>> DONNA: Good afternoon, everyone. This is Donna Sorkin from Cochlear America's HOPE program, and I want to just remind you that we'll be starting in about seven minutes. If you have just signed on I would love for you to go ahead and download the handouts for today, and they're in the file share area of your computer. We have both the handouts for the slides that Kris will use as well as the feedback form. Also just a reminder, we will be offering CEUs from both ASHA and the American Academy of Audiology, and you'll get a little e-mail about that after the course is over.
I just noticed about half of you have indicated you have not taken a HOPE Online course before, so I want to give you a special tour of our HOPE Online program. This is Donna Sorkin from Cochlear America's HOPE online program but those that are new to HOPE Online, we offer recorded versions of all our HOPE Online courses. You can find those in the HOPE area of Cochlear America's website at www.cochlear.com/HOPE, so you have got some great ones to catch up on, and I encourage you to take a look at those.

We do offer CEUs for all of the recorded courses as well as our live course today and every time we put these on. I think we're about ready to start. Melissa, you can take down the polling. I'm so pleased to share that we have eight people using the captioning today. So I know our realtime captioner will be delighted to hear that. So let's go ahead and begin the recording and start our course today.

Our course today is Families and Hearing Loss: Helping Parents with Emotional Impacts. We have with us Kris English from University of Akron, and I am delighted to introduce this course. I'm Donna Sorkin from Cochlear America's HOPE program.

This program and really all of our HOPE Online seminars demonstrate our commitment to our recipient and clinical community. Our commitment to you as professionals and as parents really goes beyond the technology that children are using. We also want to
support you in your work with families. That addresses a wide range of issues and in this case of course the emotional issues associated with having a child with a hearing loss.

So we are really delighted to have back with us Kris English who is an odd gist and President-Elect of the American Academy of Audiology. Dr. English is an Associate Professor at the University of Akron and she is really a worldwide expert on audiological counseling and she's done over 100 presentations in different locations around the globe.

This is the third in a series that she's done on different aspects of emotional impact. She also did one for adults and professionals working with adults and she did a seminar especially for parents. So the parents that are signed on today you might also want to take a look at that recorded course. So with that I'm just so happy to turn the floor over to Dr. Kris English. Thank you so much.

>> KRIS: Thank you, Donna. I appreciate the introduction. The word expert always makes me cringe a little bit. I would never say that but I know I have an insatiable association living with one with a hearing loss or as a child or the context of a family all the way through the lifespan.

I came across this book that just jumped out at me with regard to children in general, and I wasn't looking for it but I picked it up because I am interested in how children do in school because it seems to be a direct correlation to how secure they feel within their family and of course that is what we're talking about today is parents and
their children

The purpose of this book is to take a look at the dropout rate that is happening across the United States. What intrigued me was, No. 1, Chapter 1, we throw lots of money into programs but the evidence shows that the programs don't change the children's commitment to academic success. The relationships do and that would be teacher to student relationship and also teacher to parent and parent to child. That is just consistent with what I have been seeing for a decade now in taking a look at what makes the difference in terms of helping children.

Today our topic is looking at emotional impacts at having a hearing loss and looking at how professionals can help families and parents and now I'm trying to figure out how to advance the slide. Melissa, I have forgotten. Doesn't seem to do it. Here we go. All right. Okay.

So today to break up our topic into two parts. First of all the concerns and then secondly strategies that we might be looking at down the road. What can we actually do. The concerns will be -- I'm going to back up a little bit. The concerns will be evidenced-based and we're relying on research mostly; although we have our own experiences. What does the research show us? And the focus will be on children rather than the complex family dynamic simply in the interest of time. So what do we have with regard to the concerns?

These are what could be described as the emotional impacts of
children and kind of the golden age of exploring this concern from the mid 80s to the mid 90s. Davis and colleagues reported in the Voltar Review by studying 40 hard of hearing children that the parents when interviewed indicated that their children with the hearing loss had friendship problems. This was relative to their own children, the children's siblings that is, and found that there was a difference. The children with hearing loss were struggling quite a bit.

When the children themselves were interviewed they found that 50% expressed a fear of being teased. Now, there is not a child alive who is not afraid of being teased but they went to the comparable data or normative data looking at children without hearing loss and found that only 12% of children kind of live under that black cloud.

So it is certainly higher than typical of comfort -- discomfort of making friends and, consequently, finding out what do you do in your free time after school, most of the children in this study were spending time alone.

Another study that same year we're taking a look at hard of hearing children of bigger number, of broader age group. They went about finding how are children handling the emotional reactions to living with the hearing loss? First of all by asking them to complete the following sentences: I am happy when, and I am sad when, the thing I like most in the world is, the one thing I would like to change is. And then finally, because I have a hearing loss.
Now, as you can imagine, as soon as you open up those gates a lot of input comes in and they had to do a qualitative analysis of those open-ended responses. But when they did, they found out that children who were hard of hearing reported a hard time making friends and, also, felt interestingly and surprisingly unimportant within their families. That was their perception.

