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EARLY HEARING DETECTION & INTERVENTION

Part of Session 1 for this captioner, and then switched to another room. No title given.

March 17, 2024

10:15 AM – 2:30 PM (ET)
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(This session started with Navigating Other People by Understanding Communication Styles, but then captioner was switched to a different session of unknown title, after about 45 minutes after it had already started)

>> [CART ready] 2024 Early Hearing Detection & Intervention Conference Navigating Other People by Understanding Communication Styles

>> 2024 Early Hearing Detection & Intervention Conference Navigating Other People by Understanding Communication Styles

>> You good?

>> (Background chatter)

>> Good morning everyone. Welcome to EHDI. My name is Kaylynn, I will be moderating the room today. A couple of housekeeping things before we get started. You're closest emergency exit should you need them right behind me, and right behind you. And all course evaluations and CEU will be found on the app this year so you have any questions let me know otherwise I am really excited to deduce Amanda Boss she will spend the next several hours with us presenting to you all on Navigating Other People by Understanding Communication Styles.

>> AMANDA: Thank you. I want to check about access. Is anyone here wanting an interpreter? No? We might have three more people coming. Thanks. I don't know if I have Michelle's number. Perfect because I do want to make sure we have access if we need it. (off mic) Hold on let me ask. Does anybody want captioning? Is there anybody here wanting captioning? Because I will mess that up, if I don't use the microphone. Okay. I am not seeing anybody.

>> AMANDA: (off mic) (She is not meeting captions, so she is speaking off mic).

>> (Captions are not being provided because speaker announced no one needs them. And she is off mic)

>> AMANDA: Thank you. It is very honest. I got word that we have to use the microphone for captioning. We are going to honor all people to do that. Here is the microphone.

>> I'm Kendra Benedict, from Phoenix Arizona, I direct in early learning program age to 5, run the state for the deaf, hard of hearing, blind, visually impaired, deaf blind. Since my first conference EHDI, I am excited that I lead a team of about 70 folks around the state.

>> Hi good morning. Brady Mohammed. I am an information specialist with a coalition for the education of children with disabilities. And so we also are-- we have a contract with the state, and so we call parents six weeks and 10 weeks to check if they made the attempt to call to get a pediatric audiologist appointment or they need help finding one. The reason I am here is because I want to learn more different ways of communicating with others. I think I am pretty good at communicating sometimes I talk too fast. It is always good to learn sidebar are to have allergies and sinuses and I have been checked. Not positive for the -- in case you hear me sneezing or coughing do not worry. Back to Kendra. She is Doctor Kendra. She said she was okay with sitting beside me. I will put my mask on periodically. Thank you.

>> I am Bethany Colson, from Indiana Indianapolis. I am the director for the Center for deaf and hard of hearing education there, sister program within the Department of Health for EHDI. We take on once a child is identified getting services and working with children and families from that time of identification through high school exit. So similar to Kendra, I have a group of people that we lead from part-time contractors who are providing services to about 20 full-time staff members and just thought this would be an excellent way to learn how, hopefully to continue my engagement with that group. I love EHDI. I just think this conference is such a great way to go back and be excited about what we do.

>> Good morning. My name is Amanda Shiner. I work for the Michigan Department of education low instance outreach. We do statewide outreach and support for students who are blind, or visually impaired or deaf and hard of hearing. I'm here this morning because I have some coworkers and I am not communing well with them. And so needing to work on those skills.

>> Kelly Dunham. I also work with Michigan Department of Ed low incidence outreach, and I don't think I am one of the coworkers she has a problem communicating with. But throwing it out there. I am here professionally my training is as a deaf educator and I worked as an itinerant teacher for six years before I joined the team in the state what support center and I am here for the same reasons as Amanda, trying to build cohesive team dynamics and working through that. But also get the perk of this is a professional learning experience but I can apply this everywhere. So I get that freebie of using it at home and with family, and other organizations I am a part of. That is why I'm here. Thank you.

>> Good morning I am Tamra Kidd. First year as a director in the-- regional center for the Alabama entity for the deaf and blind. My boss is here. I have to be on my best behavior today. But I lead a team of about 25 employees, team members we call them. And I am here on behalf of our early intervention team. I have seven members. I am the only one here and this is my first year here at EHDI, but I also have an associate license as a counselor working on my LPC. And so communication is the end all be all. If you don't have that in any organization or any type it fails are and grumble so I'm leading a team that I have. It is very important that I am able to communicate with everybody on every level. I am excited about this, this morning.

>> Hi I am Tony Ray -- Speech therapist. I came here from -- Alaska with a cohort of people that are all here from Alaska. I have a business where I do independent contracting and some (indiscernible) and work in some villages on the western coast of Alaska. I am here to learn more about how I can improve my communication with Alaska native people for example who have different communication styles than I do. And I feel like I am often having moments where I want to figure out how to navigate our relationships better and I definitely identify, appreciate wanting to improve my concussions styles with my work relationships too.

>> Good morning I am Kim Rimon, I come from Casper Wyoming not too far away. I am here because I have found-- I am a former education, and I found my passion working when my oldest daughter was diagnosed with hearing loss, and I have three kids with hearing loss. And I work also in the pediatric audiology body where I connect with families immediately upon diagnosis and I want to find better ways to connect with families, indicate with them, and also work with professionals as well.

>> Good morning. My name is Aaron Thompson, formerly with Casper Wyoming. I currently live in McCook, Nebraska and am currently the parent of a deaf child, six. I am a chemical engineer. I don't know why people don't talk in bullet Points (laughter). What else was I going to say? Oh. This is my second EHDI conference. I love the energy of EHDI. I was with you in Kansas City, a couple of days before the World Health Organization told us about the C-word with 900 other women and me. So, it was a lot of fun. I am really happy to be here, excited in anxious to be with other parents.

>> Hello, I am Kayla Armas (phonetic), I come from North Carolina. Part educator in part consulted with EHDI North Carolina. Also the parent of a 14 years old-- he is the main idea, the main reason that I am here. Because I was used to doing things for him and being very involved. I can do it mom, don't worry. You don't have to know how to my 504 meetings, and I need to go, of course! I started a support group that is punished by parents who have children with hearing loss in North Carolina when he was three. I have been working with that and now we have four groups in North Carolina. I need to learn more how to communicate with people and to learn from them too. That is why I am here.

>> I am Isaac Beavers. I am the Executive Director field services for the Alabama Institute for deaf and blind. And I oversee a network of 10 regional centers that covers all 67 we have services seven counties of the state from birth. And we serve anybody with a sensory loss or other disability. Oversee their leaders and those team leaders oversee nearly 200 employees statewide. So, I am interested in connecting with some of you outreach people. Doctor Kendra, and you. Because we oversee the early intervention program. We are a partner in early intervention in our state. We've got some changes coming up. I am interested in finding out what some of you all think about that. I'm here because I have a lot of people I am responsible for. Any time I can improve, I need to improve.

>> Hi everyone. I am Jessica Goslin, I am from Los Angeles, California. I am an itinerant teacher of the deaf and adjunct Professor. I believe it is my role as professor that is most interested in me today, because I'm teaching the next generation of teachers how to communicate. And so the better I can be attached, the better they will be.

>> Thank you. Hi, welcome! -- Could sneak in. Going to give you a moment to get settled. But we want to know who you are. We just went around sharing who everybody is. I will re-tell you I am Amanda, from Oregon, almost born and raised and I have three kiddos and I come to EHDI because of a deaf+ child that I have and I'm here today because I love working with teens. I want to teach about personalities and communication styles, so on and so forth. So, can I hand this microphone over to you? To share your name?

>> Captioning won't catch it.

>> So my name is Crystal. I am an early intervention specialist. We go out into the homes. And we thought we would come here and see if we could get some resources to take back to our families in the home. We have a pretty good budget. So we are trying to, yep, just get some ideas to where we can better utilize our monies. Thank you.

