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EHDI – Florence

Parent Experiences Monitoring Aided Audibility

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>> Well, thank you all for being here. I'm Karen Munoz and this is Makynzie Larsen. We're going to talk to you today about a study we did looking at parents experiences monitoring audibility. Whether they were using hearing aids, cochlear implants or bone conduction hearing aids, any kind of device like that ‑‑ we wanted to look at what's happening day‑to‑day.

How many people here, are parents? We don't have any parents in the room. Okay... well... that's okay too... we're going to talk about what we learned from them and we can see from that professional perspective how we might partner with them a little bit differently.

We know when we're working with families that are teaching their children to listen and talk and use hearing technology... that that consistent audibility is something that matters for their speech and language outcomes. We've got to make sure that they've got regular, consistent quality on, you know... ongoing audibility in their days.

But... we also know there are a lot of things that can get in the way of that. And... not all of them are within our control and not all of them are within the parent's control. What that means is we need to look at how we're developing effective steams for looking at monitoring audibility on the parent's side of that, they are putting the hearing aids on each day or the device. They're making sure that they work every day. And... that they're looking at how their child is responding to sounds in a variety of different environments and situations and conditions.

On the audiologist side of this thing, we've got to make sure hearing aids and other devices are programmed appropriately to provide audibility, excuse me, that we're monitoring that device function on a regular basis and providing parents with education and support.

This is a real important collaboration and it, and I'm using words audiologist, but it clearly means, you know... early interventionist, Deaf Educator, Speech Language Pathologists have a role in this as well.

So... you can insert a different thing for audiologists if you're in another profession.

But... we're going to talk through what we learned and implications of that to consider. I'll let Makynzie share the results.

>> Makynzie: Okay... just going over real quick ‑‑ we sent out a survey to the parents, through Facebook groups, parent websites, things like that and they were able to fill it out and then we have that demographic side of it. As you can see ‑‑ there's a lot of same lariat across all device types.

So... the average age for the children was about three and a half years and as you can see... the mothers college degree was also ‑‑ the majority of mothers had a college degree. So... that's really interesting to see ‑‑ we have this similar demographic ‑‑ however... the results we got were actually very variable.

So... we broke it up into different aspects, the first being hearing device use and its factors.

Here's a hearing device use you can see, parent reported on average, ten to twelve hours a day is how often their child was using the devices, but... the variable aspect of this is the range, you can see how wide that range is, how often their child is actually wearing the device.

So... then we wanted to see what factors are influencing this? We first looked at the child age and as highlighted on the slide... early intervention age had less hours of use than the other age groups. Then we looked at the device type and cochlear implants tended to use their devices most of often in the day than other device types and we looked at the length of time they've had the device and... it seems that when they've had their device two years or more, they use their device more frequently throughout the day.

And then... we wanted to look at loaner devices. And loaner devices are important. Devices can and will malfunction at some point. When they do, the device is sent to the company for repair. As the device is in for repair, if that child doesn't have a loaner device, they don't have access to audibility. It's not happening as often as we'd like. For hearing aid devices, 60% of the parents reported they don't get loaner devices at that time.

And then we looked at ear molds and ear molds are specific to hearing aids. We looked specifically at children 0 to 3 years. This is important to note as you can see, we have 10% as highlighted. That might not seem like a big number, but it is. 0 to 3 years, that child's ear is shaping and growing, like we all know... so frequently, if they're never getting an ear mold, audibility is broken down at that point, because... sound isn't being able to process the way it should be. And then we also noted that 31% of the parents who did get an ear mold within the last year reported it took three to four weeks, shipping time. Which is also really important to note because... three to four weeks, that child's ear has already changed and you probably need to get another ear mold at that point.

And then, we looked at hearing device monitoring. This is focusing on the parent factors of monitoring the aided audibility.

We wanted to look at parent confidence. When I think of this ‑‑ I think about myself. When I'm not confident in something ‑‑ it's hard for me to want to do that thing. I either have to really talk myself into it or I just don't do it and it's the same for parents. If they're not confident in something, they're most‑likely not going to do it. We asked the parents to report how confident they were ‑‑ zero meaning they're not confident at all and 100 meaning they are really confident. We looked at those who reported lower than 50 and hearing aid parents are not very confident. 44 reported that 50 or below ‑‑ meaning they're not very confident in these aspects. And then we wanted to look at how often are they checking certain device functions?

