

This is an e-mail communication from the American Academy of Pediatrics (AAP) "Improving the Effectiveness of Newborn Hearing Screening, Diagnosis and Intervention through the Medical Home" project funded through cooperative agreements with the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC), National Center of Birth Defects and Developmental Disabilities (NCBDDD). It is designed to provide AAP Early Hearing Detection and Intervention (EHDI) Chapter Champions with resources and current clinical and other information. The EHDI E-Mail Express is sent on a monthly basis. Please feel free to share the EHDI E-Mail Express with colleagues working on or interested in childhood hearing detection and intervention issues. Distribution information appears on the last page.

**NOVEMBER 2015**

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## TALES FROM THE FRONT LINES—A REFLECTION BY BRAD GOLNER, MD, FAAP

As a general pediatrician, I want to relate a story with you that I experienced, one in which I am sure many of you can relate.

With EHDI, one thing that we all are working hard to do as Chapter Champions is to educate pediatric clinicians, with the intention of improving care for children who are Deaf or Hard of Hearing and reducing the number of babies who are lost to follow-up or lost to documentation (LTF/D). A few years ago, the EHDI team, of which I am a member in Arizona, identified a number of areas within our state that had high numbers of LTF/D. As a team, we decided that our goal was to help identify the barriers that existed in these areas and particular practices, which might be impeding these infants from receiving necessary and timely evaluation, diagnosis, and interventions. So, the EHDI team and I devised a plan. We hit the road to visit some of the practices, which we had identified, including some that were located in very rural areas.

While conducting this outreach, one particular experience stuck out, which I feel highlighted a few of the obstacles we still need to overcome in order to improve EHDI care within the medical home. During this office visit, the pediatrician I was speaking with told me—with certainty—that all babies in that practice who had been referred for a follow-up hearing screening following their initial newborn hearing screening, were sent to pediatric audiology to receive the necessary follow-up. They insisted that all families were able to receive an outpatient hearing screen and that the families encountered no problems or barriers getting their child to the appointment. While I was listening to the pediatrician describe their EHDI practice, a nurse practitioner, who was standing in the background, gave a concerned look on her face and began to shake her head NO! She went on to explain that NONE of the babies ever made it to the audiologist, due to the fact that the nearest facility was a 3-4 hour drive away. She continued to say that most of the families in the area did not have the means of transportation or the availability to make this visit. The pediatrician had no idea....

The moral of this story is that as pediatric clinicians, we need to make sure we know what's going on with our patients and be consistently identifying potential barriers which may make it difficult for our patients to receive all of the care they need. Moreover, by working together with your EHDI team, other clinicians and EHDI stakeholders, we can figure out ways to overcome any obstacles that may exist.

It is important to reflect on stories like this, because although many gains have been made in the field of EHDI, there are many more ways in which we can improve, both as clinicians and EHDI advocates.

Stay tuned for more TALES FROM THE FRONT LINES in the future!

Brad Golner MD  
AZ EHDI Chapter Champion  
AAP EHDI Leadership Team

## UPCOMING EVENTS

Event	Date	Location	Details
Reducing Lost to Follow-up: It Takes a Village Establishing Otoacoustic Emissions Screening in 10 Pediatric Offices	December 10, 2015	Webinar	<a href="#">Website</a>
Association of Maternal & Child Health Programs (AMCHP) Annual Conference	January 23-26, 2016	Washington DC	<a href="#">Website</a>
Annual EHDI Meeting	March 13-15, 2016	San Diego, CA	<a href="#">Website</a>

## THE PARENT PERSPECTIVE—TRANSITION FROM EARLY INTERVENTION TO PRE-SCHOOL

The transition from Early Intervention to preschool services can be stressful for parents. Through having a more thorough understanding of the transition process, primary care providers can better prepare families for this transition while providing comprehensive and relevant medical care to their patients who are Deaf or Hard of Hearing (D/HH).

Planning for the transition from Early Intervention (Part C) to preschool services (Part B) is a very important step in the life of a child and family. Eligible children can receive special services and assistance (special education and related services) under the Individuals with Disabilities Education Act (IDEA). Some of the changes included in the transition process at the age of three may include the following:

- A change in the people who have been serving the child
- A change in the location of services
- A change from an IFSP (Individual Family Service Plan) to an IEP (Individual Education Plan)
- A change from goals that are family directed to educational need-based goals

State law provides requirements regarding the steps involved in completing a child's transition between services. This period often includes numerous school assessments, visits to various school programs, and learning more about how one's child learns and communicates best. Most families benefit from extended transition time to discuss and consider various decisions, as well as meet the people who will be involved in key aspects of their child's life in school. This additional time can greatly ease pressure on parents as well as allow for more time for the family and school personnel to develop a positive relationship.

