

Centers for Disease Control and Prevention EARLY HEARING DETECTION AND INTERVENTION Ad Hoc Group - Teleconference Agenda

Agenda for May 2001

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LEE ANN RAMSEY: Hi. This is Lee Ann Ramsey at the Centers for Disease Control and Prevention. Also here is Dr. June Holstrum and Marcus Gaffney. I would like to welcome you to our conference call on Early Hearing Detection and Intervention, and thank you for joining us. We have a special program today in light of the observance of Deaf Awareness Month. Before we begin our scheduled program, are there any announcements or comments from our listeners? (NO RESPONSE)

Okay. We have a couple of announcements here. As you may have read in the newspaper or seen on our web site, we are now under a new center here at CDC. As of April 12th, we are no longer with the National Center for Environmental Health. We

are now under the National Center on Birth Defects and Developmental Disabilities. So when you visit our web site, keep that in mind. And also, our Requests for Proposals is out in the Federal Register now, and -- If I can remind you to mute your phone, that would be helpful. The letters of intent for the RFP's are due May 11th and the proposals are due to CDC by June 22nd. On our agenda today, we have Judy Niemeyer from the

Center for Early Intervention Professionals in Hearing Impairment. We have some parents with us today from the Atlanta Area School for the Deaf who are going to share their experiences with us on getting their children into early intervention programs, receiving cochlear implants, things of that nature. We also have Dr. Lillian Blakesly from the Atlanta Area School for the Deaf to share with us her insight on using sensitive terminology when communicating with the deaf and hard-of-hearing worlds. And we also have Dr. Susan Easterbrook from Georgia State University who is an educator for deaf and hard-of-hearing.

So we would like to begin with Ed Shroyer.

EDGAR SHROYER: Hello, everybody. Ed Shroyer.

First of all, we're very excited about getting this five-year grant and we've been very busy, much busier than we anticipated certainly, but we're excited about it and we want to share some of our excitement with you.

One of the goals is to basically develop, field-test, and disseminate preservice, and then provide preservice training program modules and materials for professionals working in the area of early intervention for infants and toddlers who are deaf and hard of hearing and their families. We would like to accomplish this through six objectives that we have.

One is to partner with agencies and organizations and training institutions in order to identify the process and general components for the training program. And in this, we're including part C lead agencies, medical communities, parents training and information centers, and community parent resources centers. We're basically including a large number of professionals and nonprofessionals in the ongoing activities of the Center.

The second objective we have is to develop a program study that focuses on the acquisition of professional competencies and skills in the area of developmental, communication, conceptual, cultural, medical, and technological needs of infants that we'll be working with.

Three is to utilize the multiple sources of expertise and input, Judy will be talking about that in a little bit to give you more detail as to what we mean by utilizing experts in the field.

Number four is to develop, field-test, and disseminate information, --well, actually training modules is what we're hoping to develop, that we can put on the internet and share with preservice professionals.

Number five, again, is basically evaluation of the Center's

performance.

longer surveys.

Number six we hope that we'll be able to establish an ongoing Center after the five-year federal project is over.

JUDY NIEMEYER: One of our first goals or activities is to do a needs assessment to find out really what types of things are currently available, what kinds of training programs, what kinds of materials, what kinds of competencies. So we have developed a systematic way of trying to do this needs assessment. We're going to do that by sending out surveys. We've actually already sent out surveys, and some of you who are at institutions of higher ed may have already received these surveys, a very short survey. That we've sent them to over 500 institutions of higher ed who have training programs in either early intervention or in education of deaf children to find out if they offer any type of training currently in the area of infants and toddlers are deaf and hard-of-hearing.

If these institutions sent the survey back saying yes, they did, they are the lucky ones to get a little longer survey to provide us some additional information about what their training program is like, what types of information they already have and what kind of information they need. We are in the process of getting those surveys back. I think we've already sent out about 12 additional

We are also surveying Part C coordinators and those went out this week. 59 surveys went to Part C coordinators asking them to give us some information about the kinds of training needs they have in their state. Then we are also going to be sending a survey to parents and service providers. Those surveys are almost ready to. We're going to be asking parents and service providers to give us feedback on what they feel the training needs are for professionals working with children or infants and toddlers who are deaf and hard-of-hearing.

In addition to that, we're also going to do a short interview of Part C coordinators after we receive their survey to fill in some of the blanks and to give us some more detailed information about the kinds of training/opportunities in their state. Then we're also going to conduct six focus groups of parents and six focus groups with service providers to give us more in-depth information again about the types of training needs they see for professionals working with infants and toddlers who are deaf and hard-of-hearing.

Ed is going to talk about one of our important meetings coming up on June 8th.

