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Tamie Hopp's new email address is Tamie327@hotmail.com. vor@compuserve.com will be disconnected soon.

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VOR Weekly E-Mail Update Friday, September 21, 2007  
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1. Surgeon General's Call to Action  
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For more information: Office on Disability US Department of Health and Human Services  
[http://www.hhs.gov/od/about/fact\\_sheets/surgeongeneralcta.html](http://www.hhs.gov/od/about/fact_sheets/surgeongeneralcta.html)

The Surgeon General's Call to Action was designed to call attention to the need for:

\*The availability of health care and wellness services for persons with disabilities when and where they need them, provided by from health care and wellness service professionals who really listen to, communicate with and respect them.

\*Americans to understand that a disabled person is more than his or her disability

\*Health care providers who treat those with a disability, have the insight to see and treat the whole person not just his or her disability; and

\*Educators willing to teach about disability

The Call to Action is based on a simple principle: Good health is necessary for persons with disabilities to secure the freedom to work, learn and engage in their families and communities.

The report is organized into four key sections that supply a public health approach framework to improve and enhance access to health care and wellness service needs for persons with disabilities:

Section 1 introduces the concept of disability; delineates the difference between disability and illness, and introduces the challenges to health care and wellness promotion services faced by persons with disability.

Section 2 describes nature of disability, who persons with disabilities are, and the range of disabilities affecting persons across the lifespan.

Section 3 explores how achieving the goals can help promote health and wellness for persons with disabilities, exploring issues and challenges at the individual consumer provider, community, and larger system levels.

Section 4 delineates strategies for action that can lead to improved interaction, communication, and cooperation of an integrated health care system and related services programs with persons with disabilities.

The volume includes real-life vignettes that highlight both the challenges to health and wellness faced by persons with disabilities and ways in which practice and policy can help overcome those challenges.

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## 2. Medical Care Often Inaccessible to Disabled Patients

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Summary: This article deals with the accessibility of community-based physician offices, especially for individuals in wheelchairs. Senator Tom Harkin (D-IA) has introduced legislation that aims to make doctor's offices, including examining tables, more accessible. S. 1050, The Promoting Wellness for Individuals with Disabilities Act of 2007 proposes new accessibility standards for medical diagnostic equipment and proposes to establish a program for promoting good health, disease prevention, and wellness and for the prevention of secondary conditions for individuals with disabilities. VOR supports S. 1050. As stated by Senator Tom Harkin (D-IA), "This important legislation will help ensure that people with disabilities have the same health and wellness opportunities as everyone else--through increasing access to accessible medical equipment, creating a health and wellness grant program, and improving the competency of medical professionals in providing care to patients with disabilities."

Medical Care Often Inaccessible to Disabled Patients by Joseph Shapiro NPR Morning Edition, September 13, 2007

Take a moment to consider a basic part of a doctor's office: the exam table. What if you weren't able to climb up on that hard, plastic table with the crinkly, white paper? Frail elderly people often can't, and they need the most medical care. Younger people with disabilities often can't climb onto the exam table, either.

There is a lot of medical equipment that requires patients to stand or climb, and the inability to use that equipment can keep people from getting the medical care they need.

Rosemary Ciotti was diagnosed with thyroid cancer in 2005. It took awhile for the cancer to be discovered, in part because Ciotti uses a wheelchair and can no longer get up on the exam table.

Sometimes a doctor would call in a couple of strong nurses to try to lift her out of her wheelchair and onto the three-foot-high table. But she got dropped and twisted - and a couple of times, she got hurt.

"It was undignified, humiliating," Ciotti says, "and you get to a point where you no longer are as proactive with your health as you should be, even knowing better." Knowing better because, she was a nurse by profession.

### Going Without Care

Ciotti started skipping routine doctors exams. The doctors she did see simply stopped giving the woman sitting in a wheelchair the kind of thorough exams she had gotten before she became disabled by an autoimmune disorder.

Research shows that disabled women are less likely to get mammograms and Pap tests. Another study found that those who get breast cancer are less likely to receive standard treatments and are more likely to die.

