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BRIDGING THE GAP: CONNECTING EARLY INTERVENTION AND EDUCATION

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>> ALEXANDRIA MESTRES: Good morning. Welcome. My name is Alex Mestres, and I'm an educational specialist with the Children's Hearing Program at the University of Miami. Those that know about the U, we are very popular and my co‑author who couldn't be here is Carrie Morgenstein at the University of Miami as well.

Thank you to the previous speaker, I am an itinerant teacher for the deaf and hard of hearing and charter schools. Let me hear a shout‑out for itinerant teachers!

That's the most important thing. And I'm like... yes, ma'am!

Today's objectives we're going to talk about connecting the medical setting with the educational setting.

Empowering providers to help families in different types of ways, and, of course, as always, talking about family‑centered care as deals with children that have hearing loss.

What we know...

We love to think that early intervention solves all manner of problems, but it doesn't always guarantee children are going to meet developmental and academic milestones. We also know that parents after diagnosis, they become that advocate. Or we want to empower them to become the advocate. It may not always happen, or it goes in cycles on how well ‑‑ or it ebbs and flows with how well or not doing at that job.

Studies tell us that parents that take an active role in their children with disabilities tend to have more positive outcomes and test scores, motivation is up. So all important things. And we do know that children spend 1,000 an hours in school per year. If you're a provider, how many times do they see you?

Once a week? Once a year? Every six months?

And hearing healthcare providers received limited training regarding the educational system. I say that because we in the educational system receive limited training on those roles as well.

You know, what my colleague tells me is that when pediatric audiologists study, they focus on diagnostic testing, ABR, CBA, all these things. Technology and device selection, whichever one it may be. Verification and validation. Evidence‑based practices. The understanding of 1/3/6 and early intervention. I'm sure everybody is familiar with that here. Basic counseling. But never once do they receive a class in what education looks like. However, what we know is World Health Organization says that interpersonal education is crucial.

Collaborative practice. They even issued a call to action saying, we know that effective collaboration will improve outcomes. Especially in healthcare.

Students ‑‑ and not the deaf and hard of hearing students, but the students in these disciplines need to learn that, is what they're saying. They need opportunities for interprofessional education.

And when talking to our SLP colleagues they said the same thing, hey, we don't get much of this.

But then these kind of things happen.

I don't have hearing loss, I'm fine, I can hear everything.

I don't like my pink hearing aids anymore, can I get beige? When I walk in a room, everybody is laughing at me. I know it's because I'm different.

My son says he has no friends. He eats alone at school.

My IEP or my IFSP says my child is easily frustrated and will scratch and bite herself or nails and hits others in the classroom.

I often think about taking my life.

And more recently in Miami, with our early steps providers we had parents coming to us saying, I can't communicate with my early step provider, what do I do?

Not really in the scope of audiological practice, is it?

But then you have the other side of it. The "me."

I am a teacher of the deaf and hard of hearing. On any given day I could be an auditory trainer. I could be a counselor. I could be an audiologist. Not for real. Just somebody once a week that might know something about hearing aids, a CI, Bahas, sign language, whatever.

I'm an IEP watchdog. Hey, teacher, this is not quite going right. Interpreter...

Social situations, sign language, you name it, I've interpreted it. Social navigator.

On a daily basis, I feel like a life coach. None of these things beyond being a deaf and hard of hearing educator was I trained to do.

And it's a problem. Because what we know about hearing loss is it's a giant spectrum. People talk about the autism spectrum. I would beg to say that our spectrum is almost bigger. You know, we have 16% of people with hearing loss that are profound. Other 84% are hard of hearing. Which can range from the unilateral hearing loss to bilateral hearing loss to conductive hearing loss and everything in between, and I think we can all agree that no two hearing losses look the same and the intervention is not the same.

So, it creates a great problem for us in education as well. Because the you look at it educationally ‑‑ and I did take West Palm Beach County numbers because this is a smaller county in Florida. It is indicative of nationwide numbers. Deaf and hard of hearing only represents 1% of the ESP population. Problematic.