Hands & Voices has resources to assist families through this time of transition. Pediatric clinicians can help parents navigate through the transition by providing this [article and transition timeline](#), among other resources that can be found on the [Hands & Voices Web site](#).

Families with additional questions and concerns can be referred for assistance to any [Hands & Voices chapters](#) for direct support.

# NATIONAL CENTER FOR HEARING ASSESSMENT AND MANAGEMENT—EHD QUALITY IMPROVEMENT

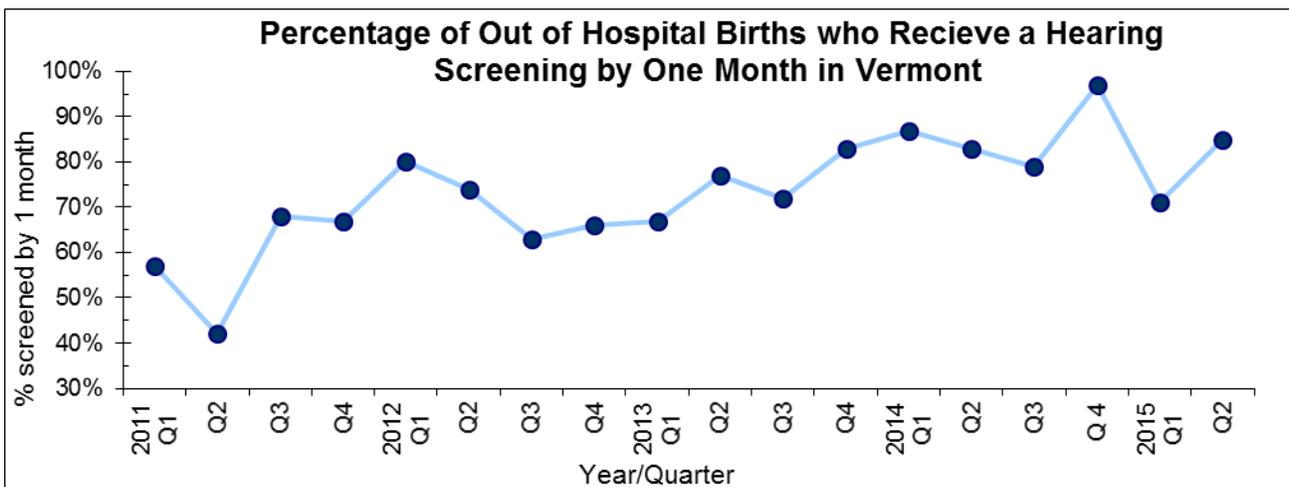
In 2011, Vermont Early Hearing Detection and Intervention (EHD) program staff recognized that a growing number of babies who had not received a hearing screen in their state were out-of-hospital births (OHB)—babies born at home. In fact, in 2010 only 10% of OHB were being screened. To increase the number hearing screening in babies born out of the hospital, the Vermont EHD program implemented a quality improvement (QI) project.

Recognizing some unique challenges related to OHB, the Vermont EHD program staff chose to engage midwives in their QI project. The Vermont EHD team focused their initial efforts on working with the 3 midwives who had the highest attended OHB in the state.

The Vermont EHD team worked with the 3 midwives to test training, hands-on screening practice, and an equipment loaning program. With diligence, the midwives and the Vermont EHD team began to consistently receive the following feedback from families:

- 1) Families were open to getting their baby's hearing screened
- 2) Families appreciated that the babies could be screened at home
- 3) Families preferred the screening be done by someone they trusted

The Vermont EHD team and the midwives found that not only had trust been built between them and the families they served, but also that the data were indicating success in terms of more babies born outside of hospitals being screened. The data showed that in 2011, 59% of OHB were being screened; this is a 49% improvement in just one year. Over time the EHD program team decided to spread these strategies and reached out to more midwives across the state to test the same changes. Additionally, the EHD program team tested new strategies such as implementing midwife screening report cards and web-based reporting. The Vermont EHD program team is now working with the majority of midwives across the state and in 2014, 83% of babies born out of the hospital in Vermont received newborn hearing screening.

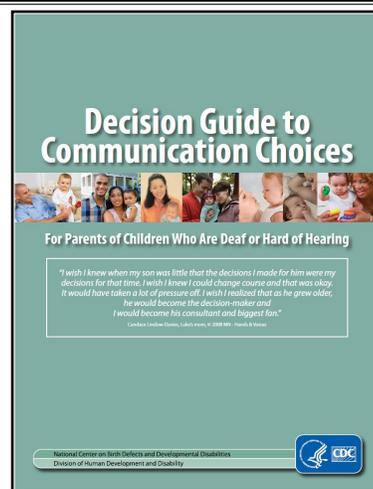


The QI work conducted in Vermont is an example illustrating the importance of building relationships with a hard-to-reach population and how these relationships can result in improvement. Through this QI project, the Vermont EHD team also was reminded of the important role the primary care provider (PCP) plays in assisting families in obtaining a newborn hearing screen if their baby is born at home. Pediatric clinicians who need more information regarding where hearing screening can be conducted if a baby in their practice is born out of the hospital can reach out to their [state EHD coordinator](#) in order to coordinate this necessary follow-up care.

