New Models

New Models for Improving Oral Health for People With Special Needs

Paul Glassman, DDS, MA, MBA

Abstract

The number of people with special needs is increasing dramatically. In this context, people with special needs refer to people who have difficulty having good oral health or accessing oral health services because of a disability or medical condition. Among these groups, the number of people with developmental disabilities and the emerging population of aging "baby boomers with teeth" are demonstrating dramatic growth. People in these groups have significantly more dental disease than the general population. It is already difficult to impossible for many people with special needs to obtain oral health services. Under the current system of care, this situation will only get worse. The characteristics of a new model, which can better address the oral health problems of people with special needs, are described.

Imagine you find yourself as the health minister of a small country. You realize heart disease is rampant in your country. Now, imagine you decide that the best way to treat this epidemic of heart disease is to train many heart surgeons. One might conclude this solution was a misallocation of resources. One might argue that systems could be developed that would better serve those people with heart disease. These systems might include a number of strategies, a focus on prevention, and training and deployment of a number of types of practitioners. Now, this small country might not be a perfect analogy to the current situation with oral health and people with special needs, but it has striking similarities. This paper will review the current situation and the oral health system for people with special needs. It also will describe some characteristics of an oral health system that might better address their oral health needs.

Guest Editor / Paul Glassman, DDS, MA, MBA, is professor of Dental Practice, associate dean for Information and Educational Technology, and director of the Advanced Education in General Dentistry Program at the University of the Pacific Arthur A. Dugoni School of Dentistry.

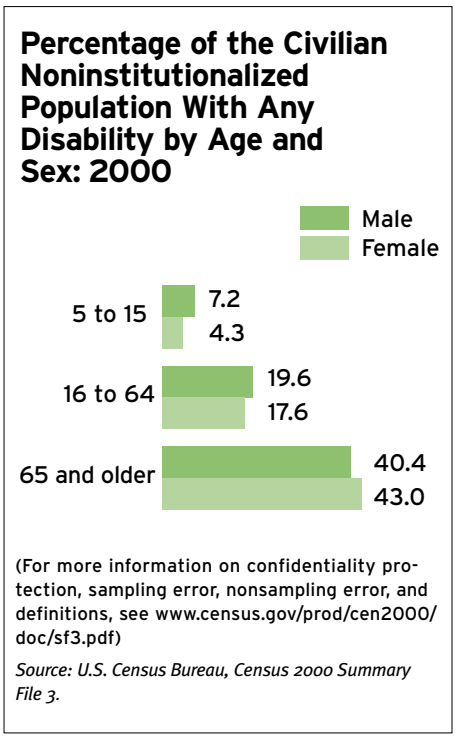


Figure 1. Population with disabilities by age. From U.S. Census Bureau.[1]

The Population of People With Special Needs Is Increasing Dramatically

The number of people with special needs who need oral health services is rising dramatically. In this context, people with special needs refers to people who have difficulty maintaining good oral health or accessing oral health services because of a disability or medical condition. The U.S. Census reported in 2000 that 49.7 million people had a long-standing condition or disability.[1] They represented 19.3 percent of 257.2 million people aged 5 and older in the civilian noninstitutionalized population, or nearly one person in five. **Figure 1** illustrates the fact that the majority of people with disabilities are over the age of 65. In **Figure 2**, it can be seen that the major areas of disability are physical, difficulty going outside, sensory, and mental disabilities. A significant portion of the population, 9.5 percent of those over age 65, also has problems with basic self-care. Also of interest in the 2000 census data was the finding that 46.3 percent people with at least one disability reported having more than one. **Figure 3** illustrates the rate of multiple disabilities found in the population.

