>> Good morning, welcome. I'm going to go ahead and start because I run run through this 30 minutes like nobody's business. It goes a lot faster than you think. Well, I said that and let me make sure -- okay, it is good to move. My name is Alexadria Mestres, my mother prefers Alexandria but everybody knows me as Alex, and I am a deaf and hard of hearing specialist at the University of Miami, and I am a deaf and hard of hearing TOD or specialist that sees kids across the state of Florida in virtual education. That was a whole different talk a different day but for the University of Miami, my role in the clinic is -- this is a clinic that supports kids with hearing aids, bahas and cochlear implants. We also support listen and spoken language as well as ASL and my role is to help families understand how to navigate the educational system. I can advocate for them, I can help them, I can do trainings and I do community outreach as well on this.

My partner in this presentation who unfortunately is not here because of a family plj is Julie Gardner, and she is the educational specialist doing the same kind of thing at Kennedy Krieger Institute at John Hopkins in Maryland, in Baltimore, Maryland. She helps children with brain injury, concussion, chronic pain, and COVID-19 rehabilitation. So she really is in an area where they focus on brain development. Now, I just -- quick question, who do I have in the room, TODs or EIs? SLPs? Parents? Awesome!

I love when the parents are in the room. So complexities in deaf and hard of hearing education. In my other talk, I talk about the dichotomies, right? But what people don't realize is hearing loss is a complexed issue, right? It's a lot of different things going on. But a bigger layer to our onion sometimes is what we seem to refer to as deaf+, right? So deaf+, some people are saying DWD now, deaf with disabilities. Depends on where you are, and this is sort of just where we're really, really identifying this as sort of new. But just so we're clear what I mean, I'm talking about any person who is deaf or hard of hearing that has another mental, physical, emotional, educational or social impact from another disorder, another illness, another set of factors. It's not necessarily always related to their hearing loss. So how many children do you actually think that impacts? Anybody have a guess? Guess? I'll take a guess. It's interactive, it's okay.

>> 40%.

>> 40%? The mom? 40%. Here's the challenge with what we're talking about is that research is sort of inconclusive. If you read research on this, they'll talk about anywhere from 25 to 50% of children having another disability with their hearing loss. So what is it? Part of the problem is the way we're looking at it. How are we looking at it? Are we looking at it from a mobility standpoint, are we looking at it from a brain standpoint. What are we doing to look at and sort of count it up? How do we count those beans, so to speak? And that's become difficult. That's why there's sort of this incon cluesivity about it, we're not really sure. But it does include what we're talking about is visual impairment or DeafBlindness, developmental or cognitive or intellectual delays, orthopedic and physical impairments, specific learning disabilities, autism spectrum disorder, syndrome-related issues, emotional and behavior issues and of course there's this very minimal population of brain injury kids. Some of this, we already know about. We're getting better at working with the kids that have hearing loss and autism. We're getting better at testing them, identifying their needs. And for children that are dual sensory impaired and have a visual component, we're getting a lot better at that. The resources are building. I just spoke with a gentleman earlier today from the DeafBlind and they have this whole parent group. Where we're really struggles is syndrome-related issues., emotion nand and behavioral issues and other behavioral impairments, whatever that seems to mean, however we qualify that. So what do we do? When we look at these kids, we go, okay, we're going to work on their hearing loss and maybe possibly simultaneously, we're going to work on these other needs. Maybe hopefully if I am the person that's able do that, or if I understand what that other need is, and that's where the challenge is. Because it causes problems with placement. It's not easy to place these kids, know what their trajectory is, understand where they're headed. It's hard to find qualified personnel. There are always delays in diagnostic -- diagnostic delays and intervention, appropriate measures of intervention, service coordination for kids that are deaf+ is extremely difficult. Identification and eligibility, whether it's early intervention identification or identification to go school age can be very difficult. And communication. Communication with families, understanding communication between professionals and that type of thing. What happens for those of us professionals that are working with these kids is we sort of face serious obstacles in helping these kids. We really do. Eligibility, placement, procedures. It's all sort of what do we do? We're sort of kind of always putting our finger in the dike, in the dam and trying to stop the water from flowing.