EDGAR SHROYER: On June the 8th, we're bringing in approximately 23 people across the United States whom we have identified as people who are heavily in infant and toddler intervention. We're bringing in individuals who have expertise with deaf and hard-of-hearing children, expertise in early intervention, and parents of children with special needs in October. So we have a very eclectic group we're bringing in. We're meeting with Experts at Highland Lake Conference Center which is just south of Asheville. I'm sorry. I'm jumping several months ahead. We're actually meeting here in Greensboro near the airport for the Partners' meeting on June the 8th. And at that meeting, we are going to have those individuals identify competencies in the area of infants and toddlers with hearing impairment. We're going to be talking about what goals or activities that we should be involved in, and we're also using the partners as an advisory board who will be working with us through the five years of the project. So we're excited about having all these people from across the country coming in on June the 8th.

JUDY NIEMEYER: The meeting that Ed started to talk about, the Experts' meeting, which we're also very excited about, is going to take place in October. And one of the things that we're going to ask our partners to do in June is to help us identify people

that they feel are experts in the field that we can bring together in October. At the October meeting the Experts will identify the competencies need for professionals working with infants and toddlers who are deaf and hard of hearing and their families. It is important to note that we will be identifying competencies in all of the different communication modes to make sure that we are meeting the needs of all families and children.

DEBBIE SHAPIRO: This is Debbie Shapiro in Honolulu, and I'm wondering if the training materials are designed for training staff or training parents, or both, that you're going to be developing?

JUDY NIEMEYER: That's a very good question. Our original intent is for training staff, but our -- we also hope to provide some materials that are for training parents. Our major focus is on training staff.

DEBBIE SHAPIRO: Thank you.

JUDY NIEMEYER: You're welcome.

UNIDENTIFIED SPEAKER: I'm not going to say who I am

because then you'll know who is kind of ignorant.

I don't even know where you're based out of and I'd

like to ask Lee Ann if there's some way we can get that information posted (inaudible) to contact you to find out -- contacted in our state. Our Part C coordinator may or may not be -- know what's going on.

UNIDENTIFIED SPEAKER: Okay. Just bottom line,

Lee Ann, can you give us the main contact people, you know, phone numbers or e-mails, because I need to contact you to find out who you're involving from our state, if you are at all, because I'm not so sure that person really knows what's going on.

LEE ANN RAMSEY: Sure, we can get you that information.

Do you -- You can -- We'll have it in the minutes, but also you can call me after this conference call at -- or you can call Judy.

JUDY NIEMEYER: Okay gthe number is area code 336/256-0524. I

can e-mail that information to Lee Ann and she can send that out either in the minutes or over the web site. I'm not sure how she'll do that. But we welcome any involvement and we welcome people who are interested. We really want people involved.

LEE ANN RAMSEY: Thanks. Also, you can -- you can call

me afterwards and I'll get you any kind of information that would be helpful. My number is 770/488-4909. Before we move on, Judy, I have a quick question. You may or may not be able to answer this. This is -- My brother has been deaf since he was three months old, and I'm wondering if -- even though you're just getting started, if you're seeing a shift in the type of sign language that parents who are using sign language as part of their early intervention strategy -- is it shifting from American Sign Language to signing exact English, or are you seeing -- are you seeing any of that shift in types of sign language that parents are choosing to use, or is that something that your program has looked into?

JUDY NIEMEYER: I'm going to be honest. My area of expertise is what I consider early intervention. So I'm going to defer to Ed Shroyer with that question.

EDGAR SHROYER: That's a good question. I wish I had an answer for you. At one time -- I'm not

sure that the movement is as strong as it was -- there was a very strong shift towards ASL. We're actually finding in public schools that the emphasis is still on mainly coded English. There are some students, older students who are using ASL, but they're certainly the minority. The overall goal of the project is just to provide materials and information and develop the modules. We're really not -- We're trying to keep out of the communication mode controversy. What we're trying to do is basically develop the materials in a way that they will be adaptable to any particular mode that people want to use at that time.

LEE ANN RAMSEY: Thank you very much -- for joining us. Next, we would like to have Peggy Woodall, whose child is at the Atlanta Area School for the Deaf. She's had quite an experience with early intervention for her child.

PEGGY WOODALL: I would love to tell it and do as many times as I can. Thank you for the opportunity to participate today.

