### Pretreatment Assessment

Information normally obtained at the time of the first appointment should be obtained prior to the visit to allow for adequate assessment of the patient and a productive treatment visit. Often, contact must be made with a person able to provide the information because frequently the individual accompanying the patient to the dental office cannot. A complete medical history is essential and consultation with the patient's physician may be necessary to clarify the patient's medical status. Specific questions regarding the disability provide valuable information on the patient's level of function and will identify the patient's support system. Consent to care must be obtained from the patient or the legal guardian. It is the dentist's responsibility to determine who is legally qualified to give consent to the proposed treatment; competency to give consent depends in part on the seriousness of the procedure. Scheduling the appointment should be at a time convenient to the patient and caregiver; the preferred timing and length of the appointment depends on the individual's particular disability. Some patients can only tolerate short appointments and procedures may have to be completed over several visits; other patients prefer longer appointments because of difficulty in transportation to the dental office.

### General Patient Management

Communication must be adjusted to the patient's level of functioning, neither overestimating nor underestimating the patient's intellectual capacity. The mode of communication must be modified for the patient with a sensory disability or if a third person is involved. Users of wheelchairs must be transferred in a safe manner to the dental chair or in some cases treated in the wheelchair. The patient's disability may necessitate adjustment of position in the dental chair from that normally used. Patients with congestive heart failure or asthma, with a high-level spinal cord injury, or with cerebral palsy and swallowing difficulties require a more upright position. Great care must be taken in moving of patients with

rheumatoid arthritis or Down syndrome, who are at risk for paralysis from subluxation of the C1-C2 vertebrae.

The patient's ability to cooperate with routine dental procedures varies widely, depending on neuromuscular deficits, cognitive function, emotional status, and previous dental experiences. The appropriate method of behavior management must be determined; modalities may range from ensuring a calm, friendly atmosphere, to behavior modification, to use of pharmacological sedation and physical restraints, and combinations of strategies.<sup>23-26</sup>

The patient's medical condition may require changes in treatment protocol. Antibiotic prophylaxis may be needed prior to invasive procedures for persons at risk for bacterial endocarditis, including high and moderate risk cardiovascular patients, certain patients on renal dialysis, and those with systemic lupus. Medications used to treat cardiovascular, chronic respiratory, and psychiatric and other disorders may interact with dental agents, such as anesthetics, sedatives, and vasoconstrictors, that must be avoided or used with caution.

### Post-treatment Considerations

Any communication regarding posttreatment care must be presented in writing to the patient or caregiver; the patient may need to be observed for complications such as bleeding or self-inflicted trauma to the soft tissues following treatment.

### Dental Disease Prevention and Home Care

Prevention of oral disease and infection is the key to the oral care of persons with disabilities. Technology for prevention of most dental disease is available, but to be effective a preventive dental program must be modified and tailored to the needs and functional abilities of the individual.

Persons with a physical impairment, e.g., arthritis or quadriplegia, may be able to brush and floss independently by using adaptive devices such as enlarged handles, universal cuffs for hand attachment, or extension rods.<sup>27,28</sup> Persons with limited dexterity or tremors, and caregivers of dependent persons may find special toothbrushes such as "triple-headed" brushes and automated (electric) toothbrushes useful.<sup>29-32</sup> Appropriate control and positioning of the patient are essential to providing safe and effective oral hygiene care to dependent persons, including those with uncontrolled bite reflexes, untoward movement disorders, or who are resistant to care.

Use of chemoprevention is strongly indicated for patients with disabilities at high risk for dental disease. Various chemotherapeutic agents, including fluoride, chlorhexidine, and sealants have proven clinically effective and economically advantageous. Fluoride is the cornerstone of treatment for the prevention of caries. Regular use of topical fluoride is essential for persons at high risk for caries such as those with xerostomia due to psychotropic or other medications, Sjogren's syndrome, or following radiation therapy to the head and neck. The application method may need alteration depending on the type of disability; for example, use of a gel formulation or brushing with fluoride instead of toothpaste may be more appropriate for persons dependent on caregivers.

Use of chlorhexidine, the treatment of choice for gingivitis, is indicated in developmentally disabled, medically compromised, and dependent populations who are unable to remove plaque by mechanical means.<sup>33</sup> Various studies have demonstrated that chlorhexidine is well tolerated by persons

with a disability. For persons unable to use chlorhexidine as a mouthwash, the agent can be effectively swabbed on the teeth with an applicator, sprayed on the teeth, applied with a toothbrush, or used as a gel. Acceptance and compliance by clients and caregivers are the key to successful administration.<sup>34-38</sup>

## RESOURCES FOR SPECIAL PATIENT CARE

As increasing numbers of persons with severe and profound physical and mental problems, and associated medical conditions are placed in the community, the provision of comprehensive treatment in the private sector becomes problematic. These patients may display resistant and maladaptive behavior and require behavior management techniques beyond the capability of the average clinician. Most private practitioners feel inadequate and reluctant to treat patients with problems such as poorly controlled seizures, uncontrolled movements, severe gag reflexes, tracheotomies, and gastrostomies. Additional issues include legal concerns and lack of adequate financial reimbursement. They tend to avoid these patients or react with frustration and apathy.<sup>39,19</sup> Patients with such complex needs require the services of special programs, clinics, and facilities staffed by personnel with advanced training and experience.<sup>40-42</sup>

Dental management of patients with disabilities, at all levels of severity, demands an interdisciplinary approach. Not only does special patient care call for a team effort by the dentist, dental hygienist, and dental assistant, but the dental team must work closely with other health care providers, family members, and social service agencies to facilitate therapy and home care.<sup>43</sup> Dental and other health professionals and caregivers must be aware of the patient's special needs, be motivated, and have the skills to provide the requisite oral care. This requires special training at various levels of education for all disciplines involved, from advanced, predoctoral, and undergraduate professional training, to periodic in-service instruction of direct caregivers. Multidisciplinary education models have been tested and proven effective.<sup>44</sup>

## INTER-RELATIONSHIP OF ORAL AND SYSTEMIC HEALTH

Oral health is an integral part of total health, and not an isolated element. Persons who are medically compromised or who have disabilities are at greater risk for oral diseases and, in turn, oral diseases further jeopardize their health. Recent studies suggest associations between oral infections, particularly periodontal disease, and systemic conditions such as heart disease, stroke, and diabetes, although causality remains to be determined.<sup>17,45</sup>

Multiple risk factors for oral disease include physical limitations that prevent normal oral self-care; cognitive, communication, and behavioral problems that cause a lack of understanding or motivation for oral self-care; and lack of caregiver motivation or training to provide oral hygiene services, particularly for the most severely impaired. Dental fear and inaccessibility of dental services also contribute to infrequency of dental visits and lead to progression of disease.

The disability itself may be directly associated with oral

problems. The following conditions are but a few examples of the oral manifestations of systemic disorders.

**Cerebral palsy** may be associated with severe bruxism, excessive tooth wear, damage to the temporomandibular joint, and swallowing deficits.

**Traumatic brain injury** also is frequently associated with heavy bruxism and swallowing defects. Affected persons may require use of pureed foods that contribute to poor oral hygiene.

**Sjogren's syndrome** is characterized by markedly decreased salivary flow and xerostomia. Lack of saliva increases the risk for caries, periodontal disease, and other oral lesions.

**Down syndrome** is noted for an increased susceptibility to a rapidly progressive form of periodontal disease. Prevalence in young adults ranges from 92 to 100 percent.<sup>46,47</sup>

**Diabetes** increases susceptibility to severe periodontal disease. Periodontal disease progresses more rapidly in diabetic individuals than in nondiabetic subjects, and is particularly marked in persons with poorly controlled diabetes and among those having local risk factors such as subgingival calculus. Oral complications of diabetes include angular cheilitis, xerostomia, candidiasis, glossitis, mucositis, smooth surface caries, and tooth mobility. Infections, including advanced periodontal disease, may contribute to a worsening of the diabetic state. Recent findings suggest that a reduction in periodontal infection increases glycemic control and results in better management of diabetes.<sup>48</sup>

**HIV/AIDS** Oral lesions are often the first clinical feature of human immunodeficiency virus (HIV) infection and may serve as predictors of disease progression and/or severe immune suppression. Although not unique to the disease, predictive lesions include major aphthous ulcers, necrotizing ulcerative periodontitis, intraoral Kaposi's sarcoma, long-standing herpes simplex virus infection, oral hairy leukoplakia, and candidiasis. While oral manifestations may improve with use of antiretroviral medications, a recurrence may signal a relapse of HIV disease.<sup>49,50</sup> A study of HIV seropositive and at-risk seronegative women indicated a high prevalence of oropharyngeal lesions; substance abuse, lack of dental care, and African-American race were associated with gingival pathology.<sup>51</sup>

Treatment of the disability may increase risk factors for oral disease and exacerbate the disease process. Reduction in salivary secretion by prescribed medications is a significant compounding etiologic factor in oral disease for many persons with disabilities. Over 400 drugs have been identified as causing xerostomia.<sup>52</sup> Another study reported oral side effects for 103 (79 percent) of the 131 most frequently prescribed medications; xerostomia and stomatitis were noted in 80.5 percent and 47.5 percent, respectively, of the 103 drugs.<sup>53</sup> Antipsychotic medications, tricyclic antidepressants, and

lithium, widely prescribed for psychiatric disorders, have notable anticholinergic effects; they can result in chronic xerostomia and increased risk of caries, gingivitis, candidiasis, and other mucosal oral lesions.<sup>54</sup>

Gingival hyperplasia is a side effect of a number of medications and can cause severe overgrowth of the gum tissue. This condition includes Dilantin hyperplasia due to phenytoin for the control of epilepsy. It is also associated with the use of calcium channel-blocking agents for the control of hypertension (nifedipine, diltiazem, verapamil, and others), as well as the immunosuppressive agent cyclosporin used in the prophylaxis of organ rejection in kidney, liver, and other transplants and in the treatment of severe rheumatoid arthritis. Other antiarthritic agents such as methotrexate may induce severe oral ulcerations, gingivitis, glossitis, and angular cheilitis.<sup>24,55</sup>

Patients receiving cancer therapy often experience serious oral complications. Surgery for intraoral and other head and neck tumors can result in permanent loss of structures and seriously compromise function. Over 50 percent of all patients receiving systemic chemotherapy and essentially 100 percent of patients who receive radiation to the oral cavity develop oral complications. Direct toxicity complications include mucositis, xerostomia, taste dysfunction, neurotoxicity, soft tissue necrosis, osteoradionecrosis, and trismus. The most prominent indirect toxic effects are oral infections and bleeding. Once a patient has received radiotherapy to the jaws, it is extremely dangerous to extract teeth or carry out any aggressive or surgical dental therapy. These patients must receive comprehensive preradiation dental care, diligent follow-up care, and intense preventive oral hygiene to eliminate all sources of infection, trauma, and irritation.<sup>24</sup>

Persons with disabilities frequently have multiple health problems that affect their oral health and dental care. Developmental disabilities are seldom isolated disorders but comprise overlapping motor and sensory deficits and associated medical conditions. In a random sample of 333 predominantly adult community-dwelling persons with mental retardation, service coordinators reported almost two-thirds of their clients had chronic conditions requiring medical intervention. The most prevalent problems were neurologic (primarily seizure disorders), ophthalmologic, dermatologic, psychiatric-emotional, and musculoskeletal or orthopedic conditions. Twenty percent of the clients required supportive measures to complete examinations and treatments.<sup>56</sup> Persons with Down syndrome have a high rate of congenital cardiac abnormalities, including mitral valve prolapse, a condition of concern in dentistry. Mitral valve prolapse has been reported in 50 percent of persons with Down syndrome, compared to an estimated prevalence of 5-15 percent in the general population. Poor oral hygiene and periodontal and periapical infection place affected persons at risk for the development of bacterial endocarditis. Depending on severity, these patients may need prophylactic antibiotics prior to dental procedures.<sup>57</sup> Furthermore, persons with developmental disabilities age earlier biologically than nondisabled persons, with the number of disabling conditions and their severity affecting the life span. In persons with multiple developmental disorders, the biologic age exceeds the chronological age by 10 years, and in Down syndrome aging changes are evident by early middle age. Age-related systemic changes must be taken into account at a younger age when

planning treatment for developmentally disabled dental patients.<sup>4</sup>

## IMPORTANCE OF ORAL HEALTH

Oral health is integral to total health and function. The mouth has been termed the lifeline for the person who is disabled, and is the center of the personality in the absence of one or more functioning faculties.<sup>58</sup> For example, for the person with a high-level spinal cord injury, the mouth may be the only part of the body over which the individual retains voluntary control, and the jaws and teeth may serve as the only functioning extremity. If the natural dentition is lost, the person with a severe physical or mental impairment of developmental or acquired origin may not be able to manage a dental prosthesis to aid in eating, verbal communication, device-activated communication, and independent management of other tasks.

