



National Center For Deaf Advocacy

September 23, 2023

Ms. Donna Sorkin, Executive Director
American Cochlear Implant Alliance
P.O. Box 103
McLean, Virginia 22101-0103

Dear Ms. Sorkin:

We would like to address your American Cochlear Implant Alliance's comments against the

Pediatrics Clinical Report published by the American Academy of Pediatrics (September 2023) entitled Hearing Assessment in Infants, Children and Adolescents: Recommendations Beyond Neonatal Screening (September 18, 2023)

As an alliance of cochlear implants promoters for "the right to receive cochlear implants" in their quest to restore hearing, ACIA exhibits an agnotological ("deliberate ignorance") understanding or knowledge about language deprivation syndrome that has become a concerning epidemic among not only deaf children but also hard of hearing and cochlear-implanted children.

For the extreme harms inflicted upon those deaf children and their families suffering from the following from the clinical report:

"...permanent deficits in language acquisition resulting in downstream effects such as poor academic performance, personal-social maladjustments, and emotional difficulties..."

your response to the above AAP clinical report was totally harmful and disproportionate.

Furthermore, many of the cited sources in your comment have had been debunked, and if we were to invest in an assessment/analysis of "empirical studies" touting both cochlear implantation and deaf children's acquisition of spoken language, we would encounter issues of trustworthiness and credibility of those supposedly empirical research.

As of today, there is NO national data of deaf K-12 academic outcomes. There must be a good reason for this circumstance, but this is not the focus of our response to your comments.

Thanks to LEADK bill (SB210) in California, we now have data showing how BOTH deaf and hard of hearing children ages 0-3 having "at age expectation" language development. When they

turned 3 years old, their “at age expectation” drop from 89.2% to 62.7%. Their “at age expectation” for deaf/hard of hearing children’s literacy hovers at 51%.

(chrome-

extension://efaidnbmnnnibpcajpcgclefindmkaj/https://www.cde.ca.gov/sp/ss/dh/documents/sb210-report-2020-21.pdf)

It has to be emphasized that there has not been any data that cochlear implantation produces language acquisition all by its own. It requires a certain hearing threshold, intervention services, and intensive therapy, all of which come at a great cost not only financially, but also to families. Language acquisition that produces healthy deaf adults must be organic and not as a result of “therapy.”

While we at NCDAA did not think that the AAP clinical report was as robust as it should and could be (after all, they signed a Hippocratic oath to “do no harm,”) we commend their recognition of language deprivation syndrome and the prospect of a signed language to mitigate the syndrome for our deaf children. This is a perspective that does not impede the proliferation of cochlear implants among the medical establishment.

It is interesting that there has not been, of late, an organized opposition to cochlear implantation but consistent hostility and resistance to a natural human need for language. And, just so you know, although we are capable of representing ourselves, Deaf people have also been consistently underrepresented and marginalized population in those medical and political discussions.

We at NCDAA would welcome a public debate about the difference of your and our viewpoints.

Sincerely,

Marla Hatrak, Ph.D.

President

National Center on Deaf Advocacy

cc:

Charles Bower, AAP author

Brian Kip Reilly, AAP author

Julia Richerson, AAP author

Julia L. Hecht, AAP author

ACIA Board President, Andrea Warner-Czyz