

Testimony

Before the House Energy and Commerce Committee Subcommittee on Health

Regarding H.R. 1344, Reauthorization of the Early Hearing Detection and Intervention Act

June 25, 2015

Good morning Mr. Chairman and Members of the Committee, my name is Dr. Patti Martin, I am the Director of Audiology and Speech-Language-Pathology Services for the Arkansas Children's Hospital, and am here today as an expert on the EHDI program and a member of the American Speech-Language Hearing Association.

ASHA is the national professional, scientific, and credentialing association for 182,000 members and affiliates who are audiologists; speech-language pathologists; speech, language, and hearing scientists; audiology and speech-language pathology support personnel; and students

I want to express ASHA's and my appreciation to Chairman Guthrie and Congresswoman Capps for their leadership in introducing and sponsoring H.R. 1344, the reauthorization of the Early Hearing Detection and Intervention Act. This important bill provides assistance to states in identifying hearing loss in new infants and young children, and places an emphasis on ensuring those identified with hearing loss receive appropriate intervention.

Hearing loss is the most frequently occurring condition for which newborns are typically screened. Three babies per thousand are born with hearing loss and this number triples by the time children enter Kindergarten. When hearing loss is detected early, children can learn sign language, be fit hearing aids or cochlear implants, and/or receive early intervention services that enable them to achieve on par with their typically hearing peers. If hearing loss is not detected early it can be devastating to children's academic and psychosocial development. There is now abundant scientific evidence showing that the brain develops in response to early visual and/or auditory stimulation—which is critical for children with

hearing loss. Almost 30 years ago a report commissioned by Congress (Toward Equality, 1988) showed that the average deaf child at that time had a 4th grade reading level when they were old enough to graduate from high school – in large part because the average age of identification at that time was 2 ½ to 3 years of age. Now that newborn hearing screening has been implemented throughout the United States, we have seen the average age of identification drop to 2-3 months of age. More importantly, deaf children who are diagnosed early and receive appropriate early intervention services, often achieve on the same level with their hearing peers by the time they reach first grade. Examples of children who are flourishing using sign language or listening and spoken language can be viewed at <http://infanthearing.org/2015EHDIReauthorize/>.

Investing in early intervention results in positive long term outcomes regardless of the way a family chooses to communicate with their child. It can result in tens of thousands of dollars either saved once a child enters school or allows for resources that can be redirected towards children requiring more specialized services. Research has demonstrated that important language skills are learned before the age of 3. This is a very critical time period during which infants can acquire language. Brain development of the auditory pathways and language cortex is occurring in young children as they respond to auditory and visual language. In families that are part of the deaf culture, these parents automatically sign from day one, so the baby is learning visual (sign) language, and the appropriate brain development is occurring. However, if a child's hearing loss is undiagnosed and the parents are unaware, the child will not receive the needed language stimulation — and the hoped-for development won't take place. The more age-appropriate sensory input a child receives, the greater the development of complex brain connections and language skills. The most important reason for early detection is so we can understand how to help a child's language and communication growth. Such stimulation needs to happen during the first few months of life in order to prevent language delays and the child's resulting frustrations with communication and social-emotional growth.

HR 1344, the Early Hearing Detection and Intervention Act of 2015 that you are considering, is a reauthorization of a very successful program which has been in existence for fifteen years. Because of this initiative, called EHDI or E-H-D-I for short, 98% of babies are now screened for hearing loss before they are discharged from the hospital. Most of these babies go home to families where it never even occurred to their parents to wonder if their babies were hearing them sing, coo or whisper, “Mommy loves you or “you’re Daddy’s big boy”. Early screening allows those infants who do need assistance to be connected with services, learn to communicate with their families using sign language and/or hearing technology and start on the path to prepare them for school readiness. Of those babies needing additional follow-up, we know that approximately 95% of them are born to hearing parents, often with little or no previous exposure to individuals who are deaf or hard of hearing. They suddenly find themselves in a situation that was unanticipated and for which their road map on parenting, their guide books full of “how-tos’ and the advice of friends and families may not apply. A great resource for many of these parents is having access to adults who are deaf or hard of hearing, or other forms of family-to-family support as stipulated in this bill.

