

**Labor Health and Human Services, Education, and Related Agencies
Witness Disclosure Form**

Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.

Your Name, Business Address, and Telephone Number:

Paul R. Rao Ph.D. CCC CPHQ FACHE
2012 Past President- American Speech-Language-Hearing Association
Vice President, Inpatient Operations & Compliance
Medstar National Rehabilitation Hospital

1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.


The American Speech-Language-Hearing Association (ASHA)

2. Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2008?

Yes No

3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.

See attached page.

Signature: 

Date: *3/27/12*

Federal Grants awarded to ASHA During 2008-2012

| Grant Title | Yr 2008 | Yr 2009 | Yr 2010 | Yr 2011 | Yr 2012 |
|--|------------------|------------------|------------------|------------------|-------------------|
| Research Symposia in Communication Sciences and Disorders | \$ 30,000 | \$ 30,000 | \$ 30,000 | \$ 30,000 | \$ 30,000 |
| Lessons for Success Research Conference: Developing Emerging Scientists in Commu Sci and Disorders | \$ 29,960 | \$ 29,960 | \$ 29,660 | \$ 29,364 | \$ 26,428 |
| Global Solutions in Research and Clinical Practice in Communication Sciences and Disorders | | | \$ 30,000 | | |
| Mentoring Network for Clinician-Scientist in Communication Sciences and Disorders | | | | | \$ 167,993 |
| <i>Sub-total</i> | <i>\$ 59,960</i> | <i>\$ 59,960</i> | <i>\$ 89,660</i> | <i>\$ 59,364</i> | <i>\$ 224,421</i> |
| | | | | | \$ 493,365 |

All 4 grants are awarded by the National Institute on Deafness and Other Communication Disorders (NIDCD).

Total amount of federal grants awarded to ASHA during 2008-2012 is \$493,365.



AMERICAN
SPEECH-LANGUAGE-
HEARING
ASSOCIATION

Testimony of Paul R. Rao, PhD, CCC-SLP
Immediate Past-President of the American Speech-Language-Hearing Association
Before the House Labor-HHS-Education Appropriations Subcommittee
Thursday, March 29, 2012
Washington, DC

Good morning Chairman Rehberg, Ranking Member DeLauro, and Members of the Appropriations Subcommittee. My name is Paul R. Rao, PhD, CCC-SLP. I am the chief operating officer for inpatient services at the National Rehabilitation Hospital (NRH) here in Washington, DC. This morning I am representing the American Speech-Language-Hearing Association, where I serve on the Board of Directors as the immediate past president of the Association. I appreciate the opportunity to testify today on three issues, IDEA funding, literacy, and funding for EHDI.

The American Speech-Language-Hearing Association (ASHA) is the professional, scientific, and credentialing association for more than 150,000 members and affiliates who are audiologists, speech-language pathologists and speech, language, and hearing scientists.

Individuals with Disabilities Education Improvement Act Funding

When the Individuals with Disabilities Education Improvement Act (IDEA) was signed into law in 2004, it authorized federal spending to increase annually from approximately \$10.5 billion in 2005 to over \$26 billion in fiscal year (FY) 2011, the last year covered by the law. The authorized federal spending was meant to provide 40% of the necessary funding to administer the regulations set forth in the Act. However, that has not been the case. The Consolidated Appropriations Act of 2012 provided only \$11.9 billion in IDEA Part B funding—a shortfall of \$14.1 billion.

The Obama Administration's 2013 budget request for IDEA Part B would freeze funding for the program and decrease the federal contribution from 16.2% to 15.8% of the national per pupil average expenditure for FY2013, well below the original target of 40%. Under the law, states are obligated to serve children and youth with disabilities. Limiting funding for IDEA places school-based speech-language pathologists (SLPs), audiologists, schools, and school districts in an unsustainable position. If this request is enacted, they will face serious struggles to meet their obligations given the dire straits of already dealing with current state budget cuts.

Further, the effects of sequestration—as called for under the Budget Control Act of 2011—will be devastating for children with disabilities. Using the Congressional Budget Office's figures, IDEA Part B funds will be cut by at least \$903 million dollars. This loss will be directly felt by close to 500,000 students and families and over 12,000 jobs will be lost, including many school-based SLPs and audiologists. Without these critical federal dollars, the ability of states and districts to provide needed services will be severely compromised.

I ask for this committee to provide the maximum funding available to IDEA, in order to revitalize what has become one of our nation's core educational programs for students.

