

MCHB/ NHS July 21, 2006 Webcast
LENDing Support to EHDI Programs

IRENE FORSMAN: Hi, good afternoon, this is Irene Forsman at the Maternal and Child Health Bureau. I would like to welcome all of you to this webcast, which I think we're all going to find very interesting. On the call today we're going to have Judy Gravel doing an update of the 2006 statement and reports of the LEND activities from Karen Anderson in Florida, from Rich Harward in Utah, Paul Brueggeman from South Dakota, Diane Sabo in Pennsylvania and Jack Roush in North Carolina and talk about activities in other states if we have time. For some of you, you will recall that a year actually 13 months ago, we had a meeting of the LEND audiologists in Washington. The purpose of that meeting a year ago was to really bring together the group and to encourage the incorporation of more pediatric content into their training programs. It was a two-day meeting. It was very busy and very productive in that when the participants left, they left us with work plans in which they indicated what they hoped that they would be able to do when they got home. Today we're going to hear from a few people what they were able to accomplish and I'm looking forward very much to hearing that. We're going to start off with Judy Gravel.

JUDY GRAVEL: Hi, everyone. I'm really pleased to be with you all. I really enjoyed last summer's meeting and looking forward to hearing how all of our activities have gone. I'm going to provide an update on the drafting of the JCIH 2006 position statement. This draft is now in peer review and so we have certainly made some progress on this. But after updating a document that is -- that was published in 2000, we've learned a lot. We got a

lot of new information and the process has been an important one but indeed a long one. So today just a brief update on where we are and some of the important issues that have faced the Joint Committee on Infant Hearing in the drafting of this new document. Could I have the next slide, please? I won't review what the joint committee is because I think we're all very aware of that. So I thought I would just highlight some areas that the joint committee 2006 position statement will address. First is the definition of targeted hearing loss. And the position statement will identify infants at risk for hearing loss as those with sensory neural hearing loss that is congenital or early onset and permanent conductive hearing loss of any degree in one or both ears in all newborns. In addition, the identification of neural hearing loss in neonatal intensive care unit infants.

Next slide. JCIH addressed the notion of hearing screening protocol and decided it was important to stress in this document that there would be separate protocols for well baby nursery and the NICU. In addition, automated ABR technology was recommended as the primary screening tool for use in the NICU. This is, of course, related to the targeting of infants with neural forms of hearing loss in the NICU that we've just previously discussed. Relative to screening protocols, JCIH thought it was important to address the notion of rescreening and rescreening would be important in both ears even if one ear fails initial screen. The first month of life is important if they have conditions associated with hearing loss such as hypobilirubinemia. The following screening of the audiological evaluation of infants who have not pass had their newborn screening and the JCIH addresses the issue of these evaluations being completed by audiologists with experience and expertise and the requisite second technologies to newborn infants.

The JCIH will recommend that one diagnostic ABR be completed for children under three years with permanent hearing loss and indeed this is a new position taken by the JCIH in audiologic evaluation. They should be individualized depending on the subsequent early hearing loss. Infants who pass the neonatal hearing screening but who have risk factors for hearing loss and regardless of any surveillance or monitoring that's done in primary care setting should have at least one audiologic assessment by 30 months of age. These recommendations, the one previous on the previous slide and this one have essentially eliminated the recommendation that was made in the JCIH 2000 position statement and has been made before in other JCIH statements for the audiologic testing every six months until three years of infants who have risk indicators for hearing loss. Next slide, please. The next section of the position statement and guidelines deal with amplification and one of the issues raised is that infants diagnosed with permanent hearing loss should be fit with amplification within one month of confirmation of their hearing loss.

Next slide, please. Relative to medical evaluations all families of infants with permanent hearing loss should be offered genetic consultation and every infant with permanent hearing loss should have at least one examination by an ophthalmologist experienced in evaluating infants. Next slide, please. The risk indicators have been reorganized from the previous document which had two lists of risk indicators for those under 28 days and those over 28 days to 36 months. Now the risk indicators are organized into a single list and they focus on early and late onset hearing loss. Next slide, please. The risk indicators are family and caregiver concern regarding hearing, speech or language and as all of you

know that and family history of permanent childhood hearing loss have been risk factors that are considered extremely important for us as we monitor for late onset hearing loss. Craniofacial disorder, those involving ear tags, temporal bone. The 48 is a hour and UIC care to five days now for babies that would be considered at risk for hearing loss. Assisted ventilation for greater than ten days, prolonged exposure to -- hypobill Rubinemia. Intrauterine infections are also again on the risk indicators for hearing loss.

The next slide, please. Post natal infections including bacterial meningitis. Degenerative disorders, head trauma requiring hospitalization, chemotherapy and it's important to note again in these guidelines the recommendation for infants with three months of OTOTIS media. The statements also talk about early interventions. All families with infants of permanent hearing loss in one or both ears should be considered eligible for early intervention services is the position JCIH takes in this new position statement. Early intervention is recognized as the point of entry for early intervention services for infants with confirmed hearing loss and that should be linked to the early hearing detection and intervention. Early intervention should be provided by professionals with expertise in hearing loss including educators of the deaf and speech/language pathologists.

Next slide, please. Early intervention also was -- is discussed in terms of the previous emphasis on the natural environment of the child. JCIH will recommend now that both home-based and center based intervention options should be considered appropriate for early intervention service provision. Next slide, please. And relative to screening and surveillance in the medical home JCIH strongly supports all infants should have regular

surveillance of their developmental milestones, auditory skills, always asking parents if they have concerns about their child's hearing or communication development and a monitoring of their middle ear status. Next slide, please. Infants who do not pass a medical home global screen, which is recommended now by the American Academy of pediatrics or if an infant if there is any concern about that infant's hearing or language, the recommendation is that the referral be made for audiologic assessment and speech/language evaluation.

