
Early Hearing Detection and Intervention Program

Pennsylvania Department of Health
Early Hearing Detection and Intervention (EHDI)
Program Report on Screening and Follow-up
for 2013 Births

Bureau of Family Health
Division of Newborn Screening and Genetics
Health and Welfare Building, Seventh Floor East Wing
Harrisburg, Pennsylvania 17120

Prepared November 13, 2015

Introduction

Each year in the United States, more than 5,200¹ babies are born with a permanent childhood hearing loss, making it the most frequently occurring condition identified through newborn screening. The National Institutes of Health supported research suggests that the most intensive period of speech and language development occurs during the first three years of life — a period when a child’s brain is developing and maturing. If a child is not exposed to language during this period due to hearing loss, he or she will have more difficulty developing spoken or signed language and reading skills. In addition, during the early stages of life, the brain builds the nerve pathways necessary for understanding auditory information. For these reasons, identifying hearing loss by the time a child reaches 3 months of age enables pursuing treatment options early, so that a child can learn to communicate comparably with his or her peers.²

Several national committees, including the National Institutes of Health, the American Academy of Otolaryngology/Head and Neck Surgery and the American Academy of Pediatrics have recommended that hearing loss in infants be identified and, when possible, treated prior to 6 months of age. This recommendation is based on studies that have shown that children identified with hearing loss prior to 6 months of age have a better chance of developing skills equivalent to their hearing peers by the time they enter kindergarten. Children experiencing late identification may experience irreversible and permanent impairments in speech, language and cognitive abilities. In general, unidentified children with hearing loss have increased difficulties with verbal and non-verbal communication skills, increased behavioral problems, decreased psychosocial well-being and lower educational attainment compared with children with normal hearing.

Pennsylvania’s Infant Hearing Education, Assessment, Reporting and Referral (IHEARR) Act (Act 89 of 2001) enables the Department of Health (DOH) to administer a statewide comprehensive newborn hearing screening and follow-up program. This report is submitted to the General Assembly in fulfillment of the reporting requirements found in Section 5(d) (4) of the IHEARR Act. The report covers the results of in- and out-of-hospital screenings for infants born in 2013. Follow-up activities for infants referred to DOH for failure to pass their newborn hearing screening occurred from 2011 through 2013. This report also covers the status of ongoing program initiatives undertaken during state fiscal years 2013 and 2014.

Background

Due to the emergence of reliable, affordable technology for early hearing detection and intervention (EHDI) in the mid-1990s, DOH began a pilot program with 26 birthing

¹ Centers for Disease Control and Prevention website: http://www.cdc.gov/ncbddd/hearingloss/2013-data/2013_ehdi_hsfs_summary_a.pdf

² National Institutes of Health Fact Sheet-Newborn Hearing Screening: <http://report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=104&key=N#N>



hospitals in 1999. The program proved the practicality of early hearing detection as a standard of newborn care throughout the commonwealth. Following the passage of the IHEARR Act in November of 2001, Pennsylvania implemented a statewide universal newborn hearing screening and follow-up program beginning on July 1, 2002.

The Joint Committee on Infant Hearing's (JCIH) 2007 Position Statement on the Principles and Guidelines for Early Hearing Detection and Intervention Programs states that physiologic measures must be used to screen

newborns and infants for hearing loss. Although there are several technologies available to screen newborns, JCIH recommends two technologies: Automated Auditory Brainstem Response and Otoacoustic Emissions. Automated Auditory Brainstem Response (A-ABR) measures the brain's response to sound. Sound stimuli consisting of clicks or tones are administered to the baby through soft earphones, and electrodes placed on the baby's head measure the brain's response. Otoacoustic Emissions (OAE) measures sound waves produced in the inner ear. Sound stimuli consisting of clicks or tones are administered, and a tiny probe placed just inside the baby's ear canal measures the inner ear's response. Both technologies provide a non-invasive recording of physiologic activity of normal auditory functioning. Also, both tests are painless and can be performed in five to 10 minutes while the baby is sleeping or lying still. A single procedure or a combination of both procedures may be used for infants in the newborn nursery. For infants in neonatal intensive care units (NICU), the JCIH recommends A-ABR technology as the only appropriate technology for this population. Since many infants with neural hearing loss are in this target population, the committee recommends this distinction for those high-risk infants.