Basics of Literacy and Reading and the Need for SLPs and Audiologists

Literacy is an essential prerequisite for social well-being, academic achievement, and lifetime opportunities. While ASHA members provide services under IDEA, they also play a valuable role in the schools. However, IDEA can be a wait to fail model for many children with communication disorders. Children who are at risk of failure in acquiring literacy skills in elementary school often have a speech, language, processing, or hearing disorders. Failure to identify these children *early*, prior to the development of a full-blown disability, is tragic, diverts resources, and can possibly impede on the academic success for many children.

For example, SLPs can provide early identification, assessment, and appropriate intervention for students with or at risk of a communication disorder and develop literacy programs in school settings. Further, audiologists play an important role in the identification and management of hearing loss and auditory processing disorders, a frequent cause of language delay and reading difficulties. SLPs have extensive training and education to recognize and understand individual differences in typical and disordered language development. This knowledge base, combined with skills in using diagnostic-prescriptive approaches for assessment and intervention, is particularly valuable in school settings.

SLPs and audiologists play important roles in ensuring that all children gain access to appropriate instruction in reading, writing, and spelling. School administrators should, but often don't, utilize the expertise of these professionals when implementing their literacy programs. Unfortunately, old and persistent attitudes towards SLPs and audiologists limit their reach to children already identified with a disability. Current federal law is silent toward the use of school-based SLPs and audiologists further undermining our members' abilities to get involved at the local level.

On behalf of the 68,622 ASHA members who are currently employed in the schools, I request that this committee direct states and school districts who receive federal funds to allow, not mandate, the use of school-based speech-language pathologists and audiologists on their school literacy teams and state advisory boards.

Early Hearing Detection and Intervention Funding

Early Hearing Detection and Intervention (EHDI) grants to states have significantly increased the number of infants screened for hearing loss at birth. In 2000, only about 40% of all newborns in the United States were screened. However, with modest amounts of federal funding through EHDI grants, 97.8% of infants are now being screened.

Although great strides have been made, significant work remains to ensure that infants who are diagnosed with hearing loss receive timely and appropriate services. For example in 2009, of the infants who were diagnosed with hearing loss at birth, 45.1% did not receive appropriate diagnostic and intervention services (also known as Loss to Follow-up/Loss to Documentation (LTF/LTD)). In 2010, that figure dropped to 38%, lower but still unacceptable.

There are also great variations among the states regarding loss to follow-up. For example, in Montana the loss to follow-up was 82.2% in 2009—the second highest percentage in the country of children who did not receive appropriate services. However, in Connecticut the loss to follow-up was much less at 17.3%.

The good news is that in 2010 state EHDI programs have successfully documented over 5,000 infants with hearing loss and 70% were identified before three months of age.

ASHA requests that the subcommittee continue to not only appropriate funding for the EHDI program but also ensure appropriate funding so that states can link screening programs with diagnosis and early intervention supports.

Thank you for the opportunity to testify before you today, I am happy to answer any questions that you may have.

Formal written testimony is submitted on behalf of the American Speech-Language-Hearing Association. For questions or additional information, please contact Neil Snyder, ASHA's director of federal advocacy, at nsnyder@asha.org or 202-624-7750.

March 27, 2012

Dear Dr. Rao,

I received an email request from Eileen Crowe to find someone from Montana with experience with the Special Education Programs in Montana as part of your testimony before the House Labor-HHS-Education Appropriations Subcommittee on Thursday.

I am currently the ASHA SEAL from Montana, but more importantly, I am the mother of a son with Downs Syndrome. My son recently turned 25 and he is a product of the Shelby, Montana Special Education system. Shelby is a town of 3376 people and the school district currently has an enrollment of 480 students. We also have a current special education enrollment of about 60 students. This number does not count those student qualified as "speech only" or it would be much higher. The Part B- State Grants are a critical help with the funding of these programs. Montana's funding for special education is based purely on a percentage of the total school enrollment. There are no allowances for multiply handicapped children, or severe behavior challenged students. I do know from my work in Washington state that some states determine funding for special education services based upon the disability of each child. This formula provides more funding where more funding is needed. Montana does not do that.

Because of the high quality of training and skill in instruction his Special Education teachers had, my son is able to read. In fact, he is always reading a book or signs where ever we happen to be. He has read all of the Harry Potter books with 70% comprehension. This is an incredible accomplishment because his reading level has been tested to be a 2nd grade level.

This reading skill has very little to do with me and a lot to do with the Special Education Program through which he was taught. As his mother and at times his Speech Language Pathologist, I read to him, but did not directly instruct him in reading, writing or math.

