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OF SCHOOLS AND PROGRAMS FOR THE DEAF, INC.

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**Conference of Educational Administrators of Schools and Programs for the
Deaf
Comments to the Health Resources and Services Administration on the
Implementation of the Universal Newborn Hearing Screening Program
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The Conference of Educational Administrators of Schools and Programs for the Deaf submits this information to the Health Resources and Services Administration (HRSA) on the implementation of the Universal Newborn Hearing Screening (UNHS) program.¹ Thank you for the opportunity to comment on this important topic. Replies should be sent to Barbara Raimondo, contact information above.

CEASD is pleased to see HRSA working to fill the gaps in UNHS. CEASD has long advocated for newborn hearing screening, early identification, and immediate entrance of families into appropriate early intervention systems. Such systems include professionals with specialized expertise in serving deaf and hard of hearing infants and toddlers and their families; connections to parents and organizations of parents of deaf and hard of hearing children; and linkage with deaf and hard of hearing adults and organizations.

In addition to considering comments through its solicitation, CEASD recommends that HRSA work to ensure that existing recommendations are implemented. For example:

- The Joint Committee on Infant Hearing developed a Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing.² These recommendations were developed and endorsed by many experts in the field, including the American Academy of Pediatrics, American Academy of Audiology, American Speech-Language-Hearing Association, and others.

¹ Health Resources and Services Administration (2018). Universal Newborn Hearing Screening Program Development. <https://mchb.hrsa.gov/maternal-child-health-initiatives/newborn-hearing-screening-intervention/public-comment.html>

² Joint Committee on Infant Hearing (2013). Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing. *Pediatrics*, Volume 131, Number 4. <http://www.jcih.org/JCIH-2007-Position-Statement-Supplement.pdf>

- The National Association of State Directors of Special Education (NASDSE) developed education guidelines, *Optimizing Outcomes for Students who are Deaf or Hard of Hearing*, including recommendations on Early Identification and Intervention (chapter 3).³ Once implemented, these guidelines have the potential to greatly improve systems serving deaf and hard of hearing children and their families.
- A diverse panel of experts published *Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement*, including 10 foundational principles.⁴ This is a rich source of information.

The responses below come from early intervention professionals working in schools for the deaf and in statewide programs, and a former university educator of early interventionists.⁵

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

Establish a specialized system. Having a system that specializes in working with deaf and hard of hearing children, with one entry point for families, can be a seamless approach, from referral to transition to school-aged services. Consistency among states and one data entry system managed at the federal level would allow families to stay in the system as they relocate from state to state. Identification in one state would mean continued access to services in another state and safeguard the family from “falling through the cracks” of the early intervention systems.

Use specialized programs to provide early intervention. The landmark study that established the efficacy of newborn hearing screening⁶ demonstrated the importance of this. Yoshinaga-Itano showed that when babies were identified early and received services from a program specializing in deaf and hard of hearing infants and toddlers, they achieved higher language levels. Thus far there is no evidence to show the benefits of UNHS in the absence of specialized services and providers. Programs that have specialized knowledge and skills in working with young deaf and hard of hearing children and families can deliver services that meet the unique needs of the child and family. They are aware of the additional resources and services available in the region and the professionals who are most knowledgeable about how to deliver the full range of communication and language opportunities. They understand what it means to be deaf or hard of hearing and understand the urgency of providing these services in

³ National Association of State Directors of Special Education (2018). *Optimizing Outcomes for Students who are Deaf or Hard of Hearing*. www.nasdse.org

⁴ Moeller, M.P. *et al.* (2013). Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement. *The Journal of Deaf Studies and Deaf Education*, Volume 18, Issue 4. <https://doi.org/10.1093/deafed/ent034>

⁵ Schools that contributed to this paper are Colorado School for the Deaf, Delaware School for the Deaf, Kansas School for the Deaf, New Mexico School for the Deaf, Rochester School for the Deaf, Utah Schools for the Deaf and the Blind, and Virginia School for the Deaf and the Blind. In addition, Dr. Marilyn Sass-Lehrer, Professor Emerita, Gallaudet University, contributed.