So... this is broken up by device type and also on the graph, we have when needed as dark purple, never is lighter purple, every few weeks is reddish color, weekly is gray and daily is blue. We're going to focus on daily.

As you can see, for hearing aid function, parents check the physical condition and the wax blockage daily. And they checked the other ones a little less frequently.

For bone conduction, they're checking the batteries daily, more frequently, but speech sound check ‑‑ external equipment and microphone quality are hardly ever checked daily.

For cochlear implants, you can see parents are checking the batteries daily and checking the external equipment more frequently than microphone quality or speech sound check.

And then we wanted to focus on what are the professionals doing, according to parent report and so... we were focusing on questionnaires. Questionnaires are things like little ears or peach that help us understand how the child is functioning and daily environments. And again... we broke it up by device type... the dark purple is never, the lighter purple, sometimes and that red color is often.

As you can see, across all of the professionals, according to parent report, we're never asking them to fill out any questionnaires.

For bone conduction, we got simple radar results. And also for cochlear implants, they're being asking a little more frequently, but still, quite a few report they're never getting a questionnaire asked by a professional.

Then we were focusing on FM systems ‑‑ these are personal FM systems. As we know that when noise is louder than speech or the signal that the child wants to have ‑‑ that audibility is broken down again. They won't be able to access the things that are important for them.

We wanted to see how many of these children have personal FM devices and across all devices, there are a few that really have personal FM devices. Hearing aids, children in particular, don't have many FM devices and bone conduction and cochlear implants have slightly more than hearing aids.

Then we wanted to look at how often they are using their personal FM systems in certain environments? It's kind of like the graph before, where that dark purple is never, lighter purple is sometimes, and reddish color is often.

As you can see for hearing aids, for those children who have them, they're not using them very often, in certain environments. They use them more‑frequently at school or events, than at any other area.

And for bone conduction, we can see similar results and... where they're hardly using them. But... we can also see that they use them a little more frequently at school and at home. And then, for cochlear implants, we have similar results as well, but they, again, use it a little more frequently at school and at events.

And some of the last questions we asked, the first was challenges. This was a written response by the parents. We found three main themes. The first was child‑related challenges. A lot of these, the parents wrote they had difficulty with the child being able to tell them when something's wrong, like the battery being dead or things like that. So... there's this communication barrier for the parents and the child.

The next one was parent‑related challenges ‑‑ which... this one is... knowing when the device is working, being confident and being able to say yes, it's working the way it should be. And then the last one was device‑related challenges and this one had to do more with not know ing for sure if that was the correct device for their child or if it was programmed correctly for the child.

And then we focused on advice. These were written responses. This was advice for us professionals. We found again, three main themes. The first was parent education and support and... I remember when I read through the responses, how frequently parents would say they want more information and then they'd also say frequently they want more information, that's understandable. So... that's something where, it really hit home to me, that's something we need to work on is giving them the information that'll be valuable for them.

The next one was relationship with parents. They want the professionals to be patient, to listen to them. A lot of parents said they want to have a professional listen to them when they felt like something was wrong. And the last one was our professional practices, just being thorough in what we're doing is what parents want ‑‑

Then we have big takeaway points. Again, it kind of goes back to that ‑‑ we had a lot of variability with the results we got, so... things like hours of use... we can see that, that consistent audibility is at risk.

And then we looked at the parent‑professional partnership and how it's essential for our monitoring. Parents want to have that education, that support as a thing that was ‑‑ I felt like, was really consistent throughout the research that we did and it's important for us to know that we need to give them that support, not just in our practices, but give them support, such as parent to parent support and group support, things like that and we also need to have that ongoing collaboration and communication with our parents. When we have that collaboration, we could help them best, when they are having problems. We can help them to have more confidence in their ability to perform these tasks.

And then... Dr. Munoz is going to talk about this.

