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**DOMESTIC POLICY SUBCOMMITTEE
OVERSIGHT AND GOVERNMENT REFORM
COMMITTEE**

**THE STORY OF DEAMONTE DRIVER
AND ENSURING ORAL HEALTH FOR CHILDREN
ENROLLED IN MEDICAID**

**Wednesday, May 2, 2007 - 2:00 P.M.
2154 Rayburn HOB**

Chairman Kucinich, Congressman Issa and members of the Committee, thank you for inviting me here today to testify concerning the state of access to oral health care for low-income children in our country.

On February 25, 2007, Maryland's Deamonte Driver, age 12, died as a result of an untreated infected tooth which led to a massive brain infection.

It is truly a shame on all of us that Deamonte had to serve as the proverbial canary in the coal mine. But let us not fail to heed the warning hid death provides. Let us not, by our indifference or incompetence, have to bear on our consciences the burden of more dead children.

We have a health care crisis on our hands – a dental care crisis – and we have had for quite some time. Somehow, it has been all right for us to ignore it. I hope it is not all right for us to ignore it any longer.

It is time for us to retire the myth that dental care for young children is desirable but not essential; that cavities in baby teeth can be tolerated because the teeth will fall out anyway. Dental disease in young children is a very serious matter, with very serious consequences indeed, including death.

You will hear a great deal of testimony today about the medical aspects of dental disease, the fact that it is epidemic among poor children, and the efforts of dentists and of federal and state agencies to address the epidemic. And I will talk a little about some of those topics as well.

But first I want to tell you Deamonte's story.

Deamonte's Story

Deamonte was born and raised in Prince George's County, Maryland. He was the third of five children, all boys. Deamonte's parents and grandparents always scabbled to make ends meet, making do in whatever way they could in rural southern Maryland. The adults were used to being uninsured; but the children usually had insurance -- through Medicaid or the Maryland Children's Health Program.

Dental disease in the Driver family followed a typical pattern. Oral health researchers tell us that dental caries is a transmissible and infectious bacterial disease, that it typically passes from mother (or caregiver) to infant, and that each subsequent child born to a mother tends to have a higher risk of infection and disease than the previous child.¹

Deamonte's mother, Alyce Driver, being uninsured and poor, did not have regular dental care. Predictably, her children, as are most children, became colonized with the bacteria that causes dental caries. And the disease seemed to be worse in each subsequent child. The first two boys experienced relatively little dental disease. Then came Deamonte, who obviously had some oral disease. And his two younger brothers also have struggled with significant oral infection.

The Driver boys all had a primary care doctor - a medical home - a pediatrician who treated their childhood illnesses, gave them their immunizations, made sure they were healthy to play sports. He was accessible and responsive to their health care needs.

But the Driver boys never had a regular primary care dentist - a dental home - an identified provider who could assess their risk for developing dental disease by age 1, check their mouths and new teeth every six months during toddlerhood, provide education to their parents about preventing dental disease, instruct the boys in how to properly brush and floss, recommend fluoride treatments and dental sealants as they grew older, clean their teeth every six months, and watch for developing cavities that could be nipped in the bud, preventing severe disease, pain, tooth loss, and, in Deamonte's case, death.

Researchers have determined that poor children are at much higher risk of contracting dental disease than are non-poor children. In addition, low-income parents are much less likely to be aware of the risks of oral health disease, and of the need for and availability of preventive dental care. The Driver family was no exception. The family's socio-economic status put the children at high risk to begin with. In addition, Ms. Driver's own lack of access to dental care as a child and as an adult, coupled with the barriers to getting dental care for her children, has meant that she has not had the opportunity to fully understand the importance of good oral health in young children and how to maintain it.

I first met the Driver family in July 2006 through my work on homeless children's education rights in Prince George's County, Maryland. The Public Justice Center was conducting interviews of selected homeless families to understand their experiences with the public school system, and Ms. Driver was one of the parents we interviewed. Then, in August, 2006, Ms. Driver contacted me for help in getting her children enrolled in school.

