



Serving the Patient with Special Needs

by Gregory Folse, DDS; Paul Glassman, DDS, MA, MBA; and Christine E. Miller, RDH, MHS, MA, as interviewed by Christine A. Hovliaras-Delozier, RDH, BS, MBA

Patients with Special Needs: Who Are They?

People with neurodevelopmental disorders and intellectual disabilities (ND/ID), frail and/or medically compromised elders, poor children, people with disabilities, and those who are severely medically compromised are all included in categories of Aged, Blind, and Disabled (ABD) under the U.S. Social Security Act. “In the U.S., there are 12,000,000 Medicaid-eligible ABD adults and children, including 5,490,000 Medicaid-eligible ABD adults,” said Gregory Folse, DDS, a practicing dentist in Louisiana who also conducts mobile dentistry with the elderly and homebound and a board member of the Special Care Dentistry Association (SCD). “Ironically, although ABD adults only represent 28 percent of the Medicaid-eligible adults, they account for 72 percent of the total health care expenditures,” he added.

Paul Glassman, DDS, MA, MBA, is co-director of the Pacific Center for Special Care, housed at the University of the Pacific Arthur A. Dugoni School of Dentistry in San Francisco, Calif. (see sidebar on page 11). When it comes to a definition of the ‘patient with special needs,’ Glassman said, “We are using a very broad one, which is basically people who would have difficulty coming into a dental office and having dental work done in a relatively normal manner.” In addition to the categories specifically defined as ABD, Glassman referenced people who are homebound as well as those with mental illnesses.

Christine E. Miller, RDH, MHS, MA, also co-director of the Pacific Center, pointed out that the term 'special needs' tends to bring to mind acquired disabilities such as HIV, rather than the development disabilities. "Ironically, there tend to be more services available to some of those populations than there seems to be for people with developmental disabilities," said Miller.

Furthermore patients with special needs need not be profoundly disabled, explained Miller. Many perform their own oral health home care. "It varies tremendously," she said. "For many people with developmental disabilities, they're quite capable of doing a good part of it themselves."

Miller explained that the Pacific Center works closely with the department of developmental services for the state of California, a social service agency that addresses the needs of patients who have autism, cerebral palsy, epilepsy and mental retardation. "The department has found that most of those folks are mildly affected," Miller said. "I think that is actually one of the stereotypes of people with disabilities—people often think of the most challenging people, rather than the many people out there, including some who are living independently with supportive services."

Glassman added that proceedings from a recent conference reported in the *Journal of the California Dental Association* cited statistics indicating that people with special needs are becoming a larger and larger part of our population.

"Our current delivery system is significantly unprepared to provide services to these special population groups," Glassman

said. "It's going to be a major challenge for the dental profession in the future to be able to provide the kind of treatment that's needed. We're going to need different kinds of dental health care delivery systems to provide the kinds of services that are needed."

What's Already in Place

With varying degrees of success, Medicaid provides oral health care services for poor, blind and disabled children, acknowledged SCD's Folse. "But when they turn 18, services are no longer mandatory, and the ABD adult population is sent out to pasture."

"Medicare covers almost nothing, private dental insurance is virtually nonexistent, and our government deems oral health services for ABD adults optional, leaving the decision to provide them up to each state," continued Folse. More than 46 states fail to provide adequate oral health services for ABD adults, he explained, citing data from a 2003 United States Senate Forum. "And many states provide no adult services at all, leaving our most vulnerable population's oral health totally neglected," Folse said.

"These people are just as deserving of oral health care and of not having horrible oral health problems," added Glassman. "But there is no coverage for it in many states, so you have people who are literally dying—elderly people in nursing homes and people with disabilities—who are literally dying because they don't get access to oral health services."

Gregory J. Folse, DDS

A 1989 LSU Dental School graduate, Folse maintains a mobile geriatric dental practice in Lafayette, Louisiana. He is a recognized national and international speaker on access for ABD patients, geriatric dentistry, and functional and efficient denture care. He is also a fervent oral health advocate for patients with special needs and believes strongly that the government needs to accept a larger role in care for the aged, blind and disabled.