>> So... one of the things that stood out to us quite a bit. These are all parents of kids that are birth to 7 years of age. If they were in school... they were barely in school at that point. That... that they really were in their advice, saying how much more they want from us as professionals. A lot of stories about you know... I come in and I know something's wrong ‑‑ I know it in my gut and want to explain it, please listen to me ‑‑ please believe me when I know something's wrong and that came through from quite a few different parents and also, the being patient came through quite a bit and... a plea to be listened to. So... I think we see some opportunities and maybe, how we're engaging in that device monitoring aspect. With parents, so that we can support them and they also were talking about wanting more information. So... we thought it might be useful ‑‑ you guys may or may not know about the resources we have on Hear to Learn. How many people know about Hear to Learn? We put this out two years ago and continue to add to it. This is a website that's geared towards parents and professionals, but particularly of kids who are about birth to 6 and they are resourced that are probably most‑useful for those parents that are pursuing listening and spoken language for communicating with their children and we've got video tutorials and language activities and access to research for parents that want to read more, but... it's something that could be considered as a bridge in your practice for that information.

When we think about the parents that we're working with, at the times we're with them, even if it's a regular monitoring appointment, it can be emotional for them. And that's actually a comment that came up from a parent. This might be routine to you ‑‑ we think about routine monitoring, it's not routine to me. And it's emotional every single time. And... when we're feeling emotional, we don't always remember things as well and... that can impact how things go when they go home. When we look at the parents of kids with hearing aids, we had the largest N for that group and they showed a lot of challenges with confidence in what they were doing and... the mom, most‑often, comes to the appointments. We see mom in the office more than anyone else... and she's got to go home... and teach dad or grandma or other family members and if ‑‑ if she's not taking it all in in the way that we think it might be happening in an appointment... there's going to be some lost information in translation ‑‑ this website might be something that's helpful. That can be a bridge and say "we're talking about this, but... it's a lot to remember, you could go here, this might be helpful to show your husband when you get home or the grandma or aunt or caregiver," whoever the important people are in that child's life that's helping them monitor audibility.

We found in other work we've done ‑‑ that really can be a break down. The mom might learn it ‑‑ the mom might get really good at this, but... then someone else is caring for the child. The hearing aids come out, the devices come out... they don't know how to put them back on.

They land in a case until mom comes home. So... you can see all of these risks that can, can get in the way for that monitoring of audibility that, that they're living with and experiencing and we can be a bridge to help them through that. In a bit more purposeful way.

So... we thought we'd share that and... just questions or thoughts or comments that you all have or you'd like to share with each other too. We'll bring the mic around. Any comments or questions?

>> So... you were saying that the zero to 3 age had the highest amount of time when they were unaided during the day. So... did anything look at like... retention problems that parents were having? And like, providers being able to kind of help them with ways to kind of ‑‑ I know that's a huge issue with a lot of parents. The little kiddos want to rip them off and don't wear them ‑‑ we had to be outside the box with that ‑‑  
 >> This particular study, we didn't ask them about what the challenges are ‑‑ we've done that in previous studies and the child's behavior is always at the top of the list because they're young.

So... in this one ‑‑ we didn't ask them what was getting in the way with it, just that ‑‑ those things are real... and they're happening and they need help with it because... that's a real interfering factor during an important language growth time. So... yeah... we do have to think outside the box.

>> I'm so glad you brought up the point about the challenges when you're explaining stuff to a mom or dad, but it's really not them that are with the little one throughout the day time. I was just wondering if you had any good strategies for that? Usually, the reason that the mom is coming ‑‑ they want that information, but... the other caregiver can't be available. And... so... I'm always concerned about explaining it all to mom and how does that translate to what she's explaining when she goes home. I'm just curious of good ideas ‑‑  
 >> I can throw out a couple ideas and others might have ideas that they use too. Do you want to share one idea?