Society values oral health. People with missing front teeth are not treated the same as those with a nice smile.<sup>59</sup> This holds true for persons with disabilities perhaps even more than for the general population. Facial appearance is of key importance to social acceptance by others. At the conclusion of an extended preventive study, a sample of adults with severe disabilities and their caregivers reported significant improvement in dental health, attitude toward oral care, smile, and quality of life.<sup>38</sup>

Severity of medical conditions and perceived general health are significantly correlated with dental functional status and severity of dental disease. Several investigators have concluded that patient-perceived dental health contributes to quality of life. The available data indicate that the impact of dental conditions is pervasive and significant.<sup>60,61</sup> For persons with disabilities, the effect of dental disease on general health and function appears greater than for similar groups without a disability. In a survey of dental emergency clinic patients, a significantly higher proportion of patients with a disability compared to control subjects without a disability reported that dental problems had affected their general health. Similarly, significantly more patients with a disability entering a special patient care clinic considered their dental problems to have a large effect on their overall health and on their ability to find employment compared to incoming patients without a disability.<sup>62,63</sup>

## ORAL HEALTH STATUS

In the absence of national data on the prevalence of oral disease in populations with disabilities, an indication of their oral health status can be derived from smaller clinical investigations of selected disability groups. Earlier studies were conducted largely of children. Studies of adults with disabilities are more limited; those carried out in other countries may not reflect conditions in the United States. All available data indicate that American populations with disabilities exhibit poor oral health and high treatment need.

In persons receiving psychiatric care, dental disease is severe.<sup>64,65</sup> Community-dwelling persons with chronic mental illness had a higher incidence of oral pathology (soft tissue lesions and smooth surface caries), risk factors for dental and oral disease, and dental treatment needs than a control group of similar socioeconomic status without psychiatric illness. Xerostomia due to psychotropic medications was postulated as

a major causative factor, with poor oral hygiene secondary to mental illness as an associated factor for oral disease.<sup>66</sup>

The prevalence of alcoholism and substance abuse is considerable among people with physical and mental disabilities. Patterns of substance abuse vary according to use before, after, or both before and after the onset of a disability.<sup>67</sup> An estimated 40 percent of persons with chronic mental illness have a history of substance abuse involving drugs and/or alcohol.<sup>68</sup> Among the homeless population, an estimated 43 percent are substance abusers and as many as 40 percent are estimated to be mentally ill.<sup>69,41</sup> Homeless adults were found to have a high rate of oral disease. Compared with the general population, homeless persons were half as likely to have made a dental visit during the preceding year and had more grossly decayed teeth. Individuals with more tooth decay and missing teeth were more likely to be older, have physical health problems, smoke more cigarettes, use more alcohol, and have worse personal hygiene.<sup>70,71</sup>

Alcohol and tobacco are major risk factors for oral cancers, with the combined use of both substances increasing the risk and accounting for approximately three-fourth of all U.S. oral and pharyngeal cancers.<sup>72</sup> Alcoholism is also associated with tooth loss, caries, and periodontal disease.<sup>73</sup>

A survey of groups of adults with spinal cord injury, chronic mental illness, mental retardation, cerebral palsy, and traumatic brain injury suggested that different disability groups vary in oral health status. Periodontal disease was more prevalent in persons with developmental disabilities (mental retardation and cerebral palsy), whereas more untreated caries was noted in those with spinal cord injury and chronic mental illness. Variation in access to dental services, quality of daily oral hygiene, and disability-related risk factors may account for inter-disability group differences, and between persons with disabilities and an equivalent sample of employed adults.<sup>74</sup>

Neglect of oral hygiene and advanced periodontal disease are the predominant oral health problems of persons with developmental disabilities irrespective of whether they reside in large institutions, smaller regional facilities, or group homes. Age, degree of mental retardation, and institutionalization are considered significant factors in determining the level of oral hygiene practice.<sup>75-77</sup> The reported prevalence of dental caries in persons with developmental disabilities is variable.<sup>78,46</sup> Incoming patients to a special care clinic, the majority of whom were developmentally disabled, exhibited a dental profile consistent with that of similar groups; while they had significantly poorer oral hygiene, their caries rate was lower compared to a control group without disabilities.<sup>63</sup>

Dental surveys of adult workers in multidisability, sheltered workshops revealed that compared to equivalent populations without disabilities, workers with disabilities exhibited poorer oral hygiene with higher rates and severity of periodontal disease, more decayed tooth surfaces, and significant dental treatment needs.<sup>79,80</sup>

## **FACTORS CONTRIBUTING TO ORAL HEALTH STATUS**

### **Dependency**

Persons with severe physical and mental disabilities who are dependent on caregivers for daily oral care characteristically

have poor oral hygiene and a greater prevalence of periodontal disease.<sup>81,74</sup> Caregivers play a pivotal role in dental disease prevention, yet many are not motivated to provide such care. Deterrents to adequate care include high staff turnover, low appreciation of oral health, fear due to resistive behavior by patients, and lack of adequate training.<sup>20</sup>

### **Fear and Anxiety**

Several studies indicate a high level of fear and anxiety in persons with disabilities. In a sample of community-dwelling cognitively impaired persons, 27.9 percent expressed fear/anxiety about dental visits and approximately half of this group reported being very nervous or terrified. Extreme fear was inversely related to frequency of dental visits and perceived oral health status.<sup>82</sup> A high level of nervousness about dental care was expressed by significantly more patients with a disability in a special care clinic compared to control subjects without a disability (11.9 vs. 2.9 percent).<sup>63</sup> In a regional survey of 106 rehabilitation agencies, fear of dental procedures was cited by 34 percent of respondents, substantially higher than the prevalence of 20 percent reported for the population at large. The high proportions may reflect a lack of regular dental care and poor past dental experiences.<sup>83</sup>

### **Institutionalization**

Institutionalized adults with disabilities comprise primarily two groups: persons with developmental disabilities and persons with psychiatric disorders. Poor oral hygiene and severe periodontal disease are characteristic of institutionalized persons with disabilities and compromising medical conditions. In recent years, institutions have been markedly downsized and the profile of remaining residents has changed. The residual population in institutions for the developmentally disabled is older, more fragile, with severe and profound mental retardation and associated maladaptive behavior, sensory impairment, severe neuromuscular dysfunction, and complex medical problems. There are indications that the more difficult to manage population has deteriorating oral health and dental needs that may exceed available dental resources.<sup>77</sup>

### **Homebound Status**

Although the majority of persons who are homebound are geriatric, this population also includes younger persons with a disability. In one epidemiological survey, 21 percent were between the ages of 35 and 59.<sup>84</sup> Typical disabilities in this group are traumatic brain injury, multiple sclerosis, and agoraphobia. National census data for 1991-92 indicate that almost 3 million persons had difficulty going outside the home to shop or visit a doctor's office. According to some studies, homebound persons perceive a high dental care need. Difficulties in getting to a dentist, paying for dental care, and poor health were cited as barriers to obtaining dental care.<sup>85,86</sup> Although mobile dentistry can meet the dental treatment needs of this population, it requires appropriate equipment and clinicians willing and knowledgeable in providing this service. A variety of portable dental equipment is available.<sup>87,88</sup>

## **IMPEDIMENTS TO MAINTAINING AND IMPROVING ORAL HEALTH**

Lack of access to dental services by persons with disabilities

has been documented and widely reported. Dental problems were identified as among the most prevalent unmet need by case managers of regional centers providing community services for persons with developmental disabilities.<sup>42,5,20</sup> Of respondents to a four-state survey of rehabilitation agencies, 88.3 percent stated that their clients had unmet dental needs; 63.4 percent cited barriers directly related to the disability, i.e., cannot find a dentist to work with disabled patients, difficulty with transportation, and lack of motivation by the caregiver.<sup>83</sup> Factors that deter persons with disabilities from benefiting from the advances in oral health enjoyed by the population at large can be grouped into the following categories: financial barriers, lacked of trained personnel, lack of recognizing the importance of oral health, and difficulty in physical access.

### **Financial Barriers**

Persons with disabilities, particularly those with severe disabilities, are deprived with respect to income and dental insurance, factors that are major determinants in the rate of utilizing dental services. Inability to pay for the cost of care, lack of dental insurance, and limited dental coverage by public funding place dental care out of reach for many persons with disabilities.

### **Medicaid**

Dental care for adults on Medicaid is an optional benefit that is determined by each state and is subject to fluctuation with state budgets. Some states have tightened eligibility requirements and have reduced the range of covered dental services for adults. The proportion of total Medicaid expenditures designated for dental services has declined.<sup>17</sup> A survey by the American Dental Association reveals that in 1997, only 27 states provided dental benefits for adult Medicaid recipients; of these, 20 states covered both categorically and medically needy adults whereas 5 states limited benefits to categorically needy (2 states did not respond). Dental services for adults on Medicaid varied according to the following categories and number of states reporting: emergency treatment (N=32), preventive treatment (N=18), diagnostic treatment (N=20), routine restorative care (N=19), and more complex services (N=18). Services in some states are limited to emergency care only.<sup>89</sup>

Reimbursement rates are low for eligible adults and vary by state with a reported norm of 47 percent of usual and customary fees.<sup>17</sup> The inadequate levels of reimbursement serve as a financial disincentive to the care provider in private practice. The rates are often significantly lower than the overhead costs incurred by the dentist. An added consideration is that persons with severe disability frequently present with complex management problems that necessitate extra time and personnel for which the provider is not reimbursed adequately in a procedure-based payment scale.<sup>22</sup>

The burden of care for patients with a severe disability, many of whom rely on government funding, falls on hospitals, dental schools, and other community clinics that accept Medicaid patients. Significantly more patients with disabilities compared to those without a disability elected to seek care at a school of dentistry because the clinic accepts Medicaid whereas other dentists would not.<sup>63,62</sup>

### **Medicare**

The absence of dental benefits for routine dental care under the Medicare system adversely affects adults with a medical disability under age 65 who are Medicare recipients. Medicare coverage is limited to inpatient hospital dental services for specific conditions, e.g., jaw fractures, extractions prior to radiation for oral and pharyngeal cancer, and dental assessment prior to renal transplant. Medicare to date has defined "medically necessary oral health care" very narrowly.

### **Lack of Trained Personnel**

The acute shortage of professional and nonprofessional personnel who can serve the oral health needs of persons with disabilities in community and institutional settings has been well documented. Education in special patient oral health care is needed at all levels, from advanced training for dental professionals, to interdisciplinary instruction for professionals in other health and social service fields, to ongoing courses for nurses' aides and personal attendants.

### **Lack of Dental Professionals with Advanced Training**

According to statewide surveys of practitioners in private practice in the 1980s, the number willing to treat patients with disabilities was in the range of 20 percent.<sup>90-92</sup> The majority of private practitioners willing to accept patients with special needs had neither training nor extensive experience in this field. They were selective in whom they would accept and indicated a greater reluctance to treat persons with developmental or psychiatric disabilities than with physical problems.

Furthermore, a survey of 300 state institutions for persons with developmental disabilities revealed that more than 80 percent of 283 responding dentists were poorly prepared or unprepared for treating their facility's residents; for 85.9 percent of the dentists, training was "on the job." Responses by dental auxiliaries indicated even less preparedness.<sup>92</sup>

It is necessary not only to increase the provider pool but also to ensure that providers are adequately trained. Educational courses at the predoctoral and prebaccalaureate level, to the extent that they currently exist, are aimed primarily at increasing the provider pool for persons with mild to moderate disabilities who can be accommodated in private-practice settings. There is a notable lack of dental professionals with advanced training to serve the acute needs of persons with severe disabilities. As the severity of disability of special-needs adults seeking community dental resources rises, the condition of those remaining in institutions also is increasingly complex. Traditionally, postgraduate pediatric dentistry programs have provided training in caring for special-needs patients. Most pediatric dentistry educators, however, believe that the provision of dental services for adults with developmental disabilities should not be the role of pediatric dentists.<sup>93</sup> In the face of growing numbers of highly challenging patients in both community and institutional settings, it is essential to train a cadre of clinicians who have the knowledge, skills, and motivation to provide quality care in this special field.

### **Lack of Trained Caregivers**

Many persons with severe disabilities are completely dependent on caregivers for maintaining an adequate oral hygiene level. In institutional settings, such residents can be extremely uncooperative and present problems for attendant staff who generally view oral care as a low priority and an unpleasant task. They are uncomfortable with saliva and gingival bleeding and are afraid of disruptive behavior. Persons living in group homes or private residences may be less severely disabled but still require supervision in their oral health care. The task of oral hygiene procedures falls mostly on attendants who characteristically are poorly paid, poorly educated, place a low value on oral health, and have a history of poor dental care and oral hygiene themselves. The high rate of staff turnover in these entry-level positions further aggravates the problem. It is difficult to repeatedly train and retrain staff in preventive procedures or build and maintain routines that address behavioral barriers to oral health.

Intervention with a multidisciplinary approach is advocated to improve oral hygiene care and spread awareness to other disciplines involved. A key issue is good communication between the dental consultant and the nondental administrative professionals who in turn must communicate with and monitor direct service staff.<sup>76,26</sup> One approach is to train managers and agency administrators who can then train direct caregivers.<sup>42</sup>

### **Lack of Financial Support for Training**

The paucity of financial support for dental professional training is critical and unless remedied will further adversely affect the availability of qualified dental providers to serve special-care patients.