Program Objectives

The primary objective of the EHDI program is to provide appropriate and timely screening to improve the quality of life for those infants identified with permanent bilateral or unilateral sensorineural or conductive hearing loss.

Consistent with national EHDI initiatives and the recommendations of the JCIH in 2007, the components of Pennsylvania's program are:

- Availability of initial and repeat hearing screenings for all infants before 1 month of age;
- Appropriate audiological and medical evaluations for all infants to confirm hearing loss before 3 months of age;
- Immediate access to high-quality technology for all infants with confirmed hearing loss (hearing aids, cochlear implants and other assistive devices when appropriate);

- Referral to local early intervention (EI) as soon as a diagnosis of hearing loss is confirmed (before 6 months of age), with services provided by professionals knowledgeable about childhood hearing loss;
- Ongoing monitoring for hearing loss in the medical home through continued communication developmental assessments of infants and children both with and without risk indicators for late-onset or progressive hearing loss; and
- Family-centered services, access to information through culturally-sensitive approaches, informed choices, parental consent, and the guarantee of infant and family rights and privacy.

Screening

Hospital Births

Newborn hearing screening is one component of a comprehensive approach to the management of early childhood hearing impairment that includes diagnostic services, early intervention, parent education and support.

Table 1 – Hospital Hearing Screening Performance

All of the state's 97 hospitals with functioning birthing departments reported monthly aggregate hearing screening results to the state EHDI program. Generally, initial hearing screenings occur prior to hospital discharge, and newborns who do not pass the initial hearing screenings receive a second screening.

Calendar year	Total hospital reported births ³	Initial screen				Follow-up screen		
		Initial screens	Percent initial screens	Newborns passing initial screen	Newborns not passing initial screen	Newborns receiving follow-up screen	Newborns passing follow-up screen	Newborns not passing follow-up screen
2013	135,668	133,796	98.6	128,264	5,861	4,832	4,067	765
2012	136,381	134,477	98.6	128,185	6,292	5,372	4,540	832
2011	137,925	136,490	98.9	128,552	7,938	6,905	5,986	919

Infants not passing initial hearing screening during their birth admission receive a second screening either before discharge from the hospital or during an outpatient appointment, usually within the first month of life. If an infant does not pass the second screening, the screening provider notifies the state EHDI program and the child's primary care physician (PCP). The PCP coordinates follow-up care by referring the newborn to an audiologist with pediatric diagnostic expertise, to a medical specialist and to EI services. The physician confirms that intervention services are being delivered, including the parent's selection of a communication method/language and the fitting of amplification devices by 6 months of age.

³ Births as reported to the EHDI program by hospitals with a functioning birthing department

