

Special Addition



children with special health care needs

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FEDERAL VIEWPOINT

Promoting Healthy Smiles

The National Agenda for Children with Special Health Care Needs (CSHCN) calls for the development of systems of care that are family centered, community based, coordinated, and culturally competent. This agenda addresses a long-term national goal presented in Healthy People 2010: National Health Promotion and Disease Prevention Objectives, which is to “increase the proportion of states and territories that have service systems for children with or at risk for chronic and disabling conditions as required by Public Law 101-239.”



“Healthy gums and teeth are essential to a child’s well-being.”

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LOCAL VIEWPOINT

Oral Health in Illinois

Preventable oral diseases account for a great deal of tooth loss and pain. Poor oral health can act as a focus of infection that can seriously affect general health problems such as coronary heart disease, diabetes, pre-term low birth weight and other medical conditions.

Illinois mirrors the nation in that oral disease and lack of access to dental care is more of a problem for some individuals than others. Families of Children with Special Health Care Needs (CSHCN) have told us they often have trouble finding a dentist willing to work with their

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The Maternal and Child Health Bureau (MCHB) has identified six critical indicators of progress that make up a comprehensive system of care: (1) a medical home, (2) insurance coverage, (3) screening, (4) organization of services, (5) family involvement, and (6) transition to adulthood.

Although the national agenda does not specifically address the oral health of children with special health care needs, it is widely recognized that healthy gums and teeth are essential to a child's well-being. Furthermore, many children, particularly children with special health care needs, face significant barriers to good oral health. With these six indicators in mind, let's look at some ways to promote the oral health of children with special health care needs.

Medical home

The medical home is a source of ongoing health care in the commu-



Primary care health professionals should receive formal training in the promotion of oral health in the medical home.

nity, where health professionals and families work as partners to meet children's needs. The medical home helps identify special health care needs; provides ongoing primary care; and coordinates with a broad range of other specialty, ancillary, and related services. The medical home can promote children's and adolescents' oral health by providing periodic oral screenings, hygiene instruction, anticipatory guidance, and referrals to oral health professionals. Additionally:

- Medical homes should follow up on oral health referrals, as they do on specialty referrals, to ensure that children with special health care needs receive necessary oral health care.
- Primary care health professionals should be compensated fairly for the time and effort needed to effectively promote oral health in the medical home.
- Primary care health professionals should make referrals to dental professionals and should consult with them on health histories and clinical management.
- State and local oral health and MCH/CSHCN programs should work collaboratively to support the adoption of oral health promotion activities in the medical home.
- Primary care health professionals should encourage dentists to provide care for children with special health care needs.

Insurance coverage

Families must be able to pay for the range of services that their child requires. Families who are underinsured or lack insurance must be addressed. Here are six ways to increase the dental insurance coverage for children with special health care needs:

- Sources of payment should be identified to help families who—because they lack dental insurance or because of the high cost of dental procedures—cannot meet the cost of necessary treatment.
- State and local oral health programs and MCH/CSHCN programs should work collaboratively to promote sources of free or low-cost care, such as special clinics, for families who lack dental insurance and financial resources.
- Insurance reimbursement should be increased to adequately compensate dentists for providing care for children with complex medical conditions or behavioral issues.
- Medicaid and the State Children's Health Insurance Program should support special clinics or supplemental reimbursement programs to increase access to care for children with special health care needs.
- Dental insurance exclusions should be eliminated and annual maximums increased for children with special health care needs who may require complex and costly dental treatment.
- Insurance should cover the cost of operating room charges for children with special health care needs whose oral health needs cannot be met on an outpatient basis.

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child. They have to drive long distances to find a dentist, or can't find a dentist willing to accept their All Kids/Medicaid card. Some general dentists are not trained to provide even routine preventive dental care for children and youth who are in a wheelchair, have cerebral palsy, autism, developmental delay and other health conditions. Therefore, some families find their child needs hospitalization and anesthesia for what seems to be fairly routine dental care.

The IFLOSS Coalition is a state-wide advocacy group for oral health. DSCC is a member of this organization, representing children and youth with special health care needs and their families. The IFLOSS Coalition, Illinois Depart-

sure to prevent and control dental cavities. Currently more than 93% of the population of Illinois receives fluoridated water.

