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According to the American Academy of Pediatrics, hearing loss is one of the most frequently occurring birth defects; approximately three infants per 1,000 are born with moderate, severe, or profound hearing loss.

Universal Newborn Hearing Screening in Ohio

Hospitals and birthing centers in Ohio have been providing Universal Newborn Hearing Screening (UNHS) for infants born in their facilities since 2004. Infants grow very quickly and research has shown that there are optimal periods in growth and brain development when the foundations are laid for development of communication skills.

The goal of screening for hearing loss early in life is to provide timely and early intervention so that by the time an infant or toddler with a hearing loss reaches the age of three, his or her communications skills are comparable to those of a child without a hearing



loss. Screening, diagnosis, and early intervention are all

keys to providing families with the necessary support for their deaf or hard of hearing infants and toddlers in order to help them build the best possible skills during the developmental stages for communications skills development.

Currently all birthing hospitals, freestanding birthing centers and children's hospitals in Ohio conduct a hearing screening and provide both the parents or guardian and the infant's primary care provider with the results. There were **139,746 births in Ohio in 2013** and **more than 97 percent of the infants were screened** prior to discharge.

Recent changes in the Ohio Administrative Code now require hospitals to report non-pass results or

Screening

Ohio hospitals use automated otoacoustic emissions (OAE) and auditory brainstem response (ABR) hearing screening methods to test newborns before discharge.

	2013	
	Number	Percent
Total babies born	139,743	100
Reported hearing screenings	136,152	97.4

infants discharged without a screening to the primary care provider or medical home within 48 hours of screening or discharge. This alerts the provider that follow-up is necessary and referrals can be made as early as the newborn's first outpatient office visit.

The hearing screening results are also reported to the Ohio Department of Health (ODH). ODH is active in supporting the goals of the national Early Hearing Detection and Intervention program (EHDI). Those goals are to screen for a hearing loss by one month of age, diagnose a suspected hearing loss by three months of age, and begin provision of early intervention by six months of age.

National averages indicate that about three infants per 1,000 births are identified with a hearing loss. One goal of the Ohio Infant Hearing Program is to ensure that all infants who do not pass their hospital hearing screening receive additional

testing to verify their hearing status as soon as possible. For those infants diagnosed with a permanent hearing loss, the Program coordinates with providers and families to ensure that these infants are provided with early intervention services for hearing loss.

Tracking families after they leave the hospital, reaching out to them when they do not understand why additional testing is important, and linking them to appropriate early intervention for their infant's special needs is sometimes a very challenging task. Quality improvement initiatives implemented by staff and key stakeholders have reduced the percentage of infants who are lost between screening and a confirmatory diagnosis from 31.8 percent in 2012 to 23.4 percent in 2013. This report also showcases the stories of two families helping their children overcome a hearing loss. Their experiences illustrate the importance of early hearing detection and intervention.



The goal of early hearing detection and intervention is to maximize linguistic competency and literacy development for children who are deaf and hard of hearing.

Screening Challenge: Ensure each family knows what to do when their infant does not pass a hearing screening.

Nearly all babies are screened at the birth hospital. The majority of those not screened are home births and Ohio laws do not require these infants receive a hearing screening although parents are informed of the importance of hearing screening when they register the birth at the local health department. The parents are also given written information and a list of the pediatric providers in the community where they could take the infant for screening.

Actions: Hospitals are doing a consistently good job of screening newborns and the focus has shifted to better communication with families. An evidence-based promising practice is to have hospital screeners throughout the state read letters from parents of children who are deaf or hard of hearing and watched the short video, *Lost and Found*, by Hands and Voices, to help them improve their communication when they tell a parent the infant did not pass the newborn hearing screening. Program staff believe that if screeners communicate in a meaningful way to parents about the importance of follow-up, more families will get the recommended follow-up testing.



Goals for Early Hearing Detection and Intervention:
 Screen by 1 month.
 Diagnose by 3 months.
 Provide early intervention by 6 months.

Diagnosis

Newborns not passing UNHS are referred to pediatric audiologists for follow-up hearing evaluations.

ODH funds nine Regional Infant Hearing Programs (RIHPs) to help arrange for prompt follow-up appointments. Audiologists can perform tests to evaluate hearing while very young infants sleep. After six months of age, sedation (in a hospital) is often necessary in order to complete the testing.