The importance of professional training on access to dental care for persons with disabilities has long been recognized. In 1974, funding by The Robert Wood Johnson Foundation of 4-year pilot projects at 11 U.S. dental schools gave an impetus to including instruction in special patient care in the dental and dental hygiene curricula. The purpose of the projects was to instruct dental and dental hygiene students in the treatment of special patients so that they would be prepared and willing to accept such patients in their practices. Guidelines for the teaching of dentistry and dental hygiene for the handicapped were subsequently issued.<sup>94-96</sup>

Training of dental professionals has been shown to have a positive outcome on the provision of care to persons with disabilities. Evaluation of students before and following courses in clinical management of patients with disabilities consistently demonstrated increases in positive attitude and confidence levels.<sup>97-99</sup> Several studies suggest that training and past experience in special patient care correlate positively with practitioners' willingness to treat patients with disabilities in their private practices.<sup>100,92,91</sup>

In the interim since the 1980s, dental education in this field has declined. Current dental school graduates do not gain the necessary expertise to treat patients with special needs. Although the majority of American dental schools in 1984 included instruction in special care, content varied widely, ranging from required coursework to no clinical component. A survey of American and Canadian dental schools, published in 1999, revealed that 53 percent of the schools responding provided fewer than 5 hours of didactic training in special

patient care; 73 percent indicated that clinical instruction in this area constituted only 0 to 5 percent of the predoctoral student's time.<sup>93</sup> Such instruction is considered outside of the regular dental disciplines. The few schools that have developed strong programs in special patient care have had to rely on outside funding to maintain these efforts.

Only a limited number of programs offer extended training at the postgraduate level. Dental Education in Care of Persons with Disabilities, DECOD, at the University of Washington, provides training in care of a wide range of disabled patients. Fellowships limited to care of persons with developmental disabilities are offered by the State University of New York at Stony Brook and by the Rose F. Kennedy Center at Albert Einstein College of Medicine.

Financial support for training is becoming increasingly uncertain at the federal and state level, and long-time educational programs in special patient care are threatened with closure. Although dentistry was recognized as one of the rehabilitation disciplines and for 20 years the Rehabilitation Services Administration supported a limited number of dental training programs, this agency no longer offers a category under which applications for training grants in dentistry can be submitted. Where support is provided at the state level, it is linked to services provided by students and faculty of the teaching institution to persons with disabilities receiving state support. The availability of such funding depends on state financing of adult dental services that are optional under Medicaid, making this avenue of support for training subject to arbitrary termination. Any further cutbacks in already limited support of training will gravely impact the number of dental professionals qualified to serve persons with severe disabilities.

### **Lack of Recognition of the Importance of Oral Health**

A general lack of awareness of the relationship of the mouth to the rest of the body is pervasive across the health disciplines, social service agencies, and public policy-makers concerned with services for persons with disabilities. Dental diseases are not recognized as infections that must be treated as aggressively as infections elsewhere in the body. Nondental staff, administrators, and government agencies generally have insufficient knowledge of the importance of oral hygiene and timely professional intervention in preventing infection and progression of disease. Students in medicine, nursing, physical and occupational therapy, rehabilitation, and social work receive little or no training in the basics of oral diseases and their prevention. Attempts to insert this topic into a crowded curriculum tend to be met with resistance.

At the legislative level, dentistry is not considered on a par with other health services. In the allocation of limited resources, whether for training or direct patient care, dentistry is given very low priority. Special patients and their care are not only underfunded, but are in large measure neglected.<sup>101</sup> Adults with disabilities are particularly disadvantaged. Dental treatment for adult recipients of Medicaid is designated as an optional service, with the result that many persons with disabilities are ineligible for basic dental care. State officials addressing a budget crisis view the adult dental program as the least harmful to eliminate. Government attention drawn to the need for expanding the definition of "medically necessary oral

health care” under Medicare resulted in a recent study by the Institute of Medicine. According to the Institute’s report, the present restrictive definition suggests that periodontal or other tooth-related infections are somehow different from infections elsewhere, and implies that the mouth can be isolated from the rest of the body, notions neither scientifically based nor constructive for individual or public health.<sup>17</sup>

Similarly, other third-party payers frequently deny medically necessary oral health care. Patients with lifelong diseases such as cystic fibrosis, multiple sclerosis, diabetes, or Parkinson’s disease are denied care on the basis that the treatment ordered by the attending physician is dental.<sup>102</sup>

### **Difficulty in Physical Access**

All too often, patients with disabilities have to travel great distances to a dental facility that is qualified and willing to treat them, placing an added burden on family members or caregivers who accompany them. Transportation issues appear to be worsening and in large measure reflect the lack of available providers for patients with special needs.

A study of patients attending a special patient care clinic at the UCLA School of Dentistry found that the distance traveled from the patient’s residence to the dental treatment facility increased in the 1987-89 period compared to 1977-79.<sup>103</sup> A survey of nondental health care providers and administrators of a social service agency in Iowa revealed that of the respondents, 47 percent identified lack of transportation and 31 percent cited the inconvenient location of the dental facility as barriers to receipt of dental services.<sup>104</sup> Among patients seeking emergency dental services at the University of Washington, significantly more patients with disabilities compared to those without a disability (10.1 vs. 1.1 percent), reported not having transportation as the reason for not seeing a dentist regularly.<sup>62</sup>

## **APPROACHES TO IMPROVING ORAL HEALTH AND ACCESS TO DENTAL CARE**

The oral health needs of adults with disabilities in America are reaching critical proportions in many parts of the country. An effective policy for oral health care for persons with disabilities requires an integrated approach to overcoming existing barriers. Oral health of special needs populations can be promoted only through a concerted interdisciplinary effort aimed at improving access to oral health services, increasing professional and nonprofessional training and research, and securing the necessary financial resources to support these endeavors. Dental preventive and stabilization services must be properly directed, based on epidemiologic findings and identification of disability-associated oral disease risk factors, and linked to the training of those who provide care to persons with disabilities. Health care professionals must be formally taught how to be effective team participants and be given the opportunity to practice the skills needed for teamwork.<sup>105</sup>

The oral health of adults must be the focus of any broad-based effort to meet oral care needs of persons with disabilities. The adult age group among those with special needs is truly the sandwich generation that has received far too little attention. It is a cohort that is growing in numbers, has extensive oral health problems, yet has a great potential for benefit in terms of

improved health, function, and quality of life.

These goals can be met only through changes in fiscal, public health, and manpower policies that ensure adequate financial support, full recognition of the significance of oral health for total health and function, and a requisite number of trained providers. Establishing innovative programs that link health, social service, and educational institutions are essential to attaining a successful outcome.

### **Integrated Health Care Delivery**

The complex oral care problems of adults with disabilities will be served best through a network of available clinical resources that include private dental offices, dental schools, institutional and community dental clinics, rehabilitation facilities, and dental hygiene and auxiliary training programs. Using an array of clinical facilities allows for optimum delivery of care on a statewide or regional basis. While acknowledging the laudable goals of “normalizing” care delivery, such a network addresses the pragmatic issues of providing oral health care to persons with special needs.

### **Regional Centers**

Establishing regional centers with outreach to satellite facilities will increase access to care in geographically strategic areas of each state. Two models for comprehensive programs of this type have been successfully tested: institution-based and dental school-based. In each case, the setting for clinical care delivery offers excellent opportunities for linkage to training and research activities that will advance the oral health of disabled populations. Such programs can also be extended to increase access to dental care for subsets of underserved populations that have a large disability component, such as the homeless and prison inmates. Successful regional centers have been developed and operated through collaborative efforts within the community. The centers facilitate access to care both directly and indirectly by increasing the provider pool of qualified dental professionals, including private practitioners, who are encouraged to participate and gain continuing education experience.

### **Institution-based Centers**

State and regional institutions for persons with developmental disabilities and with chronic mental illness in many cases have excellent dental clinics that are currently underutilized as the result of downsizing the institutional population. In several states, such clinical facilities have been used successfully to provide outpatient dental services to persons with developmental disabilities as well as to persons with mental illness. The specially equipped institutional facilities and staff experienced in treating patients with severe disabilities, including behavioral and medical complications, offer a valuable community resource.<sup>14,19</sup>

### **School of Dentistry-based Centers**

Dental schools are in an excellent leadership position to assume coordination of regional and statewide outreach programs to deliver oral health care to special patients. A successful model is the program operated by Tufts University School of Dental Medicine that offers dental services for persons with disabilities throughout Massachusetts. The Tufts

program provides dental care in more than 11 facilities statewide including institutions and smaller clinics. Tufts dental faculty, dental hygienists, and community practitioners constitute the staff, together with dental students and general practice residents who complete externships in the program on a regular basis. Pre- and postdoctoral students thus meet the treatment needs of patients with severe disabilities while gaining valuable experience in their care (D. Tesini, personal communication, October 2000). Similar programs at the University of Tennessee and through DECOD at the University of Washington provide outreach on a regional basis at satellite facilities. Other programs have successfully coordinated dental school resources with a consortium of agencies to address problems in local communities and develop model dental care delivery systems.<sup>42,40</sup>

Because university-centered programs are academically based, they offer an ideal environment for linking clinical services with interdisciplinary training and the conduct of research in the area of oral health of persons with disabilities.

### **INTERDISCIPLINARY TRAINING**

Dental care for persons with disabilities involves multiple disciplines. The dental team, other health professionals, and social service providers must have knowledge of each other's roles and be able to work collaboratively on behalf of the client. Such experience is acquired best through interdisciplinary training.

#### **Advanced Training for Dental Professionals**

There is a dire shortage of dental professionals who are qualified to treat adults with disabilities. Few practitioners have the training to provide comprehensive care to persons representing a full range of disabling conditions. Dental care providers must have special competencies and advanced training if they are to meet the complex needs of persons with disabilities, particularly those with severe conditions. They must have adequate preparation to become effective members and leaders of collaborative teams.

Support is needed for 1- and 2-year general practice residencies and special fellowships for advanced training of dentists and dental hygienists in special patient care, with a focus on the adult patient. Special care dental residencies and fellowships should be financially supported through Graduate Medical Education (GME) funds, other federal and state agencies, and philanthropic foundations. Loan forgiveness for dental professionals who complete training and agree to practice in a center serving patients with disabilities offers another means of attracting dental practitioners to this field of dentistry.

Dentists and dental hygienists who receive advanced training will gain the knowledge and skills to manage clients with severe disabilities, including those who are homebound and institutionalized. They will be qualified to spearhead interdisciplinary preventive care systems to reduce levels of oral disease in persons with disabilities, and thereby reduce their future dental treatment needs and enhance their well-being. Furthermore, dental professionals with advanced training will be in a position to fill a serious void in basic and clinical research relating to oral health and function of persons with a disability.

### **Training in Oral Health Care for Nondental Professionals and General Caregivers**

Health care providers must be trained in interdisciplinary teams if they are to work together effectively in resolving oral health problems. Physicians and nurses, rehabilitation counselors and therapists, and administrators must gain an awareness of the importance of oral health to total health. If they are to make health care decisions and direct attendant personnel in basic oral health services, they must know fundamentals of oral health and disease. These topics must be built into the curriculum of their respective disciplines. Together with caregivers and clients with disabilities, they must be taught hygiene procedures, cancer checks, nutrition concerns, and the importance of periodic professional dental care. The feasibility and value of training in interdisciplinary teams has been demonstrated in projects involving trainees from dentistry, dental hygiene, nursing, physical therapy, physician assistant, planning, and administration.<sup>106,44</sup>

Full use must be made of advances in the technology of communication and education to disseminate information on oral health care for persons with special needs. Instructional materials in lay language, including booklets, and videotapes, have been developed by several programs for the purpose of training agency staff, community program managers, direct caregivers, and family members.<sup>107,108,42,109-111</sup> Development of a multimedia resource for oral health training of medical and nursing staff has been reported in Great Britain.<sup>112</sup> Basic instructional materials must be increasingly adapted for interactive use via the computer.

### **SYSTEMATIC PREVENTION OF ORAL DISEASE**

Emphasis must be given to developing and implementing preventive protocols for persons unable to remove dental plaque through brushing and flossing. Full use must be made of safe, effective, and readily applied chemotherapeutic agents such as fluoride and chlorhexidine. State-of-the-art preventive technologies tailored to individual needs of persons with disabilities must be integrated into the daily hygiene plan as part of a multidisciplinary approach to care. To be effective, a preventive program must be simple to use, low in cost, and have the full cooperation of administrators, medical and nursing staff, personal care attendants, and clients. The resulting benefits will be far-reaching in terms of reduced morbidity, decreased pain and suffering, savings in cost through reduced need for treatment, and enhanced well-being, social acceptance, and quality of life of the individual.

#### **Research**

Many aspects of oral health of persons with disabilities, and specifically the needs of adults, have not been fully studied. Core issues that warrant further research include the following:

- The epidemiology of oral disease in selected disabled populations needs to be determined. Standardized indices must be used to allow for comparisons with the population-at-large.

- Risk for oral disease must be assessed for the individual

based on functional parameters and disability-specific risk factors. An oral disease risk score would form the basis for preventive and treatment protocols, and health services planning.

The proposed network of institutional and private-clinic settings provides ideal opportunities for study of health services issues. These include referral patterns, optimum use of dental professional auxiliary personnel, effectiveness of interdisciplinary teams, incentives for care providers to participate in special patient care, and practicality of capitation fees based on oral disease risk score, level, and category of dental care, i.e., standardized preventive and disease control treatment.

The extent of access issues nationwide needs to be fully documented.

Treatment options and preventive protocols must be tested based on oral disease/disability risk factors. Standards of care must be developed for assessment, prevention, stabilization, and dental rehabilitation services.

