Audibility-based Clinical Decision Making and Parent Counseling in Pediatric Audiology

Presenter: Caitlin Sapp, AuD, PhD

It is my pleasure to welcome Doctor Caitlin Sapp to audiology online. Doctor Sack comes to us from UNC Medical center in Chapel Hill, North Carolina. If you'd like to learn more about her, you can read about her bio on the course registration page, but at this time, I'll hand the mic over to you.

Thank you so much, Christy and I really appreciate the invitation to be here and speak to the audiology online group today about a topic that I'm so excited about as both kind of a scientist and then also as a clinician, a little bit of my background. I am a clinical pediatric audiologists. My name is Caitlin Sapp. I'm a clinician scientist joining today from the University of North Carolina in Chapel Hill. I'm the head of our clinical pediatric audiology team under the hospital so UNC Health here in Chapel Hill.

I'm also the director of the early hearing loss lab under the UNC School of Medicine. And I like today's talk because it's really going to reflect both my research in parent counseling and the best way that we approach talking to parents about early hearing loss, and also my clinical work. Having been on the ground talking to parents about these and having these really hard conversations, these are my disclosures for today's talk. I also added the caveat. I always kind of discuss this.

To preface that, my work and my research is to acknowledge that our work focuses on primarily on families who choose to pursue a listening and spoken language approach after early diagnosis with hearing loss, but certainly acknowledge that other counseling strategies may play a bigger role for families who pursue either a bimodal approach or who pursue a visual communication and language such as ASL. I don't think that there's nothing here that those families could really dive into, but I always want to acknowledge sort of my limited expertise as not the person to talk to about counseling parents who are choosing a visual communication language. These are our learner outcomes. The talk today will broadly be divided into three parts. So what are the current openings, really, and what we know about parent counseling?

If our goal is ultimately to maximize parent understanding and connect that with parent action, thinking about how much of our work relies on counseling parents rather than our true patients with hearing loss, the second part will be talking about audibility. What is audibility? How does it complement the work that we are already doing, and how does it serve potentially as kind of a connecting framework between the diagnosis piece and the intervention piece, and then thinking through the shifting lens of audibility based counseling based on some child specific and family specific factors where does the counseling shift? And will that stay the same for a single family over the time course of their care during those first few years of life? So starting it out, thinking through about, like, really, why is the issue of counseling so important?

And I think about this in honestly, kind of, in some public health terms, kind of thinking back to my early PhD work looking at the public health aspect of early universal newborn hearing screening in the United States, we screen more than 3.5 million babies every year. We have exceptionally high universal screening rates, often exceeding 98 99% of infants who are born in hospitals in the United States. We screen for two primary reasons. The first, hearing loss is incredibly common compared to other conditions that are targeted through birth screening programs. So for example, through the blood spot screen, things like PKU, things like metabolic disorders, hearing loss is much, much, much more common than all of those things kind of combined.

The second primary reason is the earlier we diagnose infant hearing loss and provide intervention, the more able we are to positively influence long term outcomes. And for this piece, I would say this is the same regardless of a family's decision to pursue either listening in spoken language or dive into a family based learning of sign language like ASL. You can't really take action until you adequately know. And that really has motivated our newborn hearing screening program development over the last 20 years. This is CDC data, but for about 1000 babies that are born, we're going to find one to two of them every year.

And if those two children are not able to access the appropriate follow up care, this diagnosis piece doesn't result in improved language and learning opportunities, then other modes of identification. Really universal screening hasn't delivered on that promise. Zooming out a little bit beyond the incidence of congenital hearing loss, thinking about late onset in cases of progressive hearing loss, if we were looking at one to two per thousand among newborns, by the time kids reach the school age years, this number will go up to about six children per thousand. This is pulling nhanes data or public large data sets publicly collected by the Department of Public Health. These kids are going to be a unique population.

They may have different counseling needs. You may need different strategies to appeal to their parents every year. The United States healthcare thinking about those two infants were finding that growing number of school age children who were entering the school age years. The United States healthcare system spends more than $23,000, all told, between all of those screenings of babies with typical or normal hearing to identify each child with congenital hearing loss. To fully realize the benefit of this investment, we want early diagnosis to lead to early intervention.

And this may be an undershoot in terms of the dollars invested per case of congenital hearing loss. For every child who has lost a follow up or whose family chooses to forego intervention delay intervention, we really lose the ROI on those resources that were invested in finding them. That feels really bloodless to sort of talk about it in terms of that. But behind every loss case is a child who's potentially not taking advantage of those early language learning years to be ready to take part in their educational environment. To realize those benefits.

We are relying on parents taking action soon after the diagnosis, and our task becomes, how are we talking to parents in a way that really connects the diagnosis? We are presenting them with the actions we're hoping that they will take. I like talking about really connecting this kind of public health piece with

parent counseling, because I think sometimes we address parent counseling as a very soft skill that's not necessarily embedded in the research as steeply as some other aspects of early audiological care. The hearing aids were choosing the signal processing. When I think about moving the needle on lost, a follow up on some of the issues that have really impacted program effectiveness for us.

I like to look at parent counseling, and there's a couple important reasons we are in control of the words that we use. I'm going to show some examples thinking about all of the aspects of early hearing loss identification and intervention where we are really, really powerless. Some cases of loss to follow up families who live far from services. I also would advocate that words are free. Words are something we could change as early as tomorrow when audiologistss are in a booth with a family, thinking about novel strategies to build on the work that they're already doing.

This is an aspect of improving pediatric audiological care that falls entirely within our purview. There are many fixed factors that impact just how successful a family can be that fall, again outside the purview of a single audiologists. These include some family factors. So thinking about the financial resources that a family needs to make and keep their appointments, we know that families who maybe come from lower resource backgrounds are more likely to have no shows before they eventually present for their diagnostic appointment. We know that geography can make accessing care really, really challenging.

So does a family have consistent transportation? Is it transportation that's shared within several members of a family? And how long are they sort of coming? Another family factor, including healthcare literacy. So navigating sometimes really complicated information, and I know there have been several efforts to improve.