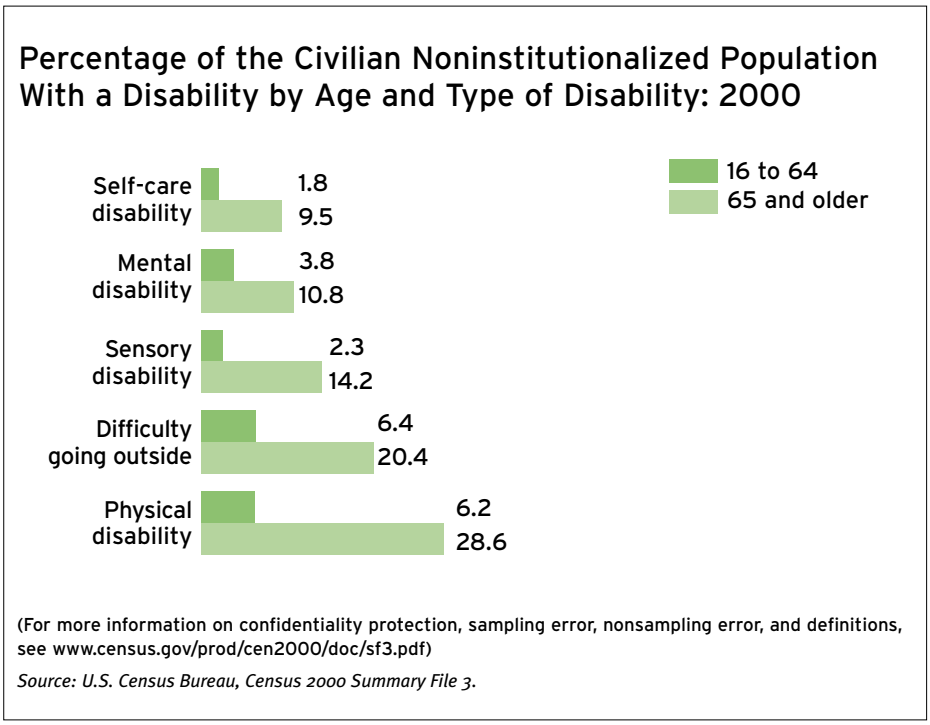


Figure 2. Population with disabilities by age. From U.S. Census Bureau.[1]

While there is a growing population of people with disabilities in general, there is explosive growth in the number of people with certain disabilities. For example, **Figure 4** illustrates the number of people with developmental disabilities who are served by the California Department of Developmental Services has been growing at more than 5 percent per year, while the general population of California is growing at approximately 1.8 percent per year.[2] In addition, the prevalence of autism in California has increased from 7.5 per 10,000 for people born in 1983-'85 to 20.2 per 10,000 for people born in 1993-'95, an increase of 269 percent.[3] Other states have shown similar or greater increases.[4]

Many reports show that people with disabilities have more dental disease, more missing teeth, and more difficulty obtaining dental care than other members of the general population.[5-10] Reports that focus on people with developmental disabilities demonstrate that those who reside in community settings have significant unmet medical and dental needs.[11-18] The situation is worse for individuals with disabilities who live in rural areas.[19]

The surgeon general's report on oral health points out that people with mental retardation or other developmental disabilities have significantly higher rates of poor oral hygiene and an increased need for periodontal treatment than the general population.[5] People with disabilities also have a higher rate of dental caries than the general population, and almost two-thirds of community-based residential facilities report having inadequate access to dental care.[20-23] Untreated dental disease

