

DEAF AND HARD OF HEARING ALLIANCE

Alexander Graham Bell
Association for the Deaf &
Hard of Hearing

American Academy
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American Society for
Deaf Children

American Speech-Language-
Hearing Association

Conference of Educational
Administrators of Schools
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Council of American
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Cued Language Network
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Hands & Voices

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TECUnit

Telecommunications
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March 2, 2009

The Honorable Lois Capps
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Jo Ann Emerson
U.S. House of Representatives
Washington, D.C. 20515

Dear Representative Capps & Representative Emerson:

We write to express our strong support for your legislation to reauthorize the Early Hearing Detection and Intervention (EHDI) Act. Your efforts helped to pass this bill in the House of Representatives last year. The Senate, however, was unable to complete work on the legislation. We appreciate your early focus on this legislation in the 111th Congress and look forward to working with you to enact this legislation for the benefit of those newborns and infants that are deaf and hard of hearing.

As you know, Congress first authorized the EHDI programs back in 2000. The legislation and subsequent funding Congress provided have helped establish statewide EHDI programs across the United States that are identifying children with hearing loss and directing them to early intervention services.

EHDI programs include screening (the initial test of infants for hearing loss), audiological diagnostic evaluations (to confirm hearing loss), and early intervention (including medical services, early intervention programs, and family support) to enhance language, communication, cognitive and social skill development, needed to be successful in school and all other aspects of life.

When the first legislation was approved in 2000, 44% of newborns were screened for hearing loss. Today, almost 98% of all newborns are screened and each year there are thousands of infants with hearing loss and their families who are enjoying the benefits of early identification.

Much work remains to be done however. Many infants who fail their newborn screening test do not receive timely follow-up due to shortages of properly trained health care providers and early intervention programs. In addition, state EHDI programs need to be better integrated with the existing public health care system.

Your legislation will provide new authority to allow improvement in these areas. First, it provides authority to address those children who are falling through the cracks and not receiving necessary follow-up after they fail the newborn hearing screening. There is an urgent need to develop better systems to reduce the number of children who are lost to follow up and encourage states to replicate successful models.

Second, it is clear that family-to-family support is critical in the first months after a child is identified with hearing loss. Excellent family-to-family support programs developed by state EHDI programs and other organizations are not yet widely implemented. Your legislation would provide the agency authority to support and disseminate such programs that are working for parents and their children.

Third, it is clear that more research and study is needed in the area of hearing detection and intervention. Your bill would enable NIH to establish a post-doctoral research fellowship program to effectively recruit researchers to become involved in early hearing detection and intervention.

Finally, your bill provides the authority for state EHDI programs to address the shortage of trained health professionals and other personnel necessary to make certain that every child who is screened and has a hearing problem gets access to appropriate diagnosis and intervention programs needed to succeed.

Clearly, the EHDI programs are serving a critical national need in a successful manner. We appreciate that your legislation builds upon this success for children who may be deaf or hard of hearing. We thank you for championing this issue within the Congress and look forward to working with you.

Sincerely,



Catherine Murphy
Co-Chair



Ingrida Lusia
Co-Chair