When comparing these results to children who had no disabilities whatsoever, the differences were quite significant.

They also compared it -- these results to children who were visually impaired. They had like a second control group, as it were. And interestingly because visual impairment does not affect communication and friendships, children with visual impairments did not have the same kinds of results.

Another study taking a look at a different group of kids, again all hard of hearing, none of them within the deaf culture. Parents were being interviewed to find out that children with hearing loss seemed less emotionally bounded to friends than the siblings could you tell hearing loss and again another way to cross-check how are kids doing?

Finally, a study by Cappelli toward the end of that golden era that I mentioned, 23 students all hard of hearing took a look at is what called sociometric status. That is, where do you fit in the great scheme of things and that is typically in the classroom. The way to go about this is to collect first of all positive nominations. Positive
nominations would mean that I, as a researcher, for instance, would talk to all the children within one classroom and say, who would be the top three children you would most prefer to play with?

Now, you may not actually play with them but who would you prefer to if you had your druthers? And then the other side of the coin is a negative nomination. Who would be the three children you would least like to play with? So we have top social status and low social status and what they found out is that the children with hearing impairment were far less likely to be identified in the positive nominations and ended up with what could be called a low social status, 39% of the time. It is important to compare again to children without hearing loss. There is always children in a classroom of 40 who are -- have underdeveloped social skills or maybe quite troubled and other children tend to avoid them. But if you just look at the general collective of children you would see about 5% of children with social status that was rated as low. So that would be a significant difference again.

But we want to take a look at this. We know the cause is the hearing loss and there is multiple affects that we want to take, kind of explore a little bit this afternoon. All of them are related to the communication problems that are absolutely tied to the ability or inability to hear.

The first aspect that we'll take a look at is the child's self-concept. I bring this up because as professionals, of course, we're not -- I'm
assuming none of us onboard here today are psychologists, speech pathologists perhaps, audiologists, teachers, and we may not see ourselves in the capacity of talking about the development of self-concept. I'm just here to suggest that we might expand our parameters or our boundaries or borders on what we do talk with parents about.

So what about self-concept? First of all what is it? Psychologists describe it as internalizing other's reactions to ourselves. In other words, it is all input that we then live with as believing to be true. We tend to perceive that if someone says that we are a valued member of our family or an important contributor to classroom work or a good sportsmen either sportsmen like attitudes or strong athlete, we accept that to be true. And if, on the other hand, someone consistent message to us is that we're not particularly worthy of attention and love or that we are a burden, we would accept that to be true. It is really quite powerful. Children by a long stretch are not ready to reject those inputs. Only maybe in late teens, certainly in midlife might we be able to step back and say, you know, what I absolutely will not accept that any more. But children are very vulnerable. And children with hearing loss, the evidence shows, are or have a relatively poor self-concept. Let's explore why.

Back to the Loeb & Sarigiani they used a tool called the Piers-Harris and they had 80 items a children would complete and an example of them was, I have good ideas. When they took a look at the results from those children in that study, those children perceived themselves
as shy, socially isolated, less likely to have a friend, less worthy of having a friend.

Back to Cappelli's study that we mentioned before, they also in the other parts of their study used a self-perception profile for children that had 36 items and it took a look at all these components that might build a self-concept, am I socially acceptable? Do I look at least reasonable within the frame of normal? How do I conduct myself? What is my self-worth relative to others? Children with hearing loss perceived themselves as socially -- less socially acceptable and also that they were not quite up to speed with regard to scholastic and athletic competence and so on, on all the domains; in other words, they felt themselves falling short to some degree.

And then more recently in this study, but take a look, that is 10 years ago, Fred Bess took a look at adolescence and he was using a tool developed by the Dartmouth School of Medicine called the COOP Adolescent Chart, many, many items that a child would be asked to respond to. For instance, during the last month how often have you felt badly about yourself, many of those kinds of questions. His results in -- and this was one that had many participants, 1200 is really quite remarkable, found that hard of hearing teens indicated a significantly greater degree of problems in this self-esteem component.

This interested me. This particular -- I'm sorry, I'm going to skip to the next slide here first. So what do we mean, we've talked a little bit
about self-concept and the hearing loss. There certainly is what could be called the hearing aid affect. We don't know at all if there is a cochlear implant affect. That is not yet to be explored. But the hearing aid affect was first identified as a phenomena by blood and -- Blood, Blood & Danhower in 1977 wherein they ran a study of several -- a large group of college students showing slides of contemporaries and asking those viewer to say rate very quickly based on first impression, is this person popular, competent, skilled, likeable, intelligent and so on? And variations would occur, different color sweaters, glasses, and on occasion a visible hearing aid. And what they determined was every time the hearing aid was visible, the scores went down. And that is what they called the hearing aid affect because nothing else seemed to make a big difference with regard to that quick, snap judgment.

