REALTIME FILE

EHDI

INTERNATIONAL D&E ROOM

TRIUMPHS AND CHALLENGES IN EARLY INTERVENTION

FOR CHILDREN WHO EXPERIENCE EARLY TRAUMA

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>> Good morning. As you are getting seated, just note that we have more than 20 minutes of video. So if you can't see the screen, you might want to pick a spot where you can see the screen. If that means sort of moving the chairs in the middle, we're okay with that. And as you are sitting, our interpreter friend Donna is going to be standing here, so just make sure you have your access needs met. Our wonderful captioner Diana is from far away, captioning for us, and the videos are captioned. So hopefully, we will have access. But if at any point there is a request for additional access, please let us know.

>> UMA SOMAN: Hi, good morning. It is 9:40, so we're going to go ahead and get started. Good morning, everybody. Thank you all for coming to the second day of EHDI presentations. I'm sure yesterday has been a lot of information with lots of things going into your brain, so hopefully today we will continue that process and engage and learn and consolidate what we are learning so we can make something happen by yesterday, which is what our keynote said. My name is Uma Soman. I'm the outreach coordinator at the Carle Auditory Oral School, which is a part of the Expanding Children's Hearing Opportunity Program in Urbana, Illinois, only two hours south of here. And I and my colleagues are going to present on a topic we did not seek to become experts in. We are in no way experts in. This is what is happening to us. This is what is happening the children and families we see, and thus, we are here to share with you what we have learned, what we are learning, and the resources we have found useful. We hope to hear from you in terms of what you have learned, shared, experienced, and hopefully together, we can add to this knowledge.

So I'll let my co-presenters introduce themselves. Go ahead.

>> SHAWNDA FULLER: Hi, I'm Shawnda Fuller, I'm an audiologist at the Carle Foundation Hospital program, ECHO, and I work predominantly in early intervention.

>> HOLLY RIEGEL: Hi, my name is Holly Riegel, I'm a speak language pathologist, and I work at the Carle ECHO program as well, mostly in early intervention, but I also work very closely with the Carle ECHO team, the cochlear implant team to do evaluations on all of our candidates for cochlear implantation.

>> UMA SOMAN: All right, thank you, friends. So today we're going to start with just some background knowledge on this topic so we're all on the same page. We're not going to go deep into any of it, and I apologize for it. Maybe a short course next year with more knowledge, right? We have 22 minutes of video from parents sharing their experiences with the process of trauma, with hearing loss, and that's what we want to spend most of our time on because these are the families that are guiding us. These are the families that we are working to meet the needs of. And hopefully in the last ten minutes we'll have some time for conversation, questions, sharing of resources, et cetera. Like I said at the beginning, we have a ton of video, so if you can't see the screen, maybe move a little bit so you can see the screen. And there we go.

A little bit about our program. We are, like I said, Expanding Children's Hearing Opportunities at the Carle Foundation Hospital. We have a birth to three program. We have a preschool program that is listening and spoken language focused, but we are first and foremost for informed parent choice. Even though our expertise happens to be in listening in spoken language, we work very hard and sometimes, you know, struggle to support parents in meeting their desired outcomes in helping their children do the choice that's right for them. I love that Hands and Voices motto. So yay, Hands and Voices.

The children we see are mostly white. Mostly in two-parent homes, low socioeconomic status. English is the language in the home for a majority of our children. We're in a pretty rural area. It's us, the university, and cornfields. That's basically it. And I love it.

Approximately 50% of the children we see have experienced some kind of early trauma, including medical trauma. And maybe because we're associated with the hospital program we're seeing more of the hospital trauma. I don't know. But the numbers are staggering, and somewhat concerning. What's even more, you know, took us by surprise, sort of, was that 12% of the person in our EI program and 20% of the children in our school program have experienced with foster homes and adoption. That's 1 in 5 children. I don't think that's the national statistic, but that's what we are seeing. So these are children with diagnosed hearing loss as well as with experience with foster or adoption situations. So we've shared a little bit about us. Clearly, you all are interested in this topic, so raise your hand, or indicate as able, how many of you are currently working with families or are families who have experience with foster or adoption in the context of hearing loss? Whoa! So maybe 1 in 5 is not that staggering a statistic.