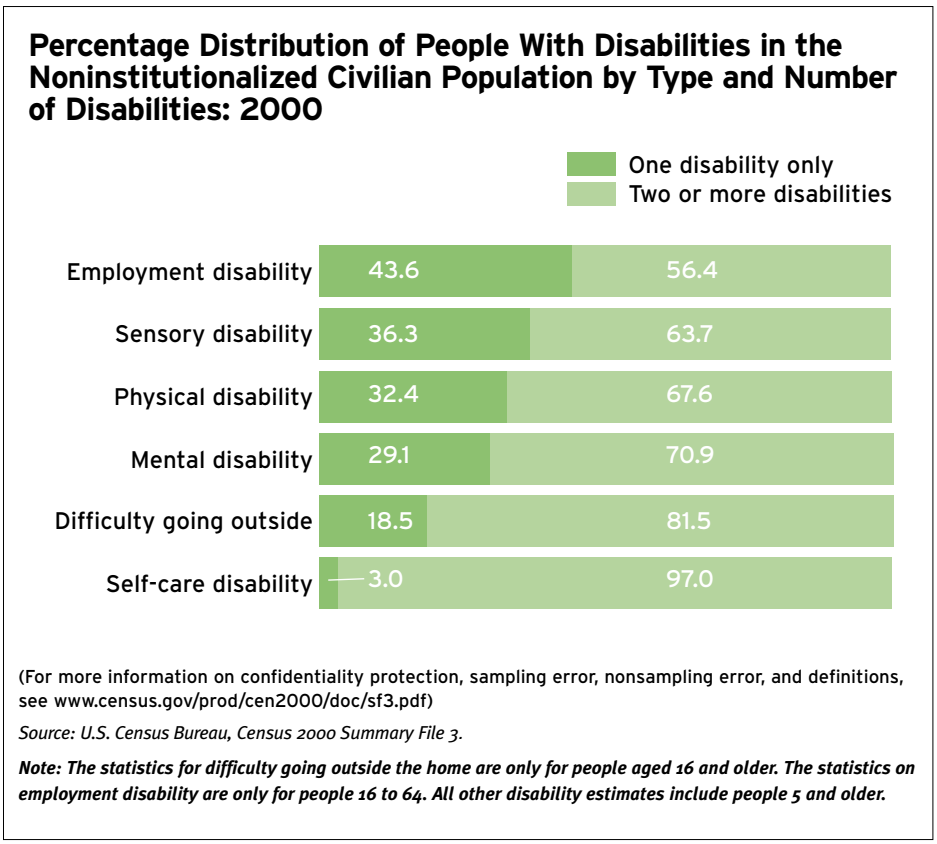


Figure 3. Population with multiple disabilities. From U.S. Census Bureau.[1]

has been found in at least 25 percent of people with cerebral palsy; 30 percent of those with head injuries; and 17 percent of those with hearing impairment.[6] A study commissioned by the Special Olympics concluded that individuals with mental retardation have poorer oral health, more untreated caries, and a higher prevalence of gingivitis and other periodontal diseases than the general population.[24]

In 1999, the U.S. Special Olympics Special Smiles Program performed extremely conservative oral assessments (no X-rays, mirrors, or explorers) of athletes of all ages, and found that 12.9 percent of the athletes reported some form of oral pain; 39 percent demonstrated signs of gingival infection; and nearly 25 percent had untreated decay.[25] These findings are in a population that tends to be from higher income families. However, people from lower socioeconomic groups and those covered by Medicaid also have more dental disease and receive fewer dental services than the general population, and many individuals with disabilities are in these