The study was replicated by Dengernick & Porter and found that preschoolers do not jump to conclusions on first impressions. They're more interested in finding out, are you going to share that toy or are you going to let me play with you? But by the time children reach first and second grade they're very sensitive, very astutely aware and picking up on the signals from the others about whether they are fitting in as expected.

Carolyn Edwards is a renowned educational audiologist in Canada. She reminded us that the hearing aid is so familiar to professionals who work with children with hearing loss that we tend to forget they can have a detrimental impact. She calls it an almost forgotten
dynamic wherein the device itself amplifies the difference between the child and the peers and I wanted to mention an experience I had one day that tells me that we can help. We can provide support for families not to resign ourselves to the fact that there is an insurmountable hearing affect and nothing that can be done about it.

I was in line with a colleague or rather a friend of mine in McDonald's. We're waiting to give our order. She had a six-year-old son with her who at the time was wearing what was really brand new, very brightly colored earmolds. They were blue. His favorite sport team color. But they were very different. And one little kid was scanning the landscape and saw the blue earmolds and immediately said as loud as can be, look, Mommy, he has gum in his ears. I thought this is going to devastate this little guy. He's going to be so mortified with his public attention. But interestingly his reaction was very different. He looked at Mom and Mom nodded her head and he nodded his head and it was over.

And so like I mentioned, my insatiable curiosity I had to ask about that later. How come he didn't get upset? Clearly you had a non-verbal communication. What was that about? She said oh, we've already discussed this. We've already prepared for it. We've had many conversations to recognize that most people don't know hearing aids or they're surely surprised to see them on a child. So let's agree now before it happens there will be some bumps in the road. When it happens we will be graceful about it and say, well, I guess they just don't know enough yet. So when he looked at me
and I looked at him, he was asking me, is this one of those times? And I acknowledged with my head nods so, yes, here we are. And so he already was ready to take that and move on because Mom had already prepared him for comments that would probably happen. And that got me thinking probably for the last 20 years, what else can we do to prepare -- help parents be prepared -- prepare their child for events that could upset them rather than say, you know, this is just part of life and we're resilient family and we can deal with this.

Our arrow then splits to another box of concerns. When a child has a communication problem certainly when the problem is the hearing loss, there is going to be an affect on the child's ability to express him or herself because there is less likelihood of having vocabulary in one's repertoire to put words to one's feelings. The evidence, the research shows, without a word to describe how one feels, one does not understand it. It is just a turmoil within. But one needs a word to be able to classify it and sort it and make sense of it and then deal with it.

So that is quite a limitation and again I remember working with a little guy who was coming to therapy to develop more listening skills. Mom had picked him up from school and I guess it was pretty tense in the car because by the time they got to the waiting room he was really agitated. Then he came to the therapy room and he was not ready to work many he was crawling under the table and flipping pencils around. Mom was fit to be tied. She didn't know what to make of it. She was embarrassed. She went in and asked him, what
is wrong today? And all he could say was, I'm upset. I'm upset. But he had no other vocabulary to explain why, what had happened, how he was going to deal with it.

Again, one of those knocks between the eyes kind of realizations that the impact of growing up with a hearing loss can result in a lack of vocabulary to express how one feels and that leads to a delay and understanding how other people feel. You really do need words to understand yourself first before you can understand hoars. And understanding others and aware -- understanding others and understanding others is a key concept of friendship development.

Let's see, Greenberg and Kusch had a study identifying feelings and there was a study looking at 12th grade females who had an emotional vocabulary of fourth grade, which again it is a bit of a domino affect. They're not able to understand themselves and therefore not understanding others either.

Why is this so important? Well, it is not new. I bet you haven't seen a picture of Freud in a long time in a presentation by an audiologist but I came across an interesting book written by a neurologist who had studied Freud. He called what he did for most people the talking cure. He couldn't explain it at the time but unless someone was truly psychotic broken, he found that if he just presented himself in the environment to be safe and a good, safe place to talk, the talker would be able to eventually work through his or her problems and confusions and come to some wisdom or understanding about it.
Well, Sue Vaughn took a look at this observation and found indeed when people talk through their problems and talk about what they're confused about, there is actually truly changes in the brain function. New, neurons develop and the more practice is involved, the more the new Rones stay in place and help us literally make up our mind or help us understand what we're thinking. So we're -- I'm giving you a very long preamble but how are we going to help parents to help their children put thoughts into words? We'll get there in a moment in part two.

Finally, this all cascades to social competence, friendship development which is key and I bet you may not be as -- wouldn't maybe not necessarily agree with my feelings but when I went to school the only reason I went was to hang without my friends, and, you know, learning was secondary. I would pick up a few facts here and there but I wanted to be with my friend primarily.