How many of you are professionals, direct service? Excellent. How many of you are parents who are also providing, you know, support services? All right. Several parents in the room. Thank you so much. How many of you are administrators? Yay, administrators! You're the ones who help us make it happen every day.

Okay. So together, like I said, we're not experts. We were hesitant to begin the conversation about this, but EHDI has traditionally been a very safe space. We hare respective of our differences. We are here to support children and families. And we are here to share the good, bad, and ugly of what we have learned in experience, and hopefully you will give us grace.

Key concept of first childhood experiences, this has been a popular topic in the media, social media, trauma-informed practices. That might be a phrase you may have seen. But first childhood experiences fall into three categories. Abuse of some sort, neglect of some sort, as well as household dysfunction. There is a really good NPR article, and I think it was an NPR story that is also in print that talks about what is your -- like you take the ACEs test, what is your ACEs score, and also, what does that mean. But as always, we know a score does not tell the whole story. A score just informs what it is what we know about individuals.

The big ones that we are seeing for our children who are in foster care or adoption has mostly been abuse or neglect. So those are the ones that we will be focusing on today. Having said that, we do have children with domestic violence in the home, family members -- substance abuse, food insecurity, shelter insecurity, and all that. In fact, I think it's pretty easy to imagine what happens if you don't feel secure, if you don't have your basic needs met. But broadly, for young children, we see the impact in self-regulation, high levels of anxiety, toxic stress. We listen to Dr. Favre (phonetic) today saying listening fatigue is showing up as stress in every day for the rest of your life. I'm going to call a toxic stress over time. So maybe be thinking about that as another -- not adverse childhood experience, but another experience that is affecting self-regulation, attention, and so on. We know from the Kaiser ACEs study that is available to review on the CDC website, long term experience of adverse childhood experience includes greater risk for health issues, substance abuse, academic and employment outcomes, and early death. There was an update of the San Diego study, again, NPR. They have a nice capsule story. Go check it out. It's really good.

Another concept we want to bring to your attention is of that relation health. To quite this interactive child at Harvard University who has a wonderful diagram linking ACEs and stress and what it means for brain development. Young children experience their world as a variety of relationships, and these relationships affect virtually all aspects of their development. It's about relationships. And this word will come up many, many, many, many times in the course of the next 40 minutes.

So I'm going to turn it over to my friend Holly, who actually does the seeing of the children and working with the families to talk about the impact of ACEs on EI. No, I'm not going to turn it over to her. I'm going to talk about it for just a minute.

So it's easy -- again, it's easy to imagine if you are already having this somewhat rough start, early intervention where people are coming into your homes and there are other areas that you need to work on. It's a situation of hearing loss plus. And that plus, this was a quote I heard secondhand from a friend who went to a talk by Christy Borders who said that for children who are Deaf or hard of hearing, having an additional disability is not an additive effect but rather a multiplicious effect. So the additional disability doesn't just add, it multiple the impact, and that's how I'm looking at ACEs.

So next, now I will hand it over to my friend, Holly, who will tell you about the parent interviews we did, and then we'll watch some videos.

>> HOLLY RIEGEL: So over the past five years, our program, we've been working with about ten different families who have -- are either fostered or adopted a child, and we have interviewed three of these families today to show you guys. And we asked them all a similar set of questions, so these are some of the questions that we asked.

So we wanted to look at, like, what were their EI experiences? What was it like working with EI providers or the EI system? What was their knowledge of early trauma? What did they know, walking into the adoption or fostering process of what trauma would look like when that child came into their home. This child may already be having trauma from the adoption fostering process while also having a diagnosis of hearing loss or additional disabilities. And then also, how has this impacted them over the years. And we wanted to know their advice. What advice would you give to EI providers? What advice would you give to other families? Because we found that we are learning the best from these parents.

So our first video, I'm going to go ahead and let Shawnda describe the first family really quick.