Now, I need to divert from Deamonte's story for a bit, and tell you about his brother, DaShawn.

In September, 2006, Ms. Driver called me to ask if I could help her find a dentist for 10-year-old DaShawn. He had severe abscesses in his mouth that were causing swelling and pain. Ms. Driver knew he needed to have some teeth pulled, and she had taken him to an oral surgeon over the summer, but that dentist had refused to treat DaShawn because he couldn't hold still enough in the dentist's chair. That dentist did not give Ms. Driver a referral to another dentist, so she wasn't sure where to turn. She called a toll-free number to try to locate another dentist contracted with DaShawn's Medicaid managed care plan, but was unsuccessful. She had reached the limit of her understanding and ability to navigate Maryland's complex Medicaid system.

I agreed to help Ms. Driver find a dentist for DaShawn. There my odyssey began. After confirming that DaShawn was enrolled in Maryland's Medicaid HealthChoice program, and that his managed care plan was United Healthcare, I called the United Healthcare customer service number. From there I was transferred to the plan's dental benefits administrator, a separate company called Dental Benefit Providers, or DBP. The very helpful customer service representative explained that DaShawn would first have to see a general dentist to get a referral to an oral surgeon in order to get the treatment he needed. She also explained that the Medicaid part of the United Healthcare company was called Americhoice, and that this was the company the dentists would be contracted with, not United Healthcare. She searched her database and forwarded to me a list of several dozen general dentists located near where DaShawn was staying at that time - with his grandparents. She cautioned me that while these dentists were supposed to be in the DBP network, and thus contracted with Americhoice (United Healthcare Medicaid), many of them had recently been dropping their contracts. She advised me to ask first whether the dentist contracted with "Americhoice through the State." Only a dentist that confirmed this would be a participating dentist in DaShawn's Medicaid plan.

My administrative assistant started calling dentists on the list, asking if they accepted "Americhoice through the State." The first 26 dentists on the list said, "No." At this point I decided that another approach was needed. I called the Department of Health and Mental Hygiene's (DHMH) Medicaid enrollee helpline. I explained the problem I was having and asked for help. The first person I spoke to argued with me for 5 minutes about what the problem was, insisting that she couldn't find DaShawn in the computer and that he must be enrolled in a Medicaid managed care plan called Amerigroup, not United Healthcare. I asked to speak to a supervisor. The supervisor understood the problem right away, was able to find DaShawn in the computer, and agreed that I needed help. She transferred me to the supervising nurse in the case management unit at DHMH.

Over the next 5 days, the DHMH case management nurse, a case manager at the Prince George's County Health Department's ombudsman unit, and an employee at United Healthcare/Americhoice worked together to find a contracted dentist for DaShawn. Finally, he saw a general dentist on October 5, 2006.

It took the combined efforts of one mother, one lawyer, one helpline supervisor, and three health care case management professionals to make a dental appointment for a single Medicaid-insured child!

And yet, DaShawn's path to adequate dental care was not yet over. DaShawn's new dentist determined that DaShawn needed to have six teeth pulled by an oral surgeon. Again I contacted the DHMH case management nurse, who with the cooperation of the other case management professionals, located a contracted oral surgeon. Ms. Driver secured the earliest available appointment for DaShawn -- November 16, 2007.

The oral surgeon agreed that six teeth needed to be extracted, and scheduled the first extraction for late December 2006. That appointment was subsequently cancelled by the oral surgeon (reportedly because of an emergency in his office), and rescheduled for early January. But by the time the January appointment rolled around, that oral surgeon had cancelled his contract with United Healthcare/AmeriChoice. So DaShawn had to find a yet another oral surgeon -- his third. He finally had his first tooth pulled in February 2007. The third oral surgeon suggested pulling one tooth each month for six months.

