

**Position paper of The Arc of Pennsylvania With Regard to  
Access to Dental Care for People with Disabilities**  
*Approved – April 7, 2008*

### **Defining the Problem**

In 2000, the U.S. Surgeon General issued the first-ever report on oral health in America. In it, then-Surgeon General David Satcher described the oral health problem as the “silent epidemic”, saying, “this report illustrates profound disparities that affect those without the knowledge or resources to achieve good oral care...and, those with disabilities and complex health conditions are at greater risk for oral diseases that, in turn, further complicate their health.”<sup>i</sup> Oral health is often perceived as secondary to physical or mental health. However, a fast-growing body of evidence links poor oral health with increased risks for serious systemic conditions such as heart disease, diabetes and aspiration associated with Chronic Obstructive Pulmonary Disorder (COPD). According to the American Heart Association and a recent study conducted by the Harvard School of Public Health, “A poor oral health diagnosis was a stronger predictor of heart disease than other markers such as high levels of HDL or “good” cholesterol, or high triglycerides.”<sup>ii</sup> This study concluded that the strongest predictors of heart disease were five common oral health conditions: infection around the third molars; the presence of root remnants; missing teeth; gingivitis; and cavities.

This relationship between oral health and overall good health is highly significant for people with developmental disabilities. Given advances in medical technology and increased life expectancy, today Americans with developmental disabilities can expect to develop the same chronic conditions as the general population including cardiovascular disease, diabetes, stroke, COPD, cancer and obesity. **In combination, these facts add up to a significantly greater negative impact on overall health—and, ultimately, health care delivery at a higher cost--for the estimated 225,000 Pennsylvanians with developmental disabilities.**<sup>1</sup>

### **Oral Health Care Access in Pennsylvania**

In Pennsylvania, as in every other state in the U.S., access to oral health care for people with disabilities has become a serious and persistent public-health problem.<sup>iii</sup> Effective delivery of dental care to this population is impacted by multiple barriers and misconceptions:

- People with developmental disabilities, who are largely unemployed or under-employed, typically rely on Medical Assistance. However, less than 20 percent of the total available dentists in Pennsylvania participate in the MA program. Of this small percentage, even fewer MA-participating dentists agree to treat MA clients on a regular basis: less than 10 percent of the dentists participating in Medical Assistance provided \$10,000 or more in dental services in fiscal year 2004-05.<sup>iv</sup>

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<sup>1</sup> This figure reflects only Pennsylvanians who qualify for the federal definition of developmental disability; there are many others—we estimate 150,000--whose intellectual disabilities also lead to problems accessing oral health care. Neither does this figure reflect all Pennsylvanians who are blind/visually impaired, Deaf/hearing impaired or have other disabilities not fitting in the above two categories.

- Dentists cite low MA reimbursement rates and burdensome administration, plus a lack of training on how to provide care for people with varying levels of ability, as barriers to treating this population.<sup>v</sup>
- More than 65 percent of the state’s practicing dentists are age 50 or older and over 21 percent of practicing dentists plan to retire in the next five to 10 years.<sup>vi</sup> Pediatric dentists, the specialty that has traditionally treated people with developmental disabilities, are retiring at even higher rates.<sup>vii</sup> At the same time, Pennsylvania’s dental schools are graduating fewer students than they were 20 years ago. If current trends continue, there will be fewer and fewer dentists to care for people with developmental disabilities, let alone a growing total population, in the future.<sup>viii</sup>
- Pennsylvania’s diverse geography creates serious disparities between urban centers and rural areas. In 2005, Pennsylvania had 46 federally designated Dental Health Professional Shortage areas (DHPSAs), i.e. shortages of dental providers in over two-thirds of its 67 counties. Practicing within a DHPSA allows new dentists to receive financial relief through student loan-repayment programs, but the current low dollar level of loan relief, coupled with strict long-term commitment guidelines, is insufficient to attract new dentists to shortage areas effectively.
- HealthChoices MCOs, since they are paid per consumer served, have little incentive to address the specific challenges of recruiting dental providers and ensuring that they do in fact regularly treat people with developmental disabilities.
- The dental community tends to group everyone with disabilities together under the general heading of patients who have “special needs.” This generalization often means that important differences in physical, intellectual, mental, sensory, behavioral and cognitive or emotional abilities are overlooked, ultimately affecting whether or not individuals receive cost-effective care in an appropriate treatment setting.

