February 21, 2019

**OPEN LETTER TO ACIA** (American Cochlear Implant Alliance):

On behalf of the LEAD-K (Language Equality and Acquisition for all Deaf Kids – Kindergarten Readiness) national team, we are responding to your web-based position paper, along with your letters to state legislators opposing LEAD-K's model bill.

ACIA’s stated mission is to promote cochlear implants. ACIA touting “parent choice” is purposely misleading state legislators and parents, confusing them with statements that have nothing to do with the states’ LEAD-K bills.

LEAD-K is a Deaf-led grassroots movement promoting a Language Acquisition and Accountability Initiative that benefits all Deaf children’s language acquisition regardless of the language and modes of communication employed. The Early Hearing Detection and Intervention program (EHDI) was established in 2000. Cochlear Implants have been in use for decades. Yet, the reality remains that the vast majority of Deaf and Hard of Hearing children enter kindergarten without a functional language.

Thus, the LEAD-K model bill is not about technology; it’s about Deaf children’s rights to language using American Sign Language (ASL) and English, both or one of the languages, to foster language development and achieve Kindergarten readiness and English literacy.

The LEAD-K model bill is intended to promote **language development & literacy**:

1. The LEAD-K model bill focuses on Deaf and Hard of Hearing Children ages 0-5 to ensure that ALL parents receive information about **language** developmental milestones which are universal regardless of the native language. The emphasis of LEAD-K is on **language** development, regardless of the communication modes used. Services, communication tools, and visual supplements; however, are NOT language but simply methods to achieve language. The LEAD-K bill also properly recognizes and preserves parental choice as the bill makes clear, the choice of **language(s)** and modes of communication are the decision of the parent(s) or legal guardians and the child's IFSP or IEP team.

[www.lead-k.org](http://www.lead-k.org) * info@lead-k.org
2. The goal of LEAD-K bills is focused on ending the epidemic of language deprivation by having a neutral state entity such as a state Department of Education to account for Deaf children’s language development by monitoring and tracking their progress and reporting the data on an annual basis during the baby’s earliest months to ensure parents are informed of their child’s progress. Addressing language development that is not at an age appropriate level remains the responsibility of a child’s IFSP or IEP team.

3. LEAD-K bill is in alignment with Federal Laws. Once the initial assessment to determine eligibility for IFSP and IEP services has been determined, the federal law requires assessments be conducted once every six months for ALL children who are eligible for IDEA services.
   
   A. Educators doing these assessments is NOT a new or additional responsibility for them. They are already required to do assessments per federal law. The LEAD-K bill simply requires utilizing an assessment for measuring language development milestones that is normed (age comparable), for Deaf and hard of hearing children. Note: Federal law defines an assessment as the ongoing procedures used by qualified personnel (educators) to determine the individual child’s present level of performance and early intervention or educational needs. 34 CFR §303.321(a) (2).
   
   B. Any assessment must be conducted in compliance with federal law which requires both parental notification and consent, so it is a family choice to participate or not. 34 CFR §303.321; 34 CFR §303.405.
   
   C. Existing assessment materials, as required by federal law, must be appropriate to assess the specific areas of developmental need and are used for the specific purposes for which they were designed. 34 CFR §303.322.
   
   D. All assessments must be selected to accurately reflect the child’s developmental level. 34 CFR §303.322. Those assessments must be administered, in a nondiscriminatory manner, in the native language of the child or family, and by qualified personnel. 34 CFR §303.322.
   
   E. State law cannot require less than federal law requirements, but state law can provide more protection than what federal law provides. IDEA leaves room for the state to interpret the federal rules and pass their own laws. Thus, a state law providing for language inclusion is not in conflict with federal law.
   
   F. While LEAD-K requires inclusion of a language development assessment, it does not restrict other assessment domains. As required by federal law, assessment materials must be appropriate to assess the specific areas of developmental need and used for the specific purposes for which they were designed. 34 CFR §303.322.

4. The LEAD-K legislation empowers parents to not only have the right to know about access to English language acquisition, but also about ASL for their Deaf baby to acquire language. Gatekeepers of early intervention and early childhood education including physicians, cochlear implant surgeons, audiologists and speech-language pathologists would better serve parents and Deaf babies if they stop denying or resisting American Sign
Language as a viable language. When one-sided interests lead to preventing ASL as a viable language option, it can and has resulted in language deprivation.

5. LEAD-K has a bibliography of research supporting Language Deprivation issue, and the need for language milestones for Deaf infants and toddler’s ages 0-5. Additionally, the American Academy of Pediatrics published a Joint Committee on Infant Hearing supplemental position paper (2007), and one of their recommendations was: All Children Who Are Deaf and Hard of Hearing Should Have Their Progress Monitored Every 6 Months From Birth to 36 Months of Age, Through a Protocol That Includes the Use of Standardized, Norm-Referenced Developmental Evaluations, for Language (Spoken and/or Signed), the Modality of Communication (Auditory, Visual, and/or Augmentative), Social-Emotional, Cognitive, and Fine and Gross Motor Skills. Thus, ensuring parent(s) have an accurate measurement of their child’s LANGUAGE development outcomes and how they can track their Deaf baby’s progress toward language milestones, is part of the key fundamental goals in the LEAD-K bill.

We know that ACIA has a medical perspective; however, using its medical position to unduly influence factors which can have a negative impact on long term effects on a child’s language acquisition and education is not acceptable. While you may be experts in the medical field, you are not experts in education, specifically, language acquisition and development for all Deaf children.

Furthermore, ACIA has a financial conflict. ACIA and its practitioners profit from parents’ hope to restore normalcy through auditory implants and by denying the benefits of full visual language access. These actions can and do result in frustrating and needless language deprivation for the majority of Deaf and Hard of Hearing toddlers. LEAD-K provides families with non-biased resources to inform them whether their child is meeting language milestones or needs additional interventions.

Ensuring Kindergarten-readiness is a win-win situation. When the Deaf child succeeds, so does the family, the education system, the providers and the community: in essence, the whole village.

Sincerely,
LEAD-K National Team: Sheri Farinha, Julie Rems Smario, Co-Chairs; Alan Amann, Tressela Bateson, Evon Black, Tina Jo Breindel, Michelle Bronson, Shae Cook, Amy Crumrine, Chriz Dally, Donna DiMarco, Nyle DiMarco, Jonathon Dollhopf, Shannon Filke, Astrid Goodstein, Marla Hatrak, Beth Hamilton, Dirk Hillard, Sarah Honigfeld, Sam Holden, Karen Hopkins, Dr. Patricia Hughes, Lauren Maucere, Alice McGill, Christopher Mick, Shane Molaison, Kim Mokris, Frieda Morrison, Teresa Nold, Gary Olsen, Patricia Sieglen-Perry, Kavita Pipalia, David O Reynolds, Raymond Rodgers, Dr. Roz Rosen, Tony Ronco, Lucia Rogerson, Nancy Sager, Terrylene Sacchetti, Robert Siebert, Larry Siegel, Darcy Sinsley, Kristi Stellato, Ashley Thompson, Robert Vizzini, and more.

www.lead-k.org * info@lead-k.org