# Choices in Deafness: Revisited

**Centers for Disease Control and Prevention EARLY HEARING DETECTION AND INTERVENTION Special Topics Teleconference August 23, 2005**
**Presentation: Choices in Deafness: Revisited**
**TO:** Special Topics Group for EHDI **FROM**: Jamie M. Elliott **SUBJECT:** Conference call information and agenda. **DATE:** Tuesday, August 23, 2005

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**Topic Abstract**
For more than two centuries the communication debate has raged in the field of education of deaf children. Parents have been expected to make a choice between sign language and speech—often on the battlefield of conflicting professional opinions. With the advent of Universal Newborn Hearing Screening, parents face this dilemma with no warning signs, and with an infant too young to provide indicators of a learning or communication style. The greatest travesty, however, is that parents often do not understand the broader concept of language when making these critical decisions. "Choices in Deafness: Revisited" presents a hierarchy of priorities for counseling parents and professionals regarding cognition, communication and language in the first year of life. Communication methodologies are discussed as a means to achieve these priorities.

**Speaker Bio**
Mary received her Bachelors degree from Smith College, and her Masters in education of the deaf from Gallaudet University. She has taught at the Montreal Oral School for the Deaf, and was an Auditory-Verbal therapist and clinical director at the Helen Beebe Speech and Hearing Center in Easton, PA. She developed the cochlear implant rehabilitation program at The Listening Center at Johns Hopkins. She has been working wth children wth cochlear implants since 1983. She is the author of *Bringing Sound to Life: Principles and Practices of Cochlear Implant Rehabilitation*," a vdeo training program, and *Word Associatons for Syllable PerceptionW*A*S*P*Mary is currently an independent Auditory Education Consultant, provding workshops, program development and staff mentoring nationwis a consultant to Advanced Bionics Corporation, Gallaudet University, Boys Town National Research Hospital and many schools and programs servng children wth cochlear implants. Mary is also an advisory board member for Hands and Voices.

# Choices in Deafness: Revisited

**Edited Transcript**

**Jamie Elliott:** You can download those slides at the website www.infanthearing.org/checkpoint. You will be prompted for a user id, which is *cdc* and a pass code which is also *cdc*.
Our presentation today is entitled *Choices in Deafness: Revisited*, and Ms. Mary Koch is presenting for us. I'm going to let her give her own introduction. We are very grateful to have her giving this presentation today. So, with that, I'm going to turn it of to Ms. Koch to begin the teleconference.

**Mary Koch:** Thanks, Jamie. Hi, everybody. It's good to be in touch with all of you even though I can't see you. I must say this is the first time I've presented on a telephone conference. I'm very dependent on making eye contact to connect with my audience. So I tried to do it through the power point, and I hope that all of you will have that power point in front of you as we go through this, so that we will have a visual connection.

I will tell you the slide number at the bottom right corner of each slide. There is animation on each slide, but it will advance automatically. You just need to advance to that slide and then you will be able to keep up with what we are doing. Right now I'm on the title slide, and I think we will just advance to the first one, which is slide number 2.

On the second slide you can "see" me (my picture) but I can't see you. I wanted to say 'hello', greet all of you. I have no idea how many of you are out there, but I wanted to give you a little idea of who I am and why I'm talking about the topic of "Choices in

Deafness Revisited.”. If we could advance to slide 3, I have listed some of the things I've done in the past, not for the purposes of sharing a resume, but to show you how zigzagged my past has been as far as methodology.

(Slide 3) I started out at 19 years of age with a real passion for sign language and what a beautiful language it was, but shortly after that I transferred to Smith College and volunteered at Clarke School, which was an oral program. To keep the zigzag going, I went to graduate school at Gallaudet where I was immersed in ASL. After graduate school. I took a job at the Montreal Oral School and was mentored by Dr. Ling. There I learned what could be done with a small amount of hearing.. After leaving Montreal I went to the Helen Beebe Center, an Auditory-Verbal Speech and Hearing Center, where I later became the Clinical Director. In 1983 I began working with children with cochlear implants going back to single-channel cochlear implants. In1994 I came to Baltimore to start the cochlear implant rehab program at Johns Hopkins. I have served on the National Association for the Deaf (NAD) Task Force, to rewrite their position paper on cochlear implants. -- . So as you can see I have worked within the methodology extreme of both ASL and Auditory-Verbal.

