

Front Page Feature

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Reinforcing Pediatrician Value and Impact

The annual EHDI meeting is always an opportunity to network, recharge your batteries and remember why we work so hard to assure the children and families we serve receive timely and comprehensive care. This year's meeting in San Diego was no different. Stories that I heard from families at this meeting—some good and some not so good—reinforce just how valuable a pediatrician can be to a family trying to navigate the system after a refer for hearing screen or a diagnosis of Deafness/Hard of Hearing. We can make that journey less difficult to travel or throw up roadblocks that delay early diagnosis or intervention.

The fact is that universal newborn hearing screening is now standard practice across the country and has resulted in earlier diagnosis and treatment for many babies. Yet despite this success, there are numerous unresolved issues that can impact timely care for children who are Deaf or Hard of Hearing. As pediatricians, we must be especially sensitive to two of these issues. The first is that nationally 30% of babies who do not pass their newborn screen are lost to follow-up or documentation. A number of these cases of "loss to follow-up," however, are actually cases where the family has simply decided that they did not need the follow-up since they felt their baby was "fine." This feeling can be reinforced if the family is given the impression that the screen is not accurate or told not to worry because "it's probably just some fluid." As pediatricians, we have the responsibility to impress upon our patients the need to receive necessary follow-up, especially when there is reluctance on their part to do so. This may take time, but the time will be well spent if it results in an earlier diagnosis.

We also need to remember a second important issue. Newborn screening will not pick up many cases of mild hearing loss or children with progressive or later onset hearing loss. Too often, families are left with the impression that, if a newborn hearing screen is passed, they never have to worry about their child developing a problem with their hearing. Pediatricians can even feed into that misconception by reassuring parents who have a concern with statements like, "I'm sure it's not that. Remember he passed his test as a baby!"

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All families should be asked about risk factors that may lead to late onset or progressive hearing loss and those factors must be documented with a plan to monitor that child more closely. A list of these risk factors can be found below. But remember two things: first, most children who develop hearing loss after a normal newborn screen will NOT have identified risk factors, so if you have a concern, do not let the absence of risk factors keep you from moving forward with an evaluation; second, remember THE most important risk factor is ANY parental concern about their child's hearing—that should always trigger a referral for an evaluation.

As pediatricians, we can have a great impact, in either a positive or negative way, in assuring timely diagnosis and treatment. Parents trust our advice and recommendations. Let's all commit to being a positive force in guaranteeing the earliest diagnosis possible for our patients who are Deaf or Hard of Hearing.

RISK INDICATORS ASSOCIATED WITH PERMANENT CONGENITAL, DELAYED-ONSET, OR PROGRESSIVE HEARING LOSS IN CHILDHOOD

Joint Committee on Infant Hearing

2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs

Risk indicators that are marked with a "\$" are of greater concern for delayed-onset hearing loss.

Caregiver concern\$ regarding hearing, speech, language, or developmental delay.	Physical findings, such as white forelock, that are associated with a syndrome known to include a sensorineural or permanent conductive hearing loss.
Family history\$ of permanent childhood hearing loss.	Syndromes associated with hearing loss or progressive or late-onset hearing loss\$ such as neurofibromatosis, osteopetrosis, and Usher syndrome; other frequently identified syndromes include Waardenburg, Alport, Pendred, and Jervell and Lange-Nielson.
Neonatal intensive care of more than 5 days or any of the following regardless of length of stay: ECMO\$ assisted ventilation, exposure to ototoxic medications (gentimycin and tobramycin) or loop diuretics (furosemide/Lasix), and hyperbilirubinemia that requires exchange transfusion.	Neurodegenerative disorders\$ such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth syndrome.
In utero infections, such as CMV\$ herpes, rubella, syphilis, and toxoplasmosis.	Culture-positive postnatal infections associated with sensorineural hearing loss\$ including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis.
Craniofacial anomalies, including those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies.	Head trauma, especially basal skull/temporal bone fractures that requires hospitalization.
Chemotherapy\$	

Quality Improvement (QI) Buzz



Lean Thinking: How Rhode Island EHDl is Doing More with Less
By Helen Zak

Last year, the contract agency that provides newborn hearing screening follow-up in Rhode Island requested an additional full-time employee. To better understand the request for additional staff, the Rhode Island Department of Health (RIDOH) decided that this would be a great opportunity to apply a Quality Improvement (QI), Lean approach (maximizing value and minimizing waste).

