Access to Dental Care for People with Disabilities:
Challenges and Solutions

A Report to Pennsylvania's Legislators

Access to Oral Health
March 2009

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This report, and additional resources can be reviewed and printed in full from the following website: www.achieva.info/advancingoralhealthcare

"Dental care now represents the number one heath care issue among people with neurodevelopmental disorders."

Dr. Steve Perlman, Global Clinical Director for the US 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.[1]

[1] 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)

Access to Dental Care for People with Disabilities: Challenges and Solutions Executive Summary

The Problem.

There is a fast growing body of evidence which links poor oral health with increased risks for systemic conditions such as heart disease, diabetes and aspiration associated with chronic obstructive pulmonary disorder (COPD). Furthermore, people with disabilities are at a greater risk for health issues related to the lack of dental care.

In Pennsylvania…

- 75% of dentists do not accept Medicaid.
- There are approximately 2,000 dentists available to treat approximately 2 million people on Medicaid. (1000 patients to 1 dentist)
- Dentists cite low reimbursement rates and lack of training as to why they can't treat people with disabilities.
- The dental workforce is aging. 43% of the dentists in Pennsylvania are between the ages of 50 and 64.
- 57% of pediatric dentists, those who traditionally have treated people with disabilities, are age 50 and older.
- 75% of people with disabilities can be treated in a typical dentist office.
- Practices that provide intravenous (IV) sedation and other specialized care are difficult to find.

Solutions.

1. **We recommend directing the Legislative Budget and Finance Committee to study and issue a report on the disparities in dental care for Pennsylvanians with disabilities.** Issues that would be helpful to review can be found under *Policy Recommendations* in the full report.

2. **Preserve what we already have**. **Maintain Pennsylvania's commitment to Medicaid funding for dental services for adults.** Proper dental care saves money, while dental problems result in costly medical care.

3. **Provide more incentives in the Medicaid rates for dental services provided to people with disabilities.** This would be an incentive for dentists to treat people with disabilities.

4. **Institute a more flexible dental loan repayment program using existing funds, to treat people with disabilities, especially in Pennsylvania's underserved areas.**

5. **Ensure that private insurance companies are mandated to provide dental insurance payment for anesthesia for children under the age of 5 and people with disabilities who need it**.

6. **Support workforce initiatives that expand the duties for dental assistants**. This will allow dentists to provide more services to all patients.

7. **Ensure that fluoride is added to our public drinking water**.

ORAL HEALTH = OVERALL HEALTH

Oral Health in America: A Report of the Surgeon General was produced in 2000 by then Surgeon General David Satcher who noted, **"You cannot be healthy without oral health. Oral health and general health should not be interpreted as separate entities."** He further stated, **"Those with disabilities and complex health conditions are at greater risk for oral diseases that, in turn, further complicate their health."**[2] In fact, there is a fast growing body of evidence which links poor oral health with increased risks for systemic conditions such as heart disease, diabetes and aspiration associated with chronic obstructive pulmonary disorder (COPD).

In 2007, the death of Deamonte Driver, a 12 year-old from Maryland, who needed the care of a Medicaid dentist to treat him, highlighted this fact. The cost for a routine extraction for Deamonte would have been $80. As it turned out, this untreated dental infection cost the life of a young boy and $250,000 in medical bills.

THE PROBLEM

In Pennsylvania, children and adults with disabilities who rely on Medicaid have difficulty accessing dental care.

Access Issue #1- Medicaid dentists.

Three-quarters of Pennsylvania dentists do not accept Medicaid. In addition, Medicaid providers can choose which patients they want to treat. Dentists often cite low reimbursement rates and lack of professional preparation as the reasons why they aren't able to care for these patients. As a result, children and adults with disabilities have a very difficult time accessing dental care.

Approximate number of practicing dentists in Pennsylvania[3]	**8,058**
Number of dentists participating in Medicaid[4]	**2,150**
Number of recipients of Medicaid in Pennsylvania[5]	**2,004,400**
Approximate number of people with developmental disabilities in Pennsylvania[6]	**221,000**
Approximate number of people with disabilities in Pennsylvania[7]	**2,111,771**

These statistics alone dramatically demonstrate the extent of the access problems, but some parts of Pennsylvania are especially hard hit. According to the Centers for Disease Control and Prevention and the Association of State and Territorial Dental Directors, two counties in Pennsylvania have no enrolled Medicaid dentist.[8]

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[2] US Department of Health and Human Services, *Oral Health in America:: A Report of the Surgeon General*, Rockville, MD: US Department of HHS, National Institute of Dental and Craniofacial Research, National Institutes of Health, 2000.

