Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs - Executive Summary

Early Hearing Detection and Intervention (EHDI) activities beginning at the birth hearing screening and culminating in early intervention, have positively impacted outcomes for children who are deaf or hard of hearing and their families in the United States and world-wide. Universal newborn hearing screening has resulted in significantly lowering the average age of identification. Screening is a necessary first step, but does not ensure the next critical steps of timely identification and diagnosis of children who are deaf or hard of hearing, amplification, and referral to early intervention, all with the goal of promoting language development.

The goal of EHDI is to assure that all infants are identified as early as possible, and appropriate intervention initiated, no later than 3–6 months of age. There is a body of literature which demonstrates that children and families experience optimal outcomes when these benchmarks are met. Additionally, communication and linguistic competence (in spoken language, signed language, or both) are achievable when timelines are met, and when optimal audiologic and early intervention services are accessible. There remain critical areas of improvement within the EHDI system to ensure newborns benefit from early recognition and have access to appropriate supports.

This current 2019 document builds on prior Joint Committee on Infant Hearing (JCIH) publications (2013 JCIH supplement on Early Intervention and 2007 JCIH Guidelines), updating best practices through literature reviews and expert consensus opinion on screening; identification; and audiological, medical, and educational management of infants and young children and their families.

The current JCIH document includes the following highlights.

Global Benchmarks and Rationale

- A review and reminder of the importance of early diagnosis of hearing loss following best-practices.
- Recognition of the value of implementation standards for EHDI information systems.
- Recognition of the frequency, and impact, of delayed-onset and/or progressive hearing loss in infants
 and the need for continued surveillance of auditory and speech-language development in all infants,
 regardless of outcome of newborn hearing screening.
- States who meet the 1-3-6 benchmark (screening completed by 1 month, audiologic diagnosis by 3 months, enrollment in early intervention by 6 months) should strive to meet a 1-2-3 month timeline.

Newborn Screening

- Endorsement of the necessity for audiology oversight of hearing screening programs.
- Recognition of the critical need for the ability to calibrate screening equipment using a uniform and validated standard across all screening devices.
- Recognition of the need for manufacturers of screening equipment to provide data on the proportion of children who are deaf or hard of hearing who pass the screening but are subsequently found to have a variety of degrees and types of hearing loss.
- An endorsement, for well-born infants only, who are screened by automated auditory brainstem response (AABR) and do not pass, that rescreening and passing by otoacoustic emissions testing is acceptable, given the very low incidence of auditory neuropathy in this population.
- An endorsement of rescreening in the medical home in some circumstances. If the rescreening is
 performed in the provider's office, the provider is responsible for reporting results to the state EHDI
 program.

Diagnostic Audiology and Audiological Interventions

- A review of current research on the physiologic/ electrophysiologic methods for diagnostic audiologic
 evaluation of hearing in infants.
- A reaffirmation of the importance of fitting hearing aid amplification using objective, evidence-based protocols to ensure maximal audibility.

Early Intervention and Family Support

- Reaffirmation of the need to provide families with individualized support and information specific to language and communication development to support children who are deaf or hard of hearing by providing exposure to language models at the earliest possible age to ensure optimal cognitive, emotional, and educational development.
- Recognition that some families may benefit from infant mental health supports. Infant mental health is
 a field of research and practice that focuses on optimizing social, emotional, behavioral, and cognitive
 development of infants in the context of the emerging relationships between parents and infants.

Medical Considerations

- Reaffirmation of the need for otologic/medical evaluation and management of the newly-identified infant to be carried out as soon as possible following confirmation, in an effort to address potentially reversible conditions, discover associated medical disorders that can impact the infant's general health, and identify conditions that can impact communication strategy choice.
- Recognition that Congenital Cytomegalovirus has a larger impact than previously recognized.
- Updated risk indicators for congenital hearing conditions, including a new table with specified intervals for audiologic evaluation.
- Consideration of reduction in the FDA-approved age for cochlear implantation to less than 12 months.

JCIH's guiding principle is for continued improvements in the EHDI system. This includes lowering the age of identification and diagnosis of infants, as well as ensuring timely and effective interventions to improve language and social-emotional outcomes in children who are deaf or hard of hearing. Amplification (hearing aids, cochlear implants, bone conduction aids) and early language interventions (whether signed language, spoken language or both) should be based on best practice protocols and evidence-based practice as soon as possible following a diagnosis of hearing loss.

The Joint Committee on Infant Hearing (JCIH) endorses early detection and early intervention for all infants who are, or who are at risk of being or becoming, deaf or hard of hearing. The goals of early hearing detection and intervention (EHDI) are to maximize language and communication competence, literacy development, and psychosocial well-being for children who are deaf or hard of hearing. Without appropriate language exposure and access, these children will fall behind their hearing peers in communication, language, speech, cognition, reading, and social-emotional development, and delays may continue to affect the child's life into adulthood. With early detection and appropriate, targeted intervention, developmental milestones for an infant who is deaf or hard of hearing can be expected to be achieved, more accurately reflecting the child's true potential (Tomblin, Oleson, Ambrose, Walker, & Moeller, 2014; Yoshinaga-Itano, Baca, & Sedey, 2010). Focusing on the importance of prompt diagnosis and timely, high-quality early intervention for such infants, EHDI systems should facilitate seamless transitions for infants and their families through the processes of screening, audiologic and medical diagnosis, and intervention.

In this 2019 Statement, the Joint Committee on Infant Hearing (JCIH) seeks to use terms that: (a) are acceptable to a range of stakeholders, and(b) clearly convey the intended meaning to the entire community. Because of the diversity of the committee's composition and represented viewpoints, a compromise resulted in choosing currently-recognized terms that reflect accepted, person-first language. In particular, the term infant or child who is deaf or hard of hearing is intended to be inclusive of the entire spectrum of children, representing varied hearing levels. This spectrum includes children who are deaf or hard of hearing whose hearing losses may be congenital or acquired, unilateral or bilateral, of any degree from minimal to profound, and of any type, including conductive, sensory (sensorineural), auditory neuropathy, and mixed hearing condition, whether permanent, transient, or intermittent. This spectrum includes those individuals who identify themselves as being a part of either, or both, the Deaf or hard-of-hearing communities.

The commonly used term hearing loss is replaced, when grammatically appropriate to the written English language, with the terminology such as hearing thresholds in the mild, moderate, severe, or profound range, acknowledging that for an infant who is born with hearing thresholds outside the typical (normal) range, no loss has actually occurred. The JCIH recognizes that terms like hearing loss, hearing impairment, and hearing level have different values or interpretations assigned to them depending on one's cultural perspective. It is the intent of the JCIH to convey audiological concepts using culturally-sensitive language whenever possible. However, there are times the term hearing loss is retained to clearly convey audiological concepts/conditions, including references to late onset and progressive types. Further, use of the word normal as a type of hearing is replaced, when appropriate, with the word typical to avoid any suggestion of the stigma of abnormality. Finally, in an effort to use clear language, the term refer for a hearing screening result that is a not-pass outcome is avoided, due to lack of clarity and confusion about the meaning and implications of the word refer. The term fail, which in years past had been discouraged in the belief that it would stigmatize infants, is recognized as a commonly-used term in the medical world to describe the outcome of a binary screening and has been adopted for use in this document.

References:

Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs (2019). *Journal of Early Hearing Detection and Intervention*, 4(2), 1-44. https://doi.org/10.15142/fptk-b748

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