There is much to be proud of about the impact of the previous legislation that is captured in this reauthorization. The Early Hearing Detection and Intervention program has enabled unprecedented collaboration between public and private agencies and across all levels of government. The EHDI program is often cited as a model of how government at different levels and public and private agencies should and can work together. The reauthorization continues to emphasize the partnership among HRSA, CDC and NIH and includes language for these agencies to collaborate with additional public and private entities that will further strengthen EHDI programs. As stipulated by HR 1344 HRSA will be responsible for developing and monitoring the efficacy of state-wide hearing screening programs and systems, the prompt evaluation and diagnosis of children referred from screening programs; and appropriate educational, audiological, and medical interventions for children confirmed to be deaf or

hard of hearing. CDC will take the lead on the development, maintenance, and improvement of data tracking and surveillance systems on newborn, infant and young childhood hearing screens, audiologic and medical examinations, and early intervention services. And the National Institutes of Health (NIH) will continue a program of research and development related to development of technologies and clinical studies of screening methods, efficacy of interventions, and related research.

Collaboration among staff from HRSA, CDC, and NIH has been an important element in the success of EHDI programs and will be strengthened by this bill. For example, staff from all three agencies participate in the National EHDI meeting (along with people from many other professional and advocacy groups such as the American Academy of Pediatrics, the American Speech Language Hearing Association, the National Association of the Deaf, the Joint Committee on Infant Hearing, and others) which brings together approximately 1,000 EHDI stake holders each year to participate discuss how EHDI programs can be improved. HRSA and CDC staff are routinely invited to each others' grantee meetings, and CDC recently worked with HRSA and ASHA to develop an online locator system for pediatric audiologists (<http://www.ehdi-pals.org/>).

I'd like to call your attention to several sections in this bill that offer examples of the wonderful benefits that the reauthorization of this bill will have for children and families.

First, HR 1344 is focused on continuing to provide limited federal support to programs already in place to improve hearing screening for newborn infants and young children. In the previous version of the bill, the focus was exclusively on infants. This bill reauthorizes services for babies and extends services to young children. This is critical because the incidence of hearing loss triples between birth and five years of age and this bill allows us to identify this group of children as well, and intervene so that they enter our schools ready to learn. Although federal money is a small part of the total resources

being devoted to EHDI programs, it is the “glue money” that holds the programs together and enables them to be successful. (Sec 3, Lines 23-26)

Another important aspect of this bill is the focus on the importance of families being involved in the process and empowered to make decisions for their child in a timely way. Research tells us that engaging and enabling families is not just desirable, but critical. Family Involvement can be described as the tipping point for children who are deaf or hard of hearing in having full access to language, whether visual, spoken, or a combination. Involvement of families is described as family-to-family support and support from a variety of professionals, including deaf/hard of hearing consumers. (Sec 4; Lines 16-20)

Because of previous funding for the EHDI program, loss to follow-up has been reduced by half over the last ten years, but more work is needed. Federal money from the current EHDI program has enabled states to work on Quality Improvement initiatives that are focused on reducing loss to follow-up and these efforts have resulted in significant progress. Of the 3.4 million reported by the CDC as being screened for hearing loss in 2013, only 10,118, -- less than 3 per 1,000 were actually lost to follow up after failing the hearing screening test. So the newborn hearing screening system is working like it should for more than 99.5% of newborns. (Section 5; Lines 6-9)

This EHDI bill is about more than just screening babies at birth for hearing loss. We “do” screening very well in all our states, but there is work to be done on getting appropriate services for many infants and young children. We have the basics in place, but systems to ensure that infants with hearing loss receive the appropriate follow up for diagnosis, medical care and early intervention services from providers that have the knowledge and skills to help them communicate with their families must be refined and improved.

When I was about ten years old, my parents took a detour on our vacation to see Ivy Green, the home where Helen Keller was raised. I was awed and amazed as I stood by the water pump where Annie

Sullivan reached into Helen's dark and silent world and opened the door to communication for her. Helen Keller has been my hero since that time. But for Helen's parents, Annie Sullivan was the true hero...she shepherded them down a path they did not choose, that was new and frightening and impacted their basic understanding of what it means to be human—to be able to communicate . EHDI is not a person, but this system of Early Hearing Detection and Intervention can continue to be a hero, much like Annie was to Helen's family, to countless families in the United States. In the words that Helen Keller herself spoke, "Alone we can do so little; together we can do so much".