And the majority of these students are in the mainstream. So causes a great amount of dilemmas that we're not ready to deal with on the medical side of it. We know the things like academic impact. Teachers have limited experience with working with children with hearing loss. There is a national lack of deaf and hard of hearing teachers. Overall, studies show that postsecondary people, teaching programs are down by 23%. In special needs it's even greater. So imagine for a 1% eligibility that number is even more effective. In fact, what we know is this year, two programs, two college programs, are closing their deaf and hard of hearing studies programs. Because they just have a lack of students.

Children who are hard of hearing are often overlooked and underserved because we don't understand it. Children who have hearing loss know what we want them to know but are struggling with how it sounds for them or how it's presented for them.

We all know these things. We know these kids have trouble in social situations. They're often missing the things we learn on the playground. And their challenges are often invisible.

A lot of people's experience with hearing loss is their aging parent. It's not children. So what happens? There is a disconnect between me and education and my friends in the clinic.

We recognize this. A few years back, the University of Miami, we said, wait a second, I wasn't there. I was actually an itinerant teacher. We recognized this and said, wait a second, but if we could bridge that gap, we might be able to ensure more positive outcomes for these students or these patients, whichever side of that you wanted to look at.

So we started looking at the problem and how we could bridge the gap. We didn't have a multidisciplinary team. We had audiologists and a speech pathologist, and a psychologist that did other things. So we really looked at what the problems were. Usually the problem is either centered around parents not understanding something, the school not understanding something about hearing loss, or the early intervention people not understanding something about hearing loss, or they're just being a general lack of resources in the community. Parents understand the educational system. Early intervention, school‑age intervention, it's all very difficult to understand.

Does the school understand the impact of hearing loss? Many child care centers do not. Is there a lack of resources in the community?

In smaller rural communities in Florida there is a definite lack of resources in the community. But what can be done about it? If I am the medical provider, is it my responsibility to reach across that gap?

So we developed a questionnaire for families. And every audiologist became their protocol to implement these questions. Name of the school. Does your child wear amplification? Simple questions. What is your biggest educational concern? Type of classroom your child is in. What assistance does your child receive at school?

Do you have ‑‑ does your child have an educational plan, whether an IFSP or an IEP?

What resources are needed to help your child at school?

And in the answers to these questions, we were able to find out where the parents' concerns lie. Is it just that they don't understand it? Is it that the school needs some assistance? Is it that there's just a general lack of resources in the community?

We were able to start to define a way to help. You know, does your child where amplification? If a parent doesn't know that, that's a problem. What type of amplification? We've asked parents, well, what is that... I had a parent tell me the other day, my child has an implant. It was a Baha, just saying. But they perceived the surgery for the Baha as an implant. You might want to tell people that's a Baha. That's kind of a problem, relied on us as the clinic to help the parent understand better. What is the biggest educational concern? The problem the parent may be having with the school.

What resources are needed? There may not be resources in the community.

Helping parents find this information. Connecting that bridge. And we started to begin to connect that bridge for parents.

We would reach out to schools. We would reach out to other providers. We would reach out to local language and speech pathologist and reached out to industry to help us.  It helped us create an interdisciplinary team. A child comes to the program and is diagnosed with hearing loss. Intervention takes place. Our immediate priorities are the 1/3/6. The problem is, once the children come in after the 1/3/6, what do we do next? Intervention starts.

Parent or provider expresses a concern. Let me tell you, sometimes audiologists are our best eyes and ears, because parents may feel more comfortable to go in and say something to them that they wouldn't say to the teacher or to the school or to the people of authority.

They express a concern at our clinic and the next place it goes, the family is referred to a member of our team, either myself as an educational specialist, our social worker, a psychologist, and hopefully then we either intervene for the family and/or the school, provide consultation and support, but we also understand this is a circle. And I guess like the last presenter, I should have found the circle.

It comes and goes.

What is a concern at three months may not be a concern at three years. There's a whole new concern. We do find this is a constant cycle in helping parents and families bridge the gap to positive outcomes.

So we are constantly reaching out for those connected services.

However, this is the ‑‑ hopefully the best case scenario.

What happens when you don't have a multidisciplinary team?

We started with consultation. We would use where and what we found. How I got associated with the University of Miami is because I had students that came with an audiogram from the University of Miami and the parents would say, but this, but that... and I would get permission to talk to the University of Miami so I could understand, then I could relay to the school what was going on or what was important or dispel any misinformation.

