REALTIME FILE

EHDI ANNUAL MEETING

INTERNATIONAL A

NOT ONE WAY: SUPPORTING COMMUNICATION WITH CHILDREN

WHO USE AUDITION FOR RECEPTIVE LANGUAGE AND SIGN

(OR TECHNOLOGY) FOR EXPRESSIVE LANGUAGE

MONDAY, MARCH 4, 2019

3:35 P.M. CST

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>> DENISE DAVIS-PEDRIE: Hi! I'm Denise Davis-Pedrie and I'm copresenting with my dear friend Dinah.

>> DINAH BEAMS: I'm Dinah Beams, and Denise and I, our next slide tells us a little bit about who we are. We both have a lot of years of experience working with families with young deaf and hard of hearing children. We are both also on the board for Colorado board for Hands & Voices. And then I'm also here representing the Colorado State EHDI program. I'm part of our state EHDI team and represent intervention on that EHDI team.

>> DENISE DAVIS-PEDRIE: I think we want to start out by telling you our premise is we want kids to communicate. This is about those kids that we don't really care how they communicate or what options they use to communicate. Our goal is just to get them to communicate.

We are not getting paid a Diddly-darn. So we don't owe anybody.

We are going to do some wonderful quotes take we found inspirational in terms of communication.

>> DINAH BEAMS: So this first quote is from an international communication project. And I know that you can all read, but I'll read it out loud. "communication is at the heart of who we are as human beings. We connect and interact, exchange info and ideas all of which is made possible through communication."

So a lot of what we are going to be sharing today, that's kind of the premise under girding everything.

Our next quote is from an American actress. "there's a world of communication which is not dependent on words." And I think those of us in this field can definitely say yes, that is true. Those facial expressions, the way little ones move and everything that they can communicate by that.

This one about empowerment and participation come with the ability to experience the world and communicate. This is from every mood counts. We will talk a little bit later about every mood counts.

This last quote I put in here just because it is funny and it what happens a lot of times with my husband and I. The single biggest problem in communication is the illusion that it has taken place.

So I think that's another thing we want to all kind of be mindful of. We think we communicated something and perhaps it hasn't been communicated as clearly as we would like to think.

>> DENISE DAVIS-PEDRIE: So Lindsey was a 20-month-old that I was asked to come in and work with as her Colorado home intervention specialist. And she had been in early intervention since birth. She had one of those conditions where there's deletions and in additions on her chromosomes and it's long and complicated and so she had had a lot of intervention. She had every kind of specialist coming in working with her and then her hearing loss was identified. She then became deaf-blind and I was introduced to the family.

I came into the house. Lindsay was propped up between two pillows. I got down face-to-face and I said to her, can I sit next to you? Dad said: She can't hear or see you. And I said I did read her file. I said but I was just getting close to her and introducing myself. So I sat down next to her. I said to the family, you know, tell me your story.

As I was sitting there I was tapping Lindsay's leg and I was doing that throughout the time we were talking. They were talking about how they had feeding specialists and PTs and I asked them: Tell me how Lindsay communicates. They said she doesn't, she has no communication at all. She is very passive. She doesn't cry. She doesn't protest and I'm continuing to tap her.

And I said well, tell me, you know, what she does if you go to pick her up.

Nothing. You know, they were ... and I stopped tapper her. Pretty soon I feel this little hand reach out and tap me. So we are continuing to talk, and I tap her and I tap her a couple times and stop and she starts tapping me a couple times. And then I'm tapping her and she's tapping me and the parents say she has no communication.

I said to her, she's communicating with me right now. Look at our hands. And they looked down and they were just fascinated. I said I introduced myself and I got her to tap. And they said well, is she reaching out just to find you? I said oh, she did originally. When I stopped she kind of reached out. But no, now she knows the game. My turn, your turn, my turn, your turn.

I said she has shown me that she can communicate and she has a right to have you as your family with guidance see if we can change that communication to become more formal and give her the right to have power in her life.

And so that talks about the value of communication.

Early communication, they said she didn't have any. Still to this day, she is now five. She is the most delightful little girl I think part of her genetic composition is that she doesn't react to pain. She has a very flat affect. And so those early communication intents like protesting, you know, wanting an object, social kinds of interaction, were very hard for her to move through. But we in terms of Dinah and I feel in all our careers we never met a child that didn't, that we couldn't figure out some way to get they will to communicate.

Sign language is often in our careers was often associated with degree of hearing loss. And looked at as a type of communication. So we want you guys to think about the fact that sign language, gestures, coactive sign regardless of what the hearing loss is, that in the spectrum of communication it certainly is something to think about. And as early interventionists, I think we are more open-minded to that than some of the school-age people. That's some of the barriers we run into when we try to help a family transition into school-age services.

Are you guys aware of what I mean by coactive sign? Hand under hand movement?

(Laughter.)

>> DENISE DAVIS-PEDRIE: Some of the conditions we've run across that are interesting kids in terms of facilitating communication development are up here. Certainly not the whole list. One of them we have up here is Lennox Gestaut. That's a syndrome that hearing loss is sometimes associated with, but it is characteristic of nonstop seizures. So when medical marijuana was passed in the State of Colorado, we had quite a few families move to Colorado for the CBD oil. Charlotte's oil was a derivative of marijuana that has been successful in stopping or reducing seizures for those kids.

And here is one of them. Here is Chloe. So I have my hands under hers. She is holding on to my hands. And I think we are singing the wheels on the bus. But I'm helping her do the movements by having her hold on to my hands.

This is some information from the research that was done at Gallaudet in terms of our kids with hearing issues and other kinds of conditions. So 40 to 50 percent at that time, children with hearing issues had other kinds of disabilities.

2010, it hasn't changed much. They've just been able to identify what those are.

That's a big chunk of the kids that we work with.

That's Braden; he has Down's syndrome. He has auditory neuropathy. Did not tolerate hearing aids. He's a little older than that now. I may talk about him in the past sense, but he's still with us.

Didn't tolerate hearing aids but had some good auditory access. So we started looking at different kinds of ways to give him a way to communicate because his behavior started to get quite extensive out of frustration at not being able to communicate.

So by the time he was 3 he had about 200 signs that he used very functionally. However, he followed directions fairly accurately without any sign. So it was very difficult for other people, other providers as well as other professionals to understand why we were using sign with him when he was doing so well receptively.

In fact, when he went through an evaluation at children's hospital in the C clinic the speech and language pathologist signed with him appropriately. Because of his fabulous strong attitude, he did not sign back to her. And so her evaluation was that he had no formal communication. That he did well receptively but had no formal communication. As his early interventionist and SLP, I was sitting there like I was just aghast watching and the developmental pediatrician tapped her on the shoulder and said: He's reading that book.

He was in the corner and it's a little book where A was apple and he pointed to the B and turned the page and was doing this. And we'll talk about that, how a lot of these kids, it's difficult to determine, assess them because they are using a combination of communication.

>> DINAH BEAMS: I'm going to transition a little bit and share a little bit about the children with -- would you all prefer that I stand? I'm awfully short. With that help you? Okay.

So it isn't just this voice coming from somewhere. Even when I stand, it is probably just a voice coming from somewhere.

(Chuckles.)

>> DINAH BEAMS: But anyway, we have on our case loads, and I'm sure many of the rest of you do, a the look of children with a combination of Down's syndrome and hearing loss. Could be unilateral, could be bilateral, maybe very mild, but it is still impacting how they communicate and how they learn language.

So I wanted to share with you this very recent research that was published by one of the audiologists there at children's hospital, Colorado. And with the C clinic -- we are not advertising for the C center. We don't mean that, but they do nice work and we are privileged to work with them.

But with the C center they have an audiologist basically attached to that clinic. She sees those children. There's some other audiologists that see the kiddos as well. Emily really works with a lot of those children.

You can see with the research study that was recently published, published just about a year ago, of the 308 children that she looked at, 25 percent of them were identified with permanent hearing loss. These are children with Down's syndrome. Another 22 percent had transient hearing loss due to otitis media or other things going on. So you are talking about roughly half of the children they were seeing had hearing loss at one time or another that was impacting their language learning.

So that's why we thought that's such a large number of kids and they are on all of our case load that we should spend a bit of time talking about those children specifically and that particular diagnosis.

Pulled some recommendations from the American Academy of Pediatrics and also from the National Down's Syndrome Society special interest group specific to how often these children should have audiological assessments. That's something for all of us to be mindful of. If you as an interventionist are working with those children you may have the opportunity to encourage the parents to go back. Perhaps they haven't been there for awhile. It just helps if you know what the standards are for that particular population, when you think about audiological assessments.

I find a lot of times as an interventionist in the roam that that becomes one of my roles is to talk with the parent and say: When was the last tile you went in? Oh, that has been a little bit ago. Perhaps we need to go in again. Let's get that scheduled.

So just that little bit of encouragement so that the family knows that we are all on the team working together.

So I think that's really important to know.

When you look at language development and Down's syndrome, I also found this information to be very interesting. You are going to probably see this and go: Oh, yeah, that makes sense. Receptive language develops typically comes on so much stronger and faster than the expressive in terms of speech, okay? So these little kid dos are attaching meaning, attaching words, attaching concepts when they are ten, 12 months of age. That receptive piece is coming on really nicely but it is not uncommon for the first expressive to be more like two to three years. So there can be quite a large gap between the receptive and their expressive language.

Again, I think that's one reason why people have had so much success using sign expressively with this particular population. I'm going to -- so again when you talk, that previous slide, it's just some information again from on the National Down's Syndrome Society about the use of sign language with children with Down's syndrome at these very young ages addressing the rate of learning between the expressive and the receptive.

That's due to everything that is going on in their world. So a lot of my conversation with families is: How do we address both? I want to really be working on their receptive language and I want to keep fostering the learning there while I'm fostering the learning with their expressive language.

And so even though there can be quite a discrepancy between the two, what strategies am I going to put into place to do that?

So I wanted to share a little bit about Blake. This guy, unilateral mild hearing loss, okay? He was amplified. It was a struggle to keep it on. I'm sure some of you have been there. Been there, done that!

And mom knew why he needed to wear the amplification. His loss was very mild. And he did quite well receptively without the hearing aid. You know, just in all honesty. So it was difficult for her in the home to be terribly motivated to keep the hearing aid on. She would not mind me saying that.

But expressively this little guy really needed to sign. So what was my responsibility as an interventionist to support the family in both of these areas. So we were able to get a sign language instructor in there, now that the language has changed with what are billable services under Part C. So we were able to have a sign language instructor in there to work with the family on sign.

We were able to get the family connected to some community groups where the family could be exposed to sign in that way.

We had a speech therapist coming into the home as an interventionist as part of their intervention team who was a speech therapist who had experience working with little ones with Down's syndrome but also a lot of experience working with little ones with hearing loss. She did sign. She was able to support the family in that way.

So they had the sign instructor in the home and they had a speech therapist who was able to work on the vocal play and everything he needed to work on speech because that's still an ultimate goal of this family. But what can we do to support the sign and keep the sign coming in?

When he transitioned to preschool -- we're going to address this in just a few minutes. When he transitioned to preschool, you had the dilemma that you often have with these kiddoes. That is, where do they go? What is the appropriate program for them? And so I really had a lot of responsibility to help mom to have gotten the appropriate assessments. How do we advocate, made videotapes showing how well he communicated in the home that we could take to that child, find part V eval, all of those kind of things. He was placed in that particular district in a program at that point in time for children who were deaf and hard of hearing so that he could use his sign and could have that peer interaction, but it was more a sim com type approach. He also had auditory.

Mom's ultimate goal was for him to go to the private school that his siblings went to. He did not go there for kindergarten, but he did go for, but not preschool.

We want to talk to you about isolation. The families feel like they don't fit in any one world because the children are using one way of communication receptively but not expressively.

How do we as providers connect the families to other families? Open it is going to be through the Internet. We all know that. Through some of those groups.

It may be with something like Down's syndrome you obviously have larger groups that you can pull from and you can help the families get connected. Some of these children that we've worked with that have used both forms of communication have a little girl just last week I was working with. She fits in this category. Her deletion has just been identified. And her dad said they think she's one of two children in the world. Okay, women, you're not going to find a group if you are one of two in the world.

So these parents were really struggling with that. My responsibility is to try to get them connected with other families who have children with similar needs. Not the same diagnosis but similar needs who are communicating in the same way so that they can support each other.

>> DENISE DAVIS-PEDRIE: We will skip Mary's story, we're running out of lime.

In the next slide are assessments we have used. We believe that every child deserves to have some sort of measurement of their successes and so some of our standardized testings don't work as well with our kids because they don't show those small steps. You guys can look over these assessments. They are all referenced in the back of our presentation. Really the value of these assessments is what we want to share in that every child deserves to be assessed. It is in a polite.

Do these look familiar to you guys that work with multiply involved kids?

Talking about kids that don't fit into a box. This little one was a premie. She has microtia, cleft palate, late repair and right on target receptively. She is wearing her Baha. But totally unintelligible expressively. So we started using sign with her and she just absolutely took off.

When it was time to transition into preschool because she has a unilateral hearing loss, didn't qualify according to the box that the part B had kids move into because she didn't have a bilateral hearing loss.