### Financial Support

All proposals to increase access to dental services and improve the oral health of adults with disabilities are predicated on availability of adequate funding. To secure the requisite level of financial support will require a consortium of funding sources, including federal and state support, industry and commerce, not-for-profit organizations, and philanthropic foundations.

### Cost of Care

Full recognition must be given to dental care for adults with disabilities as an essential health service that must be adequately covered in public and private health care funding. Oral health care is not elective health care. All efforts must be directed toward expanding dental benefits under the Medicaid and Medicare programs in terms of scope of services covered and adequacy of fee structure. Basic dental care must be a mandated service, not an optional benefit. Reimbursement rates should be based on time values for services, particularly for evaluation, diagnosis, and treatment planning that require more time for medically compromised and disabled patients than for healthy patients. The definition of medically necessary oral health care must be broadened so that Medicare and private insurance enrollees with conditions requiring control of oral infection receive the oral health services they need.

### Dental Training

To meet the acute shortage of qualified dental personnel, federal, state, and local agencies must take the lead in financing fellowships and residencies for advanced training of dental professionals in special patient care. Training in this field must be a category supported by programs such as GME and the Rehabilitation Services Administration (RSA) training grants. Training in care of adults with disabilities should also be urged through fellowships supported by the National Institute of Dental and Craniofacial Research.

Furthermore, a collaborative approach should be taken through the State Loan Repayment Program authorized by the Public Health Service Act and supported by federal and matching state and local funds. In line with the program's mission of improving access to primary and preventive health services for underserved communities and vulnerable populations, regional centers for persons with severe disabilities should receive federal designation as health professional shortage areas. Student loan repayment programs can then be extended to dental and dental hygiene students who agree to practice at such sites, thereby encouraging dental professionals to enter this field of dental practice. In addition, interdisciplinary experiences involving special dental care should be encouraged by seeking stipend support for this purpose through the National Health Service Corps SEARCH Program.

### RESEARCH

To extend the limited current knowledge base, high priority must be given to basic science, clinical, and health services research in the area of special dental care, particularly with respect to adults with disabilities. At the federal level, direct support of projects and research fellowships must be designated for this purpose by appropriate agencies, including the National Institute of Dental and Craniofacial Research and the National Institute on Disability and Rehabilitation Research. Partnerships in this endeavor must be sought with national and local organizations, industry, and philanthropic foundations.

### CONCLUSION

Adults with disabilities are a part of the population that has extensive oral health needs but limited access to dental services. The principal barriers to care are the inadequacy of public and private dental insurance, a lack of dental professionals qualified and available to meet the need, and a general lack of awareness of the importance of oral health to total health. To address the urgent oral health problems of this growing segment of the community requires a collaborative effort by the various health disciplines, social service agencies, makers of public policy, and the private sector.

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## Dental Considerations for the Frail Elderly

### ORAL HEALTH AND DENTAL CARE ACCESS CHALLENGES

#### How Many Elderly Are There?

America's older population, which includes people who are age 65 or older, grew to 34.5 million in 1999.<sup>1</sup> As Figure 3-1 illustrates, the number of older Americans is growing rapidly and has increased 10-fold since 1900. In 10 years, the "baby boom" generation will begin to turn 65, and by 2030, one-fifth of the American population will be 65 or older. The size of the older population is projected to double over the next 30 years, growing to 70 million by 2050. The population age 85 and older is currently the fastest growing segment of the older population. Projections by the U.S. Census Bureau suggest that the population age 85 and older could grow from about 4 million in 2000 to 19 million by 2050.<sup>1</sup>

#### Where Do the Elderly Live?

In 1999, about half of persons 65 or older lived in nine states: California (3.6 million), Florida (2.7 million), New York

(2.4 million), Texas (2.0 million), and Pennsylvania (1.9 million); Ohio, Illinois, Michigan, and New Jersey each had well over 1 million. The 65 or older population was slightly less likely to live in metropolitan areas in 1999 than younger persons. About 50 percent of older persons lived in the suburbs, 27 percent live in central cities, and 23 percent lived in nonmetropolitan areas.<sup>2</sup>

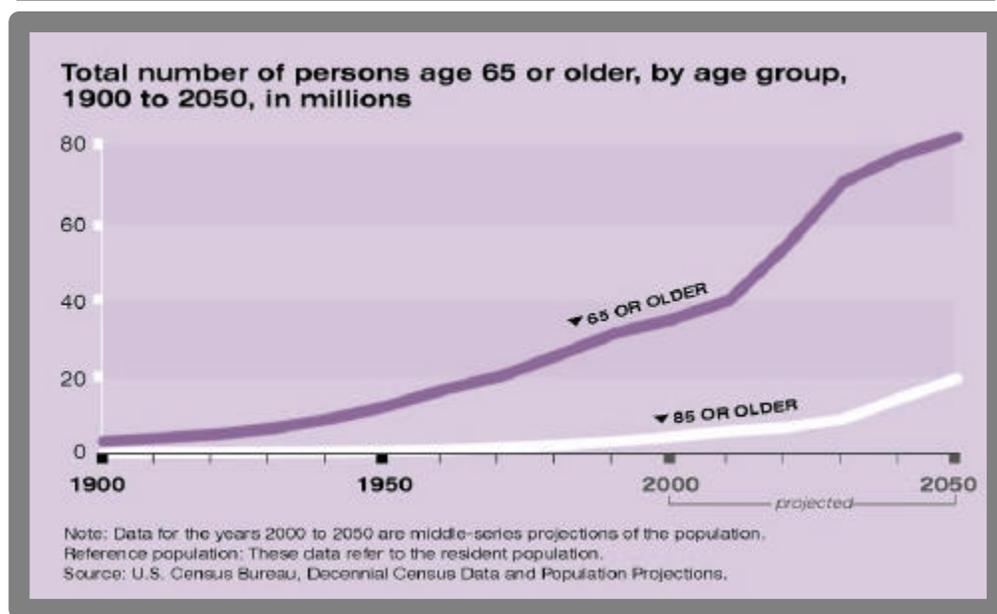
Living arrangements of America's older adults are closely linked to income, health status, and the availability of caregivers. Older persons who live alone are more likely to be in poverty and experience health problems, compared with older persons who live with a spouse or a relative. In 1997, 1.6 million elderly lived in nursing homes, less than 5 percent of the elderly.<sup>3</sup> The percentage of the population who live in nursing homes also increased dramatically with age, ranging from 1 percent for persons 65-74 years, to 5 percent for persons 75-84, to 19 percent for persons 85+.<sup>4</sup> About 558,400 older adults live in assisted-living facilities. The use of assisted-living facilities, board and care homes, continuing-care retirement communities, and other types of facilities in addition to long-term care in a nursing home has grown over

the last 15 years. Current surveys rarely distinguish between these different types of institutional settings and the characteristics of older persons within these settings, but the fact that they are increasing in numbers does indicate the growing need for health care services for frail elderly citizens.<sup>2</sup>

#### Who Are the "Frail Elderly"?

Ettinger and Beck<sup>5</sup> developed a functional definition of the elderly based upon an older person's physical ability to seek dental services. The categorization that they developed is threefold:

Figure 3-1 Total number of persons age 65 or older by age group 1900 to 2050 in millions



- The functionally independent older adult
- The frail older adult
- The functionally dependent older adult.

According to this schema, the vast majority of older adults, 70 percent, are able to get to the dentist and are categorized as functionally independent. About 14 percent of community-dwelling elderly fall under the frail adult category. These are persons with chronic conditions that create major limitations in mobility. About 5 percent of community-dwelling elderly are homebound or functionally dependent.<sup>6</sup> Another group of functionally dependent older adults are those who are institutionalized in nursing homes.

Another way to classify the frail elderly is to count the seniors who have one or more physical or mental disabilities. National surveys have tracked the numbers of older adults with disabilities, and although these numbers are helpful, they are also problematic. The concept of disability includes several dimensions of health and functioning, and several conceptual frameworks have been used to define this term. With this caveat in mind, more than half the population (52 percent) in 1994-95 reported having at least one disability. One-third had at least one severe disability. About 4.4 million older adults (14 percent) had difficulty in carrying out activities of daily living such as bathing, dressing, and eating, and 6.5 million (21 percent) reported difficulties with instrumental activities of daily living, which include preparing meals, shopping, managing money, using the telephone, doing housework, and taking medication. The percentages with disabilities increase sharply with age. The percentage of those age 80 or older having difficulty with activities of daily living is about double that of the 65 or older population.<sup>1</sup>

For purposes of the following discussion, older adults who face great dental access barriers due to physical limitations and functional dependence will be referred to as the "frail elderly." This includes the medically compromised and homebound living in the community, as well as those institutionalized in nursing homes.

### What Are Their Characteristics?

The frail elderly are predominantly female and over age 75. As early as age 65, females outnumber males by a ratio of 141:100. By age 85, this ratio increases to 237:100. Not surprisingly, many of the frail elderly are alone, having outlived spouses and sometimes their children.<sup>1</sup> In addition to decreased social and financial resources, chronic diseases limit daily activities of the frail elderly. Table 3-1 displays the percentage of common chronic conditions of those over age 70.<sup>7</sup>

For some older adults, dependencies resulting from chronic illness are managed by a combination of family and/or professional services provided in their homes. Although homebound, these individuals maintain some level of independence. Strayer<sup>8</sup> characterizes the homebound elderly as:

- Dependent in physical function.
- Cognitively impaired.
- Incontinent.
- Economically disadvantaged.
- Users of home services.
- Less likely to be living alone.

**Table 3-1 Percentage of U.S. persons 70 years of age and over who reported selected chronic conditions: U.S., 1995**

Chronic Condition	%
Arthritis	56
Hypertension	34
Heart disease	25
Diabetes	11
Respiratory diseases	11
Stroke	9
Cancer	4

Source: Centers for Disease Control and Prevention, National Center for Health Interview Survey, Second Supplement on Aging.<sup>7</sup>

When the severity of impairment, whether physical, medical, or emotional, can no longer be managed in the home, institutionalization and loss of independence results. The 1995 National Nursing Home Survey<sup>9</sup> describes elderly nursing homes residents as:

- Female.
- 75+ years of age.
- White, non-Hispanic.
- Widowed.
- Dependent in Activities of Daily Living (ADL; i.e. bathing, dressing, eating, transferring, toileting.)
- Dependent in Instrumental Activities of Daily Living (IADL; i.e. care of personal possessions, managing money, securing personal items, using the telephone.)
- Incontinent.
- Relying on Medicaid as primary source of payment.

### Why Is Dental Care of Particular Importance for Them?

The U.S. Surgeon General's report, *Oral Health in America*, emphasizes the fact that oral health is integral to general health and describes the disparities in the availability of dental care, especially for very young and very old populations.<sup>10</sup> The report uses the phrase "silent epidemic" to characterize the disparity between the epidemic of oral disease and the silence from those who need care. This report highlights many reasons that dental care is of particular importance for frail older adults:

- Oral diseases are cumulative and become more complex over time. The older adult population has high rates of oral diseases, exacerbated by the fact that many elderly adults lose their dental insurance when they retire. Medicare does not reimburse for routine dental services, and many states do not have Medicaid dental coverage for the frail elderly.
- Oral problems have a negative effect on quality of life. Oral-facial pain and tooth loss can greatly reduce the quality of life and restrict major functions. Problems with the teeth and mouth can affect the ability to eat and communicate. Individuals with facial disfigurements due to oral diseases can experience loss of self-esteem, anxiety, depression, and social stigma. Diet, nutrition, sleep, psychological status, and social interaction are all affected by impaired oral health.

- Dental disease has a significant impact on general health. The oral cavity can be a portal of entry for microbial infections that affect the whole body. Oral diseases give rise to pathogens, which can be blood borne<sup>11</sup> or aspirated into the lungs,<sup>12</sup> bringing about severe, even life-threatening consequences. Recent research findings have pointed to possible associations between chronic oral infections and diabetes, heart and lung disease, and stroke.

### Why Do the Frail Elderly Need “Special Care”?

The frail elderly need special care because they suffer from extensive oral diseases, have medical problems that complicate their care, and also because their age and state of health complicate their diagnosis and treatment.<sup>13</sup> Adding to these problems are a multitude of impediments to maintaining their oral health, as discussed in Section B of this report.

### They Have Extensive Oral Diseases

Older adults suffer from the cumulative effects of oral diseases over their lifetime. This results in extensive oral disease.<sup>13</sup> Berkey, Berg, Ettinger *et al.*<sup>14</sup> in a comprehensive review of oral health studies of institutionalized elderly published between 1970 and 1989, described the compromised oral health status of nursing home residents. Up to 70 percent of residents had unmet oral needs, exhibiting high rates of edentulism (complete tooth loss), dental caries (decay), poor oral hygiene, periodontal disease (diseases of the supporting structures of the teeth), and soft tissue lesions.<sup>14</sup> A survey conducted in 1993 on 3479 patients treated in Minneapolis–St. Paul, MN, nursing homes found that 39 percent of the edentulous had oral problems and 61 percent of the dentate (those with some natural teeth remaining) had oral problems. Of the dentate that needed care, 41 percent had dental caries, 14 percent had root caries (decay on the root surfaces), and 18 percent had retained root tips (teeth so damaged by caries that the tooth crown was no longer present) (D. Smith, personal communication / unpublished study, May 1993). Gift, Cherry-Peppers, and Oldakowski,<sup>15</sup> reporting on the 1995 U.S. National Nursing Home Survey, reported that only 15 percent of the residents were described as having excellent or very good oral health.