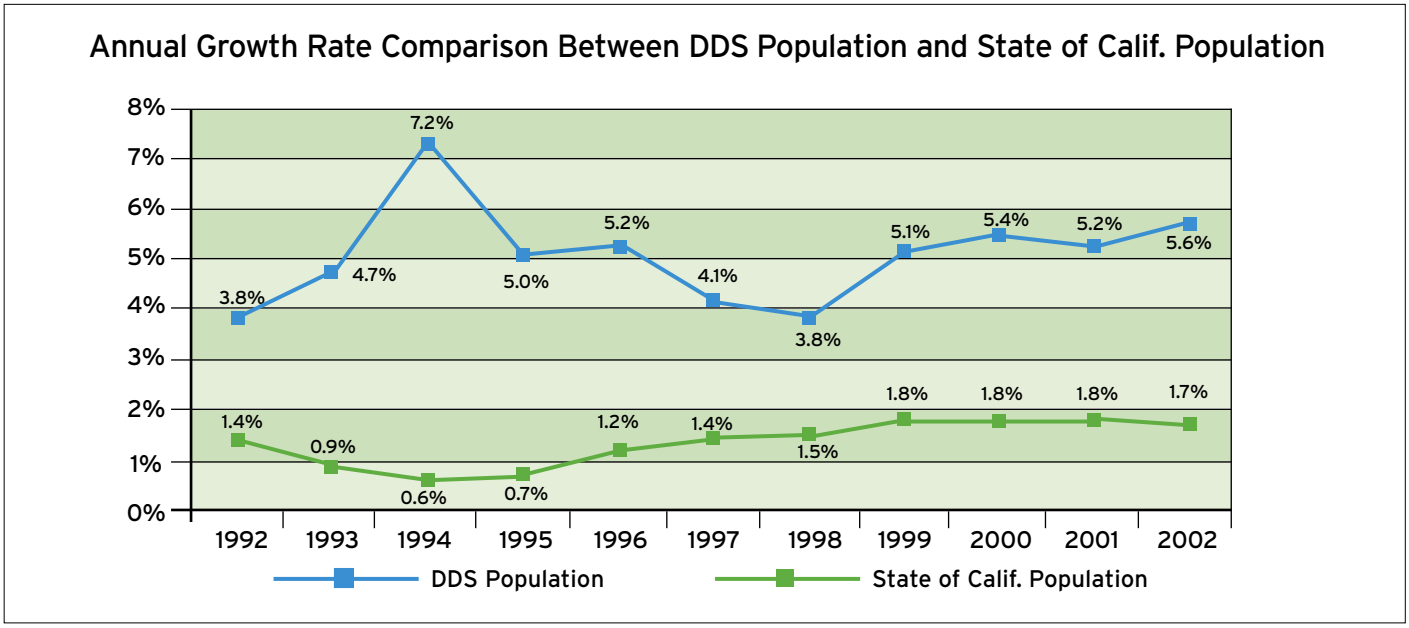
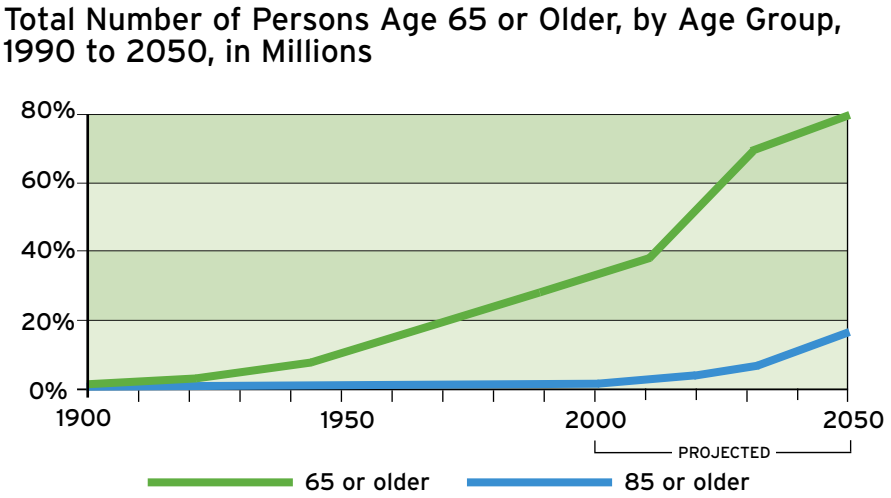
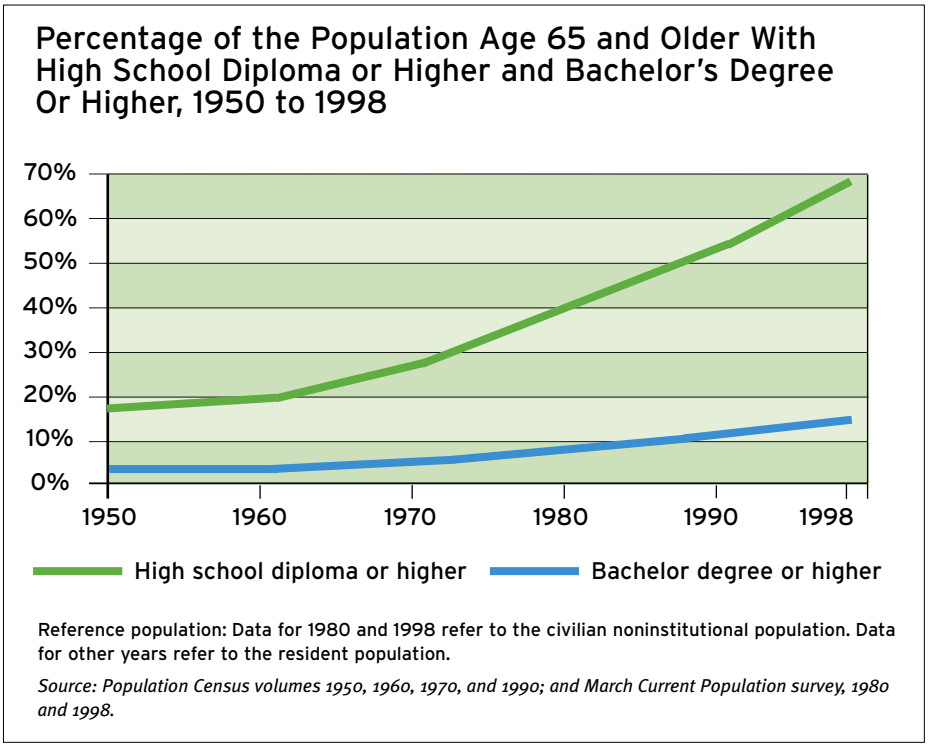


Figure 4. Growth rate comparison between the population served by the California Department of Developmental Services and the general population of California.[2]



Note: Date for the years 2000 to 2050 are middle-series projections of the population. Reference population: These dates refer to the resident population.
Source: U.S. Census Bureau, Decennial Census Data and Population Projections.