>> SHAWNDA FULLER: Let me give you a background on the first child you will see. Their child came from them directly from the hospital, and it was fairly seamless in that this child was only in one foster family and then was adopted, so it was pretty quick, which isn't what we see. Good for them. And then the adopted family, these parents are a little bit older, well educated, have a very strong -- can you hear in the back? Okay. Good. A strong faith and a very strong support network. So we'll show you child number one.

>> UMA SOMAN: Wait just a second. I'll minimize the captioning screen, but I'll pull it back up. Okay. I am not good with Windows computers, but -- and I definitely don't want to turn it off. Okay. Here we go. I'm going bring up the captioning screen again, and it is on, but the videos are captioned.

(Captioned video)

>> So I'm interested in what your takeaways are from watching that video. Jacqueline is walking around with a microphone.

>> AUDIENCE MEMBER: I do want to comment about her knowledge and exposure prior to adoption, related to trauma. I don't know that that's necessarily the norm. I offered some foster care and I think it -- (no audio. Skype disconnected.)

>> CAPTIONER: Yes, I'm here. Thanks! We're connected. Thanks!

>> So where do you live and did you work with a specific agency that helped you get that knowledge?

>> AUDIENCE MEMBER: I'm from Colorado, and the specific agency I worked with was Lutheran Social Services, did a lot of refugee work and home placement, and I'm an advocate, so I do a lot of work in the foster care system, so I understand my knowledge is different as well. So I think it's state and agency dependent.

>> Thank you.

>> AUDIENCE MEMBER: Hi, I think the video shows how easy it is to -- you're not the first person who see the child taken into foster care. This has already been discussed with the parent and you don't need to have such a discussion with them and just check to make sure someone has talked to them about early trauma.

>> All right. Let's move on.

>> So this next family we're going to show a video of, this is a mother, she and her husband have adopted multiple children internationally, and two of the children they have adopted are Deaf and hard of hearing. The path that these two different children have gone has been very different, the hearing history is different, the plan has been different, just overall experiences have been very different. So what we have found working with this family, the challenges of the program, because we've had to go back and examine whether they're pursuing the prescribed intervention plan versus what the (indistinguishable). And you'll see this in what they're saying.

(Captioned video)

>> Would anybody like to share their takeaways from the video? She's an amazing mom. She's going through a lot with these kids, and she really is the expert. She didn't give herself enough credit.

>> AUDIENCE MEMBER: I have to admit that in the first few seconds of watching the video, the mom said she watches a little bit of sign when she is working with her child, and working with my own speech pathologist and oral school and I and my colleagues have worked with families who said at the outset that their goals for the child was to speak and mainstream, kindergarten, et cetera, and what I find is, take what the parents' goals are and provide them information and, you know, models of how to attain those goals. And the research shows that, you know, not using sign is -- I guess the quickest and most efficient way to get toward -- I guess bridging the gap between typically during -- language and (indistinguishable).

So when I have parents who after stating what their goals are that, all the sudden start using sign language, maybe they've picked it up from the early provider or on their own, there's this moment of professional eye roll, parents using sign. That's not what they told me they wanted to do. And I don't think I've ever come across actual -- and I try to be as thoughtful as possible when I counsel them, just as a reminder, you know, we're not using sign because of X, Y, Z. But this video, it was a slap in the face to me, because it's much like, I think I'm not coming across as rolling my eyes or becoming impatient with them, and I really try to be patient with them, to come from a place of care and just wanting to educate and counsel them, but this was really a slap in the face. I think I need to -- I'm going to share this with my colleagues. I know they felt the same way, that we need to look at the whole picture, what the child has gone through, what the parents have gone through, why is my baby using that, and have discussions and perhaps compromise on what their needs are rather than looking at it from just a language perspective.

>> Thank you so much for sharing that and being vulnerable to sharing that in a room. I say a round of applause.

(Applause).