And the program that they wanted her to go into did not offer sign. And the teacher did not know sign so could not acknowledge any of her expressive communication.

So it was really tough to help the school district understand that she didn't fit into the rationale that they were using for their programs. We were able to find a program that she did fit into.

Helping families figure out short-term goals to get to their long-term goals. When we ask parents: What is your dream? How do you want your child to communicate? Most often they say I want them to talk, but they looked up on the Internet. They've Googled the syndrome and they say but the syndrome says my child will never talk. And trying to help them figure out the small steps towards making their dreams come true.

I apologize again for how fast we are going with all of this. We wanted to touch a bit on this idea of transitioning to preschool. We know this is a tough one. One thing we found is that sometimes your smaller school districts or your more rural school districts are a little more open to thinking outside the box than maybe my large Metro school districts because they don't have as many boxes. I'm not saying always, but sometimes they are a little more willing to work with me around the needs of an individual child because, like I said, they don't have so many identified programs.

We sometimes struggle with our larger school districts that have more resources because they really want the child to fit into this classroom or this classroom. And that can be a real challenge. I have a little girl with Down's syndrome a number of years ago who had a minimal hearing loss. She had over 300 signs that she used expressively. I mean, we had assessed her. We knew how many signs this child had.

She could tell you whole stories. She was lovely in what she could do. Her whole family signed. Her grandparents signed. The school district said no, she can't go to a program with deaf and hard of hearing kids because her hearing loss is not sufficient for that. So we want to put her in another program and we'll teach her how to use pecks. I kept saying she has a form of communication that really works and you're wanting to take that away from her and teach her something new and learning can't take place without communication.

So it was a real struggle. We had to get an advocate in there. I purposefully went to -- sometimes we pull in Hands & Voices as advocates. Sometimes we go to one of the other parent agencies as an advocate because sometimes it seems maybe they would be better for this particular child needs. That's what I did this time. I went to Arc, actually, got one of their advocates in there.

I just really felt that they needed to hear the perspective from someone else instead of from me with this district to work through that situation.

I had another parent who came in and told me that after we observed the program said that teacher doesn't want my child in her class. I could not argue with this mom. I had been in there in that observation. That mom was right. That teacher did not want her little girl. It was heart breaking for that mom. I had to go to the school district and have a conversation about what other programs would fit for this child because that mom was not going to send that child to a classroom, send her three-year-old where she knew her little three-year-old was not wanted. We can all identify for that. We say it's wrong and heart breaking, but having to work with the mom through that. Doing the observations, talking to the district ahead of type. Talking to the district sometime and letting them know that you -- I'm getting the signal.

So letting them know that this child is coming their direction, maybe a conversation you need to have with the parents' permission too so they are prepared.

>> AUDIENCE: (Speaker away from microphone.)

>> DENISE DAVIS-PEDRIE: What happened with her? We were final a able to get her into a program for the deaf and hard of hearing. It was a struggle. It was a struggle. Thank you for asking.

>> DINAH BEAMS: This is.

>> AUDIENCE: This is more of a comment than a question. Thank you. This presentation was definitely reaffirming to see child centric language and approach.

One slide I noticed that there was discussion about how sign language is not just beneficial to deaf babies but also other babies. Babies who have Down's syndrome, for example. Really, any baby, right? Any child, regardless of any diagnosis or non-diagnosis. The more we are learning about language acquisition, sign language is one of those visual languages that gross motor can really pick up on. The fine motors of producing spoken language just take longer to develop. Bottom line, there's such an advantage of learning and supposing our younger generation to sign language. Also the positive outcomes of cognitive development and gosh, just that tapping system that you sat down, just engaging physically with that child! That stimulation cognitively, physically is just wonderful.

So I think regardless of a diagnosis, I'm curious about if there is any research about hearing babies just without a diagnosis who learn sign language versus hearing babies who do learn sign language. I would be interested to see the cognitive developments of that.

>> DINAH BEAMS: I know we are out of time. Particularly with children with Down's syndrome, the National Down's Syndrome Society does have some, they do have some information about that. You can Google that particularly with that population.

>> DENISE DAVIS-PEDRIE: There is definitely research to show that children that are exposed to sign communicate sooner. It is easier to sign than to co-articulate that and there are cognitive benefits to that as well. It does not stop the development of spoken language.

>> DINAH BEAMS: We probably should let y'all go. But if someone wants to talk to us, please, come on up!

(The session concluded at 4:08 p.m. CST.)

(CART captioner signing off.)

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