>> I just came from a presentation by Michelle Graham and she talked about how she encourages families to take out their cell phones and film, like... how she's putting on the hearing aids ‑‑ how to trim the ear molds and even sound checks and things like that ‑‑  
 >> Yeah... that's a great suggestion. We've had families that do that as well. That's a really good way to do it. Another thing we've done ‑‑ even though, typically, people can't always come ‑‑ I wanted to see you ‑‑   
[laughter]  
 >>... can't always come to the appointment ‑‑ if we, if we put an invitation out there and maybe look at our schedules flexibly, we're finding people that like... they don't always think they can bring other family members. We found... you know... people that will work really closely with ‑‑ we have a pretty intensive integrated program and you think everyone felt welcome to bring them in ‑‑ and... we've had that come up with kids that have had it for a few years. They're in pre‑school and struggling with what to do with this exact thing. Take the hearing aid out... grandma doesn't know how to put it back in and when you suggest for her to come to appointments, it's like... I never thought of that. It's also an important collaboration point with the audiologists and early intervention, you know... they're going to the home, it can be a very good purposeful collaboration too. So... I don't think we have to feel like it's ‑‑ you know, just us that has to do that. Good question. Other thoughts?

>> Hi... thank you. At one of the first slides that you showed had parents perception or parent report of how many days a child wears their device and then there was another number that showed the range ‑‑ I wasn't clear if the range meant the range of responses or range of datalogging?   
 >> Range of hours. It's not datalogging ‑‑ it's parent report, so... we got the average was pretty high ‑‑ if you look at it. Like ten hours... but it was really... a wide range and... some of what we know as parent report often overestimates how much they use, especially at the younger age.

So... we wanted to put the range out there, just to show some people are, you know... reporting it lower. These are likely optimistic numbers, really. Good question. Other thoughts or questions?

>> Just a clarification, for the question that asks parents related to confidence ‑‑ is it confidence in doing all of the, like... equipment check? This one...

>> Yeah... so... we had so much information from this study ‑‑ it was very challenging to figure out what to put on these slides for you all... that's a good question. These... the questions ‑‑ there was only about four of them for each area of confidence, so... I'm going off my memory just a little bit here ‑‑ it was how confident were they in checking that it's working... changing a battery... I don't remember what they are. There's like four different items of routine things they'd do at home. The exact items weren't the same for hearing aids as they were, say, for cochlear implants, but... we took the items for the group, within that device and looked at what percent for the total items in there were lower than 50, a rating of 50. Which means they're not very confident. This is a way to think about as a general confidence within that grouping of items.

So the take away is that they're not particularly confident in those daily management tasks. Good question.

>> I think that I don't see anybody ‑‑ the real parents or anyone... but... I wondered about child care settings. Because... I get a lot of reports about the kids in my state that their families drop them off in the morning at a child care setting and it's very hit or miss as to how much that child care provider ‑‑ there's usually so many of them ‑‑ running around the place ‑‑ like... who's really responsible to make sure that little one has their hearing aids on? And... anything to do with it? And I know, sometimes they do get someone from early intervention that will do an in‑service, but that doesn't mean that every child care person that deals with that child gets that training as well. I was just wondering if that's something you might be looking at at some point?   
 >> We haven't done any study where we looked at it, but in my own experiences and probably yours as well ‑‑ that's a really tough setting. Just to share a quick story, I had a family that the little girl was 2.5ish and was in a migrant head start ‑‑ Spanish‑speaking family ‑‑ I'd been working closely, I'd done in services with the teachers, gone there, worked with them, thinking we're in good shape and... I checked one day ‑‑ I think I stopped in one day to check on them and said... how's it going with the hearing? The teacher proudly goes and gets the hearing aid case out of her backpack with the hearing aids in them and says "they're right here, they're safe." I'm like... oh no. Oh no.  
[laughter]

That was after inservices and everything, anything that we can do to bridge that I think is very important and... it's kind of where datalogging comes in. If we think the parent things, I'm sending them to school ‑‑ they're safely in the backpack, where they stayed, datalogging will give us that clue, we've got a problem. It can open the conversation to say hours of use are like two hours a day. What's happening? And the mom would be like... no... I do all these things, let's check and do it. What's getting in the way?

So... I think we've gotta use the information to help us problem solve what to do, but it's a tough place, yeah.