"Currently, my mobile practice serves 15 nursing facilities and four hospitals, and makes old-fashioned house calls for vulnerable patients in need," Folse explains. "I take care of approximately 1,500 nursing home residents including aged, blind, and disabled patients from 18 to 104 years old. Of them, around 975 have teeth. About 760 are poor, have abscessed teeth and/or severe gum disease, and have no access to dental services provided by the government."

Pictured, left to right, are patients Suzie, Harold and Charles. Their intraoral photos illustrate the results of neglect to which vulnerable adults are subject.



Folse believes that access to oral health care for the special needs population cannot be achieved without the government establishing programs to address the problem. “Many wonderful national and local volunteer programs exist and provide access, but these programs are not the national solution needed,” he said. “Oral health services must be considered a critical component of general health care for this population.”

Folse acknowledges that a number of special interest groups have proposed viable solutions to access problems, but notes that each was limited to the population with which that group was concerned. On the other hand, he says, others have proposed huge oral health care solutions through Medicare that seek to cover all citizens over 65—wealthy, vulnerable or not. “These vast ideas aren’t fiscally or politically viable,” he said.

“Medicaid and Medicare general health expenditures for the ABD population are estimated at \$215 billion and \$65 billion respectively,” Folse continued. “If we could save only 0.5 percent of these expenses through improving the general health of the ABD population by treating oral disease and infection, a cost savings of \$1.4 billion would be realized—more than enough to completely fund a national solution to these access issues.”

SCD has such a solution in mind.

The Special Care Dentistry Act would require each state to provide oral health services to Medicaid-eligible ABD adults to the extent that the state provides services to Medicaid-eligible children.

The Special Care Dentistry Act

Proposed legislation spearheaded by SCD and Folse was designed to assure oral health access to the entire special needs population as well as to address the fiscal and political challenges such efforts would face.

The Special Care Dentistry Act would require each state to provide oral health services to Medicaid-eligible ABD adults to the extent that the state provides services to Medicaid-eligible children, Folse told *Access*. It also deems oral health services ‘medically necessary’ and includes provisions to require age-specific services such as more frequent preventive needs, adult periodontal treatment, denture care, etc.

“The proposed legislation seeks only to require coverage for the most vulnerable ABD Medicaid population, which represents only 28 percent of the nation’s Medicaid-eligible adults,” Folse said. “The SCD Act also addresses state political and fiscal realities. A new federal mandate for additional state expenditures would fail, but the SCD Act addresses those concerns.”

Folse explained how, currently, the federal government reimburses states for Medicaid expenses through Federal Medical Assistance Percentages (FMAP). In 2004, this system reimbursed state governments an average of 60.2 percent for

all covered services, with the states contributing the remaining 39.8 percent. The SCD Act would increase the FMAP burden to 90 percent for oral health services provided to the ABD population and the children’s Medicaid programs.

“The result of the act will be to increase federal dollars to each state, allowing adequate funding for both populations,” Folse said. The total cost to federal government would be estimated at \$968,158,237 per year, which does not account for the cost savings that stand to result from decreased general health and emergency room expenditures. This cost represents only 0.2 percent of the total federal expenditures for health care under Medicaid and Medicare.

Presently, the SCD Act is endorsed and supported by almost every major oral health care organization in the country, including the American Dental Hygienists’ Association (ADHA). Hurricane Katrina preempted the scheduled introduction of the act; it should be introduced soon. “A strong and focused grassroots campaign will be necessary to ensure its passage,” said Folse. “I look forward to working with ADHA in this important mission. Dental hygienists and ADHA will play a crucial role in passing this legislation,” Folse said.

“The leaders and members of SCD are to be commended for their innovative approach to help solve the access to oral health care problem,” said ADHA President Katie L. Dawson, RDH, BS. “We look forward to partnering with them to move the SCD Act to passage in Congress. We applaud the SCD’s collaborative advocacy effort with the ADHA and other oral health associations, such as the American Dental Association. SCD’s members are at the front lines in delivering care to needy populations.”

What Makes Special Needs Special?

To characterize patients as having special needs separates them from patients with typical needs. But what determines the difference?