His special education program in school taught him how to read, how to write and how to tell time, and do basic math skills.

7 years after his graduation from high school, my son still uses and values these skills. He has a job and works three days per week. He uses his reading skills, time skills and writing skills to succeed at his job and communicate with his peers and supervisors.

I strongly encourage the House Labor-HHS-Education Appropriations Subcommittee to continue funding to special education services to provide highly trained and qualified instructors in rural areas for all of our children who need these critical survival skills.

Sincerely,

Laura Jo McKamey, MS, CCC-SLP/ Mom



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March 27, 2012

Dr. Paul Rao, President
American Speech Language Hearing Association
2200 Research Boulevard
Rockville, MD 20850-3289

Dr. Rao,

It is a pleasure to provide you with an example of how the Early Hearing Detection and Intervention (EHDI) program has made a difference in the lives of families with children born with hearing loss in Montana. I hope that Congressman Denny Rehberg from Montana, and chair of the Labor-HHS-Education Appropriations Subcommittee, will be most interested in hearing about the success these families have experienced as a result Universal Newborn Hearing Screening (UNHS), early identification, and referral to our program for educational intervention services; all before their babies are 6 months of age.

Since the UNHS program was established the Montana School for the Deaf and the Blind (MSDB) has worked with the Children's Special Health Services (CSHS) Bureau which manages the Maternal and Child Health Service block grant to establish an electronic referral data system to ensure that within three months of identification of their babies' hearing loss, families will receive home-based early intervention services from the MSDB statewide outreach program and if necessary, the Part C service provider in their community.

Over the past six years the number of infants identified through UNHS and referred to MSDB through CSHS has ranged between 8 and 15. On an annual basis the MSDB outreach program serves between 30% and 50% of the children statewide and under the age of three who have an identified hearing loss. These may seem like small numbers and they are. Across the state the school age population of children, served with an IEP and who's primarily disability is a hearing loss, number less than 160.

Even though the numbers are small the success for these children can be huge if the goals of the 1-3-6 from Montana's EHDI program are achieved. There are many examples of the success of early intervention but I'd like to relate just a couple that are occurring right now in the Billings area. Two little girls, one who will turn four years old next week, and one who turned two last December, were born into families where there was no hearing loss. Both were born with bi-lateral sensori-neural hearing loss of a moderate to profound degree. Both children were identified with a hearing loss through the UNHS program prior to three months of age and their

families began receiving home-based early intervention services from both MSDB and their local Part C provider by the time their infants were 6 months of age. Both children received amplification before their first birthday and one received a cochlear implant before her second birthday. The family of this child chose the use auditory and verbal input to facilitate communication and language development along with sign language as a visual support. The other family chose American Sign Language (ASL) as the primary language for their child and is using visual language as the primary method for communication and language development.

Though the approaches to language development have been different both children have both expressive and receptive communication and language that is within the average range for children their ages. Because of their measured growth and development neither child qualifies for Part C services which demonstrates the success the early identification and intervention program. Even though they are using different methods for communication and even a different language in the case of the child who is using ASL the outreach consultant expects these children to enter kindergarten with linguistic competencies that are the same as their hearing peers.

If I can be of additional assistance in providing information about the successful application of the EHDI program here in Montana do not hesitate to contact me.

Sincerely,

A handwritten signature in cursive script, appearing to read "Steve Gettel".

Steve Gettel
Superintendent

March 27, 2012

To Whom It May Concern,

My name is Wendy Williams and my husband Tal and I are the parents of two young sons ages 14 and 16. Both our boys are severely hearing impaired. However, their stories differ significantly due to early detection. Our oldest son Jace was born in 1995 and we noted at around age two that he was not talking and he had significant behavior issues. I suspected a hearing loss and proceeded on my own to have his hearing tested. After several months of diagnostic testing he was diagnosed with a severe bilateral hearing impairment and he was fitted for hearing aids at age 2. By this time he had missed those critical 2 1/2 years of language being imprinted on his brain, which meant he was significantly delayed in his receptive and expressive speech (meaning what he understood and what he could express). Intensive speech therapy was then required at two times per week. There I would learn sign language and then teach it to him at home. We also had constant meetings with Family Outreach and the Montana School for Deaf and Blind for parenting techniques on disciplining a child who we could not communicate with. Every day was a major battle just to do activities of daily living such as dressing, bathing, feeding, putting him to bed, and getting him into a car seat, etc. etc. Progress was slow but Jace became more and more able to communicate verbally and through sign language, rather than being physically aggressive to get what he needed or wanted. It was during this time that I found out I was pregnant with our second son, Witt (or as my dad so eloquently put it "haven't you dug a deep enough hole for yourself.)

