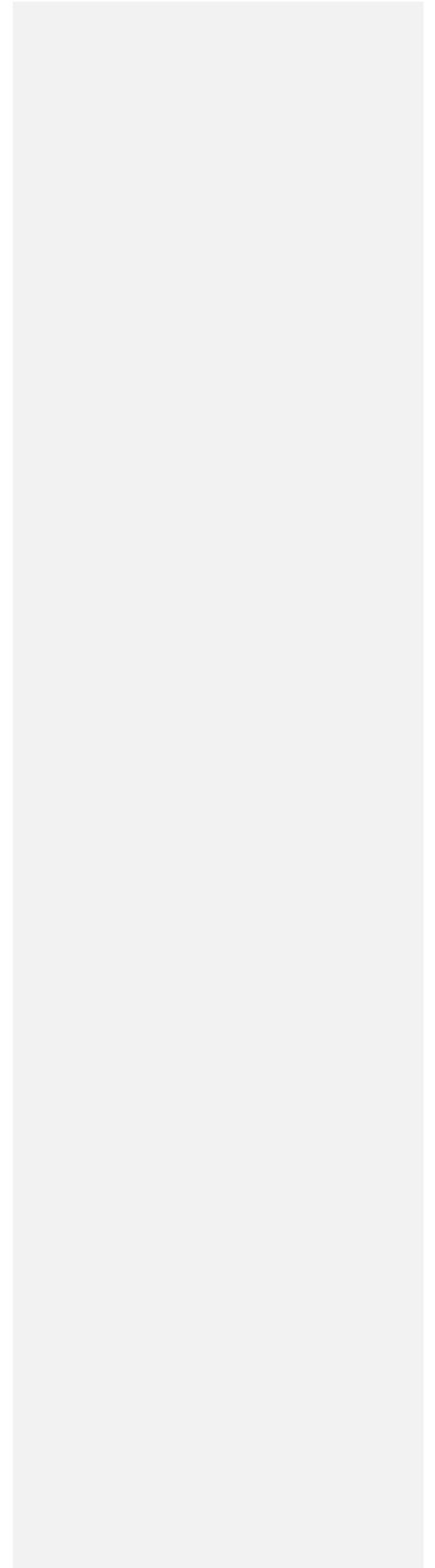


**Access to Oral Health Care for Pennsylvanians
with Disabilities:
A Rising Public-Health Issue**

Disability Health Policy Forum

**A Project of ACHIEVA
711 Bingham Street
Pittsburgh, PA 15202**



Access to Oral Health Care for Pennsylvanians with Disabilities: A Rising Public-Health Issue

Acknowledgements

ACHIEVA gratefully acknowledges the generous support of FISA Foundation for the **Disability Health Policy Forum project**. **FISA Foundation's leadership on this issue** and others pertaining to the health and well-being of people with disabilities is much appreciated.

ACHIEVA also extends its warm thanks to the following individuals, who agreed to serve on the Advisory Committee for the project. Their willingness to contribute their time, expertise and insight is recognized with sincere appreciation.

- Ms. Sandy Amador Dusek, Pennsylvania Developmental Disabilities Council
- Ms. Dee Delaney, Executive Director, FISA Foundation
- Mr. David Gates, Managing Attorney, PA Health Law Project
- Ms. Carol Horowitz, Managing Attorney, Disabilities Law Project
- Ms. Alice Kindling, Public Health Administrator, Allegheny County Health Department
- Ms. Camille Kostelac-Cherry, CEO, Pennsylvania Dental Association
- Mr. Larry Kubey, Self-advocate/ Member, Board of Directors, ARC of Greater Pittsburgh
- Ms. Emilee Langer, Founding Executive Director, Special Smiles Ltd./ public health consultant
- Senator Jane Orie, Pennsylvania State Senate
- Dr. Dennis Ranalli, Professor and Senior Associate Dean, University of Pittsburgh School of Dental Medicine
- Dr. Erik Scheifele, Assistant Professor and Director, Pediatric Dentistry, Temple University School of Dentistry
- Dr. Katherine Seelman, Acting Associate Dean of International Relations, University of Pittsburgh School of Health and Rehabilitation Sciences

- Dr. Deborah Studen-Pavlovich, Professor and Chair, Department of Pediatric Dentistry, University of Pittsburgh School of Dental Medicine
- Dr. Paul Westerberg, Chief Dental Officer, Office of Medical Assistance Programs, Pennsylvania Department of Public Welfare

Special thanks for initiating and advancing the Disability Health Policy Forum project are due to Nancy Murray, Western Area Director for Program Operations, Pennsylvania Department of Public Welfare/ Office of Mental Retardation; Marsha Blanco, CEO, ACHIEVA; Candy Smith, President of ARC of Greater Pittsburgh; and Christine Filippi, Chief Strategic Officer, ACHIEVA.

This report was researched and written by Barbara Sieck Taylor, project director for **ACHIEVA's** Disability Health Policy Forum. Ms. Taylor expresses her thanks to all members of the Advisory Committee for their input and suggestions on this report; any errors that remain are the responsibility of the author.

Table of Contents

Executive Summary.....	5
Project Overview.....	10
The Road to Inclusion.....	10
Oral Health = Overall Health.....	12
Oral Health and People with Developmental Disabilities.....	13
Current Oral Health of People with Developmental Disabilities.....	15
National Trends and Context.....	16
Oral Health Care Delivery in Pennsylvania.....	31
Medicaid-Funded Dental Care in Pennsylvania.....	37
Recent Steps Taken.....	39
Current Realities.....	40
Obstacles to Care and Best Practices in Pennsylvania.....	41
Insights from ACHIEVA’s Disability Health Policy Forum.....	44
Recommendations.....	46
In Conclusion.....	53

Executive Summary

In Pennsylvania, as in other states, access to oral health care for people with developmental disabilities (among other Medicaid-eligible populations) has become a serious and persistent public-health problem. Although the link between oral health and overall good health is increasingly well understood and documented by the health professions, oral health is often strikingly absent from discussions of public health and health care.

The awkward fit between the dental profession's predominant business model and today's public-health infrastructure is creating a troubling trend toward a double standard of oral health care in America. If current trends continue, access issues in Pennsylvania for people with developmental disabilities will worsen. Should that happen, poor oral health will ultimately take an even greater toll on the overall health of hundreds of thousands of Pennsylvanians, with commensurately higher—and often preventable--costs to the Commonwealth's Medicaid system.

The Unmet Needs

Difficulties accessing oral health care are faced by people with developmental disabilities across the country.

- Dental care represents the **number one health care issue** among people with neurodevelopmental disorders.
- Dental care is the **number one unmet health care need** for children with special health care needs.
- Compared to the U.S. population, people with developmental disabilities have **significantly higher** rates of poor oral hygiene.
- Research increasingly links chronic oral infections to systemic conditions (e.g. diabetes, cardiovascular disease and strokes). This means that **people with developmental disabilities are at higher risk for serious health problems** that lead to even higher costs in loss of function, human suffering and health-care expense.

National Trends

People with developmental disabilities may represent the proverbial "canary in the coal mine." A review of their problems accessing care raises questions about the dental community's future capacity to serve all Americans.

- **The U.S. is not training as many dentists per year as it did 20 years ago**, due in part to falling federal and state investments in dental schools and increasingly non-competitive compensation for dentists on faculty.

- Nationally, **35 percent of the nation's dentists are over age 55.** Over one-third of the existing workforce is poised to cut back on practice hours or retire outright in the next decade.
- The ratio of dentists to total population is projected to keep declining through 2020; **in 15 years there will be 10 percent fewer dentists per 100,000 Americans than there were in 1994.**
- The clustering of dental professionals in urban areas creates additional disparities in access to care. **More than 40 million Americans live in federally designated health professional shortage areas**—many of them in rural parts of the country.
- Federally funded community health centers are obligated to offer dental care to low-income groups; however, these **"safety-net" providers encounter the same severe challenges as dental schools in recruiting and retaining dentists**, especially in rural areas.

These workforce trends suggest that even if organized dentistry does not perceive a "shortage" of dentists today, if current trends continue, there will be such a shortage within the next 15 years. People with developmental disabilities are more likely to need treatment only a fully licensed dentist can provide, such as sedation to tolerate cavity preparation. For this reason, **people with disabilities are among those Americans most seriously disadvantaged by dental workforce trends.**

Dental Provider Preparedness

In addition to questions about whether the U.S. is training enough dentists, many dentists feel inadequately prepared to treat people with developmental disabilities:

- In a 2004 Web survey, **68 percent of dental students reported they had less than five hours of instruction** on how to treat patients with developmental disabilities; about half reported they had **no clinical training** with this population.
- Pediatric dentists--the specialists who have traditionally served people with developmental disabilities--comprise only some **3 percent of dentists in the country.**
- Over 80 percent of dentists are general dentists, but **training general dentists to treat this population is a low priority within the typical, already jam-packed dental school curriculum.**

Financing Oral Health Care

Most discussions of the health-care system take little note of how differently dental care services are delivered and financed, compared to medical care.

- Some 43 million people in the U.S. lack medical insurance, but about two and one-half times as many – **an estimated 108 million Americans—lack private dental insurance.**
- Patients pay more out of pocket for oral health care; in 2002, **Americans covered about 14 percent of the cost of their medical care, but paid for 44 percent of their dental care.**
- In 1999, government spending for all dental care from all sources represented only 4.6percent of national dental expenditures. In other words, **95 percent of the nation’s dental care in 1999 was paid for either by private dental insurance or directly by patients.**

Because people with developmental disabilities are much likelier to be un- or under-employed, they are disproportionately negatively affected by these trends. They are less likely to have private dental insurance and more likely to rely on public funding for dental services, putting them at greater risk for overall health problems -- and likely increasing the cost of their health care in the bargain.

Oral Health Care Access in Pennsylvania

Factors driving access issues in the Commonwealth mirror the national trends:

- A large percentage of Pennsylvania dentists (43 percent) is between 50 and 64 years old – i.e. **close to half the dentists in the Commonwealth will reach retirement age in the next 15 years.**
- Pennsylvania’s pediatric dentists—those who have traditionally served patients with developmental disabilities--have **the largest percentage of practitioners aged 50 and above (over 57 percent)**
- Thirteen percent of the Commonwealth’s population lived in dental health professional shortage areas in 2003—an estimated 1.5 million people. **Pennsylvania is estimated to need an estimated 304 additional dentists to serve currently un-served residents.**

Few Pennsylvania dentists participate in the Medical Assistance program to any significant degree:

- Of 5,024 dentists surveyed, **874 (about 17 percent) reported that they participated in Medical Assistance even occasionally.**
- In fiscal 2004-05, of Pennsylvania’s 8,700+ licensed dentists, only 856 billed \$10,000 or more in services to Medical Assistance. In other words, **fewer than 10 percent of Pennsylvania’s dentists are providing significant levels of service to Medical Assistance patients.**

The majority (85 percent) of Pennsylvania’s dentists work in private practices, and the Medical Assistance program offers them little incentive to participate.

- DPW reimbursements are sufficient only to attract the 10 percent of Pennsylvania dentists whose usual rates are lowest; additionally, DPW pays 80 percent of billed charges. In other words, **90 percent of the state's dentists do not consider DPW's reimbursement rate acceptable in full--much less at 80 cents on the dollar.**
- Patients with developmental disabilities may require extra time and staff to be treated in a community practice. Overhead (e.g. compensating hygienists, office space, equipment) typically represents close to 60 percent of total operating costs, so **dentists may only cover their overhead costs -- or lose money outright --**when they treat people with developmental disabilities and bill Medical Assistance.

Raising reimbursement rates is an obvious solution. However, Medicaid now represents nearly one-third of the Commonwealth's total expenditures, and both Pennsylvania and the federal government are attempting to control its growth. In the context of reductions in both federal and state public funding, higher reimbursement rates alone are unlikely to become the primary solution to access issues.

Recommendations

A recent study by Elwyn, Inc. documented that dentists who currently treat patients with developmental disabilities believe over half of these patients require little or no specialized equipment to be treated in their community practices. It is essential that dental providers understand that not all persons with developmental disabilities necessarily require sedation or intensive levels of care. To build capacity in the community-based dental care delivery system, we recommend the following:

Preserve Pennsylvania's assets e.g. maintain its commitment to Medicaid funding of dental services for adults, and support greater public investment in its three dental schools.

Address policies that contribute to provider shortages e.g. adjust incentives for dental professionals, including raising reimbursements as much as possible; develop consensus on the need to train more practitioners; consider new funding to support dental education; continue to streamline DPW enrollment and billing procedures; consider creating or revising dental-school loan forgiveness programs for dentists entering the workforce, tied to their treatment of Medical Assistance patients.

Increase dental provider preparedness by working with American Dental Association and dental schools to enhance curricula; identify and teach competencies specific to treating patients with developmental disabilities; establish/strengthen peer networks; and promote collaborations between dental community and disability groups.

Address obstacles to accessing oral health care, including working toward a primarily community-based provider system with “centers of excellence” to ensure timely access to intensive services; encourage more dentists to contract privately with the federally qualified health centers and similar organizations to provide services part-time; increase accountability of Medical Assistance managed care organizations (such as requiring them to document how many dentists are participating in their plans, what the MCO is doing to recruit dental providers, and establishing standards for how quickly services must be provided).

Change the perception of oral health so it is understood as vital to overall public health, including raising awareness among elected officials, policymakers and their staffs, people with disabilities, and their families.

⊞ **Consider additional policy options** including crafting new financial or tax incentives for dentists who participate in Medical Assistance; requiring minimal levels of participation from providers; or permitting a broader role for hygienists (appropriate to their training and experience).

Formatted: Bullets and Numbering

Advocate for positive change in national policy, such as pursuing designation of people with developmental disabilities as “medically under-served” under federal guidelines or advancing Special Care Dentistry’s proposed legislation.

Encourage consumer/family/direct care worker involvement including making oral health a priority, maintaining good home care routines, honoring scheduled dental appointments, and working together with dentists to anticipate and manage potential behavioral issues.

Summary

Supporting improved access to dental services represents a sound investment in primary health care. Good preventive oral health care helps people to maintain important functions like chewing, swallowing and speech/ communication. It reduces emergency room visits for dental-related problems and also helps to prevent or ameliorate chronic, costly-to-treat conditions such as heart disease and diabetes.

In 1999, people who were “aged, blind and disabled” represented 28 percent of total U.S. Medicaid beneficiaries, but 72 percent of total Medicaid payments. This suggests a significant opportunity, because even modest increases in the overall health of this group could translate into significant dollar reductions. Most important, with improved oral health, Pennsylvanians with developmental disabilities will be able to take greater part in school, work and meaningful community life.

