



The Eye of the Storm

The past couple of months have gone by in the blink of an eye! At the time of this writing, I have just completed two Town Hall meetings and am preparing to do two more. The first one was in Madisonville, KY in January. The turnout was amazing! In fact, I met a mother of an adopted deaf child whose passion really inspired me. Check out her story in this newsletter. Her story is one that I hope we can help prevent others from experiencing and stresses the importance of early hearing detection intervention. In

Written by
Liz Hill
KCDHH
Executive
Director

The second Town Hall meeting was in Danville, KY in February. This meeting took place after the devastating ice storm hit our state. People were very concerned about safety and communication when there are mass power outages. Additionally, other parents and retired Kentucky School for the Deaf staff expressed concerns about the quality of deaf education for their children. Everyone’s commitment and passion for the issues that mean most to our community is extremely encouraging.

I have two more Town Halls scheduled and I think these meetings are extremely helpful in highlighting the concerns that people have and raising awareness of the need for systems change. It provides a forum for people to come together and shows that we really are capable of uniting together in spite of different communication modalities. I encourage everyone to attend the remaining Town Halls if you have not already been to one. The next one is in Prestonsburg on March 21 and Newport on April 25. I look forward to seeing you there! When the ice storm came through our state, it had a severe impact on the deaf and hard of hearing community. KCDHH worked with KyRID and other local interpreters to check if any deaf people needed assistance while at American Red Cross shelters. Additionally, I did a video log (vlog) encouraging people to form “family trees” whereby local communities would develop a system of checking in on each other. I also stressed the importance of keeping generators and gas

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Eye of the Storm

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grills at least ten feet away from your house to prevent carbon monoxide poisonings. This storm, obviously, was one for the history books. I also referred the Program Director at the Community Emergency Preparedness Information Network (CEPIN) to the vlog on the ice storm because several constituents wrote their stories on our vlog page which highlighted concerns about being able to access instructions and timely information from the networks, from state officials, and from workers at the shelters during times of emergencies.

After the storm was over, KCDHH received news that we will be able to distribute wireless pagers. The distribution of this new equipment is under our Telecommunications Access Program (TAP). This is wonderful news because these pagers can be used to sign up for emergency notification alerts in your local community. More information will be forthcoming as the details of this new project are finalized. Stay tuned for that.

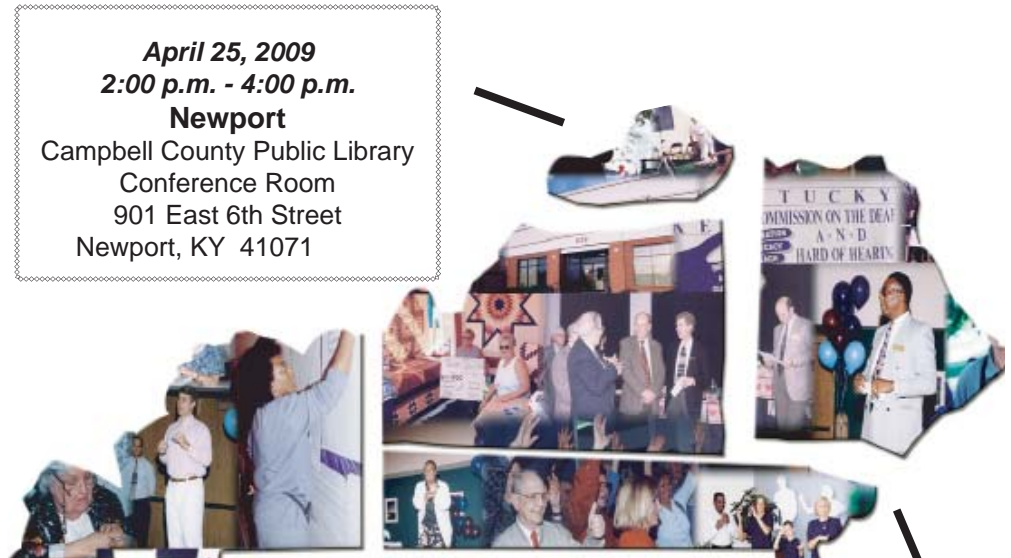
In the following months, KCDHH will be busy as ever. In addition to the Town Halls and working to implement our first ever wireless pager distribution program, which in themselves, are massive undertakings, we will be working to shape our legislative agenda for next year's session. We will also be following up on the feedback we collect from the Town Hall meetings. We will be continuing to spread awareness about what KCDHH does and what you can do for KCDHH.

