December 10, 2020

Dear Head of the Biden Transition Team:

The American Cochlear Implant Alliance (ACI Alliance) writes to express our support for President-Elect Biden’s interest in, and emphasis on, the needs of people with disabilities. The Biden Plan for Full Participation and Equality for People with Disabilities addresses topics of keen interest to people with hearing loss and the clinicians and professionals who serve them. We are excited about President-Elect’s early focus on this important set of issues and would like to take this opportunity to share with you some additional considerations involving one aspect of the Biden Plan; access to hearing technologies across the lifespan.

The ACI Alliance is a non-profit organization whose mission is to advance the gift of hearing provided by cochlear implants (“CI”) 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), educators, scientists, researchers, parents of children with hearing loss, adult cochlear implant recipients, and other advocates.

Cochlear implants and hearing aids are 21st century technology and provide people of all ages with access to hearing in ways that were never possible before. The ACI Alliance’s mission is to ensure that cochlear implants are accessible and available to those who may benefit from them and that the information provided about this life-changing technology is accurate. Hearing restoration is an extraordinary gift and one that should be available regardless of income, age, race, ethnicity, or geographic area throughout the country.

We applaud the Biden Plan for its emphasis on health care and health insurance including Medicare, Medicaid, and the Affordable Care Act (“ACA”). We also applaud the attention given to early childhood development and education, which is especially critical for the children with hearing loss we serve.

However, ACI Alliance does have concerns with one aspect of the Biden Plan on which we wish to share our perspective and offer our expertise in exploring how best to support children who are born with, or later develop, hearing loss. We believe that parents of children with hearing
Loss have the right to choose how their child with hearing loss will communicate, with full and objective information on alternatives, without pressure to pursue one communication option over others.

Language choice cannot, and should not, be legislated or regulated. Over 90% of children with hearing loss are born to two hearing parents who typically do not know sign language; they are most comfortable with teaching their children spoken language in concert with appropriate hearing technology such as hearing aids, cochlear implants or bone anchored devices. It takes at least three years to develop beginning-to-intermediate proficiency in American Sign Language (ASL) and even longer to become fully proficient. In the meantime, children in families where parents are struggling to learn ASL do not have access to a language rich environment. This language delay does not occur with children who are fit with appropriate hearing technology whose families focus on use of their own home language—whether that be English, Spanish or another language.

Children born with hearing loss are now identified at birth; for those who are deaf and qualify, cochlear implants may be provided at 9 months or earlier. Hearing aids may be fit within the first month of life. Our Federal and state laws should support parent choice consistent with existing Federal laws including the Individuals with Disabilities Education Act (“IDEA”), Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act (“ADA”).

In addition, the Biden Plan references an article on “language deprivation” entitled “Deaf Children as ‘English Learners’: The Psycholinguistic Turn in Deaf Education.” We are concerned about this article’s lack of grounding in research and the apparent bias it represents. This is an opinion piece and that is of limited value to a plan as important as the Biden Plan. This is particularly true when the issue of parent choice has heightened importance as the number of opportunities for children who are deaf and hard of hearing have increased dramatically. Nor does the perspective in this article represent the majority point of view.

The vast majority of families of children with hearing loss wish to take advantage of hearing technologies that provide their children with the best listening and spoken language outcomes when paired with parent-centered therapeutic support relying upon what parents know best—their own language. We encourage you to more explicitly support parent choice in the future as the Transition Team paves the way for the new Administration, consistent with current Federal law. Our position paper with supporting research on this topic is available here: https://www.acialliance.org/page/SupportingParentChoice

Please view us as a resource on this topic and anything related to supporting people with hearing loss. We are honored to support your disability policy efforts and will work to assist the Administration in carrying out the objectives of the Biden Plan and subsequent agency priorities. On a personal note, I, as the Executive Director of our organization, am a deaf woman who has been active in the disability field for over 25 years serving on various governmental, university and private boards, including serving as a Clinton appointee to the US Access Board. If I can ever be of assistance, I hope you will contact me directly.
Thank you.

Sincerely,

[Signature]

Donna L. Sorkin MA, dsorkin@acialliance.org
Executive Director
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