Figure 5. Growth in the elderly population.[33]



Reference population: Data for 1980 and 1998 refer to the civilian noninstitutional population. Data for other years refer to the resident population.

Source: Population Census volumes 1950, 1960, 1970, and 1990; and March Current Population survey, 1980 and 1998.

Figure 6. Percent of elderly with high school diploma or higher.[33]

lower socioeconomic groups.[5,26,27]

In the mid-20th century, many people with physical and mental disabilities were institutionalized and institution-based preventive dentistry programs were developed.[28-30] However, since the 1970s, almost two-thirds of those residing in institutional settings have been moved into community-based settings and dental care services, which had been available in the institution, are in many cases, no longer unavailable for them.[31] Deinstitutionalization has exacerbated the problem that many individuals with special needs have in obtaining access to dental care as they move from childhood to adulthood. The limited availability of dental providers trained to serve special needs populations and limited third-party support for the delivery of complex services further complicates the issue.[5] Some believe that the U.S. health care system discriminates against people with disabilities because health care professionals are uncomfortable working with people with disabilities and find ways not to treat them.[32]

The nation's growing senior citizen population is especially at high risk for dental problems, particularly those with health problems or other disabilities. An estimated 70 percent of the nation's 2 million-plus nursing home population has dental problems, including dentures that don't fit, loss of some or all of their teeth, and most significantly, poor oral hygiene.[6]

Most people are aware of the "graying of America," the phrase used to describe the dramatic growth in the proportion of the population over the age of 65. The number of Americans older than 65 increased more than 10-fold from 1900 to 2000, from 3 million to 35 million, representing almost 13 percent of the total population.[33] The number of people over the age of 65 is expected to grow to 70 million by 2030 when they will represent 20 percent of the population. Even more dramatic growth

is expected in the number of people over the age of 85, which will reach 19 million by 2050, representing 5 percent of the total population. The size of this "oldest old" age group is especially important for the future of our health care system, because these individuals tend to be in poorer health and require more services than their younger counterparts. **Figure 5** illustrates the increase in the population over 65 and 85 in the coming decades.

In addition to there being more elderly people, those over 65 are increasingly better educated than in previous generations and have a higher net worth. **Figure 6** shows the increase in the percent of elderly individuals with a high school diploma or higher, and **Figure 7** illustrates the increasing mean household net worth of the elderly population. These trends portend a population that will be better educated, have more income than previous generations, and therefore, demand better dental care.

While most people are aware of the "graying of America," it is not widely understood that, at the same time, the rate of edentulism is decreasing dramatically.[5] In California, only 13 percent of people over 65 are edentulous now compared to close to 50 percent only a few decades ago. **Figure 8** illustrates the dramatic drop in the edentulism rate from the early 1970s to the 1990s. This new population of baby boomers with teeth has invested heavily in maintaining oral health, has complex restorations that require maintenance, and will present significant challenges to the dental profession as they become less able to maintain good oral health.

Implications for the Oral Health System

The dramatic increase in the number of people with special needs who will need dental care comes at a time when there is a declining dental work-

