

Doris J. Stiefel, DDS, MS

Associate Professor Emeritus in Oral Medicine, School of Dentistry,  
University of Washington, Seattle, WA 98195; erstiefel@msn.com

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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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