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Providing Support to Families
of Children with Hearing Loss
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- [Carolyn] This time it's my pleasure to welcome Dr. Madell to SpeechPathology.com. She is a licensed pathologist and speech language pathologist as well as a listening and spoken language auditory verbal therapist. Her clinical and research interest include hearing in infants and children, management of severe and profound hearing loss, including hearing aids, cochlear implants, FMs, and auditory processing disorders. She has published five books, maybe more by now, she did submit this bio a few weeks ago, numerous book chapters, and articles. She writes the hearing and kids section of HearingHealthMatters.org blog. She presents nationally and internationally on topics related to hearing loss in children. Dr. Madell, thank you in advance for your presentation today and turning it over to you.

- [Jane] Thank you Caroline, I'm excited to be here. Yes, it's seven books now, we need to change my bio. Okay everybody, this is a topic I absolutely love. I think that if we're gonna do well for children with hearing loss we really need to be sure that we're supporting their families. So that's what I'm gonna talk about today. If you have questions, put them up, if I'm not clear, put the question up as we are moving along and if it's something that I think I need to answer right then I'll try to answer it. If the questions get too much, I'll hold them out until the end. Okay. Hmm, I've having trouble moving the slides. The learning outcomes. After this course, participants will be able to explain the effects of hearing loss on families and the support that parents need when a child has a hearing loss. We'll also talk about the key components of support groups for both parents of children with hearing loss and for children. And then we will talk about ways that professionals can help children with hearing loss and their families to advocate for themselves in things related to hearing loss. So, let's just start off with the effects of hearing loss on families. When I started in this field 100 years ago, we didn't have newborn hearing screening. So babies were not identified until their parents noticed that they weren't developing speech and language. So it took a while, but things, and so they already had a relationship with their baby when the diagnosis of a disability was made, that's not the case anymore. Now with the advent of newborn

hearing screening, babies are identified at birth, so families don't develop a bond with their baby before they get the information and they don't have time to recognize that something might be wrong. For 95% of children born with hearing loss are born to families with no family history of hearing loss so parents are stunned when they get this information. They don't know anything about hearing loss, if they know anything it's grandpa who has a hearing aid that he hates. And so they really don't know what to expect or how to proceed. So what happens, what do they need? Parents need help accepting the hearing loss, accepting that there is in fact a hearing loss. They need help understanding that hearing loss is a manageable disorder, that if we do what we need to do this kid is gonna be great. And that's what we need to help them understand, and we can only help them understand that if we absolutely believe that. We need to believe that hearing loss is a solvable problem, and I absolutely believe it. So we need to discuss for parents what has to be done, what kind of medical evaluations does this baby need now?

Talk about technology, help them accept the fact that they're gonna need hearing aids and talk about the value of an auditory based therapy program. We also need to tell parents what all the options are, but I think telling them what the options are includes being honest about what the options are. What kind of language will a child develop if they have one kind of therapy, if their parents choose one communication mode versus what happens if they choose a different one. I think every family of a child with a disability and certainly children with hearing loss need support groups to help them feel that they are not alone in this situation. So when do they need support groups? Certainly in the beginning when they're so overwhelmed they can't figure out where the door is, and a support group can help them meet other families who are a little bit ahead of them so they can feel like they aren't alone in this world. When we're changing technology, if you have to move from hearing aids to a cochlear implant, that's traumatic and parents need help there. They need help if they can have CI surgery when they're starting school or changing schools, those are all times that are

stressful for anybody and especially for a child with a hearing loss. Lots of people feel when friends of theirs, their children are having conformation or bar or bat mitzvahs, those children, they see other children doing things, they want to know if their child will be able to do those things, and those again are times when they need a little more support either from us or from other families. So how do we provide support to parents? Most hearing loss is identified at birth, as we said, and there are really big advantages to that.

The child's listening age, the time from which they get technology will be the same as their chronological age or very close. When I started in this field, we didn't know the kids had hearing losses until they were between 18 months and two years, so their listening age was two years behind their chronological age. And that makes a big difference in the way they develop language and it makes a big difference in the way that families feel about their children. So we can start fitting technology at birth. Babies get hearing aids within a couple of weeks, we can start therapy early, and the language delays will be limited.