I've been working with children with cochlear implants for 22 years and with the advent of universal newborn hearing screening and cochlear implants, we can look at communication methodology in a new way as it is an entirely new age for children with hearing loss.
We are now seeing infants, and extraordinary technologies. As a result we need to shift our paradigm as to how we deal with communication. My professional commitment is connecting with children one at a time. I do not feel aligned with any one communication methodology. I feel that methodologies are like tools in a tool box that can be brought out when needed. My knowledge of ASL still serves me very well for those children who need it; I integrate auditory verbal strategies for the children who can benefit. Communication methodologies are tools. I'm committed to helping children express themselves and understand others in the most effective way they can. Those of you who have seen *Mr. Holland's Opus* remember the great scene where the little boy is having the fit in the kitchen. The mother is frustrated says, “I just want to communicate with my child.” That’s what we want. , “Imagine if we said to Stephen Hawking, the great astrophysicist with advanced Lou Gehrig’s disease. “W*e're only going to listen to you if you speak rather than using the communication board*?” We wouldn’t know what was in that extraordinary brain. So it is with children with hearing loss. The ideas and feelings in their heads are not less important than Dr. Hawking’s.

As we look at individuals, adults and kids, one at a time, *how can we tap into what is inside of them and help them express themselves?* I speak first as a mother of two children who have taught me so much about individual instruction. And lastly, I am sick to death of the methodology wars. I think they are destructive and serve no purpose.

(Slide 5) – We are seeing infants for the first time. We have generations of professionals who have not been trained to work with infants. We need to reorient ourselves to the potential of babies as opposed what we would see when we began with a deaf child at 12 or 18 months or sometimes as late as three years old.

(slide 6). How does early identification of hearing loss impact counseling our unsuspecting parents.

(Slide 7) What happens when parents find out their baby is deaf? And in the slide that baby has vanished and another baby has really taken its place, and this baby is deaf and they're looking at this baby differently. And in we walk.

( Slide 8) In steps the professional who is juggling many things. But what do we say to these unsuspecting parents? This is another family we need to see, and we have so many things we want to tell them.

(slide 9) What has been done traditionally? And what do we need to do differently?
Traditionally we have met with families, and we present “choices” in deafness. We describe the options of ASL, auditory oral, total communication, auditory verbal, and expect that the parent to make a choice.

(Slide 10) , “*do you want your child to sign? Do you want your child to talk? Huh? What's it going to be?”* Parents may be reeling from the diagnosis.

(Slide 11) Parents are being bombarded with information about all of the different communication philosophies. And, being the responsible professional, we tell them everything they need to know!-- As articulate as we may be, the parents may not have heard a word after the statement that their baby is deaf. Now we're asking them to make a choice based on complex information that has taken us a professional lifetime to comprehend.

(Slide 12) How might we counsel parents differently? When I meet with families I provide information about communication modalities, but I don't address this as an issue of choice that they need to make. The discussion is about deafness and its

implications. There are too many things that we don't know about a six week old baby or three week old baby. No one knows yet how that baby is going to best learn to communicate.

(Slide 13): Lets back up a bit and consider first things first.
In response to what I feel is a misplaced emphasis on choosing a communication methodology, I developed a counseling tool that I call Communication Priority Pyramid. This model is designed to get the focus off of methodology and onto the higher functions of cognition, communication and language.

(Slide 14) At the foundation of that pyramid is cognition-- that is the building block for everything else that is going to occur for that baby. Cognition is the processing of sensation
and experience in one's world. Imagine being in a birthing room, where that baby is bombarded by touch, by light, by cold, by soft, by movement, by color. Sensory experiences are bombarding that baby from the instant he is born.

(Slide 15) A baby learns to transfer information from himself to someone else, which is communication. A newborn is quick to let those around him know what he thinks of his new environment!

(Slide 16) What makes us uniquely human is our ability to encode information into mutually understood symbols-- and that is language. It is language, regardless of the symbol system, that needs to be the focus of early intervention with babies with hearing loss.

(Slide17) The next tier in this pyramid is modality; that is, the manner in which language is expressed. Now, that is important because it has to be an accessible modality--how language is going to be accessed-through sign, spoken language, Cued Speech etc. What will work best? It's important but it's not more important than cognition, communication and language.