Out-of-Hospital Births

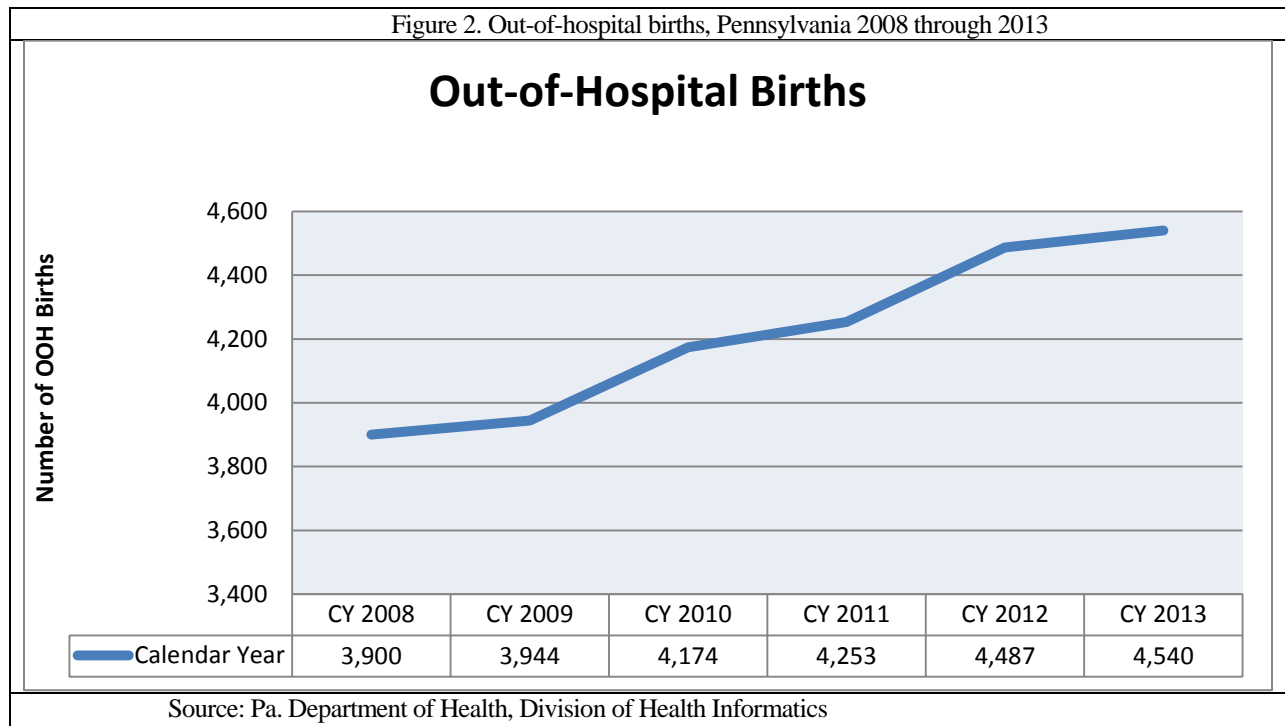
According to the Department of Health’s Bureau of Health Statistics and Research, approximately 4,500 babies are born annually in Pennsylvania in out-of-hospital settings. Midwives assisting in out-of-hospital births may participate in the out-of-hospital hearing screening program by obtaining screening equipment through the DOH. Participation in the out-of-hospital hearing screening program is dependent on birth volume and geographic concentration. The licensed freestanding birth centers are all equipped with hearing screening equipment. Infants can be referred to participating midwives or the licensed birth centers to have the initial hearing screening. Infants can also be referred to participating midwives or the licensed birth centers to have the repeat hearing screening if the baby does not pass the initial hearing screening. An infant can be referred to any local hospital that provides hearing screenings.

Program Components

Out-of-Hospital Newborn Hearing Screening Program Evaluation

In 1900, almost all U.S. births occurred outside of a hospital. However, the proportion of out-of-hospital births fell to 44 percent by 1940 and to 1 percent by 1969, where it remained through the 1980s. Although out-of-hospital births are still uncommon in the United States, they have been increasing recently. If this increase continues, it has the potential to affect patterns of facility usage, clinician training and resource allocation, as well as health care costs.