What the Town Halls are telling me and what the ice storm so incredibly reminded me of is that at the end of the day, we all really do need each other regardless of whether we use American Sign Language or not. We all care about whether newborns are accurately identified as having a hearing loss so they can be given services. We all really need a support network when the power goes out, and information is hard to come by.

Upcoming KCDHH Town Hall Meetings

April 25, 2009
2:00 p.m. - 4:00 p.m.

Newport
Campbell County Public Library
Conference Room
901 East 6th Street
Newport, KY 41071



Interpreters & Captioners on site!

Light refreshments will be served!

March 21, 2009
1:00 p.m. - 3:00 p.m.

Prestonsburg
Big Sandy Development District
Office
110 Resource Court
Prestonsburg, KY 41653

Improving Early Hearing Detection and Intervention in Kentucky

❖ Anne L. Swinford, M.S. ❖

Director of Quality Outcomes Management

Commission for Children with Special Health Care Needs

In Kentucky, since the full implementation of Universal Newborn Hearing Screening (UNHS) under the direction of the Commission for Children with Special Health Care Needs (CCSHCN) in January 2001, the percentage of newborns who have gotten hearing screenings has risen from 52% to 99% of all infants. That progress should make us proud, however what CCSHCN's Early Hearing Detection and Intervention (EHDI) program has found in our most recent data is that only 52% of those babies who do not pass the hearing screening have gotten the recommended follow-up hearing evaluation. Because we do not know what has happened with the other 48%, we are not able to be "comfortable" and celebrate our successful screening program. We know that approximately 3 in 1,000 babies are born with permanent hearing loss, making hearing loss one of the most common birth defects in America. We also know that late identification of hearing loss or lack of early intervention can lead to problems with speech and language development, academic achievement and social/emotional development. Addressing a meeting of the EHDI Advisory Committee last summer, CCSHCN Executive

Director Rebecca Cecil stated, "This situation is quite simply unacceptable. We must improve our follow-up after newborn screening so that no child is "lost to the system" and as a result misses out on the very important early hearing and language stimulation needed in those first few months of life." The EHDI Advisory Committee, which includes representation from the Kentucky Commission on Deaf and Hard of Hearing (KDCHH), made the recommendation to CCSHCN that the



Universal Newborn Hearing Screening program legislation be expanded to include follow up reporting. CCSHCN staff immediately began work designing a process to address the problem. Two federal grants were obtained to help finance efforts to reduce the "lost to follow-up" numbers. Another significant result was House Bill 5, sponsored by Representative Tom Burch and Senate Bill 160 sponsored by Senator Denise Harper-Angel. This bill requires CCSHCN to set standards for infant hearing assessment,

based on national best-practice standards and develop a list of hearing testing centers in Kentucky who meet those standards. Those centers can then choose to be included on the list provided to parents of newborns who do not pass their hospital hearing screening. Parents who choose to go to one of those centers can then be assured that their child is getting the best possible hearing testing follow up care. Another requirement to be included on the "approved providers list" is that the hearing testing center will report test results to CCSHCN so that we can make sure that all children who did not pass the newborn hearing screening have gotten the necessary follow-up testing. In addition to getting audiology services, families of children who have been diagnosed with a permanent childhood hearing loss will be referred to First Steps for early intervention services and given information about all of the services offered by KCDHH. Passage of this

legislation will help Kentucky

to meet the recommendations of the Joint Committee on Infant Hearing which are: infants are screened by 1 month of age; evaluated by 3 months of age and receive intervention by 6 months of age. But the greatest benefit of the legislation is that it will unleash each child's potential for language, socialization, academic success and future success in life. Those impacts will serve the Commonwealth of Kentucky for years to come.

Early Intervention as Prevention: Optimizing outcomes for children with hearing loss

❖Michelle Niehaus, LCSW❖

Consider Sally. At age four, she is so “out of control” that she tore her closet door off its hinges. Her room had to be emptied just to keep her safe. Her parents tried everything and were frustrated with her, themselves, and each other. The situation was wrecking havoc with their lives. At four, Sally didn’t have a solid language base and her parents were worried about serious emotional disturbance. Sally communicated her wants and needs through “acting out,” through using what she had to get her needs met – no matter what the cost to those around her. Upon moving to a new town, her family physician requested a hearing test. Sally failed. One psychiatrist told the family that Sally was “just angry that she was deaf.” They sought other opinions.