(Slide 18) At the very tip of the pyramid is the word *precision*. This is the accuracy with which something is expressed. This is dedicated to the speech language pathologist who gets a deaf child and starts working on the final s sound-- working on articulation when the child may have no concept of the give and take off communication, have no concept of the cognitive content of what they're trying to express. I liken it to Michelangelo when he carved the statue *David*. If we think of his priorities, his first priority was finding a piece of marble. Michelangelo did not start with David's fingernails, and that is what it would be like to start with articulation. We need to get the foundation of cognition communication and language before we focus on the precision elements. All of this is important, but they need to be ordered appropriately.

(Slide 19) This is a traditional model of how we have presented the issues to parents of children with hearing loss. We have started by talking about modality. We started by presenting options, sign, speech reading, and if you want to do ASL or Cued Speech or Total Communication-- Our priority has been the modality, and often parents naturally say, *"I want my child to learn to talk*." Very often what parents are thinking is "articulation." They may be concerned that their child is not saying his s's right, his l's or r's. The child may have no idea of the turn taking in exchange of language. Parents inadvertently may emphasize precision over the bigger picture of cognition, communication, and language.

(Slide 20) We can see that this is not going to stack up when it comes to developing a communicating child who has the foundation for literacy. It won't work if we start by talking about modality.

(Slide 21) Here we see the priority pyramid and what I refer to as "the Big 3". The other, modality and precision, are very important but should not be emphasized until parents are really grounded in understanding cognition, communication, and language. I had a panel one time of parents that I had started with their babies between the ages of six weeks and maybe two or three months. These families were rooted in the issues of cognition, communication, and language. Communication modality was integrated according to the infant and their needs. A question came from the audience, "how did you decide whether to sign or to talk with your child?" And I would give anything to have a video of the faces of those parents as they looked at each other and turned with this question on their faces like, "*I don't understand the question*. *How did I decide whether to sign or speak?"* Because it really wasn't a one-time decision, it was a fluid process. *We'll let our baby lead us into which is the most effective for establishing that language foundation.*

(Slide 22) Cognition, communication, and language should be the focus of counseling with newly identified families, not communication methodology. I think the communication methodology will follow very naturally once the parents are really grounded in these higher level functions.

(Slide 23) When I first saw this picture of this infant, I was very taken. I've been using this picture for probably five or six years. I was very taken by the fact that for the first time-- I live in Maryland, and we had universal newborn hearing screening pass in 2000, so for

the first time we were seeing babies about the age of this baby in the picture. We were seeing infants who had not yet developed a delay, because they were newborns! They were too young to develop a delay. This picture generated in me a tremendous sense of urgency to try never to allow a baby be delayed.
How can we look at The Big 3, the cognition, communication, and language, knowing this baby is profoundly deaf. We know that baby may be eligible for a cochlear implant toward the end of its first year of life. We need to be sure that in that first year of life we don't allow any cognitive, communication, or language delays.

(Slide 24) We now can begin intervention with hearing loss before delays can occur-- an opportunity that, if missed, is nearly impossible to make up for. So much happens neurologically in that first year of life, that the hard wiring is laid down for language development, and we have to be sure in those first two years that we capitalize on the language hard wiring to be sure that our babies get language.

(Slide 25) I like to look at the first year of life as an iceberg, and I see an infant getting the hard wiring of language, of receptive language. He is experiencing words in association with actions and objects, and processing all of that information to make these associations. However, during the first year of life, but we may see no evidence of those associations. That's the iceberg. Language in the first year of life-- the mountain that nobody sees.

(Slide26) During the first year of life, the neural pathways for language are established, first receptively and then expressively.

(Slide 27) And then comes the first word-- and the iceberg breaks the surface. We see or hear the baby's first word. It may happen at 9 months, 10 months, 12 months-- whenever the baby puts it together and figures out they can use the word expressively. This was inspired by a child I was working with. I began with her at two months of age. Mom and dad talked and signed with her. And one day she had her hand up by her face and was wiggling her fingers. We knew that it was a deliberate sign, but we didn't know what it was. And then I brought out this little plastic cat. She again began wiggling her fingers by the side of the face. Mom and dad and I looked at each other with tears in our eyes. It was her baby sign for “cat.” She had a cat at home, she had seen the pictures and the object, and she had seen the repeated signs plus the spoken word. She put it together and used a symbolic gesture for the first time. That “simple” action took all of that neural paving for her to be able to receive it and use it expressively. Well, as soon as that happened, she discovered her expressive skills. That was probably about 10 or 11 months. And by 18 months of age, when this child received a cochlear implant, she had over 300 words expressively through signs. She did not show any auditory abilities, however. After her implant, we continued to use spoken language with her along with signs, and she was able to transition her extensive language base to spoken language.