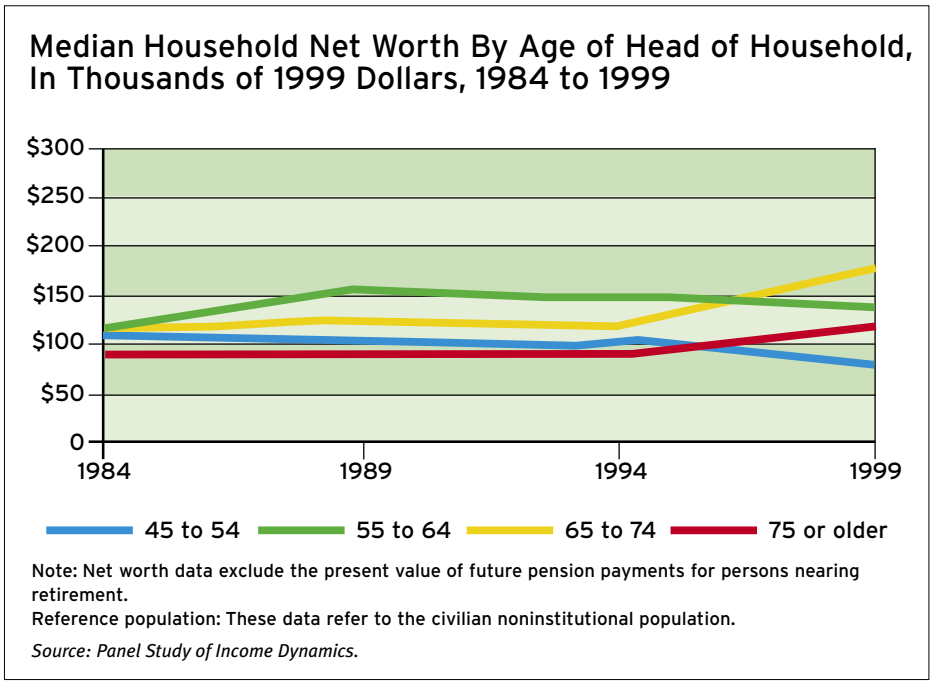


Figure 7. Mean household net worth of elderly population.[33]

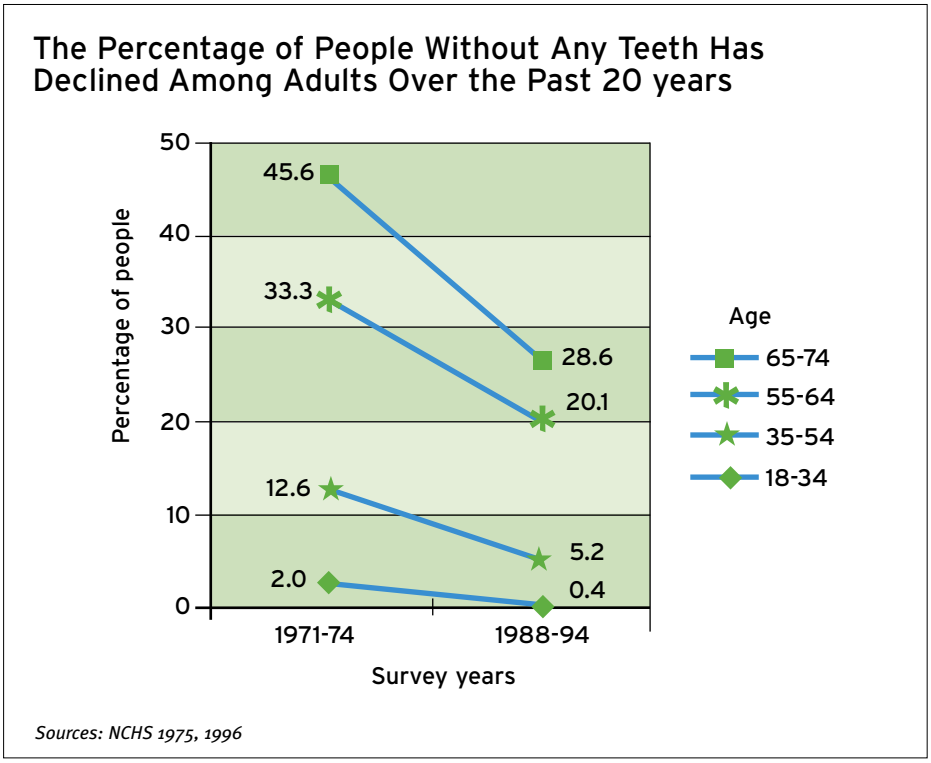


Figure 8: Rate of edentulism in U.S. population.[5]

force. The number of graduates will not keep pace with the number of retirees and the dentist-to-population ratio is expected to decline over the next 20 years and beyond.[34-37] Even the most optimistic workforce projections are based on the assumption that those populations, who do not currently receive dental care, will continue to remain outside of the current delivery system. It already is difficult to impossible for many people with special needs to find a dentist willing or able to treat them. Under the current system, this situation can only get worse.