>> Thank you. What state were you from again? North Dakota. Awesome! Okay, well I feel really humbled by all of you in this room. This is going to be really fun to get to know one another and to work together and dig into all of these materials. Two things. One, I brought-- sorry moderators you already heard this-- I am not over the sadness that I have. I brought so many goodies from Oregon, like food, because this is four hours. And I went to Trader Joe's yesterday and got fresh muffins, gluten-free, all of these bars, cuties, tea, vias (phonetic), coffee powdered and sugar cubes. And then I asked for hot water. That is all I needed, and they said oh, you can't bring your own food. So, I tried to feed you. They said you could buy tea for $150 if you wanted. My husband said "no" to that. I am sorry. I don't even have tea for you. But if we are all friends, by the end of this I am out in the hall with the big Mary Poppins bag. I have a lot of food to get rid of. Yeah. Even there, they are like going to check on you. I am the kind of person that divulges everything. "My name is Amanda, looking for hot tea, I brought goodies!" You can't do that. Getting text from the head of people. Did you by chance ask for food? We are not allowed to do that. There is a big fine. My secret is out. But we are all going to be friends by the end of this and I have my Mary Poppins bag. That is my sadness so, I will go for now. Okay. I will start with a little bit of the story for personality types.

Just to wrap our hands around the base idea of this. There are way more than like four boxy personality types, obviously. But for the purpose of today we will be looking at like all of us with maybe like a major and a minor. And, we all usually have all the personality types within us. We have different strengths, and all the different four different boxes. In a way to a want you to walk away thinking that Amanda just things that we have a very basic, four personality types. I know there is more to that. I love the story that my friend shared about why it is important that we are so different from one another. Pretend we go on a very long journey, with Trader Joe's muffins, Via coffee and tea. And you know who figured out all those things? Probably what will call the promoter who loves to party and have fun. If we're going to be on a long journey together, we have to make sure we still like, like each other by the end of this and have a good time. Because being boring, or quiet too often, is not what all of us want all the time. We have to have some fun. Did anybody see all the -- St. Patty's Day stuff yesterday? Even the promoters, don't worry about those words. These promoters need to have a good time on this journey. But without analyzing personality you might get lost on the way there. We definitely need those around us that can pay attention to the details. Do we have any bathrooms on the ship to accommodate this many people? Is there enough food? I know Amanda brought muffins, but are there eggs and water? Make sure we are in a good healthy fashion. Paying attention to storms matter.

Paying attention to all the different things that could come and could be a problem for us and we need to pay attention to that. We need people who love that detail. But we also would need a captain, which we would call a "driver" today. And a driver, pointing north. Let's get there. Can we not dillydally? Sure, we will stop here. But let's get on the road. Because you want to eventually show up for those that you will be showing up for. And then we have a supporting role. I have this role's role. They kind of help mend communication between people. They want to make people feel included. The thing that they need most of all is this like, harmony between people. Between them and others. Between others and others. And that is their main goal. If you think about it, if you're on this big long journey that is going to take months on one ship with all the same people, it feel so true to me that you truly need all of those personality types. All of the strengths were represented on the journey. So, in just a little bit I will be passing these out. And what we are going to start with is a little questionnaire. There's 20 questions.

And, yeah there are 20 questions, and you will fill it out, your answers, I want to come over here. I wrote it out. This is one of those "pay attention to detail" moments. Because, it is easy, if you know what you are doing. If you don't know what you are doing, it is kind of confusing. So, the questions will be... Let's start with the first question. Behavioral tendencies under favorable conditions. What we have here, again you will see it in just a minute, we have four options. And the thing that you're going to do is if you so there's four options here, and after each one number four is most like you. Number one is at least like you. And it is best to start with those numbers. I mean you can start with 1, oh, it is nothing like me, put a 1 there. And then go to 4. 4 and 1 will start us. This one is very much like me. This is not at all. Numbers 2 and 3, forced answer test, you will put, uhm, that sounds more like me. Yeah it is not like me. Number 4 is most like me. Number 1 is least. And it is a forced answer. You will go through that for all 20 questions. And the other thing is that this is under favorable conditions. Like when things are going well. When you wake up and the sun is shining, and the world is your oyster. And these are under adverse conditions.

When it is stressful, and things aren't going well. You are under pressure. You did not get good sleep. So under adverse conditions, you will see it separated out here. The other thing that I want to note is that all of the work that we will be doing here for the personality types and communication styles can help with your work life, home life, just help us work more effectively with people. And also figure out how we can serve other people even greater. And in-service it is crazy what happens. Just like people come alive. They respond so well. So this isn't used to manipulate people and get what you want. This is in the active service. So one last funny thing. (Bless you). I learned all the stuff from a gentleman who has been doing this for like 40 years. I still uses materials. And so I feel like it is kind of goofy. But there is this gold sticker that you cannot open until I tell you to. And I can't tell if I'm going to keep that forever. Or if ... Maybe I should. So go ahead and open up and put your name on it. As well as ... put your name on it on the first page. And then start answering the questions. Does anyone need a pen? I brought those too. From Oregon.

>> [Survey]

>> AMANDA: There you go.

>> AMANDA: I did not mention before. Go ahead and do all of the pages, three total.

>> [Survey]

>> AMANDA: All right can you guys pause. Totally fun if you're not finished filling it up. No pressure. Because people finish it up at different speeds, I'm going to give instructions to everyone and then go on to answering questions and do more stuff. Can everyone open to pages 6 and 7? Ooh! It's apparent! Yes, the gold sticker. I love the gold sticker. Okay, what we are going to do is, after you completed all the questions, you put in your answers from those questions into page 6. And if you look along the top, from supporting/ driving/ analyzing/ promoting, you will notice the numbers are 1a, 1b, 1c, 1d, from left to right. This is very critical to filling it out properly. You will do the 1's all the way across, the 2's all the way across on and so forth. Get your totals. Notice also that is under "favorable conditions." Under adverse conditions, there is a big thing to note. It starts at 6a. Not perfect in numerical order, from top to bottom of the page. So we go on through 5, 11-15. 6-10. 16-20. You will put your totals down at the bottom. Here. And then on page 7, you will transpose those numbers into this graph. And it goes from left to right. Like supporting/ driving/ analyzing/ promoting favorable conditions. Versus the adverse conditions. Any questions? Nope? Okay, so go ahead and keep filling out your questions. And then putting in your values.

>> [Survey]

>> AMANDA: All right team. Can we pause for two things? Is anyone using captioning? If not they want to switch it to a different room. Do we want to keep it? Look at that. Secondly, when you are done filling out your answers, feel free to peruse page 9. And I think 11, sorry, 9, 12 and 13. If you want to be looking. But again, no pressure to be filling this out fast. We can be in it altogether at whatever rate we need.

>> [Survey]

>> (Switching rooms)

>> ... Medical records called Team systems. No matter what red flags I sent his way ... Kind of unfortunate we are trying to get both on the same page. Sometimes I indicate red flags, I don't know what systems we use, Epic, I will send a note to say this audiogram. I am seeing red flags that look like (indiscernible), I have, heavy working with these ENTs for several years will probably have a different relationship because we worked side-by-side. It is a little bit harder because the first ENT wasn't in our system. Although we talked about patients, we did not have the same rapport. I could not really give that information that way so that provider. But I think if you can build a relationship by saying maybe, we have some red flags, you know, I think once you kind of start that process it gets a little bit easier each time. Do you remember this case? This one give me similar vibes. Which is why I just send-- my EDA and say rule out! Any other?

>> My son has EVA as well. He was not diagnosed with that until he was four. It feels like he had sedated AVR (phonetic) prior to that too. And the second one than they did the CT scan, only to get him for the candidacy for cochlear implant. That is where they found it. So it feels like anytime there is this sedated AVR, why not just do a CT scan when it takes like 10 minutes?