So what's the answer? A lot of people agree, there's a couple of studies, we always have to talk about the research, right? Is that it's imperative for people to work together. I don't think that's anything that is ground-breaking. We know that. But, what we are talking about goes beyond working together. It goes beyond working in our silo of, well, I'm a deaf and hard of hearing person so I can work with a speech pathologist, but I don't think about working with the cognitive specialist, those types of things. That's where we need to look at this approach. We talk about interdisciplinary. Interdisciplinary is something we're doing in this little circle. Transdisciplinary is involving multiple circles. And all three studies show that that's what we need and that's what's going to be effective in helping these children that are deaf+. It serves to reason that I want to go get the best expert to help me understand the other issues going on. So that's where it starts. But I've got to imagine everybody is sitting in this room, parents, speech pathologists, teacher of the deaf and hard of hearing, early interventionists. We're practical people, right? So we want to know that it can work and how it works. So let me introduce you to Nina.

Nina is a 5-year-old girl. Early intervention was done from almost age -- I would say about age 2. She had early intervention. She has a bilateral sensorineural profound hearing loss. Progressive, as near as we can figure, the hearing loss started between about a year and a half, maybe two years old is when the parents first started reporting seeing declines in her speech and her access to sound and things like that. She received her first C.I. at age 3. When in school, she does have hearing assistive technology. That means she is using her cochlear implant, the teachers all have F.M. and that type of thing, and she's had consistent AVT therapy since the time of implementation, parents were very diligent, brought her to therapy every week and mapping has been completed regularly. She is in a self-contained auditory oral kindergarten class with six other children. That's it, six. Great number, right? I want six kids in a class. And her IEP eligibility and her IFSP was a little bit more fluid because the hearing loss was progressive so they were still trying to get that, but once we got her at that transition to her IEP, she was labeled DHH and language-impaired. Genetic testing was done and showed the presence of connexin 26 but no other genetic anomalies. That's important and if you guys didn't hear from the genetics or hear the Decibel presentation I encourage you to do that because that genetics piece is becoming more and more important.

So, what happened, why am I involved in this? What happened was the school, which is attached to the University of Miami, did start to talk about some atypical behaviors that the student had, including random laughing, odd outbursts, anxiety, some aggression, and not only was it reported at the school level, it was also reported in our AVT office. So the AVT was seeing the same things the school saw. So it wasn't a group thing, it wasn't that she was in a group of six kids and it was a response to other children. It was happening consistently in every environment. They started to notice some progress gaps. So some of the kindergarten skills, she was getting some, but she wasn't getting others. The interesting part of the case was she was getting higher level skills and missing the lower level skill, so kind of odd, gives you pause, gives you pause to that. And then they were noticing that her retention, no matter how consistent and how much repetition she received, her retention was inconsistent.

She had social issues. She really couldn't find a way to interact appropriately with her peers, and none of it was resolved with redirection. And there was none of it resolved with coaching, so now what do we do? We can't resolve this with coaching as a school, what do we do? Those are our go-to toolbox, right? Redirection, coaching. What do you do when that's not working? And the school noted significant regression of behavior at times. They would think things were getting better and all of a sudden they regress.

The school attempted to address the behaviors through intervention. So they did everything they could. They developed an intervention plan, they did a functional assessment of her behavior, which was -- it looked like you know how you chart a graph and you think it's going to be one way? It was literally like somebody threw up the dots and it was scattered, like a scatter plot. So what do we do?

So the questions that I challenged the school to ask yourself before we even consider that this is an issue above and beyond her hearing loss, and this is a great resource, it's sort of a map for opening that discussion on whether or not a child has something else going on, the first question we asked is, is this a change in her hearing loss? Has her hearing changed any? Is that something we're missing in this piece? Then we say, well, now is this intervention appropriate to the child's strengths and needs? What are we doing? Are we making sure we're using her strength to leverage what she needs in this environment, or does she need a different environment? Given that this is specifically designed for deaf and hard of hearing children. And has the family, and that's another big thing is, has the family been able to access appropriate interventions? Is this happening because six hours a day, it's great in school and we're able to do some things in school, but then we go home for the remainder of the day and nothing is happening at home, and were the parents able to access those interventions that would be helpful to maintaining the consistency between school and home. And these parents, I'll be honest, had been very good at that.

