



OUR MISSION:

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

February 27, 2019

Dear LEAD-K National Team:

I am writing on behalf of the Board of Directors of American Cochlear Implant Alliance (ACI Alliance) in response to your “Open Letter to ACIA” of February 21. We are a non-profit membership organization of parents of children who are deaf and hard of hearing, adults who are deaf and hard of hearing, cochlear implant (CI) clinicians and scientists, and educators of children who are deaf and hard of hearing. Our membership represents the diversity of people who are involved in the cochlear implant community.

As an organization, we encourage awareness about cochlear implants and provide support to families and persons of all ages who are exploring their candidacy. Our professional members are continuously seeking to improve their knowledge and clinical skills. We encourage and share scientific research on outcomes in CI recipients of all ages. Of course, in children those outcomes focus on language development, reading, writing, and social-emotional competence. With the initiation of universal newborn hearing screening, children who are deaf and hard of hearing have benefitted from the ability to begin the process of learning language much earlier than was possible in the past—regardless of whether they are using hearing aids, cochlear implants, other auditory devices, or visual communication. The improvement in language outcomes allowed by early intervention has been dramatic and this has been documented in numerous studies.

Our professional members include a wide range of professionals who provide support to adults, children and family members. Professional members include not only the medical professionals in the hearing health field whom you reference (i.e., ENT surgeons and audiologists) but also speech language pathologists, social workers, psychologists and educators of children who are deaf and hard of hearing. Parents and adult CI recipients are members of ACI Alliance, participating in our advocacy and outreach.

Your letter states that we have a “medical perspective.” The organization has a broad medical and scientific perspective that addresses a range of issues for children and adults who are deaf and hard of hearing including language development with a cochlear implant. We have a blog that is specifically focused on rehabilitation for adults of all ages. Our conferences always include

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topics on (re)habilitation, as this element is a critical component of the cochlear implant process—both before and after the surgery.


Pediatric cochlear implant teams always include professionals who work with children and their families to foster language development—both before and after the child’s surgery. Speech pathologists and educators are on the staff of clinics that perform pediatric cochlear implantation. In many communities, the CI clinic also has a collaborative relationship with a school or schools in the community that provide specialized services for children who are deaf and hard of hearing. A child’s progress in this setting is carefully monitored and is also linked to child specific factors. 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 may occur depending upon the age at time of CI but children focused on auditory-based communication typically do catch-up to spoken language levels of typically hearing age-mates. Parents are provided with data on their child’s progress and how it compares to typically hearing children as this type of ongoing assessment is part of the process of parent-centered therapy and language learning.

ACI Alliance does not have a position—pro or con—on the use of sign language. We believe that whether and how a family chooses to use visual communication is based upon the specific needs of the child and the family. This is integral to the concept of *family choice*.

We have a different perspective than LEAD-K. We disagree that every child who is deaf or hard of hearing must learn ASL; rather we feel that the issue of communication modality is a function of *family choice*. Given that over 90% of deaf and hard of hearing children are born to two typically hearing parents who do not know sign language, the majority of families seek a language development model for their child that does not include ASL. We support those families as well as those who choose to use Cued Speech, ASL, SEE or another communication approach. We also support families whose language in the home is other than English, which is a large and growing proportion of families in America.

Where we agree with LEAD-K proponents is the need to monitor the functioning of state offices providing early intervention and educational services, including the state schools for the deaf. We should be holding our state agencies accountable for improving services for our children. We believe that the best approach is to make our current processes work properly, not pass new redundant legislation.

Sincerely,



Donna L. Sorkin MA, Executive Director  
American Cochlear Implant Alliance  
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