However, when Witt was one day old I requested a neurological hearing test be done on him. So we knew before we left the hospital that he was also hearing impaired. He then had further testing, but he was fitted for his hearing aids at 10 weeks of age. He had speech therapy by 10-months of age and only at twice a month, not twice a week. He therefore also never experienced any of the anger and frustrations of being locked inside his little body and being unable to communicate like his older brother did. This as you can understand makes life at home much more pleasant for everyone. If we had had newborn screening on Jace, there would have been a huge emotional and financial savings to my family and to our insurance company. I have seen with my own eyes and pocket book the cost savings to early detection verses playing catch up.

My sons are now in the 7th and 10th grades and are main streamed independent students in school and are both extremely verbal now, but I can still see the learning advantage one son had over the other. I urge you to continue support for the screening and follow up for hearing loss in newborn babies and infants in this country. Thank you.

Wendy Williams

Helena, Montana

March 27, 2012

To Whom It May Concern:

As the parent of a 13 year old daughter with hearing loss, I would like to offer my perspective on the importance of continued support for the screening and follow-up for hearing loss in newborn babies in this country. I have had an opportunity to serve on the CT EHDI Task Force for the past several years and it has allowed me to see up close how the EHDI program is growing and becoming more responsive to families and loss to follow up. My daughter was born before newborn screening for hearing loss was the norm, and was not diagnosed until first grade. As a result, we do not know if she was born with hearing loss, or if it occurred later on. She is a prime example of why early screening is critical, because we will always ask ourselves, had she started receiving deaf/hard of hearing early intervention services sooner, would her outcomes have improved? We know the answer is "YES".

In 2011, 10% of CT children screened were eligible for Birth to Three (Part C) services because they had a medical condition with a high likelihood of resulting in developmental delay, out of those screened, 70 children were found to have hearing loss. There were three programs that worked with families whose children are deaf or hard of hearing from any town in Connecticut. The programs and number of children served are as follows:

American School for the Deaf (ASD): 93 children

CREC Soundbridge: 65 children

New England Center for Hearing Rehabilitation (NECHEAR): 15 children

During the same year, there were 2,944 children who left Birth to Three at age three, and 2,609 were referred to their school district, of which 2,119 or 81% were found eligible for special education.

The Connecticut Birth to Three System received the highest determination rating for the fifth consecutive year by the U.S. Department of Education. This shows that Connecticut has fully complied with the federal Individuals with Disabilities Education Improvement Act, Part C, which is the law that defines early intervention. Connecticut is one of only 10 states to earn this highest rating over so many years.

Clearly, our CT EHDI program is also making great strides in improving the outcomes for children with hearing loss served by Part C. On the Part B side of IDEA, however, it has become apparent that an educational crisis is occurring in Connecticut based on the 2011 Connecticut State Department of Education data for CT Mastery Test (CMT) and CT Academic Performance Test (CAPT) scores. These scores show deaf/hard of hearing children with Individualized Education Programs (IEP's) are significantly behind in reading, writing, and math as compared to their hearing peers. Between 71% - 81% of deaf/hard of hearing children did NOT reach goal

for CMT & CAPT assessments as compared to 35% - 58% of their hearing peers. Research shows this is not a reflection of their intellectual ability, but rather a reflection of the lack of language and communication focus occurring in educational settings.

I am happy to report that the Connecticut EHDI Program has been instrumental in providing support and funding for the start-up of a Connecticut Chapter of Hands & Voices. Hands & Voices is dedicated to supporting families with children who are Deaf or Hard of Hearing without a bias around communication modes or methodology. They are a parent-driven, non-profit organization providing families with the resources, networks, and information they need to improve communication access and educational outcomes for their children. Their outreach activities, parent/professional collaboration, and advocacy efforts are focused on enabling Deaf and Hard-of-Hearing children to reach their highest potential. CT Hands & Voices is hard at work with the CT EHDI Program and other partners working together for the most successful future possible for our children with hearing loss.

Thank you for allowing me to share my perspective.

Respectfully yours,

Patti Silva

CT Hands & Voices Start-Up Coordinator

24 Hillcrest Avenue

Wethersfield, CT 06109

860-529-7766 March 27, 2012