Next slide. The information that is all critical for following up infants is supported again by the JCIH position statement and states are encouraged to develop management tracking system and part of an integrated child information health system is important to develop in order that we may monitor the quality of any services and provide recommendations for improving systems of care. This issue of information infrastructure is really very much targeted at the notion of lost follow-up which the JCIH has emphasized in this position statement as being critical in our abilities to provide early hearing detection and intervention services to infants, as all of us know, there is our greatest problem right now is not our ability to screen in hospitals but in our ability to follow up infants once they leave. This position statement has a great deal of emphasis on that follow-up.

Next slide, please. A linkage between health and education is recommended to determine if outcomes of children with hearing loss of school age and information is needed for the planning and establishing of public health and education policy. So a real emphasis on the importance of why this linkage between health and education and the follow-up is so

critical to us as we plan our policies regarding children with hearing loss. Next slide, please. This is the JCIH website. I will encourage you all to go to that website to find the publication date for the document. As I said, it is in final peer review and will then be going to the respective organizations for approval by their boards. It is our hope that that position statement will be published in 2006 and so we look forward to it being published and for your comments on the new position statement. And we hope very much that it is very useful to you in your work. Thank you very much.

KARL WHITE: Judy has a flight to catch for another meeting and so rather than hold questions for Judy, Irene, I think we ought to give people an opportunity to ask questions now.

IRENE FORSMAN: I agree. Any questions from anybody?

PAT: This is Pat from Virginia. Judy, in the statement are the post natal infections and the syndromes and the degenerative disorders specified in this document?

JUDY GRAVEL: They are more completely than they appear on this slide and I think the important thing in this document is that every mention of a syndrome or a recommendation for follow-up, because of any particular syndrome, is supported by evidence and so there is a very comprehensive reference list that supports the reasons for picking those risk indicators for hearing loss.

PAT: Thank you, that's wonderful.

KARL WHITE: Just a comment from Karl White in Utah. I'm pleased to see the inclusion of the eligibility for Part C services and the emphasis on both home and center based intervention options for children with hearing loss. I'm hoping that will have some impact on what is happening out there in the field because right now the eligibility criteria from state to state vary significantly. So this is excellent.

JUDY GRAVEL: Good.

PAT: That will be a problem, though, in states that have adopted the natural environment position because that's what is recommended by OSEP and that is going to be a challenge. But I'm happy to see it as well.

JUDY GRAVEL: Good, thank you.

KARL WHITE: If no other questions should we move on to the other presenters, Irene?

IRENE FORSMAN: Let's do that.

KAREN ANDERSON: Hello, this is Karen Anderson from Florida and I've been involved with the Florida EHDI program for the last five to six years and I'm very pleased to be able to present Florida's journey to attain a system of quality pediatric hearing evaluation. It has

been quite a journey indeed. Hopefully everybody has gotten to the first slide and I'll ask we advance to the next slide. I was asked to present this to really tell you how we got to where we are now. And one of the questions we had to raise is how are we in Florida doing on accomplishing quality hearing evaluation in infants? That's the motivator for changing how we've been doing things in the past. And for one reason or another I won't go into we're finally able to download some data.

Go to the next slide. The data as of March 2006 is as you can see -- I've included some information on slides here, not so that I will go through it all in detail because I don't think that's really necessary for the concerns of this particular call, but as background information and just from talking with other EHDI people I think a lot of us are on the same kind of page in terms of how are we doing and how do we develop to the next step? I have more detail on the slides in some cases than I'm actually going to talk about. This data, as you can see on this slide, it really does indicate that we're not getting the reports from audiologists for the children with confirmed hearing loss and we need to have better control of which audiologists see these infants and consisting reporting of the results.

Next slide. Why is it important to the state to identify all infant audiologists? Well, we do need to have timely follow-up to accomplish a definitive diagnosis by three months of age. That's a high priority. In our state as probably all of yours, the parents, hospitals and physicians must know about which audiologists are most appropriate to follow up children being referred from universal newborn hearing screening and in our state, for all other disorders that are identified during newborn screening like the metabolic and genetic

screening there is a defined path referral and follow-up. There are centers that have been identified in our state to refer these newborn screening failure children to. The medical community, the physicians, expect to have some sort of a system for children who are also now being referred from universal newborn hearing screening. There is an accepted path for all of the other referrals and they expect that for the newborn screening as well. And we also do need to have a process for approval of audiologists that provide some credibility and this will also allow us easier tracking of diagnostic and reporting activities. So it really is important for us in Florida to identify all infant audiologists.

Next slide. One of the first things we looked at very carefully was developing audiology centers of expertise. The idea didn't work. One of the things in talking to Karl, he said tell us -- tell the people on the call why it didn't work. The idea we had, because Florida is a sizeable state, we wanted to identify at least 20 audiology centers of expertise across the state and route these referrals to them. But we ran into some problems that were not evident, like I said, the genetic and the other metabolic screen failures are routed in a certain path to diagnostic centers and that's established. Trying to do the same thing for hearing it wasn't going to work. We needed to have the audiology centers of expertise to take all the referrals and payment reimbursement was a real issue. It is a patchwork. And no place takes all of the different types of payers that are available to families. And we couldn't have a system that wouldn't be inclusive of all children. And you think well, you know, couldn't our Title V agency, children's medical services and the Part C program, couldn't they agree to take on these children and pay for the evaluations if there was no other payer? Well, they probably could have but in Florida they were not going to because

of funding issues, as you can imagine. And with only 20 centers in the state, even if it was 25, we couldn't expect parents to go to the center that took their payment plan. They might have to go, you know, two, three or more hours and as we all recognize, the more hoops we expect a parent to go through to get the diagnosis, the fewer number of parents are actually going to follow through to do that. And there was no money and there still is no money to establish sizeable contracts to support ACE centers willing to test everyone.

