

# EHDI *Express*



Monthly ePublication of the American Academy of Pediatrics Early Hearing Detection & Intervention Program

## Front Page Feature

### Opportunity for Community Funding to Further Support State Efforts Around Early Hearing Detection and Intervention (EHDI)

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Most people are familiar with the American Academy of Pediatrics (AAP) through the guidance provided to pediatricians and the information available to the public regarding the health, development, and safety of infants, children, and young adults. In addition, you may be surprised to know that there are many other aspects to the Academy.

One of these programs is called Community Access to Child Health—or CATCH. It is housed in the Academy’s Division of Community-based Initiatives. At its heart, CATCH fosters and encourages community partnerships to address local issues on a local level, and projects are led by a pediatrician or a pediatric resident. Founded in 1993, CATCH grants supports and encourages pediatricians to collaborate within their communities to advance the health of all children. These funds have been responsible for nearly 1,800 projects across the country, and range from a small program to teach mindfulness in a Dallas elementary school to a large program in Houston that assisted in transitioning youth with special healthcare needs into adult practices.

The CATCH grants are in the form of local project grants and fall into the following three categories:

- Planning—You might consider loss-to-follow up and use a CATCH planning grant to assemble a group to do a needs assessment within your community
- Implementation—You might look to your EHDI stakeholder group to put plans into action
- Resident grants—These fund pediatric resident-created projects such as community outreach and education

You may wonder who these grantees are. About 75% are community pediatricians while the remainder are pediatric specialists. What about the communities these projects affect? Nearly 40% of grantees work in rural settings, 35% are in urban/academic centers, and 25% are in suburban areas.

With that in mind, let's examine the goals of the Early Hearing Detection and Intervention (EHDI) program. As pediatricians, we aspire to provide patient-centered care within the medical home model. We believe community-wide cooperation is necessary to achieve the optimal health and well-being of our patients. We assess outcomes for our patients—not just from the point of view of physical health, but that of overall growth and development, as well. Finally, we acknowledge the vital support that organizations like the Maternal and Child Health Bureau (MCHB), the National Center for Hearing Assessment and Management, and Hands & Voices provide, and we know that together we can accomplish great things.

As you consider the work being done within EHDI, and as we work with our national and local partners and EHDI stakeholders to accomplish the priorities supported by the current state MCHB funding, I encourage you to consider applying for a [CATCH grant](#) when the 2019 program opens early next summer. In the meantime, check out what some of the current CATCH grantees are working on—it may spark some ideas for you!

### *In Every Issue...*

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## Quality Improvement (QI) Buzz

### Unique Challenges of Geographically Disperse States Within Early Hearing Detection and Intervention: A Study to Increase Quality of Diagnostic Evaluations



**AIM:** Increase the percentage of Wyoming Pediatric Audiology Specialty Clinic (WPASC) reports with diagnostic evaluations that are rated *Excellent* to 75% by March 31, 2017.

Correctly diagnosing children with hearing loss, and effectively communicating the diagnosis and “next steps” to parents and early intervention specialists, is important to a child’s development. However, geographically disperse states with sparse populations face unique challenges in ensuring that infants receive an accurate and timely diagnosis. With most of the audiology practices in Wyoming serving older children and adults, Wyoming Early Hearing Detection and Intervention (WY EHDl) has developed a unique and successful approach to ensuring that infants who did not pass their hearing screen(s) receive an accurate diagnosis, and that the diagnosis and next steps are effectively communicated to parents.

There are inherent challenges as audiologists with limited pediatric experience may not have the necessary equipment; they also may not have the expertise that comes from evaluating infants as compared to higher-incidence locations; they may not have the adequate resources on hand for infants (eg, loaner hearing aids); and they may not know the next steps as recommended by Joint Committee on Infant Hearing after they diagnosis a baby as deaf or hard of hearing (eg, referral to early intervention, results submitted to EHDl, family support).

Wyoming EHDl used the quality improvement (QI) process to develop a system for highly qualified, contracted pediatric audiologists to review and provide feedback on diagnostic evaluation reports that could be conducted by generally non-pediatric audiologists. This evaluation report template, and guidance protocol, was intended to help treating audiologists provide clearly stated *next steps* for the parents, medical care providers, and early intervention specialists, as well as, providing

## Clinical Corner

### Rural Family Perspectives and Experiences with Early Infant Hearing Detection and Intervention: A Qualitative Study

Delays in identification and intervention for infants who are deaf or hard of hearing can cause impact to cognitive and language development. This has been shown to lead to difficulties with communication, behavior, psychosocial development, and reduced academic achievement as compared to children who are hearing and have hearing parents.

Early hearing detection and intervention for infants is an important public health issue. While support and systems of care exist for children identified as deaf or hard of hearing, many children and families in rural communities face unique challenges. This [qualitative study](#) involved families who experienced barriers and obstacles within the rural healthcare system. Families in the rural region of Appalachia reported challenges including poor communication of hearing screening results, difficulty in obtaining outpatient testing, inconsistencies in healthcare information from primary care providers, lack of local resources, insurance-related healthcare delays, and conflict with work responsibilities.

Results of the study revealed multiple barriers among both the healthcare providers and the families of children who did not pass their newborn hearing screen and who live in rural communities. These obstacles prevented children from meeting crucial benchmarks in the timeline of hearing healthcare. Important to note is that these obstacles did not diminish the participants’ willingness to seek hearing healthcare for their child. Findings support that minimizing misinformation and improving access to care can prevent delayed diagnosis and intervention services for children who may be deaf or hard of hearing.