Figure 2. Out-of-hospital births, Pennsylvania 2008 through 2013



Through previous analysis using statistical data provided by the department's Bureau of Health Statistics and Research and the electronic birth records system, EHDI program staff identified areas with the highest geographic concentrations of out-of-hospital births. Portable hearing screening machines were purchased and provided to both freestanding birthing centers and midwives in areas with high concentrations of out-of-hospital births. (Pennsylvania defines a birthing center as a facility, not part of a hospital, which provides maternity care to childbearing families who do not require hospitalization. A birth center provides a homelike atmosphere for maternity care, including prenatal, labor, delivery and postpartum care related to medically uncomplicated pregnancies). In some cases, the newborn hearing screening equipment is shared by a group of midwives in a geographic area, and this is known as a "traveling midwife network."⁴

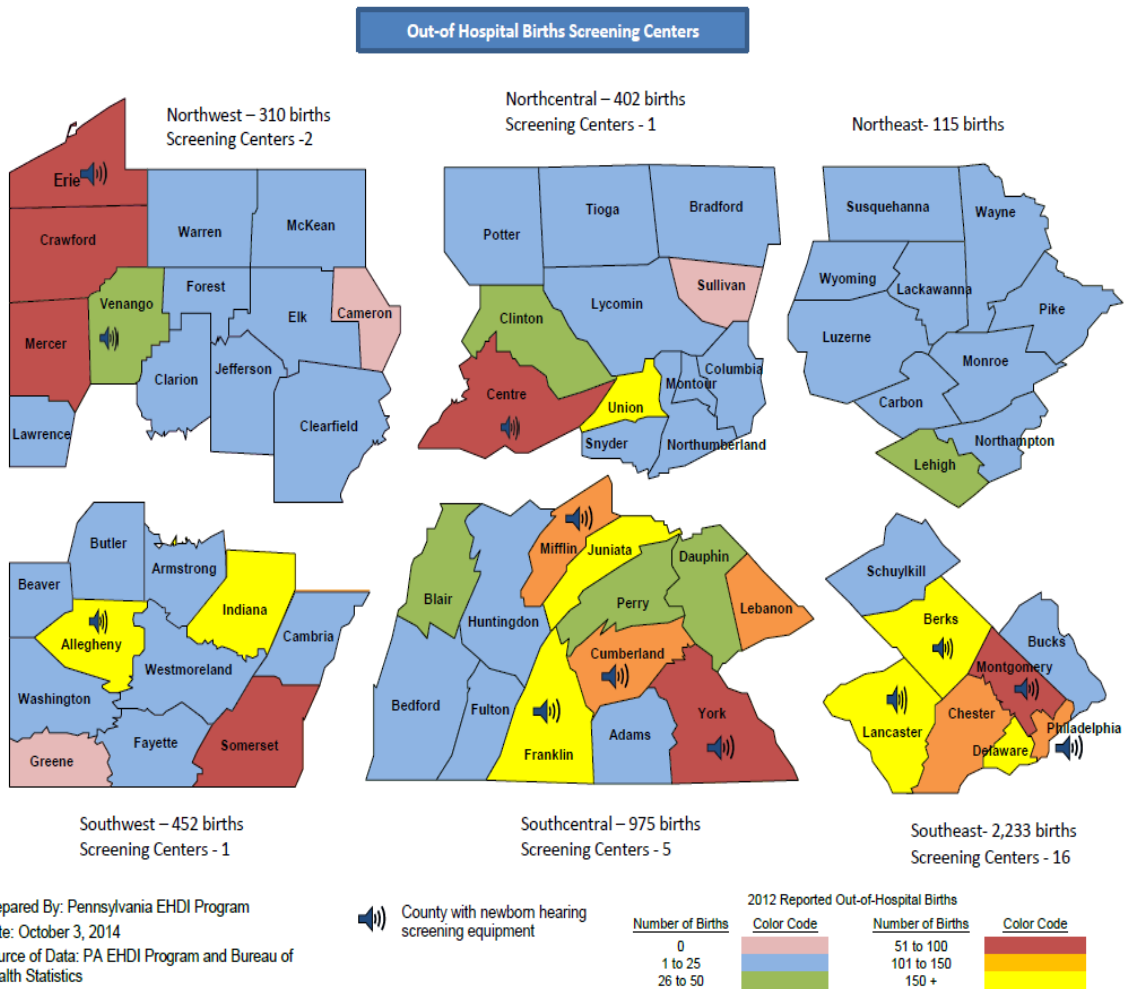
Representatives from the manufacturer of the portable hearing screening equipment and department staff provide hands-on training to midwife screeners. Each midwife signs an agreement indicating that she has been trained on the use of the equipment, affirming that she will use it only for the purpose of newborn hearing screening, and affirming that she agrees to share the equipment (if in a traveling network). Midwives agree to report monthly screening performance data to the department and to provide information on infants not passing rescreening to the department for follow-up. As a result of a review performed in 2009, the evaluation of the Out-of-Hospital Births Hearing Screening Program, the goal to increase the number of out-of-hospital births that are screened for hearing loss to 50 percent or more was achieved. This initiative also improved the quality of midwife hearing screening and reporting and established cooperative relationships between the state EHDI program and leaders in the Amish Community (which tends to have a high number of out-of-hospital births).