[3] This data provided by the DPW Dental Director with caveat, "The number of dentists actively licensed to practice in Pennsylvania on July 1, 2008 was 9,851, including dentists with out of state addresses. Of that total number, 8058 had a Pennsylvania address. The number of actively licensed dentists who are involved in direct patient care (and who are not specialists) will be somewhat less (approx. 20-30%)."

[4] This data provided by the DPW Dental Director, 2008.

[5] Accessed at www.statehealthfacts.org, Total Medicaid Enrollment, FY 2005

[6] Approximate number of people with DD in PA provided by the Pennsylvania Developmental Disabilities Council 2008.

[7] Accessed at the US Census Bureau State and County Quick Facts, http://quickfacts.census.gov/qfd/states/42000.html

[8] Accessed at the CDC National Center for Chronic Disease Prevention and Health Promotion, CDC and ASTDD Oral Health Resources Website, "Synopses by State," 2008.

According to a 2008 report from the National Academy for State Health policy, "Since the great majority of dental care available in this country is delivered by private dentists, their participation is key to improving access in Medicaid."[9]

Access Issue #2-Aging of practicing dentists & Underserved areas.
Factors driving access issues in the Commonwealth mirror the national trends:

Many Pennsylvania dentists (43 percent) are 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).**

In 2003, 13 percent of the Commonwealth's population lived in dental health professional shortage areas—an estimated 1.5 million people. **Pennsylvania is estimated to need an estimated 304 additional dentists to serve currently un-served residents.** [10]

Access Issue #3-People with disabilities may present different challenges.
They may have complex medical conditions, take multiple medications, have difficulty managing daily care routines because of physical or cognitive difficulties, have difficulties with communication or sensory difficulties, all which makes brushing teeth, flossing and other daily dental care or visiting a dentist extremely difficult.

While a minority of people with disabilities may require intensive clinical care, it has been documented that approximately 75% of people with disabilities can visit the dentist with modest physical and behavioral support.[11] Some may need medication or conscious sedation to put them at ease. Others need IV sedation-which may not be available in their local area. Individuals may also need support in making appointments, keeping appointments and help with transportation issues. However, investments in their dental care will pay off in enhanced overall health, not to mention their increased independence, employability and inclusion in community life.

These dental care access issues dramatically affect a community that has to struggle to be included in the first place. In addition to compromising overall good health, poor oral health can affect people's life functions--that is difficulty eating, chewing, swallowing, or problems with speech and communications--as well as social issues that negatively affect the potential for employment, friendships and, of course, self-esteem.

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[9] National Academy for State Health Policy, "The Effects of Medicaid Reimbursement Rates on Access to Dental Care", Borchgrevink, Snyder, Gehshan, 2008

[10] "Access to Oral Health Care for Pennsylvanians with Disabilities: A Rising Public-Health Issue", Barbara Taylor, ACHIEVA 2007

[11] "People with Developmental Disabilities and Oral Health in the Commonwealth of Pennsylvania," Elwyn 2006
"Treating dentists reported that the majority of patients with developmental disabilities do not require any specialized equipment in order to be seen in a community setting (mean = 54.32%). Behavior modification was required by an average of 23.58% of patients, and oral sedation was required by an average of 20.07%. General anesthesia was reported to be needed by an average of 24.62% of patients with developmental disabilities.

SOLUTIONS

There is progress. Pennsylvania provides dental care to Medicaid recipients over the age of 21. Managed Care Organizations (MCOs) provide extra assistance with "Special Needs Units." Pennsylvania's Department of Public Welfare (DPW) has responded with a simpler, more efficient internet-based billing system and there have been some fee increases in Pennsylvania's Medicaid program as well as the addition of "behavior management" fees.

During the last several years, key strategies have been devised to support people with disabilities in their efforts to receive dental care. On May 21, 2008, thirty-six stakeholders from around the state participated in a forum hosted by ACHIEVA to look at the most promising strategies and determine which are most viable. The stakeholders' meeting, "Strategies to Solutions," was part of a larger project at ACHIEVA, entitled, "Advancing Oral Health." This project is supported by grants from the Pennsylvania Developmental Disabilities Council and the FISA Foundation.

The stakeholders' meeting resulted in the formation of seven statewide committees that are developing and beginning to implement solutions. The committees are:

I. Loan Repayment

The committee is crafting a plan to support dentists by using Pennsylvania's existing loan repayment dollars and program infrastructure. People with disabilities are an underserved population, and the goal would be for dentists to receive loan repayment for dental school in part or full by treating people with disabilities. Loan repayment is an under-utilized incentive because it is currently only available with a full-time commitment and only in designated shortage areas at a limited amount of funding. Current student loans for dentists are approximately $200,000-$250,000. By making the terms of loan repayment more flexible for treating people with disabilities, this existing resource could be used more effectively.