Abigail is our second child. She was born in August of 1988. Normal birth. Had her first ear infection probably before she

was eight weeks old. On and off antibiotics for infections. We

noticed that her babbling sort of fell off around 10 or 11 months and had really questioned in that time period if she was hearing us or not. We did talk about it with our family doctor. He was not alarmed. She was -- It was really hard to tell for sure what was going on.My husband tested the smoke detector after changing the battery less than 10 feet behind Abigail, and when she didn't startle, we felt like that was a definitive test from a parent's standpoint. At her one-year checkup, we did receive a referral to an audiologist for an ABR. That did show that she did, indeed, have some hearing loss and they were ready at that point to say that it appeared to be mostly related to the fluid build-up. So we were referred to Emory and had tubes and also had a CT scan at that time to make sure that all parts were there. Two weeks after that -- This would have been late January of '89 -- she had her second ABR, and we had had a drop in hearing loss of maybe five to 10 degrees, or DB's. The sad thing was that it was at that point that we were told that our child had a severe to profound hearing loss and were verbally given the name of Georgia PINES, which is our early intervention program, or the Atlanta Speech

School, to contact them to find out some information. So we were sent away from Emory with a diagnosis with not a piece of paper in our hand or anything to help us understand what was going on with our child. We were also at that point about a month away from the birth of our last child. So when I made the phone calls and found out that Georgia PINES came into the home versus driving to Atlanta, probably about 35 miles, on a daily or weekly basis for the Atlanta Speech School, it helped us to lean toward Georgia PINES a little bit. Abby was fitted with her first hearing aid and we started seeing the audiologist at the Atlanta Area School for the Deaf, and we were assigned to a parent advisor from the Georgia PINES program. So at that point, our advisor came in twice a month and we were able to learn at our own pace using the Sky High materials, and as we finished a unit, they were sort of left with us to study and read

and to understand and just make a list of the questions that we had and to take care of absorbing all we could in the time frame that we were given.

We were shown things that we could do in our family and

in our home and in the community that would help Abigail be constantly exposed to language and opportunities to recognize the sounds that were around her. I think probably the thing that was most important that I heard in the Center for Early Intervention Professionals was the statement that all modes of communication would be presented and that they were going to try to stay out of the controversy on modes, and that is a biggie because that's -- as a parent, I feel strongly about parent choice, but I also feel very strongly about parent education.

And a parent that is not educated in what those choices mean for their child really doesn't have a choice. They pick what they know the most about or what they're most comfortable with and might not know everything about all the choices that are there are them. We were presented with all the modes and pretty much decided to go with total communication. At Christmas of that year, Abigail attended a Christmas pageant at a Baptist church in Atlanta and it was really the first time

she had really paid attention to and enjoyed anything that was happening outside of her little circle, and that's because it was interpreted for the deaf. It was shadow interpreted. We really understood at that point that visual communication was going to be the way to communicate with Abigail, for her to be able to give us

information that way. I think that many parents of deaf children, when they see the film "Mr. Holland's Opus," they -- we've all had our moment standing in the kitchen with a child pointing at the cabinet grunting and us having the frustration of not knowing what they wanted, and sign language was able to give us that. We found out through sign language classes through that church and through the Atlanta Area School for the Deaf -- this was just before -- well, this was in the spring before Abby was to turn three, we knew that we would be entering the education system at that point. So she was in child care with the teacher for the three-year-old class at Atlanta Area School while we were in our sign languages and they just hit it off together. We also visited the Fulton County option, which was a multi-categorical

classroom with limited use of sign language and few language models. We knew that ASE was going to be the right place for Abigail because there were four or five three-year-olds in that classroom and it was a language-rich, both visually and verbally, environment. So a week before her third birthday, we were able to put Abby on a school bus in a car seat at 6:30 in the morning going to school. We've always had an excellent connection between the Georgia PINES program, which is housed at the Atlanta Area School, and the teachers that we were transferred to once we were out of early intervention. Abigail now, she's almost 13 years old. She's working in a middle school class on a fifth-grade Quality Core Curriculum level, which is the same grade as her sister who is 17 months younger. She's doing very well in there. She has probably 30 peers, middle-school-age peers, in the group that she works with. There are six children in her class that are all pretty much on the same language level and they work together pretty much through those QCC classes.

She's a very outspoken, passionate young lady. Three or four years ago, we -- we were not concerned with whether or not Abby was going to be able to speak. We just wanted to make sure that we could communicate with her. But then three or four years ago, her speech really started to improve. And as a result, we've upped her speech therapy to four days a week now. Before, she was talkative, but it wasn't necessarily understandable. Now she's well understood and the problem is we can't shut her up. She's a delight to be around and I think that she is who she is because she's deaf. We wouldn't change that. It has added a rich dimension to our family, and I think that part of the reason that we've gotten to that point is that we had good early intervention with a good family advisor that came in. They say parent advisor, but it's a family thing. The more of the family that's involved in the early intervention, then the greater the opportunities for success are. I hope that's given you some of what you wanted on early intervention from our personal experience, anyway.

LEE ANN RAMSEY: Yes, very much. Thank you for sharing that. I think it helps us to see the parents' experience with this rather than being on the academic or professional side of it. Thank you.Does anyone have any questions, comments for Ms. Woodall?