Many times I hear "My child received a CI and the CI team said I don't want any sign language with my child." Yet when I call that team, they'll say, no, no, no, we recognize that sign language is going to be an important part of a child's life.

So just having that basic consultation, whether video phone conversing ‑‑ in the world of Zoom, who can go wrong? In the world of Skype we can all talk to each other and bridge gaps that used to be miles wide.

It does have its benefits, increased referrals, all that type of stuff. It has limitations as we, don't get me wrong, weekly therapy, unable to provide some types of services, but more and more that world is opening.

So if your child needs ‑‑ if your family is struggling with barriers for coming in the clinic and there's ‑‑ and there is somebody in the community that you can reach out to, those resources are there and are available. It's just sometimes a matter of the simple connection.

The other thing we also did was co‑location. Before we had ‑‑ before we got to this model we did co‑‑location. We are in a hospital in a university setting, so we were able to ‑‑ if we knew a family needed some help that might fall under the umbrella of what a social worker could do, we would connect that family with a social worker, even if that social worker did not understand deaf and hard of hearing per se, that may not even be the barrier. It may be some other barrier that prevents them coming to clinic or getting into school. We made parents aware there were school social workers where they didn't know there were or that was available.

So we would allow them to meet at our location, if necessary, if they needed a place to meet, we would give them a place to meet. A booth. A section of the ‑‑ of your waiting area. It was not difficult to find those avenues.

And the more we did it and built that relationship, the more it became a return relationship. If they needed our help out at the school with something, we were able to go out to the school and help with that. Or we were able to reinforce in the clinic what the school was saying.

When the school is saying, Hey, we think your child needs more, and when the parent comes in and sees the audiologist or speech pathologist and says, oh, the school says my child needs more, but I think it's fine, the audiologist, the speech pathologist, the people on the other side are armed to reinforce what the school is saying.

So having that kind of co‑location, co‑model where we're working together for the same message and cause has been very, very crucial.

And, of course, eventually we ran into the collaborative and integrative model. Now we created those relationships. We created relationships with outside providers. We created relationships across county lines.

This is starting to get us to cross state lines and even ‑‑ so that we are helping our reach and helping these parents, these families is even greater.

But it starts by reaching out. You don't have to have a huge team. It's there. The possibilities are there. And once you get to it, the outcomes, we are seeing more and more outcomes that are positive., both on the early intervention side, and once we start seeing it in early intervention side, guess what... we start seeing it in the school‑age side. So it is possible.

As for today, it's easy to say all this ‑‑ again, I work for the university. They brought me on, even two and a half days a week, that's more than most people have.

The easy solutions are a one‑page worksheet or a one‑page resource guide for parents, or stuff in your area, things in your area.

The resources are out there. Develop a one‑page resource for schools. Early childhood centers, for having a child with hearing loss.

We had a child come in the other day recently implanted at the age of two. Her datalogging was 1.5 hours.

Why?

Because when the device disconnects at the preschool, the preschool is afraid to put it back on. And unfortunately in Miami we do not have a huge B2 program. So there is not a lot of birth to two preschools available, so this mother is dependent on early childhood care. And the provider is scared that when the magnet connects it hurts the child. So being able to give that school, that parent came to us and said, I don't know what to do. We handed a one‑page resource to that school to say, it's okay. We pointed them in the directions of videos and things that supported that.

We do the same thing with sign language resources.

If there's something that they need and they don't have, we try to find a worksheet or something that we can hand to them to give them the resources that they might need.

Develop a mentor program. There's a lot of talk about a mentor program. Both for families and for children. Of course, we want to do this at an older age and school age, but even having that for the families. Having young families ‑‑ this is a beautiful conference to see families here with their children connecting with other adults, professionals, those types of things that are available.

Create a mentor program. Even in the smallest practices, this can be done.

Reach out to your local school audiologist. A lot of the connections we have are because we're connected with the school audiologist. A lot of the information that we find out about children and our ability to help comes from either the itinerant teachers or the school audiologists.

