ROUGH EDITED COPY

EHDI - PARIS

ONE FINGER POINTS AT YOU AND THREE BACK AT ME:

CHANGING THE DYNAMIC FROM NEGATIVE TO POSITIVE

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>> Hello! My name is Dinah Beams, and my colleague Denise Davis‑Pedrie, and we are going to fly through this presentation. I think we thought we had about two hours and then we find out we have 25 minutes, so you can download the presentation, there are a number of resources at the end. Feel free to look at those. My other disclaimer before we fly through this is we have a plane to catch and we were also optimistic about how fast we could get to the airport, and now we're, like, oh, we really don't want to miss this flight. So there are no questions afterwards. You have our emails. We will respond. But I'm just being really honest. We're outta here.

So anyway...

Thank you for coming toward the end of the day when you are rapidly working on being brain‑dead. I hope you've got some pretzels or an ice cream that will keep you going a few more minutes.

We are going to... nobody is paying us to do anything. So I'll just say that.

We are... I'm part of the Colorado State EHDI Team. We're also both on the Board of Colorado Families for Hands & Voices. That's our associations right now. I'm going to turn this over to Denise. She's going to formally get the presentation started, and we're just going to kind of tag team it.

>> DENISE DAVIS-PEDRIE: So, Dinah and I have had experience mentoring, doing some coaching, observing, going into school districts, as well as birth to three program. And it's a very uncomfortable situation if the person hasn't asked for your help, but somebody else asked you to help them. It always puts people on the defensive. And so often when you maybe give some suggestions, the answer is, "Well, it's because parents aren't learning to sign." Or "It's because the audiologist is telling them something different from what the early intervention is, what I tell them."

Or "The teacher doesn't follow through on the audiology strategies I give them."

So this is an icon that shows the power of pointing, of blaming someone else, and to remember that when you point at someone else, three fingers are pointing back at you.

So think about you as providers, being introspective when you do an analysis of your sessions or your interactions with families and kids.

This kind of reinforces that same philosophy.

When you're not connecting with a family orchid, what can you do? What are the steps you can take to be introspective?

These principles hopefully are the undergrid to what we're going to talk about this afternoon. Because we really want to establish an effective partnership with families. We are fortunate in Colorado that we have the opportunity to spend a lot of time with our families, but that partnership doesn't always happen with time.

These are the questions and thoughts that Dinah and brainstormed, and I'm sure all of you have probably had these same situations in families, with the families that we work with.

I know we all want to desperately connect with our families. And so this is a way to really be mindful about what is happening if you're not making the progress that you think you should.

Here are some ideas that we're going to delve into stronger as we go through this next half hour.

>> DINAH BEAMS: And I have to stand up because I'm short, in case you hadn't noticed that I was short.

>> DENISE DAVIS-PEDRIE: This makes us equal.

>> DINAH BEAMS: That's right.

[ Laughter ]

>> DINAH BEAMS: So, we want to really help each of you and ourselves to analyze our approach. So, as Denise was sharing, we are going to be talking about some of the families that you lay awake at night thinking, what could I have done differently? You leave that family's house or the family leaves your clinic and you're thinking "That didn't go the way I wanted it to, what could I have changed, what is my responsibility about this and what can I do differently?"

So there are three main approaches. There's a professional‑centered approach. This may be in a clinic. It could be in a home. I have been in homes before when another therapist, an OT, PT, whomever, would arrive, scoop up the child, go to a bedroom, mom goes and does the laundry, the person finishes what they're doing and they leave.

So, it's still very much what the professional is doing, how they're doing it.

Then you have a family‑centered approach, which is what we talk about a lot in early intervention circles and we're going to delve into that more today because that's kind of undergirding everything we're talking about. Then you have a child‑centered approach, where you're really looking at letting that child kind of guide what you're doing.

So three distinct approaches.

Sometimes there may be a bit of a blend of these depending on the situation. Sometimes you may need to modify exactly what you're doing and how you're doing it. So we're going to talk about all of that today.

I wanted to look at the International Consensus Statement on Best Practices. Some of you are probably familiar with this document. It came out of the family‑centered early intervention conference in Austria with a group of professionals who came up with this.

So family‑centered early intervention, flexible, holistic, a process, works from the family strengths and the skills that they have.

I love this next piece where it says, while promoting joyful, playful communication.

So what we don't want to communicate to our parents is that this is drudgery, this is what they have to do, but we want it to be something joyful, something playful that they're doing all the time and they can embed into what they're doing.

And enjoyment of their parenting roles. And I think several of our keynotes have talked about that.

Family wellbeing. How do we support that with what we're doing in again, looking at that whole family structure.

Engagement. How do we encourage engagement, that family, the parents with the child? What are we looking at there?