The disadvantage is that the parent didn't know and love the child before getting the information that they had a hearing loss, and sometimes that can be an issue. So scheduling parent support groups can be a little difficult. If children go to a center where a lot of children have therapy, then we can schedule support groups during therapy times so that there are several families at once who are together there at the same time and having therapy. If we get scheduled support groups in the evening, parents who work can be involved, some afternoons may be better, weekends may be better, and sometimes it's just an occasional group, a monthly group or a weekly group that will help families be able to attend and participate. And the advantages of a support group for parents of hearing loss or other disabilities or disorders, they can communicate with people who have been through the same experience. The audiologist or physician or the speech language pathologist or auditory verbal therapist

may know a lot about hearing loss but we for the most part have not been through the experience of having a child with a hearing loss. So we know some things but we don't know other things that a parent can know. There are different types of groups. Some of the groups are topic based and for parents who are very busy, they're more likely to take time out to go to a meeting that is gonna talk to them about how to improve speech and language, how to get your child to do something, how to transition or pick a school, than they are to go to a group that's gonna help them talk about them. So you have to figure out what's going on with the families and whether they're able to deal with what kind of group they're most likely to attend.

There are newly diagnosed parent groups, mother's groups and father's groups. And mothers and fathers, even with the maturity we have today and the different ways we think about life, mothers and fathers often have different concerns about their children. Mothers may have more social concerns, and fathers may worry about what is gonna happen to this child as an adult and are they gonna need care. Which they're not, nowadays. There are also grandparent groups. Grandparents have a particular interest in how children are going and how they're developing, and sometimes grandparents can be a benefit and sometimes they can be a difficulty. So support groups for grandparents helps us talk to grandparents about what their role might be. I have had grandparents who told, who when they were babysitting for a child, didn't want them to wear their hearing aids.

That's obviously gonna be a problem for speech and language. There are other grandparents who just say it's gonna be all right, it's gonna be all right, don't worry about it, but aren't willing to put in any effort. And if they are people who are caring for children on a regular basis, that's something we need to work on. It's also important to have sibling groups. Siblings of children with disabilities really struggle. The child with the disability gets an enormous amount of attention from the parents, and sometimes they feel overlooked. They may not really be overlooked, but siblings need a little

support and support from other siblings is sometimes very helpful. So what types of groups are there? There are, as I said, there are informational groups, we're gonna talk about technology, we're gonna talk about school, we're gonna talk about dealing with other family members. And then there are support groups which deal with emotional issues. Groups for mothers or fathers, mixed groups, siblings groups, and grandparents groups as we've said before. All of those can deal with emotions. Basic information about technology is critical. Hearing aids work well for children with mild to moderate hearing loss.

Cochlear implants work well for children with severe and profound hearing loss. But before children are considered for a cochlear implant they will have had a trial period with hearing aids. Some children with moderately severe hearing loss will do well with hearing aids, but others will need implants. All children with hearing loss will need an FM system in school and in other difficult situations. And this is sometimes a problem, as kids get older they may not want to use them, but if they don't then they're gonna have difficulty hearing when the person who is talking in school is more than three feet away. So here is a slide that just sort of shows who everybody is. The child, my arrow isn't turning on.

Okay, the child is in the center, as you can see, thank you, oh. Thank you very much Caroline. The child is in the center but there are a lot of people who surround the child, and all of those people are critical for a child to be successful. The family and extended family, educational audiologist in the schools, the clinical audiologist, the physicians who are dealing with the child, the school speech language pathologist and the one, and maybe there's one outside. Social worker, psychologists, educators, all of these are critical people in this child's world. And we need to be sure they're all communicating with each other if this child is going to succeed. Let me just give a short summary of the roles of the different practitioners. The audiologist is the person responsible for diagnosing hearing loss, evaluating and managing the technology, for

counseling parents and children about the effect of hearing loss, and helping schools staff understand how to manage a child with hearing loss and how to make that child's life a success. The speech language pathologist and listening and spoken language therapist are going to evaluate speech language auditory skills, develop a plan for building skills, provide therapy, monitor progress, and the speech language pathologist obviously needs to be talking with the audiologist. Deborah asked whether a child with a cochlear implant will have difficulty hearing in school without an FM system? Yes, the child with a cochlear implant will still have difficulty hearing in school without an FM system. Every child with a hearing loss needs an FM system no matter what kind of technology they're using. When they get to be teenagers they often reject them, but if we can help them understand how much better they hear with the technology, we're making a big difference. Physicians, most hearing loss has some genetic component even though we don't know about it most of the time, or much of the time. So there may be many physicians involved in managing a child and the pediatrician needs to learn something about hearing loss because most of them don't know anything until a child with a hearing loss walks into their practice.

Educational psychologists are critical for helping to identify learning issues, and social workers and psychologists can both be very, are very critical in helping provide counseling and support to both families and children with hearing loss. Client-centered counseling puts the client in the middle of the procedure. So we don't want counseling where, it's not in the family's best interest for us to just tell the family what we think we should do. That is not always something that works well. It doesn't work well because it doesn't empower families to build their own skills and to move forward. Client centered counseling in the diagnostic process begins in the very beginning when we first have contact with the family. If a baby is identified at birth, parents don't have a lot of information about the baby to share, but if a child is diagnosed later, then there is information that the parents can tell us about what they see at home about what a child is hearing. If a child is diagnosed later they have more information, so it's important to

let parents share their feelings about what they have seen and what they are observing about their child. They need to be allowed to tell their story, what do they see, and what do they suspect? It's important to involve parents in the diagnostic process. When in audiology, we can sit the parent in the test booth with the child so they can see every single thing that's happening, that diminishes the denial mechanism of I'm sorry, I just don't believe he has a hearing loss because they're in the room with the baby. It also builds confidence between the parent and the clinician, so the parent begins to trust the clinician because they can see how the clinician is making a judgment about whether the child has a hearing loss.

And with speech and language evaluations about whether the child has a speech and language delay. The research is showing that parental satisfaction with follow-up testing of children who fail newborn hearing was very much a function of how empowered the parents felt in participating in the process. Parents have a vital role, clinicians do not spend all that much time with children. What we do is important, but parents are there full time and they have to make the decisions about what's going to happen and they have to organize the follow up. So we need to involve parents actively in the test procedure. Engage them as much as possible in seeing the responses. When I'm testing a newborn baby, I'm looking for changes in sucking, I want to look at that and help the parent, tell me if you see the baby changing sucking, let me know. If we're doing an ABR, if the parent can see the screen, they can help see when there's a change in response.

We can have the parent participate in the diagnosis and then they're more likely to accept the diagnosis. So they can look for responses in behavioral testing, the OBR, OAEs, we can let them see what the child responds to with and without technology, and that helps them be willing to accept the test results and accept what the child's hearing. In corroborative testing in the sound booth, we can have one parent sit with the child, and if there are two parents, have the other parent sit with the audiologist,

have them, the one who's sitting with the audiologist we can try to describe what we're seeing, tell me what you think about this, and for the parents sitting in with the baby, have the parent help you point out responses. In speech language evaluations, let the parent observe testing and comment on performance. Parents are very often surprised when their children show language deficits, and that's because they don't see them in the same way that we see them. They are working, the parent is working with the child alone and in a situation where what they do is expected. But they're not delving deep into difficult situations, difficult language situations, complex wording. So when a speech language pathologist does an evaluation and the child is making errors, it really helps if the parent can see the errors, because that helps them understand the results and figure out what they have to do at home.

It's important that families understand the listening bubble concept which Karen Anderson developed some years ago. It describes hearing loss in the terms of how far away a child can be to understand. We think of hearing loss as having a smaller listening bubble than a child with normal hearing would have. A child with normal hearing will hear you 10, 15 feet away, and a child with a hearing loss won't. So we talk about, when we describe what a child can hear, it's very helpful to some families to talk about a listening bubble. It explains why a child will hear loud sounds or may hear when you're close to him, but not hear when you're far away. The listening bubble is even smaller when there is competing noise.

So different voices can be easier for a child to detect. The bigger the listening bubble, a bigger listening bubble may be better for dad who's got a low pitched voice than for mom whose pitch is higher. The concept is also very useful for children as they get older to help them understand their hearing loss. Another concept is, another thing that's important for everybody to understand is speech understanding. Speech perception testing is usually described in percent, but not all people really understand the concept of percent, and it's hard to understand it for parents when they're thinking

about what their child is able to hear. So some people have found it's easier to describe it in terms of the pieces missing from the puzzle. And this picture that we have down here shows us here's a puzzle, and the black spaces are the things that are missing. So if the child's got, if you've got a hundred piece puzzle and you're missing 12%, it may not seem like much, 12 pieces, but if you've got a 50 piece puzzle and you're missing 60%, it seems like quite a lot of it that is missing, and that may be easier for some people to understand. So let's talk for a minute about the counseling role following diagnosis. All the decisions that are made for a child are based on parent choice. Parents make the determination about whether the child will wear technology and what kind, about what kind of communication mode a child will participate in. Will they use listening and spoken language or sign language?

So we need to provide parents with the information that will help them make an educated decision. They need to understand in depth what all the different parts of the process are. We need to help parents become empowered here because they need to feel that they can make a decision for their child and they can follow up on it. So we need to help parents understand what their goals are for their child. I say to families, what is your goal for your child? Where do you want them to be when they're five, and 10, and 15, and 20? Almost every parent in the over 50 years I've been doing this has said to me I want him to be able to go to school with his brothers and play with the kids on the street.

And then I can say to them well what do you think it takes to get there? If you want him to go to school with his brothers then he needs to be able to develop good listening and spoken language, and then we talk about what's involved in that. We need to be honest when describing all the options because all the options are not equal and we need to be clear about that. We have different expectations for children who are in an auditory program versus children who are in a signing program, and we need to talk to families about what those expectations are. We are not saying that one is better than

the other, we are just being very clear about what you will expect if your child is in this program versus that program. So the question always comes up how much should we answer for a family? This always comes up with cochlear implants, it comes up a lot when parents are trying to decide about communication mode and when they're trying to decide about whether to go on with cochlear implants. So if this was your child, what would you do? And that is a trap we need to avoid. I mean, I can say if Andrew were my child I would have a cochlear implant, and then they want me to decide which cochlear implant. No, we can't do that, because if we do that we're sending a message to the parent that the parent is not competent enough to be able to make decisions that need to be made for their child.

And that is definitely not a message we want to give. We need to have successful outcomes by making sure that the family are the people who make the decisions, and they can pat themselves on the back that they have done a good job. Families don't learn to become responsible for the decisions for their children if they don't make them themselves. So here are some counseling tools that are sometimes useful. Saying things like I can see that you're having a hard time with this decision, tell me why this is difficult for you. And let the parents talk it through. And then, do you have questions I can answer to help you make this decision?

And it's hard sometimes, I have my fingers in my mouth biting them so I don't open my mouth and say could you please hurry up here, we need this kid to get hearing aids on. But that's not gonna help, because this parent has to make the decision in her own good time. Routinely, we need to routinely and actively engage parents in dialogue about what the goals are for their child and what they have to do to carry over those goals, what do they have to do at home to make sure everything is working? We need an effective dialogue to help them understand, to help them be knowledgeable and what it takes for success for each of these options. What's the parent's role if they choose? Spoken language, what's the parent's role if they choose sign language? We

need to be familiar and we need to help them be familiar with normal speech language, auditory, and cognitive development. What do they have to do to get their child there? We need to listen to the parents. Having a child is stressful as every one of you who has had a child knows. Having a child with a disability is even more stressful because there are many more things to do and you always feel as if you cannot wait, you don't have time to sort of hang out. We need to arrange for parent support, counseling by a clinician, one of us or a psychologist, social worker, and equally important is parent to parent support. Parents who are a little bit ahead, parents who are a year or two ahead of a newly diagnosed family are in a different place.

The initial panic is over and they have a child who they see is progressing, and so they can be optimistic and that can help newly identified families be optimistic. We also need to be sure we're validating parent's feelings. That is just critical. So let's talk about what kind of support families need when moving to cochlear implants. Moving to cochlear implants is very traumatic. When a child is not doing well enough with hearing aids, then they have to make the decision to move on and that's difficult for families at birth, if we know the baby has a profound hearing loss, we know where we are, we know we're gonna have to move on to cochlear implants right away, but for a child with a moderately severe hearing loss, maybe they're doing okay and then they start not doing okay and we start talking about cochlear implants and this can be very hard.

It's always stressful for parents when they have to think about doing surgery on their baby. And making the decision for the implant is difficult, we need to help parents understand what kind of benefit the child will get if they get an implant. How will this implant help? You need to show them that hearing aids are not working well enough and show them what we expect from children with cochlear implants. And having them meet children with cochlear implants is very helpful. Speech language pathologists need to demonstrate why the speech and language skills are not progressing at a sufficiently fast rate. And that rate is one year's progress in one year's time. Social

work services can help families develop realistic expectations and provide emotional support. We cannot expect a family, a child, who has no speech and language before getting a cochlear implant to be speaking in three word sentences two days after surgery. It doesn't work that way. But believe me, there are families who think it's going to work that way. And even if we say a lot of times to them you're not gonna like it in the beginning, and when I say to teenagers or eight, nine, 10 year olds who we can talk to, say you're gonna hate this when you first get it, but believe me it'll get better. But they don't believe you, they think it's gonna be perfect when they get it and that's not gonna happen and so sometimes that's a problem. Families and children need to understand that it takes time to build skills and that a CI alone doesn't provide magic benefit, children still need auditory based therapy and they need mapping of their cochlear implants on a regular basis.