In the meantime, two other relevant events occurred. First, 12-year-old Deamonte, who had not complained of any dental problems, began experiencing severe headaches. Over the period of a week or so in mid-January 2007, he was first diagnosed with a sinus infection, and then with a brain infection. He had two brain surgeries, had one tooth extracted, and spent six weeks in the hospital, where he seemed to be recovering well, but where he died unexpectedly on February 25, 2007.

Though Deamonte's story had the worst possible ending, DaShawn's story ended more happily. Because of Deamonte's experience, Ms. Driver had extreme concern for DaShawn's ongoing oral health situation. DaShawn's second of six rotten teeth was pulled by the third oral surgeon in March 2007, but no dentist had put him on antibiotics, and Ms. Driver did not want to wait four more months to get the remaining four teeth pulled. Because of Deamonte's death, she learned of the pediatric dental clinic at the University of Maryland dental school, and decided to transfer the rest of DaShawn's care to them. There, his four remaining infected teeth were pulled promptly.

Deamonte Was Not an Exception

Now let me move from the particular to the general. The sad thing is, we can be absolutely certain that the experience of the Driver family is not in any way unique to them. We know this because:

- low-income children have about 80% of the dental disease in this country;
- more than 50% of low-income preschool aged children in Maryland have dental decay;
- and 98% of that dental decay is untreated, each child having an average of 3 untreated cavities;
- only 31%-45% of Maryland's continuously enrolled Medicaid children ages 4-20 (representing perhaps half of Maryland's Medicaid children in that age group) saw a dentist in 2005;²
- and only 13%-16% of those children got any restorative treatment (e.g. filling for a cavity).³

From these statistics, it is clear that the typical low-income child in Maryland has dental disease and untreated dental decay. And only a very small percentage of these children are receiving any dental treatment. So it is more than safe to assume that most children in Maryland's Medicaid program are having a tough time getting access to all the dental care they need. In addition, other parents of children on Medicaid have shared with me their experiences in trying to find a dentist for their children, or in trying to find the right kind of dentist who can treat the specific dental problems their children are experiencing. They have told me:

- Of inaccurate provider lists
- Of having to call many, many dentists before finding one that is contracted, or that will accept a new patient
- Of having to wait months for an appointment
- Of having to drive long distances, e.g. more than an hour, to get to a dentist who will accept their Medicaid card
- Of being turned away at the office on the day of the appointment for unexplained reasons

Maryland Has Had A Troubled History in Oral Health

We have a particularly troubled history in Maryland concerning access to dental care in Medicaid. In 1997, our State ranked dead last in access to oral health care services for poor children. We have progressed somewhat since then, but some of that progress is due to some data "slight of hand." For example, Maryland uses HEDIS data in its annual report to the State legislature about dental utilization.⁴

The HEDIS measure was specifically designed and intended to be used to permit comparison between insurance plans or HMOs. Thus, understandably, the measure suggests that only persons enrolled continuously in a particular plan (with not more than a single break in enrollment of 45 days or less) be counted in the analysis for that plan. Even though in its reporting Maryland purports to measure the overall performance of the entire HealthChoice program, not the individual performance of each of the seven participating managed care organizations, Maryland insists on excluding from the analysis all children who failed to maintain continuous enrollment of at least 320 days *in a single managed care organization*. This results in the elimination from the analysis of many children, perhaps half of all enrolled children, especially children from lower-income families, because these children tend to experience a greater rate of disruption in their Medicaid coverage. Tellingly, while Deamonte and DaShawn were both insured by Medicaid for many years, they both probably will be excluded from the analysis for 2006 because of a 63-day break in enrollment with the United Healthcare MCO.

Current Performance Measures Are Inadequate

Historically, dental access in Medicaid has been measured by looking at the percentage of children who have had at least one dental encounter during a given year. It has become abundantly clear that these measures are wholly inadequate to describe the state of oral health of our country's low-income children. Nor are these measures serving to lead us toward the reforms needed to address the severe deficit in care that exists.

