American Academy of Pediatrics (AAP)
Early Hearing Detection and Intervention (EHDI)
Pediatrician Perspectives: Executive Summary
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Overview

This document presents key findings from a survey and interviews conducted with primary care pediatricians (PCPs) designed to gain understanding of pediatricians' knowledge and practices related to newborn hearing screening, follow-up, diagnostic testing, referral to early intervention (EI) services, risk-factor assessment and documentation, as well as to learn about their needs for education, information, and resources in these areas. The findings are intended to provide AAP EHDI program staff and stakeholders with information to assist in developing resources to support pediatricians' role related to newborn hearing screening, follow up, and management.

The AAP EHDI program was established in 2001 to improve the effectiveness of newborn hearing screening, diagnosis, and intervention, through increasing the involvement of PCPs and other pediatric health care providers in state EHDI programs. The EHDI program includes the following key features:

- A nationwide network of AAP Chapter Champions and Regional Network Liaisons.
- Develop and disseminate professional education materials and resources to support pediatricians and other pediatric health care providers in conducting hearing screenings, identifying hearing loss in infants and young children, and providing hearing loss diagnoses.
- Leadership in policy efforts and collaborations with professional medical organizations, their constituents, and other EHDI stakeholders at the state and federal levels on EHDI activities.

Using a mixed methods approach, the project included two components: 1) a 26-item anonymous pediatrician survey administered electronically to a list of 4,960 randomly selected AAP members (response rate: 6.9%); and 2) key informant interviews, conducted via telephone with a small sample of six pediatricians randomly selected from a subsample of pediatrician survey respondents who agreed to participate (for more details on background and methodology, see full report).

Key Findings

Pediatrician Survey

- Of 343 respondents, over 90.0% reported that they are either moderately familiar or very familiar with their state's EHDI program, while only 9.6% reported they were not at all or not very familiar.
- While more than 90.0% correctly identified family history of childhood hearing loss and meningitis, and 82.5% correctly identified history of cytomegalovirus (CMV) in infants, only about two-thirds recognized the other important risk factors of hearing loss, including neonatal intensive care unit (NICU) stay of more than five days (66.8%); cleft palate (66.5%); and congenital syphilis (61.5%). Meanwhile, between 20.0% and 25.0% selected the incorrect choices of congenital heart disease; frequent colds; and hypotonia as potential risk factors.
- While more than 95.0% of respondents recognized that moderate bilateral and severe/profound hearing loss have an impact on speech and language development, and nearly 90.0% recognized mild bilateral hearing loss can have an impact, only 75.0% recognized unilateral hearing loss as having an impact. Thus, one-quarter of respondents did not recognize that unilateral hearing loss can impact speech and language development.
Nearly 90.0% of respondents reported that when an infant who did not pass the newborn hearing screen comes for a pediatrician clinic visit, they tell the parent to follow up with additional screening/diagnostic testing as soon as possible. While audiologist was the most commonly specified type of provider, other responses included birth hospital; otolaryngologist (ENT); state screening program/health department; and EI.

Nearly 90.0% reported that they know where to call to obtain newborn hearing results if they are not provided with them. Most specified the birth hospital, while other common responses included the department of public health and/or the state screening program.

To a survey question that asked respondents to specify the age (in months) by which children identified as deaf or hard of hearing (D/HH) should be enrolled in EI services, less than 30.0% reported the correct answer (six months).

Over one-third of survey respondents reported that they have no knowledge of the EHDI 1-3-6 benchmarks; 9.5% reported some knowledge but not applied in practice; 19.3% reported knowledgeable and sometimes applied in practice; and only 37.0% reported knowledgeable and regularly applied in practice.

Less than 70.0% reported that they are typically notified when a patient enrolls in EI following a referral; only about 40.0% reported they are kept informed of patient progress in EI; 23.5% reported they are kept informed, but only if they request the information; and 36.7% reported they are not typically kept informed.

