January 27, 2025

The Honorable Bill Cassidy, M.D., Chair The Honorable Bernard Sanders, Ranking Member Committee on Health, Education, Labor and Pensions United States Senate

The Honorable Brett Guthrie, Chair The Honorable Anna Eshoo, Ranking Member Committee on Energy and Commerce House of Representatives

Subject: GAO Report on EHDI (GAO-25-106978)

Dear Honorable Senators and Representatives:

This letter is about your January 2025 GAO report to Congressional Committees (GAO-25-106978). First, we wish to commend you for the work done towards our collective goal of improving the overall developmental and linguistic outcomes of Deaf and Hard of Hearing (DHH) children. We are aware that, in producing Hearing Detection and Intervention, Program Connects Deaf or Hard of Hearing Infants and Children to Services, but Actions Needed to Improve Access, there was a need to follow the mandates set forth in 2022 reauthorization of the EHDI Act, including following verbatim directives:

- Analyzing how information collected through such programs informs what is known about EHDI activities to
  ensure that newborns, infants, and young children have access to timely hearing screenings and early
  interventions, including information on any disparities in such access;
- Analyzing what is known about how parents use State EHDI websites to seek health and programmatic guidance related to their child's hearing loss diagnosis;
- Identifying efforts and promising practices of the Centers for Disease Control and Prevention, the Health Resources and Services Administration, the National Institute on Deafness and Other Communication Disorders, and State EHDI programs to:
  - a. Address disparities in outreach for, or access to, timely hearing screenings and early interventions;
  - b. Ensure that EHDI follow-up services are communicated and made available to medically underserved populations, including racial and ethnic minorities.

We are disappointed, however, that the GAO report appears to offer a limited benefit, given its narrow focus primarily on *access* to intervention services, rather than the actual child outcomes of such services. We were further disappointed that the issue of language deprivation—a common and significant concern for many EHDI stakeholders—was not mentioned more prominently in the report. Language deprivation occurs during child development, particularly for DHH children, who often experience a persistent lack of access to a visual language such as American Sign Language (ASL) and fragmented access to a spoken language such as English (M.L. Hall, W.C. Hall, & Caselli, 2019). Consequently, deaf adults experience the epidemic language deprivation syndrome.

Finally, misinformation about American Sign Language continues to persist in the GAO report. ASL is a fully natural language with equal neurolinguistic status to English. It is not simply a communication method or tool. While such mis-categorization is common (Hall & Dills, 2020), research and professionals recommendations that undermine ASL and other natural signed languages have been described as "scientifically, ideologically, and ethically irresponsible" due to the direct harms of language deprivation. Deaf children who are prevented from acquiring a signed language due to such misinformation grow up to have impoverished language skills or language deprivation syndrome (p. 648, Humphries et al., 2017). Below, we provide an example of this problematic framing from the GAO report below:

"These adult mentors have a variety of hearing **loss** conditions and use a variety of communication methods, including American Sign Language, cochlear implants, and hearing aids...."

It is critical to distinguish the difference between natural languages like American Sign Language and English which offer specific neurodevelopmental benefits and tools such as speech, cochlear implants, and hearing aids. Additionally, we are concerned about the implied priorities within the EHDI. The GAO report seems to suggest speech is prioritized over language, as evidence in the quote below:

"This work is focused on both detection of and interventions for hearing loss, and includes research exploring outcomes such as speech, language, and literacy."

Putting speech before language is akin to putting the cart before the horse. Language must come first before speech development. Speaking ability does not necessarily correlate with language and cognition abilities.

Currently, there are three states with public language data for DHH babies and toddlers ages birth to five years old. All three datasets demonstrate population-wide language acquisition delays, particularly beginning

around age 3, when children are transitioned from EHDI services to Part C services. We include links to all three states' reports here below:

California	https://www.cde.ca.gov/sp/ss/dh/documents/sb210-report-2020-21.pdf
Kansas	https://kslegislature.gov/li_2022/b2021_22/committees/ctte_s_ed_1/documents/tes timony/20210211_08.pdf
Virginia	https://www.doe.virginia.gov/home/showpublisheddocument/56247/63858098611 1600000

We have communicated our concerns and a desire to collaborate with HRSA, CDC, and OSEP on this important work. We are fully committed to supporting EHDI stakeholders in our shared goal of improving the development and language outcomes of deaf and hard of hearing children. Please consider our knowledge and expertise at your service. To that end, we would welcome the opportunity to work with your offices and to engage in further discussions on how we can improve not only access to EHDI intervention services but also to ensure these services include full and timely access to both signed and spoken languages.

With gratitude,

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## cc:

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