PENNY HATCHER: Yes. This is Penny Hatcher in Minnesota.

Ms. Woodall, thanks for sharing that. I do have a

question. Early stages, what do you wish would have happened, either with the doctors or the nurses, either something you wish they would have done that they didn't do or --

PEGGY WOODALL: That's an excellent question. If there's anything I could change about our experience, it would be that

we would have been detected earlier and that we could have started intervention earlier and that we might not have the language delay that we have now. It's not a huge significant language delay, but it is a delay and it affects Abigail's ability, written and with standardized testing, to show what she's capable of. You know, when you read the studies, it shows that if you're able to

intervene early, before six months, that doesn't happen and it doesn't matter which mode of communication you choose. So, if anything, to have been detected earlier.

I have to add at that point that I'm also a member of

the Advisory Committee for the State Newborn Hearing Screening, and I'm very proud to be a part of that and proud to be a part of the education portion, hoping to educate doctors and nurses to listen to parents. Parents know their children and every week, every day earlier that we can detect a hearing loss, that's less lag for language.

LEE ANN RAMSEY: Okay. We're running short on time. We have about 25 minutes, and I want everyone to have an opportunity to

speak because we've got such a great agenda. So I'm going to try to speed things up here just a little bit.

SHERI BURRELL: Well, I can abbreviate some of mine because a lot of what Peggy just said is exactly what we went through,

ditto to the -- about the same time that we started suspecting that Evan -- My son is Evan. He's eight and a half now. It was about the same time that she said that they suspected Abigail's. We went through the same thing, fluid in the ears, tubes in the ears. Evan was a bit older. He did not have chronic ear infections or anything. He had apparently some allergies. And they put tubes in his ears when he was 14 months old and thought that everything would be just great. Evan is very bright and he had many, many ways of compensating for his hearing loss. So insome ways I can't blame doctors or somebody for not really feeling like he had as much hearing loss as I felt. But, anyway, we went on from that. They finally did the -- where they hooked the electrodes to the brain. I don't know what the test is called. I can't remember because I've blocked that day from my mind. He was 20 months old then, and they finally concluded then that he had severe profound sensory neural hearing loss. They told me about the cochlear implants. They said that this was the

type of hearing loss that could benefit from that. And of course, I, like Peggy said, wanted him to be able to communicate in any way. We waited then another eight months, and I got a lot of information from various groups. Georgia PINES was one of them. We had one here in Macon, an early intervention program with Babies Can't Wait where they did some speech therapy with him. Of course, I wrote and received a lot of information from clinics. The John Tracy Clinic was one that was real helpful. I think they're based in California. I can't remember. The University of Georgia did a couple of programs with me, but mostly they were just recording the way that hearing-impaired children develop, not so much as information as just to study -- to help in research like yours at CDC.

The big problem that I had and the loss of intervention

that I feel like we had was once they started talking cochlear implant, it was like this was going to be the cure-all, which I'm definitely not against the implant. It's marvelous. The upside has been fantastic. However, they lean towards, you know, we're going to put this miraculous thing in and then he's going to be able to learn to talk and you really don't have to worry about speech, about sign language, and this and this and this, which is, to me, ridiculous. Maybe if the implant was done when they were nine months old or something, that might be plausible, but in Evan's case, it wasn't. So we went on and he was really not

subjected -- I mean, we communicated totally through pantomime, pictures. I know he learned himself to do some speech reading, but he was -- he was a very frustrated child about six months after we had the implant done. This is not to say anything bad about this group, but there was one group that if he couldn't say a word -- if he couldn't say "cup," he couldn't have a cup, you know, that kind of thing. Well, it didn't take me long to change my mind about that. The implant has helped him with speech, more with understanding what you're saying than with his actual verbal skills, although he does have many words that I feel like he wouldn't have at all. He started the Atlanta Area School for the Deaf when he was about five and he had had some sign language in

a hearing-impaired class in Warner Robins before he started there but, basically, everything that we've done has been since we started the Atlanta Area School for the Deaf, and is where his real progress began.

Let's see, one thing that I have found just recently with Evan, and this is a lot through the school, not only his hearing impairment, but all of his other needs really need to be monitored and tested and all of those types of things on a more -- like not once every three years, like every three months or six months, because the way he learns changes constantly. That's one problem we've had. We figure out something that works well with him, it works for a little while, and then he moves on. But he's doing great. He's a wonderful child. I don't know if there's anyone at his school that doesn't know him. They all say, "Hello, Evan. Hello, Evan." The school serves his needs and the needs of all the students the best they can, as far as I've seen, and I've seen some pretty miraculous improvement in Evan and his peers.