Fast forward six months. Sally is in a classroom using Total Communication. In addition to signing, she also uses amplification. Sally’s teacher is trained in Deaf education. Each week, a Deaf adult from the Shared Reading Project comes to read to Sally and teach her mom how to sign the story. This mentor is also a great resource for the parents since they’d never met a Deaf adult before... they weren’t even sure what would be possible for their daughter until they met this successful, poised professional who happened to be Deaf. Sally and her family also attend counseling with a therapist fluent in ASL and knowledgeable about Deaf culture. She linked them to resources and other families struggling with similar issues. Sally no longer damages property and is, in fact, developing an emotional vocabulary so that she can express her feelings and needs. She still struggles with social skills and sometimes has difficulty calming herself down, but Sally is on her way to being a healthy, well-adjusted child.

What about those lost four years? What do you think life was like for Sally when she had no formal communication system? When she didn’t know how to interpret the world around her or even feel connected to her own family? What would life be like if her hearing loss had been identified at

birth and her parents had been given accurate information and support immediately? Will she ever really be able to “catch up” to peers who had language access from birth?

Unfortunately, Sally’s experience (and that of her family) is not rare. Children have often been misdiagnosed as having a behavioral disorder or intellectual disability like mental retardation when the real issue was undetected hearing loss. Prior to the Early Hearing Detection and Intervention (EHDI) legislation, the average age of diagnosis was 2-3 and, for those with a mild to moderate loss, age 4-6. Those “lost years” represent time lost in language development and early learning that can impact a child and her family for a lifetime.

Early identification and intervention is essential to optimizing the outcomes of children with hearing loss. Without effective holistic treatment, children are at a higher risk for behavioral

problems, decreased self esteem, difficulty with social skills, and poor academic performance. Untreated mental health issues in childhood lead, in turn, to poor work outcomes, difficulties in family life and social situations, and even higher risk for incarceration. In essence, early intervention can also be seen as prevention for future mental health issues.

Many people see mental health treatment as a “last resort” or “only for crazy people.”



However, families confronted with a diagnosis of hearing loss are often overwhelmed, confused, scared, and isolated. Since less than 10% of deaf children have parents with hearing loss, there is a significant “learning curve” and families often don’t know where to begin. Feelings of guilt, shame, and blame are common among parents and can lead to family conflict. Grief is also a normal reaction and can interfere with a parent’s daily functioning as well as his/her interactions with the child who is Deaf or Hard of Hearing. From the child’s perspective, living without language means living without a meaningful connection to the people and world. When early attachments aren’t developed through effective communication with adults, trust, confidence, and coping skills are affected.

Early Intervention: Optimizing outcomes...

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Working with a mental health professional can be a bridge to hope, a way of learning to look at things in a new way and becoming equipped with resources and skills to better function as a family. From the early childhood mental health standpoint, counseling goes hand in hand with the work of other involved professionals. Sessions can focus on learning about child development, sorting through information and making decisions, learning to communicate with the child, and developing skills in behavior development. Some methods, such as Parent Child Interactive Therapy (PCIT) encourage parents and children to work systematically to break old habits and create new, positive ways of interacting as a family.

Healthy child development requires involved, informed parents from day one. A 2004 study (Luckner & Velaski) looked at factors in creating healthy families that have a child who is deaf. Respondents noted that success required a commitment to family, learning to sign with their child, support from extended family, friends, and members of the community. They also noted that professional support and high expectations for the child contributed to health and success.

A diagnosis of hearing loss doesn't mean that a child will develop mental health issues. Nor does it mean that a child can't become anything he or she wants. It does mean, however, that we all have the responsibility to advocate for and provide early intervention that meets the needs of the whole child and recognizes the mental health implications when we fail to do so.

If you or someone you know is in need of a mental health referral to a person knowledgeable about hearing loss and its possible implications, please contact me at Michelle. Niehaus@ky.gov, (502) 564-4456 x4521 (voice) or (502) 564-4000 (VP).

References:

Early childhood (0-5 years) mental health and development toolkit.
<http://www.connectforkids.org/node/3003/print>. Retrieved 2/23/09

Identifying children and families at risk: Surveillance and screening.
<http://www.abcdresources.org/Activities/IdentifyingChildrenandFamilies.html>

Newborn hearing screening.