How do families find out about who is an audiologists who will see my baby and provide the right type of hearing appointment. And different states kind of approach this in a different way. But it's often really reliant on parents to navigate extremely challenging factors. There are also healthcare network factors

that are important to consider. So not just does a family have health insurance, but do they have close access to a provider who accepts their insurance, Medicaid being the obvious example there.

It doesn't matter how strong your state's Medicaid program is and your coverage for hearing devices, for ABR, for repeat hearing evaluation, for periodic monitoring ear molds, it doesn't really matter how good your coverage is through Medicaid. If you cannot locate an audiologists who accepts Medicaid for your child's audiological care. So those provider network pieces really falling outside the range of what a single audiologists can positively influence. Overriding all of these challenges is the real fact that we are making a big ask for parents. We're asking them to think about hearing loss probably at a time where they're not yet worried about early hearing loss.

They've just brought their baby home from the hospital. Especially in cases of mild to severe hearing loss, they may still be showing some reactions to sound. We're asking parents to pursue a complicated test that may be hard to accomplish for a condition that they're not worried about. Our task becomes identifying the levers for success that are within our sphere of influencing and leaning as hard as we can into those factors. And I kind of broken them out into three primary parts.

Today we're going to talk a lot about the words that we use with families. How are we talking about hearing loss? How are we talking about why hearing loss is important? We are also in control of the consistent use of evidence based practices, taking advantage of the time that we have with families. How are we going about making sure that they're connecting with the highest quality pediatric audiology care?

And this we won't talk much about today, but this is kind, kind of another aspect of my research is looking at urgency. Are we kind of using the cues that are most impactful for families, for developing urgency about hearing loss and really matching the urgency that the audiologists may be projecting kind of onto families? But today we'll focus mostly on this words that we use with families. How are we

talking about hearing loss? How are we talking about intervention, and how are we telling a story that makes sense with what the family is experiencing?

The first area we'll kind of break out today is thinking about what are some gaps in our current parent counseling paradigms. I think the pediatric audiologists has a kind of a unique challenge, because in other areas of audiology, you really can look back and say, I'm the audiologists. My patient is before me. He or she is the one experiencing the hearing loss. There's a kind of primacy about that experience where the person is describing their symptoms to you and you're able to either validate or, or corroborate their experience with some of your audiological battery and then likely choose intervention that's addressing their own concerns.

In pediatric audiology, the challenge is a little different. In this sort of situation, your patient has this infant or child who has either failed a newborn hearing screening, failed a well child check displaying delayed speech and language that has brought them in for a hearing test. And the parents in this case are acting kind of as a healthcare agent. So the infant is the one maybe experiencing the healthcare issue. In this case, hearing loss.

You are sort of the audiologists. Your task is to describe how hearing loss matters to a person who is not experiencing themselves with this overriding goal, that if we get it wrong, if we don't appeal to parents in a way that is really meaningful for them, they may not take action on behalf of their child until it's sort of too late to make up for time. We know from sort of the time before universal newborn hearing screening. If we wait until parents and family members, caregivers develop concerns about hearing loss, we've waited too long thinking through children in previous generations that weren't identified, especially who are hard of hearing, until much later. We've also decoupled the timing of diagnosis from that onset of concern by moving to universal newborn hearing screening.

As I mentioned, in 1993, the average age of diagnosis for bilateral hearing loss was two and a half years old. If you're looking at a two and a half year old who has, let's say, moderate, severe hearing loss, by the time they reach two and a half, their parents have likely developed some hearing concerns. They're noticing they're not using speech and language. That's like their peers. They may not be reacting to all environmental sounds.

They may be lagging even younger children in the family. And there's previous research that suggests by the time the pediatrician was ready to put in a referral for a pediatric audiology evaluation, the parent may have been displaying signs of concern for more than a year at that point. Today, we regularly diagnose babies, I mean younger than a month, younger than two months in those very first few weeks of life when parents may not have had an opportunity at that point. Their main job is to eat and grow and go to the bathroom. Hearing doesn't necessarily figure strongly into those first few months of life.

Parents may not yet have had concerns about hearing loss in a really natural context. So in their home, I was going to stop. When I'm talking about hearing counseling at this point and acknowledge that changing the way that you talk about hearing loss can be really nerve wracking. And I feel this myself. Before I was a clinician scientist, I was a full time pediatric audiologists.

And I think about how I like to talk about hearing loss. I have a little book with one of the pictures. It's paperclipped open to the page I like. I have my way that I describe the anatomy hits the eardrum, eardrum moves across the bones. Plink, plink, plink.

I have sort of my rehearsed description of how hearing works and how hearing loss occurs. And I recognize that when we talk about changing the way that we talk about hearing loss, this can create some anxiety. Is that to say that I've done something wrong with all of these kind of previous counseling experiences that I've gone through? It's a loss of the locus of control. If I've always been in control of the narrative, and that's worked for so many families, I'm really hesitant to have any changes.

In some cases, we have what I call evidentiary proof. In the successful cases, as the audiologists becomes more seasoned, has been in this field longer, you likely have children and families who have come through your universal newborn hearing screening program, been identified, got their hearing aids, gone to early intervention, started kindergarten. There's evidentiary proof that whatever we were doing for those families was the right choice. They really got the message, and they were able to successfully translate that into positive outcomes for their children. I think there's always room to expand how we talk about hearing loss, thinking not just about the families in your pool who are the most successful, but how have families struggled?

Who are the families that didn't come back after that? And what are sort of more holistic ways we could approach families who potentially aren't well targeted by our previous strategies? I also think about the fact that audiologistss are stretched for time. When you look at studies on burnout, what are the things that make audiologistss the most stressed at work? One of the overarching themes is that there's never enough time for all of the counseling that we would like to do.

If you are an audiologists that think this appointment is two and a half hours and we are already at time .1 and a half hours. I have to finish this ABR. I have to get earmold impressions. I have to get the next appointment. I have to make family understand they're going to get a call from so and so and so and so and so and so.

We have to be pretty efficient. And I think as audiologistss we've thought, well, adding anything new is potentially stretching that already very precious time that I have for counseling with families. I'm going to talk a little bit about what are some of the areas where research suggests there are opportunities to expand or improve how we are currently. I always want to describe this as a yes, and, and some of our research really bears this out. When we talk about adding audibility as a primary counseling tool is there's no reason for this to replace really any of the strategies that we're already doing.

It's potentially adding dimensionality to the words that we're already using. So looking at some of the background research in pediatric audiology, particularly around parent counseling, kind of thinking through what are some of the reports from both quantitative and qualitative research that can tell us about where do parents still see gaps in the counseling that they received? Parents may not always feel like they have the information that they need. They don't always get the primary takeaway. And that may be, first of all, because the parent lost the information after they first heard that diagnostic, that hearing loss word.

Once a diagnosis was made, they may not have been very receptive to sort of the next piece of parents require and want more information about what their child's unaided hearing is. And I think part of this can be reconciling what they see in terms of behavioral responses to sound at home. And we'll kind of talk about this in some of my own data in a few slides, thinking about why is my child turning to some sounds. If you've told me that you have diagnosed this hearing loss that's mild to moderate, I want to believe you, but I'm having a hard time reconciling the behaviors that I see and what is the cost of the hours that my child is not spent wearing their hearing aids? If my child doesn't put their hearing aids back on after bathroom while we're in story time, what is really the loss of that?

What are they hearing when they're not wearing their hearing aids? Parents need more information about nitty gritty hearing aid use data. So I think about the phrase we all use that says, like all waking hours, we want them to wear their hearing aids all waking hours. Well, what does that mean? What is a specific goal that I can work toward, and what are the metrics I can use to say, am I making progress over time and just greater information with the nuts and bolts of how the hearing aid works?

If we think about training up parents who are gonna take that information when they go out to friends and family and caregivers and daycare and preschool, they are gonna be the expert in that hearing aid for caregivers who are so crucial in making sure kids have sustained access to improved information,

sound information, through their hearing aid, including specific information about wear time. So some longitudinal data from the outcomes of children with hearing loss study that I'm part of this kind of ongoing collaboration of studies. We know that full time use can be different depending on if a baby is very, very young or a school age child. So discussing specific device use, including an hour time for families to aim for at UNC, based on the work done from the OCHL study, we recommend more than 10 hours per day. And we talk about that at follow up appointments.

Oh, you're working toward it. You were at this hour last time. You're working at this hour last, next time. What are we sort of working toward? As a shared goal, we need to persist across levels of hearing loss.

Some of the previous work suggests that both parents of children who have slight and mild hearing loss, and parents of children who have profound hearing loss, regardless of the fact that their unaided experience is so different, they each report increased need for information about hearing loss and then setting realistic expectations for progress with spoken language. So, knowing what we know about who is a better candidate for a hearing aid versus who might be a better candidate for a cochlear implant. Parents also report that they need information that really connects the dots for them. What is the through line between the experiences they've had? In the early universal newborn hearing screening program?

There can be poor clarity about what is a hearing screening. Knowing that a screening produces a sort of a yes or no, a binomial outcome, or it can be a pass or a fail. At this point where they're coming in for the diagnostic abrdinal, that family may have gone through a couple of screenings, knowing that over screening continues to be a problem in some of our hospitals. So preparing families that this is not going to be a pass or a fail result. Today, we will have sort of descriptive, complete information about a child's hearing status and how that influences kind of our recommendations for next steps.

Parents may also struggle to understand what are the functional implications of the hearing loss that you've just described? I'm going to dive a little bit more into this, but we have a variable understanding of what the words we use are. So if we use a word like mild, if I have no previous experience with hearing loss, I'm interpreting mild based on how I experience the word mild in my everyday life. Is this a mild salsa? I'm not expecting kind of a kick.

Are they mild weather conditions? I may be thinking about a sort of a light drizzle. Translating sort of. Some of the words that we use in audiology don't always map well to what we think the true experience with a child's hearing loss can be. And then again, reconciling behavioral responses in their home environments.

One of the things parents sometimes report is that any level of hearing loss to them equaled that their child was completely deaf, be that deaf in terms of severe, profound hearing loss, or deaf in terms of culturally deaf. And I'm going to jump to just a little bit of data from a study that we're working on. This is a project we completed using a mixed methods approach. Our qualitative arm involved extended interviews with families of young children who used hearing aids, with parents whose kids were between zero and six years of age. The interviews were about an hour long, and there were several themes that have emerged about informational counseling.

Here I've pulled out a sample that really underscored the gaps in parent counseling that are potentially well addressed by additional audibility based framing. So one of the first themes that pulled out was families struggled when they really had to integrate an entire new lexicon, including applying words that in audiology we maybe used for a different reason, like those words, like mild. So this was a mom, I think they really had to break it down. It took us a couple of appointments. What is a moderate hearing loss?

What are decibels? And acknowledging, really, that those emotional reactions made it hard to process informational counseling, even if that's really what the audiologists was tasked with doing and really felt like, was the primary focus of that appointment. As seen in previous literature, our participants struggled to differentiate hearing loss, the diagnosis of hard of hearing, or any amount of hearing loss from deafness. Early hearing loss of any degree can be hard to differentiate for the uninitiated, who have never maybe known a child with hearing loss or seen a child who uses hearing aids. I immediately jumped to the conclusion that she was profoundly deaf because hearing loss to me at the time, equaled she was deaf.

It was black and white, they were interpreting that the same way some of those screening outcomes are. It's an all or nothing prospect, which could have really different implications for how successful you anticipated child might be with hearing aids. And then we found among our participants that behavioral responses to sound made accepting the diagnosis difficult. This was a mom who described the night before the ABR doing their own kind of hearing tests in the world, we know as audiologistss that real world responses to sound without hearing aids are expected. I mean, if you have some residual hearing, I would be surprised if a child didn't react to loud sounds, like a door slamming or a dog barking outside.

But for families, that made it hard to know, is this really true, what the audiologists is telling me? And I imagine if you're struggling to understand or accept the diagnosis, it may make moving forward with next steps back to our parents struggling to understand. We also see in the literature that parents report technical jargon really inhibits their learning. So mild could be one example of technical jargon. I think also some of the anatomical descriptions can be really, really challenging in terms of where we have moved at UNC and our clinical work.

Part of the way we've combated these challenges are thinking about things like motivational interviewing techniques. So when I think about framing why a recommendation is made for hearing aids, it's not because I love hearing aids, although I do love hearing aids. You've told me that a goal of yours is spoken language. Or you've told me that a goal of yours is that he attend the public school in your neighborhood. Oh, then we probably would recommend a spoken language access through something like hearing aids.

Really centering the recommendations you're making in light of what the goals are that the parent has articulated for you. I mean, we have a couple of tools that we use to help parents elicit. Well, if you can't think of any, here are some areas to think about when you imagined having a child. What are things that seemed important to you? And then we're including the role of audibility based descriptors to address misinterpretations that can happen with words based on hearing loss degree.

What does mild mean? What does moderate mean? This is adapted from a paper from 1999 from AJA called from the authors haggard and primus. We know that parents may interpret degree based levels of hearing in different ways, and this study approached in kind of a unique way. So they took different situations that may be appropriate for a child listening.

So these are common listening tasks for a school age child. Things like learning to read, learning the names of items playing musical instruments, and parents of children with normal hearing with no previous experience in hearing loss. They listened to a simulation of hearing loss, and they saw a word like slight, mild moderate on the y axis. You can see their collapse level of difficulty that they expected. So, across listening task, we found that parents who were exposed to simulations of mild hearing loss were much more likely to rate high levels of anticipated difficulty compared to using the term mild hearing loss.

So we know that the words we are currently using have some limitations, and we built on this study for some of the research that I will point out in the next section. Above all, I think the audiologists needs to balance the need for informational counseling, you know, connecting the information that you know a family has to have for those important next steps. Knowing that hearing loss diagnosis and intervention tends to be very sequential. First you have the screening, and then you have the diagnosis, and then they will make the referral to early intervention. You'll also get an appointment for an entire we know that a lot is hinging on that diagnosis appointment.

You want that family to leave with confirmed follow up appointments. What we want to be careful of is balancing the need for informational counseling with the risk of attentional narrowing. So, attentional narrowing is a concept where a family's ability to absorb and use information is mitigated by their reaction to emotional or surprising news. So in this case, a diagnosis of hearing loss, you have important information related to the level of hearing loss, what's sort of coming next, setting up the hearing aid consult and the hearing maybe ear mold impressions in that same appointment. We know that emotional reactions are not so easily disentangled from informational counseling.

So you may have some short term informational goals, but without adequately reacting to a family's emotional reaction to news, it may be really difficult to make progress on some of your informational counseling goals.

In the next part, I'm going to move on to talk a little bit about audibility and why I think it might tell us information that an audiogram can't and be a potentially really powerful tool to add to your parent counseling belt. Audibility based descriptions of hearing test results so at the point of the diagnosis, audibility really focuses on how much a given hearing loss restricts auditory access to spoken language information. Audibility really is the proportion of sounds that are available to Lister on a really common scale using a measurement outcome called the Speech Intelligibility Index. Really? This expresses

auditory access on a zero to 100% scale, expressed either as a percentage or an index value 0.6 565 percent access to regular conversational levels of speech audibility can also be a really straightforward mechanism to talk to families about why a hearing aid is recommended, why a cochlear implant might be recommended, and what are the benefits of full time use?

Not only does the hearing aid restore some aided audibility for speech sounds, we also want to see that that device can be used well over time to really maximize the effect of audibility, or that aided audibility in motion. Aided audibility really measured and expressed using the aided speech intelligibility index and looking for the difference between the aided speech intelligibility index and the unaided to really get a feeling for what is the aided audibility benefit from a hearing aid fitting, and is it in line with where we would want this child to be? Do we think that it supports sufficient auditory access to spoken language information? The calculation for audibility really requires that you know two primary components. So if we're thinking about the span of speech information that's available to a typical hearing listener, we want to know how much of a given frequency band falls above a patient's threshold, how much of it is in a region where they can really hear it.

We want to scale that by how important is that frequency band to understanding spoken language? We like audibility because it really applies across the board. You can apply audibility to children with typical hearing. We've tested your child's hearing. They have thresholds that fall in the typical or normal hearing level range.

We estimate that they have 100% audibility to sound. That's why we're maybe not recommending urgent follow up. That's why we're not bringing you back for repeat abrdinal. The caveat here is that some of what we know about frequency importance weighting is currently based on data from adults, and I think there's some data still to be collected. And doctor McCreary at Boys town is really working on this with some collaborators at different sites and then publishing.

What do we know about how children use frequency information? And are the same bands important to children that we see are important for adults who are using language, often with a strong background of spoken language. So calculating with audibility with the SI can kind of be done in a couple of different ways. The most sort of basic example is our classic count the dot audiogram. So on the x axis, really the same layout as any standard audiogram, low frequency, mid frequency, high frequencies from left to right, and then plotting those thresholds on the y axis and a descending, how loud did we present sound before we saw that, a response was there, your standard right ear audiography.

And in this case, we see thresholds rising from mild at 250 hz, mild through about 4000 hz, rising to within normal limits by that 8000. This is a nice hearing loss to talk about. I think it often recalls for me hearing losses that could come through our ENT clinic kids who have long term, maybe under managed otitis media. They may have persisted for a while, a really common mild hearing loss. Plotted in the background, you'll notice these blue dots representing frequency information for speech.

So if we think of the dots as being 100 points representing where speech information falls across the audiogram, we are curious about which dots fall in a region that's audible and which dots fall below the level of audibility. The classic count, the dot audiogram, not accounting for things like age, not accounting for things like ear canal acoustics. This is kind of similar to the calculation that may be performed even on your audiometer if you're using a modern digital audio audiometer. So even with this mild hearing loss rising to hearing within normal limits, we see that it's restricting auditory access by almost 50%, despite the fact that it may be called just a mild hearing loss. In your clinical report, we see there are serious negative consequences for auditory access for this mild hearing loss.

The more sophisticated version is something we often are already calculating as part of our hearing aid fitting. So this is an example of a screen from the audio scan verifit two, really flipping that audiogram on its head, but displaying kind of the same information. So from x axis, working from low pitch out to

high pitch, looking at the thresholds, that red line and then looking at level. So how much information is falling above the thresholds. In this case, the aided response, looking at aided audibility.

But the same values are at work here, thinking about which bands are audible to this listener and how important are those bands. So, for example, a loss in the frequency bands between 1000 and 4000 hz on the audio scan will reflect greater decrements to the aided SII and really match up with that same concept from our count, the dot audiogram, where that 1000 to 4000 hz frequency range is really plotted where that information is densest. So deficits in that area lead to a much greater sort of hit on your audibility. For average speech sound, a child specific audibility value is influenced by a few different factors. And this is sort of why we recommend using the probe microphone system to confirm audibility, especially in cases of borderline hearing, where you think a child may or may not be a candidate for hearing technology.

So some of the factors are fixed, and some of the factors really we have room to optimize. So the level of hearing loss threshold is a fixed factor, but that will impact how much loss is present, how much of a frequency band is audible or inaudible knowing as hearing loss becomes more more serious, as there's greater degrees of hearing loss, the greater the loss for audibility will be. Child specific audibility values are also influenced by ear canal acoustics. So making that real ear to coupler difference measurement, really to know if we are estimating audibility for that frequency range, having a good feeling for how a child's specific ear canal acoustic either enhance auditory access to those different bands or deter from auditory access for those bands. And taking that into account, when we're programming the output of the hearing aid, ear canal acoustics are fixed, but our ability to make appropriate interventions and measurements related to them by using things like a child specific aided fall within sort of our ability of things we can manage.

We want to look at audibility also based on the level of the speech stimulus. So not just are we looking at what is your unaided an aided speech intelligibility index, but how does that differ for soft speech? Maybe thinking about approximating how a child might perform at a farther distance or for someone sort of close up, thinking in particular about how we talk to infants with hearing loss. The configuration of the hearing loss will play an enormous role in what a child's aided and unaided audibility will be. If we see the greatest levels of hearing loss in those frequency bands, where we see the greatest density of speech information, there's going to be a bigger hit to that child's aided audibility and then the degree of benefit from hearing aids.

So how closely are we matching fit to targets? This is, again, just like the aided, something that we can optimize. And then the last factor that I will throw in here are device use rates. So if we look at the auditory experience with hearing aids, looking at that aided line, we've matched targets. We've really boosted that level of the aided speech intelligibility index to where there's a nice separation between the aided and unaided.

That child is only going to receive that concurrent benefit if they are using the hearing aid. So a hearing aid that is turned off or a hearing aid that is in the drawer isn't deriving any benefit for a family.

I like thinking about audibility as a counseling tool because it really builds on what we're already doing. If you are a clinic that is fitting hearing aids for children. You're likely looking at screens like this all day. So this is a left ear threshold. Looking for the aided response at soft and average input.

Matching those targets, we have access to the unaided SI. So in this case, the unaided SI for soft speech is about 5% auditory access, and then measures of the aided Si. So therefore, soft speech, 71% and 86%. That's a really big aided audibility benefit. That sort of difference that we see, it also connects families with what you're doing.

If you've kind of turned away from them, you're working on the hearing aids in the box. I think reminding them that repeated appointments, bringing sort of kids back in for follow up audiological care really influences how closely we're able to maintain this fit over time and ensure optimized audibility. It doesn't represent any extra work for a practicing audiologists. It really builds on what you're already doing. It can scaffold some of those conversations.

The last piece I will point out on this screen, thinking in particular about the 65 decibels input. So, for an average conversation, you kind of notice on the purple line at 86%, that's an aided audibility. And it falls between these two kind of darker lines on the bar. That really tells us that the aided audibility that we're achieving for this fitting falls within our expected range. So for this degree of hearing loss, we would expect, based on some normative data out of the University of western Ontario, that we should be able to get a fitting within this range to really optimize for this level of hearing, to sort of come behind yourself and say, have I fit this well enough?

If I say in my report I've closely matched targets, well, how closely are you producing aided audibility? That falls in line with what we would expect to support language learning. Two children with the same degree of hearing loss on paper may have drastically different unaided audibility based on their configurations. This is real world data from our longitudinal research cohort who were tested as a part of the outcomes of children with hearing loss. And I may just pick out one group in particular, looking at the kiddos who were mild hearing loss.

So, on the x axis, the children have been placed into bins based on their four frequency aided average. We've averaged their thresholds, and if they fell in the slight range, the mild range, the moderate range, what we see in terms of their unaided speech intelligibility index on the y value is there's huge variability. So two kids who may be both named as mild on their clinical reports may have audibility in the nineties. They may have audibility down in the twenties. Their ability to benefit from unaided hearing

to be successful in a classroom is going to be vastly different, suggesting that even within the same category of hearing loss, underlying audibility can vary widely.

Looking at just a couple of examples of how this plays out in terms of configuration, this is case one. She's a five year old female. She was born and identified after a newborn screening, and she's thought to have aminoglycoside sensitivity. She tested positive for a gene suggesting that even low doses of aminoglycoside can produce hearing loss. And that seems to be this case.

When we look at this hearing loss, which is in the normal range through 1000 in the left ear, sloping to a severe hearing loss, severe to profound, pretty normal to mild through 3000, we see that there's the greatest amount of hearing loss in that region where speech information is densest. And when we look at her sort of matching speech intelligibility index, we see that that falls out. Despite the fact that she has some pretty normal hearing thresholds, her unaided audibility for average input is right around 40% in her left ear. We also can use the aided audibility to look and see that our ability to restore good access to sound in this case is severely limited by its sort of ski slope configuration. The difference between her aided audibility and her unaided is right around 11% in that year.

And we're not able to sort of achieve a fitting that really gets us in, that aided audibility values. And in her case, we made a referral for her to eventually be evaluated for an EAS cochlear implant. Our second case is a kiddo who is 18 month old and has been identified with Eva. So this is a mild hearing loss, and we see that we were able to closely match targets. And this is an example where, because of the degree of hearing loss, he's a good candidate for a hearing aid use.

In particular, we were able to match targets and see kind of check behind ourselves and say, have we done a good enough job fitting this hearing aid, seeing a big aided audibility boost from 51% to 91%, and seeing output range falling, right kind of in the piece that we would expect.

All right, I'm going to talk a little bit about, when we say counseling, what do we mean? So counseling with audibility could mean a few different things. We're using it, trying to use it at every point of our clinical environment. So things like at the level of the hearing evaluation, we've described this hearing loss potentially as mild. We're recasting in and confirming this level of hearing loss will reduce her auditory access at the timing of the hearing aid fitting, talking about that boost that kids are getting from well fitted hearing aids.

With her hearing aids on, she's getting almost 90% of even that soft speech signal and then supporting hearing aid use over time. So during each hour that she's not wearing her devices, remember, she's coming in at that lower level again. So framing the hours spent using the hearing aids and the hours spent not using the hearing aids, we are now bringing this into our counseling environment. This is an example of one of our fitting rooms here at UNC and trying to work to make it just part of our everyday clinical work. So describing the work we're doing so that parents have a strong feeling about why hearing needs were recommended, how they're fit, and what are the different pieces that we are tracking over time.

And this especially comes into play when we are discussing changes to the intervention. So, in cases of progressive hearing loss, we know a big chunk of early hearing losses will show progression over time, and our recommendations may change over time. One piece we didn't talk much about in the counseling background is that parents are sensitive to that if they feel like we maybe haven't discussed something, why did we talk about hearing aids? Why have they never talked to me about a cochlear implant? That may make a lot of sense to us on the back end, but we'll talk kind of in a minute about using some of those audibility to make specific recommendations for changes.

Our team is working with our electronic medical record as well to improve our ability to measure audibility over time. So if this is something we track the same way we may have tracked pure tone

average, what are sort of our tools to see a visualization of this? And this is something we'll probably talk about at future discussions. How are we making our EMR work for us in this way? Allowing the audiologists to really track the influence of hearing changes and also the influence of changing ear canal acoustics.

With age, counseling will really depend on what type of hearing loss, what level of hearing loss you're looking at. So for kids with mild hearing loss, we often find that our counseling relates to their unaided hearing. This is especially true for kids who were not picked up from newborn hearing screening. We know that newborn hearing screening technology is most sensitive to moderate and greater levels of hearing loss, not that it will never catch mild hearing loss loss, but especially when we're finding these kids later who maybe are showing age appropriate language, who are showing good responsiveness to sound, our focus tends to be on unaided audibility and why we do or do not think that a hearing aid would be beneficial. What is the move from the status quo?

As hearing loss becomes more profound, our focus in counseling tends to move more on aided audibility. So to what degree are we able to really restore auditory access to sound? How well is that hearing aid performing to boost access to that important speech information? And if we feel like that gets to a point where it's no longer sufficient using aided audibility to motivate future conversations for things like a cochlear implant, this is sort of even just like how we are talking about it in the clinic. We're measuring how much benefit the hearing aids are providing for accessing the sounds of speech.

We also are talking about their unaided hearing. We are often bringing it back to this to reaffirm what parents are seeing in the home home by highlighting that unaided audibility. So this value shows us that even without hearing aids, she hears some sounds validating a parent experience. This makes sense with what you're telling me about what you're seeing at home, that she wakes up every time grandpa coughs or something, kind of in that line. I would be surprised if it wasn't.

I also like talking about audibility because it's easy to talk about their peers who maybe have typical hearing. So she maybe hears 40% of speech sounds without her hearing hearing. With her hearing aid, she boosts up to, let's say, closer to 80% speech information access to sound if she's sitting in a classroom for kindergarten, how much is enough? If the kids next to her are experiencing 100% audibility, even under ideal conditions, she's already going to be missing speech information. We really want to emphasize the use of hearing aids to make sure we're always at that highest aided value.

You compared to degree of hearing loss. We have published data that suggests it's a powerful way if you want to talk about concern about hearing loss with families. So this was adapted from the Haggard and Primus study from part one, where we compared three different conditions. So families listened to some of those same simulations, or they saw a description of hearing loss using words like slight, mild, and moderate. Or they saw the audibility value associated with hearing loss.

In this case, we surveyed parents of children who were much younger. So these were parents of babies aged zero to twelve months, and we had them exposed to some common listening situations, how well do you think they would be able to learn their name or attend to sounds in a lullaby, some very specific age appropriate listening tasks? And we measured the level of parent concern about hearing loss. For example, here at the middle box, moving from left to right, kind of a medium level of hearing, hearing loss concern if we called it a mild hearing loss, almost a full unit, greater level of parent concern if they saw the equivalent audibility value. As is seen in previous research, hearing loss simulation remained a really, really potent tool for communicating with family about the impact of hearing loss on some of those really important listening skills.

This is kind of from the same qualitative project. When we talk to families about audibility based counseling, these are parents, again, of those zero to six year old children who wear hearing aids, who have gone through a really comprehensive counseling experience over those first few years of life as

they become successful parents of a child hearing aid user, we talked to them. We described audibility. We kind of did an acceptability kind of back and forth during our interview, talking about what audibility was, how they think it might be beneficial, how it might complement what they already are listening to. And here we've laid out some of the potential benefits that parents identify and some of the drawbacks.

It was extremely grateful to these parents for participating in this research because it was certainly aspects of audibility based counseling that were not on my radar. So they described understanding the link between diagnosis and then what the implications of hearing loss were in kind of real world situations. They discussed taking that audibility values and using that as a tool to help describe the results to families and friends. Describing it is clearer than words like mild and modernization helpful for differentiating the benefit of amplification. So contrasting that aided audibility with their unaided audibility.

And really the parents that I don't think this has to replace words like mild and moderate. I think this would complement the degree based descriptions that they all reported their audiologistss were using. They also called out potential drawbacks that really have made me stop and think about how are we packaging this for, for wider use. Parents were concerned about the capacity that audibility based measures would exclude children. So they said, well, you know, my child has mild hearing loss.