⁶ Yoshinaga-Itano, C. *et al.* (1998). Language of Early- and Later-identified Children With Hearing Loss. *Pediatrics*, Volume 102, Number 5. <https://www.ncbi.nlm.nih.gov/pubmed/9794949>

a timely manner. They possess the training and skills necessary to help children develop age appropriate language.

Improve collaboration among agencies. Build relationships among deaf and hard of hearing specialized programs, the Part C lead agency, medical communities, schools for the deaf, and other early intervention service providers. All of these entities are key components of the system, yet they often do not communicate with each other. When these relationships exist they can benefit families by connecting them easily with specialists who can support them.

Provide professional development for state early intervention program managers. With enhanced capacity, they can better serve deaf and hard of hearing children and be able to identify and partner with specialists in services for this population.

Require states to provide Medicaid coverage covering medical technology. This would allow all children can receive testing, equipment, and services.

Ensure that parents receive a proper packet of resources and information. This should include positive information, including resources about early intervention in the state, schools that provide services in the area, types of language learning opportunities, family support groups, and deaf mentors. Families should walk away from the confirmatory audiology appointment with a “backpack of resources.”

Models

New Mexico has a Memorandum of Understanding/Intergovernmental Agency Agreement (MOU) among all state partners responsible for 1-3-6 EHDI outcomes. This document, along with frequent meetings and joint data collection, makes for a strong system in our state. Our MOU has been replicated in other states due to its effectiveness. This collaborative system allows families to receive services quickly. It also creates multiple safety nets for children and families.

The **Colorado** Home Intervention Program, (CHIP) is a program within the Outreach Department at the Colorado School for the Deaf and the Blind (CSDB). The CHIP program includes eight Regional Colorado Hearing Resource Coordinators (CO-Hears) employed in various regions of the state to support families receiving early intervention services and knowledge of resources. After confirmation of deafness by a pediatric audiologist, the CO-Hear receives a referral and connects with the family within 48 hours. The CO-Hear links the family to local early intervention agencies, state EHDI programs, regional events offered through CSDB, and other family supports.

Utah Schools for the Deaf and the Blind Parent Infant Program (PIP) is required by Utah code to serve all children ages 0-3. Audiologists refer children to us after they have not passed two hearing tests. This is typically the newborn screening and a follow-up. We have staff all over the state of Utah. They do home visits and provide teleintervention.

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 communications modalities, as appropriate.

Recommendations

Ensure that every contact with the family provide accurate and comprehensive information. Families have frequently reported that they did not hear or process information from just one source at just one time. Even though time is of the essence in EHDI, families need an opportunity to process information. Multiple people interface with families and children in their 1-3-6 journey: birthing hospitals, primary care providers/pediatricians, state EHDI systems, audiologists, ear, nose, and throat doctors, early interventionists, family service coordinators, schools for the deaf, deaf mentors, family support agencies, etc. The list is frequently extensive and can be overwhelming.

Provide parents with connections with families with deaf and hard of hearing children and family organizations who support deaf and hard of hearing children. These connections can provide guidance and support.

Provide parents with connections with deaf and hard of hearing adults and organizations of deaf and hard of hearing adults. Set up a framework for them to meet regularly with families to share their experiences and provide encouragement and support regarding communication with their children.

States should establish a resource point of contact housed under a public entity. This public entity could be, for example, the Department of Health and Human Services or Department of Public Health. This person/office would be responsible for maintaining all resources shared with all families regardless of location - medical office, school, etc. This individual could work with a task force of individuals to review information to ensure it is up-to-date and accurate. This point of contact could attend national EHDI meetings to connect with other states and share materials. There should also be a website of information that is constantly updated with new resources. The message to families and others should be positive and supportive.

Models

Utah Schools for the Deaf and the Blind provides "all the tools in the toolbox". We do not advocate for one communication methodology over the other. We give families all the information in order for them to see what works for their child and how they can encourage development in all areas. We have a Listening Spoken Language (LSL) specialist and also an American Sign Language (ASL) specialist. We provide assessments in both ASL and spoken language. We provide training for staff to support both LSL and ASL.

