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2018 EHDI Annual Meeting

WHAT I WISH I KNEW THEN: TWO PERSPECTIVES

Topical Session 3

Capitol 2

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>> SHERRI FICKENSCHER: Can you hear me? Hold on, Caroline. So I'm wondering if the captioner can share phone numbers with Caroline directly. No, no, no don't do anything yet. We'd have to have you call a captioner directly.

[ I'm not on a telephone line. I'm on Skype ]

So this is what I'm going to do for now. This is what I'm going to do for now: Feel free to stand up and go to another conference. I'm not going to be offended at all. If you want to hang, you can hang, and maybe we'll present and maybe we won't. I don't know what else to tell you, other than that.

But since I was going to start, and they can caption me, I'm going to speak a little bit about reflective practices. I'm going to give you the outline of what we were hoping to do today, and I apologize. So we'll see.

Oh, here we go. Can she call the captioner ‑‑

[ Captioner has lost audio ]

Is there anyone here that needs captioning?

Or just since we have an interpreter...

We're okay?

All right.

[ Off Microphone ]

Okay, all right.

Thank you for being with us ‑‑

[ Captioner's audio is going in and out ]

I worked with Caroline I guess starting 9 years ago when her little guy Teddy was diagnosed with [ inaudible ] hearing loss. He's 9 years old now. He's a bilateral cochlear implant user and today we wanted to just kind of talk about our journey together, her perspective from a mom's point of view, and my perspective from the therapist's point of view, and what we learned from working together.

So I don't know if your slides were accessible, the presentations seems like EHDI's are accessible even though everybody did put them up. I put them up but they're personal reflections more than anything.

I'm just going to talk very briefly about reflective practice, and why we think that's so important in the work that we do.

Mainly, the thing about reflective practices is being able to hear our own stories, to be able to listen to our own stories and to be able to be a little kinder to ourselves than we tend to often be.

It's being able to practice self‑empathy. If we really want to be empathic people, we have to start with ourselves. We have to give ourselves some empathy, and that involves a lot of reflection, which isn't always really easy to do.

So it means we talk about things that we do well, actually more than the things that we need to work on. We talk about the things that we do well, and we build on those, and we don't do that enough, I don't think, in our society in general.

So the final thing about reflective practices is that we want to plan for change. Doesn't mean we're not doing a good job. It just means we're striving to do a better job all of the time. So the main thing that I have found, I'm sure all of you are the same way, is when you're working with families, the most important thing for you to do is to be able to build trust.

And for me, I've had to practice on the idea of being present in the moment. I'm a fairly impulsive person. My mind races a lot, so I'm not always in the moment, enjoying the moment, and listening. I'm the person that's thinking about what I want to say next, because I like to talk.

So that was a challenge for me, learning to be present.

Big thing for us, working with parents, is nobody really wants your sympathy, but they do want your empathy, and empathy is trying to understand the position that somebody else is in. A long time ago, somebody really wise said: Use the word "I imagine" instead of "I know."

"I know this must be difficult for you." Well, how could I really know? How could I really know? I'm not you. But saying something more along the lines "I imagine," "I'm imagining this is difficult for you," was a good learning point for me.

Being reliable. People trust you if you're reliable, if you do what you say you're going to do, not once every three or four times but every time, time and time again. You are where you say you're going to be when you say you're going to be. And that's really important to parents sometimes even more so than you bringing your knowledge set to them. They want to know that they with rely on you.

Boy, you have to admit when you don't know something. I think Caroline's probably heard me a lot of times say: I don't know. She's laughing.

I'm not sure about that, but usually I would know where to go to find that answer, right? I'm not sure, but I'm going to go look somewhere for that answer.

Holding confidence is a big thing, isn't it? If it's not my story to tell, and I don't have permission to tell the story, then it's not mine to tell. And if I tell you a story about somebody else, I'm guessing you're not going to trust me too much. So it's really important to hold confidences. We're going to go through today. The way we're going to work this, I have a slide. When the presentation gets up at some point, it is there, they're going to release it to everyone, simple little guideline, parent involvement ‑‑ [ inaudible ]. Okay, we're going to go through today the different phases. We're going to talk about diagnosis. We're going to talk about Early Intervention. We're going to talk about preschool. We're going to talk about transition to kindergarten and we're going to talk about today, all in the next however many minutes we have. So I'll turn this over to Caroline now, she'll introduce herself a little bit and she'll talk to you a little bit about what she was thinking or feeling when she received the diagnosis that her son had a severe to profound hearing loss.

So Caroline, it's all you.

[ Captioner does not have audio ]

Do you want to talk about what you wish you would have known then?

[ Comments by Caroline ]

Okay, so how did I feel about diagnosis? I got to walk in and meet Caroline and tiny little Teddy, 7 weeks old, with his hearing aids in. How did I feel?

Woo‑hoo! Right? Excited about this. This is a new family. This is a new chance to start over. I'm going to do better this time than I did last time. But we have to [ inaudible ].

I'm a fairly nice person. I think Caroline liked me eventually but [ inaudible ] when I walked in her house that day she was wishing I wasn't there.

[ Audio is going in and out ]

Kind of, yeah. She's wishing like, really? Now somebody's gotta come to my house and she's going to direct my life and all of those things? So I think the diagnosis for us as professionals is so different than the diagnosis for the parents and we really need be pretty aware of that. And then we need to think about: What's the message? What's my message that I want to send, you know?

My message is one of hope. No matter what communication option you've chosen, Caroline chose listening and spoken language for her son. But whether or not that's the communication option, hope is the message that we all should be sending to families. What do I wish I knew then? There's a great resource and if you don't know it ‑‑ I didn't know it at the time ‑‑ called Zero to Three. If you don't know it I would really suggest that you figure it out and dive into it. Tremendous resources there [ inaudible ] Early Childhood development.