We didn't have the 100, 200, quarter million dollar contracts to be able to support each of these centers. We had a little bit of EHDI money we wrote into our last grant but it was hardly enough to pay for much of anything so we had to think creatively and do a little divergent thinking. How could we still attain the goal of identifying the infant audiologists and trying to get the children who fail the screening to them? The next step, the next critical step, was to identify all the audiologists come potent and willing to perform evaluations on infants. What we did is we worked, we meaning newborn screening in our state, and early intervention or early steps program worked with the children's medical services program, our Title V agency and we all happen to be under the same division within the Department of Health. We're all in the same floor and within calling distance so what is CMS network decided to do is accept audiologists and their first non-physician or physician extender category within the CMS network of services.

Next slide. How did we get there? Well, we have had an EHDI advisory committee since 2000 and one of the last things that they did before they were dissolved was the EHDI advisory committee defined the protocol for follow-ups. It was approved in June 2004.

Thus that document made it possible to describe what an infant audiologist does. And then we went and looked at what kind of enrollment forms are required by the CMS network for physicians and adapted them so they would be more applicable to audiologists. We needed to define an audiologist review committee. Six audiologists who would look at the applications and approve them by our deputy secretary of children's medical services and the Audiology Review Committee would meet monthly. This is all about to kick off. The letters to the audiologists with this information are due to go out either this -- well, they didn't go out this week, so next week. Next slide. I've just included information, a website for you if you wanted to see all the information on the CMS audiologist enrollment info for your information in case you're interested.

The next slide. Requirements for completing the CMS audiologist application. The next few slides are very detailed. I'll go over them. If you care about the detail you can go back and look at them at your leisure. We made requirements about minimum equipment and preferred equipment that we would like to audiologist to also have. Because we're a large state with a lot of rural areas, we're going to run into places that have audiologists that are willing to see infants but might not have all the equipment. They might not have a Tim Panometer. We put a caveat in there if they don't have all the equipment to still complete the application and then we'd look at those. We do have some grant money that can support some infrastructure. Not equipment per se but can support seeing if we can get them on board to be able to do this for us in all areas. Next slide. We also needed to have the basic information on the application about the license and the Medicaid status and resume and work history and such references.

Next slide. We thought it was important to have some caseload information. Now, there is no minimum caseload required. It's not like we're looking for people who only have 20% of their practice being with children under six months of age because there are probably three places in the state that have that. We thought it was important to get information about the caseloads of these people and so you can see this information here. Next slide. One of the things I'm pretty pleased with is a competency self-assessment. In being CMS network enrolled, there would be or there will be no site reviews as there would have been if we were able to get the ACE centers. The only way we can measure competency outside of seeing reports is to have people rate themselves. So this is the one to five rating scale that they're going to use. Next slide, please. And then they get to rate their competency for different services.

Next slide. And then they also -- that's it for the competency rating. We also wanted other information like the practice type and the sedation and reimbursement options even though this is a moving target. And some other necessary things like malpractice and disciplinary action history. Next slide. And then this all ends up in an agreement and attestation section that they must sign and in this section is where we have the real meat that defines what it is we want the infant audiologists in Florida to be doing when they receive a referral from universal newborn hearing screening. This is our protocol. I hope it agrees with the new protocols recommended by JCIH. I haven't had a chance to look at that document yet. Next slide. Here is more about the test protocol. Again, this is for your

information in case your state is looking at defining specific protocol and has not done so yet.

Next slide. Then we really needed to have requirements for time lines and reporting, recognizing that you can't control everything about getting a baby in a timely manner. We did need to have some definite time lines and reporting requirements and you can see them there. Next slide. More about time lines and reporting and follow up and completion of the test battery and faxing the confirmation of hearing status and such. We require in this state and have said very clearly it's the audiologist's responsibility to refer a child with confirmed hearing loss to our early steps program within two days of diagnosis. That means confirmation of hearing loss, that doesn't mean when you receive all the information you want on every threshold in both ears. Next slide. This also talks about amplification and trying to get that on within 30 calendar days whether it's a loaner or purchased application. We have a loan bank for infant Part C children.

Next slide. We thought it was important within this -- the application document even though we're really being very clear the protocol we want and the reporting time lines we want, that we needed to have in writing that there is going to be times when the test for protocol and reporting requirements need to be waived in the interest of the child or family in some situations. Next slide. So that's the application. And now I need to go across the state and do some recruiting so that audiologists recognize not only the benefits to the state and children and families but also to the audiologist and it is a recognition of their competence in infant audiology. They would be part of a recognized network of infant

audiologists and included on a state-sanctioned list representing an important part of the overall newborn screening tracking system. Something our medical providers expect us to have in place. Hopefully this will increase referrals and it will allow them to have a relationship to our helps providers, parents who follow up and make phone calls to families of the kids who are being referred from newborn screening. And with this link in place, the audiologists can notify our office that perhaps a child has skipped an appointment or is a no show and this will trigger that the helps person would make another call to that family and have a parent to parent support moment to try to encourage them to be sure they make that audiology appointment. It would also encourage a relationship with early steps and our relationship program does provide funding for amplification and such. We'll save comments and questions for later so thank you for allowing me to present on Florida's process.

IRENE FORSMAN: Let's move on now to Rich Harward from Utah.

RICH HARWARD: I guess I need to take the mute button off. One of the ideas that came out of the LEND meeting was the renewed interest in collaboration with other agencies. Utah the early intervention program that's responsible for follow-up with kids and families with hearing loss is the parent/infant program from the Utah school for the deaf. So armed with the appropriate data sharing agreements we compared our strategy database, a high track system and the parent infant program database to see how well we matched. Specifically are the kids identified from newborn screening making it onto the roles of the early intervention program. We looked at kids entered between 2003 and 2004 looking at

the top two boxes there were 135 kids identified with permanent hearing loss in the EHDI database and 30 kids that had an identified with permanent hearing loss so a difference of eight kids doesn't look so bad too far until you start to compare the two databases. 81 kids were matched between the two databases. 62 of the 143 kids on the parent-infant programs were not identified in the EHDI database as kids with hearing loss.