And then the other question is, now we start to ask ourselves, does this child have any other risk factors that would impact language or cognitive acquisition? Why do we have such an issue with retention? Well, it's not hearing loss. The interventions were appropriate for that program, for that school, they felt like they had a handle on who she is because at some point, she would do well. The family, like I said, had sought out appropriate intervention. The cochlear implant and a hearing aid -- sorry, I meant to mention she's bimodal, they went to the audiologist regularly. So we were taking all those little things off the table.

Now the question began, is there another impact? So they come to the clinic and what do we do? We're a full multi-disciplinary team, we're an interdisciplinary team, we have an educator, that's me, we have psychologists and we have audiologists. That's important. I'm an educator of deaf and hard of hearing students, of deaf and hard of hearing children. Our psychologist specializes in working specifically with the deaf and hard of hearing population. Of course audiologists, well, we all know what they do.

So we were asked to do a psychoeducational evaluation. Seems to be the next logical step in all of this. Our findings were, her full scale IQ was in sort of this low average range, along with a non-verbal IQ that was sort of in this low average range. So there shouldn't be -- why are we seeing these retention problems? Because even the children with low average are still able to work, and what was interesting is that her non-verbal and her verbal IQ or her standard IQ were very similar. So it wasn't an auditory access issue. She had access. And she was doing stuff with her access.

The so that was off the table for us. Her cognitive profile, though, showed us there were issues with working memory. Some issues with inhibition and self-monitoring as well as meta cognitive problem solving. So that's why we were seeing the gap skills. She wasn't able to cross that line and say if we said 2 plus 2 is 4 and I said 2 apples plus 2 apples is 4 apples, she wasn't able to cross that line when we added the apples. However, if I just talked about the apples or I just talked about the addition, she was able to do that. So that sort of is where her meta cognition was impaired with the problem solving.

Socially, she was found to have issues understanding and maintaining appropriate social constructs. So if you made a sad face, she didn't quite -- she knew you were sad, but it was almost like she was ambivalent to it. Yeah, sad, but whatever. She understood it but it was just her level of interaction and being able to understand how to socially construct a situation or read that situation based on those emotions and socially. And her adaptive scores showed concerns in communication and socialization. They did, I know everybody is thinking autism!

But they did rule that out. Because there were -- there was times where she was able to maintain that social construct. But it was very, very gappy. So it was very random. Then the behavior inventories showed us there were concerns in the area of atypicality, withdrawal, social skills, attention skills and risk for social disorders.

The overall diagnosis was unspecified neurological disorder. Tell me how you develop an education plan for a child that has hearing loss and an unspecified neurological disorder. Anybody got any ideas? Because you're challenged because you say, okay, I have an educator that specializes in working with deaf and hard of hearing kids. I have a psychologist that specializes in the same, and we have audiologists. So we can answer a lot of those questions on the slide before, but how do we move forward to create a plan that works for this student? Or this child?

Well, here enters in the other clinic. This is the Kennedy Krieger Institute. They do a lot with the brain. They focus on the brain. They have an educator at Kennedy Krieger Institute that specializes in brain. Brain function. Brain dysfunction. Brain atypicality. And they have a group of neuropsychologists that understand all this. So what did we do? That's the other -- that's my friend Julie, and I contacted her and say, I have this patient, and I don't know what to do because I don't understand what a unspecified neurological disorder is, so I am not sure how to support this child beyond her hearing loss. Well, they requested the patient's IEPs, evaluations and medical history. And their findings, something we weren't looking for and we -- we didn't miss it, we knew it was there, but we didn't understand the impact, was that at approximately the age of 2, it was reported that she had lesions on the brain in a variety of different areas.

