



AMERICAN COCHLEAR IMPLANT ALLIANCE

Research. Advocacy. Awareness.

OUR MISSION:

To advance access to the gift of hearing provided by cochlear implantation through research, advocacy and awareness.

January 11, 2019

George Sigounas, M.S., PhD
Administrator, Health Resources and Services Administration
US Department of Health and Human Services
Universal Newborn Hearing Screening Program
5600 Fishers Lane, Room 18W59
Rockville, MD 20847

Sent electronically to unhs@hrsa.gov

RE: ACI Alliance Comments on UNHS Program Development

Dear Administrator Sigounas:

The American Cochlear Implant Alliance (ACI Alliance) appreciates the opportunity to submit comments on the Universal Newborn Hearing Screening (UNHS) program as the Health Resource and Services Administration seeks to improve implementation of this critical program that was authorized by section 399M of the Public Health Service Act, as added by the Children's Health Act of 2000 § 702 (P.L. 106-510) and amended by the Early Hearing Detection and Intervention (EHDI) Act of 2017 (P.L. 115071).

Organizational Focus

ACI Alliance is a non-profit 501(c)3 organization whose mission is to advance the gift of hearing provided by cochlear implantation (CI) and other implantable prosthetic hearing implants through research, advocacy and awareness. The membership includes clinicians who provide the CI intervention (e.g., ENT surgeons, audiologists, speech language pathologists, other professionals on implant teams including educators of deaf children, psychologists, researchers, adult cochlear implant recipients, parents of children with cochlear implants and other advocates. The organization seeks to ensure appropriate access to, and quality of, clinical care relating to cochlear implantation and other auditory technologies.

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ACI Alliance has a strong focus on pediatric care including hearing technology and the full spectrum of family services needed by children with moderate to profound hearing loss to develop language. The organization is strongly committed to *parent choice* and the right of parents to select hearing technologies and communication strategies that they believe will best serve their child in the context of their own family environment. Parents make choices about a wide range of health and educational topics on behalf of their children and it is our job as professionals and parent/consumer advocates to ensure that parents have early access to accurate and comprehensive information to facilitate their informed decision-making. It is also our job to support whatever choices parents make.

Key Findings

The most common concern that we hear about from families and professionals who serve families is that too often parents receive incomplete, inaccurate and biased information from early intervention professionals. We have heard this comment from parents and professionals in most states. Our comments here draw upon input and suggestions from those who reside and/or provide services in Virginia, Maryland, Ohio, South Carolina, Florida, Maine, Arizona, New Jersey, Texas, Utah, and California.

We believe that the comments we received are representative of parental experiences in the country as a whole. A common bias provided via early intervention and especially from personnel employed by state schools for the deaf are that the child and family must learn ASL in order for their deaf or hard of hearing child to develop language—regardless of whether or not the family chooses to use hearing technologies. Parents are counseled that a spoken language approach for a deaf child will not allow the child to develop full access to language.

A parent from South Carolina relayed this experience about the family's first early intervention specialist: "We were told that if we used only spoken language, our deaf son would never be able to say his own name." The mother asked that the specific individual (from the SC School for the Deaf) not be sent back to her home. Another early intervention (EI) specialist provided services going forward. The child received an early cochlear implant and went on to participate in the Scripps National Spelling Bee.

Professionals who provide early intervention advisement in Utah from the State School for the Deaf are not allowed to discuss a listening and spoken language approach; to do so would be "biased."

Parents have reported receiving information that emphasized spoken language or strongly urged Total Communication. Such pressure and bias is never appropriate. There are differences in how advisement is carried out between various states and there are even differences within the same state.

New Jersey and Connecticut are two states that have been characterized as places where the advisement process generally works well. HRSA should aggressively work to eliminate bias from the early intervention system and replicate processes in states that provide options for families.

Families in VA, MD, SC, FL, OH, AZ, UT, and CA have been encouraged by early intervention professionals to wait until the child "is older" to pursue cochlear implants.

Delays result in less than optimal results given that one of the most important factors impacting child outcomes with a CI is duration of deafness. The best CI outcomes for a child born deaf are implantation at 12 months of age or earlier (Ching et al, 2013, Outcomes of early- and late-identified children at 3 years of age: Findings from a prospective population-based study. *Ear Hear*; Niparko et al, 2010, Spoken language development following early cochlear implantation, *JAMA*).

Families and professionals in VA and OH note that EI personnel have little or no training on communication options and on hearing technology. Families must fend for themselves. Those with higher income and more resources are better able to negotiate the system but those with less education and income have difficulty.

Professionals in South Carolina and Arizona also strongly advocate for better training of early intervention specialists. In South Carolina, individuals involved in newborn hearing screening sometimes tell parents that failing the hearing screen is “no big deal” as there are so many false positives. This may lead to a lack of timely follow-up by families.

Professionals in Texas, Arizona, South Carolina and Virginia note that there are special challenges in serving families in rural areas where there may not be access to specialized listening and spoken language personnel appropriate to work with families. One professional in Arizona noted that families in her state come in to locations that have trained personnel for up to a week for intensive therapy and parent training, an expensive and burdensome approach.

Early intervention professionals may not understand what is involved in spoken language development for young who are deaf and hard of hearing. For example, the example was given of a child in Arizona with a severe to profound hearing who was receiving therapy once every two weeks. The early intervention professional deemed this to be sufficient. The recommended amount of therapy for a young child whose family is pursuing spoken language development is one to two hours per week as supported by published research (*Position Paper: Pediatric Habilitation Following Cochlear Implantation*, ACI Alliance Board of Directors, <https://www.acialliance.org/page/ACITherapyStatement>).

