



AMERICAN COCHLEAR IMPLANT ALLIANCE

Research. Advocacy. Awareness.

Position Paper: Supporting Parent Choice for Children Who are Deaf and Hard of Hearing

ABOUT US

The American Cochlear Implant Alliance (ACI Alliance) is a non-profit, 501(c)3 organization whose mission is to advance the gift of hearing provided by cochlear implants through research, advocacy and awareness. Members include those who provide the intervention (e.g., ENT surgeons, audiologists, speech-language pathologists), other professionals on implant teams (e.g., psychologists, social workers), teachers and therapists in educational settings, researchers in clinical and academic settings, parents of children using cochlear implants and other hearing assistive technologies, adult recipients, and other advocates. For more information: www.acialliance.org

Widespread early identification of hearing loss and provision of advanced hearing technology—hearing aids, cochlear implants and other 21st century auditory technologies—affords children with all levels of hearing loss the opportunity to function in whatever communication model families wish to pursue while being supported by their chosen medical, language development and educational teams. A body of federal law emphasizes a family’s right to pursue a communication program that respects the unique needs of their child through the Individuals with Disabilities Education Act (IDEA, P.L. 101-46) and the Early Hearing Detection and Intervention (EHDI) Act of 2017 (H.R. 1539, S. 652).

American Cochlear Implant Alliance opposes state LEAD-K laws that may:

- Disrupt parent choice on communication modality for children who are deaf or hard of hearing.
- Conflict with a key provision of Federal IDEA law requiring a “multidisciplinary assessment of the unique strengths and needs of the infant or toddler and the identification of services appropriate to meet such needs” (IDEA 2017).
- Emphasize one communication modality over others.
- Minimize the importance of 21st century technology—hearing aids and cochlear implants—in the acquisition of spoken language for children who are deaf and hard of hearing.

American Cochlear Implant Alliance encourages strengthening processes that support parent choice via existing federal legislation including IDEA, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act (ADA). We oppose state laws that would recommend intervention services for children with hearing loss based solely on standardized milestones for children with typical hearing without consideration of a range of child specific factors such as age of identification, age of fitting with technology, other medical issues, demographic and audiologic factors. The proposed state laws fail to account for the assessment of a child’s unique strengths and needs by qualified interdisciplinary teams per IDEA law.

Background

The proposed state laws reflect a non-evidenced based perspective that all deaf and hard of hearing children benefit from American Sign Language (ASL). This has led to an organized national effort by those who promote ASL to pass state laws that would require the evaluation of language development of young children with hearing loss based upon norms for children with typical hearing without regard to a child’s unique needs, including other medical issues besides hearing loss.

The suggested legislative language would allow the results of such evaluations (based upon milestones of children with typical hearing) to be used as part of the Individualized Family Service Plan (IFSP) or goal-setting for the Individualized Education Plan

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(IEP) for a child with hearing loss. Standardized tests of language development serve as important tools but must be used in the context of a child's own characteristics including age of auditory technology fitting, duration of use and other child specific factors. Spoken language delay is often expected but children focused on auditory-based communication can “catch-up” to spoken language levels of typically hearing age-mates (Percy-Smith 2010). This research-based evidence directly opposes the proposed state laws whose proponents suggest that without use of ASL, deaf and hard of hearing children fall behind in their language development. No current studies support the benefits of ASL for all children with hearing loss, and no studies demonstrate superior overall spoken language outcomes in children who use ASL versus those focused on spoken language alone (Fitzpatrick 2013).

RATIONALE

- 1. While the LEAD-K approach in which an advisory committee recommends milestones to parents, educators and providers does not supersede the wishes of the parents and the IFSP team per se, these milestones have the potential to skew the decision made by the parents and IFSP team for early intervention services. **The milestones tactic undermines IDEA in a manner that may restrict the authority and responsibility of the IFSP team to individualized determinations for the child and family and to include in each child's IFSP those services that the team determines are appropriate to meet the unique needs of the child and family** (20 U.S.C. § 1436; US ED Letter 2002).**
- 2. In 2017, 98% of newborns were screened for hearing loss** (NIH 2017). Early identification, combined with advanced hearing technology, provides access to sound and the ability to develop spoken language (if this is the family's choice)—regardless of the child's level of hearing loss. Children require early intervention including proper fitting with technology for their level and type of hearing loss and appropriate support therapy and educational services (Percy-Smith 2010).
- 3. Even children born deaf can develop spoken language outcomes similar to typically hearing children** if they receive early cochlear implants and appropriate family centered aural habilitation. Children implanted at or before 12 months of age have the best opportunity to develop age-appropriate language abilities (Rubin 2018). Those who had the best spoken language development had never used ASL (Geers 2017).
- 4. Children with cochlear implants develop language in synchrony with their hearing peers** and demonstrate “catch-up” growth **if they are provided with a therapy program focused on listening and talking** (Dettman et. al, 2013; Dornan et al., 2010; Geers 2011, Nicholas 2007).
- 5. Over 90% of children with hearing loss are born to two typically hearing parents who do not know sign language** (NIDCD 2016). Unlike children born to deaf parents who already know and use sign language fluently, children with hearing loss in households in which the parents are learning some form of sign language while teaching their child, are often language delayed in their acquisition of spoken language (Davidson 2014, Hassanzadeh 1984).
- 6. Young children with hearing loss experience the least language delay when intensively exposed to the language of the home**—whether that be English, Spanish, ASL or another language (Bunta 2016). The professional language development community has moved away from requiring “English only” for young children with hearing loss (Crowe 2013).
- 7. Hearing loss in children is associated with a higher incidence of other disabilities** with rates ranging from 19-40%. These children often require additional services alongside of treatment for hearing loss. Some children will benefit from sign language or Cued Speech while others are unable to use a visual system because of blindness, cognitive abilities or physical limitations. Each child is unique and requires an individual assessment (Fortnum 1997, Ear Foundation 2012).
- 8. These state model laws will result in inefficient use of public funds.** Implementation will require an allocation of state monies for a program that will compete with existing IDEA laws, which are jointly funded by federal and state governments. The suggested programs are unnecessary and will create roadblocks and confusion for families.

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