



**Testimony by Dr. Stephen Corbin before the U.S. House of Representatives  
Committee on Energy and Commerce, Subcommittee on Health – “Insuring  
Bright Futures: Improving Access to Dental Care and Providing A Healthy  
Start for Children”**

**The Honorable John D. Dingell, Chairman**

“Sure, it would be nice to save the dental program, but, let’s face it: No one really dies from a toothache.” I start out my testimony today paraphrasing a common misperception that state legislatures have debated over the past three decades about Medicaid dental programs. As you will see, this statement is both prescient and false and underlies much of what is wrong with public dental programs in the country today.

Good morning. I am Dr. Stephen Corbin, Senior Vice President for Constituent Services and Support at Special Olympics International. I am honored to be invited to participate in this important hearing on access to dental care. This is a matter to which I have dedicated years of study and service and, I am loathe to admit, have not seen the breakthrough progress that is so badly needed.





I understand that the recent tragic death of 12-year-old Deamonte Driver from the complications of untreated dental decay has heightened awareness all the way up to the halls of Congress that action is essential so that such a tragedy never happens again. As with so many things in society that are unjust and preventable, it often takes a sudden tragedy to garner attention on long-standing tragedies. It appears that this may be such a case. If we can use the moment constructively, we can honor the memory of a young child who became the victim of a failed system. He and his family were ill-served. They did not have any control over the office policies of any healthcare providers or payment policies of a public financing system.

What we all need to realize is that Deamonte Driver not only died as a result of the passive complicity of a failed system, but he suffered for months, possibly unaccounted years, from the chronic pain of infections that invaded his teeth and eventually spread to supporting structures, his blood stream and his brain. Was this some exotic new infectious invader unknown to medical science? Was this a unique case, such as had never been seen before? Was this a clinical condition for which there is no known treatment? Sad to say, the answers to these questions are “no, no and no!”

If you were to track back to the cause of death in this instance, one could say that the immediate cause of death was heart failure, precipitated after an infection of the brain, arising out of a





blood-borne infection, that moved from an infected pulp of a tooth, that had been preceded by a deep carious lesion of the dentin of the tooth, that was preceded by an extensive carious lesion of the enamel, that was preceded by a minimally invasive carious lesion of the enamel, that was preceded by a barely detectable lesion of the enamel, that was preceded by an insensitive, incomplete and under funded medical system that never gave Deamonte Driver the chance he needed. The chance that he needed to recover and survive.

The bottom line is there were numerous points along the way where this death march could have been halted; where the infection could have been prevented or intercepted early, or if late, still could have been tackled. And, a young life could have been saved. Why did Deamonte Driver have to die from probably the most common childhood affliction, from a disease that we have known how to prevent and treat for more than a hundred years? The answer to this question is complex, and I hope that, by the end of this hearing, we will know enough to be able to move forward with specific actions to change this situation permanently.

While I am a dentist and a Board Certified Public Health Dentist (a rare breed indeed), I currently lead a global multi-disciplinary health program for persons with intellectual disabilities, some 2.25 million Special Olympics athletes worldwide, more than half under the age of 21. Special Olympics has stepped forward as a global leader to address the burden of unmet health needs for the more than 170 million persons around the world, including 6 million in the United





States, with intellectual disabilities. Not because we were inclined to, as a sports organization, but because we really had no choice. Where those who should have taken care of this have failed to do so, Special Olympics stepped up. If you are not healthy, how can you successfully compete as an athlete at any level?

Our athletes have this in common wherever they live around the world: they all have a permanent intellectual disability; they all demonstrate courage on the athletic field and acceptance of others; they all get sick on occasion and have health challenges like everyone else; they care whether they are well or sick; when they get sick, they need care; when they have tooth infections they hurt, even if they don't complain; when they get sick and can't get the care they need, they suffer and get sicker; when they finally do get care, too often it is as a last resort when their options aren't particularly good.

The way they differ from other people is that they tend to have few available resources for assistance; be underemployed or unemployed – thus, they tend not to have private medical care, including dental insurance; no one expects them to be pretty or handsome; no one expects that they need to have a bright white smile; no one really worries if they are missing some of their front teeth; no one knows if they have dental infections; no one knows if they are in pain from dental disease; no one, or hardly anyone, feels responsible for helping them to achieve oral health.





Allow me to lay out some hard facts for you. Special Olympics, through its Healthy Athletes® Program, provides free health assessments and some care to more than 130,000 Special Olympics athletes each year. We conduct more than 600 health screening events in some 70 countries through the volunteer efforts of 13,000 healthcare professionals and students, supported through the generosity of the U.S. Centers for Disease Control and Prevention, Lions Clubs International and several corporate and academic partners. And let me thank the U.S. Congress for appropriations directed to our Healthy Athletes Program over the past five years that makes this broader largesse possible.