School based sealant programs — IDPH has expanded its school based sealant program. As of 2005, 971,255 dental sealants have been applied to 341,323 children and further expansion is expected based on the Oral Health Plan II.

School dental exams and oral health education — New state law requires dental exams for school entrance. The Cavity Buster Pilot program, a comprehensive school health curriculum, was created and is used in many Illinois schools.

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ment of Public Health (IDPH), Division of Oral Health, the Illinois State Dental Society, SIU Carbondale and UIC dental schools, along with many other advocates, have worked hard to improve oral health and access to dental care in Illinois.

Statewide efforts to improve oral health in Illinois include the following:

Illinois Oral Health Plan — This is a five-year plan with goals and strategies focused on improving oral health and access to dental care. The first plan started in 2001. A second plan has been drafted based upon input from public town hall meetings and the collaborative work of an oral health steering committee.

Water fluoridation — Fluoride in community water systems is the most effective public health mea-

Efforts to expand dental services through the All Kids program — Uninsured children will have access to dental services through the All Kids program. The Illinois State Dental Society and the IFLOSS Coalition have worked with the All Kids/Medicaid program to advocate for increased funding for dental services in an effort to increase the number of dentists willing to accept children covered by the All Kids program.

Increased numbers of dental providers in underserved areas — The SIU and UIC Schools of Dentistry have increased community-based experiences for dental students in underserved areas in an effort to increase services in areas where services are sparse.

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Did You Know?

By Claudia L Fabián, FAC Chairperson and IATP Board member

As our children grow, we may find ourselves with technology and equipment that our children do not use any longer or have outgrown. How many times have you thought what to do with those pieces? Or, on the other hand, how many times have you wanted your child to try some new piece of equipment, but couldn't afford to buy a new one?

Well, the Illinois Assistive Technology Program (IATP) now has AT Classifieds that you can access through their Web Site (www.iltech.org), or for more information you can call them at 217-522-7985.

IATP - AT Classifieds

AT Classifieds is designed to provide consumers of assistive technology an opportunity to buy, sell, or donate pieces of equipment. AT Classifieds provides a listing of pre-owned assistive technology devices available for sale or donation. Information is updated weekly.

AT Classifieds Disclaimer

The Illinois Assistive Technology Program is not responsible for negotiations between the buyer and seller and accepts no liability in the exchange. 🌸

Safety Net Dental Clinics — The IFLOSS Coalition has helped expand safety net dental clinics and outreach programs for uninsured and under-insured individuals. Safety net dental clinics are located at various sites throughout the state in federally qualified health centers, community health centers, local health departments, private not for profit clinics, schools of dentistry, dental hygiene clinics and school-based clinics. Information for locating these clinics can be found at www.ifloss.org under “Resources.”

Raising public and professional awareness of the importance of good oral health practices, how to prevent dental caries and how oral health is part of general health — The IFLOSS coalition has developed training programs and materials that are distributed throughout the state by the dental

and health care workforce to help educate the public and professional staff working with families.


The Donated Dental Service Program — This program provides donated dental care to individuals with disabilities, the elderly and medically compromised individuals in need of dental services. Contact information: phone: (309) 689-6785 website: www.nfdh.org

Expansion of the Early Childhood Caries (ECC) prevention program — More training programs are being provided for individuals who have contact with parents about how to prevent childhood cavities, e.g. pediatricians, family physicians, licensed day care workers, educators, WIC programs, health department staff and DSCC staff.

For information about how to help infants, toddlers and teens have good oral health and prevent cavities visit: www.colgate.com. Click on any of the articles listed under “Oral and Dental Health at Any Age.”

For information about where to find safety net dental clinics who accept All Kids/Medicaid and other dental care resources visit the IFLOSS website at: www.ifloss.org or visit these websites:

American Academy of Pediatrics: <http://www.aap.org/commpeps/dochs/oralhealth/resources.cfm>

National Foundation of Dentistry for the Handicapped: http://www.nfdh.org/joomla_nfdh/ 

Our Adventures with the G-Tube

By Evonne Kosnar

Suppose like any adventure you have to have a beginning. Ours began on October 5, 1999 when we welcomed our micro preemie Erica Lee into this world. Born only 11lb 11oz and 25-½ weeks gestation, we knew we had a long journey ahead. We welcomed her with so much love and joy I think that’s what helped her to survive. She finally left the hospital after 2 months 2 weeks and 4 days with a suitcase full of diagnoses.