What does social competency mean? There is actually according to Greenberg & Kusch seven domains, and this is one framework to work with.

Take a look at how they build and build and build. In other words, one cannot happen until the next one is happening. The first one is good communication skills and we already are in a deficit mode with children with hearing loss on occasion. That leads to capacity to think for one's self-. Remember your Mother is saying would you you jump
off a bridge just because your friend did. That is what she's trying to get at, think independently. Then capacity for self-direction and control and understanding others, being flexible, being able to tolerate frustration. Remember thinking about that little guy who said, I'm frustrated. He was not able to tolerate it because it all went back to his underdeveloped communication skills. And then ultimately healthy relationships.

Back to another study from '92, these researchers found looking at preschool environments that children with hearing loss had fewer opportunities to practice. These conversational and communication skills and when social rules were starting to be infracted but not sharing and taking one's turn, and what they found is the teachers and the adults would dive in and repair it rather than give the child the opportunity to figure out how. So parents and professionals may inadvertently think that they're helping but it is interesting one only learns how to be a three-year-old from another three-year-old where that peer-to-peer is vital. In adults, you know, again with good intentions interfere it could delay that social development as well.

I do want to point out that all those studies were from two decades ago. What is the case of the situation -- the world today?

Well, Mary Moeller makes a good point in a medi analysis of these studies. She had this published slightly over a year ago to take a look at the current state of knowledge. What she finds out is first of all we cannot compare one study to the next as an apples and oranges kind
of a thing. Not the same kinds of children. Not the same ages of children. Not the same measurements. Ultimately what she wanted to remind us, we have a new generation of children since those studies were conducted. Children identified at birth, amplified immediately thereafter, implanted within the first birthday. We don't know enough about how they're doing and just informally I still note and I imagine most of you do, too, some children struggle. Unilateral so knowing this is not necessarily particularly-helpful to us. I kind of gave you a crash course of oral rehab 101, for instance. And I would like to posit that knowing that these are not going to be enough. It just stays on the back burner. Our challenge is not to only use our thinking mind with these data but also use our feeling mind. This concept comes from Daniel Goleman's book on emotional intelligence. And I wonder if we could have a vote, those that have read the book could we have a show of hands? I'm not seeing anything here. I'm not sure it is possible.

Interestingly it was a best seller and in 2005 a 10 year edition was released. It is still a very popular book. I strongly recommend when you have free time to get around to reading it. It is in your library and it is remarkable.

What he presents really overwhelming evidence to show that we think and feel at the same time. So let's kind of shift our minds from the thinking mind to the feeling mind for the rest of our time together.

The five domains of the emotional intelligence that he describes,
these will sound familiar because we're already addressing them indirectly knowing one's own emotion. That could be called self-awareness. Managing one's own emotions. Unlike the little boy I mentioned that was crawling under the therapy table, can you shake off a bad mood? Can you practice self-restraint? Ultimately can one motivate oneself not to be impulsive which is a common observation in children with hearing loss but to delay the immediate gratification to what might have been pleasant and get the hard work done ahead of you. I think something is missing. There is five domains and I guess we're only focusing in on these three.

There is a paradigm shift in our approach that we want to be aware of. Please hold -- if you don't mind excuse me for just a moment. I have a bit of a cold and I feel a sneeze coming on.

I apologize. I'm back. That shift that I referred to with regard to using only ones thinking mind but also in addition using one’s feeling mind, that means being a little more open and a little more receptive to who we are as social beings, emotional beings and trying to work with that.

There is a very interesting report that was published by the Pew Health Foundation in 1992 taking a look at what can be viewed as relationship centered care. First of all that is a review to look at what care has typically been in the health setting. Initially it was steers centered. And that makes sense. That is kind of how things started about 150 years ago. But patients were chronically dissatisfied to
say, you know, my experience of living with this disability or this disease is not being respected or factored in at all.

The next step occurred from that clinical care, clinical model that we're so familiar with to what is called patient centered care in the 1960s but what was still missing was a sense of even if we focus all our attention on the patient they're not the only one in the room. We have a professional here as well. In fact when we're working well together between us we've developed a relationship and might that have actually been helpful to us. Might that be something we could billed on.

Well, they took a -- listened to patient reports and focus groups and found that when healthcare works well for patients, the relationship with their provider may often be the most therapeutic aspect of their encounter. And then they started looking at patients with really hard decisions to make. Sticking to a dialysis treatment. Sticking to a very strict diet. Deciding to quit smoking. They found that when the hard decisions had to be made, they were far more likely to be made when the patient also reported feeling a therapeutic relationship with their healthcare provider.