Access to Oral Health Care for Pennsylvanians with Disabilities: A Rising Public-Health Issue

Project Overview

In Pennsylvania, as in other states, access to oral health care for people with disabilities (among other Medicaid-eligible populations) has become a serious and persistent public-health problem. As described below, if current trends continue, the difficulties with access will only worsen and the consequences will ultimately take an even greater toll on both human lives and public dollars.

With the generous support of FISA Foundation, in mid-2005 ACHIEVA established its Disability Policy Health Forum project to focus attention on oral health care and people with disabilities. The project goal was to raise awareness regarding this issue on the part of policymakers, the insurance industry, government officials, legislators and the medical community, and to develop and advocate policy recommendations.

Following the formation of an Advisory Committee (list attached in Appendix A), a public policy forum was organized and convened in Pittsburgh on November 10, **2005. At that gathering, two of the country's leading** dentist-advocates, Dr. Steven Perlman and Dr. Paul Glassman, made presentations on the policy issues related to serving people with disabilities and some possible solutions (the forum agenda is Appendix B). Following that forum, the Advisory Committee met and developed preliminary recommendations. This report documents both the issues discussed **and the advisory committee's recommendations.**

The Road to Inclusion

Over the past 40 years, people with disabilities have made tremendous progress in securing their place as fully included members of American life. A critical gathering took place in 1976, when the White House Conference on Handicapped Individuals brought together more than 3,000 people to discuss federal policy pertaining to people with disabilities. This sparked a number of pieces of significant legislation that were enacted during the 1980s and 1990s.

One of the most important bills was the Americans with Disabilities Act (ADA) of 1990, which made it illegal to discriminate against persons with disabilities with respect to employment, state and local government services, public accommodation and telecommunications. Subsequently, in June 1999, in *Olmstead v. L.C.* the Supreme Court interpreted Title II of the ADA to direct states to administer their **services, programs and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities."** In its decision the Court stated, "Unjustified isolation...is properly regarded as discrimination based on disability."

The *Olmstead* decision culminated four decades of advocacy and represented one of the broadest judicial actions ever taken. Its ramifications are far-reaching, and

among the sectors it affects is public health and health care policy. When people with disabilities lived in state-run institutions, they received their health and dental care in that setting, with concerns frequently raised regarding the quality of that care. Thanks to changes in social policy, almost two-thirds of former institutional residents have now relocated from institutions to living with families or in community-based facilities.¹ Almost all community residences are too small-scale to provide health care services on site. As a result, the movement toward full inclusion has dramatically shifted the responsibility for treating people with disabilities from segregated institutions to the community-based dental delivery system. In short, the playing field has changed.

As described below, many private practitioners are reluctant to serve these **patients, and accordingly "safety net" programs are overwhelmed and unable to meet demand.** As a result, in many parts of the nation, the public health system does not have the capacity to serve those with special oral health care needs. Even more troubling, the number of Americans who may need special oral health care—those who have cognitive, physical or sensory disabilities, who have limitations on their self-care, or who are homebound -- is clearly growing.

According to the U.S. Census Bureau, in 2000 there were 49.7 million Americans over the age of five with a longstanding condition or disability.² Certain sub-populations are growing and growing quickly. For example, many more children are being diagnosed with autism spectrum disorder (ASD) today than twenty years ago.³ In addition, thanks to advances in medical care, the life expectancy of people with developmental disabilities is now approaching that of typical Americans. In 1929, for instance, a person with Down syndrome had a life expectancy of nine years; today, people with Down syndrome commonly live to age 50 or more.⁴

In summary, as a group, people with developmental disabilities are living longer, healthier lives and need to be able to rely on their communities for their primary health care. The days when anyone with any kind of a disability automatically went to certain segregated settings for health care are over. This means that community-based systems of delivering health care, including oral health care, must adapt to serve changing needs.

¹ Glassman, P. "New Models for Improving Oral Health for People with Special Needs," *Journal of the California Dental Association*, Vol. 33, No. 8 (August 2005)

² Glassman, P. "New Models for Improving Oral Health for People with Special Needs," *Journal of the California Dental Association*, Vol. 33, No. 8 (August 2005)

³ The Centers for Disease Control estimates that the incidence of autism spectrum disorder now ranges from 2 to 6 per 1,000 children aged three to ten--up from 1 in 500 to 1 in 166. While there is no consensus that this represents a true increase in incidence, there is no doubt that the rate of diagnosis is higher than ever before. (Accessed online at www.nimh.nih.gov/publicat/autism.cfm)

⁴ National Institute of Child Health & Human Development, accessed online at <http://www.nichd.nih.gov/publications/pubs/downsyndrome/down.htm#TheOccurrence>

To address the challenges of providing appropriate oral health care, all stakeholders will need to work together constructively to refine the delivery system for these services as part of community-based practice, consonant with safety and quality. First, it is the law. For another thing, as Americans age, the demand for special-needs dental care will likely continue to increase. But most important, people with developmental disabilities must be able to rely on the same community health system as everyone else does because anything less is morally unacceptable. Simply put, it is the right thing to do.

Oral Health = Overall Health

"There's a dentist at Boston University who puts it this way: Floss, or die."

Steven Perlman, DDS, Global Clinical Director,
Special Olympics/ Special Smiles

(remarks during ACHIEVA's Disability Health Policy Forum)

The close relationship between oral health and overall good health has received increasing attention from public health and policy professionals in recent years. A number of influential reports and studies, including *Oral Health in America: A Report of the Surgeon General*, have emphasized this relationship and the consequent need to make oral health part of primary care for all Americans.⁵

Oral Health in America also reported on the existing disparities in Americans' access to oral health care. As then-Surgeon General David Satcher noted, the existing **disparities mean that "Those with disabilities and complex health conditions are at greater risk for oral diseases that, in turn, further complicate their health."**

Poor oral health care can result in chronic infections arising from the teeth and gums, and those infections have been persuasively linked to higher rates of illness and death from cardiovascular disease, stroke and diabetes – three of the major killers affecting all Americans. For instance, recent research from the Mailman School of Public Health at Columbia University has documented that people with higher levels of certain bacteria in the mouth were also more likely to have thickening or other changes in the carotid artery, suggesting atherosclerosis.⁶ Another study conducted by the Centers for Disease Control and Prevention documented that the more teeth people have lost, the greater their risk of cardiovascular problems.⁷ A growing body of research finds that periodontal disease and oral infections are related to an increased likelihood of heart attacks

⁵ U.S. Public Health Service, *Oral Health in America: A Report of the Surgeon General* (September 2000), accessed online at National Institute of Dental and Craniofacial Research at www.nidcr.nih.gov/AboutNIDCR/SurgeonGeneral

⁶ Nagourney, E., *The New York Times*, "Dental Health: Flossing Can Be a String to the Heart," February 15, 2005

⁷ Bakalar, N., *The New York Times*, "Brush and Floss (To Save Your Heart, Of Course)," January 10, 2006

and strokes, as well as contributing to the difficulty of managing chronic conditions such as diabetes.

Decayed or missing teeth and dental discomfort also obviously affect chewing and **swallowing. This in turn affects a person's diet and nutritional intake, leading to** disorders such as failure to thrive, weight loss, osteoporosis or other conditions related to nutritional deficits. High levels of bacteria in dental plaque can contribute to pneumonia and other bacterial infections that can become serious and, in some circumstances, even fatal.

The vast majority (over 90%) of systemic diseases have oral manifestations.⁸ There are also a number of diseases that can be detected in their early stages by an oral examination. Swollen gums, mouth ulcers or other periodontal problems may be symptoms of leukemia, oral cancer, kidney disease, anemia or other disorders.

Unlike many other physical conditions, dental disease does not simply "heal" or resolve itself. Untreated, it steadily progresses, often without major symptoms until discomfort and pain make major restorative work a necessity. For this reason, by neglecting preventive care, patients often wind up having to incur significant preventable costs – costs both in their well-being and also in health care dollars. And the most common oral health conditions – [dental caries](#) (i.e. cavities) and periodontal disease -- are ironically also the most preventable.

In short, prevention and treatment of oral health issues is essential not just to protect the function and appearance of teeth, but also to prevent those issues from contributing to other systemic conditions. Unfortunately, although this link is increasingly well researched and understood in the health professions, much of the public is unaware of this important connection. The increasing popularity of dental procedures such as bleaching and whitening contribute to the misperception that dental care is primarily cosmetic, or a luxury, rather than a fundamental dimension of good health.

Oral Health and People with Developmental Disabilities

For purposes of this project, the terms "developmental disabilities" refers primarily to neuro-developmental or intellectual disorders, which result from an estimated 350 known causes.⁹ Some of these diagnoses are due to a genetic anomaly, such as Down syndrome and Fragile X Syndrome. Others are acquired, pre-natally or later, due to an infection such as rubella; exposure to a toxic substance (as in fetal alcohol syndrome); or trauma (e.g. cerebral palsy). In most cases, such as in autism spectrum disorder or pervasive developmental delays, the exact cause of the disorder is unknown.

⁸ Pennsylvania Department of Health, "Some National Oral Health Facts," (accessed online at www.dsf.health.state.pa.us/health/lib/health/some_national_oral_health_facts.htm)

⁹ Steven Perlman, remarks during ACHIEVA's Disability Health Policy Forum, November 10, 2005

Collectively, people with developmental disabilities are at an increased risk of oral health problems. For many, their oral health care concerns are similar to those of the general population and they can be addressed as long as the person is receiving consistent, quality care. However, others with developmental disabilities may have medical needs that are more complex. Some may have congenital abnormalities that require surgeries or other treatment. Sensory difficulties—for example, hypersensitivity to pressure—may make it difficult for some to tolerate tooth-brushing or any contact with oral tissues, making cleaning and preventive care difficult. People with spasticity, such as from cerebral palsy, may have problems **with tongue thrusting, clamping their jaws tightly shut, teeth grinding or 'pocketing'** their food instead of swallowing. Other people with disabilities may need management of their oral health due to side effects of medications, such as those **for seizure control, particularly if they result in 'dry mouth.'**

People with developmental disabilities may also face communications challenges that complicate their ability to maintain oral health. Those who have cognitive disabilities, who are nonverbal, or who cannot communicate readily may experience considerable pain and suffering if oral health issues are not identified. If not attended to, dental problems can ultimately result in self-inflicted injuries or aggressive behavior towards others.

People with complex medical needs, or those with behavioral challenges, face some of the most difficult access challenges. For instance, if a patient with developmental disabilities requires intravenous sedation or anesthesia to tolerate cavity preparation, the dentist needs to have more pharmacological expertise and / or work with an anesthesiologist, as well as ensure that both appropriate monitoring equipment and trained staff are on hand.

In addition to the medical challenges above, people with developmental disabilities may face logistical or other obstacles to receiving oral health care. These often **include the physical limitations of a practitioner's office, e.g. lack of ramped access** or inadequate space to use and turn a wheelchair. Another issue cited as a frustration is public transportation, the unreliability of which can make it difficult for people with developmental disabilities to control their time and honor their scheduled appointments.

Despite these obstacles, maintaining good oral health for people with developmental disabilities is arguably even more important than for the general population. It is not just a medical or health-care issue, but a functional one. In addition to making it more difficult to eat, chew and swallow, untreated dental conditions can present additional challenges to speech and functional **communication. Poor oral health can also negatively affect an individual's social** interactions, self-esteem and potential for employment, and thus it can have a direct bearing on how fully a person with disabilities can participate in a meaningful community life.

Current Oral Health of People with Developmental Disabilities

Dental care now represents the number one health care issue among people with neurodevelopmental disorders, according to Dr. Steven Perlman, Global Clinical Director for the U.S. Special Olympics/ Special Smiles program. A September 2005 article in the journal *Pediatrics* documented that dental care represents the number one unmet health care need for children with special health care needs – not prescription medications, not preventive care, not specialty medical care, but dental care.¹⁰

The same *Pediatrics* study found that unmet dental care needs affected the most children overall, compared to other health services, and that more severe levels of disability increased the odds of unmet dental needs. Given that dental services are **mandated for children under Medicaid regulations, but classified as “optional” for adults**, it is virtually a certainty that these levels of unmet need persist into adulthood and, most likely, worsen.

The Surgeon General’s 2000 report documents that, compared to the general population, people with cognitive and other developmental disabilities have significantly higher rates of poor oral hygiene. They not only have higher rates of poor oral hygiene, they are also more likely to have gingivitis and periodontitis.¹¹ They also have a higher incidence of dental caries, and direct-care staff at almost two-thirds of community-based residences have difficulty securing dental services for their residents.¹²

Since 1993, the U.S. Special Olympics/ Special Smiles program has provided oral health screenings for hundreds of thousands of its athletes, and its findings suggest the widespread scale of the access problems. In 1999, when Special Olympics conducted oral health screenings of program athletes, it found that 39 percent of them—both children and adults—showed signs of gingival infection. Nearly a quarter of the athletes had untreated tooth decay. These findings are disturbing in and of themselves. However, given that Special Olympics athletes tend to come from higher-income and more engaged families, the corollary is that there are many more adults with developmental disabilities who are likely to have even more severe unmet oral health needs.

Since evidence increasingly suggests that chronic oral infections can lead to serious systemic diseases, people with developmental disabilities are therefore at higher risk for these health problems, leading to even higher costs in loss of function, human suffering and health-care expense.

¹⁰ Lewis, C., Robertson, S., Phelps, S., “Unmet Dental Care Needs Among Children with Special Health Care Needs: Implications for the Medical Home,” *Pediatrics*, Vol. 116, No. 3 (September 2005)

¹¹ Waldman, B. and Perlman, S. in *Mental Retardation*, Vol. 42, No. 6 (December 2004)

¹² Glassman, P., “New Models for Improving Oral Health for People with Special Needs,” *Journal of the California Dental Association*, Vol. 33, No. 8 (August 2005)

National Trends and Context

Poor access to oral health care is neither a new nor a simple problem – it has multiple causes and dimensions, many of them deeply embedded in how dental services are delivered in the U.S. The principal challenges can be grouped in three categories: the capacity of the dental profession; education and training of dental professionals; and systems for financing the cost of care.