Examples of states where solutions have been implemented:

- Maryland provides $99,000 over a three-year period in loan repayment for dentists who practice in a location of their choice and who have a minimum of 30% of their patient population as Medicaid recipients per year.
- Utah offers dentists a reimbursement "bonus" once a designated number of Medicaid patients are treated.
- Michigan and Missouri offer tax credits.
- New Mexico increased its reimbursement rates for dentists who are certified to treat special needs patients.
- Massachusetts offers loan repayment on the basis of a dentist's commitment to serve patients with a cognitive disability 16 hours per week for a minimum of two years.

II. Levels of Care

This committee is creating a "Levels of Care" framework for the delivery of Medicaid-funded dental services that assesses each consumer's physical, behavioral and emotional

needs. The Department and Public Welfare and the Department of Health (DPW/DOH) will also need to add an identifier for each dental provider that establishes his or her capacity to treat patients at each of level of care. However, with those two elements in place, the "levels of care" framework could steer consumers to the right dental setting based on their identified needs. This would enable Pennsylvania to use its existing resources more effectively than is possible at present–by directing those who can be served in the community to community providers, and reserving the capacity of highly specialized clinics for those who require the most complex care.

This committee is developing an assessment plan that would outline levels of need and treatment plans specific to a patient's needs. The committee is currently working on clinical definitions of these levels and planning to develop a worksheet for consumers as well as dentists, to understand where the level of need may be.

Ultimately, these levels will be translated for people with disabilities and their families and providers so they understand which dentists are most comfortable and capable to treat at specific care levels. In addition, patients won't be "pigeonholed" into receiving one level of care. For instance, someone may respond to level one care for a cleaning, but need level three care when they need more intensive work. Also, throughout the course of a person's life, the level of care needed may change. For example, as a person becomes de-sensitized to the dental office and procedures, he or she may need less intensive support.

It will then be critical to tie these levels of care to levels of MA reimbursement, so that dental providers who care for patients whose needs are most complex are appropriately compensated for their time and expertise. This creates the financial incentive for providing the right care in the right setting, and could also help Pennsylvania recruit additional dental providers. They could accept patients with a disability with more confidence knowing that the patient could be supported in their office. In addition, dentists would know there is a network of dentists to which they could refer, were they unable to provide the level a particular patient needs.

III. Dental Professional Education (All Health Care Providers)

This committee is developing a plan to ensure that all dental professionals and health care providers are made aware of the issues surrounding the lack of access to oral health care for individuals with disabilities, as well as to provide educational opportunities on how to treat people with disabilities. Pennsylvania is fortunate to have three dental schools. It is critical that those schools prepare their graduates to serve this population if the Commonwealth's investments in dental schools are to benefit all of its citizens.
As a result of our learning through focus groups of people with disabilities from various cultural groups in Pennsylvania, it is imperative that we weave information about different cultural groups into all of our planning for dental education and training.

This will include both clinical and didactic training for students at the dental schools and dental hygiene programs; practicing dentists and hygienists, and other health professionals. It will include web training and print materials. This may not require substantially increased resources; however, existing or additional funds for curriculum development, for example, must be used to ensure that people with disabilities' needs are covered.

IV. Dental Care Coordinator Position

This committee is exploring ways to develop a dental care coordinator position- either a social worker, case worker and/or dental professional to support people with disabilities and their need for access to dental care.

Development of a dental care coordinator role could help Pennsylvania's dentists serve people with disabilities more readily, since the dentist would have a specially trained coordinator addressing the time and labor-intensive details of capturing complex health histories, providing dental health education and arranging for transportation. If a dental professional, this coordinator would act as a dental "bridge" providing professional services which would decrease the incidence of cavities and gum infection, while supporting individuals to access appropriate dental referrals.

V. Education of People with Disabilities & Families

This committee is developing a training and communications plan specifically for people with disabilities and their families regarding daily oral health care, how to find a dentist and how to make dental visits effective.

As a result, the Pennsylvania Department of Public Welfare's Office of Developmental Program's Health Care Quality Units (HCQUs) have just completed a planning session with their trainers. They have developed a comprehensive and very detailed outline of the curriculum. They hope to complete the manual in December, 2009. In addition, they will add modules that focus on the specific needs of people with autism spectrum disorder, cerebral palsy and Down syndrome. We will widely distribute the curriculum, throughout the disability community. These will have a variety of learning modes, such as picture training as well as text. We will have the training modules available by web links as well as printed materials. We are working to ensure the materials will be translated to meet the needs of people with disabilities from different cultures.