In talking to Kennedy Krieger, what I learned was that the placement of those lesions had direct impact on her executive functioning, there's the working memory, social development and functioning, and problem-solving. Okay. So now we can talk.

The geneticist yesterday that spoke, if you went to the lunch and learn, talked about symptoms, diagnosis and treatment. And he said, you know, sometimes with kids, we have this symptom of hearing loss, and then we go right to treatment and we forget what the diagnosis is. And I thought that was really profound because he said that's why they're supporting genetic testing, but even in this case, and when we deal with the deaf+ kids, this is crucial. This is why this idea of transdisciplinary, outside of your organization, outside of your group, interdisciplinary is fantastic. Transdisciplinary is what's going to support these kids. That allowed us to see the big picture. Not just her hearing loss picture. The other picture. What is the other part of this? And that allowed us to sort of open the door to how we could help her and support her both academically and with the interventions that were going on at home.

So we created a plan. And we made changes to our IEP. The first change we made was eligibility. Now, we all have, in life, hills we'll die on. This is the hill that I will die on. Eligibility sets the tone in an IEP, does it not? And Wright's law will tell you that 85% of the cases that go to due process go to due process because of eligibility issues. When they root down to it, it's an eligibility issue. So it's really important that when these children are deaf+, that we're not just treating it, that we're finding that diagnosis, because that makes a difference in the treatment, and I think that's been the problem -- or that's been not the problem but the challenge. It's hard. We add another health impairment so we made sure when somebody looked at that IEP, they didn't look at it through the lens of just her hearing loss. We need them to look at it in terms of her neurodiversity. We did training for the staff, John Hopkins helped us with this or Kennedy Krieger, the educator helped us with this, we did training with the staff on her neurodiversity profile, which made an increased difference in school. We were able to academically intervene and justify an academic paraprofessional. I know that's in the bubble world. That's a hard thing to get, but we were able to make that justification because of the information that we had. We were able to put in behavioral supports, which were supported also by the academic intervener paraprofessional including positive feedback, we were able to better model for her in a way she understood the adult and pure behavioral interaction and social interaction, so it really made a difference, understanding where those lesions on the brain were creating the gaps in her development helped us set that plan and make the intervention more appropriate, more directive to her, and not just this general let's throw something up on the wall and hope it sticks and keep trying and trying and trying. We were able to really target what we needed. The cognitive supports included explicit and systematic instruction. Now we do that in the DHH world. We do. But this needed a little bit of a different angle. And then real life context for problems. And yes, some of that mirrors what we do in the hearing loss classroom. But it was, again, from a different perspective. As far as it wasn't as visual as it was hands-on and tactile. She needed that physical hands on touch it, feel it, do it kind of thing.

We were also able to limit instruction and processing for cognitive load. That's something we didn't realize, is cognitive load was really important to her and how cognitive load -- how much cognitive load she had was very crucial. So having those teachers be able to have that timing for knowing when that cognitive capacity just became too much for her. Scaffoldings, I do, you do, we do kind of things. Predictive tasks, visual supports and independent choices. But it had to be limited in such a way that she could understand. And front-loaded learning and vocabulary in small increments and nare rate knowledge and activities.

So these were all things that sort of opened the way that we were able to strategically provide assistance for Nina in the classroom. And what we learned was, it had to be a highly structured classroom environment. Even above and beyond what we may see in a DHH setting. And cognitive-based behavioral therapy was also something that was recommended to the parents. This is not something -- even though we did a functional assessment of behavior, she had a BPI, all these things, this was never something I thought to recommend to the parents. So having that neural profile or that profile allowed us to sort of build this plan to create the IEP that is now benefiting this child and she's actually making gains. Whereas before, our gains were random, and I wouldn't say she was making reasonable progress. That was the key to our success, looking at that neurological disorder we didn't know anything about and this hearing loss and sort of coming together on this old Venn diagram, everybody remember the Venn diagram? Finding out where we met in the middle, what things could we say that were impacted by both, but what things were very specifically impacted by that, by the neurology or the hearing loss? So we did a comprehensive file review including the medical records. Sometimes we forget about those medical records in education, how important that is. If we're not talking to audiologists and the neurologists, we're not talking to those people, we forget to look at those medical records.