>> In our hospital, I would say in the last five years, a lot of this kids would do a sedated AVR. Tubes are not tubes. We are also doing imaging if they are getting sedated. Why would we want to sedate them more than once? It is also a red flag.

>> I am mom so if this question is obvious forgive me. Is there any pattern with the EVA diagnosis with the girls? Do you tend to see that the ball starts to drop it or run a certain age? With my daughter it showed up about one year prior to starting her menstrual cycle.

>> I mean I haven't specifically in the cases I have. But I have ... I don't know. I do have a fair number of teenagers that have it. But we are monitoring them so closely. I don't think I see big drops within a year. We see this kids every six months to a year for audiograms. I have not seen a pattern in that specifically. Any other questions about this case?

>> We need to move on. I realize I forgot to ask parents in the room. If they are a parent, I forgot that category. Let's move on to case number 2.

>> All right. So, for those audiologists in the room, this referral said, "check inner ear due to frequent vomiting." I opened the case in the chart. And I said, what are we doing? So this was a little confusing for me. I definitely ... Obviously the vomiting led them to think there was something dissimilar going on potentially and that is why should be checking the inner ear. But again this was a 14 month old coming in. Birth history, full-term baby. No complications in the initial stay. Left the newborn nursery within a day. Readmitted five days old in the NICU for 40 days due to mitochondrial metabolic acidosis. Okay. What is this? Gabe will talk about this a little bit. This is an interesting case of why this doctor was referring to audiology. So, wow! Oh goodness. Sorry, I must have touched the mouse. So, I am 14 months old. And as you know, 14 months old are usually not cooperative. Sometimes they are. This baby came in, in a stroller, with kind of a curved seat. Was or is until. Mom had baby laying flat in the stroller. And that is really interesting. Okay. I do the OLE (phonetics), laying back in the stroller. Not looking so hot. Abnormal response in OLEs. That is where 0 is.

All the low 0s. At this point in time we have normal temps, shallow, not abnormal looking temps. That is an abnormal test for non-audiologists, and then going into the sound booth. Trying to do this behavioral test to see how he is responding to sound and see if there is any concern for hearing loss based on this abnormal test I am giving. And this was something to mom that was upset about my directions and what we are going to be doing next. He said, he can't sit up! He is going to vomit. And I said tell me more about this. Every time you say something he throws up. “All right, so I said well, this is kind of our next step. We do need to try to get a little bit of information. So as you can see I was super successful. Got one response. He didn't throw up. But he definitely ... I don't know how the parents in the room when kids have acid reflux as babies, and they do that (indiscernible) the back thing, he was very uncomfortable in the upright position. Which obviously made mom very upset and very nervous. And I said okay. Let's stop here.

So that my discussion was, okay, there are the tests we can do. One of the tests we can do is we can do a test where you baby go to sleep. You come in over naptime. We will try to do what is a (indiscernible), the baby does not have to sit up. Lying down is okay. Mom was in agreement with that. So, one week later I was able to squeeze him, and I was pretty nervous about the OEPs, with attempts being close to normal. This is a response one week later on and APR. At this point I am pretty concerned. Temps were similar. OLEs were similar and the AVR is below 20, abnormal on this test. So what I did is, this baby was around the time with our newer ENT. I said hey, red flag! Something is going on with this baby. They passed their newborn hearing screening, not getting good responses on AVR. Can you do a consultation as soon as possible? So I am 14 months old at this time. As you know, sometimes it can take us a while to get to that ENT process. And get things moving. At that point, the ETS said, well there might be some inner ear fluid. Okay that's fine so we did a sedated AVR in tubes and a scan on the little guy. The scan was normal. But you can see this is at 19 months old. So five months later we were able to do (indiscernible) as well. But you can see we did have a 40-60 so moderate degree of hearing loss bit laterally in the presence of the PE tubes that are patent.

One of the other things we always do, if during the AVR testing today when they are sedated it we find hearing loss, are you okay with us taking impressions to discuss hearing aids, if that is what you want to do? And so we were able to take ear mold impressions for AVR as well. And this guy was fit with hearing aids two weeks after the sedated AVR, around 20 months old. Fit with hearing aids. They lived in our town for another year following this AVR. So one of the other things that did not mention in this whole thing was, this was a non-English-speaking family. So there was also cultural barrier, which Gabe will talk about in a minute. So we are going to talk about now for a little bit, cultural barriers with hearing aids. Family was on board. They said okay, that is what we want to do. Hearing aids. It was a real struggle for the year and managed him. Trying to get them to have the hearing aids on. Again this entire time, with his medical condition, still dealing with vomiting. Still dealing with not sitting up. Obviously rolling down a lot. That was a fair amount of feedback issues within laying on hearing aids all day. And so the medical side of his diagnosis, with the MA, he ended up having-- the family decided to move to the East Coast. He medically was too complex. Our hospital wasn't as versed maybe in his pathology. They started seeking specialists elsewhere. And got some different support out on the East Coast than they could get in Boise. So I don't know. I don't have any updates. By the time he left he was wearing hearing aids about three hours a day. Talked many times about the importance of amplification and use of amplification. This family wanted auditory/oral. They did not have a background in ASL. Also did not speak English. A lot of cultural barriers to consider, when their background was not English. They were in this country learning some English. But the interpreters at appointments try to establish consistent hearing aid use for this little guy was difficult. Sometimes, those are the variables we deal with when we are talking about kids, and amplification and other plans which are in the mix as well. I'm going to let Gabe talk a little bit about this guy.

>> You've done most of it. I could sit back and listen to you. So for those of you that are not-- anybody familiar with this condition? Yeah, right. I teach pediatric audiology. And so we go over it as much as we can in classes. Right? I tell them, you have to be ready to Google, go to pub med, talk to each other. Anybody heard of this one? Reach out to your friends. A lot of times they haven't. I know at least two of you in this audience know. How many syndromes and disorders are connected to genetics that we know of? Right? Over 400. So there's going to be new things that come through our door every day, that we have to start searching. This one, mitochondrial powerhouse for ourselves, this is affecting the inner ear. And how those chemicals are going through. That is the part that is affecting our hearing with this disease. But there's also effects on the brain, muscles, the heart. Hearing my not be the priority for this little guy. Because we are trying to keep him alive, and functioning. And so, as Jess indicated, hearing was not mom's biggest concern. It was the fact that he got sick every time they try to sit up and snuggle with babies. A lot of things that we needed to think about, besides the cultural considerations which Jess already talked about, so I'm not going to go in-depth into that one. If you want to look more into the mitochondrial metabolic acidosis, the NIH has some good information on it. And then also there's a lot of research going on in the UK. So London has some good information about the foundation over there. Great place to go for more information. And you did the rest of it. Oh, questions, thoughts. Anybody have any thoughts or questions? Got to get Jess her exercise.

>> I want to know how often you do it mold impressions while a kid is sedated.

>> Good question. Going to give you my two thoughts about this. One, it is easier to take a mold while they are sedated. However, I personally-- when it is my patient-- I don't love to do that for two reasons. I still do it while sedated but do not like to do it for two reasons. One, I don't feel impressions are always the best mold from the child in that position. That is the first. And I will forgo that if this is a very difficult child in my clinic. Two, the other part of this is, I do feel like for parents, it is a good experience to have to fight through that process. So they know what is going to happen the next time we have to do it. So, it is hard. We only have a couple of audiologists that do sedated AVRs. I am one of them. If one of them is the patient and asked me to do it, I am doing it. If it is my patient I have that background with the patient in the clinic. So okay, good I probably hold this kid with mom, and get it in the clinic? Because I think it is valuable for the parents to have the experience that. Because six month later, when we have to go and get the second set of ear molds and we are not sedating them, it is a very traumatic experience sometimes. So I think there are benefits to doing it with the family, so they see the residency what is happening. You have experience with that?