Capacity of the Dental Profession

Although the U.S. population is growing, the number of fully licensed dentists in the U.S. is projected to decline in the next 10 to 15 years. This is due partly to the characteristics of the current workforce as well as the challenges of training the **nation's dental professionals.**

Decline in Number of Dental Schools

A 2005 report for the National Center for Health Workforce Analysis at the federal Health Resources and Services Administration (HRSA) highlights the financial **pressures on the nation's 56 dental schools, the impact on the dentist workforce and the implications for the public's oral health.**¹³ The number of dental schools in the U.S. reached a peak of 60 in 1980, but with declines in public support between 1985 and 1995 six of those schools closed. At the same time, class sizes in the remaining schools were significantly reduced. One more school has closed and three new ones have opened in the decade since 1995.

Nationally, this means that today there are 56 dental schools, located in 34 states (including three in Pennsylvania), the District of Columbia and Puerto Rico. Decreases in public support for dental education are considered a significant contributor to the shrinking capacity of U.S. dental schools over the past two decades – **indeed, the HRSA report describes the situation as "an impending crisis in dental education."**¹⁴ Overall, the U.S. is simply not training as many dentists per year as it did twenty years ago.

Scant Increases in Dental School Graduates

As a consequence of the closings and downsizings of dental schools, graduation of new dentists declined over the past twenty years, and in recent years it has stayed relatively flat. In 1983, U.S. dental school graduates totaled 5,756. Since then, the supply of new dental school graduates has dropped, and by 1990 it dipped

¹³ National Center for Health Workforce Analysis, Health Resources and Services Administration/ U.S. Department of Health and Human Services, "Financing Dental Education: Public Policy Interests, Issues and Strategic Considerations," 2005 (accessed online at <http://bphr.hrsa.gov/healthworkforce/reports/dental>)

¹⁴ National Center for Health Workforce Analysis/ HRSA report, p. 12

below 4,000 graduates per year.¹⁵ In 2003, it increased slightly to 4,443 new dentists per year – this to serve a growing and steadily aging U.S. population.¹⁶

The total number of new dentists is not, of course, the entire story. The number of **hygienists and other dental practitioners who work under dentists' supervision** is increasing, and these staff members enable dentists to use their time much more productively. For individuals with developmental disabilities who have routine oral health care needs, as well as the general population, this makes good clinical and financial sense.

However, as a group, persons with disabilities are much more likely to need specific expertise such as knowledge of behavior management techniques, administration of IV sedation or anesthesia, management of complex medical conditions, consideration of medication interactions or the services of a pediatric dentist, an orthodontist or an oral surgeon. The corollary is that any decline, however slight, in the number of fully licensed dentists has a disproportionately negative impact on persons with disabilities.

Falling Public Investment in Training Dental Professionals

Unlike many other professions, dentistry is taught largely in a clinical setting and clinical instruction contributes heavily to the expense of dental education. While dental students attend lectures and use training simulations, a substantial amount **of a student's time is spent learning diagnostic, preventive and other procedures** during supervised practice with patients. This makes the cost of training a dentist relatively high – on average, \$70,501 per student per year in 2002.¹⁷

The U.S. government and individual states have taken a less-than-consistent approach to investing in the field of dental education. Federal dollars to support dental education have decreased over the past twenty years, and as of 2001 they represented less than 1 percent of pre-doctoral dental education revenues for schools.¹⁸ State and local public support have similarly declined, from 66 percent of total school revenues in 1991 to 49 percent in 2001. With rising costs and public sources of support still falling, dental schools have increasingly been forced to **turn to increases in tuition and fees to continue to train today's students.**

Rising Dental Student Indebtedness

Not surprisingly, the increases in dental school tuition inevitably lead to rising levels of student **indebtedness upon graduation. Tuition at the nation's dental schools**

¹⁵ National Center for Health Workforce Analysis/ HRSA report, p. 8

¹⁶ American Dental Education Association, "Dental Education at a Glance 2004," accessed at www.adea.org

¹⁷ National Center for Health Workforce Analysis/ HRSA report, p. 2

¹⁸ National Center for Health Workforce Analysis/ HRSA report, p. 2

ranges between public, private and state-related institutions, but it can exceed \$50,000 per year.¹⁹ According to the American Dental Education Association (ADEA), as of 2003, dental school graduates began their professional lives with an average debt of \$122,500 – and many of them owe even more.²⁰

While borrowing to pay for a dental education still represents an attractive investment, these levels of indebtedness cannot help but influence new **practitioners' decisions. In most states, dentists, unlike physicians, are not** required to go through residencies in order to practice: once they graduate they are free to take licensing examinations and directly enter the workforce. The high **costs of loan repayment therefore affect young practitioners' early choices about** whether to pursue further training and specialization, where to set up practice, and what populations to treat as they begin their careers.

Because most dentists work in private practice (see below), carrying substantial debt therefore has the unintended consequence of encouraging a new practitioner to focus on making a practice as profitable as possible. This creates a powerful disincentive to treat people who cannot afford usual and customary rates or who rely on Medicaid reimbursements to pay for services.

Faculty Recruitment in Dental Education

It is a challenge for dental schools to graduate more students for a number of reasons, but a primary one is the difficulty of recruiting and retaining dental school faculty. According to a 1999 report for the American Dental Education Association, the vacancies in budgeted faculty positions have increased dramatically since 1992.²¹ As of 2004, the ADEA reports that there were about 11,332 full- and part-time faculty in U.S. dental schools, and the number of vacant positions was about 280, the majority of them in the clinical sciences.²²

The ADEA identifies retirement as the most significant factor influencing these shortages, followed by faculty leaving teaching to enter private practice. Tightening revenues at dental schools make it impossible to keep faculty salaries competitive with compensation in private practice, which is increasing at approximately twice the rate.

Clearly, a shortage of dental school faculty represents a threat to the oral health of all Americans. However, the accumulated expertise of dentists who have experience treating persons with special oral health care needs represents an

¹⁹ National Center for Health Workforce Analysis/ HRSA report, p. 18

²⁰ American Dental Education Association, "Dental Education at a Glance 2004," accessed at www.afea.org

²¹ National Center for Health Workforce Analysis/ HRSA report, p. 19

²² American Dental Education Association, "Dental Education at a Glance 2004," accessed at www.afea.org

especially critical body of knowledge to capture and transfer to the next generation of practitioners.

Increasing Demand for Dental Care

In 2004, dentists held about 150,000 jobs in the U.S., the majority of them (128,000) as general practitioners. According to the U.S. Department of Labor, the demand for dental care should grow substantially through the next decade or so.²³ The past several decades have seen significant advances in preserving and protecting teeth, so more Americans are expected to retain more of their teeth as they age.

Now that the “baby boomers” are reaching middle age, many of them will require complicated restorative or prosthodontic dental treatment. Seniors today are also more likely to retain their teeth than they were 20 years ago, so they will also require much more care to preserve them. While dental hygienists provide routine preventive care, it is likely that overall there will be increasing demand for specialized dental services related to the aging of the general population.

Dental Workforce Retirement Rates and Composition

Nationally, 35 percent of the nation’s dentists are over the age of 55, and of this group, 9 percent is over 65.²⁴ According to a 2003 survey by the American Dental Association (ADA), the average age at which dentists plan to retire is at 63.9 years. A very substantial percentage of the existing dentist workforce, then, is poised to cut back on their practice hours or retire outright in the next decade.

At the same time, the dentist workforce is also becoming increasingly female -- from less than 3 percent in 1982 to a projected 28 percent in 2020. While **individual practitioners’ decisions will of course vary considerably, this trend is** worth noting because as a group female dentists tend to practice fewer hours than their male colleagues.²⁵

According to the ADEA, the ratio of dentists who were professionally active peaked in 1994 at 60.2 to every 100,000 Americans. But the projected retirements and **today’s graduation rates combine to paint an ominous picture.** According to the ADA and HRSA, the ratio of dentists to total population “is projected to decline, continuously, throughout a 2020 projection period, to about 54 professionally active dentists per 100,000 population.”²⁶

²³ Bureau of Labor Statistics, U.S. Department of Labor, *Occupational Outlook Handbook, 2006-07 Edition*, Dentists (accessed online at <http://www.bls.gov/oco/ocos072.htm>)

²⁴ National Center for Health Workforce Analysis/ HRSA report, p.3

²⁵ National Center for Health Workforce Analysis/ HRSA report, p. 19

²⁶ American Dental Education Association, “Dental Education at a Glance 2004,” accessed at www.adea.org

In other words, in the next fifteen years there will be 10 percent **fewer** dentists per 100,000 Americans than there were in 1994. Moreover, that workforce will include a higher percentage of female professionals, who as a group may practice fewer hours per week than their male counterparts. These workforce trends, together with projected increases in the U.S. population, will likely intensify the challenges of ensuring access to oral health care services for people with developmental disabilities.

Urban/ Rural Provider Distribution

At the same time as the ratio of dentists to overall population is worsening, the geographical distribution of dental professionals creates additional disparities in access to oral health care. Because dental practitioners typically cluster in urban areas to assure an adequate base of patients, rural areas often have even greater difficulty with maintaining the capacity to deliver dental services.

In many parts of the country (including Pennsylvania, as detailed below) a number of areas have been designed as Dental Health Profession Shortage Areas (DHPSAs) by the HRSA, based on standard federal criteria. Some of them represent underserved population groups, while others are tied to underserved geographical areas, which are mostly rural. In either case, the number of these shortage areas is quickly climbing: the number of DHPSAs grew from 792 in 1993 to 2,041 in 2002.²⁷

In 1993, HRSA estimated that it would take 1,400 dentists to serve those shortage areas. Not ten years later, because of population growth, it re-calculated that the number of dentists required to meet those needs had exploded to more than 8,000. At this writing, HRSA estimates that more than 40 million Americans live in dental health professional shortage areas.²⁸ In many cases, these documented shortages are in rural parts of the country. Moreover, there may be additional rural areas experiencing similar shortages that have simply not gone through the formal DHSPA designation process.

* * * *

It should be noted that there is no consensus within the dental profession as to **whether the above picture represents a true “shortage” of dentists. Certainly the increased role of dental hygienists practicing under dentists’ supervision has transformed how Americans receive oral health care. Effective use of dental hygienists makes good sense when it comes to routine preventive services like prophylaxis (i.e. cleanings).**

²⁷ National Center for Health Workforce Analysis/ HRSA report, p. 3

²⁸ National Center for Health Workforce Analysis/ HRSA report, p. 3

That said, none of the stakeholders involved in oral health care can argue that the U.S. has too *many* dentists active today. The projected retirements and other **workforce trends suggest that even if there is not a “shortage” of dentists today, if current trends continue, there will be one within the next 15 years.**

Moreover, it is abundantly clear that treating certain populations, such as the elderly, may demand the training levels and skills of fully trained dentists, if not specialists who pursue residencies and further professional training. The specialized oral health needs of certain populations will not be appropriately served simply by the addition of more hygienists. And among the populations who could be most seriously disadvantaged by these workforce trends are many of the 50 million Americans with disabilities.

Education and Training of Dental Professionals

In addition to questions about whether there is an adequate supply of dentists, research conducted by dentists in the public-health sector and organizations like **Special Olympics reveals that the nation’s dental students are not receiving adequate training to treat people with developmental disabilities.**

Constraints of Current Dental School Curricula

Training and preparation for the dental profession differs from training in medicine in some key respects. As noted above, most states (including Pennsylvania) will permit graduates of accredited dental schools to take licensing examinations without completing a residency. A period of residency is a prerequisite for practicing as a licensed M.D., but dentistry as a field has opted not to require an analogous course of training.

The current training model therefore aims to prepare dental school graduates to go directly into general practice. However, as the U.S. population ages and its treatment needs become more diverse, and as the scientific and clinical knowledge base continues to grow, it has inevitably become more difficult to cover all the requisite knowledge and skills.²⁹ The practical effect is that preparing students to step into a practice that includes patients with developmental disabilities is an increasingly tall order.

Readiness to Treat People with Disabilities

As a result, most dental students have extremely limited preparation on how to treat people with developmental disabilities. This gap in their training has been thoroughly documented: in a national study of American and Canadian dental schools, conducted in the late 1990s, more than half of the schools reported spending less than five hours of didactic training, and almost three-quarters of

²⁹ National Center for Health Workforce Analysis/ HRSA report, p. 37

them dedicated 5 percent or less of their clinical training, to the needs of this population.³⁰

Since then, the situation has not improved. In 2004, almost 300 third- and fourth-year dental students were surveyed to determine their experiences pertaining to serving special-needs patients.³¹ Based on this survey, 68 percent of dental students reported they had less than five hours of instruction. About half (50.8 percent) of the students had no clinical training. Little wonder, then, that 60 percent of the students reported they had little or no confidence in their ability to provide appropriate care to people with developmental disabilities.

U.S. Special Olympics recently probed these questions further. It funded the American Academy of Developmental Medicine and Dentistry (AADMD) to conduct a web-based survey to document levels of readiness to treat people with disabilities in both medical and dental education. The principal investigators, an M.D. and a D.M.D., distributed 17 different surveys to six different groups representing over 2,500 medical and dental school deans, residency directors and students.³² Again, **in this survey 60 percent of dental students responding agreed that, "Most graduates are not confident to treat people with intellectual disabilities."**

There were several bright spots within the AADMD survey. One was that **three-quarters of the dental students described themselves as "interested" in serving this population.** Dental school deans and residency directors also strongly agreed that their students should receive significant clinical training in treating this group (77 percent). Finally, virtually all dental program deans (97 percent) and residency directors (94%) said that they would be interested in implementing a curriculum on treating people with developmental disabilities if one were available.

Given the above-described pressures on dental education, it is a challenge for dental schools to aggregate the resources to develop a new curriculum and integrate it into an already over-stuffed course of study. However, it is encouraging that the desire is there. In one heartening development, the state of Wisconsin has recently engaged the AADMD as a consultant to develop such a curriculum.³³

³⁰ Waldman, B. and Perlman, S., *Public Health Reports*, "Why is Providing Dental Care to People with Mental Retardation and Other Developmental Disabilities Such a Low Priority?", Vol. 117 (September-October 2002)

³¹ Wolff, Waldman, Milano and Perlman, "Dental Students' Experiences with and Attitudes Toward People with Mental Retardation," *Journal of the American Dental Association*, Vol. 135 (March 2004)

³² AADMD Curriculum Assessment of Needs (CAN) Project, findings presented by Steven Perlman at ACHIEVA's Disability Health Policy Forum, November 10, 2005

³³ Remarks by Steven Perlman, National Conference of Executives of the Arc, July 29, 2006

The projected retirement of dentists who have treated large numbers of patients with developmental disabilities, plus the need for updated and standardized curricula, also represents an important opportunity. We need to capture their experience and perspective and ensure that this knowledge base is updated, refined and widely shared.

