ROUGHLY EDITED COPY

EHDI

Mineral D/E

Getting the Most From Your Audiology Appointment

Casey Judd

1:45-2:10p MT

March 20, 2018

CART/CAPTIONING PROVIDED BY:

ALTERNATIVE COMMUNICATION SERVICES, LLC

[WWW.CAPTIONFAMILY.COM](http://WWW.CAPTIONFAMILY.COM)

"This text is being provided in a rough draft format. Communication Access Realtime Translation (CART) is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings."

>> Excuse me, everyone, we have two minutes left until the next session begins. If you were in the previous session and you aren't staying and you don't mind exiting the room, we can get ready for the next presentation, thank you very much.

>> This one worked when you said that. It came up. You want to use that one? It's working now... but it's slow. It's working, but it's very slow.

>> What's working?   
 >> The closed captioning ‑‑  
 >> They're just ‑‑ they'll catch up. They're here ‑‑ let me just doublecheck ‑‑ CART captioner, can you hear us okay?

>> Okay, that was faster. They just transcribed what I said and didn't answer my question, but that's okay, they're hearing.  
[laughter]

>> It works.

>> Just seemed ‑‑ okay... go ahead and start. Okay... I think we'll go ahead and start. My name is Kathy Johnson. I'm the audiologist at Montana School for the Deaf and Blind and I've been the audiology there for 38 years. I'd like to introduce LeAnne Gauss also. Just so you know what our life is like... her territory goes from Montana, Canada border, down about... I don't know, a couple hundred miles and takes out the center part of the state of Montana. And she puts about 3,000 miles on her car every month. I go with her some of the time.

Okay... first and foremost, when you're looking for an audiologist, this is a partnership, so... you need to feel comfortable with this person because you may all be spending a lot of time together. Especially if your child likes to hide their hearing aids or flush their ear molds. This is a journey, one in which your audiologist needs to be happy, willing and prepared to share with you and... that was a picture of what our commute looks like. Communication with each other is the key. Your audiologist should make you feel that there's open and free communication and that you're not being judged, ever.

You should feel that you can ask any question that you need to ask, especially if you don't understand the big words they are using or the acronyms. They should be willing to explain, explain, explain and explain some more until you get it.

You should not feel rushed during your appointments. You should feel like your audiologist likes children and can handle children with special needs and challenging behaviors. You should feel that your audiologist will be able to keep their cool no matter what.

You should be able to feel that they'll be able to help your child get through the hearing test. I call the otoscope a flashlight and shine it on their tummy first. When their mom is pinning them down for their testing, I say "mommy's going to hug you." "Hug mommy!" They should be willing to use headphones if your child has sensory issues and can't handle headphones.

And your audiologist should be able to handle getting kicked, pede on, pooped on, thrown up on and still smile and say "it'll all be okay."

Your audiologist should make you feel that they can help you, the parent, get through the hearing test, even if you're afraid of enclosed spaces or you have a fear of clowns. I have clown faces on my speakers, and... they were made for me by one of the students ‑‑ a deaf‑blind student many years ago and clowns have worked out really well, until lately, now they seem to have a lot of scary clown movies and I'm going to have to change that, I think.

Okay... your audiologist should make you feel they have kid‑friendly offices. That they understand that while audiology is their choice, it's not your choice and sometimes you don't think you can handle one more thing.

Your audiology should understand that you, your spouse, your parents, and the grandparents and the baby's siblings all may need help too and should understand and help you get that help.

Your audiology should make you feel they know where to help you find those answers, even when they don't know the answer and I feel like you should be willing to admit... I don't know the answer to that, let's look it up together and see what we can do.

And it's okay if the audiologist has a different opinion than you have come to for whatever reason. They should always make you feel that way too.

Your audiologist should help you understand how the hearing mechanism works and what is going on with your child. I want to tale you that Leanne and I were both in the middle of Montana on an Indian reservation last week and we had the dad explain why he thought his child had a high frequency hearing loss. And it's like... wow! I'd like to say that I did that for him, but he looked it up himself too.

Your audiologist should be able to help you understand how hearing aids work and what other technology may be available to help your child hear better at home and at school.

They are willing to help you, your child and family, and your school, and your community make this work. Your audiologist should be able to refer you to the right programs, early intervention people, speech pathologists, listening and spoken language people, sign language teachers, ENTs, pediatricians, geneticists, and babysitters.

Your audiologist should be willing to write down what they did and adjust your child's hearing aids or CI so you can give it to the school because they understand that after you leave the office, you can't remember what they said and they are okay with that.

Your audiologist should understand that sometimes you want to cry when you see them because they give you the bad news and coming to see you brings up bad memories. Ditto IEP and Family Service Plan meetings.

Your audiologist should make you feel that you won't think bad thoughts about you if they know your dog chewed up another ear mold because that dog actually licked it off the kid's ear. Really. It's happened.

They are excited about your child's progress and care about how hard you have worked to get to this point. And they should convey that to you.

Here are some things that can help the audiologist help you. What we're looking for is information to help us know where to start with the hearing evaluation. So... I like to know whether I should be starting conditioning at low frequencies versus high frequencies.