That pretty much is all I have to say, except that parents do need to be educated and they do need to know all of their

various options, not so much from a medical standpoint even but from like parents talking like this. I didn't have any idea what I was doing when all this started. I had two much older children and I'm the oldest of six kids. So I thought I knew kids and had some idea of what I was doing, but I certainly didn't.

LEE ANN RAMSEY: Thank you. Does anyone have any questions or comments for Ms. Burrell?

SUSAN EASTERBROOK: Hi. I don't have a question, but I

would just like to expand on something that Sheri said, which is just really important, when she said that it's important to look at the whole child, not just the hearing, and look at the whole child routinely. I think sometimes we get so vested in looking at the ears and the technology surrounding the ears that we forget that there's a brain there, there's arms and legs, there's emotions and interactions, and a whole range of characteristics that make up any given child, and the need to address — for early interventionists, to address that with families as well is very important.

SHERI BURRELL: I agree a hundred percent.

LEE ANN RAMSEY: I agree. Okay, well, thank you very,

very much for sharing those stories with us. We're going to move on to Dr. Lillian Blakesly, also of AASD. And one of the reasons we asked Dr. Blakesly to be on this call, along with Dr. Easterbrook, is every day we hear about political correctness and cultural sensitivity. And one of the things that we end up discussing a lot is just the use of the words "hearing-impaired" versus "hearing loss," saying "children who are deaf" rather than "deaf children" and putting the disability after the person. We would just like to hear your insights on terminology and any other insights you might have seeing early intervention as a spin-off from Ms. Woodall and Ms. Burrell.

Lillian Blakesley: My purpose today is to speak about my "Perspective on Early Intervention and Using Sensitive Terminology." First I want to clarify that while the Georgia PINES program is housed at the Atlanta Area School for the Deaf it is a statewide network and works with agencies and early intervention programs statewide. This program serves families of children who are deaf, hard of hearing, deaf/blind, or deaf multi-handicapped.

It is exciting that the State of Georgia is participating in the National Institute of Health's Universal Newborn Hearing Screening initiative. Beginning on June 1, 2001 Georgia will have staff from Children First follow up with the families whose babies fail the

hearing screenings until a diagnostic evaluation can be completed. These procedures and the professionals who are qualified to diagnose infants hearing loss are listed on the Georgia Department Human Resources wed site.

Once a diagnosis of hearing loss is made, an intake person with Babies Can't Wait and an Early Hearing Orientation Specialist with Georgia PINES conduct an informational home visit. Both are State agencies. This visit takes approximately three hours. An overview of hearing loss, degree of loss, communication options, programs, etc. are reviewed with the family. The family may enroll for early intervention services at this visit. This enables families to begin getting the help they need to make wise communication decisions for their infants

Now about terminology and sensitivity. Historically there has

been a controversy over terminology and communication choices used in the field of deafness. Can you remember when you first heard someone say the words "deaf and dumb" when they were speaking about an individual who was deaf? Can you remember how your stomach would get in a knot? Of course the term meant

that the person was unable to speak, but when it is used in

current times, it is a very offensive term. Unfortunately I still hear

that term once in a while from older individuals who are not familiar with deafness. Other terms that hearing individuals do not mind, are offensive to individuals who are deaf. Terms such as hearing-impaired, hearing loss, hearing disability, auditorially impaired, hearing difference, hearing disorder, Deaf with a capital d, deaf with a lowercase d, and culturally deaf cause reactions. Many individuals who are deaf are offended by the terms,

impaired, disorder, disability, and loss, to mention a few. We

have auditory oral, auditory verbal, auditory training versus auditory learning, simultaneous communication, pigeon sign, contact sign, and signed English which also create controversy!

After teaching a couple of years, I remember on "terminology" situation vividly. I was discussing a three-year-old child with her parent and used the term 'deaf' in describing the child. The parent became visibly upset and told me that her child was not deaf, her child was hearing impaired, and not to call her that again. This helped me realize that I was insensitive to the parent's needs at the time. I had been around individuals who were either deaf or hard of hearing most of my life and it was not an emotional issue to me.

I have been employed in the education of deaf children for numerous years and when I revisit my past, I am amazed at the amount of time that professionals and deaf individuals have spent discussing and actually arguing over terminology. It is not an enjoyable situation. It's very important that we are sensitive to terminology as we communicate with families and Deaf individuals.

Professionals do a disservice to families with their own biases about communication options. The brain is an amazing thing and we have to continually remember that we are working with the child's brain! Children need to have the chance to develop the brain with the communication option that allows them to develop their language.

