

American Academy of Pediatrics National Resource Center for Patient/Family-Centered Medical Home Early Hearing Detection and Intervention Chapter Champion Program Evaluation Executive Summary

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Overview and Purpose

This executive summary presents key findings from an evaluation of the American Academy of Pediatrics (AAP) Early Hearing Detection and Intervention (EHDI) chapter champion program. The AAP EHDI program was established in 2001. It is funded as part of a cooperative agreement between the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) and the AAP. This cooperative agreement is known as Advancing Systems of Services for Children and Youth with Special Health Care Needs. The AAP EHDI program has four primary goals:

- Ensure every child with hearing loss is diagnosed and receives appropriate, timely intervention.
- Enhance pediatricians', other physicians', and nonphysician clinicians' knowledge about the EHDI 1-3-6 guidelines—screening by 1 month of age, diagnosis of hearing loss by 3 months of age, and entry into early intervention (EI) services by 6 months of age.
- Ensure newborn hearing screening results are communicated to all parents and reported in a timely fashion according to state laws, regulations, and guidelines.
- Incorporate EHDI into an integrated, medical home approach to child health.

A key component of the AAP EHDI program involves the efforts of chapter champions—usually AAP members who support their state AAP chapters and engage with other pediatricians, trainees, and nonphysician clinicians to improve the effectiveness of newborn hearing, screening, diagnosis, and intervention, within the context of the medical home model. Chapter champions receive ongoing support from the national AAP, including EHDI related education, technical assistance, tools, and resources. They engage in a variety of advocacy, outreach, and education efforts on behalf of children who are deaf or hard of hearing (D/HH) and their families. Chapter champions serve other pediatricians and pediatric clinicians within each AAP chapter by providing education about EHDI and relevant tools and resources to help achieve the program's goals. They are also encouraged to work with their state EHDI coordinator on state-based initiatives, outreach, and education.

The purpose of the evaluation was to gain insight and understanding into EHDI stakeholder perspectives pertaining to the effectiveness of the chapter champion activities in supporting the primary goals of the AAP EHDI program. The results will be used to make improvements to the AAP EHDI program.

Methods

The evaluation employed a mixed methods design that included the following components: 1) stakeholder surveys targeting chapter champions; state EHDI coordinators; and families of children who are D/HH; and 2) stakeholder focus groups: four focus groups were conducted via teleconference with chapter champions; state EHDI coordinators; nonphysician clinicians; and families of children who are D/HH ([see full report](#) for more details on background and methodology).

Key Findings

- Stakeholder survey and focus group results consistently showed that chapter champions engage in a variety of activities to support the program goals, many of which involve collaborative efforts with state EHDI coordinators, including connecting and collaborating with state EHDI programs; participating in state EHDI advisory committees; and connecting and collaborating with state family-based organizations. A key theme among all the stakeholder focus groups was the importance of these collaborative activities and the need for more collaboration among chapter champions and EHDI coordinators at the state and national levels.
 - According to survey results, chapter champions reported that the resources and supports provided to them by the AAP EHDI program are effective or very effective in helping them reach the program goals, especially attendance at the EDHI Annual Meeting, template presentations, and coaching and partnership with AAP EHDI regional network liaisons (regional network liaisons provide AAP-district support to chapter champions in their local efforts to improve the effectiveness of newborn hearing screening, diagnosis, and intervention). While focus group results also highlighted the importance of the EHDI Annual Meeting and template presentations, chapter champion focus group participants expressed the contrasting view that the regional network liaisons' coaching was not beneficial.
- Educating pediatricians, other physicians, and nonphysician clinicians about the EHDI 1-3-6 guidelines was reported as the most important program activity and the most effective program activity across all stakeholder groups. Results indicated that a variety of different education modalities were considered effective, especially state-based quality improvement projects, "Just in Time" education (eg, guidelines sent to pediatricians at the time a baby is found to have referred on their newborn screen), grand rounds, and resident education.
 - Focus group findings supported these results, with common themes that included the need for more Just in Time education for pediatricians; more peer-to-peer interventions that target individual pediatricians; and collaborating with state EHDI coordinators and Learning Communities in state educational initiatives; all of these validate the chapter champion's key role as a point person, educator, and liaison between state EHDI coordinators and the pediatrician community in state EHDI systems.
- Survey and focus group results indicated that stakeholders perceive chapter champion activities as important, however, the results also suggested some variation in the level with which these activities are being implemented--for some activities, as many as 55% of chapter champions reported that they participated 0 times in the past year.
 - These results were supported by focus group findings, with common themes that included varying amounts of chapter champion involvement and issues with chapter champion recruitment and retention. Participants related these issues to the volunteer program structure. In all stakeholder focus groups, participants expressed the importance of finding ways to incentivize chapter champion activities, including the common theme of funding chapter champions' attendance at the EHDI Annual Meeting. Other suggestions included more structured training and mentoring for new chapter champions, and term limits.
- The majority of stakeholders reported that the chapter champion model is effective or very effective in its goals of enhancing physician knowledge about the EHDI 1-3-6 guidelines and ensuring every child with hearing loss is diagnosed and receives timely intervention.