Out-of-Hospital infant receiving hearing screening in Lancaster, Pa.

⁴ <http://amishamerica.com/amish-state-guide/#pennsylvania>

At this time, there are 25 out-of-hospital birth newborn hearing screening centers established throughout the commonwealth (see map below).



Follow-up and Diagnosis

Five community health nurses in the department's EHDI Program receive referrals (from both hospitals and midwives) for infants who did not pass either the first or second hearing screening. Letters are created through the data system and sent to the family and PCP to ensure the PCP is aware that an infant in his/her practice did not pass a hearing screening and that audiology assessment and evaluations must be completed. The



nurses also confirm diagnosis and receipt of treatment and/or EI services by 6 months of age. The nurses record all of their contacts with the PCP, audiologist and family in the contact notes area of the newborn screening data system. Additionally, the screening results and diagnostic test results are entered into the data system to complete the child's record.

Three-hundred-seventy-eight infants born in 2013 were diagnosed with some form of hearing loss. In 2012, 360 were diagnosed, and in 2011, 358 were diagnosed.

Table 2 – Diagnostic Information

The table below summarizes activities for follow-up for 2013 births. The data for 2011 and 2012 births are provided for comparison.

2011-2013 Diagnostic Information			
	Calendar 2013	Calendar 2012	Calendar 2011
Total Not Passing Hearing Screening ⁵	2,178	2,270	2,007
Diagnosed With Normal Hearing			
Diagnosed with normal hearing before 3 months of age	1,337	107	1153
Diagnosed with normal hearing before 6 months of age	102	70	82
Diagnosed with normal hearing after 6 months of age	23	34	26
Diagnosed with normal hearing age unknown	1	474	0
Total diagnosed with normal hearing	1,463	1,148	1261
Diagnosed With Hearing Loss			
Diagnosed with permanent hearing loss before 3 months of age	135	107	105
Diagnosed with permanent hearing loss before 6 months of age	50	70	52
Diagnosed with permanent hearing loss after 6 months of age	18	29	20
Diagnosed with permanent hearing loss age unknown	0	0	0
Total diagnosed with permanent hearing loss	203	206	177
Diagnosed with non-permanent conductive hearing loss	175	154	181
Total diagnosed with hearing loss	378	360	358
No Known Diagnosis			
Infant expired	1	7	3
Parent declined services	299	337	157
Moved out of state	10	18	27
Unable to contact/unresponsive/unknown	202	176	201
Total no known diagnosis	512	538	388

⁵ Information presented includes both hospital and out-of-hospital births.