Pediatric and General Dentistry

"What we're dealing with are more than 50 million U.S. residents who fit that definition [of having a disability]. Considering that there are fewer than 5,000 pediatric dentists in the entire U.S., it's a numerical impossibility for us not to have general dentists help us with this. We [pediatric dentists] cannot possibly do this alone."

Dennis Ranalli, DDS, MDS, Senior Associate Dean, University of Pittsburgh School of Dental Medicine
(remarks during ACHIEVA's Disability Health Policy Forum)

Further complicating the picture is the historical relationship between the specialty of pediatric dentistry and the disability community. Traditionally, pediatric dentists have been the practitioners who have served people with developmental disabilities. However, their numbers are small: pediatric dentists comprise roughly 3 percent of the dentists in the country.³⁴

The number of pediatric dentists is unlikely to grow substantially in the foreseeable future. Although the specialty is in demand, and more students are applying for pediatric residencies than ever before, federal Graduate Medical Education (GME) funding for advanced dental education has not kept pace. When U.S. accredited dental residency training programs were surveyed in 2002/2003, only 509 residents focused on pediatric dentistry out of a total of 5,257 residents.³⁵ In other words, few new dentists are now acquiring the training for this specialty although Americans with developmental disabilities have traditionally relied on pediatric dentists for their care.

In addition to the limited numbers of pediatric dentists, there is the additional reality that treatment by a pediatric dentist may not be appropriate for people with developmental disabilities once they are past their teens or early 20s. While this is something for each consumer and each family to determine, it should be acknowledged that these patients are in fact adults, and that adults are typically treated in a non-pediatric setting. In addition, an adult with developmental disabilities who is being treated by a pediatric dentist may face logistical and clinical

³⁴ National Center for Health Workforce Analysis/ HRSA report, p. 20

³⁵ American Dental Education Association, "Dental Education at a Glance 2004," accessed at www.adea.org

constraints: for instance, a pediatric dentist may have hospital privileges only at a **children's hospital**, where their adult patients may not be able to be admitted.³⁶

Today, over 80 percent of dentists are general dentists. Moreover, the majority of the pediatric dentistry performed in the U.S. today is now provided by general dentists – one estimate is 80 percent of pediatric care.³⁷ This means that most of **the dental care system's current capacity clearly rests with general practitioners.** To have significant impact on access to care for people with developmental **disabilities, then, the nation's dental** schools will need to place a higher priority on preparing general dentists, as well as pediatric dentists, to provide care to this population.

Paying for Oral Health Care

The field of dentistry occupies a special niche in the health industry, and most discussions of the health-care system take little note of how differently dental **services are delivered and financed from other medical services.** Dentists' professional decisions are driven by factors quite different from those that affect physicians, nurses and hospital-based health professionals.

The Private Practice Model

"Pediatric dentists expect to be treated like any other business entity which provides products and services to the Commonwealth."

Christopher Luccy, DDS

(remarks during ACHIEVA's Disability Health Policy Forum)

In sharp contrast to the practice of medicine, about 90 percent of nation's dentists provide services in private practice, the majority of them either as solo practitioners or with one or more partners.³⁸ Unlike hospital-based health providers, most dentists must concern themselves to a great degree with practice management: that is, hiring and managing staff, maintaining their productivity, buying equipment and leasing or purchasing professional space. In other words, this model requires that dentists devote considerable time and effort to owning and managing a small business.

A critical corollary is that the typical overhead rates of a private dental practice are high. Typically, some 60 percent of the fee that dentists charge is to cover their professional expenses including hygienists, assistants, office space, equipment and the like.³⁹ **Given a practice's high operating costs, using staff's time productively is**

³⁶ This was the case for one of the plaintiffs in *Clark V. Richman*, discussed later in this report.

³⁷ Dennis Ranalli, remarks during ACHIEVA's Disability Health Policy Forum, November 10, 2005

³⁸ National Center for Health Workforce Analysis/ HRSA report, p. 20

³⁹ American Dental Association, accessed online at <http://www.ada.org/ada/prod/survey/faq.asp>

paramount; cancelled or missed appointments result in a direct financial loss to the dentist/ owners. For this reason, **patients who are repeatedly late or who are “no-shows” can create resistance to being scheduled for treatment in the future.**

While many patients with developmental disabilities can be served in a community practice, it often takes extra time – and thus costs the practice more – to accommodate these patients. Patients with behavioral challenges often require longer appointment times and additional staff, and dentists may also incur costs for **special equipment, staff training and other adaptations to an office’s usual practices.** All these factors result in higher costs for providers – but since Medicaid reimburses by the procedure, there is no difference in the amount a practice can financially recover.

Financial Incentives for New Dental Professionals

As described above, dental students commonly graduate with high levels of debt, so paying off school loans is a foreground concern during their early professional years. In 2003, the average indebtedness of dental students who took out student loans was \$122,500 at graduation.⁴⁰ The cost to lease or buy the equipment needed to set up a new dental practice can be another \$150,000; securing office space and hiring staff may cost up to another \$200,000 per year. With these up-front costs, young dental professionals are understandably motivated to get their new practices off to a good start.

Once a practice is up and running, as noted above, the overhead costs for a dental practice are substantial. The ADA calculated that, in 2003, practice expenses typically accounted for about 59 percent of a general practitioner’s gross billings and 52 percent of a specialist’s gross billings.⁴¹ The up side for new dentists is that they have considerable earning power. According to the ADEA, the average net income of solo, full-time dentists in private practice has increased over 89% since 1990, and it reached \$177,980 in the year 2000.⁴²

These financial realities mean that newly licensed practitioners have a powerful incentive to set up their practices to be profitable as soon as possible. In practical terms, that often means practicing in an urban (versus a rural) location to ensure an adequate base of patients, exacerbating the disparities between urban and rural access to care. High levels of debt also encourage new professionals to concentrate **on treating clients who can cover dentists’ customary rates** – another factor that tends to work to the disadvantage of people with developmental disabilities.

⁴⁰ American Dental Education Association, “Dental Education at a Glance 2004,” accessed at www.adea.org

⁴¹ American Dental Association, accessed online at <http://www.ada.org/ada/prod/survey/faq.asp>

⁴² American Dental Education Association, “Dental Education at a Glance 2004,” accessed at www.adea.org

Declines in Dental Insurance

While some 43 million Americans lack medical insurance, about two-and-a-half times as many – an estimated 108 million-- lack private dental insurance and 150 million have no dental coverage at all.⁴³ Only 60 percent of the baby boom generation has dental insurance through employers, and most older workers lose their dental insurance at retirement.

Even with private dental insurance, benefits often cover a fraction of the cost of services. An unfortunate corollary is that the widespread lack of insurance coverage and expense of dental care encourages people to think of oral health as an “add-on” or a luxury – not as a necessity for overall good health.

Medicare, one of the nation’s two principal public-health financing systems, also contributes to this misperception: it does not include dental benefits. This is simply because when Medicare was established, in the mid 1960s, there was a much lower expectation that people aged 65 and over would still have their teeth. Over the past 30 years, however, there has been a dramatic increase in the number of patients who keep their teeth as they age. In the early 1970s, over 45 percent of people aged 65 and up had no teeth; in 1994 that percentage was 28 percent and continuing to fall.⁴⁴ This has important consequences for the kind and scale of dental care that Americans will be seeking in the next 15 to 20 years.

These trends will put continuing pressures on more and more Americans to pay for their dental care either partially or completely out-of-pocket. This does not bode well for moderate- and low-income Americans. And because people with developmental disabilities are much likelier to be un- or under-employed, they are disproportionately affected by these trends.

Out-of-Pocket Cost of Dental Care

The Surgeon General’s report documented the primary obstacles to oral health care, which include lack of dental insurance and other issues such as transportation or the necessity of taking time off from work for appointments. But one of the most commonly cited barriers to care is out-of-pocket cost.

Dentistry differs from other health care services because it has already substantially transitioned toward a small-business model and is already less linked to the insurance industry than the medical community. As a result, patients pay directly for much more of the cost of care. In 2002, patients covered about 14 percent of

⁴³ PA Department of Health, accessed online at www.dsf.health.state.pa.us/health/lib/health/some_national_oral_health_facts.htm

⁴⁴ Glassman, P. “New Models for Improving Oral Health for People with Special Needs,” *Journal of the California Dental Association*, Vol. 33, No. 8 (August 2005)

the cost of their overall medical care, but they paid for 44 percent of their dental care.⁴⁵

For those who cannot afford to pay out-of-pocket, the level of public support for dental services is not adequate. In 1999, government spending for all dental care (combining federal, state and local sources) represented 4.6% of national dental expenditures -- compared to public support of 32.3% of physician expenditures and 59.5% of hospital care spending.⁴⁶ **In other words, 95% of the nation's dental care** in 1999 was paid for either by private dental insurance or directly by patients.

Because people with developmental disabilities tend to be un- or under-employed, they are likely to have lower-than-average incomes. This in turn makes them less likely to have private dental insurance and disproportionately reliant on public funding, specifically Medicaid, for their dental and other health services. Again, this puts many of them at a significant disadvantage when it comes to accessing and paying for appropriate care, thereby putting their overall health at greater risk and increasing their overall health care costs in the bargain.

Pressures on State Medicaid Programs

As widely reported, the rapidly increasing costs of Medicaid represent a major concern for both the state and federal budgets. The Deficit Reduction Act (DRA) of 2005, signed in February 2006, will have serious impact on all Medicaid-funded programs. The DRA is projected to reduce federal entitlement costs by \$99 billion from 2006 to 2015, including net reductions of \$4.8 billion from Medicaid over the next five years and \$26.1 billion in the next ten.⁴⁷ Given that Medicaid is the principal source of health coverage and long-term care for people with disabilities, **the Act's impact will be felt keenly by this community.**

Many of the policy changes permitted by the DRA will allow states to shift more costs to beneficiaries. For the first time, states will be permitted to impose **cost sharing on services to children under Medicaid; adults' benefits could also be more limited than in the past.** Loosening of some long-standing Medicaid provisions will also change the picture considerably, since states now have increased flexibility over benefits: they will be able to impose cost sharing for some Medicaid-eligible populations without having to apply for and secure a waiver of Medicaid rules.

Overall, reduced federal support of Medicaid will only increase the financial pressures on state Medicaid programs and the difficulty of maintaining broad access **to care. According to the Kaiser Commission on Medicaid and the Uninsured, "a**

⁴⁵ Abelson, R., *The New York Times*, "Dental Double Standards," December 28, 2004

⁴⁶ Waldman, B. and Perlman, S., *Public Health Reports*, "Why is Providing Dental Care to People with Mental Retardation and Other Developmental Disabilities Such a Low Priority?," Vol. 117 (September-October 2002)

⁴⁷ Kaiser Commission on Medicaid and the Uninsured, "Deficit Reduction Act of 2005: Implications for Medicaid," February 2006

large body of research has found that premiums and cost sharing can create barriers to obtaining or maintaining coverage, increase the number of uninsured, reduce use of essential services and increase financial strains on families who already devote a significant share of their incomes to out-of-pocket medical expenses.”⁴⁸

Not surprisingly, people who fall under the category of “aged, blind or disabled” represent a larger share of Medicaid expenses than suggested by their share of the Medicaid-eligible population. In 1999, these populations represented 28 percent of total U.S. Medicaid beneficiaries, but accounted for 72 percent of total Medicaid payments.⁴⁹ This suggests an important opportunity, because even modest increases in the overall health of this group of people could translate into significant dollar reductions. And, as indicated above, improved oral health is a good investment in preventing or ameliorating chronic, costly-to-treat conditions such as heart disease.

Medicaid Reimbursement Rates

Not surprisingly, **states’ budget constraints create pressures to keep Medicaid costs down;** in practice, the reimbursement rates for treating Medicaid-eligible patients **are typically discounted below dentists’ usual and customary rates (UCR)** nationwide. As owners of what are essentially small businesses, dentists in private practice cannot reasonably be expected to serve large numbers of Medicaid-eligible patients if reimbursement rates do not even cover operating costs. This is a major consideration in Pennsylvania specifically, as described below.

Disability advocates also point out that Medicaid funding still shows bias in favor of institutions, which further complicates making the shift to community-based health care. In 1998, national Medicaid spending on long-term care totaled \$59 billion, but only 25 percent of it was for community care rather than institutional care.⁵⁰ **The federal government has taken the positive step of funding a “Money Follows the Person” demonstration project that states can use to test a variety** of approaches to providing home- and community-based services rather than institution-based ones (Pennsylvania was among the states funded in this demonstration). As people with disabilities are more fully included in the community, this structural imbalance will need to be more fully addressed.

Notably, when it comes to disincentives to treat Medicaid patients, the effects of recent policies have not been restricted to dentistry. As reported by the non-

⁴⁸ Kaiser Commission on Medicaid and the Uninsured, “Deficit Reduction Act of 2005: Implications for Medicaid,” February 2006

⁴⁹ Glassman, P. and Folse, G., “Financing Oral Health Services for People with Special Needs: Projecting National Expenditures,” *Journal of the California Dental Association*, Vol. 33, No. 9 (September 2005)

⁵⁰ Pear, R., *The New York Times*, “U.S. Seeks More Care for Disabled Outside Institutions,” February 13, 2000

partisan Center for Studying Health System Change, strenuous state and federal efforts to contain the growth of Medicaid costs have met with some success: the **nation's Medicaid payments increased modestly between 1998 and 2003, although** Medicaid enrollment increased 8 percent just between 2000 and 2003 alone.⁵¹

Strikingly, despite these increases in payments and enrollment, the HSC report documents that the proportion of physicians who would accept Medicaid reimbursement actually **decreased**. As of 2004-05, 14.6 percent of physicians reported no Medicaid revenue and more than 20 percent of them indicated that they were not accepting new Medicaid patients. In other words, there are higher concentrations of Medicaid patients among fewer physicians. And, among the physicians not accepting new Medicaid patients, 84 percent of them pointed to inadequate reimbursement rates as a primary reason. This is the same dynamic demonstrated within the dental community: some of the challenges of publicly funded dental care are reflected in the broader health-care field as well.

It is true that dental expenditures represent only a small percentage of total Medicaid costs. But even so, the policy environment for immediate increases in reimbursement rates—**part of any proposed solution, from the dental community's point of view**--is far from favorable.