June Isaacson Kailes studies the issue. She's the associate director of the Center for Disability Issues and the Health Professions at the Western University of Health Sciences in Pomona, Cali.

"For people with a variety of limitations, the old instructions to hop up, look here, read this, stay still, can be extremely difficult to impossible, which means people don't get the procedures done they need," she says.

Kailes did a national survey and found that people with disabilities have trouble using X-ray machines, rehab equipment, scales and scanning devices, like MRIs.

But the most common problem was getting onto a doctor's exam table. Kailes says the tables are particularly troublesome for elderly patients. She says that doctors often think, mistakenly, that they can thoroughly examine a person who is sitting in a wheelchair.

"You're missing half of a person's body when you're only looking at them sitting in a chair," Kailes says. "You wouldn't be getting a thorough examination of your skin, looking for beginning skin changes or small cancers, if you're sitting down. You wouldn't be getting a thorough clinical breast exam. That needs to be done while you're prone."

Kailes has cerebral palsy and uses a power scooter. She has trouble with balance and coordination, which makes the exam table trouble for her. But she goes to the gym three

times a week and she can pull herself to a standing position on a treadmill. Unlike a doctor's exam table, it has grab bars.

### Finding Accessible Clinics

Federal civil rights laws require medical offices be accessible. But few are, and those rare offices are hard to find. There is no one "clearinghouse of information," says Dr. Kristi Kirschner of the Rehabilitation Institute of Chicago. But people need sources of information to find doctors and hospitals that have accessible equipment, such as exam tables that go up and down.

Instead, Kirschner says, patients are left to figure it out on their own.

"Lot of times (it's) word of mouth and often just calling and talking to providers about whether they work with people with disabilities," she says.

Kirschner helped start a reproductive health clinic at the Rehabilitation Institute of Chicago, specifically for women with physical disabilities. She had heard stories from her patients of how they had stopped going to the doctor because they couldn't get in the door or use the medical equipment.

Kirschner tells her patients to call doctors' offices before an appointment and to ask a lot of questions - the more specific the better.

That's how Rosemary Ciotti found her new obstetrician-gynecologist in Arlington, Va. She made more than a dozen phone calls.

"I asked specifically, 'Do you have an exam table that lowers to ... at least 20 inches?' - which is the minimum that you would need to transfer easily from a wheelchair. This receptionist actually put me on hold and measured it," Ciotti says.

That story makes her new doctor, Sandy Caskie, smile.

"Well that's the kind of people I have working here," Caskie says. "But ... remember, too, that they've seen other people be accommodated. So they knew that we do this all the time."

In an exam room in her office, Dr. Caskie shows the procedure table she now uses for Ciotti and other disabled and elderly patients. With a flick of a switch, a motor raises or lowers the table.

It costs a few thousand dollars extra for a doctor to buy something like this. But Caskie says it's also easier on her: She doesn't have to twist around so much to examine her patients. And, most important, she knows her patients will get the health care they need.

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### 3. No One Dies from Dental Decay, Do They?

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13 March 2007

By Stephen B. Corbin, DDS, MPH Senior Vice President Constituent Services and Support  
Special Olympics International and Parent

And

Rick Rader, MD President American Academy of Developmental Medicine and Dentistry Editor-in-Chief, Exceptional Parent magazine

Tragic news of a 12-year-old boy dying unnecessarily from tooth decay which spread to the brain sent shockwaves across the Washington, DC, area, and is working its way across the United States.

Deamonte Driver's story, featured in the 28 February Metro section of "The Washington Post," is sounding an alarm that health-care gaps among the most underserved populations have serious implications. The majority of children, like Deamonte, experience some tooth decay. However, lower income families who typically are without dental insurance are at extreme risk for dental disease complications.

Deamonte's mother, aware her son suffered with toothaches for months, sought care. Multiple administrative snafus, combined with the challenges of finding a dentist who accepted Medicaid and was receptive to seeing Deamonte, eventually doomed him. The toothaches gave rise to a headache, but little did Deamonte's mother know that this was no "regular" headache; a bacterial infection spread to Deamonte's brain. After hospitalization, extraction of the infected tooth and brain surgery, Deamonte showed some improvement, but he died suddenly on 25 February.

