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EHDI Annual Conference 2024 - Topical Session 7 & 8

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1:15 PM - 4:00 PM (MT)

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START TIME: 1:15 PM

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>> That's fine. Yes. I'm going to started. It's going to be very tight.

>> Okay.

>>Hi, I'm going to go ahead and get started, because we have 25 minutes and I'm going to try to get through everything I have today. I'm a pediatric audiologist and director of audiology services in California.

My colleague is the director of education program and the mind behind this presentation and getting her and I to EHDI to present to you today. We're going to provide some information that we hope you'll find useful in your own centers to find counseling and care when a hearing loss is identified. John Tracy Center's mission is to provide parent-centered services locally and globally to children with hearing loss offering parents hope, guidance and

encouragement. We do that through a collaborative approach to care.

In addition to diagnostic audiology services we have a parent program for parents of newly diagnosed infants and toddlers. We also have counseling services offered virtually or in person with support groups and family guidance.

We have listening and spoken language auditory verbal therapists and speech and language pathology services. We also provide deaf and hard-of-hearing support for local school districts and charter schools and a worldwide patient education program where families can take part in virtual classes or receive information by mail. We have a deaf and hard-of-hearing teacher preparation program in a master of science and partner with St. Mary's university in Los Angeles.

This is the path towards empowerment to the families we serve. Starting with hearing loss to providing information, support, education, encouragement, appropriate services based on family choice and family coaching. This process starts in audiology with the evaluation and identification of hearing loss. At JTC we provide diagnostic hearing evaluations from birth to 18 including outpatient newborn hearing screening, diagnostic AB Rs and behavioral testing .

The audiologist is responsible for relaying information in a clear way. The audiologist must explain the hearing loss options for communication, technology, education and next steps. We know that we need to provide families with information in a way that is sensitive to their specific family needs and culture. 90% of children identified with hearing loss are born to parents that are hearing and not expecting this news. Families may absorb 40 to 80% of what's presented in an initial appointment, so make sure information is clear, concise and useful is important. The information and follow up is important for families to be on a path to success.

We'll continue to talk about ways to provide appropriate counseling, audiological

information, resources and education in the ways that we've been able to be successful at John Tracy center to provide you with tools to use in your own setting. So, for the purposes of this talk, we gathered information and reviewed several research articles looking for information on what families and providers have found to be successful when providing information following the identification of hearing loss. The articles we reviewed found that parents want and need emotional support for making decisions. Audiologists can feel overwhelmed, support and access to counselors would be beneficial. Support embedded in family services was integral to parent's coping and the overall consensus is the support is more effective when targeted, individualized and family focused.

We also internally sent out a questionnaire to the current families who are receiving services at John Tracy center to gather more input. The families surveyed are currently receiving services with us but not all of those families were initially identified with hearing loss at John Tracy center. If not identified at John Tracy center they found their way to us by word of mouth or collaboration with the community provider-based on their choice for communication for their child.

With this questionnaire, we received 19 completed surveys and there's a lot of great information that we received with regard to how families feel supported within our programs. But something I want to focus on is a specific question: Could provider's awareness of these specific aspects suggested by research help families.

The aspects were parents may need time and repetition to process information. A network of providers may decrease frustration on referrals.

A family's journey can have many challenges getting information and support and services. Parents may want connections to families using the same device or mode of communication. Access to counselors or parent peers can be helpful initially and later. Providing

recommendations can improve parent confidence. Options of response were yes, unsure, no.

The results of this question seemed obvious and are not surprising, it makes sense that these aspects what families feel they want and need to get them to a sense of understanding and empowerment. But also within the review of some of our research, unfortunately we found there's areas of deficit in audiology when it comes to counseling. Audiologists dominate the conversation. Parents don't feel heard. Not given appropriate information and clear next steps.

The identification of hearing loss can impact a family for the rest of their journey. The American speech and hearing association has developed a set of guidelines to assist clinicians in providing support and counseling. The goal is to provide families and audiologists with support to help this process throughout the journey starting from the beginning. To be able to provide unbiased information, information that's family focused, for that specific family and that specific appointment, to be able to have emotional availability and support to understand the family and the information they are receiving and understand that what they're receiving may be traumatic.

The clinician must understand that families have different states of coping. This graph demonstrates that grief or coping is not a straight line but is something circling and upward spiraling. Families may learn to cope, but ever changing and adapting, so we need to meet families where they are in that moment. John Tracy center found an approach to counseling that utilizes many similarities to ASHA and it's represented by the acronym enough. The E for empathy to acknowledge their feelings sit still and listen and not provide unsolicited advice. N for nonjudgmental, accept no right way to react to this news and be present.

U for unconditional being still and present without making assumptions or imposing preconditions. F for feelings focused. Letting the family feel how they feel and give them

space for those feelings. We have found this approach to counseling to work for our team and the families we see. The counseling process within our program at JTC is continuous and ongoing. It starts what audiologist in initial appointment and throughout the journey we communicate with families. The audiologist provides counseling by explaining results of the evaluation, education options and the most important next steps based on that family's specific needs.

If the family needs additional support within the initial appointment our family counselor can be called in to support within that initial appointment. This can be instrumental for a family, but it can be instrumental for the clinician too. Following the initial appointment with the audiologist, the audiologist sends a note to our initial contact team which includes our family counselor and other members of education team.

The family counselor reaches out to the family to follow up with the family. She addresses initial feelings and responses to that initial diagnosis. What initial questions might they have following that infectious appointment that they didn't have space to ask before . Have they been contacted by early intervention provider within their local school district? What services have been established if any.

The family counselor may also help the family navigate where they are in the process of follow-up appointments. So we're a diagnostic center. We don't currently provide hearing devices for families so we refer out to managing centers. Oftentimes the families need help to make sure that these authorizations have been received so within these initial follow up contacts, our counselor sees where they are in that process. Have they received their authorization for the managing center?