The Fraying Safety Net

Given that Medicare does not provide dental benefits at all, and that Medicaid dental benefits for adults in most states are limited or non-existent, people without dental insurance also rely on hospitals, community health clinics (CHCs) and charitable programs to access oral health care. Due to falling numbers of dentists relative to the population and low Medicaid reimbursement rates, the capacity of **these "safety net" providers to provide dental services** is also severely strained.

Many patients unable to afford care postpone treatment until the dental problem has progressed, and wind up in hospital emergency rooms. An analysis from the state of Maryland revealed that when its Medicaid program dropped adult dental benefits in 1993, local hospitals saw a 12% increase in emergency room visits due to dental problems.⁵² But emergency rooms, especially in rural areas, may not be well prepared to handle dental problems: there is often no dentist on staff and there may be little a hospital can do apart from dispensing painkillers or antibiotics. Moreover, emergency rooms, needless to say, represent an inordinately expensive approach to dental care.

Other potential providers, especially in rural areas, are federally qualified health centers, many originally established in 1965 as part of Lyndon Johnson's "war on

⁵¹ Center for Studying Health System Change, "HSC Tracking Report: Medicaid Patients Increasingly Concentrated Among Physicians", August 2006

⁵² Cohen, L.A., Maski, R.J., Magder, L.S., Mullins, C.D., *Dental Visits to Hospital Emergency Departments by Adults Receiving Medicaid*, 2002, referenced online at www.scdonline.org

poverty.” These federally funded community health clinics (CHCs) were created to serve low-income groups, the uninsured, and the working poor, as a condition of receiving federal grants, they are obligated to either provide dental services or contract with a dentist. However, staffing these services is becoming a tall order.

In a study described in the *Journal of the American Medical Association* in March 2006, a shortage of primary care physicians and others (including dentists), plus the reduction in funds for physician training, creates widespread difficulty in hiring practitioners for funded positions. A 2004 survey of all 846 federally funded CHCs conducted for this study found that recruitment of clinical staff poses a “substantial challenge,” especially in rural areas.⁵³ As the authors note, “Physician recruitment in CHCs was heavily dependent on National Health Service Corps scholarships, loan repayment programs, and international medical graduates with J-1 visa waivers. Major perceived barriers to recruitment included low salaries and, in rural CHCs, cultural isolation, poor-quality schools and housing, and lack of spousal job opportunities.” They go on to note that dentists specifically are “in high demand and short supply. The aggregate demand for dentists is greater than for other non-physicians, and almost half of the rural grantees [i.e. CHCs] have had vacant dentist positions for 7 or more months.”

University-based clinics, which serve both to train dental students and also provide care for underserved populations, are another partial solution. However, there are clear limits to their capacity: the limited number of dental students and limited number of dental school faculty (both described above) place a natural cap on how many patients can be served. Moreover, it is difficult for university dental schools to sustain treating Medicaid patients financially, any more than private dentists can.

In recognition of the gaps in access to dental services, many state dental societies also sponsor voluntary programs to deliver free or discounted dental care. One good example is the oral health screenings conducted by Special Olympics/ Special Smiles as part of its Healthy Athletes program: local coordinators recruit volunteer dental practitioners to perform these screenings, with continuing education credits available from American Dental Association and Academy of General Dentistry. Another widespread charitable effort is the Donated Dental Services programs, which are operated in many states by National Foundation of Dentistry for the Handicapped (an affiliate of American Dental Association). Based on a year 2000 survey, the ADA calculates that 74 percent of private-practice dentists occasionally provide their services free of charge or at a reduced rate to one or more groups.⁵⁴

* * * *

⁵³ Rosenblatt, R., Andrilla, C. H., Curtin, T. and Hart, G., “Shortages of Medical Personnel at Community Health Centers,” *Journal of American Medical Association*, Vol. 295, No. 9 (March 1, 2006)

⁵⁴ American Dental Association, “State and Community Models for Improving Access to Dental Care for the Underserved: A White Paper,” October 2004

In summary, the factors affecting oral health care for people with developmental disabilities nationwide are troubling. If current U.S. trends continue, over the next 20 years:

- Fewer dentists will be expected to treat a larger overall population
- Dentists who used to treat large numbers of persons with disabilities and have gained specialized expertise will have retired from practice
- The number of pediatric dentists specifically is not keeping pace with replacing the current workforce or meeting the projected need.
- Most new dentists will feel clinically unprepared to treat people with developmental disabilities as part of a private practice
- Fewer dentists will be participating in Medicaid-funded dentistry
- Fewer dentists will be practicing in rural areas

At the same time, people with developmental disabilities are more likely than the general population to be un- or under-employed, more likely to lack private dental insurance and more likely to use Medicaid-funded programs for dental care.

Clearly, if nothing changes in current systems of care, for people with developmental **disabilities today's access problems will grow worse**—putting their overall health at greater risk and very likely increasing the costs of their overall health care.

Oral Health Care Delivery in Pennsylvania

Based on the U.S. census in 2000, Pennsylvania is home to over 3.7 million non-institutionalized residents over age five with disabilities. Those with developmental disabilities, like everyone else, are subject to the national trends described above when they seek oral health care. However, relative to other states, the Commonwealth has some significant strengths.

First among these is the presence of three dental schools (University of Pennsylvania, Temple University and University of Pittsburgh), many of whose students remain in the state after graduation. Among all respondents to a 2005 survey of dentists by the Department of Health, 88% of those who graduated from dental school in Pennsylvania are employed in Pennsylvania.⁵⁵ This is good news, especially if Pennsylvania re-affirms a commitment to preparing future practitioners.

Another advantage for Pennsylvanians with developmental disabilities is the **Commonwealth's decision to reimburse for routine adult dental services, like examinations and cleanings, in its state Medicaid-funded health program, known as Medical Assistance (MA).** While dental services for children are mandated by federal statute under federal Early Periodic Screening, Diagnostic and Treatment (EPSDT) requirements, dental services for adults are considered "optional" under

⁵⁵ PA Department of Health State Health Improvement Plan, "Special Report on the Characteristics of the Dentist and Dental Hygienist Population in Pennsylvania," Vol. 2, August 2006

federal Medicaid guidelines. As a result, in most states, Medicaid reimbursement for dental care for adults with developmental disabilities is limited or non-existent. The sad reality is that by the time a patient secures help for a dental problem, the only course of action may be an extraction. In contrast, Pennsylvania has at least so far maintained a commitment to providing some level of dental care to adults.

One way of evaluating how Pennsylvania compares to other states and to the nation is via the work of Oral Health America (www.oralhealthamerica.org). This nonprofit advocacy organization generates periodic "report cards" on the oral health across the U.S. A pair of 2003 reports from Oral Health America document both Pennsylvania's laudable goals and where it falls short of meeting them. In the first report, which focused on older adults and Medicaid dental benefits, the Commonwealth's stated commitment to adult dental benefits was recognized with a "B," but Pennsylvania (along with a great many other states) earned "Fs" with respect to reimbursement rates for a range of services. Pennsylvania's overall state grade for adult Medicaid dental benefits was a "D+" in the context of grades ranging from C+ (for New York and California) to no less than 15 states given an "F." The nation's overall grade was a disappointing "D."

In an overall state-by-state report card for 2003, Oral Health America documented similar observations. Pennsylvania earned an "A" for appointing a state dental director and a "B" for its state plan; however, it earned "Fs" under "Significant Medicaid Dental Providers" and "State Support for Oral Health Budget" – both measures that have high impact on patients with developmental disabilities.^{56 57}

It is highly commendable that Pennsylvania continues to reimburse for adult dental care services; at this writing, it is one of only six states in the country still doing so. **That said, the obligation to reimburse for services does not mean that people with disabilities are actually getting them.** Indeed, the statutory right to access those services is meaningless unless all stakeholders ensure that there are dentists prepared to provide them and accept the state's reimbursement.

Capacity of Pennsylvania Dental Providers

Pennsylvania's dental care providers generally mirror the composition of the country as a whole. An August 2006 report resulting from a survey of licensed Pennsylvania dental providers, prepared by the Department of Health, confirms that Pennsylvania's dentists show the same characteristics and workforce trends as on the national level.⁵⁸

⁵⁶ Oral Health America, "Keep America Smiling: Oral Health in America," 2003

⁵⁷ Oral Health America, "A State of Decay: Oral Health for Older Americans," September 2003

⁵⁸ PA Department of Health State Health Improvement Plan, "Special Report on the Characteristics of the Dentist and Dental Hygienist Population in Pennsylvania," Vol. 2, August 2006

According to that report, the number of state-licensed dentists was 8,757 in 2005. (The number of dentists actually practicing in the state is likely to be lower; according to the Chief Dental Officer at DPW, as many as 1,000 dentists may maintain a Pennsylvania license but not actually practice in the Commonwealth.) Not surprisingly, the dentists responding to the DOH survey reported the following:

- The primary employment sectors were solo practitioners (65.2%) and partnerships with other dentists (19.9%)
- The average age of active dentists engaged in direct patient care in Pennsylvania is 50.3 years
- A large percentage of dentists (43%) is in the age cohort of 50 – 64 years old – i.e. heading toward retirement
- Over 21% of dentists engaged in direct care report they are planning to leave dentistry in next 5-10 years
- Among providers with specialty board certifications, pediatric dentists had the largest percentage of practitioners aged 50 and above (57.3%)

In other words, based on the respondents to this survey, over 85% of **Pennsylvania’s dentists are in private practice, as in the case nationally, and a significant percentage of them are nearing their retirement years.** The specialty that has traditionally served patients with developmental disabilities—pediatric dentists—has significantly more older practitioners than dentists overall.

Another dimension of the situation that is specific to Pennsylvania is the relatively high percentage of elderly residents in the Commonwealth. Based on Census Bureau data for 2004-05, 14% of Pennsylvanians are aged 65 and up, putting it among the top five states with the most elderly residents.⁵⁹ This suggests that, relative to other states, more Pennsylvanians may experience problems with their **dental care related to aging. This can range from needing dentists’ offices that are accessible to wheelchairs or walkers, to finding more dentists who specialize in treatments commonly needed by seniors.** It may also be the case that, compared to other states, **even more of Pennsylvania’s dentists are themselves older.**

Rural/ Urban Disparities in the Commonwealth

In addition to what may be considered a shortage of dentists overall, dental providers in Pennsylvania are highly concentrated in urban areas. The Center for Rural Pennsylvania—A Legislative Agency of the Pennsylvania General Assembly **has calculated that of the state’s 67 counties, 38 can be considered as having**

⁵⁹ Accessed at www.statehealthfacts.org (Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates, based on the Census Bureau’s March 2005 and 2006 Current Population Survey (CPS: Annual Social and Economic Supplements).

inadequate numbers of dental providers.⁶⁰ In a May 2004 report, the Center states **that the proportion of active dentists relative to Pennsylvania's population is** estimated to have declined by 10 percent in the past 10 to 12 years, and that as practitioners retire, there are fewer new dentists to take their places.⁶¹ In many parts of the state, then, access to dental services is a concern for everyone, including patients with developmental disabilities.

Based on standard federal criteria, as of October 2006 Pennsylvania has 37 federally designated Dental Health Profession Shortage Areas (DHPSAs).⁶² Two of them are geographic DHPSAs, based on the total population of the area and the number of providers. The remaining DHPSAs are population-based, which compare an identified population (such as Medicaid-eligible persons) with the number of providers available to treat them. In both cases, in these shortage areas there are not enough dental providers to meet public need, even before the specific access concerns of those with developmental disabilities are factored in.

Health Resources and Services Administration (HRSA), the federal agency charged with ensuring access to health care for vulnerable populations, calculates that **13 percent of the Commonwealth's population lived in dental health professional** shortage areas in 2003, and that Pennsylvania would need an additional 304 dentists to meet the needs of those un-served residents.⁶³ This confirmed the **state's 2002 "Oral Health Needs Assessment," which found that over 1.5 million** Pennsylvanians lived in shortage areas.

Needless to say, if there is a shortage of dentists in a community overall, it is even more difficult to locate a practitioner who is prepared to treat a patient with special oral health care considerations, let alone one who accepts Medicaid reimbursements for that care.

Pennsylvania's Dental Student Loan Repayment Programs

One way to help address disparities like those above is via loan repayment **programs, under which newly graduated professionals "work off" their dental school** loans by treating people in under-served areas. Pennsylvania established such a **state-level loan repayment program in 1992, which is modeled after HRSA's** National Health Service Corps program and administered by the Department of Health.

⁶⁰ Schwartz, M., Davis, L., Cardelle, A. and Whitmire, K., "Dental Service Supply and Demand for the Indigent Populations in Rural Pennsylvania," The Center for Rural Pennsylvania (May 2004)

⁶¹ Schwartz, M., Davis, L., Cardelle, A. and Whitmire, K., "Dental Service Supply and Demand for the Indigent Populations in Rural Pennsylvania," The Center for Rural Pennsylvania (May 2004)

⁶² PA Department of Health, accessed online at <http://dsf.health.state.pa.us/health/lib/health/primarycare/denthpsa.pdf>

⁶³ National Center for Health Workforce Analysis/ HRSA report, p. 34

Newly graduated general dentists may have up to \$64,000 total of their student loans forgiven by the Commonwealth if they agree to provide services in a federally designated dental health professional shortage area. This means that they must be continuously employed full-time at an approved location for a minimum of three years (four years to earn the maximum of \$64,000).

According to DOH in August 2006, 43 dentists have participated since the inception of the program, 10 of whom were currently within the two- to four-year process. DOH has sufficient funding to provide loan repayment for 30 primary-care positions (physicians and nurses, as well as dentists) per year, but does not always utilize all the available funding. In the dental community, it is easy to see why: given their potential earning power, new dentists can pay off debt more quickly if they simply establish themselves straight away in a location that will support a profitable **practice. Given the market realities, Pennsylvania's loan repayment program** simply does not offer enough financial incentive to attract very many dentists.

The loan repayment program is a line-item appropriation, and must be re-authorized in every session of the General Assembly. According to DOH staff, efforts have been made virtually every year to change its scope, although to date none of the proposed changes have advanced. Thus, dollar amounts and terms of the loans have not changed since the original enabling legislation was passed in 1992. Given the under-utilization of this resource by the dental community, efforts to increase its attractiveness should be considered.

Funding and Infrastructure of Medical Assistance

In Pennsylvania, the Medicaid-funded Medical Assistance (MA) program pays for health care, including dental care, for both low-income individuals and persons with disabilities regardless of income. Funded by a combination of state and federal matching funds, Medical Assistance currently serves nearly 2 million people in the 67 counties of the Commonwealth.