We have accumulated across our seven Healthy Athletes screening disciplines, without a doubt, the largest database of health status and health needs of persons with intellectual disabilities that has ever existed. Our Special Smiles® screening protocol, one of the first disciplines implemented by Special Olympics, was established and validated by the U.S. Centers for Disease Prevention and Control nearly a decade ago. Over the past five years alone, Special Olympics has conducted 530 Special Smiles screening events around the world. More than half of them have taken place in the United States. We have provided about 12,500 dental screenings at those events to athletes age 8 years and older.





In this day and age, where dental art and science can produce almost any smile one could wish, consider the following. Of Special Olympics athletes (n=5447; average age 24 years) volunteering to participate in the Special Smiles Program in the United States:

- o Some 12% report pain in their mouths at the time of the screening;
- o More than a third have obvious signs of gingival (gum) infection;
- o Nearly a fourth have obvious dental decay (without probing or x-rays);
- o One quarter are missing teeth, reflecting end-stage treatment of common dental diseases (like Deamonte Driver);
- o Too many have extensive dental plaque that leads to infection of oral tissues, hard and soft, and ultimately, loss of teeth;
- o And, too many athletes and families report that they have never been able to secure a regular source of dental care for their child, even as nearly one in ten are in need of “urgent” dental care.





Further, Special Olympics, the sports organization, has done research into the preparation of dental and medical students in the United States to understand the scope and quality of their professional education in dealing with the health needs of people with intellectual disabilities. What did we find? The vast majority of dental and medical students do not feel adequately prepared to work with this population when they graduate from school. They say they want to be prepared, they just are not. Further, the deans of dental and medical schools and graduate medical and dental programs acknowledge that their graduates are unprepared to deal with the needs of this population. If you survey a listing of continuing professional education courses that address the needs of the intellectual disabilities population, you would be hard pressed to find any.

So, if healthcare professionals aren't trained during their basic professional preparation, and there is no marketplace for continuing professional education in this area, should we be surprised that people with intellectual disabilities and their families have difficulty in securing reliable, receptive, qualified sources of dental and other healthcare for their children?

Here is one of my most recent disappointments. In September 2005, Special Olympics created a Web-based directory of healthcare providers nationwide. That is, we created a user-friendly way for clinical providers in virtually all health disciplines to identify themselves to persons with intellectual disabilities and their families as willing to speak with them about the opportunity to





receive health care. Not a guarantee to health care! Not a guaranteed price for health care! Just the opportunity to discuss the opportunity for healthcare.

After a year and a half of proactive outreach to professional organizations, we have fewer than 1,000 of the more than 1 million U.S. health professionals registered. Regarding dentistry, we have only 248 names listed (as of February 20, 2007) out of more than 150,000 dentists in America. If you were a person with intellectual disabilities seeking a chance to be healthy or a family with a child with intellectual disabilities, whom you worried about in terms of their health care, how would all of this look?

I can tell you that Special Olympics Healthy Athletes is special its own right. It is a place that athletes know is *their* place. And it is a place for volunteer healthcare professionals where, for example, a 40-year veteran of clinical healthcare delivery can say tearfully and happily, “Now I know why I invested 10 years in my professional education and all of that money learning how to care for people.” In the end, one can say that it “ain’t” brain surgery. But, for Deamonte Driver, it was brain surgery when it didn’t have to be. When we do our Special Smiles dental screenings, in addition to examining the teeth and oral cavity, providing dietary and oral hygiene education, constructing mouth guards where appropriate and providing preventive supplies, we also provide our athletes with a report card on their health, as well as referral information for follow up where needed. Additionally, we provide lists of community dental providers – lists that





are always too short or where the providers are not conveniently located. We do our best to get athletes connected with locally-based providers for follow-up care but, sadly, our lists fall short of provider information despite all our efforts.

Now, I need to share a compelling image with you. This is Mr. James Pierce. James is a person with a moderate intellectual disability. I can show you this picture because James gave us permission. James went to the dentist, Dr. Henry Hood of the Underwood and Lee Clinic in Lexington, Kentucky, a special dentist and friend of mine, with what you see. One does not have to be a dental professional to look at the picture of James and see that he is sick. There is obvious extensive dental disease, swelling around the eye, a contorted barely alive look. James did not get this way overnight. This is the accumulated neglect of years of lack of proper dental care combined with a lack of proper self care. Likely these problems started in childhood or adolescence and just perpetuated. The bottom line is that James was generally sick from dental infections. Is this a person who an employer would let interact with customers, or is this a person that “belongs in the back,” if anywhere at all.

