Each of us is an important stakeholder in the system of Early Hearing Detection and Intervention (EHDI), and each of us play a part in insuring that children and families who are deaf or hard of hearing are identified, provided appropriate interventions, and supported throughout their journey.

The Health Resources & Services Administration (HRSA) Maternal and Child Health Bureau (MCHB) has coordinated a national EHDI initiative where partnership has directly influenced progress. Over the past 6 months, much work is being done to further strengthen the spirit of collaborative partnerships and better aligning the work between all constituents involved in EHDI at the national and state level(s). The Academy has further strengthened its partnerships with the MCHB, the National Center for Hearing Assessment and Management (NCHAM), and Hands & Voices (H&V). We are now working more in alignment than ever before with the goal of supporting states so that they succeed in the planning and implementation of their EHDI activities.

Via the state EHDI Funding Opportunity Announcement (FOA), EHDI programs are required to develop learning communities to promote statewide, comprehensive, and coordinated programs and systems of care that further ensure that newborns and infants receive appropriate and timely services including screening, evaluation, diagnosis, and early intervention (EI).

As part of that initiative, the AAP has lead the development and implementation of a 3-part webinar series intended to provide clarity and direction to assist states in achieving the goals related to their learning communities; the AAP EHDI work has focused on care coordination and the utilization of a Shared Plan of Care (SPoC) as outlined in the state FOA.

The first webinar, Coordinating Care for Children and Youth: Practical Application for Early Hearing Detection and Intervention Programs, was led by Hannah Rosenberg with support and leadership from Richard Antonelli, MD, FAAP from Boston Children’s Hospital and the National Center on Care Coordination Technical Assistance. The focus was on the fundamentals of care coordination; several tools and resources were shared that can help with assessing and documenting care coordination activities in various parts of the “system of care.” Additionally, the webinar included a presentation from a state EHDI coordinator, Patricia Burk (Oklahoma), who provided framing of care coordination as it relates to early hearing detection and intervention (EHDI) and what states are embarking on related to action learning communities and Quality Improvement (QI) work including some focus on care planning and shared plans of care.

The second webinar was led by Jeanne McAllister and focused specifically on Shared Plans of Care. The primary goal was to provide background, context, and perspective about shared plans of care and to provide examples of how they can be used in practice/real life for children and families who are deaf or hard of hearing. Janet DesGeorges and Lisa Kovacs— Hands & Voices staff—provided illustration of the family perspective regarding the development of and use of a Shared Plan of Care and highlighted the role of the family in the development and implementation of same.
– The third webinar will occur in early 2018 and will focus on the specifics of implementation of the tools and resources presented in the first two webinars.

As EHDI Chapter Champions, you have an important role to play in the establishment of your states’ learning community and implementation of key activities. Your advice, clinical experience and wisdom, and knowledge of the practice of pediatrics is invaluable to the state EHDI programs.

If you have something to share from your state’s activities and/or learning communities, or the work you are doing at your clinical practice related to care coordination and/or Shared Plans of Care, we want to hear from you! All Chapter Champions can benefit from knowing more about what is happening in other states—in the spirit of collaboration, partnership and information sharing.

Quality Improvement (QI) Buzz

The CARE Project and Vermont EHDI — Opportunity for Collaborative Family Engagement

The CARE Project (TCP) provides emotional support for families with children who are deaf and hard of hearing through use of counseling tools, family retreats, and advocacy experiences. In fall 2017, The CARE Project collaborated with the Vermont Early Hearing Detection and Intervention (VTEHDI) program, families, and community partners to share, learn, and grow together. Families and their children, ages 6 months to 14 years old, who are deaf or hard of hearing were invited to attend, and volunteers provided childcare to better enable parents the time to learn, share, and connect with other families.

During the weekend, there was time devoted to each participant. Young children went on nature walks, scavenger hunts, enjoyed bubbles, and decorated the property with sidewalk chalk. The older children were able to enjoy a hike, time in the arcade, and learned to make slime and silly putty. The inside space was buzzing with diverse modes of language, noise, and activities such as a small reading nook, napping space, a dress-up area, and more. It was heartwarming to see the older children interact with the younger ones as they each participated in activities and support programs.

Parent support came in the form of presentations provided throughout the weekend, in addition to the many breaks for meals, naptime, and unstructured free time where families, professionals and volunteers were encouraged to interact. Presentations were available from local audiologists as well as Dr Patti Martin and Dr Johnny Sexton, from The CARE Project. Topics included the following: technology, the EHDI continuum, Cytomegalovirus (CMV), audiology, and the emotional journey. Parents also had the opportunity to participate in roundtable discussions that were led by parents and for parents only.

The energy of the weekend was amazing! The location and design provided a platform for a natural learning community to develop with many opportunities for participants to connect with one another. Parents, professionals, and children were all engaged in sharing, supporting, and learning from one another.

This was an invaluable opportunity for family engagement to take place in a collaborative learning environment where VTEHDI, community partners, and families discussed exciting ways to work together, support each other, and offer support to new families as they begin their journey through the EHDI process.

Families shared what they appreciated most…

“Meeting other families in similar situations and updates on technology.”

“Information, knowledge, and feeling less alone!”

“Everything was great, and our family could not thank you all enough for this weekend.”