Utilization of cochlear implants by children in the United States who have moderate to profound hearing loss is the lowest in the developed world; approximately 50-55% of eligible U.S. children are using cochlear implants compared with 90% or more of eligible children in Western European countries like the United Kingdom, Belgium, and Denmark (Sorkin & Buchman, 2016, Cochlear implant access in six developed countries, *Otol Neuro*). The reason for this utilization difference is the nature of the advisement process in the United States and the lack of accurate information that many families receive.

Programmatic Questions

ACI Alliances addresses below a number of the programmatic questions included in the HRSA request for comments.

1. *What strategies or programs at the family, community, state or national level would help to ensure children who are identified as deaf or hard of hearing are able to access services?*

Recommendations:

- HRSA should aggressively address the need for comprehensive and impartial parent advisement consistent with the reauthorized EHDI law. Individuals who provide parent counseling must include information across all methodologies without expressed modality preference.
 - HRSA should require training of early intervention personnel and monitoring of the advisement process must be required. States should not be permitted to have ill-qualified personnel advising families.
 - HRSA personnel must publicly express their support for parent choice to set the stage and demonstrate the expectation that nothing less than full support of comprehensive parent information and the range of options for parent decision-making is acceptable. Parent choice must be publicly endorsed.
 - Given the expressed preference by most personnel from state schools for the deaf for use of American Sign Language (ASL) by all children with any level of hearing loss and “waiting on the CI”, we must rethink whether individuals with a strong bias for one modality over all others should be involved in the initial parental advisement process at all. Such bias in counseling impacts informed decision-making on communication options as well as provision of information on use of hearing aids and cochlear implants at the earliest possible age. Indeed there is a conflict of interest for such personnel to be involved in parent advisement.
2. *What strategies or programs would help to 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 communication modalities, as appropriate.*

Recommendations

- **Expand the adult mentors to include those who use technology and spoken language.** At present, individuals from the states surveyed (and noted above) indicate that deaf adult mentors are mostly ASL users and that there is a shortage of mentors using technology and spoken language. Given that individuals sent from state schools for the deaf are often employed by the schools (and hence can provide counseling as part of their employment responsibilities), there is need to involve (and reimburse) others who use technology and spoken language. Such individuals could be sought from cochlear implant centers, audiology centers, and universities. Such individuals are typically in mainstream employment positions. If the adult mentor program in a state does not include individuals from every modality, it should be disbanded.
- Parents of children who are deaf and hard of hearing are appropriate mentors and could be enlisted as well.

- The early intervention system cannot be pushing for only one communication approach. To do so violates the letter and spirit of the statute itself.
 - **Innovative strategies such as those being tried by Parents Place of Maryland** (which received a HRSA grant) could test whether and how pediatrician and family physician office personnel such as nurses and physician assistants in combination with a parent advocate could provide appropriate support. Care providers in the child's medical home should be engaged and connected; these include the pediatrician, audiologist, speech language pathologist, occupational therapist, physical therapist, teacher of the deaf, neurologist, and geneticist.
 - **Beginnings for Parents who are Deaf and Hard of Hearing** began in North Carolina. It is a non-profit organization that helps parents and families understand hearing loss and the diverse needs of children who are deaf or hard of hearing. The organization's impartial support helps families make informed decisions and empowers them to advocate for their child's needs. This is a model that works well and could be encouraged by HRSA.
6. *What strategies or programs would help to support state and territory EHDI program to ensure that all newborns are screened by one month of age, a diagnosis is made by three months of age, and children who are deaf or hard of hearing receive inter4ventino services by three months of age?*

Recommendation

- **Provide expanded training for those involved in newborn hearing screening** to ensure that parents are fully informed of the importance of timely follow-up following a failed screen. Ensure training personnel understand the implications of parents not following up after a failed screen.
7. *What new evidence-based or promising approaches that help deaf or hard of hearing children meet language, literacy, social, emotional, and other developmental milestones would be helpful to consider?*

Recommendations

- **Improve training and funding to support consistent speech and auditory therapy sessions** which have shown to be most effective in allowing children to "catch up" to their hearing peers.
- **Between 50-100 hours of therapy per child** should be the standard for families who opt for a cochlear implant. As each child is unique, the medical professional team working with the family may recommend more or less therapy sessions depending on progress and the child's other medical needs.
- For children in rural areas with limited or no access to appropriately trained listening and spoken language professionals, **initiate teletherapy programs that could facilitate the provision of needed therapy by trained professionals**. There are a number of successful programs that could be replicated including that undertaken by The Children's Cochlear Implant Center

at UNC <https://www.med.unc.edu/earandhearing/> which pioneered programs to provide therapy to families distant from the center by providing technology and Internet access to achieve weekly parent-centered therapy in conjunction with monthly in-person therapy with trained professionals. Telehealth models have been explored and documented as effective (Houston et al, 2018. Using telepractice to improve outcomes for children who are deaf or hard of hearing, in the NCHAM ebook, *A Resource Guide for Early Hearing Detection and Intervention.*)

Thank you for the opportunity to submit comments on this important issue. If you would like to meet with the ACI Alliance to discuss these issues in greater depth, please contact me at dsorkin@acialliance.org or 703.534.6146.

Sincerely,

A handwritten signature in black ink, appearing to read "Donna L. Sorkin". The signature is fluid and cursive, with the first name "Donna" being the most prominent.

Donna L. Sorkin MA
Executive Director
American Cochlear Implant Alliance