Front Page Feature
A Glimpse into the Kentucky Early Hearing Detection and Intervention (EHDI) Learning Community

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Chaos! Little Alex—who is 15 months old—is running back and forth, under the table, and to and from his mother. Six school-aged children are eating pizza and are about to head off with volunteer babysitters to the game room at the community center. The adults are preparing to “work”. The team from my office—3 medical providers and our lead nurse—are eating and visiting with the mothers who were invited to join us tonight. Representatives from the Kentucky Early Hearing Detection and Intervention (EHDI) program, staff from Family to Family and Hands & Voices, our evaluation team, and other community partners are finishing their dessert and settling down to get started. We do not have any adult participants who are deaf or hard of hearing, but each of the family members speak Spanish, and our Spanish interpreter is introducing herself to everyone around the room.

Everyone was very excited to be at our second learning community meeting and to get started doing the work we need to do. Our first meeting had gone well. That was a first-time experience for many of the medical providers to sit down with families and discuss the care being provided to their children. We asked how well our office was doing in meeting their needs as parents—and meeting the needs of their children. It was a bit intimidating, but as providers, we know we have opportunities to improve, and we know this is a unique and incredibly valuable opportunity to learn and do better.

Our first meeting was held a few weeks prior and was very informative. We focused on 1-3-6 education, explaining the goals of the overall project, and discussing resources available for families. In this second meeting, we focused on building bridges with the parents, establishing bi-directional trust, and engaging in open conversations at a deeper level. Starting with this meeting, we will begin each of our meetings with a story about one child’s journey. One of the parents—who attended this meeting in her role as lead of Hands & Voices—shared her son’s story. She provided an overview of her son’s journey from screening, to diagnosis, through health care experiences, and through the education process. She also shed light on her journey as a mom through this experience. Everyone was moved and inspired. Seeing the other mothers nodding, and smiling, and listening in a way only those who had been on a similar journey could do was truly amazing.
The next step in this learning community is to adopt and test a written Shared Plan of Care (SPoC). We reviewed a draft SPoC at the meeting and discussed the purpose and value of this living document for families and professionals. One of the families volunteered to be the first to pilot it, and we developed action steps to get started.

At the end of the meeting, we sent everyone home with the food that remained, and the core team discussed how they felt the meeting went. We celebrated that we had such an amazing group of families who were willing to take time away from their busy lives to participate, to guide our work, and to share their experiences with us.

**NOTE:** Learning Communities are an important element within the state Funding Opportunity Announcement established by the Health Resources and Services Administration Maternal and Child Health Bureau. The intent is to develop a comprehensive and coordinated statewide Early Hearing Detection and Intervention (EHDI) system of care targeted towards ensuring that newborns and infants are receiving appropriate and timely services, including screening, evaluation, diagnosis, and early intervention (EI).

States are asked to develop a state-based learning community for pediatric health care professionals and families to increase knowledge and engagement within the EHDI system. Pediatric health care professionals from various health care organizations (eg, hospitals, federally qualified health centers, community health centers, private pediatric medical practices) will participate in the learning community and partner with state/territory Title V Children and Youth with Special Healthcare Needs programs on systems integration and family-centered care coordination. If you are not already involved with your state’s learning community, contact your state EHDI Coordinator for more information.

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**Clinical Corner**

**Using Data to Improve Services for Infants with Hearing Loss: Linking Newborn Hearing Screening Records with Early Intervention Records**

A recent study matched records of infants with permanent hearing loss from the New York Early Hearing Detection and Intervention Information System (NYEHDI-IS) to records of infants with permanent hearing loss receiving early intervention services from the New York State Early Intervention Program (NYSEIP). The goal was to identify areas in the state where hearing screening, diagnostic evaluations and referrals to the NYSEIP were not being made or documented in a timely manner. Data from 2014-2016 NYEHDI-IS and NYEIS information systems were matched using The Link King, a free record linkage software. There were 274 infants documented in NYEIS Information System as receiving early intervention services but did not have documentation of failed hearing screening (n=103) or a diagnostic evaluation confirming hearing loss (n=171) in NYEHDI-IS. There were 40 infants with hearing loss in NYEHDI-IS who were not referred to NYSEIP, and 19 of these infants’ providers documented in NYEHDI-IS that a referral to NYSEIP was made. The results from these analyses were used to direct targeted technical assistance to audiologists to educate them about the importance of early identification and referral and the reporting requirements to the New York State Department of Health with the goal of improving NYSEIP and the NYEHDI Program.

Quality Improvement (QI) Buzz

The California Part C Referral System: Ensuring that Every Infant Identified through the California Newborn Hearing Screening Program is Referred to Early Start Services

In 1998, under Assembly Bill 2631, California began screening newborn infants for potential hearing loss. Infants who did not pass their hospital hearing screen were referred for outpatient screening. Infants who did not pass the outpatient screen were then referred to an audiologist for a diagnostic evaluation. At this appointment, the audiologists would evaluate the infants and identify who was deaf or hard of hearing. Those audiologists also had the responsibility of referring the newly identified infants and their families to Part C (birth to three) services, which are called Early Start services in California.