This is a parent, and I've been doing this for a while, yes, sure, whatever. Every time this parent says, hey, I want to talk, I'm like, okay. Like I have to -- because it's not the professional eye roll, but I know it's going to be something different than what is the easy thing for us to do as a program. Every single time I walk away from a conversation with her with a new perspective, with new understanding, new knowledge. To say, all right, okay. I get it. Yes. We're going to figure out how we meet this need within the constraints of what is the school program and still, you know, you all maintain your sanity. One more question here, and then up front.

>> AUDIENCE MEMBER: (Indistinguishable) to see that video, I'm an audiologist and one of the greatest things that I have -- the languages, and I see sign language as another language, and none of us know where that child is going to end up, and I think it's best -- get them signing, get them early, we can see a lot of developmental -- almost being ahead of the game if they can sign, where they spend a lot of their life otherwise just being behind, always being slightly different. Where if you can get that confidence built up, it makes a huge difference to them. It is difficult. They need a lot of assistance when you're trying to do both at the same time, and (indistinguishable), speaking things to my children, English as a family.

In the 2 1/2 years -- both (indistinguishable). And it's hard. It is. I find the support out there, whether it's trying to be bilingual as a parent, teaching them speech and sign, it's very hard to get the whole team on board and support what you're doing, and it would be great if there were a way of dealing with that.

>> Absolutely. Thank you for that. And here, there, and then we'll go to the next video, which I think we'll -- no. Jenna, and then one more, and then we'll go to the next video.

>> AUDIENCE MEMBER: Thank you for sharing the voices of parents, their perspectives, and as professionals, we have a whole lot to gain by looking at this intensively, and this parent has studied the attachment and the adversely to her children. I think we listen to parents who don't have such a polished academic record, because they too have very clear knowledge on their children and are experts in their children, even if they show up in our clinics or we show up in their homes and it doesn't look as clean and neat and refined in the messaging. We have plenty to learn from all the kinds of parents.

>> Excellent point, yeah. And one more over here.

>> AUDIENCE MEMBER: I just want to add a quick comment about this family. Their first child was adopted at 3 1/2, has a moderate hearing loss. The orphanage happened to be next to an auditory verbal center. So the kid went and got ABT every day. And was in an environment, came with language -- a different language than English, but came with language.

The other child, profoundly Deaf, was never spoken to, who was used as a reward to get her to do anything, such as the cookie was raised up to have her stand up and raised down to have her sit down. Right? So this mom happens to be from the same state I am from originally. I'm not going to go into details. And she is in my office, she's like, okay, so the plan is, we're going to go, we're going to do this, and in six months, implants.

I said, look, I've never said this to a parent, but let's think about the short term. You go there, get the child, you're going to foster in country. Just connect whatever you need to use. It's all going to be good. You understand attachment. I know something about communication. We'll figure it out. Who cares what language you're using as far as there is communication and attachment. When you come back to the US, we'll figure out the rest. We'll make a plan. Right now, don't think long term.

And in hindsight, she was like, that was really good advice. I didn't know what to do with the advice, but in hindsight, that was good advice. So don't think long term until a few things have been figured out.

>> AUDIENCE MEMBER: As an adoptive and foster mom, one of the things -- yeah (indistinguishable), one of the things you're working against is DHR.

>> What is that?

>> AUDIENCE MEMBER: Department of Human Resources or whatever it's called in your state. Their goals and their rules and their procedures, whether you know what is correct for the child that's in your home, you still have to fight, not only them, so when -- all you do is fight. The whole time the child is with you, you're fighting for everything. You're fighting for language acquisition. You're fighting to see a parent who doesn't want to see them. You're fighting to get them to go to the bathroom by themselves. You're fighting for them not to walk off with a person in the shopping center because they have no attachment to you so they like that person better. You're fighting every single day.

So something that happens with these foster adoptive parents, you feel like the whole first part of your life with this child is a struggle, a battle. So when you have providers who are -- who listen to you and who -- like that parent said, who don't say to you, well, your child is going to be a signing child, and you're like, I don't care what they do. I just want them to be able to communicate with me that they have to go to the bathroom. I don't care how that happens. But when you have someone who is immediately negative toward you about your choices, you're like, okay, you too. I don't care. And you just go, well, okay. That's just how it's going to be.