What if his unaided audibility was so good that they wouldn't give him hearing aids? This was a mom who perceived great benefit from her hearing aids. Her child's data logging was off the charts, really, really successful hearing aid using family, and she was concerned, well, what if they had used this kind of measure to keep my kid from getting hearing aids. What we know about audibility is that even slight and mild degrees of hearing loss likely pushed children into regions where they would benefit from hearing a aids. But I think it was important to address that this family identified a risk of exclusion.

Families worried that low aided audibility and unaided audibility would be perceived as, like a failing grade. And then in cases of mild hearing loss, they worried that what if the audibility loss is not that great? All right, pushing through here to our idea about using some audibility based referral and fitting criteria. We're using it maybe to talk to families. How are we putting it into, into action to identify appropriate intervention?

As we kind of laid out the focus as hearing loss becomes more severe, may shift to aided audibility, and this can help support decision making for technological transitions. This figure, which has lived in my head for a long time, really represents the continuum of hearing. If we could have that unknown truth in the universe, what if you could sort of know the outcome with absolute certainty and know what conditions would foster the best hearing and language outcomes for families pursuing listening and spoken language on the continuum, from typical hearing on the x axis, from typical or normal hearing all the way out to profound hearing loss. The hardest part of the audiologists's job is to help ascertain, you know, which of these bins is a single child in front of me coming from? Let's say the x axis represents pure tone average.

If you find a child over here with maybe a pure tone average of 25, did they fall in the distribution of kids who really don't need to use any hearing technology, or do they fall in that distribution of kids who benefit from wearing hearing aids? And we're looking at aided audibility and unaided audibility to help make those distributions narrower. Can we decide there are better ways than the pure tone average alone to help decide who would benefit from hearing technology? At UNC, we're moving our device, counseling, really, towards some of these objective measurements of auditory access. So currently we're approaching it using data from the McCreary et al.

2020 paper. So if unaided audibility is poorer than 80%, we're recommending at least a trial with a hearing aid. Not to say we never recommend it for kids with aided audibility, you know, between 80 and

100%. If there are slight and mild hearing losses. That data just supported that.

Although there may be deficits, it's less clear whether hearing aids alone will address that and improve some of those listening outcomes. We are also now looking at their aided audibility to say if we're restoring up to or less than 65% auditory access for average speech. We are recommending that families at least pursue a discussion with our cochlear implant team to talk about how a cochlear implant may restore hearing in a different way and potentially provide more sustained auditory access for learning. This is data from a paper from a colleague out of boys town, and she was really looking at what are some longer term outcomes in kids who are using hearing aids? These are 182 pediatric hearing aid users and 78 of their peers with typical hearing.

And in this publication, they examined some outcomes through a lens of auditory factors. How restricted must that aided audibility be? How low is that aided speech intelligibility index when kids before kids no longer display the same benefit from wearing hearing aids? So we're at the point that the hearing aids don't seem to let them keep up with their peers who have either typical hearing or have greater benefit from hearing aids aids. And they found that an aided SII value below about 0.61% was associated with risk for underperformance with their hearing aids.

So they weren't getting as much benefit as kids who had more than 0.61% at UNC. We're currently pursuing a study look taking some of those same values from the Weissman et al. Publication and using it to validate it on a retrospective cohort. So this is a cohort design of children who were referred for cochlear implants during sort of three years, with our most up to date referral criteria. So a retrospective chart review between 2017 and 2021.

These were all pediatric patients who were referred for a cochlear implant evaluation at UNC. And you're looking at how well the aided audibility really separates kids who were not candidates. So who either displayed strong aided speech perception who did not currently qualify for a cochlear implant

implant, and kids who did qualify for a cochlear implant. The red dash there on the y axis represents that cutoff point at 0.61. So if we use the value from Doctor Weissman's paper, we really see a nice separation between our patients who were candidates for a cochlear implant and our parents who were patients who were not a candidate for a cochlear implant, showing high sensitivity.

When applying that cutoff, upwards of 96% in our data set, it actually was more sensitive than pure tone for that same question, really validating sort of the takeaways from the Weizmann et al. Paper. And this work continues sort of that there's an optimal range for aided speech intelligibility. There's an at risk range for speech intelligibility centered on about 0.61 or 61%, and certainly a region where aided audibility is insufficient to support ongoing spoken language development. And this really aligned with other estimates, including some work from Tomlin et al.

On the outcomes of children with hearing loss studies showing a risk region below about 71%. I include one more case, really thinking about a kid who we did refer for cochlear implants, sort of based on her pure tone average, this is a stable, age appropriate, long term hearing aid user. She's eight. She's in a typical classroom. She's at the very, very top of her class.

She loves to read. She loves science. She's an absolute delight. She's been a successful hearing aid user. But her hearing certainly falls in a range where, under our current guidelines, we may refer for a cochlear implant evaluation to at least start that conversation.

So based on her aided audibility, she had values that hovered right near that cutoff of 62% and 64%. We made a referral for a cochlear implant evaluation, thinking she has pretty restricted access to sound thinking. Also, about testing in the test box represents sort of a best case scenario. This is testing in quiet, under ideal situations. Ultimately, she was not a candidate.

She showed aided speech perception in the eighties and nineties in both ears. Really reiterating that a referral for a cochlear implant evaluation is not the same as ascertaining if someone is a cochlear implant candidate. But certainly framing that conversation of we're concerned about that cutoff because we think overall our goal is that she have sustained auditory access long term. The last section I'm going to end with is really just kind of putting this in place with all of our other pieces of the diagnostic battery and the really the management tools we're already using. I want to end the talk by bringing audibility into focus as just one piece to support holistic language experience.

When I think about audibility, it's not just a measure in a test box or a probe microphone in an ear canal. It's what is that hearing aid doing for a child in the real world? Effective audibility to me is that aided hearing aids set in motion. It's not just how close we're fitting a hearing aid to target, but are those targets the right targets to build a true auditory experience?