At the **New Mexico** School for the Deaf, we receive an automatic referral on newborns from the state. We present information to families in person and at home visits, and we leave videos and written information. We also have a form we review with families as we discuss topics. The family checks off the items on the list to ensure that all topics have been covered.

3. What strategies or programs would help to support the identification and receipt of timely services for young children (ages 1-3) who are deaf or hard of hearing?

Recommendations

A national research-based information system could offer families a “one stop shop.”

This could help them gain an understanding of the complexities of the early intervention system, as well as communication and educational opportunities.

Referral from identification (EHDI) should be made automatically to early intervention programs with expertise in deaf/hard of hearing and culturally responsive practices.

Make available a professional in early intervention for deaf and hard of hearing children to meet with the family at the audiology appointment where the child’s hearing status is confirmed. This will help families feel connected before they leave the office.

Provide logistical support to families. This includes resources to ensure that their children and families are able to access appropriate services, such as transportation, assistance for child-care, support from employers for the time to participate in early intervention services, respite care for other family members, and availability of services that are free or nominal to ensure that no family is prevented from receiving services.

Systems should support text capability to message families. This will address loss to follow up.

Add a healthy child hearing screening to well visits between ages 1-3 to identify late onset hearing loss.

Develop training for pediatricians to better understand the hearing levels, services, reporting timelines, and educational services.

Models

Many states report waiting lists for confirmation of hearing status. In **New Mexico**, there very few pediatric audiologists, and they are centrally located in our very rural state. One strategy that has helped tremendously in New Mexico is that children who have referred twice on their newborn hearing screens are referred to specialized early intervention services through the New Mexico School for the Deaf (NMSD). We do not wait for confirmation. All families, including those whose children ended up not having differing hearing levels, appreciated these services. There have been relatively few false positives and no time has been wasted before receiving services.

It is imperative that services are culturally responsive. NMSD hires staff who are Native American and Latino who are able to provide services that are meaningful to the family.

The **Virginia** School for the Deaf and the Blind has two representatives on the Virginia EHDI Advisory Committee and is involved with projects to support improving efficacy and outcomes.

4. What strategies would help to ensure families, parents and caregivers are continuously engaged as active partners in the EHDI system?

Recommendations

A national EHDI model and data system would focus energy and support for families.

This would support continuous engagement while eliminating confusion. As children get older, parents may benefit from a list of opportunities for family involvement within the EHDI system.

State and local EHDI advisory boards should have multiple seats designated for parents.

EHDI professionals should strive for a collaborative relationship between EHDI and parent support organization(s).

5. What models would be helpful for HRSA to consider in fostering family-to-family and deaf and hard of hearing consumer-to-family supports by families and adults who are deaf or hard of hearing?

Recommendations

Each state should develop a fully staffed deaf mentor program. Deaf mentors should receive appropriate training, professional development, and certification. A state registry of deaf mentors should be created as part of this. Allow for deaf mentors to provide services in flexible ways such as alternating between in person and on line, or fully on line if distance is a barrier.

Deaf mentors should be trained as early interventionists. An essential component of deaf mentor services is an understanding of infant/toddler development and early communication strategies that are foundational for both signed and spoken language.

Make available a variety of deaf mentors using a variety of languages. Languages should include English, American Sign Language, Spanish, and other languages used by families in a given locality. They should include visual and spoken languages.

Make parent groups available. Parents can be linked up with other parents who can provide information and support. Parents should have the opportunity to meet with a variety of other parents who have chosen different communication opportunities for their child. This can help parents determine what is best for their family.

Ensure that center-based services are available. Many states have moved to a home visit only early intervention model, but this limits opportunities for parents to benefit from the range of knowledge and expertise concentrated at a center-based deaf education program.