In January 2016, RIDOH organized a KAIZEN event—KAIZEN refers to activities that improve all functions and involve all employees and often used in Lean QI. The KAIZEN event was facilitated by an outside vendor and a staff member from RIDOH to assess the workflow of the current, dedicated staff. The ultimate goal behind the KAIZEN event was to eliminate activities in the “follow-up process” that were of no value so that the process moves more efficiently.

Prior to the KAIZEN event, the core EHDl QI team met to take a closer look at the internal follow-up process. The team utilized two different process mapping tools—GEMA Walk and Value Stream Mapping—to help identify processes that could be streamlined to be more effective and efficient. The tools helped reveal the following:

- The current process was overwhelming
- There were too many repetitive steps and workarounds
- Diagnostic results were not being reported within the required 48 hours
- Many letters that were mailed were returned unopened
- There were too many manual processes, and there was not a clear understanding of all the processes.

Clinical Corner

Language Outcomes in Young Children with Mild to Severe Hearing Loss

This study examined the language outcomes of children with mild to severe hearing loss during the preschool years. The longitudinal design was leveraged to test whether language growth trajectories were associated with degree of hearing loss and whether aided hearing influenced language growth in a systematic manner. The study also explored the influence of the timing of hearing aid fitting and extent of use on children’s language growth. Finally, the study tested the hypothesis that morphosyntax may be at particular risk due to the demands it places on the processing of fine details in the linguistic input.

The full cohort of children in this study comprised 290 children who were hard of hearing (CHH) and 112 children with normal hearing. Mixed modeling procedures were applied to examine the rate of change (227 CHH; 94 children with normal hearing) in language ability over time in relation to the following: degree of hearing loss; aided hearing; age of hearing aid fit and duration of use; and daily hearing aid use.

In this study, children with mild to severe hearing loss, on average, showed depressed language levels compared with peers with normal hearing who were matched on age and socioeconomic status. The degree to which CHH fell behind increased with greater severity of hearing loss. The amount of improved audibility with hearing aids was associated with differential rates of language growth; better audibility was associated with faster rates of language growth in the preschool years. Children fit early with hearing aids had better early language achievement than children fit later. However, children who were fit after 18 months of age improved in their language abilities as a function of the duration of hearing aid use. These results suggest that the language learning system remains open to experience provided by improved access to linguistic input. Performance in the domain of morphosyntax was found to be more delayed in CHH than their semantic abilities.

The data obtained in this study largely support the predictions, suggesting that mild to severe hearing loss places children at risk for delays in language development. Risks are moderated by the provision of early and consistent access to well-fit hearing aids that provide optimized audibility.

Source: Tomblin JB, Harrison M, Ambrose S, Walker, EA; Oleson JJ; Moeller MP. Language outcomes in young children with mild to severe hearing loss. *Ear & Hearing*. November/December 2015;36:76S–91S.

Based on examining the process, the QI team developed the following AIM statement: Improve the effectiveness and efficiency of the follow-up process, to increase the number of diagnostic follow-up from 75% to 85% by March 30, 2016.

The KAIZEN event was very successful. Staff were focused only on the specific changes needed to help reach the aim and test the changes. By the final day of the event, the team was able to reduce its follow-up process from 29 steps to 19 steps.

One area of significant improvement was follow-up letters. A strategy was developed to reduce the large number of letters printed and mailed to parents on a monthly basis. The core team reviewed all letters and identified opportunities for content and process improvement. During the KAIZEN event, the team tested the revised letters via PDSA cycles with parents who were sitting in the waiting area. Feedback from parents and a pediatrician expressed that the proposed revised letters should be less wordy, provide clear instructions and express the urgency of follow-up. Additionally, the volume of letters mailed to parents was reduced by eliminating the second and third letter completely.

