July 18, 2022

Ms. Sandra Battiste, MPH
Public Health Analysis
5600 Fishers Lane
Rockville, MD 20857 U.S.A.

Via email: ehdi@hrsa.gov

Dear Ms. Battiste:

Thank you for providing the opportunity for American Cochlear Implant Alliance (ACI Alliance) to comment on the Health Resources and Services Administration (HRSA) Request for Information: Early Hearing Detection and Intervention Program (EHDI). ACI Alliance is a non-profit organization of physicians, speech language pathologists, audiologists, adults with hearing loss, family members of children with hearing loss, and educators of children who are deaf and hard of hearing. Our members play active roles in EHDI – whether as service providers or as families who receive EHDI services. We take a great deal of interest in this essential program that is so critical for families of children with hearing loss. We support efforts to improve the program and submit these comments with that intention.

Question Five: What strategies or programs would ensure that families of children who are deaf or hard of hearing receive information that is accurate, comprehensive, up-to-date, and evidence based, as appropriate, to allow families to make important decisions for their children in a timely manner, including decisions with respect to the full range of assistive hearing technologies and communications modalities, as appropriate?

ACI Alliance recommends that HRSA support the development of more consistently robust content on EHDI websites. In late 2021, we completed a review of the 51 EHDI websites; the analysis will be published in an upcoming issue of the Journal of Early Hearing and Intervention. The HRSA Notice of Funding Opportunity 2019 notes the need for EHDI maintained websites that provide specific information related to the EHDI process. Studies have found that parents utilize the Internet to seek health information including information on hearing loss for their children after diagnosis. Our study revealed variability in the completeness and quality of information for families on the state EHDI websites. While some state sites offered unbiased,
medically sound information on hearing loss, technology, communication options, and outside resources, others fell short with incomplete (or no) information or other support materials. One option to achieve consistently comprehensive state website content is to provide a template and common content on the required topics such as hearing loss, technology, and communication options. Resources would likely vary by state and each state would need to develop that section. Of course, states could always supplement what was in the provided template. Another possibility would be to have web technical support available through HRSA.

Given parents are now using social media to gather information, we recommend that EHDI programs highlight their offerings on social media to amplify what is on their websites. Webinars and seminars can be offered inexpensively on virtual platforms. NCHAM, Hands & Voices, Hearing First, National CMV Foundation, ACI Alliance, AG Bell and others provide such opportunities—typically without cost.

**Question Six: What strategies would help ensure families, parents, and caregivers are continuously engaged as active partners in the EHDI system?**

Parent empowerment to make the best choices for their child and family is a key objective of early intervention services. ACI Alliance suggests HRSA consider a diverse approach to engaging with parents who are typically unprepared for their child’s diagnosis of hearing loss and are often overwhelmed by the need to quickly learn about options and make choices for their child. A 2018 study found that parents thrive on a variety of resources and that consistent and open two-way communication keeps parents engaged and focused (Vasconcellos, 2018). The study also discussed the importance of communication and support during the transition between the IFSP and IEP.

The 2019 Pedersen study found that actively reaching out to fathers, as well as mothers, increased family engagement (Pedersen, H. F. et al. 2019). Flexibility, helping parents to develop confidence in supporting their child, and facilitating father-to-father engagement were all shown to be beneficial. We also recommend HRSA look at the partnership between Virginia EHDI and the Virginia Center for Family Involvement that fostered improve lost to follow-up (Yarbrough, D. V. et al, 2018). By partnering with an established broader disability mentoring program, VA EHDI was able to leverage their experience for training and supporting families, mentors, and staff.

**Question Seven: What approaches that foster family-to-family and deaf and hard of hearing consumer-to family supports by families and adults who are deaf or hard of hearing should be considered?**

Hands & Voices, a family-led organization, is often cited as a premier way of supporting parents. Their chapter approach focuses on local support groups for families. The ACI Alliance review of websites found that the Hands & Voices Guide by Your Side was listed as a resource on many EHDI websites. Guide By Your Sides features prominently in a 2019 study on adult
participation in EHDI mentoring programs that stated 59% of newly diagnosed parents desire a deaf or hard of hearing adult to engage with (Shuler-Krause, E. & White, K. R. (2019).