And then self‑efficacy. So the family really feels good, feels strong about what they're doing.

This is my son and his wife and two of their three children. So I had to put that in there, of course. But anyway, we want to talk today about encouraging providers to have a family‑centered approach that is also child led. So working on the themes that the child enjoys, that motivate the child. We all learn better if we're motivated and we enjoy what we're doing.

So now I'm going to shift gears a little bit and pretty much the rest of the presentation, we're going to be talking about some of those barriers that we brainstorm, some of the places that we may not connect well with a family. And hopefully give you just two or three strategies. That's really all we have time for. In each of these areas.

Love this quote from Frederick Douglass. "It's easier to build strong children than repair broken men."

I just thought that really encompasses things and that's what we are trying to support, is strong children, self‑confident kiddos, kiddos who know their place in the world and can pursue that.

One in five children in the U.S. are living below the poverty level. So we want to talk just a little bit, briefly, about what that means. Because if it's one out of every five, you're working with those kids and families. You may or may not be thinking about the way poverty impacts that family.

Go ahead to the next slide.

>> DINAH BEAMS: So really wanted to look at these three areas of poverty. Income poverty, we're like, yeah, I get that one. Severe material hardship. The family that doesn't have enough money to make it really from paycheck to paycheck, okay?

So you may not realize at the beginning how they're struggling, but how are they going to pay their utilities, their food, medical care? And then adult health issues. A number of years ago I was working with a mom, single mom, a little boy who is Deaf‑Blind. Mom called me. She had just been diagnosed with cancer that was pretty advanced, had no family support. She called me because I was the person she had connected with, okay?

So, part of the reason her cancer was so advanced is she had not gotten to any medical care until it had gotten to that point. She had not had any kind of just routine medical care. And so what was my responsibility as an interventionist to support this mom, to support this family, to get some resources and some help for her.

So that was... it's kind of an example of how the adult health problems end up impacting that child, they impacted that little boy, because single mom and what was going to happen?

So what do we do? What are some strategies for that?

If you have an interventionist who has walked in those shoes, who really understands, who can empathize with that family, that's a great person to put in working with that family.

Being an active listener. With this mom I just mentioned, a lot of my role was to listen, and then to work with her to give her resources. I'm contacting the chemo center and infusion clinic and talking to them, okay, this mom, we need help this way, this way, this way. I'm helping to organize people to get meals to her, that kind of thing. Checking our judgment and misconceptions at the door. I think this is big one. We're standing at the front door getting ready to ring the doorbell, just taking those biases, those judgments, locking them away somewhere and walking into that house like that.

So that's a big one. You know, if that has not been your experience, you may not really understand how that poverty impacts a family.

78% of Americans live from paycheck to paycheck. So it may be the family is in the poverty level and it may be families living paycheck to paycheck. If you're living paycheck to paycheck, it doesn't take much to really stress you out. And so maybe the family is not following through with what you're asking them to because, as my son would say, my bandwidth is all used up. I just don't have any more bandwidth to do anything else. I think that's some of our families.

And sharing resources to address those life issues that that family is dealing with.

Then we were kind of brainstorming other stressors in life. Denise works a lot with our families who are in the military. So what is that like to support a family when there's deployment, when there's concerns about deployment, when both families ‑‑ when both mom and the dad are in the military. If you have questions about that, she's your go‑to person. She does that beautifully.

High job stress. I had a family I worked with a number of years ago, both parents were attorneys. And I walked into their house one evening, because they wanted me to come at night. And they had twins. One parent was sitting in one chair like this...

And one parent was sitting in the other chair like this...

And they both wanted to be there and be present, but they were in these really high stress jobs, and by 6:00 at night, they just didn't have anything else to give. So how do I work with that family, with that situation?

Job hours. You know, we have interventionists who perhaps go on a Saturday or something like that.

We were talking a bit about how adults learn. Most of us have been trying to work with children. We haven't been trained to work with adults. So what does that look like?

Adult learners are not the same as kid learners.

Although sometimes it is kind of interesting, there are some commonalities. But one example is, I was working with a dad who had both a Ph.D. and M. D. and I went in making an assumption that he would like information a certain way. And so I asked him, I said, "So I'll bring in all this research..."

And he just looked at me funny.

Or how would you prefer to get the information?

And he said, I look at research all day, just tell me what you think. I do not want to see any research.

So I made the leap because of his profession that he would just want me to come in with stacks of research. That was not what that dad wanted. So I would have really misjudged him. So asking those questions, how do you want information? How do you learn? And then honoring that.

>> DENISE DAVIS-PEDRIE: So know that it takes a long time to form a relationship with people and you may never ever know what is ‑‑ what they come with, what their experiences have been, what their life experiences are.