The evidence to that is really quite overwhelming so I'm quite -- I wait for evidence to convince me and I am convinced there is something to this. What they concluded in their monograph is that relationships between -- help patients grow in the face of changes within themselves and their environment. And as I first read this
article I was reminded so frequently of previous career I had as an educational audiologist sitting in on IEP meeting after IEP meeting wondering what was the disconnect? I could bring my records to indicate, for instance, that to the parent that his or her child had been optimally amplified from the moment they got off the school bus until the moment they went home and we had back-up hearing aids and Soundfield systems and everything we could do. They would be quite appreciative and that was fine. But over time I started to realize this that parents were not yet there in terms of that hourly, daily commitment. They were quite comfortable with the child leaving the hearing aids off when they got home from school and then weekends there is camping and not so much with the hearing aid use or again I can't speak to cochlear implants because it is quite different. But then think about all summer, too, months and months of little or no amplification. I began to wonder, did parents lack a relationship with their healthcare providers to help them understand why there was such a strong interest inconsistent amplification and might that have been better if relationships had been properly developed?

Well, from all that evidence it is starting to shift to the training being made available to professionals. For instance, this is a classic textbook being used in medical school. They're talking about the initial medical interview. Take a look at the first function to do is to build the relationship. Then one assesses the problem and then manages the problem.

So in medical school and certainly slowly but surely I can speak to
audiology and speech pathology we realize that relationship is vitally important.

The highlights from all of this is to remember that I'm indicating the audiologist but all healthcare providers onboard with us today, only we can advance the patient relationship. If the parent desires it but the professional says no, it will not happen.

How to build trust toward this relationship building means that we have to think about what the word "expert" means. I mentioned a certain sense of discomfort with that word in the beginning. Most practitioners feel that they deserve expertise recognition because they have a degree and experience and a license. But there is more to it when you think about the relationship that, of course, the patient or the family knows as much about living with hearing loss and certainly more than we do. So that needs to be factored in.

The first goal then would be to give the patient or the family every reason to find ways to trust us.

Well, now, we're at the how. How are we going to help that? How are we going to enhance the centrality of the child audiologist relationship? And I would say by proxy we're really looking at enhancing the parent-child relationship with the audiologist's support because we're not raising that child, of course. The answer would be, if you think about that three-pronged arrow, we're going to zero in on how we can provide opportunities to give a child practice with
self-expression and also self-awareness and self-understanding. Just another moment.

>> CAPTIONER: Please stand by. Your event will continue momentarily.

>> DONNA: Kris will be right back with us. She's been not feeling very well. Just needed to take a little bit of a break. So she is back.

>> KRIS: I'm sorry, Donna. I thought I turned it back on. When did you lose me? Shall I go back?

>> DONNA: I think we didn't have that slide at all. I think you should start with part two strategies.

>> KRIS: Okay, much apologies. I'm also on some medication owe a little bit off the track. Okay. So let me kind of refresh my memory on where this segued into. Yes, okay.

So we're now at the how part of what we mean by helping families, helping us develop relationship with families and encouraging family to say help provide children opportunities to express how they feel, express and understand their own awareness of their reactions to life and circumstance which is would lead to self-understanding.

We are talking about counseling. This is short-hand term for a slew of strategies and concepts, but I did want to clarify when we mean counseling in this situation, we're not talking about the usual informational exchange. I have information about how cochlear implants work so let me explain that to you or I have information on why you should be wearing amplification or your child everyday, all day. I will try to persuade you to see it my way.
Rather we should go back to the field of counseling and take a look at what they describe it as. It is not a one way monologue. It is a two way conversation, a learning conversation in that there is two sides to the story and let's both find out what we mean.

To help open the door, I find it helpful to use the metaphor of a door between myself and the other person; either the parent or the child to say, it just inherently is human nature there is something between us. So let's think about what we can do to bridge that gap to open the door.

One of the safest ways to go about this is to use a self-assessment. I have a couple of examples in a moment. A self-assessment is where a person will look at some questions independent from my clipboard and my questions to them directly. But how would I react to a situation? What do I think about a situation? What are my feelings, strong or not to my circumstances? It takes the pressure off what we could call that personal self-shores.

Most people, when we're talking about that notion how to establish trust early on there is very little trust. Even if we're seeking to trust there has to be some ground work to be built. We can also find out just more about what the children is perceiving by seeing the self-assessments.

One of them that is available and by all means feel free to e-mail me.
I would be glad to send you a copy -- is called the "child peer relationship scale" or the CPR scale. It is just eight items. The thing that really seems to be necessary is to remind the child it is not a test. This is simply a way for us to talk to each other. Certainly this could be shared with parents as well. It has eight discussion points. It is meant to broach kind of warm up to the topic of friendship development. One of the questions might be, for instance, mostly other kids like me or sometimes other kids don't like me and the last one other kids don't really like me. Now, it is difficult to have children indicate that last box. But very important to broach the topic rather than to pretend that all is well.

These are some other items. The first one is actually a warmup, not related to friendships per se unless it is indirectly so but I like school. School is okay; or, I don't like school. That gives a little bit of practice on how to think through the three options, check where I stand right now, then let's talk about it a little bit. Another item is I have some friends at school or I don't. I have a best friend. I sort of have a best friend.