Okay, I'm not seeing any questions so I'm gonna go on and talk about support for children and then we can talk about, if there are questions about parents we can talk about that at the end. Okay, so what is the issue? Children with hearing loss are, for the most part, are educated in mainstream settings. 85% of children with hearing loss are educated in the mainstream. The advantages of mainstream education are that the kids have normal language models and the school has normal developmental, academic, and social expectations, and these kids have a better opportunity as adults because of their language skills. The disadvantage is that they're often the only child with a hearing loss in the school, so they have no contact with other children with hearing loss. That's a problem because they have a disorder that requires that other things happen, that they need therapy, they have difficulty hearing in certain situations in school, they're gonna have questions about management, and that's gonna be an issue with them. Meeting with other children with hearing loss is often a very big problem. Children with hearing loss, if their language skills are not at typical hearing levels, will have limited social opportunities, and so we need to figure out what we can do to help this, and providing support groups for kids with hearing loss is one of my very favorite activities.

So what kind of support groups do these kids need? They're in a situation where they have better academic and language models, but they may frequently be isolated and their friends don't understand the issues of hearing loss. If they go to someone's house and have a sleepover they take off their technology to go to sleep, they can't hear anything that's happening as they get older, social issues become more significant, kids in special education classes feel less isolated, but they have lower expectations and they may need assistance dealing with people outside of school because they don't have language skills that will enable them to do that. So as with parents, we have informational counseling and support counseling, and we need to provide both. Informational counseling, we provided a lot of informational counseling to parent when the children's hearing loss was identified.

We don't always think about the fact that we need to provide the same kinds of counseling things to children and we need to do that as soon as the children are ready to get it. So social skills we need to remember are dependent on language age. Children socialize well with other children as long as they have the language to communicate. Children do really well in preschool through first grade. By the middle of second grade, if language skills are not equal to their peers, they're going to start having socialization problems because they can't follow the games that are being played, and they can't participate as much in the discussion.

By the age of eight or nine, children begin to recognize that they are different. As children get older and are more aware of hearing loss, the fact that they're different, they begin to resist things that can help. They may resist wearing an FM microphone, some of them resist going to therapy and some of them decide they're not going to wear their technology, which is going to be a disaster. Children with disabilities are also more likely to experience bullying, and it's the responsibility of all of us who work with children with hearing loss to check with children and see if they're having problems. When a child comes in and says he wants to take off his cochlear implant, or most

likely his FM system, the first thing I wonder about is whether they're being bullied. Is somebody teasing them about the fact that they have to carry a microphone from class to class, that they have this extra stuff that calls attention to themselves. So we need to think about ways we can help children deal with the fact that they're being bullied. So we counsel parents at diagnosis and we need to counsel children as they are ready for it. They need to understand the degree of hearing loss and what this hearing loss means. They need to understand technology. Why do they have a hearing aid or a cochlear implant? What does the remote microphone system do for them and why do they need it? We need to give them an opportunity to talk about their feelings about having a hearing loss. It stinks, you're right, it's not fair.

I'm sorry this is happening to you, but it is happening and we have to do some things to fix it. We need to help them talk about the social issues that are related to hearing loss. What kind of problems do you have, where are you having difficulty, what can we do to fix it? We also need to help them build self-advocacy skills, excuse me, so that they can ask for help. They need to be able, if they don't understand something one of their friends says, they need to be able to say I didn't hear that, can you say that again? They need to be able to say that to the teacher at school. But we also need to give them permission to feel bad about the fact that they have a hearing loss and that they're in a situation they don't want to be in.

Let's talk about counseling in older children. When we test a child who is old enough to understand, we need to describe to them what they're hearing without technology and what they're hearing with technology. And discuss how this affects every day listening. If you have an audiogram that has all the phonemes on it, you can help them understand that they're missing all of these things if their technology isn't providing it, or if they're trying to get by without using technology. We need to talk about the difficult listening situations they have every day and what technology can do to help. We need to be careful about how much information we provide, you need to judge

what the child wants to know and what they're ready for at that time. Tell me what you want to know about your hearing loss. I had a six year old when I said that sentence to him said to me I want to know when I'm gonna be old enough not to need hearing aids any more. His mom and I looked at each other and we both realized that we hadn't made it clear to him that this was gonna be a lifelong thing. So we need to answer the question when it comes up. Will it go away? No. Will it get worse? I hope not. What will happen if I don't hear hearing aids? And then we need to talk about what will happen to language and what your future is? I had a middle school student who said I don't want to wear hearings aids any more, what will happen if I don't wear them? And I said to him, do you want to go to college? Yes. Where do you want to go to college? Harvard, Princeton, and Yale. Okay, good goals.