>> (off mic)

>> Yeah, it depends too on their anatomy. Some years are tortuous ears. Sometimes it is gotten those done in AVR. If they are going to fight you, you might not get the best impression in the clinic. But I do think there is value in parents having to go through the process. But there are some patients, we have seen multiple times in the clinic, now going to the AVR. Mom is saying just please do whatever you can. Just get the mold done. Great question. Any other questions? About this little guy?

>> All right. We have had all these patients as well. This little guy came to us at almost two and a half years old. They had speech delays. Mom came in to clinic. She was very pregnant. Wow! We are ready to have a baby. She was due in a week. Brought in this little guy. He was the first baby. Pregnant with second baby. Ready to have another baby. This little guy was saying about 10-15 words. None of them were two-syllables, ga, ah, ma... Can't remember the other ones, not a lot of spoken words. And was nonspeech therapy. This kiddo came in. Two and a half years and I was shocked that this child was in speech therapy at this point. Came in for a regular hearing eval, not an AVR at this point. So, I am two and half years old. These were my OAEs. And the VRA audiogram. So for those not audiologists, for this particular equipment the DP is what we are looking at and comparing to the SNR response. All the DPs were negative, and the SNR response was also poor. Right to left. Right here at a normal eardrum function. And the left eardrum did not have normal function. There was visible for it actually in the left side. So ... ah! These buttons are very sensitive apparently. So for the VRA he was very consistent and very reliable, very comfortable in the results matched with the speech awareness threshold as well. And he was showing moderate hearing loss, and severe hearing loss in the left ear. So, at that point, I was like, what happened? Why? Have you not seen an audiologist before? Two and a half. What happened?

So I dug through his medical records. One month old, he had an audiology appointment and he was referred to an appointment for failed hearing screening. And he was no-show. It was documented in his medical record that it was a no-show. Two months old he went in for a well child check. Pediatrician reviewed it, referring to audiology. Four months old. When in for a well-child check. Dad was concerned about testicular function, interesting on a four month old. Even the statement was unusual for parents who had no medical background to referral was made to audiology. Came in at six months old. Parents had no concerns. No concerns. Still has not seen audiology. Again referred back to audiology. Nine months old came in. Refer back to audiology. Same story. 12 months old came in. Parents were disappointed, according to the pediatrician, refusing to go to audiology. His Appointment, spring of 2020. Suspicions about why the family was choosing not to go to audiology at that point. Who knows what their thoughts were, what that process was. A year goes by before the next well-child visit. I think most people see the doctor between visits, but who knows it was Covid two years old came in speech concerns with concerns. Refer to audiology. It wasn't until the two-year, four-month old appointment, they had an urgent care visit with the pediatrician. Left ear infection. Speech concerns. Refer to audiology. We saw the previous slide, two years five months. It wasn't until the ear infection at two years four months, that the family went to audiology for their visit to have a hearing test. At this point obviously, from the first slide, failed the newborn screening. He was at significant risk for having hearing loss, speech delays, the whole works at that point. So, back here for a second. The previous slide showed you the audiology visit that we had. With the VRA, behavioral responses on the test. At that point I made an urgent call to ENT. Hey! You need to see this kid.

One week after the appointment mom had the second baby. The family is going through a lot of things. Baby number two is here. And dad is calling me constantly. Unfortunately and fortunately, I gave him my cell number. He was just like one of those people that was very worked up. He said how fast can we get the sedated AVR? Ear tube in the left ear, he saw this happening. So the ENT. This is not happening in getting to the ENT within four weeks, unusual in our clinic because there are three months out appointment. Four weeks after his initial visit with me he got scheduled for a sedated AVR with PE to placement, two weeks after ENT. That never happens. That is so unusual. But this dad was like, why is this happening? Come to find out grandparents are both physicians in another state. There is this medical thing. Neither parent is, but the grandparents are, you have to do this right now! Why did this happen along the way! Why is this so urgent? I am glad they were urgent and persistent. But, here is our sedated AVR after they remove the fluid from the left ear which had mucoid infusion which means a thick booger in the left ear and is symmetrical hearing loss on the AVR. In this case I did take impressions, because dad wanted things to move as fast as possible.

And so he said if there is a hearing loss on that AVR, I want him to have hearing aids as quickly as we can. And so he was then fit two weeks after his surgery with his set of hearing aids. At this point he is two years, six or seven months old. And getting fit with hearing aids for the first time. Obviously such a delay in intervention with the family, which was really unfortunate, but he got hearing aids. And then second baby was born. I talked about that. Oh, I'm going to show the slide first. This EHDI roadmap, I hope you have all seen this. We missed this whole roadmap so far. So far, beyond this roadmap, we got to outpatient-- got to inpatient hearing screen, and then not on the map. And so let's talk about baby 2. At 21 days old baby 2 came in for AVR. Baby 2 failed newborn hearing screening. Not as significant of a hearing loss as baby 1 or child 1 I should say. But obviously nonetheless, there was hearing loss for baby number 2. And baby number 2 was subsequent if it with hearing aids within two weeks of the AVR. Baby 2 was fit by two months of age. The family did not qualify for Medicaid. This was quite the shock to their system from the emotional standpoint. And a financial standpoint. Two kids. Two sets of hearing aids within a month. This was like, I couldn't drop a bigger bomb on the family. And I did. But I think that was partly why this family was going through so much, having a second baby, having two kids diagnosed with hearing loss. Why did I give dad a phone number to text me? He still texts me occasionally. I need ear molds! Or I need this! Unfortunately, this was not the situation that happened for baby 1.

Baby number 2, we are and on the roadmap with baby 2, intervention happened earlier. Fast forward these kids are not kindergarten yet. So 4 and close to 2. Such a different set of kids. Number 2 in the clinic, is doing CPA at 2 two years old. Which is kind of unheard of. This kid has grown up in our clinic. And is doing all the testing without fight from day one. Luckily, he had a brother that was modeling clinical skills for him along the way. Now, baby 1, child 1 is still really not ... at 4 he had two frequencies, and then run around clinic, and then one more frequency. It is a very interesting path that happened with these two kids, in the same family. Just a very different dynamic for both of them. And, speech wise, baby 2 is meeting all their milestones, at age-appropriate levels. And we are still behind with baby 1. Because he was so far behind at 2 1/2. He is now starting to use senses at 4. But he is pretty far behind. I do talk to his ... one of our deaf and hard of hearing elementary schools in our town he is in an auditory classroom. Does not know sign. He is not a great participant in the classroom. He comes to the class intermittently with his hearing aids. Put them on. He fights a little bit about them. Baby 2 is the opposite. A different experience that the family has had with two kids with hearing loss. Probably since birth for both. Okay.

>> GABE: Your turn to participate. What could we have done different? How could this have been altered? Any thoughts? What do you guys do?

>> I'm wondering about well, in your area, when the referral is made, what does that look like? Do you give that to the parents and say, you call and make an appointment? What do you call the audiologist, and the audiologist makes the appointment? What is the referral process look like in your area?

>> When they had the newborn screening in Idaho we partnered with EHDI. The primary care physician would get a note. The parents would get a note. And they also go ahead and schedule that appointment with audiology directly which is why when Jess went back and looked at the medical record, they missed that first appointment. It was already scheduled for them. I feel like in Idaho we are doing a lot of those things, trying to reduce the loss to follow-up but it did not work with this family for some reason. Yeah. One of the other things while Jess is running back there is that we have a parent whose child is deaf and hard of hearing and calls every single parent. When they don't pass the hearing screening. But they don't call until after the diagnosis. Correct?

>> JESS: The parents will call if they are no sharing. And then she calls after diagnosis. It will report back as audiologists that the family was a no-show to their appointment, they will call. Like breast cancer, which scares a lot of them. So we do have a parent that will call if they are no showing for their APRs.

>> GABE: And knowing Andrea she did that, whether she got a hold of them is a different story.

>> In Alabama we have a lot of rules families. And one of the things we have recently started up his mobile audiology to go to the areas. So when they our no-show driving an hour plus or two hours plus to a pediatric audiologist they are going to the families.