<http://emedicine.medscape.com/article/836646-overview>. Retrieved 2/12/2009

Resources on Early Childhood Development and Mental Health



www.zerotothree.org

www.connectforkids.org

www.naeyc.org

www.ffcmh.org

From “Nothing”

❖ A loving mother ❖

My husband and I had only been foster parents for about four months when we met a family of children who would forever change our lives and our hearts. Two of the boys, 8 and 7 at the time, were placed in our home and the two youngest siblings, almost 2 and 3 weeks old, followed a few weeks later when their current foster placement did not work out due to one child's out of control behavior. The evening we met the youngest two, our eyes and hearts were immediately drawn to “John”, the nearly 2-year-old child. He was completely out of control and his oldest sibling told us immediately that he would hit, scratch, bite and throw things at us and that they all thought it was funny. John did all that and more, but he never uttered a word. He even laid his beautiful blond curly head on the floor and banged it against the concrete to all of our surprise – then he would just sit up and laugh.

John's tantrums were frequent and unavoidable. He was aggressive towards all of the children in our home and seemed to lash out at his two month old brother more than anyone. However, we noticed the more we kept him on a schedule, the better he acted. We also noticed that if we made him look

at us when we talked, he understood what we were saying better.

On one particular parental visit to the social services offices, the social worker and his supervisor called me to their office to inform me that due to John's continued aggressive behavior toward his younger brother Paul, DCBS had begun to make phone calls to have John placed in an institution in Louisville. Tears stung my eyes as I asked why they would do something like this to a two-year-old child. She replied they thought John was going to kill someone some day – that “he just had that look in his eyes.” When my husband and I looked in his eyes, we saw a beautiful, loving little boy who was trying to express himself. How could they see a killer? I begged them to allow us the opportunity to keep him and help him get whatever type of treatment he needed. They agreed to do this with First Steps coming to our home for intervention.

First Steps completed their standard evaluation and admitted to us that they were told he would be the worst case they had ever had. He received every service they had, including speech therapy. They all used “basic” sign language with him and we could see a difference with him as he began to acquire some language skills. He could now use a few basic words and signs; however, all of the therapists at First Steps encouraged us NOT to use sign language with him because we needed to encourage him to speak.

In the meantime, we were also required by DCBS to take him to several psychiatrists and psychologist where he was diagnosed with Reactive Attachment Disorder, ADHD, Obsessive Compulsive Disorder, possible Bi-Polar and probably Autistic. We

were overwhelmed, but committed to him. By this time, DCBS had made a decision to remove all of the other children from our home, insisting that John was a danger to them.

When he was three years old, he transitioned from First Steps to Head Start. The Head Start personnel recommended he have an evaluation at the Weiskopf Center in Louisville, the leading authority in Kentucky for autism. It was several months before we could get an appointment. When he entered Head Start in August, it was a nightmare from the beginning. The teachers complained about him constantly. There were constant reports about how badly John had behaved, how many times he had thrown things, bitten others, spit, etc. They always implied he would never make it in a regular classroom.

We traveled to Weiskopf Center in Louisville in October 2004. The staff and doctors there told us before we left that they did not believe John was autistic. Their report indicated that he made far too much eye contact and was too interactive to be on the autism spectrum.

My father had said since the day he had met John that he didn't think he could hear so we took it upon ourselves to have John's hearing tested. The hearing test we had done came back “normal” with comments that he was probably testing negatively due to his environment.

When he entered his second year of Head Start, the label on his IEP was PDD-NOS or Pervasive Developmental Delay – Not Otherwise Specified. I did not want him labeled developmentally delayed without knowing the cause; however, we could not find two professionals to agree on what was causing John's behavior. While we were seeing improvements at home, the school contended that they were not. We continued to take him to required therapy, doctor's visits and another



to “Everything”

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hearing test because we still had concerns that he could not hear. This hearing evaluation came back “inconclusive” but with a note that it was due to his “autistic tendencies”.