Interestingly when this was first piloted, an audiologist was very interested in the fact that one of the children had indicated, I have a best friend. And she said oh really, who would that be? And she mentioned a little girl, let's say her name was Mary. And she said that is nice to hear. She then cross checks with the teacher who is quite surprised at that answer because to the best of her knowledge the child with the hearing loss and Mary are never in the same
conversational space. They don't stand next to each other in line. They don't play outside together. This is what the child might think might be a best friend. But it is kind of a wishful thinking here. It was helpful to find that out, her perception. Of course, life is not all about school of course. There might be life after school and maybe that is important to find out.

There is the issue of teasing, the issue of whether one is alone in the world with regard to knowing other children with hearing loss. Because the research shows that is very important to have a peer group. It would be worth finding out.

Finding out just a personal reaction about wearing their amplification devices and what are their reactions. And that is a third thing as they say. It is not me drilling you on -- and asking you to spill your guts as it were which most children are not going to do because they don't necessarily trust us. But this would be a way to say so here is the results. What would you like to talk to me about them?

I mentioned the pilot study. We had 22 children complete this just to see what was the language -- not confusing, were the choices pretty clear? We had the age of 7-10 years old. We also asked the teacher to say complete a version for their -- for the child in their classroom. I was wondering how accurate would they be to predict the answers for those children? Well, we found out that they only correlated 40% of the time. And a guess would be 33%, 1/3 for each. So it made me worried that we might over rely on teacher reports by indicating
or determining that apparently all is well or not. We probably should go straight to the source and ask the child.

Another way to model or to move forward in opportunity to discuss these issues is to ask a child, how would you complete this sentence? I am happy when? And maybe just leave it at that the first time at the first appointment or the first effort. Because what I notice that is many children more so with hearing loss than not have a hard time answering that question and how lovely to finally put into words what makes me happy. Then another time it feels safe to say so, how would you complete this sentence? I am sad when or the thing I would like most in the world and so more. And again that comes from Cappelli's study.

Another example would be scenarios -- and I have one to show you in a moment. This scenario is actually this -- this strategy is actually being used by a young lady who had just entered a residential School for the Deaf and was never fish nor fowl as you could say. Did not have communication down and very little sign language and here we're talking about a 14-year-old at a deaf school who is going to have some trouble struggling this with fitting in. Really had no self-advocacy skills and could not identify what the issues were nor how to address them.

This is available free from the Educational Audiologist Association. I think there is 24 plates altogether, and there is the 800 number and for shipping and handling and they'll send you a copy. I would also
be glad to send that to you as well.

It is called the Hearing Performance Index for Children or the HPI-C. Here is one at the plates and it says underneath, this teacher is talking. He's in front of the class. Does your teacher do that? Is it hard to hear him speaking?

I do want to caution the adults that want to jump right in and say what you could do is move to the front of the class and insist we use an FM and all the other solutions. But really the point is to find out, of course this happens on occasion. What are your strategies and what are your reactions? Let's find out from the child first to really explore that and see if they can see themselves in the role of being a problem solver.

Early on children don't see themselves in that role and other scenarios it shows the class is giving a test and the teacher is giving direction and is this hard for you and listening to announcements on the PA or fire drill or kid when you're in the locker section of the hallway or in small groups. We know the answers. We know that these happen all the time in school. What we're looking for is to explore how children can express their responses to the situation and also whether they have any strategies on how to repair them. Again holding back and not owning it as it were. Children need practice, practice, practice on explaining themselves, understanding it before they can handle it themselves.
One might want to go the route of Oprah who has made a national past time of book clubs. This is one that is out there. I would suggest you read it yourself first before you decide it is going to be helpful or not. It is called alone in the mainstream. It is a controversial book and has an agenda. What I would like to know some day is it is reflective of this woman's childhood several years ago to today. What she was reporting but with an interview of 60 hard of hearing and deaf adults who all grew up at the same time that she did that the school -- school age experience and mainstream was resulted in an excellent education. No one disputed that. But the social isolation was really important to consider.

She also reported that the children were not educated about their hearing loss because they were the one and only and no one had taken the time or recognized the need for them to understand what they were experiencing.

A friend of mine had run kind of like a focus group during the summer many it was meant to be a high school class but 12 teens would sit around and talk to each other and at one point a teen said, I am so tired of my familiarly, I feel like leaving them. Last night at dinner was the last straw. They were having their dinner conversation and once again forgetting that I couldn't follow them and I'm so disgusted and angry. The other 11 teens were so surprised to find out that her family was exactly the same as their family. They had the same dinnertime challenges. They did not know this is part of the condition of living with the hearing loss. They thought it was their family being
mean and exclusive. And, so, it was one of those universalization experiences. Well, that is helpful to find out. What might be due now that we know better.