In 1997, the Commonwealth was granted a waiver from Centers for Medicare and Medicaid Services (CMS) to use managed care organizations in administering its Medicaid programs. Accordingly, today there are three Medical Assistance systems: **mandatory managed care (the "HealthChoices" program), voluntary managed care,** and fee-for-service (FSS). As of June 2005, dental services were provided through HealthChoices in 25 of Pennsylvania's 67 counties; **the other 42 counties utilize the fee-for-service system.**

The state Department of Public Welfare (DPW) administers the fee-for-service program working directly with dental providers, and contracts with managed care organizations (MCOs) to serve consumers enrolled in HealthChoices counties. Five of the seven managed-care organizations working with the Commonwealth have sub-contracted with a dental service delivery company to administer their dental benefits. Typically, MCOs negotiate a per-member-per-month fee, the level of

which covers providing health services as well as administration and profit for the MCOs and their sub-contractors.

The terms of the contracts between Pennsylvania and the HealthChoices managed care organizations are key. **As noted by HRSA, "the specific provisions of this contract [between any state and MCOs] are critical to the success of this [managed-care] approach to dental coverage. "It goes on to note that, "The Medicaid agency can use the contact with managed care organizations to address oral health standards of access, quality, utilization, reimbursement and data reporting."**⁶⁴

Provider Participation in Medical Assistance

The proportion of dentists who report that they participate in any of Pennsylvania's Medical Assistance programs mirror the national trends. Of the 5,024 respondents **to the Department of Health's survey, 874 dentists, or 17.4%, reported that they participated in Medical Assistance at least on an occasional basis.**

Of the few dentists who do participate, even fewer submit many actual claims for reimbursement. According to information provided by the Chief Dental Officer at DPW, **1,425 dentists participated in Medicaid for service dates in Pennsylvania's fiscal year 2004-05.** Of those dentists, 856 of them billed over \$10,000 in services **during the year. This suggests that approximately 10% of the state's dentists are providing any significant level of service to MA patients.**

There are multiple reasons why providers opt not to participate in the state's MA programs. Low reimbursement rates are virtually always cited, along with the high **administrative costs and "hassle factor" of obtaining prior approvals, billing requirements and paperwork,** and waiting for reimbursement to be processed. A **high rate of "no-shows" among Medical Assistance patients is also a frustration for dental providers:** missed appointments cause practices to lose money (and people with developmental disabilities are among those groups that are often forced to rely on erratic public transportation). As noted above, the trend of Medicaid patients becoming more concentrated among fewer providers is not confined to the dental community or to Pennsylvania: it is part of a national pattern.

Dental School Curricula

As indicated above, dental schools are under pressure to include more and more content in the same period of training. The three dental schools in Pennsylvania all offer basic training in treatment of patients with developmental disabilities, going about it in slightly different ways. A recent report developed by Elwyn, Inc. (which is described in detail below) summarizes their offerings as follows:

⁶⁴ Health Resources and Services Administration, U.S. Department of Health and Human Services, "A Medicaid Primer – Oral Health Services," accessed online at www.hrsa.gov/medicaidprimer/oral_part3only.htm

- Temple University School of Dentistry offers a one credit-hour didactic course on **“Dentistry for Persons with Disabilities.”** Although there is no associated clinical experience, the training is intended to prepare graduates to provide routine care to persons with disabilities and to make appropriate referrals.
- University of Pennsylvania School of Dental Medicine integrates most of the training regarding people with developmental disabilities into its Oral Medicine curriculum, and also offers a course on management of medically complex patients.
- University of Pittsburgh School of Dental Medicine includes training in treating this population in a third-year rotation in the school’s pediatric dentistry clinic. A third- or fourth-year, 15-week special-needs elective course, also at the clinic, is offered, as is graduate dental education in treating patients with developmental disabilities as part of the general dentistry clinic. The school also operates one of only two programs in the nation to train dental anesthesiologists.

The University of Pittsburgh’s dental school has provided special-needs dentistry within one of its clinics for the past three decades, and has begun construction for a Center for People with Special Needs as of early 2007. When fully operational, the Center will enable the school to expand its clinical services from one and one-half days per week to five days per week. While one goal is to reduce waiting times for current patients of record and increase the number served, an equally important goal is to educate dental students in best practices in special-needs dentistry.

Medicaid-Funded Dental Care in Pennsylvania

“For those of us who are established, who don’t have school loans, who don’t have leasehold improvements to pay, who don’t have equipment payments, who have very, very efficient practices: we can treat a reasonable number of these patients as children, and with reimbursement the way it is now, we can break even. That’s all.”

Christopher Luccy, DDS
(remarks during ACHIEVA’s Disability Health Policy Forum)

Stakeholders in oral health agree about what many of the barriers are to accessing appropriate dental care for people with developmental disabilities. Some of those barriers relate to the specific clinical needs and characteristics of people with developmental disabilities, but many more are tied to the broader trends in the dental workforce and dental education, as well as state funding and infrastructure. A lawsuit filed in early 2000 by Pennsylvania Disabilities Law Project against the Department of Public Welfare articulated the nature and extent of Pennsylvania’s access problems and some of the reasons behind them.

Pennsylvania's Class Action Lawsuit (Clark et al v. Richman)

In this lawsuit, the Disabilities Law Project alleged that the agency had not met its legal obligation to deliver dental services. The lawsuit was certified as a class action in late 2002, and documented many of the difficulties accessing dental care for people with developmental disabilities in Pennsylvania. Among the undisputed facts presented were the following:⁶⁵

- In 2002, more than 275,000 adults and children with disabilities in Pennsylvania received no dental services at all – representing a 17 percent increase over those unserved in 2001.
- Twelve counties out of the 67 in the state did not have a single dentist who participated in the Medical Assistance program.
- **Over 85 percent of the state's dentists did not participate in the state's MA program** – with the standard of participation being a single claim in the past 12 months.
- Of consumers enrolled in the **Commonwealth's five Medicaid managed care** organizations, the percentage who did not receive any dental services at all in 2002 ranged from 64 percent (Three Rivers) to 81 percent (AmeriChoice).
- **Among the consumers who use DPW's fee-for-service program**, in 2002 91,113 of them received no dental services at all.

Reimbursement rate levels were explored in considerable detail in arguing the case. As documented by Dr. James Crall, who was retained by the Disabilities Law Project to provide expert testimony, DPW pays Pennsylvania dentists rates that are far below market and that very few dentists consider acceptable.

In his report, Dr. Crall analyzed the DPW rates for 15 commonly used dental procedures (both in fee-for-service and HealthChoices programs), comparing them with regional rates received by dentists in the mid-Atlantic area. His analysis revealed clearly why many patients have difficulty finding a dentist who will agree **to treat them with Medicaid reimbursement: "For 11 of the 15 selected services, PA Medicaid FSS payments fall below the 10th percentile of dentists' charges—meaning that fewer than 10% of area dentists would view these payments as comparable to their usual charges."**⁶⁶

In other words, DPW pays a rate that is sufficient only to attract the 10 percent of **dentists charging the lowest rates in the state. Additionally, DPW's reimbursement**

⁶⁵ Disabilities Law Project, Clark et al v. Richman, Motion for Partial Summary Judgment, filed October 27, 2003

⁶⁶ PA Disabilities Law Project, Clark et al v. Richman, Motion for Partial Summary Judgment filed October 27, 2003

is discounted: it pays 80 percent -- not 100 percent -- of the amount that 10 percent of the state's dentists will accept. Since 90 percent of the state's dentists will not consider the state's reimbursement acceptable at all, much less at 80 cents on the dollar, it is apparent that these reimbursement rates can only act as a disincentive. Under these circumstances, participating in Medical Assistance means agreeing to be underpaid, plus assuming the headaches of getting prior authorizations, filing Medicaid paperwork and waiting for reimbursement to be processed.

Dr. Crall further wrote, "[O]ne could say that these rates would not cover the overhead cost of providing services for "average" patients for roughly 90 percent of PA general dentists—let alone provide adequate economic incentive to provide services for more difficult to treat patients such as those who are disabled and require additional resources for even routine services." His conclusion was that the state's rate structure was not likely to engage more than a small percentage of the state's dentists—which, based on the 2005 DOH survey, has proven an accurate assessment.

The DPW fee schedule was last updated in 2000 with a subsequent targeted increase in January 2006 for fees pertaining to sedation, general anesthesia and behavior management. There has not been an across-the-board fee increase for 15 years. When one considers the rises in dentists' costs of doing business, it is self-evident that the reimbursement rates cannot possibly have kept pace.

Recent Steps Taken

Stakeholders in Pennsylvania have been aware of and concerned about access issues in oral health care for some time. In 1999, state officials created an Oral Health Task Force and convened a statewide dental summit, which brought together policymakers, advocates, dentists, government officials and managed care organizations to discuss improving access to care. After the Disabilities Law Project filed the original Clark v. Richman claim, a second summit was held in 2001.

By 2001, incremental progress had been made. This included simplifying the provider enrollment procedures, appointing a Chief Dental Officer at the Office of Medical Assistance in the Department of Public Welfare, and adopting the American Dental Association's billing codes. Some modest fee increases were also instituted (e.g. raising the reimbursement for a pediatric exam from \$17 in 1999 to \$20 in 2000).

Also among the outcomes of the 1999 summit was a proposal to create a dedicated community dental facility for Medicaid-eligible patients with special needs. After negotiation and contracting with Medicaid MCOs, the Special Smiles, Ltd. practice was ultimately created by Pediatric Dental Associates. This community practice, based in Temple University Hospital's Episcopal campus in Philadelphia, has in its six years provided over 5,100 full mouth rehabilitations and become the home for ongoing care to more than 3,000 patients of record; in the process, it has attracted national attention as a successful model of a Medicaid-funded dental practice.

Meantime, a \$939,590 grant was awarded to the Department of Health by the Robert Wood Johnson Foundation in January 2003, which was to test three efforts to better serve low-income, minority and disabled populations. The grant included three components: training to increase the number of expanded function dental assistants (EFDAs) to broaden the provider network; development of a dental recruitment and referral component for the DOH Special Kids Network; and a \$100,000 equipment fund to purchase equipment to replicate the Special Smiles, Ltd. clinic model. Efforts have been made to encourage replication, including a 2004 Request for Proposal to create another dedicated facility using this model and, **in 2005, a partnership between DPW and DOH's Primary Care Community Challenge grants.** Despite these efforts, to date no providers have taken on replicating the specific Special Smiles practice model in other parts of Pennsylvania.

In 2005, the class-action lawsuit was decided in DPW's favor, indicating that raising reimbursement rates alone had proved insufficient to resolve access issues in other states. **Although the plaintiffs' arguments did not convince the judge, DPW did respond with some targeted rate increases:** in late 2005, funds were identified by **DPW's OMAP to increase reimbursement rates for dental anesthesia and behavior management.**

Another approach to easing access to care was proposed by the PA Dental Hygienists Association (PDHA) in 2005/06. PDHA developed and advocated legislation that would amend state law to permit dental hygienists, after additional training, to provide services they are now licensed to provide, but without a **dentist's supervision. This would take place specifically within public-health settings** such as schools and community residences. While the legislation stalled in 2006, it is likely that PDHA will continue to work on its passage.

For its part, the Pennsylvania Dental Association has worked hard to promote prevention by advocating HB 1588, the Community Water Fluoridation bill. The proposed bill would require fluoridation of public water supplies serving 1,000 or more domestic lines. While fluoridation can generate local debate, there is little doubt that it effectively prevents dental caries. The Pennsylvania General Assembly voted 150 to 42 to pass the bill in June 2006, and it went to the Senate for consideration. While this bill did not ultimately move forward in 2005/06, the PDA will likely continue to advocate for it.

Current Realities

"As advocates, we know there is a lot of work to be done to hold the line where things are now, never mind to push the government to spend more money to increase people's access to health care -- including dental care."

Francesca Chervenak, Managing Attorney,
Pennsylvania Health Law Project
(remarks during ACHIEVA's Disability Health Policy Forum)

Like other state lawmakers, Pennsylvania's elected officials are working to increase efficiencies in Medicaid programs. Pennsylvania's total Medicaid costs (including the federal share) were \$15.8 billion in FY2005. Those costs have increased an average of 9 percent a year every year since 2001, down from an average of 12 percent for the prior decade ⁶⁷

Since Medicaid represents nearly one-third of the Commonwealth's total expenditures, it is no surprise that managing Medicaid spending is a foreground concern for state officials. The reality is that in the context of Pennsylvania's efforts to balance its budget, higher MA reimbursement rates alone represent an unrealistic expectation to solving oral health care access issues.

In addition, because oral health represents a fraction of health-care costs and is not fully integrated into other health-care delivery systems, oral health issues are not a priority for most state lawmakers. Both legislators and policymakers may need to better understand the relationship of oral health to overall well-being, and the human and financial toll of dental neglect.

Another reality that affects the potential for positive change is the readiness of the dental community to treat people with developmental disabilities. There is clearly considerable willingness to take part in charitable efforts, such as through Special Olympics/ Special Smiles and the Donated Dental Services programs operated by National Foundation of Dentistry for the Handicapped. While these and other voluntary programs are important and well appreciated, charitable efforts cannot be expected to reach everyone currently unserved. Moreover, these programs in and of themselves do not establish an ongoing "dental home" that provides for regular care.

Many individual dentists express concern about underserved patients, and there are likely numerous undocumented instances of dental practices treating people with developmental disabilities on a discounted or donated basis. That said, when it comes to ensuring that people with developmental disabilities have access to care, organized dentistry has not made it a top priority to change the status quo.

Obstacles to Care and Best Practices in Pennsylvania

Since ACHIEVA's Disability Health Policy Forum was held in November 2005, another significant contribution has been made to the policy dialogue regarding oral health care for persons with disabilities. The Pennsylvania Developmental Disabilities Council (PADDC) provided grant support in 2005 to Elwyn, Inc. to assess access to quality dental care for people with developmental disabilities and to document best practices. The grant project team included representatives from Elwyn, Inc., Drexel University School of Public Health, Special Smiles, Ltd. and Philadelphia Coordinated Health Care.

⁶⁷ Kaiser Commission on Medicaid and the Uninsured, accessed online at www.statehealthfacts.org

The resulting excellent report, completed in September 2006, documents the perspective of both dental providers and consumers by means of surveys and focus groups, as well as identifying best practices within the Commonwealth.⁶⁸ In that document, the team also developed and advocated for a conceptual framework that would refine service delivery by identifying appropriate levels of care and building appropriate capacity at each level.