(Slide 28) The first word emerged toward the end of the first year, evidence of the mountain of neurological foundations that make the single word possible.

(Slide 29) Every day that goes by without appropriate intervention, an infant with a hearing loss falls behind in the foundational skills of cognition, communication and language.

(Slide 30) Whatever modality best achieves growth in cognition, communication and language
should be used during the first year/s.

(Slide 31) Early intervention should be like a dance, where we are following the baby's lead, keeping “the big three” as the focus. I had the good fortune of working with two babies that were nine days apart. They were both aided full-time at six weeks. I used the same strategies with both-- gave them lots of auditory stimulation. I gave them some sign support as I saw they needed that. There was a lot of spoken language modeled. Both of them had flat ABR's, but one little boy did have some residual hearing. He used it. He had consistent use of amplification from the age of 6 weeks and he took off with spoken language, so it was very natural to let the signs drop away. The other little boy who was nine days younger was very profoundly deaf and had no auditory skills. However, we continued to use consistent amplification, modeling spoken language, with more and more emphasis on the sign because clearly that was going to be his avenue now for getting the language foundation that he needed. He received a cochlear implant at ten months. When both boys got to the age of four or five, transitioning into kindergarten, you would not have known which was which. Both children were functioning at age level with 100% intelligible speech, but both in the first year of life had had the full access, maybe not full access. In the first year of life, both had language in a modality that they could access.

(Slide 32) As the baby develops, learning strengths will be identified and strategies or modalities can be modified to optimize the language learning. We can see if one child is clearly needing more sign, we can give that child more sign. If that child is being much more auditory and verbal we can drop the sign, but we are following the foundation that the baby is leading us to.

(Slide 33) This is sort of a footnote just to be sure that this is clear. The development of residual hearing, consistent use of amplification and focus on listening should be emphasized regardless of the primary modality of communication. Even if a child has not shown any auditory response prior to candidacy for cochlear implant, I like to encourage the full-time use of appropriate amplification because, even if there's the littlest auditory stimulation, that will keep that auditory pathway open in preparation for a cochlear implant. Much like we would keep our pipes from freezing in the winter by keeping the water dripping, we want to keep that auditory stimulation going. Even if we're using other modalities, we have to still have a high priority on listening and hearing aid use.

(Slide 34) Spoken language can be the goal (and it is-- When I work with children, spoken language is my goal.) However, I have a tool kit that enables me to use lots and lots of different tools to address the issues of language, and very often sign will be one of those tools. But my goal is still spoken language. So, spoken language can be the goal, however, other strategies including sign can jump start the foundation of language in the early months and years.

(Slide 36) Here we see a picture taken in the 1960's where the children are hard wired to a desk, using huge head phones. They're probably getting 130 dB pumped into their poor little cochleas. Sign language use may have inhibited spoken language development when access to speech sounds was limited. You know these little kids would run back off to the dorm or on the playground, and they would be signing because they couldn't hear and the speech reading was only giving them 30%. But now

(Slide 37) we have the cochlear implant era, and sign language, when used appropriately, may foster spoken language use when children have full access to speech sounds. I started working with the little girl in the picture when she was two months old. She was implanted at 18 months, but just prior to that we were playing with this little Playmobile car set, she put her two hands up in the air, palm out, rocking back and forth and said “ah ”. And then she patted the top of one hand with the other hand and she said “gee”. What she was doing was the baby sign for “car” and the baby sign for “chair.” She wanted a car seat for this little Playmobile set. What it was showing me was that she had connected symbols. She now is in the gifted program at school. She didn't have a delay in the early months and year prior to her cochlear implant. She had discovered the power and use of language.