One factor is a patient’s complete or partial dependency on another human being to mechanically perform care, Miller explained. Oral health requires regular disruption of oral bacteria through mechanical action such as toothbrushing. “If caregivers are not reliable, not consistent, or not thorough, oral health will suffer. If you are partially or completely physically disabled, and your caregivers do not have the attitude or the ability to get the job done, your care will be focused on crisis management of the mouth and it will be hard to prevent further oral disease from occurring.”

“It does depend on the individual in terms of what kind of dental problems you see, but I figure they fall into separate categories,” Glassman added. “One is related to difficulties with performing preventive procedures, which would lead to both dental caries and periodontal disease. Other people’s problems are more specific to the particular kind of medical problem that they have, such as side effects of medications, which depend on what the medication is.”

“Then, there are people who have general medical problems that don’t necessarily relate to causing intraoral pathology, but the medical problem(s) make it harder to treat them because of all the special considerations related to their medical diseases,” Glassman said.

Despite the individuality of the patient and his or her special needs, however, prevention is critical for all patients with special needs. “For many people with special needs, once they have dental problems it becomes very difficult to treat them,” Glassman said, adding that this can mean extra time, medical consultations, sometimes even hospitalization so that procedures can be performed with anesthesia. “Because of that, the need for prevention is really paramount with that group,” Glassman said.

Another commonality is the need to be made comfortable. “To treat a patient with special needs, one must get close to them first, physically and emotionally,” Folse said. “Many have cognitive difficulties and can’t be approached through reasoning. This concept is sometimes difficult for providers to grasp. We examine our patients, make treatment recommendations, plan treatment, discuss fees and arrangements, and treat using our skills, intellect, and wisdom. Apply those same communication techniques to some patients with special needs and you’re in for a wild ride. These patients live instinctively and emotionally. Approach them that way. Specifically, show kindness and love.” Folse even advocates telling patients with special needs that you love them, despite the initial discomfort it may cause you. “Even many severely cognitively impaired patients relate ‘I love you’ to good things,” he said.

Challenges Associated with Patients with Special Needs

Patients with special needs present certain challenges to the oral health care practitioner. “Some of them may not understand what you’re trying to do,” said Glassman. “There are people who can’t sit still. People have complicated medical problems that you need to understand prior to treatment. In some cases, once you’ve performed dental work, people have difficulty maintaining it, so you need to work with the patient and their caregivers to prevent further problems from occurring. And of course, for each given entity or

The Pacific Center for Special Care

The Pacific Center for Special Care was founded in 2000 with a \$2 million grant from The California Endowment, a private statewide health foundation. It has been instrumental in educating dental professionals throughout the California community on treating people with special needs and eliminating the fears that many dental professionals have about treating people with disabilities. Co-directors Christine E. Miller, RDH, MHS, MA, and Paul Glassman, DDS, MA, MBA, founded the center after many years treating patients with special needs and after working together on a number of other community projects dealing with the access to care issues for persons with disabilities.

Their passion for such work stemmed from early concerns about availability of care for those who could not easily seek and receive it. Miller used her dental hygiene education as an inroad to associate herself with numerous health-related grant projects, including one dedicated to working with teenagers with developmental disabilities such as muscular dystrophy. Glassman’s interest was sparked in dental school when he realized the narrow focus of the profession.

“I think when I was in dental school that it became clear to me that my dental education was pretty focused on people who had a relatively easy time getting into a dental office and holding their mouth open, sitting still and not having a lot of complicated problems,” said Glassman. “I knew there were a lot of other people that didn’t fit into that category.”

In 1985, a few short years after accepting a position at the University of the Pacific Arthur A. Dugoni School of Dentistry, Miller founded a special needs clinic. Glassman, accepting a position in 1989, began working with Miller on a number of community access to care projects for people with special needs, solidifying their common interest, and eventually leading to the creation of the Pacific Center for Special Care.

different kind of condition, there’s a whole bunch of specifics that go under all those categories.

“But these are the types of challenges one dentist or one hygienist faces with one patient in one chair,” Glassman continued. “If you look at broader health care delivery challenges, then you need to think in terms of how our health care delivery system is organized: what’s good for practice? What are various levels of dental personnel allowed to do? And then, of course, there’s the issue of funding.”