Over 30 percent of community-dwelling elderly in 1997 were edentulous with the rate rising to 43 percent of those over 85.<sup>7</sup> Approximately one-third of community-dwelling elderly have untreated coronal or root caries, and other oral health problems including periodontal disease, attrition, unreplaced missing teeth, abrasion and erosion, broken or failing older dental restorations, dry mouth, mucosal diseases, oral cancer, and alveolar ridge atrophy.<sup>16</sup> The homebound often face insurmountable dental access barriers. Among the elderly receiving home health services noted in one study, the majority reported their oral health was “fair” or “poor” and nearly 80 percent reported a perceived dental care need. In addition, only 26 percent reported having been to the dentist within the past 2 years, while 40 percent reported not having been to the dentist in more than 10 years.<sup>17</sup>

### Medical Problems Complicate Their Care

As we age, we experience a number of significant age-related changes. Fortunately, most of these normal aging changes do not cause oral diseases.<sup>18,19</sup> Instead, it is the cumulative effects

of both oral and systemic diseases that account for the extensive pattern of oral disease among the elderly. It is interesting to note that increasing numbers of “well elderly” are able to retain their natural teeth and enjoy normal oral function throughout old age. For the frail elderly the situation is quite different.

Shay and Ship<sup>20</sup> provide an excellent overview of how oral and systemic diseases contribute to poor oral health in the elderly. They explain that, “loss of one or more teeth as a result of disease can predispose to further tooth loss,<sup>21</sup> destruction of alveolar bone (the bone surrounding the teeth),<sup>22</sup> dependence on and compromised function of prosthetic replacements (dentures),<sup>23</sup> and mucosal disease.” The same oral diseases that lead to tooth loss also cause tooth sensitivity, pain, and impair chewing and speaking ability. In addition, lesions of the soft tissues of the mouth can interfere with mastication and can affect nutritional status.<sup>24</sup> Oral cancers such as squamous cell carcinoma can cause extreme disfigurement and even death.<sup>25</sup> Systemic diseases may directly or indirectly harm the oral cavity by altering saliva flow, which plays an essential protective role in the mouth.<sup>26</sup> The effects of oral diseases are not limited to the oral cavity. Oral diseases can release blood-borne bacteria<sup>11</sup> or cause bacteria to be aspirated into the lungs.<sup>12</sup>

A major impact of systemic diseases on the oral health of older adults is caused by the side effects of medications. With increasing age and associated chronic disease, the elderly are prescribed an ever-expanding variety of medications. Besides the desired therapeutic outcome, adverse side effects may alter the integrity of the oral mucosa. Problems such as xerostomia (dry mouth), bleeding disorders of the tissues, lichenoid reactions (oral tissue changes), tissue overgrowth, and hypersensitivity reactions may occur as a result of drug therapy.<sup>27</sup> Ship and Chavez<sup>28</sup> summarized these effects in Table 3-2, which illustrates many of the oral health problems created by commonly prescribed medications.

Cardiovascular diseases were the leading cause of death among the elderly in 1997, followed by cancer, stroke, chronic obstructive pulmonary diseases, pneumonia and influenza, and diabetes.<sup>2</sup> For those over 85, heart disease accounted for 40 percent of all deaths.<sup>29</sup> Beck, Offenbacher, Williams *et al.*<sup>30</sup> and others<sup>31</sup> have published research suggesting a possible link between cardiovascular and periodontal diseases, but more research is needed to clarify the findings. Heart diseases may trigger symptoms that appear in and around the oral cavity, such as when angina presents as pain in the neck, jaw, or teeth.

Cancer, the second leading cause of death among the elderly, also has a significant impact on the oral cavity. Oral and pharyngeal cancers account for about 5 percent of all cancers, and they increase in prevalence with age. Cancer treatments including chemotherapy, radiation, and surgery can cause severe stomatitis (inflammation of the mouth), xerostomia (dry mouth), disfigurement, altered speech and mastication, loss of appetite, and increased susceptibility to oral infections—including those that cause caries and periodontal diseases.<sup>32</sup>

Stroke, pulmonary diseases, and diabetes are also common among the elderly. Each has important consequences in managing oral care for the elderly. In addition to these conditions, impairments in hearing, vision, and orthopedic function are the most common impairments among the elderly,

**Table 3-2 Overview of oral problems caused by medications**

Drug Category	Drug	Oral Problem
Analgesics	Aspirin NSAIDs <sup>a</sup>	Hemorrhage, erythema multiforme
	Barbiturates, Codeine	Hemorrhage, erythema multiforme
Anesthetics (local)	Benzocaine, Procaine, HCl Lidocaine	Taste disorders
Antiarrhythmics	Procainamide	Lupus-like reaction
	Quinidine	Lichenoid mucosal reaction
Antiarthritic	Allopurinol, Auranofin, Colchicine, Dexamethasone	Taste disorders
Antipyretic	Hydrocortisone, Levamisole	
Anti-inflammatory	D-Penicillamine, Phenylbutazone, Salicylates 5-Thiopyridoxine	
	Gold salts	Taste disorders, lichenoid reaction, oral pigmentation vesiculoulcerative stomatitis
Antibiotics	All	Oral candidiasis
	Erythromycin	Hypersensitivity reaction, vesiculoulcerative stomatitis
	Penicillin	Hypersensitivity reaction, erythema multiforme, vesiculoulcerative stomatitis
	Chloramphenicol	Erythema multiforme
	Ciprofloxacin, Clindamycin, Dapsone, Isoniazid	
	Sulfa antibiotics, Tetracyclines	
	Minocycline	Melanosia
	Chlorhexidine	Brown pigmentation of teeth and tongue
	Ampicillin, Cefamandole, Ethambutol HC1	
	Griseofulvin, Lincomycin, Metronidazole, Niridazole, Sulfasalazine, Tetracyclines	
Anticoagulants	All	Hemorrhage
Anticonvulsants	Carbamazepine	Erythema multiforme, taste disorders
	Phenytoin	Erythema multiforme, gingival enlargement, taste disorders
Antidiarrhea	Bismuth	Dark pigmentation of tongue
Antihistamines	All	Salivary dysfunction
	Chlorpheniramine maleate	Taste disorders
Antihypertensives	All	Salivary dysfunction
	Calcium channel blockers	Gingival enlargement
	ACE <sup>b</sup> inhibitors	Vesiculoulcerative stomatitis, pemphigus vulgaris
	Chloramphenicol	Vesiculoulcerative stomatitis
	Hydralazine	Lupus-like reaction, erythema multiforme
	Methyldopa	Lupus-like reaction and lichenoid mucosal reaction
	Thiazide diuretics	Lichenoid mucosal reaction
	Minoxidil, Verapamil	Erythema multiforme
	Acetazolamide, Amiloride	Taste disorders
	Captopril, Diazoxide, Diltiazem, Enalapril	
	Ethacrynic acid, Nifedipine	
Antilipidemics	Cholestyramine, Clofibrate	Taste disorders
Antimicrotics	Griseofulvin	Erythema multiforme, black pigmentation of tongue
	Amphotericine B	Taste disorder

Drug Category	Drug	Oral Problem
Antineoplastics	All	Oral candidiasis, oral hemorrhage, recurrent oral viral infections, aphthous stomatitis, vesiculoulcerative stomatitis
Anti-Parkinsonian	All Levodopa	Salivary dysfunction Taste disorders
Antireflux agents	All Cimetidine	Salivary dysfunction Erythema multiforme
Antithyroids	Carbimazole, Methimazole, Methylthiouracil Propylthiouracil, Thiouracil	Taste disorders
Antioxidants	Octyl gallate	Allergic ulcerations
Anxiolytics	Benzodiazepines	Salivary dysfunction
Chelating agents	Penicillamine	Ulcers and pemphigus vulgaris
Corticosteroids immunosuppressants antiproliferatives	All  Azathioprine, Bleomycin, Carmustine Doxorubirin, 5-Fluorouraci, Methotrexate, Vincristine, Sulfate Cyclosporine	Oral candidiasis, recurrent oral viral infections, vesiculoulcerative stomatitis  Taste disorders Gingival enlargement
Hypoglycemics	Sulfonylurea agents Glipizide, Phenformin and derivatives	Erythema multiforme Taste disorders
Muscle relaxants	All Baclofen, Chlorzoxazone	Salivary dysfunction Taste disorders
Others	Etidronate, Germine Monoacetate, Idoxuridine, Iron Sorbitex, Vitamin D	Taste disorders
Psychotherapeutics	All Glutethimide, Meprobamate Phenothiazines Lithium carbonate Trifluoperazine HCL	Salivary dysfunction Erythema multiforme Oral pigmentation, tardive dyskinesia Erythema multiforme, taste disorder Taste disorders
Sympathomimetics	Amphetamines, Amrinone	Taste disorders
Vasodilators	Bamifyline HCL, Dipyridamole Nitroglycerin patch, Oxyfedrine	Taste disorders

<sup>a</sup> NSAIDs - nonsteroidal anti-inflammatory drugs.

<sup>b</sup> ACE - angiotensin converting enzyme.

Source: Ship and Chavez.<sup>28</sup>

and each has consequences for maintaining oral health.<sup>13</sup>

### Geriatric Diagnosis and Treatment Planning Are Complex

The dental treatment needs of the elderly differ from those of younger adults, and newer cohorts of elderly have significantly different needs than older cohorts. Shay<sup>33</sup> reports that in 1957, 70 percent of adults over age 75 were fully edentulous, while today the number has dropped to less than 40 percent. This means that 40 years ago, most dental treatment for older adults

involved making and repairing full dentures. Today the picture has changed dramatically, with far more natural teeth present, and significantly different attitudes towards oral health and dental care among newer cohorts of the elderly. The elderly now receive a full range of dental services from examinations and preventive services to complex restorative and periodontal services.

Aging has an impact on oral tissues just as it has on other tissues throughout the body. As teeth age, the enamel, dentin, and pulp undergo progressive changes. The enamel becomes

less hydrated and may gain fluorine superficially if fluoride toothpastes, rinses, or drinking water are used.<sup>34,35</sup> In addition, the thickness of the enamel decreases as enamel is lost from abrasion and attrition. Dentin changes more profoundly over a lifetime. The dentin volume expands into the pulp chamber as secondary dentin forms in response to decay and mastication. Many dentinal tubules narrow and others close altogether, forming sclerotic dentin. These changes make the older tooth more brittle, less resilient, less soluble, less permeable, and darker in color.<sup>36,37</sup> The pulp chamber, where the blood vessels and nerves of the teeth are located, also undergoes significant changes. The volume of the chamber declines as secondary dentin is deposited. The blood vessels and nerves in the pulp decline with a loss of myelinated nerve fibers and a gain of dystrophic calcium.<sup>38</sup>

All these changes in the teeth have implications for many dental restorative procedures. Acid etching and bonding materials and techniques, for example, need to be modified. The aging of the teeth affects the design of cavity preparations, the choices of restorative materials, and the anatomy and esthetics of the final restorations. Pulpal sensitivity is diminished in older teeth, and normal symptoms of dental decay or pulpal infections are reduced, altered, or eliminated. The radiographic appearance of teeth is also affected by aging, requiring modified interpretations and diagnosis.

It is not just the teeth and other oral tissues that change with age and have an impact on the special needs of the elderly. With increasing disability, functional impairments, and declining cognitive functions in the frail elderly, the dental team is faced with important ethical issues that have an impact on dental diagnosis, treatment planning, and how dental care is actually provided. Shuman<sup>39</sup> reviews a number of these key ethical concerns and offers guidelines for addressing them. Securing informed consent when the cognitive function of an older adult is impaired requires interaction between the clinician, the patient, and the guardian. The clinician must be able to make mental status assessments and to form judgments about a patient's capacity to understand and act upon choices. In addition, the clinician must be knowledgeable about the legal and ethical responsibilities placed on those providing geriatric care to vulnerable adults. In situations where the patient is incompetent to make treatment decisions, the clinician must be familiar with two alternative care standards, the substituted judgment standard and the best interest standard. The best interest standard suggests that the dentist should plan care that reflects what other reasonable people would do under similar circumstances, while the substituted judgment standard suggests that the dentist should plan care that the patient would have chosen if he or she could have expressed their wishes.<sup>40</sup>

Other important special care issues for the frail elderly involve knowledge about the use of sedation, behavior management and restraint in cognitively impaired patients,<sup>41</sup> issues related to death and dying,<sup>42</sup> and issues related to elder abuse.

## **IMPEDIMENTS TO MAINTAINING AND IMPROVING THEIR ORAL HEALTH STATUS**

### **Lack of Effective Dental Care Delivery Systems**

It has been said that the greatest failure in modern dentistry is

the failure to treat. At the same time that dentistry is able to provide implants, esthetic veneers, and other "high-tech" treatments that would have been unimaginable only a few years ago, large segments of the population, including the frail elderly, lack access to necessary basic care. Why are current dental care delivery systems failing to meet the needs of the frail elderly?