(Slide 38) This quote from Christine Yoshinaga-Itano says that “language in any modality is the most important factor influencing spoken language.” That is so key! Imagine if there was an orphanage in Russia, and they had a policy not to speak to children because most of the children will be adopted by English or Spanish or French speaking families. They might think, *we don't want to confuse them by having them learn Russian*. *They will learn the language of their home once they are adopted*. We would never do that. We would much rather adopt a two year old fluent in Russian up to his age level and then transition to English rather than start from scratch at age 2. So here language at any modality is the most important factor influencing spoken language.

(Slide 39) The questions we need to ask ourselves-- where is language processed in the brain, and is it different for sign language than it is for spoken language?

(Slide 40) It's all about ”location, location, location. Languages with radically different sensory modalities such as speech and sign are processed at similar brain sites.” This is based on the research of Petittto and Zatorre, and there's lots of information about whether speech or sign are processed at similar brain sites. We're putting it in the same “bank account,” whether sign or language. We're making our deposits that will benefit the overall development of language.

(Slide 41) This is from a book called What's Going On in There? “The brain's language network properly and permanently wires up only when it is exposed to coherent combination of sight, meaning and grammar in any single human language.” We are wiring the brain very, very early on.

(Slide 42) This slide illustrates what we should have as our goal, and that is the 12 month’s growth in 12 months. This is what we would like to see in whatever modality.

(Slide 43) If we don't start until 24 months, and we still have 12 month’s growth, we're going to have a two year delay by the age of 3.

(Slide 44) This, unfortunately, is what we often see in addressing the needs of children with hearing loss. We see children making less than 12 month growth in 12 months. In this case the child is five years old has the language of a 2 year old.

(Slide 45) This is what we want to see in language and other areas. We want to see more than 12 month’s growth in 12 months.
(Slide 46) So, if it is the same area of the brain for both sign and spoken language, can sign serve as a foundation for the development of spoken language in deaf infants?

(Slide 37) Children that receive sign as a springboard in the early months and years can transition to spoken language with minimal delays in language and speech.

(Slide 48) This is a schematic of the research of Christine Yoshinoga-Itano. She measured language at children post-implant. You can see that the use of sign language was more at the beginning and use of spoken language was less. You can see over time how sign language decreased and spoken language increased. This is what we can see if systematic strategies are used to make this transition.

(Slide 49) How about when a cochlear implant is introduced? We've established a language for a baby, hopefully using the appropriate modality that is most effective for that baby. At 12 months we introduce the cochlear implant. (Slide 50) Imagine a cochlear implant as being like an acorn— A cochlear implant has potential to provide access to spoken language and give the person the ability to understand speech, but it doesn't do it by itself. An acorn has all the potential to become an oak tree, but if it just sits upon the table it's not going to become an oak tree, it has to be in the right environment.

(Slide 51) To take this metaphor a little farther and tie it in with language and cognition, we can see the first four" trees" of sight, smell, taste, and touch representing the chronological sensory development of a child with a hearing loss. Following a cochlear implant, they then have access to hearing, but that hearing has to grow just like a seedling has to grow. And you can see the language and cognition is delayed, it not as developed as the sensory systems.

(Slide 52) This is what we would like to see in preparation for a cochlear implant. We see the language and cognition being almost as fully developed as the other sensory systems. All we really need to develop is the hearing aspect of language development. But the language is already there. The cognition is already there.

(Slide 53) This is a continuation of the metaphor as a model for a post implant rehab and education. We would continue to allow the flow of language and cognition to be primarily visual because we want to keep that child's language growth curve on target. But at the same time, we would be developing their auditory skills and getting that auditory pathway opened up to become a primary avenue for learning.

(Slide 54) So, as the hearing develops, more and more of the learning of the language and cognition will be transferred to the hearing avenue until that can become as primary an avenue for learning as it might be in a child with normal hearing,

(Slide 55) Now, just briefly (and I know we're coming upon time to have discussion) I'm going to go a little quickly through the next few slides just to talk about how we traditionally look at educational issues in terms of modality and then we'll stop for questions.

(Slide 56) Here we have a continuum of the choices. We have auditory-verbal, auditory-oral, cued speech, total communication, and ASL. Going from the left, auditory to the right, visual. Then we can re-frame this to just talking about the sensory modality from fully auditory to fully visual,

(Slide 58) There was a study done at Oakland Children's Hospital with children who were fully auditory represented by the first data bar and then the number of children that were in auditory plus visual. They might be primarily auditory and need a little visual support. They might depend on an equal amount of visual and auditory information. They might be primarily visual and yet still benefit from auditory information. As you can see by the data, the majority of children needed a visual component for language.