Source: Elpers J, Lester C, Shinn JB, et al. Rural family perspectives and experiences with early infant hearing detection and intervention: a qualitative study. *Journal of Community Health*. 2016;41(2):226-233.

information regarding areas of childhood development that may be affected by the degree of hearing loss identified.

A Likert scale of *poor to excellent*—based on specific criteria—was developed and the WY EHDl team trained a small number of non-pediatric audiologists to use this scale as they improved their diagnostic evaluations and conversations with families. Using previous reports as baseline, WY EHDl experienced significant improvement over a 2-year period.

Results showed the following:

- From Wyoming Pediatric Audiology Specialty Clinic (WPASC) appointments during 2014 and 2015, a sample size of 18 non-pediatric audiological reports were reviewed, and 44% were rated excellent by independent reviewers and 50% were rated as good.
- Appointments at the WPASC during 2016 and the 1<sup>st</sup> quarter of 2017, a sample size of 46 non-pediatric audiology reports from were reviewed, and 89% were rated excellent with an additional 9% rated as good.

As parent guide Kim Reimann described, “The new report format reduces ambiguity of what comes next after learning of a diagnosis. Parents leave knowing exactly the next steps for follow-up both medical and audiological, and there is clarity regarding enrollment in early intervention and availability of parent support. The report also helps parents better understand how different types of hearing loss can affect a child emotionally, socially, and educationally.”

By teaching the audiologists how to best provide results from diagnostic testing, parents feel more supported and knowledgeable, there is improved transition into early intervention, and connections with others within the EHDl system are more easily identified. Currently, WY EHDl is reviewing the data from this project and will determine next steps for expanded application.

## Family Partnerships

### Information and Support for Children, Families, and Professionals

The [American Society for Deaf Children](#) (ASDC) is a source of information for caregivers of children who are deaf or hard of hearing (D/HH). The ASDC is committed to empowering all families who have a child identified as D/HH by encouraging full access to language-rich environments through mentoring, advocacy, resources, and collaborative networks.

The vision for ASDC is that all children and youth who are D/HH shall have the opportunity to thrive in every aspect of their lives through the empowerment of their families and the support of the community. In supporting families of children who are deaf or hard of hearing, ASDC works to ensure that medical, audiological and educational professionals:

- Are informed about successes of all Deaf persons, including those who choose American Sign Language (ASL) as their primary language and those who both do, and do not, choose cochlear implants;
- recognize the benefits of early language, including sign language, and work to ensure that language development progresses at a rate equivalent to that of their hearing peers; and
- refer parents to multiple sources of information including the opportunity to meet and speak with Deaf individuals, families with children who are deaf or hard of hearing, schools for the Deaf, and representatives from organizations that support parents and Deaf adults.

The ASDC provides comprehensive support to children who are D/HH, their families, and the professionals who serve them, regardless of whether a cochlear implant, hearing aids, other hearing technology, or no hearing technology at all is chosen. In supporting language development for a child who has been identified as deaf or hard of hearing, ASDC works to encourage language development using both [sign language](#) and [visual language](#).

## Medical Home Resources

### Family Engagement Quality Improvement Project Change Package

Efforts among Early Hearing Detection and Intervention (EHDI) stakeholders are underway to develop learning communities, and to ensure that children who are identified as deaf or hard of hearing are provided comprehensive care coordination and the development of a [Shared Plan of Care](#).

The [National Center for Medical Home Initiatives](#) (NCMHI) has developed a Family Engagement Quality Improvement [Change Package](#) that provides practical tools, resources, and strategies to plan and implement tests of change or Plan, Do, Study, Act (PDSA) cycles. The resources developed are specifically intended to assist pediatric practices in implementing shared decision-making in partnership with patients and their families. Shared decision-making is a collaborative process that enables patients, parents, and health-care providers to make collaborative decisions taking into consideration the best scientific evidence available and balancing that with the patient and family's values and preferences. The model is based on introducing the concept of choice, describing options available, and helping patients and families explore preferences.

## And More....

### Pediatric Resource Guide to Infant and Childhood Hearing Loss

Pediatric residents from major hospitals throughout the San Francisco-Oakland Bay Area gather once a month at the [Center for Early Intervention on Deafness](#) (CEID) to learn about hearing loss in infants and young children.

The Pediatric Residents Training is a model program that has been an integral component of the CEID outreach to professionals. There is no charge to the residents for the training that includes copies of the CEID authored and published [Pediatric Resource Guide to Infant and Childhood Hearing Loss](#). The guide is used as the basis for the specialized trainings which take place at the CEID Berkeley facility with classrooms and services for children who are deaf or hard of hearing. During the half day training, members of the CEID professional team demonstrate how to read audiograms, explain the importance of language acquisition and early support, and provide the opportunity for residents to observe students in classrooms and in speech and language therapy. The training and the book address the critical roles of pediatric providers in the Early Hearing Detection and Intervention system, and offer parent perspectives using first-hand experiences of families served by the CEID.

**Disclaimer:** The information and opinions contained in this newsletter are compiled from various sources and represent a multitude of opinions and methodologies. They do not necessarily represent policy or recommendations from the American Academy of Pediatrics. For questions regarding content, or recommendations for future content, contact [Sandi Ring](#), Program Manager, Early Hearing Detection and Intervention, at the American Academy of Pediatrics.

The AAP EHDI program implementation staff send this e-newsletter to the Academy's EHDI Chapter Champions, other interested AAP members, state EHDI coordinators, and other stakeholders. For additional information on hearing screening, or to access tools and resources relevant to early hearing detection and intervention, click [here](#). If you would like to unsubscribe to this newsletter, contact Sandi Ring at [sring@aap.org](mailto:sring@aap.org) or 847/434-4738.