Some additional barriers to care include:

- Lack of experience, equipment and staff in private dental offices to deliver safe and effective dental treatment, sedation or general anesthesia;
- Limited hospital facilities to care for people with advanced dental and medical complications;
- Lack of coordination of social, medical and dental services for people with developmental disabilities;
- The absence of a standard of care or a requirement for pro bono services or reduced fees within the dental practice community;
- Issues with transportation, resulting in missed appointments and “no-shows”;
- Long travel times to reach providers capable of providing appropriate treatment

Addressing access to oral health care in Pennsylvania will require collective action to preserve the current dental provider base and create incentives that attract more dentists to treating this population. The Arc of Pennsylvania is firmly committed to the goal of full inclusion and therefore to building the Commonwealth’s capacity for community-based care. We recognize that specialized settings can be highly effective for the individuals they serve, and for the

minority of patients whose needs are complex, there are clinical as well as economic advantages to aggregating scarce resources like operating rooms and anesthesiologists' time to provider quality care most efficiently. However, excessive and needless referrals to specialized clinics can result in more invasive and costly dental care and over-use of sedation or general anesthesia. **Dentists currently treating this population estimate that some 75 percent of people with developmental disabilities can be safely and effectively treated in the community.** <sup>ix</sup> **For this reason, and because the vast majority of dental care is delivered via a private practice, Pennsylvania's top priority must be to build maximum dental provider capacity at the community level.**

### **Recent Efforts to Improve Access to Dental Care**

Recent efforts within the advocacy community to improve dental care access in community-based settings have proven frustrating. A class-action lawsuit was filed by the Disability Law Project (now Disability Rights Network) in 2001, and while it succeeded in documenting the severity of the problems, a federal judge eventually ruled against the plaintiffs. In an attempt to expand access, in 2001 Pennsylvania supported the development of a specialized clinic model for oral health services, resulting in Philadelphia's Special Smiles program (a Medicaid-funded private practice limited to patients with disabilities who require general anesthesia). The Special Smiles program operates profitably, but attempts to encourage other dental providers in replicating this model in other parts of the state have not succeeded to date.

Two research/ policy initiatives were undertaken in 2004-2005 with the support of FISA Foundation and the Pennsylvania Developmental Disabilities Council. In April 2005, Elwyn, Inc. received a grant from the PA Developmental Disabilities Council to document and assess the access to and availability of quality dental services via surveys, interviews and focus groups. Over the next 15 months, a coalition including Elwyn, Drexel University School of Public Health, Philadelphia Coordinated Health Care and Special Smiles conducted an exhaustive literature search into best-practice models and surveyed both the provider and public community to determine the barriers to accessing dental care. The result was a comprehensive report in September 2006 which summarized attitudes and beliefs about dental care based on survey results; information from 29 interviews spanning six states; and information shared by more than ten different advocacy agencies throughout Pennsylvania. In western Pennsylvania, ACHIEVA sponsored a November 2005 public forum focused on oral health care access, which featured presentations by two of the nation's leading dentist-advocates, Dr. Steven Perlman and Dr. Paul Glassman, plus additional speakers from dental schools, dental providers and the advocacy community. In March 2007, an ACHIEVA report on oral health for people with developmental disabilities compiled the insights from the forum and placed them in state and national context.

There has also been recent legislative activity at the state level. SB 455, introduced in 2006/07 and now signed into law, revised Pennsylvania's licensing definitions to allow for the establishment of an "independent dental hygiene practitioner." It will allow an appropriately trained dental hygienist to practice in a public health setting (such a school or group home) without the supervision of a licensed dentist, and to provide radiographs. While yet untested, this approach may help improve access to basic preventive care.

On the federal level, HR Bill 2472 (the "Essential Oral Health Care Act of 2007") was introduced in early 2007 after national news coverage of the death of 12-year-old Deamonte

Driver from an untreated dental abscess.<sup>x</sup> The proposed bill would amend the Social Security Act to increase the Federal Medical Assistance Percentage (FMAP) specifically for oral health care (in Pennsylvania's case, this would increase the federal match from about 50 cents to as much as 80 cents on the dollar); these FMAP increases would be granted only in states that ensure that Medicaid-eligible children have access to oral health care to the same extent as the entire pediatric population of the state. This bill would also amend the IRS Code to allow dentists a tax credit for the donation of qualified dental services to low-income individuals.

## **Recommendations**

No single “silver bullet” will fully address this long-standing and complex problem, but a “combination lock” of inter-related steps could result in meaningful progress. The Arc of Pennsylvania recommends the following:

**Recommendation 1** –Launch a statewide public education campaign to include direct care providers, individuals and families and other allied health professionals on the importance of dental care in the disability community.

**Recommendation 2** – Establish a “Levels of Care” framework for delivery of Medicaid-funded as well as privately insured dental services for adults and children identified as having developmental disabilities that assesses each person’s physical, behavioral and emotional needs and steers them to the right dental setting:

- Level 1 – Community-based care for people who are cooperative in a dental office or not excessively fearful of the dentist, who require little or no intervention to complete comprehensive dentistry.
- Level 2 – Community-based care for people who are somewhat uncooperative or fearful, who may require analgesia or conscious sedation to complete comprehensive dentistry
- Level 3 – Community or specialty clinic-based care for people who require IV or general anesthesia due to maladaptive behaviors or medical complexity, and who therefore require a specialized setting, ambulatory surgical center or hospital to complete comprehensive dentistry.

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. DPW/DOH will need to add an identifier for dental providers that establish their capacity to treat patients at each of the three levels of care. Safeguards need to be in place to ensure that an individual is treated at the best level for them not automatically sent to a hospital setting.

**Recommendation 3** - Require a mandatory oral health assessment as part of an individual’s Individual Support Plan (ISP), to establish the level of care an individual needs and to document the dental treatment plan.