(Slide 59) Currently we have programs that provide services to children who are "Big A"— primarily auditory. And we have programs that serve children who learn through a primarily visual mode. In the center is the population that we need to address. We need to address the programs that can be primarily auditory but give that child the visual support they need. Or they can be primarily visual for a child who has really topped out on his auditory skills but is still getting some auditory benefit. We need to honor that auditory benefit but recognize that child learns primarily through vision.

(Slide 61) You have to be flexible because the child may be able to do the routines in a classroom in a much more auditory way, however needs to have novel information presented in a much more visual way.

(Slide 62) What is our responsibility as professionals? We need to have and maintain a sense of urgency about this.

(Slide 64) We need to get an early start. We are all in early intervention, and I recognized that I may be preaching to the choir. We know newborn hearing screening gives us a chance to start at birth, but we do have to maintain that sense of urgency in getting families identified and getting them started in an effective way of language learning.

(Slide 65) We need to provide accessible language at an early age. The early use of visual language-- I'm not advocating for all children, but for the ones who need it-- along with spoken
language and listening can provide a child with age appropriate language opportunities.

(Slide 66) We need to administer standardized language tests every year as our kids get older. We must be accountable by measuring language progress each year. We don't know what is working if we don't measure.

(Slide 67) Our goal needs to make at least 12 month's language progress in one year, and this should be the minimum standard for all children. But we need to measure. We can't just say, *oh, he's doing well*. We have to say how well and measure all aspects of language.

(Slide 68) We need to aim for more than 12 month's language progress in a year. Our goal needs to be closing the language gap.

(Slide 69) And this is key: If something isn't working, modify it. Change it. Stop doing-- if the child is not developing cognition communication and language, do something differently so that he does before it's too late. Before that child has so many learning delays that language is nearly impossible to learn. If, based on language testing, the child is not making at least 12 months progress in a year, a different modality should be considered. This is important: The goal of spoken language need not be abandoned, just supplemented.

So, in review, an early start, accessible language, standardized language test every 12 months, targeting more than 12 months, if something isn't working, modify it. In summary, language must take priority of communication modality, children's learning styles need to be considered in determining which modality will work best, progress must be measured, strategies must be flexible.

(Slide 72) I thank you.

**Jamie Elliott:** This is Jamie. I just want to say thank you again for a very interesting presentation you've made, and perfect timing. We have about five minutes for questions. We have a lot of people on the line today, so go ahead and ask away.

**Kathy:** Hi. When you were with at the slide with the girl in the jungle gym, what did you mean as far as sign language used appropriately.
**Mary Koch:** That's a great question, and that is really the focus right now of what I'm working on in saying how do we – a) how do we establish the sign language and, b) how do we transition to spoken language and how can it be done systematically. There are a lot of strategies I would use, and one is the golden rule for me, especially as a child has access through a cochlear implant is "auditory first." I would want the child to be listening. I use the metaphor of a lazy eye. We cover the strong eye to encourage the lazy eye to work. When we have an under-developed sense of hearing, we reduce visual dependence as we want that auditory to kick in. One of the ways to do that is to present the auditory first, so, I might say, "Go get your coat" before I make any move to get the coat or before I sign it or gesture it. I would be auditory first. This is in the transition, but I would clarify it through visual means and then I would be auditory again which brings you to the auditory sandwich. That is auditory first, visual clarification, and then auditory again. One of the things that is not appropriate is the continual simultaneous spoken language and sign language, because what happens there is the child will continue to be visually dominant. So, if it's simultaneous communication, that child -- those auditory skills will not be optimized, if it's always presented simultaneously. That's sort of a workshop in a sentence or two.

**Carolyn:** This is Carolyn in Indianapolis, School for the Deaf. I agree with the comments that are made, but I do think people assessing American Sign Language need to have an understanding of the linguistics, because that's vocabulary, I believe having deaf linguistics involved.
**Mary Koch:** I think that's a great suggestion, have them really do an assessment of ASL. I know at Boys Town they are doing a lot of assessment and video taping of language samples, and I know they are looking how we measure that early language.

Again thank you, Mary Koch, for your participation and for everyone for joining today's call.
(End of Call)