

# Special Addition



children with special health care needs

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## Federal Viewpoint

### Have you heard?— the Universal Newborn Hearing Screening and Early Intervention program

by Irene Forsman, Health Resources and Services Administration

*Hearing loss is the most prevalent birth defect. Approximately two to three infants per thousand are born with some level of hearing loss.*

Within the past 10 years, the percentage of infants screened for hearing loss before hospital discharge rose from less than five percent to 90 percent. Because of technological advancements, hospitals and birthing centers can now easily perform cost-effective



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## Local Viewpoint

### Newborn Hearing Screening in Illinois

by Leslie Frederick, Division of Specialized Care for Children (DSCC)

Hearing can be tested at any age now. Advances in medical and audiological technology now make it possible to detect hearing loss in the early days of a newborn's life.

The development of good communication skills happens in the

first months and early years of a baby's life. Therefore, it is very important for hearing loss to be detected as early as possible so the child and the family can receive audiological services and intervention as soon as possible. These services

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*"A clean conscience is a soft pillow."*

“There is clear evidence that universal newborn hearing screening substantially lowers the age at which children with congenital permanent hearing loss are identified.”



Research also shows that infants enrolled in an intensive intervention program by six months of age perform as much as 20 to 40 percentile points higher on school-related measures (reading, arithmetic, vocabulary, articulation, intelligibility, social adjustment and behavior) than children who do not receive such intervention.

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physiological hearing screening on all infants before hospital discharge, and therapeutic intervention before six months of age.

Most established programs are able to screen more than 95 percent of all newborns before discharge. Many states have legislative mandates that

require universal hearing screening. Few states, however, include follow-up services, reimbursement, or requirements for reporting and tracking as a part of these mandates.

The Universal Newborn Hearing Screening and Early Intervention (UNHSEI) program funds grants to states for universal newborn hearing screening before hospital discharge, diagnostic evaluation by three months of age, and appropriate intervention services by six months of age. The program reflects expansion of newborn screening and early intervention expressed in Goal #5 of President Bush's New Freedom Initiative (see box on page 7).

### Diagnosis and intervention

There is clear evidence that universal newborn hearing screening substantially lowers the age at which children with permanent congenital hearing loss are identified. Typically, one to three percent of those screened require referral for further diagnostic evaluation and admission into an early intervention program.

Yet appropriate and timely diagnosis and intervention continues to be a major challenge. In the U.S. the average age at which children have been identified with hearing loss is two and a half years, with milder losses frequently not recognized until

a child enters school. In addition, attrition rates as high as 60 percent between initial referral and diagnostic confirmation are still typical. Linkages between screening programs and early intervention programs are not well established. Further, data management and tracking of infants through this process are still in the developmental stage.

### State grants

In April 2000, the Health Resources and Service Administration (HRSA) awarded 22 state UNHSEI grants. In October of 2000, the Centers for Disease Control and Prevention (CDC) awarded 15 state grants to assist with developing Early Hearing Detection and Identification (EHDI) tracking and data management systems. This was the culmination of a concerted effort to promote newborn hearing screening programs using physiologic testing before hospital discharge.

The states use the grant funds to develop statewide systems of newborn hearing screening, audiologic diagnostic testing by three months of age, and enrollment in early intervention programs by the age of six months, with ties to a medical home and family-to-family support services. Currently, HRSA is supporting 53

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will support babies who are identified with hearing loss to learn language and build connections with their family and their world during their early learning.

Research shows that permanent congenital hearing loss of greater than 25dB HL (hearing level) in the poorer ear is present in at least three newborns out of every thousand babies. Given Illinois birth rates, approximately 500 infants will be born each year with significant hearing loss.

In 1999, the Illinois legislature passed the Hearing Screening for Newborns Act. This law required that by December 31, 2002, all hospitals performing deliveries screen all newborns prior to discharge and report the results to the Department of Public Health (DPH). The Department of Human Services (DHS) was required to establish a Hearing Screening Advisory Committee to develop policies necessary to implement the law. DSCC is a member of this committee. As a result of the work of this committee and other dedicated individuals, all 137 birthing hospitals are screening newborn infants for hearing loss. In 2003, 98% of the infants reported to DPH were screened, and 4% of those

were referred for follow-up. The average age that babies in Illinois were diagnosed with hearing loss was 3.2 months. The goals for the Illinois newborn hearing screening program are the same as those in the national article: hearing loss diagnosed by 3 months and intervention by 6 months.

Illinois has received grant money from the Centers for Disease Control and Prevention to assist in implementing the program. DSCC has applied for a grant through the Maternal and Child Health Bureau (MCHB) to improve the program and focus on intervention.