If any of you have attended some of the trauma discussions at EHDI this time, really understanding that trauma makes an impact in the brain even if memory is not there to remember the trauma. So to have empathy for all of our families, because you never know what they're going through. Whether they have not felt valued, whether they have had bad experiences in school. I remember one of the moms that I worked with that said, "Are you going to put my child on an IEP? I was on an IEP and I hated being on an IEP."

This was the second meeting with a two‑month‑old. I said, we'll talk about... there is some paperwork we have to fill out in order for you to get this help, but...

And so I already knew that she was ‑‑ had had a bad experience in school and was already worried about what was going to happen to her child.

You never quite know who is ‑‑ what the constellation of the family is.

We have all had situations where we're working maybe with mom and all of a sudden you hear a voice from the kitchen that sounds like grandma saying... that's not the way we do things... or dad that may say, I want you to come into the home when I'm here.

So being flexible in terms of understanding the hierarchy of a family constellation. Families with different cultures have different ways of accepting services. I know that some of my families that I worked with from central and South America had a really hard time with a family‑centered approach. I was the maestra and I knew what to do and they wanted me to tell them what to do. So really trying to meet those families where they are.

I met a family of a two‑week‑old, profound hearing loss. I walked in and Mom said... we want to learn ASL. We want to be part of the Deaf community. I've been online.

Or as my mother with dementia says... "Did you Giggle that information?"

Dad said, "I want a cochlear implant, when can we set up the surgery?"

Those were parents coming from two different places. They had both been online. They both had made decisions that worksheet kind of in opposition right a ‑‑ that were kind of in oppositions right away in terms of what their future goals were, and I was able to spend some time to get them to be a happy couple in their decision.

Sometimes parents are just not comfortable with what we ask them to do. I always try and say when I first meet a family, if there's anything I ask you to do that is an activity that you may not value, that may not be part of your daily routine, that is out of your scope of comfortable, please let me know.

It takes a long time for parents to let us know those kinds of things.

Remember I said to Dad... Mom was deployed in Afghanistan. Dad was with the baby. And I said, I want you to sing to your baby, hold her and sing and dance and stop. Be quiet. Hold her and sing and dance and be quiet.

We want her to start understanding sound off and on. After two weeks when I come back and say, how did this activity...

Oh, I didn't get to that. I finally said... you're not comfortable singing and dancing with your baby, are you? He's like, no.

Okay, so we'll do this whole stereo thing. We'll use your iPod instead.

But those are some of the things you need to really think about.

Again, not knowing what struggles parents have gone through, not knowing how they were parented, not knowing what their models were.

>> DINAH BEAMS: So I want to talk about being aware how common maternal depression is and how that may be impacting what that mother is able to do with you at that time. I did not ‑‑ I'm going to confess. I did not know much about this until my own daughter‑in‑law suffered from maternal depression, and I got really worried. So, you know, I knew the term, I had been to the workshops, but when it hit me that close to home, it was very different.

So if you don't know much about it, I would encourage you to learn. One out of nine women, more common if it's multiple births, NICU, poverty, health issues for the baby. The mom has a history of depression. I mean, how many of our families does that reach, what I just said?

We've got families that it was severe

The other thing I want to mention to you is fussy baby. It's real. These babies with reflux... again, worked with a lot of families. The mom would say, baby has reflux, the baby is on medication.

My daughter's first little one had reflux. My daughter gave me permission to share this.

My daughter is a speech therapist who works in EI. And she sent me a text, she said, mom, you can tell people this. For the first nine months she never slept more than three hours at a stretch.

She said, if I had had an EI provider at that point in time ‑‑ and this is a woman who is a speech therapist herself, she said, if I had had an EI provider at that point in time, they would have classified me as one of those moms who didn't care, who wasn't following through. And she said, it was just that mentally, I couldn't do it. I was too exhausted. I was holding it together. I wasn't remembering stuff.

So that was really powerful. and we are almost out of time. I told you with we weren't going to get through this. This was our halfway marker.

I told you we didn't make it.

[chuckles]

What I will tell you, the rest of them, as we went through all of these things where we have struggled with families. You're going to see a central theme. The theme is having a dialogue with the family and analyzing the "why."

So taking the time to ask the parents the questions, figure out why you are not connecting with that family. So you're going to see that as a theme, whether it's keeping the hearing aids on, whatever it happens to be, having that dialogue with that family, having created enough rapport that the family feels very, very comfortable being honest with you. And that takes some time to have been vulnerable enough that that family can be honest with you.

So we encourage you to delve into this. There are some resources, like I said, about fussy baby, maternal depression, child poverty. Some of those things, if you don't know much about it, I would encourage you to look at those more carefully. With that being said... we're outta of here, ladies?

>> Our Uber is three minutes away.

Wish us luck!