### **Inadequate Facilities and Equipment**

Inadequate facilities and equipment in nursing homes, private dental offices, and many portable dental services create a significant dental access barrier. Permanent dental offices located within nursing homes, when they exist, generally do not have sufficient equipment to provide primary dental care. Such basic equipment as an X-ray machine and developer are frequently not available. Although a few permanent dental clinics within nursing homes do have adequate equipment, they often do not have the portable equipment necessary to serve bedridden residents. Some bedridden residents cannot be transported or transferred to a dental chair even if it is located within the nursing home. Like the homebound, these residents must have access to portable dental services in order to receive dental care at their bedside.

Research into the availability of either permanent dental clinics within nursing homes or portable dental services has been conducted in several states. In a study of Louisiana nursing homes, Garbee, Legett, Lee et al.<sup>43</sup> stated: Dental resources in the surveyed nursing homes were almost non-existent. Over 98 percent of the homes surveyed had no dental equipment. There was no regular staff dentist in 93 percent of the homes, and 82 percent had no staff hygienist. Most of the homes (84 percent) called upon non-affiliated private dentists to take care of their patients, on an ad hoc basis, whenever emergencies arose. Some of the homes (34.1 percent) took their residents to outside dental clinics for their dental care. This data suggests that the only nursing home residents who receive more than emergency dental care are those who are sufficiently mobile to be transported to either a private office or clinic.

Although 34.1 percent of the nursing homes reported that they transported some of their residents to outside dental clinics, the other 65.9 percent did not.<sup>43</sup> It is important to note that transporting residents is generally not undertaken for primary dental care, but rather occurs when problems or emergencies arise. Further, even those nursing home residents who are physically capable of being transported to dental offices must overcome other nontransportation-related barriers to receive the care they need.

Siegal<sup>44</sup> conducted a survey of dentists practicing in New Mexico. He obtained responses from over 70 percent of all the dentists practicing in the state (N=410), making his study the most representative study of its kind available. Only 2.2 percent of the dentists in New Mexico indicated that they owned portable equipment. This contrasts with 32 percent who stated that they made more than one visit to homebound patients during the previous year. How could these dentists be providing dental care to the homebound, in their homes, without portable equipment? Siegal addresses this question as follows:<sup>44</sup> This relatively small number of New Mexico respondents (who own portable equipment), when compared with the larger number who reported making at least one

home visit in the previous year, raises questions about the distribution of the equipment and perhaps the nature of the care provided.

Siegel found that 67.8 percent of the dentists had not made a single visit to a homebound patient within the previous 12 months; 27.8 percent of the dentists reported making one to five visits during the same period. Thus, a total of 95.6 percent of the dentists reported making five or fewer visits during the previous 12 months. How many patients could these dentists treat in 1 year? Elderly patients who seek regular dental care average 3.26 visits per year,<sup>45</sup> so each dentist could treat only about two patients.

Lack of basic portable equipment such as portable high- and low-speed drills, portable X-ray equipment, and common dental supplies creates a significant barrier to primary dental care. Traditional delivery systems characterized by permanent offices and immobile equipment cannot adequately meet the needs of the long-term care population group.

### **Lack of Special Equipment for Special Patients**

Many patients cannot be treated without special equipment. A Hoyer Lift, for example, is a crane-like device that is used in hospitals and nursing homes to transfer patients to and from beds and wheelchairs. By providing on-site dental care within a nursing home, those patients who need the Hoyer Lift can be treated using the nursing home's lift. Many homebound patients have these lifts in their homes, but are unable to transport a large Hoyer Lift to or from a dental office. A Hoyer Lift is one example of a special device that enables access to care for a number of long-term care recipients.

Many long-term care recipients suffer from Alzheimer's disease and other types of dementia. These patients are profoundly confused and disoriented and must often be sedated for dental care—even for something as basic as an adequate oral examination or dental cleaning. Because of their age, and the presence of multiple medical problems and medications, sedating these patients must be a cooperative effort between the physician, nursing staff, and dentist. At the nursing home, the medications most appropriate for each patient are available and, if on-site dental care is provided, the nursing staff can administer the sedation and help monitor the patient both before and after dental treatment. Thus, by providing dental care that is integrated into overall care at the nursing home, a very large group of mentally impaired nursing home residents can gain access to primary rather than emergency dental care.

### **Lack of Nursing Staff in Traditional Dental Offices**

The nursing staff could provide several essential services for frail elderly nursing home residents seeking care in a traditional dental office. However, for a variety of reasons, including financial, residents who receive dental care outside the facility are accompanied by nurses' aides rather than nurses. As a result, several vital nursing functions are lost to the dental team. For example, sedation and patient monitoring which facilitate care of the cognitively impaired resident cannot be provided by a nurse's aide. The nursing staff plays other critical roles when dental care is provided within the nursing home. The nursing staff has intimate knowledge of the functional capabilities of each nursing home resident and can help assess the ability of residents to provide self-care including oral hygiene. The staff can provide information about the resident's

ability to tolerate appointments at certain times of day and on the need for medications when breathing problems or angina occur. If severely handicapped or incontinent residents need to urinate during a dental procedure, the nursing staff can help the resident as needed. Incontinence is one of the most common problems of nursing home residents and the homebound.

### **Lack of Properly Trained Oral Health Providers**

Dental disease continues to be widespread and unchecked among functionally dependent older adults. One reason for this is that few dentists have received the level of training needed to make them comfortable in providing oral health care services outside the traditional office situation.<sup>8</sup> Dr. Teran Gall, Director of Special Projects for the California Dental Association and a recognized expert in geriatric dentistry, makes the following observation:<sup>46</sup> Dental education is limited largely to working on well patients. Most dental school interactions are not with compromised patients and there are very few opportunities for students to work with patients in nursing homes or do mobile dentistry and visit homebound individuals. Dental school training does not afford students the same opportunities as medical school opportunities to work with physically and medically compromised patients. As a result, many dentists may be uncomfortable working with patients who have special needs.

Ettinger, Watkins, and Cowen<sup>27</sup> reviewed the status of geriatric dental education and found that the number of dental schools reporting the existence of didactic geriatric content has risen to 100 percent but that great curricular variation exists. Often a course in geriatrics is taught as an elective, so only a portion of the dental student body receives it. Variability exists in faculty training as well. The most recent survey reports that 12 percent of schools still have no required course and 17 percent have no specific geriatric course. Clinical preparation in geriatric dentistry lags behind. Ettinger, Watkins, and Cowen<sup>27</sup> state: Regardless of repeated epidemiological evidence of the increasing dental need and demand of the older patient, over 25 percent of schools still report no geriatric clinical component. In addition, years after the Omnibus Reconciliation Act mandating a dentist of record in each nursing home facility, 45 percent of dental schools do not offer students any opportunity to experience working in a nursing home environment.

Dr. Michael Strayer, a Professor of Geriatric Dentistry and Gerontology at Ohio State University College of Dentistry, is involved in one of the few programs in the country that offer students experience in treating geriatric patients. Dr. Strayer acknowledges that treating older patients presents diagnostic challenges:<sup>46</sup> "One of the things I try to stress to students is that as patients get older, the signs and symptoms are not the same as they are in younger adults. For example, when older patients have pneumonia, they don't necessarily present with a fever or cough. They often just have a general, vague feeling of not being well. The same thing can apply to periodontal disease or even dental abscesses in natural teeth. They may have dental problems but don't have the symptoms you would find in a younger population. So it becomes problematic for practitioners."

### Lack of Medical Integration with Oral Health Care

Physicians, nurses, and nurses aides have regular contact with homebound and nursing home residents. But training to recognize oral problems, oral lesions, or oral sequelae of chronic systemic conditions and the medications to treat these conditions is limited.<sup>47</sup> The following exemplifies how the limited training and lack of medical integration with oral health care contributes to unmet need. Federal legislation enacted into law in 1992 (Omnibus Budget Reconciliation Act or OBRA 1987) was an ambitious effort to improve the standards of nursing home care in all areas, including oral health and dentistry. Any nursing home accepting Medicare or Medicaid reimbursement is required to complete a Minimum Data Set (MDS) assessment upon resident admission and at least yearly thereafter.<sup>48</sup> Two sections of the MDS deal specifically with oral conditions. A nurse typically completes the oral/dental status section; a dietician completes the oral/nutritional status section.

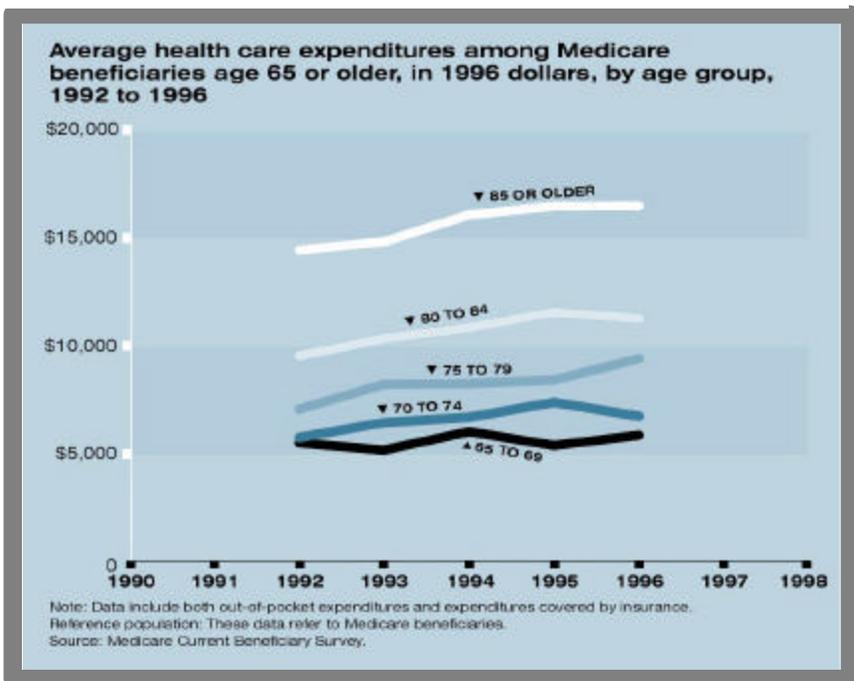
Thai, Shuman, and Davidson<sup>49</sup> investigated the adequacy of the MDS to identify oral health problems. MDS data from Minnesota nursing homes and records of subsequent dental care were compared. Of 466 residents, nurses identified 3.2 percent with oral debris; 3.0 percent with broken, loose, or carious teeth; and only 4 (0.9 percent) with gum inflammation/soft tissue problems. In contrast, subsequent utilization measured in dental visits per year and gross dental charges per year bore no relationship to the MDS findings. The authors concluded that the nurse's assessments identified few oral health problems and that the problems identified did not translate into dental treatment.<sup>49</sup> A study by Blank, Arvidson-Bufano, and Yellowitz<sup>50</sup> found that more experienced nurses were able to identify broken or carious teeth nearly 85 percent of the time among nursing home residents. However, regardless of the nurse's experience level, they were less able to identify soft tissue lesions.<sup>50</sup> Taken together, the potential for misidentification and underreporting of oral health problems is difficult to ignore.

### Lack of Dental Insurance or Financial Resources

While only about half of all Americans have any type of dental coverage, most with this employment benefit lose it upon retirement and subsequently decrease their utilization of dental care. As a result, most older adults lack dental insurance and must pay for dental care as an out-of-pocket expense.<sup>51,52</sup> This phenomenon unfortunately occurs at a time of increased oral health needs and, with declining function into old age, oral health needs often are further relegated due to other pressing health care needs as well as a reduced ability to pay for services out of pocket.

Further eroding dental access for seniors is the fact that

Figure 3-2 Average health care expenditures among Medicare beneficiaries age 65 or older, in 1996 dollars, by age group, 1992 to 1996.

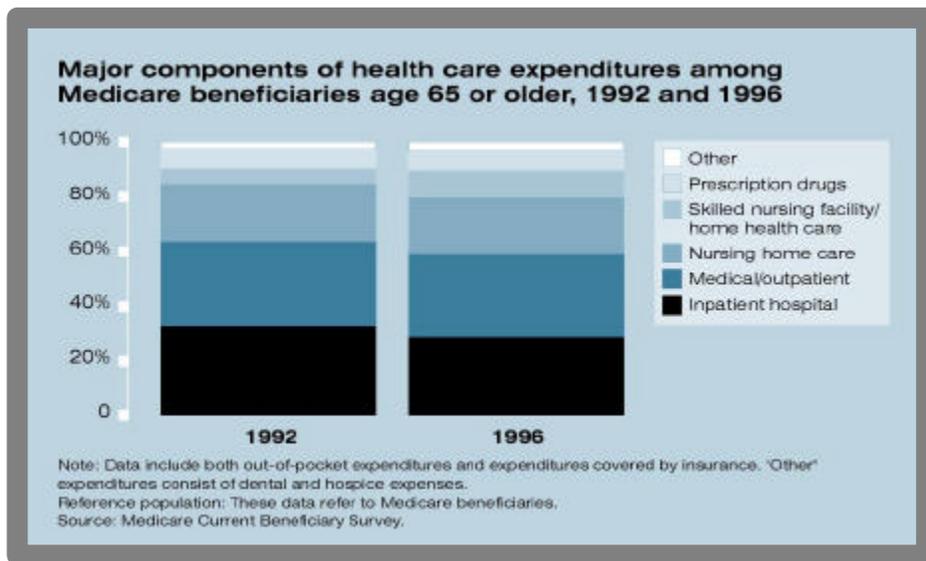


many states' Medicaid programs do not provide dental coverage for adults. Even in states with adult dental benefits, dental services vital for the frail elderly are frequently not covered. For these Medicaid recipients, dental coverage represents an empty promise because access is limited by extremely low levels of participation by dentists who cite low fees, complex administrative policies, and a host of other reasons for not participating. Numerous states have recently made significant changes in their Medicaid dental programs to increase dental provider participation. Although the American Dental Association has recommended that fees be set at the 75th percentile in order to increase participation, there is a pressing need to also simplify administration, eliminate treatment delays, and, in general, reduce provider disincentives within the program.