**Recommendation 4** – Create and pilot-test a dental coordinator position, staffed by licensed dental hygienists, based within the supports coordination unit. Dental coordinators would monitor whether consumers are accessing appropriate oral health care and integrate oral health

into ISPs; they could also be deployed to conduct examinations and cleanings, train direct-care staff, make referrals for follow-up care and recruit additional dental providers. These positions could potentially be funded using targeted service management dollars.

**Recommendation 5** – Formalize organized dentistry’s public-health obligation to serve this population of patients. We recommend that the PA State Board of Dentistry amend its licensing renewal criteria to require all dentists renewing their Pennsylvania licenses to provide 50 hours per year of pro bono or sliding fee scale services to individuals with developmental disabilities. This annual requirement could be met by any of the following:

- Providing direct patient care to people with developmental disabilities, pro bono or on a sliding fee scale.
- Donating services to patients with developmental disabilities via the National Foundation of Dentistry for the Handicapped (Donated Dental Services) program
- Participating in oral health screenings for Special Olympics/ Special Smiles or other events serving people with developmental disabilities
- Completing continuing education credits specific to the treatment of people with developmental disabilities
- Teaching other dental providers techniques to use in treatment of people with developmental disabilities

Providers could also meet this public health obligation by demonstrating that they serve 50 percent or more of their patient population in a Medical Assistance funded setting.

This approach recognizes the contributions of those dentists already treating patients with developmental disabilities and provides an incentive for others to undertake additional training to meet a similar obligation. It would document the dental community’s care to this population, increase the level of service delivered and build provider capacity at the same time.

To offset the costs of providing pro bono care, Pennsylvania could reserve a portion of the increased FMAP (if approved) and establish a fund to reimburse extraordinary costs for qualifying services. This would serve two purposes:(1) provide incentives for dental practices to complete comprehensive care and (2) ensure that the increased FMAP reimbursement is targeted to improving access rather than an across-the-board fee increase. In lieu of the FMAP offset, the State Board of Dentistry could institute an annual license renewal fee to be reserved in a fund to reimburse dentists’ extraordinary costs. (The Pennsylvania Dental Association already administers such a fund, restricted to support families of dentists who undergo drug and alcohol rehabilitation).

**Recommendation 6** – Expand and refine the existing state loan repayment programs for dental school graduates. Revisions for consideration should include:

- Increase the total maximum loan repayment amount (currently \$64,000 -- about half the average debt of a dental-school graduate) for individuals making a full-time commitment to a DHPSA as currently defined.
- Permit a part-time commitment to a DHPSA, using either a specific number of hours or a reduction in total number of years a dentist must commit to the program.

- Increase incentives for dentists willing to relocate to rural areas of Pennsylvania.
- Tie loan repayment not to a specific DHPSA, but to a specified number of hours per week or month treating people with developmental disabilities.

**Recommendation 7** – Strengthen the dental school “pipeline” in Pennsylvania’s three dental schools. Public investment in dental education could be targeted to advanced training in treating patients with disabilities, or tied to benchmarks that demonstrate increasing numbers of graduating dentists who have been trained to treat people with disabilities.

**Recommendation 8** – Revise dental school curricula across the Commonwealth to include a **mandatory** education and clinical training program on treating people with developmental or acquired disabilities. This should include additional training in behavior management, management of poly-pharmacy, and background on physical/ mobility adaptations. Dental schools should also promote the availability of loan repayment programs and incorporate advanced education on treating people with developmental disabilities as part of their ongoing continuing education programs.

**Recommendation 9** – Require that HealthChoices MCOs formally report to DPW on the number of children and adults with developmental disabilities who received dental services, over and above EPSDT reporting requirements. In addition, MCOs’ required provider network reports should include information about the number of general dentists and specialists who were added and retained in their networks, who demonstrate a record of providing services specifically to people with developmental disabilities.

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<sup>i</sup> U.S. Surgeon General: *Oral Health in America*, May 2000

<sup>ii</sup> Accessed at [www.americanheart.org/journal](http://www.americanheart.org/journal) report, 02/17/2004

<sup>iii</sup> ACHIEVA, *Access to Oral Health Care for Pennsylvanians with Disabilities: A Rising Public Health Issue* (March 2007), (available at [www.achieva.info/docs/DHPFreport.doc](http://www.achieva.info/docs/DHPFreport.doc))

<sup>iv</sup> *Access to Oral Health Care for Pennsylvanians with Disabilities*

<sup>v</sup> Elwyn, Inc., *People With Developmental Disabilities and Oral Health in the Commonwealth of Pennsylvania* (September 2006), p. (available upon request from the PA Developmental Disabilities Council)

<sup>vi</sup> 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

<sup>vii</sup> *Access to Oral Health Care for Pennsylvanians with Disabilities*

<sup>viii</sup> *Access to Oral Health Care for Pennsylvanians with Disabilities*

<sup>ix</sup> *People With Developmental Disabilities and Oral Health in the Commonwealth of Pennsylvania*

<sup>x</sup> Accessed at <http://thomas.loc.gov/cgi-bin/bdquery/HR02472>