“In dentistry we’re like a car-repair service because we can’t charge for our time, we charge by procedure,” added Miller, “which can be very challenging for both the provider and the patient.” Miller explained that patients with special needs can benefit from, or even require, considerations such as desensitization, which can take extra time. “But there’s really no mechanism—or it’s poorly understood in some states—to get reimbursed if you spend the extra time.

Patients with special needs can benefit from considerations that can take extra time, but there’s no mechanism to get reimbursed if you spend the extra time.

Basically, you still get paid only for the service that you actually deliver in the patient's mouth," she said.

One way to ensure cost-effective use of the provider's time is to treat a patient in a hospital operating room under general anesthesia, Miller said. However, this puts the patient at more risk of adverse effects from the anesthetic and might not necessarily be in the best interest of the person with the disability.

"If restraint is to be used, whether physical or chemical, make sure the entire health care team understands the plan and the state laws governing those issues if applicable," added Folse. If patients don't require a restraining environment, then they can come to the office with assistance or may be treated in their own environment whether it be their

home, wheel chair or their hospital bed. "Treating patients in their own environment is beneficial to many with special needs. Whether in their home, bedroom, hospital bed, wheel chair or nursing home, patients stay calm with less behavior problems when they recognize and are comfortable with their surroundings," said Folse. "Mobile services can decrease the need for sedation and/or restraint for many patients. If

mobile services aren't applicable, spend a little time with the patient in the treatment room before you begin dental procedures. Make them as comfortable as possible and try to get to know them. Schedule an extra 10 minutes for their treatment and both you and your patient will have better results."

Glassman put socioeconomic factors on the list of challenges facing oral health providers who care for patients with special needs. "If you have a life-long disability, it's harder to get an education. If you can't get an education, it's harder to get a good job where you have health care coverage including dental insurance."

Yet another challenge is finding a provider who feels prepared to treat patients with special needs. "There are a lot of dentists and dental hygienists who, even if they had an adequate system and adequate reimbursement, still don't feel like they have enough education to understand the various conditions," said Glassman. In addition, he said, there are social aspects to coordinating care for a patient with a complicated health history. "That's part of the model that we've developed using what we call the dental coordinator—basically a dental social worker who's linked to a social service agency." The dental coordinator works to reduce "social barriers" so that when the patient with special needs arrives at the dental office, all that's required of the staff is the dental work.

Who Should Be Involved

A team approach is necessary when treating patients with special needs, said Folse. The key players are the patient

and their responsible party and/or family—who are not always the same—along with the patient's health care team including the dentist, dental hygienist, assistants, front office staff, primary physician, specialists, nurses and daily care givers. If the patient lives in a residential facility, appropriate staff are included as well.

Glassman points out that guiding a patient with special needs through a dental appointment could include psychological treatment, behavior management, observation and previously mentioned, general anesthesia in the hospital. Furthermore, working with patients with special needs means working with third parties—caregivers who might help patients comply with prevention, and also people who are responsible for consent, which can sometimes get very complicated. "Many people with special needs are involved with social service agencies," he said, "and there can be a lot to understand about how to bring all those diverse parties together in the right way for a given patient."

"Acting as a Lone Ranger is necessary at times for emergencies, but should be avoided," said Folse. "Great information can be gained and patients treated most appropriately when the team acts together, sharing crucial plans, goals and possible complications. However, a nonfunctioning team member should not serve as an excuse for turning a patient away."

Folse offers guidelines for knowing when to treat a patient with special needs: "Treat patients with special needs when you will do no harm, when you can help the patient and when you have the support of the health care team," he said, adding that providers unsure whether to offer care or not should ask themselves these questions:

- Am I the appropriate provider?
- Am I the patient's only hope for care?
- Does the responsible party and/or family understand my level of expertise?
- Does the responsible party and/or family understand the risks of treatment?

Folse said that it is sometimes a temptation for providers to refer patients with special needs to another professional who has more training and expertise. "Sometimes referral is the best option, but many patients have little hope to receive services. An empty referral into a nonexistent infrastructure can leave vulnerable patients neglected. Don't do that," he said. "Informed consent also helps in this situation. Have a frank conversation with the patient, responsible party and/or family, and openly discuss these facts and the patient's options. Treatment risks should always be discussed, especially for the frail elderly and the medically compromised, and all of the conversations documented."