Information and clear instructions are now provided to parents in the initial letter with a list of testing centers and encourage parents to schedule appointments sooner. Returned mail was also reduced by 50% by updating the EHDI database with address updates from KIDSNET, a statewide child health database.

Other improvements were made in the reliability and timeliness of documentation in the EHDI database. This KAIZEN event supported the Rhode Island EHDI Program to eliminate repetitive processes, reduce staff time, and decrease postage cost and returned mail, which all increased efficiency in the follow-up process. These results contributed significantly to help reach the program AIM listed above and to support the provision of high quality services to infants and families. This experience has had a profound impact on the way work is conceptualized and the EHDI teams' ability to utilize quality improvement effectively.

Family Partnerships

O.U.R. Children's Safety Project

O.U.R. at Hands & Voices stands for Observe, Understand, and Respond. Hands & Voices has created a community of learners to enhance the safety and success of children who are Deaf or Hard of Hearing. With the tremendous support of researcher and board member Harold Johnson, formerly at Michigan State University, Hands & Voices and the community of learners are dedicated to increasing the understanding of the scope of this problem, partnering with supporting agencies (who often need to learn more about deafness), and teaching about how best to Observe, Understand, and Respond to children who are Deaf or Hard of Hearing. The goal is to keep children safe and free to grow up in the innocence of childhood.

We do not like to think about it, but children who are Deaf or Hard of Hearing are at a higher risk for both abuse and neglect. As children who might not always be able to communicate easily and fluently, or understand the nuances of conversation with neighbors, caregivers, or strangers, they are at an even higher risk of being victims. Hands & Voices aims to spread the message about this important work and also share the valuable [resources the Hands & Voices community of learners has collected over the past few years while working on this project](#). Take time to familiarize yourself with these resources so you can share them with the families you work with.

As part of this initiative, Hands & Voices is partnering with [Childhelp](#) and together have created a toll-free number specifically for support for children who are Deaf or Hard of Hearing. This number—1-800-222-4453—can be called by anyone anonymously who needs information/support about a particular situation. Hands & Voices has also partnered with [Kidpower](#) as part of this initiative.

Medical Home Resources

[The Hali Project: Innovative Strategies to Enhance Care Coordination and Family-Centered Care](#)

The National Center for Medical Home Implementation (NCMHI) collects evidence-based and evidence-informed promising practices in pediatric medical home implementation. One such practice, the Hali Project, utilizes paid parent navigators to enhance care coordination within pediatric practices. This model is particularly important for families of children and youth with special health care needs, including those who are Deaf or Hard of Hearing. Parent navigators connect families to community resources, provide peer support, and improve and patient/family experience. [Sign up for the NCMHI listserv](#) to receive future information about promising practices in pediatric medical home implementation.

And More....

True or False: Does Medicaid Mean Poorer Care?

What does the data tell us? Read [this article](#) about the importance of Medicaid for children, especially children with special health care needs. Compared to CHIP (Children's Health Insurance Program) and private insurance, Medicaid benefits are more comprehensive, children have increased access to care (including specialty care), and families' out-of-pocket expenses are more affordable.

PS: The correct answer is false.

Upcoming Events & Opportunities

Event/Opportunity	Date	More Details
Webinar: Improving the Quality of Your Hearing Screening Program. Intermediate Level Webinar for Early Head State Programs Early Childhood Hearing Outreach (ECHO) Initiative	May 10, 2016, 2pm CT	Register
14th International Conference on Cochlear Implants and Other Implantable Technologies	May 11-14, 2016	Website
53rd Biennial National Association of the Deaf Conference	July 5–9, 2016, Phoenix AZ	Website
Cytomegalovirus (CMV) Public Health & Policy Conference	September 26-27, 2016, Austin TX	Website
AAP National Conference & Exhibition (NCE)	October 22-25, 2016 San Francisco CA	Website

The AAP EHDl program implementation staff send this e-mail update to the Academy's EHDl Chapter Champions, other interested AAP members, state EHDl coordinators, and other stakeholders. For additional information on hearing screening and to access previous editions of the EHDl E-mail Express, click [here](#). If you would like to unsubscribe to the update contact Michelle Esquivel at mesquivel@aap.org or 847/434-4989.