That same study reported on the challenge of finding mentors who demonstrate diversity in their age, race, and communication option as the majority of currently enrolled mentors are deaf and communicate with ASL (Shuler-Krause, 2019). Mentors should include people who reflect a range of hearing loss characteristics and communications options (i.e., using technology to listen and talk as well as those who use various forms of sign language). Families should be connected with mentors who reflect diversity or if a family prefers, mentors who reflect the technology and/or communication option they wish to explore. Choice should be part of the match process. Hearing First (www.hearingfirst.org), encourages family-to-family mentoring on its private Facebook group page. Hearing First also facilitates small forums where parents can chat with professionals and families on their everyday challenges and successes. Continuing to foster these and similar organizational partnerships with EHDI state programs benefits parents.

**Question Eight:** What new evidence-based or promising approaches that help deaf or hard of hearing children meet language, literacy, social, emotional, and other developmental milestones should be considered within EHDI Programs/the EHDI system?

The Starts Hear Awareness Campaign developed by Hearing First released results of the campaign’s first year in 2022. Launched in 2021, outcomes demonstrated that consistent and repeated outreach to parents was vital in boosting follow up screening after an initial failed newborn hearing screen. Follow-up with early intervention appointments helps children achieve developmental milestones. The Starts Hear Awareness Campaign sent text messages to newly diagnosed families on the importance of following up and reminders, which saw 25% increase in awareness (Hearing First, 2022). Meeting the needs of parents where they are at during an emotional time matters.

A 2021 article discussed the positive outcomes of a project that focused on fostering changes to parenting approaches among families of lower socioeconomic status. By showing how responsive parenting can result in higher literacy and school readiness, parents altered their approaches of child rearing with positive results (List, et al, 2021). Early interventionists should consider demonstrating parenting strategies that can promote positive outcomes utilizing brief videos during their interactions. Watching how, rather than hearing about, is a powerful method of mentorship.

Persistent and repetitive use of age-appropriate language – parents conversing with their infant – is one of the key ways to promote language development, along with meeting the EHDI 1-3-6 guidelines (Yoshinaga-Itano, C., 2020). Furthermore, the approach of providing and encouraging an in-home language curriculum for parents of low socioeconomic status developed by Dana Suskind in 2016 should be considered.
Question 10: What ongoing and emerging gaps in access to services are present within the EHDI system? Are there populations that are experiencing inequities in access to timely identification and receipt of services? What approaches should be used to address these gaps?

ACI Alliance acknowledges that underserved populations are more likely to live in rural areas and/or be racial or ethnic minorities. Such populations are more likely to have Medicaid as their health insurance provider. Low insurance reimbursement under Medicaid impacts the number of providers that will accept new patients (Alexander, D., 2019; Polsky, D., et al., 2015). When reimbursement is increased, more pediatric offices accept new patients (Suk-fong S. T. et al. 2018). Low reimbursement rate is often cited as a reason why physicians do not accept new Medicaid patients (Saulsberry, L., 2018). Furthermore, children who require specialists, such as an audiologist or speech therapist, are most vulnerable when state Medicaid programs enact new complexities for access (Currie, J., et al. 2021). We suggest HRSA support EHDI programs by engaging with state Medicaid offices on the importance of early intervention services to the life-long development of the child. Such considerations are a component of the Federally mandated Early Periodic Screening and Treatment (EPSDT) provisions of Medicaid.

A positive outcome from the COVID-19 pandemic is the elevation of telehealth as a successful tool in reaching families in all situations. We encourage HRSA to explore providing support for EHDI programs to continue to offer telehealth interventions for those families that are unable to afford travel or to travel long distances. Sometimes children have other medical issues besides the hearing loss, which can make travel to appointments difficult. A 2021 review reported positive outcomes from telehealth appointments for families living in rural areas (Butzner, M., 2021). The study documented widespread willingness of patients to utilize telehealth as well as their increased satisfaction with telehealth options.

Thank you for the opportunity to provide input on possible ways to improve EHDI. We are pleased to be able to support this critical program for children with hearing loss and their families.

Sincerely,

Donna Sorkin
Executive Director
American Cochlear Implant Alliance

References

https://doi.org/10.3386/w26095


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