The dramatic population shifts previously described present increasing challenges for the oral health care system. There are many reasons why the oral health of people with special needs is poorer than the general population, and access to dental services is more restricted. In addition to those factors already mentioned, there are also limitations in individuals' understanding and physically being able to perform personal prevention practices, or to obtain needed services. Some oral problems are exacerbated by medical problems, side effects of medication, or by the disability itself.[5] Additionally, many dentists are not trained, or are not willing, to manage complex medical, social, and behavioral problems experienced by many individuals in this group.[6]

Most people with disabilities who live in community settings are adults.[38,39] Older individuals with mental retardation have more missing teeth and are at higher risk for poor oral health compared with their younger counterparts and those in the general population.[24] Annually, 36.5 percent of severely disabled persons 15 years and older reported a dental visit, compared with 53.4 percent of those with no disability.[27] Few states cover dental services for adults under Medicaid. Even in those states with Medicaid coverage, low reimbursement rates and the reluctance of practitioners to accept those rates, reduce the availability of care, including hospitalization and anesthesia required for treating patients with disabilities.[6]

All of the factors mentioned thus far lead to the inevitable conclusion that the current oral health care system is not working well for those populations described. Increasing oral health workforce shortages; inadequate training of oral health professionals; a reimbursement system that does not reward the kinds of services needed by these populations; inadequate knowledge and application of preventive practices; and other factors all contribute to the failure of the current system for these groups. The result, as previously outlined, is significant oral health disparities with more dental disease, fewer preventive services, and significant access problems for people with special needs.

If good oral health is to become a reality in the future for people with special needs, a new health care system will be needed.

If good oral health is to become a reality in the future for people with special needs, a new health care system will be needed. This new system must address the unique characteristics of populations of people with special needs. The remainder of this article explores the characteristics of such a system and strategies that might lead to improved oral health for these populations.

A New Oral Health Care System

A new health care system would need to have some characteristics different than the current one if it is to provide health care services for people with special needs. Seven characteristics of a heath care system that could meet the needs of these populations are:

■ **A focus on prevention** — The rapid growth of populations of people with special needs and the barriers they experience in receiving dental treatment, has and will continue to produce a tremendous burden of disease that the current system cannot address. The only way to address this burden of disease in the future is to reduce the incidence of new disease. It will therefore be critical in the future to shift the focus of oral health care in these populations from treatment to prevention. This shift will require a focus on prevention of oral diseases by oral and other health professionals, social service systems, caregivers, families, and people with special needs themselves.

■ **A reward system that addresses services is likely to improve oral health for these populations** — The current system rewards surgical interventions and does not reward other activities that might be less costly overall, and might be more likely to lead to better health outcomes. Reimbursement systems, and even fee schedules for people who pay for oral health services directly, include reimbursement for procedures performed by oral health professionals, primarily in dental offices and clinics. They include little or no reimbursement for preventive education, screening and referral, case management, or other less procedure-oriented interventions. A new system should reward early promotion of preventive practices, early identification of potential and actual

oral health problems, application of the least invasive solutions, and major surgical interventions as a last resort. In this context, one could consider restorative dentistry procedures such as fillings and crowns as major surgical interventions. They are certainly major compared to remineralization procedures applied early in the caries process.

■ **A system integrated with other community health and social service systems** — The dramatic increases in the numbers of people with special needs, the declining dentist-to-population ratios, and the increasing burden of disease experienced by special needs populations are all contributing to a reduced ability of the oral health profession to address the oral needs of these populations. It is critical that dental professionals partner with other professionals to address these problems. If we consider an emphasis on preventive education and early intervention to be important aspects of a new oral health system, then it can be argued the dental office is not the best or most efficient place for such activities to take place. These interventions might be better applied in the context of other community health and social service systems. If general health and social service professionals could work with oral health professionals and become involved in activities to promote oral health, the number of people who could be reached could be increased tremendously. This would not only integrate these services with social and general health services, but it would allow dental practices to focus on those more complex procedures where surgical intervention is needed.