2011 EHDI Website of the Year

2013 National Achievement Award

PA EHDI website address: www.paeearlyhearing.org



The department recognizes the importance state Early Hearing Detection and Intervention (EHDI) programs play in ensuring the availability of accurate and user-friendly information pertaining to newborn hearing screening, diagnosis and early intervention services. In June 2010, PA EHDI staff along with staff from the Pennsylvania Chapter of the American Academy of Pediatrics (PA AAP) launched the PA EHDI website. Staff from both the PA EHDI program and PA AAP worked closely with members of the Infant Hearing Screening Advisory Committee and key stakeholders on website layout and content. To make navigation easy, the website contains individual pages for key stakeholders, including families, physicians, audiologists, birth facilities and early intervention staff. The family page and the physician page feature a link to allow users to easily find local pediatric audiologists. Recently, information for the family support program, Guide By Your Side (GBYS), was added to the website. This page includes a referral form for PA GBYS services that parents can complete online.

The annual "Best of EHDI Website" national award is used to recognize state EHDI websites that do the best job of providing:

- Accurate, useful, timely and comprehensive information that contributes to the accomplishment of 1-3-6 milestones for infants and young children who are deaf or hard of hearing;
- Information for various EHDI stakeholders (families, health care providers and interventionists), as well as correct information about the EHDI process; and
- Appropriate and visually appealing design and layout that allows for ease of finding information.

The award is made yearly at the national EHDI conference by the conference sponsors, the Centers for Disease Control and Prevention, the American Academy of Pediatrics, the Health Resources and Services Administration, and the National Center for Hearing Assessment and Management.

In 2011, at the national EHDI conference in Atlanta, Georgia, the first year that awards were made, the Pennsylvania EHDI website was selected as the national “EHDI Website of the Year”. Two years later, at the national EHDI conference in Glendale, Arizona, the Pennsylvania EHDI website received a national award for “Outstanding Achievement for Continued Excellence in EHDI Website Design.”

Family Support and Partnership

Family support is an essential component of an effective Early Hearing Detection and Intervention (EHDI) system. State EHDI programs, providers and other stakeholders, such as a family support program, have a responsibility to ensure:

- **Families are supported:** EHDI systems must ensure that families get access to culturally-competent information to help them make informed decisions. This also includes providing access to family support groups to help provide emotional support as only other caregivers can offer.
- **Families are partners in decision making:** EHDI systems must honor family decisions about what is best for their own child and family. At a systems level, families with diverse perspectives can offer their expertise to guide EHDI practices and policies, resulting in more family-centered EHDI systems.

In July 2011, the Pennsylvania EHDI Program and the Pennsylvania Training and Technical Assistance Network launched the Hands & Voices Guide By Your Side of PA Program (GBYS). GBYS is dedicated to supporting families and their infants and toddlers who are newly identified with hearing loss by offering them an opportunity to talk or meet face-to-face with a parent guide. Parent guides are trained parents of a deaf/hard of hearing child, and they are able to provide assistance using their personal experience and knowledge. The guides receive formal training, are strategically located throughout the commonwealth and are able to bring their direct experience, specialized knowledge and personal compassion to their role while making the family's needs their primary focus. Any family of a Pennsylvania

infant or toddler (ages birth to 3) who has a hearing loss is eligible for the program, and services are provided to the families at no cost.



Three-hundred and forty-four families have received support services since the inception of the GBYS program in November 2011.

Matches between parent guides and families are made based not only on geographic proximity, but also on the similarity of diagnoses, hearing levels, communication strategies and technology choices, such as cochlear implants or hearing aids. Families have also been provided with opportunities to meet deaf adults through

community events.

The support provided to families who enroll in GBYS includes providing unbiased materials on the communication strategies, face-to-face meetings, newsletters, support via telephone and email, informational teleconference training calls, loans of library materials, and postal mail of letters of support to families who do not use email. Parent guides have shared their children's stories with enrolled families through articles, photos and many different types of experience books.

The GBYS team has collaborated with many community partners to expand support received by enrolled families. Contacts and connections have been made with the Special Kids Network System of Care, Parent to Parent of Pa., state schools and programs for deaf and hard of hearing children, Hands & Voices chapter events, and other community-based events for deaf and hard of hearing children and their families. An example of other activities includes story times and play groups at local libraries.