>> That is not the problem.

>> Maybe during Covid.

>> So when I look at all the times in audiology, I would like to know why they didn't go. We talked a lot about logistical things to make life easier. I am from a real rural family. Like two hours, ugh! For scheduling the appointment. But also there are these perceptual components we have to factor in. Why are you making this is you are? And as soon as the risk was understood it was a call every couple of days. To me that says there is something perceptual that needed to be worked through before this constant referral that we knew was going to go unanswered, because they hadn't for the past 12 months.

>> Hundred percent agree. They were following up with the well checks, that medical part was important. What was the physician saying? That was a part that we might have missed, that we need to do some education with these primary care physicians. How are you addressing that they need to follow up with audiology? Oh, I see you have a referral to audiology. Make sure you do that. Why? This is the why. Connecting back that speech and language because of his that he could see this kiddo was not developing speech and language the way they were supposed to. How do we make that connection? How do we make it higher on the priority list? We have to have the hearing checked. Please go in and check. I am going to walk you over there. Let's go! Give me your hand. Make it a priority. Elevate that to the level of ear infection for mom and dad.

>> Just wanted to not brag or anything. I research perceptual barriers. That is a huge one that we look at. Is the risk, what we call vulnerability, even understood? If anyone is interested. Just saying.

>> You touched on this, and I work with the parents of my clinic. My right hand woman and in the EHDI when we have a referral she contact the family first. She is the first point of contact and I call for the magic worker. Literally I had this happen, we had a family schedule three times before and AVR, they were six months even getting into the clinic. They were not showing up. We had her call. They came in the next time. And they were a family, still in high school, there were reasons why they were probably not coming in. But I think from a parent point of view she is able to talk through like this is why it is important. She has two kids that had hearing loss happen at two different parts of their lives. It helped us in that way. We are also lucky that we can provide mileage reimbursement for families. That is a huge thing. Having a strict position with the family, can you make it to the appointment? Do you need a gas card? Do you need a family to pick you up? We will also send a letter to the physician. If all that does not work we are sending a letter calling the physician to see if we can get them into the physician's office to have that conversation to get into there. But those are things that have helped us a little bit.

>> Breaking down some of those barriers. And for this family particularly I was thinking that if mom and dad were physicians, that might be like "nothing is wrong with my child! Stop!" Mom and dad they are fine. So we have the parental thing going on.

>> My question is do you say that his parents or her parents were physicians? Is that why it finally hit home? When did the physicians got involved?

>> Interesting. So yes. Mom's parents are both physicians. One is an orthopedic surgeon; cannot remember what the other one is. And not in our state. I think they live a couple of states away. And it was interesting. The very first appointment, that behavioral one, just mom in there. Dad called close to that. The fitting appointment, grandma was there. She was in the room. Grandma is a physician. She was highly engaged. I think her level of engagement at that point was why things started to move quicker. She flew in for the ENT appointment. Grandma flew in, and was like ... I think it was something needed to hit home for them. I think grandparents getting highly involved was huge.

>> (no one talking). (no audio)

>> It died. Ok, sorry. I will say that we have our GCIH physician Statement. Has some nice information there, with information to highlight that this is important. And we need to make sure families understand the urgency from the get-go. Use a script. Be clear. You can check out -- a newer publication. By Ryan Recurion (phonetic), individuals at Voice Town, for ways to look at those strategies. I think we talked about that. Let's move on to the next one.

>> Okay. So, let's talk about another ... failed hearing screening. We are going to call this "family choice." The patient was one year old, and failed newborn hearing bilaterally. No complications with delivery, birth. A little bit different than the last case. There was already identified family hearing loss. So at one month old this was the AVR. On the baby that came in. And mild to moderate hearing loss bilaterally. Just a really interesting, you know, appointment because parent is a deaf adult. Has one CI that she uses for I would say more auditory awareness scales. She is ASL, manual communicator. We have an interpreter at every appointment for the parents. And again, this is now the third child getting diagnosed with a hearing loss. I will show the other two kiddos' audiograms or AVRs. The whole point was different. There was not a sense of urgency. Mom was yeah. I got this. Baby number three. She was like you know; it wasn't surprising to her. Maybe a little bit. Oh ... okay. Another one. There was no grief that she was showing. Everything was kind of an easy, relaxed appointment. And at the time, okay, so you know, I will talk about the other siblings, but do you want to do hearing aids? This family is an ASL family. Although by the way they have multiple members who can hear. Not just the two with hearing loss they do have multiple children there are hearing. It is not using dynamic.

What do you want to do? I don't know I guess we could do hearing aids when baby is like a year. A year? Okay. Well let's talk about that a little bit more. You know what? She is a very capable individual, teaching her child ASL. That is her whole background. Obviously, there is also an adult as of the second model spoken language for the child. Although we cannot hear spoken line which is good as we should. I was not worried about this family. Okay. This is your choice. This is what you want to do. Well, can we do another AVR in a couple of months? Not go to one until we see you again. She was like let's see how things go. So I want to show you the other siblings AVRs. And so one of these children the AVRs at birth. Now once a teenager, the other in elementary school. Similar AVR to the baby in the teenager. Very close. Mild-to-moderate. This child is a hearing aid user. She is very attached to her hearing aids. She gets really mom when mom forgets about her batteries. And now we use rechargeables. She has always been a good hearing aid user. She did not get them until she was three years old. This was the first child to get diagnosed in the family with hearing loss. So she had some speech and language delays. But obviously was using ASL at home as well. So communication was not a concern for them. This little guy, he had a different AVR at birth. He had a profound, severe to profound AVR. He was implanted at 12 months of age. And this is before he was implanted at nine months. He was a 12 month implant. I don't see this patient. But just a different dynamic with his family. Again, there is no sense of urgency. She's got this. She knows how to work with kids that have hearing loss. She grew up as one. She's got two other kids who are very successful communicators with their family. Again let's look at that roadmap. They did all the right steps. Well they got to diagnosis. And there is-- they were in intervention. May not have been intervention in the clinic, but mom was intervening on her own. She was teaching them communication skills that she knew on her own I think that is why I was not so worried about her not wanting to embrace hearing loss, she was doing all the right things as a parent. So I will let Gabe talk for a minute.

>> GABE: So the question is delayed intervention? Is it? Probably not. For this family. Right? They were doing what they needed to do. They had communication. That is the whole point of early hearing detection and intervention. To get them connected to communication. They had it. We are all good. We are following Mom's choices. We are all good. What do you guys see? And for those of you that are thinking, yeah it was delayed. Was it? Was there internal bias possibly? We should have done something different and forced hearing aids? We both know audiologists that would do that. No, we have to put this baby with hearing aids. We have to respect parents’ choice. We have to. The other ones that are the experts on their kiddos. If we don't allow space for their choice, they are not going to trust us. They are not going to come back and want to be provided services of the audiologist. So yeah. Any thoughts? Any body else wants to jump into this ring?

>> Thank you I would say that spectrum family's choice and maybe not pushing a little bit, but they were getting ASL at home. They were getting that line which foundation. But there is such more concern for those who do not want to do intervention at all. Like the two and a half-year-old that came in late. I guess that is the main concern. How do you deal with that? This case was like yes, the child is getting language. Which is the biggest thing. But, for the other kids that don't have that, what do you say to these families? That actually helps them move along with the intervention?