“Advocating for your child and knowing what the requirements are.”
**Clinical Corner**

**Scheduling Hearing Appointments Prior To Hospital Discharge Improves Follow-up After Failed Newborn Screening**

A recent study aimed to identify if there was a relationship between a follow-up hearing appointment scheduled prior to hospital discharge (hospital scheduled appointment) and follow-up status, including loss to follow-up or loss to documentation (LTF/LTD); early follow-up initiation; and early completion of audiological diagnosis. The study included 4,597 children who were born between January 2015 and June 2016 in Louisiana birthing hospitals and failed newborn hearing screening (NHS) prior to hospital discharge. Of the study population, 56.1% of children were scheduled for a follow-up hearing appointment prior to hospital discharge. Among children without a hospital scheduled appointment, the rate of LTF/LTD and the rate of early follow-up initiation were 52% and 25%, respectively, higher than children with a hospital scheduled appointment. There was no statistical association of early completion of audiological diagnosis with a hospital scheduled appointment. Thus, a hospital scheduled appointment improved LTF/LTD and early follow-up initiation among newborns who failed NHS.


**Medical Home Resources**

**Tools and Resources for Impacting Care Coordination within the Early Hearing Detection and Intervention (EHDI) Population**

To further support the Maternal & Child Health Bureau (MCHB) funding opportunity and ongoing Early Hearing Detection and Intervention (EHDI) initiatives within each state, the American Academy of Pediatrics (AAP) has worked collaboratively with our National Partners to share resources that are vital to the development of a comprehensive and coordinated system of care targeted towards ensuring that newborns and infants are receiving appropriate and timely services including screening, evaluation, diagnosis, and early intervention (EI) within the context of a medical home.

The AAP spearheaded the development and implementation of a webinar series intended to provide clarity and direction regarding Care Coordination (October 27 webinar) and Shared Plans of Care (SPoC) (December 12 webinar) as they relate to EHDI.

When working to establish comprehensive care coordination, the National Center for Care Coordination Technical Assistance (NCCCTA), a partnership between the National Center for Medical Home Implementation and Boston Children's Hospital Integrated Care Program, can provide technical assistance and support to pediatric clinicians, Title V programs, family organizations and other stakeholders to further advance the pediatric medical home model of care. The NCCCTA Web page has been updated to include new tools and resources related to care coordination.

By integrating a Shared Plan of Care (SPoC) into the care coordination process, families and providers can work closely together to ensure that needs are met, goals are achieved, families and clinicians are partners, and care is patient- and family-centered. Published in collaboration with the National Academy for State Health Policy, the Shared Plan of Care fact sheet discusses strategies for state Title V programs and other state agencies to support utilization of shared plans of care and enhance family engagement.
Family Partnerships

A Parent’s Guide to Deaf and Hard of Hearing Early Intervention Recommendations

Upon learning that an infant has been identified as deaf or hard of hearing (D/HH), parents may ask the question, “How do we know if our child is receiving the right services?” The road ahead can be filled with appointments, therapies, interventions, and services that are new and sometimes confusing, and parents often have little guidance about what they should do first. They may be frightened by the prospect of not choosing the right services at the right time based on what is right for their family.

Parents/Caretakers need information, guidance, and support. In an effort to empower parents and caregivers with information about services that are available to them, a group of parents of children who are deaf or hard of hearing, as well as a diverse group of professionals who support families from diagnosis, through early intervention, and beyond, developed a Parent’s Guide to help families understand their rights regarding enrollment into early intervention (EI), and access to appropriate services regardless of where they live.

This guide is intended to do the following:

- Help parents understand best practices for Early Intervention (EI)
- Assist families in assessing appropriate Early Intervention services based on the standards recommended by the Joint Committee for Infant Hearing (JCIH)
- Empower families to advocate for appropriate EI services
- Improve partnerships between families and professionals to help children receive best practices in EI services

As EHDI professionals at the clinical, organizational, and state levels, consider sharing this resource with families so they can access the support and resources available to assist them in navigating the EHDI system of care.

And More….

Impact and Importance of Deaf Adults as Mentors

There is great value in connecting children who are deaf or hard of hearing (D/HH), and their families, with Deaf adults. Deaf adults are available to interact with the family and provide various types of support and guidance through one-on-one interaction. A variety of terms are used to describe such individuals; see the following:

- "deaf mentors"
- deaf "guides"
- "role models" and
- "partners"

The National Center for Hearing Assessment and Management (NCHAM) promotes the activities of the D/HH Adult Involvement Learning Community because of the following:

- It captures a broad range of service delivery models
- It is inclusive of supports offered to children who are hard of hearing as well as deaf
- Deaf/HH adult involvement can use a variety of communication modalities and a variety of assistive devices
**Hands & Voices** encourages the inclusion of **D/HH mentors/role models** as they often have a profound impact for everyone—child, parent, and professional. Mentors who are deaf or hard of hearing themselves are uniquely qualified to provide the child, parents, and professionals with a positive and hopeful perspective from their day-to-day, real life experiences as a person living in a hearing world. In sharing these experiences and insights, D/HH mentors may be able to articulate what the child cannot, which brings an important perspective and credibility to the team discussion of the child’s needs in everyday life.

Reach out to [NCHAM](https://www.ncham.org) or **Hands & Voices** for more information about how to integrate a Deaf Mentor into your state or practice system of care.

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**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](mailto:sring@aap.org), 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](https://www.aap.org). If you would like to unsubscribe to this newsletter, contact Sandi Ring at [sring@aap.org](mailto:sring@aap.org) or 847/434-4738.