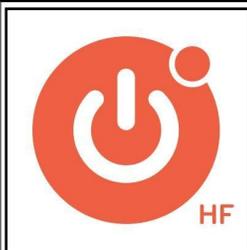
## CENTERS FOR DISEASE CONTROL AND PREVENTION—DECISION GUIDE TO COMMUNICATION CHOICES

The Centers for Disease Control and Prevention (CDC) has developed a number of resources for both parents and professionals to improve care for children who are Deaf or Hard of Hearing (D/HH). Among the resources available is a [Decision Guide to Communication Choices](#) which leads parents through the difficult process of identifying which communication choice, or choices, might be best for their child and family.

This resource takes parents through a step-by-step approach to identifying the various communication options available and ensuring they not only have the necessary information about each option, but also the support needed to make an appropriate decision. This resource can also be valuable for pediatric clinicians to use in their practice to ensure that parents of children who are D/HH have tools necessary to assist them in making an informed decision.



## HEARING FIRST WEB SITE NOW AVAILABLE



[Hearing First](#) is a subsidiary organization of the Oberkotter Foundation which provides information and resources regarding listening and spoken language (LSL) options for children who are D/HH. If families are considering, or have chosen, LSL as a communication option, this organization offers information on LSL, tools for parents and professionals, and access to professionals who can provide additional services.

## WHICH COMPONENTS OF MEDICAL HOMES REDUCE THE TIME BURDEN ON FAMILIES OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS?

The medical home and the primary care clinician play key roles in providing comprehensive and effective care for children who are D/HH. This study found that at [least three out of the five medical home components were associated with lower odds of time burdens](#) and reductions in burdens for providing care.

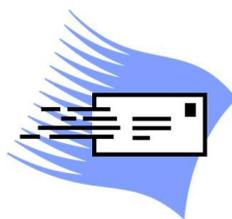
The medical home is defined by the American Academy of Pediatrics as primary care organizations that are “accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.” For the purpose of this study, a family was determined to have a comprehensive medical home if they had a personal doctor or nurse, a usual source of care, if they received family-centered care, had care coordination, and were able to obtain referrals. Using the 2009–2010 National Survey of Children with Special Health Care Needs, families who had all five components of the medical home in place were found to have a 36% reduction in odds of a time burden for arranging and coordinating care. This study specifically identified that care coordination, family-centered care, and the ability to obtain referrals led to the greatest reduction in time burden for families. This study shows the value in ensuring that all children with special health care needs, including children who are D/HH, have medical homes in order to provide high quality and timely medical care.

Miller JE, Nugent CN, Russell LB. Which components of medical homes reduce the time burden on families of children with special health care needs?. *Health Services Research*. 2015(2):440-461.

## COCHLEAR IMPLANTATION AMONG DEAF CHILDREN WITH ADDITIONAL DISABILITIES: PARENTAL PERCEPTIONS OF BENEFITS, CHALLENGES, AND SERVICE PROVISION

An increasing number of children who are D/HH and have other developmental disabilities, are receiving cochlear implants (CI). This study sought to evaluate parent perception regarding the associated daily benefits and challenges. The study found that the most common benefits reported were an increase in their child's awareness of environmental sounds (43%) and communication ability (35%). Some parents (17%) also reported that the CI contributed to their child's well-being. However, a significant number of parents also reported difficulties such as communication breakdowns in child-parent interactions, implant drawbacks (including equipment breakdowns or not wearing the devices), and interactions with other children, among others. This study recruited 45 children from a CI program at a Children's Hospital in Canada and included both a questionnaire and interview in order to capture quantitative and qualitative feedback. The study highlights potential areas for continued training and guidance of families and children who are D/HH and chose CI to maximize the effectiveness of the CI intervention.

Saidman-Zait A, Curle D, Jamieson JR, et al. Cochlear implantation among deaf children with additional disabilities: parental perceptions of benefits, challenges, and service provision. *Deaf Studies and Deaf Education*. 2015:41-50.



### **Distribution Information:**

The AAP EHDI Program implementation staff send this e-mail update to the Academy's EHDI Chapter Champions, other interested AAP members, staff and state EHDI coordinators. For additional information on hearing screening and to access previous editions of the EHDI E-mail Express, click on the following link <http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Early-Hearing-Detection-and-Intervention.aspx>. Previous e-mail updates are available upon request from Stephen Crabbe, [scrabbe@aap.org](mailto:scrabbe@aap.org) or (847) 434-4738. If you would like to unsubscribe to the update, please notify staff by responding to this e-mail.