- Compared to the other program goals, fewer stakeholders reported the chapter champion model is effective in ensuring newborn hearing screening results are communicated to all parents. Focus group results provided the insight that stakeholders perceive this goal as irrelevant to the AAP EHDI program because pediatricians typically do not conduct hearing screenings in their offices, nor are they the ones who typically report the results to parents.
- Somewhat fewer stakeholders reported the chapter champion model is effective in incorporating EHDI into an integrated medical home approach to child health, compared to the other program goals. The focus group findings suggest that stakeholders feel more guidance and structure from national AAP is needed to promote a shared understanding among state chapters, chapter champions, and EHDI coordinators about what incorporating EHDI into a medical home looks like and how it can be implemented.
- Some focus group participants shared innovative projects for incorporating EHDI into the medical home from their states, including an app for pediatricians that lists specialists, services, and supports in their state for families of children who are D/HH; developing and disseminating a shared plan of care; and a card that new parents can bring with them to the pediatrician that shows their child's vaccination status and hearing screening results. Participants suggested that these and other promising practices should be promoted to other states for potential replication.
- Stakeholders' perceptions regarding chapter champions' role in supporting families with children who are D/HH were mixed. According to survey results, slightly over half of chapter champions and state EDHI coordinators reported families are well supported or very well supported by chapter champions, however, a substantial percentage of between 30-40% reported being undecided.
 - These results were consistent with focus group findings, in which some participants expressed that chapter champions' role should not involve direct support to families but should focus instead on helping pediatricians support families with follow-up, referrals, and connecting them with family support organizations. Meanwhile, other participants emphasized that chapter champions' role should involve building connections with family leaders and family organizations.
- Findings from the family survey highlight the need to support families with children who are D/HH, especially in the context of a medical home: less than half of families surveyed reported that their child is receiving care within the medical home model and, while on average, parents reported that their child's pediatrician has good listening skills, is culturally sensitive, and works with them to make decisions; they also reported their pediatrician does not usually ask about how their child's condition affects their family nor does their pediatrician help to explain their child's needs to other professionals.
 - Family focus group findings supported these results, in which many participants shared similar experiences with having a pediatrician who did not know the steps to take after the initial hearing screen was failed. Participants also expressed frustration with what they perceived as a tendency among their physicians to minimize the situation and/or try to make them feel better, rather than focusing on care coordination. Participants suggested that the AAP EHDI program conduct a national campaign to raise awareness and educate pediatricians on communicating more effectively with families of children who are D/HH and improving care coordination for these families. Other suggestions included educating pediatricians to be more understanding and compassionate about the impact of having a child who is D/HH on the family; and understanding and connecting with the Deaf community.

Conclusions and Key Recommendations

Overall, the evaluation findings suggest that key stakeholders, including chapter champions, state EHDI coordinators, nonphysician clinicians, and families, view the AAP EHDI program as an important component of the larger EHDI system. Further, the chapter champion model is perceived as effective in enhancing physician knowledge about the EHDI 1-3-6 guidelines and ensuring every child with hearing loss is diagnosed and receives timely intervention. In addition, the findings offer constructive lessons learned for reconsidering the program's potential to influence the process of communicating newborn hearing screening results to parents. Finally, the results reveal new opportunities for program leaders to incorporate EHDI into an integrated medical home approach to child health; advance the overall EHDI system of services; and improve the lives of children who are D/HH and their families.

Key Recommendations

1. Enhance the program's focus on educating pediatricians, other physicians, and nonphysician clinicians with additional EHDI-related topics that include care coordination; connecting families to resources and supports, including family-based organizations; and understanding deaf culture and family perspectives.
2. Support state-level peer-to-peer learning and networking opportunities for chapter champions and other EHDI stakeholders.
3. Explore options for incentivizing chapter champion activities.
4. Strengthen national partnerships with relevant professional organizations, including Hands & Voices, National Center for Hearing Assessment and Management, American Academy of Audiology, American Speech-Language-Hearing Association, Directors of Speech and Hearing Programs in State and Welfare Agencies; American Academy of Family Physicians, and others, to discuss developing and promoting collaborative guidance and messaging for EHDI best practices and care coordination.
5. Collaborate with relevant stakeholders to develop national guidance for integrating EHDI into the medical home; consider collecting and disseminating state promising practices for potential replication.
6. Continue to support parent involvement in EHDI planning, implementation, and improvement initiatives, including participation on state advisory committees and EHDI-related medical home initiatives.