■ **A case management approach where oral diseases can be identified and people referred to care settings that best match their situation and needs** — Currently, many people with special needs have trouble finding sources of oral health care. It has been shown that a case management model can significantly decrease problems people have in finding sources of care.[40] Case management models employ triage, referral and tracking systems, as well as resource identification and development components. In this manner, people in need of oral health services can be identified and matched with sources of care that best meet their needs. In a three-year demonstration project using such a system, there was a 38 percent improvement in visible caries, a 44 percent improvement in decayed fillings or crowns, and a 21 percent improvement in gum disease.[41]

If the individual is not capable of complete self-care, it is essential that people who are in daily contact with the individual being served become engaged in the prevention of dental disease and other aspects of the individual's oral health care.

■ **A tiered delivery system with oral health professionals serving as coaches, mentors, and supporters of other health and social service professionals** — As the population of people with special needs continues to grow at a pace that is far greater than the growth of the general population, the current and future oral health workforce will never be able to provide all the preventive education, minor treatment procedures, and surgical interventions that are needed to maintain their oral health. It is therefore critical that other people become involved in these oral health preventive and treatment activities. Ideal candidates for involvement are general health and social service professionals and caregivers of people with special needs. It has been demonstrated that oral health professionals can act as coaches, mentors, and supporters of other health and social service professionals, thereby multiplying their effectiveness.[41]

■ **A system that engages those caregivers closest to the individual in playing a major role in maintaining oral health** — Most oral health preventive procedures must be applied on a daily or more frequent basis. It is clear there is no way oral health professionals can be in contact with people they are trying to serve with that frequency. Therefore, if the individual is not capable of complete self-care, it is essential that people who are in daily contact with the individual being served become engaged in the prevention of dental disease and other aspects of the individual's oral health care. If oral health professionals act as coaches, mentors, and supporters of caregivers and other health and social service professionals, then it may be possible to support those individuals who provide care and are in contact with people with special needs on a daily basis in their application of oral health prevention practices. For example, it has been demonstrated that educational materials, applied in such a "pyramid" training approach can be effective in reducing dental disease.[42]

■ **A tiered delivery system where increasingly complex care is performed by those with most extensive training to deliver such care and less complex care is delivered by those with less extensive training** — Conceptually, it is possible to separate interventions that can improve oral health of people with special needs

into those that can be applied outside of dental offices or clinics by people other than oral health professionals; those that can be applied outside of dental offices or clinics by oral health professionals; and those that must be applied in dental offices or clinics. This conceptual model could form the basis for a tiered system of care.

At a conference sponsored by the Pacific Center for Special Care at the University of the Pacific Arthur A. Dugoni School of Dentistry, a protocol was developed for preventing dental disease in people with special needs residing in community settings.[43,44] Application of the interventions described in this protocol could be one of the functions of the tiers of a new delivery system that are closest to where the individual being served lives or spends time.

If the bulk of preventive activities and less invasive oral health treatment procedures were integrated with activities of other community health and social service systems, this would enable dental providers to concentrate on the most complex procedures that only they are trained to perform. Such an approach would require increased training about oral health for caregivers and general health and social service professionals, and possibly development of new professionals or oral health professionals with new roles who could function in general health and social service settings and concentrate on oral health issues.

Conclusion

If we return to the analogy of a world with heart disease with only heart surgeons to treat this disease, we can see the advantage of a different world where there are heart surgeons, cardiologists, nurse practitioners, dieticians, and physical fitness coaches. In addition, the advantages are clear for having teachers, social workers, cooks, and others being aware of the problems with heart disease and strategies for its prevention. We also can see how these professionals and nonprofessionals might be supported by information about healthy diets, physical fitness programs, statin medications, and public awareness campaigns.

The challenge for the oral health profession is to take the leadership role in finding the analogies to this world for dental disease in people with special needs. The profession has the opportunity now to design a new model for delivering oral health services that can better serve people with special needs. This may require rethinking the role of the profession at a fundamental level. However, given the dramatic increase in the number of people with special needs, the staggering health disparities in these populations, and the inability of the current oral health care systems to solve these problems, it is essential that oral health professionals become aggressively involved in partnership with policy makers, advocates, as well as general and social service professionals in addressing these issues. It will take an increased awareness of these problems and the engagement of many individuals and groups to create a world where people with special needs can also benefit from a lifetime of oral health. CDA

This may require rethinking the role of the profession at a fundamental level.

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To request a printed copy of this article, please contact / Paul Glassman DDS, MA, MBA, University of the Pacific Arthur A. Dugoni School of Dentistry, 2155 Webster St., San Francisco, Calif., 94115.