As long ago as 1998, an expert panel commissioned by CMS determined that the current measures should be replaced by new measures: *Use of Dental Services by Children* profiling the range of different types of services provided, as well as measures to begin to address the domains of effectiveness of care, satisfaction with the experience of care, involvement in decision making and the cost and value of care.⁵

It is long overdue that CMS develop these new measures, and require States to use them.

Many Resources Are Available to Guide Reform

The problem of access to oral health care for poor children has been a long-standing one and has been studied extensively. As a result of all this study, we know what causes children to become infected with oral bacteria leading to dental caries.⁶ We know that the disease is a systemic, endemic, chronic and epidemic problem among poor children.⁷ We know the nature of the numerous obstacles to ensuring that poor children receive adequate dental care.^{8,9} We have a pretty good idea of what we need to do, from a medical and policy standpoint, to eliminate these obstacles.^{10,11,12,13} And there are models for effective dental care delivery systems for low-income children.^{14,15,16}

What we seem to be lacking is the political will to challenge the corporate interests that benefit from the current arrangement, to spend the money it will take to provide truly adequate levels of care to this neglected population and to prevent a recurrent disaster in the next cohort of children, and to provide adequate federal oversight of program performance.

A culture has grown within certain levels of CMS and within some of our State's agencies that clearly condones gross underperformance in Medicaid, particularly in terms of low profile areas such as access to oral health care. Any elementary school child knows that if they pay for something but don't get it, they are not going to pay the same person again and again. CMS needs to understand and act on this same principle. States know that CMS will keep paying and not enforce their waiver conditions or federal law regarding adequate access to care. The CMS employees responsible for overseeing State programs know there is no likelihood of enforcement by their agency so they lose heart and perpetuate the problem. The culture of accepting underperformance becomes widespread and entrenched. It becomes all too easy and common for access to dental care to reach unacceptable levels. The system fails. The taxpayer and children are abused.

This problem can be fixed, but Congress must insist on accountability and performance as well as provide CMS with the necessary tools to get the job done.

What CMS Can Do

- Require every State to comply with OBRA89 by developing and publishing a distinct *dental* EPSDT periodicity schedule, with dental care beginning no later than age 1 as recommended by the American Academy of Pediatric Dentistry and the Medicaid/SCHIP Dental Association.
- Require every State to actively monitor, and report to CMS concerning, participating dentists' compliance with the State's dental EPSDT periodicity schedule.
- Begin immediately to require States to report to CMS on dental access for, and the oral health status of, the age cohort 1 to 20.
- Require every State to provide a "dental home" for each child enrolled in a State plan.
- Effectively enforce current oral access standards as described in the January 18, 2001 Dear State Medicaid Director Letter, SMDL #01-010.
- Effectively enforce existing Terms and Conditions in states with Medicaid managed care under an 1115(b) waiver.
- Implement performance measures, and require States to report to CMS using them, to address the domain of effectiveness of care, looking at dental outcomes for these children, consistent with the recommendations of the CMS/NCQA Pediatric Oral Health Performance Measures Project.
- Develop and implement a high visibility long-term nationwide public education campaign about the importance of oral health in children and how to achieve it, similar to the "back to sleep" campaign which has so successfully reduced the occurrence of sudden infant death syndrome (SIDS) in the United States.
- Enforce meaningful sanctions (withholding of federal financial participation) against States that fail to meet specified performance measures for achieving oral health for children enrolled in a State plan (see What Congress Can Do, below).
- Develop a portfolio of model State dental delivery systems based on State programs that meet specified performance measures and achieve oral health for enrolled children, and coach failing States to adopt or adapt these models.