Along with the help of professionals from audiology, medicine and

the valuable help of those from the deaf/hard of hearing community, services are available to parents and their babies through State agencies such as DPH, DSCC, DHS and the Part C Early Intervention program. DPH is charged with collecting information on each child with a positive hearing screening result and maintaining a registry of confirmed cases, including information needed for the purposes of follow-up. DSCC is responsible for

providing payment for diagnostic hearing evaluations for babies who do not pass the hospital screening tests, linking families with other beneficial programs and helping arrange for treatment and hearing instruments when hearing loss is confirmed. DSCC can also pay for this treatment for families who meet income guidelines. Early Intervention programs are responsible for providing education, training in communication and language, hearing instruments and case management.

DHS, DPH, and DSCC are all working together to assure that

babies born with a hearing loss are able to receive early identification and intervention, as outlined in the national

article, so that babies have the greatest opportunity to develop normal communication skills.

If you have any questions about the newborn hearing screening program, please call DSCC at 1-800-322-3722. If you, as a parent or grandparent, want to talk about your questions or concerns about your baby's hearing or the newborn hearing screening done at your hospital, please call the DPH Newborn Hearing program at 217-782-1234. □

Some babies are born listeners but all babies need a "sound beginning!"

## ATTENTION DSCC FAMILIES

Watch your mailbox for our survey!



During the months of January and February of 2005 DSCC will be asking for your feedback through a survey that will be mailed to your home. The Survey called, "Illinois Children with Special Health Care Needs Survey," will be your opportunity to share both the positive and negative points on a variety of issues regarding the health care needs of your child. The last survey, completed 5 years ago, helped DSCC address many issues identified by our families. So, watch your mail for the survey and return it as soon as you can in the self-addressed envelope. We look forward to hearing from you soon.

## Family Advisory Council

### A member's perspective

I joined the Family Advisory Council in 2001, shortly after my daughter, Victoria, enrolled in DSCC's Home Care Waiver program. Victoria is a darling 9-year-old girl who has severe medical complexities. She has brought me into a world that I never expected to enter. Through it all, she has been my greatest teacher. She has taught me to appreciate the little triumphs, which are precious blessings, and to gain important insight from the perceived struggles. One of her many gifts has been to get me actively involved in advocating for families of Children with Special Health Care Needs (CSHCN). That is why I joined DSCC's Family Advisory Council.

It is rewarding to give DSCC leadership comprehensive feedback on the family perspective concerning what it is like to raise a CSHCN from the only people who can truly understand: parents and guardians of CSHCN. This, in turn, helps the leadership when they decide on policies, rules and regulations that affect these families. We review and make suggestions on policies such as the annual Title V Block Grant application and report. Last year we offered suggestions on family materials like the Family Handbook, Illinois Family Survey, and even HIPAA documentation. After our June 2004 meeting, we decided to restructure our format in order to better serve DSCC. We will assist with promotion of the Medical Home, which is one of the goals of the Healthy People 2010 initiatives. It is exciting to be part of the cutting edge of what is happening on the Federal and State levels.

Everyone at DSCC is very interested in our input. They want DSCC's family-centered care to be reflected in everything they do for families. There

are parents from DSCC's Core and Home Waiver programs. Having parents' feedback from both programs offers DSCC leadership important insight. There is a feeling of partnership between the DSCC leadership and the parents on the Family Advisory Council.

Other parents ask me how I have the time to participate with DSCC Family Advisory Council. My response is, how can I not make the time? It is a rewarding experience in which I gain as much as I give. Being on DSCC's Family Advisory Council has many benefits. I have gained the satisfaction of knowing that I am making a difference that will positively impact the lives of the 25,000 families that DSCC annually serves all over Illinois. Preparing for meetings keeps me abreast of what is going on at DSCC and even at the Federal level. I feel that the time commitment is an investment in the future of my child and all DSCC children. It has helped to turn my life around. When Victoria was born, I went through a grieving process and was looking for the help and support of other parents. Now, being on the DSCC Family Advisory Council and involved with other advocacy organizations, I know that my unique perspective is respected and valued. This gives me the confidence to continue on my pursuit to improve the lives of other families with CSHCN.

As parents of CSHCN, we have something to offer that no amount of schooling could ever teach. In myself, and in other parents, I have seen personal growth by giving back. I have heard from parents who say they are nervous about joining a Board. Once they join, they excel in self-discovery as they find hidden talents they didn't know they had, and realize how many strengths and skills they truly have acquired from parenting their special child.