How could this happen? How could an otherwise healthy child die from not receiving proper care for one of the most common childhood diseases-and one that we know how to diagnose and treat? Sad to say, there are many children suffering from tooth decay, like Deamonte. We need to take action before it is too late. Dental care has never been better for those who can afford it or have insurance covering not only care for disease, but cosmetic services such as tooth whitening or braces. The truth is, there are tens of millions of people who just cannot afford dental care even when lives depend on it; Deamonte's passing reminds us that lives do.

Sadly, insufficient dental care affects other high-risk populations, including people with intellectual disabilities representing some 6 million people in the United States. Special Olympics has taken a proactive approach to provide invaluable health services to athletes through the Healthy Athletes® program; Special Smiles, the dental screening arm of Healthy Athletes, was one of the first programs implemented when the program began 10 years ago. Through Special Smiles, Special Olympics discovered that one-third of its athletes have decay in their molars, half have obvious gum infections, more than one in 10 report mouth pain at the time of their screening exam, and too many are missing teeth where extraction was

selected as the method of treatment over restoration. The reasons for this are many and include challenges that people with intellectual disabilities have with personal preventive practices; but, more incriminating are the lack of willing providers to treat this population, lack of adequate health insurance or programs to support this care and a quiet conspiracy of indifference among policy makers who could help solve this if they wanted to. We were shocked to discover that people with intellectual disabilities are not officially considered a "medically underserved" population by the federal government.

There is now significant documentation reporting the health needs of people with intellectual disabilities. In fact, the last two Surgeons General have issued reports on this problem, calling for more and better care, better preventive services, and better trained health professionals who can treat this population. Special Olympics has, through U.S. Congressional testimonies, publications and conference presentations, clearly elucidated the health status and health needs of this population. In recognizing and trying to improve a void in finding medical professionals who treat patients with intellectual disabilities, Special Olympics designed a Web-based Provider Directory ([http://www.specialolympics.org/Special+Olympics+Public+Website/English/Initiatives/Healthy\\_Athletes/Provider\\_Directory/default.htm](http://www.specialolympics.org/Special+Olympics+Public+Website/English/Initiatives/Healthy_Athletes/Provider_Directory/default.htm)) which allows health providers to self-identify themselves as service providers for people intellectual disabilities or their families. But, sadly after being in operation for more than a year, and following an aggressive promotional campaign targeting health profession organizations, the Web site has drawn interest from fewer than 1,000 of the more than 1 million health professionals in the United States.

U.S. policy makers at local, state and national levels over the years have slashed funding for dental care programs, explaining that dental disease doesn't lead to impending danger. At Special Olympics we recently heard a moving story from a Special Smiles participant who, due to a screening at one of our athletic competitions, was diagnosed with gum cancer, received follow-up care, and is now cancer-free and has gone on to become an athlete leader and global spokesperson for our movement. Deamonte's tragic story reminds us that you can in fact die from dental disease, but in this day and age, with numerous preventable options available, you shouldn't have to-especially if you are a child or a person with special needs. Health professional organizations have taken important steps in initiating education about critical public health concerns; however these programs are totally inadequate for the underserved. We still have much more work to do and sadly not much to smile about today.

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#### 4. Expect the Best for Your Child's Dental Home

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By Dr. Paul Casamassimo September 5, 2007 EXPECT MORE, EP's online newsletter Vol. 1, Issue 05 September 2007

[Dr. Paul Casamassimo is Professor at the Ohio State University College of Dentistry and Chief of Dentistry at Nationwide Columbus Children's Hospital, in Columbus Ohio. He has devoted his career to care of exceptional children and adults for the last 30 years.]

Too many parents of children with special healthcare needs come upon dental care for their child out of necessity or urgency. In order to make the relationship most beneficial, the preferred way is to establish a Dental Home during your child's infancy.