What Congress Can Do

- Insist that CMS do everything on the above list.
- In the context of H.R. 1781:
 - Make it a prerequisite that a State applying for a grant under Section 101
 - Develop a strategic plan for ensuring the achievement of oral health for children enrolled in a State plan under title XIX or a State child health plan under title XXI (including a description of the size of the unmet need); and that data collection and reporting include outcome performance measures intended to measure achievement of, and maintenance of, oral health.
 - That “adequate payment rates” be defined as those rates sufficient to enlist enough dentists to ensure the achievement of oral health in children enrolled in the State plan, and require the State to ensure that it will raise rates to these levels.
 - Revise Section 102(b) to require States to report to CMS using outcome-based performance measures, as recommended by the CMS/NCQA Pediatric Oral Health Performance Measures Project, instead of the repeatedly discredited CMS 416 EPSDT participation measures.
- Enact meaningful sanctions (withholding of federal financial participation) against States that fail to meet specified performance measures for achieving oral health for children enrolled in a State plan.
- Demand that CMS provide adequate, even aggressive, oversight of State Medicaid programs and enforcement of waiver conditions and federal laws to ensure that taxpayer dollars allocated to oral health services are accountably and effectively spent on oral health services, and that State’s Medicaid oral health delivery systems are rationally designed and effectively managed.
- Hold CMS accountable for enforcing the January 18, 2001 Dear State Medicaid Director Letter, SMDL #01-010.

¹ *Oral Health Risk Assessment Timing and Establishment of a Dental Home*, PEDIATRICS, Vol. 111 No. 5, May 2003.

² A range of percentages is given because of inconsistent reporting by DHMH between the CMS 416 EPSDT dental utilization data and HEDIS dental utilization data.

³ See endnote 2.

⁴ See *Report to the General Assembly: Dental Care Access under HealthChoice*, October 2006.

⁵ See *Guide to Children’s Dental Care in Medicaid*, CMS, October 2004, p. 18.

⁶ See *Oral Health Risk Assessment Timing and Establishment of a Dental Home*, American Academy of Pediatrics, PEDIATRICS, Vol. 111 No. 5, May 2003, pp. 1113-1116.

⁷ See *Oral Health: Dental Disease is a Chronic Problem Among Low-Income Populations*, U.S. General Accounting Office, GAO/HEHS-00-71, April 2000.

⁸ See, for example, *Oral Health: Factors Contributing to Low Use of Dental Services by Low-Income Populations*, U.S. General Accounting Office, GAO/HEHS-00-149, September 2000.

⁹ *Instability of Public Health Insurance Coverage for Children and Their Families: Causes, Consequences, and Remedies*, Laura Summer and Cindy Mann, Georgetown University Health Policy Institute, June 2006.

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- ¹⁰ *Guide to Children's Dental Care in Medicaid, CMS, October 2004.* See especially pages 3-6, Contemporary Dental Care for Children, and pages 6-19, Policy and Program Considerations.
- ¹¹ *American Academy of Pediatric Dentistry, 2006-2007 Definitions, Oral Health Policies and Clinical Guidelines*, available at <http://www.aapd.org/media/policies.asp> .
- ¹² *Opportunities to Use Medicaid in Support of Oral Health Services*, U.S. Dept. of Health & Human Services, Health Resources & Services Administration, December 2000.
- ¹³ See the many excellent policy materials available on the website of the American Academy of Pediatric Dentistry, <http://www.aapd.org/> .
- ¹⁴ *Pediatric Dental Care in CHIP and Medicaid: Paying for What Kids Need/Getting Value for State Payments*, Milbank Memorial Fund, Reforming States Group, 1999.
- ¹⁵ *Michigan Medicaid's Healthy Kids Dental Program: an assessment of the first 12 months*, Stephen A. Eklund, James L. Pittman, Sarah J. Clark, JOURNAL OF THE AMERICAN DENTAL ASSOCIATION, Vol. 134, November 2003, pp. 1509-1515.
- ¹⁶ *Medicaid EPSDT - State Innovation Leads to Improved Oral Health Participation Rates*, National Health Law Program, February 2006.