>> JESS: I think it's important to support families in all different ways. They are all in different spaces. Right? And I think as an audiologist, I try to teach the students that I work with, just to try to get a feel for the families. If they seem like you have dropped that bomb, and they are not listening I guess at that point, they are probably not ready to talk about hearing aid at the AVR. Right? Let's bring them back in a month, two weeks. Given the space to take this home and think about it. I'm going to give you a non-audiologist example. My son has food allergies in addition to hearing loss. When he was about 15 months old, I had had given him peanut butter before. And he got hives all over his face. And so he is allergic to peanuts. My husband and I aren't. What we can probably figure this out. And then they do the testing. Yes he is allergic to nuts and eggs. Eggs! Who is allergic to eggs? I have been feeding him eggs for his entire life -- Once he started eating. Oh my gosh! Have I been posting my kid? I got so sidetracked on this and stopped listening. Let's go get him ta da da. My husband said, he can't eat that. Had this been a family that did not have this background, and I could tell they were not in that space, I would say we are not going to take impressions or talk about hearing aids. Just come back on another day. Let them have the space to figure things out. But still be there to support them. I always am a provider that calls them or emails them. Let's exchange information so we can contact them when they are ready.

>> GABE: To has to be some education evolved too. Let's wait to one year of age. I have had parents say I want to wait and let them have that choice. Do we let them choose? Do we let them choose whether they are going to wear clothes or not when they are babies? We have to allow them to have the ability to make choices when they are able to. But it is going to be different depending on the communication that they are using.

>> I wouldn't say that there would be delayed intervention in communication. I am an audiologist for an early intervention program in Nevada. I wonder whether there was any other intervention offered. Because, yeah ...

>> JESS: This particular family, this adult grew up in our state. She went through our school for the deaf. Went through an early intervention when she was little, and she had two other kids that have been diagnosed. I knew she had-- in our state it is called AESDB, Adult Education services for deaf and blind. She knew people in the group. At diagnosis I said, what do you want? Do you want to get in touch with them? I let her do that. She had a connection there. But she did not want people coming to her house and giving her direct intervention services. Yes I did offer that service. She did not want to have a speech pathologist. Services were offered. But she said I got this. I could call the person whenever she felt she could call. I saw another hand.

>> So one final note. I put up-- these are a couple of the newer publications out they are talking about family choice. And the need to support. If you want to go read some more information or can't sleep at night and need something to read, Jones and Roberts have a good article that now. There may be some good ways to think about internally, for those that might see a different pathway for some of these individuals.

>> JESS: We are not done. Because the story changes. Okay. Update. Child is now closer to one. This is a recent press that I did. Actually with similar results on two separate tests. Baby is now closer to one. Came in a few months ago. And said, oh update. Fitted her with hearing aid at six months. Mom said let's just get the hearing aids. Put the hearing aids. Came in about 10 months or so. Yeah, we're not really wearing the hearing aids. I figured they wouldn't be. But she is not hearing us, not responding. Oh, are you noticing that? I don't notice because mom doesn't hear things. But dad says she is not hearing. So that visit with the two similar audiograms, she was sick on that day, so she had flat temps, her eardrums looked unhealthy. At that point, I was concerned about some middle ear stuff going on. And I said, let's come back in a few weeks. Maybe this is a cold. Let's see what happens in a few weeks. Came back again and unfortunately still had abnormal temps. This was just last week. I got this test. And the sister, who is like the best sister, the one with hearing aids, yeah, she does not hear. Okay great. So I go over this with mom and dad also was on the phone. We talked about it. And all of a sudden mom says, well, can we get a cochlear implant now? Wait! We haven't even done hearing aid trial. So it was different. All of a sudden there was this immediate sense of urgency from her that I wasn't ready for as a provider. Because we've had this very slow moving train. And she was let's speed up and see how fast we can we get with the ENT? How fast can we do this? It was an interesting change in our experience with her, because now there is a sense of urgency.

Because mom remembers from the first, well second child, he was implanted at one. And she was like, one? Well we have to address the middle ear stuff. We might be talking tubes. Probably need a scan. I also had referred to ENT. She went to an ENT back at the initial diagnosis. So it was an interesting change to the story. Because she still knows her child the best. She still has a very good communication option for this child. But now she is in a different place. Let's change gears a little bit. All right. So this is a weird one. Maybe these have all been weird, I don't know. But this child was referred to me from the pediatric ENT for hearing evaluation. Eight months old referral, hearing evaluation. As I go digging through the chart, this is the newborn hearing screening results. From -- our hospital scan in the stickers from the newborn spinning machine which I love, and I get really sad when I cannot have them, so that I can see how good was the test? But it is interesting you look at this. The myogenics, the noise of this baby was 0%. This baby was quiet in his sleep. The left ear, after 1000 sweeps, very quick. Less a minute. A quick test when it is 1000 sweeps. But the right ear passed over 10,000 sweeps. But still passed.

And of course our screenings are going to pass this baby. No reason not to pass this baby so the baby passed at birth. While the coming into seeming? At two years old pediatricians have babies with normal ears bilaterally. Four-week old pediatrician so the baby. Normal but the right ear is smaller than the left. There is a skin tag on the right side as well. Okay. That is maybe some abnormality on the right side, the side that had the 10,000 suite pass. Two months old. Normal years. Small air tag on the right. Four-month old. Normal ears. Five months old. Now it appears to be narrow. And not patent. Cannot visualize the TM or ear canal. Not able to pass a curet through the canal to refer to ENT. Interesting because the whole way they were saying it was normal. Now they are saying it is not a normal ear canal. Not sure if it is a severe stenotic, or almost closed. If not closed. Refer to audiology for an AVR. So this child is referred for testing because of the ENT thinking there is something going on with the right ear. And boy were they right! Okay? This is the AVR on this baby. For those non-audiologists, this is a moderate to severe hearing loss conducted. "Conducted" means the red bracket is the bone connection. Which we stopped testing at 20 on our bone connection AVRs. It was a normal response on the bone connection AVR. And, a significant conductivity loss on this baby. There was not a canal I could find.

So, as I was saying about the family, at eight months old, I am sitting there with the families thinking this is so strange the passed their newborn hearing. How do we have a (indiscernible)? Which is a congenital abnormality, born without an ear canal. And so when I am asking the family like, did you notice anything happening? Mom said yeah it was weird. I feel like overtime or ear canal just closed. Really? You could kind of see it there. And then canal almost closed off eventually. I was thinking this is the weirdest thing. I had never heard this. I have never seen this before. So the really interesting thing. Kind of an update. This is our AVR, estimate of hearing loss obviously, and update. We were able to do behavioral responses. I assume it was a true hearing loss test. It is still a 45-60, so like a 60-ish Db hearing loss conducted. She was fitted with a soft ear Baja; she has been wearing a Baja successfully the whole time until this test. And again initially, how could newborn hearing have missed this? Right? Was there something in the 1000-10,000 sweep? How could this have been missed? Gabe talked

about the uniqueness of this.

>> GABE: Is it unique? Yeah. The data says .6 cases per 1000 were developed acquired atresia. It does happen. Obviously for this one the most common is a fibrotic plug. Those are typically for adults. Or if they have already had a surgery, and it grows as an artifact from that surgery, in this case it was probably the bone structure itself that was growing into the ear canal. And so that would have to be essentially drilled out, and drill down, in order to make a canal. There is not much publication out there about this. Mostly case studies that are available. Yeah. There's a couple that I found that are fairly new, 2017 case report on several different studies. But only two for children. Again pretty rare. So we need to publish the stuff and do a case study. All right. So, you can see the causes on the right. There are some different causes. Again most were adults. Usually some kind of hearing difficulty when they already have an ear surgery, not growing of the bone, which is probably what happened in this case. So is it a unique case?

>> JESS: So, then after this, again got me thinking. Have I ever seen something like this before? I got thinking about the case that I have on this child. And this child had failed her newborn hearing screening at birth. And was seen in a different part of our state, different audiologist. Came to me at 11 months old, again because of a referral. So this is this child's history, from the time they came to me. At three months old they had failed their newborn hearing. Saw an audiologist who said there AVR was normal and that they had fluid. So a tympanogram said it did not have a good eardrum function but had a normal year. And I don't have access to this AVR. But this is a report. And then in the same area, they saw an ENT. And the ENT said there is fluid. I don't think I can get tubes in there. Why? Could not get tubes in. So they refer to a second ENT which happened to be one that I work with. He saw this baby at eight months of age, because they were from another part of the state.