My favorite takeaway is always matching aided audibility targets. Doesn't matter if we've generated the wrong targets in terms of generating and sustaining auditory experience for learning, using effective audibility is really twofold related to the accurate diagnosis and then the high quality hearing aid management. So using some of those effective EBP this evidence based practice strategies in the classroom, starting with high quality hearing evaluations. So using up to date hearing thresholds so we know that over time hearing can progress in children and that if every time they come in, their thresholds have shifted by five and three months later they've shifted by five to ten, and three months later they've shifted maybe just another five at some frequencies over the course of a year, you have an audiogram that may be severely underfit if you haven't updated hearing hearing aid output based on those changing hearing aid thresholds. Choosing an invalid age appropriate test paradigm so using ABR and continuing with ABR if that's indicated for children who can't sort of participate in behavioral audiometry and switching to age appropriate ear specific behavioral audiometry at the earliest moment, applying appropriate correction factors when using ABR and being aware of the limitations of correction

factors as the degree of hearing loss gets poor and then cross checking objective measurements with behavioral measurements and vice versa.

So using ABR when necessary, moving to behavioral testing and using some ongoing measurements to things like oaes when appropriate to monitor the good hearing ear in cases of unilateral hearing loss and always being aware of the influence that abnormal tympanometric function can influence if our thresholds are decreased by 20 across the board today because of a flat tympanogram, that amplification is going to be considerably less accurate and give less of a boost for speech sounds and then using high quality hearing aid fitting improving the auditory access through your own steps in the fitting room using probe microphone verification knowing that there is still a big chunk of audiologistss who are not consistently verifying hearing aids or not repeating those verifications choosing child appropriate targets we use DSL based on the UWO pediatric amplification guidelines line seeking a low air in your fitting, trying to match those targets, not just approximating them, but really getting into the nitty gritty of how closely have you matched those targets. Using up to date real ear decoupler difference. So repeating this when there are changes in the child's ear canal acoustics, are you making that measurement to account for those where over time do we see the same fixed level of amplification is softer and softer in the ear canal because the ear canal has gotten bigger and bigger and then talking about full time device use, engaging them with tracking options in some of the apps. Now, if families log in, they can see device you. So if they know what the goal that you have recommended for them, and if you've talked about that explicitly, they have some tools for measuring that on their own.

The last case, I think, really engages this need for the accuracy in hearing threshold measurement before we can even think about generating appropriate amplification targets. This is a case thinking about hearing aid programming in cases of auditory neuropathy. So in an earlier generation, when we sort of knew less about auditory neuropathy, there was this idea that starting with a low gain hearing aid, if we can't yet use, there's no ABR thresholds we can use. They're not valid in this case for

programming a hearing aid, starting with a low gain hearing aid, really to start there and make sure we're doing something for families who want to move forward with hearing technology. In this case, I've plugged in the thresholds.

This is programmed for a flat 25 decibels hearing loss, a low gain hearing aid, and it's really closely matching those targets. This is a well fit hearing aid for a flat 25 decibels hearing loss. What we sort of know now is there can be a vast variability in what the behavioral thresholds that a child shows who actually has auditory neuropathy when we end up getting them in the booth and being able to cross check that. So now these are that same low gain hearing aid, but set against the thresholds of a real world patient here from our clinic. So it's the same low gain hearing aid, but using those real world thresholds, we now see significantly under fit.

So this child is walking around potentially using a hearing aid full time, but really, really below where we would expect there to be meaningful targets. So in this case, it may be tempting to say, well, the hearing aid was not helpful, but the hearing aid was set consistently below where we would. The takeaway point being our starting point matters. It doesn't matter how closely we've matched targets if we were using the wrong targets. So the need for not only closely monitoring aided audibility, but making sure the input pieces are accurate.

So choosing that accurate threshold measurement paradigm and updating those over time. So, jumping just to a couple of takeaways, I'm going to wrap up here to just reinforce the highlights from today's talk. The number of families who are lost to follow up or never present to audiology have to be among the parents that we think about when we are considering our counseling approaches, the current strategies that we use are likely very powerful for the families that we have successfully shepherded across the finnish line. I'm always advocating for a yes and approach to finish, really, that work of early hearing loss detection and intervention. Let's use degree of hearing loss.

Let's use simulation. And I think there's a role for adding audibility, in particular to talk about the benefits of amplification and monitoring auditory access over time, the decision to focus on how unaided hearing affects listening opportunities, or how the limitations of aided hearing aid drive. Our recommendations will vary with each family, and that approach can change over time, especially with some of our etiologies most associated with progressive hearing loss. And then in particular, thinking back to the, you know, approaching counseling as a malleable factor. This is a thing within our purview to change for families thinking through what are you doing to maximize early auditory experience for every family who comes through your booth?

This is a quote from a colleague of mine from a grant proposal several years ago where she really described language is an experience dependent phenomenon associated with being a human. Hearing loss takes what should be an effortless process, the learning of language, and really requires that families invest a ton of effort to keep up, no matter if they choose a listening and spoken approach or a manual communication using language like ASL. I've really brought this back to thinking about how do parents see themselves as capable agents to really influence this? I talk about how effortless we think language acquisition typically is. I like to ask parents, tell me about how you pictured teaching your baby language.

Parents are faced with a lot of decisions when planning for a child, and they may have felt that they were prepared for everything coming their way. But likely hearing loss or thinking about how they would teach their baby language may not have figured among them because we inherently know language to be such an effortless acquisition process. And this has really come to be the heart of my counseling approaches, thinking about how you learn language, thinking about how you picture teaching your baby language, and making you aware of all the strategies that we have, including hearing technology, to really put you back on track for that natural language learning, using exposure to spoken language in the home for families who choose that approach thank you so much for attending. This is sort of the

end. I want to express my thanks to audiology online for hosting today's webinar and letting me join you to talk about counseling for our pediatric patient population.

I don't see any questions in the queue currently. Doctor Sapp, if you wanted to leave any closing comments I'll hand the mic back over to you. No, I don't think I have any closing comments except for all the pediatric audiologistss watching this. Thank you. I meet you and I talk to you at talks like this in my clinical work, and I never fail to be impressed by the work and the degree to which pediatric audiologistss really grapple.

What is the best way to help the family in front of me? And I appreciate getting the chance to talk to you about my research and our clinical approach today. Thank you so much, everyone. This concludes today's presentation. We hope you have a great day.