We didn’t care what we had to endure; for all we knew our baby was going home to finally begin a family life. Oh what a life we have had so far with our Lee Lee, as her grandmother so lovingly nicknamed her.

We began our great adventure first with oxygen tanks all over the house and 2 apnea monitors and a nebulizer close at hand. From there we graduated from all of that into surgeries. So far we have had three brain surgeries, the last one being a double shunt, with one being revised, hip derotation osteotomy, eye correction, and a couple little ones with ear tubes and adenoids and tonsils being removed. Through all of those surgeries we all faired well, especially our Erica. She recovered so quickly from each one it was amazing. I think she had the tenacity and stubbornness from the time she was born to fight everything and get better. The one

“Always always remember you are your child’s one and only advocate.”

surgery that was so hard on all of us, especially her, was the G-tube.

The surgery went well but she was not happy afterwards. She seemed so uncomfortable for the first two weeks but we did not have a clue what to do for her! They basically throw this not so cute little button on your baby and ship you out. Through the advice of our doctors and their trusty little calculators they knew exactly how much to tube her. W R O N G!!! It was

horrible; they first told us she needs the equivalent of 24oz in a day so just get it in her. Just get it in her?!!

No set schedule, no instructions on

how much and how often, nothing. Here is this petite little dolly, my Erica, who didn’t even weigh 20lbs only 3 ½ years old, who was consid

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ered almost on the verge of malnutrition, (even though I still have all her feeding schedules to this day on how much I fed her and when) and they wanted me to just blow her up overnight! I still remember to this day how my girl would cry from tummy aches or throw up often from being tubed too much but we didn't know. It broke our hearts to see her like that. Besides all of that there was the wonderful issue of DRAINAGE. What??

Yes, drainage. That's all the doctors said when we would call quite often to ask why she was so red and oozing by the button. Their recommendation was Poison. The doctors didn't call it poison; it was officially called silver nitrate, but when you got the medicine it had big warnings all over it "Poison." Well, I suppose from their point of view that was the best medicine that they thought should be used to get rid of the excess tissue from her button, but it was horrible. We were afraid to even have it around our house when we also had another little baby who was just starting to explore her new world.

As it was, we used it because we just didn't know. Erica cried and screamed when we did, another heart wrenching ordeal. Well after having the tube for only three months our Erica wound up in the emergency room three times due to the severe redness, tissue growth and throwing up. By the third visit, when she was actually hospitalized for 3 days due to another complication, besides the g-tube, I was at my wits end. I was so upset and helpless on how to help her. With every diagnosis she has, I made it a point to study them and to know what to do: side effects, signs of trouble, etc. When she got the G-tube I was so overwhelmed with this new thing that her body was fighting that I didn't have time to even know where to begin to find literature on G-tube feeding. The hospital didn't

give us any paperwork; the doctors didn't give us any pamphlets, nothing. Well on that third visit I had to find answers. I had to help our little girl. No one can take better care of their child than their parents. I was

“The hospital didn't give us any paperwork; the doctors didn't give us any pamphlets, nothing.”

determined to find relief for her and us. I went to the hospital library and spent over 3 hours looking for anything on G-tubes. Nothing! And what was worse was a lot of the books and articles looked so old. Finally, I stumbled across a Nurse magazine from the early 1990's and it actually had a 6-page article on G-tube!

I read that article twice and couldn't quite understand it, when I got to the last page the last paragraph and almost the very last line, there it was; "if you need any more information on this article or G-tubes please contact the Oley Foundation."

Almost the minute we arrived home with Erica from the hospital I ran to try to call that 1-800 # in hopes that it was still in existence. I do remember I was sitting on the floor and when I nervously dialed that number I was so afraid it was another dead end. To my wonderful surprise a beautiful voice came on the line "Hello this is the Oley Foundation." I had to ask her if she was real, if this place can really, really help me with my baby's G-tube and she said "of course." I was crying so much as I am doing now just remembering that wonderful moment of elation of hope of finally being able to help our Erica. Within a couple of days they sent me a huge envelope filled with newsletters, articles on cleaning the button, what to do about drainage, etc. I carried that envelope around for days like a bible. I had to tell every-

one I found it, I found information, I couldn't believe my fortune. To this day Erica has had no problems with her button because of her wonderful and determined mother who would go the ends of this world to make

her better. She deserves it for all that she has to go

through. Our family does everything to improve the quality of her life.

Through the Oley foundation I learned to crush Carafate tablets and sprinkle it over her site whenever it looks a little irritated. By the next morning, Poof! It is barely a shade of light pink. Some days if it seems a little too red I actually just put some over-the-counter Hydrocortisone cream around the button and that helps to sooth the redness that she may feel. She has never had any more tissue come out because I learned how important it is to continuously check the water volume in the balloon to keep it snug up against her skin. For school I learned to put gauze around the button and to put a form fitting mesh tubing around her waist so it doesn't get tucked too much. I also learned to change the button myself. Ok, I admit I usually make my husband do that under my watchful eye and I feel by changing it we're eliminating a lot of germs you may catch at the doctor's office. I just learned now that her skin seems to be getting a little irritated by the latex gloves. Right now it doesn't seem so severe that I can't clear it up but I am monitoring it very closely. The most important thing I learned was that even though the doctors want her to have a certain quantity of fluids tubed, Erica's body couldn't tolerate it. She has been on Prevacid since she received her tube but as

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of this year she no longer takes it because she has never had any more issues on reflux. Why? Because I know how much she can tolerate. When I hear her coughing too much in the night I know I have to reduce the amount of drips per hour she can handle. Best of all the doctors agree with me because bottom line is she is still gaining weight.

When I received all this info from the Oley Foundation I was so thrilled to tell everyone especially the doctors. I wanted to help other parents. I wanted to get this wonderful place known to them. Thankfully we do have great doctors even though the conditions we were given to care for Erica in the beginning were not helping I know they were doing what they knew, they would not intentionally try to harm her or any one else. The doctors were thrilled also to get some info and asked me if I didn't mind if they gave it to some other parents. Of course I didn't mind. I was elated.

Yes, I was finally able to help others.

I had the opportunity to go to one of the Oley Foundation's conferences, which they hold once a year. They have the conferences all over the United States. I was fortunate to go to the Chicago one downtown at the Rush Hospital. Wow, what I learned there blew me away. I was actually able to talk to adults who had the G-tube and they told me how it feels to be tubed and the difference of even the water temperature being flushed (it should always be lukewarm not cold-it gives muscle cramps in the leg). Since my daughter is non verbal, I now know I finally have a voice to communicate the true feelings of how this button feels to her !! I have been a member with them for over three wonderful years and sometimes if they don't hear from me in awhile they send a cute postcard out to see if we're ok. They actually send out newsletters 2-3 times a year and in the letter they have a page on Medi-

cal Exchange where you can give or receive unused medical bags, tubes, food, etc. FOR FREE. You just have to pay for shipping!

I hope this article has at least helped one if not many of you and that hopefully you will become as fortunate as us to finally come to the end of a very long journey with the trials and tribulations of the G-tube. Always always remember you are your child's one and only advocate. The doctors are there to advise you, you are there to take charge, Do that by listening to your child and their needs and know when something isn't right and never give up on your babies. God gave you that special angel for a reason and even though sometimes you may not feel like you're strong enough to handle it you truly are. Have Faith, Hope, and Love and you'll get through anything. 🌸

1-800-776-OLEY or www.oley.org

Illinois Life Span . . . New and Improved

The "411" for Illinoisans with developmental disabilities has undergone a complete makeover to better improve the quality of life for its users

The Illinois Life Span Project is a statewide information and referral resource network for people with disabilities seeking advocacy, services, and/or supports. Mike Kaminsky, Director of the Illinois Life Span Project of The Arc of Illinois, announces the launch of the "new and improved" Illinois Life Span website at www.illinoislifespanspan.org.

Basics such as housing, transportation, employment and recreation are often difficult if not impossible for people with disabilities to access. In 2001, the Illinois Life Span Project, under The Arc of Illinois, was

created to answer that need. The Project was funded through a grant from the Illinois Council on Developmental Disabilities.

In a continuing effort to respond to consumers, the "new and improved" website contains interactive features and a new easy to use format. A Forum section where people can contribute ideas, share information, and ask questions of others who share the same concerns is one of the important new interactive elements. In the new Classified Ads section, registered users can advertise job openings, shop or sell items, or even look for a roommate.

The new website has the ability to keep Illinois consumers up to date on important events as well as informed about timely disability-related issues.

As in the past, the Illinois Life Span Project offers knowledgeable information specialists who staff the toll-free hotline and are available to assist consumers to find the support and services they are seeking. For additional information, please contact Illinois Life Span Project staff at our toll-free number, 1-800-588-7002 or visit us on the web at www.illinoislifespanspan.org. 🌸

Screening

Infants and children with health conditions that place them at high risk for oral health problems must be identified early so that they receive the care needed to prevent oral disease and promote optimal development. There are a number of ways to increase screenings for oral disease and developmental problems:

- Advocates for children with special health care needs covered by Medicaid should be familiar with their state's latest Early and Periodic Screening, Diagnostic and Treatment periodicity schedule relating to oral health services.
- Programs that serve children with special health care needs should include oral health screenings as part of general-health or life-quality assessments.
- State and local oral health programs and MCH/CSHCN programs should provide technical assistance to other programs that wish to incorporate oral health screening activities.
- Health professionals should routinely screen children with special health care needs for oral disease and developmental problems and should provide parents with anticipatory guidance on how to inspect and take care of their child's mouth.

Organization of services

For services to be of value to children with special health care needs and their families, the health care system should be organized to identify oral health needs and should provide services in accessible, family-centered, and culturally appropriate contexts. Oral health can be included in "systems of care" in these ways:

- Primary care health professionals should promote "seamless" systems of health care by ensuring that children and adolescents with oral health problems are referred to oral health professionals.



Screening protocols that are part of early intervention programs for children with special health care needs should include inspection of the mouth.

- Families should receive help navigating complex medical and oral health care systems through the use of care-coordination or patient navigation services, family support programs, and advocacy programs.
- If appropriate oral health services for children with special health care needs are not available in the local community, health professionals – including oral health professionals – should recommend other sources of care, such as hospitals or specialized clinics outside the community.
- State and local oral health programs and MCH/CSHCN programs should be familiar with local and regional oral health resources, and should advocate for adding necessary resources to deficient oral health care networks.

Family roles

Families are pivotal in making any system of care work for children with special health care needs. Family members, representing the diversity of the community, must play meaningful roles in the development of systems at all levels of policy, programs, and practice. The role of families in the oral health of

their children can be promoted in these three ways:

- Health professionals, health departments, and parent support organizations should take an active role in empowering parents to act on behalf of their child.
- State and local oral health programs and MCH/CSHCN programs should collaborate to undertake surveys to assess oral health status and treatment needs and should seek input from families.
- State and local advisory bodies and planning groups that address issues related to children with special health care needs should involve families interested in improving the oral health care system.



Parents should be taught to take care of their child's mouth at home and to understand how to obtain appropriate oral health services.

Transition to adulthood

When adolescents with special health care needs become adults, they must be able to expect good health care, employment with benefits, and – to the extent possible – independence. Appropriate adult health care options must be available in the community and must be provided within developmentally appropriate settings. Adolescents must be prepared to take charge of their own health care to the degree that they are able. As

(Federal Viewpoint) please see page 8



Adolescents transitioning from the home to more independent living arrangements should be taught to select oral health care products, to perform oral self-care (e.g., regular toothbrushing), and to eat foods that promote optimal oral health.

adolescents with special health care needs transition to adulthood, their oral health can be promoted in the following ways:

- Caregivers should assume daily responsibility for maintaining the oral health of adolescents who are unable to do so for themselves.
- Caregivers and agencies responsible for the care of adolescents with special health care needs who are living out of the home should perform periodic oral assessments and arrange for necessary oral care.
- State and local oral health programs and MCH/CSHCN programs should provide technical assistance to caregivers and agencies that promote the general welfare of adolescents living outside the home.
- Adolescents with special health care needs often lack employment-

related dental insurance and may lack Medicaid dental benefits as adults; for these adolescents, alternative sources of dental insurance and reduced-fee options should be identified. 🦋

Adapted (with permission) from the policy brief Promoting the Oral Health of Children with Special Health Care Needs—In Support of the National Agenda, written by the Association of State and Territorial Dental Directors, Children with Special Health Care Needs Advisory Workgroup, with special thanks to Jay Balzer, DMD, MPH, who served as project coordinator and primary author.

For further information visit:
<http://www.mchoralhealth.org>

VISIT THE DSCC WEBSITE

www.uic.edu/hsc/dscc/

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Alternate formats are available on request by calling
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