Have they been able to schedule an appointment with the EMT and are they scheduled with the managing pediatric audiology center. We also provide the services we offer in the

center. Including family Friday school program. Families at JCT are offered the opportunity to come every Friday for parent education classes. We provide child care from birth to three in DHH classrooms with JCT classrooms with SLPs, sometimes audiologists and other volunteers that help with the child care.

While the children are in child care, the parents are able to attend parent education classes that are geared toward advancing their knowledge in their new journey. Following the parent class there's a weekly support group led by our family counselor. The family support group allows for connections support.

The family support group has been noted to be one of the most important staples in the coping process for families that have gone through JTC, where they've made lifetime connections with other families. An effective counseling strategy includes giving parents the education, support and confidence to move towards the next step to meet the EHDI 136 guidelines. A strong support system comes before the first appointment. So for us to have follow through, confirming appointments with phone calls, text messages that provide clear information about date, time and directions to our facility.

Providing instructions in ways for families to be prepared for the evaluation, so bringing in a baby that's tired and hungry and ready to sleep. At JTC we have a video that we have called what to expect that we send out with our appointment reminder confirmation text. This includes the important of the test, how long the test is, what the test entails and what a family can do to prepare the baby to be ready to sleep for the evaluation.

Following the identification of hearing loss, the next step in the 136 model is to ensure intervention by six, if not three months of age. This is done by making the appropriate referrals in a timely manner. Giving families information to follow through on scheduling of next appointments. The 136, if not 123 is something we strive to meet. There are challenges

unfortunately within the system that can often delay this timeline, including insurance authorizations, the Medi-Cal Medicaid program in California as many states grossly understaffed and we see a lot of delays in getting authorizations approved.

We have a lack of pediatric audiologists and often those appointments are delayed. Lack of pediatric centers that are authorized to have Medicaid insurance and there can be additional delays that we have to consider that include infants who might be medically fragile who need more time in NICU and we also see delays due to cultural differences, individual coping strategies and the individual needs of families. Sometimes there's limited resources it takes time off of work that they may not be able to do. They have to have transportation to get to the clinic. Sometimes it's difficult for families just to make the appointment.

Providing effective care in counseling support services to help overcome these challenges, the families may be having is crucial from the beginning. The collaboration we have between service providers is key in making sure that families get pointed in the right direction from the very start. In California we have the hearing coordination center who provides newborn hearing screening and they follow up to see when their schedules, did they show up to the appointment, they keep us responsible, too, to make sure we're going the right reporting.

JTC is a diagnostic center so it's important for us to maintain strong relationships with pediatric audiology centers in managing hearing loss that provide technology, so we send reports and referrals insurance requests for families to be seen at a center that's closest to where we are that has a focus or support for communication and the strategy they choose.

We also communicate with pediatricians to provide records and make sure families are established for appropriate services within intervention for deaf and hard-of-hearing, speech, physical and occupational therapy if needed. Part of how we do that at JCT is remaining connected with families. Maybe the Friday school program, the family infant program. We

have chart reviews, families within our services, this is another way to stay connected with families and where they are in this critical process. We're able to follow up with them, again, after the family counselor makes that initial contact to make sure they're moving in the right direction in this process. We also maintain relationships with manufacturers so we can stay up-to-date on technology and services offered through each company.

We communicate with ear nose and throat physicians and state up-to-date on different referral processes for different centers so as not to delay appointments and services. Some specific strategies and important steps that the audiologist takes is review test results with other clinicians and other team members. Sometimes we collaborate and look at wait forms or test results to see if we're seeing the same thing and making an appropriate diagnosis. Maybe clinicians need to be coached by more experienced staff, so reviewing results together, taking step back from appointment to look at results before going back in and giving the information to a family.

Coordinating with staff and counselors, bringing the family counselor into the appointment can be critical not only for the family but also the clinician. To be clear and concise while demonstrating enough principles and sharing family friendly materials.

Our staff counselor plays a pivotal role in our process and I'm sorry she couldn't be here to share some stories. But being available to families in initial appointment and providing support in that initial phone call following the initial appointment, but our family counselor also checks in with staff. He calls families quickly and frequently. She provides information for ongoing care and support including early intervention services. We provides group support during early family Friday school.

One reflection I had from one of my audiology clinicians within John Tracy center described the experience they had when she had to deliver the results to a family with newly identified

hearing loss. The presence of the family counselor de-escalated feelings within the appointment that allowed the family to open up more and move forward with next steps.

Patterns within our JCT program who have experienced the care approach we utilize have provided some of this feedback. So some of you in the back I'll read it for you we've had life changing experience with John Tracy that made our experience with son's hearing loss a beautiful journey rather than a loss. I don't know where we would be without them as a resource and a dehydrated.

Another family said the audiologist made themselves available to us and provided information for cochlear implant providers. Giving that diagnosis is not an easy one. The follow up call from the family counselor extending invite to Friday family school changed our lives. I don't know where we'd be without this. Being a deaf and hard-of-hearing parent can be lonely and JTC provides us with support system and lifelong friends.

This is additional feedback that we received from current families. I think I'm going to come back to this. We need to provide so much to the families on this journey and we'll be the child's best advocate and we need to provide information that is pertinent to their specific needs that is positive and proactive.

We realize that our audience, today, comes from all over the country in different types of centers and families who have had different experiences and we encourage you to do what you can to implement family centered approach with follow up to the family if possible. That can be time-consuming and difficult. Here are ways and resources that you might be able to find valuable. Utilizing the EHDI-PALS resource has information about what centers you can go to or where you can get lots of other valuable resources.

We also have a plethora of information on JTC Web site as well. It's important to be familiar with your deaf and hard-of-hearing leaders and be informed on your early intervention

referral process and find peer parent mentors within your area. We found that families who have gone through this journey want so bad to give back and want to be parent mentors.

Also, additional family organizations locally or nationally, community stakeholders or invested partners. Other agencies within the state system. Our family centered approach to care starts with family centered approach to hearing loss and provides family with counseling, resources and education to feel empowerment through hope, guidance and encouragement. Never believe that a few caring people can't change the world for indeed that's all whoever have. This is just some of our references. And ways to contact us, if you have any questions.

I wanted to quickly go back if we have a few seconds if anybody wanted to share what might be working in your area or your center with regards to your counseling process. Thank you for coming. I know you had a lot to choose from, so I'm grateful you're here. Thank you very much.

>> Hello, everyone. We're going to begin. So welcome to our presence on deaf and hard-of-hearing training modules that we created for family resource coordinators. I'm Julie Walker and I'm the manager at Washington State department and health. So this is my fellow presenter Anna Dodd. She's a follow up coordinator in Washington EHDI program. No financial disclosures. So at the end of this presentation we want you to walk away understanding the process we use to create online training modules and we want you to identify the learning objectives that were developed for the training modules as well as learn about any challenges that occurred during the project and how they were addressed.

So just some background, like many states, Washington State has EHDI advisory group. It consists of 18 members. We meet approximately five times a year. Our members are healthcare professionals, parents or caregivers of children who are deaf and hard-of-hearing, deaf adults, early support providers and individuals from other agencies that interact with our

EHDI system. Over the past few years our EHDI group has really wanted to focus on improving early support or early intervention in Washington State.

Just a little bit of background on our Part C program in Washington, so Part C, birth to three, is children youth and families. It's the early support for infants and toddlers program, ESIT. This coordinates our Statewide system of early support services and in Washington a local controlled state so every early support program in the county are different depending on where you're located. So when a child is first referred they meet with a FRC. They're the first person locally that that family will meet. Unfortunately in Washington, the FRCs they don't always receive training on working with families that are deaf and hard-of-hearing. So during our August 2021 EHDI advisory group meeting we decided to access our services in Washington State.

We used the JCIH principles and guidelines for early intervention put out in 2007. If you don't know what this document is, there's a link available and our PowerPoint is online so you can look at that, but this GPO of this document is basically to enhance early support systems to help EHDI programs improve systems and develop systems capable of continuous evaluation or early support and promote quality assurance in early support programs.

We took those goals in JCIH, which documents there's 12 of them and we ground into eight areas. As you see there's eight areas and the 12 goals are attached to the area. I'll give you time to look at what they are.

We then had our EHDI advisory group members rank those eight areas, so they ranked them from highest to lowest and keeping in mind which activities are feasible. We didn't want an activity that was high importance but low feasibility, so in the end they decided on knowledgeable service coordinators that had the highest importance an highly feasible. So we took that information and used it in November 2007 EHDI advisory group meeting. In that

meeting we used early detection system, self-assessment created by Minnesota. They took the JCIH document and made it into easy self-assessment that states could use.

We focused on goal two all children deaf and hard-of-hearing and their families experience timely access to service coordinators who have specialized knowledge and skills related to working with individuals who are deaf and hard-of-hearing. So I do see this one focuses on that knowledge service coordinators.

This is just an example of what that self-assessment looks like. So there's the goal up top and the rationale that I'll go over a little bit on the next slide and three questions that are EHDI advisory group answered in that August meeting. So what's the rationale behind this goal? As many of you know service coordinators is the person responsible for implementing the IFSP. One of the main jobs to coordinate with agencies providers and families and they're that first point on contact. They need knowledge regarding deaf and hard-of-hearing children and families and resources available. They need to be able to answer the family's questions, on-screenings, diagnostics or any communication opportunities the family is interested in.

So one quote is studies did reveal that a program with specialized service coordinators and EI service providers is related to positive family and social emotional outcomes. In addition there is evidence in the literature that some parents experience negative emotions when service coordination is provided to individuals without the core knowledge of working with children who are deaf and hard-of-hearing. So at the EHDI advisory group meeting in August of 2007, we asked our members four questions. So the first three questions are the same questions that were on goal two. So the exact same questions. Has Washington developed qualifications for FRCs with contact families after a child an identified as DHH. The majority of members thought that we had just begun in Washington meeting that goal.

As Washington identified core knowledge and skills for FRCs based on evidence-based

practices and the recommendations of professional organizations and national policy initiatives. 50% of respondents felt we were just beginning on this one as well. For the question three of goal two can Washington identify the number and percent of families timely access to FRCs. Only 50% felt we were making good progress and already doing this in Washington. Which item should we focus on? 70% of responses felt focus on core knowledge of skills.

We did this by creating training modules. So we contract -- I'd like you to notice the background was all '21, COVID hit two years later, so it's been going on for a while. In April '23 we contracted with a group and they assisted us in making three modules. To start this process, we created a work group. That work group was comprised of our EHDI advisory group members as well as other community partners. We had ESIT, CYSHCN, office of deaf and hard-of-hearing, we had early support providers mostly in major metro areas however we had some in more rural Washington.

We had representatives from all DHH programs or service providers, we had ASL and LSL were represented. We had audiologists and many individuals in this group were professionals that are deaf and hard-of-hearing.

And so, Anna, is going to do about the training modules.

>> For our first meeting work group, we looked at learn objectives. Meeting 2 and 3 we reviewed and drafted the training content and discussed additional learning resources that were needed. Outside of meetings was a lot of back and forth between members working out the final details and edits. We used a focus group to review the training modules and provide us feedback. So we ended up with three training modules with three specific areas we wanted to focus on. First focus on specialized services and then look at knowledge building and importantly bias awareness. Each training is one hourlong. While they are not required for

professional development training we're trying to emphasize how valuable can be to providers in the area. There's parts of our state that don't have deaf and hard-of-hearing children born often, sometimes a few years, so we want to make sure those areas that have less, we can help support. Here is the QR code that can taking to the modules.

You can take a look the volume may start that's okay. We know that. I'll give another minute. I see a few more cell phones. Cool. Thank you. Okay. So our first training module we focused on specialized providers and services. Parents and caregivers need information to make important decisions about what they're going to do with each step of child's development and they welcome assistance and guidance who can connect them to those services. The goal is to increase FRC knowledge of people who work on the team and the families and children who are deaf and hard-of-hearing.

Specialists in deaf and hard-of-hearing services must be involved from the beginning. An FRC and service providers need to know how to connect with them and collaborate with in them. First module focuses on guiding FRCs through these objectives here. In addition, each module includes a resource section that you can access throughout the module. Materials include guidance for parents, covers Department of Health or Washington Hands & Voices and also national resources such as sign it, national center for DeafBlindness.

Our second training is knowledge building, so this is really kind of looking at the science behind hearing accessibility and audiology. It was important to us to teach FRCs about this component of a deaf and hard-of-hearing, it's a big part of their life and it's important for us to support that they connect the family to the specialist no know the deep rich components of the area of audiology. So we want FRCs not to make determinations, or explain the audiogram, but we want them to sit alongside families and work to interpret them and connect with the services that are available to them to move on.

Also included in this module are reflections for audiology jargon and we offered a glossary as well. Our third module is around bias awareness. We know that these folks probably have not had training or direct instruction around deaf and hard-of-hearing community and culture, so our goal is to increase the FRC and ESIT provider's awareness of and address their own potential biases or biases that they witness out in the field. They need to provide families with accurate and unbiased information about all opportunities and includes additional links to trainings on competency and antiracism.

We advertise in a lot of different ways and we'll look at how advertisements paid off. We use ESIT's weekly newsletter. Goes out to all folks in the state. So a broad newsletter for parents and providers. Then of course our EHDI program Web site houses a link as well and we have e-mails sent out to EHDI advisory group members and the workforce that worked on creating the modules to check out and use the training. Then our last thing at the end of the month was an ESIT presentation. We'll see how many folks tapped into the site.

We discovered that we tackled too much. Three modules was too much. We had a lot of wonderful individuals including 0 to 3 providers, parents, deaf adults, hearing providers, a massive group of individuals with a variety of perspectives and while this was necessary and not change our diversity in the future, we would limit the can of how many people would be on the work group.

We had challenges of making sure we were representing and had a balanced representation of all opportunities for children when it comes to communication modalities in Washington statement and the last part was determining where we could put the modules. While ESIT was a partner with us, because they did not produce them, we couldn't house on their site. The Department of Health was concerned about security so we couldn't house it on our site, so we found the Washington portal. Healthier Washington collaborative portal is

designed to accelerate collaboration or resource sharing between Washington State public health and community-based organizations, like a health and wellness learning site.

Successes, we did read three modules and we're proud of that you can see the site activity we had in the month of February. The numbers kind of change a little bit if you get to the third module. One thing we don't know about this if the individuals hog to the site to watch the training, did they click the training or watch the whole thing. We don't have a way to measure the full participation of the trainings by those who joined.

The larger cities with the most people who visited, three are in King County. That's our largest metropolitan county in Washington State it has the most linguistic and ethnic diversity and the most options for parents who have deaf and hard-of-hearing children in the state and the most complex ESIT system we have, so we're happy and pleased that King County is working to get this training to the site. Exciting.

So we'll look at these quickly. This is trends that we saw with dates and times and how people attend to the site in correlation with our advertisements. So things we can observe is that Tuesdays were busy days for folks visiting the site. The ESIT newsletter comes out on Friday at totally different times of the day, so not easy to predict when people will see that. We saw a lot of activity go up on Tuesdays. We found and we sent out the large e-mails and Julie did the largest training with ESIT providers at the end of month it picked up.

This is the knowledge building and the next graph here is for bias awareness. If you look at it, it all goes together. So people are hitting the site and seem to be going to all three. Next steps, we are very interested in training about transition from Part C services to Part B school district services for deaf and hard-of-hearing children. We do want to make sure we're aligning with 136 and improving the goals so we're interested to early support services and track the enrollment to deaf and hard-of-hearing services and how dates and times align and

how families getting into both services equitably. Also family support services. One last thing we realize is that we would love a way to get feedback from those who do join the modules and have opportunity to go through them to give us information how no improve for next time and information from the community can give us new ideas of next projects.

This last slide is our work group, so it was a lot of people. An incredible amount of people from all over the state in different early support programs, hospitals, school districts. That's everything. Do we have any questions?

>> I was wondering since you contracted out to create these modules if the information needs to be updated, is that going to be easily updated for your guys?

>> Kind of. It really depends on what information, so anything that's actually in the module, it's going to be difficult to update. One thing we did strategically is in the modules, we would say go here to get that resource because we didn't want anything too specific in the module like here's the list of all the early support programs in Washington. It was just going down to Word documents or PDFs but that is something that we have thought about to change anything is not cheap, so we wanted it to be something that maybe could stay like this for a while because we don't know if we'll get this money again, so that's something to think about if doing trainings.

>> Do you have pre and post knowledge testing to see if you have the games.

>> We haven't done that. We're looking at that. This thing was supposed to be posted in September so we were very much like I need something for EHDI. We are reporting on this and that's one thing we're hoping to look at is using 136 data. One issue is kids getting DHH services timely, like have MSP, but two months later in DHH services. Can we approve that? We'll look at that type of data to see if the training modules have helped. We're talking about getting a pretest, post-test and seeing if we can get a little bit of information too.

>> Hi, can I ask about the educational backgrounds of your family resource coordinators?

>> It really depends. Typically there's early childhood education background. Special education background. A lot of parents into this role. Typically, we don't have individuals who are doing this role that have a background in deaf education or deaf culture or you know deaf psychology, so we're looking at how we can approach individuals who are new to this unique community and shaker the importance of how yes all these services with deaf and hard-of-hearing services, if that makes sense?

Thank you so much everybody for coming.

>> I'll put our information up if you want any more info.

>> Hi.

>> How are you?

>> I'm cold.

>> Thanks for being here today.

>> I need to do jumping Jacks.

>> We have 15 seconds.

>> We're going to get started. I'm super excited to see how many people in this room, I'm super nervous too. We're having a stressor right now.

>>ALLISON CUNNINGHAM: So thank you, everyone, for coming. This is a topic that is near and dear to both of our hears. I'm Allison Cunningham and this is Sarah Robinson, she has a dual role of SLP consultant. We're deaf and hard-of-hearing adults as well as professionals. This is a topic near and dear to our hearts which is listening fatigue.

We know how much it impacts our patient population because we have personal experiences with it as well. We've allowed ourselves to be more vulnerable about our own personal experiences within recent years and we're being more honest about the impact of

listening fatigue as deaf and hard-of-hearing individuals. These are our disclosures.

And then just a quick outline, we're going to talk about what is listening fatigue and discuss the research that listening fatigue does exist. Not just making it up. What are some strategies to support listening fatigue. We're specifically talking about strategies in birth to three. That's not talked about a lot. Most of the research is being completed on adults or school aged children. Not really research on this patient population of birth to three and I think it's important that we discuss it. The sooner we have discussions with our families the more supported that families with DHH children will feel. We'll talk about trauma informed care and nervous system regulation and dysregulation.

So, what exactly is listening fatigue. So some of you may have seen this duck picture and duck analogy. The duck is a nice analogy because it does match the experiences as we as DHH adults and the children we serve have. So like this duck it may appear that we're doing well on the surface, however, others are unaware of how furiously we are paddling underneath the surface to keep up. So in talking up listening fatigue this is defined as high level efforts from prolonged listening activities.

So we know that focusing on listening can be mentally and physically exhausting which leads to ability to not be able to process sound. Listening in challenging situations requires individuals with a hearing difference to allocate additional cognitive resources to auditor tasks in order to understand speech. We need to concentrate harder, which is mentally and physically tiring and there's stress in trying to listen and this increases fatigue, so a vicious cycle in many ways. We fake it until we can't and there's a little note about what we mean for passive versus active listening. A lot of you relax and the sound comes to you and there's not a lot of additional load that's having to be completed in order to receive the information.

For those of you deaf and hard-of-hearing and that use listening for communication, we're

in a much more active state. We're in a state of hypervigilance, so think about that that's doing to our body. What impact this has on our bodies and especially little bodies, babies, preschool on up.

So in thinking about the research, again I mentioned most of the research is being done on adults and school age children but we can draw conclusions that likely apply to patient population we work with and we do know there are changes happening in our body and changes happening in our brain and what's interesting is when you look at imaging studies there's increase of activity in prefrontal cortex which suggests there's a greater degree of cognitive load when doing listening TAFs. There's a difference when adult with hearing loss is engaging in listening activity.

And then real quick, noisy environments require more processing to fill in the gaps. Hillary has done incredible work on listening fatigue and it shows that more mental effort is required. Children with hearing differences are likely to have experience moderate to severe listening fatigue compared to hearing peers. Hormonally things are going on, there's an article that shows we exhibit more stress with elevated cortisol levels in early morning. There's a physiologic impact that can be measured as a result of listening fatigue.

>>SARA ROBINSON: I'm Sarah Robinson. I would imagine everybody here no matter what your hearing levels is feeling fatigue at this point in the conference. If not I'd like to learn your secret. All of this I see highlighted in myself and imagine other -- don't want to speak for others -- but a lot of us are feeling listening fatigue from all the engagements we have here this week as wonderful as it is. And Allison mentioned that Dr. Hillary Davis from Vanderbilt University, he was interviewed on the podcast. If you are not familiar with this podcast, it's fantastic.

Back in February of last year they did an episode on listening fatigue and they stated that any type of degree, laterality or type of hearing loss can result in significant fatigue and their research found no connection between degree of hearing difference and reported levels of fatigue and listening effort. It's important to keep in mind that we do not minimize reports of listening fatigue from our patients and families depending on the laterality, degree, type of hearing loss and make sure we're paying attention to this for all of our families and children.

So, what does listening fatigue look and feel like especially the birth to three. I do feel like this duck, actually, and especially when I get to my pillow tonight. We see in young children sleeping more, emotional swings, so quick rages that are bigger than what the situation might warrant. Sudden outbursts. Removing hearing devices. Preferring solo play and looks like avoiding or isolating from others. This might look like they're shy. They might appear to be not hearing, ignoring, not paying attention and wild and what you might think is that this list sounds like your average toddler, which is not entirely untrue, but a lot of these factors are often related to listening fatigue in young and deaf and hard-of-hearing children. Example of this is a parent of a toddler who told me about how he refuses to wear cochlear implants after dinner.

This is a child that wants them on in the morning and he enjoys auditory input but after dinnertime, we're done. He pulls them off and wants to play on his own. He needs that decompression at the end of the day.

I had a family of a 14-month-old and came in to see me for therapy, less than a week later, she's sound asleep. Has she been sleeping since her cochlear implant are activated. Her mom said yes outside of her normal schedule. She has brand-new auditory input she's trying to sort out and brain and body are tired from that. So there's a lot on this particular slide and I apologize if you're in the back of the room.

But this is uploaded if you want to take a look at it and this is pulled up out of the research from Dr. Hillary Davis and this is what they saw when look at families of deaf and hard-of-hearing children and this is school age here.

So not everything on here is applicable from birth to three. But I think what's important is that we can see there are physical, mental and social emotional impacts of listening fatigue. I want to point out here in the middle these are the experiences of listening fatigue that the school age children reported. Some of physical experiences they reported were feeling drained, exhausted, tired, complaining of headaches, checking out, looking like today daydreaming, not paying attention, saying their brain feels tired.

Some of emotional experiences can look like behavioral problems or acting out. Frustration or anger, giving up or shutting down or withdrawing from others. It seems like it can be on a continuum. Some kids depending on temperament or personality can act out because brains are tired from listening or other kids may withdraw or pull in. I am a withdrawer when I'm in a high state of listening fatigue so that's what it looks like for me.

A quick note about why we talk about listening fatigue, so just as context for you our children's hospital Colorado has a family support team so it's myself, another deaf and hard-of-hearing professional and teacher of the deaf and we can meet with any family via telehealth or in-person to discuss a wide range of topics. This service is free to families because grant funded so it's fantastic to be able to offer this support and what we have noticed is as we have met with families especially since the COVID time, listening fatigue is one of our biggest topics of conversation. It keeps coming up over and over and over again.

As parents describe their concerns for their child, we notice that a lot of parents have never heard of listening fatigue. When we explain this and talk about it some of them are brought to tears saying this makes so much sense. I wish I had known about this earlier . So because of

this we did a parent workshop or adolescents last year and you see some comments about how parents which should they had known about this earlier.

So that's why we feel it's so important to bring this topic to the birth to three population and start talking about this so families understand when this starts to come up for their child. How can they let their kid know that this is okay. Nothing wrong with you feeling extra drained or tired. How can we comity ahead of time to have better knowledge in this area.

So one of the activities our team does with families can experiential different where we use if duck we talked about and we ask families to think about what they or others see from their child on the surface and what might be happening under the surface related to listening fatigue and we ask them to write a few words above the surface and below the surface. So I did this with two families- month or so to bring you examples of what parents are reporting in young children.

So this is completed by parents of a 23-month-old who uses bilateral cochlear implants. They said that on the surface their daughter appears happy, silly, talkative, bossy and sassy which is my favorite. Any 2-year-old should have those adjectives to describe them. They noticed that beneath the surface she has outbursts and whining that's not attributed to your day to day things. They noticed she's complaining of headaches. One thing I thought was insightful is that these parents said she has delayed listening and he needs that extra time for processing and if you don't know her you don't realize that's what's happening. She needs extra time to process what you said and respond.

Refusing cochlear implants. This is an example of a little one who is 19 months old and also a bilateral cochlear implant user, on the bottom mom notes he'll go play by himself sometimes due to listening fatigue. This is a little one takes them off after dinner. It's not related to him ignoring you. He's not understanding related to potentially listening fatigue.

If you're not familiar, I would encourage you to look up the Vanderbilt listening fatigue scales. These are for ages 6 to 17 for pediatric scales, so not designed for birth to three but it gives conversational starting points and as parents and kids with ageing out of the early intervention making sure they have this intervention as they go into school is helpful to inform maybe accommodations for IEPs and 504s and things like that.

>>ALLISON CUNNINGHAM: We're going to segue into strategies for listening fatigue. A lot of these are strategies to support ourselves as adults or school age churn and they might be written into IEP or 504. A lot of similarities. Includes listening breaks, whether structured or unstructured. Giving parents permission to leave a social or family event early and that's protective of your energy an time and your child's energy and time. Use of remote microphone technology. I know this is something that many of you are already familiar with but thinking about it from a listening fatigue perspective of just increasing the auditory access, particularly in those noisy environments, will help combat listening fatigue.

Face to face communication. A lot of these are intuitive, we know it, but it supports the listening fatigue component. Use closed captioning, why choose closed captioning on for a baby.

I think a lot of this is also helping children early on understand that having visual access is so helpful. I think it also using closed captioning is fostering advocacy as well as potential early literacy as well. There's a lot of benefits to it. Looking at your schedule of the day, one of the ways that you can look at ways of putting breaks in and opportunities to maybe not do certain activities. Again keeping listening fatigue in mind. You as a parent, are there certain things you can do with your voice, adjusting your volume and slowing your rate of speech, particularly if noticing signs of listening fatigue. Getting down on their level and connecting at eye level.

Acoustic modifications, I think one of the things -- I have a room that's open concept, so it's challenging to hear in my own house and I found that when I change up the carpet and the drapes it improved my access to sound. So what are things you can potentially do in your own home to help with those acoustic modifications. Providing a schedule.

Activities that regulate the nervous system. Hillary Davis in article said that parents reported that strategies and coping mechanisms were not employed by their siblings with typical hearing, so they're noticing differences with DHH as opposed to typical hearing.

So, I think some of you may have come to my talk yesterday on trauma informed care, so for those of you not aware trauma informed care is a service based delivery model that considers trauma experienced by an individual and aims to provide environment and services that are physically and emotionally safe. So using a trauma informed lens we see that chronic listening fatigue is a stressor and perhaps listening dysregulation.

This can lead to poor health outcomes as well as mental health outcomes. So what is happening in our bodies that could be leading to poor outcomes? Yesterday I talk on neural development and one of the things I didn't talk about is what's happening in what we neuroendocrine disrupters. So we call the HPA axis. I'm not going to spend time on defining it but happen to talk about afterwards, essentially the body thermostat good or bad. When exposed to repeated chronic stress or listening fatigue you're having over activation of HPA axis. This looks like in children irritability and health outcomes as adults and also thinking about chronic activation of this axis could lead to decreased tolerance.

So for those of us experiencing times of hypervigilance, so we're hyperaroused, the result is we're going to swing back rapidly in hypoarousal, appearing numb and fatigued. We've been spending a state in hyperarousal our reaction is to go to hypoarousal.

It's important to call out that early childhood experiences may impact listening fatigue. So

deaf and hard-of-hearing who have experienced early and significant trauma and stress in their life may experience underlying deprivation and more listening fatigue. This might contribute to the data that suggests that listening fatigue has no bearing on type of hearing loss. What if the differences we're seeing are rooted in early childhood experiences which we may not be screening for.

Finally, I want to get back to this nervous system dysregulation, if thinking about listening fatigue as a result of nervous system dysregulation, how can we get back to regulating that you are nervous system. My son is in OT now and it was a light bulb moment for me, what if we can instill these activities throughout the data whether sensory seeking or sensory avoidance, depending on the pattern that these kids are exhibiting. Throwing or pushing a heavy ball or laundry basket full of clothes. Or squeezing, playing with Play-Doh. Prioritize activities so gymnastics, swimming, soccer, swinging, jumping on the trampoline, getting outside and even better if in the company of animals. These are things that help regulate our nervous system and simple stuff like providing oral activities like chewing on crunchy foods or chewy foods.

Giving opportunities to use a straw to eat or drink, ways to regulate our nervous system and what can we learn from occupational therapy to help support our kids who might be experiencing listening fatigue.

>> So listening fatigue is complex, it's prevalent and it's real and challenges that are faced by many deaf and hard-of-hearing individuals and luckily there are more resources and supports and vendors being made available and the we are talking about it more and we open our review of literature today, as well as our own experiences as well as using a trauma informed lens has given you better tools to support the kids that you're seeing. Thank you. .

>> Hello, everyone. We'll be starting the next session in one minute. If you're conversing about the last session, step in the hallway or come on in.

I think we are ready. Thank everyone for coming to the last talk on Tuesday. You made it. Crazy. What are amazing segue from previous talkers so this is routine based microphone strategies in the home and focusing on 0 to 3 but any age can be applied. So quickly introductions.

>> I'm Brittany Slaff, I'm an audiologist over at Rocky Mountain hospital for children and I run our cochlear implant team. I love to give a fun fact, I'm avid gardener and I have indoor basement garden.

>> My name is Sarah I'm audiologist by trade. I serve as coordinator for western Colorado. I do not have a green thumb at all I wish I did, but I have a younger brother who's profoundly deaf so this field is near and dear to my heart.

>> I'm Elaine, Sarah and I work for the Colorado school for the deaf and blind. I'm the coordinator for northern Denver. I have a deaf dog and I did not plan that, she found me. We're all salaried employees.

>> We're going to talk about learning objectives. We want to give a brief overview of RemoteMic technology use in day to day world and look at case studies of how we implemented it on the day to day routines and talk a little bit about access to RemoteMic technology, so what does the research say about recent mic systems?

First and foremost many of us have exposure to this it reduces background noise. So that primary speaker make the boys louder than the background noise. For children that utilize RemoteMic technology they hear 11 more words per minute than individuals who don't use that technology, so in terms of getting language in the more words per minute, the more access to language.

So a couple other less tangible items, too, is it increases child attentiveness, reduces parent repetitions, increases the willingness to talk from a distance, so if dad or mom in the another room, can continue conversation with child in another space is more likely.

So the presentation before us is perfect segue for that listening and background noise. One caveat is how did you learn to listen in background noise? We know our listening skills in background noise, our goal is to create that solid foundation so we can make the appropriate guesses in that more challenging listening environments. So I'm sure a lot of you have seen this image before but really showing the impacts of distance on listening, so for every doubling of distance you're essentially halving the loudness, so reducing the signal by six DB, so you can see 24 feet which can be a typical classroom and you're reducing that signal from 60 DB to 42 and then that's not even factoring background noise.

Continuing on what the research says about RemoteMic technology so the average home signal to noise ratio is 7 to 9 DB, so the speaker's voice is 7-8 D louder than background noise. We need at least a 15 DB signal to noise ratio for optimal language acquisition and language access, so that helps, too, with special case consideration like individuals who have really noisy medical equipment.

So they're experiencing if wearing on their person a lot of ambient noise. So we're creating a better signal at the level on ear. I'll pass on to Sarah here.

>> Now that we know about what the research says, we wanted to make it more functional. What does this mean for families and how do we incorporate use of remote microphones into everyday routines and what strategies can we suggest. When thinking about routines in the home, these are different activities we came up with as good places to use remote microphones so thinking about meal preparation or cooking and the baby is in another room or maybe in the same room but not at eye level with the child.

When you're playing at home they're exposed to ambient noise at the level of the ear, so even if the caregiver is on the floor, that child is exposed to background noise at the level of the ear. Large family gatherings more of a challenge, a lot of background noise and a lot of people talking at once and listening fatigue there and some of those smaller group or one-on-one activities like reading books or singing songs.

I'm going to talk about three different families that I'm working with that we have utilized remote microphone technology and what their experiences have been.

I have 15-month-old boy I work with, he was born at 27 weeks gestation. Six months in NICU. Top priority was keeping this child alive. He spends a lot of time in one room or on the chair. Mom was struggling to leave that room. Dad is a firefighter so gone for two and a half days and then home so mom is the primary caregiver. We used strategies with both parents. We focused on narration and getting her comfortable leaving that room but still talking to her child. He wears two cochlear BAHA devices and she is getting more comfortable leaving that room because she can talk to him and feel like he's an in the conversation. So will moving laundry over, unloading the groceries, it's allowed her to leave the living room and still talk to him.

What I noticed from him side is he's much faster to calm down. When she talks to him he calms more quickly and she doesn't have to be in his line of sight. He's able to Army crawl so he's excited to find her throughout the house. It was great to see this simple tool that we can use and allow mom that freedom to leave the living room and not feel like leaving her child. I have another boy born with bilateral -- he's almost two.

He wears bone anchor hearing aids on both sides. Large family gatherings are prominent for this family. It's an important part of their community and support system but mom reported when in environments he's quick to take off the hearing aid and it's an

overstimulating environment and experiencing listening fatigue. At home when families come for holidays or family dinners he's quick to have tantrums and outbursts.

Mom has a connect clip and he in this it's a game and he has to find her and running around and laughing and his stress has come down and he's less anxious. So using this tool that sat in a box for two years is helpful in reducing the stressors and increase the comfort of parents knowing how they can use in and how it can help.

When thinking about outside the home -- I apologize. My little one who's born at 27 weeks gestation he's relying on a trach and feeding tube and he's exposed to noise from medical equipment all the time so the remote microphone is message for mom to use and she's noticed he's more attentive during the differences because of signal going to his devices. When we think about outside the home, where are areas where these mics are helpful. Thinking about car rides, going to the playground, walking around the block, going to story time at the library, extracurricular activities like sporting events. The mic may not work for everybody. These are the ones we came up with.

My little one born at 27 weeks, 3 months ago was the first time to take a walk around the block. Loading him into the stroller. A major milestone and beautiful to witness. Mom and I talked about if we use this microphone what are things we can talk about. We discussed auditory queueing so if you hear the wind or a bird in the tree or of cow, stop the stroller get down on level and talk about what you're hearing and seeing and give them that language input and this allowed her the comfort of talking to him.

Before it didn't seem like he can hear her, using that remote microphone has allowed it to go into his devices and he hears her a lot more and he gets to be in this new different environment.

I have a third little boy with unilateral hearing loss. He wearing a cochlear BAHA device on

that side and he's motivated by being outside. He has two older brothers and constantly running outside. What she has noticed is when he used her remote microphone he's more apt to play further away from her. He's not near as anxious and needing to be right in her line of sight and he'll get to the other side of playground and I have to check in with him and he comes running back to me. He's gotten a new sense of confidence to explore his surroundings and feel safe.

His day care teachers have started to use in remote microphone in the classroom and they notice he's more attentive during activities. They don't have to repeat themes near as much. The repetitions come down significantly when remote microphones are used because the child has a better access. Mom said with at the park his two older brothers figure out if I lean close to him, I can hear what she says and they all have this secret way of communicating with mom and they love working with this device. As audiologist we're scared to use these. That's a conversation that happens with the clinical audiologist and the team, when we feel it's appropriate, I've seen beautiful things happen and a lot of language that the child can be exposed to through simple narration activities and auditory queueing and greater sense of confidence develops and being willing to explore and play further and not feeling like they have to be in direct line of sight with mom and dad. Pass it over to Elaine to discuss access to technologies.

>> Actually I was listening but not listening, but there's a safety pope as well for our kiddos that have auditory device thorough that safety component if there is no functional use of the speech perception and things like that, so this is helpful for our kiddos that have that visual access to language, the American Sign Language, the family I work with has a baby in the living room and mom is about 10 feet away in the kitchen and she's able to localize her mom's voice. That's fun to see too.

So this is an infographic that came out a couple years ago from here to learn and we talked about these different routines that who can use, right? Who can use a remote microphone and it's anyone. Anyone that's in the child's community, their parent a sibling, parent, a coach, anyone that has access to this technology and communicating with the child with the listening and spoken language approach. There's a fun infographic to share with families.

So where can families get access to this technology? If there are any audiologists in the room I'm pretty sure some of us have a closet in our clinic with random microphones hanging out collecting dust. That happens, but now, actually, a lot of the hearing aid manufacturers and cochlear implant manufacturers provide remote microphone technology with the purchase of hearing device, so this can come free in pediatric package. These allow for that possibility. If there's another hearing aid technology or company that the family is utilizing, really cool with our smartphones nowadays. If you have an iPhone or apple juice drinker you can enable the WiFi on iPhone and allow it to most hearing aids too.

Specifically here in Colorado, there are remote microphone loaner banks so the Colorado school for the deaf has one and this is specific for school-age children to utilize remote microphone technology in their classroom if their school district doesn't have the funds or want to trial at this time before they purchase one at the school and the same or Colorado Department of Education is a similar loaner bank as well.

If not from Colorado, wondering where you can look in your own home state is the Department of Health or infant hearing.org if a way to find different loaner banks in your community. The clinical pediatric audiologist is the 1st that give that green light to say everything is looking good with hearing aid technology, the family is ready and we can utilize that remote microphone. So when that is purchased through the hearing aid manufacturers, typically that's going to be added in-home use.

Of course working with educational or school based audiologist they may have access to that remote microphone especially if indicated on child's IEP. When children are adults and working thinking about how to access this at work, organizations can help provide that technology in the work setting. We put together -- not exhaustive, so many different technology companies for hearing aids, but we did try to find the major ones with the links and Brittany made a beautiful QR code to click and access the different links. It's easy. Most of this is on YouTube or manufacturer Web site, with most microphone technology you need to pair it once and good to go. Remember to charge it like everything else we have.

These are our references, and that is all. Yeah. I think we have time for questions. Oh, yes.

>> I'm going to do that best so my QR code goes to my personal YouTube. I'm going to keep it updated with my newest technology, as new things come out point your families to here's a list. This is specific to remote systems not the systems used in the school systems. So your child may have a specific system at school that's different to your personal system. I'm not muddying the waters to make this specific to at home systems.

>> Thanks so much. This was helpful. My daughter has unilateral hearing loss and she wears a hearing aid and we started using her RemoteMic. She does tumbling and we tried it with her instructor. It wasn't successful, when talking to her it's great but then six other kids that she hears all that instruction that she doesn't really need. Do you have any tips. I think at school when everyone is listening to the same thing it was successful but we were having one-on-one and the instructor's were moving to other kids and almost contributing to her hearing fatigue.

>> It's a fine balance and this is what we talked about that we want to learn to listen to noise and learn and have incidental listening and learning when we're passively listening versus actively listening. It's a bit of an art with the instructor it's like a gymnastics class. I love that's

a part of your routine.

For the instructor there is art to mute the remote microphone so if I'm going to be working one-on-one with another child to click on that mute button and then working back into that general conversation or working with your daughter to unmute and turn it back on. It takes some practice, I think, but that -- do you have anything else you want to ask?

>> The mute function, I think that's great because this is something that we have to encourage with parents. When you go to the bathroom mute it. Let the teachers know that. It's a very fine art. As they get older, I encourage my families to check in, one boy is approaching three. Ask does it membership when I use this? He's a good reporter and able to do that. Getting their input is helpful. We don't want it to be more stressful or more work but it's finding those areas where it is helpful and a little bit can go a long way. 11 more words per minute that's great. We don't want them to be exhausted. Hearing four other conversations they don't need to hear.

>> The other thing as a deaf person who uses a RemoteMic occasionally, I don't love it, the other thing I think about is that the active listening and passive listening and the other thing you can do is train the person using it to not just use mute but to also say the name of the child they're talking to first. Then that cues your child to know I have to pay attention or I can ignore that. So that's another strategy it's kind of natural. She's also picking up, maybe she missed something and she's going to pick up something by having that passively streaming into her ear.

>> I love that idea. Thank you.

>> I wanted to make one comment here. I see a lot of children with single sided deafness that we're implanting, we might lean on remote microphone, whether connected to a computer to do teletherapy with auditory teletherapist or encourage a sibling or parent to employ listening

skills at home, where another parent is in another room and doing a listening activity from a distance to target that implanted ear. That's one of the activities that I emphasize for my patients as well.

>> Thank you.

END TIME: 4:00 PM