	2013	
	Number	Percent
Total non-pass screening results	3,793	100
RIHP Follow-up and Tracking		
Diagnostic evaluations completed	2,624	69
Lost to follow-up*	889	23.4
Other^	188	5.0

*Lost to follow-up includes: unable to contact, unresponsive, or unknown

^Other includes: infant died, family declined evaluation, nonresident, or moved out of jurisdiction

Diagnostic Challenge: Ensure that each family with a non-pass hearing screening receives the support needed to obtain timely and comprehensive diagnostic evaluation for their infant within three months of birth.

ODH funds RIHPs to provide outreach to families, respond to needs for support, offer assistance with scheduling appointments, and “close the loop” by obtaining a copy of the diagnostic report confirming either normal hearing or a hearing loss. Even with targeted outreach and offers of assistance, some families do not keep scheduled appointments or are lost to contact before the infant’s hearing status is confirmed.

Actions: ODH has worked with audiology providers to reduce barriers to obtaining diagnostic evaluation for hearing loss. While screeners stress the importance of early follow-up, audiologists have tested reminder calls to families, providing information on keeping the infant awake prior to the appointment or feeding immediately before the appointment so the infant will sleep and the evaluation can be completed in one visit. These efforts all work incrementally to improve appointment outcomes. Another potential barrier has been removed by Medicaid since eligible families may also receive assistance with transportation to medical appointments. ODH recently collaborated with Cincinnati Children’s Hospital to collect data on a federally funded research project providing rescreening at WIC clinics. Results for this experimental group indicate that extensive personal education improved compliance with scheduled appointments.

Early Intervention

Infants diagnosed with permanent childhood hearing loss are eligible for Early Intervention services. The RIHPs provide language and auditory stimulation, information about communication options, counseling and family support, and interaction with the deaf community. RIHP services are provided in all 88 Ohio counties. Families of infants with hearing loss are enrolled in Help Me Grow (HMG), Ohio's birth to age 3 early intervention program, and may receive assistance with other developmental delays in addition to the hearing loss. (Please visit www.ohiohelpmegrow.org to learn more.)

	2013	
	Number	Percent
Diagnosed with hearing loss	221	100
Enrolled in EI by 6 months	82	37
Enrolled, all ages	137	62
Receiving RIHP services	349	

Early intervention services are available up to the age of three for families of all infants diagnosed with a hearing loss.



Early Intervention Challenge: Ensure each family of an infant with a confirmed hearing loss understands the importance of providing their infant with early intervention services.

Habilitative services are available up to the age of three for families of all infants diagnosed with a hearing loss. There is no charge to the family for these services and they can be provided in the home or other setting a family chooses.

Actions: When the RIHPs receive confirmation of an infant's hearing loss, they offer habilitative services to the family. If a family agrees to participate in a habilitative program for their infant the RIHP coordinates with the Help Me Grow Early Intervention program to include provision for RIHP habilitative services for early intervention for hearing loss in the infant's Individual Family Service Plan. ODH is surveying families to determine strategies to remove any barriers to program participation. Program staff believe a family's understanding of the impact of early intervention on their infant's communication skills will persuade more families to enroll their infant in early intervention.

Ashley Schmitz' story

My fourth son, Tate, was born on May 13, 2011. His hearing was screened and the hospital screener gave me the results saying my son had “referred” but it was probably nothing to worry about.

Tate and I went home the next day and I remember being confused about what “referred” meant. We were scheduled to go back for a follow-up appointment so that Tate could have another screening.

When Tate did not pass this screening and they said he needed to come back in a month for more testing, I went from being unconcerned to super-concerned. I went home and did the typical things parents do such as slam the doors and bang pots and pans to see if he would respond to loud sounds but I just could not tell if he could hear or not.

I spoke to my pediatrician about my concerns and he helped schedule follow-up diagnostic testing quickly. Tate was tested at three weeks of age and he was diagnosed with a bilateral mild-moderate hearing loss in both ears.

At that time, I was referred to the Regional Infant Hearing Program. The RIHP Parent Advisor contacted me and was right there every step of the way to answer questions, make me feel comfortable, and give me some hope that things were going to be okay.

Tate was fitted with hearing aids at 10 weeks. He started to notice his surroundings and he connected more with the hearing aids on. Our

parent advisor would come to our home monthly and I could see a difference in how Tate was responding each time she came.