Provide professional development for teachers. So one of the things that I am able to do as a part of University of Miami now is in child care centers or places where they don't have teachers of the deaf, I am able to go out and provide one to two hours of professional development about hearing loss and what that looks like in a classroom. Before I came on board with University of Miami, guess what...our audiologists did it, our speech pathologists did it, at least the child care center will have some knowledge how to move forward with a child with hearing loss.

It's a daunting task, but it definitely can be done, and, of course, we put a few other things up that we have done prior to having this great multidisciplinary team.

A few of our favorites... we also have a collaborative forum where we go to parents and talk with parents, something they can take with them. Or if we talk with a school, we have a collaborative form that we can give to parents and say, this is what is going on, this is what is said, just kind of brings the conversation all together between the people talking at the table.

We also rely on our industry partners. We challenge our industry partners to help us every day. When we want to have a parent night, we challenge our industry partners to support it. We're providing something for them, provide something for us.

And they do. We've had Resound and Phonak and Cochlear America, Med‑EL, all have stepped up and provided. They provided food for family nights. They provided time, resources and things like that.

All we had to do was ask. Sometimes that's the hardest part, the asking. But it's out there. And they will do it. Just push a little.

And, of course, we always arm parents with our favorite resources. And for those of you that don't know, there's also a great book out there now that is supporting this idea. Particularly in early intervention. It's not a book in the traditional sense that you're going to read from beginning to end. It's a series of articles and studies that talk about the importance of early intervention and connection. There are many articles that discuss the relationships between the medical profession and the educational setting.

And time after time, every time that connection is made, it does nothing but ensure positive outcomes.

So is bridging the gap wishful thinking?

I guess. But if you don't dream big, the dream can never happen. So we challenge you. You can connect.

How many audiologists are in the room?

Speech and language pathologists?

Teachers?

This is a powerful message right here. Imagine if we were all talking to each other. Whether we're talking about a child that is birth to three, three to five, six to ten... it doesn't matter.

One of our biggest successes right now isn't happening in early intervention per se. We've kind of ‑‑ we're sealing up those gaps. It's been in the impact of mental health with deaf and hard of hearing students 11 to 18 years old. Currently right now our clinic as protocol gives a mental health screener to deaf and hard of hearing students between the ages of 12 and 18. It's a simple screener, an online screener, but it's something that ‑‑ one of the things we know is these children suffer a lot in silence. They don't say what is going on. They're the onlies in schools. They don't talk about depression or anxiety or those types of things because they think nobody will understand. So we've been doing that.

So when you notice the need, there is potential out there to help, whether ‑‑ again, whether it's early or later. It's always there. You just have to kind of bridge that gap.

It's hard work, but I can tell you right now it's worth it. We're building our teams slowly but surely.

Educate the future professionals. If you're an audiologist, it's good to say, this is important to those audiologist students, if you're an educator, hey, influence those teaching students. We can do it. Same with speech and language pathologists. Don't make assumptions. Just don't assume that I'm with the school system and I don't want to talk to you. I certainly do. Relationships are crucial. Think outside the box. Always a good challenge to people.

Beyond the technology, this isn't necessarily about amplification. It's about intervention and supports.

And collaboration is crucial. There's nothing more to be said than that is the most crucial component of being successful with deaf and hard of hearing students.

And dynamic is ever‑changing, an ever‑changing journey.

Thank you very much. I'll take any questions.

>> AUDIENCE MEMBER: Do you have any resources or anything that you guys use, like a model for professional development for teachers or staff?

>> ALEXANDRIA MESTRES: Sure, I'm happy to share that with you. I will more than happily share my card or resource with you. I'll be happy to share with you what the professional development looks like. And it is literally an hour presentation.

Any other questions?

Yes, ma'am?

>> AUDIENCE MEMBER: [ off microphone ]... did the University of Alabama develop the online screening for teens?

>> ALEXANDRIA MESTRES: We did not develop it. It was a resource our psychologist was aware of and we used it there. It's a fairly simple resource to use. Now our audiologists administer the screening and it can be done on an iPad. I'm happy to share that resource with you.

All right. Well, thank you very much. I hope you enjoy the cold weather and your day here at EHDI.

Thank you so much!

[Applause]