Where to start conditioning responses. And one of the important things is how is your baby's vision? Can they see the reinforcement materials and things in the booth?

We're looking for the cause of the hearing loss, if possible, to help implanting and to know the outcomes. To help what other issues may affect your child and how these issues may affect your child's health, hearing loss and learning.

You're looking to watch for middle ear problems, which complicate every hearing loss even further. We're watching for progressive hearing loss and risk factors for such losses.

Some of these risk factors are... premature birth, low birth weight, complications during your pregnancy or delivery, exposure to cytomegalovirus, rubella, toxoplasmosis, et cetera, drug exposure. In my practice, I found that Meth can cause some very interesting hearing issues, including auditory processing and cognitive function issues, even though it doesn't necessarily cause a hearing loss.

If your child has had jaundice, especially if your child has required a transfusion. If you or your baby were ill, if you were ill during your pregnancy or the baby was ill right after birth or you were ill at the birth. Was there an RH factor issue in your pregnancy? How much time did your baby spend in the NICU? Did your baby breathe on its own after delivery? Does your baby or toddler have feeding or swallowing issues?

Did your baby refer on the newborn hearing screening? Does your child or baby have a cleft lip or palate or congenital atresia? Does your child have Down Syndrome? Cerebral palsy? Vision loss? Nystagmus? Do the eyes move back and forth sometimes? Do they have balance problems?

The risk factors are speech and language delay in an older child. And family history of hearing loss. Were they on ECMO, assisted ventilation after birth? Has the baby been exposed ‑‑ or the child been exposed to ototoxic drugs? There are several genetic syndromes associated with progressive hearing loss. Neurofibromatosis, Usher Syndrome, Pendred, Stickler, Waardenburg, Hunter‑Hurler, bacterial infections.

Have they had head trauma? Skull fracture? Minor head trauma and concussions can cause issues. Has your child had chemotherapy, ear infections? We'll talk about that more in a minute. Do they have enlarged vestibular aqueduct syndrome? Do they have feeding issues associated with structural problems like a submucosal cleft palate? Has their oxygen ever been cut off during the birth process or after he brought them home? Has your child had a seizure?

Please be sure to keep your audiologist informed as you receive more information about your child. It can change our recommendations and ideas about what can help you. If you have a genetics evaluation, it's important to share that information with the audiologist because... it might change how we deal with your child and the recommendations that we make for your family.

I'd like to talk about some more information that you can give the audiologist. What listening situations are difficult for everyone, including you and the child? And what can we do about this? And I like to say, let's brainstorm what we need to do to help. Are they showing indications that any sounds are uncomfortable? What sounds are uncomfortable? Is it because of how loud the sound is or can they just not handle that much background noise?

What progress is your child making in their speech and language development? Can they hear the ling sounds? This is why the ling sounds are important. The ling sounds are designed to let the audiologist and you know where your child is actually hearing through their amplification, through their hearing aids, or cochlear implant. The ling sounds, low, medium, and high frequency sounds in the speech region.

So... if your child, for example, is not hearing the high frequency sounds in the speech region, it will give the audiologist or the mapping audiologist information about what they need to do and what they need to work on to reset the hearing aids or remap the cochlear implant processor.

Are your children, is your child uncomfortable with their ear molds? Are they pulling at their ear? Are they fussy? Do they have a sore on their ear?

I like to have the parents, at some point, let me know they understand how the hearing aid works and are comfortable with all of this. They know, they know why the batteries sometimes go dead a half hour after you just tested them, put them in and they were working just fine. I have one child on my caseload that keeps showing up at school with dead batteries and so... the, we had to talk to the parent about how they were testing and how the battery can actually use up enough to turn the hearing aid on and... yet by the time they get to pre‑school, it'll be dead.

If you have ever noticed a change in your child's hearing after you buy a trampoline, start karate and gymnastics or if your child has ever hit their head... this may be an indicator that they have enlarged vestibular aqueduct syndrome. If I have a minute at the end, I can talk more about that. But I have three kids on the caseload now who developed hearing loss right after the family bought a trampoline, that's because... that jarring, caused large vestibular aqueduct syndrome, but the jarring from the trampoline caused a drop in their child's hearing.

Okay... I need to know if, as a parent, there's any piece of this that you can't cope with? The baby, the equipment, the other medical professionals, if you can't cope with me, I need to know that too, if you can't cope with one other thing, if you can't cope with the schedule you need to keep, if you can't cope with the grandparents and what other people and the grandparents say to you, please let me know, I'll try to help you if I can.

If your child's hearing is changed in any way, it's important to figure out why. And this may mean a visit with the ear, nose, and throat specialist, neurologist, geneticist, and CT or MRI scan in addition to seeing me.

Some children will experience days where they have better hearing than other days. They can have days where they have variations in their understanding. In other words, they can hear you, but can't understand what you're saying to them. This seems to be a hallmark for kids with EVAS or CMV. A minor head bump can cause a significant change in their hearing. Including... if they have a fever.