Untapped Potential for Community-Based Treatment

A pervasive theme throughout the Elwyn report is the observation that patients with developmental disabilities tend to access whatever oral health care is available, not necessarily the care they need. Patients who might be successfully treated in the community are referred for treatment in a clinic or hospital, at far greater expense, simply due to an assumption that everyone with developmental disabilities needs specialized care. As the Elwyn report notes, “Many patients are referred out of the community setting into specialized care or general anesthesia simply because of a stereotype or a behavior that could easily be overcome by a desensitization plan.” In other cases, persons with disabilities who do need specialized services suffer through lengthy waiting periods and are forced to travel long distances or incur considerable expense, when they can get treated at all.

Among the most encouraging findings from the Elwyn team’s research is its assertion that **many, if not most, patients with developmental disabilities may be successfully treated in a typical community practice.** Two surveys of dentists currently serving patients with developmental disabilities, as well as a subsequent conference call, confirmed that most patients with developmental disabilities could be included in a community dental practice. Responding to a detailed dental provider survey, only 23.3% of dentists felt there was difficulty incorporating patients with developmental disabilities into their practices. The same group of dentists indicated that over half (54.3%) of patients with developmental disabilities would require little or no specialized equipment to be treated in that setting.

The Elwyn report emphasizes the importance of this finding, and of communicating it widely. It is essential that providers understand that not all persons with developmental disabilities require intensive levels of care. As this misperception is addressed, efforts to increase the number of providers have a better likelihood of easing access to care. With greater numbers of patients being treated at the community level, persons with developmental disabilities whose needs demand more intensive services will have less difficulty accessing them.

Appropriate Levels of Care

One of the major consequences of moving toward full inclusion has been the shifts in where and how people with developmental disabilities receive their health care.

⁶⁸ Elwyn, Inc., “People with Developmental Disabilities and Oral Health in the Commonwealth of Pennsylvania” (September 2006)

Thirty years ago, most people with developmental disabilities were treated inside residential institutions, regardless of whether their health-care needs were minimal, moderate or severe. As de-institutionalization has progressed, the **Commonwealth's health care system has not fully shifted gears so that care can be determined not by the fact of having a developmental disability, but by the complexity of the individual's actual needs.**

Given that more than 3.7 million Pennsylvanians have some kind of physical or intellectual disability, there is obviously variation in the level of oral health care required and the degree of adaptation that may be necessary to treat them appropriately. The Commonwealth was already taking steps in this direction when it made efforts to replicate the Special Smiles model outside southeast Pennsylvania. In its report, the Elwyn team advocates further steps toward a service delivery system that allows for different levels of care, such as:

- Level I – Community dental providers
- Level II – Pediatric and general dentists with additional training, regional and safety-net providers with capacity to offer in-office sedation and provide technical support to Level I
- Level III – Centers of Excellence, which have capacity to offer IV sedation or general anesthesia; train new practitioners; and provide technical support to Level II.

Based on the provider surveys mentioned above, it is possible that some two-thirds of the Commonwealth's residents with developmental disabilities could be served by community dentists in Level I. The three levels could be mutually reinforcing, since community dentists could look to level II and III staff for technical assistance. Articulating this system will help improve access by guiding patients to the level of care most appropriate for them; it will also use public-health dollars more efficiently by reserving delivery of most intensive services to those whose needs warrant them.

Anesthesia: A Special Concern

Notably, the PADDC-funded report by the Elwyn team highlights anesthesia as an area of particular concern for those patients with developmental disabilities whose needs are most complex and challenging.⁶⁹ **In response to a child's death, in 2005** the Commonwealth tightened its requirements for dentists applying for the permits needed to administer sedation intravenously. In order to secure the permits, dentists need to invest additional time and money in further training, including certifications in emergency care, as well as additional monitoring equipment such as defibrillators.

According to the Elwyn team's report, the number of dental licensees who hold Level I Anesthesia Permits fell over 60% between December 2004 and July 2006 –

⁶⁹ Elwyn, Inc., "People with Developmental Disabilities and Oral Health in the Commonwealth of Pennsylvania" (September 2006)

from 439 to 173 licensees. The number of applications for “Unrestricted” permits also fell in the same time period, though less precipitously.

This shift in the dental **community’s capacity to provide sedation has immediate** consequences for those patients with developmental disabilities whose behavioral challenges or medical needs make treatment without sedation an impossibility. In addition to decreasing the absolute numbers of dentists who can offer this critical service, the regulatory changes effectively prohibit the remaining dentists from using sedation other than nitrous oxide for adult patients – which may not be the most appropriate drug.

These new conditions are likely to discourage new graduates of dental schools from applying for the anesthesia permits, which will preclude their treating some patients with developmental disabilities. Providers who currently hold these permits, based on the declines seen in the past eighteen months, may not seek to renew them. As dentists have begun to confront these circumstances, anecdotal evidence suggests that more patients will simply be referred to hospital settings, exacerbating already long waiting lists and escalating the costs of their care.

Insights from ACHIEVA’s Disability Health Policy Forum

“It’s pretty clear that the dental profession delivery system that’s set up now is one based on practitioners who are running businesses, and they have a primary interest in having a successful business. It’s a very different system than if you had a system where... [the] primary interest was reducing health disparities and improving the oral health of the population.”

Paul Glassman, DDS, Co-Director,
Pacific Center for Special Care, University of the Pacific
(remarks during ACHIEVA’s Disability Health Policy Forum)

ACHIEVA organized and hosted the Disability Health Policy Forum on oral health care on November 10, 2005 (agenda attached as Appendix B). In this event, experts in the field within Pennsylvania presented a range of perspectives regarding the background issues, much of which covers ground discussed above. As part of the Forum, ACHIEVA also invited two nationally recognized experts, Dr. Steven Perlman and Dr. Paul Glassman, to speak in addition to local and regional leaders in special-needs dentistry.

Opening Address: Dr. Steven Perlman

Dr. Steven Perlman, the Forum’s initial speaker, created the Special Olympics/ Special Smiles program in 1993 and now acts as its Global Clinical Director. An Associate Professor of Pediatric Dentistry at Boston University’s Goldman School of Dental Medicine, Dr. Perlman is among the leading experts in the nation on the oral health care needs of people with developmental disabilities.

In his opening address, Dr. Perlman described the extent of dental disease found among Special Olympics athletes and others with developmental disabilities; research documenting attitudes among educators and practitioners; and articulated **the multiple barriers to care (described above), including many dentists' self-described unreadiness to treat people with developmental disabilities.**

Among the obstacles to care Dr. Perlman identified was an emerging issue he **described as "fear of accusation."** As he pointed out, **liability costs are high,** consent issues for special-needs patients can be complex, and many dentists are justifiably concerned that they may be sued. As Dr. Perlman put it, a single miscommunication could result in a lawsuit **that jeopardizes a dentist's livelihood.**

Notably, under Dr. Perlman's leadership, the Special Smiles program has acted to go beyond the oral health screenings provided by volunteers: it has partnered with the American Academy of Pediatric Dentists and, just recently, the Academy of General Dentistry Foundation to link dental providers and Special Olympics athletes.⁷⁰ In addition to compiling extensive data on the oral health needs of its athletes for research purposes, Special Olympics has also launched an online database of health-care providers who identify themselves as prepared to treat people with developmental disabilities.

In his presentation, Dr. Perlman proposed that the disability community consider following up on a recently identified federal strategy to improve access to care. People with developmental disabilities have never been formally designated as a **"medically underserved" population under federal guidelines.** To be so identified, a population must meet federal HRSA criteria, as follows:

- The percentage of the population living below poverty level
- Percentage of population over the age of 65
- The infant mortality rate among target population, and
- The ratio of primary care practitioners to patients in target population

In his presentation, Dr. Perlman asserted that people with developmental disabilities did in fact meet the federal HRSA criteria, that this designation was warranted and that it should be pursued. He also indicated that, in his experience, many federal officials were unaware that this was not already the case.

Should people with developmental disabilities secure designation as a "medically underserved" population, new dentists could meet their obligations for federal student loan repayment by serving them (as is the case with low-income or selected ethnic groups). This designation could also potentially help dental schools compete for federal funding for residencies and fellowships in special care dentistry, as well as research dollars. Finally, federal funding could potentially be tapped to

⁷⁰ In addition, based on the success of the Special Smiles program, Special Olympics has now involved other health practitioners in an overall Healthy Athletes program. Screenings of athletes are now arranged with optometrists, podiatrists, physical therapists and others.

train foreign-born dentists who could help serve this population, as is now already done in the medical community.

Closing Address: Dr. Paul Glassman

In this presentation, Dr. Paul Glassman described the model developed since 1999 **in California, which created a new role for staff called "dental coordinators."** Dr. Glassman is Associate Dean at the Arthur A. Dugoni School of Dentistry at University of the Pacific, and Co-Director of the Pacific Center for Special Care. (Much of the information he presented at the Forum is available online at www.pacificspecialcare.org.)

In California's community-based model, a dental coordinator is based inside one of California's 21 regional centers, organizations established to provide resources for people with developmental disabilities and their families. The dental coordinator, who is often a hygienist, functions as the liaison between dental professionals, the regional center staff, consumers, their caregivers and families. Dental coordinators work to integrate oral health into ongoing health care; recruit and retain community dentists; make referrals for care and provide logistical support for dentist visits; and deliver training to families and residential caregivers in home oral health care.

For its part, the Pacific Center for Special Care provides technical assistance to community dentists, as well as continuing education courses. In some sites, dental professionals, often dental hygienists and students, **now are taking part in "Adopt A Home" programs supported by the dental coordinators; these efforts provide an ongoing source of monitoring and addressing the oral health needs of both the residents in a community living facility and their direct care workers.**

In addition to developing the role of dental coordinators, the Pacific Center for Special Care has created other resources for families, caregivers and dental professionals. Included on its web site, for example, is an online resource area that helps users select and order publications (e.g. information for families on home care) and equipment like adapted toothbrushes or a dental headrest for a wheelchair. The Center also offers web-based, post-graduate training in oral health care for special-needs patients for hygienists seeking continuing education credits, or who wish to become Registered Dental Hygienists in Alternative Practice.

Dr. Glassman emphasized the advantages of focusing on preventive care for persons with special oral health care needs – he argued that if adult dental services **were federally mandated for all "aged, blind and disabled," that the costs would be more than offset by cost reductions in use of emergency rooms and hospitalizations for serious dental issues.**

To demonstrate his point, he showed a video sharing the story of "Sarah," a young woman in California who is nonverbal and diagnosed with autism spectrum disorder. At one time she developed behavior problems and began to act aggressively against members of her community residence. Her behavior became so extreme that she was admitted to a psychiatric facility before a dental

coordinator discovered that in fact she was suffering from dental problems. Once treated, her aggressive behaviors stopped and she was able to return to her former residence. **Had Sarah's oral health needs not been identified and addressed, she would have stayed in the psychiatric facility, enduring needless suffering, at a cost to the state of California of \$150,000 a year.**

Recommendations

"I personally believe that there is a lot of money out there for health care. ...How is it that we have an additional \$82 million to build new buildings [for Children's Hospital of Pittsburgh], but we don't have the money to treat our patients?"

Christopher Luccy, DDS

(remarks during ACHIEVA's Disability Health Policy Forum)

The combination of the dental profession's business model and today's public-health infrastructure is creating a troubling trend toward a double standard of oral health care in America. States, the federal government and the dental community all **share the goal of improving the public's oral health; however, there is not yet consensus on the best means of achieving that goal.**

The challenge of improving the oral health delivery for persons with disabilities, especially through Medicaid-funded programs, is one that Pennsylvania shares with every state in the nation. Among the longest-standing issues are the limited participation of dental providers within Medicaid programs and the difficulty of ensuring access in rural as well as urban locations. Add to this the severe financial pressures that Medicaid poses for the Commonwealth and federal efforts to limit Medicaid spending, and it is apparent that there is no **"silver bullet" to developing solutions.**

As DPW's Chief Dental Officer Dr. Paul Westerberg has put it, addressing these issues requires not a silver bullet but a "combination lock." There are a number of possible policy steps that, taken together, can help improve access.

Preserve Pennsylvania's assets

Among Pennsylvania's goals should be to ensure that the overall supply of dentists does not fall any further, and that available sources of funding are not cut back. To this end, advocates should work to:

- Preserve the commitment to Medicaid funding of dental services for adults.
- Preserve the federal/ state partnership in financing Medicaid.
- **Support continued public investment in Pennsylvania's three dental schools.**
- Help advance the Commonwealth's efforts to articulate service delivery systems based on appropriate levels of care.

Address the policies that contribute to provider shortages

Efforts to address the supply of dentists prepared to treat people with developmental disabilities should be made, and the Commonwealth should consider these steps:

- Adjust the incentive systems for oral health professionals, including more reasonable compensation for services provided. Reimbursement rates need to better reflect the time and expertise involved in treating special-needs patients, and Pennsylvania should make every effort to make its reimbursement rates more competitive with what private insurers pay.
- Work to develop consensus on the need for more dental practitioners.
- In collaboration with dental schools, consider new funding and initiatives to increase support for dental education, especially pediatric residencies, and/or to encourage increasing dental school enrollments.
- Accelerate provider recruitment efforts at DPW and DOH, in partnership with the PA Dental Association.
- Continue to streamline enrollment, billing and other administrative requirements at DPW for dental providers in the MA program.
- Re-structure and expand the DOH student loan repayment programs to encourage greater utilization by new dentists. Higher dollar levels are the most promising strategy, along with easing geographical limitations and allowing beneficiaries to fulfill their loan requirements working part-time rather than full-time. Early in 2006 in Massachusetts, a similar loan repayment program was re-structured to permit repayment on the basis of a **dentist's commitment to serve patients with cognitive disabilities part-time** (16 hours per week) for a minimum of two years, but retaining the flexibility to extend or cut back the time commitment in exchange for renegotiating the level of repayment. This seems a promising strategy.

Strengthen dental provider preparedness

There are a number of steps that can be taken to help more dentists, both those entering the field and those currently practicing, feel confident in their ability to treat patients with developmental disabilities:

- **Strengthen the dental schools' curricula and training regarding treatment of people with developmental disabilities;** in particular, work to make this training a higher priority within the training of dentists who are interested in a general practice.
- Work with ADA and ADEA to identify professional competencies specific to treating patients with developmental disabilities, and strengthen the existing accreditation standards for teaching and assessing these competencies.

- Establish/ strengthen a peer information network for dentists regarding treating special-needs patients. Disability advocates need to convey the message that people with developmental disabilities have widely differing needs. For example, the providers currently treating patients with developmental disabilities who were recently surveyed by Elwyn could share how they successfully included patients with disabilities in a community practice. Another resource is the dentists taking part in the Donated Dental Services programs: NFDH reports that a total of 657 Pennsylvania dentists **were DDS participants in 2005/06, or approximately 7 percent of the state's dental workforce.**⁷¹ Together with dental school faculty and other dentists already known to be providing MA services, these groups of dentists can become the nucleus of a peer network and a core of mentors for younger dental professionals.
- Seek guidance from the dental community on how to engage and update additional individual practitioners. Some possibilities include presenting before local dental societies, articles in newsletters and journals, and raising public awareness through press coverage. There is anecdotal information to suggest that a number of dentists provide care to special-needs patients at a discount or donate their services, but they are reluctant to make this widely known for fear of being overwhelmed with similar requests. Perhaps another possible strategy is to encourage these dentists to recruit others.
- Promote partnerships between dental community and disability groups. For instance, the national Academy of General Dentistry Foundation has recently announced a partnership with the Special Olympics/ Special Smiles program. Pennsylvania contacts within AGD Foundation and Special Olympics in various regions should be contacted and actively encouraged to pursue this **partnership, especially the effort to identify "dental homes" after athletes receive oral health screenings.**

Address obstacles to accessing oral health care in Pennsylvania's Medical Assistance systems

- Continue to work toward a service delivery system that articulates different levels of care across Pennsylvania, as recommended by the Elwyn team. **Establish/ strengthen three "centers of excellence" in the east, middle and west of the state to ensure timely access to intensive services.** Develop an assessment of how many consumers might need each level of care and build capacity accordingly.
- Work to encourage more dentists to contract privately with the federally **qualified health centers and "look-alikes" to provide services part-time.** According to Pennsylvania Forum for Primary Health Care, there are now 29 such organizations with 150 primary care service sites, operating in 37

⁷¹ It is noteworthy that among all states with active NFDH/ Donated Dental Services chapters, Pennsylvania is among the five states with the lowest rates of dentist participation.

counties. As noted by the American Dental Association, the private-contracting approach has the advantage of not requiring any legislative or regulatory changes and reimbursement rates can be negotiated between the two parties. While dentists will likely need to be approached and encouraged to enter into these arrangements, some incentives may be that community health centers typically handle scheduling, case management, liability insurance and also provide support with logistics such as accessing public transportation, leaving contracted dentists more free to concentrate on patient care. This model has been implemented successfully in Connecticut.⁷²

- Consider piloting a dental coordinator in Pennsylvania, perhaps in coordination with one of the Donated Dental Services programs or one of the **proposed centers of excellence**. **The coordinator's goal would be to help recruit and retain more MA providers; provide both patients and dentists with logistical support; offer trainings on home care; and work to link patients with developmental disabilities to ongoing "dental homes."**

One of the primary assertions of the DLP class-action lawsuit was that DPW's monitoring of the HealthChoices managed care organizations could be improved. Under Medicaid regulations, managed care organizations are required to assure health-care access and quality, and in order to achieve this their contract provisions must be clear and enforceable. The following steps can be considered:

- DPW can increase the accountability of MCOs in the HealthChoices zones, especially as HealthChoices is expanded. This could include requiring MCOs to document how many dentists are actually participating in their plans, the degree to which they participate, and what the MCO is doing to recruit dental providers.
- **DPW's contract with HeathChoices MCOs does not mandate when referrals** must be made, or any timetable for how quickly services must be rendered. DPW can take steps such as recommending or requiring regularly scheduled dental check-ups and cleanings; that MCOs must refer patients to a program dentist if they show symptoms suggesting dental problems; and that such referrals be accomplished within a designated time period.
- DPW can also help create higher consumer expectations for incorporating oral health care into overall health care. It could require that MCOs and any sub-contractors provide information about dental benefits to their enrolled consumers and that they distribute information and resources regarding proper oral health care at home.

⁷² American Dental Association, "State and Community Models for Improving Access to Dental Care for the Underserved: A White Paper," October 2004

- Encourage or require MCOs to designate a staff person inside their special needs units who is responsible for working on and resolving access issues in dental care.

Work to change the perception of oral health so it is understood as part of overall public health

A great deal of public education still needs to be done to promote awareness of oral health and the importance of good home care. Among the steps that can be taken are:

- Help educate elected officials, policymakers and their staffs regarding the links between oral health and overall health, and the potential health care costs of dental neglect and related health conditions. This is an essential insight, and the importance of understanding this connection is also something on which organized dentistry, dental schools, public-health officials, advocates and consumers readily agree. The medical community and medical schools (such as UPMC) can also be brought into this effort.
- Lend support to **the Pennsylvania dental community's efforts to advance community fluoridation**, as a public-health preventive measure.
- Encourage efforts by DOH with respect to general public education regarding oral health and overall health.
- Encourage collaboration between dental and medical communities so oral health care becomes better integrated in the health care system. For instance, Pennsylvania Academy of Family Physicians and the Pennsylvania chapter of American Academy of Pediatrics are both operating demonstration **projects to encourage the creation and proliferation of "medical homes" for children and young adults with disabilities**. The dental community could be linked to these efforts, or perhaps a similar effort could be designed within the dental community **to encourage the proliferation of "dental homes."**
- **Disability advocates can gather representative consumers' stories and share them with press and policymakers.**

Consider additional policy options

Some policy options that Pennsylvania could hold as possibilities:

- Consider crafting new incentives for dentists who provide Medical Assistance **services. Pennsylvania could review ideas like Utah's reimbursement "bonus"** once a designated number of Medicaid patients are treated, tax credits as used in Michigan and Missouri, or increased reimbursements for dentists who are certified as prepared to treat special-needs patients, as in New Mexico.
- **Consider policy elements now in place in other states: California's work with dental coordinators and its effectiveness in encouraging better provider**

participation has been picked up and is being further explored by the American Dental Association; this model also bears further investigation.

- Consider minimal, mandatory participation in Medical Assistance, similar to **attorneys' obligation to provide *pro bono*** legal services. This approach obviously raises a great many challenging questions, but in addition to partially addressing access issues, it would go far toward building the public expectation that oral health care should be just as routine and available as other primary care.
- Expanding the role of hygienists (for services appropriate to their training and professional experience) is a strategy that engenders intense debate within organized dentistry. Many dentists oppose it, citing concerns about the standards of care, but in some other states hygienists are already providing services beyond those permitted in Pennsylvania.⁷³ Some members of the Advisory Committee for this project have expressed reservations about this approach, while others are in support. Given the challenges of building greater capacity within the dental profession, all parties should be encouraged to continue discussion and dialogue regarding this option.

Advocate for positive change in national policy

Some broader efforts to address oral health care access issues have been recently proposed. Consumers, families and disability advocates in Pennsylvania should consider lending support to the following:

- Special Care Dentistry legislation

Special Care Dentistry Association has introduced legislation known as the Special Care Dentistry (SCD) Act, which would support Medicaid-funded dental **benefits for "aged, blind and disabled" adults nationwide as well as strengthen** oral health programs for children. The SCD bill has been endorsed by the **nation's major dental professional groups as well as a number of advocacy** groups. Its approach is to expand the federally required Medicaid dental coverage to low-income **"aged, blind and disabled" Americans, supporting states** to meet this requirement with 90/10 federal/state matching dollars.

In a recent article in the *Journal of the California Dental Association*, Dr. Paul Glassman and another leading special-needs dentist, Dr. Gregory Folse, developed **cost estimates for the SCD Act, extrapolating from California's** experience in providing adult dental care. They estimate that the new federal dollars needed to implement this legislation would be about \$968 million. Drs. Glassman and Folse contend that this amount would be more than offset by what is estimated conservatively as a 0.5 percent reduction in emergency room

⁷³ As of March 2007, the Pennsylvania Dental Hygienists Association is advocating legislation that would permit hygienists with additional training to provide preventive care in public-health settings such as schools without direct supervision by a dentist.

and hospital charges for treatment of serious dental problems, as well as a decline in the incidence and severity of health conditions like heart disease and diabetes.⁷⁴

- Pursue designation of people with developmental disabilities as a “medically underserved” population

As described by Dr. Steven Perlman, it may be possible to designate people with **developmental disabilities formally as a “medically underserved” population**, using standard HRSA criteria. This has the advantage of requiring no new funds, but it would enable dental schools to better compete for the available **federal dollars and may positively affect dentists’ use of NHSC student loan repayment programs** as well. At this writing, the designation is being explored by the legislative staff of at least one U.S. Senator.

Encourage consumer/family/direct care worker involvement

There are many publications and other written resources available for consumers and their caregivers, and Pennsylvania can do a better job of sharing them. Some suggestions follow:

- Create/expand on the DOH website an updated map and database of dental providers. A database of dental and other providers is currently housed within the Special Kids Network site, and so is unlikely to be accessed by those seeking services for adults with developmental disabilities.
- Create/ expand a resource website similar to that of Pacific Center for Special Care, with information on home dental care techniques, family training and where to find adapted equipment. This could be in conjunction with the DOH website or hosted by another agency.

DOH, DPW, HealthChoices MCOs and disability advocates can also work to educate people with developmental disabilities, their families and direct care workers that good home and preventive care should be a high priority. Among the messages that need to be conveyed:

- Encourage consumers to seek out and establish a relationship with a dentist and honor scheduled appointments.
- Encourage consumer feedback to managed care organizations, DPW and DOH to make them aware of access issues.
- Coach families and caregivers on how to work collaboratively with dentists on anticipating and managing potential behavioral issues, including strategies such as requesting a sensitization visit or arranging pre-sedation.

⁷⁴ Glassman, P. and Folse, G., “Financing Oral Health Services for People with Special Needs: Projecting National Expenditures,” *Journal of the California Dental Association*, Vol. 33, No. 9 (September 2005)

In Conclusion

"[My dentist]...tells me step by step what he's gonna do--what he feels is gonna happen. I need people to talk to me because it takes my mind off going in there, and he does it with respect and dignity."

(A self-advocate)

"[It really helps when] he tells you when it's gonna hurt, and what kind of hurt it is."

(A self-advocate)

"Yeah--I like that."

(A second self-advocate)

The above statements were made by several adults with developmental disabilities, discussing their positive experiences with oral health care.⁷⁵ While their comments are self-explanatory, the words alone do not convey the relief on their faces and their appreciation for the dentists who cared for them with sensitivity and professionalism.

Today's dental school graduates are among the first who have grown up with special-needs peers who are included in their schools, workplaces and communities. As inclusion is ever more fully practiced and embraced, the hope is that all of tomorrow's dental professionals will be able to draw upon their own personal experiences to help them treat their patients who have developmental disabilities with skill and understanding.

⁷⁵ Comments made to the author on May 31, 2006

Appendix A
ACHIEVA Disability Health Policy Forum - Advisory Committee Members

Ms. Sandy Amador Dusek
Pennsylvania Developmental Disabilities Council

Ms. Dee Delaney
Executive Director, FISA Foundation

Mr. David Gates
Managing Attorney, Pennsylvania Health Law Project

Ms. Carol Horowitz
Managing Attorney, Disabilities Law Project

Ms. Alice Kindling
Public Health Administrator, Allegheny County Health Department

Ms. Camille Kostelac-Cherry
CEO, Pennsylvania Dental Association

Mr. Larry Kubey
Self-advocate, Member, Board of Directors, ARC of Greater Pittsburgh

Ms. Emilee Langer
Founding Executive Director, Special Smiles Ltd.

Senator Jane Orie
Pennsylvania State Senate

Dr. Dennis Ranalli, DDS, MDS
Professor and Senior Associate Dean, University of Pittsburgh School of Dental Medicine

Dr. Erik Scheifele
Assistant Professor and Director, Pediatric Dentistry, Temple University School of Dentistry

Dr. Katherine Seelman
Acting Associate Dean of International Relations,
University of Pittsburgh School of Health and Rehabilitation Sciences

Dr. Deborah Studen-Pavlovich
Professor and Chair, Department of Pediatric Dentistry,
University of Pittsburgh School of Dental Medicine

Dr. Paul Westerberg
Chief Dental Officer
Office of Medical Assistance Programs, State of Pennsylvania Department
of Public Welfare

Appendix B
DISABILITY HEALTH POLICY FORUM
Thursday, November 10, 2005
Agenda

- 8:15 AM Coffee/ continental breakfast
- 9:00 Introduction and welcome – Former Pennsylvania State Senator Allen Kukovich
- 9:10 Opening address: encouraging dental care for people with disabilities
- Steven Perlman, DDS (Associate Clinical Professor of Pediatric Dentistry at Boston University's Goldman School of Dental Medicine; Global Clinical Director, Special Olympics/ Special Smiles program)
- 10:00 –
11:15 Divide into two tracks – Levy Hall and Adult Learning Center/ Aaron Court

A. Current policy challenges

- Francesca Chervenak (PA Health Law Project) – Medicaid reform efforts, current state budget
- Dennis Ranalli (University of Pittsburgh School of Dental Medicine) – efforts to train and prepare dental professionals, **enrollment trends, students' debt burden, health consequences** of dental neglect
- Christopher Luccy, DMD – **dental professionals' provider trends**, how dentists typically operate, ADA and PDA contributions to solutions
- Emilee Langer (Special Smiles Ltd.) – Special Smiles model – Medicaid-funded private practice for treating persons with disabilities

Moderator: Marsha Blanco, CEO, ACHIEVA

B. Consumer/ policymaker dialogue

- Nancy Murray (Western Area Director for Program Operations, Office of Mental Retardation, Pennsylvania Department of Public Welfare) – **how funding flows, federal/ state match, DPW's** efforts to maintain services, impact of federal and state funding cuts
- Paul Westerberg, DDS, MBA (Pennsylvania Department of Public Welfare, Chief Dental Officer) – **DPW's efforts to increase access** to dental care
- Demetrios Marousis (MedPlus, director of Special Needs Unit) and Dr. David Pavasko (MedPlus dental director) – Managed

care organizations' goals and operations, efforts to serve special-needs patients

- Robert Runzo, DDS – practitioner perspective, clinical questions, health consequences of no treatment, home-care strategies

Facilitator: Candy Smith (Director of Family Supports, ACHIEVA)

11:20

Closing address: other states' strategies and solutions

Paul Glassman, DDS, MA, MBA, Arthur A. Dugoni School of Dentistry at University of the Pacific and Co-Director of Pacific Center for Special Care

12

Adjourn