They had 54 kids diagnosed with permanent hearing loss that the parent-infant program didn't know about, either. A bit of a note of the 62 kids in the database unknown to EHDI, almost half of them, 29 were born out of state. Next slide. The remainder, the other 33 you can see here 14 passed the initial screening. Two passed the screening for one reason or another and were referred for diagnostics and passed that as well. Six kids failed the initial screening. 11 kids who failed the screening fell into abyss. Our assumption is that the 16 kids in the A and B group are either late onset or false negative screens. The six kids in the C group could be late onset or false negative diagnostics, possibly even neuropathy kids and the 11 kids that fell off the radar screen are part of an ongoing effort to develop better tracking systems.

Next slide. Back to the 29 kids who missed the initial screen the kids born out of state will continue to be tracking problems but some of the 29 may just have plain been missed.

We're currently working on a state data integration system that will link the EHDI database with other child health systems. When we can compare the EHDI data and birth certificate data, metabolic screening data we can pick up more kids we're losing. Next slide. Now we're back to the 54 kids who were identified as having permanent hearing loss in the

EHDI system but are unknown to the parent infant program. The parents of these kids may or may not have known about the parent/infant program. We're finding a significant numbers of kids aren't being referred to pip. Some chose to get referral privately or maybe the families aren't getting early intervention services at all. Whatever the reason, this has all the ear marks, no pun intended, of a real problem. A third of the kids identified by newborn screening may not be getting linked with the appropriate early intervention services.

Next slide. The next piece of this little project will be to talk to the families for the kids who weren't in the EHDI database, how did they get a diagnosis? For the kids in the EHDI database identified with hearing loss but not on the pip roles, were they told about the early intervention services from the state? We need to look at that. We need to look at factors that may have made follow-up easier and quicker for families and lastly we need to keep improving our ability to share information between agencies. We have another little project going that we're calling -- next slide. Birth certificate orders. Go to the next slide again. We're involved, one of the projects to find some of these lost follow-up kids is actually being funded by the AUCD. We're trying to identify kids who may become lost to follow-up in a different method.

Go to the next slide. I'll do this quickly. This project is an effort to link the birth certificate database with the EHDI database through our charm data integration program. In Utah when you apply for a birth certificate to get one. You actually have to apply here. When a family applies for a birth certificate either at the desk and the vital records office, by

Internet or mail, the all-over database, the birth certificate database will query through the EHDI database and find out if the kids are on the EHDI database, whether they've missed a screening or whether they're still in need of diagnostics. And then back through the charm system an alert will be sent to the birth certificate clerk that they can hand to the family and then will track what kind of activities are -- result in the best response from the families to get these kids back in for services. That's just a quick heads-up. I think we'll wait for questions later.

IRENE FORSMAN: Thank you very much, Rich. Let's move on to Paul Brueggeman from South Dakota. Paul.

PAUL BRUEGGEMAN: Hi, my name is Dr. Paul Brueggeman. I'm an assistant professor at the University of South Dakota in the Department of communication disorders here. I'm also the LEND audiology discipline head in South Dakota. I'm involved in several clinical training activities for LEND students. We're involved in two Native American -- we see kids birth to six years of age. Along with that clinic, the LEND student gets other opportunities to experience unique clinical activities such as fetal alcohol syndrome clinics, down syndrome clinics but that's really not going to be the scope of what I'll talk about today. Just to give you a little flavor of some of the things that our students are involved in here. I'm going to discuss with you today two projects that I'm currently working on with our LEND students in audiology that relate to newborn hearing testing and follow-up treatment. The first project I'm going to discuss with you is titled, enhancing parental education, the infusion of EHDI material into a system-wide childbirth course curriculum.

Judy mentioned the importance of information infrastructure in her presentation. I would say that this first topic I'm going to discuss is along those lines. As part of a comprehensive EHDI program in our state I find it necessary to not only put a program in place that is effective, but also to inform the parents of the necessity of newborn hearing screening and follow-up.

This is due to the fact that our statewide EHDI system is not a mandate or a law in our state and as such there is a voluntary basis on the part of the parent to consent to the testing. Now, it came to my attention in 2005 that the largest provider of healthcare services in our state did not include parent education materials regarding the purpose or importance of newborn hearing screening. As one of the goals from the last meeting held at the headquarters in 2005, I made it one of my goals to enhance the current EHDI program that is in place in our state. Because the current LEND student as well as myself at that time when I attended that meeting were busy working on other research and outreach projects, only preliminary work on this project has begun. Now,--

CADE MODERATOR: Whoever has their computer turned on, you need to turn your computer volume down.

PAUL BRUEGGEMAN: I was going to say there is a little reverberation. I don't want to hear myself twice here.

IRENE FORSMAN: It's why we said at the beginning of the call anyone on the call needs to mute their computer.

PAUL BRUEGGEMAN: Boy, this is interesting. I can still hear myself talking.

CADE MODERATOR: That's the 20 second delay.

PAUL BRUEGGEMAN: We'll see if someone can turn that off. Hopefully I won't begin stuttering on the call. But -- okay, I think we might have it off now. Our state's EHDI program does provide materials to parents but what I'm really hoping to do is serve as a conduit in disseminating this material to parents. The way that I found out that the largest healthcare system in our state doesn't provide this information to parents was because my wife and I attended these childbirth classes and no mention was made of the importance of newborn hearing screening, follow-up, no information was given regarding hearing speech milestones during the first year. So I felt that it was important to work with the director of parent education at this healthcare system to start to develop that into their curriculum. Because these courses that are put on are a set of six week courses where each week you meet for three hours for six weeks. So it's fairly comprehensive and it not only goes over what to expect when you're expecting but also what to expect during the delivery and at the hospital. They did cover other screening tests performed but there was no mention of the importance of hearing screening or that it was even available. I'm going to work with the director of parent education to try to infuse that material into the curriculum. So right now we are working with them on developing relevant materials.