The Department of Health Care Services (DHCS) Newborn Hearing Screening Program (NHSP) Advisory Task Force—whose members were parents and Early Start teachers—were skeptical that audiologists could effectively refer children and their families to Early Start. Dr Hallie Morrow (DHCS) and Nancy Grosz Sager (California Department of Education [CDE]) spoke to audiologists at the California Speech-Language-Hearing Association (CSHA) conference about Head Start programs and found the responses to inquiries about Head Start quite surprising. Most of the audiologists said they had never heard of Early Start, and they had no idea how to make a referral. One audiologist had heard of Early Start, but when he tried to make a referral, there were multiple, “Don’t call here – call there,” responses. He gave up trying to make that referral.

California’s Early Start system is complicated because it is a local control state. This means that depending on where the family resides within the state, Early Start services could be provided by various entities. Some services were provided by the county office of education, some by a nearby school district—but not necessarily the school district in which the family lived, some through an agency called the Special Education Local Plan Area (SELPA), and still some were served by both the school & by the Department of Developmental Services regional center. Audiologists struggled to navigate this complex situation, and found it was unclear where a referral should go.

In order to improve the referral system, the CDE proposed becoming the central point of entry for all state referrals. Every audiologist in California would send their referrals to CDE, and the CDE staff would refer to the appropriate Early Start provider. A central-point-of-entry referral system was established; however, implementation was a challenge. It often still took multiple attempts to identify the correct referral provider as it was dependent on where the family lived in the state. Experience gradually led to the development of a zip code directory identifying the appropriate Early Start provider for each location within the state, so that CDE consultants could readily determine which families should be referred to school district, county office of education, or SELPA. This zip code directory streamlined the referral process allowing staff to simply match the family’s address with the Early Start provider for that location.

Today, this service is managed by an office technician at CDE, and it ensures that every infant identified through the NHSP is referred to the appropriate Part C Early Start services for where the family lives. This is a success story thanks to active leadership in addressing a problem, and perseverance in developing a solution.
Family Partnerships

Hands & Voices Family Leadership in Language and Learning (FL3) Project

Hands & Voices is thrilled to announce the launch of the FL3 section of our website which has been many months in planning. This section is designed to be easy-to-use and includes information for all Early Hearing Detection and Intervention (EHDI) system stakeholders—from families looking for practical information to EHDI stakeholders searching for ways to support families. Over the next few months, Hands & Voices staff will continue to add information, research, and resources on family-to-family support; family leadership; Deaf and Hard of Hearing adult involvement; and language, literacy, and social-emotional development.

Within the Explore Our Topics section you will find designated tabs for Language, Literacy, and Social Development. Hands & Voices has convened a Scientific Language and Literacy Advisory Board of National Experts to serve as advisors to the FL3 Project. As part of the foundational work of this advisory board, the members created a list of questions to be used to summarize research in the areas of language, literacy, and social development for families. Each board advisor is submitting summaries monthly to be uploaded to this section of the website, so it will continue to offer new summaries. Along with research summaries, Hands & Voices will be adding parent education and professional education materials related to Language, Literacy, and Social Development in the coming months. Feel free to send us information to be considered for inclusion.

To stay current on activities of the FL3 project, Hands & Voices has created a bi-monthly FL3 E-News; to receive the e-news, click here to subscribe.

Medical Home Resources

Pediatric Integrated Care Survey

Developed by the Boston Children’s Hospital Integrated Care Program, the Pediatric Integrated Care Survey (PICS) measures a family’s experience with the integration of health services, particularly children and youth with special health care needs. The tool is available in English and Spanish. Additional information about validation and utility of the tool is available in Pediatrics.
And More....

Building Effective Partnerships

Partnerships are an important component of community advocacy efforts. Partners can enhance community engagement in projects, increase community awareness of the issues being addressed, and establish a framework for the continued support of services that support child health in communities.

You know how important partnerships have been in the success of the EHDI program at the national and state levels. The following are some examples from the American Academy of Pediatrics of how building effective partnerships can further program goals and objectives and ultimately enhance the health of children:

- Working in partnerships will help multiply the power of advocacy efforts and build strength in numbers.
- Working in partnerships includes getting other individuals, organizations, alliances, and coalitions involved to accomplish your advocacy goal.
- Getting more individuals and groups involved helps us win on the issues that are important to us.
- Working in partnerships helps us increase the number of people and groups working to improve children’s health and well-being and builds strength.
- When working with others—whether it is an individual or a group—try to understand their motivations and interests.
- Remember that partnerships can include the “usual suspects” as well as unlikely partners. The only way to know if someone will support your issue is by asking.

For more information and examples of what potential roles pediatricians can play at the community advocacy level, click here. Consider sharing these tips with other EHDI stakeholders in your state. It may spark some ideas for activities and partnerships going forward!

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 or 847/434-4738.