1. Have a designated hospital EHDI coordinator.

Having a coordinator in place who is responsible for tracking positive screens, assuring reports are sent to DOH, and coordinating screens from both NICU and newborn minimizes the number of possible errors in tracking, follow-up and reporting. This position should have clear roles and responsibilities defined. If more than one individual is involved in this role, it should be clear who has responsibility for: coordinating screens from NICU and newborn, assuring information gets to PCP, sending aggregate and individual reports to DOH, scheduling follow-up for those who fail the newborn screen, training and supervising staff who perform hearing screenings, and ensuring maintenance and updating of hearing screening equipment.

2. Link babies to follow-up prior to hospital discharge.

Linking babies that do not pass their hearing screening to outpatient follow-up prior to hospital discharge will minimize the number of babies lost to follow-up. It is preferable to have a formal relationship with an audiology center, but, obviously, this is not always possible. However, knowing the centers to which a baby will be referred and giving parents information and/or making an appointment for them greatly increases the chances the family will follow up.

3. Track the number of no-shows if outpatient rescreens are done.

If outpatient rescreening is done at the same institution, it is important to track the number of no-shows for follow-up. This is the only way of knowing how many babies with failed screens in the newborn nursery are being lost to follow-up. If this number is excessively high, steps can then be taken to correct this problem. This may involve sending out reminder cards, making phone contact or other methods. If the return rate cannot be increased, consideration should be given to referring those babies who fail the hospital screen directly to an audiology center for evaluation.

4. Identify and communicate with the baby's PCP prior to discharge.

It is critical for a number of reasons to correctly identify the baby's PCP prior to hospital discharge and have a mechanism in place to send that PCP a complete summary of the newborn stay, including the results of the hearing screen. It is not enough to send only the PCP screening results if they are positive. All babies should have all results sent to their PCP in a timely fashion, preferably within 48 hours, when most babies will be seen for the first time after hospital discharge.

5. Assure that correct information is sent to DOH.

In addition to communication with the PCP, the EHDI system requires that accurate information is sent to DOH regarding the number of babies screened, the number that fail the screen, and individual information on those babies that either fail the hospital screen or do not return for a rescreen. In addition to this information being sent, it is vital that the data is accurate, including family demographics, the baby's last name after discharge, the correct PCP and alternate contact information. The reason this is so important is that DOH tracks and follows all individual referrals to assure that they receive appropriate follow-up. This cannot occur if inaccurate information is sent to DOH on the referral form. Finally, the number of individual referrals sent to DOH should regularly be reviewed to determine if this number is consistent with the monthly aggregate reports. Obviously, assuring correct information is being sent to DOH can best occur if this task is given to as few people as possible, preferably a hospital EHDI coordinator as outlined above.

6. Make hearing screening part of hospital QI activities.

Improving the quality of newborn hearing screening can be accomplished in a number of ways, including: having a formal training for any new staff that will be involved in screening babies, making the performance of screening part of annual competencies, and working with an audiology center to assist in training staff.

In addition to setting quality standards for the actual performance of an OAE or A-ABR, quality measures can also be established for insuring that families are given appropriate information stressing the importance of follow-up for babies who do not pass, as well as the need for families to seek care if they have any concerns about hearing, even if the baby passes. Finally, hospitals can create quality standards for: the number of babies screened, the percentage of babies who fail the screen and the number of parents who refused the screen for their newborn.

Monthly aggregate reports can be evaluated against these standards to assess the quality of screening and referral.

7. Identify high risk conditions in addition to screening.

Although there is currently not a system to report babies to DOH who pass the newborn screen but have high risk conditions, identifying these babies and assuring that this information is communicated to the PCP will increase the chances that these babies will be tracked appropriately and diagnosed more readily if hearing loss should occur.