Do you think that you can get in there if you don't have good school grades? Okay, let's think about what your grades will be if you're missing half of the phonemes. So we need to just talk things out, if they ask a question, answer it. Offer the information on a regular basis so that they know what we're trying to tell them. We need to talk about why they need speech language therapy, we needed to discuss skills and what they need, we need to talk about language and what can be done to build skills. They need to know that hearing helps them learn language.

Somebody asked the questions that I said that children start to recognize at about eight or nine that they are different, but I didn't say at what age they start to grieve. It's about the same in time. It's about at age eight or nine when they first start recognizing that they are different that they start to grieve. So let's talk a little bit about support groups. With today's technology, most children are educated in the mainstream. They may not have contact with other children with hearing loss. I would love to get schools and I try to do this with schools to organize support groups, have a pizza party at lunch once a month or at least once every other month where all the kids with hearing loss can get together and meet with peers. They have someone else who understands the

situation that they're in, give them an opportunity to talk about what they feel. In those situations there needs to be a moderator that can help them understand. I usually have somebody either type in to show on a screen or someone write on a blackboard what the concerns kids are listing are, and then we go around in a circle and all make suggestions for how to handle those concerns. I've had situations where a child with a hearing loss was giving up their technology. I couldn't make a change, but the other kids in the group helped her understand what she was doing to herself if she gave up using technology. And so kids can provide support that we can provide to them. They can provide support for each other. When I run a group, I set the group up by age and communication mode. I don't worry about degree of hearing loss, because with whatever technology they're wearing, if it's set well they should be hearing well and be able to communicate. I started off by saying tell me something funny about having a hearing loss, and the one that comes up all the time is when the teacher forgot to turn off the microphone and they heard things they weren't supposed to hear.

And then I suggest that they name me their five or 10 things that their family and friends know about them. And it's very interesting to me how many of them, some of them will say in that list of 10 things that they have a hearing loss, and others say that's not something that matters, I can communicate fine. Is there anything good about having a hearing loss? And some of them say they get more attention from parents. And then what are the problems, and this is the critical part. List all the problems on the board and then go around in a circle and have everybody make a suggestion about whether or not they can provide the problem. Talk about social issues, talk about bullying, talk about teasing. If they don't bring those things up, I bring those things up. And most kids don't want to leave at the end of the hour, and it's something that they crave and we need to work on it for them. Kids with counseling issues that are typical for children with hearing loss. They, fear of parent anger, they've been yelled at in the past for not hearing or for losing a hearing aid. Parents are concerned about how much hearing aids cost and they don't want to tell their parents that their hearing aids aren't

working well. Ridicule from siblings or other children. Refusing to wear hearing aids happens to a lot of kids, usually the kids who have relatively mild hearing losses. Or sometimes kids with profound hearing losses who are not doing well. With younger children, rejection of hearing aids is usually the result of parent attitudes. They can see that their parents are upset about it. With older children it's usually related to attitudes of peers. We need to talk to parents about their concerns about the child having a hearing aid and provide them with support and sympathy, but we need to help them understand what the effect of their child not wearing a hearing aid will be. How it will affect his speech and language and learning and what that means about what his possibilities are as an adult we need to help children talk about their problems, ask what their concern is about.

Do you only hear part of it when someone talks to you? Encourage parents to share their concerns, what have they observed about what their child is missing, what behaviors under what conditions, and have the child there so they can hear that parents to recognize that they're missing things. Discuss that we all have problems hearing sometimes, even people with perfect hearings, but let's talk about the situations where you have a problem and let's see what we can do to fix it. And sometimes that helps families understand that it may be necessary to change technology.

And with older children and with teenagers, if we test their speech perception in the loud speaker with technology and without technology, we can show them very clearly. At normal conversation you understand 86%, at soft conversation you only understand 48%. That means you won't hear unless the person is standing three feet away from you, which means you'll miss what's happening in the classroom. Test them in noise, see what's happening there. The speech perception results will more clearly demonstrate to both the parents and the children how much the child is missing. I know this is difficult, I know this is hard for you. We need to let kids express their

frustration and their anger and also let the parents do that. With teenagers, talk about the problem of the pieces missing from the puzzle. Talk about how in school you're getting new and complex information and if you're only hearing part of it you're gonna not learn well. We need to talk to everybody about the fact that hearing loss is fatiguing. You have to listen much harder to fill in the blanks, you're doing extra work in order to listen and this is hard. But we also need to make children understand that other students recognize that something is wrong.