If your child has bumped their head, some ENTs recommend they have a tapered dose of steroids to see if the hearing can be saved. Some also recommend this for children with fluctuations due to CMV. So... we need to know and get that diagnostic work‑up done right away so the child can get on the steroid quickly.

Know that fluctuating hearing and/or decreases in hearing can be a source of significant stress for you and your child. They will do better when you stay calm, even though you don't feel calm. And get help if you need it.

Clingy behavior, fear of the dark, not wanting to sleep at night, speaking in a louder voice, can all be signs their hearing is fluctuating or decreasing. Most of the time these changes are due to middle ear problems, but see your audiologist as soon as possible if you notice changes in their listening behaviors.

We're going to talk for a minute about middle ear problems because this is the bane of all of our existence. Yours and mine. This is a significant issue, also, because... the increased risk for meningitis if your child has a cochlear implant, also because our most‑common antibiotics are losing efficacy against bacteria.

This is also a concern if your child has enlarged vestibular aqueduct syndrome or Mondini's dysplasia and there may be structural issues that predispose them to meningitis.

Prevention of ear infections is a better solution and these are some of the suggestions I'd have for that. Encourage breastfeeding rather than bottle feeding. If bottle feeding, never let the baby hold the bottle himself when lying on his back. Babies need to suck hard on a bottle to help open their eustachian tubes. This isn't a true if they have a cleft palate.

Maintain an upright head position after feeding your baby to encourage all the milk to go down. Bed time bottles should contain water after the child is nine to ten months old and getting adequate nutrition during the day. If you can't do that with your baby, try to give them a couple swallows of water after they're done with their bottle. You want to flush the formula down because... that can, if it is puddling at the back of the throat, that can cause ear infections.

Children shouldn't be exposed to cigarette smoke. If you use a wood stove for heat, make sure it's well‑ventilated, burning cleanly and the child isn't exposed to any smoke in the house.

Physicians are now using caution in antibiotic prescription. Remember to give the antibiotic until it is gone, even if your child feels better.

Children with cochlear implants need to be on an antibiotic no matter what. It might be worth it to buy an otoscope for home to help monitor the middle ear problems.

Check for allergies to see if the allergies are a contributing factor to middle ear problems. Wheat and milk allergies are the two most‑common culprits in my practice. Milk allergies often suspected in children who are mouth breathers, have dark circles under their eyes, even when getting plenty of sleep. These children tend to crave milk and cheese.

This ‑‑ multihandicapped children have a higher rate of middle ear problems than the general population. Especially critical for children that can't sit up on their own or are wheelchair bound. If your child has a cleft lip or palate or other feeding issues, you and your physician will need to be especially vigilant about ear infections or fluid behind the eardrums and you can have fluid without having an ear infection Parrs maintain good head position during the day, especially after feeding of some kind. That includes tube feeding.

Be sure you know how well your multihandicapped child is swallowing and how well they're handling food and liquids. They may need to have a swallow study to be sure, especially if your child had pneumonia or choking episodes.

Be sure to know if your child has reflux. This can take the form of colic. Reflux can contribute to middle ear problems, you may need to prop your baby up while sleeping as well as after eating. Be sure they're up for at least an hour after feeding to make sure there's no reflux. Help your child maintain good health.

Here's what I'd like to share with all my patients and I don't. When you cry, I'd like to cry along with you, but I try hard not to. I know all of this is hard. I know even if it is hard, you'll all be okay, including the grandparents. I try to keep everything as calm and low‑key as I can, because... this will keep your child calm too. Especially when I'm giving a family bad news. It's my job, sometimes to give people bad news.

I understand that it's almost a full‑time job for one parent to handle all of the appointments, meetings, devices, home therapy, et cetera. The divorce rate is 90% here at MSDB. I can see the dynamics of what happens when one parent takes on all the work, the other one goes to work at their job because they don't know what else to do.

The kids that do the very best are the ones in situations where they know they can count on their family members for help and support and everybody supports each other.

I know this isn't what you thought you'd be doing, but this can enrich your life in countless ways and I'm grateful to share this journey with you.

Okay... we have like a minute for questions. Okay...

>> Hi, thank you for your information. I did see some good information in there. Do you have references or resources for some of your information?

>> This is all based on my practice.

>> Okay.

>> Like... ‑‑  
 >> Anecdotal?   
 >> Yes.

>> Do you give your family good news as well?   
 >> Yes, that happens a lot.

>> I'd like to suggest that you involve parents in some of your documents and reviewing them. Sometimes when you ask questions of parents, what you think is clear, and understandable, is not and they interpret it differently. So... we've invited our parents to look at our questionnaires to make sure that the way we're asking the question is how they perceive it, because... sometimes there's a big difference. And... they don't know what we mean.

>> And I'm always really surprised at sometimes, what parents thought I said. Because... I think I've explained it really well and sometimes that's not what they took away from it. And I think that's pretty common with all the, all the other audiologists I've talked to too.

I think that's it. Thank you very much.  
[applause]

[Presentation concluded at 4:11:00 p.m. ET/2:11:00 p.m. MT].

"This text is being provided in a rough draft format. Communication Access Realtime Translation (CART) is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings."