>> Okay, I'm going to get us started right on time. Thank you for coming right after lunch. I appreciate it. This is "Taking a Trauma Informed Approach to Family Engagement" I am a licensed marriage and family therapist. I'm Stephanie Lucas in the state of Oregon. I'm also a parent of a child who is deaf. I love this picture. Can't help but share it. She's gorgeous. I am a Hands & Voices parent guide in Oregon. One thing I noticed that is different between mental health presentations and presentations at EHDI is in mental health presentations there are always people standing up and moving around and doing yoga on the side. So I know it's right after lunch. If you need to move around, I'm used to that, that's totally fine. The other thing is we always tend to run over, so I'm going to try really hard to keep it on time, but if I'm moving at a fast pace, that's why.

So what is trauma? We need a working definition just to start us off and understand how we're helping families that we're seeing every day. It's a lasting emotional impact of a terrible event, and we really want to think about it in two different ways. A lot of people think about what we call big T trauma when we use the word "trauma" be something like a car accident, assault, something an episodic event that has a start and stop time. One big thing that happens. That's what we think of when we think of trauma. But oftentimes trauma is a little t trauma, chronic or complex events. Things that happen a little bit over and over again. Maybe if you get beat up on a playground one time, it six, and you tell somebody about it and you can resolve it. But if you get beat up on the playground every time, that's going to lodge as trauma in your brain. You might start to escalate when you see a playground, even as an adult, right? You might see kids of the same age when you were beat up and start to feel some physiological symptoms that remind you of that time.

This little chart on the right, I know it's small, it's a really nice way of thinking about how the brain is lodging trauma. It's notices an event and interpreting it as danger. It sends some lovely chemicals to your brain that you don't need to remember. But that results in a rapid heart rate. It results in digestive issues. It results in a difficulty focusing, shaking, dry mouth, and even hearing loss and vision loss. Your body is going into fight-or-fright response. It's trying to help you survive. If surviving means being able to run as fast as you can or fight somebody off, I geese to give you the tools to do that. Unfortunately not always the tools we actually need to survive trauma. That's why it's a very physical experience.

The key markers of PTSD include intrusive symptoms. These are things like nightmares and flashbacks that you think of as typical with PTSD. Avoidance is also a key marker. You might not drive past the playground. You might not pick up the phone when the EHDI coordinator is calling you because the last conversation you had was a real doozy, right? You might have negative thoughts and mood. You might feel like something is overly your fault. You might feel like nothing is going to get Bert because this repeated experience is changing the brain chemistry for you and I's hard to think of the positive.

You might have heightened or altered arousal state. This is look a few different ways. We have hypervigilance, when you body is constantly scanning the room for danger. It's constantly looking for where could this come from? How else could I be threatened today? And that makes people very agitated. Sometimes that looks like angry and sometimes that looks like anxious, but it's all being carried in your body. It's all this heightened level of arousal because you're looking for what could be coming next.

We also have increased startle response. If you hear a door slam down the hallway and you jump, that is a start response because your body is like, oh, danger! I know it! Let me give you a ton of adrenaline and your body is responding to that.

The last is dissociation. This is when your brain decides, okay, my body can't get out of this... but I can. Right? And it will fog you out. As I say to my clients, or check out. People have difficulty focusing and difficulty with memory when they're dissociating. You can see a glazed look go into the eyes and you're like... are you really here? Hello? And they might snap back to it when you do that, because their brain is like, I can't handle this, I don't want to remember it. If it has to happen, I don't want to be here for it. So their brain is checking them out of that situation.

Who has trauma? I'm going to blast through this slide. This is important information. 5-8% of American adults will have PTSD in a given year and statistics are similar for children. Interestingly, I focused on postpartum, since we see a lot of new parents. Up to 16% display clinically significant postpartum PTSD symptoms. And the definition of trauma is expanding. We have secondary trauma by learning about something that has happened to someone we love, and we're also starting to define things like a global pandemic as a complex trauma.

So what is your trauma-informed care? This is the ability as a provider to go in understanding these concepts and how to be gentle with these ideas and how to best treat someone who is experiencing trauma or has a trauma history. The common thread is that your safety, belonging or value are perceived as at-risk, and you're unable to cope with that stress. An important way of thinking about this in of family engagement is that young kids, zero-to-three kids are getting all otheir safety, belonging and value from their parents. So when we're also being trauma receptive to the parents, we're providing that for our kids as well. In we can't really provide them belonging and value when they're a year old. They get that from their parents. So when taking a trauma-informed approach, we have to think of the whole family.

There are four steps to being trauma-informed. Realizing what trauma is, you are doing that just by our last slide and by being here, which is awesome. Recognizing it. So we'll go through -- we went through some symptoms, but we'll walk through a few examples what that could look like for an EHDI family. Responding, knowing how to be more responsive and be gentle with our trauma symptoms, which we'll also talk about.

And resisting. Knowing how to not reperpetuate someone's trauma.

So I made a long list of examples. This would be a good one to take a picture of. I won't be able to talk about them all, but these are the three different categories and what they might look like for common EHDI families. Two of the acute traumas that are common are either a medical or birth trauma or diagnosis trauma. One of my good friends talks in her book about the moment her son was diagnosed with hearing loss, the ENT walked in and sat down and said, well, your kid is deaf, you need some cochlear implants, probably some speech therapy and probably be mainstreamed. Any questions?

She was like... uhh... what?

And she still talks about that. Her kid is 17. It's still a big moment for her, right?

And we didn't take a trauma-informed approach and we sat down and told that family a diagnosis. So thinking about even that moment can be a trauma for someone.

Medical trauma or birth trauma, there may be difficult events that related to that that can then be carrying into the few months when trying to most engage with a family. Chronic trauma might look like medical system fatigue deaf and hard of hearing kids don't always have only that going on. Have they had a million appointments? Have they had appointments that didn't go very well. Have they had a bunch of events happen and now this is the last thing on their checklist, and they're just tired, right? They just want it to be done. And here we are like, you're not even close to done.

So we need to be able to think about that and figure into that.

Social stigma. Maybe you grew up getting bullyed because you were short or whatever. Right?

And then all of a sudden you have learned that your child is going to be different in some way and all of those memories of getting bullyed have come back and now you're very worried about your kid and heightened because your memories of getting beat up on the playground are now being applied to your child in your mind.

Complex trauma, global pandemic. Complex trauma, chronic illness. Systemic racism and ableism are all examples of things coming from everywhere. You never expect when you are going to have that moment of experiencing something that is traumatic related to one of those sources.

All right, so these are all real examples -- well, two real examples and one example I conglomerated from stories from providers, but this is a real example. Z is a two-year-old boy, three now, who is implanted with cochlear implants at 11 months old and had brain surgery at two. Mom reported she noticed Z was becoming increasingly anxious before falling asleep, experiencing nightmares, and was associating sleeping away from home with fear and panic. So those are some obvious trauma symptoms. He has intrusive thoughts, avoidance and that physiological arousal escalation around sleep specifically so this would be an acute trauma. Mom believes the repeated experiences of falling asleep and waking up somewhere else or in pain contributed to Z feeling afraid to sleep.

Mom asked EI and health nurse for support and wondered if she had done the right thing, how she can help him through this when he does not have language to understand or express.

So for now we're going to learn about cases and then you learn different ways to implement how to treat these cases.

So example 2 is my conglomeration. K was diagnosed with mild/moderate hearing loss at three months old after prolonged stay in the NICU. EI had a difficult time engaging with parents. So we see some avoidance here, right? And this is one of the hardest ones for anybody with early intervention is all you know is they didn't answer the phone. You're not quite sure why and it's hard to get more information sometimes.

When a parent guide gets ahold of them they're told, we don't think she really needs any treatment. She seems fine and we just want things to go back to normal. This is a great time when collaborating is important, because that parent guide can then tap in with EI and say, hmm... I got some messages here about maybe having some medical system fatigue or feeling really overwhelmed by everything that has gone on. So when EI reaches out they can be a little more trauma-informed in the way they talk to this parent.

But when the EI assessment occurs, the case parent is adamant there's nothing wrong with her and they don't want her to be different or weird from other kids. Those are some signs that some social trauma maybe happened to this parents and they're trying to avoid that for their kiddo.

Example 3, biracial Latina-white company who recently moved to a predominantly white area of the U.S. Upon initiating services with new providers, Latina parents reported two instances being asked if she was the nanny when joined her husband at the appointment. These mothers recorded repeated incidents of surprise and fact checking when she would present with anglo last name or speak fluent English with providers. This mother reported these microaggressions resulted in feelings of anger, resentment towards providers and reduced desire to engage in services. We're not always the perpetrator of trauma, but sometimes we get in our own way and make a mistake or say something and don't realize it and sometimes that can cause a reaction for people who have a complex trauma, who are in experience that is are the difficult. And we want to be careful with that, especially when providing services.

All right, let me check my time here. Perfect!

So we have six principles from SAMHSA, a federal mental health and substance abuse organization and they put forward six principles of trauma-informed care. It's not as complex as you think it is, thank goodness.

For today I'm just going to review the client side, just to keep things simple. But I do have a 30-second spiel. As providers, working in an employment -- what is the word I'm looking for? -- environment that is also trauma-informed is so important. And hard to find. We spend so much time and energy focusing on clients and best presenting for them that we don't realize that sometimes our own organizations are not trauma-informed.

And how can we provide appropriate services with trauma-informed care when the place where we work is traumatizing us, right?

So I do have that information up there for employees, for people who are employers, to be thinking about at that and realize that is a huge trickle-down effect. If you're not taken care of as an employee, how can you be taking care of clients? I use the word "clients," that's a mental health word, but you can translate.

So safety is number one. Physical and psychological. Psychological safety looks like knowing you are not going to be yelled at. It looks like knowing where the exit is, and not seeing images or words that alienate you in the environment that you are in.

This is really the only one we can give to kids. We can give them safety and child proof our office and help them feel like we won't enter their space without consent. Those are always providing safety, but it's also important to provide that for the parents. There was a question in the plenary yesterday in the morning, the first one. What do I do when a mom has just fled domestic violence the night before and I'm supposed to be talking about high tones with her? And I want to say, I think if you tell her wow, I can't believe you made it here today, that's amazing. Just really acknowledge that for her and say, you're safe here. And if you need to go and do something else, that's okay. I am not your top priority. Safety is your top priority. Just acknowledging that for her, you are going to do so much more for that relationship and her ability to come back and be focused than you would have if you just tried to plow through and talk about high tones.

Principle 2 is trust worthiness and transparency. This with clients look likes roadmaps, being very clear about what is treatment going to look like? How long is it going to take? How many people does it involve? When do I have choice? Right? Am I just signing this piece of paper and you're going to show up at my house every week whether I tell you to or not? I don't know. So being very transparent about what that looks like. Willingness to engage in difficult topics. A lot of people will report people don't want to talk about the difficult stuff and it's hard for them because it creates a sense of uncertainty, which can be traumatizing. Surprises and uncertainty can reperpetuate that trauma because we don't know what is about to happen. And in the past when we didn't know what was about to happen, I was something bad.

You hear a common complaint that when people fail a newborn hearing screening they're told it's probably just fluid, right?

That's not very transparent. It could be just fluid. It could be a few other things. And parents who wind up with a diagnosis are resentful that they were told that in the beginning, and they're resentful they weren't told all their options from the beginning. So this is an important area to think about in terms of trustworthy and transparency. Following through an appropriate assessment. How many walked in a doctor's office and they didn't read our intake forms, and you have to tell them again, this is my diagnoses, this is my preferred pronouns, this is my preferred language. If we're assessing appropriately, we're building trust with our clients that we're going to give them appropriate care.

Principle 3 is peer support. So I stole this off of the Internet. Sorry, Amanda. This is Oregon Hands & Voices family camp last year. Which always a really fun time. Really understanding that you are not alone. Trauma is very isolating. And feeling like you're the only one who ever has experienced this is really isolating. So being able to meet someone else who has had the same experience, who is doing okay, is really healing. In fact, it's kind of the opposite of trauma, right? If you're able to be in community with people, you are then able to heal that trauma and integrate it instead of having it last and stick in your mind for 17 years.

Principle 4 is collaboration and mutuality. Making sure people feel they have a voice. They can speak up and say, I don't like this, or I want something different.

A common complaint I hear in the deaf and hard of hearing community is no one even mentioned ASL to us. That may be true. Or they maybe mention it and stuff it under the rug because they're not well-trained in it. So collaboration and mutuality might look like saying, hey, I don't know ASL or how to teach you ASL, but here are resources for someone who does if that's of interest to you. Or saying I was trained in a modality that doesn't believe in using ASL, but other people are trained in different modalities, and it's okay if you want to learn from them too, not being defensive of our own ideas and presenting all the options for parents. Making clear the roles and availability and methods of access for all your providers. This is who I am, this is how often I'm going to call you. Yes, you can text me, no you can't text me after 7:00 p.m., and just making that really clear. It creates predictability and predictability builds safety. Making sure things are mutual. People feel like they can speak up and have a voice.

All right, empowerment and choice. This is another great example from another parent guide from Oregon. So she actually collaborated with a teacher of the deaf in her area and they happened to have a bunch of high school -- deaf and hard of hearing high schoolers who were graduating, so they did a deaf panel of all high schoolers. This is a huge moment of empowerment, right? Saying, yeah, you're in a weird identity shift, you're a teenager and a teenager with a disability, and that's hard too. We're going to highlight you and show your strengths and build you up as a team and ask you to share your story and tell you it's important. That's a beautiful example of empowerment and choice. Everybody saying to the fictitious mom from our example who fled domestic violence the night before and saying, my gosh, you made it here today, that's huge empowerment. You're still coming to your kids' medical appointments even though you ran out of your house the night before, that's amazing, and I salute you for that and you're strong for that. It's going to be huge for your relationship with her.

Cultural, historical and gender issues. Having an awareness of how identity can be influenced by just the way we interact with people. This is one of the things where providers are sometimes well-trained but the front desk staff are not. And the front desk staff are often the perpetrators of issues in this area, and they may not have cultural sensitivity or may not have language sensitivity or gender identity sensitivity, and those are the first people that our clients are seeing. And sometimes they can be the perpetrators of that trauma because they just don't have the historical training in order to be receptive to what clients are bringing in for us.

Having appropriate resources and referrals, and being proactive versus reactive in policies. Don't wait until there's someone who needs appropriate accommodation in your office to make a new policy.

So we're going to revisit the three scenarios and see what we can implement here to be more trauma-informed. So here ask a direct quote from Z's mom. Unfortunately no one really helped us through this. The one thing I didn't like that people would say is that kids are so resilient, he won't even remember it. Yes, he's resilient, but he does remember it. And though he won't remember it the way we did, everything we go through is part of our experience and contributes to who we become. To discredit his experience by saying he won't remember it is showing a great deficit in compassion. I would urge providers to listen with compassion and learn appropriate responses to parents' hurts and struggles. I know sometimes it's hard to know what to say and these phrases just come out. Instead you can help equip providers with better words when they don't know how to say, for instance, like "wow, that sounds really difficult, I'm not sure how I can help, but let me look into it and see what I can find."

I love this because she just asked for transparency and follow-through. Very clearly. It's okay to own that you do not know what to do with that. And I's actually safety building when you own that. You're not pretending. You know what to do about that, but you're saying you will ask around. And following up and saying I asked around and nobody knew anyone, whatever you hear.

I lived in this person's town and no one found me even though I'm a mother to a deaf child and trauma and therapist. So looking around and knowing the referrals to make is important.

I think collaboration and mutuality are also important for this mom. She didn't feel believed. She didn't feel that what she was saying was really recognized and actual issue, oh, lots of three-year-olds have sleep issues, just kind of generic sleep advice. So a different thing to say, now that you are trauma-informed would be, I know how hard it is to see the child when the brain is registering danger. You have a panicking toddler at nighttime, see ya later, that's hard. Just acknowledging that is trauma-informed. What makes him feel safe? How can we integrate that more in his experience? Are there ways I can support this during our time together? Can you help build routine and consistency for that kiddo to teach him what "safe" looks like?

Scenario 2. This is K. So I want you to think about physical symptoms and the physical stress that we experience. So look at this little picture of the crying baby on the left here. We kind of start to feel it too, if you look too hard, right? We kind of regulate with that baby like, oh, that baby is angsty, not happy. Maybe when they walk in the office for the first time, they're aware of that because babies are much more self-expressive than we are as adults. But their body is carrying that energy. What can we do? This baby on the rate, very co-regulated, very relaxed, chilling out on a caregiver, right?

So for thisty wanted to bring it up because I think it's hard one for any of our systems, when avoidance is what we're dealing with and what we really want to do is emphasize choice. We want to say, I need 20 minutes of your time and I know that feels like a lot, right? And at the end of the 20 minutes, I'm going to have explained to you what all your options are and then you get choice. Then you get to say, yep, I never want to talk to you again. Or, okay, I'll do this one thing, right?

And really pointing that out from the beginning. You are going to have choice at the end of this conversation. I'm not enrolling you in anything, I'm just giving you options. It's my job to tell you what your options are

Clear and collaborative roadmapping really eliciting a lot of feedback from a parent who is not really interested in your services, right?

And providing that peer support and normalizing language. Sometimes when we are -- especially with that cultural or social trauma where you're worried about being different, if you can see a peer who is a little further down the road that you, who isn't the way you imagined it would be, right? That kid is not getting made fun of. That kid is fine. That kid is an amazing athlete, and you can see the future different than the way they experienced it, they can start to let go of the image that that is what is going to happen to their kiddo too. So emphasizing those pieces of it and helping their system regulate, not rushing. The more you rush someone whose strategy is avoidance, the more they are going to avoid. Take really small chunks when working with someone like this.

B's mom shared a meaningful moment in all of this. One of the providers who asked if I was a nanny pulled me aside later to apologize. I appreciated that she did it one-on-one and really took accountability that what she did wasn't okay. She told me she would understand if I preferred to work with a different provider. I chose to stay with her, because my daughter seemed to like her, but that moment and her ability to put my feelings and needs first over her own pride really helped to repair our relationship.

So that's trust and transparency and having the hard conversation, right? Owning when you committed a microaggression is really hard. And it's really important too, because if you can say, I recognize that this happened, I'm sorry, and you have options and choice. That is really offering to this parent that, yeah, I'm not going to sit here and say that was okay. I'm not going to pretend it didn't happen, and I'm going to give you choices so that it won't happen again. And then she chose to stay because she actually built more trust with that provider than someone new. Having that awareness is really important. Sometimes we don't know we have done it. And then offering the choice and collaboration with the parent and letting the parent decide what is best for them.

All right. Great! We have five minutes. That's perfect. We have a little bit of time for questions. Or you can take a potty break if you need to.

This is my contact information. And, yeah, that's all the juicy stuff I have for you today.

Question?

>> AUDIENCE MEMBER: You said something, and I wasn't able to write it all down, so I wanted to ask you again. You said something like the more we rush families with avoidance behaviors, the more... I can't remember the rest. They will avoid...

Well, that just made me think about the, you know, full-time wear. That's what that made me think of. How much pressure there is on that and how unrealistic that is for a -- I mean, it's just very challenging, and eyes on... I mean, eyes open, ears on is honestly just not realistic. Steph I would agree with you, and being able to own that for a parent and say, it's going to be a process. It's going to be baby steps. There will be days when you are too tired to try for all the time, right? And really owning that, because parents will go into that black-and-white, well, if I can't do it, I won't try, right? If I can't get there, then I'm not even going to engage, I'm going to avoid, because maybe failure is a trauma for them, right? Or maybe feeling like they can't serve their child feels traumatic. So if we can be very gentle and say, you're doing the best you can, you got from four hours to six hours last week, that's amazing, right? And really highlight those strengths. You're going to be more on the same team. Yeah, absolutely.

So we have time for one more question.

>> AUDIENCE MEMBER: First I want to say I can identify as an empathetic provider and just seeing the emotion that comes over your face when you talk about these kids is impeccable. I wanted to ask... I'm thinking of a specific family I'm working with right now, and I notice sometimes when I try to use trauma-informed care and really empathize and identify what the problem is and use active listening, that the mother particularly has a defensive reaction, almost as if I'm patronizing her, and I wanted to know your advice on how to maintain that balance between like, I understand what you're feeling and, like, oh, I totally get that. I'm so glad you're here today, without coming off being patronizing almost.

>> STEPHANIE: Yeah, absolutely. I think in that situation, just making a few assumptions about what is going on, I would really -- when I see that hard pivot, really show how I see them. I think in that moment they're saying, I'm competent, I know what I'm doing, I don't need you to patronize me.

So saying, look at all you have done, I can see all these accomplishments you have. I see all this intelligence that you have. And it's like sneaky empathy, right? It's amazing! But being a little more assertive about it. I'm saying, wow, you're so...

If I can bring 2% of my knowledge to you, that would feel great to me, just to say, yeah, I have a little something to give to you, but you already have a lot, and just being empathetic in that.

>> AUDIENCE MEMBER: Thanks so much.

>> That is all the time we have today. Remember to fill out the evaluations. Thank you so much.