By this time, because my husband and I had accepted that John probably had some type of autism, I studied everything I could get my hands on about the condition. One of the things I began to do was to make John look at me when I talked to him. The first phrase he said was “look at me”. Then we started noticing that he repeated things we said loudly to him: “Stop... don’t...quit”. These were words we were yelling at him in order to try to protect him when he was doing something he shouldn’t do and we were afraid we couldn’t get to him in time. Then we started noticing that he said “NOTHING” when we would ask him something or make a statement to him. It surprised us why he would choose that word, but it was one of his favorite words. My family and friends all had nicknames for him like “Jungle Boy” or “Mowgli” because his behavior was so wild and he would only grunt his words. However, his smile would light up a room. His laughter would fill the house. We knew there was a little boy inside of him just struggling to be free from whatever was holding him back. We could see that he wanted to learn and he picked up on things in his environment “visually” quicker than others. John continued to amaze us at home with how quickly he learned new things. We knew there was a brilliant little boy inside what other people saw as a menace. When it came time for his transition to kindergarten, Head Start told the DoSE (Director of Special Education) that he would never be able to sit in a regular classroom -- he was out of control. We fought back and insisted that he be given the opportunity to attend school at HIS school -- the “least restrictive environment”. We had

his ARC meeting, everyone argued; I held my ground and won the battle. However, before school began, the DoSE told the rest of the team that he would never make it and this would be the worst kid they had ever seen come into the mainstream. I was shocked and dismayed and told her so. She has since apologized and has told me that John will be one of those kids that will haunt her for the rest of her days because she didn’t see it coming.

When he began school in the fall, it was difficult at first and the special education teacher (who I have great respect for) told me she hoped it would work and she would be honest with me if it didn’t. The DoSE had insisted that we get a re-evaluation at Weiskopf Center, so we scheduled that for October. After about one month of school, the special education teacher came to me and asked if we’d had his hearing checked. I repeated the story to her. She told me she didn’t think he could hear. I immediately made an appointment with our ENT and he told me there was no infection, no scarring, nothing that could be “seen”. However, he recommended an audiologist in Owensboro. We made the appointment and after John was tested and it came back “inconclusive”, we thought, “here we go again”. However, this time, they recommended we go to the Commission for Children with Special Health Care Needs. We made the appointment and had the hearing test done there. When it came back inconclusive, they recommended an ABR (Auditory Brain Response). We were told then they thought he had severe hearing loss.

After the ABR, we were told that he had a response at 80db in his left ear and no response at 90 db in his right ear. At the age of 5

years old, after being told we should institutionalize him, take him for psychiatric counseling, put him in an autistic unit, etc., we were now being told that our son was deaf. It didn’t seem possible. The otologist recommended a hearing aid for the left ear and we feared he would never wear it. He cried constantly the first day, but when he heard the telephone ring for the first time, he was so excited and amazed that he didn’t want to take it off!!

Even though it was difficult for us to process and we were in denial in the beginning (because like most of the hearing world we could not understand if he could “hear” how could he be “deaf”) we began to educate ourselves and realized that his hearing was far below the “speech banana”, that we needed to make choices about his language and communication, and that the biggest issue was what we had known for years -- he was in a world all his own and we needed to help him out of it. The DoSE was in severe denial and told us she believed there were other issues even if he did

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Advocating For Your Child: One parent's approach to securing health insurance coverage for hearing aids

❖ Trish R. Freeman ❖

Realizing that your child has a hearing loss can be overwhelming—even devastating for some. Then, just as you start to believe you have come to terms with the situation, you learn that your child's hearing aids, which may cost as much as \$4000-\$5000, are not covered by your health insurance. How do you negotiate with your insurance company for coverage and effectively advocate for your child?

As a parent of two children with a hearing loss, I can personally relate to these feelings and experiences. For several years, I just accepted the fact that "hearing aids are not covered services." When my youngest son's hearing declined again last year and we were faced with the need to purchase new hearing aids (our fourth set in three years), I decided to challenge what seemed to be an arbitrary stance against hearing aid coverage by our insurance company.

After several months of research, preparation, and correspondence with the insurance company, including testifying at a formal grievance hearing

before a committee of physicians and other health care providers, I was ultimately successful. I want to share my experience with other parents and to provide suggestions on how one may approach an insurance company in a similar situation. Important steps to consider in the process are outlined below:

STEP 1: EDUCATE

The first step in effectively advocating for your child is to educate those involved in the process about hearing loss and how it affects children. Most people without first-hand knowledge of hearing loss—including representatives at your health insurance company—are not aware of the consequences of an unmanaged or improperly managed hearing loss. If your child is a newborn or infant, make sure these people fully understand the concept of "auditory brain development" and that early, consistent access to auditory information is imperative for this development to occur.