Another outcome from Gene Olean's study, many persons growing up as hard of hearing the one and only in the schools, they called them solitaires, tried to see why they had a hearing loss because thing in Tennessee was to feel that you are not different. That is a bit of a -- like living a lie. I think you would agree. It is not a healthy way to keep one's self-presenting one's self to the public and what I found this exercise, especially young teens what this means in terms of disclosure. Breaking people off into a team or even a one-on-one to say, you know, there is pluses and minuses to every decision.

What would be the pluses of hiding your hearing loss? And kids come up with a lot of interesting suggestions. Well, what would be the minuses and that would be really starting to push to realize you're actually sacrificing some things there and then what would be the pluses and minuses of acknowledging a hearing loss? Again, we could already predict as professionals and as parents what those answers are but what would be an opportunity to give the students, the children an experience and practice to describe and explain what they already are aware of, but maybe they have never put them into words before. Again, I have done this as a team activity, but I've also done it one-on-one. If the time allows or maybe just one-half of it or one quarter of it just for practice and opportunity.
So that notion of keeping the door open, we have to remember that once we've opened it, we do have to actively listen to what the child is hearing -- what the child is saying to us and that we're really struggling to understand not to solve their problems or own the situation. It has been said time and again -- just as a reminder -- listening is not passive. We might use minimal encouragers which are simply head nods and acknowledgments, really, I did not know. Paraphrases are opportunities did I understand you right this is what you're saying? We do this with our friends and family members all the time but we tend not to take the steps with children for whatever reason. I'm trying to check my understanding. And can knowledge the feelings that I do believe I heard.

Acknowledging feelings you're thinking we're switching from Oprah to Dr. Phil, but I do have to say he didn't invent it. In fact it has been classic ways of healthy people helping themselves many there is no magic bullet or script to follow. Just an indication that you're trying to understand and not just the words but the underlying emotional responses behind them.

If we think about wanting to encourage children to transition or evolve from not being immature to being mature, to taking on responsibility, to becoming a self-advocate, that is a change and making a change is scary and it as Stone indicates in their book difficult conversations people almost never change if they don't feel understand.
There is a misstep that we want to be aware of what could be called counseling by persuasion, trying to encourage the people to do things what -- what we think they should do without their full buy in just because I have all this information and they don't mean that is going to work. We might want to -- when we're in a point of our conversation we may say something that was come up. Before we get to this I would like your input. How ready are you for this to happen? And I use this routinely in the school setting because I was given a budget to purchase FM systems and finding out because I was naive that students didn't necessarily want them. So I had to adjust my approach to say before I spend taxpayer dollars on this expensive equipment I need to know if you're ready to use it. On a scale of one to 10 -- and I brought this task down to five years old and people seem to understand it. They know that if one means not in a million years I'm not going to use it no matter what you say up to 10 meaning I'm absolutely ready, this helps me find out what they're thinking, what is on their mind, why are they not ready, what are the conditions that will help them be ready. And again, it is just one more strategy to help have a child put into words their responses to the situation.

Now, let's compare of all these strategies to a case study that came my way not too long ago. I'm not sure why but an audiologist from a Children's Hospital called just to give me a heads up to say, so we've got this little guy. We identified his hearing loss two years ago. He's been wearing his hearing aids. We think fairly consistently. But lately something has come up. He's been telling the school he left his
hearing aids at home. But then he goes home and tells his family he left the hearing aids at school. So they just dove in without talking to him to develop a behavior modification program.

Now, I won't take the time to ask what you think on this but research would show this probably won't work. You'll probably have a short-term gain because there is going to be a reward. Right? That is the whole point of behavior modifications if you wear the hearing aids every day of the week you get pizza on Saturday. Is it likely to affect real change in probably not. We never really found out what was going on to begin with why not? What could we do instead? These are some strategies or the strategies that I brought up for your review and your consideration might be some ways to go about what is going on really.

And then the notions of relationship because we were referring to this before, relationship centered care. I see my bullet jumped around a little bit. The idea two things could be confused. Professionals in particular feel responsible but I'm talking about a different look on things, about being instead not only responsible but in addition being responsive. What are the differences there? This comes from a lovely book called skilled dialogue and it is while feeling responsible means I come up with the solution and the answers and I manage and I own it and there is a right or wrong and no discussion about it and we focus on details and performance.

Having been part of educating audiologists for several years, I think
this describes audiologists a lot. Maybe not speech pathologists. I think they might be admit that regard and certainly teachers.

The comparison to being responsible would be to be responsive. And what is more important than the solution is the dialogue. Again, the opportunity to create, co-create some results and some plans and providing choices rather than the one choice that I know what you should do and therefore we will do that. Listening and gathering in multi-perspectives and that means you have to live with ambiguity. You have to live with sometimes conflicting points of view. But hearkening back to buying FM systems for children who would not use them, I was taking a misstep. I was assuming that my authority of an audiologist was going to carry the day. But I didn't recognize that the children had their own points of view, their own conditions, their own perspectives. And I was really tunnel visioned and absolutely missed something and missed the opportunity to talk with them, so there is a process rather than focusing in on immediate outcomes, okay, and that allows us a little bit of time for questions.