They had to travel forever to get to the other side. And this ENT said, there is no ear canal at eight months of age and refer to an audiology for a Baja consult. When I see this baby for an AVR consult, it was quite a significant difference from an AVR reported as normal and three months of age. So again, it got me thinking. Was this acquired? Did this happen to this child? Did not pass the newborn hearing, but they were told it was normal. Obviously unfortunately in this case this really did delay intervention, because this is bilateral. And so this baby was not identified until 11 months of age. Then I got looking back at the chart. What could have been done differently? How could this have been caught? Why would this baby be seen by audiology and say it was normal? I started looking. This baby is also cleft palate baby. It was a preemie and in NICU. And in addition to the failed audio hearing, there were a lot of factors for hearing loss in this case so it is hard to say what could we have changed for this baby. That did get intervention.

Obviously, it was not until much later. But a year the baby was hit by bilateral Baja’s, able to get loaners quickly. She is a little bit older now. She will throw a fit in the clinic if I take them off. I did take one off at a time. Go clean it. Check it. Put it on. And then the other one. It is so interesting to see that this is a similar thing. We can all

speculate. It is possible that it was not a great test in three months. I don't have access to it. But again, the ENT said they saw fluid. There was also this medical provider supporting kind of this diagnosis they were given as well.

>> GABE: Of we will ready talked about most of his body goes back to those risk indicators. Baby number one had an ear tag. Jess have had conversations. Lately there's a lot of physicians who say they are not going to refer anymore for tags, because it happens often, and they end up having normal hearing. What about the percentage that doesn't? That is the only risk they have. Can we identify that hearing loss early? So again it is back to education, and communication with the other providers. There is a reason why that is on the risk indicator list. Please refer them. It is just a quick appointment with the audiologist, and then we can monitor and make sure they don't have any issues. Follow those risk indicators. Any other thoughts or comments about this case? Anybody else have an acquired atresia out there?

>> I suspect it is missing in both cases. I think all of us get that. Not perfect. Newborn hearing is not perfect. Diagnostic AVRs are not perfect so we have to live with imperfection, and we have researched data to show it. Is unfortunate when it happens. But yeah, I think we all know that (indiscernible), and tags are associated with hearing loss but also with typical hearing. Sorry have not seen acquired atresia. Obviously, the ENT who said he could not put tubes in there, must've had a reason.

>> We are all human. To be human is to err. Right?

>> JESS: Yeah?

>> I will let you word it correctly. So the right ear passed at 10,000 sweeps, is there a perfect range that you would like to see those sweeps in for -- Because with AVRs, at least get 2000 to get a clean wave or whatever and sometimes you can get it earlier. But in those newborn screenings, what does that look like?

>> JESS: Because it is an automated system, I mean we would take kids in who would get up to 15,000 sweeps, and they failed. And they have a normal AVR diagnostically. So, was that fluid from birth or whatever? So they will be kids that will go beyond 10,000 sweeps potentially and have normal hearing. There is not a perfect system. The computer will pass them if it detects a response and that is what happened in this case.

>> So there is a range where that discrepancy is concerning?

>> It is time stamped. It is going to run those sweeps for a specific amount of time. If at that time it reaches that greenlight "go," then it is green checkmark. You have a pass. It is time stamped. If it does not reach that point within that time, it would be considered a fail. Most of the individuals doing the screening are not interpreting the AVR. They are just looking at the screener for that checkmark of good or bad.

>> JESS: We encourage screeners not to look at that. I will talk to families that said they almost passed. They look at the numbers. What numbers? What are they talking about? We are encouraging screeners not to interpret the numbers. I am showing this because of this particular case. We don't want them to try to interpret the numbers as meaningful that the passed quickly or that they quickly pass in a long time of the failed quickly. Does not equate with normal hearing loss.

>> Any audiologist attend the CHOP (phonetic) online conference last week? No? It is timely that we are doing this. It is an interesting thing. They did have a couple of congenital CNP (phonetic) topics in the conference, in my reference. This particular case, those cytomegalovirus, does everyone know what that is in this room? Everybody heard CMV? This particular baby failed normal hearing bilaterally in both ears. Diagnosed with systematic CMV.

So let's look at the medical history. Baby was born at 33 weeks. 2.4lbs. At birth. Because of the birth weight and because of the head size, our NICU did a urine CMV test. At two days old, it was diagnosed with congenital CMV based on the urine sample. So before baby even had a newborn screening we were in congenital CMV diagnoses in that one week old, we jump to the bottom, 34 weeks gestation, baby fill in the right ear. Passed in the left ear. okay? Go back to the top, three weeks old and then the plasma positive, the blood test came back to confirm CMV. So we read screen again. Baby is still in the NICU. Four weeks old. 37 weeks gestation. Full-term by NICU standards, not on our due date. Again baby failed in the right ear, passed in the left ear. okay? So let's go through what happened. Baby is discharged from nursery. Six weeks old comes into audiology for the first AVR based on the failed right only hearing screen. At this time, again we are still not at 40 weeks gestation, 39. Not at the due date but really, really close. Left ear has a normal AVR finding. Right ear has a moderate hearing loss. At this time, the right ear had abnormal middle ear function. And the left ear had normal middle ear function. Type A for the left and type B for the right. Maybe suspicion because the left ear had a normal temp and normal OIEs (phonetic). We are going to have to retest this. I am not convinced if the right ear is conductive or not because there is a flattened tympanogram. Now we are at 43 weeks gestation. We have met our due date, three weeks old we are comparing to due dates. But nine weeks old technically.

This is our AVR at nine weeks old. We've got a moderate to severe sensory neural hearing loss. At this point we are going to call the (indiscernible) because we don't have great temps, and now they are on both sides. At this point this is not a conductive hearing loss. We are going to call this mixed, because we could not get bone connection. She was not very cooperative. But I was able to get flat temps; hearing loss is obviously progressing in some ways and sloping. I reached out to the ENT and the ENT got her in immediately. Let's get moving forward. This is an urgent case, progressing potentially. We passed left ear at birth. And now we are at this point. So we were able at four months old to coordinate MRI and tubes. Even though we are dealing with middle ear stuff because mom wanted to move forward with the obligation quickly. At four months old, after the PE tube placement, we got this as our AVR. Which is interesting. The left ear is now looking worse than the right ear, which was the initial pass at birth. An interesting Progression of this particular hearing loss. At this point, is probably not a mixed component. We removed all the fluid that there was. Now we are dealing with the sensory neural hearing loss. He we are going back from the first AVR, it looked CV-progressive in both ears. So if you look at the last one, fast-forward, this is my wrap behaviorally.

She is now closer to three. If anybody has worked with kids with CMV, it is so interesting looking back at this history with her. When she came in at nine weeks old -- Sorry-- six weeks old, she was such a typical looking baby. There was nothing looking at her, oh, I am surprised I am seeing CMV. She was a NICU baby, she was small but there weren't any red flags. Over the time frame with her, she is in OT; she has a lot of autistic- behaviors at 2 1/2, 3. Delayed speech even with the amplification starting early. She had a lot of those CMV subsequent findings I guess. I don't think we are going to get CPA for much longer because she is just not a typical developing child. When did that change in her development? Those first few months, there was nothing about her that seemed really atypical. It did change around a year, when she was delayed in walking, and all of these things. In addition to the sensorineural hearing loss, we battled this overlaying conducting component with her. She had had multiple sets of hearing tubes and unfortunately every time the put new tubes in, she drains for weeks and weeks at a time and cannot wear hearing aids. Has delayed auditory access for speech. She has been in intervention her whole life. She has been doing speech therapy, OT, PT, she is talking but it is definitely an interesting case when we are dealing with all of these in addition diagnoses findings with congenital CMV. So, like a little controversial depending on how you guys think about congenital CMV. In our hospital, this is before Covid, 2019. I went to our infectious disease, NICU Doctor, ENT, and said we were close to Utah. We were getting lots of push from parents. And from the Utah folks about doing at least targeted CMV screenings on our babies at the hospital. We are the biggest birth hospital in the state, and health system in the state. And so the four of us met. Me, NICU, infectious disease and ENT. ENT and I said yes, we want to know these kids have congenital CMV. We want to do testing on patients. By the time we get to audiology at four weeks old, the get to the pediatrician, and out of the window of doing accurate CMV testing so we want information. Unfortunately, we have this big meeting. We finally got them on board. Okay, March 2020 happened. And that got put in the back corner. 2021, early 2022 I reached out again. Can we revisit this again? Were going to do this pilot program. Oh yeah, we were.