As professionals we need to be aware of the "baggage" we carry to the parents of infants who are diagnosed with hearing disorders. The issue really is that we must convey to parents of newly identified children that there are multiple options to develop communication skills with deaf children. Some professionals have a great deal of experience with various communication options and some professionals have experience

with only one or two. Certainly it is preferable for the parent to

determine, or buy into, the option. It is important to commit to that option long enough to determine if that is the best option for the child. We want all children to become proficient language users...and by that I mean to be able to express themselves and to eventually be able to read and write to the best of their ability.

With the improvements in cochlear implants and the ability to implant babies at a younger and younger age, many infants who are deaf will have a chance to learn through listening. If learning to listen is possible for a child, hopefully the ramifications for his/her educational future will be positive. Now that Universal New Born Hearing Screening is in the hospitals, children who are deaf have opportunities that were never available before... the opportunity for early diagnosis so that intervention can begin and the brain can be a better language learner, no matter which communication option is chosen.

If the child is not able to acquire language though listening, the professionals who work with the child need to have significant documentation about how the child is learning and if the child has additional needs. The child's cognitive functioning level and auditory memory skills, as well as parental support are vital in the selection of the communication option.

It is a fact that hearing aids and cochlear implants are better than ever before. We know more about how the brain works than ever before and we know more about early intervention than ever before, etc. But we still have students who are deaf or hard of hearing who benefit most from visual communication options. As professionals, we need to keep an open mind, communicate with other professionals' and work together to meet the needs of these students according to their needs, not according to our biases.

If a child enters an educational setting, significantly behind, very few children "catch up" with their hearing peers. How can we best meet these students' needs? No one has the "right" answer...but as professionals we keep trying. Parents still have to be manned with knowledge to make the decisions that need to be made for their child. Everyone needs to remember that we're looking at the hearing abilities of the child, the cognitive function, the auditory memory skills, and the parental support that a child has. It doesn't matter which communication option is used, we need to be cognizant of those abilities.

At the Atlanta Area School for the Deaf, we serve children from age three to age twenty-one. We receive referrals from Local School Systems. We are really an extension of the public school systems in the Atlanta area, and right now we have children who attend our school from 27 different counties. About one third of the students have additional disabilities. Twenty students have had cochlear implants; some after the age of three, but most after the age of five. Also we serve children who, in spite of good hearing aid management, are not able to access language through hearing/listening. They continue to need significant instructional modifications to learn. While the majority of the students are sign language users, the school is increasing the services to the students who can access information through their ears. Many are children who have been placed in the mainstream, yet they were not able to benefit educationally in inclusion settings. Some of these students have parents who are very committed to their child's learning; other parents have difficulty providing a quality language environment for various reasons. Many of them are using language to the best of their ability. Some of them have very intelligible oral English but their written language suffers. Usually students are referred to our school because they need an intensive "wrap around" program.... trained teachers, speech/language pathology, audiologists, OT, PT, etc. The main thing is that students must have their individual needs met so they can continually improve their language use.

LEE ANN RAMSEY: Thank you. Does anyone have any questions or comments?

YAOLI LI: This is Yaoli Li from Minnesota. Dr. Blakesly, so between these two words, which one would be better, the hearing-impaired or hard-of-hearing?

LILLIAN BLAKESLY When referring to individuals who are

deaf, the National Association for the Deaf recommends the use of the terms Deaf and hard of hearing to describe hearing disabilities.

SUSAN EASTERBROOK: The term "deaf" and "hard-of-hearing" is the one that's recognized by the National Association of the Deaf, by the Council on Education of the Deaf, and by most of the professional organizations in education of students who are deaf and hard-of-hearing to my knowledge, but that may be changing as we speak.

BARBARA RAIMUNDO: This is Barbara Raimundo from the

American Society for Deaf Children, and I just want to make a comment. We're all, you know, sitting here talking about people

who are deaf and hard-of-hearing, and please correct me if I'm wrong, but I don't believe there are any deaf people on this call and maybe no hard-of-hearing people either. I don't know that for a fact, but I think we also need to be very careful when we're talking about a population, to not -- to respect their views and to include them in our conversations about them whenever possible. I'm a little uncomfortable with us talking about a group when the group is not represented here.

JULIE TERRELL: This is Julie Terrell from Nebraska,

and I am deaf and hard-of-hearing in one ear. I represent the State of Nebraska's hearing program, and it is nice to hear somebody say that because we do like to be included in everything that's going on.

EDGAR SHROYER: This is Ed Shroyer at University of North Carolina at Greensboro. One of our project directors, Ann McNally, is hard-of-hearing herself and she's participating in this conference also.

LEE ANN RAMSEY: Also, Dr. Krista Biernath -- I don't

know if she's on the line -- she is hard-of-hearing. Is that correct? She's usually on the line, but I think she's out today. But you're right, maybe we can try somehow to make this available through TDD. We'll put the minutes out and maybe we can get some response. That would be nice.