Look at James today and tell me what you see. Is this someone who can be confident in meeting people; someone who could work out in front? Is this someone who could succeed at some level? Is this someone you might be interested in knowing? Dr. Hood, a knowledgeable and caring dental professional, took the time to do an overall assessment of James and his oral health





prognosis and provided the appropriate care. James is doing well and is employed. If James were your son, brother, friend, which treatment and care would you have preferred? I don't think we need to count the votes.

Can we muster the backbone to do what is right; to match our scientific knowledge with our social responsibility? Would we allow or condone those of minimal means to drive cars without seat belts because we might have to pay for them? Of course not.

Why would we sacrifice childhoods and even lives for failure to implement the most obvious of solutions?

Here are some suggestions that could help prevent future dental tragedies:

1. Change the culture around dental care for children. It should be as important as getting kids immunized or making sure they wear seat belts in cars. Dental care for children is universally needed.

2. The marketplace is not sensitive to many underserved populations as desirable business targets. That is, reimbursement levels in public programs have not been adequate to attract a significant increase in willing providers. In general, enhancements in public dental program





reimbursement rates have been inadequate to achieve the behavior change in providers that is necessary. Reimbursement levels need to be enhanced to where they are market rational. Thus, we need to work to build opportunities that work toward full access to dental care for children. Strategies could include incentive payments for individual providers or community-based programs such as health centers when they reach target goals for providing care to high-risk populations.

3. Public oral health programs that are operated by government entities need to be designed to be proactive, not residual or reactive. It is not enough that a child is eligible to have dental care paid for. There must be a premium on children getting in for early and regular oral health care. Thus, public programs need additional resources, not just to pay dentists for care, but to provide a solid underpinning for a program that can produce real results in increasing access and reducing the prevalence of dental need.

4. Expand eligibility for children needing oral health care. Dental services should not be elective for states under SCHIP. And, programs should be designed with enough flexibility so that children are not constantly bounced off eligibility roles because of “hair trigger” provisions.

5. For special high risk populations, such as people with developmental disabilities, extra efforts are needed, including training of clinical providers and enhanced reimbursement provisions that





reflect the additional time that is sometimes required in patient management and treatment. And, while we are at it, why is it that the population with developmental disabilities is not considered a “medically underserved” group by the federal government. That warrants some close follow up and future discussions by this Committee. How is it that when a child with an intellectual disability hits a certain age, even though their disability condition is permanent, they “age out” of their Medicaid (EPSDT) dental benefits in most states to dramatically reduced “adult” service levels, if they are even available. Children with intellectual disabilities who are fortunate to receive care under Medicaid or SCHIP, all of a sudden get pushed out of the system – after years worth of investment of public resources in their care. This makes no sense at any level.

6. Provide needed quality oversight, research and evaluation of policies concerning dental care for children and vulnerable groups. This should be an ongoing responsibility of government. It is not enough to be responsive when a highly publicized tragedy takes place.

These suggestions are not complete, but, hopefully, can help point our collaborative efforts in the right direction.

“Deamonte Driver Saved” – “DDS.” It is possible if we commit ourselves to the right actions.

Thank you.

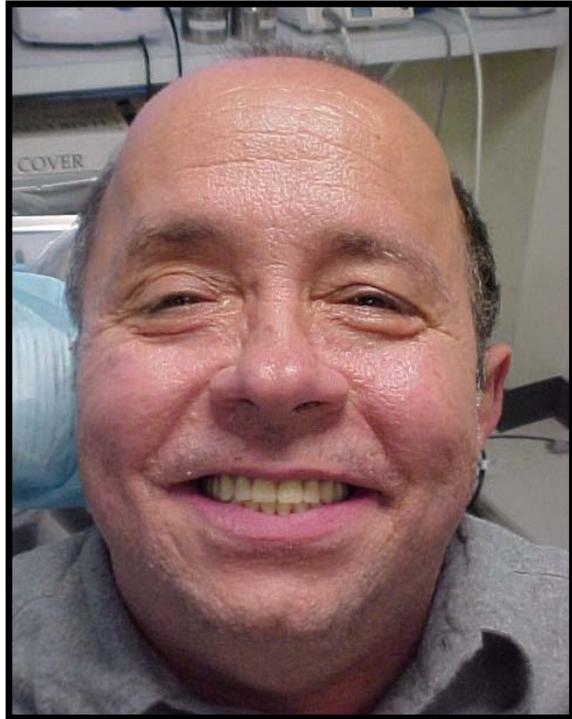




**Special Olympics**



Before



After

Mr. James Pierce

Photo Provided By: Underwood and Lee Clinic, Lexington, Kentucky



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