Figure 3-2 shows the average health care expenditures for older adults from 1992 to 1996. Health care costs for the elderly have been rising over time, and are higher for older cohorts. Adults 85 years of age and older have significantly higher health care costs than those who are in the 65 to 84 age bracket. This phenomenon, where various diseases and health care costs are pushed farther and farther into old age is sometimes called the "compression of morbidity."

Institutionalization not only changes access to a routine source of dental care, but also reduces the out-of-pocket resources available to pay for services. Dental services for older adults are largely an out-of-pocket expense (79 percent), with only 10 percent covered by private insurance.<sup>53</sup> Unfortunately, public programs do not fill the gap. Medicare does not cover routine dental services, and Medicaid does not offer dental benefits for adults in many states. Figure 3-3 shows the small portion of the total health care expenditures of

**Figure 3-3 Major components of healthcare expenditures among Medicare beneficiaries age 65 or older, 1992 and 1996.**



Medicare beneficiaries that went towards dental care in 1992 and 1996.

### Lack of Understanding of the Importance of Oral Health

Lack of knowledge and low expectations about oral health and its value influence care-seeking behavior and can result in care being deferred or neglected entirely. Among the elderly living independently, the most commonly cited reason for not seeking dental care is a lack of perceived need.<sup>54</sup> Seeking help for a dental problem is less likely when there is a belief that tooth loss is inevitable or oral problems are part of the aging process. For the institutionalized elderly, often the decision whether or not to receive care is determined by others. Warren, Hand, and Kambhu<sup>55</sup> investigated the role of nursing home residents' family members in the utilization of dental services for nursing home residents. "Utilization of dental services" was defined as consent for the completion of a comprehensive dental examination. Overall, the next of kin or guardian decision-makers accepted treatment for 64.2 percent of the residents. Resident characteristics that increased the likelihood of accepting an oral examination included being female, being ambulatory, having natural remaining teeth, and having a higher level of education. Other factors that influenced the decision were next-of-kin characteristics: perceived need, age, and relationship of resident to next of kin (relative vs. nonrelative). Little difference in rate of acceptance was found based on resident age.<sup>55</sup>

Family and caregiver's attitudes may be even more powerful in limiting access to care. Dolan and Atchison<sup>56</sup> report that nursing home administrators pointed to lack of interest by the resident and lack of interest by the resident's family as barriers to care. In addition, consulting dentists to nursing homes identified apathy of nursing home administrators and staff as significant barriers.<sup>56</sup> Gordon, Berkey, and Call<sup>57</sup> found a very substantial discrepancy between Colorado hospice patients and administrators

regarding their perceptions of the importance of oral health. Of hospice patients, 86 percent reported that maintaining or improving their oral health status was either "important" or "very important" to them, whereas only 18 percent of administrators believed this to be true.<sup>57</sup>

Knowledge about dental health care is, however, increasing over time. Dr. Michael Helgeson, a geriatric dentist, emphasizes that the population of people age 65 and older is a very diverse group with a wide range of needs and expectations:<sup>46</sup> "The people born between 1900 and 1910 are dramatically different from the people born between 1920 and 1930 in terms of the health care they have received and their lifetime access to dental services.

Each age cohort is very, very different." As the number of aging Americans continues to rise, dentists will be working with more elderly patients in their everyday practice and will be seeing greater numbers of older patients who bring high expectations for quality dental care. In the last 15 years alone, dentists specializing in care for older individuals have seen shifts in attitudes toward prevention of oral disease. They note that increasing numbers of patients are retaining their natural teeth, and there is a higher level of dental health knowledge emerging among older patients and their families.

Helgeson<sup>46</sup> cites his experience working with frail elderly adults living in nursing homes served by Apple Tree Dental in Minneapolis/St. Paul. When the nonprofit mobile dental program opened in 1986, 61 percent of the nursing home residents treated had no teeth. Ten years later, the percentage of residents with no teeth had dropped to only 40 percent. He notes that more and more elderly patients are retaining their natural teeth. Furthermore, patient expectations are changing as well.

"When Apple Tree began in 1986, it was very rare to have either a patient or the son or daughter of a patient question a treatment plan that called for extracting teeth. Rarely, if ever, would the patient or the family ask if the teeth could be saved. The prevailing attitude was that teeth were dispensable. During the 15 years since that time, we are dealing with people who have completely different personal histories with dentistry. They are much more familiar with saving and repairing their teeth. The idea of going without any teeth at all is much more unacceptable now than it was 15 or 20 years ago."

### Lack of Effective Patient Self-Care or Caregiver Assistance with Oral Care

Over half of those persons 75 years and over report limitations caused by chronic conditions.<sup>1</sup> Self-care, in general, and oral health care in particular, can be adversely affected by these chronic conditions. Prevalent visual, manual, or shoulder and

arm impairments can make effective cleaning of the teeth and mouth difficult. Increasing needs for help in other areas of life may overshadow a declining oral health situation.

Either the older adult or their caregivers must become aware that daily oral care is not being done effectively. Problem recognition may be slowed by a number of factors. The older adult may be unable or unwilling to admit that an additional level of self-care (and independence) is being lost. The caregiver, particularly if they are a spouse or other family member, may be so burdened with other needed care that oral concerns are not recognized. If health services are being brought into the home, oral health issues may not be recognized or addressed by the home health worker.

In the nursing home, nurse's aides provide oral hygiene services. These individuals, who are minimally trained (75 hours or less), provide up to 90 percent of hands-on care that residents receive. It has been reported that the majority of residents require some or complete assistance with oral care. Nearly 75 percent of nurse's aides indicate that behavior and physical difficulties prevented adequate oral hygiene from being provided.<sup>58</sup> A Connecticut study explored the beliefs, attitudes, and knowledge of nurse's aides regarding oral health care for nursing home residents compared to other body care services that the aides performed such as bathing, toileting, and dressing. Mouth care was seen as a disliked task both by the aides and, in the aides' opinion, by the residents despite being perceived as a significant benefit to the residents.<sup>59</sup> Kambhu and Levy<sup>60</sup> noted that poor hygiene levels correlated with uncooperative residents (82 percent), nurse's aides who lacked a perceived need for good oral hygiene care (68 percent), and a perceived lack of time (49 percent).

Lacking the ability to provide oral self-care, the frail elderly depend on someone with the necessary willingness and skill to provide or assist with that care on a consistent basis, either daily or every other day at a minimum. Judging by the extensive oral health needs of the homebound and institutionalized elderly, that key component of oral health maintenance is missing.

## **APPROACHES TO IMPROVING THEIR ORAL HEALTH AND ACCESS TO DENTAL CARE**

### **What Can Be Done to Improve Their Oral Health?**

Improved oral health will lead to improved quality of life through increased personal dignity, improved nutrition, better appearance, greater cleanliness, and greater comfort or relief from pain. But meeting the oral health needs of frail elderly adults requires new approaches to dental treatment planning that take into account the special needs of the elderly.

Berg, Garcia, and Berkey<sup>61</sup> have described a process called "spectrum of care treatment planning." This model emphasizes essential steps in clinical decision making for both patient and dentist. The process begins with an interview of the patient to determine his/her concerns and perceived needs. This process addresses four domains of subjective and objective needs: function, symptoms, pathology, and esthetics. Eliciting this information may require considerable geriatric skills. Older patients are less likely than younger patients to report symptom complaints, and often they are completely unaware of pathology that would create dramatic symptoms in younger

patients. In one study of older adults, more than half of 20 potentially serious medical symptoms were never reported to a health professional.<sup>62</sup> These data contrast with a popular misconception that the elderly are prone to exaggerate their health care complaints.

The next step in treatment planning is the objective assessment of the patient by the dentist. Because elderly patients have generally lost significant numbers of teeth, assessment of function can be difficult. Many older adults have complicated patterns of missing teeth together with fixed and removable prosthodontic devices (full and partial dentures). The effectiveness of the few remaining teeth on the patient's ability to chew and to speak must be assessed carefully, and the alternative treatment options explored fully. In older adults, this planning process is generally much more involved than in younger individuals.

A thorough medical history must be integrated with the dentist's oral health findings while dental treatment options are developed. In addition, the dentist must assess the patient's ability to tolerate the potential stress of treatment. The ability of an older adult to tolerate stress is highly individualized, so it is important for the dentist to be comfortable with geriatric medicine and the need to consult with the physician and others when necessary. In addition, the dentist must evaluate the patient's functional capability and resources for maintaining oral health. According to Berg, Garcia, and Berkey,<sup>61</sup> "The functional capability of the patient to maintain restorations, prostheses, and periodontal health successfully is a critical element in treatment planning, as are the financial resources the patient and/or family are able to dedicate to treatment." If the patient is functionally impaired and unable to carry out brushing and flossing, then the family and caregivers' ability to help with daily oral care must be assessed. Other risk factors that could cause treatment failures need to be assessed, including the history of recent decay and periodontal disease, presence of xerostomia (dry mouth), the presence of failing older restorations, drifting or tipped teeth, bruxism (teeth grinding habit), alveolar bone loss (shrinkage of the ridges following tooth extraction), loss of host resistance due to medical problems, and a variety of factors effecting the patient's manual dexterity.

Once the medical and dental information has been collected and processed, the dentist must begin to formulate treatment options that are often extensive. In geriatric treatment planning, the focus should be on identifying levels of care and seeking a level of care that is optimal for the patient, given all the factors that have been assessed. Levels of care range all the way from "none" to "very extensive." In planning care for older adults, it is not appropriate to equate an optimal level with the "highest level technically possible." Instead, the goal of geriatric treatment planning is to seek the highest level of care that is appropriate and necessary to maintain the individual patient's oral and general health.

The final step in treatment planning is reviewing the treatment options with patient and/or their caregiver. Although the dentist generally recommends the highest appropriate level of care with the best long-term prognosis, it is important to offer reasonable alternatives along with their costs and risks. The principles of informed consent and patient autonomy must be clearly understood by the dentist, and agreement must be reached before treatment is started. Because the course of

**Table 3-3 The senior friendly dental office.**


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To ensure ease of access:

- No stairs (ramp or elevator)
  - Adequate, safe parking
- 

For ease of being seated and standing again, reception furniture should be:

- Not low to the floor
  - Firm
  - With arms
- 

To reduce risk of falls, flooring should be:

- Consistent throughout the office
  - No deep pile carpeting
  - No throw rugs or clutter on the floor (watch hoses and cords)
  - No slippery areas/surfaces
- 

Lighting to reduce age-related vision

- Adequate lighting without glare
  - Consistent level of lighting throughout the office
  - Avoid small print
  - Use contrasting paper and ink colors for written materials
- 

To adjust to age-related hearing loss:

- Stand closer to the patient
  - Enhance visual and auditory clues
  - Remove mask
  - Maintain face-to-face, eye level, eye contact
  - Touch appropriately
  - Drop pitch, speak distinctly
  - May increase volume but do not yell
  - Minimize background noise
  - Use quiet locations for interaction
  - Turn off any music
  - Turn off dental equipment whenever possible
- 

Other communication enhancements:

- Use titles and surnames unless asked specifically to use first name
  - Provide written instructions to reinforce verbal
  - Communicate with caregivers as appropriate
  - Do not communicate with caregivers at the expense of speaking with the patient
- 

Source: Erickson L. The senior-friendly office. *Gen Dent* 2000;48(5): 562. Reprinted with permission of the Academy of General Dentistry.<sup>63</sup>

treatment is often complex, it is recommended that a written treatment plan be reviewed and signed by patients or their representatives.

Dr. Kenneth Shay, Director for Geriatrics and Extended Care for the Department of Veterans Affairs<sup>46</sup> explains that when treating elderly patients, dentists encounter “clinical challenges that are not necessarily unique to the elderly but are encountered with unique frequency and often with unique presentations. In addition, dental care can be complicated by medical, functional, behavioral and situational factors that are associated with aging. It means treating those same familiar

dental procedures in unfamiliar settings or on patients who have medical or functional difficulties. You may have to use different techniques to accomplish the same ends.”

### Getting Patients to Dentists or Dentists to Patients

Many frail older adults can be seen at a dental office, provided that they are mobile and the office is accessible and senior-friendly. More severe functionally dependent elderly persons benefit from receiving on-site, mobile care.

### The Senior-Friendly Dental Office

While most dental offices are suitable for children and adults, some modifications are needed in order to accommodate the frail elderly adult. Elderly patients almost always have one or more chronic medical conditions, so it is especially important to review the medical history each time the patient visits the office. Information should also be collected about types of medical conditions and medications, as well as recording contact information for the patient’s physician. According to Dr. Linda Niessen, Clinical Professor at Baylor College of Dentistry:<sup>46</sup> “In dentistry we are surgeons. We see disease: we cut it out. We will always be surgeons. But a practice that is treating an older population will increasingly take on more oral health medicine components. It will be increasingly important for us to gather a complete medical history on the patient and know if they have heart problems that may require systemic antibiotics or if the person has had a hip replacement, or stroke. It’s important to know that the ulcers in the patient’s mouth may be a result of their arthritis medication. The medical management of the patient will increase.”