SUSAN EASTERBROOK: Lee Ann, before I start, let me ask

this. I'm prepared to talk for about 15 minutes, and I notice we only five. So would you rather that I give a very brief synopsis or would you rather that I present this in its entirety another time?

LEE ANN RAMSEY: Well, we can go over a few minutes. So that would be great.

SUSAN EASTERBROOK: Okay. Lee Ann asked me to talk

about the topic of cultural sensitivity in early intervention and what we're teaching new educators. I'm going to discuss this in three different parts, first talking about sensitivity to deaf culture, followed by discussion of other hearing cultures, and then I'm going to end with just some other things that I go over in my teacher prep program. The development of a healthy personality is integrally tied into one's relationship with the culture of the family and with the culture of the larger society. The main issue of concern is that of identification, both as a valued member of the family and as a valued member of the larger society. When a student has a hearing loss, that basic identification process is impacted. Many hard-of-hearing and some deaf children are fortunate to have families who work to develop a bond with them through communication. However, large portions of the population with severe and profound hearing

losses don't have that kind of support. The process of familial and cultural identification depends on two key variables: a common language and shared experiences. A deaf culture exists in response to this human need for identification based on a common language and shared experiences. The deaf community uses a common language as you know, American Sign Language, as a tool through which they interact. And as such, it has a cherished status within the deaf community. Another important issue that forges community and cultural bonds is that of shared experiences. Members of the deaf community share a common heritage and are proud of deaf individuals throughout history who have made medical, social, educational, and humanistic contributions. However, the most important aspect of the deaf community is that it provides easy communication on an

individual-to-individual basis that allows the individual to develop a sense of identification. As long as there are individuals with hearing losses who are left behind in the normal developmental processes of identification with their families and with the larger society, there will always be a need for the deaf community to provide this context. The need to belong is primary for most individuals.

Attachment, belonging, identification, and self-actualization are

driving forces for all humans and deaf individuals are not -- not exempt from that. We need to recognize the contributions of the deaf community and its cultural and linguistic heritage in the identification and self-actualization it affords to many individuals

who would be at a loss without it. The second part of my talk has to do with hearing cultures and, as you know, today we're facing increasing diversity at all levels. You don't have to go very far, at least in the Atlanta area, to see a billboard in another language. It's a basic truism that we learn best from those we trust. We, as early interventionists and teachers, must make every effort to understand the culture of others so that basic trust can develop.

There are many possible sources of misunderstanding

between cultures. They usually fall into verbal and non-verbal

categories, the verbal being obvious and the non-verbal more subtle. Non-verbal aspects -- The non-verbal aspects of communication that I discuss with my students are kinesics, proxemics, captics, artifacts, silence, and time. Kinesics refers to all bodily movements such as head shake or gestures. Gestures, in particular, do not have a shared meaning from culture to culture and the gestures used by one culture may be offensive to another. It's not just from, say, English to Spanish. It's English to English. I have a friend who lives in England and she was over here with her son. And in England, instead of pointing with the index finger, they point with the middle finger, and this child got in big trouble in school over here. So even from English culture to English culture, there are huge variations in the meaning of gestures. Proxemics refers to personal space and physical

distance, such as walking side-to-side or whispering in someone's ear. Each culture has it's agreed-upon norms for personal space, especially as it relates to cross-gender space and cross-generational space. Violating these norms can be offensive in some cultures.

Captics refers to all touching. Even a pat on the back

doesn't work in some cultures. That would be considered aggressive. Artifacts are materials created to communicate certain messages such as the use of formal or informal attire. Attire is directly related to status in some cultures, and there are many cultures that would not tolerate a dress-down Friday. In particular, teachers are expected to dress in a manner that would not lower their status in many cultures. So when a teacher comes into the home in blue jeans, the home of a family who sees this as important in their culture, that might be considered offensive. Silence refers to the amount of time we feel

comfortable with before we feel obligated to talk to another person. Teachers, in particular, are not comfortable with giving children more than a few seconds before they expect a response. In some cultures, if you speak before the other person has time to respond, you are considered rude or considered to be displaying self-important behaviors. Finally, time is viewed differently from culture to culture. Time is viewed along a continuum from being a commodity, which we look at it -- just how we look at it in the U.S -- We don't want to waste time or have others waste our time --

versus being an opportunity to connect with yourself, with others, or with one's own spirituality. Also, some cultures revere the past while others worship the future. These are fundamental differences that influence interaction on a daily basis. They each hold the possibility for many subtleties of perception, and these perceptions influence how we take in information from other sources. If we want students and parents to get what it is that we're trying to get across to them, then we need to spend some time investigating how their culture responds to non-verbal aspects of communication. In addition to verbal and non-verbal communication differences, there are many basic value differences that we have here in the U.S. that are quite different from many other countries worldwide. I have a long list of them, and if you want -- would want, Lee Ann, I can send you a copy of this by e-mail so you can post the whole time, but in the interest of time, I'm just going to go on. So it's essential that we establish trust with the children and with their parents if we want to have a positive impact on their development. The early interventionist needs to take the effort to understand the cultural differences, both deaf cultural and culture in the larger sense.