Provide statistics related to the potential negative educational outcomes of children with hearing loss and the social-emotional and behavioral issues that can significantly affect these children. In addition to the potential negative educational, social-emotional, and behavioral outcomes, research indicates that those with unmanaged hearing loss are also at higher risk for certain negative health outcomes, such as alcoholism, depression, and addiction. AG Bell publications are wonderful resources for this type of information.

STEP 2: FOLLOW THE RULES

Every health insurance company should provide a "certificate of coverage" or benefits booklet or brochure. In your coverage information, a grievance or appeals procedure should be outlined. If you do not have the grievance

procedure in writing, request a copy from your health insurance company's benefit department. Follow this procedure exactly. When you write letters to the company, reference the step of the grievance procedure you are completing at that time. This keeps you on track and makes the company aware that you know your rights and are knowledgeable about your coverage. Be courteous and respectful at all times; provide written materials to support the statements you make in your correspondence. It is important to document every phone conversation and keep copies of all written correspondence between you and the company for future reference.

STEP 3: BUILD YOUR CASE

To effectively advocate for insurance coverage for hearing aids for your child, you must first look at your coverage and plan a strategy. Some plans will list hearing aids as specific exclusions under the plan; others will make no mention of hearing aids at all. Your strategy may vary depending on the exact language in your benefits book. Some strategies to consider are outlined below.



Advocating: One parent's approach...

Mandated Coverage of Newborns with Congenital Defects of Birth Anomalies

Many states have mandates that require insurance companies to pay for services related to the treatment of newborns with congenital defects. For example, Kentucky Revised Statutes Sections 304.17-041, 304.18-032, 304.18-033 reads: "Newborns: Policies providing family coverage must provide benefits for newborns from the moment of birth for injury or sickness, including treatment of medically diagnosed congenital defects and birth abnormalities." If your child was diagnosed at birth, or if you have had genetic testing done that indicated your child's hearing loss was present at birth, you may be able to receive benefits under this mandate.

One key issue is whether your current insurance plan is the same one you were covered by when your child was born. If not, then your current plan might not be responsible for this coverage. Also, if your employer is self-insured, they might not be obligated to follow state insurance coverage mandates. Check the following website (<http://www.eri.com/codes/Kentucky.htm>) to see whether your state has such a mandate, substituting the name of your state for Kentucky.

Prosthetic Device Coverage

If your benefits include coverage for prosthetic devices and hearing aids are not specifically excluded, then you might consider this as your approach. According to one certificate of coverage, prosthetic devices or appliances are defined as "appliances which replace all or part of an absent body organ (including contiguous tissue). Prosthetic appliances are also appliances which replace all or part of the function of a permanently inoperative or malfunctioning body organ." You can then argue that the

ear is an organ and that the hearing aids are prosthetic devices that replace part of the function of this permanently inoperative or malfunctioning body organ. This approach has been successful for some when hearing aids are not specifically listed as an exclusion.

Trish Freeman is the mother of two boys with hearing loss and one daughter with normal hearing. She is Chair of the KCDHH board and is active in the A.G. Bell Association at both the national and state level. Freeman resides in Harrodsburg, KY, with her husband, Ken and their children.



prosthetic devices or appliances as outlined above? If so, then you might point out that it is discriminatory to provide a prosthetic appliance such as a leg brace to a person with a physical disability, but exclude coverage to treat a sensory disability with a prosthetic device such as a hearing aid.

Make the case for the difference between sensorineural hearing loss and conductive hearing loss. Most plans provide coverage for ear tube placement to relieve chronic middle ear fluid and restore hearing to patients with conductive losses of this nature. Find out whether your plan covers surgical procedures such as stapedectomies that restore hearing to patients with conductive losses by replacing a bone of the middle ear with a prosthetic bone. If so, you may point out that hearing aids are the only treatment for persons with less than profound sensorineural hearing loss, and to deny coverage for hearing aids while providing coverage for persons with conductive hearing loss is discriminatory.

Discrimination

Does your plan provide coverage for vision services and eyeglasses but not for hearing aids? If so, then maybe you want to consider the discrimination argument. The Americans with Disabilities Act (ADA) specifically prohibits discrimination against persons with disabilities. Some people have been successful in getting insurance coverage for hearing aids by pointing out that the lack of coverage for hearing aids may violate the ADA.

Does your plan provide hearing aids under some circumstances, such as chemotherapy or drug-induced hearing loss, but not others? If so, then you may also consider the discrimination argument. Does a child who lost his or her hearing because of drug therapy or illness deserve to hear more than a child who lost his or her hearing for reasons that are not known?