The Dental Home is the oral health corollary of the Medical Home concept that the American Academy of Pediatrics (AAP) has fostered to improve the quality of care for children, beginning at birth. Midway in this current decade, most professional organizations concerned about oral health of children united to push for a national practice shift to place every child in a Dental Home by his or her first birthday. The American Dental Association (ADA), the AAP and the American Academy of Pediatric Dentistry (AAPD) all support the Dental Home-a concept now synonymous with the age-one dental visit.

The Dental Home is a place for your child, but as you will see throughout this article, it really is a relationship, a frame of mind, and peace of mind. The purpose of this article is to mentor families to seek the best care for their child and to establish a life-long relationship with a dentist who can meet your needs and those of your child.

Start early. Do not wait for the first birthday to begin thinking about finding a Dental Home. Special needs often touch the oral cavity, and your child's relationship with a knowledgeable dentist may begin with feeding issues, changes in oral structures, and preparing you and your child for developmental changes coming down the road-all right from birth. As you read and learn about your child, make mental notes about what to discuss with your child's dentist.

Find a pediatric dentist. Honestly, what you may find as the parent of a special child in some cases is what you have experienced when seeking medical care-a willing dental professional with the best of intentions but a little rough around the edges. Of course, there are exceptions. If he or she has worked with families like yours and trained beyond dental school in caring for children with disabilities and special medical needs, then he or she is better qualified to treat your child. For instance, a pediatric dentist is trained beyond dental school in caring for children with special healthcare needs and has probably cared for many children like yours in training and then in practice. General dentists do not uniformly receive training in the care of special patients, although some may have had additional training after dental school encompassing patients with special healthcare needs. Pediatric dentists are also more likely to have affiliations with hospitals and established relationships with pediatricians and other child specialists, which creates a network of health professionals dedicated to your child's well being.

Come prepared and knowledgeable. After 30 years of practicing in a pediatric hospital and several developmental centers, I still have lots to learn about my patients. Most parents of children with special needs are eminently versed in their child's disability and the adjustments of family life, so a dentist's lack of familiarity should not be a turn off. Many conditions exist, many are mixed, and medical treatments change frequently. Therefore, your child is truly an exceptional child in every sense of the word! It is up to you to present your expectations or a chief complaint and a view of daily life or family, medical, and social histories, because your child is unique. Bring your child's history and articles about your child if a condition is rare or mixed. The list of medications is a must. Bright Futures, a set of national health supervision

guidelines, encourages parents to attend every health visit armed with questions and information to maximize the benefit of that visit.

Trust a clinician who listens. Most dentists who care for children with special needs will agree that they are no more prone to common dental problems, such as tooth decay and gum disease, if provided with early preventive therapeutics and parental education. Similarly, treating most children with special needs requires skills that dentists use on everychild. What may be different is the dentist's preventive plan and treatment approach for your child because of his or her constellation of strengths and weaknesses. The skilled dentist will listen, look, and learn a little from initial trial and error-all with your help.

The practice should be welcoming. Basic accessibility is not taken for granted, but does the office or clinic demonstrate the attitude and aptitude for your child and you? This can range from things such as asking about special needs at the first phone call or showing diversity in artwork and décor. A dental office ready to care for all children is staffed by personnel who make you and your child feel at home and safe. This past June, while screening athletes at the Special Olympics, I asked parents about their choice of a dentist for their child. They said, to one, that the dentist's demeanor, patience and willingness to "go with the flow" were the package they looked for...and appreciated.

The Dental Home should be linked to other services. The dentist you choose should have established relationships with other health professionals, both medical and dental, as well as with support services, such as physical therapy, speech and language pathology, and psychology. Most families will have already established an array of service providers they trust, but the dentist must be able to work with these other professionals for the benefit of your child, as might be the case when oral health is a part of the child's Individual Education Plan (IEP), or an intra-oral device is needed to improve oral function. Networking is an important part of continuity of care across the health spectrum

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Tamie Hopp Director of Government Relations and Advocacy Tamie327@hotmail.com

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