Over half (55.7%) of respondents reported that they were either not at all aware or not very aware of the types of family support resources available in their state for parents of children who have been identified as D/HH. Meanwhile, less than half (44.3%) reported that they were either aware or very aware.
Pediatrician Interviews

- According to the pediatricians interviewed, the main concerns of parents/caregivers of patients identified as D/HH or who may be at risk of late onset hearing loss (LOHL) include the following:
  - Wondering that they may have done something to cause the hearing loss; wondering if it is 'their fault.'
  - Wanting to know if hearing loss is 'curable.'
  - Wanting to know how profound it will be and whether/how it will affect their child's learning.
  - Accepting that their child has or may have hearing loss; in the words of one pediatrician, "it is a major adjustment."
  - Wanting information on hearing aids and insurance coverage.
  - Following up—even for parents who understand the importance of hearing loss.

- Most of the pediatricians interviewed expressed that lack of access to information is not a primary problem for parents/caregivers of their patients identified as D/HH or who may be at risk of LOHL; instead, pediatricians reported the following barriers/concerns:
  - Lack of specialty care and community services in the area.
  - Lack of parent compliance with following up.
    - Some parents doubt the accuracy or importance of the hearing test results in the nursery, which leads to lack of compliance with following up.
    - Some parents are dealing with pregnancy complications and follow up care for themselves, which makes it difficult for them to follow up with their child's hearing.
  - Lack of family resources; education; and/or motivation.
  - Lack of insurance coverage.

- When describing the role of the pediatrician in managing potential hearing loss in a young infant; the most common themes included the following: connecting families with resources; providing support with follow up; coordinating referrals; and being a medical home.

- Nearly all pediatricians interviewed expressed that they are not very familiar with their state's family support organizations that provide EHDI resources and support; some mentioned that they are located in areas that do not have many services in general or where services are not easily accessible to families who need them.

- Pediatricians suggested a diversity of topics for future training, support, and resources related to EHDI, including the following:
  - Offer an EHDI EQIPP module.¹
  - Produce educational podcasts with the EHDI guidelines and scenarios for physicians to learn while driving.
  - Compile state/region lists of audiology, screening, ENTs and other relevant resources for pediatricians, especially new physicians who do not know the system yet.
  - Create handouts with listings of EHDI resources by state and community.

¹ EQIPP (Education in Quality Improvement for Pediatric Practice) is an online learning program offered by AAP. For more details, see the AAP EQIPP website: https://eqipp.aap.org
Develop lists of the resources available in local schools so pediatricians can provide better guidance to families.

Conclusions and Recommended Next Steps

This summary of key findings suggests that, while the vast majority of pediatricians reported that they are either moderately or very familiar with their state's EHDI program, their knowledge may be lacking in key EHDI-related topics and concepts. For example, many pediatricians did not recognize the risk factors for hearing loss; the impact of hearing loss on speech and language development; or the importance of screening by one month of age, diagnosis of hearing loss by three months of age, and enrollment into EI services by six months of age (the EHDI 1-3-6 benchmarks).

Further, only two-thirds of pediatricians surveyed reported that they are typically notified when a patient identified as D/HH enrolls in EI following a referral, and less than half reported that they are kept informed of the child's progress in EI by someone other than the parent. These results suggest a need for more coordination and information sharing between pediatricians and state EI programs.

Results from both the pediatrician survey and interviews indicated that the majority of pediatricians are not very aware of the family support resources available in their state for parents of children who have been identified as D/HH. In spite of these results, pediatricians reported that they perceive their role in managing patient hearing loss as connecting families with resources; providing support with follow up; coordinating referrals; and being a medical home. These findings highlight the need to provide pediatricians with more information and resources on EHDI-related supports and services for their patients.

Based on the findings presented in this report, EHDI program stakeholders may wish to consider the following recommendations for next steps:

- Discuss strategies for providing more targeted and easily accessible education and resources for pediatricians. Consider engaging EHDI Chapter Champions in these efforts.
- Provide pediatricians with more opportunities to support EHDI-related practice improvements, including Quality Improvement/Learning Collaborative projects.
- Continue to support medical homes and promote the EHDI Guidelines for Pediatric Medical Home Providers.
- Consider opportunities to partner with relevant professional organizations and state agencies to promote collaboration and information sharing.
- Develop strategies for disseminating information on family support resources and organizations, such as Hands & Voices, more broadly among pediatricians.