The third part of my presentation has to do with what it is that we're teaching teachers in our teacher preparation program.

As you know, deaf ed has a long and glorious history of disagreeing with itself. In 1995, the Council for Exceptional Children and the Council on Education of the Deaf developed mutually agreed-upon standards for all beginning teachers. One standard identified that all new teachers, in addition to learning what they're learning in their teacher preparation program, should be able to identify how and where to find out information about other philosophies, modes, and languages that they may encounter when out in the schools teaching. This was a refreshing change from previous perspectives. I'm not sure how other programs do this, but I require all my students to develop a manual of where to get more information on other approaches, on all the approaches, and then I also require them to have practical experiences in a variety of settings. In addition to information about cultures, I -- in my introductory course, I address the issue of bias head-on and I talk to them about roadblocks to multiple pathways. (inaudible) is the title of my little talk. In other words, I try to get them to explore their own preconceived notions about how a child should or should not be taught, and I discuss five mind sets. First is the notion of modality bias. This comes from the assumption that we have the right to choose the modality through which a child is going to learn best. In fact, the individual characteristics of the learner and the characteristics of his or her environment have more of an influence on the modality he will end up using. And frankly, most children are educated in the mode that is used in the school that they live closest to. It would be nice to think that everyone has options but, in fact, many people do not. The second notion is of a language bias. We explore the fact that ASL is a bona fide language as well as spoken Hindi, or Spanish, or whatever. The point is that the brain doesn't care what kind of language it uses. Only society cares what kind of language it uses. Hence, we have conflicts and struggles between cultures because of our ethnic-acentric perspective. If the brain doesn't care what kind of language it receives, then that changes some of our arguments. and the important question becomes, which language can this particular child most easily access in all its complexities?

The third notion that I discuss is the concept of stepping on each other's toes, and sometimes new teachers are afraid to

state their piece about what they think a child needs or is afraid to make waves. So we address when is it appropriate to step on the toes of somebody else's philosophy. The fourth notion that we discuss is that of blaming the child for his or her failure to use the given modality or technology. If we are sensitive to the child's home situation and how his or her brain is handling information, then we have to step back and look at the treatment/child's match, not at what we want that child to

do. You'll never be able to force them to learn a language he cannot learn, to use a technology he cannot support, or to think in a way his brain is not able to think. A child is not responsible to meet our expectations, but we are responsible for making available to him what he needs. And then the final point that we discuss is the fear of betraying our roots. You know, I was raised in a very strong -- very strong perspective, and it took me many years out there of working with all kinds of children to realize that I had to broaden my perspective to recognize that all kids are different and that some children did, in fact, do better in the other philosophies than the one that I was trained

in, and vice-versa. So when our folks get out, I think it's very important or them to be aware that these are real kids in the real world with real families and real problems, and looking at -- staying true to your roots may not be the appropriate thing to do for any given child. In closing, I think we've made progress, and the acceptance of the spectrum of needs that children who are deaf and hard-of-hearing have, I think

acceptance of the spectrum of needs that children who are deaf and hard-of-hearing have, I think it's sad that changes in the make-up of society and advances in technology have been the driving force behind our changing perspective rather than our own wisdom, but whatever it takes, I'm glad to see that we're moving forward. Thank you.

LEE ANN RAMSEY: Well, thank you all very much for attending conference. Before we close, are there any last comments, questions, or announcements?

PENNY HATCHER: Yes, this is Penny in Minnesota. In regards to the last teleconference, there was that study of -- related to reimbursement, I think, for hearing screening and like the Medicaid EPSDT program that was supposed to be out in the spring and there were some guest speakers. Do we have any feedback on that report and its availability yet?

LEE ANN RAMSEY: We don't have any feedback from it yet, but when we do, we will let you know.

PENNY HATCHER: Okay.
UNIDENTIFIED SPEAKER: Can you repeat your web site, please?

LEE ANN RAMSEY: It's http://www.cdc.gov/ncbddd/ehdi for Early Hearing Detection and Intervention.

LEE ANN RAMSEY: Thank you. Our next call will be July 3rd at 2:00 Eastern Time. Thanks for joining us and we'll talk to you in July, and thanks to all of our speakers. Bye-bye.

[Whereupon, the teleconference was concluded at approximately 3:07 p.m.]