Models

Many deaf mentor programs exist, including those at:

- Maine Educational Center for the Deaf and Hard of Hearing (<https://www.mecdhh.org/parents/asl-for-families>)
- New Mexico School for the Deaf (http://www.nmsd.k12.nm.us/statewide_services/early_intervention_programs/deaf_mentor_program_dm_)
- Utah Schools for the Deaf and the Blind (<http://www.deaf-mentor.skihi.org>)
- Wisconsin Educational Services Program for the Deaf and Hard of Hearing (<http://wesp-dhh.wi.gov/outreach/servicesprograms/dmp/>).

6. What strategies or programs would help to support state and territory EHDl programs 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 intervention services by three⁷ months of age?

Recommendations

Use employees rather than volunteers to do the screening. Ensure they are trained not only in the equipment but in using positive terminology with families. All too often parents report that screening results are reported as a “fail” and the individual sharing the news appears sad and upset. This does a disservice to families. Training could also include education about resources for families.

Increase the number of pediatric audiologists. Many states are in desperate need of pediatric audiologists. Incentives related to increasing capacity should be developed.

Increase number of ways to communicate with families, such as sending reminders through texts and apps.

Bring screenings to the home so families don't have to return to medical sites.

Doctors and other medical personnel should emphasize the importance of screening to parents. They should explain the importance of an accessible language from birth. “Language deprivation” is a very important and impactful term to share and explain with parents. Personnel should convey the message that the period of the first three years of a child's life is the optimum time for language acquisition.

Model

Virginia School for the Deaf and the Blind (VSDB) Outreach Services include having the VSDB audiologist provide free audiological evaluations to children who are not students at VSDB. Last year, 140 of these evaluations were provided; many were unseated ABRs and OAEs on infants to follow up on a screen that was not passed. Others were children who passed but were suspected of having a hearing loss, possibly progressive.

In addition, VSDB Outreach Services provides webinars, and regional and statewide professional development for early intervention providers, educators (including early childhood educators), and related service providers who work with children who are deaf or hard of hearing. These trainings focus on working with families, promoting language, communication, and cognitive development using different modalities/languages.

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

Consider legislation that requires states to assess and track deaf and hard of hearing children's language development. Assessments that are valid for deaf and hard of hearing

⁷ Probably should be “six.”

children and tracking tools can provide professionals with the information they need to help children meet developmental milestones. Additionally, coordination with preschools to implement consistent assessment practices that track developmental milestones from birth through the preschool years will ensure continuity in progress monitoring.

Continually assess and monitor progress in all areas of development. Use assessments that are appropriate for deaf and hard of hearing infants and toddlers, and include families as primary resource of information, such as through family interviews. Elicit information from families about their child's social-emotional development and provide information and support to enhance the bond within the family. Include interdisciplinary teams that are knowledgeable about young children who are deaf and hard of hearing. Include deaf and hard of hearing professionals as part of the assessment team.

Model

New Mexico School for the Deaf analyzes child specific and program-wide trends based on a system of assessment data that has been tracked longitudinally for about 20 years. We have standardized the assessment tools and reporting format used through state standards. In this way, new approaches (e.g., video visits) can be tracked for effectiveness within the state. States will differ in their needs and how they address those needs, but assessment data is the backbone of ensuring that practices are not only evidence-based but also effectively implemented.

Tools and Resources

- American Sign Language Content Standards <https://www.gallaudet.edu/k-12-asl-content-standards>
- Center on Literacy and Deafness <https://clad.education.gsu.edu>
- Deaf Adult Involvement programs <http://infantheating.org/dhadultinvolvement/states/index.html>
- Family Leadership in Language and Learning <http://www3.gallaudet.edu/clerc-center/family-leadership-in-language-and-learning.html>
- Hand & Voices Guide By Your Side <http://www.handsandvoices.org/gbys/>
- Laurent Clerc National Deaf Education Center resources Clerc Info to Go, Language and Communication <http://www3.gallaudet.edu/clerc-center/info-to-go/language-and-communication.html>
- Visual Communication and Sign Language Checklist for Deaf and Hard of Hearing Children <http://vl2.gallaudet.edu/resources/vcsl/>

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