In addition to the work of the committees, we continue to develop educational and marketing resources for people with disabilities, their families and dentists. Our website will be completed in early 2009 with links and resources, probably the most comprehensive website of its kind in the country. It will feature resources such as *How to find a dentist,* links to organizations which already provide good daily oral health care information and information that addresses the unique issues faced by people with various disabilities. The website will also include resources for people with disabilities and their families who speak various languages and who represent various cultures. The website will also include links to information on Americans with Disabilities (ADA) compliance and complaint procedures in Pennsylvania.

VI. Legislation and Education

This committee has developed the *Recommendations* found at the end of this report.

VII. Data, Statistics, Information

This committee supports the other Stakeholder Committees. This committee will be developing other ways to capture data that is currently not available. There is little information that is specific to people with disabilities, particularly adults, and their ability to access dental care. In addition, a plan must also be developed to better measure quality from consumer and family perspectives and developing a more comprehensive annual published review system.

POLICY RECOMMENDATIONS

1. **We recommend that a member of the Pennsylvania Senate or House of Representatives introduce a Resolution directing the Legislative Budget and Finance Committee to study and issue a report on the disparities in dental care for Pennsylvanians with disabilities.**

   These are some of the questions we would like the committee to consider:

   - Examine the availability and need for additional dental providers specifically for people with disabilities throughout the state of Pennsylvania by county (children and adults 21 and over).
   - Examine the availability of physically accessible dental offices and availability of dental equipment by county to serve people with physical disabilities.
   - Examine the availability of specific services: community-based care as well as specialized care (such as dentists with permits for deep sedation/anesthesia, conscious sedation and nitrous oxide) for children and adults with disabilities throughout the Commonwealth who also accept Medicaid, identifying those counties which need additional support and specifically what is needed.
   - Examine the quality of care for individuals with disabilities. Review and ensure that quality services are provided.
   - Examine what HealthChoices MCOs are doing to recruit and, if necessary, prepare oral health providers.
   - Include a summary of research in the medical field that links poor oral health to other medical conditions.

2. **Preserve what we already have. Maintain Pennsylvania's commitment to Medicaid funding for dental services for adults.** Proper dental care saves money, while dental problems result in costly medical care.

3. **Provide more incentives in the Medicaid rates for dental services provided to people with disabilities.** This would be an incentive for dentists to treat people with disabilities.

4. **Institute a more flexible dental loan repayment program using existing funds, to treat people with disabilities, especially in Pennsylvania's underserved areas.**

8. **Ensure that private insurance companies are mandated to provide dental insurance payment for anesthesia for children under the age of 5 and people with disabilities who need it**.

9. **Support workforce initiatives that expand the duties for dental assistants**. This will allow dentists to provide more services to all patients.

10. **Ensure that fluoride is added to our public drinking water**.

CONCLUSION

Many people with disabilities, their families, advocates and dental professionals across the state have joined efforts to work on this very real health disparity.

We continue to work with the available resources at the state and county levels to change the way people with disabilities access dental care.

Many who have engaged in this effort have done so because they have witnessed the damaging effects from lack of access and poor quality care, poor daily care, the effects of medications and chronic medical conditions to oral health. They are sincere in their interest of ensuring that oral health be managed effectively for people with disabilities, thereby increasing the potential for community inclusion through socialization, employment and overall health.

Advancing Oral Health 2008 "Strategies to Solutions" Stakeholder Committees

Loan Repayment (all or in part, person rather than place)

Mark S. Goldstein, DDS, President, Special Smiles
Joan Gluch, RDH, PhD., University of Pennsylvania School of Dental Medicine
Dr. Pate, DMD York Hospital Dental Center
Marc Holmes III,Temple University, Kornberg School of Dentistry
Howard R. Tolchinsky, DMD, Pennsylvania State Public Health Dentist
David Williams, PhD Qualdent

Levels of Care (Tied to Repayment)

Dina McFalls, Director SE HCQU
Jerome Blum, DDS, Dental Director United Concordia
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Wayne Zaayenga, DDS, Devereux
Paul Westerberg, DDS, Chief Dental Officer PA DPW
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Dental Professional Education (All Health Care Providers)

Barb Jumper, Executive Director, Arc of Dauphin & Lebanon Counties
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Dental Coordinator Position

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Don Ziegler, Civil Rights Advocate, Abilities in Motion
Jeff Fromknecht, UCP Kids Pittsburgh

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Legislative-Educate General Assembly

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Data, Statistics, Information

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