>>> DONNA: This is Donna back again. We have time, if people want to type their questions to Kris, there is a little chat area on my screen. It is on the left side but while I give you some upcoming information I would like for you to type your questions to Kris. We have some great HOPE Online seminars coming up, including show me the money, which is going to be about reimbursement for therapy and that will be on February the 5th. And then the following week Mary Kay Therres will be back with us on what to do when cochlear implant outcomes are guarded, and MaryKay is a great speaker and
has been with us before.

We have some live workshops coming up in our tour with Teresa Caraway and Joanna Smith. Actually hesp location has an adult habilitation element in the evening and then the following day is an intermediate level pediatric habilitation workshop. We have two of those left this year in March and April and I have given you the locations there so we encourage you to join us if you're in those locales.

We have three remaining locations left in 2009 with Don Goldberg and this is one day introductory seminar for intervention and educational professionals and I've given you the dates and locations there so again I hope you'll join us. These are also appropriate for parents of young children.

We're doing the same tour in two other locations with Mary Kay Therres in Central Michigan on March 3rd and then Rochester New York on March the 5th. There is two different sign-up areas for those two events.

And then Kris has been very kind in sharing her e-mail with you so you can do some follow-up questions if you want after the seminar. As always, I welcome your input and ideas and please return the feedback form to the e-mail address there. I'm going to turn it back to Kris. Kris, it looks like you have got some great questions there.

>> KRIS: Yes, thank you, Donna. Actually one person asked about
contact information and I was going to advice it would pop up and there we are. Please feel free to stay in touch with me.

One person wrote are the challenges at dinnertime the same as for CAPD children? The answer is I would probably expect that they would because what is happening at dinner of course it is not hearing pure tones it is listening and that is the challenge that APD children have as well.

Another question comes up the child about the kids in McDonald's, we have used that type of situation as a means of spreading the knowledge about hearing aids and hearing loss rather than ignoring a person's comment. In all instances, the information was welcomed by the people who did not have any experience with hearing aids or cochlear implants. That would probably -- I had to move maybe a year of that but knowing this Mother that would have been her plan. As a 5-year-old I'm imagining she didn't expect a 5-year-old to go into any great lengths of discussion. She just mainly wanted to protect him in terms of what people might say. But that would be the next step in terms of self-advocacy, wouldn't it, to be able to say. Glad you asked. Let me tell you some more why they're blue. Here is what I have got and why I'm so happy that I have them. I'm sure they're there.

I wanted to end on a slide and I realized I forgot to send it to Donna and you don't have it. But there is an interesting book called "hear if you need me," and this is really the theme that I was trying to
develop throughout our time together was, when parents are working
with or concerned about their child's emotional reactions to the world
around them and living with the hearing loss, can we say that we're
here if they need us? This woman who wrote it was a chaplain for a
warden department -- I'm not saying that right. It is a warden
service. It was in the mountain, in the hills of Maine. And she was
meant to -- she was on-call and would be called upon when things
happened when they felt that they could use a chaplain. And the
book starts out with the anecdote wherein a little girl wanders off
from a family picnic site and is lost enough where they need to call
the wardens to bring in a search team. With that call comes the
warden as well. So the search team is out there in the woods looking
for the daughter. The Mother turns to the chaplain and says, it is so
cool that the warden service has a chaplain to keep us from freaking
out. And she says ah, I'm not here to help you to keep you from
freaking out. I'm here to be with you while you freak out or while you
grieve or laugh or suffer or sing and I see the role of the professional
working with parents to be with you, with them while they suffer,
while they grieve, while they laugh. Again, that relationship is
centered care.

I'm going to see if we have any more questions. Cochlear implant
children are mainstreamed at a young age into the regular ed
classroom. Our efforts to assist their self-advocacy are different due
to developmental level many thank you, Patricia. I would say no. I
think they may be more advanced because they may have been given
advocacy skills earlier because of the nature of their care. But I
would take every child as they come and determine what they need.

There is a wonderful tool developed again by the education audiologist association called Kip, knowledge is power. I bet people on this list of attendees are already familiar with it. But it has several self-advocacy skill domains that are developed by beginner, intermediate and even an advanced level, and those are available for I would say $40 these days. I think that is all for our questions.

>> DONNA: Kris, I would like to thank you for being with us again. It is really wonderful always have to you at a HOPE session. Thanks to all of you for joining us and we'll see you next time. This is Donna Sorkin from Cochlear America's HOPE program.

>> KRIS: Thank you.

>> CAPTIONER: Please log out. Your event has ended. Thank you.

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