We meet three times a year in DSCC's Springfield office and have conference call meetings several times a year. I even enjoy the ride to and from Springfield. I get to be on my own, with no interruptions listening to a book on tape or my favorite music. It's very relaxing. I would highly recommend that any DSCC parent or guardian who is interested in making a difference and growing personally to join DSCC's Family Advisory Council.

If you are interested in the Family Advisory Council contact Bob Cook, Family Liaison, at 1-800-322-3722 or at his e-mail [rjcook@uic.edu](mailto:rjcook@uic.edu). □

## Illinois Resources

The organizations listed below are called Parent Training & Information Centers which provide training and information to parents of infants, toddlers, children, and youth with disabilities and to professionals who work with children. This assistance helps parents to participate more effectively with professionals in meeting the educational needs of children and youth with disabilities.

These programs are funded by the Office of Special Education Programs in the US Department of Education.

### Parent Training & Information Centers can help parents to:

- Understand their children's specific needs
- Communicate with professionals
- Participate in their children's educational planning processes
- Get information about programs, services, and resources

*please see page 5*

Internet Site  
Check it Out

## Family Village

A global community of disability-related resources  
[www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)

The Family Village website integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those that provide services and support.

Family Village includes informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature, and much, much more!

Personally, I have found this website a very valuable resource in my journey with my family. So stop in, stroll around, and visit some of the Family Village's attractions. Simply click on a place to explore and discover a cornucopia of useful information!

Bob Cook - Family Liaison

### VISIT THE DSCC WEBSITE

[www.uic.edu/hsc/dscc/](http://www.uic.edu/hsc/dscc/)



This newsletter is available online and in alternate formats in English and Spanish upon request by calling 1-800-322-3722.

## Teen Corner

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Please contact any of the Centers in Illinois for assistance

### Designs for Change

29 East Madison, Suite 950

Chicago, IL 60602

312-236-7252 VOICE

312-857-1013 TTY

312-236-7927 FAX

E-mail:

[markse@designsforchange.org](mailto:markse@designsforchange.org)

Website: [www.designsforchange.org](http://www.designsforchange.org)

### Family Matters (ARC Community Support System)

2502 South Veterans Drive

Effingham, IL 62401

217-347-5428 VOICE

217-347-5119 FAX

866-436-7842 Toll-Free

E-mail: [info@fmptc.org](mailto:info@fmptc.org) or

[deinhorn@arc-css.org](mailto:deinhorn@arc-css.org)

Website: [www.fmptc.org](http://www.fmptc.org)

Serving: Statewide except Chicago

### Family Resource Center on Disabilities

20 E. Jackson Blvd., Room 300

Chicago, IL 60604

312-939-3513 VOICE

312-939-3519 TTY/TDY

312-939-7297 FAX

1-800-952-4199 IL only

E-mail: [frcdptil@ameritech.net](mailto:frcdptil@ameritech.net)

Website: [www.frcd.org](http://www.frcd.org)

The purpose of this article is to share the thoughts of youth with special health care needs. The Family Advisory Council developed the questions for this article. A member of the Council asked the following question to her teenage son.

*“Are your peers comfortable with you and your disability?”*

**Curtis**—For the most part, my parents brought me up in a household that did not dwell on “disability.” For this, I have never really seen myself as different early on. As I aged, there were things that I wanted to do, but my disability kept me physically from participating—like contact sports. My peers or classmates started to school as I did when it was expected. For the most part, they saw me as “Curtis” who does things a little differently, but also as a friend/competitor, as I was always included in everything everyone else did. If I needed an assist, my classroom aide might be available or an assigned “buddy” was there to pick up the slack. I always wanted to do for myself if I could, but knew someone was there in the event I needed help. Everyone knew me and would say “hi” or “how are the Cardinals doing?” They knew what my hobbies were so that we had some common ground about which to converse. In my neighborhood, “rural” as it is, 3-4 of my classmates were also my neighbors, and my best friend’s mom drove my van. So I had a good support network. Not to say there may be a few that questioned my appearance and differences—but when they found I could participate and also meet or match them on several different planes, they changed their opinions. Now that I’m out of school, I don’t see my friends on a daily basis, but all of the contacts are still there and I’m still highly visible in my community. My community has limited resources available to people with disabilities and programs to meet the needs of different degrees of disability. I keep active by attending local school sports functions and I was voted the “SuperFan” my senior year. I also have the Cardinals that keep me active on a daily basis and hopefully a World Series banner this coming year. I’m happy and healthy and do what I enjoy. Who can argue that?