>> So... I think we all struggle with those things. We have children that come on at the pre‑school age on a bus up to two hours. If there's traffic, sometimes more. So... parents will often ‑‑ I mean, I think they're putting them on the bus sleeping, right? Their kids may be picked up at 6:30 in the morning. From that perspective, they're thinking, why would I put equipment on my child? Or a 3‑year‑old on a bus who is not sleeping, is pulling things apart and who knows where those pieces are going to end up by the time they get to the program? But... starting, we have ‑‑ we see different challenges for the families that start with us at 3, versus the families that started with us at 3 months, right?   
 >> Mm‑hmm.

>> So... we talk about the datalogging, at the beginning, so it's not gotchas, right? And I think Boystown, on their website, has posters about the number of hours you have to ‑‑ your child needs to wear their aids and that type of thing ‑‑ so... we find that helpful. We don't talk about it as what you have to do today ‑‑ for a 3‑month‑old, they might not be up eleven hours a day. We talk about that as the goal. So... when people talk ‑‑ think about how they approach families ‑‑ sharing that information at the beginning... and then tracking with datalogging or what have you to troubleshoot what those problems are ‑‑ works for some families ‑‑  
 >> What I really love about what you said is that, you know... talk about it at the beginning and that just puts you on the same page with them. That makes you guys on the same team. Say... we've got goals we're working towards together. As professionals, we don't have answers about how to get there, but we're working towards the same things together and... let's say you've got the 3‑month‑old that's not awake ten or more hours a day to have them on. Elizabeth Walker is here if anyone wants to ask her.

We've got that nice benchmark to go with and... let's say the baby is, is up ten or more hours a day but we're seeing eight hours a day of hearing aid use. That's maybe worth a conversation, you know... when ‑‑ I don't think we have great data ‑‑ because every child's a little bit different about how many hours a day are they awake? What makes sense for that family? If we all know where we're going and how we're getting there and what's, maybe, getting in the way, then we can work through it carefully together. So... great approach.

>> I'm thinking specifically of one family, the datalogging hasn't improved greatly. Mom's in a place of shame ‑‑ if we had her make a series of videos... saying this is for extended family or... I think she's the primary provider at home... they're not spending time in daycare ‑‑ that might, might ‑‑ I don't know ‑‑ alleviate some of that ‑‑ I'm teaching someone else to help reinforce all of these skills of managing the devices.

>> Yeah... that's a great point. That's a lot of pressure on the moms when you think about it ‑‑ they're with us, learning... and then they're out there all alone. Teaching these other family members ‑‑ we had a mom ‑‑ we did a talk on the question prompt list yesterday and I shared this story ‑‑ we had a mom that, she was brought up ‑‑ she had the hearing aids for several years, the kid was in pre‑school, saying, how do I tell their family members this is important? You'd think I know what to do at this point. I'm almost shamed to ask this question, but what do I do? That's not an easy answer. We think they've got it down and then can explain it to everyone else, but that's tricky. They need support from us about how to do that tools, suggestions, talking it through, offers to bring them in and help them with it.

So... I think our ability to identify what's harder for them to take away and go do and where we can bridge our support is a helpful thing to consider. Good question.

>> I was just going to add ‑‑ I thought this was very interesting ‑‑ the parent confidence, I find fascinating. It looks like the age range is about the same for the children, using the different devices, but that hearing aids, their confidence was so much less, I guess.

>> Yeah.

>> And is it like... how frequently they're coming back for hearing aid checks or where the information ‑‑ how come that is so high for hearing aid users? As well as... when you're doing the areas ‑‑ if there was one area, more or less competence in versus another? Does that give us some kind of indication that we need to focus more on one specific area than another?   
 >> One area that stood out for the hearing aids was their confidence in knowing that their child was fit appropriately with their amplification, so... we do a lot of things, you know... with our verification to make sure the hearing aids are fit appropriately, and... we may vary a lot in how we help parents have confidence that their child is having audibility, that their hearing aids are fit appropriately and... so... I think some of it was around that ‑‑ that stood out as the biggest place that they lacked confidence, so... I think there's some space about how we talk about that and I don't ‑‑ I don't have a way to look at like did that vary by degree of hearing loss or something. I don't have anything there ‑‑ I don't know if parents of children with a more mild degree are having less confidence there or not. There may be other factors like that, that trickle in.

And... our time is over. Thank you.

[Session concluded at 4:30 p.m. ET].

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