8. Provide clear, supportive and easy to understand information to parents.

It is important to provide parents with information on newborn hearing screening and the results of their baby's hearing screening in a clear, supportive and easy to understand manner. This helps ensure that babies who did not pass their hearing screening receive follow-up care. It also educates parents about the importance of hearing and the need to talk to their baby's PCP if they have any concerns in the future. Training staff on how

to talk to parents and providing printed materials on hearing screening for parents to take home helps ensure a consistent message. For parents of babies who did not pass their hearing screening, it is important to balance emphasizing the importance of follow-up without minimizing the potential problem.

9. Engage medical staff.

Engagement of staff physicians in quality initiatives and communicating results of hearing screening to parents will reduce any mixed messages they receive in regard to the importance of follow-up.

Infant Hearing Screening Advisory Committee

The successful progress of the Pennsylvania EHDI program is made possible largely by significant collaboration and input from the Infant Hearing Screening Advisory Committee. This six-member committee is appointed by the secretary of health and makes recommendations to the department regarding infant hearing education, assessment, reporting and referrals. Issues include program regulation and administration, diagnostic testing, technical support and follow-up for the EHDI Program. The committee operates under a set of bylaws and meets three times per year. In addition to attending meetings, members provide program staff with ongoing advice and consultation on a variety of topics and occasionally serve as presenters at conferences, training workshops and presentations.

The committee is currently comprised of three audiologists, one educator for the deaf and hard of hearing, one otolaryngologist and a parent advocate with a young child with hearing loss. The committee is a valuable part of Pennsylvania's hearing screening program.

**CURRENT MEMBERS OF THE
INFANT HEARING SCREENING ADVISORY COMMITTEE**

Elca Swigart, Ph.D (audiologist) Committee Chair

- Director Speech and Hearing Center, Reading Hospital at Wyomissing Plaza

David H. Chi, M.D. (otolaryngologist)

- Assistant Professor Otolaryngology, University of Pittsburgh School of Medicine, Director Hearing Center, Children's Hospital of Pittsburgh

Judith S. Sexton M.S., M.S., C.E.D., LSLs Cert. AVEd. (educator)

- Director, Clarke School, Bryn Mawr, Pennsylvania

Hadley Haas, BA, The University of Michigan (parent advocate)

- Pittsburgh, Pa.

Janet Juracich Trychin, Au.D. CCC-A

- Associate Professor, Adjunct Status at Edinboro University

Carol Knightly, Au.D.

- Director, Center for Childhood Communication at Children's Hospital in Philadelphia

Conclusion

The Pennsylvania newborn hearing screening program continues to progress to become a national top hearing screening program.

DOH has also made considerable progress in the areas of providing screening resources for out-of-hospital births and providing outreach to hospitals, primary care physicians and audiologists by offering technical assistance to select hospitals. Our website, www.paearlyhearing.org, continues to grow as a source of education and information. With the vast growth in internet learning, we are proud of our website design and award. It is a model for other states to grow their hearing screening programs.



Opportunities for improvement still exist, especially with Part C of the Individuals with Disabilities Education Act. Part C of IDEA requires to the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate. (34 CFR §303.12(b)).

Early intervention providers could be more aware of, and responsive to, the type and severity of each child's hearing loss, each family's preferences, and the different communication options and instructional methods. Progress on these efforts will enable the Pennsylvania EHDI Program, with its partners, to mature to the level envisioned for model programs by the Health Resources and Services Administration and the Centers for Disease Control and Prevention.

Contact information

Department of Health Early Hearing Detection and Intervention Program
717-783-8143

Carolyn Cass
Director, Bureau of Family Health
Email: ccass@pa.gov

Kelly Holland
Director, Division of Newborn Screening and Genetics
Email kholland@pa.gov

Joseph Wagner
Program Manager, Newborn Screening and Genetics
Division of Newborn Screening and Genetics
Email: josewagner@pa.gov

Arthur Florio
Program Administrator, Newborn Hearing Screening Program
Division of Newborn Screening and Genetics
Email: aflorio@pa.gov