Testing, the nature of hearing, the importance of newborn hearing screening, as well as distributing information on speech and hearing milestones that can serve as a reference for the parents down the road. So the current audiology LEND student I'm working with will be involved in putting this program in place with the director of parent education, so that's the first project I wanted to report on. And I would invite any comments later on today. Anyone that has done anything similar that has ran into roadblocks I would sure like your input. The second topic I would like to talk about that involves newborn hearing screening is this. In the last year, myself and the LEND audiology student from last year -- I can still hear myself as an echo. Someone needs to turn off their computer. Audio there. We worked on a research project that is titled the specific noise event contributors in a level three. This is a two-year research project that has been started about 11 months ago. What is occurring is in this hospital which is the largest hospital in our state, they're transitioning from a standard style environment to a family suite style.

Other hospitals, mercy medical center in St. Louis has adopted this style. I've worked with the chief of neonatology, the director of LEND in our state working with him trying to develop a research protocol to determine the contributors to the noise levels in the current, and in the new family suite-style NICU. We have the data collected from the old NICU environment and we're currently running statistics on that. My goal for the next year, this next year is to repeat those measures in the new family style NICU and look at the contributions from different noise sources in that environment as well. The way this research was conducted was to give you just a snapshot off it. The LEND audiology

student was sitting in the NICU while taking similar recordings in the bassinet and sound level recordings of the environment and at the same time making her own subjective comments as to where the noise sources were coming from. Was it coming from the staff, was it an alarm, was it a door slamming, was it someone bumping up against the bassinet and the real reason for doing this was the lack of data out there as to what are the specific contributors to noise in an environment like this. The connection with our meeting today is really this.

Due to the known connection between NICU noise exposure and physiologic changes in neonates it was deemed important to document the noise contributors in the existing NICU first. This portion of the study has been performed throughout the past year as part of the audiology LEND student's research project. The data collection in that new environment will begin this fall. We're hoping to compare the newborn hearing screening pass/fail rates of the children in these two NICU environments as well. After all the data is collected and we have ran the statistics on it, we're looking to publish this as well. That is really what I have to report on. Those are the two main topics I've been working on relating to newborn hearing screening and parent education.

IRENE FORSMAN: Thank you very much, Paul. Let's move on to Diane Sabo from Pennsylvania. Diane.

DIANE SABO: Hi, everybody. I'm Diane Sabo from Children's Hospital in Pittsburgh. I'm part of the LEND that is located in Pittsburgh but I'm also going to be reporting a little bit

about the LEND that is also in Philadelphia. We kind of looked at this a little bit differently in that we thought about some of the major goals that are faced in our LEND program. What I did was kind of break down then my report into two slides. One is going to emphasize some of the benefits that I think collaboration to the state, some of the benefits to the state that the collaboration between LEND and EHDI. And then also look at some of the benefits to the trainees. If we go to the first slide. We look at the benefits to the state. There are some such as adding resources to collaboration, innovation and awareness. One of the things the meeting that we attended helped to do but also to help in general was to enlighten more people about what we need to do. The two things in Pennsylvania that we struggle with are loss of follow up and shortage of qualified audiologists. It's not unique to Pennsylvania and we realize that. It might be a good opportunity to use our resources differently.

Children's Hospital in Philadelphia went home after that meeting and what they actually did was applied for a grant to try to address the need for loss to follow-up. What they wanted to do is try to get more into the communities to set up programs where they would actually network with the hospitals and they're still working on this plan and hope to be able to have this plan come into fruition in the next year. So I think it was a really large leap because Philadelphia actually encompasses quite a few -- more than half of the births in our state. So that would be a great way to address our loss to follow-up.

Collaboration again is something that I think we've been able to draw more on with used our LEND trainees to help with a parent brochure so they've been able to get involved a little bit on the state level with putting together information for parents. It's allowed us to

look at a wider network from which we can draw expertise. One of this then falls under innovation as one of the LEND leaders that we have in the state, Heidi, is in Pittsburgh. What we looked at there was looking at the loss to follow-up.

One of the things that she was able to do to help arrange and also to create is that we came up with a web-based program for physicians for training. Now, all along we have been training positions by doing grand rounds throughout the state. The biggest impact comes whenever you have a child who has been identified with a hearing loss and so often that's when more questions arise about what do I do with management, how do I go about taking care of this child? So we have a web-based program that's geared toward physicians and other healthcare providers who have children who have been recently diagnosed with a hearing loss. And they are notified about the web-based program. It is there for CMEs and they can go in and out of the program taking different steps. So it covers background information on hearing and hearing loss, about the screening process, but what we also did was try to help them to understand management. We came up with some case scenarios as a way to help them understand case management. It is interactive, it's question and answer. They are posed different questions and they have to answer them. And some of the cases have to do with what do you do with children who have persistent middle ear fluid and continually not pass their hearing screening? Which is always of concern because some of these children cycle out there for quite a while before they get the proper care.

We address children with unilateral minimal hearing losses and we address the last case has to do with the bilateral severe loss who might be a cochlear implant candidate. How do they go about and what information needs to be provided to families? This was a really innovative way for us to use the LEND expertise and the resources they had available as a way to really get the word out to those physicians and other healthcare providers who are taking care of the children. What it has done, I think, is allowed us to really get out because LENDs are multidisciplinary, to reach out to a much broader audience than we might have been able to. We have been able to use the medical school personnel, we've been able to use residents to really look at the web-based training and we can use that training -- we used it originally to get feedback from them but we're using them as a way of educating them about newborn hearing screening and especially in Pennsylvania. Trying to think if there is anything else.

I think I'll go on to the next screen then or the next slide which is really talking a little bit about some of the benefits to the trainees. Some of the benefits then are the awareness that I think we have been able to infuse into the trainees and these trainees are not only within the discipline of audiology but also because the LEND programs are multidisciplinary we're able to reach out to many other disciplines and make sure they have a better understanding about screening and the screening process and the follow-up that's needed. What we've been able to do is infuse into many aspects we do formal presentations about EHDI programs in Pennsylvania as part of the curriculum. Another thing we do as part of the LEND clinic is we also have made awareness to the point that most of the disciplines are anxious to ask about whether or not hearing screenings were

conducted and what the results were so it's been able -- they have been able to put into practice not only some of the things they've heard, and I think it's engraining into their system that children need to be screened at birth.

Collaboration has also been very good and we've been able to allow, as we talked about already, about the collaboration with having the LEND trainee being able to participate in collaborating with parent brochures. We've also had some interest in other projects. While so far we have not been able to get them fully underway, the encouraging part is that students are much more willing to think of ideas that are directly related to hearing, hearing screening and follow up. We've been able to put into our courses as well, as part of the awareness, then, some things that are directly related to hearing screening. The genetics course we've added into our curriculum so the students have a better feel for some of the issues that we're finding related to children with hearing loss. Many of them also have other issues. Not just have hearing loss. We've also been starting to develop, as part of our training for students in audiology, not only do we do a formal lecture in their pediatric place but we're also developing cases here that are looking at early identification to have the child fully evaluated and some discussion about management of hearing loss, which often comes up, about how much hearing loss do you need in order to fit a hearing aid and at what age.

Not only the critical age of six months but also real practical issues about very tiny infants and their ability to wear hearing aids effectively and counseling families. One of the biggest issues we've discussed has to do around getting the word to families in a way that

they can really understand what is going on. So we've allowed trainees as well to get more working experience with the advisory committee and all in all I'd say that both the state then and the trainees have been able to benefit from this collaboration and while we've made some progress, I think we still have a ways to go to work together to be a little more cohesive in using the resources we have available in Pennsylvania. That's it.

IRENE FORSMAN: Thanks very much, Diane. Can we move now to our last speaker, Jack Roush from North Carolina.

JACK ROUSH: There are no slides for my presentation. I'm an audiologist and for the past ten years been the director of the speech and hearing sciences at the Chapel Hill School of Medicine. We have a large medical center here that sees many of the children referred from screening programs in the state. We also have a longstanding LEND program which I've been involved with here in Chapel Hill since 1988. I have four items to share, all related mainly to involving LEND trainees in the EHDI program activities here. And designed hopefully to provide some leadership training opportunities for these students. One which illustrates a specific EHDI-related LEND project which I'll elaborate on more and then three others which I'll summarize briefly so we can stay on schedule here. I attended the meeting, along with many of you, in Washington last summer with our LEND trainee, her name is SHANA. She's not on the call but I will describe what she did and what she's doing. And she's an AOD student, second year student in our program and we both left that meeting last summer feeling very positive about the possibilities for E panneding EHDI-related activities within our LEND program. And we wanted to design a

project that drew on her interests in infant screening and we came up with a project that is relevant to one of the key points that Judy Gravel addressed in her remarks about the 2006 JCIH position statement which is now in peer review. It should be published in the next few months. That is, the issue of screening technology used in the neonatal intensive care unit, specifically the use of OAEs and we also asked the respondents to estimate the number of infants identified with neural forms of hearing impairment.

We designed the survey that SHANA adapted to one of the web-based survey instruments. And with Karl White's assistance, distributed it to all the stated EHDI coordinators. Thank you for responding and for providing additional comments that were really quite useful and interesting and I won't go into detail on the findings since this meeting is really more about the LEND program and the trainees, but you'll not be surprised to hear that there are a substantial number of NICUs that are using auto acoustic emissions at this point. There are a substantial number of states that aren't sure about that. There is really quite a bit of variability in state's ability to report some of these things, particularly with regard to tracking sensory versus neural hearing impairment and some challenges in the diagnostic process. It is also an issue of getting proper diagnostic evaluation. But in any event the LEND trainee had a great learning experience reviewing the literature, obtaining the data, reading the comments of the state EHDI coordinators. She presented the findings at the national EHDI conference in Washington. She did a superb job and a real confident-building experience and attending that meeting was also a very positive and good learning experience for both of us. And by the way, that report back in February was based on responses from 25 states and since then we've added

about 24 -- I don't know, we're not quite up to all 50 but very close. And again we appreciate the responses.

SHANA will be the lead author in a manuscript now in preparation co-authored by Karl White and me. That was the first item just to illustrate a specific example of involving a LEND trainee in an EHDI-related project helping her prepare it for submission, presentation and eventually seeing it through to submission and acceptance for publication in a peer review journal. The other three items that I'll comment briefly on, first is we're in the first year of a newly-funded Department of education OSEP grant to prepare infant specialists in audiology and we have -- part of our application described a plan to involve these training grant students in the LEND program. Usually we think about expanding opportunities for the LEND trainee but in this case it was aimed at taking the LEND experience to a larger number of students interested in pediatric audiology. So again without getting into detail I'll just say that each of the training grant students has sort of like a mini LEND experience where they participate in certainly the clinical services, but also in staffings, grand rounds and other activities associated with our LEND program. I think that's really allowed us to extend that experience to a larger number of students who have an identified interest in working and are willing to make a commitment to the federal government that they will work in pediatric audiology. That's why I think the leadership education is so important here.

The third one involves involving the LEND trainees in the state EHDI advisory group. Diane is already doing this and other states are, too. I think it's really valuable. The

audiology students get a lot of audiology but it's an opportunity for those who have special interests and leadership potential in this area to get exposure to the politics, the legal issues, hear other stakeholder groups including parents who in our group are quite outspoken. That's a relatively easy thing to do in most states. Then finally, this was an idea that we came away from the meeting last summer with and that is converting our LEND trainee slot to a fourth year AUD externship and just briefly we have some folks on the call who are not in universities but are state EHDI coordinators. The AUD students spend their last year in an externship placement. I was talking to Len ore and a couple other university representatives doing this or had it in the planning process and I hadn't thought about that. It obviously means adding more to the LEND -- it means everything we would normally do in the LEND training slot plus some other things that we were able to supplement. We aren't doing that this year. This will be our last year in using that as a more traditional externship placement. Beginning next year it will become a fourth year externship experience that I think will be quite valuable to the students. That is my summary.

IRENE FORSMAN: Thanks very much, Jack. I think that we're going to -- we ought to open it up for other individuals on the call who would like to ask a question, make a comment, indicate what it is they're doing in their states and so -- before I do that, I'm going to take the prerogative of asking the first question. Jack, tell me a little bit more about these externships? Are these people supported for them?

JACK ROUSH: This is not like a CFY, Irene, clinical fellowship year, because they're still students. Now, I anticipate that these fourth their externs will be Chapel Hill students. If there wasn't a taker we would invite other audiologists from universities doing this sort of thing to chime in here. Our plan is these are full-time externship experiences for students who have not yet gotten their degree but have finished their course work.

IRENE FORSMAN: We'll have to have some more conversation about that. Now I want to open it up to the wider audience.

HALLY: This is Hally in California. My questions for Karen in Florida. I was quite intrigued by your putting out a call for audiologists who want to -- I'm interested in a couple of things. Number one, what your response rate was for that and number two, you don't require that they see Medicaid patients but they have to see all the patients that come from your program, a significant number I'm sure would be Medicaid. Were there any issues about reimbursement through Medicaid. That has been a huge issue in California.

KAREN ANDERSON: Good question. First, our response has been nothing so far to this because the letters are just going out to audiologists next week letting them know far and wide. We have about 800 some audiologists in our state. This will be the first HOORAH about what the enrollment process is and encouraging them to sign up. We're expecting somewhere between 70 and 130 folks will step up to the plate. That's our estimation of how many pediatric audiologists we have that see at least some babies. In terms of the Medicaid issue, we recognized from our discussions with audiologists when we were

exploring the audiology centers of expertise there are audiologists that don't take Medicaid and not interested in doing that and yet they do see a lot of babies. So we needed to be able to have them be in our network of enrolled CMS audiologists but because they're CMS audiologists they do need to take CMS patients and how I imagine this will play out will be on a one by one basis. Because CMS does not take kids that are referred directly from newborn screening, I don't think there is going to be very frequent times where the referral is going to be coming from CMS to have the child screened, rescreened or diagnosis done. So I don't think we'll be having a lot of situations where this occur and we'll have to figure it out.

HALLY: I'd be very interested to know how this works out for you.

KAREN ANDERSON: Me, too.

HALLY: Good luck.

KAREN ANDERSON: Thank you.

IRENE FORSMAN: More questions? Comments?

VICKIE THOMPSON: Hi, this is Vickie Thompson in Colorado. I have a question for Karen.

KAREN ANDERSON: Hi, Vickie.

VICKIE THOMPSON: Hi. We did something similar but not to the degree that you did several years ago. We created a list based on a survey we sent out to all the audiologists asking them if they wanted to be on a list based on their equipment and expertise. And then we also required them to participate in several videoconferences and what we found is that despite that, there were audiologists on this list who still weren't using the appropriate protocol and misdiagnosing with the threat of being sued by a parent. And that concerned us in terms of our liability here at the health department even though we had a disclaimer on the list saying that we're not certifying these audiologists, they're stating they have the expertise. Did you have any concerns about that when you think about publishing this list?

KAREN ANDERSON: We started out with a list as well. I did a survey in 2001 and we've been working off that list of pediatric audiologists knowing full well that some of them should not be seeing young infants. And the thing about going through the process where we enroll them through CMS is that we have that Audiology Review Committee that will look at the applications and make some decisions about whether they think that the person is qualified. And then it is going to be up to Dr. CHIARO, our deputy secretary of CMS, to approve them. It is not a credential, per se, but they're approved and he can't be sued so that's why he gets to do that. And then it's just going to be a matter of if they're on the CMS enrolled audiologist list and we have a signed application stating they're agreeing

to do these procedures, that if they do not follow through, they'll be very -- they're going to be the ones that are liable.

IRENE FORSMAN: Okay, great. We just might adopt your plan. It sounds great.

KAREN ANDERSON: Thank you. We'll see how well it works.

IRENE FORSMAN: Okay.

IRENE FORSMAN: More questions?

ANNE MURRAY: This is Anne Murray in Nashville. I had a question for Diane. I was wondering -- I'm intrigued, really, about the web-based system that you developed and I'm wondering, is that shareable?

DIANE SABO: I can find out for you.

ANNE MURRAY: Okay.

DIANE SABO: Right now they had talked about it. One of the concerns they had is that we did tailor it to Pennsylvania so it would need tweaking. But I can find out how -- you know, I can find out for you, okay?

ANNE MURRAY: That tweaking might be a good project for our LEND trainees, actually.

DIANE SABO: Right.

ANNE MURRAY: Great. Thank you Diane.

DIANE SABO: I'll get back to you.

BARB: This is Barb from Iowa. I'm filling in. The question also relates to the one that was just asked to Diane. If you get the information to her I would be most interested in it also.

DIANE SABO: Okay. Do you have any statistics as to how many folks actually have taken advantage of that?