So when we watch these videos with these parents, I immediately see -- well, I see myself and I see the struggle and I see the fight, and I see they're still fighting. And that's something we never stop doing. We never stop. And as parents, you know with a child with a hearing loss, you will be fighting forever with them. With foster-adoptive parents, you're not only fighting the hearing loss, you're fighting the system, every single day. Thank you, you're right. You fight the system every single day. And when you finally get to adopt them, you're still fighting.

>> Thank you for sharing that.

(Applause).

>> So this next family is a really good example of what she was just saying. This family has adopted a child who had moved from foster home to foster home to foster home. I saw this child and I transitioned to each home with him as he moved, even so specifically to the point that I went with him to his one foster placement at the very first day he met the foster parent and I leave him there, think about him finding -- I was one of two EI providers consistently seeing him over this time period. It was -- it was a really hard time for me. But one of the things that I focused on a lot was, you know, just reeducating each foster parent about this child's hearing loss. And so this is something with EIT (phonetic), this man adopted him.

Okay. This is another captioned video.

(Captioned video)

>> So we'll have questions here at the end. Our takeaways or lessons we have learned are best captioned after listening to these three interviews and listening to the parents and what their concerns and wants and goals are for these children. So Dr. Karen Purvis, she founded the TBRI, Trust-Based Relational Intervention, out of Texas Christian University. She said, it is not you against the child. It is you and this child against this child's history. It is not a personal attack on you.

The next -- here we go. Another great quote. No significant learning happens without a significant relationship. And that is one of the key things that's really stuck with me, talking to these moms and learning about what trauma is, what it looks like, and how we need to fill that need in order to build language or anything off of it.

The next quote. So I'm a school-aged person. I live (indistinguishable) in taxonomy and action verbs and cognition. This quote tends to stay with me. This has been -- you can't do the Bloom's stuff until you take care of the Maslow stuff. Maslow's hierarchy before the Bloom's taxonomy. And the final quote Shawnda is going to talk about.

>> SHAWNDA FULLER: Take a moment and read that quote by Bruce Perry. So the thing I really like about this quote, he talks about the healing power of love, and I feel like the mothers in these videos really talk about that too, just having that one person in your life who you can trust and count on and who is consistent makes all the difference for these kids who have been through lots of trauma. Thanks.

>> UMA SOMAN: So we didn't go through a lot of the resources. A couple of things I can give to you right now, come and look at the books. Come and look at the CDC website on ACEs. Look at the Empower to Connect website. Just search trauma and informed education and practice. There's a lot out there. And a surprisingly high number is good. So check it out. If you are looking on research for perspectives of parents who have adopted children who are Deaf or hard of hearing, there is a recent research paper by Rosen spikes Mullen and Hartman, out of Texas Christian University. If you would like the actual citation, come see me. And I want to make one more appeal. If you think this is an important area of study, and it is me wearing my own hat, not representing my school. If you think this is an important area of study, a friend of mine, Elizabeth, is doing her dissertation on ACEs and children who are Deaf and hard of hearing, a 30-minute parent survey followed by sharing of some test scores. She is desperately looking for kids. She aims to have 100 children in her study. If you know of families who might be interested in participating, please come see me and give me your email. I will share that information with Elizabeth, and she will get in touch with you. Clearly, this is an important topic that we are still learning a lot about. And what will we take away, what can we do by Tuesday, is what we should be thinking about. We have three minutes, so we will open it up to questions and comments, but we can stay a little longer if you want to hang with us. Otherwise, thank you all. Thank you for coming. But let's stay until we get some questions and comments.

One in the back, and then one up front, and then one in the back. All right.

>> AUDIENCE MEMBER: Just really quick, I want to really thank you guys. This is a topic that is near and dear to my heart, and you did a phenomenal job, so kudos.

(Applause).

So one of the things, I'm an audiologist and trying to change the language that we have of delivering the news and being more trauma informed in a hospital setting. One of the things that I'm trying to wrap my head around do is support the parents who go through ACEs themselves because so many of them don't have the social-emotional competencies or factors needed to raise a child who is -- and all the resources and supports to raise a child who is Deaf or hard of hearing who may experience ACEs themselves, and I know this is a really large question, but just initial thoughts, supports, resources, any ideas.