The effects of hearing loss can be subtle but they will be noticed by other students and it would be better to get the hearing loss dealt with and to see what they're missing. We should also talk to teenagers about the lifelong impact of having a hearing loss. Adults with hearing loss who wear hearing aids make 50% more during their lifetime than those who do not wear hearing aids and try to get by. About 30% of people in prison have some sort of hearing loss and maybe it's because they didn't hear things that were happening around them and made bad choices as a result. We need to help children deal with self-concept.

They're internalizing the reactions of others. When people look at them annoyed, it makes kids feel bad. Children aren't ready to tune out the reactions of people who treat them badly. Children with hearing loss often have a relatively poor self-concept if they don't have the language to compete with their peers. Children with hearing loss may have fewer opportunities to interact with peers if their language is not as good as their peers. They have less opportunities to practice social rules. They may misinterpret social interactions. They may, if they don't understand sarcasm and annoyance and jokes and certain idioms, they will not be able to compete, and it's the job of everyone who is working with the children to make sure that they have the language that they need. Hearing aids along may cause a self-concept problem. Wearing the device amplified the difference between the child and his peers. Children with hearing loss who have fewer options to socialize, especially will have this problem if their language

skills are not at age level. We need to make sure that children with hearing loss have the vocabulary to express their emotions, and we need to talk to them about emotions and help them learn to recognize emotions in other people. This is not a test, but it's the child peer relationship scale. There are eight discussion points which we can ask kids to fill out and then ask them, they can check, they can check the points and we can see what happens. So mostly other kids like me. Sometimes other kids don't like me, other kids really don't like me. I like school, school's okay, I don't like school. All of these are things that are a way to get kids to talk about things.

If we get them to just check which one is them, they can then, we get a better picture of where they are and what kind of assistance they need. Is it specific therapy assistance, is it technology assistance? Is it a support group, is it counseling, and we get that by looking at all of this technology. Then there's the Cappelli, I know it's not a test, it's a way of finding out where kids are. I am happy when? I am sad when? The thing I like most in the world is, and we can get an understanding of where a child is and then we can talk to, a counselor can help them work through these issues. There are some self-assessment tests for teens which are available on the internet, and they also provide good information about to help us figure out where a child is and what kind of help they need.

And we can also do some scenario discussion. Here's a picture of a child sitting in the front of the room, a teacher standing in the front of the room and talking. Does your teacher do that? Is it hard to hear your teacher when your teacher is standing in the front of the room? How much of it do you miss? It's an opportunity to get kids to talk about this. The IDA Institute, IDA, has a game, sort of a setup thing where you can setup situations and help children talk about what their experiences are. We need to be sure when we're talking to children that we're keeping the door open. We need to make sure that the children understand that we have heard them and we understand that they're struggling. We need to give them some encouragement, we need to paraphrase

what they're saying. I think what you're saying is that you're having a hard time talking to kids in places like the lunch room where it's very noisy. Let's think about what we could do about that, or show that you heard, acknowledge their feelings, and then try to help them solve the problem. And any indication that you're struggling to understand the emotional content of what a child is saying makes it hard for them to go on and say it more. So people never change, almost never change, if they don't feel like they are understood. So we need to be sure we're making it very clear that we really understand where a child is. Counseling missteps by my good friend and colleague and mentor David Luterman. We need to be really clear that when we counsel families, we don't give them the impression that we have all the answers and they don't. I have all this information and training, you don't, so I'm just gonna tell you what to do. I mean we probably don't say it in exactly that way but the message is still clear.

I know more than you do, and that's not the message we want to give, we know more about some things but they know more about the child and they know more about themselves. And we need to be clear that we're providing counseling in a way that we need to be clear that the counseling we provide has them feel that we are listening to them and that they are capable of coming up with the answers. Here's an example, a 10 year old boy who tells the school he left his hearing aids at home and he tells his family he left the hearing aids at school.