BARB: That's our next step right now is that we're looking to see how is it being implemented? Is it being implemented the way we want it to be? We're going to do a quality look at everything we've done so far.

DIANE SABO: Thank you.

DIANE SABO: Uh-huh.

KARL WHITE: This is Karl White in Utah. Diane, did you look at or were you aware of the work that the American Academy of pediatrics has done on their module?

DIANE SABO: Yes. That was one of the reasons why we did this. That's a module -- their module is packed full of information and one of the things that was a concern was the amount of time that it would take to really address some of the concerns that we had and some of the things we really wanted to see emphasized. And so our chapter champion really was behind helping to develop this because he had some concerns about whether or not that module would really be utilized in the best way. So he felt tailoring something truly -- also the expense. We wanted -- there was at the time we did this there was more expense incurred through the pediatric module where we're doing it through a grant and for free so the physicians could get their CMEs. That they wouldn't have to have any expense incurred.

KARL WHITE: That sounds excellence. If you do find that it is shareable and would like us to help in sharing it with beyond Andrea in Tennessee we would be happy to do that. I think it sounds like a great idea.

DIANE SABO: I will let you know.

IRENE FORSMAN: Are there any other questions? Comments?

KARL WHITE: Irene, this is Karl in Utah. I have a question, first a comment and then a question for Rich Harward. What a wonderful resource the LEND programs are to the state EHDI programs and listening to some of the activities from these five states and I'm sure there are many other activities and would encourage anyone else on the call to speak up about some of the things you've been doing. As I listened to the reports in these particular states of some of what you've been doing, it's impressive of how central these activities are to what we all recognize as some of the main challenges with the EHDI program from developing networks to reducing loss to follow up to parent education to specific research projects to physician education. If we were to go through and prioritize the lists of issues we ought to be working on, these would be at the very top of them so I think we need to continue to emphasize to the state EHDI coordinators what a resource the LEND programs are and how to facilitate those sorts of collaborations. With respect to your project, Rich, the implications are that loss to follow-up is a significant issue, that are rates in your state to loss to follow-up are not as serious as we had thought previously that about probably 1/4 of the kids that we thought were lost to follow up are really found. They just aren't being reported to the state EHDI database. Is that the way you interpret it? What ideas do you have to continue to capitalize on that?

RICH HARWARD: That is one of the interpretations that can be taken from that, Karl. We're just not good at sharing information so the big take-home message for me at that point reviewing this information is that we just need to get better at being able to share information. One of the issues that we have in Utah and it may be a national issue as well, is that we tend to live with each program, we tend to live in silos. So the immunization

people live in their own silo and the heel stick and the EHDI folks all live in their own silo and if we can begin to figure out better ways and legal ways with the regulations to share information, then some of these kids that we're thinking are lost to follow-up may not be lost to follow-up, we just don't have access to the information. So as we continue to link programs together and talk to families about how they got into the system we'll be able to answer more of those questions.

IRENE FORSMAN: Rich, I want to respond to your HIPAA comment. We are negotiating a contract right now to have somebody look at those issues and look at how we might break down some of those barriers. And the people that are looking at this are luminaries in the world of disability law and information sharing. So I'm really looking forward to some not only thorough analysis, but some very sound recommendations.

RICH HARWARD: That would be helpful for a lot of programs. Because I think the thing that scares people the most when you start talking about sharing data is whether they'll have to go to jail or not for sharing information. We've had to be very specific and have legal review of specific data sharing agreements, have everybody sign off on what pieces of data can be shared. And it's been -- it's been a huge hurdle.

IRENE FORSMAN: Yeah, well—

RICH HARWARD: Any help you can give us will be appreciated.

IRENE FORSMAN: This is a six-month contract so we'll have the information fairly quickly. Are there any other comments? Questions?

CRYSTAL: Irene, this is Crystal from AUCD and I just had a comment. First of all, Irene and MCMB I wanted to thank you for the opportunity to continue the sharing and learning about all these other programs as well as thank Karl for the agenda. And also for drumming up the energy for getting everybody together. It is really amazing to hear like Karl said one year later the activities that are going on and the outcomes from the one conference that we had last year. This has proven to be a very, very strong discipline and group of people in continuing those activities and I hope that this -- that it does continue over the coming years. It's been great to hear about LEND programs are working with the state not only to improve systems for kids and for families, but also to expand those into leadership opportunities for trainees. I think that can only be a wonderful thing for the future of audiology and children and families is to have these trainees get started early and work on the big picture. I also just want to encourage everybody who has both spoken on the call about some of your activities and the folks who maybe have not that -- to share your ideas and your activities via the AUCD network to others not only to audiologists that weren't on the call but other training directors. I think it can spawn great ideas in other locations. Contact me if you're interested in doing that. We have a number of publications and listservs on our website but also the upcoming conference at the end of October for poster sessions and concurrent sessions to share some of your things with the network. Thank you and congratulations to all of you. This is great.

IRENE FORSMAN: Thanks, Crystal. I can only add my thanks. I have to say that I'm really not surprised at the level of activity because I've known and worked with the UAP program for a number of years and the LEND programs for a number of years and I know the quality of the people and of their work. But I am delighted with the presentations today and I'm sure that there are probably a dozen more like them that we didn't get to hear. So in closing, I would like to thank AUCD for its part in helping us and our partners down the hall in the Bureau who oversee the training program. I would like to thank all the speakers for their excellent presentations. The audience for their participation. And finally, Steve Hitchcock and Nate Shreve at the University of Illinois for their considerable technical support. Karl, do you want to add anything?

KARL WHITE: No, just amen to what you said. I think this has been great and I look forward to hearing more good things coming out of the LEND network.

IRENE FORSMAN: We have not done away.

KARL WHITE: It's a great resource.

IRENE FORSMAN: Thank you and goodbye.