>> Okay. So like I said, there is more information on trauma-informed care, even just in working with parents. I so far have not found adult support groups or anything like that. However, one of the things -- our fourth collaborator on this was our social worker at school who was herself an adoption preservation social worker, adoptive mom herself, and she always talks about the trauma of adoption and the motivation behind adoption at times. And how that trauma is feeding into all of this. So the best I can say right now is, do the work and tell us what you learned, and, you know, keep the trauma at the forefront.

>> AUDIENCE MEMBER: So I am here as a professional (indistinguishable) as well as an adoptive parent of a child with hearing loss, and it strikes me how many adoptive parents are here, whether the children have hearing loss or not and perhaps adjusting to EHDI that they -- almost a special interest group in a way, and we are going to network because I think there are some real similar experience and needs, depending where you are on the path.

The other thought was to add a resource. There's a project, the Bucharest Early Intervention Project and they've had the opportunity to do long-term testing and follow-up and research on children who remained in orphanages in Romania instead of foster care and what happened to the children and they have written a book on that. And I heard one of the key researchers speak and their experiences inform a lot of what we're talking about and what parents are dealing with, depending on the adoptive situation in those early days, weeks, months, being able to tease out, what part of this may stay with us, what interventions do we need, and what supports are really important.

And this afternoon, Smolen and Hartman are speaking about the paper that was mentioned. So if you want to hear about that, that's an opportunity.

>> Thank you. There was a question here and in the book and then in the second to last row.

>> I also want to say, yes, this has been deep and heavy. These kids are doing phenomenally. I am responsible for tracking data, and we have, you know, a line graph of how the kids are doing. They're going (indicating), which is great. Just great.

>> AUDIENCE MEMBER: I just had a lot of questions. I know a lot of your research, with all of our kiddos who are Deaf and hard of hearing, one of the things that I'm learning about right now is EMDR therapy and how that affects trauma, and as a trauma and PTSD survivor, that is one thing that I am personally going through, and it has helped tremendously for me, so thinking about our kiddos who are D/HH, the sensory, the tappers, I have referred four students from my son's kindergarten and D/HH program that has zero language and other things and their parents have also said, never did we think that tappers would help our kids, but thinking about that sensory piece and that stimuli has really affected their ability to be more receptive to therapy. So have you guys in your research, I'm sure, just using traditional therapy and that and has EMDR -- when they're talking about trauma?

>> No. One of the things that the parents have all said, we think our children will need therapy at some point. So given that they're four and 5-year-olds at this point, they haven't pursued therapy options. So I'll be happy to take back the EMDR as an option for them. None of the kids are directly receiving talk therapy or, you know, therapy for that. All they are in is speech-language therapy. This is a long story. So our school is a TBRI school at this point. We are all trained in TBRI. We have changed our school model, our school schedule, our school rules, to be more trauma informed in what we do. Every class, irrespective of language level or hearing loss, that helps children learn strategies to manage themselves, self-regulation, so on and so forth. So that is the tiniest bit of direct intervention that is happening at this point. But EMDR is not something that I have come across or that parents have mentioned. So thank you for that.

>> I'll try to speak fast. I turned the microphone away, and I have to speak now. And EMDR-trained therapist, can EMDR be used with newborns. I'm seeing that infants and EMDR parents do it, and a shameless plug, I'm developing a trauma informed treatment that will be freely available for families who address the needs of ACEs and most people in the helping professions also have ACEs or adult traumatic experience, so it has the three-tiered process of how to work with your own nervous system, the support parents' nervous system, the support kid's nervous system, so that is being developed and will have ASL and hopefully Cued Speech, the Wisconsin Hawthorne Project.

>> Will you share your name, please?

>> Jessica Dolman.

>> And with that, thank you, all. We have some business cards. If you want to look at the books, please do so. Thank you for coming, and enjoy the rest of the conference.

(Applause).

(End of session at 10:45 a.m. CT)