At about 17-18 months we were really struggling about Tate’s hearing. He did not want to learn sign language and he was not meeting communication goals. We learned that his hearing loss was getting a little worse. Our parent advisor helped us find more information and additional resources.

As a family, we needed to consider our choices. We decided we wanted Tate to speak and not to rely on sign language so at 18 months Tate was enrolled in a Toddler class at a school for children with hearing impairments.

Tate exited the RIHP program at age three and has started preschool. He wears his hearing aids all of his waking hours. He is doing fabulous and talks all the time. We want him to reach his full potential to listen and talk. He is still a deaf child, but one who can learn fast and that’s the right setting for him.

During our hearing journey, my first phone call was always to my husband and my second was to my Parent Advisor. Our RIHP Parent Advisor was there to help, answer questions, and provide the support my family needed every step of the way. The transition out of the RIHP when my son turned three was hard for me but my parent advisor has helped me become a strong, knowledgeable advocate for my child.



Tate

Kari Nelson's story

The day my son, Benjamin, was born, September 19, 2011, was easily the most amazing, and life-changing, day of my life. Anything can happen, and as a parent it can be very hard to be prepared for all of the things can go wrong. Being a parent is without a doubt one of the most amazing, yet terrifying experiences a person will ever have the privilege of having.

At first glance, Benjamin seemed like a perfectly normal and healthy baby. He had nothing physically wrong with him. Our stay at the hospital was just overnight. All we needed to do was have the doctors do the standard tests and we were ready to go.

However Benjamin failed the hearing test on his right ear. The news of these results completely crushed me. I began wondering what I could have done wrong during my pregnancy or what I could have done to prevent this from happening. I was terrified thinking of the struggles that he might encounter later on in his life and what this would mean for him.

The hospital staff assured me that it was nothing to worry about, many newborns fail their initial hearing tests and then pass the followup with flying colors. They referred us to an audiologist for further testing. The audiologist confirmed that Benjamin had a hearing loss.

We were then referred to another audiologist for more comprehensive diagnostic testing to determine the level of Benjamin's hearing loss. Although we didn't choose our audiologist, I'm not

sure we could have chosen anyone more perfect for Benjamin and I. Benjamin was only a few weeks old so he slept during a majority of the testing but several times he woke up in the middle of tests. This made it very difficult to get accurate test results and we ended up having to do multiple

appointments to ensure that the test results were correct.

Finally our audiologist confirmed Benjamin had a mild to moderate hearing loss in his right ear and mild hearing loss in his left ear. He was fitted with hearing aids when he was about four months old. He was so young that he wanted to pull them out and play with them instead of wearing them.

Benjamin was diagnosed with epilepsy and was enrolled in Help Me Grow, Ohio's early intervention program. We later learned he also has a rare genetic disorder called wolf-hirschhorn syndrome. When his hearing loss was confirmed, we were referred to the Regional Infant Hearing Program (RIHP).

I was overwhelmed with everything that was going on, but luckily for me I was blessed with a RIHP Parent Advisor who is one of the most supportive people that I've ever known. Our parent advisor has shown me multiple ways to work with



Benjamin

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Benjamin, shown me different techniques to help Benjamin communicate, and ensures that I can always find comfort in knowing that I'm not alone in the battles that Benjamin and I have had to face.

My parent advisor helped me decide to introduce sign language to Benjamin to help him communicate his basic needs, and to also accompany those signs with speech in hopes that they would later inspire him to begin talking. She's been there to share all the highs and lows we've encountered.

In addition to his hearing loss, Benjamin was having multiple seizures every day that delayed his

progress. Now that his seizures are under control he has been making huge progress. Benjamin has learned to walk, he is comfortable wearing his hearing aids, and he is communicating his basic needs despite the fact that he is still not talking.

Benjamin's journey with RIHP is ending now that he's turning three. If it wasn't for the RIHP, and my parent advisor's positive attitude and comforting words, I'm confident that Benjamin wouldn't be anywhere near where he is now as far as communication and development.

I'm truly thankful that there are RIHP services such as these available for families, because I would have been truly lost without the amazing support system that they provided for Benjamin and me.

—Kari Nelson



Benjamin

For more information about
the Infant Hearing Program,
please contact:

Ohio Department of Health

614-644-8389

www.ohiohelpmegrow.org