And then a big key was understanding, for me and our team to understand those lesions on the brain and where they were and what that impacted on the brain. And as soon as it was said to our psychologists, our psychologist said, oh, yes, absolutely. Understood they had to understand the impact of hearing loss. Because they're like this and this but oh, that's sort of hearing loss-related. So we really did sort of view these intersecting points between the neurological disorder and the hearing loss to come up with a plan.

Moving forward, because this was successful and we thought, wow, this is great, this transdisciplinary, we brought in another circle of knowledge, because we did that moving forward, we've been able to consult on other cases. We had William, a 4-year-old boy with CMV who had limited functioning on the right side. He had bilateral profound hearing loss and was implanted at age 1. He was in an auditory/oral classroom with challenges in pre-math, motor skills and pre-writing. He was hemi-negligent on left side because the right side of the brain is what was infected. My favorite part of this whole situation was the OT/PT told me he hemi-negligence and his vestibular issues were tied to the fact that he had a cochlear implant. I said wow, I've been in this a long time, I've never heard that before. What we did was we added other health impaired to the IEP, we equated OT/PT, we did a cognitive profile with BDI and LAP-D. Then we had training for staff on the impact of CMV on the brain. Does it always? No. But it can have impacts that go above and beyond our understanding. So collaboration is key.

This population is changing. That's why we don't have a handle on whether it's 25%, 40%, 50%, because this is a changing story. We need to work across disciplines. Work together to develop more comprehensive evaluation measures and clarify current measures. That's a problem -- I don't know what state you guys are in, but in my state, if a child is deaf/hard of hearing, we immediately go to a non-verbal IQ. But sometimes what we need are some of the tests that are in that standard IQ to determine things. So being able to work together to make sure that we're using the appropriate measures for the appropriate issues and to give us a bigger picture is extremely important.

There are resources out there. Here's a list of them. I did make sure that our presentation is online, so you're welcome to go and grab any of these from the presentation. And with that being said, I'll take any questions. Yes, ma'am.

[applause]

>> inaudible question.

>> It did not. That's a work in progress. That is probably -- just for the captioner, she asked me how that collaborative piece got covered financially. That's a big issue for any institution, right? We're working on that. Because we didn't ask John Hopkins to diagnose this child. They were just asked to look at a set of resources, and it comes from -- in this particular case, it came colleague to colleague. But sometimes that's how it starts, right? We find a colleague that knows something that we don't know, and we share that information. They were willing to share at this point they were willing to come with us and just sort of evaluate the information and part of my job as the educator at University of Miami is I get to do outreach on hearing loss. Great!

Well, thankfully, for her part of her job at Kennedy Krieger Institute is that she gets to do outreach on brain -- she does brain injury specifically, but anything cognitive, she can do outreach on. So there was sort of this -- what do I want to say -- professional courtesy that was handed. Is that going forward going to be the challenge? Yes, that's always going to be the challenge. But if we don't start the conversation, it's never going to happen. Let start the conversation and then we'll let the people that are above our pay grades figure out who is going to pay for it.

Now, if it had gone further and we felt she would have been a benefit to see the parents and see them over there, then they would have had to work that out through insurance.

I will tell you that just like I am and she is, we like to call ourselves the courtesy services at these institutes. We recognize, I recognize that the University of Miami, having an educator on staff, in their Children's Hearing Program, is unique. It's huge, I know. There's seven of us across the country. We talk regularly. NYE has it. NYU has one, USC has one. There's very few that have educators. I would say the same for the Kennedy Krieger Institute. Although because it's brain injury, they have a few more than we do, but they are also the courtesy service. So there's that.

Any other questions? I hope this helps a little bit. It can be done. Open the conversation. Guys, I hope you have a fantastic day.

[applause]