Does your plan provide coverage for

HMO Approach

Is your health insurance plan classified as a health maintenance organization (HMO)? If so, you might consider addressing the issue of hearing aids as a treatment that works to "maintain the health of your child." Provide statistics related to the potential long-term negative health consequences of hearing loss as discussed earlier. If your child is receiving speech therapy under the plan, you might argue that properly fitted aids providing the necessary amplification to meet the needs of your child will increase the benefit of the other services currently provided by the plan.

STEP 4: JUST DO IT!

It may seem intimidating to take on your insurance company, but you can do it! As you follow the appeal process outlined in your benefits book, seek input from the physicians, audiologists,

Advocating...

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and other professionals who care for your child. It will help to have a letter from each of them justifying medical necessity and providing their reasons why coverage of hearing aids should be approved.

Do not be discouraged if your case advances to the final step in the appeals process, with the insurance company continuing to uphold denial of coverage. In many cases, the final appeal is a hearing where you may be able to plead your case before a committee of external and impartial medical experts who might be more receptive to your arguments than the in-house insurance company representatives. Legal representation during the appeals process is not necessary. However, if you find yourself at the end of the appeals process and the denial for coverage has been upheld, then your only option at that point may be to litigate.

Although coverage of hearing aids may seem like an expensive option for health insurance companies, some are beginning to recognize the wisdom of providing coverage for children, possibly averting the need for more costly treatments in the future.

Most of the tools needed to effectively advocate for your child are found within you: inspiration, motivation, information, and persistence are the key elements. I hope my story has provided you with some of these tools. Now is the time to put them to use for your child!

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Dr. Patricia Freeman, Chair of the Kentucky Commission on the Deaf and Hard of Hearing, successfully lobbied for insurance coverage for hearing aids for children.

Read below...

SB 152: Health Insurance Coverage for Hearing Aids

SB 152, which went into effect in July of 2002 requires health insurance companies issuing policies in Kentucky to provide coverage for hearing aids and related services up to a maximum of \$1400 per ear, every 36 months, for children under the age of 18 years old. Specifically the hearing aids must be prescribed by an audiologist and dispensed by a hearing aid dealer licensed in Kentucky. Many audiologists are also licensed as hearing aid dealers.

Most insurance companies already have a network of audiologists as service providers, but typically do not have a network of hearing aid dispensers. Please remember that the new law has set a maximum benefit of \$1400 per ear for the aids. If the aids you are getting for your dependent cost more than \$1400 each, your insurance company is not required to reimburse you the full amount. Only your insurance company can tell you what you should do to obtain the benefit under your individual insurance policy.

For additional information, persons with a need to access the benefit should call the benefits department of their insurance company (the number should be readily available in the benefit booklet or certificate of coverage sent to you by your insurance company) and ask for specific details.

It is important to note that certain types of insurance plans do not have to follow state legislative mandates. Employers that are self-funded (ERISA plans) are exempt from mandates. If you are unsure whether or not the insurance provided by your employer falls under ERISA, please contact the benefits manager of your employer.

If you believe you are entitled to receive the benefit from your health insurance company and are having trouble accessing the benefit, please call the Kentucky Department of Insurance at (800) 595-6053 for advice.



“Nothing” to “Everything” *(continued from page 7)*

have some hearing loss. We kept the appointment with Weiskopf and was told again that he WAS NOT autistic. They agreed (before we had the ABR by the way) that he had severe hearing loss; they also diagnosed him as having Tourette's syndrome and OCD.

John received his first hearing aid in November of his kindergarten year. No one at our school had ever worked with a deaf child, so they were not sure what he needed. His kindergarten teacher was wonderful with him, as was his special ed. teacher. John loved school and seemed to do very well. He was not a behavior problem at all.

Since all this has happened, we made the decision for John to be bi-lingual. We began learning ASL as quickly as we could. We began searching websites, reading books, getting information any way we could. The audiologist at CSHCN told us we should contact Debbie Wagner who is a consultant for KSD. She couldn't believe the school had not already brought KSD in as a consultant. We did that and asked that she come to our school. We attended the Family Learning Vacation and met a lot of people and found out about different things we needed to be doing for John. We found out about the regional program in Owensboro, which is only about 50 minutes from our home. We felt this would be a better solution for us than going to KSD, given John's previous attachment issues and the fact that Danville is 3 hours from our home.