"One our mantras is 'prevention, prevention, prevention,'" said Miller. "When you think about prevention for the general population, you tend to think of brushing teeth with fluoridated toothpaste. But for this population, I would emphasize things like fluoride varnish. It's important to be clear with patients and caregivers about how much at risk people are in terms of caries, hyposalivation or xerostomia."

"An empty referral into a nonexistent infrastructure can leave vulnerable patients neglected. Don't do that," Folse said.

Words of Encouragement for Dental Hygienists

Miller offered advice to the dental hygienist who would be prepared to work with patients with special needs. “Join the American Dental Hygienists’ Association and network,” she said. “Join the Special Care Dentistry Association—there are fabulous dentists and hygienists who are members, so you can network with other professionals, not only across the country, but internationally. So when you’re feeling lost and alone, and you might feel like you’re the only person in town doing this, you have a resource of colleagues to turn to for support, and advice and tips and tricks. And it’s a lot of fun to meet people who are like-minded and willing to take, frankly, more risk and more challenges with their professional life.”

Glassman cautioned against being afraid of people whose diagnosis might seem daunting at first. “There are many people with conditions like mental retardation, or cerebral palsy, or seizures who can be treated just fine with a little time and patience—and for many people, that’s all it takes. Some people just don’t want to see the person at all. I’d say give it a try, jump in and do it—it’s very rewarding when you stretch yourself a little bit beyond where you think you can go, and then you do some good for somebody.”

Folse, who works from a faith-based perspective, describes the rewards of treating patients with special needs in terms of a divine reward. “It’s hard to describe the elation one can feel when a patient who doesn’t speak to anyone speaks to you. The personal nature of the care we provide can open doors that years of neglect and disease have shut. The entire team functions to do these things, and all share in these heavenly rewards.”

At the Pacific Center, Miller has worked with dental hygienists who started out apprehensive. She told them, “People don’t care how much you know until they know how much you care. Those hygienists all did really well because their hearts were so into it. It sounds a little corny, but their love for their fellow humans spoke volumes, often times nonverbally, and the intellectual part of what comes along with working with folks with disabilities just falls right in behind that.”



Gregory Folse, DDS, maintains a mobile geriatric dental practice in Lafayette, Louisiana. He is a recognized national and international speaker on functional and efficient denture care, geriatric dentistry, dentistry for Aged, Blind and Disabled patients and oral health advocacy. He is currently working with the United States Senate’s Special Aging Committee, Centers for Medicare and Medicaid Services (CMS), the American Dental Association (ADA), and Special Care Dentistry (SCD) to nationally improve oral health care access and infrastructure for Aged, Blind, and Disabled US citizens. Through those efforts he was the original author of the Special Care Dentistry Act.



Paul Glassman, DDS, MA, MBA, is professor and associate dean for information and educational technology at the University of the Pacific School of Dentistry in San Francisco. He is also director of the Advanced Education Program in General Dentistry at Pacific. In addition, he is the immediate past president of Special Care Dentistry, a national organization of oral health and other professionals dedicated to improving oral health for people with special needs. He is also co-director of the Pacific Center Special Care at the University of the Pacific Arthur A. Dugoni School of Dentistry and co-director of the California Statewide Task Force on Oral Health for People with Special Needs.



Christine E. Miller, RDH, MA, MHS, director of community programs and associate professor, started the Special Needs Clinic at Pacific in 1985. Over the past several decades, she has promoted the inclusion of oral health into generic social and health service programs. As director of Pacific’s Center for Special Care, she and her co-director have brought in over \$5 million in grants to promote community-based oral health model for people with special needs.

Update: Special Care Dentistry Act

The Special Care Dentistry Act was introduced on Saturday, December 17 as H.R. 4624 by Rep. Boustany (R-LA). The text of the bill, as introduced, is not yet available on the Library of Congress Web site. The bill is currently pending in the House Committee on Energy and Commerce.

More information on the bill should be available in coming days.