So what do we do to manage this? We have to think about why the child is doing this and what can we do to change the behavior? We can't just yell at the kid that he didn't wear the hearing aids. We have to talk to him about what's going on. You must be really upset about wearing hearing aids if you're refusing to wear them. Tell me about this. Is that what the problem is? Is it hard in school, are kids teasing you? Does it make you feel bad that you have to wear hearing aids and other kids don't? Do the hearing aids help you? What do they help you hear? And sort of talk to them, give them a chance to talk about how awful the situation is and then we can help them go on. So

summary. At all stages, it's essential that the professionals empower parents and kids and help them to process the emotions associated with the hearing loss. They need the opportunity to get it all out. We need to involve parents as co-diagnosticians for children of all ages. We need to encourage parents to identify what their goal is for their child and help them with how they're going to achieve that goal. We need to try to be unbiased in providing information about their options. We need to remember that counseling is critical for children. We talked to parents when the child was identified, but we need to talk to children in detail about what they need to do. We need to provide fact based information about the lifelong impact of hearing loss, and we need to give everyone a chance to express their feelings. There are both positive and negative helper responses, but we need to resist the urge to rescue them and let them work it through themselves.

Okay, questions. Do I recommend hearing loss simulators to help parent, family, and other people understand hearing loss? I hate the hearing loss simulators. I use them only when I think parents are really resisting understanding what the effect of the hearing loss is. And the reason I feel this way is that I think, I think it makes it sound so much worse than it is. Maybe I'm not saying that right. It makes it sound, if you listen to a simulator for a moderate hearing loss, you start to wonder weather there's any possibility that a child with a hearing loss can learn anything. And I don't want parents to have that.

But if they'll say he'll manage without the, he'll manage without having to wear hearing aids, then I'll use a simulator so that I can help families understand what it sounds like to have a hearing loss. But no, for the most part, I'm not crazy about simulators. I just don't like the effect that they give. But if we can show a simulator, we need to also be able to show what it'll sound like with the technology on and what children can get from technology. Okay, next question. How can social workers learn hearing loss basics and technology basics? That's a very good question. Social workers who work

in programs for children with hearing loss should develop those skills by meeting with the clinic staff. I actually think it would be a wonderful idea if Audiology Online presented a course basics for social workers or other people not in the hearing loss biz and to help them understand the basics of understanding hearing loss and understanding technology. And I would love to do that. So if you think that's an issue, if that's something that's possible, I think that's a good topic. I think it's easier for them than trying to read a basic audiology textbook. Do I have a favorite resource where we can find those lifelong impacts of hearing loss? I have collected them from so many different places I really am not sure that I know. I'm sorry, I don't have an answer to that question. Anything else that anyone is asking? I mentioned support groups for children with hearing loss in school, are there sometimes not enough kids in a school with hearing loss?

Well it's usually done in a district way. School support can be provided if there are several kids in one school that's good, but it's usually not the case. So we can arrange for school district in cities, that's not a problem. A school district can arrange to have all the kids with hearing loss meet for lunch in one particular school or can arrange to have kids with hearing loss meet at two o'clock, sort of end of the day some place at some school and have a support group that way. You can also get support groups outside of school. AG Bell, the Alexander Graham Bell Association for Deaf and Hard of Hearing has a wonderful program in the summertime called LOFT. I'm blocking right now on what it means, but it's a group, kids who are teenagers go and meet, usually in Washington, sometimes other places in the country, and meet with other kids with hearing loss and the people who are running the group are young adults with hearing loss who have probably been through the LOFT program. The kids who have been through it find that they get wonderful opportunities to share their thoughts with other people who have hearing loss. And once they meet each other, with the technology that we have now with the ability to text each other and talk to each other, there's lots of possible things. Movies or blog recommendations for kids with hearing loss is the

next question. That's a good idea. Well I have a movie, it's called "The Listening Project" and it's a documentary that I made a few years ago with Irene Taylor Brodsky who is an Emmy award winning filmmaker, and we interviewed 15 kids whose hearing loss I had identified when they were babies who are now young adults in their 20s and 30s. And we talked about what it was like growing up with a hearing loss. And it's available on DVD, it's available, the full version, and it's also available in a short version for schools. Schools have found it really, schools who have used it have found it very helpful in first giving other kids in the school an understanding of what it's like for the kid with a hearing loss, but also schools are using it to teach empathy. And the kids with the hearing loss who see it have really felt, what they've said is that there's somebody out there who feels what I feel. So the listening project is a possibility. I don't know about blogs, but that's a good question, I'm gonna have to research that. I'm sure there are blogs for children with hearing loss. And I will, I think that's something I'll have to look out for. Okay, I think our time is up. We've reached an hour. Caroline, would you like to come on in now?

- [Carolyn] Thank you so much Dr. Madell, I learn so much every time I listen to you. I think this course is going to benefit so many professionals across professions, so thank you for your time and expertise, thanks to all of our participants for joining today, and we hope to see you all online in another course soon.