When John's first grade year began, he was learning ASL along with us. We asked Ms. Wagner to set up an evaluation at KSD so that we would know exactly where John was and what he needed. She did but it created major problems in our school environment. Apparently, it was an issue that it had not gone through the regional co-op and we had asked for the service directly. The DoSE was upset that we hadn't included her in the decision (it was not our intent to leave her out, we were new to this process and knew that KSD was the authority on deaf education and wanted to find out what John needed). We received the report in late November, had the ARC meeting in December and at that time, my husband and I asked that John be transferred to the regional program in Owensboro because we felt that he was so language deprived that he needed to be immersed in language (ASL and English with ASL as his primary language) to be able to communicate better. The "ARC" decided it was not in his best interest and was not the Least Restrictive Environment. Ironically, several years earlier I had fought to keep him at this school.

I have a good relationship with our DoSE and believe that she is trying to do everything she can to set up a good program in our county. She hired a "language model" for John because they were not able to find an interpreter and it was agreed by everyone involved that John would not know how to use an interpreter if we found one. The hunt began for a teacher of D/HH. The aide hired to assist John is also deaf. He was part-time for the remainder of his first grade year and was hired full-time this past year.

I felt at this point we had lost 1 1/2 years of his education. We knew that he was going to have to repeat first grade and we were greatly disappointed because we know how intelligent he is -- as do his teachers. They were frustrated because they know it is a language barrier, not an intelligence factor that is hindering him. His teachers and other staff members have taken ASL classes with my family members, ASL is used on the news, we have an after school club called "Talking Hands" that the deaf aide assists me with so that we can raise awareness about the deaf community and hopefully teach some basic ASL to students. In addition, four of our staff has been trained in Visual Phonics which has been a great tool for John. He has an FM system also but there have been times when his hearing aid has been broken and he's had to go without it for periods of time. His teachers are frustrated because they know he is not receiving instruction when he doesn't have his aids. They know that even though they know "basic ASL" they can't communicate with him as effectively as they are with other students.

MY CONCERN IS THAT JOHN NEEDS TO BE IMMERSSED IN LANGUAGE. I believe the DoSE is earnestly working to do what she can to set up a unit in this county. It has been a long and laborious road; however, we need assistance, whether it is through recruitment, retention, financial, planning or direction. I am excited to see that Liz Hill has a passion for deaf children, early identification and intervention. I can only imagine where John would be now if he had been identified as deaf when he was an infant – or even when he was two, three, four. He is learning language now but still has a need for language immersion. He is learning to use ASL and spoken English. He doesn't use the word "nothing" as much as he uses the word "everything" now – because he loves "everything"!

There are more children like John out there. It is not only necessary but should be mandatory that EVERY child has a newborn screening. I believe if medical professionals are trained on how to recognize hearing loss that children like John will not have to suffer through years of no language. The lack of language leads to most of the other problems these children have. Remember earlier in the story when I said one of John's favorite words was "Nothing" and we could not figure out why? We finally realized it after attending a conference sponsored by KSD. Every time one of us said something that John didn't or couldn't understand, we were responding "nothing, John, nothing", thinking we were helping him. All we were doing was teaching him that he wasn't important – that he was "nothing" when it came to being informed and being involved in communication. So when he began saying it back to us when we would ask him something, we began to realize how hurtful the word "nothing" can be. These children deserve more than "nothing"... they deserve "everything"...everything that language can provide. If we do what is necessary and right, children like John will never have to hear the word "nothing" used in that way again.



KCDHH

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An agency of the Kentucky Education and Workforce Development Cabinet

Calendar of Events

MARCH

March 25th - MegaDEAF Conference - Teleconference
March 27th - An Evening of ASL Storytelling with Marlon Kuntze - Owensboro, KY
March 28th - ASL & English: The story behind the stories - Owensboro, KY

APRIL

April 7th - Actors Theatre of Louisville: Wild Blessings: A Celebration of Wendell Berry
April 15th - 19th - ADARA Conference - San Antonio, Texas
April 30th - Hearing Loss in Medical Situations - Owensboro, KY

MAY

May 1st-2nd - Building Bridges: A celebration of Detection and Intervention of Hearing Loss – Annual Conference of the Division of Audiology - Cincinnati, OH

For more information on these and other events, please visit the KCDHH Web Bulletin Board at <http://www.kcdhh.ky.gov/home/bulletin.html>