Erickson<sup>63</sup> has developed the following list of essentials for the “senior-friendly office” shown in Table 3-3. Some of the recommendations refer to the physical office setup, and others suggest about ways of interacting with seniors to show respect and to facilitate communication.

### On-site Delivery Systems

Functionally dependent older adults are often best served by bringing dental services to them, rather than transporting them to the dental office. Pictured in Figure 3-4 is an example of a mobile dental office that can be set up within a nursing home.

The provision of on-site care has many unique aspects besides mobile dental equipment. According to Helgeson and Smith,<sup>64</sup> mobile and on-site dental care delivery systems are not simply traditional private dental practices located in nursing homes. They are interdisciplinary team efforts designed to systematically address the oral health needs of nursing home residents. The provision of dental care involves not only dental staff, but also nursing staff, primary care physicians, patient representatives, and third-party payers who each have important roles to play. In addition, on-site delivery systems must assist in establishing preventive programs, provide education for nursing staff, and participate actively in the medical-dental management of medically compromised patients.

The traditional fee-for-service funding model for dental care has provided excellent access to care for patients and population groups who are able to pay for needed care. Unfortunately, the connection between ability to pay and the availability of dental care creates financial barriers for nursing home residents. Because on-site delivery systems have

Figure 3-4 The Apple Tree Mobile Dental Office



Mobile Equipment delivered during the evening



Complete mobile dental office operational on-site

contractual responsibilities for meeting the oral health care needs of an institution, they take on a uniquely public health character, functioning as dental care access programs. Nursing homes and Medicaid programs that pay for services demand nondiscriminatory care and cost-accountability. All these factors point to the need for new, nonprofit delivery systems with interdisciplinary organizational structures.

New legal agreements are needed to clarify dental and nursing staff responsibilities and assure regulatory compliance. New methods of communicating, care planning, record keeping, and scheduling are needed for on-site teams to function smoothly. To maintain and improve quality, new team management structures, levels of accountability, and management information systems are essential.

On-site providers must provide documentation that meets the needs of the nursing home and can be incorporated into the medical record. The use of terminology appropriate to the training of nursing staff will facilitate communication and follow-up care. Interpretation of dental records and typical follow-up orders should be included in the training of nursing personnel.

Just as with any dental practice, effective scheduling is essential. Mobile care schedulers must first determine a monthly schedule of site visits to each of the facilities served. Visits must be scheduled with sufficient frequency to keep facilities up-to-date while effectively utilizing the time of dental personnel. Schedulers must track the number of new patients, patients undergoing treatment, dental emergencies, and those due for recall. Each site visit must be coordinated through the facility's dental liaison. As the number of sites served by the mobile practice grows, the complexity of this task is magnified. Large facilities may need weekly visits, while small ones may need a combination of on-site visits and off-site referrals to assure that resources are used cost-effectively.

Nondental personnel in the long-term care setting are critical in identifying their residents' oral health needs and connecting them to dental personnel who can address those needs. Nursing homes that receive federal reimbursement are

required by OBRA 1987 regulations to demonstrate that they can "actively provide or obtain dental care for their residents." They are required to:

1. Assist residents to obtain routine/emergency dental care.
2. Provide/obtain dental services by hiring staff or contracting with a dentist.
3. Assist/arrange for appointments and transportation to a dental office.
4. Refer a resident with lost or damaged dentures to a dentist promptly.<sup>48</sup>

Making these more than "paper requirements" requires that non dental personnel, particularly the nursing staff, can identify problems to refer and facilitate care as necessary. An important function that can be performed by a non dental nursing home employee is that of "Dental Liaison." The Apple Tree Dental (ATD) model illustrates the key roles this individual plays in facilitating dental care. The Dental Liaison fulfills the following responsibilities:

1. Training nursing staff and intake workers on protocols and procedures for routine and emergency care, and assuring that all residents are referred for routine care.
2. Serving as the dental communication link, routing reports of dental problems to the dental team and conveying information from the dental team back to the facility.
3. Assuring that the dental team receives charts, health status, and nursing assessment information and other assistance needed to provide care.
4. Assuring the availability of the work area, and making arrangements to have it cleaned before and after on-site clinic days.
5. Assuring that nursing staff and residents are informed in advance of appointments.
6. Providing regular feedback for quality improvement.

In this system, nurses play several key roles, such as providing health status updates when necessary, and relaying dental concerns to the dental liaison. Following on-site visits,

nursing staff are responsible for carrying out postoperative orders and for modifying daily oral care plans as directed. Nurses must also be involved in medical-dental consultations and in the coordination and administration of medications needed to provide dental care. Finally, nurses may need to assist with communication, mental status assessment, resident transfers, and behavior management to enable every resident to obtain needed care.<sup>64</sup>

The contributions of the interdisciplinary care planning team are valuable adjuncts in the provision of appropriate oral health care to the functionally dependent adult. Physical therapists can evaluate existing function. Occupational therapists can make recommendations regarding the resident's oral self-care ability. Social workers can provide insights into family interactions and any discharge potential. Nurses and physicians can provide critical information about the resident's medical condition and nursing interventions.

Just as dental personnel should refer unknown or inadequately controlled medical problems like diabetes and hypertension, so nondental personnel should refer patients when oral disease is detected. They can advocate for the importance of oral health care to general health, stress that oral disease can exacerbate other health problems, and dispel the misconception that oral disease and tooth loss are unavoidable parts of aging.

### **Expanding Dental Insurance Coverage through Government Programs (Medicare, Medicaid)**

Because oral health problems are increasingly linked to general health pathologies, there is clearly a need to consider inclusion of dental benefits under Medicare, the federal program that has largely made access to health care a reality for American retirees. In fact, despite the inclusion of dental benefits at the inception of Medicare, it now covers virtually no oral health services. For some, preventive dental care may be obtained through purchase of "Medi-gap" policies, but for many this is an unaffordable option.

While much energy has been spent reforming Medicaid dental programs, most of the attention has been focused on improving dental access for children. Because the oral health needs of the elderly are vastly different than those for children, there is a great need to develop policies relevant for the oral health needs of the frail elderly, such as cost-reimbursement models for providers serving this population. Current national trends indicate a growing number of elderly living longer and retaining larger numbers of their natural teeth. Together, these phenomena indicate an increasing need for dental care into old age.

- Dental insurance coverage needs to extend past retirement into old age. It is well known that people with coverage tend to utilize more preventive services than those without. Dental insurance needs to address the reality that dental diseases increase as patients progress from functional independence to become frail and functionally dependent.
- To prevent the rapid onset of dental problems that occurs prior to the need for home health or nursing home services, Medicare should be expanded to cover dental services. Alternately, Medi-gap and private-sector retiree policies should include dental coverage.
- For the frail elderly who are poor, Medicaid needs to be

expanded to cover dental services for adults in all states. Covered services need to include house call fees, gross oral cleanings, behavior management, and other services needed by frail elderly patients.

- Medicaid programs should be patterned more like private insurance.
- Medicaid reimbursements should be raised to levels closer to usual and customary levels. The American Dental Association (ADA) recommends reimbursement at the 75th percentile.
- Medicaid program administration should be simplified to reduce administrative costs, treatment delays, and provider disincentives to participation.
- Medicaid programs should be permitted to contract for special access programs on a cost-reimbursement model or modified capitation model.
- Medicaid programs should not discriminate on the basis of the age of a recipient, but rather provide benefits that are "appropriate and necessary to maintain the health of recipients."

### **Necessary Training and Experience for Caregivers as well as Primary Health Care Providers in Nursing, Dentistry, and Medicine**

An overarching theme that must be considered in each aspect of training at all levels is that both didactic and hands-on experience is needed. Further, the training experience must be long enough and of appropriate intensity that trainees feel comfortable providing the care. An excellent method for getting the disciplines to work together is to have them train together, in both didactic as well as clinical settings. Interdisciplinary training in the learning environment fosters interdisciplinary collaboration in the workplace.

### **Caregivers (Home Health Aides, Nurse's Aides, Family Members)**

The most critical training needs for caregivers are that they:

- Know the importance of daily oral hygiene care to maintaining oral health
- Can use basic oral hygiene devices (toothbrush and floss) to clean someone else's teeth
- Can provide oral hygiene services while practicing effective infection control
- Know when professional dental help is needed.

### **Primary Health Care Providers (Nurses and Physicians)**

Undergraduate medical and nursing training should incorporate:

- Oral medicine for identification of common oral diseases including periodontal disease, caries, oral cancer, and various soft tissue abnormalities
- Oral pharmacology for familiarization with the adverse oral side effects of commonly used chemotherapeutic agent prescribed for chronic diseases of the elderly
- Clinical training in head and neck examination with a strong intraoral component
- Guidelines for dental referral
- Oral consequences of systemic disease and systemic consequences of oral disease including recent research findings linking oral disease to heart disease, exacerbation

of lung disease, and incidence of aspiration pneumonia.

In addition, continuing education in nursing and medicine should incorporate all of the same training noted above for undergraduate medical and nursing students plus provide clinical training for nurses to do the oral component of the Minimum Data Set assessment.

## ORAL HEALTH CARE PROVIDERS

### Undergraduate Training

Although most dental schools have some undergraduate didactic training in geriatrics, most have limited clinical training, particularly in providing care to the functionally dependent elderly. Over the past 27 years, the University of Iowa has developed a model program of didactic and clinical training for their dental undergraduates. The adoption of this model by other schools of dentistry would vastly improve the level of experience and confidence of graduating dentists. The components of the Iowa program include:

- Required didactic course for junior dental students during spring semester
- Required 5-week clinical program (Special Care Program) for senior students split between the school-based and nursing home-based clinics.<sup>27</sup>

### Graduate and Residency Training

The University of Minnesota has been providing graduate-level training in geriatric dentistry since 1981 in a program called Oral Health Services for Older Adults. One of the strengths of Minnesota's program is that it has established clinical training sites in environments that provide the full spectrum of aged individuals, from the relatively well elderly to the functionally dependent nursing home patient. Currently, the program offers two tracks: a 1-year advanced clinical training program and a 2-year didactic and clinical program that results in an M.S. degree. This program has served as a leadership-training program for the country. Previous graduates currently hold positions in several dental schools, within the Veteran's Administration, and in the private sector.

### Continuing Education for Dental Professionals

Opportunities exist for intensive training at various U.S. locations. An example of one such program is a 5-day course, "Miniresidency in Nursing Home Care for the Dental Team" directed by University of Minnesota School of Dentistry faculty. This program draws on the expertise of individuals delivering dental care, both fixed and portable, in several long-term care settings. The program is designed specifically to teach dentists, dental hygienists, and dental assistants how to deliver care more effectively in nursing homes. Several other long-standing training programs exist. Additional information about these offerings can be obtained from Special Care Dentistry (formerly the Federation of Special Care Organizations in Dentistry) at (312)440-2660 or [www.scdonline.org](http://www.scdonline.org).

### Recommendations for Title VII and VIII Programs

One of the undeniable facts about living is that every day we are getting older. And, as the baby boom generation in

America ages, more of us are on the gray side of the picture. In 30 years, the U.S. Census Bureau projects that one out of every five Americans will be 65 or older. The population age 85 and older is currently the fastest growing segment of the elderly. When we look ahead 50 years from now, we can expect that over 20 million people in this country will be 85 or older. The size of this group is especially important for the future of our health care system because it includes most of the frail elderly, people who tend to have lower income, poorer health, and require more health care services. This population group has extensive oral disease, medical problems that complicate their oral care, and unique dental treatment challenges.

What can health policy makers do to assure that there are enough trained health professionals for America's future? Based on the dental needs of frail elderly adults discussed the authors of this paper recommend the following:

#### **Work to Change Perceptions Regarding Oral Health and Disease So that Oral Health Becomes an Accepted Component of General Health**

- Include oral health services in all health promotion, disease prevention, and care delivery programs. Develop training programs for nondental health professionals to emphasize how they can and should work to enhance oral health.

#### **Accelerate the Building of the Science and Evidence Base and Apply Science Effectively to Improve Oral Health**

- Survey dental needs among older adults living in a variety of settings, including senior housing, board and care homes, assisted living facilities, nursing homes, and other long-term care facilities.

#### **Build an Effective Oral Health Infrastructure that Meets the Needs of All Americans**

- Develop community-based dental care delivery systems at regional and state levels to reduce gaps in prevention and care for low-income older adults, nursing home residents, and elderly people with disabilities.

#### **Remove Known Barriers between People and Oral Health Services**

- Increase the number of dental professionals who are trained to provide mobile, on-site dental care for frail elderly adults and other groups with special dental access needs.
- Provide oral health benefits in all public health programs, especially those for elderly adults.

#### **Use Public-Private Partnerships to Improve the Oral Health of Those Who Still Suffer Disproportionately from Oral Diseases**

- Increase the number of dental, medical, and nursing programs with active partnerships or cooperative working agreements with public and private community-based

organizations that serve people with special access needs, such as frail elderly adults.

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