The final thing for me about diagnosis time is the Director of the school where I work doesn't like the word "help." She's always saying: I don't like when you say "help." I'm like: Okay, Judy.

We don't need to help. Help is like: Oh, they need your help. Oh, no, we need to coach. We need to coach and we need to guide. And so I think I knew that back then, but I think I know it a lot more now.

So we're going to move right into Early Intervention, and this is when the work between the Linzes and I really started to beef up. So Caroline, why don't you talk about your feelings during the Early Intervention time.

[ Comments by Caroline ]

>> SHERRI FICKENSCHER: What I wish I knew then was what the real meaning of "non‑judgment" was. This family was a terrific family to work with. Not only was mom at most sessions, but dad was at most sessions, and they rearranged their schedule, and I'm not sealing you out here Caroline but [ inaudible ] late for things, but never for our sessions.

They'd go what, really? No, they were at every session. They were there, and they put the time in. But, boy, were they busy. They were so busy. Sometimes I went into their house and I felt like I was sucked into this tornado of just busyness.

And I think when I look back now, I wonder if that was a little bit judgmental of me, you know? I think I wasn't fully understanding that they didn't need to fit into my world of what I thought it was supposed to look like. My role was to insert myself into their life, and to teach them about auditory living, and not to really change the way that they wanted their family to be, or the way that they wanted to live.

So I think I'm getting a little bit better about that right now. I think what I really value about working with Caroline and Brian is that they were really honest with me so there were weeks when we were working on something and I'd go back and I'd say, so how did that go? And they'd be like: Yeah, yeah, we didn't [ inaudible ]. They didn't get to it. But they told me. They were really honest with me and that was the good place for me to be in because I think that continued our [ inaudible ] about trusting them.

[ No audio ]

Okay, since we still have the stage, we're moving on to preschool. Teddy is growing fast.

He remains at our school. I work for Clarke Schools for Hearing and Speech. And he spent his preschool years with us. He stayed in preschool so once he turned 3 in Pennsylvania, I no longer worked with the family in the home. But Teddy was in our preschool, and at this point I was one of the administrators of the preschool so of course I kind of kept my fingers in it a little bit with Teddy's progress and rate of progress.

So you want to talk about the preschool years, Caroline?

[ Comments by Caroline ]

I'm going to make one brief comment because we have about 8 minutes left. My one brief comment is that transitions are hard for big people, too. You know? Hard to let go. And I guess what I wish I knew then, and I would caution all of us, anybody who's a professional in here, that some people [ inaudible ] you send a message to the parents they can't move on from you, and even though Caroline really had great relationships with all the teachers that she worked with, you really want to encourage them to kind of move on, to not, like, oh, they gotta come back to you all the time. They have to trust other professionals.

So Caroline, we're going to go into the transition to kindergarten, and I think for time's sake if you want to do transition to kindergarten and then kind of give us a little update on Teddy today, and then we have a really short little video of Teddo today.

[ Comments by Caroline ]

So what's Teddy up to now? I'll show a little video at the end. So why don't you just explain where Teddy is now at school, what [ inaudible ], any other fears you still have looking to the future.

[ Comments by Caroline ]

I'm really excited about the future for Teddy. I just can't wait to see what's gonna happen next for this kid. I guess maybe it was like 8 months ago, we were somewhere together and I said, well, Ted, how's it going? He said I'm going to be famous. He said you can follow me if you want. I'm like I can follow you, okay.

He said give me your phone. What do I do? I give him my phone, and he uploads the Musical.ly app and he tells me I can follow him on Musical.ly. That's just Teddy in a nutshell, and the best part about it is, he's really, really happy.

If anybody has time afterwards, Caroline just sent me a little audio clip of him with his voice coach talking with a little British accent.

[ Off Microphone ]

Sorry, his singing [ inaudible ].

So we have a little video clip of Teddy, so let me just pull that up.

And I don't know if this will caption or not. Let me see if I can get this... Can everybody see that okay?

Okay.

Hopefully it will work. Sorry.

No sound. Hold on. We're having a lot of technical difficulties. Can you take your earbuds out for a minute? Let's see what happens. It's only a 40‑second clip. So we'll figure it out.

That's a good idea.

Sorry, I don't know if ‑‑ [ inaudible ].

I'm going to try one other [ inaudible ].

[ Captioner's audio is going in and out ]

I'm going to try and see if I can...

I'm thinking I might be able to just pull it up on YouTube.

I'm not used to not using a Mac ‑‑ so we have [ inaudible ] with Teddy. But I think we're out of time.

I have it on my phone that I could it to all of you but I really don't want to run too much over. But I'll tell you what I will do, so we can't see a video, but some of you can maybe hear him. I don't know how that's going to translate there. But how about if we just listen to him instead, real quick?

I can get this up quick and we can listen through the audio.

[ Off Microphone ]

That's true. Hold on. Yes, I can.

That's a great idea. That's a great idea!

But I have to hit it at the same exact time. Let's see if this is gonna work.

If this works, it will be a miracle because I'm a little bit of a spaz.

>> 9 years old and I like to ski, dance, sing, do gymnastics, swim, and I like to play with my brothers, my three brothers, and my friends. And I have two ‑‑

>> SHERRI FICKENSCHER: It's a 40‑second clip. It's really quick. Oh, she can't hear us. Okay, Caroline, it worked a little bit.

But anyway, we're out of time, but thank you for coming. I'll hang around, and Caroline can hang around for a minute, too, if anybody has any questions afterwards. So thank you, everybody. Sorry for the technical difficulty.

[ Applause ]

[ End of session ]

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