Can we pilot it in your hospital? Do some targeted screening? And see if after a year ... I have to do little, tiny suggestions. I can't do big ones. They allow me to do little ones. I said let's see if we can pilot this right here and see what you guys think after we analyze the data from a year of targeted screening. Targeted screening means they would screen the babies who failed their newborn hearing screening for CMV. We are not screening every baby. No way we would do that. They were willing to do it forget failing newborn hearing screening. So we are going to show two little subsets of this data because they started this at the end of 2022. I got them to start doing this pilot program. I looked at the start date to the end date of the year. It would pick up from the day we started for one solid year, there were 406 targeted screenings opportunities. Okay? That is how many babies failed in our hospital systems during that period of time. You can see it will look at these numbers, we've got 82% of them with negative CMV. They were doing the cheek swab CMV screenings at the first step of the screening; we had 17% that were not screened. 1% had a positive CMV test in this cohort.

This data is looking at 7 hospitals; we have seven hospitals within our system. In Boise we have the biggest hospital in Burling center. And then we have some smaller ones around our part of the state. And, looking at it, at this number, how many of these were negative? When we look at percentages, 334 were negative. 67 babies were that 17%, not screened. So, looking at this, when I dug into the data more, may be that not screened happened at the beginning when we started the pilot project and maybe all of those 67 babies were missed for the first couple of months because they were getting all of these hospitals on board, building into the template of the newborn process. But looking at this particular data set, in the first six months they missed 37 kids. In the last six months they missed 30 kids. I attribute it to the new process but unfortunately it was not widely missed kids. So we looked at this. The positive CMV screenings. Of the 406 babies during this timeframe, we had five positive CMV Screenings reported. And again we started with the cheek swab. This was the cheek swab on the five babies. And then we go down to the next step in the protocol. To confirm it with a blood test the plasma test. Only one baby was confirmed positive for congenital CMV based on the blood test. So having two blood tests match. Two babies did not receive the second stage of the screening process with the screened blood test and two babies came back negative on the blood test for CMV. So you can see of those babies, the one that had two positive CMVs was diagnosed with a profound sensorineural hearing loss. On the other side, we have those four babies who were either negative or not confirmed with blood, who have normal hearing on their AVRs. And I did review their AVRs so I could look at them. They were normal. So kind of an interesting finding. So we then had our hospital go back to them, and we gave them these findings and they looked at the findings as well which Gabe is going to talk about as well. She's going to talk about where hospitals are based on these findings.

>> GABE: So as Jess said, the numbers look a little bit different because have a total of 402 here that were failed. And 363 is the number that they came out of. But it still came back to that only one being positive twice. So the pediatrician that Jess works with essentially wrote a white paper, documenting all of this. And also putting in the financial burden of what it costs for the two-stage screening. And obviously, it indicated this is not cost-effective to do it this way. Essentially, the outcome was we need to stop this process. And I have here that the data suggests testing should stop. But what it should say, and those with the exact words from the white paper, it should say it needs to stop in the way they are doing it. Not effective. Instead of doing that cheek swab, maybe we do the blood spot first. And make it quicker. Right? If that is the screening or the test that is a little bit more sensitive, let's start with that. Right? So back to you guys. Yeah! How many out there are doing CMV screening in their states? Are we doing it with all babies? Just that were referred or failed?

>> Hi. I am from Minnesota. We have incorporated CMV screening for all babies, from the blood spot. We have a few posters and stuff out there with results. But I enter all the data. I enter those kids into our system. And many, many of them passed the newborn screening. We are still doing the follow-up for the hearing loss piece of it. I also work for the EHDI program and follow kiddos in the longitudinal follow-up. And CMV is definitely a cause. I don't have the numbers off the top of my head as to how many we've found. For what the results are. But Gina has all of that out there. And she is doing a presentation I believe.

>> GABE: Yeah and as Jess indicated, this was crawling in. For any of you don't know, Idaho does not have a state legislation on newborn hearing screening. Our EHDI program is the one that has championed the state and we do have a very good newborn hearing screening rate, but we don't have legislation. That gives you a little window into how difficult it is to try to change things within the state of Idaho. Even getting the screening accomplished on those that failed, the newborn hearing screening was pretty hefty on Jess's part. But you are right. We are targeting the wrong group. Not just the ones that failed, but all of them.

>> I am from Utah. So we do have the targeted CMV testing for failed newborn hearing screenings. And failed the outpatient and inpatient we do this. We are getting a lot of the CMV testing from those NICUs. It is a big thing not to do the hearing target but the NICU protocol as well.

>> For the NICU protocol, do you screen all the babies? Do you know?

>> Honestly don't know. We have a document that they are supposed to follow. The IUGR is one of them.

>> JESS: When the physician sent out the paper, after we looked at all the data, I was a little heartbroken. I know it did not come up to the numbers they wanted to see to make it worth their time. But again, from an ENT/audiology standpoint we want that information so we also want information on the kids who passed the newborn hearing who might have congenital CMV. But listening to the chat last week, I was a little bit defeated after this. Because things have stopped in our hospital. Since we are the biggest hospital system in the state, a lot of things that happen in the EHDI program and the things that came out of the risk management program has come from the hospital, doing what we do. And so unfortunately, we were unable to get them on board with this.

>> I am from Connecticut, they just started screaming and started universal, integrating blood spot testing. I was working with a clinician, working with the family. The child had other things going on and they were able to pull his newborn blood spot at two and go back. He was able to be diagnosed, even though he was outside the window by the time the period was considered. That is something that functionally made it easier also integrating it into the tests that we were doing and the banks that already exists and the protocols that exist. A lot of the things came from parents and that is why it passed in Connecticut. Parents and grandparents got together and said we are going to make this happen.

>> JESS: He will look at some of the CMV, the presentation was interesting out of CHOP, a map of the US and had states that had some kind of legislation and Idaho was highlighted. Wha? We don't have any legislation or anything. I looked. We had a bill passed to allow for education on CMV. So we do not have legislation for any kind of screening. But we do have a bill that has legislation for allowing education to happen in our state.

>> Which is the exact opposite of what we can get in Connecticut. I worked with a parent advocate. I tried for years to get education and I just accept screening, but I want education too.

>> I want to-- you did not mention treatment-- but to remind you that early identification of the CMV are also candidates for antiviral medication. The data is not super exciting, but it seems to slow the progression of hearing levels.

>> Unfortunately or fortunately, when we had the initial meeting-- in fact, infections disease was one of the physicians at our meeting, he was very concerned about kids who or parents asking for antivirals. Because of the negative side she thinks about giving antivirals to kids who may be less than thematic. I thought he would be more on our side in this whole endeavor. But he was more the opposite. He was the one that the ENT and I were trying to convince of this whole targeted screening with him.

>> GABE: Anyone else? We have a couple of minutes left. Okay. Well it sounds like we need to go check out the posters on CMV out there. And keep communicating. I think that is what is going to help. And also publisher results. That also helps when we can show data from other individuals or states and what is going on, when other states are trying to get this stuff passed. Please publish stuff out there all of you EHDI people. We already did that. Thank you so much for your time. And for taking part in our conversation. Good luck with your kids!

>> [End]