Curtis/Mom

*“A bully is always a coward.”*

## Spasticity Management Options Available for Youths with CP

by Nancy A. Murphy, M.D., FAAP and W. Carl Cooley, M.D., FAAP

**M**ore than 100,000 U.S. children are disabled by cerebral palsy (CP). Over the past two decades, CP has increased in prevalence by 18%, from 1.7 to 2 one-year survivors per 1,000 births.

Providing a primary care medical home for children and youth with CP includes coordinating the optimal management of complications.



Dr. Murphy

Ideally, this involves planned co-management with appropriate specialists or a multidisciplinary neuromotor clinic. Spasticity is the most common

movement disorder complicating CP. Symptoms may include hypertonicity, hyperreflexia, incoordination and weakness. Undertreated spasticity or delayed treatment can contribute to orthopedic deformities such as hip dysplasia, joint contractures and neuromuscular scoliosis.

Spasticity can cause pain directly, but also can contribute to chronic musculoskeletal pain, feeding and elimination disorders, sleep disturbances, decreased participation in school and community activities, and a slowly progressive functional decline. Physical therapy is the foundation for essentially all therapeutic interventions in children with spastic CP. Physical therapists focus on gross motor skills, establishing individualized range of motion and strengthening exercise programs and addressing adaptive equipment needs. Similarly, occupational therapists focus on fine

motor skills and activities of daily living (dressing, bathing, toileting) through the use of therapeutic exercise programs, upper extremity orthotics and adaptive equipment.

Therapy alone, however, often is not enough, and is best prescribed in combination with other interventions. In a quick office-based procedure, botulinum toxin can be injected into the muscle bellies of targeted spastic muscles, providing focal relaxation for three to six months. The toxin can be injected into calf muscles to reduce toe walking and into hip adductors to reduce scissoring and progressive hip subluxation.

When spasticity is generalized, systemic medications such as baclofen, diazepam, dantrolene and tizanidine can be prescribed. Side effects, particularly fatigue and weakness, can limit the usefulness of these systemic medications in many children. In such instances, surgical interventions may be indicated.

Chronic shortening of spastic muscles leads to contractures that threaten immature bones and joints. When this occurs, children with spastic CP often undergo lengthening procedures of the hip flexors, adductors, hamstrings and heel cords. These soft tissue procedures address the results of spasticity but not the spasticity itself, and therefore, should be coupled with other spasmolytic interventions. Children with primarily lower extremity spasticity may benefit from selective dorsal rhizotomies, in which

neurosurgeons identify and cut those sensory rootlets from L2 to S2 that trigger abnormal motor responses. When oral medications are ineffective or poorly tolerated, intrathecal baclofen therapy offers a good alternative. A programmable, refillable pump is implanted into a subcutaneous abdominal pocket and is connected to a tunneled catheter system that infuses baclofen continuously into the spinal canal. Pediatricians providing a medical home are vital to coordinated interdisciplinary care for patients with CP and their families. They need to be aware of the many spasticity management options now available for children with CP. Research efforts

over the past decade have focused on reducing spasticity, and children with CP now can benefit through the translation of findings into clinical care. With timely and appropriate interventions, children with CP can enjoy increased quality of life, immediately and across their lifespan. □



Dr. Cooley

*Drs. Murphy and Cooley are members of the AAP Section on Children with Disabilities.*

### Footnotes

A new clinical report from the AAP Committee on Children with Disabilities titled Providing a Primary Care Medical Home for Children and Youth with Cerebral Palsy will be published in the October issue of *Pediatrics*.

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state/territorial programs and a national technical support center. These grants are located in 49 states plus the District of Columbia and three US territories (Guam, the Northern Marianas, and Puerto Rico). The national technical support center is the National Center for Hearing Assessment and Management (NCHAM) at Utah State University, under the direction of Karl White, PhD. NCHAM provides nation-wide technical assistance and consultation to projects in all of the program areas. These projects, which represent broad geographic distribution, as well as rural/urban areas, all have some level of newborn screening and early intervention activity to date, with the majority of states screening more than 95% of infants.

### Two state programs

Kentucky and Massachusetts are just two examples of productive screening and intervention programs. In Kentucky's case, 99.4% of all infants born are screened. Of those who fail screening, 4.1% are referred to audiologic evaluation. The average age of diagnosis is 5 months and the average age for early intervention is 6 months. Most (98.1%) of the infants have a medical home, and Kentucky has a parent-to-parent network group. In addition, Kentucky also uses a state-of-the-art web-based data tracking system.

In the case of Massachusetts, although 99% of all infants are screened, only 1.4% are referred for further audiologic evaluation. Of those referred, the majority (76%) are diagnosed at 3 months or earlier. Like Kentucky, Massachusetts has a family-to-family network. Massachusetts, however, uses the electronic birth certificate to collect metabolic and genetic testing data.

The program enjoys strong support from professional organizations, including the American Academy of



**“nearly half of all newborns who do not pass hearing screening tests do not return for follow-up services”**

Pediatrics (AAP). To increase the awareness and involvement of physicians with UNHSEI programs, the CDC and HRSA awarded funding to the AAP for *Improving the Effectiveness of Newborn Hearing Screening, Diagnosis and Intervention through the Medical Home*. As part of this program, AAP chapters have appointed an EHDI chapter champion as the point person on EHDI-related issues at the state and local levels. Most states have a chapter champion.

Currently, there is limited information that indicates parents and primary care physicians are in favor of screening and early intervention. Consequently, it is the goal for the AAP chapter champion program to increase the awareness of the newborn hearing screening programs in their states. AAP also plans to expand its outreach to family

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### Title V and President Bush's New Freedom Initiative

Title V of the Social Security Act, revised in 1989, authorized funds for fiscal year 1990 and each fiscal year thereafter for the purpose of enabling each state to provide family-centered, community-based, coordinated care (including care coordination services) for children with special health care needs and to facilitate the development of community-based systems of care for such children and their families.

The Integrated Services Branch (ISB) of Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB), Division of Services for Children with Special Health Needs (CSHCN), which administers this provision of Title V, promotes leadership and support for the development and implementation of innovative, replicable models of community-based care for children with special health needs in six program areas: Medical Home, Family Professional Partnership/Cultural Competence, Financing/Managed Care, Community Integrated Services, Early and Continuous Screening and Early Intervention, and Healthy and Ready to Work.

The primary objectives of the CSHCN program are to fulfill the *Healthy People 2010* goals set under Maternal, Infant, and Child Health (Goal 16-23) and accomplish the following specific goals under President Bush's *New Freedom Initiative*:

1. Development of community-based systems of services that are inclusive of CSHCN and their families, where substantial decision-making authority is devolved from the federal government to the states to the communities.
2. Recognition that families are the ultimate decision-makers for their children and encouragement of participation in making informed decisions.

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physicians, public health nurses, physician's assistants, and nurse practitioners.

### Reducing the number who do not seek follow-up services

Although states and hospitals are well on the way to meeting the objective for completing hearing screenings for all infants, national data indicate that nearly half of all newborns who do not pass hearing screening tests do not return for follow-up services (a hearing re-screening, audiometric evaluation, and medical diagnosis). Individual states are using a variety of strategies to mitigate this problem, most of which involve existing public health systems, such as local public health nurses. The collaborative effort with the AAP described above is also expected to reduce the number lost to follow-up.

### Head Start programs

In 2001, the Head Start Bureau initiated an interagency agreement to support a demonstration project of hearing screening in Migrant and American Indian Head Start and Early Head Start sites in Oregon, Washington, and Utah. In 2002, the three states received supplemental funds to reach out to the Head Start programs to assist in providing follow-up testing, diagnosis, and early intervention

services as needed. This has resulted in strong collaborative relationships among service providers in all three states.

To date, more than 100 Head Start staff in 69 program sites have been trained, and 36 pieces of screening equipment have been placed. Screening has been provided to 3069 infants and children; 171 have been referred for medical and/or audiological diagnosis. Most of the abnormal findings were the result of a process occurring after the newborn period, primarily infection. This project has now been expanded to Kansas and North Carolina. Ultimately, all states will have the option of joining this effort and promoting the concept of early and continuous screening.

### Further follow-up

The CDC EHDI is currently funding 29 states and 1 U.S. territory to assist in the development of data surveillance and tracking systems to minimize loss to follow-up. In 2002, the CDC and HRSA entered into an intra-agency agreement to support targeted investigation of the reasons for loss to



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3. Development of standardized elements of the medical home for CSHCN. In addition, the agency will develop and disseminate models of the medical home, and provide additional training resources to primary care professionals to develop medical homes.
4. Review of the variety of reimbursement mechanisms that affect CSHCN.
5. Through the MCHB grant (Title V of the Social Security Act) and the Newborn Genetics program (Title XXVI of the Child Health Act), expansion and strengthening of newborn screening and intervention systems. Promotion of on-going screening of CSHCN.
6. Ensuring that youth with special health care needs receive the services necessary to make the transition to all aspects of adulthood, including conversion from pediatric to adult health care, from school to employment, and then to independence.

follow-up in five diverse states. The investigation will be completed in the summer of 2005. Results will be disseminated. In addition, MCHB began a program-wide review of its newborn hearing screening program in the fall of 2004. □

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Watch for the DSSC Family Survey  
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